

# **UNIVERSITY OF MALAWI**

# **College of Medicine**

Antiretroviral Therapy Adherence and The Youth: An Assessment of Teen Clubs'

Implementation Fidelity in Southern Malawi

Ву

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(March, 2020)

# **CERTIFICATE OF APPROVAL**

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# **DECLARATION**

I Gertrude Kunje Magomero, hereby declare that this dissertation is my original work and has not been presented for any other awards at the University of Malawi or any other University.

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# **DEDICATION**

To Eliora my daughter and Emmanuel my husband "the lord is my Light, and amole nati sum"

#### **ABSTRACT**

**Introduction:** Globally there are 2.1 million adolescents living with HIV. 1.7 million are in sub Saharan Africa. Malawi has one of the highest HIV/AIDS prevalence rates in the world with 12.0 % of those aged 15-49 years infected. Adherence to ART has proved to be difficult for people living with HIV and often falls below the required levels and thus, youths living with HIV are among the population groups with poorer ART adherence rates. Fidelity is defined as adherence, integrity and quality of implementation of an intervention. However high levels of adherence are crucial to the success of HIV therapies in order to sustain viral suppression.

**Objective:** To assess the fidelity of implementing teen clubs designed to enhance ART adherence in Blantyre District

Methods: We conducted a Formative Evaluation Qualitative Research that was guided by a Consolidated Framework for Implementation Research using Key Informant Interviews to establish if teen club intervention is implemented with fidelity. The study was conducted in five Blantyre Health Centre Teen Clubs namely: Chilomoni, Chileka, South Lunzu, Mpemba, Ndirande and Light House Clinic at Queen Elizabeth Central Hospital. We used a case study method and purposive sampling. Eligible study participants were teen club facilitators who have facilitated teen clubs for at least a year. In depth Interviews were audio recorded and then transcribed verbatim. Thematic content analysis was used to analyze the data manually.

**Results**: Half of the sampled teen clubs had guidelines for conducting Teen Club Activities. The existed guidelines complied with the Baylor International Pediatrics AIDS Initiative. However, some elements were not followed. Training of the teen club

facilitators was one of the factors that influenced compliance with the guidelines.

**Conclusion**: From the results, the assessment has generated information on attributes that lead to compliance and noncompliance of HIV teen club guidelines in relation to implementation fidelity of the teen club intervention. A teen club cannot be operated without the designated guidelines that are established to be followed as such they should be complied with.

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# **ACRONYMS/ ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescents Living with Human Immune Deficiency Virus
ART	Antiretroviral Therapy
BIPAI	Baylor College of Medicine International Pediatric AIDS Initiative

CFIR	Consolidated Framework for Implementation Research
COMREC	College of Medicine Research Ethics Committee
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
FE	Formative Evaluation
HIV	Human Immune Virus
HSA	Health Surveillance Assistant
IDIs	In Depth Interviews
KII	Key Informant Interview
LMIC	Low and Middle-income Countries
LTFU	Loss to follow up
NGOs	Non-Governmental Organizations
SSA	Sub Saharan Africa
UNAIDS	United Nations Program on HIV and AIDS
YLHIV	Youth Living with Human Immune Virus

# 1. INTRODUCTION

## 1.1 BACKGROUND INFORMATION

This was a Formative Evaluation Qualitative study of Blantyre HIV teen clubs' implementation fidelity in relation to Youths' Antiretroviral Therapy adherence. A purposive non probability sampling method was adopted in which Teen club mentors were purposively sampled to participate in the study. We used a case study design in which six teen clubs were selected as cases for the study. The teen clubs were Chilomoni, Ndirande, South Lunzu, Mpemba, Chileka and Light House. Data was collected through in depth interviews with the teen club mentors to solicit an in depth understanding on how Teen clubs are being implemented. Fidelity is defined as adherence, integrity and quality of implementation of an intervention (1). Furthermore, it is the extent to which the delivery of an intervention adheres to the guidelines model as intended by the intervention developers. Fidelity comprise five distinct dimensions which are: Adherence, Exposure, Quality of delivery, Participant responsiveness and Program differentiation (1). It has been argued that over the decade, researchers and policy makers have highly emphasized the need to develop comprehensive evaluations to understand the results produced by a program, as well as the programs strategy and elements (1). Thus for an effective ART adherence results, the programs designed must be rolled out as prescribed by the model in which they are derived from (2). The dissertation has been put into five categories which are: Introduction of the study, Methodology used, Findings presentation, Discussion of the findings and conclusion and Recommendations of the study.

Globally there are 2.1 million adolescents living with HIV - ALHIV, in which the majority 1.7 million live in the sub-Saharan Africa - SSA. HIV/AIDS is the second leading cause of

adolescents' morbidity and mortality worldwide, and the leading cause in Africa. Malawi has one of the highest HIV/AIDS prevalence rates in the world with 12.0 % of those aged 15-49 years infected. Antiretroviral Therapy - ART has transformed HIV infection from a progressive typically fatal infection to a manageable chronic disease. Adherence to ART has proved to be difficult for people living with HIV and often falls below the required levels (3). Youths living with HIV are among the population groups with poorer ART adherence rates. Effective ART adherence results in virologic suppression, immune reconstitution and decreased morbidity. However, the relationship between ART and virologic suppression is mediated by excellent treatment adherence.

# 1.2 PROBLEM STATEMENT

For the past decade Antiretroviral Therapy - ART coverage has increased significantly in nations and in sub Saharan Africa - SSA (4,5). Despite the resource limited tremendous success of the large scale public sector provision of ART to HIV infected people in Malawi, failure to adhere to ART has threatened to undermine the massive benefits made and remains one of the most critical obstacles to achieving the UNAIDS 90-90-90 targets for 2020 which are intended to be a core milestone towards ending the HIV epidemic by 2030 (5,6). Studies have indicated that adolescents have worse treatment outcomes, and higher loss to follow up - LTFU and worse adherence (7,8). Hence, ART treatment remains demanding and requires a 95% degree of adherence (9,10). Studies comparing treatment outcomes in adolescents and young adults to older adults have shown poorer outcomes in terms of virologic failure and retention in care for the adolescents (10). There is a multitude of social barriers to the care and support of Adolescents Living with HIV- ALHIV that makes this population particularly vulnerable to attrition from care, poor adherence and treatment failure (7,11). Advances in Antiretroviral Therapy (ART) have resulted in swift declines in HIV associated morbidity and mortality. However high levels of adherence are crucial to the success of HIV therapies (11,12) in order to sustain viral suppression. Disruptions in taking ART can result into loss of virologic control, which may lead to advent of drug resistance and loss of future treatment options for individuals (13). Nonetheless, adherence to ART has proved to be difficult for people living with HIV and more often on the adolescents. Despite treatment advancements and vibrant interventions such as HIV teen clubs, Youths Living with HIVs'(YLHIV) related morbidity and mortality remains high in Sub Saharan Africa (14) where it was estimated that more than 80% of the global adolescent population was living with HIV.

The teen clubs core purpose is to support adolescents living with HIV in their critical years to achieve optimal treatment outcomes in which adherence is among them. However, there is slight HIV-specific or general adolescent evidence to inform the most effective service delivery interventions and approaches for this vulnerable population.

# 1.3 LITERATURE REVIEW

Adolescence is a stage of transition from childhood to adulthood associated with specific challenges (including puberty) and vulnerability (such as early sexual debut, HIV and STI acquisition). Adolescents have been identified as vulnerable population group that need to be prioritized for adherence treatment (5,15). Adolescents among various constraints, coping with the clinical and psychological impacts of HIV imposes a substantial addition drain. HIV infected adolescents face challenges that include sustainability of effective treatment and management of therapeutic failure. Treatment failure in resource limited nations estimated to be 26%-50%, is thought to be due to a combination of poor adherence, inadequate drug levels, and acquired resistance from maternal ART exposure (14). Furthermore, HIV infected adolescents encounter several known economic barriers to access HIV care. For example; cost of transport and long

distance to access a health facility (3). Adolescents experience unduly high rates of poor ART outcomes compared to adults despite prolonged use of ART in southern Africa treatment programs (5)

## 1.3.1 BIPAI MALAWI TEEN CLUB

"Teen Club," is a targeted psychosocial support intervention, which uses strategies and others to address the barriers faced by ALHIV in achieving optimal treatment outcomes (16–18). The teen club uses peer counselling and support, improved accessibility to clinic and youth friendly services. Baylor College of Medicine International Pediatric AIDS Initiative at Texas Children's Hospital- Malawi (BIPAI) introduced the concept of the Teen Club, and has collaborated with the University of Malawi over the years. BIPAI-Malawi Teen Club was started in 2003 in response to the growing need for services that focus on adolescents living with HIV in Lilongwe, Malawi. The Teen club is designed to deliver care, treatment and psychosocial support to adolescents living with HIV in an adolescent friendly clinic environment (17).

#### 1.3.2 CURRICULUM BACKGROUND AND CONTENT

BIPAI curriculum serves as a resource and reference for health care workers and community groups about issues that are relevant to adolescents living with HIV. It provides information related on key areas for ALHIV including: Disclosure, Adherence, Sexual and Reproductive Health, Stigma, Emotional Health and Life Skills (16,17,19). Teen clubs provides Adolescents living with HIV - ALHIV on Antiretroviral treatment - ART with dedicated clinic time, sexual and reproductive health education, peer mentorship, ART refill and support for positive living treatment and adherence

(11,16,17). Better adherence mechanisms would lessen depression and anxiety among adolescents (7,8,20).

#### 1.3.3 IMPLEMENTATION FIDELITY

One of the major debates in implementation research turns around fidelity and adaptation (21). Implementation fidelity refers to the degree to which an intervention or program is delivered as intended (21,22). Implementation fidelity acts as a potential moderator of the relationship between intervention and their intended outcomes. It relates to how far an intervention affects the outcomes. By appropriate evaluation of the fidelity with which an intervention has been implemented, a valuable assessment can be made of its contribution towards its outcomes (19,21,23,24).

A study in Malawi has shown that Teen clubs improve adherence to ART among HIV-infected adolescents. Of the 1,700 adolescents in the cohort across 18 health facilities, 91% were retained in care since January 2015, signifying the teen club model contributes to increased adherence to ART (25)

In Swaziland, an evaluation was done, which established that the Teen Clubs Program is relevant as it addresses some of the most precarious challenges facing ALHIV, including Loss to Follow Up (LTFU) resulting in defaulting on treatment, poor adherence, self-stigmatization and stigma in communities (26)

A compre-hensive care program in Kenya offering individual and group psychosocial support and treatment literacy for children and caregivers within a tailored, child-centered care model found improved clinical outcomes, though individual components of the program could not be assessed (27). A greater evidence base is found for interventions directed at improving adherence. Adherence, counseling and education interventions have been effective in some settings. However, studies assessing

interventions directed at women, children, and adolescents and other special populations are scarce in LMIC (27)

Despite growing interest in undertaking research in adolescent HIV, the current pace of interventional research in particular remains very low compared with the needs of ALHIV. Considerable exertion is still required to understand what works best for this population. More vigorous evidence is needed to inform the design of innovative and targeted interventions that inform adolescent HIV policy. This will rally outcomes for adolescents and help reach global targets for an AIDS-free generation by 2030. Due to limited funding for HIV, there is a need to enhance available resources by focusing research efforts on priority areas with the utmost impact for this population (8,28).

# 1.3.4 CONCEPTUAL FRAMEWORK

The Consolidated Framework for Implementation Research - CFIR guided this study. The CFIR is a conceptual framework that was developed to guide systematic assessment of multilevel implementation contexts to identify factors that might influence intervention implementation and effectiveness (23). It is a comprehensive, practical taxonomy of constructs that have an established evidence base in the literature. CFIR organizes constructs that may influence implementation into five major domains: Intervention characteristics, Outer setting, Inner setting, Individuals involved and the Implementation process (23). This framework was chosen because it helps in assessment of the potential barriers and facilitators of an intervention. Below is a table showing the interplay of the CFIR domains against the fidelity factors used in the study.

CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH: CFIR (23)

CFIR DOMAINS	FIDELITY FACTORS
Intervention Characteristics	Teen club manuals
	Costs related

	Adaptation		
2. Outer Setting	Human Resource		
	Conducive environment and		
	infrastructure		
3. Inner Setting	Training of mentors		
	Available resources		
	Learning culture		
4. Characteristics of Individuals	Personal attributes		
	Knowledge and beliefs		
5. Process of Implementation	Compliance to the guidelines		
	Execution on the ground		
	• Evaluation		

Table 1 CFIR with the interplay on fidelity factors

# 1.4 RATIONALE/ JUSTIFICATION OF THE STUDY

As earlier indicated AIDS kills young adults in their most productive years, depriving the nation of the skills and knowledge so vital to human and economic development. There is a significantly large cohort of adolescents living with HIV in Malawi (18,29). Increasing ART adherence among them will not only improve their individual lives but also benefit the community. HIV infected adolescents who are virally suppressed are less likely to infect other people, thus significantly contributing to attaining the 90-90-90 targets. (11). Thus, this study is important as it seeks to determine whether teen clubs intervention at the selected health facilities are implemented with fidelity (7,30) Furthermore, the study will provide much needed literature required for developing

contextually effective interventions for improving ART adherence among adolescents in Malawi. The findings will also add to the existing literature to inform policy on ART adherence among adolescents in Malawi.

## 1.5 OBJECTIVES OF THE STUDY

# 1.5.1 BROAD OBJECTIVE

To assess the fidelity of implementing teen clubs meant to enhance ART adherence

## 1.5.2 SPECIFIC OBJECTIVES

- To establish the existence of guidelines for implementing teen clubs
- To determine the extent to which the teen club guidelines are complied with
- To explore the factors that influence compliance or non-compliance with teen club guides/ manuals

# 2. METHODOLOGY

This was a Formative Evaluation Qualitative study that adopted a Case study design. The design was chosen because the value of a case study fairly relates to the in depth analysis of a single or small number of units in which our scenario were the sampled teen clubs. Furthermore, Case study design was used to describe an entity that forms a single unit such as a person, an organization or an institution (31).

Data was collected through Key Informant Interviews - KII were employed to establish if teen club intervention meant to enhance ART adherence are implemented with fidelity. The following emergent themes were derived: 1) teen club establishment, 2) training of facilitators, 3) challenges that limit teen club participation 4) suggestions and recommendations for smooth running of the teen club.

A qualitative research is a method of inquiry employed in many different academic disciplines with the aim of gathering in-depth understanding of human behavior and the reasons that govern such behavior (31). A KII is a qualitative in-depth interview, with the purpose to collect information from a wide range of people including experts who have immediate knowledge with the research question (31,32). These experts with their particular knowledge can provide insights on the nature of the problem and give recommendations for solutions (31). The interview guide contained an outlined script and a list of open ended questions relevant to the topic. Starting with the most factual and easy to answer questions, then following those questions that ask the opinions and beliefs of informants. It ended with questions that asked general recommendations (32).

A Formative Evaluation - FE is an assessment process designed to identify potential and actual influences on the progress and effectiveness of implementation efforts. It is therefore an approach capable of providing critical information about implementation (22). Evaluative activities undertaken during the design and pretesting of programs/intervention helps to guide the design process. It is a method of judging the worth of an intervention while the intervention activities are being conducted. FE is an assessment that focuses on the internal dynamics and actual operations of an intervention in order to understand its strengths and weaknesses and changes that occur in it over time (22).

# 2.1 STUDY PLACE

The study was conducted at Queen Elizabeth Central Hospital Light House Clinic and five Blantyre Health Centers that had active teen clubs designed to enhance youths' adherence to ART. The health centers included, South Lunzu, Chilomoni, Ndirande,

Mpemba and Chileka.

# 2.2 STUDY POPULATION

The study population involved Teen clubs' mentors and facilitators because they are the ones that are involved in teen club program facilitation.

## 2.3 STUDY PERIOD

The study proposal was submitted in October 2018 to the College of Medicine Research Ethics Committee and was approved in December 2018. Data collection was carried out in January 2019. Analysis and report writing was done between February and August, 2019.

# 2.4 SAMPLE SIZE

This Formative Evaluation - FE study employed a purposive sampling method and a case study design was used. (23,33,34). A total of six Key Informant In-depth Interviews were conducted across the selected Health facilities; QECH, South Lunzu, Chilomoni, Ndirande, Mpemba and Chileka. The selected teen clubs were our case studies and the teen club mentors and / facilitators for the selected facilities were interviewed. In total six in-depth interviews were conducted.

# 2.5 DATA COLLECTION

The study conducted six Key Informant In-depth Interviews on each selected health facility to explore and assess the factors that influence compliance to teen club guides (see Appendix 4,5). To have an effective Key Informant Interview, they were scheduled within working days: Monday to Friday at their convenient time as these days are not busy facilitating the teen clubs' sessions. Recorders were used during the Informant Interview and a research assistant took down notes through out as a backup of the

collected information and in case the participant mentors refused to be recorded. The researcher moderated the interview and a research assistant took down notes.

## 2.6 DATA MANAGEMENT AND ANALYSIS

The in-depth interviews were done in Chichewa and or English if possible and were recorded by a voice recorder. These were transcribed verbatim in the recorded language which was a mixture of English and Chichewa. All transcriptions were translated into English. Analysis of the transcriptions was done manually. The researcher developed an analysis plan based on study objectives in line with the Consolidated Framework for Implementation Science (35). Then a coding scheme was developed after reading all the transcriptions. With the supervisor, it was agreed on the code definitions to avoid double meanings and ensuring coding consistency. Quality assurance was ensured by training the research assistant before data collection using procedural quality criteria (35). Field supervision was done since the researcher was the moderator during data collection. This study used a conventional content analysis, the codes were determined and derived from the data during analysis. The study has reported the main themes in line with the Consolidated Framework for Implementation Research - CFIR from the in-depth interview (35,36)

# 2.7 RESULTS PRESENTATION

The study has reported the major themes and the necessary quotes found from the Indepth Interview describing the factors that influence compliance and noncompliance of teen club guides.

# 2.8 ETHICAL CONSIDERATION

Informed consent was sought from the teen club facilitators before conducting the interviews. Those agreeing to take part in the study either signed or thumb-stamped on

the informed consent document (see appendix 1, and 2). To ensure confidentiality study numbers or codes were assigned to the participants - Teen Club Mentors. Ethical approval was obtained from the College of Medicine Research and Ethics Committee (COMREC). See attached letter of approval in Appendix.

## 3. RESEARCH FINDINGS

The findings of the study are presented in this chapter. It starts with a description of demographic features of the study participants and institutions. These teen club facilities are situated in Blantyre district and are affiliated to their respective clinic and health centers. The study institutions were Chileka, Mpemba that are located in the rural part of Blantyre District, while Chilomoni, Ndirande, South lunzu, and Light House teen clubs have been located in the urban part of Blantyre District. These teen clubs are guided by the mission and vision of BIPAI curriculum. The mission is to empower HIV positive adolescents to build positive relationships, improve their self-esteem and acquire life skills through peer mentorship, adult role-modelling and structured activities. The vision is that the mission will ultimately lead to improved clinical and mental health outcomes as well as a healthy transition into adulthood for the teens. Chileka has 168 teens attending the teen club, Chilomoni has 95 teens attending the teen club, Mpemba has 135 teens attending the teen club, Ndirande has 200 teens attending the teen club, South lunzu has 110 teens attending the teen club and Light House teen club has 540 teens' attendees that are integrated in 6 groups of 90 adolescents. Below is a table describing the total number of teens attending respective teen club and their demographic location.

Name of the teen club	Total number of teens in	Location (urban of Rural)
	participation	,

Chilomoni	95	Urban
Chileka	168	Rural
Ndirande	200	Urban
South lunzu	110	Urban
Mpemba	135	Rural
Light House	540	Urban

Table 2: Description and Demographic features of study institutions as of 30<sup>th</sup> July 2019

## 3.1 CHARACTERISTICS OF THE PARTICIPANTS

Data was collected from Chilomoni, Ndirande, Chileka, South lunzu, Mpemba health centers and Light House Clinic at QECH. While Light house teen club is the only teen club that gets full funding from the light house organization for its running of activities, Chileka, Chilomoni, Mpemba, South Lunzu and Ndirande only gets lunch snacks and refreshments for teens and facilitators allowances from Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). At each facility, a teen club facilitator who had worked for more than a year was interviewed except for one teen club. In total, six facilitators were interviewed. The study participants were all male and had a mean average age of 34 years. Some had attained tertiary education in other fields, and some attained training in health related disciplines. Occupation of the participants extended from health surveillance assistant, field tracer, clinician and data entry clerk.

The findings of the study are presented using 4 emergent themes. These include: 1) teen establishment, 2) training of facilitators, 3) challenges that limit teen club participation 4) suggestions and recommendations for smooth running of the teen club.

# 3.2 TEEN CLUB ESTABLISHMENT

Under this theme, participants were seen to understand the goal for the establishment of the teen clubs. They expressed general knowledge on what should be offered at the teen club. They indicated that the teen club is established to offer support in reinforcing good habits, and provide a safe nurturing environment that would help them deal with stigma, discrimination and build up their self-esteem. This has been encapsulated in this comment:

At first when it was established since it was established by BAYLOR from Lilongwe, so it was an initiative to help the kids to deal with stigma and discrimination. So basically we follow that and on top of that we do aim for adherence, focus on viral load suppression and we give a purpose for fun to attract the teens that they should come again and attend the teen club. [Respondent 1]

Participants indicated that teen clubs were important in helping ALHIV to adhere to their medications. The facilitators explained in the following way:

Teen club helps a lot in terms of adherence and psychosocial support [Respondent 3]

To achieve the goal of a teen club, it ought to have a teen leader who is in the same age group as the club members. The study sought to find out if this is complied with and the impact it brings on the teens. Some facilitators described this tendency as following:

So we have successful stories of these teen. We have another kid we started with him in 2014, the guy has passed his MSc and now the one community has employed him and is working. Another teen is now at such technical college and is doing so well; to us it's an achievement so these teens are working as

inspirations to the other teens in the teen club. The counselling that we offer help them a lot to do better in their various aspects of life. [respondent 4]

## 3.2.1 GUIDELINES EXISTENCE

It is important to run a teen club with a guiding manual. Existence of the guidelines affect the delivery of the content activities to be offered. Half of the sampled facilities reported to have had a manual for running their teen club. For this reason they have displayed to know the contents that the manual has.

yes we have a manual, we have a roster that we use and we follow it every month [respondent 3

By contrast, other participants indicated that they do not have a manual instead they use experience and intuition when facilitating the teen club. This is usually guess work, as they only offer components that fit the scenario at that particular time.

No we do not have manual book, we just decide and choose topics and teach them [respondent 6]

# 3.2.2 COMPLIANCE OF GUIDELINES

The curriculum is a booklet which has been premeditated to offer guidance to the facilitators when providing support to the adolescents. It is therefore supposed to be complied with. Thus, this study referred compliance in terms of the disclosure status of the teen and the age range for the recruitment.

## 3.2.2.1 DISCLOSURE STATUS OF THE TEENS

The study facilitators have revealed that they are aware of enrolling only those adolescents that have disclosed their status. These are teens that know the reason why they are on ART and the facilitators have indicated to have complied with that:

...every time before the sessions we do assess if they (children) were disclosed

or not. If not, we send them back because we cannot conduct what we call accidental disclosure since the curriculum we use is only for the disclosed teens [respondent 1]

However, other facilitators thought that it is not right to leave out other adolescents that are not disclosed. They feel that the manual could have included an aspect of some adolescents that are not disclosed.

I feel that in most cases the manual does not flow well, because it has not included the kids that are not disclosed. So it is a challenge since we have kids less than 14 years so the manual only applies to those that are partially disclosed. And in our case we just teach these kids what we know and we teach them separately [respondent 3]

## 3.2.2.2 AGE RANGE RECRUITMENT

This subtheme reflects the recommended age group of the participants to be recruited. As teen club the age starts from 13 to 19 years. Whereas the facilitators have described to have enrolled the participants that are within and outside the age range. The facilitators have described not complying with this component due to lack of the manual.

Some guidelines are not followed; we need the manual so we can follow. People decide anyhow. And we have cases where by kids that are less than eight years are referred to come to attend the teen club. And there should be a proper guideline on how we can transition the teens to adult care. It needs a proper procedure to follow that. There is a need for the manual [respondent 5]

# 3.3 TRAINING OF THE FACILITATORS

Training of the facilitators on how to run a teen club was seen as an important tool in

delivery of the curriculum content. Having a certificate in teen club facilitation also provided an evidence that the facilitators do follow the guidelines as indicated.

yes I was trained, all mentors were trained and they do have certificates [respondent 1]

On the contrary some facilitators from other facilities were not trained. And they have expressed being unsatisfactory in their delivery of the teen club activities.

the training that we did, was not a training at all but more less like an induction and this we did when I was a mentor not a facilitator [respondent 5]

## 3.3.1 TEEN CLUB ACTIVITIES

The activities that are conducted at the teen club include drama sessions, role playing and sporting activities for example football. The activities are usually intentional and have a meaning at the end of it. They are beneficial and are fun.

for example, playing football and the teams should consist Team A with 10 people and Team B with let's say 100 people. So from this type of game we derive and explain about the virus on how related the game is to HIV, as a result the teens easily and better understand the concepts with these vivid examples that we give. By the end of the activity we translate it into adherence of medication, and each and every activity at the teen club is intentional [respondent 4]

# 3.3.2 MEETING TIME FOR THE TEEN CLUB

It is equally important to assess the meeting time of the teen clubs. The meeting time of the teen club should accommodate participation and be conducive to teens that have responsibilities at home and those that travel long distances to reach the teen club venue.

our teen club is categorized into 6 groups and each group has 90 teens. We meet 3 times in a month on a Saturday [respondent 1]

It was however noted that in other facilities the same weekend is not favorable. They have tackled issues of privacy on the day; there is no privacy for the teens. Non privacy of the room make the teens feel uncomfortable and thus spurn away some of the meetings. The overall rate participation has been rated substandard.

...the environment is not conducive in as far as privacy is concerned, because the day we meet these teens we also have a male friendly clinic, so some of the teens do not feel comfortable with this as a result they stop coming to the teen club. The overall rate we cannot say is satisfactory, due to the factors that I have raised. The turn up is not 100%. [respondent 3]

# 3.3.3 Strategies used to motivate teens at the teen club

It is vital to motivate the teens in patronizing the scheduled meetings. This motivation leads not to slip a teen club day. Facilitators have spoken of using different strategies that enable retain the adolescents.

# 3.3.3.1 CATEGORIZED CLINICS

A specified clinic dealing with specified issues for example counselling on adherence result in sincerity of the adolescents and more willing to express what they are going through. The facilitators revealed that girls are given a special treatment on specific issues that affect them.

And mostly the girls are also being given a special care by the Women adolescent facilitator who is helping them [respondent 2]

#### 3.3.3.2 SNACKS AND TRANSPORT REFUND

Many facilitators felt the need to offer snacks and transport refund for the adolescents.

The adolescents get highly motivated.

Yes, we use snacks, we provide lunch, and they are given another snack when going and we do give them transport when going back home. [respondent 1]

However, in other facilities snacks are offered but there is no transport refund.

Facilitators complained that transport should be refunded because some teens travel from far.

I feel that the food given to them is just too much, I think if they can reduce the amount of money used to buy the food and be used for transport for them. It is my wish that the teens be provided transport as a way of motivating them [respondent 3]

# 3.3.3.3 FOLLOW UP THROUGH CALLS

In some facilities they have advanced in using phone calls to follow up teens that miss a teen club day. With a phone call the facilitators get truck of even the adolescents who are loss to follow up.

we use calls for those that have missed their clinic days [respondent 1]

# 3.3.3.4 GUARDIAN SESSIONS

Most parents tend to leave out their parental responsibility onto the facilitators just because the adolescents are attending a teen club. Thus, the study sought to find if there is any involvement of parents and guardians in the nurturing of the teens at the teen club and how often are the parents involved in the teen club program.

we do give guardian session also, because we discovered that most parents

leave that huge responsibility to us and they do not follow what is happening with their teen. Yes, we have a plan like after every 3 months we meet the guardians to share the experiences and discuss with them how they can handle and deal with their teen in their respective homes. [respondent 1]

# 3.4 CHALLENGES THAT LIMIT TEEN CLUB PARTICIPATION

This theme involves the common challenges among facilitators which they have noted to have affected the adolescents in participating in the teen clubs. Facilitators explained that the challenges bring different perspectives among the adolescents. For example, coming from a poor family as a challenge, has a positively influenced the teens to actively participate in the teen club meetings.

## 3.4.1 SOCIO ECONOMIC STATUS OF THE ADOLESCENTS FAMILIES

The facilitators have indicated that adolescents from poor families enthusiastically patronize the teen clubs and they usually never slip a meeting day.

mostly those teens who come from low socio economic status do not easily give up on attending the teen club sessions while as those from well to do families do give up on attending the sessions [respondent 3]

By contrast, other facilitators have indicated to have a mixture of teens from both rich and poor families and they have described no difference in terms of patronization of the teens.

We have a mixture of classes because our teen club we do intensify on love, so we are not much considerate on where exactly they come from, but yes different classes do meet, poor, and rich. We have teens from high school, academy here we do not negotiate [respondent 1]

## 3.4.2 Transport Costs and Long Distance

Although other facilities reported to have snacks and refreshments for the teens, they have further expressed lack of transport and long distances as a challenge. Some facilitators reported that lack of transport for the adolescents let them be absent for a meeting.

....But another thing is lack of motivation to the teen that come from poor families because a lot of them come from far distant places, so if it was possible to refund their transport, I mean just the snacks are not enough on its own. [respondent 2]

# 3.4.3 TEENS' LACK OF KNOWLEDGE ON HIV

In some adolescents lack of knowledge becomes a barrier to fully understand and participate in the teen club, especially when these teens come from low income families. This made facilitators to conclude that the teens from these poor families face trauma and stigma, and thus do not participate fully in the teen club activities

We face difficulties with those teens from low income families due to lack of knowledge. As a result, they are stigmatized. They experience trauma in their life. [respondent 6]

## 3.4.4 INFRASTRUCTURE

Some facilitators felt a need for a conducive environment. Because a well conducive place ensures safety and privacy. When the environment is not conducive enough the adolescents are frustrated and do not come to attend in fear of violation of their privacy.

having a proper infrastructure which will guarantee privacy, apart from what we

use. I would say the environment that we have is not conducive [respondent 2]

## 3.4.5 HUMAN RESOURCE

Many facilitators complained of shortage of staff to facilitate a teen club for example, counsellors. This affects good performance of the teen clubs in that other processes that need to be done are forgone because the workers are overwhelmed with workload.

We need also adequate clinicians, nurses and other workers for the process of counselling these teens [respondent 4]

Despite the shortage of human resource in some facilities, other facilities have reported to have adequate human resource to run their teen club. Thus, adequate facilitators are there to deal with even the troublesome teens that disturb other teens during the process.

we have adequate human resource. And we have adequate mentors that do that.

So far we have 26 mentors, but on each meeting we have 19 mentors that do come. So these help in dealing with these knotty teens [respondent 1]

#### 3.5 SUGGESTIONS AND RECOMMENDATIONS FOR SMOOTH RUNNING OF THE TEEN CLUB

This theme reports the suggestions and recommendations that facilitators suggested to assist the smooth running of the teen club.

# 3.5.1 GOVERNMENT SUPPORT

Some facilitators explained that implementation of the teen clubs should be done in liaison with the government. They feel that the government leaves out a whole huge responsibility on donors. They have reported that the government should train adequate health care workers specifically for facilitation of the teen clubs

I think that the government should take part in these teen clubs. They should

work together with the donors, not just leaving everything to the donors. Just like how nutrition program is done. We want to have well trained human resource for the teen clubs [respondent 5]

## 3.5.2 INCLUSION OF MALAWIAN EXAMPLES

Other facilitators suggested that the teen club's activities should be practical in the sense that they are manageable by the health workers. They have reported a need of including Malawian examples in the curriculum. For example, some of the vegetables they indicate should be the ones that a lay Malawian know and can afford to buy.

I also feel that they should include Malawian examples for example they should give examples like known vegetables and not giving us an example like lettuce [respondent 3]

#### 3.5.3 PROACTIVE FACILITATORS

In other facilities, it was reported that the facilitators tend to be lenient on the adolescents, but it was recommended that the facilitators should be very proactive in how they handle the adolescents.

sometimes some teens would want to be pompous (mashasha) and they like dominating, so that takes us as a challenge, because with their silly comments they distract the audience of their friends what matters is for the mentors to be more active, the mentors should be very more proactive to help these adolescents [respondent 1]

Some facilitators reported that younger teens do not participate in the topics that directly involve a larger cohort of older teens. For this reason, other facilitators have selected a few topics suitable for younger teens and other topics suitable for the older teen to ensure flexibility.

we have discovered in the curriculum that younger teen when teaching the topics do not benefit since we have a large cohort of older teens dominating and these younger teens do not even answer questions they are always quite [respondent 1].

# 3.5.4 ESTABLISHMENT OF A ONE STOP CENTER

Some facilitators suggested that the teen club should offer all the services that a teen would need, since some services are just being told and referred to, but in essence they are not provided by the facility.

We would want to have a one stop center for all the services right here. Because we only teach them, but we would want to give them access to those that would love to use them. For example condoms [respondent 1]

## 3.5.5 PERFECT TRANSITION TO ADULT CARE

Throughout the interviews, the facilitators recommended that the teens should go through a perfect transition process, where the teens move from the teen club to adult care. Because the teen that are due for transition are reluctant to transition because they lack adequate training on how they can cope with the adult care environment.

it is my plea that the benefits and all the activities that we do here at light house, I would have loved if it spreads to other health centers. Because these teen clubs are really helping so it was better to be doing such activities together with other health facilities. Like transition, most of the health centers do not do that, but that transition process is really helpful since it prepares them for that other life on adult care [respondent1]

## 4. DISCUSSION

This chapter reflects on the main findings of the research in terms of its contributions to the key issues on the case studies and questions raised when implementing HIV teen clubs. The key issues are existence of teen club guidelines, extent of compliance to teen club guidelines and barriers that limit facilitators to comply to the teen club guidelines.

#### 4.1 EXISTENCE OF TEEN CLUB GUIDELINES

Although the guidelines for running the teen clubs exist in some facilities, certain elements are not trailed. The teen club curriculum is a booklet designed to guide facilitators of teen clubs in a program to provide psychosocial support for its participants, who are HIV-positive adolescents (16,17). The teen club offers information on how the adolescents can mitigate stigma, how they can build their self-esteem as well as attainment of support on mental health and wellbeing. This corresponds with other studies that were conducted in which it stipulates that when teen clubs are implemented following the guidelines, there is a likelihood that the ART adherence of the teens improve for the better (25). An implication of not having a guideline and not following it could be that other components would be left out when facilitation and the delivery of the activities would be done without fidelity, hence compromised. (12,16).

# 4.2 EXTENT OF COMPLIANCE TO TEEN CLUB GUIDELINES

The activities done at the teen club compliment the delivery and patronization of the teen club meetings. Compliance of the guidelines is facilitated with training of the facilitators, in which encompass activities that are done at the teen club meeting. Activities tend to be different from one facility to the other. They ranged from facilitated art, drama sessions and youth targeted in door games and sport (37)(38). Training of

facilitators has proved to be a better way of retaining teens and improved retention on treatment at the teen clubs based on a study that was conducted (25). It is evident that teen clubs are largely established by a non-governmental organization called BAYLOR, and further, it is recognized that the existence of teen club guidelines affect the apparent running of the teen clubs. Advantages derived from the activities done at the teen club are promoted with the training of the teen club facilitators and the usage of the teen club guidelines. Well trained facilitators will upshot on how to deal with the adolescents in an effective and subtle manner. Furthermore, they will pay attention to special characteristics of adolescents and respond to them more effectively and with greater compassion(38).

Compliance of guidelines is well articulated in following on the meeting time and day of the adolescents if it is conducive. The teen clubs meet on Saturdays which is in line with the teen club recommendations. This corresponds with the teen clubs' guidelines in other African countries for instance Swaziland where it is described that it is equally important on the structure of the clubs onto when the time the clubs meet. The time is important because teen Club activities be scheduled in a way to enable the teens to prepare well and not to miss classes at school. The meeting schedule should as well incorporate participation by teens who have responsibilities at home, or who have to travel long distances to reach the Teen Club venue (16)

The general understanding of different methods used to maintain the adolescents at the teen club have a profound impact on the adolescents' participation in different activities that are offered. The outcomes can impact their academic performance as well as answering their social and emotional needs. The strategy on giving out some incentives for example snacks and refreshments, places the adolescents with power to stay longer at the meeting day (16). Despite all the effort that the facilitators offer

through the NGOs to the adolescents, some parents do not render the support required to the adolescents. Siblings and family support leads to the adolescent's adherence to their medication. Indeed, the family's supportive environment, plays an integral part in enforcing the adherence to

treatment (15,20,39,40). The use of parents helps to retain teens that have high viral loads and teens that miss teen club meeting. The rationale behind agrees with other studies conducted where it was suggested that reinforcement of family closeness and support to the adolescents result in adherence to their treatment as well as good attendance at a youth friendly service (38,41,42)

# 4.3 BARRIERS THAT LIMIT FACILITATORS TO COMPLY TO THE TEEN CLUB GUIDELINES

#### 4.3.1 LACK OF KNOWLEDGE

As with previous studies facilitators do face multiple challenges that impede their ability to discharge duties effectively as stipulated in the curriculum. These challenges were either due to the adolescents, their parents/ and guardians or the system/ facility. Lack of knowledge on HIV for the adolescents collaborate other studies reporting the challenges faced with the facilitators suggesting thorough training for the adolescents on how to facilitate the teen clubs. In sub Saharan Africa, just 26% of adolescent girls and 33% of adolescent boys aged 15-19 years have comprehensive HIV knowledge (26,43). In other studies, it is highlighted that Knowledge of how HIV is transmitted is crucial to enabling people to avoid HIV infection, and this is especially exact for young people, who are habitually at greater risk because they may have shorter relationships with more partners or engage in other risky behaviors. Thus, it is argued that some adolescents lack adequate knowledge on HIV that would enable them grasp the

importance of attending the teen clubs and not miss mainly due to poor access to information (39,44,45). These findings are in agreement with what was found in other studies, that there is an absence of information about adolescents sexual and reproductive health and rights (46) and they do not know where HIV services are or how to access them (39,47)

#### 4.3.2 LACK OF FAVORABLE INFRASTRUCTURE

In addition, there is need to provide conducive and convenient places for the meeting of the adolescents, that ensure safety and privacy, as the current ones are not conducive at all. The rooms for a teen club should be adolescent friendly as in safe, spacious and supportive, where the adolescents are free to learn and talk about issues on Sexual Reproductive Health and HIV (39,48,49). The findings continue to demonstrate that safe spaces should be well equipped with indoor/outdoor games and other forms of edutainment that make the teen club sessions interactive and attractive to the adolescents (39). Lack of infrastructure with privacy in the teen club meetings can result into what is known as environmental stigma (20).

#### 4.3.3 SHORTAGE OF HUMAN RESOURCE

Shortage of human resource was also associated with poor delivery of the curriculum content. In other studies it is acknowledged that shortage of human resource is one of the major constraint to scaling up HIV/AIDS treatment and care which a teen club falls into (42). Due to this shortage it poses a heavy pill burden of a teen club facilitator or a health care worker per patient (20,50,51)

#### 4.3.4 PARENTS / GUARDIAN SOCIAL ECONOMIC STATUS

The socio economic status of either parents or guardians has a likelihood of influencing the participation of the adolescents to the teen clubs. In other studies, it is

indicated that "Adolescents are not yet financially independent; they depend on adults for transport fares. If the caregiver does not have money for transport, there is a high chance of the adolescent under their care not to collect ART medicine in time, resulting in missing to take some doses, a situation that constitutes poor adherence." (20,49,52). These findings continue to demonstrate the need for increased support of these adolescents especially the ones that come from low income families (45,52). It is worth noting that financial uncertainty negatively affects the adolescent's ability to attend medical appointments and collect their ART prominent to periodic gaps in medication adherence (41)

#### 4.4 POSSIBLE CONSTRAINTS

The findings of this study are limited to the teen clubs that were purposively sampled. We acknowledge that some teen club facilitators were interviewed even though they had not facilitated a teen club for more than a year. The small number of participants enrolled, limited the strength of the study and such the results cannot be generalized.

#### 5. CONCLUSION AND RECOMMENDATIONS

This chapter highlights the conclusions and recommendations identified after substantially analyzing the findings of the study.

#### 5.1 CONCLUSION

From the results, the assessment has generated information on attributes that lead to compliance and noncompliance of HIV teen club guidelines in relation to implementation fidelity of the teen club intervention. The results should assist in the designing of future intervention for the Youths Living with HIV and improvement on the existing intervention to achieve their intended goal. There should be an evaluation

system that should guide and analyze if the teen clubs are being implemented in line with the developers' goals. As it stands, a teen club cannot be operated without the designated guidelines that are established to be tailed. The training of teen club facilitators absolutely influences the compliance of teen clubs' guidelines and delivery of the content; thus, implementing the teen club with fidelity meant to enhance ART adherence.

#### **5.2 RECOMMENDATIONS**

Given that the teen clubs do not have guidelines for running the club activities it is strongly recommended that:

- All the teen clubs should be given the guidelines for their running of the activities
- Teen club facilitators should attain the required training for them to faithfully follow and remain to the guidelines.
- Facilitators should strongly be encouraged to follow the guidelines
- BAYLOR initiative should be highly recommended for the support offered to the teen clubs
- EGPAF should as well be acknowledged for the refreshments that they offer to the teens and facilitators.

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**APPENDICES** 

APPENDIX 1

CHICHEWA INFORMED CONSENT FORM

Leave box empty - For office use only		

#### University of Malawi, College of Medicine Kupempha chiloleza chotenga nao mbali mu kafukufuku

ACHINYAMATA PA NKHANI YAKUMWA MA ARV MWA NDONDOMEKO NDI MOSADUMPHITSA: KUFUFUZA NGATI MAGULU A ACHINYAMATA(TEEN CLUBS) AKUTHANDIZAPO PA NKHANIYI KU CHIGAWO CHA KUMWERA KWA DZIKO LA MALAWI.

Mukupemphedwa kutenga nao mbali mukafukufukuyi. Chikalatachi chiperekedwa kwa inu ndipo mufotokozeredwa mwatsatanetsatane zonse zokhudza kafukufukuyi. Dziwani kuti kutenga nawo mbali mu kafukufuku ameneyu ndi ufulu wanu, ndipo musachite mokakamizidwa. Yemwe acheze nanu mukafukufuyi akufotokozerani ubwino komanso chiopsezo chimene chingakhalepo pa moyo wanu pamene mukutenga mbali mu kafukufukuyi. Izi zikuthandizani kuti mupange chiganizo choyenera. Mukhale omasuka kufunsa funso linaliri lonse lokhudza kafukufukuyi.

Mkulu oyendetsa kafukufuku: Gertrude Kunje Magomero, Ophunzira ku College of Medicine

Dipatiment: School of Public Health, University of Malawi, College of Medicine. Keyala: College of Medicine, Private Bag 360, Chichiri, Blantyre 3

#### Chifukwa chiyani ndikupemphedwa kutenga nawo mbali mu kafukufukuyi?

Mukupemphedwa kutenga nao mbali pakafukufukuyi yemwe cholinga chake ndikufufuza ngati magulu a achinyamata (Teen Clubs) omwe anakhazikitsidwa mzipatala za boma zosiyanasiyana akutsatira buku la ndondomeko zoyenera pakayendetsedwe kagulu lawo. Tikufuna kudziwa zambiri pakayendetsedwe kama Teen club omwe adakhazikitsidwa pofuna kuonetsetsa kuti achinyamata omwe ali ndi HIV akumwa ma ARV mwandondomeko yake, mosadumphitsa. Mfundo zimene mugawane nafe zithandiza pakayendetsedwe ka ma teen clubs. Mwasankhidwa kutenga nao mbali mukafukufukuyi pozindikira kuti ndinu mtsogoleri wa teen club pachipatala chino.

Monga tanena kale, kutenga nao mbali mukafukufukuyi ndi ufulu wanu. Musawumirizidwe. Kuvomera kapena kukana kutenga nao mbali, sikukhudza konse ubale wa inu ndi woyendetsa kafukufukuyi, ogwira ntchito pa chipatala pano, sukulu ya ukachenjede ya za umoyo (College of Medicine) kapena wina aliyense, lero kapena mtsogolo muno. Mukasankha kutenga nao mbali, muli ololedwa kusiya kutenga nao mbali kafukufukuyu ali nkati, nthawi ina iliyonse pamene mwaganiza kutero pa zifukwa zina.

Dziwani kuti atsogoleri a ma teen club okwanira asanu ndi m'modzi mzipatala zazing'ono zosiyansiyana za mchigawo cha kumwera kwa dziko lino atenga nao mbali pa kafukufukuyi.

#### Kodi cholinga cha kafukufukuyi ndi chiyani?

Kafukufukuyi wakhazikitsidwa pofuna kudziwa ngati ma Teen club omwe anakhazikitsidwa mzipatala zazing'ono mdziko muno akutsatira buku la ndondomeko ya kayendetsedwe ka magulu awo. Ma Teen Clubs anakhazikitsidwa pofuna kuthandiza achinyamata omwe ali ndi HIV kuti adzimwa ma ARV mundondomeko yake, mosadumphitsa. Tikufuna kudziwa za mmene mumayendetsera ma teen club'wa achinyamatawa akasonkhana. Tikufunanso kudziwa za luso lanu pothandiza achinyamatawa akabwera kuno kudzapeza thandizo. Zomwe mutifotokozere zithandiza mabungwe osiyanasiyana komanso boma pa momwe angathandizire kupititsa patsogolo ma teen club'wa mdziko muno.

#### Kodi titsata ndondomeko yanji mukafukufukuyi?

Tikhala tikucheza ndi kukambirana pa malo a chinsinsi pofuna kudziwa ngati mumagwiritsa ntchito buku la ndondomeko zakayendetsedwe ka ma teen club. Ngati mumatsatira ndondomekozi, mumatsatira motani? Tikambirananso za zifukwa zina zimene zimapangitsa kuti musamatsate ndondomeko za m'bukuli. Kucheza kwathu kutitengera pafupi fupi ola limodzi ndi theka, koma sikuposera ma ola awiri.

Mukucheza kwathu tidzafuna kudziwa zambiri za inu; maphunziro anu, luso lanu poyendetsa teen club komanso za mavuto amene mukukumana nawo poyendetsa teen club. Tifunanso kudziwa maganizo anu pa zomwe mukuona kuti zimapangitsa ma teen club kuti asamayendetsedwe motsatira buku la ndondomeko lomwe linakhazikitsidwa. Tidzakambirananso maganizo anu pa m'mene ma teen clubs wa angayendetsedwere pofuna kuthandiza achinyamata kuti adzimwa ma ARV mwandondomeko komanso mosadumphitsa.

#### Nanga pali chiopsezo chanji potenga nawo mbali mukafukufukuyi?

Palibe chiopsezo ndi pang'ono pomwe pamene mukutenga nawo mbali mu kafukufukuyi. Simudzapweteka mwa njira ina ili yonse. Khalani omasuka kusayankha mafunso omwe mukuona kuti simuli okonzeka kuyankha.

Mwina nkhawa nkukhalapo kuti mwina anthu ena adzadziwa kuti munatenga nawo gawo mu kafukufuku ameneyu. Musadandaule. M'musimu tili ndi gawo lokutsimikizirani kuti mbiri ndi zonse zokhudza inu zidzasungidwa mwachinsinsi. Palibe yemwe angadziwe za mbiri iliyonse yokhudza inu, komanso zomwe mwalankhula mukafukufukuyi.

#### Nanga pali phindu potenga nawo mbali mu kafukufukuyi?

Phindu liripo ndithu. Inuyo mudzathandiza boma komanso chipatala chino ndi maganizo anu ndipo izi zidzathandiza achinyamata amene amalandira thandizo pa teen club ya pa chipatala pano.

Sipokhapo, maganizo anu adzathandiza boma ndi mabugwe onse okhudzidwa

kuunikira ndi kukonzanso mwina ndi mwina momwe zinthu sizimayenda bwino mu ma teen club.

#### Nanga chinsinsi chanu chidzasungidwa bwanji?

Patha kukhala chiopsezo choti mbiri yanu komanso zomwe mwanena pa kafukufukuyi zitha kuululidwa kwa anthu omwe sakupanga nao kafukufukuyi. Izi zaunikiridwa kale, ndipo pali ndondomeko zokhwima zomwe zidzatsatidwe posunga mbiri yanu ndi zonse zomwe mwafotokoza. Anthu okhao omwe akutenga nao mbali pa kafukufukuyi ndi omwe angadziwe zomwe mwanena; koma dziwani kuti iwo sangaziulule kwina kulikonse mwa njira ina iliyonse. Anthu ena pachipatalachi, malinga ndi udindo wawo atha kudziwa kuti ndindani yemwe akutenga nao mbali pakafukufukuyi.

Mbiri yanu komanso mfundo zonse zomwe mugawane ndi kafukufukuyi zidzasungidwa mwachinsinsi. Tigwiritsa ntchito manambala osati maina pofuna kusiyanitsa makalata omwe akugwiritsidwa ntchito polemba mayankho amafunso onse. Zikalatazi zidzatayidwa kafukufukuyi akadzatha. Mbiri yanu ingathe kuululidwa kwa ena pokhapokhapo inu eni ake mutaloreza polemba kuti izi zichitike.

Mfundo zonse zomwe mwafotokoza ndipo zalembedwa mu kafukufukuyi, zidzasungidwa mu kabati yokiyidwa bwino ku sukulu ya ukachenjede wa za zaumoyo. Palibe mfundo zomwe zingapite chisawawa kwa ena. Dzina lanu lokha basi ndi lomwe lilembedwe pa chikalata chovomereza kutenga nao mbali mu kafukufuku ndipo chikalatachi chidzasungidwa motetezedwa ndi mosiyana ndi zikalata zina.

Mfundo zonse zomwe zipezedwe mu kafukufukuyi zidzatayidwa pakatha zaka zitatu kuchokera pomwe kafukufukuyi atathere.

Pamene zotsatira za kafukufukuyi zidzasindikizidwa kapena kukambidwa m'misonkhano, dzina lanu silidzatchulidwa ndipo sipadzakhala chizindikiro choti ena nkudziwa kuti inu munatenga nawo mbali pa kafukufukuyi.

#### Ndilipira chiyani kuti nditenge nawo mbali pa kafukufukuyi?

Kafukufukuyi ndi waulere ndipo simupereka ndalama ina iliyonse.

#### Ndiyembekeze kulandira kalikonse potenga nawo mbali mukafukufukuyi?

Simulandira ndalama kapena mphotho inailiyonse mukasankha kutenga nawo mbali pakafukufukuyi

# Kodi ndingasiye kutenga nao mbali kafukufuku ali mkati kapena ndingathe kuletsedwa kupitiliza pamene kafukufuku ali mkati?

Mwaufulu wanu muli ololedwa kutenga nao mbali. Mwaufulu wanunso muli oleredwa kusiya kutenga nawo mbali kafukufuku ali mkati mutafuna kutero. Omwe mukucheza nawo mukafukufukuyu, nawonso ali ndi ufulu kukuletsani kupitiliza mu kafukufukuyu ngati ataona kuti simukutsatira malamulo kapena ngati ataona kuti mukuyankha mafunso mowinyawinya.

#### Nanga ngati ndili ndi mafunso ena okhudza kafukufukuyi, ndifunse ndani?

Ngati muli ndi mafunso ena okhudza kafukufukuyi, lankhulani ndi mkulu woyendetsa kafukufukuyi yemwe ndi ophunzira pa sukulu yaukachenjede ya College of Medicine (COM), Gertrude Kunje Magomero, pa nambala iyi 0996408396. Mukhozanso kulemba

kalata pa keyala iyi: College of Medicine, Private Bag 360, Chichiri, Blantyre 3.

#### Kodi ufulu wanga ndiotani ngati mmodzi mwa otenga nao mbali pakafukufukuyi?

Mwanjira ina iliyonse ngati mwaona kuti simunalemekezedwe kapena mwaphwanyiridwa ufulu, kapena muli ndi mafunso ena alionse pa kafukufukuyi, chonde tumizani madandaulo anu onse kapena china chilichonse chokhudzana ndi kafukufukuyi kwa akulu akulu oyendetsa za kafukufuku ku sukulu ya ukachenjede ya za umoyo. Imbani lamya pa nambala iyi1-871-911. Muthanso kulemba kalata pa keyala iyi: COMREC, Private Bag 360, Chichiri, Blantyre 3.

<u>Kumbukirani:</u> Kutenga nao mbali pakafukufukuyi ndi kwaufulu. Musaumirizidwa mwa mtundu ulionse. Chisankho chanu kulola kapena kukana kutenga nao mbali pakafukufukuyi sikukhudzana mwamtundu ulionse ndi ubale wanu ndi sukulu yaukachenjede ya zaumoyo. Mukasankha kutenga nao mbali muli ololedwa kuleka nthawi ina iliyonse. Ngati pali pena pomwe simunamvetse, kapena ngati muli ndi funso lina lililonse, mutha kundifunsa.

Ngati mwavomereza kutenga nao mbali pakafukufukuyi, chonde musaine dzina lanu m'musimu.

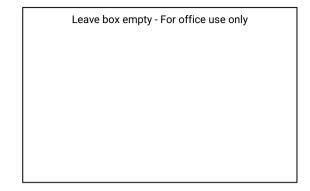
Kusaina mmusimu zitathauza kuti mwavo Mulandila kope ya kalata imene mwasainay	· ·	yi
Dzina la otenga nao mbali	Tsiku	
Siginecha		

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October, 2018

APPENDIX 2

**ENGLISH INFORMED CONSENT FORM** 



#### University of Malawi, College of Medicine Research Information and Consent for Participation in Research

# ANTIRETROVIRAL THERAPY ADHERENCE AND THE YOUTH: AN ASSESSMENT OF TEEN CLUB'S IMPLEMENTATION FIDELITY IN SOUTHERN MALAWI

You are being asked to participate in a research study. Researchers are required to provide a consent form to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask me any questions you may have.

Principal Investigator Name and Title: Gertrude Kunje Magomero, Student Department and Institution: School of Public Health, University of Malawi, College of Medicine.

Address and Contact Information: College of Medicine, Private Bag 360, Chichiri, Blantyre 3

#### Why am I being asked?

You are being asked to be a subject in a research in which we are trying to assess the fidelity of implementing the teen clubs that are meant to enhance ART adherence. We want to learn more about your experience in facilitation of ART teen Clubs at this health center facility. This information will help people understand how best to help and support the established Teen Clubs that are meant to enhance ART adherence among the youths. You have been asked to participate in the research because you are the mentor for the Teen Club.

Your participation in this research is voluntary. Your decision whether to participate or not will not affect your current or future dealings with the researcher, the clinic staff and or the University of Malawi. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

6 Teen club mentors from different health Centre facilities will be involved in this research.

#### What is the purpose of this research?

The purpose of this study is to assess the fidelity of implementing the Teen Clubs that are meant to enhance ART adherence. We also want to learn about your experience in facilitating the Teen Clubs in the Malawian context. The information obtained will help people and organizations understand how best to help and support Teen club intervention to be as effective as possible in the Malawian context.

#### What procedures are involved?

This research will involve an interview conducted in a private room at this clinic to establish the existence of guides/ manuals for implementing the teen clubs. Would also determine the extent to what level are the manuals adhered to and would also explore factors that influence compliance to teen club manuals. The interview will last about 90 – 120 minutes.

In the this interview you will be asked about your demographic background, your experience as a facilitator, your challenges faced in the facilitation process. I will also need to take down information on the characteristics of the teen that you engage with and your personal perceptions and suggestions on how best the teen clubs would be facilitated.

#### What are the potential risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. You are free not to answer any questions that make you feel uncomfortable.

Another possible risk of this research is a loss of privacy that is others knowing that you are taking part in this study. Below we will tell you how we will protect your information.

#### Are there benefits to taking part in the research?

The direct benefit for you is that you would contribute to the nation and to the hospital at large. Beyond yourself, we think the information that you provide will be useful in developing programs aimed at supporting interventions that are effective in the Malawian context

#### What about privacy and confidentiality?

A possible risk of the research is that your participation in the research or information about you might become known to individuals outside the research. We will protect your information and answers to the best of our ability. The only people who will know what you said in your interview are members of the research team. Others in the clinic may know who is a research subject.

All information will be kept confidential. We use identification numbers and not names to differentiate documents belonging to various people. These documents will be destroyed at the end of the research study. Information about you will only be disclosed to others with your written permission.

All information will be stored in a locked cabinet at the College of Medicine in Blantyre. No data will be shared. The consent form is the only document with your name on it, and it will be stored separately from the others in a locked cabinet.

All data will be destroyed 3 years after the study is completed. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

#### What are the costs for participating in this research?

There are no costs to you for participating in this research.

Will I be reimbursed for any of my expenses or paid for my participation in this research? No, participation in this research is voluntary and no any benefits would be received as compensation.

#### Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. The Researchers also have the right to stop your participation without your consent if they noticed that you were very uncomfortable with the questions.

#### Who should I contact if I have questions?

If you have any questions about this study or your part in it, contact the researcher conducting this study, Gertrude Kunje Magomero, student at the College of Medicine. Her cell phone number is 0996408396 and her address is College of Medicine on Private Bag 360, Chichiri, Blantyre 3.

#### What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the College of Medicine Research Committee, at 1-871-911 or e-write to College of Medicine on Private Bag 360, Chichiri, Blantyre 3.

<u>Remember</u>: Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the hospital or the Universities. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

If you did not understand anything or you want to know more, please ask me.

If you decide you want to be in this study, please sign your name.

Signing your name at the bottom means that you agree to be in this study. You will receive a copy of this consent document after you have signed it.

Name of Subject	Date
Signature	

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October, 2018

#### APPENDIX 3 KEY INFORMANT INTERVIEW GUIDE CHICHEWA VERSION

#### MUUNI WAMAFUNSO

ACHINYAMATA PA NKHANI YAKUMWA MA ARV MWA NDONDOMEKO NDI MOSADUMPHITSA: KUFUFUZA NGATI MAGULU A ACHINYAMATA (TEEN CLUBS) AKUTHANDIZAPO PA NKHANIYI KU CHIGAWO CHA KUMWERA KWA DZIKO LA MALAWI.

#### Mbiri ya oyankha mafunso:

Jenda	a. Mamuna b. Mkazi
Zaka	
Udindo wanu	Wamkulu oyendetsa Teen club
Maphunziro:	<ul><li>a. Pulaimale</li><li>b. Sekondale</li><li>c. Anadutsa sekondale</li></ul>
Ntchito:	a. Namwino b. Dotolo c. Zina
Mwakhala wamkulu woyendetsa teen club kwa nthawi yaitali bwanji?	

#### Mafunso ofunikira:

#### Mafunso okhudza ntchito ngati mkulu oyendetsa ku teen club pa chipatala.

- Kodi mwagwira ntchito yoyendetsa teen club kwa nthawi yaitali bwanji pachipatala pano? (Funsitsani ngati adagwiraponso ntchito ngati yomweyi pachipatala china)
- 2. Kupatula kukhala woyendetsa teen club, kodi ndi ntchito inanso iti yomwe mumagwira pachipatala pano? (Funsitsani kuti mudziwe kuti ntchito yawo yeni yeni ndi iti?
- **3.** Kodi mwagwirako ntchito kuma dipatimenti ena pachipatala chino? Ngati yankho liri eya, funsitsani kuti zawathandiza bwanji pakaendetsedwe ka ma teen club?

- **4.** Mungafotokoze zotani za ntchito yanu ngati wamkulu woyang'anira teen club?
- **5.** Pa teen club pano mumakumana ndi achinyamata amakhalidwe otani? Zochita zawo ndi zotani?

#### Mafunso okhudza luso pakayendetsedwe ka teen club

- **6.** Ma teen club adakhazikitsidwa chifukwa chani? Ndi ntchito iti yomwe amayenera kugwira? (Funsitsani kuti mudziwe ngati akudziwa cholinga cheni cheni cha ma teen club)
- 7. Kodi muli ndi buku la ndondomeko yakayendetsedwe ka ma teen club yomwe imakuunikirani za kayendetsedwe ka gululi? (Funsitsani kuti mudziwe ngati anaphunzitsidwa za kagwiritsidwe ntchito kake ka bukhuli. Afunseni maganizo awo ngati atsogoleri pamabuku amenewa.
- 8. Ngati bukuli palibe, mumayendetsa bwanji teen club yanu? (Fufuzani kuti amadziwa bwanji choyenera kuchita pakayendetsedwe ka teen club pamene alibe buku. Pa njira zomwe amagwiritsa ntchito, fufuzani kuti ndi iti yomwe amaidalira kwambiri ndipo ndi iti yomwe samaidalira kwambiri potsogolera teen club?

#### Mafunso okhudza za kudalirika kwa ma teen club.

- 9. Kodi mukuganiza kuti ma teen club amathandiza achinyamata ndi onse obwera ku teen club mwapayekhapayekha? (Fufuzani kuti zimathandiza bwanji. Yesetsani kuti oyankha mafunso apereke zitsanzo. Ngati ayankha kuti sizithandiza, fufuzani kuti sizimathandiza bwanji? Yesetsani kuti oyankha mafunso apereke zitsanzo kapena zifukwa.
- **10.** Kodi maganizo anu ndi otani pantchito yotukula m'mene ma teen club akuyendetsedwera? Kodi mungakonde kuti pachotsedwe ziti ndi ziti?
- **11.** Tasimbani za chidwi cha achinyamata pa ntchito ya ma teen club. Kodi amatenga nawo gawo motani?
- 12. Kodi mumagwiritsa ntchito njira ziti pokopa achinyamatawa kuti asamajombe ku teen club? (Kodi munayesa mwaimbirapo lamya achinyamata ena kuti abwere ku teen club? Nanga munayesa kugwiritsapo ntchito zakudya, ndalama kapena mphotho zina kuti muwakope a chinyamata? Munayesapo kugwiritsa ntchito makolo?
- **13.** Kodi ndemanga yanu ndiyotani pa njira zomwe munagwiritsapo ntchito pokopa achinyamata? Kodi zinali zofanana kapena zosiyana motani? Zinayenda motani?
- 14. Nanga mumakumana ndi mavuto anji poyendetsa ntchito za teen club?
- 15. Muli ndi maganizo anji pa zomwe zingachitike poyesa kuchepetsa mavutowa?

- **16.** Kodi teen club imachita chiyani poonetsetsa kuti achinyamata akumwa ma ARV mwandondomeko yake ndi mosadumphitsa?
- **17.** Kodi njira zomwe zimagwitsidwazi ndizokwanira? Ngati sizokwanira, nanga ndi chifukwa chiyani?
- **18.** Kodi kuwerengera kwa ma pilitsi, kugwiritsa ntchito makina akomputa komanso kuyezetsa magazi kuti achinyamata adziwe kuchuluka kwa tizilombo mnthupi mwawo kungakometsedwe bwanji kuti achinyamata adzikopeka?
- 19. Pafunika chani kuti maganizo anuwa atheke ndikupindulira achinyamata?
- **20.** Tingatani kuti mabuku a ndondomeko yakayendetsedwe ka ma teen club m'Malawi muno akhale aphindu kwa achinyamata m'ma teen club?
- **21.** Kodi muli ndi malingaliro ena alionse omwe mungakonde kugawana nafe pa nkhani ya kayendetsedwe ka ma teen club?

Zikomo kwambiri chifukwa cha nthawi yanu ndi povomera kutenga nao mbali pakafukufukuyi.

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#### APPENDIX 4 KEY INFORMANT INTERVIEW GUIDE ENGLISH VERSION

#### KEY INFORMANTS INTERVIEW GUIDE

ANTIRETROVIRAL THERAPY ADHERENCE AND THE YOUTH: AN ASSESSMENT OF TEEN CLUB'S IMPLEMENTATION FIDELITY IN SOUTHERN MALAWI

#### Demographic data:

Gender	c. Female d. Male
Age	
Role:	Teen club mentor
Education level:	d. Primary level e. Secondary level f. Tertiary level
Occupation:	d. nurse e. clinician f. Other
Length of service as teen club mentor/facilitator	

#### **Key questions**

#### Service

- **22.** How long you have been working as a teen club facilitator/ mentor at this health centre facilityl? (Probe: if have worked elsewhere as mentor)
- **23.** Apart from facilitating teen clubs, what services do you provide? (probe: which one is the main responsibility)
- 24. Have you worked in any other department of this hospital?
- 25. How can you describe your experience as a teen club mentor?
- 26. What is the general characteristic group of youths that you have worked with?

#### Teen club facilitation

- 27. What do teen clubs aim at achieving? (probe: what is their main purpose)
- **28.** Do you have any manual that guides you when facilitating? (probe: if they were trained on how to use the manual, what they think about the manual)
- **29.** If no manual, how do you facilitate? (Probe: what informs them what is done during facilitation; what do they find most effective, least effective way of approach when facilitating?

#### **Teen Club efficacy**

- **30.** Do you think the teen club help individual adolescents /participants? (probe: how it helps / does not help, any evidence or reason why they think so)
- **31.** what if anything can be done to improve the process, what would you like to exclude?
- 32. In general, what is the response/ participation overall rate?
- **33.** What strategy do you use to bring the youths together? (prompt: have you ever used calls..... snacks......incentives...... parents?)
- 34. Were the methods that you used same or different? How did it work?
- 35. What special challenges do you face when facilitating the teen clubs
- **36.** What suggestions do you have in terms of how we might mitigate these challenges?
- 37. What does a teen club do to ensure ART adherence of the adolescents?
- 38. Are these activities adequate? Why not?
- 39. How might pill counts, electronic systems, viral load be improved?
- **40.** What would be required to make the recommended requirement
- **41.** How best can we integrate the teen club manuals in the Malawian context.
- 42. Do you have any ideas that you would like to share?

**Closing remarks**: Thank you very much for your time.

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## APPENDIX 5 CERTIFICATE OF ETHICAL APPROVAL APPROVAL CERTIFICATE



### APPENDIX 6 MAP OF STUDY AREA

