

**CAUSES OF DELAYED PRESENTATION AMONG PATIENTS WITH  
ADVANCED OCULAR SURFACE SQUAMOUS NEOPLASIA  
PRESENTING AT KENYATTA NATIONAL HOSPITAL**

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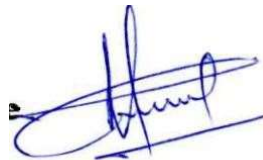
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**DECLARATION**

I declare that this research is my original work and has never been published or presented for a degree in any university.

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## **LIST OF ABBREVIATIONS**

OSSN-	:	Ocular Surface Squamous Neoplasia
SSA-	:	South Saharan Africa
ART-	:	Antiretroviral Therapy
HBM-	:	Health Belief Model
LMIC-	:	Low to Middle Income Countries
ASIRS-	:	Age Standardized Incidence Rates
KNH-	:	Kenyatta National Hospital
TNM-	:	Tumour Size, Nodal Status, Metastasis
SLE-	:	Slit Lamp Exam

## **ABSTRACT**

**Background:** Ocular surface squamous neoplasia (OSSN) encompasses a spectrum of disease involving abnormal growth of squamous epithelial cells on the surface of the eye. In Africa and in Sub Saharan Africa (SSA) specifically, the incidence of OSSN is the highest in the world at 3.0-3.5 cases/year/100 000 population. Delayed health seeking in cancer patients has been linked to late-stage presentation. Delay in most cases leads to limited and often ineffective treatment options. Understanding the reasons behind delay in initial presentation and delays between subsequent hospital visits for diagnosis and treatment of OSSN would result in a better appreciation of why patients make the decisions they make regarding their care.

**Objective:** To explore the factors contributing to delayed presentation among patients with advanced OSSN at Kenyatta National Hospital.

**Methods:** A qualitative study using the phenomenological approach was undertaken interviewing all newly diagnosed patients with advanced OSSN in Kenyatta National Hospital during the months of March to May 2023 to a data saturation point. An alternative OSSN clinical classification criterion was employed to facilitate the case definition pre surgical intervention. Interview data underwent content and thematic analysis and a thematic map of possible causes of delay developed.

**Results:** Five major themes and nine sub themes were found to influence delay in presentation among OSSN patients. The major themes were, Triggers to Action, HIV comorbidity, Cost of care and Fatalism and beliefs. The sub themes identified were pain and reduced vision, perceived severity, HIV related morbidity and CCC follow-up, Actual, perceived and opportunity cost of care and lastly fatalistic religious and cultural beliefs.

**Conclusion:** OSSN was found to commonly present as a painless eye swelling leading to low patient awareness of perceived severity of the swelling contributing to delay in seeking care. While actual initial cost of care wasn't found to be a barrier to initial presentation, the opportunity cost of care contributes to delay in healthcare seeking when more health visits are needed. HIV co-morbidity directly contributes to delay in these patients while fatalistic attitudes and patient beliefs interact indirectly with other factors in the thematic map to contribute to delay. Reduced awareness among healthcare workers in CCC may be further contributing to delay.



## CHAPTER ONE

### INTRODUCTION AND LITERATURE REVIEW

#### 1.1 INTRODUCTION

Ocular surface squamous neoplasia (OSSN) encompasses a spectrum of disease involving abnormal growth of squamous epithelial cells on the surface of the eye. It ranges from Squamous Dysplasia to Invasive Squamous Cell Carcinoma. Globally, incidence of OSSN is much lower compared to Africa. Incidence of OSSN in the United states and Australia has been reported to be as low as 0.03–1.9 per 100 000 persons/year .(1) This relatively low incidence is largely attributed to the temperate climates and significantly lower rates of HIV infection in that population.(2)

In Africa, cancer rates have been on the rise. In Sub Saharan Africa (SSA) specifically, the incidence of OSSN is the highest in the world at 3.0-3.5 cases/year/100 000 population in some countries.(3) This higher incidence rate has been attributed to the tropical climate with higher UV light exposure, longer exposure times due to outdoor occupations and HIV infection.(3)A study in Zambia found 68% of study participants to be HIV positive and of these patients about 45 percent presenting with invasive disease vs 29 percent of the participants with non-invasive disease. The climatic, socio-cultural and economic picture of countries within SSA is by and large similar and these findings would largely be representative of the epidemiology of OSSN in other SSA countries.(4)

Delayed health seeking in cancer patients has been linked to late-stage presentation. Delay in most cases leads to limited and often ineffective treatment options. These poor outcomes then have an interactive effect on the patients host community perceptions of modern health care treatment methods resulting in a cycle of more delay and poorer outcomes from cancer diagnoses.(5)

In Kenya, a study based on the delay involved in care seeking for OSSN patients demonstrated that 74 percent of the OSSN cases had HIV infection. Sixty three percent of these patients were on antiretroviral therapy (ART). Despite these group of patients being within the HIV care program with regular follow-up by clinicians, they still experienced delay. This study also showed that being female was associated with delay. Women in Sub Saharan Africa are the primary caregivers taking care of children and the home hence may have these responsibilities

contributing to delays in healthcare seeking. Women in this setting also don't have control of household resources further being dependent on their male spouses to agree for them to seek medical care that requires finances. (2)

The study also found that visiting more than one health facility for OSSN treatment was associated with a higher risk of delay. (2) Referral from the first health facility visited for OSSN treatment appreciably delayed surgical treatment and put off became associated with larger tumours at the time of surgical operation. HIV related stigma remains a potent stressor among HIV positive patients. It's associated with poorer adherence to treatment regimens, worse health outlook in the long term and poor health seeking behaviour especially when such health seeking leads to more frequent sero-status disclosure to people including health care workers.(6)

Understanding the reasons behind delay in initial presentation and delays between subsequent hospital visits for diagnosis and treatment of OSSN would result in a better appreciation of why patients make the decisions they make regarding their care.

## **1.2 LITERATURE REVIEW**

This section will provide a review of available literature on the behavioural models behind health seeking behaviour, findings of studies on delay characteristics of healthcare seeking and the possible factors that influence delays in health seeking. This will be done through examining research and generally accepted and adopted models and theories of health seeking behaviour and the factors that influence such behaviour.

### **1.2.1 Healthcare Seeking Behaviour**

Healthcare in search of behaviour may be defined as movements undertaken by way of people who perceive themselves to have a fitness problem for the motive of locating an appropriate remedy (7). Research on health seeking behaviour has been applied to generate an understanding of the way and why particular practices are engaged when the need for healthcare arises. Individuals have different willingness to seek care from health care providers.

While some people only seek care when in great pain and in the advanced stage of an illness, others readily visit health centres for care. Comparisons can be made between these two behaviours based on the time difference between the onset of an illness and contact with a healthcare provider, the type of healthcare professional and health facility patients sought and reasons therein, compliance to recommended actions/treatment offered by health providers and reasons for not seeking help in the first place.(7) Any decision to seek care goes through a decision making process that is influenced by individual and/or household behaviour, community norms, beliefs and expectations as well as provider-related characteristics and behaviour. (8)

Several models of healthcare behaviour and healthcare utilization have been developed to provide a framework that describes the interplay of the aforementioned factors. They have evolved to tools that help in the understanding of how people engage with the health care systems in their respective socio-cultural, economic, and demographic circumstances.

The Andersen and Newman healthcare utilization model is a conceptual model aimed at demonstrating the factors that lead to the use of health services. Developed in 1995, the model describes three key elements: predisposing, enabling and need for care factors which either expedite or hinder the utilization of healthcare services by individuals. Predisposing factors include demographic characteristics (age and sex, social structural variables (ethnicity) and an individual's basic beliefs, attitudes and knowledge pertaining to health services. Enabling factors include availability of financial resource. Need factors include illness and symptoms, and other health conditions needing care.(9)

The Anderson model has had several revisions and iterations all aimed at improving the models' ability to not only predict but explain health related behaviour. Using this framework, the directionality of the different factors can be analysed. Although widely utilized in healthcare behavioural research, the model has some drawbacks. It's been criticized for placing individual need factor as more influential than social or cultural aspects.(9)

The health belief model (HBM) is a healthcare specific behavioural cognitive model developed in the 1950s and has since been refined and expanded. It is based on the beliefs that behaviour is a function of the subjective value of a desired health outcome and of subjective expectation that a particular action will achieve the desired health outcome.

According to this model, healthcare behaviour is influenced by:

- i) Perceived susceptibility: Belief about how vulnerable one is in relation to getting an illness.
- ii) Perceived severity: Beliefs about the possible unfavourable outcomes of having a disease.
- iii) Perceived benefits: Beliefs that the suggested or intended behaviour will be both effective and practical.
- iv) Perceived barriers: beliefs about the barriers to the intended actions
- v) Perceived self- efficacy: Beliefs that a patient can actualize the actions they decide to take.
- vi) Cues to Action: The presence of triggers that motivate healthcare seeking.

These two models despite their criticism elucidate the various factors that could interplay and influence how patients make decisions, and how these can contribute to delayed care.

### **1.2.1 Cancer Incidence and Awareness**

Overall incidence of cancer worldwide has had a 2-fold to 3-fold increase. This increase has been noted to be higher in middle to low-income countries. As such, efforts to build sustainable cancer prevention measures and build capacity towards provision of cancer care in these countries is critical for global cancer control.(11) A Meta-analysis of data from cancer registries shows that Africa leads the world in the incidence of OSSN.(12)

A lack of awareness of cancer and cancer preventive care among patients has been linked to advanced disease presentation at diagnosis.(13) Cancer patients require a high degree of health literacy to facilitate decision making in regards to their cancer diagnosis and treatment. Low cancer awareness and general low health literacy make navigating the healthcare system challenging. Cancer awareness is desperately lacking in many low to middle income countries(LMICs) where low health literacy, cancer related stigma and myth, health and social inequities interplay to contribute to the high degree of late-stage diagnoses.(13)Advanced disease contributes to higher mortality and hospitalization rates placing a tremendous burden on health systems. Research on the delay characteristics of OSSN patients in Malawi found that 83 percent of patients in that study reported a lack of awareness on the availability of treatment services as one the factors influencing delays in seeking care. 77 percent of the study participants had no prior knowledge of the disease and its possible complications. A small percentage of patients, nineteen percent, considered their diagnosis life threatening. Other

factors such as transport challenges and low suspicion of cancer were also noted. Majority of patients in this study had a delay of at least one month from noticing of the ocular lesion and seeking care.(14)

The study on the epidemiology of OSSN in Uganda found a 10-fold increased risk of conjunctival squamous cell carcinoma in HIV infected patients, compared to HIV uninfected individuals.(15) A similar study done in Kenya found 71 percent of study participants to be HIV positive, of whom 63 percent were in HIV care programs and on antiretroviral therapy (ART) (2). Awareness among health care givers within HIV care programs of the spectrum of eye disease including OSSN that HIV patients are at higher risk of may be wanting. This lack of awareness may explain why patients who are in regular contact with these healthcare givers for their HIV care still experience delay in presentation of OSSN.(2)

The patients on ART are more likely to have advanced or severe immunosuppression and thus at higher risk for comorbidities such as tuberculosis (16) The time and financial resources expended in seeking care for such comorbid conditions may further delay HIV patients from seeking care for a new painless eye lesion.

### **1.2.2 Low Social Economic Status and Education Level**

Prolonged UV light exposure and exposure to UV light of high intensity as is the case in the tropics has been linked to higher incidence of OSSN in sub-Saharan Africa. The agricultural sector is a major employer of the populous in Kenya resulting in a lot of the work and time spent outdoors.

The OSSN study in Kenya showed that 65 percent of the OSSN patients worked outdoors (2).A case control study in Uganda on OSSN found risk of OSSN increased with increasing time spent in direct sunlight ( $p=0.003$ , adjusted for age, sex, residential district and HIV serostatus)(17). 80 percent of these economic activities were low or middle income in nature.

Health and poverty are inextricably linked. Poverty, defined by the world bank as living on less than 2.15 dollars a day, contributes to poor health by significantly exposing poorer people to environmental risks for illness and disability. The study on the epidemiology of conjunctival squamous carcinoma in Uganda found the risk of conjunctival carcinoma to be significantly

lower among those with a high personal income(OR 0.4, 95% CI 0.2–0.7 P 0.001).(15) Poverty has been linked to increased incidence and mortality of cancers in general.(18)

Individuals living below the poverty line are also more likely to have comorbidities due to the multivariate risk factors that they are exposed to i.e. poor diet, poor housing, low education, and environmental exposure. This morbidity burden serves to not only extinguish limited financial reserves contributing to delayed care but also influences health seeking behaviour towards more emergent health issues versus silent less painful ones.(19) People in poor countries tend to have less access to health services. Access in this context incorporates quality of healthcare available, the geographic placement of said healthcare and acceptability of the care to the people seeking it.(20)

Low social economic status has also been associated with low education and poor overall health. These factors often interrelate in a vicious cycle. Low education level contributes to less knowledge about activities to promote health and when/where to access health care if the need arises.(20)The OSSN study in Kenya found the education levels of the participants to be varied.125(79 percent) had finished primary education or above, and 67(42 percent) had completed secondary college schooling. The look at did not discover income or stage of formal education as a barrier to presentation in patients with OSSN, but these two factors contribute significantly to the purchasing power and degree of financial reserve in a household. Hence, the opportunity cost of lost income during the care-seeking journey and not the absolute cost of care could play a part in influencing the decisions of when and where to seek care for OSSN patients.

### **1.2.3 Cancer Stigma and Fatalism**

Cancer is a stigmatized disease. Stigma refers to special, discrediting traits, rendering its bearer tainted via others especially other network and own family participants. Most cancers-related stigma impacts fitness-looking for behaviour, treatment adherence, fine of lifestyles and psychosocial health in most cancers' sufferers. The exact ways of how it affects these aspects are complex and not properly studied among cancer patients.

Evidence also suggests that cancer stigma varies with location of the cancer in the body with disease in more visible areas being more stigmatised than those more hidden.(21) In the USA, a study on the relationship between selected sociodemographic variables (e.g. ethnicity, perceived financial status, and social desirability), healthcare system distrust, cancer stigma and the time from symptom onset to medical help-seeking behaviour in individuals with symptoms suggestive of lung cancer found that Lung cancer stigma was independently associated with timing of medical help-seeking behaviour. The other sociodemographic factors were also associated but not independently and their interplay varied based on ethnicity and perceived financial status among other factors.(22)

A study in south Africa on cancer stigma as a barrier to access to treatment reveals that it contributed to delayed treatment, influenced patients to use traditional healers instead of mainstream healthcare providers and generally encouraged secrecy of symptoms and/or diagnosis from both family/community members and healthcare providers.(21) (23)

Early detection and intervention in OSSN would reduce morbidity related to societal stigma and psychological disturbances. This may be due to changes in appearance related to disfigurement either because of advanced orbital disease at presentation or the management of advanced OSSN through radical orbital/facial surgery such as exenteration.(24)

Cancer related stigma has been associated with a cancer patients' emotional and behavioural outlooks. These associations have been hypothesized to then influence behaviour significantly towards the seeking of care of either suspected or a confirmed cancer diagnosis.(25) Depression has been found to be more commonly associated with a cancer diagnosis in comparison to other chronic non cancer diseases. This association together with other perceived negative attitudes including health system distrust, social desirability and economic factors do have an influence in health seeking behaviour of cancer patients. (26)

The concept of fatalism also influences medical help seeking behaviour. Cancer fatalism is described as deterministic thoughts about the outside reasons of the disorder, the lack of ability to prevent it, and the inevitability of death at diagnosis. This belief is heavily influenced by cultural and spiritual practices with patients often ascribing a cancer diagnosis to providence whilst leaning more on traditional medicine and religious practices at the initial stages of a cancer diagnosis. This contributes to delay in seeking care especially after the initial suspicion of cancer following a healthcare visit.(27)

OSSN is highly associated with HIV disease. With sexual transmission being the main mode of transmission of HIV in the Kenyan population, the societal stigma on OSSN is amplified on the backdrop of questionable morality of the patients suffering this disease. A study in Kenya on cervical cancer related stigma shows that its highly correlated with HIV stigma possibly supporting this assertion(28) Hence HIV patients may be less likely to seek care in other health facilities other than those within the HIV care program.

#### **1.2.4 Patient Related and Health System Factors**

Health-care utilization is determined by several factors. These include patient related factors and those at the level of the health system. They are, the need for care, whether people know that they need care, whether they want to obtain care, and whether quality care can be accessed. Quality is a construct separate from access and is related to the achievement of favourable outcomes associated with utilization. In theory, health-care utilization should correlate highly with the need for it. But, some services are needed and not obtained while others are indicated but obtained only after several hospital/care centre visits.(29)

Poorly developed health systems tend to have inadequate resources to implement early detection of cancer and adequate basic treatment. Inequalities in social determinants of health i.e. lack of awareness of preventive and curative cancer care, lack of efficient and geographically accessible referral pathways, patient navigation challenges within the available care system, and inadequate health care funding can lead to advanced disease presentation at diagnosis (13)

The OSSN study in Kenya examined the care-in search of journey of 158 patients with new lesions. 88 (55.7percent) of those patients provided directly to the four observe centres and 70 of them (44.3percent) supplied in a roundabout way to the have a look at centres as referrals from one or greater health facilities. Referral past the first facility markedly extended delay (indirect presenters took longer to receive surgical treatment than direct presenters (5.5 vs 9.6 months,  $p = 0.001$ ), this is regardless of having a shorter time to first presentation. Referral to a couple of health facility earlier than the study centre contributed to the longest delay among these sufferers. The extra time in getting from the first or second clinic to the study centre turned into in large part accountable.



Al Attas' et al study in Tanzania on understanding delay in accessing specialist eye care following eye trauma found that Injury on a weekend, being female, using topical drops and visiting other health facilities other than the specialized eye centre were independently associated with delay greater than 24 hours and greater than 48 hours. The study identified health system problems contributing to delay such as lack of clarity in the referral systems, lack of awareness of hospital opening times and healthcare staff absence as contributory to delay.(30)

A study in Angola on the factors associated with patient and health system delay in the diagnosis of tuberculosis found that the level of health facility in the first contact (whether specialized in treating TB or not) was an independent risk factor for both patient and health system delays. This study also found that patient level education level was an independent risk factors for patient delay but not health system delay.(31)

The OSSN study in Kenya found 31.4 percent of indirect presenters presented to level 5 county referral hospitals while 18.6 percent opted for private clinics. In majority of these facilities an operating theatre was available. Whether at the point of their first contact ophthalmic surgical services were available however, could not be established. This puts into question the reasons behind healthcare provider-initiated referral past first health facility in the setting of availability of an ophthalmologist and presence of an operating theatre(2).

The OSSN study in Kenya also found the median distance to 1<sup>st</sup> health facility for the indirect presenters to be 20km (5-56km) and for the direct presenters 30km (20-89km). Although the travel costs for the enrolled patients was not analysed, the nature of travelling to access care necessitates a chaperon/Companion further increasing cost of travel and care.(2) A literature review on distance as a barrier to cancer diagnosis and treatment showed that cancer related increase in travel requirements was associated with more advanced disease at diagnosis, inappropriate treatment, a worse prognosis, and a worse quality of life.(32)

Travel burden here being described as increased travel requirements due to a diagnosis of a disease and its treatment. The Kenyan study did not find income or level of formal education a barrier to presentation. But the opportunity cost of lost income during the care-seeking period for the patient and other adults involved in supporting this care could not be estimated but could be a significant financial deterrent to timely presentation to the healthcare facility. (20)

## **CHAPTER TWO**

### **STATEMENT OF RESEARCH PROBLEM, JUSTIFICATION AND STUDY OBJECTIVES**

#### **2.1 STATEMENT OF THE RESEARCH PROBLEM**

Global burden of cancer research describes a rise in the Age-standardized incidence rates (ASIRs) per 100 000 for most cancers in the world including Africa. With increasing incidence in OSSN in SSA and studies characterising delays in presentation for care among OSSN patients in this region, knowledge on the factors responsible for such delay is key. Some studies have elucidated the association between knowledge of behavioural and societal factors influencing healthcare seeking of cancer patients and better outcomes for these patients.(33) Such insights are lacking in Africa amongst OSSN patients and research towards this end would begin to build an understanding of these factors among health care practitioners.

#### **2.2 STUDY JUSTIFICATION**

Ocular surface squamous neoplasia presents in an easily visible part of the eye. Its recognition at inception and progress as it grows are thus easily visible to patients, friends, and family members. Despite its obvious visible location, patients still present to hospital for care in advanced disease. Furthermore, majority of patients are HIV positive on antiretroviral therapy hence in HIV care programs. They regularly visit comprehensive care clinics and are in contact with clinicians for their care. Despite this, these patients still present with advanced disease.

There are no studies to the best of our knowledge that seek to elucidate the reasons behind this delay among OSSN patients in Kenya. This study would build the knowledge available in literature about aspects of delayed presentation in these patients and provide a Kenyan context of the same.

## **2.3 MAIN OBJECTIVE**

To explore the factors contributing to delayed presentation among patients with advanced OSSN at Kenyatta National Hospital.

## **2.4 SPECIFIC OBJECTIVES**

2.4.1 To describe the care seeking experience of patients presenting with advanced OSSN at Kenyatta National Hospital

2.4.2 To describe the reasons behind delays in the care seeking journey among patients presenting with advanced OSSN at Kenyatta National Hospital

## **CHAPTER THREE**

### **STUDY METHODOLOGY**

#### **3.1 Study Design and Location**

This study is a qualitative study using the phenomenological approach. It was conducted at the Eye Clinic (Clinic 35) and Eye Ward (Ward 1c) within Kenyatta National Hospital (KNH), Nairobi. KNH is the largest facility offering referral eye care in East Africa hence manages majority of the advanced patients with advanced OSSN.

#### **3.2 Study Population**

The population of interest in this study are newly diagnosed patients with advanced Ocular Squamous Cell neoplasia (OSSN) attending the Kenyatta National Hospital for treatment. Advanced OSSN is defined as tumour invading adjacent structures excluding the orbit (T3) and Tumour invading the orbit with or without further extension (T4) in AJCC(American Joint Committee on Cancer) TNM 8 classification 2016.(34) Advanced OSSN is treated with Surgery (Enucleation or Exenteration) with or without subsequent radiotherapy.

The study population are patients with advanced OSSN interviewed pre-surgery to avoid the participants modifying their answers following receiving treatment for OSSN. The AJCC TNM 8 criteria requires histological diagnosis hence is assigned post-surgery. Hence for this study, an alternative OSSN clinical classification criterion will be employed to facilitate the case definition for the study.

A 2018 study on the clinic demographic profile and treatment outcome in patients with ocular surface neoplasia proposes a clinical criterion that classifies OSSN as small (<5mm basal diameter or <3 limbal clock hours of involvement), large (6-15mm basal diameter or >3-6 limbal clock hours of involvement) and diffuse (>15mm basal diameter or > 6 limbal clock hours of involvement or if there is conjunctival fornix or eyelid involvement).(35)

In this study of 56 patients, this criterion categorized 67% of the patients as either having large or diffuse tumours. 75% of patients with overt orbital disease on imaging (Advanced OSSN) were categorized as large tumours and 67% of patients with overt clinical or radiological intraocular disease (Advanced OSSN) were categorized as diffuse tumours. The proposed criteria thus facilitate the clinical classification of OSSN as either early or advanced disease without a histological evaluation. Another study of 612 eyes on the clinic pathologic correlation of OSSN found similar findings with advanced disease correlating with larger and thicker tumours clinically.(36)

### **3.2.1 Inclusion Criteria**

1. Patients with large tumours. 6mm-15mm basal diameter or >3-6 limbal clock hours of involvement on slit lamp examination (SLE)
2. Patients with diffuse tumours. >15mm basal diameter or > 6 limbal clock hours of involvement on SLE or if there is conjunctival fornix or eyelid involvement.
3. Patients with overt orbital disease based on clinical and/or radiological findings.

### **3.2.2 Exclusion Criteria**

1. Patients below 18 years of age

### **3.3 Sample Size**

The sample size for this study was chosen based on the principle of saturation. This term is taken to indicate that data already collected from the sample and subsequently analysed is sufficient and any more data collection and analysis is not necessary to further shed light on a phenomenon. This concept can be further explored as either theoretical, thematic/sub-thematic saturation or data saturation. (37)

For this study the principle of data saturation was employed whereby saturation is defined as a point of repetition in information gathered during an interview process effectively stopping subsequent recruitment of other participants into the study. Hence any new data collected from a study participant becomes redundant.(38)

A similar study on the reasons behind delayed health seeking among patients with advanced breast cancer in KNH achieved data saturation at 14 participant interviews.(39) Another study on the health seeking behaviour and delayed presentation in patients with oral cancer done in Pakistan achieved data saturation at 6 individual participant interviews.(33)

### **3.4 Data Collection Method and Research Procedures**

This study employed in depth interviews as the technique for data collection. A semi structured interview guide was used by the principal investigator and research assistant to ask questions during the interview. The patient's verbal responses were recorded.

The questions in this interview sought to get a description of the experience from the patient's point of view from first recognizing the eye lesion to getting definitive treatment. They probed on the reasons behind the care decisions taken and the influences on the same. The estimated time for each interview was 45 minutes. An appropriate venue conducive for data collection was identified. In situations where there was need to use local language(s) to ease communication, research assistants were available.

Study participants were recruited during the oculoplastic clinic that runs on Mondays and Tuesdays weekly at the eye clinic in KNH and the Eye ward, ward 1c. Once the patients attending the clinic for the day have done registration, the principal investigator with the help of Clinic 35 clinical personnel will identify possible study participants. The principal investigator will then examine these patients on SLE and examine any radiological scans done so far and evaluate whether they meet the inclusion criteria for the study. Patients admitted in ward 1c for treatment by exenteration will also be evaluated and included in the study pre-operatively.

The patients identified were informed of the study details and their willingness and suitability will be assessed (conversational levels in English or Kiswahili). Written informed consent will then be sought. The interview will then be conducted by the principal investigator and the research assistant at a designated room in clinic 35. This room will accord the necessary privacy and space necessary to conduct the interview without interruptions. After the

interview, a care plan (admission/booking for surgery, radiological investigation) will be instituted by the principal investigator and consultant in the oculoplastic clinic. The data collection period for this study is targeted to be in May 2023.

### **3.5 Data Analysis**

Data collected went through the processes of data translation into the English language and typed using MS Word software. This was done by the research assistant and confirmed by the principal investigator. Data transcription and familiarisation then followed using supplemental notes taken from the interview process.

Data was then be categorized into various themes (recurring ideas and beliefs/notions) generated from the data in line with the study objectives (thematic and content analysis). Where applicable, data was re-categorized and or merged. These data categories (themes) then provide an analytical framework for the data allowing the linkage of recurring themes and sub themes with study objectives and in effect find meaning to the data collected. The data was described in tables, participant journey lines, in verbatim and non-verbatim forms from transcribed data.

### **3.6 Ethical Consideration**

Approval to conduct this study was sought from the Kenyatta National Hospital – University of Nairobi Ethics and Research Committee. Informed consent was sought from the study participants following an explanation of the study purpose/objectives and a demonstrable understanding from the participant has been achieved. Participant confidentiality was achieved through coding of their names in the interview guide.

Confidentiality was strictly observed. All interviews took place in convenient places where privacy and confidentiality of the participants was maintained. All raw data was protected as confidential and availed only to the research team. Emphasis was be made not to collect identifying information (such as names or addresses) of participants even when conducting

voice recording. No individuals will be identified in dissemination of the findings or in any report related to this study.

### **3.8 Limitations and Delimitations**

Information bias was one of the limitations in this study. This describes the participant's only giving information that they perceive the interviewer wants to hear based on their understating of the study objectives. To mitigate this, study participants were encouraged to respond based on their lived experiences. An open, safe, private, and non-judgmental environment was sought to encourage openness in the responses.

The principal investigator may also experience interviewer bias where the knowledge of studies priori themes may affect the framing of questions and the degree of rigor that the interviewer expends at clarifying participant responses. To minimize this, bracketing of prior themes was employed at the interview stage to encourage alternative themes to be questioned further. Piloting of the interview guide was done to ensure that the questions are well understood, and responses are appropriate to the study objectives and any adjustments to the guide was done at this stage.



## **CHAPTER FOUR**

### **STUDY RESULTS**

#### **4.0 Introduction**

This chapter describes the study findings based on qualitative data collected from participants. The participant's demographic characteristics are outlined first followed by the emergent themes and sub themes from the data analysis.

#### **4.1 Demographic Characteristics**

This study interviewed 9 patients at which point data saturation was achieved. The patients were identified as IDI 1- IDI 9 (In-Depth Interview). The sample was comprised of three male and six female patients. The median age was 46 years (IQR 41-60.5) with a range of 38 to 72 years. Eight of the patients were HIV positive and on anti-retroviral therapy (ART). One patient resides in Nairobi, two in semi urban towns and six in rural parts of Kenya. Seven out of nine patients were small scale farmers by occupation and two were retail shop owner operators. One participant had a college education, six had secondary school education and two had a primary school education. A summary of characteristics presented in table 1.

Table 1. Demographic characteristics

<b>Participant Code</b>	<b>Age</b>	<b>Sex</b>	<b>HIV Status</b>	<b>Occupation</b>	<b>Education</b>	<b>Location*</b>
	Median: 46 years (41-60.5) Range: 38-72 years	6 females 3 Males	8 Positive 1 Negative	7 farmers 2 shop owners	College: 1 Secondary:6 Primary:2	Mean: 188km (SD 115)
IDI 1	46	Male	Negative	Farmer	Secondary	Elburgon
IDI 2	43	Female	Positive	Farmer	Secondary	Sagana
IDI 3	67	Female	Positive	Trader	Primary	Isiolo
IDI 4	41	Male	Positive	Farmer	Secondary	Busia
IDI 5	72	Female	Positive	Farmer	Primary	Kitui
IDI 6	38	Female	Positive	Trader	Secondary	Nairobi
IDI 7	49	Female	Positive	Farmer	College	Thika
IDI 8	54	Female	Positive	Framer	Secondary	Bungoma
IDI 9	41	Male	Positive	Farmer	Secondary	Nyeri

*\*Location: represents the usual residence of the participants with KNH being the reference point.*

The mean distance of their location from KNH was 188km (SD115). The furthest patient from KNH was located 360km away.

The locations of the participants are presented in figure 1.

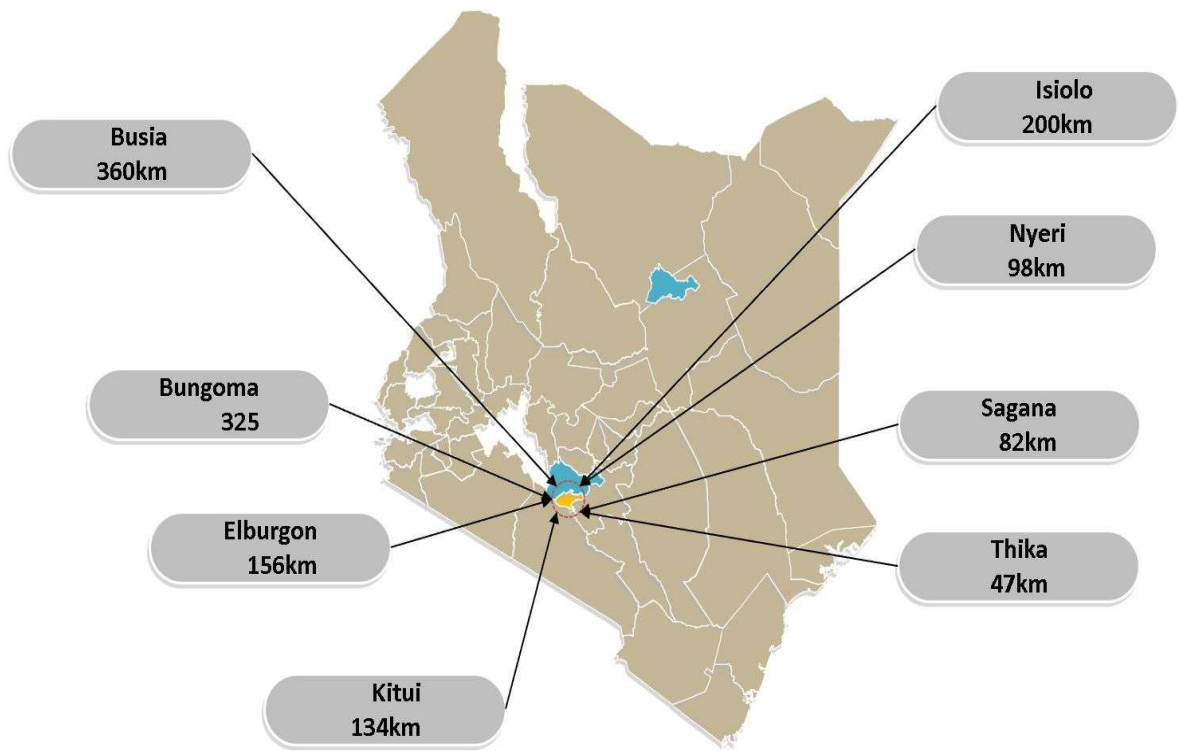


Figure 1: Map profile of the usual residences of the patients.

*Source: Google map. Additional illustration by the author.*

#### 4.2 Patient Journey

The care seeking experience of the nine participants is described in this section. A Journey map for each participant was constructed. They are portrayed in figures 1-9.

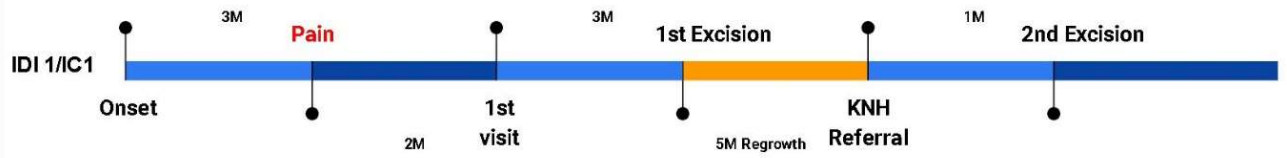


Figure 2.



Figure 3.



Figure 4.

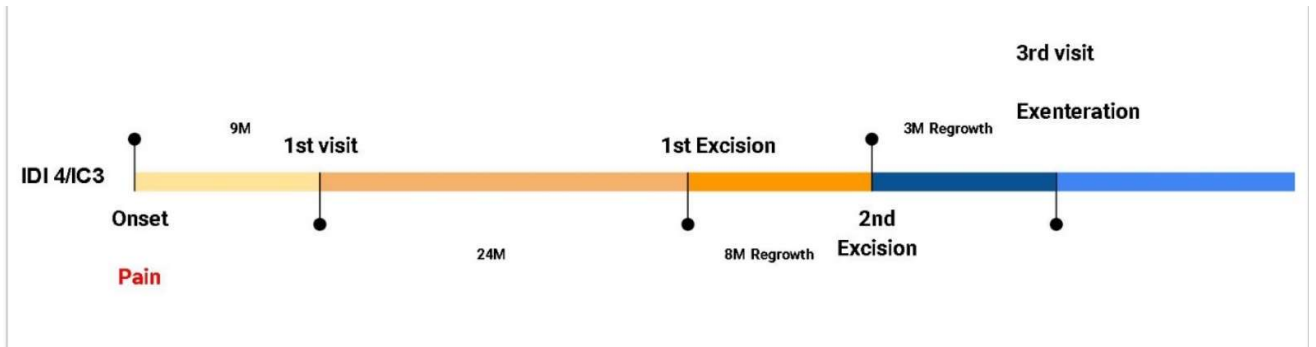


Figure 5.

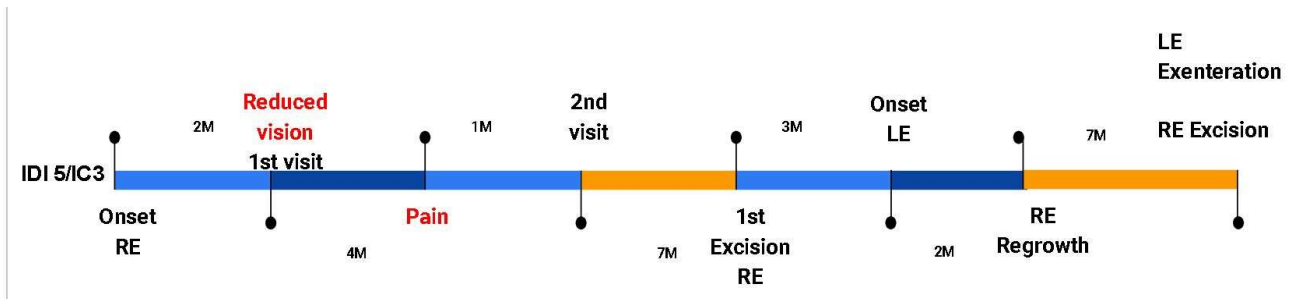


Figure 6.

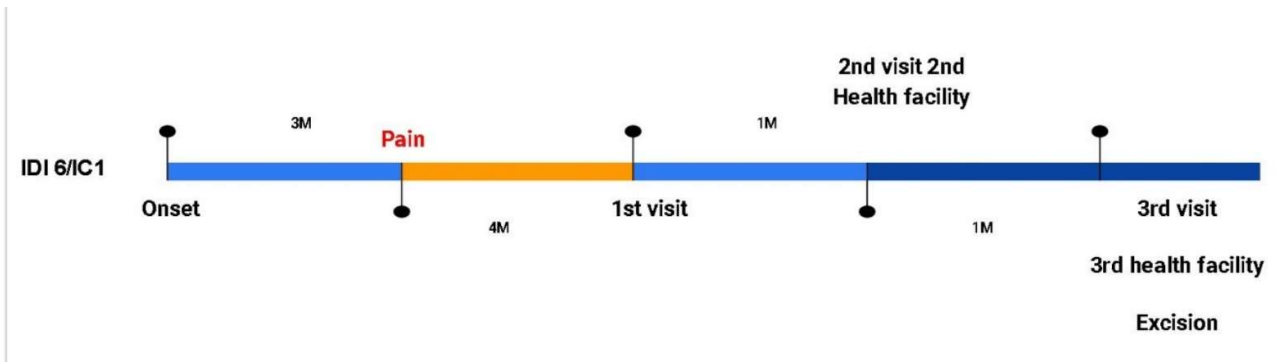


Figure 7.

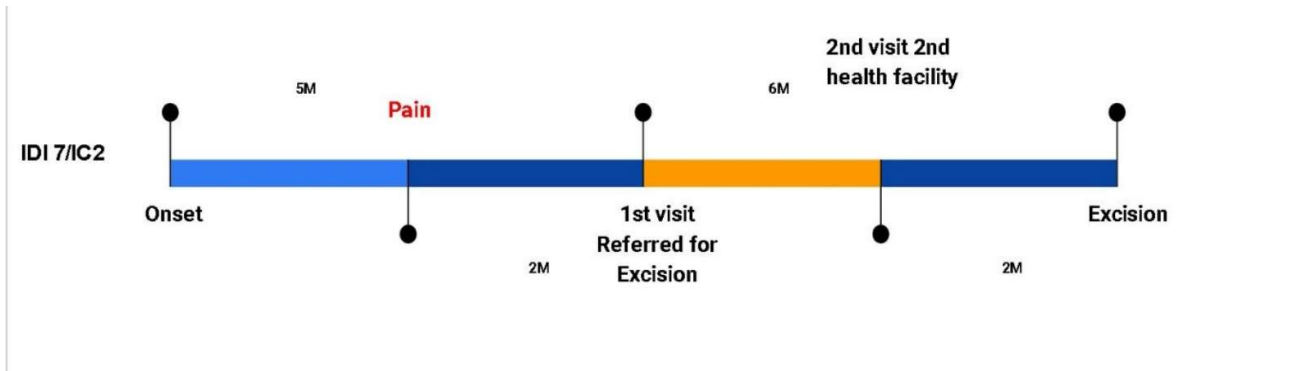


Figure 8.

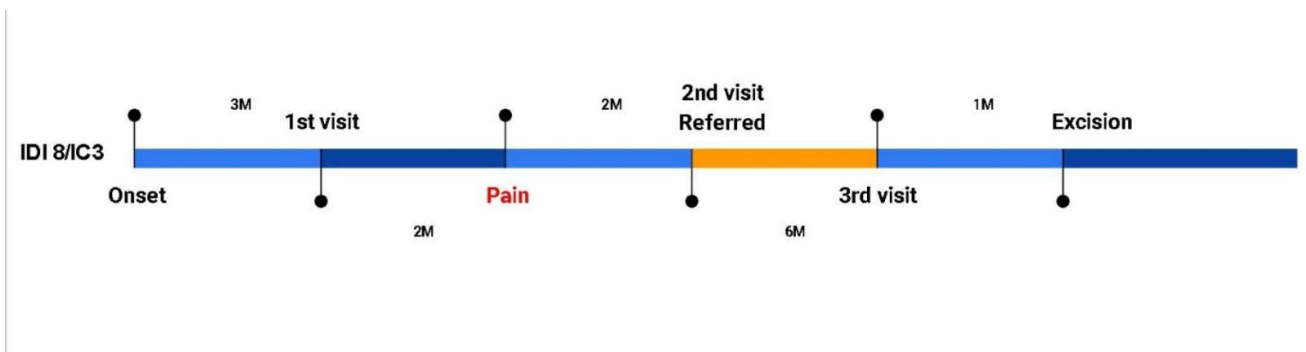


Figure 9.

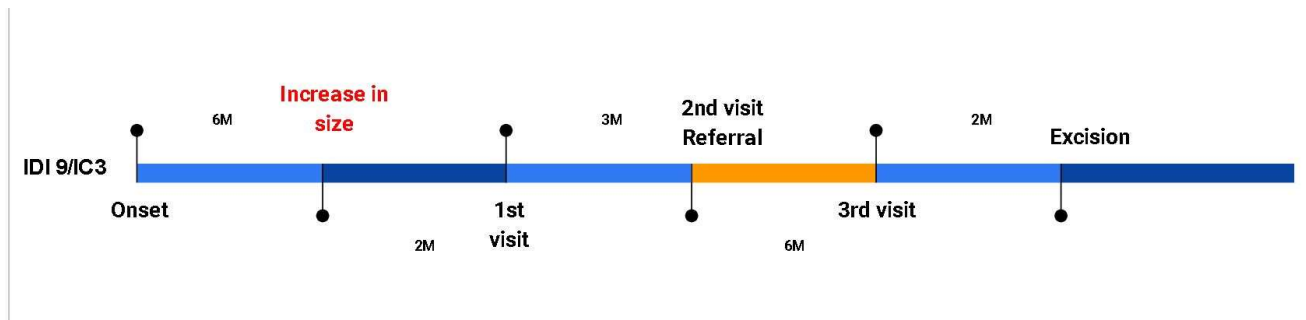


Figure 10.

#### 4.2.1 Symptom Experience

All patients describe a swelling in the eye as their first symptom. For eight patients, the eye swelling was associated with itchiness but had no associated pain. IDI 5 described a reduction of vision among her first symptoms in addition to swelling and itchiness.

*“I was just working inside my storehouse one day, and I couldn’t see the one side of it properly, that has never happened before” (IDI 5)*

*“It was a small thing, sometimes it was itchy” (IDI 7)*

The onset of pain for seven of the nine patients followed the initial symptoms with a mean onset time of 4.3 months (SD 1.10). One patient, IDI 9, did not experience pain at any point from onset of eye swelling to excision.

*“It has never pained me or disturbed me until it grew big and whitish” (IDI 9)*

*“The pain just started slowly, these things you never even notice much, but it was not a good feeling” (IDI 6)*

Only IDI 4 described pain as his first symptom in addition to swelling and itchiness. The pain was on and off with a small associated swelling.

Invariably for all the patients, the use of Over-the-counter eye drops for symptom relief followed the initial symptoms. This provided relief for itchiness. Some patients reported a reduction in the size of the swelling after eye drop use. None of the patients presented to a health facility at onset of their symptoms. For all patients the swelling progressively got larger over months and became easily visible in the eye. Patients got progressively less relief after using OTC eye drops with worsening eye swelling and with onset of pain.

*“I used the one with green on one side, it worked well but sometimes it didn’t. Maramoja also helped when it was very sunny” (IDI 4)*

IDI 6 expressed a concern for her cosmesis. The swelling was eliciting distress as several customers were mentioning the swelling in a day.

*“All the time, were you hit? I was getting worried everyone asking me the same question. You can’t do this business when people are always staring at you” (IDI 6)*

Seven out of the nine patients had other people other than themselves also notice the onset and progress of symptoms in the course of the illness. These were relatives and friends.

None of the patients thought that the lesion could be cancerous at onset of symptoms. Patients got increasingly worried about the possibility of a more serious illness with onset of pain, as the lesion grew and as more people around them noted and commented on the swelling. IDI 5 expressed worry about the lesion at onset due to reduction of vision, but she did not think it could be cancer.

#### **4.2.2 Delay**

All patients experienced delay either in its primary form, before 1<sup>st</sup> visit, or secondarily in-between visits and appointments for treatment. In this study delay is defined as a patient not seeking care for symptoms that are apparent to them and/or to others. The mean delay time from symptom onset to first hospital visit was 7 months (SD 3.6). The secondary delay was variable. The mean delay time after referral past 1<sup>st</sup> health facility was 4 months (SD 2.6) for the six patients who were referred. The earliest presentation was at 2 months from onset and latest was 15 months.

Three patients presented to facilities other than their local hospitals. These participants experienced longer primary delay. One patient travelled > 250km for her first presentation. Two patients visited eye camps for their symptoms. IDI 3 visited an eye camp at her local church after awaiting 6 months.

*“I have eyes of old people, they said when they come again they can remove it, the cataract. But this one is small (referring to the eye swelling), I wanted to see what they will say about it” (IDI 3)*

IDI 6 went to the eye camp after her 1<sup>st</sup> visit for a second opinion and in hope for better service. She had a two-month delay past her scheduled clinic date due to this.



*“I heard on radio that they were coming. The tent is not far, I could walk there. They are fast not like government” (IDI 6)*

The other participants went to their nearest health facility at first presentation.

Two HIV positive patients experienced delay due to other comorbid conditions that necessitated treatment in the form of hospital admission. IDI 2 experienced a 15-month delay to her first visit.

*“I was very sick; I forgot the days sometimes. I was there for a long time. My weight (body weight) had gone I couldn’t believe it” “My knees used to be very cold, and my chest had pain” (IDI 2)*

IDI5 experienced a 7-month secondary delay in attending her subsequent clinic appointment. She was admitted in hospital on treatment for hepatitis.

*“My stomach was painful, and I was vomiting a lot. I couldn’t go to Machakos like that” “I stayed there (hospital) for almost 5 months then I could eat well again” (IDI 5)*

All the HIV positive patients expressed a fatalistic view of life at diagnosis of HIV. Two of these patients persisted in this view of life up to the time of interview at KNH. IDI 4 experienced primary delay in presentation of 9 months despite having pain as one of his initial symptoms.

*“This thing (HIV) doesn’t get better” (IDI 4)*

IDI 6 perceived herself unlikely to survive. She noted an increase in the swelling in her eye and new onset pain, but this did not elicit any impetus to seek care. She had a four-month secondary delay after pain onset.

*“I am going (in reference to dying) doctor, I know that. But better to know what it is, that’s what I think anyway” “Either way, I can’t do anything about it” (IDI 6)*

All the participants expressed distress that they lose more money when out of their farms and shops compared to what they spent on treatment at the initial presentation. IDI 1 describes

that clinic ‘take too long’ and sometimes you are not seen at clinic. He delayed his 1<sup>st</sup> excision by three months to allow the harvesting season to be end.

*“How can someone stay there (in hospital) the whole day and you can’t leave! You don’t even eat; you doctors are very funny...laughs...” (IDI 1)*

*“I pay 100 kshs there (at first health facility), that is ok, they came to help us (referring to county governments) but other days you don’t get seen” “when I don’t take my maize to them I lose a lot of money, a whole truck, and the school holiday was over, so I went back after I came from the border (referring to Kenyan border point where he delivers his farmed maize)” (IDI 1)*

IDI 3 reports she closes her shop every time she goes to hospital as she can’t leave it to anybody. She never considered going to hospital over the holiday season due to loss of business as there are many travellers.

*“You can’t trust people nowadays, I usually close my shop when going to town” “my children are far in Nairobi, they can’t help me there” (ID 3)*

*“I spend 700ksh at the hospital in town and lose 10,000 kshs on a good day when there are a lot of buses (public transport buses stopping near her shop)” (IDI 3)*

Three study participants sought alternative treatment in the form of religious prayers and traditional medicine. IDI 2 and IDI 6 who sought religious prayer sessions, mentioned that due to their ill health they sought to be closer to God. She had a 4-month long delay secondary to onset of pain.

*“When I knew, a lot was going on in my mind. Now my health was running out. My friend told me about going for prayers to get better, I went once with her and returned another time” (IDI 6)*

IDI 4 sought traditional means of healing. He had an 8-month secondary delay after 1<sup>st</sup> excision and regrowth. He stopped seeking care at health institutions in the duration of this endeavour.

*“In reserve (rural area) there are things you can do” (IDI 4)*

Three expressed regrets on what they feel was wasted funds. None of the three participants was willing to divulge the costs involved or the total number of visits sought.

The presenting symptoms and delay are summarized in Table 2.

**Table 2. Presenting Symptoms and Delay**

<b>Symptom At Onset Of OSSN</b>	<b>Eye swelling:</b> All nine patients <b>Pain:</b> 1 patient <b>Itchiness:</b> All nine patients <b>Mean duration to onset of pain:</b> 4.3 months (SD 1.10) <b>Mean duration from onset of pain to 1<sup>st</sup> health facility:</b> 3 months (SD 2.8)
<b>Delay</b>	<b>Mean Delay:</b> 7 months (SD 3.6) <b>Mean Delay past 1<sup>st</sup> health Facility:</b> 4 months (SD 2.6) <b>Shortest Delay:</b> 2 months <b>Longest Delay:</b> 15 months

### **4.3 Possible Causes of Delay**

The factors that contribute and interplay to prompt the decision to seek and continue to seek care for patients in this study are presented based on the five emergent themes and nine sub-themes from the thematic analysis of the transcribed data.

#### **4.3.1 Triggers to Health Seeking**

##### **4.3.1.1 Pain and Reduced Vision**

The onset of pain acted as trigger to visit a healthcare facility. Eight patients experienced pain at some point from onset of the disease. Six patients who developed pain after initial swelling presented to hospital on average 3 months (SD2.8) after onset of pain.

*“When it started to ache, I got worried because it was getting worse now” (IDI 1)*

*“I always thought it was nothing, but when the pain started. I bought drops and they weren’t working” (IDI 3)*

*“Two months after the pain was long enough, at some point you get tired and want to know what is wrong with your body, my eye had a problem. I finally I asked my brother to take me, and we went to the hospital” (IDI 7)*

IDI 2 says she could not remember the exact time of onset of pain. She says she noted increasing swelling and increasing pain, but she was too sick and admitted to hospital at the time. Nonetheless the onset of pain during her admission signified to her that the swelling might be more serious than she had previously thought.

IDI 4 had swelling with associated pain from onset of symptoms yet presented nine months later for the first time. He had significantly longer delay times compared to other patients who experienced pain.

*“I used the one with green on one side, it worked well but sometimes it didn’t. Maramoja also helped when it was very sunny. The pain was always there when I noted something was growing” (IDI 4)*

IDI 9 did not experience pain but rather noted progressive increase in swelling that caused concern to him leading to a hospital visit.

*“It has never disturbed me until it grew big and whitish” (IDI 9)*

IDI 5 experienced a reduction in vision in addition to eye swelling at onset of symptoms and sought care at a health facility within two months, the shortest primary delay time. Pain followed 4 months later and prompted a second visit within 1 month of onset.

*“I don’t see well in that eye and now it is painful, I had to go back to hospital, I called my daughter” (IDI 5)*

None of the other patients had reduced vision at onset or in early disease.

#### 4.3.1.2 Perceived Severity

None of the patients had any perceptions of unfavourable outcomes because of their eye lesions. IDI 3 and IDI 6 attributed their symptoms to probable allergic reactions due to their area of residence being dusty.

*“These dry areas are very dusty; my eyes are always feeling sandy inside and itchy. I am used to it. I just splash water” (IDI 3)*

*“Allergies are many in my family, you see my skin. (Shows lower legs with darkened marks) plus where I work there are many trucks with smoke, I am used to it” (IDI 6)*

Four participants thought that it was not unusual to see small pimples on the body.

*“It was just like a pimple, I have them once in a while, but they go away, you don’t go to hospital for a pimple that is scratchy” (IDI 7)*

*“It was just a small growth doctor. Even you wouldn’t be worried” (IDI 1)*

*“It worried me when it turned whitish, you could see it from far. I wasn’t worried before” (IDI 9)*

Two patients simply put eye drops for the symptoms and did not give them serious thought.

Three patients portrayed a perception that eye services are specialized and therefore all their eye complaints can be diagnosed and treated better in an eye hospital. IDI 9 chose to go to a level 6 health facility sidestepping a level 5 hospital in his vicinity. He mentions he has accessed surgical services there before for a wound.

*“I came to Nairobi because you know the eye is sensitive. I got treated there for a machete wound and it healed well. But I don’t think they can treat my eye properly” (IDI 9)*

He was not sure what kind of eye services are available at his local hospital, but he would rather not risk it.

IDI 3 delayed seeking care primarily to wait for a yearly eye camp at her local church. She waited 6 months despite having a health facility within 20 minutes from her. She regularly accesses the same health facility for other general medical services.

*“I have old people eyes, they said when they come again they can remove it, the cataract. But this one is small (referring to the eye swelling), I wanted to see what they will say about it” (IDI 3)*

IDI 8 presented to an eye unit at first presentation which was 250km away from her residence despite having multiple other level 4 and 5 hospitals closer home.

*“I finally decided to go to hospital, I was still unsure that it will help but I came to town because my brother was there and it’s a big hospital, I was going to get better doctors there” (IDI 8)*

Seven participants had increased anxiety and worry of a more serious problem when more people in their environment commented on the lesions. For these patients, symptom anxiety invariably sparked the decision to seek care. In IDI 3 with a 6-month previous delay, she had her first visit and excision of the lesion within month after her daughter came home over the holidays and noted the mass.

*“When my daughter came, she was worried and was on the phone a long time, she took me to hospital the next week and now we are here” (IDI 3)*

IDI 4 mentions it was pressure from his wife and brother that made him go to hospital for a diagnosis.

*“She got my brother to agree with her, and they complained a lot and they thought it was a bad disease. We went to hospital after we had that argument” (IDI 4)*

## **4.3.2 Cost**

### **4.3.2.1 Actual Cost**

Actual cost of care is defined as the cost of consultation, diagnostic testing, medication, and procedures that are expended in the process of seeking care for an ailment. All patients said that health services closer home was more affordable. Seven of the participants had NHIF

covers and two were paying out of pocket. IDI 1 describes the cost of his initial consultation to be cheap at Kenya shillings 100.

IDI 7 mentions she paid Kenya shillings 500 as consultation and said she was not worried if the cost for excision was as high as Kenya shillings.

*“Even if they asked for 5000 kshs I was going to pay, that amount I could get” (IDI 7)*

IDI 8 and IDI 9 sought care for their lesions in larger more high-level hospitals that were further away. They delayed their travel to these hospitals as they were further away and would cost them more to get there.

*“When you go to Nairobi, you have to be prepared with money” (IDI 9)*

*“I finally decided to go to hospital, I was still unsure that it will help but came to town because my brother was there and it’s a big hospital, I was going to get better doctors there” “I looked for the money for a while, he added some for me and we went” (IDI 8)*

The cost burden of follow-up with subsequent visits following excision of eye lesions lead to a steady increase in anxiety on the ability to afford care and ultimately led the inability to pay for health services required. This was especially true of repeat excisions.

*“Now this is taking a lot of my money and time, if it was removed once for all I would have been happier” (IDI 1)*

IDI 5, and IDI 4, who needed exenteration and subsequent radiotherapy for their disease also suffered significant anxiety about the high bills they had to pay.

*“I have been in hospital for a long time, and now again I have been here for a month. Where will the money come from? My son is trying to find some before I am better” (IDI 5)*

*“Now my pockets are empty, I had to raise some money from friends to come and do the CT scan the time round, NHIF paid for the other two but refused this one” (IDI 4)*

IDI 4 reports that his NHIF cover ran out during treatment and had organized fundraisers to cater for his hospital bills.

#### **4.3.2.2 Perceived Cost**

Following referral past the first health facility, the perceived cost of care caused worry about the increased cost involved. The hospitals they were referred to were out of the towns they lived in. IDI 1 was referred to Nairobi for his second excision. He expressed worry that Nairobi is an expensive place, and he would need more money.

*“It costs a lot more in Nairobi, but I don’t have a choice, its growing again and they don’t want to remove it again” “I had to go and look for money” (IDI 1)*

IDI 6 was seen at a local facility in Nairobi and sent to a specialty eye hospital but chose to go to a different eye hospital as she thought that they would be cheaper.

*“I thought of going there but they are expensive, it’s better to look for cheaper options first” (IDI 6)*

IDI 3 waited for a yearly eye camp for 6 months. She wanted to wait partly because she does not pay any money there. None of these patients report knowing the actual cost they would pay at these facilities.

#### **4.3.2.3 Opportunity Cost**

Five patients described the actual cost paid at the hospital for their first visit was less than the cost of lost income from not being at their places of work. IDI 3 had to close her shop when she went to hospital and wouldn’t consider it unless she got sick.

*“I am always open, otherwise you lose money and lose your business, I don’t close unless I am very sick. I don’t have anyone to run it for me” (IDI 3)*

IDI 7 who runs a shop in her local town waited till after the school reopening period to go to hospital so that she doesn’t lose money from sales.



*“When schools open you must be open, otherwise you lose ‘back to school’ sales. I couldn’t go until the children went to school and business was low” (IDI 7)*

IDI 1 lost an opportunity to transport his produce to a ready buyer in a different town. He subsequently went to hospital only when the harvest season was over. The schools were also opening, and he did not have fees.

*“When I don’t take my maize to them I lose a lot of money, a whole truck, and the school holiday was over, so I went back after I came from the border (referring to Kenyan border point where he delivers his farmed maize)” (IDI 1)*

*“A trip with a full truck is 30,000 kshs that is good money, I couldn’t lose it again, I went after harvest season” (IDI 1)*

### **4.3.3 Fatalism and Beliefs**

#### **4.3.3.1 Fatalism**

All the HIV positive patients expressed fatalistic view of life at the time of suspected and confirmed diagnosis of HIV. For these patients, the diagnosis of OASN was made after the HIV diagnosis.

*“This thing (HIV) doesn’t get better” (IDI 4)*

*“I am going (in reference to dying), I know that. But better to know what it is, that is what I think anyway” “Either way, I can’t do anything about it” (IDI 6)*

*“I am not leaving this place (referring to not getting better and going home” (IDI 2)*

IDI 2 mentions that she was very sick and had no hopes of leaving the hospital alive. She had lost her farming business and her family had abandoned her and her children. When the swelling got bigger while in hospital, she didn’t really concern for it. IDI 8 says she was very depressed and didn’t want to start her ARV as the disease will not be cured anyway.

*“I couldn’t do anything for a long time, my life was over, and I would never be better however much I tried. I heard those drugs wouldn’t help me much” (IDI 8)*

Seven patients report that this view dramatically changed and improved over several counselling sessions with family members and at CCC counselling sessions. The fatalistic attitude reignited with the possibility of a cancerous lesion in the eye became apparent to them. IDI 3 believed she was unlikely to get better with the new diagnosis of cancer in the eye.

*“Now I have two bad diseases and I am old; the future doesn’t look ok but that is life” (IDI 3)*

IDI 2 and 4 persisted in this fatalistic view at the time of the interview.

#### **4.3.3.2 Cultural and Religious Belief**

Three patients sought alternative treatment in the form of religious prayers and traditional medicine. IDI 2 and IDI 6 who sought religious prayer sessions, mentioned that due to their ill health they sought to be closer to God.

*“When I knew, a lot was going on in my family. Now my health was diminishing. My friend told me about going for prayers to get better, I went once with her and returned another time” (IDI 6)*

*“When you get very sick, you have to seek God” (IDI 2)*

IDI 4 sought traditional means of healing. He had every expectation of healing due to previous experience and stopped seeking care at the hospital in the duration of this endeavour.

*“In reserve (rural area) there are things you can do” (IDI 4)*

The three patients report spending money seeking this alternative forms of care. IDI 2 sold livestock from her farm. They were not open to having more discussion about actual costs and number of visits they had.

#### 4.3.4 HIV

##### 4.3.4.1 Comorbid Conditions

IDI 5 and IDI 2 who were HIV positive were admitted for care for hepatitis and pulmonary tuberculosis respectively during the progression of their eye swelling and onset of pain. IDI 5 experienced secondary delay in attending her subsequent clinic appointment due to admission in hospital. She was on treatment for hepatitis.

*“My stomach was painful, and I was vomiting a lot. I couldn’t go to Machakos like that” “I stayed there (hospital) for almost 5 months then I could eat well again” (IDI 5)*

*“The swelling wasn’t disturbing me, I had bigger problem with my stomach” (IDI 5)*

IDI 2 had never presented to a health facility primarily for her eye swelling. She reports that she was sick in hospital at the time her swelling started to get painful. She was admitted on and off for nine months.

*“I was very sick; I forgot the days sometimes. My weight (body weight) had gone I couldn’t believe it” “My knees used to be very cold, and my chest had pain” (IDI 2)*

She was discharged and referred to KNH directly. She had her first eye examination at 15 Months from onset of eye swelling. At the time of interview, she had a fungating mass in her eye and facial swelling.

##### 4.3.4.2 Comprehensive Care Centres

All HIV positive patients were on ART and attending regular clinic visits for drug refills and yearly viral loads. These patients describe regular attendance at their CCC during the onset and progression of their symptoms. None of these patients had a healthcare practitioner notice or examine the eye lesion in any of their visits.

*“When you go to CCC it’s a quick affair unless you are having blood taken, there isn’t much talking, that’s why I like it” (IDI 6)*

*“They (CCC) told me I had a liver problem, they never told me about my eye” (IDI 5)*

None of the patients mention presenting their eye complaints to the CCC clinicians. All HIV positive patients report experiencing stigma due to their HIV diagnosis. Three participants report to have disclosed their status to family. The other six had a feeling that it was known to close family members but was never discussed explicitly.

*“Only my daughter knows because she is a nurse”. (IDI 3)*

*“Nobody knows me there, so it’s better to go there than here... .. And it’s not far from here (Nairobi)” (IDI 6)*

*“At CCC you don’t feel anxious, nobody asks you your status, it is assumed” (IDI 6)*

*“I can’t even imagine if my workmates knew” Coming to CCC in kerugoya (30km from where she lives) helps a lot, I am not worried here” (IDI 5)*

She also reports having awkward conversations when she discloses her status at other healthcare facilities.

*“When you go to some facilities they look at you oddly sometimes, so when it’s just a flu I don’t say” (IDI 6)*

*“Some illnesses are embarrassing, and I am old. I only go to CCC when I am sick or buy from the chemist” (IDI 3)*

None of the participants report experiencing stigma due to the cancer diagnosis at onset of symptoms.

*“Nobody can guess what it is...the eye swelling isn’t a problem” (IDI 9)*

## CHAPTER FIVE

### DISCUSSION, CONCLUSION AND RECOMMENDATIONS

#### 5.0 Introduction

This chapter discusses the results and emergent themes from the study. It examines similar studies, similarities and differences compared with postulated factors that influence health behaviour from accepted and adopted theories of health seeking and utilisation.

#### 5.1 Demographic Characteristics

The median age for this study was 46 years (IQR 41-60.5) with five patients in their 40s, one at 38 and two above 50 years old. Two participants in our study describe their age as a factor contributing to delay. They felt they did not have personal agency to initiate care seeking and navigate the health system without the help of their family members. Personal agency is defined as an individual's belief and ability to make decisions towards their own wellbeing. The elderly population is largely dependent on family members for healthcare cost payments. Amendah *et al* in Ghana found that 87 percent of family members report to be supporting their elderly in meeting healthcare costs contributing to significant financial stress (43) This financial dependency could explain this reduced agency in making a decision to seek care.

There were more female than male patients 66 percent vs 33 percent. This was similar with findings from Nguena, Gichuhi, and Ogun *et al*. Female patients did not present with more advanced disease than males in our study. They also did not experience more primary or secondary delay than the male patients.

Eight out of the nine patients were HIV positive. HIV status and related comorbidities contributed to both primary and secondary delay. Two patients with the most advanced disease in this study were HIV positive. Siyumbwa *et al* similarly found that HIV positive patients have more invasive disease than those who are seronegative for HIV.

Visiting more than one health facility for treatment led to more delay. All the patients referred to higher level health facilities for specialized care had to leave their towns of residence. This finding was similar to Gichuhi *et al* who found that indirect presenters (Those referred past first health facility) had a delay of 4 months to surgical excision over the directly presenting patients.

The nine patients came from varied locations in Kenya. This represents the position of KNH as a referral facility catering to the whole Kenyan demographic. The patient with the longest delay, 15 months, resided 100km from Nairobi. The one who resided the furthest, 400km, had 9 months delay to first presentation. Both patients had other factors influencing health seeking. Distance to health facility hence does not seem to influence delay directly but may do so through an interplay of other factors such as cost of care.

The study patients were mainly small-scale subsistence farmers living in rural locations of Kenya. Two were shop owners in an urban and Semi-Urban area. This finding was similar to Ateenyi *et al* in Uganda who found more OSSN within farmers especially those cultivating in the open sun for more than 20 hours a day (15) Gichuhi *et al* in Kenya found similar findings where OSSN patients were mostly farmers(12)

Two patients had a primary school education, six had a secondary school education while one had a college education. All participants report having no suspicion of cancer at onset of symptoms. Their level of education did not seem to influence either delay or trigger to health seeking. This is similar to Gichuhi *et al* that found that level education is not a barrier to early presentation of OSSN (12).

## **5.2 Patient Journey**

### **5.2.1 Symptom Experience**

All patients describe an eye swelling as the initial symptom. It was associated with on and off itchiness. Eight participants had no associated pain at onset. One participant had pain and swelling as the initial symptoms. These findings are similar to Gichuhi *et al* who found that eye swelling and pain amongst others are the more commonly experienced symptoms of OSSN (2). Pain signified an increase in perceived severity of the swelling for all patients.

All patients used over the counter eye drops to treat their symptoms before seeking definitive care. Hameed *et al* in Pakistan invariably found the use of OTC drugs for painless chronic mouth ulcers leading to delay in presentation of oral mucosal carcinoma (44) Five patients describe their symptoms at onset as common place and of little concern. One patient had a history of allergic conjunctivitis and frequently had irritative eye symptoms. She also lives in

a dusty environment and attributed her swelling and irritation to an increase in her allergic symptoms. Another mentions that having a small pimple in the eye is of no concern to her as she has pimples on her body from time to time and she doesn't think much of them either. They come and go spontaneously. One patient experienced a reduction in her vision as one of her initial complaints. This finding was similar to Julius et al in Zambia who found that over 76% of patients with OSSN had vision better 6/12 in the affected eye. Vision reduction is not a common presenting symptom of OSSN.

At the onset, the presence of swelling or irritative symptoms did not elicit any worrisome feelings to any of the patients. This lack of awareness on cancer and cancer related symptoms has been associated with advanced stage of cancer at diagnosis, Kamaranju et al USA (13). One woman describes anxiety towards her cosmesis at onset of symptoms. This apprehension did prompt her to seek care although she had overlapping pain and swelling at the time. For all the patients, the steady increase of the eye swelling, the reducing response and relief from use of OTC and the presence of pain elicited worry towards the seriousness of their symptoms.

### **5.2.2 Delay**

The delay time measured in this study is defined as the time from onset of symptoms to definitive treatment. This can be primary, from symptom onset to first health visit, or secondary which is the time in between clinic visits. When delay in health seeking is measured as an undifferentiated total time value, it may confound the multivariate factors that may influence it. The definition of primary and secondary delay helps to ascribe factors that would affect one and not the other. Primary delay may also be further divided into appraisal delay and illness delay. Appraisal delay is the time between one noting a symptom to when it is recognised it as a sign of illness. Illness delay is the time it takes patients who know they are ill to seek care at a health facility (45).

The delay time varied from 2 months to 15 months. Gichuhi et al found the average time from awareness of symptoms to excision of lesion to be between 5 to 9 months for the direct and indirect group respectively(2). This difference is most likely because of recruitment of patients with advanced disease for this study. Hameed et al describes the interval of primary delay among patients presenting with advanced breast cancer in Pakistan to be between 31-128 months (44).

Delay following referral past first health facility was noted for three of the six patients referred. Hameed et al found similar findings with referral past a local health facility to a larger hospital contributing to delay due to increased costs involved (44) They noted that a lack of awareness of where to go for care contributed to this delay. Delay due to referral to another facility was perceived to be and was more expensive leading to more delay in the subsequent visits. This was to arrange for finances to cater for the costs involved but also more significantly to arrange for smooth transitioning of their home and occupational responsibilities since further distance meant being away from their place of work or home for more than one day.

### **5.3 Possible Causes of Delay**

Thematic analysis of the study findings generated four main themes and nine constituent sub-themes contributing to delay among OSSN patients. The thematic map is presented in figure 11. Each of these themes is discussed in the sections to follow.



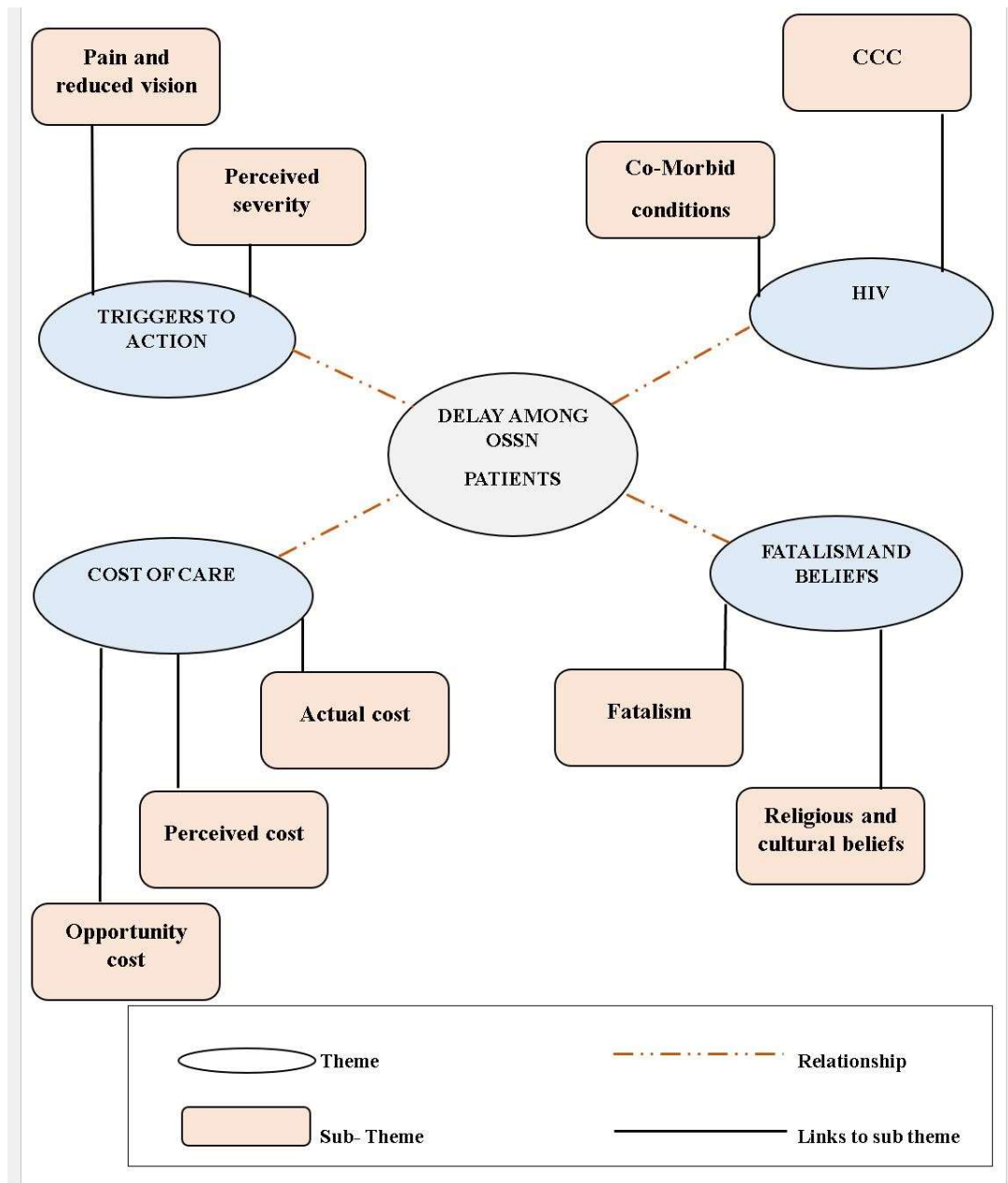


Figure 11: Schematic construction of the thematic analysis contributing to delay among OSSN patients seen at KNH.

Source: Author, 2023.

### **5.3.1 Triggers to Health Seeking**

#### **5.3.1.1 Pain and Reduced Vision**

The average onset of pain in our study was 4.3 months (SD 1.10). The presence of pain prompted a visit to the health facility within 3 months of onset for eight of the nine participants. This underscores the significance of pain in the health seeking journey of patients irrespective of aetiology. Pain at onset of any illness shortens the appraisal delay, safer et al (45). Pain was a common presenting symptom for direct vs indirect presenters in the Gichuhi *et al* (2). These group of patients had definitive surgical excision earlier than the later. A similar study on the factors influencing delay in women with advanced breast cancer in KNH found similar findings. The mean age to presentation to a health facility after onset of pain was 2 months, Anyira *et al*, (39). Hameed et al found pain to significantly reduce quality of life and triggered a health visit within 2 months of onset, (44). One patient in our study had pain at onset of symptoms and yet did not seek treatment until 9 months later. This patient was HIV positive and had other strong influences on his decisions that will be tackled under the theme of fatalism and belief. Vision reduction was present in association with swelling and irritation for one patient. She was the earliest to present among the nine patients with a primary delay time of two months. This finding was similar to Bidwell et al that found that vision reduction or the fear of it prompts hospital visits for those with awareness of causes of blindness, UK (46).

#### **5.3.1.2 Perceived Severity**

This is defined as the negative consequences that an individual associates with an event e.g., onset of eye swelling and with the actual diagnosis of a condition once evaluated e.g., OSSN, (47). This concept is a component of the Health Belief Model (HBM) by Hochbaum 1958 and was developed to understand the uptake of prevention and early detection behaviours, such as early presentation and attendance to clinic. The HBM proposes that perceived severity of a symptom or illness forms a ‘threat response’ that motivates action to seek treatment. The model also posits that the particular action taken by a patient is determined by beliefs about the options available to counter the threat. A particular behaviour will only be adopted if its perceived benefits (i.e., potential to reduce the disease threat) outweigh its perceived barriers such as cost of care and health system factors like accessibility to care.

For all patients in this study, their initial symptoms did not elicit any worrisome thoughts as to the potentially serious diagnosis of cancer. Hameed et al found that having no awareness that

a chronic painless mouth ulcer could be cancerous increased primary delay. Shamana et al also found that lack of awareness of cancerous lesions and their symptoms contributed significantly to delay, (48). The presence of pain therefore shortens appraisal delay as it heightens perceived severity of the illness.

Increased apprehension due to more people noticing an easily visible mass in the eye also increased perceptions towards the possible seriousness of their condition and partly contributed to action in the form of a hospital visit. Immediate family members and friends were the people who mostly noted these eye swellings, 77 percent and expressed worry. It brings to focus the value of social support and its role in promoting health seeking for early diagnosis and treatment. Lack of social support is associated with more morbidity and mortality in cancer patients, Awolu *et al*, (49) .

Three of the nine participants chose to seek care specifically in facilities other than those in their immediate access due to the perception that the eye symptoms they were having were worrisome enough to require eye specialist care. One participant had a six-month primary delay awaiting an eye camp in her area to present her eye symptoms despite going to her nearby hospital for all of her other healthcare needs. The second patient presented to an eye hospital in Nairobi 250km away from her usual abode to present her symptoms the first time. The third participant self-referred to KNH for excision after advice for surgical excision was made at her first health facility although he was booked for excision within a month at the facility. He preferred KNH due to the perception that he will get proper eye doctors there.

Hameed *et al* study describes patients choosing to go further away for care to obtain better service and seek second opinions often leading to higher costs and delay in definitive management, (44) . This 'eye illness for eye hospital' belief can delay care as choosing to go further delays the action to present early. It takes more planning and costs more versus going to a local hospital. Gichuhi et al found that direct presenters travelled further for their care and ended up getting surgery earlier,(2). Direct presentation to a tertiary hospital can have its benefits in some patients, especially with inefficiency and poor services in the locally available hospitals.

### **5.3.2 Cost of Care**

#### **5.3.2.1 Actual Cost**

Actual initial cost of first visit was not an impediment to accessing care in this study. Seven out of nine participants had an NHIF cover and describe it as covering the cost of most of their regular medical care needs. Hameed *et al*, (44) found similar findings with access to primary care facilities and the costs involved therein not a barrier to early presentation of cancer patients. For the two who didn't have NHIF cover and were paying out of pocket, the out-of-pocket cost at their local health facility were affordable to them and it didn't contribute to delay to first visit. All participants describe an increase in costs involved with care after referral past 1<sup>st</sup> health facility. Gichuhi *et al*,(2) also found similar finding especially for referrals out of a patients area of usual residence. The actual cost of care also increased once the need for repeated surgery and other diagnostic tests increased. This led to extinguishing of NHIF cover limits for 3 patients with resultant fundraisers to help in paying for their care. This contributed to delay of subsequent visits and treatment as these funds were organized. Hameed *et al*, (44) showed that for its 14 participants, at the time of diagnosis and definitive treatment for advanced cancer, all health insurance covers were expended and some patients relied on fundraising for payment.

#### **5.3.2.2 Perceived Cost**

Referral for specialized and repeated services elicited anxiety in all patients on the expected increase in the cost of care. For some participants this led to delay and a return to using OTC for a period as next steps were thought out. This perception was driven by previous experience seeking care for other ailments and experience from others. The nature of the healthcare journey in Kenya is characterised by patients accompanied by chaperones as they seek care further away from home, Gichuhi *et al*, (2). This especially true for the elderly patients or for patients from rural areas as they seek care in major towns and cities increasing the perceived cost of travel, cost of boarding for overnight stays. Hameed *et al*, Pakistan, describe patients as having a fear of the burden of cost that wasn't really founded in factual cost of care, (44) leading to increase secondary delay.

### **5.3.2.3 Opportunity Cost**

Seven out of the nine participants were subsistence farmers with themselves and their families being their primary source of labour. Two participants manned their own retail shops as sole proprietors. This is similar to Gichuhi et al that found that most OSSN patients were farmers, (2). For all the participants, the cost of initial care was far less than cost of lost income due to being away from their areas of work. This was true in the early and advanced stages of the disease contributing to total delay, both primary and secondary. It was much easier and more economical to use OTC for the irritative symptoms when symptom appraisal was low. One participant, a truck driver describes having lost the opportunity to transport merchandise due to him having to travel for a second excisional biopsy in another town. He would have rather waited for a month as he didn't have school fees for his children. This underlines the challenge that despite the awareness of the eye lesion, the suspicion of it being a serious disease, and even the presence of a clear diagnosis and path to seek care, a patient can decide to delay care due to losses to be incurred in their occupations in the process of seeking care.

### **5.3.3 Fatalism and Patient Beliefs**

#### **5.3.3.1 Fatalism**

Fatalism is the belief that all events are predetermined and therefore inevitable. It leads to a submissive attitude to events resulting from a fatalistic attitude. Fatalism can breed indifference to the result of a disease process, (27).

All HIV positive participants describe a fatalistic attitude to the outcome of their HIV diagnosis. They describe the news to be earth shattering and changed their prospects for life. This attitude was tackled at their regular counselling sessions at CCC and steadily reduced when their understanding of their condition increased. For all the HIV positive patients, the HIV preceded the onset of symptoms. The point of awareness and illness appraisal of a possible cancerous lesion in their eye, revamped this view for all patients and caused emotional distress. For two patients a fatalistic attitude was present at the time of interview. One patient had pain among the symptoms that he experienced at onset of symptoms. He nonetheless presented 9 months later for his first visit. This is despite the presence of pain being a recognised factor in reducing primary delay irrespective of aetiology.

The second patient was evaluated and diagnosed with advanced OSSN 15 months since onset of her symptoms. She didn't have pain at onset and had a swelling that grew over a period of one year. She is HIV positive and suffered other comorbidities requiring long admission and expending a lot of her financial resources. She subsequently lost her farming business and the means to earn a living and provide for her children. She also suffered abandonment with lack of social support. She expressed a perverse fatalistic attitude and in the presence of a growing mass in her eye, wasn't interested in what it is because she will not survive her condition anyway. Fatalism can shadow normal triggers for health seeking. Although it steadily reduces with counselling, for those that it persists, it can act as a major impediment to better outcomes of cancer treatment.

### **5.3.3.2 Cultural and Religious Belief**

According to the HBM model, a patients' beliefs affect health seeking behaviour by affecting the choice of available options after illness appraisal. Two participants sought religious prayers from spiritual leaders during their health seeking journey. During this period, they continued to seek care and followed up with appointments. They did not seek prayers for the purposes of healing but rather due to the perception that they were not in good health and sought to be closer to their faith.

Traditional healing was sought by one participant during treatment and lead to an 8-month long secondary delay. This participant also held a fatalistic attitude at the time of the interview. He stopped seeking care from hospital at the time and was lost to follow-up but later restarted care. Hameed *et al* showed that the presence of traditional medicine visits in a patient's health journey line was associated with more delay to definitive treatment, (44). In this endeavour all three participants expended significant sums of money from their businesses and sell of personal property. The role of patient beliefs in increasing the cost of care in the health seeking journey and the predatory nature of such undertakings in our society today cannot be understated. The patients were unwilling to go into the actual costs and number of times these treatments were sought.

### **5.3.4 HIV**

#### **5.3.4.1 Comorbid Conditions**

Tuberculosis and other systemic comorbidities increase the morbidity burden of HIV, Lawn *et al* (50). For two patients who are HIV positive, they describe themselves as being too sick to seek care for their slowly progressing swellings. One patient was admitted for tuberculous pneumonia on and off over a period of 9 months during which she had progressive increase of eye swelling and onset of pain. She presented after 15 months of primary delay with Orbital SCC. The second patient suffered abdominal hepatitis that led to a 4-month admission and a 7-month secondary delay. She describes her eye swelling as a lower concern at the time. The perceived severity of a painless eye swelling is much lower than that of tuberculous pneumonia or hepatitis in any setting but especially so in HIV positive patients with immunosuppression. Hence presentation of OSSN is delayed, or definitive treatment is delayed as more emergent issues are treated. The cumulative cost of treatment for co-morbid conditions in HIV also extinguishes limited personal financial reserves, depleting cover schemes and increasing out of pocket costs, Cohen *et al* (51).

#### **5.3.4.2 CCC Programs**

The HIV positive patients all report regular follow-up at their CCC for drug refills and blood checks. None of these lesions were noted or diagnosed during these visits. This is similar to Gichuhi *et al* who found that this group of patients with OSSN still experienced delay despite regular CCC follow-up, (2). Some of the patients report having experienced Stigma due to their HIV status in health facilities while they seek general care. One patient report that for mild ailments like flu, she would seek care and not disclose her status to healthcare practitioners. She preferred to seek care at her CCC where their diagnosis isn't an issue and report more health concerns there. One patient they report going out of town for her CCC follow-up as they wouldn't want to be seen there by people they know in their areas of residence. CCCs' therefore act as haven for HIV patients due to the stigma associated with disclosure. Awareness in CCC programs about eye lesions and the likelihood of OSSN seems to be low.

## **5.4 CONCLUSION**

In summary, the study aimed at exploring the factors contributing to delayed presentation among patients with advanced OSSN at Kenyatta National Hospital. Overall, OSSN commonly presents as a painless eye swelling. Patient awareness of perceived severity of the swelling is low and contributes to delay. While actual initial cost of care isn't a barrier to presentation, the opportunity cost of care contributes to delay in healthcare seeking. HIV co-morbidity directly contributes to delay while fatalistic attitudes and patient beliefs interact indirectly with other factors to contribute to delay. Awareness among healthcare workers in CCC may be further contributing to delay.

## **5.5 RECOMMENDATIONS**

1. This study recommends awareness programs amongst CCC healthcare workers and patients attending these clinics on OSSN.
2. This study recommends the continual counselling of HIV patients attending CCC to address fatalism and other detrimental cultural and religious beliefs.



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**APPENDICES:**

**APPENDIX I:**

**IN-DEPTH INTERVIEW GUIDE**

**CAUSES OF DELAYED PRESENTATION AMONG PATIENTS WITH ADVANCED  
OSSN AT KENYATTA NATIONAL HOSPITAL**

**IN-DEPTH INTERVIEW GUIDE**

<b>BIODATA</b>				
<b>Code</b>				
<b>Sex</b>				
<b>Age</b>				
<b>HIV status</b>				
<b>Location:</b>			<b>Occupation:</b>	
	<b>Bracketing</b>	<b>Questions</b>	<b>Probes</b>	<b>Supplemental Notes</b>
<b>1.Patient Experience</b>		Describe your journey from awareness of lesion to today.	<ul style="list-style-type: none"> <li>• Experience of symptom recognition, initial decisions, and actions</li> <li>• Note delays between visits</li> </ul>	
		What would you say were the main contributors to delays? (If any)	<ul style="list-style-type: none"> <li>• Probe on gaps in the care journey</li> </ul>	
<b>2.Awareness of cancer diagnosis</b>	<i>(Awareness influences decision to seek care)</i>	When were you first aware of the eye growth?	<ul style="list-style-type: none"> <li>• Was there pain?</li> <li>• The patient or someone else noticed.</li> <li>• Who was it?</li> </ul>	

			(HIV care program personnel if seropositive)	
		When did you first seek care?	<ul style="list-style-type: none"> <li>• Did knowledge of lesion affect seeking of care.</li> <li>• How long was the wait before awareness to 1<sup>st</sup> visit</li> </ul>	
		Did you know where to seek care from?	<ul style="list-style-type: none"> <li>• Awareness of healthcare facilities i.e., eye hospital vs closest health facility</li> </ul>	
		Did they suspect it could be cancerous?	<ul style="list-style-type: none"> <li>• Effect of referral past 1<sup>st</sup> facility</li> <li>• Role of stigma on next steps</li> </ul>	
		What was the advice after visiting the health facility?	<ul style="list-style-type: none"> <li>• Did knowledge of possible cancerous lesion affect seeking of care (stigma on cancer)</li> </ul>	
<b>3. HIV diagnosis and comorbid conditions</b>	<i>(HIV disease and its care influences care of other illnesses)</i>	Was diagnosis of HIV made before or after eye growth?	<ul style="list-style-type: none"> <li>• If before, were they on ART and on follow up at CCC?</li> </ul>	
		Did you suffer illness warranting continuous care at time of awareness of tumour and care of OSSN?	<ul style="list-style-type: none"> <li>• Admissions</li> <li>• Comorbid diagnosis (e.g., TB)</li> <li>• Regular hospital visits</li> <li>• Medications and investigations required (cost burden?)</li> </ul>	
<b>4. Cancer and HIV related stigma</b>	<i>(Cancer and HIV stigma may influence decision to seek care)</i>	Have you experienced stigma due to HIV disease?	<ul style="list-style-type: none"> <li>• Did this affect their decision to seek care and where to seek care? (Do they prefer their CCC clinic due to stigma elsewhere?)</li> </ul>	

		Have you experienced stigma due to cancer disease?	<ul style="list-style-type: none"> <li>• Have they experienced this before diagnosis (from others in community/treatment effects of cancer)</li> <li>• Did the fear of stigma affect disclosure and/or decision to seek care? (e.g., when and which facility to go to)</li> </ul>	
		Have you sought alternative care?	<ul style="list-style-type: none"> <li>• Religious/Traditional</li> <li>• When did they do this? after awareness of possible cancerous lesion? or during treatment and the inherent challenges therein</li> </ul>	
		Is anybody else aware of the diagnosis?	<ul style="list-style-type: none"> <li>• Who and why them</li> <li>• (Role of stigma of disclosure and availability of support during treatment)</li> </ul>	
<b>5. Health system factors</b>		<i>(Distrust is a factor in decision to seek care and where to seek care) (Cost of care and opportunity cost of follow up may influence care decisions)</i>		
		Where did you first seek care	<ul style="list-style-type: none"> <li>• Health system distrust (influence of</li> </ul>	

		<p>previous experiences/personal or otherwise on decision)</p> <ul style="list-style-type: none"> <li>• Effect of distance on decision</li> <li>• Effect of prior knowledge on facility on decision (i.e., eye issue for eye hospital)</li> </ul>	
		<ul style="list-style-type: none"> <li>• If referred: reason given and implications of cost and distance of decisions to follow</li> </ul>	
	<p>Why did you choose to go there?</p>	<ul style="list-style-type: none"> <li>• Why did you choose to approach this health facility?</li> <li>• Distance and cost implications</li> </ul>	
	<p>Did presumed cost of care affect your choice of when you went to hospital?</p>	<ul style="list-style-type: none"> <li>• Effect of presumed cost on decision</li> <li>• Consultation cost</li> <li>• Transport cost</li> <li>• Cost of not being at work (was missing work a factor in choice of where and when care is sought i.e., wage economy)</li> </ul>	



**APPENDIX II:**

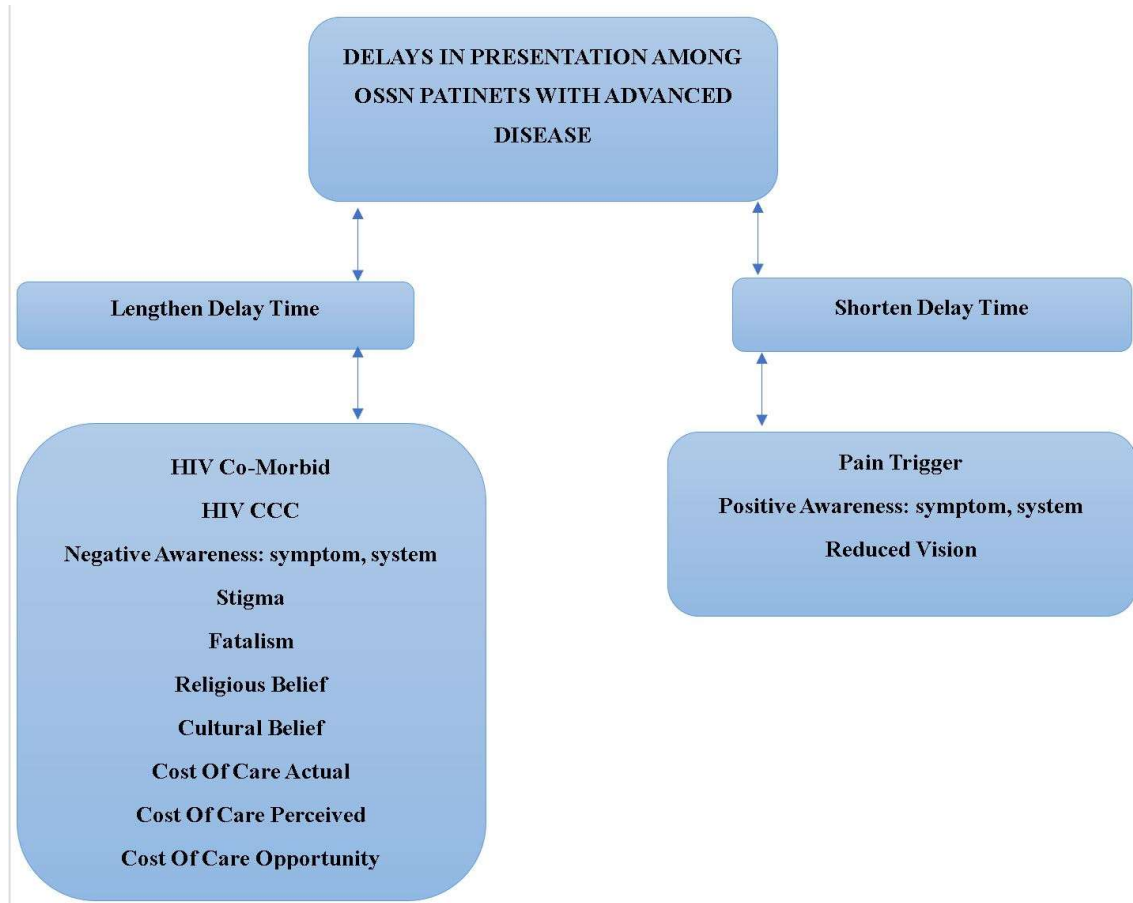


Figure 12. Hierarchical Coding Frame