

**INDIVIDUAL AND SOCIAL FACTORS ASSOCIATED WITH
ANTIRETROVIRAL TREATMENT ADHERENCE AMONG
HIV POSITIVE ADOLESCENTS ATTENDING CARE AND
TREATMENT CLINICS IN DODOMA MUNICIPALITY**

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By

Leonarda Cleoplace Pastory

**A Dissertation Submitted in (Partial) Fulfilment of the Requirements for the
Degree of Master of Public Health of**

**Muhimbili University of Health and Allied Sciences
October, 2017**

CERTIFICATION

The undersigned certify that he has read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled “*Individual and social factors associated with antiretroviral treatment adherence among HIV positive adolescents attending care and treatment clinics in Dodoma Municipality*” in (Partial) fulfilment of the requirements for the degree of Master of Public Health of Muhimbili University of Health and Allied Sciences.

Dr. Mughwira Mwangi

(Supervisor)

Date

DECLARATION AND COPYRIGHT

I, Leonarda Cleophace Pastory, declare that, this **dissertation** is my original work and that; it has not been presented and will not be presented to any other University for a similar or any other academic award.

Signature.....

Date.....

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DEDICATION

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ABSTRACT

Background: Treatment adherence is generally regarded as an important factor in achieving optimal outcomes across many disease states. Unfortunately, most HIV-infected adolescents find it extremely difficult to adhere to their dosing schedules consistently. ALHIV often face multiple barriers to adherence including structural barriers in fitting medication into complex patterns of daily life, low expectancy for outcome of antiretroviral therapy and mental health/substance abuse

The increased access to antiretroviral treatment (ARV), has resulted to children who have survived the diversity of the disease and are now adolescents or young adults. This cause the number of HIV positive adolescents to grow with high incidence rates. Adolescents are vulnerable to HIV due to the physical and emotional transitions, and potentially heightened risk-taking behaviour, inherent to this period of life

Following the UNAIDS post 2015 ambitious plan of averting HIV and AIDS in the globe, 90% of all diagnosed HIV positive clients should be initiated into life saving treatment, should be retained into care and be virally suppressed by the year 2020. To achieve this, all people initiated in ARV should remain in care and maintain good treatment adherence on ARV medication.

Objective: To assess the level of adherence and identify the individual and social factors associated with antiretroviral treatment adherence among HIV positive adolescents in care and treatment clinics in Dodoma Municipality.

Methodology: This was a cross-sectional study employing qualitative approach to data collection and analysis. The study population were seventeen HIV positive adolescents (10-19 years) who are on ARV medication attending at care and treatment clinics, twelve parents/care takers of HIV positive adolescents and six health care providers providing HIV care and treatment services at the two selected high volume facilities in Dodoma Municipal. The sample size was 24 indepth interview and one Focus Group Discussions (FGDs) with twelve members. Adherence level was measured using multi-method approach incorporating three different tool (self-reported, visual analogue scale and Pill identification tests).The setting was at the Care and Treatment Clinics during normal

adolescent clinic days at Dodoma Regional hospital and Makole Urban health centre in Dodoma Municipal

Findings: The findings in this study suggests that very few adolescents (2/17) have high or good adherence level (above ninety five percent) to ARV medication while majority (15/17) present low level of adherence. Delayed disclosure of HIV status, unfriendly time (school hours and during examination) were among the individual factors found to be associated with poor adherence. Fear of parents to disclose to their children due to stigma, inadequate knowledge on psychosocial support and unfriendly environments including families and schools were among the social factors associated with poor/low adherence among ALHIV.

Conclusion: Delayed disclosure has a big impact on ARV treatment adherence among HIV positive adolescents. Parents/care takers should be empowered to provide early disclosure to their HIV children to enable them cope with status. Family and communities should be supportive to ensure good adherence among ALHIV

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ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ALHIV	Adolescents Living with HIV
ART	Antiretroviral Therapy
ARV	Antiretroviral
CDC	Centre for Disease Control
CTC	Care and Treatment Clinics
DHIS	District Health Information System
DMO	District Medical Officer
DRRH	Dodoma Referral Regional Hospital
FGD	Focus Group Discussion
HCW	Health Care Workers
H/C	Health Centre
HIV	Human Immunodeficiency Virus
HIV+	HIV positive
IDIs	In-depth Interviews
MUH/C	Makole Urban Health Center
NACP	National AIDS Control Program
PIT	Pill Identification Test
RAs	Research Assistant(s)
REPSSI	Regional Psychosocial Support Initiatives
RRH	Regional Referral Hospital
TACAIDS	Tanzania Commission for AIDS
TZs	Tanzanian Shillings

UKIMWI	Upungufu wa Kinga Mwilini
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VAS	Visual Analogue Scale
VVU	Virusi Vya Ukimwi
WHO	World Health Organization YFS

CHAPTER ONE: INTRODUCTION

1.1 Introduction

This chapter presents the background to the study, the statement of the problem, the purpose or goal and the study objectives. It also includes the research questions, conceptual framework, and the rationale of the study.

1.2 Background

In 2015, about 1.8 million adolescents between the ages of 10 and 19 were living with HIV worldwide, about 1.4 million (80%) live in sub-Saharan Africa with adolescent girls being the most affected (58%). Adolescents account for about 5% of all people living with HIV and about 12% of new adult HIV infections (UNAIDS, 2015; 2016). In Tanzania, an estimated 81,000 adolescents (6% of all PLHIV) were living with HIV in 2014.

The increased access to antiretroviral treatment (ARV), has resulted to children who have survived the diversity of the disease and are now adolescents or young adults (Idele et al., 2014; UNAIDS/UNICEF, 2015). This cause the number of HIV positive adolescents to grow with high incidence rates. Adolescents are vulnerable to HIV due to the physical and emotional transitions, and potentially heightened risk-taking behaviour, inherent to this period of life (UNICEF, 2011a).

In 2014, the UNAIDS provided its post 2015 ambitious plan of averting HIV and AIDS in the globe. This plan aimed at initiating and retaining into ARV medication treatment 90% of all diagnosed HIV positive clients, and that 90% of all initiated and retained clients be virally suppressed by the year 2020. This will be possible if most people initiated in ARV maintain good treatment adherence to ARV medication.

In Sub Saharan Africa, only 37% of all people living with HIV aged 15 years and above had access to or were receiving life serving treatment and out of those, only 29% had achieved viral suppression by end of 2013 (UNAIDS, 2014 P.24).

ARV treatment adherence is referred to as a high level of person's sustained observance in taking ARV medication so as to suppress the viral replication and improve and reduce the risk of transmitting HIV (WHO, 2013).

High level of adherence on ART medication is believed to respond to suppression of the viral replication and improve immunological and clinical outcomes. It reduces the risks for new HIV infections and HIV related deaths (WHO, 2013).

Adolescence being a challenging age that it is, adolescents living with HIV/AIDS encounter difficulties of a more personal nature such as self-awareness, defining their identity, building their peer group, making plans for the future and dealing with their sexuality (Idele et al., WHO, 2013, 2014; UNICEF, 2015)

Treatment adherence is generally regarded as an important factor in achieving optimal outcomes across many disease states (Nsimba, 2010; Schaecher, 2013). Unfortunately, most HIV-infected youth find it extremely difficult to adhere to their dosing schedules consistently (UNICEF, 2016)

Although coverage data on adolescents receiving treatment is limited, adolescents' access to and uptake of ARV treatment is often reported to be lower than for other age groups (UNICEF, 2016)

Poor adherence to antiretroviral therapy (ART) among adolescents is associated with a number of factors including lack of psychosocial support, living with non-parental care taker, treatment longevity and unfavourable school environment and being unaware of HIV status, (Ankrah, Koster, Agyepong, & Lartey, 2016; Close & Rigamonti, 2004; Nyogea et al., 2015).

In Tanzania, HIV and AIDS pose a significant public health threat with adolescents and young people. This population accounts for more than 5% of all people living with HIV in the country (UNAIDS, 2015). By end of June 2017, there were 920,565 patients initiated on ART in the country. Out of those, 38,196 were tested for viral load and out of these, 2,518 (6.4%) were identified with high viral load of more than 1000 copies per mills (DHIS2, 2017). Although there is limited data with age segregate for adolescents on ART coverage, it is believed that adolescents is the major group with poor adherence and low viral suppression.

Few studies conducted in Tanzania on ARV treatment adherence (Nsimba, 2010; Nyogea et al., 2015; Ramaiya et al., 2016) have primarily been focused on adults and children. The only study conducted by Daniel Nyongea on adherence among adolescents in Ifakara found that the optimal adherence among HIV positive children and adolescents (2-19 years) ranged between 40-84% (Nyogea et al., 2015). It is therefore important for this

study to explore on the individual and social factors associated with ARV treatment adherence among adolescents living with HIV in Tanzania.

1.3 Statement of Problem

Despite the notable decrease (40%) in AIDS related deaths among people living with HIV globally, HIV and AIDS continues to be a leading cause of death among adolescents in sub-Saharan Africa and number two globally. (UNAIDS/UNICEF, 2015; UNAIDS, 2015; Wang et al., 2016). Whilst ART has had a remarkable impact on long-term survival for people living with HIV, adherence to ARV treatment is reported to be poorer during adolescence for all adolescents living with HIV infections (Ankrah et al., 2016; Denison et al., 2015; Nabukeera et al., 2015).

Adherence challenges faced by ALHIV include structural barriers in fitting medication into complex patterns of daily life, low expectancy for outcome of antiretroviral therapy and mental health/substance abuse. Large pill burden if stigma and fear of disclosure; concerns about adverse effects; peer pressure and perceived need to conform or not remembering to take medications.

For effective health outcomes of ART medication among people living with HIV and AIDS, a high level of sustained adherence is necessary to suppress viral replication and improve immunological and clinical outcomes. It also helps decrease the risk of developing ARV drug resistance and reduce the risk of transmitting HIV (WHO, 2013).

In Tanzania, little evidence is available on ARV treatment adherence among ALHIV. The few available studies primarily focus on adults and children (Lyimo et al., 2014; Nsimba, 2010; Nyogea et al., 2015; Ramaiya et al., 2016). Available data shows that by end of June 2017, a total number of 38,196 had tested for viral load and 2,518 (6.4%) were found to have high viral load. Of more than 1000 copies per mill (DHIS2, 2017).

Although there is limited information about treatment adherence with specific age desegregate in the country, site data from fields (health facilities) shows that most adolescents with recorded HIV viral load results presents high viral load. This means that their adherence to ARV medication is questionable.

A study done in Ifakara Tanzania found that adherence level among children and adolescents (2-19 years) was optimal, ranging from forty to eighty four percent (Nyogea et al., 2015).

This research aimed at assessing the adherence level of ARV treatment with the associated individual and social factors among adolescents living with HIV in Tanzania.

1.4 Rationale

The unique nature and importance of adolescence mandates explicit and specific attention in health policy and programs. (WHO, 2014; (Literacy et al., 2010; NACP, 2013; UNICEF, 2011a; Yakob & Ncama, 2016)). The changes in adolescence have health consequence not only in adolescence but also over the life-course. Despite the many interventions being conducted for over three decades in HIV prevention, care and treatment services, there still reported new HIV infections among adolescents. In 2015, about 220,000 new HIV infections occurred (696 infections every day) among adolescents aged 15-19 (UNICEF & UNADS 2016)

Although there is limited data about adolescents of 10-19 years (most available data are categorized among the children under 14 years and adults above 15 years) in Tanzania, field experience shows that adolescents face biological failure and some have undergone ARV treatment failure. There is a need therefore to establish potentially effective psychosocial support intervention programs that will ensure and promote the idea of good adherence to ART treatment.

This research will contribute new knowledge about the intrapersonal and interpersonal (individual and social) factors affecting ARV treatment adherence among adolescent living with HIV in Tanzania.

Results are expected to help different stakeholders to strategies on how to best improve adherence of ARV medication among adolescents. It will also help sociality (all forming social part for adolescents) to be supportive and helping ALHIV cope with their status and adhere well to their ARV medication for their improved health outcomes.

1.5 Research Questions:

1.5.1 General question:

What is the adherence level and associated individual and social factors among HIV positive adolescents in antiretroviral treatment clinics in Dodoma?

1.5.2 Specific questions:

1. What are the individuals' perceptions on antiretroviral treatment adherence among HIV positive adolescents attending the care and treatment clinics in Dodoma municipal council?
2. What are the social factors associated with antiretroviral treatment adherence among HIV positive adolescent who attend the care and treatment clinics in Dodoma municipal council?

1.6 Research objectives:

1.6.1 Broad objective

The purpose of the study was to assess the level of treatment adherence and the associated individual and social factors on antiretroviral treatment among HIV positive adolescents who attend the care and treatment clinics in Dodoma Municipal.

1.6.2 Specific objectives:

The study was guided by the following objectives

1. To assess the individual perceptions on antiretroviral treatment adherence among HIV positive adolescents attending at the care and treatment clinics in Dodoma Municipal.
2. To assess the social factors associated with antiretroviral treatment among HIV positive adolescents who attend the care and treatment clinics in Dodoma municipal.

1.7 Conceptual frame work

The conceptual framework adopts the Ecological models of health behaviour which emphasize the environmental and policy contexts of behaviour, while incorporating social and psychological influences. The concept of an ecological model is that behaviour has multiple levels of influences, often including intrapersonal (biological, psychological), interpersonal (social, cultural), organizational, community, physical environmental, and policy issues.

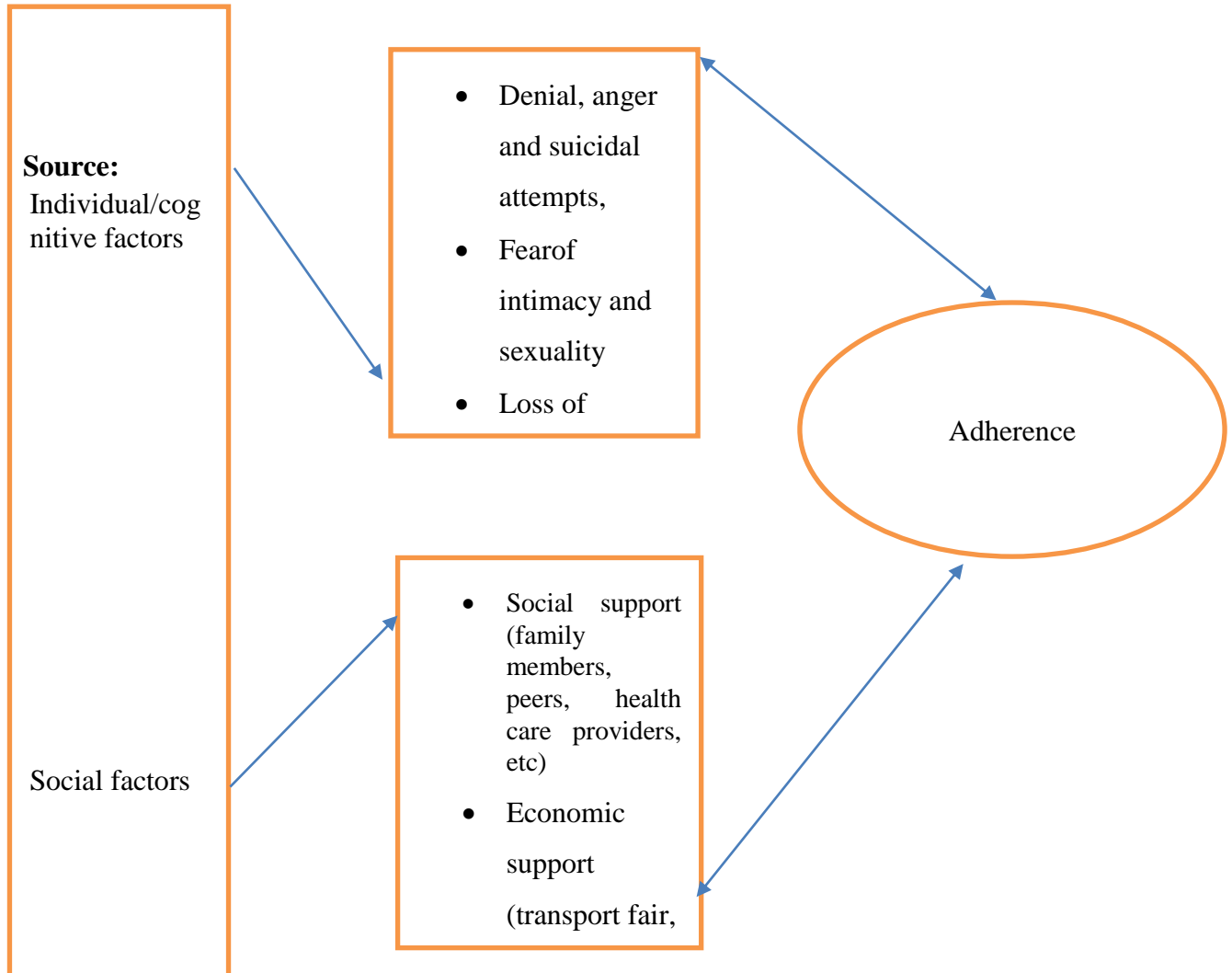
This study will focus on the two levels of ecological model which are intrapersonal (biological, psychological) and interpersonal (social, cultural). The Biological and Psychological aspects refer to individual perception on HIV, beliefs and emotions Social and cultural aspects include (social networks, family and social support.(Estripeaut et al., 2016; Kaufman, Cornish, Zimmerman, & Johnson, 2014; Mathieson, 2010; petersen I., 2011)

In adopting health behaviour, the physical, social and cultural context that we live in cannot be ignored and in fact have to form the basis of our understanding of health. Hence the individual and social factors affecting adolescent living with HIV are critical issue which cannot be ignored in the adherence to care and treatment service. The interplay between individual and social factors were investigated in this study so as to determine how they can influence either positively or negatively the treatment adherence among adolescents living with HIV in Dodoma Municipal.

In the intrapersonal level, the researcher is interested to find out if denial, anger and suicidal attempts, fear of intimacy and sexuality, loss of identity and social isolation contribute to poor treatment adherence among HIV positive adolescents. Similarly, at the interpersonal level, the researcher will assess if social support (family members, peers health care workers etc.), economical support and status disclosure have any influence or can be influenced by treatment adherence.

Below is the conceptual framework illustrating the above mentioned variables that are thought to influence and be influenced by ARV treatment adherence among adolescent living with HIV as adopted from the concept of social ecological model by McLeroy et al 1988as presented in the following figure:

A conceptual framework on the individual and social factors affecting and affected by adherence among adolescents living with HIV



CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

A literature review is an account of what has been published on a topic by accredited scholars and researchers. This chapter consist of both theoretical and empirical framework conducted previously by other researchers about the similar study topic.

2.2 Theoretical review

A social-ecological model

This model was used in this study to provide a comprehensive and clear understanding of the factors that hinder treatment adherence among HIV-positive adolescents. The factors that are related to ARV treatment adherence were identified at five different levels of influence (intrapersonal, interpersonal, organizational, community and public policy levels) (McLeroy et al 1988: P 351-377)

A social ecological model provides a promising framework for understanding the individual, family, and societal factors contributing to non-adherence to treatment of paediatric HIV. In this model, behaviour is viewed as being affecting and affected by a multiple level of influence in specific settings (Yakob & Ncama, 2016). The theory clearly stipulates that—in all social interventions—the interrelatedness and interdependency between individuals and their immediate social contexts should be taken into account (Masquillier et al., 2016)

In the context of HIV prevention, care and treatment, the individual (intrapersonal) level includes factors comprising the micro-level, such as individual perceptions, beliefs, or emotions. The interpersonal (social) level includes family influences, such as relationship satisfaction or social support, health care worker's relationship and peer support.

At the individual (intrapersonal) level of this model, HIV+ adolescents perceives themselves as worthless/ insignificant, and thinks that they will die soon because of their HIV status. This kind of feelings make them disappointed, as a result they become violent and sometimes refuse to take their medication as supposed to. Most of them tend to give up in their lives thinking that they will die. Since they are in the trial age (adolescence) others can decide to infect/spread the virus intentionally as a vengeance. (Rukundo et al, 2016; Shayo, 2014)

At the social (interpersonal) level, family, friends and peers plays a big role in influencing the individual's perceptions and decisions. Where family, peers, friendly and general social environments are supportive, HIV+ adolescents will be more likely to adhere effectively into their medication.

Contrary, none supportive environments have big effects on adolescents' lives including their adherence to treatment. Reports shows that, poor treatment adherence among PLHIVS is highly caused by lack of psychosocial support, stigma (both social and internal stigma) and discrimination, judgmental treatment, unfriendly health services and many other alike factors leads to suicidal attempts among adolescents living with HIV. They cause them to avoid intimacy and other sexual affairs; they cause them to withdraw/isolate them from other social affairs.

2.3 ARV Treatment Adherence among adolescents

Adherence means taking medicine consistently and as prescribed by a health care provider at least 95% of the prescribed dose (WHO, 2013). It is a routine action of taking ones HIV drugs when and how he/she is supposed to (Ankrah et al., 2016; Arg et al., 2016; Lyimo et al., 2014).

Firm adherence to antiretroviral treatment (ART) is important to unrelenting HIV suppression, reduced risk of drug resistance, improved overall health, quality of life, and survival. It decreases the risk of HIV transmission. (Ankrah et al., 2016; Nyogea et al., 2015; Schaecher, 2013). Propel living with HIV require at least ninety five or higher percent of adherence to ARV to achieve viral suppression for greater health outcomes.

Adherence to ART among adolescents has been noted to be relatively low (Lowenthal et al., 2014; Nabukeera-barungi et al., 2015; Nyogea et al., 2015). Evidence shown that for every 10 percent decrease in adherence, there is a 16 percent increase in HIV-related mortality among ALHIV (Steel, Gavin; Nwokike, Jude; Joshi, 2007; Nyogea et al., 2015). Some studies have indicated that being well/healthy is associated with adolescents' poor adherence in ARV treatment.

A study in Ifakara-Tanzania (the only study on adherence among adolescents in Tanzania), found that the optimal adherence level among adolescents in Tanzania was 70% and the average was 84%. Nevertheless, there has been no enough documentation of anti-retroviral (ARVs) treatment adherence and possible contributing factors to non-adherence among

adolescents living with HIV in Africa (Nabukeera-barungi et al., 2015; Nsimba, 2010; Nyogea et al., 2015; Ramaiya et al., 2016). Data shows that HIV related death is still the leading cause of mortality among adolescents aged 10-19 years (UNAIDS/UNICEF, 2015)

2.4 Factors associated with adherence to treatment

Adolescent adherence is particularly complex because of the socioeconomic pressures related to orphan-hood, neurocognitive deficits associated with chronic and severe HIV infection, and stigma and discrimination (UNICEF, 2011). ARV treatment adherence is influenced by not a single factor, but a number of factors. There are those which are social-economic related, patient and family related, health system related, and medical related factors. Others associates adherence with institutional and system related factors, medication related and psychological related factors (Nsimba S et al 2010; Reda A et al 2012; (Kaufman et al, 2014; Lowenthal et al., 2014)

2.5 Individual factors associated with treatment adherence among HIV positive adolescents

HIV remains highly stigmatised and for many HIV positive people there is frequently a fear of other people finding out. This can build a negative experience of having HIV, as it becomes viewed as shameful, emphasising difference (UNICEF, 2016, Pg 10-11). These negative associations can be internalised, and for the adolescent who is struggling to work out who they are, the negative social responses to HIV can lead to a profound experience of self-stigma (UNICEF, 2011b).

This can reinforce feelings of difference, isolation (particularly from peers) and being of less worth than others. Poor adherence and engagement in clinical care during adolescence is normal for all health conditions. The common perception of HIV being associated with an imminent death and limiting opportunities can lead to ALHIV becoming fatalistic and so their risk taking behaviour may be seen as more extreme than their HIV negative peers. (Fabianova, 2011; UNICEF, 2011a). ALHIV often experience low self-esteem and struggle to see a future for themselves. But adolescence is also a time of opportunity and creativity and it is important to remember that adolescence is a transition period that may be turbulent, but it will end.

ALHIV describe the impact of HIV making them feeling isolated and different. In all HIV prevalence settings, the stigma that surrounds HIV and the lack of people living openly means that ALHIV can feel like they are the ‘only one’. This sense of isolation and feeling alone can have a negative impact in ARV treatment adherence (Petersen I., 2011). Given the nature of adolescence in the context of HIV, the following issues can develop and affect their adherence in effective antiretroviral treatment.

2.5.1 Denial, anger and suicidal attempts

HIV/AIDS is associated with several clinical, psychological, and social factors which increase vulnerability to suicidal attempts as intensified by anger and denial. In their studies, Elizabeth Lowenthal and Godfrey Lukundo in Mbalala-Uganda and Gaborone Botswana consecutively, found that the rate of suicidal ideation and attempts among people living with HIV was high and the factors which were associated to that were anger and denial (Lowenthal et al., 2014; Rukundo et al., 2016)

Denial and anger have been associated with poor ART adherence among PLHIVs (Ankrah et al., 2016; Bezabhe et al., 2014; Cluver et al., 2015; Lyimo et al., 2014). Various studies conducted by Ramsey Lyimo (Tanzania), Chalmers Bezabhe (Ethiopia) and Daniel Ankrah (Ghana) basing on facilitators and barriers of treatment adherence among people living with HIV; found that people who are using ARV are more likely to stop taking their medication because of feeling healthy. They tend to deny the fact that being healthy doesn’t guarantee cure. Denial is been aggravated by perceived stigma and anger that make them stop for some time or completely taking their medication.

It has been noted also that some people react to HIV status news by denying it especially when they see that they are physically healthy (Fabianova, 2011), when this happen, the person tend to ignore taking medication as required hence poor treatment adherence.

2.5.2 Fear of intimacy and sexuality

Adolescents living with HIV require effective, targeted and sustainable HIV services to navigate safely through adolescence. Due to restricted access to accurate information, appropriate guidance, or comprehensive reproductive health services, HIV infected adolescence are more likely to experience significant unmet needs in their sexual and reproductive health and rights.

Other studies conducted by Elizabeth Closson and Mathew Mamiaga in Thailand, Zambia and Brazil on patients infected with HIV, found that however participants (PLHIV) had degree of awareness on some protective sexual behaviour, they still reported high level of struggles for intimacy and fears of isolation, including: fear of infecting a sex partner, guilt about sex, sexual communication difficulty, HIV-stigma, and worry about sexual partnerships (Closson E & Mamiaga M et al 2015; Guest, Bunce, Johnson, Akumatey, & Adeokun, 2005).

This was also noted by Mergui and Giami in their literature review study on “sexuality of HIV infected adolescents and thinking the unthinkable of sexuality”. They found that the subjective experience of an HIV-positive status among adolescents was rarely studied and the type and mode of contamination has an effect on the general sexual experience of being an adolescent. They urged for more researches to be developed on the subjective experience of HIV-positive adolescent sexuality and its impact on sexual experience (Tangmunkongvorakul et al., 2015).

2.5.3 Bereavement, grief and loss of identity

Adolescence is particularly a vulnerable period for HIV-infected people in relation to mental health problems and engagement in high-risk behaviour such as non-compliance with medical treatment (Murphy, Roberts, & Herbeck, 2013; Petersen I., 2011)

The patient, family members, caregivers, and physicians experience this grief, which has many dimensions and it is very complicated. In Petersen’s study on “Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa”, found that dealing with loss of biological parents in the case of orphans; coming to terms with their HIV+ status including identity difficulties; external stigma and discrimination; and disclosure difficulties, affected the general wellbeing of HIV+ adolescents.

It is obvious that death and bereavement is a difficult situation for every human being. Coping with the loss of beloved ones is hard to deal with. It is also evident that adolescents living with HIV may have more experience with death and bereavement than peers whose families have not been directly affected by HIV. Bereaved HIV positive adolescent suffer a

multiple loss that can lead them to more mental and physical impacts including withdrawal from social contact.

The WHO guideline for public health recommendations on adolescent HIV counselling and testing (2013) assert that grieving adolescents must be able to discuss and acknowledge their loss. They must have an opportunity to release their grief, and be encouraged to verbalize their fears. Their feelings should be validated and discussed, not dismissed or minimized (WHO, 2013c)

2.5.4 Social isolation

People with chronic illnesses such as AIDS worry about telling their family and relatives about their situation, some family and friends choose to detach because of fear of death, helplessness, shame and fear of acquiring HIV. Internalized stigma is noted by several researchers as a main contributor of social isolation (Estripeaut et al., 2016; Petersen I., 2011)

In her study on “HIV/AIDS Competent Household interaction between a Health-Enabling Environment and Community-Based Treatment Adherence Support for PLHIV” in South Africa, Caroline noted that people living with HIV rarely live in isolation, yet community-based interventions for supporting chronic HIV patients have largely ignored the social contexts in which they are implemented (Masquillier et al., 2016)

Social isolation has also been noted in Lenka’s study on Psychosocial Aspects of People Living with HIV/AIDS. His study reveals that PLHIV tend not to care anymore about things which made them happy, they submit to their fate, they do not see any hope and wait for the death to come (Fabianova, 2011).

Social isolation can be in parts; the patient him/herself and the social environment surrounding him/her. Due to natural sadness, the patient may lose the sense for relationship with parents, children, friends or life partner, as well as with other people. On the other hand, due to stigma, the social environment may isolate the HIV positive person for various reasons. All these can lead to good or poor treatment adherence.

2.6 Social factors associated with treatment adherence among HIV positive adolescents

For ART to be effective in the long term, it is important that adolescents are supported to adhere to treatment and remain in care (WHO, 2013). Family and general social support is very crucial in the wellbeing of any individual's life. Family, friends and peers plays a big role in influencing the individual's perceptions and decisions. Supportive families, friends and neighbours can influence the behaviour of HIV positive adolescents and help to improve their adherence.

In a study done by Sharada and others found that lack of family support acted as a barrier to adherence and family arguments stopped them (adolescents) from taking medication (Wasti et al, 2012). Where family, peers, friendly and general social environments are supportive, HIV+ adolescents will be more likely to adhere effectively into their medication.

In reviewing the guidelines on the use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents, the National Institute for Health discovered that low level of social support, stressful events, nondisclosure of HIV status, denial and stigma were among the behavioural, structural and psychosocial barriers to effective adherence among adult and adolescents living with HIV (Arg et al., 2016).

Since adolescents depend much on parental/care givers' guidance and supervision, anything that comes from the people or environment surrounding him/her have an impact in his life. This can have positive or negative influences when it comes to adherence to ARV medication. The treatment, judgement or support they receive can affect their adherence to ARV medication. HIV status disclosure, stigma and discrimination, economical support and other factors were reported to be among the social factors affecting ALHIV hence have impact in their treatment.

2.6.1 Status disclosure

Adolescence can be a difficult, frustrating, challenging, demanding and unreasonable age that needs extra attention. Early or late disclosure in HIV positive adolescents determines their future life in coping with HIV status and medication adherence (Estripeaut et al.,

2016; Fabianova, 2011; Francis, 2009). HIV status disclosure is essentially linked to poor or good adherence to antiretroviral treatment. Studies have shown that early and proper disclosure in HIV positive adolescents promotes trust among family and healthcare staff, improve their access to support services better adherence, lead to improved family communication and promotes good mental and physical health (Francis, 2009).

The WHO report on Adolescent HIV testing, counselling and care in Implementation guidance for health providers and planner indicates that, “when adolescents living with HIV can disclose their status to a trusted family member or friend, they are more able to live positively with HIV..... disclosure creates a network (even if it is very limited) of people who can provide emotional and practical support” (WHO, 2013 Pg. 23). Therefore disclosure can play an important part in adolescents’ medication treatment

Moreover, the World Health Organization guidance for HIV testing, Counselling and care for adolescents living with HIV indicates that disclosure was associated with higher CD4 counts while nondisclosure was associated with biological failure at 48 weeks (WHO, 2013c). It is important to study this variable and see if it has any association with treatment adherence among adolescents in the context of Tanzania.

2.6.2 Income/economic support

Economic status plays a big role in treatment adherence. It determines the access to the health care services needed. This can include bus fair to and from the health facility, nutrition support and other related factors that can support or hinder an adolescent to access required treatment services. A study conducted by Woldesellassie and others in Ethiopia found that economic constraints impaired treatment adherence among people Living with HIV. Movements for seeking employment, food insecurity and lack of money for transport were among other economic factors that appeared to affect the level of adherence among PLHIVs in their findings (Bezabhe et al., 2014).

Other studies (Bezabhe et al., 2014; Fabianova, 2011; Petersen, 2011; Reda & Biadgilign, 2012) reports that social economic factors are very much linked to treatment adherence. It was reported that lack of financial support prevent caregivers of children or adult patients from collecting medication on time.

The issue of distance barrier or lack of transportation facilities to the ART clinic has also been noted. Moreover, some patients still believe that medications need to be taken with good meals otherwise it will lead them to side vomiting and other chaos. As a result they tend to avoid taking medication.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents Research Methodology used to answer the research questions so as to meet the intended objectives. The chapter contains description of the research design, area of the study, study population, sample and sampling procedures. Data collection methods and tools, analysis plan, study limitation and mitigation plans are also presented in this chapter. The chapter includes also ethical consideration.

3.2 Study Design

This was a cross-sectional study employing qualitative approach to data collection and analysis. The study was carried out in two health facilities (Dodoma RRH & Makole Urban HC) with large number of HIV positive clients in the care and treatment clinics. Data collection was done at care and treatment clinics at these facilities during normal clinic days for adolescent clients in order to get good number of participants.

3.3 Study area

The study was conducted in Dodoma municipal Council in Dodoma region. Dodoma is located in the central part of Tanzania, the country's growing city. The region population is more than 2 million with 94,250 being adolescent girls and boys aged 10-19 years (NBS, 2012). The region has 2.607.6km area with 157.6 inh.km² density. According to National AIDS Control Program report number 23 of 2013, there were 28,319 clients in 2012 enrolled into care in Dodoma region, among which 10,919 were current on ARV treatment (NACP, 2013)

As of December 2016, Dodoma municipal council had a total of 35,872 (10326 M and 25546 F) HIV positive clients receiving care and ARV treatment services in 21 care and treatment clinics available in the council. The District Health Information System (DHIS2) reports that in the year 2016 alone, a total of 15,570 (8694 F, 6876 M) adolescent girls and boys (10-19years) were tested for HIV, out of which 601 (3.9%) were found HIV positive (DHIS2, 2016). Although there is limited data on general treatment adherence and particularly for adolescents, the data above portrays a great

problem about this age group that needs immediate intervention as to determine the adherence level and its associated factors.

3.4 Study population

The study participants were HIV positive adolescent aged 10-19 years who are on ARV treatment and knows their HIV status, health care workers at those CTCs and parent/guardians of the HIV positive adolescents attending at the selected care clinics (Dodoma RRH & Makole U/HC).

Any adolescent who was on ART at selected facilities but not aware of his/her HIV status was not included in the study. Also those whose parents/care givers did not consent to be interviewed were excluded.

3.5 Sampling and sample size

3.5.1 Sample size

The study composed of 23 In-depth Interviews and one FGD (with 12 members). Participants in the IDI include 17 adolescent and (10 M, F7) and 6 health care workers (M3, F3). The FGD involved 12 participants (4 Male, 8 Female) who were parents/care givers of the HIV positive adolescents.

3.5.2 Sampling

Adolescent participants were selected with the help of health care providers in respective facilities upon prior information. A total of 18 (10 M, 7 F) adolescents had consented to participate in the study, but one was excluded due to the fact that she was not aware (not disclosed) of her HIV status. The 17 adolescent interviewed were selected basing on three age categories of young adolescents (10-14 years), middle adolescents (15-16 years) and older adolescents (17-19 years).

Of the 17 interviewed adolescents, 3 (2 M, 1 F) were young adolescents aged 10-14 years, 8 (5 M, 3 F) were middle adolescents between 15 and 16 years while 6 (3 M, 3 F) were older aged 17 to 19 years. This selection was purposeful for getting different views and perception among these age groups. The 6 health care workers interviewed were selected according to cadre. At each facility, one clinician, one ART nurse and one counsellor were interviewed in order to get different views in their experiences of

providing care and treatment services to ALHIV. All interviews were conducted at CTC in a special room set for the purpose. Privacy and confidentiality were highly guaranteed for all participants.

During data collection, adolescents who were informed of the study were requested to come with their parents/care givers so that we could have their consent especially for those aged below eighteen years. All parents of the 13 adolescents who were below 18 years, consented for their children to participate by signing in the consent form presented to them. Before signing the consent form, the researcher explained to them on the purpose of the study and they agreed to allow them.

After IDI, the researcher decided to conduct one FGD with parents/care givers to see their views regarding ARV treatment adherence among adolescents as they (parents) form an important part of social support for the HIV positive adolescents. However, this was very confidential that no information given by adolescents was shared with parents during group discussion. In this discussion, a total of twelve (12) participants (4 M, 8 F) were involved in the discussion.

For a parent to participate in this study, he/she should be a real guardian of an HIV positive adolescent, know the status of her child and or should be an HIV positive herself attending at that particular facility under study. A secure middle size room used for conferences at DRRH was set to ensure conformability for the discussion.

All participants sat in a round table discussion after they had been assured of confidentiality of their information's in the discussion. This discussion was mainly focussed on HIV status disclosure as a main factor (disclosure) that had been identified in IDI among adolescent participants as big factor associated to their poor adherence.

3.6 Data collection methods and Tools

3.6.1 Data collection methods

Using Swahili language, In-depth Interviews (IDIs) and Focus Group Discussion (FGD) were conducted to collect information from participants. Semi-structured interviews were conducted using key predetermined questions regarding individual and social

factors associated with treatment adherence among HIV+ adolescents. Interview guides were developed for use for all three groups.

3.6.2 Data collection tools

A trained research assistant on the study under investigation was involved to collect data. Interview guides and tape recorder for recording conversation during interviews were used so that the researcher don't miss points. Pens and note books were also used to record or summarize key points during conversations.

In measuring adherence level among ALHIV, a multi-method approach was deployed using three different tools (Visual Analogue scale, Pill Identification and simple self-report) (Steel, G. et al, 2007).

WHO guidelines states that accurate assessment of adherence is necessary for effective and efficient treatment planning (WHO, 2013). Without formal assessment, health care workers are unlikely to accurately identify adherent and no adherent clients, missing the opportunity for reinforcement and constructive interventions respectively.

The researcher in this study used multi-method approach to measure adherence level that will promote validity and reliability in making any decision resulting from this study's adherence measured.

Using VAS tool, the respondent was given a measure scale with numbers from 1-10 and was required to point at any number where he/she thinks fits his/her adherence level. Pill Identification Test (PIT), was used to identify if the respondents really know the type of and dose offered, time/schedule and instruction regarding that particular dose. In self-report method, participants were requested to honestly tell if they had ever missed any dose on the prescribed dose for the past one month.

3.7 Data Analysis Plan

After the interviews, the research assistants transcribed verbatim digitally audio recorded interviews in Swahili language. The second author frequently reviewed the transcripts using the side notes and relevant ideas were noted. Thematic content analysis was used to process all participants' descriptions along with identification of relevant concepts and ideas found in the transcripts linked to the topics of inquiry. Relevant ideas were categorized under specific themes and later coded.

The team agreed on the code definition so as to avoid double meaning. In order to ensure trustworthiness especially in the coding scheme, the codes were independently examined by an independent reviewer who was not part of the team who run query report for each theme before using them in writing the results. Themes were reviewed in order to ensure internal coherence and strong distinctions between them. The researcher then defined and named them in order to capture their essences before writing an analytical report.

3.8 Ethical consideration

The study received ethical clearance from Muhimbili University of Health and Allied Sciences through Institutional review Board. Letter of introduction was taken to Dodoma Regional Administrative Secretary office for approval. Parents/caretakers of all below 18 years' adolescents signed the informed consent forms for their children to participate in the study. The five adolescents who aged 18 and above consented for themselves.

Adolescent participating assented to answer the questions. Records were anonymised and patients were identified by unique identifiers during analysis and reporting. As per routine procedures in the clinic, patients who were identified with poor adherence levels were further followed up by physicians.

Secure places (special rooms) were reserved at CTC to provide privacy and free conversations between principal investigator and the participants. Participants had adequate information regarding the research and had freedom to choose or decline participation without giving any reason. They were assured before the study that declining participation would not in any way influence their present or future health care

CHAPTER FOUR: STUDY FINDINGS

4.1 Introduction

This chapter presents the findings from the study as analysed according to the objectives.

4.2 Characteristics of study participants

Out of 25 contacted adolescents to participate in this study, 18 consented to be interviewed. Of the consented adolescents, 17 were interviewed. Only one was not interviewed due to exclusion criteria that he was not aware of his HIV status by the time of data collection. All interviewed adolescents were aged between 11-19 years. They were all aware of their HIV status, were receiving their care and treatment services at one of the selected health facilities (Dodoma RRH or Makole). All informants were using ARV medication for not less than one year since initiation on ART (1-12 years).

More than half of adolescent participants (9/17) were in school/still studying. From the interview, most adolescents are orphaned. They either live with one parent or grandparent/relative after parents died. Only 3 out of 17 lived with their both or biological parents.

In the parents/care givers participants in the FGD, most parents are not employed, they are doing small businesses for a living. More than half (8/12) of participants in this group were females and most of them are also on ARV treatment. Half of participants in this group are married and live in the city, Dodoma Municipal. Just few (3/12) come from distant area to access treatment at the selected facilities. Parent participants aged between 32-71 years.

Table 1& 2 presents the demographic characteristics of both adolescent and parent participants in IDI and FGD respectively.

4.2.1 Table One-Adolescent participants (IDI)

Age (Years)	Sex	Duration On Art (years)	Education status (In school/ out of school)	Type of primary care giver
12	F	6	In school	Grand mother (Parents died)
14	M	3	In school	Grandmother (Parents died)
11	M	2	In school	Mother (father died)
15	M	12	In school	Biological parents
16	F	3	Out of school	Father and step mother
15	F	7	In school	Mother (father died)
15	M	6	Out of school	Grand father
16	M	10	In school	Aunt (Parents died)
15	F	8	Out of school	Brother and relatives
16	M	1	In school	Father (mother died)
15	M	11	In school	Biological parents
18	M	2	Out of school	Grand mother
19	F	10	Out of school	Mother (father died)
19	F	6	In school	Grandmother (parents died)
18	F	1	Out of school	Biological parents
19	M	12	Out of school	Self-care (parents died)
17	M	4	Out of school	Grand mother

4.2.2 Table Two-Parents/care givers participants (FGD)

Age	Sex	Residence	Marital status	Economic activity	Own ART use
32	F	Makole	S	Small business	Yes
35	F	Nkuhungu	M	Small businesses	Yes
59	F	Kisasa	S	Small business	No
48	M	Bahi	M	Employed	Yes
38	F	Viwandani	M	Peasant	No
71	M	Viwandani	S	Peasant	No
46	F	Makole	S	Small businesses	Yes
56	M	Viwandani	M	Employed	No
34	F	Chamwino	S	Small business	Yes
43	M	Nkuhungu	M	Small business	Yes
38	F	Kongwa	M	Employed	Yes
41	F	Makole	S	Employed	No

4.3 Adherence measure among adolescent participants

Definition of measures:

In this study, adherence measure used main three terms as used in the mult method approach tool as high, moderate and low adherence (Steel et al, 2007; WHO, 2013).

High adherence is referred to as a person taking 95% or more of his/her prescribed pills.

Moderate adherence is defined as a person taking 75% to 94% of the prescribed dose and

low adherence is described as a person taking 74% or less of the prescribed dose.

Findings from the study shows that most participants demonstrated fell between moderate and low level of adherence to ARV medication. Majority reported to have missed some doses in the past one month and either did not remember the name of the dose or were confused of the type of medication they were using during the interview. Very few reported high adherence level as they did not miss their pills or were knowledgable about the type and description of the medication they were in. the table below summarises the findings on the level of adherence among interviewed ALHIV.

4.3.1 Table Three-Adherence Assessment

Measurement tool	Measurement Level		
Self Report	NO to all Questions	YES to 1 question	No to 2 or more questions
#Respondent	6	11	0
Visual Analogue Scale	95%	74-94%	Less than 75%
#Respondent	3	5	9
Pill Identification Test	Dose, Time and Instructions	Dose and Time	Dose only or confused
#Respondent	5	10	2
Overall Adherence	High	Moderate	Low

From the table above, majority participants responded yes in the self-report measure, they reported to have not missed a dose or forgot to take their pill. In the second measure (VAS) majority participants pointed between numbers 1-9 meaning that their adherence level ranged from 10% to 90%. The last measure was on Pill identification test, most of respondent just remembered the type of medication and or time of taking them only. They did remember both type, time and instruction from the prescriptions provided by the health care workers.

4.4 Factors associated with ARV treatment adherence

4.4.1 Table Four-Themes associated with ART adherence from analysis of IDI and FGD

Knowledge And Perception	<ul style="list-style-type: none"> • General understanding of HIV/AIDS disease, how ARV work and the consequence of no adherence • Perceived benefits and burdens of treatment • Perceived risks /fear of life long treatment
Intrapersonal Experience (Individual)	<ul style="list-style-type: none"> • Disclosure of HIV status (feel deceived) • Tiredness of taking pills everyday • Presence or absence of biological parents • Home stability and financial concerns (food, transport,) • Boy/girlfriends • Fear about the future • Feelings of rejection and unworthy
Interpersonal Relationships (Social Part: Parents, Health Care workers, Teachers)	<ul style="list-style-type: none"> • Communication, counselling and/or conflicts with caregivers (fear to disclose status to children) • Others: support from family, health care workers, teachers and friends, role models, support psychosocial support groups, religious groups
Daily Life Environment (Social Life)	<ul style="list-style-type: none"> • Busy schedules and activity engagement • School environment and lack of privacy • Bad influences from friends • Experience of discrimination and/or internalized stigma of HIV/AIDS

4.5 Individual factors impeding adherence to treatment among adolescents

At an individual level, various factors were frequently mentioned such as late disclosure of HIV status by parents to adolescents, getting tired of taking drugs, bereavement and loss of identity, nutrition and bus fare issues. Other factors were such as anger and denial, time barrier and school hours or coincidence with examination time.

The social factors reported by care providers and parents/care takers included stigma and discrimination especially in schools, fear of parent to disclose to their children, nutrition and transport fare issues which cut across at all level. Lack/shortage of trained health service providers on psychosocial support and unfriendly environment for friendly adolescent/youth friendly services the care and treatment facilities were also mentioned to have an association in the general treatment adherence among adolescents

4.5.1 Late disclosure of HIV status

Adolescents feel deceived by not being told the truth. Some others become violent when they find out especially at a later age and can refuse to take drugs. *“....then it reached a time I refused to take the drugs. My grandmother was telling me that I had chest problems, but I wondered why I have never felt any chest pains. Then I stopped taking the pills to see if I will get sick...”* (Male, 15, IDI). *“Yes, being lied to be not good. It’s bad. This causes others to stop taking their medicine. Why hide it from me?”* (Female 18, IDI)

As a result, some adolescents attempts suicide when they come to find out the truth especially from others outside their parents/care takers.

“I got mad why she was not telling me the truth ...I found out from my nurse after several showing stubbornness regarding the drugs I was taking every month. I took ten Panadol pills so that I could die” (Male 17, IDI).

It was also reported that another adolescent lost his life because of this. He became frustrated and refused to eat and talk to anyone until his death. One of the health service provider says;

“.....we recently lost one boy in last month. He already knew his status but he was angry at his mother why she was not telling him the truth. He refused talk, eat or take his drugs. He died instantly” (HCW, IDI)

However, some parents and guardians gave a different impression that it was important for parents to disclose to their children. Some shared their experiences of what had faced them

due to late disclosure. One parent narrated sharing her experience with her situation in her son's disclosure;

"I beg you my fellow parents please tell them the truth and do it yourself. Don't underestimate your children's capacity. They can understand and if you don't they will question you..... My son was very clever, at first I didn't want to tell him because I thought he wouldn't understand a thing. But then he stated asking questions about why I was taking her to the hospital every month and not his siblings! He questioned why he was the only one taking pills every day and not his half-sisters!

I became frightened of how I should tell him. But then I called the nurse and explained to her, she told me to tell him the truth but I couldn't. Then I decided to take him (son) to her (nurse) and asked her to explain it to him. He cried so much, he asked me why mom? Since then he started isolating himself, he didn't want to go to school any more thinking that he was dying soon! But then I gained courage and explained to him. I thank God; he understood and regained his strengths back. He is now fine and doing well in his form four class".

4.5.2 Getting tired of taking the drug

This was reported by several adolescent participants that sometimes they get tired of taking the pills every day.

"Sometimes I get tired of taking drugs. I ask myself why am I taking drugs every day and others don't. Why am I the one to go to hospital every month and my siblings don't? (Male14, IDI).

Sometimes they refuse to attend their clinics unless they are motivated by something they demand.

"....he told me, if you want me to go to hospital you have to buy me a new trouser first..... I bought it and he accepted to come with me" (Female parent, FGD).

Another adolescent revealed that because of fear of being scolded by nurses at the clinic upon missing the appointment, they decide to attend every appointment as required and pick the pills but not take them.

.... "I tell you the truth sister, if ARV were for sale, I would be rich by now.If one goes to my cupboard will find plenty of bottles, when I get tired of taking them I put in cupboard

so that no one will notice am not taking them. I leave few pills in one bottle so that when aunt comes to count will think am taking them every day” (female18, IDI).

Some adolescents feel that taking drugs every day is a life sentence. They wish to take all drugs at once so that they get out of it for good. *“He asked me; ...Aunt, if you say these drugs are for life, why not then give me all the pills now so that I finish them now and not take them ever!”* reported one parent of a 13 years boy

4.5.3 School environment and lack of privacy

School time hours was also reported to affect ARV adherence among adolescents. This factor was reported by both parents and adolescents. For most of those taking double pills (morning and evening) reported to have been taking only one pill in the evening as one puts it;

“Most of the time when I go to school in the morning I forget to take my pill in the morning” (Female, IDI).

Wrong practice was also observed as some respondents reported to have been taking all the two doses at once in at night

“.....Or I take them both (double the morning and evening pill at once) in the evening” (Female 12, IDI).

Others reported that they miss taking their pills during school examination times. *“Sometime when I have an exam, I study till mid night. I skip taking my pill because it will make me sleep and not study again”* (Male 16, IDI).

This was also associated with stigma that most of adolescents studying do not take their morning pills while at school because their peers would know about their status and discriminate them.

“One day my friends saw me taking pills in the class, they started asking me what I was suffering from and lied that I had malaria. The following day I did not bring my medicine....then I stopped taking the morning pill. I take one at night or sometimes both” (Male 15, IDI).

4.5.4 Home stability and financial concerns (nutrition, transport issues)

These were also reported as impeding factors to treatment adherence. Some reported to have missed taking their pills due to lack of food while others reported that lack of

transport/bus fare were main reasons for them not to effectively adhere to medication. *“When you don’t eat well you fear taking them, they make you weak”* (Female 16, IDI). Service providers reported to have experienced such challenges where they attend those clients who present poor adherence due to nutritional issues. *“Sometimes they come here without taking anything any food, you look at them they don’t look well, their health are deteriorating due to poor diet.....when you investigate you will learn that they have diet issues and so they don’t take well their medication”* (HCW, IDI).

“I stopped going to clinic because some issues at home. When we go to school and grandmother is sick, she can’t find food for us. In the evening I don’t take medicine because am not okay. I would feel horrible if I did..... At the hospital, the nurse used to buy me food and I eat then go to school and take my pills. But then I had to stop going there again..... because she would buy food for me but what about my grandmother at home! She has no food. Then I stopped and never took the medicine for some months..... Until when my health got worse...” (Male 19, IDI)

Transport issue or lack of bus fare was also reported to have impact on treatment adhere among adolescents. *“....I have no bus fare to come to clinic. Uncle tells me that he has no money. I stay till when he gives me some and I come to pick my medicine”* (Male 13, IDI). *“Sometimes nurses would observe that I have missed my appointment, when I come they ask and I tell them that I had no fare to come”*(Male 14, IDI).

4.5.5 Stigma and isolation

Several respondents mentioned stigma and isolation as a barrier factor to ARV adherence among adolescents. This was presented in various ways ranging from an individual to social level. At an individual level, respondents reported to have felt unworthy and that it was useless to take the drugs. *“When I learned about my HIV status I was 12 years. I couldn’t eat, I felt helpless. I refused going to school and didn’t want to take the pills anymore.....because I felt I was dying anyway”* (Female 15, IDI). Internalized stigma seemed to destroy adolescents trust on ARV drugs.

Stigma was also revealed at social level, this was expressed in different ways from family members, schools and other public personalities.

“When my brother is not around, she (sister in law) denies me food. She prohibits me to touch anything in the house that I will infect them.... She even told my brother to chase me out of the house....” (Male16, IDI).

“She (blood sister) did not want to live with me. Her husband told her to take me to hospital but she refused, she never cared about my health.....she told me not to use the plates and not to teach her children again. I had to leave and go to my other sister in Dar es Salaam. I did not take my card or medication with me so I stayed for more than six months without them” (Female 18, IDI).

Stigma was also reported in schools as teachers tell parents to put special labels on the shirts of their HIV infected children so that they can be easily identified and not to be punished. *“Teachers tell us to put a red label on their shirts so that they can be identified”* (Parent, FGD). Due to this, sometimes parents or adolescents find it very hard to request permission to attend clinics. *“They told me to bring an official letter from the hospital explaining his (HIV+ adolescent) health problem so that they can give him permission to miss classes and attend his clinic appointment”* (Male guardian, FGD).

4.5.6 Denial, anger and suicidal attempts

Several respondents reported that due to anger and depression, they had sometimes refused to take their medicine as required. The feelings of being rejected or unworthy caused them to stop taking their medicine for some times; *“Yes, sometimes I get angry by myself and with everybody. I don’t want to hear anything including medicine”* (Female 17, IDI). Some others reported to have stopped taking drugs after feeling a bit better. *“Sometime they stop coming to clinic after feeling better, but they come back in bad shape”* (Health service provider, IDI).

Very few (2/17) reported to have attempted suicide after learning that they had HIV. This was mostly expressed as a result of delayed disclosure especially when parent hide the truth from their children about their status, they become violent when they come to find out by themselves. *“...I had not told him about the drugs he was taking..... one day we were watching television and he heard story talking about HIV testing... he quickly responded saying; “ if I were me found with the HIV, I will kill myself””* (Female Parent, FGD). *I felt furious, I asked myself why she was lying to me that I had chest pain..... I took ten Panadol pills so that I could die... ”* (Female19, IDI).

4.5.7 Fear of intimacy and sexuality

This was common among older adolescents who reported to have missed their doses due to fear that their sexual partners would dump them if they found out about their HIV statuses. *“No. of course I can’t tell him otherwise he will leave me. He can’t see me taking those pills..... When am with him I don’t take them”* (Female 19, IDI). Some reported to have been discriminated in their previous relationships and so fear to start another affairs. *“..... He found out from my best friend that I had HIV; he humiliated me in front of people in our street and told everybody about my status..... I don’t think I can ever love a man. Maybe being HIV + you don’t have that right....”* (Male 19, IDI)

4.6 Social factors associated with poor treatment adherence among HIV infected adolescents

Being asked about their thoughts towards treatment adherence among HIV + adolescents, health care providers reported that the general adherence among most adolescent was not good. Among other factors mentioned lack of food and bus fare issues, shortage of trained health service providers on psychosocial services to dealing with HIV+ adolescents and fear of parents to disclose/tell their children about their HIV statuses seemed to be a challenge as explained by a health care worker, *“It’s not that good indeed, most of them have few CD4 counts and frequently present opportunistic infections* (HCW, IDI).

On the other hand, parents and care givers presented different perception about their HIV positive children. Some (especially those who are not biological parents) felt like their children are troublesome and do not like take medication. *“Children are stubborn. They don’t want to take the medicine.When I remind her of her medicine she get mad and can even refuse to eat food”* (Male Guardian, FGD)

Some adolescents were reported to have been hiding themselves during the time of taking their medication. *“He asks me, when is the end of taking these medicine? Nowadays he tends to hide himself under his bed so that I don’t give him the medicine”* (FemaleGuardian, FGD)

Shortage of trained health care providers on psychosocial support among HIV positive adolescents was also mentioned as an issue towards supporting adolescents in ARV treatment adherence. Health care providers reported to have experienced difficulties in dealing with HIV positive adolescents for they sometimes present difficult cases to handle;

“It is hard to deal with them sometimes, they present serious issues that you don’t even know where to start, or others won’t talk even if you see them deteriorating physically and even clinically due to so many challenges that are hard to solve as a nurse..... We need to be equipped” (HCW, IDI).

4.7 Factors enhancing good adherence among HIV+ adolescents

Supports from family, teachers and health care providers, teen clubs and psychosocial support were reported factors to enhance adherence to treatment.

It was reported that adolescents from where the families are supportive present a good adherence level on treatment. *“I make sure that they eat well and take medication every day. Sometimes when I forget, they are the ones to remind me” (Female Parent, FGD).* *“....his health has improved tremendously, I make sure to count all the pills every day and make sure he takes them”.* (Female guardian, FGD)

Support from school enables them to attend clinic appointment properly. *“The teachers are supportive, when I request permission to go to hospital, they let me go. She told me that whenever I don’t feel well, I should rest at home no problem” (Male 16, IDI).*

It was also informed that some teachers are very understanding in some school. They understand and take responsibility in supporting the HIV+ adolescents especially when parents are open to them. *“At his school, teachers are nice to him.They told me it’s okay; when it’s time for hospital, I just inform them (teachers) and let him (adolescent) go to take his medicine. They really don’t disturb him at all” (Male guardian, FGD).*

It was reported that availability of psychosocial support and teen club meetings in health facilities enhanced treatment adherence among HIV positive adolescents. Asked on how they support their children to adhere well to medication. Parents whose children are attending monthly teen club meetings mentioned that those meetings have helped their children to change into positive living and are taking their medication well unlike in the previous days when they used to skip them,

“The other thing, I think it is the club. This has helped them. My daughter has changed completely--- I pray that they continue coming. Imagine she is now the one reminding me to give her the medicine!” (Female Parent, FGD)

It was also clarified that in supporting the HIV positive adolescent’s services, facilities have set special day for conducting children and adolescent health services so as to enable

them participate freely and learn from one another. The services are now provided on the last Saturday each month.

“We can really see the change in attendance and health improvement than when we did not have these special clinics services on weekends” (Health service provider, IDI)

4.7.1 Table Five: Summary of Findings

CATEGORY	ADHERENCE FACTOR
Individual factors associated to non-adherence to treatment	<ul style="list-style-type: none"> • Getting tired of taking pills • Late disclosure of HIV status by parent (being lied to or hidden by parents) • Denial, anger and depression • Fear of intimacy and sexual relationship • Poor or lack of food (diet and nutrition issues) • Stigma and isolation • Lack of bus fare/to clinic/health facility
Social factors associated none adherence to treatment	<ul style="list-style-type: none"> • Bereavement and loss of identity • Fear of parents to disclose to children • Lack of support from family members • School hours and during exams • Social stigma from schools and friends • Shortage of trained health care personnel's on psychosocial issues among HIV infected children and adolescents
Individual and social factors enhancing ARV treatment adherence among adolescents	<ul style="list-style-type: none"> • Support from friends, family members and teachers in schools • Support from health care providers • Peer support/teen clubs • Psychosocial Support

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This study was conducted in order to assess the adherence level among HIV infected adolescents and the associated individual and social factors. Although adolescents presented good knowledge on general understanding of HIV/AIDS disease, how ARV work and the consequence of no adherence, the general adherence level was moderate (below 95%). Several factors on perceived benefits (of taking ARV as required), the burdens of treatment and perceived risks /fear of life long treatment appeared to affect or be associated with poor treatment adherence among this group.

Some of the individual factors mentioned to constrain adherence include stigma and isolation, none disclosure of HIV status by parents/care givers, lack of food and bus fare issues. Others were denial, anger and depression, bereavement and loss of identity as well as fear of intimacy and sexual relationships resulting from stigma.

Fear of parents to disclose to their children, social stigma from schools and friends, lack of support from family members and shortage of trained health care providers on psychosocial support for HIV positive adolescents were among reported social factors impeding ARV treatment adherence among adolescent.

On the other hand, peer support/teen clubs, psychosocial support, early status disclosure, support from family members, teachers and health care providers were found to be associated with good adherence to treatment.

This study is one of the few to clearly identify factors associated with treatment adherence among adolescents in Tanzania. The findings in this study show that the adherence level among most (11/17) adolescents is moderate (75%-94%). Some (4/17) presented low adherence level ranging from 30% to 70% and very few of them (2/17) presented high level (>95%) of adherence to treatment.

A study on determinants of antiretroviral adherence among HIV positive children and teenagers in rural Tanzania, found that the overall average ART adherence level was 84.2% ranging from 2.3% to 100% (Nyogea et al., 2015). A similar study done in Ethiopia

using unannounced home based pill count versus caregivers' report on adherence among children, found disproportionately low rate of adherence at 34.8% (Biresaw et al, 2013)

Literature has reported that patients tend to overestimate their adherence in self-reports. By comparing urine assays with self-reports for short-term assessment of adherence ART, Rachel et al. found that 29% of participants in Rwanda had not taken the last dose that they reported taking (Baptiste et al, 2008).

On the other hand, studies by Nebukeera in Uganda and Nsimba in Tanzania, showed that the Adherence level to antiretroviral therapy for adolescents living with HIV was relatively good >90% (Nabukeera-barungi et al., 2015; Nsimba, 2010).

Therefore from this study findings, it is obvious that relying on a single tool for measuring adherence might not provide accurate results since most respondents tend to overreport especially on self-report and pill count is not reliable as many clients falsify on this. this was also noted in Janet's study in Thailand (Gare et al., 2015)

5.2 Individual factors associated with treatment adherence

On treatment adherence and associated factors, non-disclosure of HIV status to adolescents, poor or shortage of food and getting tired of taking drugs appeared to be the major factors for poor adherence. These factors cut across at an individual and social level affecting both adolescents and parents/care takers. Reports by various researchers in different studies (Ankrah et al., 2016; Nsimba S. et al 2010; Nyogea D. et al., 2015), shows that fear of parent/care takers to disclose to their children becomes a big challenge for good treatment adherence among adolescents in many places.

HIV disclosure for children and adolescents is stated in the WHO guideline, section of HIV testing, counselling and care for adolescents living with HIV that; "Children of school age should be told their HIV status and that of their parent/s or caregiver/s. Younger children should be told their status incrementally to accommodate their cognitive skills and emotional maturity".(WHO, 2013. P 23)

Nevertheless, this is not the case or practice in various situations where adolescents are often not aware of their own HIV status while continue taking the ARV pills. This was evident in my finding where out of 12 parents/care givers in a FGD, 8 revealed to have not

disclosed to their children. The main reasons reported was out of fear on how will the children take it and or by thinking their children are too young to understand.

One parent reveals that she has not told her son of his HIV status because of fear on how to tell him,

This non-disclosure is associated with significantly lower retention in HIV care and can cause adolescent to stop taking their pills. They feel they have been deceived when they come to find out from different people none parent or outside their families. Studies done in Uganda and Tanzania, found that delayed disclosure of HIV status by parents or guardians leads to poor adherence. Parents/caregiver feared to tell their children because they thought they could easily hurt themselves (Nabukeera-barungi et al., 2015; Nyogea et al., 2015)

From the study findings, it was clear that delayed status disclosure was caused by continued stigma in the society. Parents felt that if they disclose to their children, they (children) might reveal their status to others and so become stigmatised. Stigma was revealed in among family members and in schools where some teachers required parents to put a red label to their HIV infected children so that they can be identified at school and be excused from other duties.

Lack or shortage of food was also reported as a main barrier for good adherence to antiretroviral. As reported by service providers, some adolescents were found to have very high HIV Viral Load (HVL) results due to poor adherence. When their parents/care givers were called for enhanced adherence counselling, they reported to have challenges in getting food at home. Other adolescents reported had stopped ARVs at some time because of food issues.

As pointed out in various studies,(Mghamba et al., 2013; Nabukeera-barungi et al., 2015; Nsimba, 2010; Nyogea et al., 2015; Ramaiya et al., 2016; Ssali et al., 2014) most adolescents reported to lack food and complained of abdominal pain whenever they take the medicine on an empty stomach. This leads to loss to follow up and poor adherence to treatment.

From the semi structured interview results, denial and anger, social isolation and bereavement were reported to be associated factors to ARV treatment adherence among young adolescents aged 10 to 14 years. Most of the respondents were orphaned by either

one or both parents and live with their care takers most of whom are grandmothers. These are the mostly affected in treatment adherence especially when they remember their deceased parents they tend to refuse taking drugs as reported by one of care takers.

Moreover, fear of intimacy was observed to have been affecting older adolescents aged 17 to 19 years who are sexually active. Some of these presented dire stories of having experienced bitter relationships and had been damped /rejected by their sexual partners upon disclosing their sero status to them. It is evident that by this kind of treatment, most of those in sexual relationships do not disclose their status to partners and skip to take their medicine effectively whenever they are with their sexual partners so that they cannot find out about their status. this was evident in Luyi's study in Thailand when he found out that 5 out of 6 adolescent informants reported having to hide to take the medicine in fear of revealing their HIV status, and expressed concerns about lack of privacy when taking medications at school or with friends (Xu et al, 2017)

Other impromptu individual factors presented were such ach fatigue or getting tired of taking drugs every day, depression, giving up, alcohol and substance use and peer pressure.

5.3 Social factors impeding treatment adherence

Lack of support from family members was reported to be a main challenge that caused some adolescents to miss some doses of their ARV medication. As stated in Nebukeera, Nsimba and Nyongea's reports, family and peer support are very important to ensuring good adherence and retention into treatment for adolescents (Nabukeera-barungi et al., 2015; Nsimba, 2010; Nyogea et al., 2015).

This was evident as adolescents from supportive families and those without support presented different stories regarding their treatment adherence. Those with supportive families and friends reported to good adherence as they were reminded by their family members.

When asked of why they sometimes forget taking their drugs, the responses were different. One participant reported to have even stopped taking her ARV for some months due to stigma from her blood sisters that caused her to stop taking her medication for some months.

Lack of financial support (bus fare) and food was also reported to be associated with poor treatment adherence among adolescents. From the interviews, it was clear that some adolescents come from poor families where even food is a problem, and most of these are the ones with many viral loads.

When discussing with health care providers, they shared experience on dealing with HIV adolescent and the challenges they face regarding their treatment adherence.

Another response was from an adolescent who revealed to have once become a lost to follow up on treatment due to nutrition issues at home. This was also reported in Dora, and Godfrey's studies which cited that food insecurity posed a big threat on treatment adherence among people living with HIV in most Sub Saharan Africa (Estripeaut et al., 2016; Ramaiya et al., 2016; Rukundo M. 2016).

This seemed to also affect health care workers in facilities who face difficulties in supporting adolescents when they come hungry for their monthly appointments. As a result, they are sometimes forced to give their own money to buy food and support them.

Observation from this study shows that middle and older adolescents 15-19 years have more challenges in treatment adherence. This was evident as the researcher made follow up of the viral load results on the sample tested on May after data collection. This results suggested that of the 17 adolescents interviewed during this study on April, only two had good adherence with viral suppressed below 1000copies per ml at both facilities. The rest fifteen had high viral load above 1000 and were placed under enhanced adherence counselling sessions. Retesting was done on October this year. Close follow up is needed and perhaps might suggest a different picture or another study on this issue.

5.4 Strength and weaknesses in the study

5.4.1 Strengths:

The study is one of the few to assess adherence and associated factors among adolescents in Tanzania. The use of multimethod approach to measure adherence level was good to show how different tools work to reach or obtain validity in actual adherence rather than depend on a single measurement tool that might not be reliable as observed in some studies.

5.4.2 Weaknesses:

The issues of parental consent might have brought difficulties in getting right participants especially those whose parents/care givers could not come during the interview day. Also, the issue of sex among adolescent participants was not balanced. More adolescent boys participated in this study than adolescent girls. The study might have missed different views from adolescent girls who did not appear during the interview. This was the case with parent/care givers participants whom more than half were female.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The chapter presents conclusion and recommendations for actions and for further studies according to findings and study objectives.

6.2 Conclusion

Adolescents living with HIV face unique challenges in ART adherence as they come of age. Using in-depth interview and focused group discussion to both HIV positive adolescents, health care workers and parent/care givers, this study's findings highlighted the importance of both individual and social factors associated with ART adherence among this group.

Although participants showed good knowledge on ARV treatment adherence, its importance and perceived risks in case of poor or low level of adherence, most adolescents in this study presented moderate/suboptimal level of adherence to ARV treatment.

Delayed disclosure of HIV status appeared to be the main factor affecting treatment adherence among adolescents in this study. Parents fear to disclose to their children by thinking that they are too young to understand, adolescents themselves feel being lied to/deceived by not being told the truth about their health, as a result they become so violent and reluctant to take their medication as required.

Other reported factors included stigma and isolation, food insecurity and lack of transport fare due to economic constraints, getting tired of taking pills and school environment that lack privacy all those were individual factors associated with treatment adherence among adolescents. Social support (school teachers, friends/peers, health care workers) appeared to be an important factor too as supportive families/social environment seemed to enhance adherence while non-supportive families and stigma appeared to impede adherence.

6.3 Recommendations

- 6.3.1. The researcher recommends that the government through NACP provide/put in place a mechanism/system that provide age desegregated data that would enable easy analysis of adolescent information's in other future studies
- 6.3.2. It is recommended that further researches be conducted on ARV treatment adherence among HIV infected adolescents as this age group is very challenging and very prone to poor adherence on ART. More is needed to be done to identifying issues that aggravate this problem.
- 6.3.3. Parents/care givers should be empowered to disclose to their HIV positive children and adolescent at an early age as required by the national guidelines so as to enable them to cope with their statuses and make informed decisions about their treatment life. Families and general community (teachers, peers and friends) should be sensitized to stop stigmatizing HIV positive adolescents but be supportive and enable them to be good adherent to their medication for improved health benefits

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APPENDICES**Appendix 1: Informed Consent Form (English Version)-****CONSENT FORM FOR A PARTICIPANT (ENGLISH)****MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES****DEPARTMENT OF BEHAVIORAL SCIENCES****FORM NO:**

Title of the Research: Assessing antiretroviral treatment adherence level and associated Individual and social factors associated among HIV positive adolescents attending care and treatment clinics in Dodoma Municipal Council.

Principal Investigator: Leonarda C. Pastory

Institution and address:

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES (MUHAS)

P.O Box 65001,

DAR ES SALAAM – TANZANIA

Introduction

This consent form contains information of the above named research. In order to be sure that you are informed about participating in the research, we are asking you to read (or we read to you) this consent form and understand it. You will also be asked to sign it (or make your mark in front of the witness). You will retain a copy of this form. This form might contain words that are unfamiliar to you, please ask us to explain anything you may not understand.

Before contacting you, we have obtained permission to conduct this study from the district authority, the regional Administrative Secretary and Medical Officer of Dodoma municipal.

Purpose of this study

To assess the individual and social factors that are associated with antiretroviral treatment adherence among HIV positive adolescents who attend at the care and treatment clinics in Dodoma municipal.

Participation

We will ask you some questions related to ARV treatment adherence in your daily life in attending the care and treatment clinics. You will be asked to explain according to your experience in taking ARV drugs if you have ever missed any dose or not and the reasons for that if any. You will be asked about the name/type of drug you take, the schedule and time you take them daily. You will then be given a form to showing numbers from 1-10 where you will be asked to put a mark on any number that you think fits your adherence level. Please do feel free to participate.

Confidentiality

All issues concerning your participation will be treated as confidential; no any authorized person will have access to this information. We will be compiling a report, which will contain responses from several participants without any reference to individuals. We will not put your name or any identifying information on the records of the information you provide.

Risks

Be assured that no harm or risk will be involved for those who will voluntarily participate in this study.

Right to Withdraw and Alternatives

Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study, you will not get harm. You can stop participating in this study at any time, even if you have already given your consent.

Benefits

Participating in this study will give us an opportunity to identify if there is any association between various individual and social factors with treatment adherence among HIV positive adolescents. This information will help create awareness to policy and decision

makers on various interventions to address adherence challenges and make improvement strategies or interventions in the district and country as well

Contact

The research has been reviewed and approved by Ethical Research Committee of Muhimbili University of Health and Allied Sciences, MUHAS. Please if you have any question about your rights as a participant, you may contact **Dr. Joyce Masalu**, Chairman of the Senate Research and Publications Committee, **P.O Box 65001, Dar es Salaam (Tel 022-21503002-06, 2152489)** or **Dr. Mwangu Mughwira; MUHAS: P.O Box 65001, Dar-es Salaam. (Tel. 0713-253 513)** who is the supervisor of this research.

Agreement Part

I therefore request your participation in this study; participation in this study will involve asking some questions and you will be required to respond according to what you know basing on your own experience on the given options.

DO YOU AGREE? (Please tick for appropriate response)

() YES

() NO

If you agree, sign below

Participant’s sign..... Date.....

Investigator’s sign..... Date.....

Appendix 2: Informed Consent Form (Swahili Version)**FOMU YA RIDHAA YA KUSHIRIKI KWENYE UTAFITI****CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI****IDARA YA SAYANSI YA TABIA****NAMBA YA FOMU:**

Utafiti juu ya: Mambo ya binafsi na kijamii yanayohusiana na ufuasi wa dawa za kupunguza makali ya VVU—ARV miongoni mwa vijana balehe wanaoishi na VVU wanaohudhuria katika kliniki za huduma na tiba manispaa ya dodoma.

Jina la Mtafiti: Leonarda C. Pastory**Jina na Anwani ya Taasisi:****CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI (MUHAS)****S.L.P 65001, DAR ES SALAAM – TANZANIA.****Utangulizi**

Fomu hii ina maelezo juu ya utafiti tajwa hapo juu. Ili uweze kujua habari muhimu zinazohusu huu utafiti na kushiriki inakubidi uisome hii fomu kwa umakini (au tukusomee kwa sauti) na kuielewa. Utaombwa kutia saini baada ya kuisoma (au kuweka alama ya dole gumba mbele ya shahidi). Utabaki na nakala yako. Hii fomu inaweza kuwa na maneno usiyoyafahamu, tafadhali tuulize ili tukueleweshe.

Kabla ya kukufikia, tumepata ridhaa ya kufanya utafiti huu kutoka kwa uongozi wa manispaa ya dodoma.

Dhumuni la utafiti huu

Utafiti huu una lengo la kutaka kufahamu uhusiano uliopo kati ya baadhi ya mambo binafsi na yale ya kijamii na ufuasi wa dawa za kupunguza makali ya VVU miongoni mwa vijana wanaoishi na maambukizi ya VVU wanaohudhuria katika kliniki za huduma na tiba hapa manispaa.

Ushiriki

Tutakuuliza maswali kadhaa yanayohusiana na mambo ya ufuasi wa dawa za kupunguza makali ya VVU-ARV maisha yako ya kila siku ya kuhudhuria katika kliniki ya huduma na tiba. Utaombwa kueleza kadri ya uzoefu wako katika kutumia dawa hizi, kama umewahi kusahau kumeza dawa au la! Na sababu zilizo au zinazosababisha kama zipo. Utaulizwakuhusu aina ya dawa unazomeza, mara ngapi unameza na kwa muda gani. Kasha utapewa fomu yenye namba kuanzia moja hadi kumi 1-10 ukiombwa kuweka alama katika namba yotote unayofikiri inaonyesha kiwango chako cha ufuatiliaji wa dawa. Tafadhali jisikie huru kushiriki.

Usiri

Unahakikishiwa kwamba taarifa zote juu ya ushiriki wako kwenye utafiti huu zitakua siri. Tutaandaa taarifa moja kutokana na maelezo ya washiriki mbalimbali hapa kituoni. Hatutaandika jina lako wala hatutainesha utambulisho wowote kutokana na taarifa utakazotupatia.

Madhara

Unahakikishiwa kuwa utafiti huu hautakuwa na madhara yoyote kwa mshiriki.

Haki ya kujitoa kwenye utafiti

Kushiriki katika utafiti huu ni uchaguzi wako. Endapo utachagua kutoshiriki au kutoshiriki katika mahojiano haya, hautapata madhara yoyote yale. Unaweza kusimamisha ushiriki katika mahojiano haya muda wowote hata kama ulikwisha kuridhia kushiriki.

Faida

Ushiriki wako katika utafiti huu utasaidia kutambua kama kuna uhusiano kati ya mambo au sababu mbalimbali za kibinafsi /kijamii na ufuasi wa dawa za ARVA mongoni mwa vijana waishio na VVU. Taarifa hizi zitatusaidia kujenga uelewa kwa watunga sera na watoa maamuzi juu ya namna nzuri ya kutatua matatizo/changamoto mbalimbali zilizopo katika ufuasi wa dawaza ARV na hivyo kupata namna nzuri ya kuweka mikakati ya kuboresha huduma katika wilaya na nchi kwa ujumla.

Mawasiliano:

Utafiti huu ulipitiwa na kukubaliwa na kamati ya mapitisho ya utafiti ya chuo kikuu cha cha afya na sayansi shirikishi Muhimbili. Iwapo una maswali kuhusu utafiti huu, unaweza kuwasiliana na

Dr. Joyce Masalu, ambaye ni Mwenyekiti wa kamati ya chuo ya utafiti na machapisho, **P.O Box 65001, Dar es Salaam (Tel 022-21503002-06, 2152489)**, au **Dr.Mwangu Mughwira; MUHAS: P.O Box 65001, Dar-es Salaam. (Tel. 0787 721 377)** ambaye ni msimamizi wa utafiti huu.

Makubaliano

Hivyo basi, unaombwa kushiriki katika utafiti huu; tutauliza maswali ambayo yatahitaji kupata maelezo kutoka kwako. Utaombwa kujibu kadri uwezavyo kulingana na uzoefu wako.

JE WAKUBALI? (Weka alama ya vema panapohusika)

() NDIYO:

() HAPANA

Endapo umekubali, tia saina hapa chini:

Saina ya mshiriki Tarehe.....

Saina ya mtafiti..... Tarehe

Appendix 3: Consent Letter for Parents/Guardians for the Under 18 Years Adolescents

P. O. Box 65001,

Dar es Salaam.

Mzazi/Mlezi

Ndugu,

YAH: KUOMBA RIDHAA YA KUMRUHUSU MWANAO/KIJANA WAKO KUSHIRIKI KATIKA MAHOJIANO YA UTAFITI JUU YA UFUASI WA DAWA ZA ARV MIONGONI MWA VIJANA WAISHIO NA VVU KATIKA MANISPAA YA DODOMA

Tafadhali rejea kichwa cha barua hapo juu.

Wanafunzi wa chuo kikuu cha tiba na utafiti cha Muhimbii wapo katika zoezi la kufanya utafiti mbalimbali wa kiafya. Mimi LEONARDA PASTORY, ninafanya utafiti juu ya mambo binafsi na ya kijamii yanayohusiana na ufuasi wa dawa za ARV miongoni mwa vijana wanaoishi na VVU katika wilaya ya Mufindi.

Hivyo basi, ukiwa kama mzazi/mlezi unaombwa kumruhusu kijana wako ili aweze kushiriki katika mahojiano haya. Mahojiano haya yatakuwa ya hiari ambapo kijana anaweza kukubai au kukataa kuhojiwa kwa sababu yoyote ile. Mtafiti atahakikisah usiri wa hali ya juu kati ya mshiriki na mtafiti. Hakuna taarifa yoyote itakayotoka nje ya mazingira ya mahojiano labda kwa ruhusa ya mshiriki mwenyewe au mzazi/mlezji wake

Kwa barua hii, ninakuomba umruhusu kijana wako ili aweze kujifunza na kushiriki na vijana wenzake katika kuleta mabadiliko juu ya afya za vijanakwani ushiriki wake ni wamhimu kwa ajili ya kujifunza dna kusaidia vijana wengine nchini Tanzania.

Natangauliza shukrani nikamini kuwa ombi langu litakubaliwa.

Asante.

Makubaliano:

Mimi _____ mzazi/mlezi wa _____,
ninakubali kuwa nimesoma na kuelewa maelezo hayo hapo juu. Hivyo
ninamruhusu/simruhusu kijana wangu kushiriki katika mahijiano haya.

Sahihi ya mzani _____ Tarehe: _____

Appendix 4: Interview Guide for Adolescent Participants (English version).

Research question: What are the perception and attitude on factors associated with ARV treatment adherence among HIV + adolescents attending in the care and treatment clinic in Dodoma municipal Tanzania?

Introduction

I would like to thank you for taking time to meet with me today. My name is _____ and I will be facilitating this interview as part of my study that seeks to find out about the individual and social factors affecting ARV treatment adherence among adolescents living with HIV/AIDS in Dodoma municipal council, Tanzania. I would like to talk to you about your experiences in taking ARV treatment drugs.

The interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments.

All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. I encourage you to share your opinions with me, because your contribution is valuable and important. Please note that there are no any right or wrong answers, so feel free to express both positive and negative viewpoints

Are there any questions about what I have just explained?

Are you willing to participate in this interview?

Interviewee Witness Date

To be signed by the legal guardian (for all under 18 adolescents)

Self-introductions:

- a) Icebreaker Question: Let me start by introducing myself to you and tell me about your personal life, family life/school and age.

Thank you very much and let us begin

Adherence measure for HIV infected adolescents (Individual factors)

A: Pill Identification Test (PIT)

- 1. Can you please tell me about the type or name of your ARV drugs?

Probe: Efavirenz, Lamivudine, 3TC etc.

- 2. Please tell me about the number of pills and schedule of you take medication-meaning that how many pills do you take per day and how many times a day

Probe: 4 (2*2,) Once or twice a day

B: Self Reporting adherence

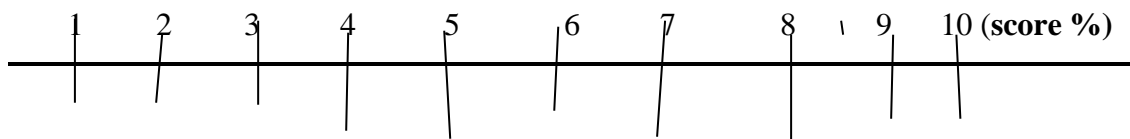
- 3. Can you recall how many times you missed /didn't take your drug (pills) in this particular month?

Probe: Didn't miss/ several times/

- 4. If you missed your drugs, what do you think are the reasons for that? Please explain.

C: Visual Analogue Scale measure

- 5. In the following line, please mark the number that you think fits your adherence level on ARV drugs



Perception on factors associated with treatment adherence among infected adolescents

General questions:

6. Please tell me something about your experience in living with HIV
7. Would you please tell me something you know about ARV treatment adherence?
8. How long have you been taking ARV drugs?
9. Please tell me about your perception on the following factors (Loss of identity, denial, anger and suicidal attempts; fear of intimacy and sexuality; social isolation). Do you think they can in any way be associated to treatment adherence?
10. In your experience, have you ever encountered any of these issues? Please explain what among these and how did it affect your treatment adherence.
11. If there, how did or do you overcome it?
12. What other factors do you think are likely to affect your daily ARV treatment adherence?
13. What is your recommendation for proper treatment adherence to all adolescents living with HIV?

Thank you for participating in this study today. Do you have anything else to add?

Appendix 5: Interview Guide for Adolescent Participants (Swahili Version)

Mazungumzo ya mtu mmoja

Utangulizi

Napenda kukushurkuru kwa kukubali kuhudhuria katika mahojiano yetu. Jina langu ni Leonarda Pastory, ninaongoza mahojiano haya kama sehemu ya masomo yangu ya kutaka kuelewa juu ya ufuasi wa dawa kwa vijana wanaoishi na virusi vya ukimwi katika wilaya ya mufindi. Kazi yangu kubwa ni kuongoza mahojiano haya na kuelekeza mtiririko wa mahojiano haya ili kuhakikisha kuwa tunazungumzia sehemu kuu za mjadala

Mazungumzo yetu hayatachukua zaidi ya lisaa limoja. Kulingana na kwamba siwezi kusikiliza na kuandika kwa haraka pindi tutakapokuwa tunaongea, naomba kuwa ninarekodi mazungumzo haya ili niweze kupata kila maelezo yanayotolewa na kila mmoja wetu. Pamoja na hayo, nitakuwa nikiandika baadhi ya maelezo katika mahojiano haya.

Mahojiano yetu haya yanachulia katika usiri mkubwa. Hakuna atakayeweza kuyaona au kuyasikia mara baada ya kumaliza mazungumzo yetu isipokuwa tu kwa sisi tunaofanya utafiti huu. Na pamoja na hayo, hakuna atakayeweza kubainisha jina lako popote pale katika utafiti huu.

Tafadhali kumbuka kuwa, hualazimishwi kuzungumzia juu ya kitu ambacho hujisikii kukiongelea. Na pia unaruhusiwa kukatisha mazungumzo mahali popote katika mahojiano haya. Ninakushauri utoe maoni yako kadiri uwezavyo kwani yatakuwa msaada mkubwa kwa watu wengine.

Zingatia kuwa hakuna jibu lililo sahihi au lisilo sahihi katika mazungumzo haya kwani kila mtu ana uhuru wa kuzungumza chochote katika mahojiano haya.

Je una swali lolote katika haya niliyoyazungumza?

Je umeridhia kushiriki katika maungumz haya?

AMERIDHIA/HAJARIDHIA

Isainiwe na mzazi/mlezi kwa wote vijana wote walio chini ya umri wa miaka 18

Lengo na agenda

Mahojiano yetu yanalenga kutafuta mawazo juu ya mtazamo kuhusu ufuasi wa dawa za ARV miongoni mwa vijana wanaoishi na Virusi Vya UKIMWI wanaohudhuria kliniki za huduma na matibabu katika manispaa ya dodoma.

Sheria za Msingi

Kabla hatujaanza majadiliano yetu ningependa kuzungumzia sheria chache za msingi.

Kujitambulisha

Swali la kuvunja ukimya:

Tuanze kwa kujitambulisha nami nitaanza kujitambulisha kwako na wewe utajitambulisha kwa kuniambia yafuatayo: Niambie kuhusu maisha yako binafsi- umri wako, Maisha ya familia

Mtazamo binafsi-vipimo vya kuchunguza ufuasi wa dawa za ARV kwa mteja mmoja mmoja

A: Kipimo au jaribio la kutambua aina ya dawa

1. Tafadhali nielezee kuhusu uzoefu wako katika kuishi na Virusi Vya UKIMWI

Hoji: muda (miezi/miaka)

2. Je ni kwa muda gani umekuwa ukitumia dawa za kupunguza makali ya VVU (ARV)?

Hoji: (miezi/miaka) katika matibabu

3. Je waweza kuniambia/kunitajia ni aina gani ya dawa huwa unatumia (jina)

Hoji: Efavirenz, Lamivudine, 3TC etc.

4. Tafadhali nitajie idadi ya vidonge unavyotumia kwa siku na unamezaje?

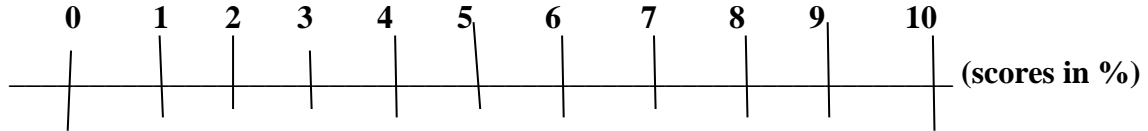
Hoji: (1/2/4) mara moja au mbili kwa siku

B: Kipimo cha taarifa binafsi ya mteja kuhusu umezaji

5. Je unaweza kukumbuka ni mara ngapi umesahau kumeza dawa katika mwezi huu?

Hoji: Sjawahi kusahau/ nimesahau mara kadhaa.

6. Je kama ulisahau au hukumeza dawa zako, unafikiri ni sababu zipi zinazoweza kuwa zili au zinapelekea wewe kufanya hivyo? Tafadhali elezea.

C: Kipimo cha kuangalia kiwango cha umezaji au ufuasi wa mteja katika asilimia**Maswali ya Jumla**

7. Tafadhali nieleze nini una muda gani ukiwa unaishi na VVU.
8. Je unafahamu nini kuhusiana na matibabu ya ARV?
9. Tafadhali niambie nini mtazamo wako kuhusiana na mambo yafuatayo ambayo inasemekana yanaweza kuwa na uhusiano kati ya ufuasi wa dawa katika matibabu. (Kutokujua uhalisia wako, kukataliwa, hasira na kujaribu kujiua, uoga juu ya mahusiano na mapenzi, kujitenga au kutengwa na jamii).
10. Kwa uzoefu wako katika matibabu ya ARV, je umewahi kukutana na mojawapo katika hayo.
11. Kama umewahi, je ulifanya au unafanya nini ili kukabiliana na hali hiyo?
12. Je ni mambo gani mengine unayofikiri yanaweza kussababisha wewe kutokutumia vizuri dawa zako za ARV kama inavyopaswa?
13. Je ni nini maoni yako kuhusiana na ufuasi mzuri wa matibabu ya ARV miongoni mwa vijana wenzako wanaoishi na VVU?

Asante sana kwa kukubali kushiriki katika mahojiano haya leo.

Appendix 6: Interview Guide for HCW (English version).

Research question: What are the perception and attitude on factors associated with ARV treatment adherence among HIV + adolescents attending in the care and treatment clinic in Dodoma?

Introduction

I would like to thank you for taking time to meet with me today. My name is _____ and I will be facilitating this interview as part of my study that seeks to find out about the individual and social factors affecting ARV treatment adherence among adolescents living with HIV/AIDS in Dodoma municipal council, Tanzania. I would like to talk to you about your experiences in taking care or serving HIV positive adolescent at this clinic.

The interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments.

All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. I encourage you to share your opinions with me, because your contribution is valuable and important. Please note that there are no any right or wrong answers, so feel free to express both positive and negative viewpoints

Are there any questions about what I have just explained?

Are you willing to participate in this interview?

Interviewee Witness Date

Self-introductions

Icebreaker Question: Let me start by introducing myself to you and tell me about your personal life, family life/school and age.

Thank you very much and let us begin

Social factors/ attitude (for care workers)

1. What is your opinion on general treatment adherence among adolescents living with HIV and AIDS, and why?

Probe: Good/ poor/

2. In your opinion, what do you think are the social factors that are associated with good or poor ARV treatment adherence among HIV positive adolescents?
3. Please tell me about how do you support them in ensuring that they adhere well to their treatment

Probe: psychosocial / economically/ clinical support

Appendix 7: Interview Guide for HCW (Swahili Version)

Mazungumzo ya mtu mmoja

Utangulizi

Napenda kukushurkuru kwa kukubali kuhudhuria katika mahojiano yetu. Jina langu ni Leonarda Pastory, ninaongoza mahojiano haya kama sehemu ya masomo yangu ya kutaka kuelewa juu ya ufuasi wa dawa kwa vijana wanaoishi na virusi vya ukimwi katika wilaya ya mufindi. Kazi yangu kubwa ni kuongoza mahojiano haya na kuelekeza mtiririko wa mahojiano haya ili kuhakikisha kuwa tunazungumzia sehemu kuu za mjadala

Mazungumzo yetu hayatachukua zaidi ya lisaa limoja. Kulingana na kwamba siwezi kusikiliza na kuandika kwa haraka pindi tutakapokuwa tunaongea, naomba kuwa ninarekodi mazungumzo haya ili niweze kupata kila maelezo yanayotolewa na kila mmoja wetu. Pamoja na hayo, nitakuwa nikiandika baadhi ya maelezo katika mahojiano haya.

Mahojiano yetu haya yanachulia katika usiri mkubwa. Hakuna atakayeweza kuyaona au kuyasikia mara baada ya kumaliza mazungumzo yetu isipokuwa tu kwa sisi tunaofanya utafiti huu. Na pamoja na hayo, hakuna atakayeweza kubainisha jina lako popote pale katika utafiti huu.

Tafadhali kumbuka kuwa, hualazimishwi kuzungumzia juu ya kitu ambacho hujisikii kukiongelea. Na pia unaruhusiwa kukatisha mazungumzo mahali popote katika mahojiano haya. Ninakushauri utoe maoni yako kadiri uwezavyo kwani yatakuwa msaada mkubwa kwa watu wengine.

Zingatia kuwa hakuna jibu lililo sahihi au lisilo sahihi katika mazungumzo haya kwani kila mtu ana uhuru wa kuzungumza chochote katika mahojiano haya.

Je una swali lolote katika haya niliyoyazungumza?

Je umeridhia kushiriki katika maungumz haya?

AMERIDHIA/HAJARIDHIA

Lengo na agenda

Mahojiano yetu yanalenga kutafuta mawazo juu ya mtazamo kuhusu ufuasi wa dawa za ARV miongoni mwa vijana wanaoishi na Virusi Vya UKIMWI wanaohudhuria kliniki za huduma na tiba katika manisipaa ya dodoma.

Sheria za Msingi

Kabla hatujaanza majadiliano yetu ningependa kuzungumzia sheria chache za msingi.

Kujitambulisha

Swali la kuvunja ukimya:

Tuanze kwa kujitambulisha nami nitaanza kujitambulisha kwako na wewe utajitambulisha kwa kuniambia yafuatayo: Niambie kuhusu maisha yako binafsi- umri wako, Maisha ya familia

Maswali:

4. Tafadhali nieleze nini maoni yako kuhusu ufuasi wa dawa za ARV kwa vijana wanaoishi na VVU?

Hoji: wa juu/ kati/ chini

5. Kwa maoni yako, unafikiri ni mambo gani ya kijamii yanawezwa kuhusishwa na ufuasi mzuri au mbaya wa matibabu ya ARV miongoni mwa vijana wanaoishi na VVU.
6. Je ni aina gani ya huduma mazowawapatia vijana hawa wanaoishina VVU ili kuhakikisha ufuasi wao katika matibabu unaimarika?

Hoji: misaada ya kiakili, ushauri, kiuchumi, kimatibabu.

Hoji: Ushauri, Chakula, nauri, kiimani n.k

Asante sana kwa kukubali kushiriki katika mahojiano haya leo.

Je una chochote unachoweza kuongeza katika haya

Appendix 8: Focussed Group Discussion Guide for Parents/Guardian (English version).

Introduction

I would like to thank you for taking the time to meet with me today. My name is _____ and I will be facilitating this interview as part of my study that seeks to find out about the individual and social factors associated with ARV treatment adherence among adolescents living with HIV/AIDS in Dodoma municipal council, Tanzania. I would like to talk to you about your experiences in taking care of the HIV infected adolescents with regard to their ARV treatment

The interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments.

All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time. I encourage you to share your opinions with me, because your contribution is valuable and important. Please note that there is no any right or wrong answers, so feel free to express both positive and negative viewpoints

Are there any questions about what I have just explained?

Are you willing to participate in this interview?

Icebreaker Question:

Let's go around (the group) and everyone will introduce him/her self by telling the name, where you come from and the name of your adolescent who attends at this clinic.

Thank you very much and let us begin

1. What is your experience in raising an HIV positive adolescent?
2. When did you tell him/her about his/her HIV status and what was the reaction?
3. How do you see/perceive your child's adherence to ARV medication and why?
4. What do you think are the challenges in taking ARV medication among adolescents?
5. What factors do you think are associated with poor or good treatment adherence among HIV positive adolescent?
6. Please tell us how do you support them in ensuring that they adhere their medication well

Appendix 9: Focussed Group Discussion Guide for Parents/Guardian (Swahili Version).

Muongozo wa Mahojiano Katika Vikundi (Kwa Wazazi/Walezi wa Vijana)

Utangulizi

Napenda kuwashukuru kwa kukubali kuhudhuria katika mahojiano yetu. Jina langu ni Leonarda Pastory, ninaongoza mahojiano haya kama sehemu ya masomo yangu ya kutaka kuelewa juu ya ufuasi wa dawa kwa vijana wanaoishi na virusi vya ukimwi katika wilaya ya Dodoma mjini. Kazi yangu kubwa ni kuongoza mahojiano haya na kuelekeza mtiririko wa mahojiano haya ili kuhakikisha kuwa tunazungumzia sehemu kuu za mjadala

Mazungumzo yetu yatachukua zaidi ya lisaa limoja. Kulingana na kwamba siwezi kusikiliza na kuandika kwa haraka pindi tutakapokuwa tunaongea, naomba kuwa ninarekodi mazungumzo haya ili niweze kupata kila maelezo yanayotolewa na kila mmoja wetu. Pamoja na hayo, nitakuwa nikiandika baadhi ya maelezo katika mahojiano haya.

Mahojiano yetu haya yanachukuliwa katika usiri mkubwa. Hakuna atakayeweza kuyaona au kuyasikia mara baada ya kumaliza mazungumzo yetu isipokuwa tu kwa sisi tunaofanya utafiti huu. Na pamoja na hayo, hakuna atakayeweza kubainisha jina lako popote pale katika utafiti huu.

Tafadhali kumbuka kuwa, haulazimishwi kuzungumzia juu ya kitu ambacho hujisikii kukiongelea. Na pia unaruhusiwa kukatisha mazungumzo mahali popote katika mahojiano haya. Ninakushauri utoe maoni yako kadiri uwezavyo kwani yatakuwa msaada mkubwa kwa watu wengine.

Zingatia kuwa hakuna jibu lililo sahihi au lisilo sahihi katika mazungumzo haya kwani kila mtu ana uhuru wa kuzungumza chochote katika mahojiano haya.

Je una swali lolote katika haya niliyoyazungumza?

Lengo na agenda

Mahojiano yetu yanalenga kutafuta mawazo juu ya mtazamo kuhusu ufuasi wa dawa za ARV miongoni mwa vijana wanaoishi na Virus Vya UKIMWI wanaohudhuria kliniki za huduma na matibabu manipaa ya Dodoma.

Kujitambulisha

Swali la kuvunja ukimya:

Tuanze kwa Kukaa katika kikundi kasha tujadili kwa pamoja. Tutaanza kwa kujitambulisha kila mmoja jina lake, umri na uzoefu wake katika matumizi ya au ufuasi wa matibabu ya ARV.

Uzoefu au maisha ya kifamilia (kwa wazazi/walezi)

1. Je mnaweza kushirikisha uzoefu wako katika kuishi na kijana mwenye maambukiziya VVU?
2. Tafadhali tueleze ni lini ulimwambia ukweli kuhusu hali yake ya maambukizi ya VVU?
3. Je unachukuliaje au unaonaje umezaji wake wa dawa za ARV?
4. Je ni changamoto zipi unazofikiri zinaathili umezaje wa dawa za ARV miongoni mwa vijana wenye maambukizi
5. Ni mambo gani unayoufikiri yanachangia ufuasi mbaya au mzuri wa dawa za ARV miongoni mwa vinajan wenye maambukizi ya VVU?
6. Je ni changamoto zipi mnazokutana nazo kaktika kuwalea vijana wenu walio katika matibabu ya ARV?
7. Mnafanyaje ili kuhakikisha mnawasaidia vijana wenu wawe wafuasi wazuri wa matibabu ya ARV katika maisha yao ya kila siku?
8. Tafadhali tueleze ni msaada gani unaompatia kijana wako ili kuhakikisha kuwa ufuasi wake wa dawa unakuwa mzuri?

Ni nini ushauri wenu kwa wazazi wenzenu walio na watoto /vijana kama hawa?

Je, kuna lingine mnalotaka kuongezea kabla hatujamalizia mjadala wetu?

Napenda kuwashukuru sana kwa usiriki wenu na kufanikisha mjadala wetu.

Aksante