



**University of Nairobi**

**PERCEIVED STRESS AMONG CAREGIVERS OF ADOLESCENTS ON HIV  
TREATMENT AT KENYATTA NATIONAL HOSPITAL COMPREHENSIVE CARE  
CENTRE**

**By**

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## DECLARATION

I declare that this research paper is my original work and has not been submitted for examination in any University

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**APPROVAL**

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## **DEDICATION**

This paper is dedicated to my loving husband Cyprian Ouma and children Maya, Ronan, Chantal, Natalie. It is you who gave me the courage to move on with this course. Thank you for your emotional support and encouragement. May this be a reminder that when we stand by one another nothing is unattainable.

## **ACKNOWLEDGEMENT**

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I also thank my family members and friends for their moral and spiritual support.

## **LIST OF ABBREVIATIONS**

CCC- Comprehensive Care Centre

HIV- Human Immunodeficiency Virus

KNH/UON-Kenyatta National Hospital/ University of Nairobi Ethics Research Committee

SPSS-Statistical Package for the Social Sciences

UNICEF- The United Nations Children's Fund

WHO- World Health Organization

## **OPERATIONAL DEFINITIONS**

**Stress-** a state of mental or emotional strain or tension resulting from adverse or demanding circumstances.



## ABSTRACT

**Introduction:** Studies done to investigate the impact of caring for the Human Immunodeficiency Virus (HIV) infected persons on a caregiver have reported that sides physical exhaustion, the psychological well-ing of the individual is usually at stake. However, other researchers have differed citing development of resilience and coping mechanisms.

**Study objective:** The study aimed at assessing the level of perceived stress among caregivers of HIV infected adolescents on treatment at the KNH CCC and the associated factors

**Research Design:** The study utilized a descriptive cross-sectional research design

**Study Site:** The research was carried out at the Kenyatta National Hospital HIV/AIDS Comprehensive Care Centre (KNH, CCC)

**Target Population:** The study targeted caregivers of HIV infected adolescents that seek treatment at the KNH, CCC

**Sample size:** Systematic sampling was used to get 236 participants.

**Research Instruments:** A researcher- designed questionnaire and the Perceived Stress Scale- 10 was used in the study

**Data Analysis:** Data analysis was done using SPSS version 23 and presentation of data was done by use of frequency tables, bar charts and pie charts. Association tween variables was done using Chi square test. Pearson's Correlation (r) statistics was used to show relationships tween continuous variables, while Cramer's Phi Coefficient was used to show correlation tween categorical variables.

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## **CHAPTER ONE: INTRODUCTION**

### **1.1 Background**

It has been reported that globally, the estimated number of adolescents living with HIV is over 400,000. This extrapolated figure is an estimate from the 250,000 adolescents between the age of 5 and 19 that were found to be HIV positive in the year 2017 (UNICEF, 2018). The number of adolescents that live in Africa is said to almost 2.1 million and therefore it's assumed that a higher percentage of these adolescents who are infected with HIV come from the continent. In Kenya alone, which is said to have one of the highest numbers of HIV infected adolescents, the estimated number of adolescents with HIV in the year 2016 was 130,000 (UNICEF, 2016). This is even though HIV testing is generally lower among adolescents and therefore there is a huge probability of many having undiagnosed HIV infection. UNICEF (2018) also reported increased incidences of death among HIV infected adolescents as opposed to other age groups. This was however attributed to perinatal infection at birth for most adolescents (Lowenthal, et al., 2015). Because 18,000 new infections happen every year among adolescents in Kenya (UNICEF, 2016), adolescence had been identified as a vulnerable age with regards to HIV infection in Kenya.

Several setbacks have been reported in HIV management among adolescents. This is in reference to medication adherence. Generally, it has been found that most adolescents do not adhere to their medication regimen (Shroufi, Gunguwo, & Dixon, 2013; Firdu & Jeremy, 2017). This has been largely attributed to the cognitive and psychosocial developmental factors that could impact greatly on how well an adolescent adheres to their medication. Most adolescents are not able to manage their health care needs and might lack the required knowledge to care for themselves and consequently most of them have been reported to be prone to acquiring mental health problems,

behavioral concerns and even engaging in substance use that may lead to lack of adherence (Bucek, Leu, & Benson, 2018; Mellins, Tassiopoulos, & Malee, 2011). These researchers found that in comparison to older individuals, adolescents had poor or lower rates of viral suppression and instead experienced virologic rebounds. Adolescents were generally reported to disappear and avoid follow up which resulted in poor quality of life, quick disease progression and early demise (Agwu & Fairlie, 2013). These challenges clearly depict the need for caregivers for HIV infected adolescents.

With regards to the impact of HIV diagnosis on the caregivers which is the primary focus of this study, any HIV diagnosis is well understood to alter the family dynamics (Cazenave, Ferrer, Castro, & Cuevas, 2005). These researchers found that in most cases although an entire family could be affected by chronic illness diagnosis like HIV, commonly one individual assumed the care giving role. Unlike in most chronic illnesses where the caregiver is healthy, in most cases, particularly in adolescents, the caregiver is usually but not limited or exclusively the infected vulnerable mother (Cazenave, et al., 2005). The caregiver is tasked with attending to the adolescents physical and emotional needs which normally can take a toll on them physically, emotionally and psychologically (Astudillo, Mendinueta, & Astudillo, 2002). The various ways that caregiver stress can manifest is through physiological and psychological symptoms. Some caregivers have been found to suffer from headaches, memory lapses, anxiety, depression and some cases aggression (Mutiso, Chesire, Kemboi, Kipchirchir, & Ochieng, 2010).

This clearly affects the level of care they offer the adolescents and their own level of coping. It is suggested that it is important that caregivers also given pragmatic support (Jackson, et al., 2004). The support which should primarily focus on improving the psycho-social well-being of the



caregiver could in turn help them offer better care for the adolescent. Basically, it is very important in HIV care to understand the experience and to gain a clearer perspective on the caregivers concerns and their perceived stress and this seeks to achieve this. It investigates care givers level of perceived stress while caring for an infected HIV adolescent and the related factors.

## **1.2 Problem statement**

It is imperative that adolescents on antiretroviral to have proper care with regards to their physical, psychological and social development. Their caregivers are particularly tasked with ensuring that these three aspects of development are progressing well in addition to medication adherence. Therefore, caregivers come an important part of the comprehensive approach that is needed to improve outcomes for the adolescent on treatment which is dire.

However, the common question that this type of arrangement begs is “who cares for the carer?” studies have been done that investigate the impact that caring for the chronically ill can have on an individual and it has been reported that sides physical exhaustion, the psychological well-being of the individual is usually at stake. However, other researchers have begged to differ citing development of resilience and coping mechanisms.

Studies that have been done on the same in Kenya with many being household studies have reported the presence of challenges for caregivers. However, these studies are not exhaustive and have been done in few areas in Kenya (Most affected areas like Nyanza and Laikipia). More importantly, most of these studies have not really focused on caregivers who specifically care for adolescents who have been infected with HIV. Instead, there has been notable overgeneralization with regards to age criteria and hence caregiver experience as well with most studies including children and young adults. Moreover, a study on the same done at Kenyatta National Hospital

Comprehensive Centre (KNH CCC) which cares for quite a number of adolescents with HIV in Nairobi and beyond is yet to be done and published. Consequently, this study aims to determine the level of perceived stress among the caregivers of adolescents that receive their treatment at the KNH CCC, and the factors associated with their perceived stress. The study also seeks to determine the challenges they face as they care for the HIV positive adolescent.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 Theoretical Framework**

The theoretical underpinning for this study is the cognitive stress appraisal theory by Lazarus and Folkman (1983). They posit that cognitive appraisal involves two steps; the production and acknowledgement of stressors that emanate from the environment and the response or reaction that the individual has towards these stressors. These processes are referred to as cognitive appraisal and they occur in two phases. Primary appraisal where an individual consciously decides what the stressor is and what impact it can have on them and secondary appraisal that basically refers to feelings related to dealing with stressor.

This study aimed to determine the level of stress the caregivers perceive they have. In essence it assesses their cognitive appraisal of the situations they go through as they take care of the HIV infected adolescent. What situations they consider as stressful, how they appraise the situation with regards to how they feel the situations affects them. The researcher in this particular study relied on the participants' cognitive appraisal to determine their level of perceived stress cause different situations evoke different reactions as per the individuals' cognitive appraisal of the situations.

It is important to note that according to Lazarus and Folkman, primary and secondary appraisal occurs simultaneously. However, the theorists also suggested that not all individual go through this process. Especially when met with sudden situations that don't allow for cognitive appraisal. For instance, for adolescents that were not infected perinatally, is the stress level of their caregivers higher or less than those that were infected perinatally?

## **2.2 Perceived Stress among Caregivers of HIV infected Adolescents on Treatment**

Studies done in the early 2000, reported that care giving for individuals that have been infected with HIV and AIDS generally posed a challenge. This finding was said to cut across all ages and gender of the patients and the caregiver (Wight, 2000; Land, Hudson, & Stiefel, 2003). Stiefel et al (2003) found that caregivers were negatively impacted by the stressors that they endured and hence they were prone to suffer from mood disorders like depression and this could be accompanied by suicidal ideations. Their study involved gay and bisexual men who were caring for other gay and bisexual men with HIV or AIDS. In a study that was conducted to determine whether increased stress from care giving had an impact on the psychological wellbeing of the caregiver, it was found that greater levels of stress was associated with depression (Pirraglia, et al., 2005). The study concluded that the informal caregivers would benefit significantly from mental health services and support with regards to reduced work load through assistance in care giving. Findings haven't changed significantly in recent studies.

In a study that was conducted in five countries, it was established that most caregivers that care for sick children who were sick or suffered from psychological difficulties experienced high levels of stress and felt overburden with work causing significant burn out (Razavi & Staab, 2010). This was especially significant for those caregivers who worked in institutions. The study notably looked at how caregivers of children (not exclusively HIV positive) experienced stress as opposed to adolescents which is this study focus. It also focused on caregivers that worked in institutions. However, it is correct to assume that the impact of the burden would be the same (Razavi & Staab, 2010).

A Kenyan study that was conducted in Western Kenya among HIV infected adolescents and their caregivers receiving treatment at the various clinics, it was established that caregivers were overwhelmed with stress as they cared for the adolescents (McHenry, et al., 2017). besides citing internalized negative self-perception due to stigma, they also felt that there was reduced or lack of social and economic support. Lentoor (2017), in their study found that similar results in their study that was conducted to determine psychosocial factors that influence HIV caregiving in Eastern cape in South Africa. Another kenyan study that was conducted to explore kenya's life lessons through the lived experience of rural caregivers in Laikipia region, it was reported that grandmothers who were normally tasked to come the primary caregivers after the death of their children due to HIV/AIDS did not have the capacity either physically, emotionally or psychologically to care for the children and adolescents (Cappiccie, Wanjiku, & Mengo, 2017). Therefore the possibility of being overwhelmed by the responsibility was very high. This was despite the fact that the researchers understood that the care giver burden could differ per the cultural exposure.

Even though studies have associated caregiving with stress, some researcher have reported contrary findings. Vitaliano, Zhang, & Scanlon (2003), in their study that sought to determine whether caregiving was hazardous to the caregivers health, found that despite its demanding role, caregivers were able to combat stress by using their social capital and psychological resources. The less they exposed themselves to stressors and vulnerabilities the more the alleviated the stress. However, their finding leads to the question of whether it is possible to avert or avoid stress in some situation for example extreme poverty or sudden major life events like death of a parent of the adolescent.

Similarly, in a study that was conducted to explore the experiences of caregivers of children living with HIV and AIDS in Uganda, it was reported that indeed they dealt with stressors that could affect their coping strategies (Osafo J. , Knizek, Mugisha, & Kinyanda, 2017). However, the caregivers also noted that they reduced their level of stress by turning to spirituality (instrumental), relying more on their social capital or networks, sharing their concerns and issues with the individual receiving care and ensuring that they managed their relationships (Osafo et al., 2017). Clearly different situations evoke different reactions from individuals depending on their cognitive appraisal. This study sought to find to determine how the caregivers perceived their stress and hence allowing a clearer look into their stress levels as they care for the HIV positive adolescents.

### **2.3 Factors associated with Perceived Stress among the Caregivers**

Several factors have been associated with caregiver burden/ stress. Hayden & Otaala (2005), found that the amount of work caregivers were involved in was directly related to their level of stress. Their study which was conducted in Namibia, sought to determine how young children affected and infected with HIV/AIDS lived. Though their study didn't touch on adolescents, the reported results are reflective. The study concluded that stress levels were due to higher demands on the caregivers brought on by the psychological and psychological implications of their role (Hayden & Otaala, 2005).

Razavi & Staab (2010), reported that lack adequate social capital and support could also lead to higher levels of stress among the caregiver. For institution based caregivers, this was also largely associated with job dissatisfaction. The researchers suggested this circumstances were most likely to lead to burn out which in turn will lead to poor care for the HIV infected adolescent.

McHenry, et al (2017), found that despite the fact that there was increased dissemination of information and knowledge about HIV/ AIDS, and more so improved access to treatment, stigma from the community was still a major concern. This was significantly associated with the reduced or loss of economic and social support and inturn caused serious negative perceptions towards self. This was further found to result in non-adherence of medication. Nondisclosure of status to child or others and increased mental health problems for the caregiver.

Socio-economic factors have also been found to largely affect caregivers for HIV infected adolescents. In Uganda, researchers reported that caregivers were burdened with food insecurity and inaccessibility of health care services (Osafo et al., 2017). These researchers found two emerging themes in their qualitative study as key challenges for caregivers for adolescents with HIV; labour and burden of caregiving and survival. These factors were noted to greatly impact the psychological or mental well-being of the caregivers (Lentoor, 2017). Lentoor, suggested that single headed families where grandmothers came primary care givers were most likely to experience caregiver burnout and stress. besides food insecurity and general low socio-economic status, education challenges were also noted to influence the coping mechanism of the caregivers. Other factors were lack of male support and neglect issues (Cappiccie, Wanjiku, & Mengo, 2017). These factors have been established in studies that generally looked at experiences of caregivers who care for HIV patients. This particular study assesses the factors that are associated with caring for HIV positive adolescents who receive treatment at the KNH CCC in relation to stress levels experienced.

## **2.4 Significance of the Study**

This study's contribution was to first and foremost help improve the perspective on caregiver experience while caring for HIV positive adolescents in relation to their perception on stress. Notably, from the literature reviewed, most studies focus on children or a general over view of experience caring for all ages. The study hopes to highlight the need for inclusive psychosocial support for the caregivers while the adolescents receives treatment at the centre.

## **2.5 Justification of the Study**

Comprehensive care in HIV has shown great success through improvement in the quality of life of the infected persons. Caregivers being an integral part of that care delivery also need to be cared for. This study investigated an area of care that has not been explored empirically at the KNH CCC especially for the caregivers for adolescents with HIV. Therefore, this study was to add to the already existing literature on the same and give insight into the challenges the caregivers who bring their adolescents at the CCC face. The results from the study will hopefully help in better management of HIV positive adolescents coming up with and implementation of strategies by stakeholders and policy makers that are geared towards empowering the caregiver socially, economically and psychologically.

## **2.6 Research Questions**

1. What are the levels of perceived stress among caregivers of HIV infected adolescents on treatment at the KNH CCC?
2. What socio-demographic factors are associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH CCC?
3. What psycho-social factors are associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH CCC?



## **2.7 Study Objectives**

### **2.7.1 Broad Objective**

To assess the perceived stress among caregivers of HIV infected adolescents on treatment at the KNH CCC and the associated factors

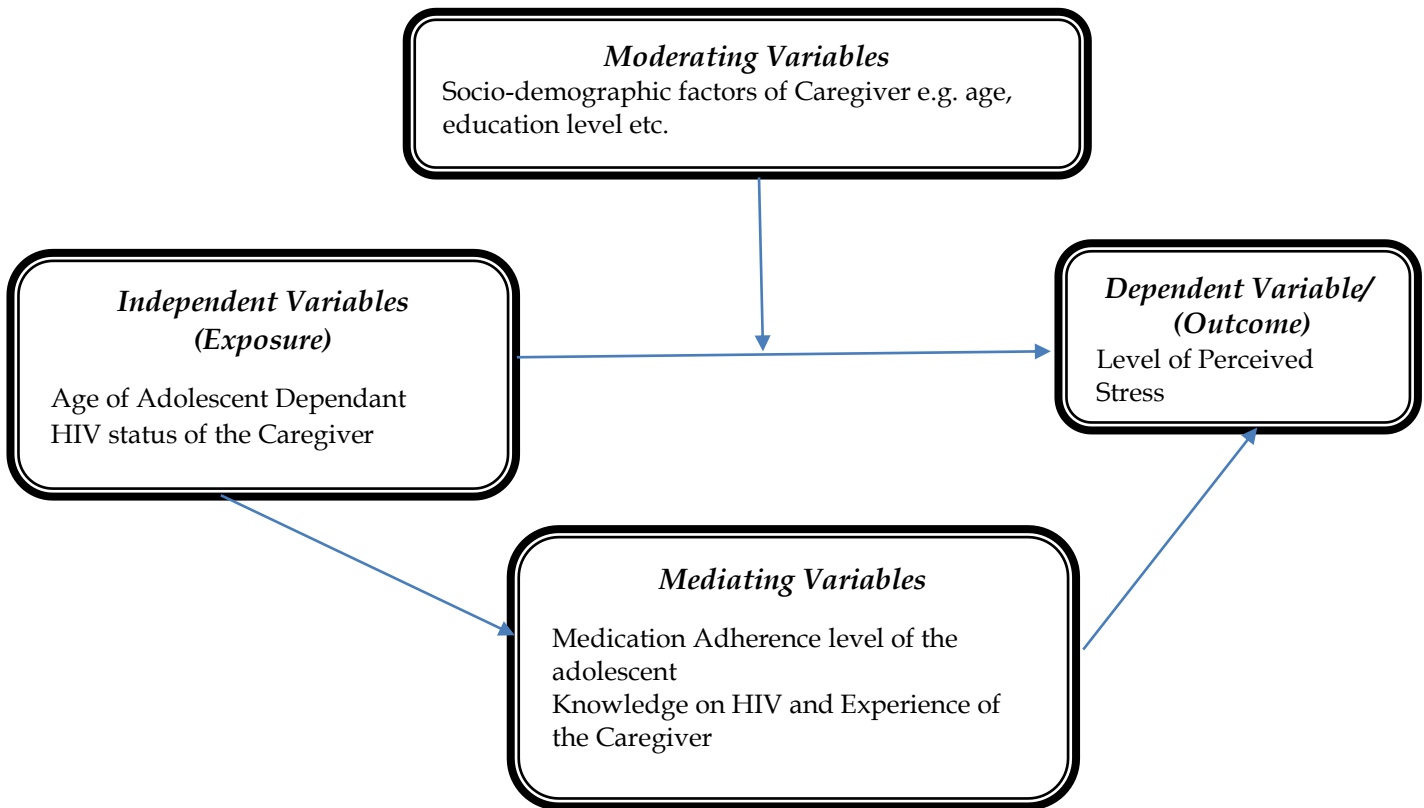
### **2.7.2 Specific Objectives**

1. To assess the levels of perceived stress among caregivers of HIV infected adolescents on treatment at the KNH CCC
2. To determine the socio-demographic factors associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH CCC?
3. To determine the psycho-social factors associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH CCC?

## **2.8 Conceptual Framework**

The conceptual framework shows how variables interplay. The independent variables in this study is the HIV status of the caregiver and adolescence stage of the dependent. The moderating factors are the socio-demographics factors which are gender, occupation, education level, marital status and the number of children and the socio-economic factors of the caregiver. The mediating variables are medication adherence level of the adolescent and knowledge on HIV and experience of the caregiver

**Figure 2. 1:** *Conceptual Framework Showing the Variables*



*Author: Lydia Muleyi\_ 2019*

## **CHAPTER THREE: METHODOLOGY**

### **3.1 Introduction**

The chapter is presented in the following sections namely: the research design, target population, sampling design and sample size, data collection, data management and analysis and ethical consideration.

### **3.2 Study Design**

This was a cross-sectional study where the researcher collected data from a representative subset (the caregivers) at one given point and time. The researcher was also able to make observations while collecting data.

### **3.3 Study Site**

The study was done in Nairobi County in Kenya at the Kenyatta National Hospital Comprehensive Care Centre (CCC). Although the CCC is situated in the oldest and largest referral in the Kenya, the CCC was developed in 2005. This was a product of a well formulated 5 year strategic plan to improve management of HIV infected patients accessing the hospital. The centre offers clinical consultation and treatment for new and old HIV infected patients. This includes initiation into HIV treatment, laboratory service, HIV testing and counseling, adherence counselling and psychotherapy to the patients. Nutritional services are also provided at the centre, physiotherapy, social support services and acting as data custodians.

### **3.4 Study Population**

The study targeted 260 adolescents' caregivers, both male and female who take care and live with them and accompany them to take their monthly refill of anti-retroviral medication.

### 3.5 Inclusion and Exclusion criteria

The inclusion criteria were:

- i. Caregiver aged 18yrs and above
- ii. Caregiver who gives consent to participate in the study
- iii. Caregivers who has been taking care of the HIV infected adolescent for over 6 months

The exclusion criteria were:

- i. Caregivers who have taken care of the adolescent for less than 6 months

### 3.6 Sample Size Determination

The total number of registered adolescents who attend the Kenyatta National Hospital Comprehensive Care Centre is approximately 750. The sample size was calculated by adopting Yamane Taro's sample size determination formula low (Yamane, 1967)

$$n = \frac{N}{1 + N(e)^2}$$

*Where n is the sample size of target population needed for the study*

*N is the entire population size of target population*

*e is the level of precision (error estimate) which is 0.05*

$$n = \frac{N}{1 + N(e)^2} = n = \frac{750}{1 + 750 (.05)^2} = 260 \text{ respondents}$$

Therefore, the number of participants required to participate in the study was 260;

### 3.7 Sampling method/technique

Systematic sampling technique was used to sample the number of respondents needed for the study. The interval number was determined by the following calculation

$K = \text{Total Number of Adolescents (hence Caregivers) Registered (N)} / \text{No of caregivers needed (n)}$

Therefore:  $K = 750 / 286 = 2.6 (3)$ .

Therefore, every third participant was approached and requested to participate in the study.

### **3.8 Recruitment and consenting Procedure**

Approximately 50 adolescents and their caregivers come in weekly at the KNH comprehensive Care Centre to get their medication. Therefore, the researcher was systematically select every third participant (who was their caregivers).

Once the adolescent was selected; their caregivers were approached and kindly asked to participate. If the respondent met the inclusion criteria, they were requested to sign consent forms that indicate that their participation is entirely voluntary. Prior to the respondents consenting to participating in the study, they were adequately informed about the purpose or aim of the study and the study expectations and their roles as participants.

### **3.9 Study Instruments**

Two study instruments were used in the study; a socio-demographic questionnaire and the perceived stress scale (PSS- 10 item scale). The socio-demographic questionnaire addressed variables such as age, gender, socio-economic status and level of education of the respondents. The Perceived stress scale was used to measure the level of non-specific stress the caregivers feel they endure which in turn affects their coping mechanisms. The standardized tool was created and published by Cohen, Kamarck, & Mermelstein in 1983.

Researchers have reported relatively satisfactory reliability estimates for scores on the 14- and 10-item forms. Roberti, Harrington, & Storch (2006), reported reliability estimates of PSS items at

0.85 and 0.82. Convergent validity with the perceived helpnesses and self efficacy scales was also estimated to be roughly the same. The researchers conducted the study among university students. Similar results were reported later in a study that focused in the psychometric analysis of the 10 item PSS (Taylor, 2015). The study was carried out among middle aged adults.

The PSS is scored as follows; Scores ranging from 0-13 was considered low stress while scores ranging from 14-26 was considered moderate stress. Finally, scores ranging from 27-40 was considered high perceived stress.

### **3.10 Pre-Survey and Pretesting**

The researcher conducted a pre-survey of the study site before conceptualizing the study methodology. This helped in determining the number of adolescents that received HIV treatment at the Kenyatta National Hospital CCC. The researcher intends to pretest the socio-demographic tool to ensure that the questionnaire addresses the variables that it needs to capture from the participants.

### **3.11 Ethical Consideration**

First, approval from the Hospital and University of Nairobi ethics and research committee was obtained. The HIV Comprehensive Centre Management was also well informed about the study. Consent from the study participants was obtained for participation in the study. Prior to obtaining the written consent, the study participants were adequately informed about the study, instructions, study objectives, risks and participant rights.

Participation in the study was entirely dependent on the participants' willingness to per take in the study. The participants were also informed that they can withdraw from the study at their own

peril. This was not inviting any penalties or have any negative consequences. Since no names was indicated in the questionnaires, the participants were also assured of their anonymity.

The study could pose a psychological risk on the participants as their participation could evoke psychological distress. Respondents showing signs of distress were referred to the Centre's psychologist. For participants with severe levels of stress, referral for further psychiatric evaluation and psychotherapy was done at the same facility.

### **3.12 Data Collection Procedure**

The researcher got permission from the KNH/ERC before starting data collection. Permission was also sought from the Kenyatta National Hospital Comprehensive Care Centre management. The center's administration was requested to offer one office where the data collection was conducted in privacy and confidentially.

Once the participants are identified through systematic sampling, written consent was obtained first at the study site. Once the respondents signed the consent the researcher then administered the socio-demographic questionnaire and the Perceived Stress scale. The tool was self-administered and therefore was translated to Kiswahili for those respondents that were not conversant with English. The researcher stored the filled in questionnaires after completion.

### 3.13 Flow Chart of the Data Collection Process

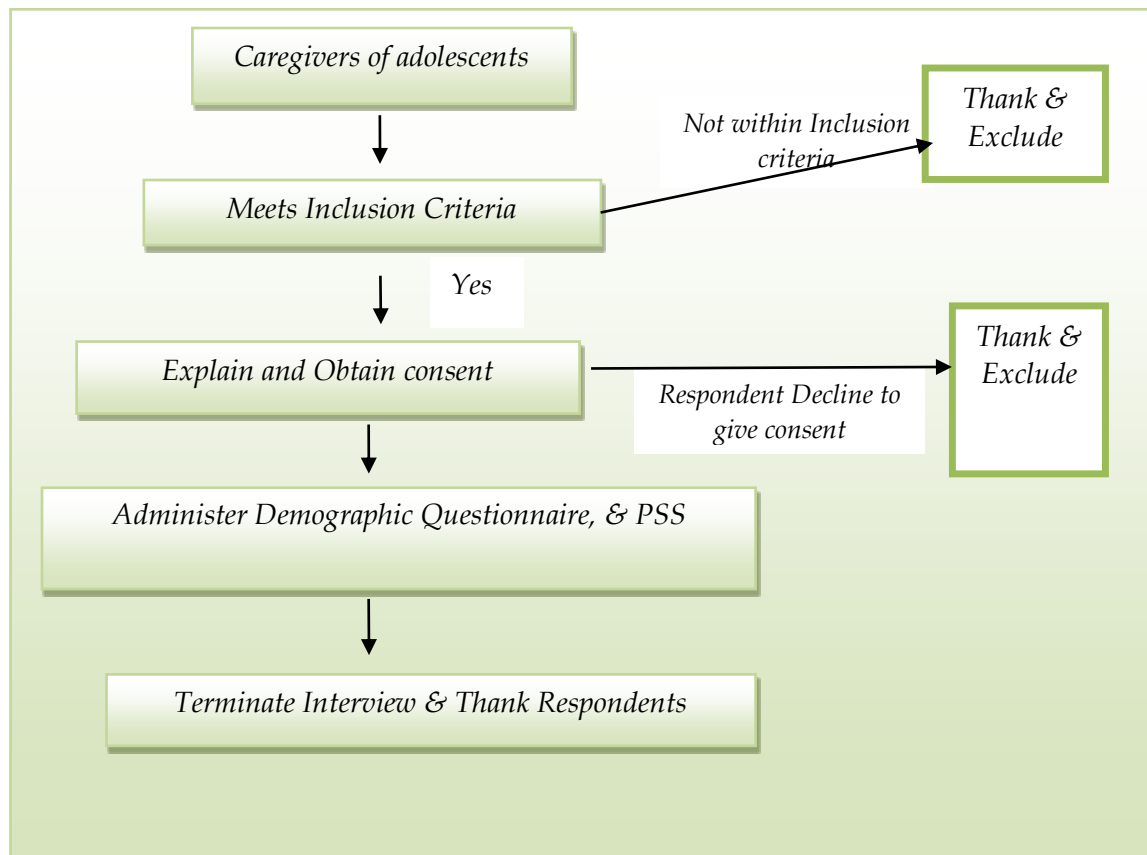


Figure 3. 1: Flow Chart for Data Collection Process

Author\_ Lydiah Muleyi

### 3.14 Data management

Completed questionnaires were collected, kept in a secure box. The questionnaires were only accessed when data entry and analysis commenced.



### **3.15 Data analysis and Presentation**

After data collection, data entry and quantitative statistical analysis was done using Statistical Package for Social Sciences (SPSS) version 24. Frequency tables, bar graphs and pie charts were used to present the socio-demographic factors and prevalence rates of perceived stress among the caregivers. Association between the variables was presented using Chi-square tests, correlation between variables was determined by Pearson's correlation or Cramer's Phi coefficients for categorical variables.

### **3.16 Study Limitation**

Owing to the sensitive nature of the study, some participants were having reservations and were uncomfortable in participating in the study. However, the researcher convinced them through assuring them of their anonymity and privacy.

## **CHAPTER 4: RESULTS**

### **4.0 Introduction**

This chapter entails the analysis of the data collected. The results are presented according to the study objectives which were:

4. To assess the levels of perceived stress among caregivers of HIV infected adolescents on treatment at the KNH Comprehensive Care Centre
5. To determine the socio-demographic factors associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH Comprehensive Care Centre
6. To determine the psycho-social factors associated with the perceived Stress levels among the caregivers of HIV infected adolescents on treatment at the KNH Comprehensive Care Centre

### **4.1 Response Rate**

The sample size population for the study was 236 respondents and the response rate was 82.5%. Respondents participated in the full interviews once they signed the consent forms.

### **4.2 Respondents' Socio Demographic Profiles**

Table 4.1 presents socio-demographic characteristics of the respondents who were caregivers of HIV sero-reactive adolescents' individuals that visit the Comprehensive Care Centre at the Kenyatta National Hospital.

Most of the respondents were female (162 (68.6%)). The male respondents were 74 which represented 30.9% of the sample population. Most females' respondents were mothers to the adolescents.

The mean age of the respondents was 39.75yrs (SD = 9.749). The mode was 40yrs while the median was 39.

Forty-four-point nine percent (44.9% (106)) of the respondents were married. Twenty-two-point eight percent (22.8% (54)) were single or never married and 17.8% (42) were widowed while 14.4% (34) were divorced.

Only 1.7% (4), had not been exposed to formal education. Nineteen-point five percent (19.5% (46)) of the respondents had reached primary school, 38.6% (91) had either started or completed secondary school education only, and 40.3% (95) had been to college or University.

Majority of the respondents indicated that they were employed 67.8% (160), the remaining 32.2% (76) were unemployed.

Twenty-two percent (22.0% (52)) of the respondents were HIV negative, 67.8% (160) were HIV positive. Eight-point five percent (8.5% (20)) didn't know their status.

The average time the respondents had taken care of the adolescents was 7.89yrs (SD 4.709), the mode was 10yrs. 84% (35.6), had taken care of the adolescents for 2 to 5yrs. Respondents who had taken care of the HIV positive adolescents for more than 11 yrs. represented 29.7% (70). Twenty-eight-point eight percent (28.8% (68)) of the respondents had taken care of the adolescents for 6 to 10yrs. Only 5.9% (14) of them had taken care of the adolescents for 1yr.

The average salary of the respondents was Kshs.26742.35 (SD= 27752.543). the median was 20,000. The mode was 20,000.

**Table 4. 1: Respondents Socio-Demographic Profiles**

| Variable                  |                                | Outcome 236/100% |                |
|---------------------------|--------------------------------|------------------|----------------|
|                           |                                | Frequency (n)    | Percentage (%) |
| Gender                    | Male                           | 74               | 30.9%          |
|                           | Female                         | 162              | 68.6%          |
| Age                       | 18-25yrs                       | 15               | 6.4%           |
|                           | 26-33yrs                       | 43               | 18.7%          |
|                           | 34-41yrs                       | 90               | 39.1%          |
|                           | 42-50yrs                       | 34               | 18.2%          |
|                           | 51yrs +                        | 30               | 13.0%          |
| Marital Status            | Married                        | 106              | 44.9%          |
|                           | Single                         | 54               | 22.8%          |
|                           | Widowed                        | 42               | 17.8%          |
|                           | Divorced/Separated             | 34               | 14.4%          |
| Level of Education        | No formal Education            | 4                | 1.7%           |
|                           | Primary School                 | 46               | 19.5%          |
|                           | High School                    | 91               | 38.6%          |
|                           | Under & Post graduate/ College | 95               | 40.3%          |
| Occupation                | Employed                       | 160              | 67.8%          |
|                           | Unemployed                     | 76               | 32.2%          |
| History of Mental Illness | Yes                            | 9                | 3.8%           |
|                           | No                             | 227              | 96.2%          |
| HIV status                | Positive                       | 160              | 67.8%          |
|                           | Negative                       | 52               | 22.0%          |
|                           | Don't Know                     | 24               | 10.2%          |
| Length of Time            | 1yr or less                    | 14               | 5.9%           |
|                           | 2 to 5yrs                      | 84               | 35.6%          |
|                           | 6 to 10yrs                     | 68               | 28.8%          |
|                           | 11yrs & above                  | 70               | 29.7%          |

### 4.3 Caregiver Perceived Stress

#### 4.3.1 Care Giver Scores & Interpretation

The level of perceived stress was assessed using the Cohens perceived stress scale. The mean score of the respondents was 17.87 (SD 5.020). The median was 18 and the Mode was 18.

The scores interpretation was as indicated on Table 4.2.

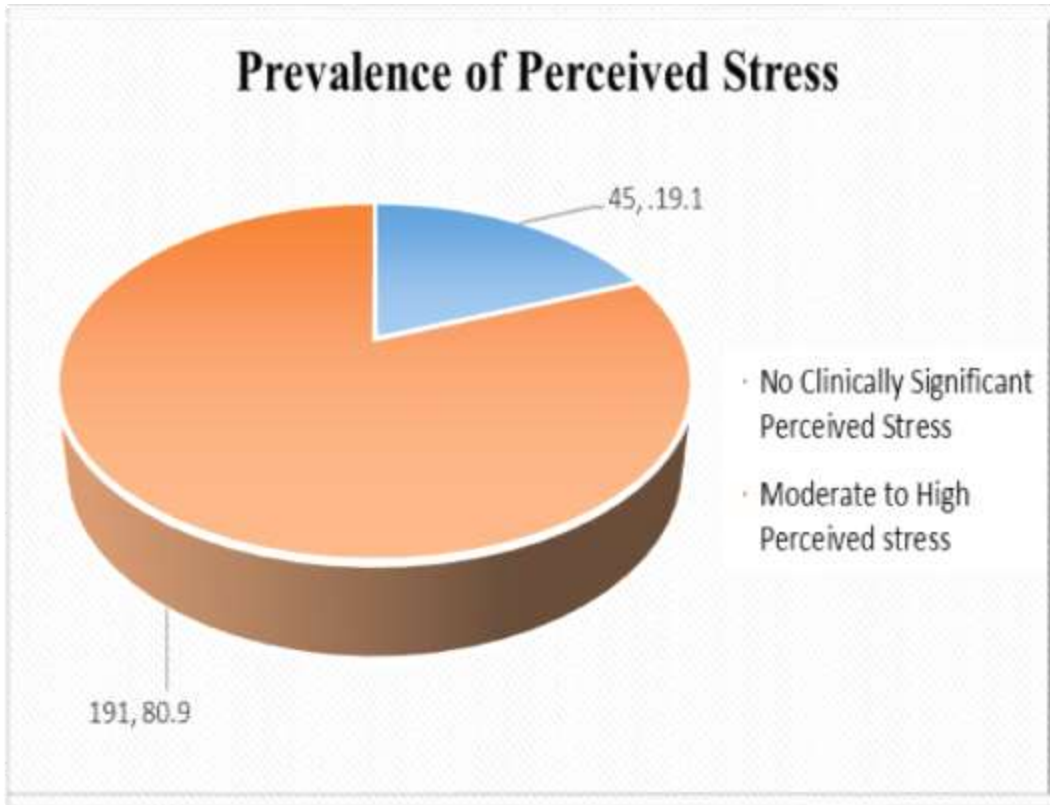
Nineteen point one percent (19.1% (45)) of the respondents had low perceived stress levels, 76.7% (181) had moderate perceived stress and 4.2% (10) respondents were found to high stress levels.

Table 4. 2: Respondents Perceived Stress Levels

| <b>CPS Scores Interpretation</b> | <b>Outcome 236/100%</b> |
|----------------------------------|-------------------------|
|                                  | <b>(n/%)</b>            |
| 0-13 (Low stress)                | 45(19.1%)               |
| 14-26 (Moderate Stress)          | 181(76.7%)              |
| 27-40 (High Perceived Stress)    | 10(4.2%)                |

#### 4.3.2 Overall Prevalence of Perceived Stress

The prevalence of caregiver perceived stress levels was determined by considering every respondent that had moderate to high perceived stress. As shown in the Fig. 4.1, the prevalence was 80.9%.

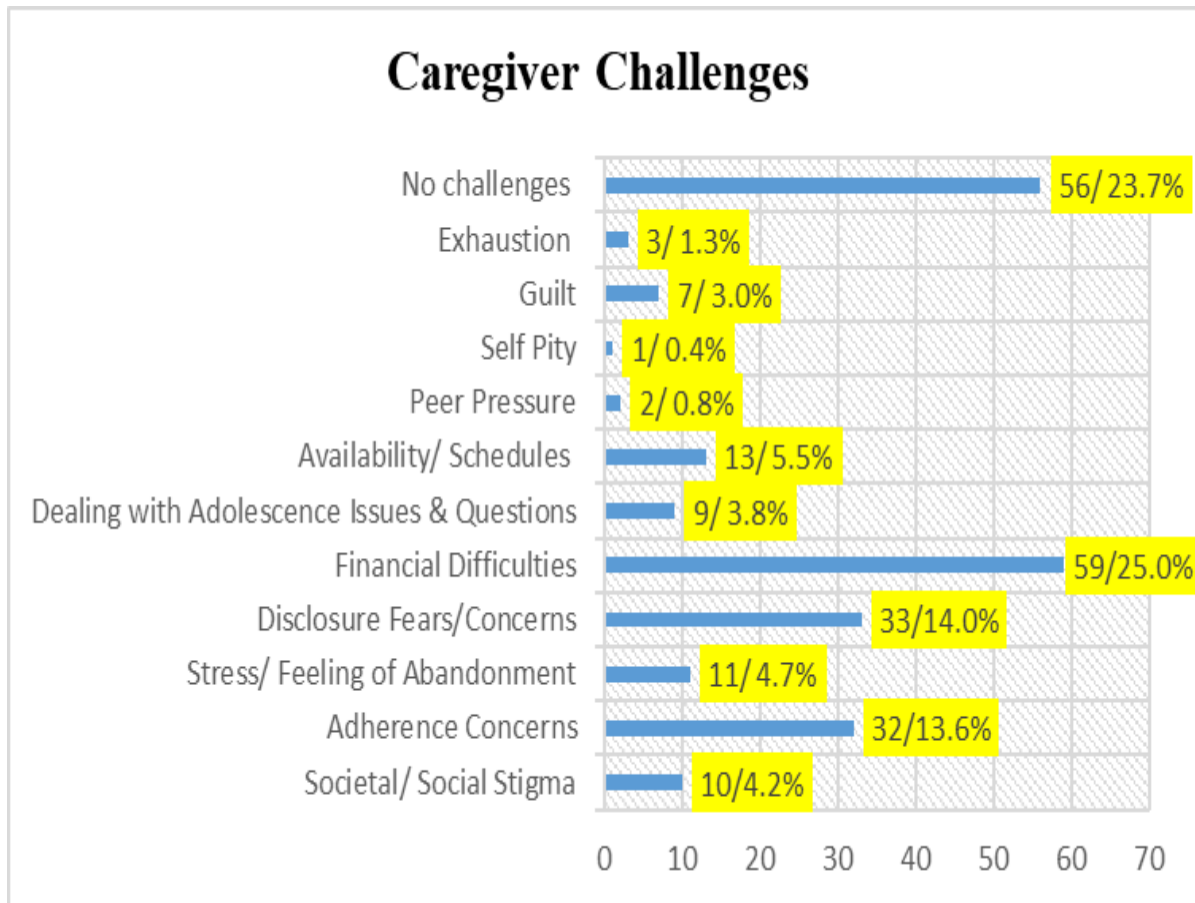


*Figure 4. 1: Prevalence of Perceived Stress among the Caregivers of HIV positive Adolescents*

#### **4.4 Psycho-social Factors Affecting Caregivers of HIV Positive Adolescents**

##### **4.4.1 Caregiving Challenges**

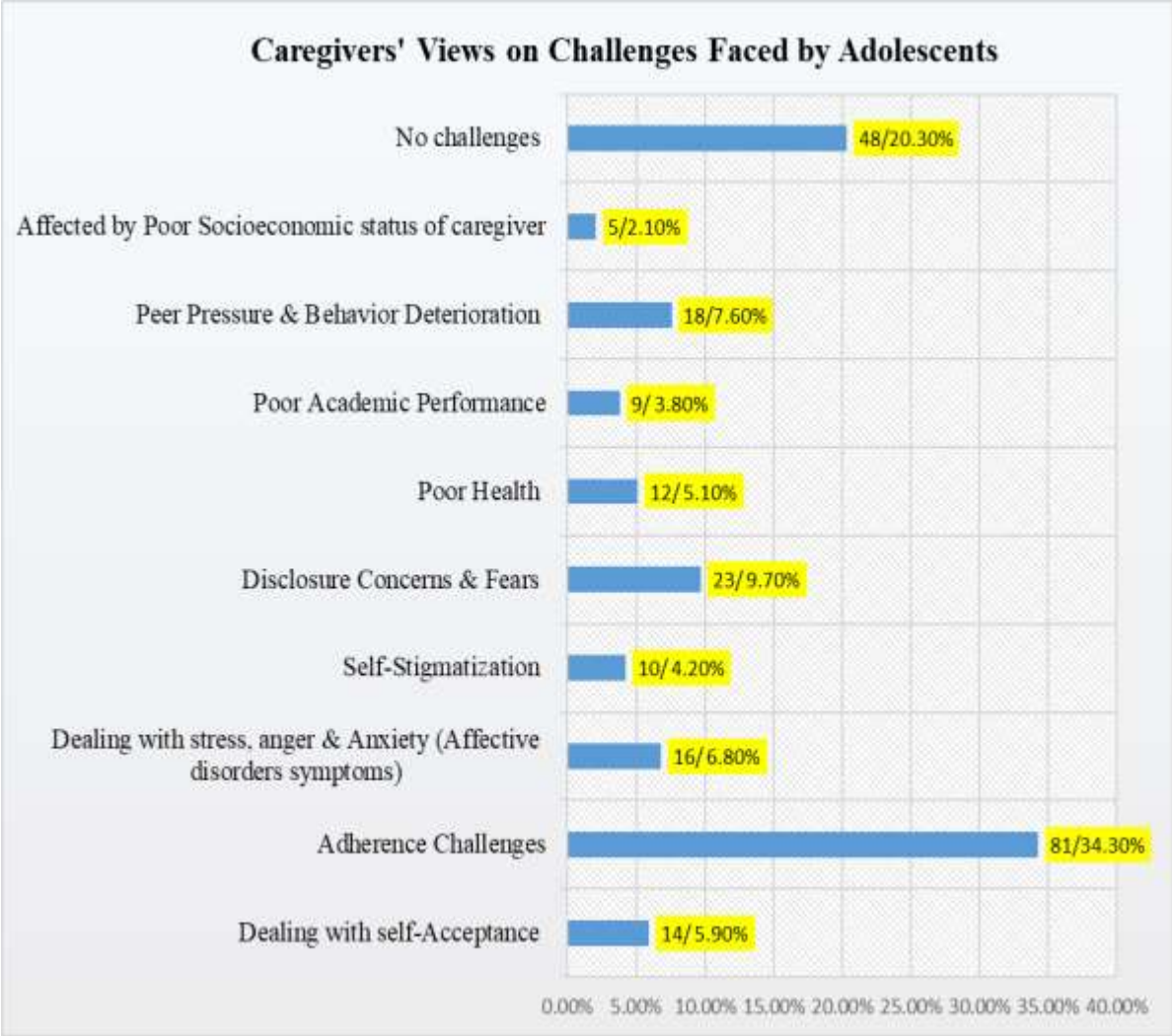
The caregivers were asked what challenges they faced while they took care of the adolescents and their responses were as illustrated in figure 4.2 below. Twenty-five percent (25.0%, (59) of the respondents felt that the financial challenges were overwhelming. Fourteen percent (14% (33) of the respondents felt that thoughts of disclosing the status of the adolescents and their own in most cases was stressful. Thirteen-point six percent (13.6% (32), were concerned about the adherence to the antiretroviral medicine by the adolescent. Some mentioned that they constantly had to remind the adolescent to take the medication who would be unwilling to do so.



**Figure 4. 2: Psychosocial Factors/ Challenges that the caregivers face**

#### **4.4.2 Challenges the Adolescents Face (Caregivers Views)**

The caregivers were further asked what challenges they knew the adolescents faced and in turn also increased their levels of perceived stress. Their responses were as illustrated in Figure 4.3 below. 20.3% (48) of the caregivers felt that the adolescents had no challenges. However, 34.3% (81) indicated that their adolescents were struggling with adherence to medication. The other concerns were disclosure concerns and dealing with affective mood disorder symptoms which were mentioned by 9.7% and 6.8% of the respondents respectively.



**Figure 4. 3: Challenges that the Adolescents face**

**4.5 Association between socio-demographic and Psychosocial factors and Respondents Level of Perceived Stress**

To establish association between socio-demographic factors and respondents’ levels of perceived stress, the Pearson chi square test was done. Occupation was the only socio-demographic factor significantly associated with perceived level of stress among the caregivers ( $X=7.483$ ,  $df=2$ ,  $p=0.024$ ). More unemployed persons seemed to have high perceived stress. It can also be seen that individuals who had low perceived stress were employed compared to the unemployed persons.



The Cramer's Phi- coefficient correlation statistics was calculated to determine the strength of effect of the independent variable on the dependent variable. As indicated in Table 4.4, the Cramer's V =0.178. This indicated there was a weak relationship between the two variables.

**Table 4. 3: Association & Correlation between Socio-Demographic Factors & Perceived Stress Levels**

| Variable   |            | Level of Perceived Stress |            |         | Pearson's Chi Square (PValue) | Cramer's V |
|------------|------------|---------------------------|------------|---------|-------------------------------|------------|
|            |            | Low                       | Moderate   | High    |                               |            |
| Occupation | Employed   | 29(12.3%)                 | 128(54.3%) | 3(1.3%) | X=7.483,<br>df=2<br>P= 0.024  | 0.178      |
|            | Unemployed | 16(6.8%)                  | 53(22.5%)  | 7(3.0%) |                               |            |

No psychosocial factor was associated with Perceived level of stress among the respondents at a P value= 0.225. A chi square test was performed between perceived level of stress and challenges the respondents listed.

#### **4.5 Relationship/ Correlation between Variables**

As indicated in table 4.5, there was a positive linear relationship between age of respondents and estimated family income at ( $r = .202, p = \leq .009$ ), meaning that the older the respondents were the more likely they were earning a better income or estimated better income in the study.

There was also a positive linear relationship between the age of the respondent and the length of time they had taken care of the adolescent ( $r = .304, p = \leq .001$ ). Implication being that the older caregivers had taken care of the adolescents for a longer period than the younger ones hence had more experience.

There was a negative linear relationship between gender and estimated family Income ( $r = -.304, p = \leq .002$ ). Which meant that the male participants in this study generally indicated that they earned less money than the female participants. However, it is important to note the number of male respondents was significantly lower.

A positive linear relationship was noted between gender and HIV status at ( $r = .209, p = \leq .002$ ). This indicated that more male caregivers were HIV negative compared to the ratio of females that were HIV negative.

There was a negative linear relationship between perceived stress levels and estimated family Income at ( $r = -.298, p = \leq .001$ ), implication being that higher scores in perceived stress was related with lower income and vice versa.

There was a negative linear relationship between perceived stress and history of mental illness at ( $r = -.129, p = \leq .048$ ). Implication being that higher scores in perceived stress was related with presence of history of mental illness in the family.

**Table 4. 4: Pearson’s Correlation statistics showing Relationship between Variables**

|  |                     | Age of Respondent | Estimated Family Income | HIV Status | Time caregiver has cared for the Adolescents | History of Mental Illness |
|--|---------------------|-------------------|-------------------------|------------|--|---------------------------|
| Age Of Respondent  | Pearson Correlation |                   |                         |            |  |                           |
|  | Sig. (2-tailed)     |                   |                         |            |  |                           |
| Estimated Family Income                                      | Pearson Correlation | .202**            |                         |            |  |                           |
|  | Sig. (2-tailed)     | .009              |                         |            |  |                           |
| HIV Status   | Pearson Correlation | -.100             | -.109                   |            |  |                           |
|  | Sig. (2-tailed)     | .154              | .172                    |            |  |                           |
| Time caregiver has Cared for the Adolescents                 | Pearson Correlation | .341**            | -.025                   | .128       |  |                           |
|  | Sig. (2-tailed)     | .000              | .748                    | .070       |  |                           |
| History Of Mental Illness                                    | Pearson Correlation | .035              | -.007                   | -.043      | .049   |                           |
|  | Sig. (2-tailed)     | .596              | .926                    | .533       | .473   |                           |
| Gender   | Pearson Correlation | -.103             | -.237**                 | .209**     | .078   | .008                      |
|  | Sig. (2-tailed)     | .120              | .002                    | .002       | .254   | .897                      |
| Prevalence Of Perceived Stress                               | Pearson Correlation | -.084             | -.298**                 | .005       | -.053  | -.129*                    |
|  | Sig. (2-tailed)     | .204              | .000                    | .939       | .433   | .048                      |
| **. Correlation is significant at the 0.01 level (2-tailed). |                     |                   |                         |            |  |                           |
| *. Correlation is significant at the 0.05 level (2-tailed).  |                     |                   |                         |            |  |                           |

## **CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATION**

### **5.1 Discussion**

#### **5.1.1 Caregivers Socio-demographics**

The study found that most (68.6%) of the caregivers of the HIV positive adolescents were female. It also established that most of the female caregivers were the adolescents' mothers. Similar findings have been reported in other studies. For instance, a Malawian study that looked into the socio-demographic, clinical, and psychosocial factors associated with primary caregivers' decisions regarding HIV disclosure to their child aged between 6 and 12 years living with HIV reported that 61% of the caregivers were mothers to the children and young adolescents (Kalembo & Kendall, 2019). In a qualitative study that was conducted in Uganda to explore the experiences of caregivers of children and adolescents living with HIV and AIDS in Uganda, the researcher found that the gender ratio (male to female) of caregivers was 1 to 5. Generally indicating that most caregivers for HIV positive adolescent were females as in this current Kenyan Study (Osafu J. , Knizek, Mugisha, & Eugene, 2017).

This Kenyan study also established that the age of the caregivers that brought adolescents to the Kenyatta National Hospital CCC was mostly 40 years. The mean age of the respondents was 39.75yrs (SD = 9.749) while the median was also 39. Kalembo & Kendall (2019), in their study, reported that most of the caregivers in their study (61yrs) were between the age of 41 to 50yrs. This current study also established that most of the caregivers were married (44.9%), a finding that is generally shared by most studies done on HIV caregivers (Osafu, et al., 2017; Kalemba & Kendall, 2019). The Malawian study reported that 64% of the caregivers were married .

Contrary to most studies that have found that caregivers are not very well educated (Osafo, et al., 2017; Kalemba & Kendall, 2019), this current study found that over 40.3% had been to college or University. The same findings were noted when looking at the respondents occupation situation. This current study found that nearly 70% of the respondents were employed and earning a salary and that the average salary was Kshs.26742.35 (SD= 27752.543). contrary finding have been found in different settings that caregivers for HIV positive children and adolescents have been engaged in studies. Most studies report financial constraints and lack of employment as major challenges (Akintola, Hlengwa, & Dageid, 2013, Garcia, et al., 2013).

### **5.1.2 Caregivers Perceived Stress levels**

The caregivers perceive stress was determined using Cohens perceived stress scale. The study revealed that 19.1% of the respondents had low perceived stress levels while 76.7% had moderate perceived stress. Only 4.2% respondents were found to have high stress levels. Similarly, a South African study that was done to assess the perceived stress among caregivers reported that most of the volunteers (over 70 %) had moderate-to-high levels of stress (Akintola, Hlengwa, & Dageid, 2013 ). The researchers found that the 'role/work overload' 'lack of support' and 'overwhelming nature of the disease' explained most of the variance in stress. Similar to this study, there was a relationship between age and level of stress perceived. In this current Kenyan study, the older persons seemed to have less stress. Contrary to this finding, the South African study reported the older caregiver seemed to be stressed because of the workload (Akintola, Hlengwa, & Dageid, 2013 ). Other factors that seem to affect the caregivers and exacerbating the stress levels were; lack of support, stress emanating from perceived stigma and lack of training; and the overwhelming nature of AIDS.

In another study that was done in South Africa that assessed the level of parenting stress among HIV caregiver for young children (including young adolescents), it was reported that the parenting stress levels in the caregivers who participated in this study were extremely high at the baseline assessment ( $103.95 \pm 19.51$ ). Since the score were above 90 most respondents in that study was to be referred warrant referral for further investigation as their stress level were clinically significant (Potterton, Stewart, & Cooper, 2007).

In this current study, employment status was found to be significantly associated with perceived stress among care givers. The study found that no income and low income situations increased the level of perceived stress among the respondents. Garcia, et al., (2013) found that being both HIV-positive and persistently food insecure strongly and synergistically increased the risk for maternal perceived stress. Their study sought to determine whether persistent household food insecurity, HIV and maternal stress are correlated (Garcia, et al., 2013). The study was carried out in Ghana. Clearly, caregiver burden among individuals that care for HIV positive adolescents is an issue that needs further studies especially on mitigation strategies that help build resilience and better coping mechanism.

### **5.1.3 Caregivers Psychosocial Challenges**

The most notable challenge was financial constraints. 25.0% of the respondents indicated that they had difficulty taking care of the adolescents financial needs and their own financial obligations. For some of the respondents providing a meal or transport to get to the clinic was a major problem. Similar sentiment were revealed from a qualitative study that entailed exploring critical coping challenges facing caregivers of persons living with HIV/AIDS and other terminally ill persons in Botswana (Kangethe, 2009). The researchers found that the caregivers needed an increase of

incentive and the food basket. The study was done in Kanye Care Program in Botswana. A Brazilian study that was done in Rio de Janeiro, also found that financial constraints were among the challenges that the caregivers faced (Bruna, Giovana, Daiani, Camila Magroski, & Deise, 2016). The study sought to explore difficulties and facilities of the family to care for children with HIV/AIDS. The same findings were reported from a study that was done in Zimbabwe. In this study, not only was the financial costs one of the challenges for the caregivers', it was the biggest challenge as they faced difficulty in meeting care costs, procuring food and catering for their transport and medical costs. This study was also qualitative (van Deventer & Wright, 2017).

This current Kenyan study also found that 14% of the respondents felt that thoughts of disclosing the status of the adolescents and their own in most cases was a major challenge. This was despite the fact that 67.8% of them knew their status. Higher numbers have been reported in other studies. In an Ethiopian study that looked into Perinatally acquired HIV-positive status disclosure and associated factors in Dire Dawa and Harar, Eastern Ethiopia, which was a health facility-based cross-sectional study, they reported that 50% of the respondents had not disclosed their status or the child's/ adolescents status (Melkamu, Yadeta, & Aklilu, 2018). In the Malawian study previously mentioned, the prevalence of non-disclosure of HIV status to children was 64% (Kalembo & Kendall, 2019). Similar to this Kenyan study, the reporters found that caregivers reluctance was caused by anticipated social stigma and discrimination, concerns about the child's inability to cope with the news and lack of self acceptance. Though not significantly evident on this Kenyan study, a lack of knowledge on how to disclose HIV status seemed to be a concern to about 19% of the respondents in Malawi (Kalembo & Kendall, 2019). Since non-disclosure is associated with the number of dire clinical cases and directly related to adherence, it is assumed that adherence level of those adolescents could be poor.

Adherence was a challenge the caregiver of these current study faced. 13.6% felt following up on the adolescents to take their medicine was a challenge. Conversely, this means that the adherence rate was at 86,4% among the HIV positive adolescents who attend the KNH CCC. This is considered below optimal levels for ART therapy. The same findings have been found in other studies. Tadele & Lwam (2014), in their study that was done in Ethiopia, found that adherence amongst adolescence and children was at 83.4%. These were figures that were reported by caregivers. Another study that was also done in Ethiopia found suboptimal adherence to ART medication among the adolescents that participated in the study (Naod, Fikre, & Degu, 2017). The researchers further found that having a caregiver who is a parent or a widowed parent was associated with optimal adherence levels among adolescents.

## **5.2 Conclusions**

The conclusion drawn from the study findings is that caregivers for HIV positive adolescents endure or perceive their task as stressful. This was mainly because majority of them had moderate stress levels. Considering the fact that minimising of symptoms tends to happen in self reported survey, then it is safe to assume that most of these respondents actually had between moderate to high perceived stress levels. The study also concludes that poor socio-economic status seemed to largely affect the caregiving capabilities of the caregivers and this was very frustrating for them. The psychosocial factors that increased caregiver burden in this study was the adherence concern they had for the adolescents. By the time the study was being conducted the adherence levels among the adolescents was at suboptimal levels which is a major determinant of treatment outcomes. Another concern is that the possibilities of dealing with stigma after disclosure are rife. The study also concludes that more women than men are caregivers for HIV positive adolescents.



### **5.3 Recommendations**

The study recommends that:

1. Caregiver psychosocial support should be offered at the KNH CCC. Screening, counselling or psychotherapy for the caregivers should be considered in the treatment plan as high levels of stress could negatively impact their health and well-being
2. Self-empowerment talks and if possible, grants should be offered by the government (policy makers) to help the caregivers start small business and be able to take care of their financial obligation
3. To facilitate disclosure and hence encourage adherence, caregivers should be counselled about the appropriate age of disclosure and related misconceptions that hinder it. The adolescents should also be counseled on the importance of adherence to the medication and more importantly be made aware of the consequence of lack of adherence
4. It is also apparent that caregivers need to be guided as to how to address children's frequent questions about their health status.

### **5.4 Suggestions for Further Studies**

The study focused only on the caregivers' views on the challenges they faced and what challenges they thought the adolescents faced. The adolescent wasn't engaged in the study as a participant at all. Therefore, there is no information on the adolescents that can be referred to in the study such as age or their views on challenges they face. Another study should be done that will also consider the adolescents views on a few of the key issues revealed by this study.

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## **APPENDICES**

### ***Appendix 1: Informed Consent Explanation***

**TITLE OF STUDY:** Perceived Stress and Associated Factors Among Caregivers Of Adolescents On HIV Treatment At KNH Comprehensive Care Centre

**PRINCIPAL INVESTIGATOR AND INSTITUTIONAL AFFILIATION:** Lydiah Muleyi, MSc Clinical Psychology, University of Nairobi.

#### **INTRODUCTION:**

The researcher is conducting a study on the topic above. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. Feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called “informed consent”. Once you understand and agree to be in the study, I request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research:

- i) Your decision to participate is entirely voluntary
- ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal
- iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. We will give you a copy of this form for your records.

#### **May I continue? YES/ NO**

This study has approval by The Kenyatta National Hospital–University of Nairobi Ethics and Research Committee Protocol No. \_\_\_\_\_

#### **WHAT IS THIS STUDY ABOUT?**

The researcher listed above is interviewing adult caregivers of HIV infected adolescents who receive treatment at the Kenyatta National Hospital Comprehensive Care Centre. Participants in this research study will be asked questions about their perceived stress among other questions that was focus on the psycho-social and demographic factors.

There Will be approximately 286 participants in this study systematically chosen. We are asking for your consent to consider participating in this study.

#### **WHAT WAS HAPPEN IF YOU DECIDE TO BE IN THIS RESEARCH STUDY?**

If you agree to participate in this study, the following things will happen:

You will be interviewed by the researcher who is a counselor in a private area( designated office at the Clinic) where you feel comfortable answering questions. The interview was last approximately 15 minutes.

After the interview is done, the psycho education and probably treatment will be accorded as per diagnosis. Referral for psychotherapy could be done.

We will ask for a telephone number where we can contact you if necessary. If you agree to provide your contact information, it was used only by people working for this study and was never shared with others. The reasons why we may need to contact you include: clarification of information given.

### **ARE THERE ANY RISKS, HARMS, DISCOMFORT ASSOCIATED WITH THIS STUDY?**

Medical research has the potential to introduce psychological, social, emotional and physical risks. Effort should always put in place to minimize the risks. One potential risk of ing in the study is loss of privacy. We will be keen keep everything you tell us as confidential as possible. We will use a code number to identify you in a password-protected computer database and was keep all of our paper records in a locked file cabinet. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any question asked during the interview.

It may be embarrassing for you to have to give details of your personal life. We will do everything we can to ensure that this is done in private. Furthermore, the researcher is a professional with special training in these examinations/interviews. Referrals for psychological review (counselling) was done for individual with moderate-severe perceived stress levels.

In case of any injury, illness or complications related to this study, contact the researcher right away at the number provided at the end of this document.

### **ARE THERE ANY BENEFITS ING IN THIS STUDY?**

Determining if you have severe stress levels was helpful especially in improving your ability to care for the HIV infected adolescent hence better outcome and quality of life of both you and the adolescent.

The information you provide will be a contribution to science and knowledge in understanding the psychological impact of caring for HIV infected adolescents and hence improve their level of care.

### **WAS ING IN THIS STUDY COST YOU ANYTHING?**

There was no financial cost to you as the data collection was carried out during your clinic visit.

**WERE YOU GET REFUND FOR ANY MONEY SPENT AS PART OF THIS STUDY?**

As indicated above, you were not to spend any money to take part in this study. Hence there was no compensation.

**WHAT IF YOU HAVE QUESTIONS IN FUTURE?**

If you have further questions or concerns about participating in this study, please call or send a text message to the researcher at the number provided at the bottom of this page. The researcher was pay you back for your incurred costs related to communication.

For more information about your rights as a research participant you may contact the:

**KENYATTA NATIONAL HOSPITAL-UNIVERSITY OF NAIROBI ETHICS AND RESEARCH COMMITTEE**

SECRETARY/ CHAIRPERSON,

Telephone No. 2726300 Ext. 44102,

Email [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke).

**PRINCIPAL INVESTIGATOR (RESEARCHER)**

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## **WHAT ARE YOUR OTHER CHOICES?**

Your decision to participate in research is voluntary. You are free to decline participation in the study and you can withdraw from the study at any time without injustice or loss of any benefits.

### ***Appendix 2: Statement of Consent***

#### **Participant’s statement**

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with the researcher. I have had my questions answered in a language that I understand. The risks and benefits have been explained to me. I understand that my participation in this study is voluntary and that I may choose to withdraw any time. I freely agree to participate in this research study.

I understand that all efforts were made to keep information regarding my personal identity confidential.

By signing this consent form, I have not given up any of the legal rights that I have as a participant in a research study.

I agree to participate in this research study:    Yes    No

I agree to have the questionnaire preserved for later study:      Yes    No

I agree to provide contact information for follow up:                                  Yes    No

**Participant printed name:** \_\_\_\_\_

**Participant signature / Thumb stamp** \_\_\_\_\_

**Date** \_\_\_\_\_

#### **Researcher’s statement**

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has willingly and freely given his/her consent.

**Researcher’s Name:** \_\_\_\_\_

**Date** \_\_\_\_\_

**Signature** \_\_\_\_\_

**Role in the study:** \_\_\_\_\_

### *Appendix 3: Ridhaa Ya Kushiriki Kwa Utafiti*

#### **UTANGULIZI**

Majina yangu ni Lydiah Muleyi, mimi ni mwanafunzi wa chuo kikuu cha Nairobi na waania shahada ya uzamili ya Clinical Psychologia.

Mada ya utafiti ni: Kiwango cha shida na wasiwasi na sababu zinazohusiana na wasiwasi hizi kati ya wanaohusika kuwashughulikia vijana wanogonjeka Ukimwi na kupata matibabu katika hospitali ya Kenyatta kwenye kituo cha huduma ya kina wa ugonjwa wa Ukimwi.

#### **MADHUMUNI YA UTAFITI**

Kuchunguza kiwango cha shida na wasiwasi inayowakumba wanao husika na kuwashughulikia vijana wanogonjeka Ukimwi na kupata matibabu katika hospitali ya Kenyatta kwenye kituo cha huduma ya kina wa ugonjwa wa Ukimwi.

#### **MAELEZO YA UTARATIBU WA UTAFITI**

Umechaguliwa kama mshiriki mdhaniwa wa utafiti huu kwa sababu unakidhi vigezo vya kuingizwa vya utafiti huu yale yalikuwa. Nakuhimiza usome fomu hii na uulize maswali yoyote ambayo unaweza kuwa nayo kabla ya kukubali kuingia kwenye utafiti huu. Ni ya muhimu kutambua kuwa utafiti huu utachapishwa baada ya kukamilika.

Ikiwa unakubali kuwa katika utafiti huu, utaombwa kusaini fomu ya kibali kama uthibitisho wa hiari wa ushiriki. Baada ya kutia saini kwenye ridhaa, basi utaendelea kama mshiriki and kujazaa orodha ya maswali yatayo anadikwa kwenye karatasi tatu tofauti. Kujibu maswali hayo yote yatachukuwa kama muda wa dakika kumi na tano.

#### **HATARI, MADHARA NA USUMBUFU INAYOHUSISHWA NA UTAFITI HUU**

Hakuna hatari ya kiafya wowote inayohusishwa na utafiti huu. Ingawaje, inapopatikana kuwa unawasiwasi au shida ya hali ya juu, utapewa rufaa iliupate matibabu ya kina, sana sana ya kipsychologia.

#### **FAIDA YANAYOHUSISHWA NA UTAFITI HUU**

Faida inayohusishwa na utafiti huu ni kuwa mshiriki atapate kujua kama anashida ama wasiwasi, hivyo basi matibabu kikamilifu yataanzishwa.

#### **SIRI YAKO KAMA MSHIRIKI**

Lakini tutahakikisha kuwa unacho tueleza kama mshiriki itakuwa siri. Tutatumia msimbo kukujua kwenye data itakayokuwa kwa kompyuta ambayo imelindwa na neno la kificho. Isitoshe, makaratasi yetu yote yatawekwa na kufungiwa ndani ya kabati ya faili.

## **NITAREGESHEWA PESA AMBAYO NITATUMIA KAMA MSHIRIKI WA UTAFITI HUU?**

LA, kama ilivyoelezewa, hautahitaji pesa kuhusishwa kwa utafiti huu.

## **HAKI YA KUULIZA MASWALI AMA KURIPOTI WASIWASI**

Kama unamaswali zaidi ama wasiwasi yeyote kama bado utafiti unaendelea au baada ya kushiriki kwenye utafiti, tafadhali wasiliana nami kwa simu au unaweza tuma ujum kwenye nambari hii ya mtafiti au, unaweza wasiliana na karani/ Mwenya kiti, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee.

## **HOSPITALI YA KENYATTA- CHUO KIKUU CHA NAIROBI KAMATI YA MAADILI NA UTAFITI WA KISAYANSI**

SECRETARI/ MWENYE KITI,

Nambari ya Simu. 2726300 Ext. 44102,  
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### **MTAFITI MKUU**

Lydia Muleyi  
Idara ya Psychiatry  
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Nambari ya Simu-0713664047  
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### **WASIMAMIZI WA KIACADEMIA**

#### **Dr Fredrick Owiti**

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Chuo Kikuu Cha Nairobi  
Nambari ya Simu-0720959587  
Barua Pepe: [drmulindi@yahoo.com](mailto:drmulindi@yahoo.com)

## **HAKI YA KUJITOA KWENYE UTAFITI**

Uamuzi wako kushiriki ni kwa hiari yako. Uko na huru kukataa kuwa mshiriki wa utafiti huu. Unaweza kujitoea kama mshiriki wa utafiti huu wakati wowote bila udhalimu au upungufu wafaida yoyote kwako. Unahurusa ku tokujibu swala lolote ama kujitoea kabisa kwenye utafiti wakati wowote ukiendelea na unaweza pia kataa majibu yako kutumika.

### ***Appendix 4: Fomu Ya Ridhaa Ya Mshiriki***

#### **KAULI YA MSHIRIKI**

Nimesoma fomu ya ridhaa hii ama nimesikiza maneno ambayo nimesomewa. Nimepata muda wa kujadiliana juu ya utafiti huu na mshauri wa utafiti. Maswali yangu yamejibiwa kwa lugha ambayo ninaelewa. Nimeelezewa juu ya madhara na faida na ninaelewa kuwa kushiriki kwenye utafiti huu ni kwa hiari yangu na ninaweza kujitoea wakati wowote kama mshiriki. Ninakubali kuhisika na utafiti huu.

Ninaelewa kuwa watafiti watafanya juhudi na mikakati ambayo yatahakikisha kuwa mambo yangu (utambulisho) yatabaki kuwa siri.

Kwa kutia saina kwenye fomu hii, sijawapa au kukana haki zangu za kisheria ambayo ninazo kama mshiriki wa utafiti huu.

|   |      |    |
|---|------|----|
| Nakubali kuwa mshiriki wa utafiti huu   | Ndio | La |
| Nakubali kuwa dodoso yangu inaweza wekwa na kutumika<br>Katika utafiti mwingine | Ndio | La |
| Nakubali kuwapa nambari yangu ya mawasiliano iliniweze<br>Fuatiliwa virahisi    | Ndio | La |

Jina la Mshiriki: \_\_\_\_\_

Saina la Mshiriki / Kidole \_\_\_\_\_ Tarehe \_\_\_\_\_

Mtafiti

Mimi niliyepiga saina yangu hapa, nimemweleza mshiriki maneno yote muhimu juu ya utafiti huu na nina amini kuwa ameelewa na kuamua kwa hiari yake kuwa mshiriki wa utafiti huu.

Jina la Mtafiti: \_\_\_\_\_ Tarehe \_\_\_\_\_

Saina \_\_\_\_\_

Jukumu langu kwa utafiti huu: \_\_\_\_\_

Kwa maelezo zaidi, tafadhali wasiliana na Lydiah Muleyi kutoka saa mbili asubuhi hadi saa kumi na moja na nusu jioni (Jumatatu hadi Ijumaa ).

**Appendix 5: Socio-demographic Questionnaire**

**Respondent code.....**

**Date of questionnaire completion.....**

**Instructions:Please Tick one answer**

1. Gender?
    - a. Male
    - b. Female
  
  2. What is your age?.....
  
  3. What is your marital status?
    - a. Single, never married
    - b. Married
    - c. Widowed
    - d. Divorced/ Separated
  
  4. How many children do you have? Please indicate.....
  
  5. What is the highest level of education you have completed?
    - a. Primary school or less.....
    - b. High school graduate or GED.....
    - c. Some college/AA degree/Technical school training.....
    - d. College graduate (BA or BS).....
    - e. Graduate school degree: Master’s or Doctorate degree (MD, PhD, And JD).....
    - f. No education
  
  6. Occupation?
    - a. Employed
    - b. Unemployed
- If Unemployed, is it cause of the seizures?.....*
7. If employed; Check the box that st corresponds to your current work situation.  
(Indicate “Yes” or “No” for each question.)
    - a. Working full time.....
    - b. Working part time.....
  
  8. Estimated Family income?.....
  9. Where do you live.....
  10. What is your HIV status.....

11. How long have en caring for the adolescents?.....

12. What challenges does the adolescent face that you try to manage?

.....  
.....  
.....  
.....

13. What challenges do you face as a caregiver of the adolescent?

.....  
.....  
.....  
.....

14. What are some of the societal/ external challenges you face as you care for the adolescent?

.....  
.....  
.....

15. Any Family history of Mental Illness?.....

**Appendix 6: Maneno Ya Kijamii Na Idadi**

Kodi ya Mshiriki.....

Tarehe ya kukamilisha Maswali .....

1. Jinsia
  - a) Kike
  - b) Kiume

2. Unamiaka mingapi?.....

3. Hali yako ya ndoa ni nini?

(Jibu Moja)

- a) Kamwe Hujao
- b) Umeoa
- c) Mjane
- d) Umetalakiwa
- e) Umetengena kwa ndoa

4. Una watoto wangapi? Tafadhali eleza.....

5. Ni kiwango gani cha juu cha elimu uliyokamilisha?

(Jibu Moja)

- a) Chini ya shule ya Msingi au Shule ya Msingi.....
- b) Shule ya Sekondari.....
- c) Chuo kikuu /chuo cha elimu(haujamaliza).....
- d) Zaidi ya shahada ya kwanza (MD, PhD, And JD).....
- e) Hakuna elimu rasmi
- f) Umekataa kujibu

6. Je, unafanya kazi kwa kulipa nje ya nyumba?

(Jibu Moja)

- a) Ndio
- b) La

7. Angalia sanduku ambalo linalingana na hali yako ya sasa ya kazi.

(Onyesha "Ndiyo" au "Hapana" kwa kila swali.)

- a) Kufanya kazi wakati wote
- b) Kufanya kazi wakati mmoja

8. Nini kipato chako cha jumla cha familia kwa miezi 12 iliyopita, kabla ya kodi, kutoka kwa vyanzo vyote, mshahara, msaada wa umma / faida, msaada kutoka kwa jamaa, alimony, na kadhalika? Ikiwa hujui mapato yako halisi, tafadhali tathmini.....

9. Unaishi wapi? .....

10. Hali yako ya virusi vya Ukimwi ni gani?.....

11. Umekuwa ukimshughulikia kijana kwa muda gani?.....

12. Ni shida gani kijana hupitia ambayo wewe hujaribu kutatua?

.....  
.....  
.....  
.....

13. Ni shida gani wewe binafsi hupitia ukimshughulikia kijana?

.....  
.....  
.....  
.....

14. Ni shida gani zitokazo kwa jamii unayopitia kama mtu ambaye anayemshughulikia kijana anayevirusi vya Ukimwi?

.....  
 .....  
 .....

15. Historia ya mtu yeyote kwa familia kupatikana na ugonjwa wa akili?.....

**Appendix 7: Perceived Stress Scale**

**COHEN PERCEIVED STRESS**

*The following questions ask about your feelings and thoughts during THE PAST MONTH. In each question, you was asked HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are small differences tween them and you should treat each one as a separate question. The st approach is to answer fairly quickly. That is, don t try to count up the exact numr of times you felt a particular way, but tell me the answer that in general seems the st.*

*For each statement, please tell me if you have had these thoughts or feelings: never, almost never, sometimes, fairly often, or very often. (Read all answer choices each time)*

|  | Never | Almost<br>Never | Sometimes | Fairly<br>Often | Very<br>Often |
|--|-------|-----------------|-----------|-----------------|---------------|
| B.1. In the past month, how often have you en upset cause of something that happened unexpectedly?   | 0     | 1               | 2         | 3               | 4             |
| B.2. In the past month, how often have you felt unable to control the important things in your life? | 0     | 1               | 2         | 3               | 4             |
| B.3. In the past month, how often have you felt nervous or stressed?                                 | 0     | 1               | 2         | 3               | 4             |



|   |   |   |   |   |   |
|---|---|---|---|---|---|
| B.4. In the past month, how often have you felt confident about your ability to handle personal problems?                   | 0 | 1 | 2 | 3 | 4 |
| B.5. In the past month, how often have you felt that things were going your way?  | 0 | 1 | 2 | 3 | 4 |
| B.6. In the past month, how often have you found that you could not cope with all the things you had to do?                 | 0 | 1 | 2 | 3 | 4 |
| B.7. In the past month, how often have you been able to control irritations in your life?                                   | 0 | 1 | 2 | 3 | 4 |
| B.8. In the past month, how often have you felt that you were on top of things?   | 0 | 1 | 2 | 3 | 4 |
| B.9. In the past month, how often have you been angry because of things that happened that were outside of your control?    | 0 | 1 | 2 | 3 | 4 |
| B.10. In the past month, how often have you felt that difficulties were piling up so high that you could not overcome them? | 0 | 1 | 2 | 3 | 4 |

**Perceived Stress Scale Scoring**

Each item is rated on a 5-point scale ranging from never (0) to almost always (4). Positively worded items are reverse scored, and the ratings are summed, with higher scores indicating more perceived stress.

PSS-10 scores are obtained by reversing the scores on the four positive items: For example, 0=4, 1=3, 2=2, etc. and then summing across all 10 items. Items 4, 5, 7, and 8 are the positively stated items.

Your Perceived Stress Level was \_\_\_\_\_

**Appendix 8: Perceived Stress Scale (Kiswahili Version)**

**COHEN PERCEIVED STRESS**

*Maswali yafuatayo yanauliza juu ya hisia zako na mawazo wakati wa mwezi uliopita. Katika kila swali, utaulizwa JINSI ulijisikia au unafikiria njia fulani. Ingawa baadhi ya maswali ni sawa, kuna tofauti ndogo kati yao na unapaswa kutibu kila mmoja kama swali tofauti. Njia bora ni kujibu kwa haraka. Hiyo ni, usijaribu kuhesabu idadi halisi ya mara ulizohisi njia fulani, lakini uniambie jibu kwamba kwa ujumla inaonekana kuwa bora.*

*Kwa kila kauli, tafadhali niambie kama umekuwa na mawazo haya au hisia: kamwe, karibu kamwe, wakati mwingine, mara kwa mara, au mara nyingi sana. (Soma maamuzi yote ya jibu kila wakati)*

|   | Kamwe | Karibu Kamwe | Wakati Mwingine | Mara kwa Mara | Mara Nyingi sana |
|---|-------|--------------|-----------------|---------------|------------------|
| B.1. Katika mwezi uliopita, ni mara ngapi umekasirika kwa sababu ya kitu kilichotokea bila kutarajia?             | 0     | 1            | 2               | 3             | 4                |
| B.2. Katika mwezi uliopita, ni mara ngapi umehisi kuwa hauwezi kudhibiti vitu muhimu katika maisha yako?          | 0     | 1            | 2               | 3             | 4                |
| B.3. Katika mwezi uliopita, ni mara ngapi umehisi wasiwasi au usisitiza?  | 0     | 1            | 2               | 3             | 4                |
| B.4. Katika mwezi uliopita, ni mara ngapi umejisikia ujasiri kuhusu uwezo wako wa kushughulikia matatizo binafsi? | 0     | 1            | 2               | 3             | 4                |
| B.5. Katika mwezi uliopita, ni mara ngapi umejisikia kuwa vitu vinaendelea?                                       | 0     | 1            | 2               | 3             | 4                |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| B.6. Katika mwezi uliopita, ni mara ngapi umepata kwamba huwezi kukabiliana na mambo yote unayohitaji kufanya?         | 0 | 1 | 2 | 3 | 4 |
| B.7. Katika mwezi uliopita, ni mara ngapi umeshindwa kudhibiti yanayokuudhi katika maisha yako?                        | 0 | 1 | 2 | 3 | 4 |
| B.8. Katika mwezi uliopita, ni mara ngapi umesikia kwamba ulikuwa unaweza shughulikia mambo yako vilivyo?              | 0 | 1 | 2 | 3 | 4 |
| B.9. Katika mwezi uliopita, ni mara ngapi umekuwa hasira kwa sababu ya mambo yaliyotokea yaliyo nje ya udhibiti wako?  | 0 | 1 | 2 | 3 | 4 |
| B.10. Katika mwezi uliopita, ni mara ngapi umesikia kwamba matatizo yalikuwa yamekuja juu sana kwamba huwezi kushinda? | 0 | 1 | 2 | 3 | 4 |

Kiwangu cha wasiwasi na shida unayohisi ni \_\_\_\_\_

**Appendix 9: Study Timelines**

| <b>Activities</b>                             | <b>Dec 2018-<br/>April 2019</b> | <b>April<br/>2019</b> | <b>May<br/>2019</b> | <b>June<br/>2019</b> |
|---|---------------------------------|-----------------------|---------------------|----------------------|
| Proposal Writing                              | √                               |                       |                     |                      |
| Presentation of the Proposal for Approval     | √                               |                       |                     |                      |
| Ethics Approval                               |                                 | √                     |                     |                      |
| Data collection                               |                                 |                       | √                   |                      |
| Data Analysis                                 |                                 |                       | √                   |                      |
| Presentation of research project for approval |                                 |                       |                     | √                    |
| Finalizing project for presentation           |                                 |                       |                     | √                    |

**Appendix 10: Budget**

| <b>Activities</b>   | <b>Total cost per Activity</b> |
|---|--------------------------------|
| <i>Proposal Writing-Sourcing for Material &amp; Books. This includes purchasing of stationery, food and transport</i> | 5,000/=                        |
| <i>Sampling of respondents and Piloting of Data Collection Instrument</i>   | 8,000/=                        |
| <i>KNH/ERC fees</i>   | 2,000/=                        |
| <i>Printing and Photocopying of tools (Questionnaires)</i>  | 5,000/=                        |
| <i>Data Collection</i>  | 10,000/=                       |
| <i>Data Entry and Analysis</i>  | 30,000/=                       |
| <i>Presentation of the research project for approval including Printing &amp; Photocopying</i>                        | 2,000/=                        |
| <i>Miscellaneous Expenses e.g. phone credits</i>  | 3,000/=                        |
| <i>Total</i>  | 65,000/=                       |