RELATIONSHIP BETWEEN STAGE OF HIV DISEASE AND FAMILY FUNCTIONING AT INITIATION OF CARE AT KANGUNDO SUB-COUNTY HOSPITAL, KENYA.

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MAY, 2015.
DECLARATION

Declaration by the candidate.

This thesis is my original work and has not been presented to any training institution as a research paper for the award of any academic degree.

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ABSTRACT.

**Background:** About 40% of all new patients initiated on HIV/AIDS care globally come late with advanced disease – World Health Organization stage 3 or 4 and or CD4 count less than 200/mm³. The family is the basic social unit of society and the first point of care for sick members and thus the quality of healthcare decisions at this level are greatly influenced by family functioning.

**Objectives:** To determine the relationship between the stage of HIV/AIDS disease and family functioning at the time of initiation of care.

**Methodology:** This was a hospital based cross sectional study done in the comprehensive care clinic at Kangundo Sub-County Hospital, Machakos County in Kenya. The socio-demographic characteristics of all new patients were recorded and levels of satisfaction with family support was measured using the family Adaptation Partnership Growth Affection and Resolve scale.

**Results:** A total of 188 clients participated in the study, 115(61.2%) were female, 89(47.3%) were married. The mean age was 40(SD 10.3) years, 84(44.7%) had at least secondary level of education. 132(70.2%) were tested through PITC and 36(19.1%) through VCT, mean number of children per respondent was 2(range 0-8) and mean household size 4(range 2-11). Those employed were 36.7%, 86.7% had disclosed their HIV status and 34(18.1%) were using alcohol. Among the 152 who reported to have partners, 51(33.6%) were reported to be HIV concordant, 13.2% HIV discordant while 53.3% did not know the serostatus of their spouse. Respondents’ distribution by WHO staging: I 14.9%, II 35.1%, III 39.4% and IV 10.6%. More than half of the respondents 116(61.7%) had CD4<200 cells/µl. Among the early entry group (WHO I & II) 66% had functional families compared to 69.1% of the late entry group (WHO III & IV) and 52 (72.2%) of those with CD4 ≥200/µl had functional families compared to 75 (64.7%) of those with CD4 <200/µl.

**Conclusion:** Most of the people living with HIV and AIDS had normal functioning families. There was no significant difference in family functioning scores between respondents in early and those in advanced HIV disease at the time of initiation of care.

**Recommendations:** More local studies on the determinants of late presentation for HIV care. Secondly, a study to assess and compare the baseline family functioning of the general population and that of PLWHA. A study to validate the family APGAR scale in the African population is recommended.
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**LIST OF ABBREVIATIONS.**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>APGAR</td>
<td>Adaptation, Partnership, Growth, Affection, Resolve</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>CCC</td>
<td>Comprehensive Care Clinic</td>
</tr>
<tr>
<td>ICAP</td>
<td>International Centre for Aids Care and Treatment Programs</td>
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<tr>
<td>HAART</td>
<td>Highly active Antiretroviral Therapy</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>KSCH</td>
<td>Kangundo Sub-County Hospital</td>
</tr>
<tr>
<td>PITC</td>
<td>Provider Initiated Testing and Counseling</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living With HIV/AIDS</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for Social Sciences (SPSS)</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Testing and counseling</td>
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<td>WHO</td>
<td>World Health Organization</td>
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DEFINITION OF TERMS.

**Family** – Family is a group of two or more people, one of whom is at least 18 years, who belong to a household and related by blood, marriage and or socioeconomic factors (Australian Bureau of Statistics, 2013)

**Family functioning** – is the level of satisfaction by the patient from their family support and care as measured by adaptation, partnership, growth, affection and resolve (Valencia & Nicomedes, 2003, Zhang et al. 2014)

**Alcohol use** – measured by whether the participant had taken alcohol in the past one year (Dawson, 2003)

**Time of initiation of care** – is the time the HIV positive client is registered for care at the HIV comprehensive care clinic.
CHAPTER ONE: INTRODUCTION.

1.1 Background.

HIV/AIDS pandemic is the epitome of biopsychosocial diseases with unprecedented impact on individuals, families, communities and nations (Govender, 2011). About 50% of married or cohabiting HIV positive individuals in stable partnerships in East and Southern Africa are in an HIV sero-discordant relationship and Highly Active Anti-Retroviral Therapy (HAART) has been shown to reduce risk of transmission to the uninfected partner by 96% (Biraro, 2013). More than 40% of all new infections in Kenya occur in married or long term cohabitating relationships. This is because a vast majority of these couples are unaware of their HIV infection and (Biraro, 2013) perceive the marriage institution as a low risk for HIV infection with no need for testing or adopting HIV preventive measures (Kaiser, 2011). The success of the management of HIV/AIDS hinges on early diagnosis, timely initiation of treatment and consistent adherence to treatment (El-Sadr, 2010). Generally, a significant proportion of new patients enrolling for HIV/AIDS care come in late stage of HIV disease at their index visit (WHO stage 3 or 4 or CD4 ≤200 cells/µl) when risk of transmission to others and probability of poor prognosis is highest (Krawczyk, 2006, Abaynew et al. 2011, Phillips et al. 2010). The transmission rate of HIV is 3.5 times higher in those unaware of their HIV status and these individuals are responsible for more than 50% of new sexually transmitted infections including HIV (Zaller, 2011). The transmission can be to other individuals within and outside the family.

The family being the basic social and emotional unit of the community and society and the first point of care for sick members, it plays a big role in mitigating delays which are responsible for late initiation of care and treatment for People Living With
HIV/AIDS (PLWHA) (Muyibi, 2010, Belsey, 2005, South Africa, 2012). This can only succeed if the family unit is functional and has adequate supportive environment and resources because family dysfunction may lead to inadequate patient support resulting in delay in accessing health care and poor disease control (Muyibi, 2010). Family dysfunction may also disrupt optimal care and support of PLWHA whose long term prognosis is greatly influenced by the timing and stage of HIV disease at initiation of care (Belsey, 2004).

Family based approaches to HIV prevention and care will improve HIV/AIDS indicators and improve overall family health. Our literature search on this subject found few published articles from low income countries, particularly those in Sub-Saharan Africa, about the family functioning characteristics of HIV-infected individuals who present late for care at clinics.

1.2 Problem statement.

HIV/AIDS is still one of the leading causes of morbidity and mortality globally (WHO/UNAIDS/UNICEF, 2013). Millennium development goal number six stresses the importance of combating HIV/AIDS among other diseases (WHO/UNAIDS/UNICEF, 2013).

Studies have shown that a significant proportion of new patients enrolling for HIV/AIDS care come in advanced HIV/AIDS disease at their initial visit and this leads to poor disease outcomes (Phillips, 2010, Krawczyk et al. 2006, Abaynew et al. 2011). Although PLWHA may be identifiable through signs and symptoms associated with HIV/AIDS disease or opportunistic conditions, in dysfunctional families there could be less support and more internal and self-stigma leading to poor health seeking behaviour.
(Ngozi et al. 2009, Latham et al. 2001, Mahajan et al. 2008). Targeted public health and family based primary health care interventions to facilitate earlier entry into HIV care are needed, as well as additional studies to determine what causes late presentation (Kigozi et al. 2009, Muyibi et al. 2010). There are high proportions of HIV sero-discordance, unawareness and transmission rates in the families of PLWHA (Biraro et al. 2013, Kaiser et al. 2011). This scenario is worsened by the fact that most of Kenyan adults perceive themselves to be at low risk of HIV infection especially those in a married or cohabiting relationship (Kimanga et al. 2014).

The family is the most important primary source of resources and support for family members to respond to stressors such as HIV/AIDS disease (Hawley et al. 1996, Walsh, 1996, United Nations, 2014, Brown et al. 2010). Consequently functional families facilitates testing, disclosure, initiation of care, adherence and prevents loss to follow up (Ditekemena et al. 2012, Rochat et al. 2011). Family and caregiver distress in dysfunctional families can impair optimal care and support of the patient and especially for PLWHA whose long term prognosis is greatly influenced by the stage of HIV disease at initiation of care (National Institutes of Health, 2001). This may lead to delayed testing and late enrolment for care, poor adherence and poor health related quality of life.

We found limited data from Sub-Saharan Africa to determine the reasons for late initiation of HIV/AIDS care. Delaying HIV diagnosis and initiating treatment at an advanced stage leads to increased HIV/AIDS morbidity and mortality.
The nature of response and outcome to stressors (positive or negative) like HIV/AIDS is determined by the level of family functioning. The level of family APGAR determines the amount of care and support given to PLWHA by their families. Consequently, it impacts on PLWHAs’ health seeking behaviour where in functional families, couples and family members will be willing to test for HIV, disclose their status, initiate treatment early and adhere to treatment for better disease outcomes and better health related quality of life.
1.3 Justification of the Study.

For us to achieve the WHO/UNAIDS vision 2020 of 90% testing, 90% access to Anti-Retroviral Therapy (ART) and 90% durable viral suppression, we need multipronged approach to HIV testing, treatment initiation and retention in care. Control of HIV/AIDS is dependent on early diagnosis, timely initiation of treatment and consistent adherence to treatment and preventive interventions.

The family is the first point of care for sick members and it plays a critical role in mitigating delays which are responsible for late initiation of care and treatment for PLWHA. A functional family will support the patient and reduce stigma and ensure psychological well-being to enhance optimal adherence which is at the core of HIV/AIDS management (National Institutes of Health, 2001). A functional family will give priority to the health of its members by seeking healthcare timely when they fall ill.

The World Health Organization (WHO, 2003) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Therefore measurement of health must not only include estimates of the frequency and severity of diseases, but also well-being and health related quality of life and this includes family functioning. This is particularly true for patients with HIV/AIDS because of the chronic and debilitating nature of the illness, stigma, and a high rise of premature deaths especially when treatment is started late (Ana, Maria et al. 2011, Phillips et al. 2010, El-Sadr et al. 2010).

Establishing the association between the stage of HIV disease and family functioning at the time of initiation of care will assist health care professionals in prioritization of resources and in designing family related and family based intervention strategies to overcome barriers to early HIV care. Importantly, the provision of quality health care
to people with HIV infection will be most successful if provided in the context of and considering PLWHA’s defined family unit or structure (Latham et al. 2001). Early initiation of HIV/AIDS care within a functional family environment will prevent further transmission within and outside the family, lead to better disease outcomes and better health related quality of life for PLWHA (Biraro et al. 2013).

Few researches have been done in developing countries to determine the socioeconomic reasons for late presentation and late initiation of HIV/AIDS care and specifically no study was found on the relationship between stage of HIV disease and family functioning (National Institutes of Health, 2001).
CHAPTER TWO: LITERATURE REVIEW.

The number of people living with HIV/AIDS globally by end of 2013 was estimated at 35 million (WHO/UNAIDS/UNICEF, 2013). Sub-Saharan Africa remains the region most heavily affected by HIV/AIDS accounting for 71% of all PLWHA (WHO/UNAIDS/UNICEF, 2013). This region also had nearly 70% of all new HIV infections and 73% of the world's AIDS-related deaths in 2013 (WHO/UNAIDS/UNICEF, 2013). As of 2013, 12.9 million (36.9%) were on antiretroviral drugs globally and 91% of them were from low and middle income countries (WHO/UNAIDS/UNICEF, 2013).

East Africa is second to South Africa in HIV prevalence and Kenya is fourth globally in HIV/AIDS prevalence. An estimated 1.6 million people are living with HIV and around 1.2 million children have been orphaned by HIV/AIDS in Kenya. Kenya’s HIV prevalence peaked during the year 2000 to about 13.5% and has since then been reducing to the current prevalence of 5.6% (Kimanaga, 2014, KAIS, 2012). There are wide regional variations in prevalence within the country with the highest being in Nyanza province at 14% and lowest being in North Eastern province at 1%. Many people in Kenya are still not being reached by HIV prevention and treatment services (WHO, 2006).

The challenges of control and management of HIV/AIDS are the large number of individuals with undiagnosed HIV, delay in diagnosis, late initiation of Anti-Retroviral Therapy (ART) and difficulties with consistent long-term adherence to therapy (El-Sadr, 2010). Globally, 19 million of the 35 million PLWHA do not know their HIV status (WHO/UNAIDS/UNICEF, 2013). Regionally, 25% of HIV-infected individuals in the U.S. are unaware of their infection status and the transmission rate is 3.5 times higher in this unaware group (Zaller, 2011). A nationally representative study done on
adults between ages 15-64 years in 2012 found that over 50% of all HIV infections in Kenya are undiagnosed and 85% of Kenyans perceive themselves to be at low risk of HIV infection (WHO/UNAIDS/UNICEF, 2013, Kimanga et al. 2014). Evidence suggests that the undiagnosed individuals are responsible for more than 50% of new sexually transmitted infections including HIV (Zaller, 2011, Hall et al. 2012). A large proportion of HIV-infected individuals in the developed world, roughly 15% - 43% present at clinics for care with advanced or severe disease at WHO stage 3 or 4 or CD4 count ≤ 200 cells/µL (Assefa et al. 2011, Abaynew et al. 2011). Though HIV/AIDS awareness is comparatively high in Kenya, many PLWHA face high levels of stigma and discrimination which prevents people from testing, seeking treatment and disclosing their HIV status. Delays in HIV care have serious public health implications because opportunities to prevent further transmission through effective treatment with antiretroviral drugs are lost, and there are worse treatment outcomes than when treatment is started earlier (Hall et al. 2012, Phillips et al. 2010). Though the reasons for delayed presentation are not entirely clear, age, gender, level of education, sexuality, poverty, marital status, HIV stage (symptoms), comorbid conditions, drugs and alcohol abuse, HIV status awareness, disclosure, stigma and perceived ART side effects have been studied and shown to influence timing of presentation for care (Santiago & Mattos, 2014).

The family, the basic social unit of society, bears the brunt of HIV infection of a family member and tends to take most of the responsibility for care and support of PLWHA (National Institutes of Health, 2001). For the family to effectively take care of members with HIV/AIDS, it must be functional and this depends on the strength of bonds and support structures within the family network (National Institutes of Health, 2001). HIV infection occurs mostly in the context of the family during sexual relationship,
pregnancy, delivery and breastfeeding (Belsey, 2005, United Nations, 2014). Apart from low levels of serostatus awareness and perception of low risk for HIV infection, married and long term cohabiting relationships also have the highest rates of new HIV infections in Kenya (Kaiser et al. 2011). A functional family is the first line of defence against HIV infection and plays a critical role in determining how well individuals and communities cope with HIV/AIDS and its consequences. There is increasing evidence that adequate social support has tremendous effect on individuals’ response to disease, the use of primary care services and self-care behaviours (National Institutes of Health, 2001, United Nations, 2014). This is why the emphasis on healthcare has moved from treating just the disease towards comprehensively treating the whole person (body, mind and spirit) and helping people lead independent and productive lives (Ministry of Health, 2007, Van der Voort, van Kasteren, Chege & Dinant, 2012).

Several tools have been developed to assist researchers and clinicians to assess family functioning and the need for psychosocial support (Appendix 5). No single measure can capture the complexity of family functioning completely (Wilson, Pritchett, Kemp, Minnis, Bryce & Gillberg, 2011). There are challenges in using self-report family functioning measures. For instance, do they measure individuals’ perceptions or whole family functioning status, and do respondents give accurate or simply socially desirable answers? (Wilson et al. 2011). These instruments help assess and measure social roles, satisfaction with relationships, adjustment to life situations like HIV/AIDS disease and presence of emotional support. Measures of family function are often developed with a particular purpose in mind and can broadly be classified into six groups:- parent-child relationships, parental practices and discipline, parental beliefs, marital quality, global family functioning and situation-specific measures (Wilson et al. 2011). Using family systems model of family functioning, Gabriel Smilkstein in 1978, evaluated the
interactions of family members and the impact of conflicts, crisis, coping style and resources of the family (Muyibi et al. 2010). He conceptualized family functioning to include the level and quality of adaptation, partnership, growth, affection and resolve (APGAR) existing in the family unit. Adaptation involves the quantity and quality of advice, resources and support given to the HIV/AIDS infected member of the family by other family members in order to respond appropriately to the stress of living with HIV/AIDS (Silva, Victor, Mota, Soares, Leite & Oliveira, 2014). Partnership is the reciprocity and connectedness exhibited in the family’s communication and problem solving process. Growth is the availability, acceptance and support of the family to changes in roles and emotional development of its members. Affection includes intimacy and emotional interaction in the family context. Resolve is associated with decision, determination and resoluteness in the process of solving differences in the family unit. It is a brief five item measure which has been proposed as a useful tool to quickly gain useful information about a patient's satisfaction with current family functioning. Each of the five APGAR domains are assessed by asking the respondent a standardized question whose answer is graded as per how frequent the patient perceives it in the family on a 3-point likert scale: 0 = hardly ever, 1 = sometimes and 2 = almost always. The total score for the five domains is the level of family functioning and can range from 0 to 10. A higher score indicates a greater degree of support and satisfaction with the family. The APGAR was chosen for this study because it is a validated and reliable tool, brief and easy to administer (Wilson et al. 2011). The other instruments of measuring family functioning are lengthy, relatively expensive, time consuming to administer and unlikely to be used in actual clinical practice.

There is usually difficulty in measuring social support due the subjective nature of the individuals’ perceptions and also in that it may be influenced by underlying
psychological illnesses like depression or physical influences. Family APGAR scale has been widely used to study family relationships in family practice offices. Initial evaluation of the instrument by Smilkstein, Ashworth, and Montano (1982) indicated that it had reasonable content validity and adequate test-retest reliability (Bellón, Delgado, Luna del Castillo & Lardelli, 1996, Shapiro et al. 1987). However, there was no literature found on whether the APGAR scale has been validated in the African settings.

Low levels of APGAR indicate family dysfunction where there is inadequate family support which could lead to delay in accessing health care and poor disease control (Muyibi et al. 2010). Functional families have been found to have a significant positive effect on self-esteem and resourceful coping strategies while dysfunctional families have been associated with greater risk for emotional distress. Dysfunctional family could stem from alcoholism or chronic health problems, the effect of which could be felt over several generations (Muyibi, 2010). Other factors that have been shown to influence family functioning are age, gender, level of education, socioeconomic status, marital status, number of children, family size, and family structure (Kigozi, 2009, Santiago et al. 2014).
CHAPTER THREE: RESEARCH QUESTION, OBJECTIVES AND HYPOTHESIS.

3.1 Research question.
Does the stage of HIV/AIDS disease have a relationship with family functioning at the time of initiation of care at Kangundo Sub-County Hospital?

3.2 Research hypothesis.
H\textsubscript{1}: There is a relationship between the stage of HIV disease and family functioning at initiation of care.

H\textsubscript{0}: No relationship between stage of HIV and family functioning at initiation of care.

3.3 Broad objective.
To determine the relationship between the stage of HIV/AIDS disease and family functioning at the time of initiation of care at Kangundo Sub-County Hospital.

3.4 Specific objectives.
1. Determine the proportion of PLWHA in WHO stages I, II, III and IV and those with CD4 $\geq 200/\mu l$ and CD4 $< CD4 200/\mu l$.

2. Determine the proportion of PLWHA with functional and dysfunctional families.

3. Determine the association between early entry and late entry groups of PLWHA and family functioning.
CHAPTER FOUR: METHODOLOGY.

4.1 Study design.
Cross Sectional study.

4.2 Study site.
The study was done at the Comprehensive Care Clinic (CCC) at Kangundo Sub-County Hospital which is a level 4 hospital in Machakos County about 70 km to the east of the capital city of Kenya, Nairobi. Kangundo Sub-County Hospital is a public hospital run by the Government but the CCC also gets support from ICAP – an NGO supporting HIV/AIDS care in Kenya.

4.3 Study population.
All adult HIV positive patients newly registered for HIV care at Kangundo Sub-County Hospital were eligible. According to the public health record, the hospital has a catchment population of 229,485 people, attends to an average of 260 people daily and HIV seropositivity in the general outpatient section is 8.1%. The CCC has 3,291 registered PLWHA on care and 1,284 (39%) on ART. The CCC attends to a total of 1,950 clients monthly and enrolls for care an average of 26 new clients per month. An average of 16 patients are started on ART every month in this clinic. Counselling and testing for HIV is done in all points of clinical service in the hospital. A positive outcome from a rapid sensitive screening test (Determine) is confirmed by a specific rapid test (Bioline) The HIV positive patients are then referred to the CCC for long term care.
4.4 Sample size determination.

To measure and compare the proportion of patient with functioning and dysfunctional families in both the early and late entry groups, the sample size formula for association between two proportions was used:

\[
N = \frac{(Z_{\alpha}/2 + Z_{1-\beta})^2 (P_1(1-P_1) + P_2(1-P_2))}{(P_1-P_2)^2}
\]

Where:

\( P_1 \) = Proportion of PLWHA in WHO I and II at initiation of care (0.6).

\( P_2 \) = Proportion of PLWHA in WHO III and IV at initiation of care (0.4).

\( Z_{\alpha} \) = The standard normal deviate for \( \alpha = 1.96 \).

\( Z_{\beta} \) = The standard normal deviate for \( \beta = 0.84 \).

\( N \) = Total number of subjects (sample size)

The approximate prevalence of PLWHA in WHO III and IV at the time of initiation of care was 40% obtained from a study done in Uganda by Kigozi et al in 2008.

Therefore \( P_1 = 0.6, P_2 = 0.4, Z_{\alpha} = 0.05, Z_{\beta} = 0.84, N = 94 \) and so the total sample consisted of 94 patients in early entry group and 94 patients in late entry group, giving a total of 188.
4.5. **Sampling method.**

Consecutive sampling method was used. The enrollment register was used in sampling and client participants were recruited for the study in the order of their registration for care. All new clients were eligible and were recruited in the registration order as in the enrollment register until the required sample size for each group was achieved.

4.6. **Inclusion criteria.**

Consenting HIV positive patients above 18 years newly initiated on care at the CCC.

4.7. **Exclusion criteria.**

1. Destitute individuals who had no identifiable family relations.

2. Those restarting care after being traced from defaulting.

3. Mentally unstable patients who could not objectively respond to the study tool.

4.8. **Data management.**

4.8.1. Data collection and entry: The data was collected by the principal investigator assisted by a trained HIV/AIDS care nurse as research assistant using an interviewer-administered and pre-tested structured questionnaire (The tool was pretested by administering it to a group of twenty clients in the HIV comprehensive care clinic). The data was collected between March, 2012 and December, 2012. The HIV positive clients reported to the HIV comprehensive care clinic after being confirmed HIV positive at the various service points of the hospital like general outpatient, chest clinic and wards. At the CCC, they were received, triaged, and registered in the pre-ART register and assigned a registration number, a file was opened and their biodata was recorded in the file. Those eligible for the study were interviewed starting with signing informed consent (Appendix 1) Then a comprehensive history and physical examination were
done, WHO staging done, the family APGAR scale administered and samples taken for CD4 count and other baseline investigations. The interviews were conducted on one respondent at a time in a private room in the clinic and the respondents were allocated to the two arms of the study – early entry group (WHO stages I and II) and late entry group (WHO stages III and IV). Thereafter, the respondents were managed and referred accordingly as per the Kenya National AIDS and STI Control Program (NASCOP) guidelines (see schema below)

4.8.2. Sociodemographic data: The respondents’ socio-demographic characteristics and behavioural factors were recorded on the questionnaire (Appendix 2)

4.8.3. Clinical and immunological staging: The respondents WHO stage were determined by the principal investigator thorough clinical evaluation and documentation (Appendix 3).
4.8.4. Apgar family functioning scale: To examine family functioning the Family Apgar Scale was used (Appendix 4). This has five constructs of “adaptation, partnership, growth, affection, and resolve” which measures how the family works as a unit and its ability to cope and adjust to different difficult situations. The family APGAR scale has five statements denoting the five parameters of assessing family functioning (adaptation, partnership, growth, affection, and resolve) to which the clients is supposed to respond to depending on the frequency of feelings of satisfaction with each of the five parameters. The APGAR scale was translated and back translated to Kiswahili, a language which all the respondents could understand. The client’s responses were scored as follows: 0 = hardly ever, 1 = sometimes and 2 = almost always. The total score was obtained by adding the values for the five items and ranged from 0 to 10. These constructs reflect a family member’s perception of and satisfaction with the functional state of his/her family. Scores of 0 – 3 denotes severely dysfunctional family, 4 – 7 denotes moderately dysfunctional family and 8 – 10 highly functional family. The scores can still be dichotomized to 0 – 6 denoting dysfunctional family and 7 – 10 denoting functional family like in this study. It has been found to be a reliable and internally consistent measure of family functioning that is easy to administer in traditional and nontraditional families. It is used commonly by family physicians for assessing family functioning in the clinical setting.

The family APGAR functioning questionnaire was administered to the newly diagnosed HIV/AIDS client being enrolled for care at the hospital’s Comprehensive Care Clinic. The total scores were added up and classified into functional (7–10) or dysfunctional (0–6).

4.8.5 Data management, analysis and statistics: After the interviews, the questionnaires were checked for errors and completeness and coded accordingly. The data was then
entered into Epidata base. Data was exported from Epidata to SPSS version 20 for analysis. Descriptive statistics were determined for continuous variables and expressed in mean, median, standard deviation and inter-quartile range while frequencies were worked out for categorical variables. To test for association between respondents characteristics including stage of HIV disease and family functioning, the chi-square ($\chi^2$) test was used. Fisher’s exact test was used to test association between dichotomous categorical variables. P-value ≤ 0.05 was considered statistically significant.

4.9. Ethical considerations.

4.9.1. Study approval: The study was approved by the Institutional Research and Ethics Committee (IERC) of Moi University. Permission to conduct the study was also sought from Medical Superintendent for Kangundo Sub-County Hospital.

4.9.2. Study risks: This study involves minimal risks of confidentiality in case the subjects’ information is accessed by unauthorized persons. This was minimized by using code numbers on the questionnaire instead of real names. The filled up questionnaires were kept in safe custody by the principle investigator and were only used for the purposes of the study.

4.9.3. Study benefits to the subjects: No direct benefit for patients participating in this study. The principal investigator was serving in the county health services and at Kangundo Sub-County Hospital during the time of collection of data. The results from the study might be used by the Ministry of Health and other health stakeholders in mobilizing resources towards strategies at the family level that will reduce late initiation of care for people living with HIV/AIDS.
4.9.4. Informed consent: Signed informed consent was obtained from the participants before the interview was conducted. The respondents were explained about the study, the benefits, the risks and assured of confidentiality.

4.9.5. Confidentiality: Participants’ information was confidential and not used for any other purpose other than the study. All interviews were conducted in a secluded room with one individual subject at a time and the filled questionnaires were kept confidentially and safe by the principal investigator. All research questionnaires will be destroyed at the end of the research. No patients’ personal details will be included in the computer data entered for analysis thus participants cannot be identified through it.

4:10. Study limitations.

There is no gold standard criteria for evaluation of family functioning which we could use to compare Family APGAR with. There was no literature found on validation of the family APGAR in the African family settings. APGAR is a single person’s perception of family functioning and may not agree with the rest of the family members’ views. Cross sectional studies are a snap shot of a situation and thus will only bring out the general association but not elucidate the cause-effect relationship between different factors or variables. It is also prudent to caution on interpretation and application in the general population the results of this study because of the unpredictable external validity factors. In cross sectional studies it is difficult to establish the time sequence of events, for instance which came first between family dysfunction and the HIV infection.

4.11. Budget.

The research was wholly financed by the principle investigator from his own resources.
CHAPTER FIVE: RESULTS.

Table 1: Socio-demographic Characteristics. (N = 188)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total (%)</th>
<th>N = 188</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>73 (38.8)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>115 (61.2)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>89 (47.3)</td>
<td></td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>37 (19.7)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>23 (12.2)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>39 (20.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤Primary</td>
<td>104 (55.3)</td>
<td></td>
</tr>
<tr>
<td>≥Secondary</td>
<td>84 (44.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>69 (36.7)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>119 (63.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Spousal/Partners Status (n=152)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>20 (13.2)</td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>51 (33.6)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>81 (53.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Disclosed HIV status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>163 (86.7)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>25 (13.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Alcohol use</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34 (18.1)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>154 (81.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td>Mean</td>
<td>40.0 (SD 10.3)</td>
</tr>
</tbody>
</table>

We interviewed 188 respondents, 94 from WHO I and II and 94 WHO III and IV. More than half, 115 (61.2%) were female and 89 (47.3%) of all subjects were married. The mean age (in years) was 40 (SD 10.3) and 84 (44.7%) had attained at least secondary level of education as in table 1. Sixty nine (36.7%) of all respondents were employed,
163 (86.7%) had disclosed their HIV status and 34 (18.1%) were using alcohol as indicated in table 1.

Fig.1: Entry point to CCC. (N = 188)

PITC was the dominant point of entry with 132 (70.2%), and VCT had 36 (19.1%) as in figure 1.

The mean number of children per respondent and household size was 2 (Min 0, Max 8) and 4 (Min 2, max 11) respectively.
Fig 2: Partner’s/Spousal HIV status. (n = 152)

Among the 152 (80.9%) respondents who reported to have partners, 81 (53.3%) of them reported not to know their partners HIV status, 51 (33.6%) and 20 (13.2%) reported that they were HIV concordant and discordant respectively as in figure 2.

Fig 3: WHO stage. (N = 188)

Majority of the respondents were in WHO stage II and III at 66 (35.1%) and 74 (39.4%) respectively as indicated in figure 3.
The median CD4 (IQR) was 127 (46, 327). More than half of the respondents (61.7%) had CD4 < 200/µl as in figure 4.

Fig 5: WHO stage by family functioning. (N = 188)

Among the early entry group (WHO I & II) 66% had functional families compared to 69.1% of those in the late entry group (WHO III & IV) as in figure 5. However, after Pearson Chi-Square analysis, the family functioning proportions of the two groups of early entry and late entry were not statistically significant ($\chi^2 = 3.122, p = 0.373$).
Fig 6: CD4 by Family functioning. (N = 188)

Among those with CD4 ≥200/µl, 52 (72.2%) had functional families compared to 75 (64.7%) of those with CD4 <200/µl as shown in figure 6. After Pearson Chi-Square analysis, the family functioning difference in the CD4 count proportions was not statistically significant ($\chi^2 = 1.161, p = 0.337$).

Fig 7: Family functioning. (N = 188)

Two thirds of all the respondents 127(67.6%) had functional families as indicated in figure 7.
Table 2: Variables associated with family functioning (Categorical) (N = 188)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Family functioning (%)</th>
<th>X²-Value</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Functional</td>
<td>Dysfunctional</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51 (69.9)</td>
<td>22 (30.1)</td>
<td>0.29</td>
</tr>
<tr>
<td>Female</td>
<td>76 (66.1)</td>
<td>39 (33.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>63 (70.8)</td>
<td>26 (29.2)</td>
<td></td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>24 (64.9)</td>
<td>13 (35.1)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>14 (60.9)</td>
<td>9 (39.1)</td>
<td>1.029</td>
</tr>
<tr>
<td>Single</td>
<td>26 (66.7)</td>
<td>13 (33.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤Primary</td>
<td>69 (66.3)</td>
<td>35 (33.7)</td>
<td></td>
</tr>
<tr>
<td>≥Secondary</td>
<td>58 (69.0)</td>
<td>26 (31.0)</td>
<td>0.155</td>
</tr>
<tr>
<td><strong>Spousal Partners status (n=152)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td>16 (20.0)</td>
<td>4 (80.0)</td>
<td></td>
</tr>
<tr>
<td>Positive</td>
<td>33 (35.3)</td>
<td>18 (64.7)</td>
<td>1.577</td>
</tr>
<tr>
<td>Unknown</td>
<td>55 (32.1)</td>
<td>26 (67.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Disclosed HIV status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>109 (66.9)</td>
<td>54 (33.1)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>18 (72.0)</td>
<td>7 (28.0)</td>
<td>0.260</td>
</tr>
<tr>
<td><strong>Alcohol use</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25 (73.5)</td>
<td>9 (26.5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>102 (66.2)</td>
<td>52 (33.8)</td>
<td>1.676</td>
</tr>
<tr>
<td><strong>WHO stage</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>I &amp; II</td>
<td>62 (66.0)</td>
<td>32 (34.0)</td>
<td></td>
</tr>
<tr>
<td>III &amp; IV</td>
<td>65 (69.1)</td>
<td>29 (30.9)</td>
<td>3.122</td>
</tr>
<tr>
<td><strong>CD4 level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD4 ≥200/µl</td>
<td>52(72.2)</td>
<td>20(27.8)</td>
<td></td>
</tr>
<tr>
<td>CD4&lt;200/µl</td>
<td>75(64.7)</td>
<td>41(35.3)</td>
<td>1.161</td>
</tr>
</tbody>
</table>

As indicated in table 2, none of the factors was significantly associated with family functioning (p>0.05).
CHAPTER SIX: DISCUSSION.

The mean age of our study population (40, SD 10.3 years) is comparable to a similar study done in Nigeria on roles of family functioning on adherence to Highly Active Anti-Retroviral Therapy (HAART) among People Living With HIV/AIDS (PLWHA) where the mean age was 40.8 (SD 9.9) years (Afolabi, Odewale, & Olowookere, 2013). This is explained by findings that HIV/AIDS has the highest morbidity and mortality in the age group between 20 and 50 years in sub-Saharan Africa (Salami et al. 2011).

Our study found that 61.2% of all the respondents were female. Afolabi et al found a female preponderance of 60.7% in a similar study in Nigeria. This is because HIV infection is more prevalent in women than men (UNAIDS, 2012, Ajayi et al. 2013, Wekesa et al. 2014, KDHS, 2014). This increased vulnerability emanates from women’s biological, behavioural and socioeconomic factors responsible for the spread of HIV and the difficulties associated with abstinence, fidelity and condom use especially in marriage.

Our study shows majority (47.3%) of all respondents were married and the average number of children per respondent was two. Wekesa et al found comparable outcomes in a study on fertility desires among PLWHA in Nairobi slums where 55% were married and 69.6% had between one to four children (Afolabi et al. 2013, Wekesa et al. 2014). This can be explained by the premium placed on marriage and children as a sign of success and fulfilment of life especially in the African communities even for PLWHA (Wekesa et al. 2014, Latham et al. 2001).

Our study had 44.7% of all the respondents having attained at least secondary level of education comparable to the Kenya national figures where 49% of men and 43% of women aged 15-54 years had at least secondary level of education (KDHS, 2014).
More than two thirds of the respondents 132 (70.2%) were tested for HIV through Provider Initiated Testing and Counselling (PITC) and 36 (19.1%) through Voluntary Counselling and Testing (VCT). PITC is acceptable and has reduced stigma and helped increase HIV testing by more 50% especially in the antenatal and TB patient groups (Panganiban-Corales & Manuel, 2011, Kennedy et al. 2013, Leon, Lewin, & Mathews, 2013, Mahajan et al. 2008).

Support from a functional family improves physical and psychological health outcomes and increases PLWHA motivation for seeking treatment and adopting preventive and self-care behaviours (Ameneh, Zahra, Homeira, Yahya & Masoumeh, 2013, Ditekemena et al. 2012). Our study found no significant relationship between the stage of HIV disease and family functioning at the time of initiation of care but we found that 67.6% of PLWHA in our study had functional families. The lack of association between the stage of HIV disease and family functioning at the time of initiation of care could be attributed to the strong family interactions and support noted in the African family structure and the sociocultural inclination towards protection of family deficiency which has been said to diminish the objectivity of the family APGAR scoring evaluation (Muyibi et al. 2010). Other studies which have used the family APGAR scale to study family functioning in PLWHA found that most of the families of PLWHA are functional (Ana Maria, Jorge & Rafael, 2011, Afolabi et al. 2013). Afolabi et al in Nigeria found 85.1% of PLWHA had normal functioning families in a study evaluating the roles of family dynamics on adherence to HAART among PLWHA. This contributed to majority (99%) of PLWHA in his sample being adequately adherent to HAART (Afolabi et al. 2013). Despite the different study sites, these studies showed comparable sociodemographic characteristics of the studied populations to our study (Ana Maria et al. 2011, Afolabi et al. 2013). However, Rasaki et al found high levels
of family dysfunction (73%) in PLWHA on a study looking at family dysfunction and depression among HIV/AIDS patients in Nigeria (Rasaki, Baba, Ganiyu, Abdulraheem, Sunday & Odeigah, 2014). The high levels of family dysfunction could be explained by the differences in gender, marital status and education level between our study and Rasakis. Rasakis study had higher level of non-formal education (30.7%), higher proportion of female respondents (83.3%), and only 6% were married (Rasaki et al, 2014). The other possible reason for lack of association between stage of HIV disease and family functioning in our study is that 86.7% of our sample had disclosed their HIV status meaning that stigma is comparatively low especially at the family level (Kaiser et al. 2011). PLWHA who experience internal and external stigma are unlikely to disclose their HIV status (Mahajan et al. 2008, Ngozi et al. 2009). Stigma also hinders HIV/AIDS prevention and care seeking because HIV/AIDS is a disease perceived to be associated with deviant groups, sexual activities, irresponsible behavior and it is thought to be contagious and fatal (Mobolanle & Izegbuwa, 2010, Yebei, Fortenberry & Ayuku, 2008). It is also possible that the high levels of adaptation, partnership, growth, affection and resolve together with sociocultural factors in our study population contributed to the outcome of the study (Cao, Jiang, Li, Hui Lo & Li, 2013, Prabhu, 2010). In extended families, which are common in African communities, family members share the burden of caring for the sick in that the extended family environment helps develop strong family ties, adaptability and resilience when crises occur (Annie foundation, 2013, Cao et al. 2013).

Other findings from our study were that age, gender, level of education, marital status, number of children, household size, all of which influence both the level of family functioning and the stage of HIV disease at the time of initiation of care, were comparable to studies done elsewhere (Mitrani et al. 2009, Leon et al. 2013, Ajayi et al.
Like in our study other studies conducted elsewhere did not show any significant association between age, gender and family functioning of the studied population (Santiago et al. 2014, Cao et al. 2013). Some studies have reported significant association between gender, marital status, educational level, occupation, socioeconomic status and perceived family functioning (Chung, 1990, Muyibi et al. 2010, Ana Maria et al. 2011, Latham et al. 2001, Afolabi et al. 2013, Rasaki et al. 2014, Cao et al. 2013).

HIV/AIDS has negative impact on family functioning, resources and resilience in many communities and this is reflected in our study where only 36.7% of the respondents had a form of employment as a source of livelihood (Muyibi et al. 2010, Belsey, 2005, Panganiban-Corales et al. 2011, Ameneh et al. 2013). Economic power (employment) has been shown to reduce the risk of family dysfunction and ensure resources for coping with family crises and facilitating timely health seeking behaviour (Holborn & Eddy, 2011, Muyibi et al. 2010, Cao et al. 2013).

Among the 152 respondents who reported to have partners in our sample, 53.3% did not know the HIV status of their spouses or sexual partners. According to KAIS 2012 accurate knowledge of spousal HIV status among the concordant and discordant couples in Kenya was 69.5% and 65.5% respectively. Low awareness of partner status could be due to fear of stigma and other psychosocial adverse consequences of disclosure of HIV status like physical assault or marriage dissolution. Other possible reasons for unawareness of partners HIV status are difficulties associated with discussions and negotiation of sexual relations in a marriage setting, assumption that marriage confers a safe status against HIV infection, and lack of research data and intervention programs on HIV/AIDS in stable heterosexual relationship (Biraro et al.
2013, Belsey, 2005, Mobolanle et al. 2010). Low awareness of partner HIV status and
high risk of infection within the family calls for strengthening of partner testing as a
standard practice and integration of partners in testing, care and prevention in the
existing HIV/AIDS programs as recommended by the World Health Organization
(Kaiser et al. 2011).
CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS.

7.1 Conclusion.
Most of PLWHA in both the early and late entry groups had normal functioning families. This study showed no relationship between the stage of HIV/AIDS disease and family functioning at the time of initiation of care.

7.2 Recommendation.
We recommend more local studies on the determinants of late presentation for HIV care to help in devising effective interventions to enable early diagnosis and timely initiation of care. A study to assess and compare the baseline family functioning of the general population and that of PLWHA will help to determine the impact of HIV/AIDS on family functioning. A study to validate the family APGAR scale in the African family settings is recommended.
REFERENCES.


APPENDICES.

Appendix I: Informed consent.

Study number: ------------------

**Title and reason for the study:** The study is to determine the relationship between the HIV/AIDS stage and your family functioning during initiation into care.

**Invitation to participate:** You are requested to participate in this study. Participation is voluntary, no reward for participation and you can withdraw at any stage of the study.

**Procedures:** You will be asked questions about yourself, HIV, your spouse and family. A blood sample will be drawn for CD4 count - to determine your level of immunity.

**Benefits:** The knowledge from the study may help us improve services through additional family interventions. You will be screened for family dysfunction.

**Potential risks:** You will be asked sensitive personal and family questions. You will feel slight pain when blood is being drawn. We will be careful not to harm you.

**Confidentiality:** We guarantee confidentiality, your name will not appear on any materials or reports of the research findings.

**Participant’s statement:** I voluntarily agree to participate in this study. All information as above has been given to me and all questions have been adequately addressed.

Signed by the participant: ----------------------------- Date: -----------------------------

**Investigators statement:** I confirm the participant’s voluntary consent, I have discussed and clarified the study details to the participant and I commit to respond to all questions.

Signed by the investigator: ----------------------------- Date: -----------------------------
Idhini.

Namba ya utafiti: ---------------

Madhumuni ya utafiti: Uhusiano kati ya kiwango cha ukimwi na hali ya familia ya mshiriki wakati anapoanza matibabu.

Mwaliko kushiriki: Unaalikwa kushiriki katika utafiti huu. Kushiriki ni kwa hiari na hakuna malipo.

Utaratibu wa utafiti: Utaulizwa maswali kuhusu wewe binafsi, familia yako, na ugonjwa wa ukimwi. Utatolewa damu kidogo kupima kiwango cha CD4 au hali ya kinga yako.

Manufaa ya utafiti: Matokeo ya utafiti huu huenda yakasaidia kuboresha huduma za afya.

Athari za utafiti: Utaulizwa maswali ya kibinafsi, utahisi uchungu wa kutolewa damu.

Usiri wakati wa utafiti: Tunakuakikishia kuwa jina lako halitaonekanakwenye maandishiau matokeo au taarifa au matangazo ya utafiti huu. Tutahifadhi siro zako na vifaa vyote vinavyohusiana na utafiti huu.

Taarifa ya mshiriki: Mimi kwa hiari nimeamua kushiriki kwa utafiti huu. Sahihi yangu inaonyesha ya kuwa nimeelewa habari niliyozelewa baada ya kujadiliana na watatolewa damu yangu yamejibiwa kikamilifu.

Sahihi ya mshiriki: ---------------------------------------------- Tarehe: -------------------------

Taarifa ya mpelelezi: Mshiriki amehiari kushiriki na nimejadili na nimemfahamisha kinaganaga juu ya utafiti huu na utaratibu wake. Nimejitonea kujibu maswali yake yote.

Sahihi ya mpelelezi: ---------------------------------------------- Tarehe: -------------------------
Luusa.

Namba ya ukunikili ------------------------

Syitwa na vata wa ukunikili: Yiulu wa uusiano wa uwau wa muthelo na ngwatanio nyumbani ya muwau ivindani yila unikambiisya uiti.

Ukulyo wa kulika: Nukulwa ulike nthini wa ukunikili uu.

Mutalatala: Nukulywa makulyo yiulu waku mwene, musyi waku, na uwau uu.
Nukumwa kiasi kinini kya nthakame ikathimwe CD4.

Vaita wa ukunikili uu: Vai vaita, ituvi kana mithinzio kwondu wa kwiyumya ukunikilini uu indi usungio wa ukunikili nutonya kuseuvya uiti kilinikini kii kitu.

Uthuku wa ukunikili: Makulyo ma nyumba yaku na woo wa kumywa nthakame.

Kimbithi: Vai isitwa yaku yikakunithwa mathanguni ma ukunikili uu kana kutangaaswa mausungioni ma ukunikili uu. Mauvoo maku onthe makeethiawa kimbithi.

Wivito wa kwiyumya: Nyie ninaamua kwa ngoo ya kwenda kulika ukunikilini uu, ninaelewa vyu yiulu wa ukunikili uu na makulyo makwa onthe masungiwa nesa.

Saii wa muwau: -------------------------- Matuku: ------------------------

Wivito wa mukunikili: Muwau uu niweeyumya kulika ukunikilini uu kwa kwenda, niwaelewa ni mtalatala wa ukunikili uu na makulyo make onthe niwasungiwa nesa.

Saii wa mukunikili: -------------------------- Matuku: ------------------------
Appendix II: Enrolment questionnaire.

Demographic data.

Date…………………………. District…………………………

Number……………………….. Location…………………………

Measurement data.

Age…………. Gender/Sex □ Male □ Female

Marital status: □ Married polygamous □ Widowed
□ Married monogamous □ Cohabiting
□ Divorced/Separated □ Single

Number of children……………. Household size…………………

Patient source/Entry point:

□ PMTCT □ VCT
□ In-patient □ TB clinic
□ Others (specify)…………………

Education level………………….. Employment □ YES □ NO

Date confirmed HIV +ve………….. Disclosure □ YES □ NO

Date enrolled on HIV care………….. WHO stage……………CD4………………

Spousal HIV status □ -ve □ +ve □ Unknown

Alcohol use □ YES □ NO

**WHO stage 1.**

Acute sero-conversion syndrome,

Asymptomatic,

Persistent generalized lymphadenopathy.

**WHO stage 2.**

Moderate unexplained weight loss (<10% of the presumed or measured body weight)

Recurrent upper respiratory tract infections (sinusitis, bronchitis, otitis media, pharyngitis)

Herpes zoster (past or current episode in the last 2 years)

Angular cheilitis.

Recurrent oral ulcerations (2 or more episodes in 6 months)

Papular pruritic eruptions, seborrheic dermatitis, fungal nail infections of fingers.

**WHO stage 3.**

Severe weight loss (> 10% presumed or measured body weight)

Unexplained chronic diarrhea for > 1 month.

Unexplained persistent fever (intermittent or constant for > 1 month)

Oral candidiasis.
Oral hairy leukoplakia

Pulmonary tuberculosis (diagnosed in the last 2 years)

TB adenitis.

Severe presumed bacterial infections (pneumonia, empyema, pyomyositis, bone or joint infections, bactereamia, meningitis)

Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis.

Unexplained anaemia< 8gm/dl, neutropaenia< 1,000/mm3 or thrombocytopaenia< 30,000/mm3 for > 1 month.

**WHO stage 4.**

HIV wasting syndrome.

Pneumocystis carinii pneumonia (PCP/PJP).

Recurrent severe bacterial pneumonia.

Cryptococcal meningitis.

Toxoplasmosis of the brain.

Chronic orolabial, genital or anorectal herpes simplex infection for > 1 month.

Kaposis sarcoma.

HIV encephalopathy.

Extra pulmonary tuberculosis (except TB adenitis)

Cryptosporidiosis with diarrhoea> 1 month.
Isosporiosis.

Candidiasis of the oesophagus or the airways.

Cytomegalovirus (CMV) retinitis or disease of organs (other than the liver, spleen or lymph nodes)

Non typhoid salmonella septicaemia.

Cerebral lymphoma or B cell NHL.

Visceral leishmaniasis.

Oesophageal candidiasis.

Invasive cervical cancer.

Cryptococcosis (extrapulmonary.)

Disseminated non-tuberculous mycobacterial infection.

Progressive multifocal leukoencephalopathy (PML)

Any disseminated endemic mycosis (e.g. Histoplasmosis)
Appendix IV: APGAR Family functioning assessment questionnaire (Silva, Victor, Mota, Soares, Leite, & Oliveira, 2014).

<table>
<thead>
<tr>
<th>A = Adaptation.</th>
<th>Almost always. Kilawakati. Mavindaamthe 2</th>
<th>Sometimes. Wakati mwingine Mavindaam we 1</th>
<th>Hardly ever. Hapana/La Nongi/Aie e. 0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Am satisfied with the advice and support that I receive from my family when something is troubling me.</td>
<td>Naridhika na mawaidha na ushirikiano ninaopata kutoka kwa familia yangu ninapopata shida.</td>
<td>Ninianiwe ni mautao na ngwatanio ila ngwataa kuma nyumbani yakwa ila nina thina,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P = Partnership.</td>
<td>Am satisfied with the way my family discusses items of common interest and shares problem-solving with me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Naridhika na vile familia yangu hujadiliana na kusuluhisha mambo na shida pamoja nami.</td>
<td>Ninianiwe ni undu nyumba yakwa ikomanana na kuneneeya na kuthusyania yiulu wa maundu na thina syitu vamwe nakwa.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G = Growth.</td>
<td>The relationship between me and my family is cordial/friendly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Uhusiano wangu na familia yangu ni mzuri.</td>
<td>Wikalanio wakwa na nyumba yakwa ni museo.</td>
<td></td>
</tr>
</tbody>
</table>
### A = Affection.
Am satisfied with the way my family expresses affection and responds to my feelings such as anger sorrow and love.

Naridhika na vile familia yangu inavyonipenda na kujihusisha na hisia zangu za hasira, huzuni na mapenzi.

Ninianiwe ni undu nyumba yakwa imbonasya wendo na ngwatanio ila ngwiwa woo, kiuuyu na wendo.

### R = Resolve.
Am satisfied with the way my family and I are able to resolve our differences in opinion and arrive at solutions.

Naridhika na vile mimi na familia yangu tunavyosuluhisha tofauti zetu.

Ninianiwe ni undu nyi na nyumba yakwa tuneenaa na kumina uteti kati yitu.

**TOTAL**
Appendix V. Self-report instruments used to measure family functioning

(Wilson, Pritchett, Kemp, Minnis, Bryce & Gillberg, 2011).

<table>
<thead>
<tr>
<th>Family functioning Instrument</th>
<th>Founder</th>
<th>Number of questions/items</th>
<th>Age applicable</th>
<th>Time taken (minutes)</th>
<th>Validity</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family APGAR</td>
<td>Smilkstein 1978</td>
<td>5</td>
<td>12+ years</td>
<td>5</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Family adaptability &amp; cohesion evaluation scale III (FACES III)</td>
<td>Olson et al 1985</td>
<td>42</td>
<td>12+ years</td>
<td>20</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Structural family interaction scale</td>
<td>Perosa &amp; Hansen 1981</td>
<td>68</td>
<td>12+ years</td>
<td>11</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>McMaster Family Assessment Device (FAD)</td>
<td>Epstein et al 1983</td>
<td>60</td>
<td>12+ years</td>
<td>20</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Family environment scale (FES)</td>
<td>Moos &amp; Moos 1981</td>
<td>90</td>
<td>12+ years</td>
<td>10</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Beavers self-report family inventory (SFI)</td>
<td>Beavers RW et al 1985</td>
<td>36</td>
<td>11+ years</td>
<td>30</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
<tr>
<td>Genogram</td>
<td>Murray Bowen 1978</td>
<td>Variable</td>
<td>All ages</td>
<td>Variable</td>
<td>Acceptable</td>
<td>Acceptable</td>
</tr>
</tbody>
</table>
Appendix VI. Moi University institutional research and ethics committee approval.

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORÊT
Tel: 3347123

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORÊT
Tel: 3347123

Reference: IREC/2011/157
Approval Number: 000723

29th September, 2011

Dr. Katua Daniel Kasungwa,
Moi University,
School of Medicine,
P. O. Box 4606-30100,
ELDORÊT, KENYA.

Dear Dr. Kasungwa,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:

"The Relationship between the Stage of HIV Disease at Initiation of Care and Family Functioning at Kangundo District Hospital in Kenya"

Your proposal has been granted a Formal Approval Number: FAN: IREC 000723 on 29th September, 2011. You are therefore permitted to start your study.

Note that this approval is for 1 year; it will thus expire on 28th September, 2012. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change(s) or amendment(s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Yours Sincerely,

Dr. W. Arusa
AG. CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc: Director - MTHR
    Dean - SOM
    Dean - SPH
    Dean - SOD