

Treatment Delay in Kaposi Sarcoma Patients in Uganda

by

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Duke Global Health Institute
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Jackson Orem

Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science in the Duke Global Health Institute
in the Graduate School
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ABSTRACT

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Abstract

Background

Significant delay occurs in initiating cancer treatment worldwide. In Uganda, there has been an increase in HIV/AIDS related malignancies due to the large number of people with HIV/AIDS. One particular cancer that has had a very large increase in prevalence is Kaposi Sarcoma. Despite the availability of chemotherapy for Kaposi Sarcoma at the Uganda Cancer Institute, many patients will present with advanced disease. Most studies on delay in cancer have been done in developed countries and very few have been done in Africa. Even fewer studies have been done in the context of HIV/AIDS and KS where patients are under continuous care. This study sought to establish the causes of treatment delay and describe the pathway to care in KS patients in Uganda.

Methods

The study was a cross sectional study carried out at the Uganda Cancer Institute. The study enrolled adult consenting patients that presented to the Uganda Cancer Institute with histologically diagnosed Kaposi Sarcoma. The study used an interviewer-administered survey that comprised questions on demography, socio-economic status as well as different aspects of HIV/AIDS and KS care. The study lasted from July to August 2011.

Findings

180 patients were enrolled in the study, and 27% experienced delays in treatment initiation lasting more than 3 months. 44% of the study participants used traditional healers and of these, 33% experienced delays greater than 3 months (P value=0.05) compared to 23% in those that did not use traditional healers. The odds of delay in those who visited traditional healers was 2 times the odds of delay in those who did not use traditional healers (P Value= 0.07). Other factors that were correlated with delay were education status, attendance of HIV care clinics, use of HAART and marriage.

Discussion

Treatment delay still remains a significant problem in cancer patients in Uganda despite the increasing knowledge about cancer, and in HIV/AIDS related malignancies, despite the availability of evaluation in HIV care clinics. Some of the factors contributing to treatment delay include use of traditional healers, and lack of knowledge of cancer and the potential care, which is available. It is important that we address the lack of knowledge about cancer symptoms in the patients if we are to address treatment delay sufficiently. It is also imperative that we address the challenges in the health care systems that contribute to delay in order to ensure access to diagnostic and treatment services.

Dedication

To Gash, Joan, Lynn and Connie

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TREATMENT DELAY IN KAPOSI SARCOMA PATIENTS IN UGANDA

1. Introduction

In December 2009 there were an estimated 33.3 million people living with Human Immunodeficiency Virus (HIV) /Acquired Immune Deficiency Syndrome (AIDS) worldwide. Sub Saharan Africa, has more than 80% of the total burden of HIV/AIDS in the world(UNAIDS, 2010). Despite the expansion of prevention and treatment programs, the incidence of new infections is still high and the worldwide prevalence increased by 20% between 2000 and 2008 (UNAIDS, 2010). The high prevalence of AIDS in Sub Saharan Africa has been accompanied by a rise in the incidence of AIDS-associated malignancies such as Kaposi Sarcoma (KS) and Non-Hodgkin's Lymphoma(Mbulaiteye et al., 2006; Sasco et al., 2010). Uganda has an HIV prevalence of between 5 and 15%. The HIV epidemic in Uganda has led to marked increases in the prevalence of KS. The incidence of KS in Uganda between 1960 and 1966 was 3.2 cases per year but rose to 39.3 cases per year between 1995 and 1997 and the sex ratio of men to women affected by KS decreased in the same period from 18 to 1 to 1.7 to 1 (Wabinga, Parkin, Wabwire-Mangen, & Nambooze, 2000). All these changes coincided with the peak of the HIV epidemic. The HIV incidence has more or less declined but the incidence of KS is still rising (Parkin, Nambooze, Wabwire-Mangen, & Wabinga, 2010b).

The management and treatment of KS has significantly improved and survival rates are high with the availability of chemotherapy and anti-retroviral drugs for HIV/AIDS. In Uganda, cancer patients get an average of 1.8 cycles of chemotherapy free and although they require six cycles, overall survival from KS

is generally good (Nguyen H, 2009). Antiretroviral drugs are free for most patients. This would translate to a higher mean survival for patients who present with KS, but given late presentation with advanced disease, survival from KS is poor. Many of these patients will usually be attending HIV care clinics and yet, will still be diagnosed late in the course of the cancer. For those patients with advanced cancers, palliation is usually the only form of treatment available. Additionally, for these patients, the benefit of chemotherapy is usually minimal, as they do not respond to treatment appropriately. Treatment and cure options are limited. Van Schalkwyk and colleagues estimated the mean delay in presentation in cancer patients to be between 17.1 months and 28.4 months in a study involving women with cervical in South Africa (van Schalkwyk, Maree, & Dreyer Wright, 2008).

Reasons have been advanced for delay in seeking medical care in patients and some of the reasons are to do with the fact that people are ignorant about their condition and for some, a fatalistic perception that nothing can be done about the condition (Aitken-Swan & Paterson, 1955). This perception may explain why patients do not seek medical help until the cancer is in advanced stages. In contrast KS is a treatable disease and patients can be expected to live a reasonably normal life. Other causes of delay are inherent in the health system with diagnostic delays and poorly facilitated health systems.

This study sought to establish the mean delay and causes of the delay from symptom recognition to presentation to hospital, and to diagnosis and treatment. We interviewed 180 patients obtaining care at the Uganda Cancer Institute.

1.1 Background and Study Rationale

Globally, cancer, cardiovascular disease and accidents are among the ten major causes of death (Olweny, 1991). The burden of malignancies in the developing world is increasing and the health systems in these countries are not equipped to handle this increase in cancer cases. In many developing countries, there are weak cancer screening programs and treatment centers are very few and ill equipped. Most patients in developing countries will either present or be diagnosed with advanced stages of cancer. There is a significant delay between when patients get symptoms, and when they eventually start treatment for their condition. Goldsen and colleagues have defined delay in seeking treatment for cancers as postponement of treatment seeking for more than three months from the onset of noticeable signs and symptoms (Goldsen, Gerhardt, & Handy, 1957). This definition is considered in many studies to be acceptable for describing delay in cancer patients. The pattern of delay in cancers is different from delay in other diseases but KS is representative of nearly all the cancers since the referral pattern is the same and will be used in this study as the referent cancer. The chief variation is that patients with KS will usually be attending ART and HIV care clinics. Additionally, the diagnosis of KS can be made on visual inspection. We would expect earlier diagnosis of the disease and earlier initiation of treatment but this does not always happen.

The impact of delay is such that delayers will come to hospital in more advanced stages of disease. In a study of Chinese women with breast cancer, women who had total delays of between 3 and 6 months, presented with increased tumor size, a more advanced stage of the disease and had a poorer long term prognosis compared to those whose delay was less than 3 months

(Lam et al., 2009). It is estimated that between 18 and 34% of women with breast cancer will wait for more than 3 months with symptoms before they will consult a physician. It is not uncommon to see patients in Mulago with stage IV breast disease, yet this would have been much better treated if they had presented early.

Delay can be broken into three categories depending on where the delay occurs. Delay can either be appraisal delay, illness delay or utilization delay (Martin A. Safer, Quincy J. Tharps, Thomas C. Jackson, & Howard Leventhal, 1979). Appraisal delay occurs at the time the patient notices their symptoms, it is determined by what the patient perceives their symptoms to mean and is affected by such things as the socio-demographic characteristics of the patient and the cultural context. Illness delay occurs after appraisal delay. Once the patient has determined that they are ill, what do they do about the illness? Do they decide to seek professional help or do they decide not to act on the symptom? Sometimes, after determination of this, it may change through the course of the illness and they will seek care as the symptom worsens. Utilization delay occurs at the point of care and these include cost as well as physician skills and availability of resources to be used. The total delay is a sum of delay accrued from each of these stages.

Several reasons have been advanced for delay in patients with cancer. Some of these are to do with the patients socio-demographic characteristics while others are cultural and some are even socio-economic. The major impact of socio-economic and cultural factors is in the appraisal delay. Goldsen compared socio-demographic characteristics between non-delayers (those that sought almost immediate attention for their symptoms) and delayers and found that patients'

socio-demographic characteristics were related to whether they delayed or not. The study found that those patients on a lower level of income, education and occupation were more apt to delay than those on higher level. The study carried out in New York showed that 41% of the delayers were in the lower socio-economic class while 31.2% were in the higher socio-economic class. Gender has also been showed to contribute significantly to delay. Men are more likely to delay than are women and this is evident in health seeking habits for diseases other than cancers (Leydon, Bynoe-Sutherland, & Coleman, 2003; O'Mahony & Hegarty, 2009). Socio-economic status is implicated in almost every form of health care disparity and in this study it was also determined that those patients that were unemployed were more apt to delay than those in the labor force. Some of this delay may be because patients in the lower socio-economic classes cannot afford the cost of care or the cost to the point of care.

The patients' perception of what their symptom means will greatly influence the extent to which they will delay seeking care. While it may be expected that those patients who self-diagnose themselves with cancer will come to hospital immediately, this is not always true. Self-diagnosis of the symptom as cancer is associated with what these patients interpret a cancer diagnosis to mean and is also related to how much knowledge patients have on cancer and cancer symptoms (Sheikh & Ogden, 1998). Those who think that this is curable or probably curable will seek care more than those that self-diagnose as incurable. In a study in Thailand on factors affecting patient delay (Bhosai, Sinthusake, Miwa, & Bradley, 2010), 32% of patients who thought that cancer was incurable delayed compared to 13% who thought it was curable. What this draws attention to is the importance of education of the community on different cancers and their

prognosis. KS is a treatable cancer, and patients with knowledge on cancer and cancer treatment options are more likely to seek treatment early.

Goldsen notes that the noticeability of the symptom seemed to have more effect than nature of the symptom (Goldsen, et al., 1957). They established that in those patients who had an overt or noticeable symptom, delay was more likely than in those that had signs that they thought were concealed. 40.8% of patients with overt signs delayed compared to 27.4% that thought they had non-apparent symptoms. This is contrary to what would be expected, that is namely, that patients would seek care for apparent symptoms and vice versa. While in breast cancer, if the sign was a lump or an ulcer seemed to have no bearing on whether patients delayed or not. KS has several overt and noticeable signs.

Social support mechanisms are important in cancer care and in help seeking behaviors. Those patients with functional support structures are more likely to seek care. If a patient had a supportive husband or family they are more likely to seek care as opposed to those that don't. This is closely associated with social disclosure. Those patients that reveal their symptoms or disease to their family or peers are likely to get to hospital or seek some form of care before those that do not (Lam, et al., 2009). It is also important that the social supports do not have negative perceptions about cancers as it has happened sometimes that instead of offering help, these same supports are the source of stigma and further delays in seeking care.

Delay is more common in elderly people than it is in the young, despite older people having the greater risk of cancer. In a study of women with breast cancer, the median patient delay for older women in breast cancer is twice that of younger women (Ramirez et al., 1999). And although, there is delay in the young,

the causes of the delay are different in each of the groups. In the elderly, other underlying illnesses and the fact that elderly people only prioritized symptoms that affected their daily functioning and this contributed greatly to delay in this group (Burgess et al., 2006).

Social exclusion and stigma in HIV/AIDS may contribute significantly to delay in seeking care for KS. Many studies have studied the impact of stigma and social exclusion on HIV/AIDS treatment seeking, but hardly any on its impact on help seeking for HIV/AIDS related malignancies. Stigma and social exclusion have been cited as one of the factors that affect adherence to anti-retroviral drugs and whether patients will seek care. Patients are afraid to reveal their status because of perceived stigma and discrimination, and consequently this will affect whether they take their medication or not (Bond, 2010; Kagee & Delpont, 2010). A study in Uganda found that once patients tested positive for HIV, they suffered stigma and social exclusion, in many instances being deserted by their families (Nyanzi-Wakholi et al., 2009). Some of the participants in the study preferred not to test for fear of social exclusion. There is stigma attached to admission at the Uganda Cancer Institute. In Uganda, there is a perception that everyone that is admitted to the Uganda Cancer Institute is going to die. Many patients are afraid to seek care at the Uganda Cancer Institute even after referral. This may contribute significantly to delay in treatment initiation.

The health system contributes significantly to utilization delay in accessing care in cancer patients. Some patients will have visited their physician several times before the complaint is investigated and sometimes the cancer has advanced. In a study of South African women with cervical cancer, there was in some cases a period of up to 17 months from when the patient presented to the

physician with symptoms to diagnosis (van Schalkwyk, et al., 2008). Some patients are not offered screening tests despite having signs and symptoms of disease. In Uganda, cancer care is offered at the Uganda Cancer Institute and there is a measure of time that is lost in the health system. Most of the rural and lower level health centers are unable to do pathological diagnosis and will thus usually send samples to Kampala for histological diagnosis after which patients are referred to the Uganda Cancer Institute. Time is always lost in this process and some patients get tired being sent to and from the hospital awaiting results and some do not come back while others will return when the symptoms worsen. This study seeks to examine what extent the health care system contributes to delay in seeking help in patients with KS.

There is a complex relationship between traditional medicine and conventional medical/health care systems and how patients interact with the two systems of care. A study in Ethiopia showed patients starting the process of care from traditional healers and then to the conventional treatment, but sometimes these patients reverted back to the traditional healers and back to the conventional health system (Dye et al., 2010). A study in South Africa showed that traditional healers usually are the first interaction for many patients with cancer and thus, the need to work with them to pass pertinent information to patients (Steyn & Muller, 2000). These alternative and competing sources of care create significant delay and on average, people who use them have a greater delay than those that do not (Malik & Gopalan, 2003). Use of traditional healers is an important contribution to treatment delay in KS patients in Uganda.

While help seeking behavior may be generalized in nearly all cancers, KS and other HIV related malignancies are unique. Patients with HIV/AIDS will be

attending anti-retroviral clinics and will be expected to get an early diagnosis but this is not always the case as they are subject to the same kind of delay. What factors are responsible for this delay in patients who are continually seeking care for other illnesses? It is not uncommon for a patient to conceal their signs from their HIV care physician only revealing them later in the course of the disease. HIV/AIDS associated malignancies also affect a younger population relative to other cancers and thus, the causes of delay may differ from those in other cancers.

Most studies on help seeking behavior and delay in cancer patients have been performed in Europe and the United States with only a handful of studies done in Africa, and even fewer on HIV/AIDS malignancies in the context of patients continuously seeking care for one disease and getting diagnosed, and treated with advanced cancers. The importance of these studies cannot be underestimated. They guide policy and intervention. A study by Aitken and colleagues found that the proportion of women seeking care for their symptoms increased after education on cancer and cancer symptoms (Aitken-Swan & Paterson, 1959). Thus, with the right knowledge we can be able to change the mean outcome for patients with a diagnosis of cancer. In the context of HIV/AIDS and KS, it is important to realize what else needs to be done to reduce the delay, given the high prevalence of HIV/AIDS in Uganda.

2. Research Questions

Due to the constant interaction of the HIV positive patients with the health system, the number of patients with KS who delay diagnosis and thus treatment initiation should be significantly less than in other cancers. But it is not. This study seeks to answer the following questions.

- 1) What are the causes of treatment delay in KS patients in Uganda?
- 2) What is the pathway to care for KS patients in Uganda?

2.1 Main Objective

This study seeks to describe treatment delay in KS patients in Uganda and establish the reasons why despite constant interaction with the health system and massive HIV-related public health education, there are still patients presenting with advanced stages of KS.

2.2 Specific Objectives

- To determine the mean delay in seeking treatment and causes of delay in patients with KS
- To describe the path from symptom presentation to treatment for KS patients at the Uganda Cancer Institute.

3. Methods

3.1 Study Area and Setting

The study was carried out at the Uganda Cancer Institute, Mulago Hospital, Uganda's only specialized cancer care center. The health referral system in Uganda is structured such that patients move through different levels of health care before they get to the cancer institute, although this pattern is not always followed. At the Uganda Cancer Institute, the definitive cancer management is started.

The Uganda Cancer Institute was started more than 40 years ago as a center for the care of patients with Burkitt's lymphoma. It was started as collaboration between Makerere University Medical School and the United States National Cancer Institute. It evolved into the current center that treats all types of cancer, and is presently Uganda's only cancer care center.

The Uganda Cancer Institute is a semi-autonomous institute and admits histologically diagnosed cases of cancer. In many cases, these patients will have been referred from lower level health centers to Mulago Hospital from where the histological diagnosis is made.

The major diagnostic facilities are located in the capital, Kampala close to the hospital. Many patients will have their biopsies taken off and sent to Kampala for histological analysis. Sometimes this takes quite a while, creating delay. After the histological diagnosis has been made, patients will then be referred to the cancer institute to start treatment. However, in some cases, patients are referred to Mulago Hospital and the histological diagnosis is made from there.

Historically, KS in Uganda was mainly associated with elderly men and those mainly living on the slopes of volcanic mountains, such as in Western Uganda. With the advent of HIV/AIDS, KS is now mainly associated with immunosuppression in this group. KS is one of several HIV-defining malignancies.

With support from PEPFAR and the Global Fund, many HIV/AIDS patients will be enrolled under ART and AIDS care programs. Some of the largest of these include at Mulago Hospital, Infectious Diseases Institute and the Joint Clinical Research Centre (JCRC). Most HIV/AIDS patients are under some sort of HIV/AIDS care.

3.2 Study Design and Methods

To answer the questions we carried out a cross sectional survey using mixed methods. We employed both qualitative and quantitative approaches in data collection. At the Uganda Cancer Institute, the patients who were admitted were identified with the help of the nursing in charge of the ward and once identified, interviewer-administered surveys were carried out for individual patients. These were patients with histologically confirmed KS. The interviews lasted approximately 30 minutes each. The interviews used structured questionnaires that were administered by teams including the researcher and research assistants.

The second group of patients was those KS patients who were attending the outpatient clinics at the Uganda Cancer Institute. The same questionnaire was used for both the in patients and out patients. Most of the chemotherapy is

administered on an out patient basis for Kaposi Sarcoma but if a patient is critically ill whether from KS or any other illness they will be admitted for closer management and observation. In essence, therefore, most of the participants were out patients who had come either for chemotherapy or for clinical review.

3.3 Data Analysis

The data was cleaned, coded and analyzed using Stata 11. Delay was defined as initiating treatment after 3 months or more from the time the patient notices symptoms of disease. Patients who started treatment after more than 3 months were considered “delayers” and those who initiated treatment in less than 3 months were considered “non-delayers”. The two groups were then compared on different characteristics such as the SES, education, gender, and attendance of HAART clinics and use of traditional healers. Fisher’s Exact Test was done on all these relationships. Logistic regression was also done to delineate the predictors of delay.

3.4 Study Population

3.4.1 Inclusion Criteria

- Adult patients with histologically confirmed KS receiving care from the Uganda Cancer Institute who are able to consent to the study. All the patients that were enrolled had histology results attached in their patients’ charts.

3.4.2 Exclusion Criteria

- Patients under 18 years or those unable to consent to the study
- Severely/critically ill patients
- Patients without a histological diagnosis of KS

3.4.3 Sample Size

The study population was of 180 patients with histologically diagnosed Kaposi Sarcoma attending care at the Uganda Cancer Institute.

It is estimated that up to 15% of cancer patients delay seeking care, at a 95% CI, the sample size can be obtained thus;

$$0.05 = 1.96 \sqrt{\{(0.15)(0.85)/n\}}$$

Where n is the sample size. Solving the equation for n yields a sample size of 196

3.5 Data collection

The study used interviewer administered structured questionnaires. Patients were identified with the help of the duty nurse. After the nurse had identified the potential participants, they were consented from a private patient side room. The questionnaires were translated to Luganda for those patients that could not comprehend English. Three research assistants were enrolled to help with the study. The research team comprised two doctors, a nursing officer and the principal researcher who is also a medical doctor.

Questionnaires tackled aspects of patients' demographics; age/date of birth, sex, socio-economic data (employment, income), religion, family size and social support system/structure

- Health seeking patterns; whether and where patient seeks health care when sick and if this has a function in delay
- Role of stigma and social exclusion in creating delay
- Knowledge and perceptions on cancer symptoms and treatments, diagnosis and prognosis
- Previous experiences with cancer symptoms and delay
- Whether they have disclosed their HIV status and whether they attend ART clinics

3.6 IRB Approval

Approval for this study was obtained from the Duke University IRB as well as the IRB at Mulago/Makerere University, College of Health Sciences under which the Uganda Cancer Institute falls and the Uganda National Council for Science and Technology.

3.7 Confidentiality

All data was coded using numbers. Names and other patient identifiable information as voter's registration numbers or driving permit numbers was not collected. No information in the study will be traceable back to particular patients.

4. Results

Table 1: General Characteristics of Participants.

Age	Male	Female	Single	Married	Divorced	Widowed
<20	2	2	5	1	0	0
20 – 29	34	25	36	21	2	0
30 – 39	41	26	24	39	1	3
40 – 49	14	4	4	22	1	1
50 – 59	6	1	1	5	0	1
>60	6	2	0	5	2	1

65% of the participants were male while 35% were female. Of the male participants, 30% were aged 20 – 29 years, 36% were aged 30 – 39 years. And 21% were aged between 40 – 49 years. Only 5% of the participants of the male participants were aged greater than 60 years.

Of the female participants, 40% were aged 20 – 29 years while 41% were aged between 30-39 years. Only 6% were aged 40 – 49 years and only 3% were aged greater than 60 years.

The P value on the distribution of age by gender was 0.036, which is statistically significant. Thus there was a statistically significant difference in distribution of Kaposi Sarcoma by age and gender.

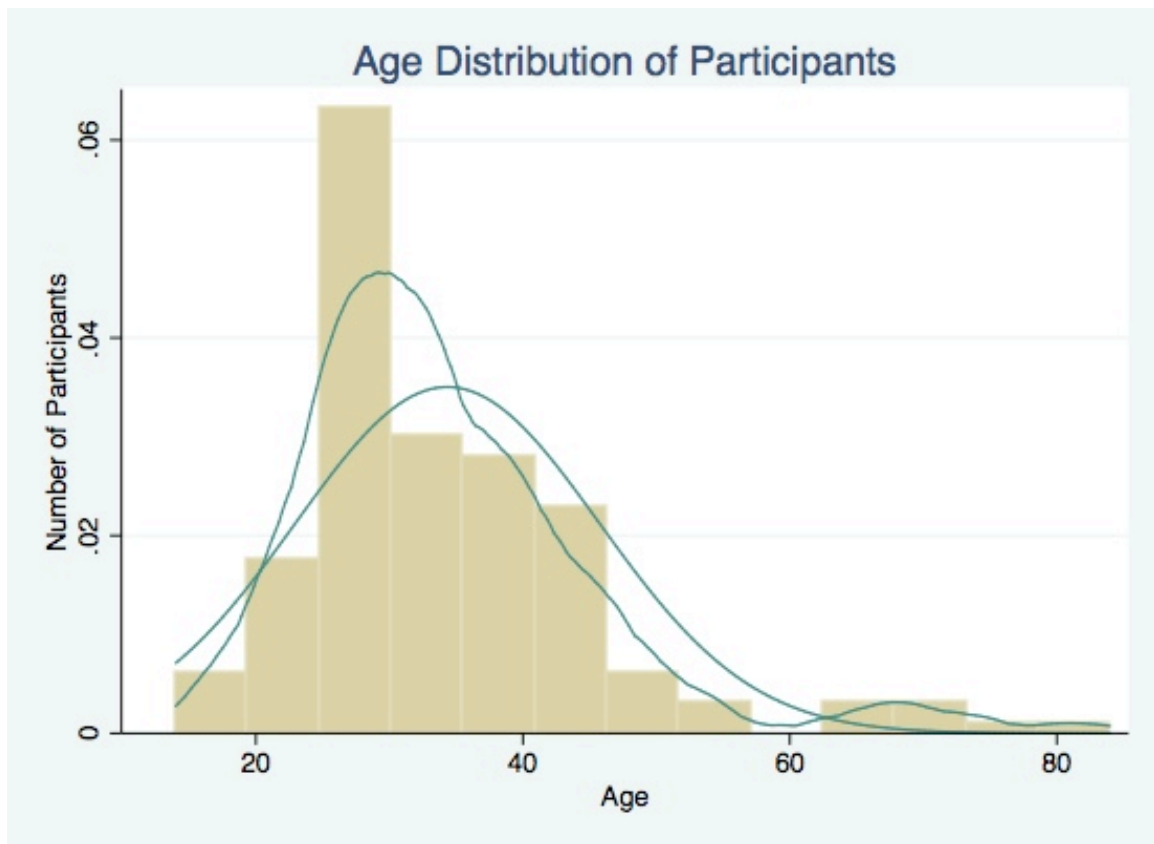


Figure 1: Age Distribution of the Participants

The graph shows the age distribution of participants with a normal distribution curve and a kernel density curve interposed over the histogram. The peak prevalence of KS in the participants is between the ages of 20 and 40 years.

The age distribution of the participants varies by gender. The graph below shows the age distribution of the participants by gender. There is a small difference between the distributions in the male and in the female population of participants.

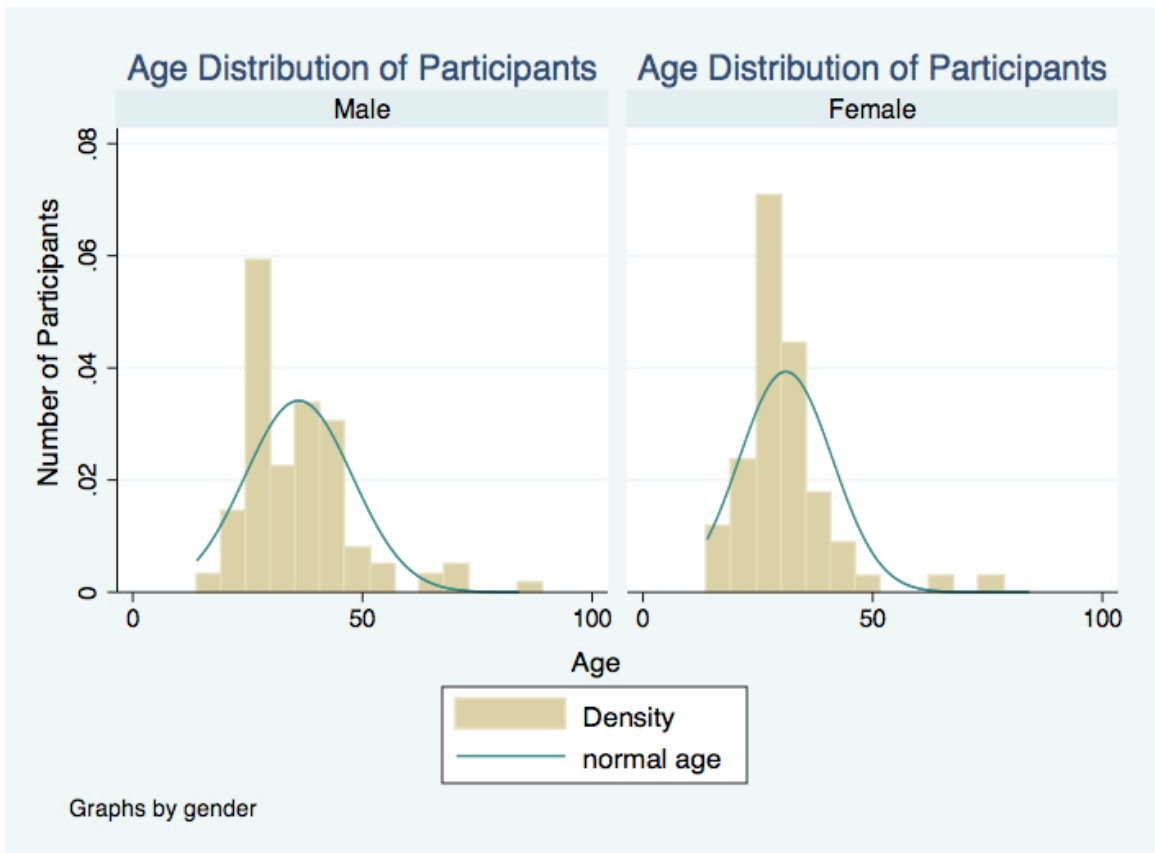


Figure 2: Age Distribution of the Participants by Gender

4.1 Marital Status

52% of the participants were married, 41% were single and never married. 3% of the participants were divorced and 3% were widowed.

4.2 Education Status

Table 2: Education Status of Participants.

<i>Education Attained</i>	<i>Male</i>	<i>Female</i>	<i>Total</i>
None	3	2	5
Primary	53	24	77
Ordinary	49	25	74
Advanced	7	9	16
Tertiary	4	2	6

Pearson chi2 (4) = 3.7892 Pr = 0.435

Fisher's exact = 0.430

3% of the total participants had no education at all. 46% of the participants had attained primary education (7 years of education) while 42% had attained ordinary level education (4 years of post primary education). Only 12% of the participants had attained more than 6 years of post primary education (advanced level education and tertiary level education).

There is no statistically significant difference in education between males and females. The P value is 0.43, which is below the significance level of 0.05. There is also no statistically significant difference in advanced education between males and females. 12% of the females had advanced and tertiary level education compared to 9% of the men. (P value =0.318)

4.3 Employment Status

55% (99) of the participants were employed while 45% were unemployed. Of the employed, 50% earn less than 100,000 shillings, 27% earn between 100,000 and 500,000 shillings. 22% of the participants who had jobs earned more than 500,000 Uganda shillings.

4.4 HIV Serostatus

94% of the participants sampled were HIV positive while 6% were HIV negative. 1 patient was of unknown HIV serology.

Of those that were HIV positive, 12% had been diagnosed within the preceding one month, 23% within the previous 2 to 6 months. 14% had been diagnosed with the preceding 6 to 12 months. 51% of the participants had been HIV positive for more than 12 months.

4.5 Patients' Interpretation of Symptoms and Diagnosis

There were varied responses to the meaning of the KS symptoms by the patients. While some patients interpreted them rightly to mean cancer (24%), majority of the patients thought of the symptoms as something else. 44% of the patients knew that they were sick but did not know the disease they were

suffering from. The responses varied from syphilis, witchcraft, and drug side effects to benign skin lesions. Most of the patients thought the signs and symptoms were a manifestation of local diseases.

36% of the patients interpreted a diagnosis of cancer as a disease that can't be cured. 24% of the patients when told they had cancer thought that they were going to die soon. Other responses as to what a diagnosis of cancer meant were; that some cancers can be treated, long stays in hospitals and others did not think anything of the diagnosis.

4.6 Total Delay

Of the 180 patients surveyed, 132 patients reported that they had presented to the hospital for definitive management within 3 months of noticing disease symptoms. 48 patients started treatment after more than 3 months. This represents 27% of the total number of participants that experienced delay. Several factors are associated with the delay and are analyzed below.

Table 3: Delayers and Non - Delayers.

	<i>Number of patients</i>	<i>% Represented</i>
Delayers	48	26.67
Non Delayers	132	73.33

4.6.1 Effect of Symptom Interpretation on Delay

77% of the patients who correctly interpreted the signs and symptoms to mean cancer did not experience delay.

Of those who interpreted the signs and symptoms as some form of disease, only 24% experienced delays of more than 3 months. 76% of those who interpreted the signs and symptoms as evidence of disease did not delay.

These differences however, were not statistically significant as the P value associated with the difference was 0.64.

4.6.2 Effect of Education on Delay

Table 4: Effect of Education on Delay

<i>Education attained</i>	<i>Delayers</i>	<i>Non-Delayers</i>
Primary and below	41	115
O'level and above	7	17

Pearson chi2(1) = 0.0885 Pr = 0.766
Fisher's exact = 0.806
1-sided Fisher's exact = 0.469

Of the patients with an education status of primary school and less, 26% experienced delay while the corresponding percentage in those with an education of ordinary level and above was 29% (P value 0.81).

Table 5: Logistic Regression of Effect of Education on Delay

<i>Education Level</i>	<i>Odds Ratio</i>	<i>P value</i>	<i>95% CI</i>
Primary	0.655	0.640	0.111 – 3.864
Ordinary	0.846	0.853	0.144 – 4.963
Advanced	0.667	0.697	0.087 – 5.127

The odds ratio for primary education compared to those with ordinary level and greater, was 1.55 (P=0.766, 95% (.447 - 2.985)). The odds of delay in those that were educated at primary levels and below was 1.55 times the odds of delay in those that ordinary level education and above.

4.6.3 Effect of Employment on Delay

Table 6: Effect of Employment on Delay

<i>Occupation status</i>	<i>Delayers</i>	<i>Non-Delayers</i>
Employed	29	70
Unemployed	18	62

Pearson chi2(1) = 1.0544 Pr = 0.304
 Fisher's exact = 0.393
 1-sided Fisher's exact = 0.196

29% of the employed patients experienced delay compared to 23% of those that were unemployed, but this difference was not statistically significant.

Of the patients that earned an income, 34% of those that earned less than 100,000 shillings delayed, 15% of those that earned between 100,000 and 500,000 shillings delayed while 40% of patients that earned above 500,000 shillings delayed.

Importantly, only 29 of the study participants earned more than 500,000 shillings.

The P value associated with this difference was 0.07. It is marginally statistically significant.

The odds ratio of those employed compared to the unemployed was 0.701 (P= 0.306, 95% CI, 0.355 - 1.384). The odds of delay in the employed were 0.701 times the odds of delay in those that were unemployed.

4.6.4 Use of Alternative and Complementary Medicine

44% of the study participants used some sort of alternative or complementary medicine. These varied from the priests to the traditional healers, witch doctors as well as herbalists.

Table 7: Effect of Use of Healers on Delay

	<i>Delayers</i>	<i>Non - delayers</i>	<i>Total</i>
ACM Users	26	53	79
No ACM use	21	79	100

P value =0.05

Of those that used ACM, 33% experienced delay while only 21% that did not use ACM delayed. The P value associated with this difference is 0.05, which is statistically significant.

There was no significant difference between those that used traditional healers and those that did not. 33% of those who used traditional healers were likely to delay compared to 23% of those that did not use traditional healers.

This difference was not statistically significant. The P value associated with this difference was 0.06, which is just above the level of significance of 0.05.

The common diagnoses that were made by the traditional healers were “Etaalo” and witchcraft.¹ Other diagnoses included syphilis and a multitude of local dermatologic illness.

The odds of delay in those who did not use traditional healers was 0.5 times the odds of delay in those that used traditional healers (P value = 0.07, 95% CI 0.277 - 1.061)

4.6.5 Marriage and Delay

60% of all the participants that were widowed experienced delays of greater than 3 months in initiating treatment for Kaposi Sarcoma. The corresponding percentage with participants who were married was 22% while only 17% of those that were single delayed.

There was only a small effect of family size on delay. 29% of the participants who lived in households with less than three people were more likely to delay that those in households with more than 3 people where 33% were

¹ “Etaalo” which is also part of the whole witchcraft paraphernalia is an illness characterized by swelling and is attributed to witchcraft. It used to describe any range of illnesses that involve any swelling of the lower limbs such as Kaposi Sarcoma as well as cellulitis, DVT and many others.

likely to delay treatment initiation. This difference was not statistically significant with a P value of 0.50.

That percentage drops to 24% in households with more than 5 people and drops to a further 14% in those households with 10 or more people. All these effects of family size on delay were not statistically significant with $P > 0.05$.

Table 8: Logistic Regression of Effect of Marital Status on Delay

<i>Marital Status</i>	<i>Odds Ratio</i>	<i>P value</i>	<i>95% CI</i>
Single	1.483	0.278	0.728 – 3.022
Divorced	0.725	0.776	0.079 – 6.657
Widowed	3.625	0.136	0.667 – 19.711

The odds of delay in single people 1.6 times the odds of delay in those who were married. The odds of delay in divorced people was 0.7 times in those who were married and the odds in the widowed was 3.6 times the odds of delay in those who were married.

4.6.7 HIV Associated Stigma and Delay

There seemed to be no contribution of stigma to delay. 92 patients, representing 51% of the sample population said they had experienced stigma. 88

Patients said they had not felt that they were being stigmatized. Patients who said they experienced stigma were just as likely to delay as those who did not delay. The effect of stigma was in deciding to seek treatment for HIV. After making the decision to seek care for HIV/AIDS, stigma then played no role in influencing care seeking decisions. 24% of patients that said they experienced stigma delayed as opposed to 28% that said they had not experienced any stigma. The odds of delay in those who said they were affected by stigma were the same as in those who were not affected by stigma. (P value = 0.313).

4.7 Attendance of HIV/AIDS Care Clinics

80% of the participants were attending ART clinics.

26% of the participants that attended ART clinics experienced delays compared to 56% that did not attend ART clinics. The difference is not statistically significant, $P=0.09>0.05$.

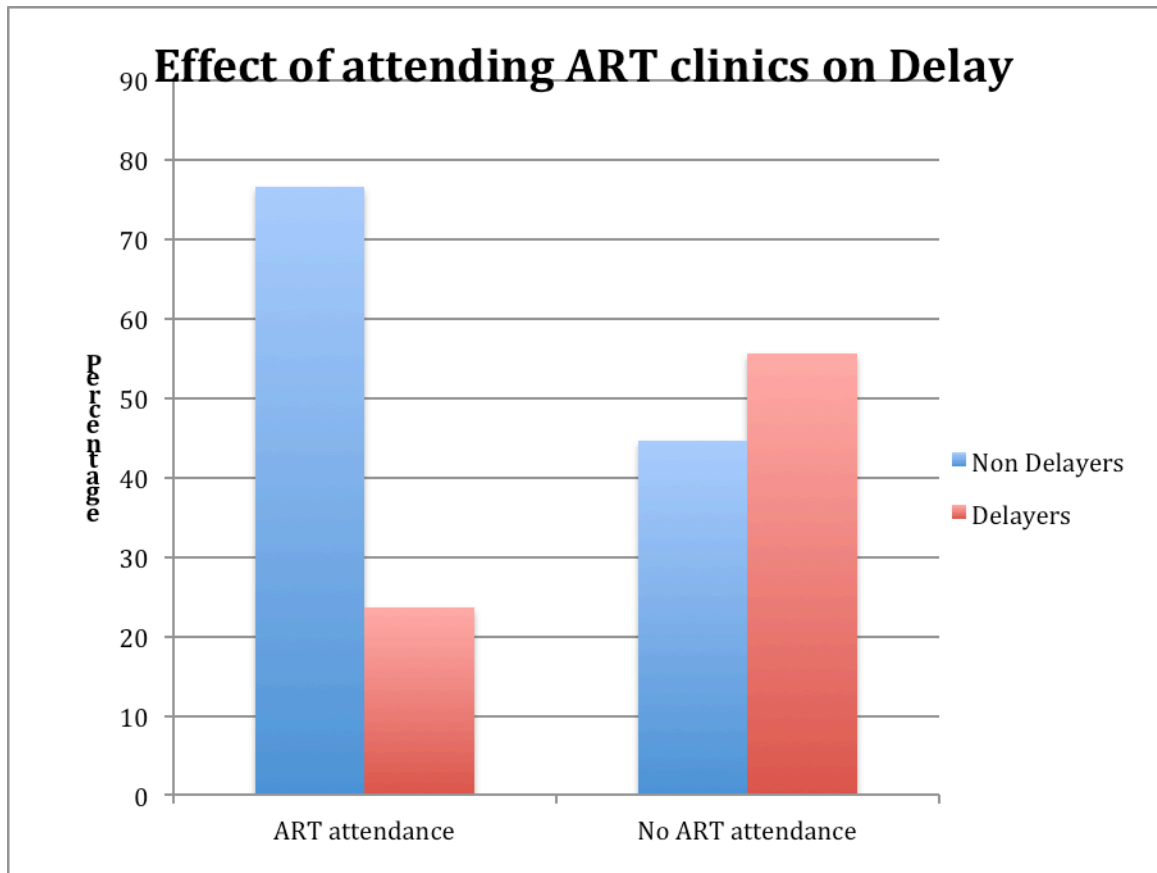


Figure 3: Effect of Attending ART Clinics on Delay

The odds of delay in those who did not attend HAART clinics were the same as the odds in those who did not attend the HAART clinics. (P value = 0.94, 95% CI, 0.987 - 1.017).

4.7.1 Duration of HIV Care

The duration for which these patients had attended ART clinics varied and it was expected that delay would be different in the different groups.

Table 9: Effect of Duration of Attendance of ART Clinics on Delay

<i>Duration of ART attendance</i>	<i>Number of participants</i>
1 to 3 Months	33
4 to 5 Months	23
6 to 12 Months	28
> 12 months	59

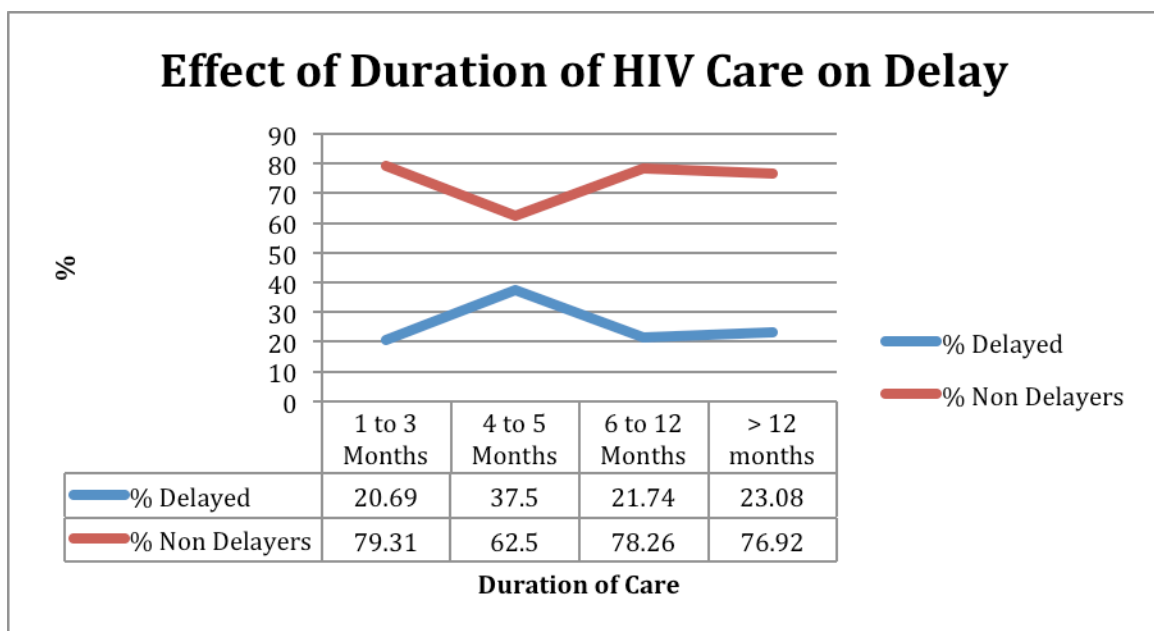


Figure 4: Effect of Duration of HIV Care on Delay

Table 10: Logistic Regression of Effect of Duration of HIV Care on Delay

<i>Duration of Care</i>	<i>Odds Ratio</i>	<i>P value</i>	<i>95% CI</i>
< 1 month	1.511	0.578	0.353 - 6.469
2 – 6 Months	0.850	0.854	0.151 - 4.775
6 – 12 Months	2.784	0.125	0.750 - 10.297

The odds of delay in those patients who had been attending HAART clinics for less than one months was 1.5 times the odds of delay in those who had been attending HAART clinics for more than one year.

Generally, there was a decrease in delay with increase in duration of HIV care. Those patients that had been attending HAART clinics for longer periods were more likely to seek care earlier than those that had attended HAART clinics for only a short duration.

There was no appreciable effect of the duration of HAART use on care on delay. There was no pattern to the changes in delay with increased duration of usage of HAART.

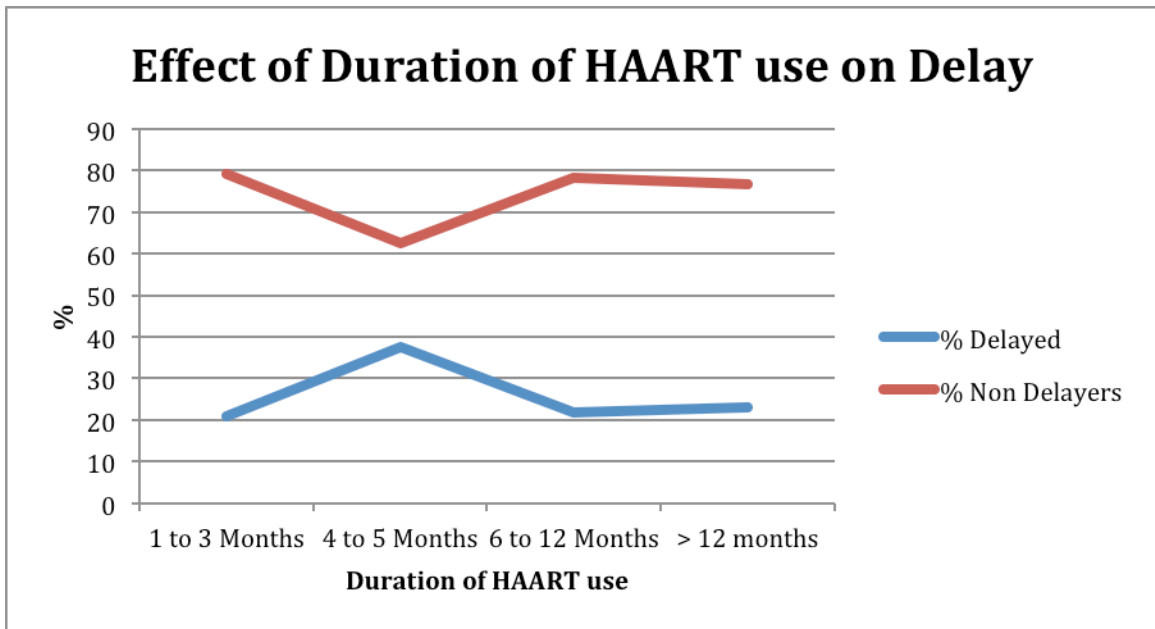


Figure 5: Effect of Duration of HAART Use on Delay

4.7.2 HAART Adherence and Delay

Participants who adhered to their HAART regimens as prescribed were less likely to delay than those who did not adhere well to the treatment regimens. Only 27% of those patients who adhered to their treatment regimens delayed compared to 31% who did not adhere to their HAART regimens that delayed, although it was not a statistically significant difference. Adherence was described as taking medication as prescribed. Non-adherence on the other hand was described as not taking medication as prescribed for whatever reason. Some of the reasons included severe side effects, HAART running out; severe other

illness and some patients said that they simply did not want to take the anti-retroviral drugs. Definition of adherence was arbitrary on what the patient said was prescribed. There was no pill count done to ascertain strict adherence. If a patient says they had been taking their medications as their physician prescribed, it was taken to be adherence although this would not be reliable since even those that did not adhere could say they adhered.

4.8 Health System Factors in Delay

4.8.1 Effect of User Fees in Delay

Some patients said that they had been charged fees for some of the services. Some of these charges were related to investigations that were required before initiation of treatment. Other fees were in the form of consultation fees that were charged at the different hospitals that patients visited before getting definitive care. 28% of those patients that said that they had been charged fees delayed compared to 23% that said they had not been charged (P value=0.18). Patients said that they had to go look for the money before care could be dispensed. The odds of delay in those who said that user fees were a barrier were the same as in those who did not have an issue with user fees.

4.8.2 Distance and Delay

Distance was measured in terms of nearness of the care facility to the patient. An in district facility was termed as close and those that were out of the district were said to be distant.

The location of the health care facility seemed to have a significant effect on whether patients delayed or not. 29% of patients who described themselves as far from a health care facility delayed while only 25% of those that said they were near to a health care facility delayed (P value=0.47).

Generally, all patients were referred to the Uganda Cancer Institute where they got definitive cancer care. The time taken to refer a patient after diagnosis varied across the board. Also patients after referral took varying times to follow through with the referral.

4.8.3 Average Time to Make a Diagnosis of KS After Patient Presentation

When patients make the decision to seek care, they will go to different health centers. Sometimes, the patients will visit tertiary institutions where the diagnosis is made immediately, but occasionally, patients will move through different health centers before a diagnosis is made.

Even when the diagnosis is made, there is delay in referral. This delay is two ways; the physician or health center will delay in referring the patient but also after referral the patient will take time making the trip to the referral unit. This delay according to the patients is because of many reasons. The patients delay because they are looking for money to make the trip. There is also the assumption, not always true in Kaposi Sarcoma; that admission for cancer will result in long stays in the hospital.

Table 11: Time Taken to Make a Diagnosis

<i>Time Taken</i>	<i>Number of Patients</i>	<i>% Patients</i>
Within 1 week	91	50
2 to 3 weeks	52	29
After 1 month	15	8
2 to 3 months	12	7
> 3 months	3	2

50% of the patients will be diagnosed with Kaposi Sarcoma within one week of presentation. 2% of the patients will be diagnosed after more than 3 months from the time of presentation at the health center. The patient with the greatest amount of delay in making a diagnosis after presentation had a delay of

18 months from the time of presentation. On average however, about 50% of the patients were diagnosed after more than one week from presentation. It is important to note in most of these cases it was a clinical diagnosis of Kaposi Sarcoma and not always histological. The histological diagnosis was often made at the referral unit.

4.8.4 Average Time Taken to Refer a Patient After Diagnosis

Table 12: Time Taken to Refer a Patient After Diagnosis

<i>Time Taken</i>	<i>Number of Patients</i>	<i>% Patients</i>
Within 1 week	121	68
2 to 3 weeks	36	20
After 1 month	6	3
2 to 3 months	7	4
> 3 months	2	1

After diagnosis, only 68% of the patients were referred on to the tertiary care institution with 1% of the patients being referred after more than 3 months.

4.8.5 Average Time Taken to Follow Through a Referral

Table 13: Time Taken to go to Hospital After Referral

<i>Time Taken</i>	<i>Number of Patients</i>	<i>% Patients</i>
Within 1 week	125	70
2 to 3 weeks	38	21
After 1 month	7	4
2 to 3 months	4	2
> 3 months	5	3

After diagnosis and referral, 70% of the patients followed up on the referral within one week. The rest of the patients took variable times in following up the referral with 3% of these taking more than 3 months to follow through with the referral.

4.8.6 Average Time Taken to Treatment Initiation at UCI

It is expected that when patients present to UCI, they start treatment within the first week of presentation. However, the treatment initiation time varied greatly. While most patients initiated treatment within one week, there were some that even initiated treatment after six months.

Table 14: Time Taken to Initiate Treatment

<i>Time Taken</i>	<i>Number of Patients</i>	<i>% Patients</i>
Within 1 week	95	53
2 to 3 weeks	64	36
After 1 month	12	7
2 to 3 months	4	2
> 3 months	1	0.6

5. Discussion

The results of this study go to show that treatment delay in KS patients is still a significant problem in Uganda despite the presence of HIV/AIDS care clinics in which the patients will be enrolled. 27% of all the participants experienced treatment delays greater than 3 months. There were different factors that were associated with delay such as the age of the participants, use of HAART clinics, use of traditional healers, education and income of the participants. Treatment delay is still a big challenge despite the fact that patients are now enrolled under HIV/AIDS care clinics and thus are expected to know more about Kaposi Sarcoma. Patients are also expected to present early in the course of the disease but patients will present with advanced disease.

5.1 Gender and Age of the Participants

As will be seen from the results, Kaposi sarcoma is very prevalent among the younger age groups. Most of the participants are below 40 years of age. In fact, only 25% of the total number of participants is aged above 40 years. This distribution of KS affected individuals attending the Uganda Cancer Institute among the younger age groups may mirror the general distribution of HIV/AIDS among the Ugandan population. It is estimated that the HIV prevalence in Uganda is 6.8% and most of this is in the age groups 15 to 49 years. The HIV prevalence decreases below this age group (expectedly) and then decreases above 49 years. UNICEF estimates that there are an average of 1.2 million adults living with HIV/AIDS in Uganda. Only about 150,000 of these are children (less than 14 years) (UNICEF, 2011). The gender characteristics do not differ very

much across age groups and young men are just as likely as young women to have HIV. The prevalence of Kaposi Sarcoma tallies very well with the prevalence of HIV and follows a similar distribution. As noted in Wabinga et al, the ratio of males to females with KS in Uganda has fallen from 18 to 1.7; we would thus expect to see an almost equal number of women seeking care for the disease as men (Parkin, Namboze, Wabwire-Mangen, & Wabinga, 2010a). In this study, 35% of the participants were women while 65% were men.

In a 2008 Globocan estimate, Kaposi Sarcoma was the second most incident cancer in Uganda while it was the third in women (Globocan, 2008). The same report estimates that about 2872 men got Kaposi Sarcoma, which represented 24.4% of the total cancers incident in men in 2008. In 2008, 2343 women got Kaposi Sarcoma; about 15.3% of the total incident cancers in women that year. We thus expect to see more men attending care for Kaposi Sarcoma than women. Additionally, it is also known that Kaposi Sarcoma is more prevalent in men than women.

28% of the males with Kaposi Sarcoma experienced treatment delays compared to 35% of the women. However, 68% of those who delayed were men while only 32% were women. The increase in percentage of males who delayed could be attributed to the fact that there were more males in the study than females. Generally, it is thought that women have a better health seeking behavior than men and this could explain the reduction in percentage delay by women. The delay in women may be increased because of the associated social economic challenges. In Uganda women are less likely to be employed and thus have less financial independence than men and will depend on men for financial help. This may contribute to delay in some instances.

In this study, 60% of the men were employed while only 40% of the women were employed. This goes to show that lack of financial independence maybe a contributory factor to delay.

5.2 Effect of Employment and Gender on Delay

Table 15: Effect of Employment and Gender on Delay

Employed		
	<i>Male</i>	<i>Female</i>
Delayers	20	9
Non Delayers	50	20

Unemployed		
	Male	Female
Delayers	28	6
Non Delayers	34	12

As already stated, males were more likely to be employed than women, however, unemployed men were more likely to experience delays than unemployed women. 33% of unemployed women experienced delays, conversely, 45% of the men that were unemployed experienced delays. Of the participants that were employed, 31% of the women experienced delays while 29% of the men experienced delays (P value=0.06). In general, therefore, it seems that men were more likely to seek care if they were employed and less likely to do so when unemployed. This may point to a social construct that made it more difficult for men to seek care while unemployed. If women are unemployed,

there is a possibility that they may get financial help from their spouses for care seeking purposes. In our society (Uganda), the converse is not always true; that men will seek help from women to seek care. They will not seek care at all if they do not have the money.

5.3 Pathway to Care

The KS patients did not always come to the hospital when they noticed their symptoms. The pathway to care for these patients usually involved use of complementary and alternative medicine before seeking definitive care. The sources of care for these patients varied from traditional healers, priests and self-medication. The schematic below shows the pathway to care of the patients presenting at the Uganda Cancer Institute.

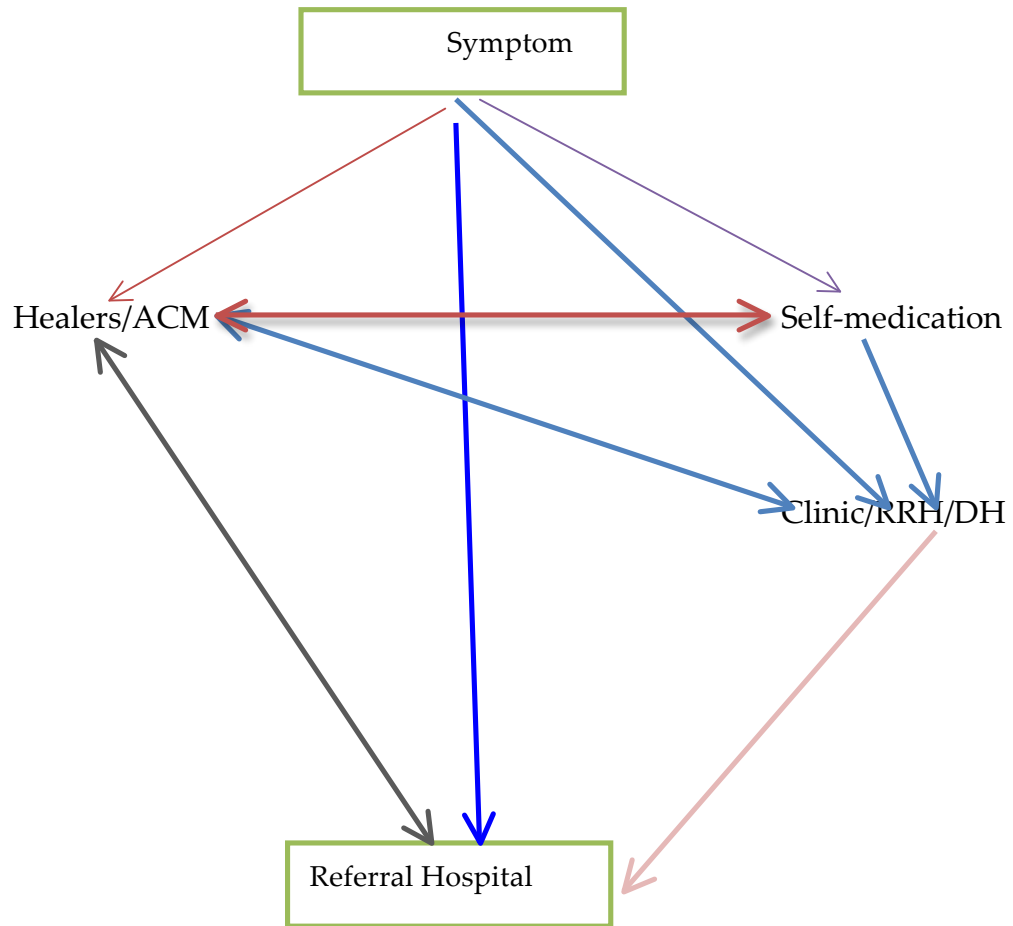


Figure 6: Pathway to Care for KS Patients In Uganda

44% of the patients after recognizing the illness used some form of alternative health system. Many patients after noticing symptoms will move to traditional healers and after the traditional healers, then patients may have either of two paths: patients may self medicate if the traditional healer does not provide satisfactory care or go to clinics. From self-medication, patients may then move back to a traditional healer or they move to a health center where a definitive

diagnosis will be made and treatment initiated or may be referred to a tertiary care center where treatment can be started. Patients may also move directly from symptom recognition to tertiary care centers where care will be initiated. Some of the patients we interviewed did not use one exclusive health system; the health systems interacted for them. Some of the patients were attending care in Hospital while concomitantly getting care from traditional healers and often moved to and from the traditional healers and the hospitals.

The sources of delay are fairly obvious in the schematic above. Patients will lose time visiting traditional healers, self-medicating and may lose time at the lower level health centers as a diagnosis is made and consequent referral made. As will be seen below, there was a significant portion of delay contributed in the health system as diagnosis was being made.

The choice of which route to take in the pathway to care is affected among other things by the interpretation of the symptoms. If a patient correctly interpreted the symptoms to mean cancer, there was a chance that this patient went directly to a hospital or clinic. As is seen from the results, only 10% of the patients that correctly interpreted these symptoms to mean cancer delayed while 26% of those who did not correctly interpret the symptoms delayed.

The choice of care may also be affected by education and availability of the formal health care as well as funds and employment status. Other factors that affected choice of health care system were the socio-economic status, age, education and gender.

5.4 HAART and Delay

As already noted, most of the KS patients will be enrolled in HIV/ART care programs and thus are likely to be in constant clinical care. In this study, 80% of all the participants were attending ART clinics. It is expected that if someone is in constant care, they are less likely to experience delays than those patients that were not in constant care. 26% of the participants that attended ART clinics experienced treatment delays greater than 3 months compared to 56% of those that did not attend any ART clinics. This difference however, is not statistically significant with a P value of 0.09. It can be assumed that the reduction in delay of those patients that were attending ART clinics is due to a number of factors: it is possible that these patients because of constantly going to the health centers to have their medication refilled, could have been diagnosed incidentally. Indeed, some patients had been diagnosed incidentally while at the ART care clinics for other concerns.

It is also possible that these patients were more educated on the symptoms and could have correctly interpreted their symptoms to mean cancer and thus sought care early.

By and large, attendance of ART care clinics was a contributory factor to reduction of delay.

5.5 Role of Stigma

There was no significant effect of stigma on delay. This can be due to the fact that patients do not put any correlation between HIV disease and Kaposi Sarcoma. While there is stigma in seeking care for HIV/AIDS, it does not exist in

seeking care for KS. This is due to the fact that many people do not know what the lesions mean and thus cannot stigmatize the sufferers. The stigma will only come if people can correctly link Kaposi Sarcoma to HIV, which is not happening at the moment.

5.6 Effect of Health System on Delay

From the schematic, patients may move directly to the national referral hospital/Uganda Cancer Institute where they will get definitive cancer care. Patients more often than not, however, will move from lower level health centers to the National Referral Hospital/Uganda Cancer Institute.

5.6.1 Structure of Uganda's Health Care System

Uganda's health system is organized such that patients will always start from the lowest levels and eventually be referred to the referral centers. The smallest unit is the Health Center I that serves a population of less than 1,000 people and the largest is the National Referral Hospital at which level the Uganda Cancer Institute is. The National Referral Hospital serves the entire population of about 33.4 million.



Figure 7: Structure of Uganda's Health Care System

The patient then essentially will move from Health Center I, which is the lowest level of health care to the National Referral Hospital, the highest level of health care in Uganda. The patient however, can bypass some of the levels of care to the highest level of health care.

In the process of moving through the different levels of the health system, there is delay experienced, which contributes to the total delay in initiating definitive cancer care.

From the study, about 49% of the patients were diagnosed with Kaposi Sarcoma after more than one week of presentation with 12% of the patient being diagnosed after more than 3 months from the time of presentation. Some of the patients were even diagnosed after one year from the time they presented at the

health centers. Clearly, this is a significant portion of delay made at the time of contact. KS is usually a relatively easy cancer to diagnose but that there is this amount of time taken to diagnose patients is a pointer to the inadequacy of the diagnostic facilities. Part of the challenges in diagnosis arise from the fact that pathology services are accessible only in Kampala, which in itself would not be a problem but there are no pathology pick up services. Sometimes, the diagnosis is dependent on the patient making the trip to Kampala or the hospital sending it to Kampala where the process may take a while to be completed.

It was also established that even after a diagnosis is made, patients were not immediately referred for definitive care. While a majority was referred within one week of diagnosis (68%), 32% were referred after more than one week.

Additionally, even those who were referred did not immediately go. Only 70% of the patients went to hospital within one week of referral. There is significant time lost between diagnosis and when patients eventually make it to the tertiary referral units for definitive care and management. Many of the patients interviewed said that if they had money they would have gone to the hospitals sooner while others said that if the hospitals were nearer then they would have sought definitive care soon. The challenge in accessing care thus is in the distance to and accessibility of care.

It is expected that for the majority of the patients when they reach the Uganda Cancer Institute, definitive care would commence within one week of being seen. However, only 53% of the patients initiated care within one week of presentation at UCI. Some patients (4%) initiated definitive treatment after more than 3 months. when patients come to UCI; they expect to start treatment

immediately. Coming to UCI is a costly venture for many patients and when during the course of staging investigations, they run out of sustenance funds, they will return to their homes and return when they have saved up enough money for the sustenance. It would be important if all the staging investigations would be done within UCI and the time incurred is reduced.

It is thus important to note that the health system contributes significantly to delay. To reduce delay, this should be the first to be tackled and then we can think of tackling the other causes of treatment delay in KS patients in Uganda.

6. Study Limitations

Recall Bias

Patients could not accurately recall when they first noticed symptoms and so it was difficult to accurately gauge the time when patients first noticed symptoms. Recall bias also makes it difficult to breakdown delay into the three component parts of appraisal delay, illness delay and utilization delay. Patients could not recall many details about their health-seeking journey and only gave rough estimates of the time.

Sampling Bias

The study was limited to patients who were already seeking care at the Uganda Cancer Institute. The implication of this is that the study only captured those patients already in care and could potentially have excluded other patients that were not at UCI. Although It is true that most patients seek cancer care at UCI, the study would have been helped by sampling outside of Kampala including the regional referral hospitals.

Generalizability

It can be expected that these results can be generalized to any other cancer; however, the study would be helped by a larger sample size. It is also important that before this study can be generalized to other cancers the study be broadened to include such areas as patients that are not receiving care from UCI such as those under palliation at Hospice; those under gynecological surgery and surgical oncology.

7. Conclusion

- The health system contributes significantly to delay. The delays experienced in diagnosis of, referral and initiation of treatment for Kaposi Sarcoma and cancer in general is one of significant contributors to delay.
- The formal health care sector receives significant competition from the traditional healers as well as other alternative forms of care and this contributes to delay.
- As was seen, patients who are under HIV care organizations are less likely to delay and thus the need to extend ART and HIV care services to more people.
- Stigma has no role in delay of treatment for KS patients. The role of is in seeking care for HIV/AIDS but because people do not associate the KS to HIV, there is no effect of stigma on seeking care for KS.
- Lack of knowledge is a significant contributor to delay. If people cannot the symptoms as those of cancer, they are unlikely to seek care for the cancer. It is important to educate people about cancer in the local communities so they can identify the symptoms as those of cancer and thus seek appropriate care. If people interpret the symptoms as witchcraft or “etaalo”, they are more likely to go to traditional healers than seek definitive care.

8. Recommendations

Several measures need to be put in place to reduce treatment delay in cancer patients in Uganda. Some of these measures include but are not limited to the following:

- Improve delivery of diagnostic services. There is a dire need to improve diagnostic services to populations outside of Kampala. This can be in the form of increasing the number of trained health workers available to rural populations so that patients can access a health worker when they need them. Providing pathology services in up country areas is also an important way of improving access to diagnostic services. These can be courier services that provide transport of tissue samples to say Makerere where the histology services can be provided and transport of results back to those health centers.
- Extend the reach of HIV care services. As noted, people who are attending HIV care services are unlikely to delay and therefore the need to increase reach of these services.
- Increase sensitization of the masses on the presentation of these illnesses so people can correctly interpret their symptoms and thus seek care for them. Sensitization should also include the availability of treatment for these cancers so that people are aware that drugs are available and thus a reason to seek care.
- Increase number of trained health workers at lower level health centers, as well as the tertiary units. Part of the challenge in diagnosis is that there are not enough health workers that can diagnose the disease. At the tertiary units, there are not enough oncologists to initiate definitive treatment for KS.

9. Bibliography

Aitken-Swan, J., & Paterson, R. (1955). The cancer patient: delay in seeking advice. *Br Med J*, 1(4914), 623-627.

Aitken-Swan, J., & Paterson, R. (1959). Assessment of the results of five years of cancer education. *Br Med J*, 1(5123), 708-712.

Bhosai, S. J., Sinthusake, T., Miwa, S., & Bradley, E. (2010). Factors affecting patient access in Thailand: Understanding delay in care seeking for patients with cancer. *Global Public Health: An International Journal for Research, Policy and Practice*.

Bond, V. A. (2010). "It is not an easy decision on HIV, especially in Zambia": opting for silence, limited disclosure and implicit understanding to retain a wider identity. [Proceedings Paper]. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*, 22, 6-13. doi: 10.1080/09540121003720994

Burgess, C. C., Potts, H. W. W., Hamed, H., Bish, A. M., Hunter, M. S., Richards, M. A., & Ramirez, A. J. (2006). Why do older women delay presentation with breast cancer symptoms? [Article]. *Psycho-Oncology*, 15(11), 962-968. doi: 10.1002/pon.1030

Dye, T. D., Bogale, S., Hobden, C., Tilahun, Y., Hechter, V., Deressa, T., . . . Reeler, A. (2010). Complex care systems in developing countries. *Cancer*, 116(3), 577-585. doi: 10.1002/cncr.24776

Globocan. (2008). GLOBOCAN 2008 FAST STATS.

Goldsen, R. K., Gerhardt, P. R., & Handy, V. H. (1957). Some factors related to patient delay in seeking diagnosis for cancer symptoms. *Cancer*, 10(1), 1-7.

Kagee, A., & Delpont, T. (2010). Barriers to Adherence to Antiretroviral Treatment The Perspectives of Patient Advocates. [Article]. *Journal of Health Psychology*, 15(7), 1001-1011. doi: 10.1177/1359105310378180

Lam, W. W. T., Tsuchiya, M., Chan, M., Chan, S. W. W., Or, A., & Fielding, R. (2009). Help-seeking patterns in Chinese women with symptoms of breast disease: a qualitative study. *Journal of Public Health*, 31(1), 59-68. doi: 10.1093/pubmed/fdn088

Leydon, G. M., Bynoe-Sutherland, J., & Coleman, M. P. (2003). The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers. [Article]. *European Journal of Cancer Care*, 12(4), 317-326.

Malik, I. A., & Gopalan, S. (2003). Use of CAM results in delay in seeking medical advice for breast cancer. *European Journal of Epidemiology*, 18(8), 817-822. doi: 10.1023/a:1025343720564

Mbulaiteye, S. M., Katabira, E. T., Wabinga, H., Parkin, D. M., Virgo, P., Ochai, R., . . . Engels, E. A. (2006). Spectrum of cancers among HIV-infected persons in Africa: The Uganda AIDS-Cancer Registry Match Study. *International Journal of Cancer*, 118(4), 985-990. doi: 10.1002/ijc.21443

Nguyen H, O. F., Ssewankambo F, Magaret A, Johnston C, Wald A, Kambugu A, Corey L, Orem J, Casper C. (2009). AIDS-associated Kaposi sarcoma in Uganda: response to treatment with highly active antiretroviral therapy and chemotherapy. *Infectious Agents and Cancer*, 4(05).

Nyanzi-Wakholi, B., Lara, A. M., Watera, C., Munderi, P., Gilks, C., & Grosskurth, H. (2009). The role of HIV testing, counselling, and treatment in coping with HIV/AIDS in Uganda: a qualitative analysis. [Article]. *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*, 21(7), 903-908. doi: 10.1080/09540120802657498

O'Mahony, M., & Hegarty, J. (2009). Help seeking for cancer symptoms: a review of the literature. *Oncol Nurs Forum*, 36(4), E178-184. doi: E62672525146KQ85 [pii]

10.1188/09.ONF.E178-E184

Olweny, C. L. M. (1991). Global inequalities in cancer care. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 85(6), 709-710. doi: 10.1016/0035-9203(91)90420-4

Parkin, D. M., Namboozee, S., Wabwire-Mangen, F., & Wabinga, H. R. (2010a). Changing cancer incidence in Kampala, Uganda, 1991-2006. *Int J Cancer*, 126(5), 1187-1195. doi: 10.1002/ijc.24838

Parkin, D. M., Namboozee, S., Wabwire-Mangen, F., & Wabinga, H. R. (2010b). Changing cancer incidence in Kampala, Uganda, 1991-2006. *International Journal of Cancer*, 126(5), 1187-1195. doi: 10.1002/ijc.24838

Ramirez, A. J., Westcombe, A. M., Burgess, C. C., Sutton, S., Littlejohns, P., & Richards, M. A. (1999). Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *Lancet*, 353(9159), 1127-1131. doi: S014067369902142X [pii]

Safer, M. A., Tharps, Q. J., Jackson, T. C., & Leventhal, H. (1979). Determinants of Three Stages of Delay in Seeking Care at a Medical Clinic. *Medical Care*, 17(1), 11-29.

Safer, M. A., Tharps, Q. J., Jackson, T. C., & Leventhal, H. (1979). Determinants of three stages of delay in seeking care at a medical clinic. *Med Care*, 17(1), 11-29.

Sasco, A. J., Jaquet, A., Boidin, E., Ekouevi, D. K., Thouillot, F., Lemabec, T., . . . Dabis, F. (2010). The challenge of AIDS-related malignancies in sub-Saharan Africa. *PLoS One*, 5(1), e8621. doi: 10.1371/journal.pone.0008621

Sheikh, I., & Ogden, J. (1998). The role of knowledge and beliefs in help seeking behaviour for cancer: a quantitative and qualitative approach. *Patient Education and Counseling*, 35(1), 35-42. doi: 10.1016/s0738-3991(98)00081-0

Steyn, M., & Muller, A. (2000). Traditional healers and cancer prevention. *Curacionis*, 23(3), 4-11.

UNAIDS. (2010). *AIDS Epidemic Update*.

UNICEF. (2011). *Statistics by Country*, from http://www.unicef.org/infobycountry/uganda_statistics.html

van Schalkwyk, S. L., Maree, J. E., & Dreyer Wright, S. C. (2008). Cervical cancer: the route from signs and symptoms to treatment in South Africa. *Reproductive Health Matters*, 16(32), 9-17. doi: 10.1016/s0968-8080(08)32399-4

Wabinga, H. R., Parkin, D. M., Wabwire-Mangen, F., & Nambooze, S. (2000). Trends in cancer incidence in Kyadondo County, Uganda, 1960-1997. *Br J Cancer*, 82(9), 1585-1592. doi: S0007092099910716 [pii]
10.1054/bjoc.1999.1071