Factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma at Muhimbili National Hospital.

Nicholaus Benedicto (MD)

MMed (Ophtnaimoiogy) Dissertation
Muhimbili University of Healthy and Allied Sciences,
October, 2020

Muhimbili University of Health and Allied Science
School of Medicine Department of Ophthalmology



FACTORS ASSOCIATED WITH REFUSAL FOR ENUCLEATION AMONG PARENTS/CAREGIVERS OF CHILDREN WITH RETINOBLASTOMA AT MUHIMBILI NATIONAL HOSPITAL.

By

Nicholaus Benedicto

A Dissertation Submitted in (Partial) Fulfillment of the Requirements for Degree of Master of Medicine (Ophthalmology) of Muhimbili University of Health and Allied Sciences, October, 2020

CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled: **"Factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma at Muhimbili National Hospital''** in (partial) fulfillment of the requirement for the degree of Master of Medicine (Ophthalmology) of Muhimbili University of Health and Allied Sciences.

_____

Dr. Anna Sanyiwa

(Supervisor)

Date_____

_____

Dr. Suzan Mosenene

(Co-supervisor)

Date_____

DECLARATION AND COPYRIGHT

I, **Dr. Nicholaus Benedicto**, declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature..... Date.....

This dissertation is a copyright material protected under the Berne Convention, the Copyright Act of 1999 and other international and national enactments, in that behalf, on intellectual property. It may not be reproduced by any means in full or in part, except for short extracts in fair dealings; for research or private study, critical scholarly review or discourse with an acknowledgement, without the written permission of the Directorate of Post Graduate Studies, on behalf of both author and the Muhimbili University of Health and Allied Sciences.

ACKNOWLEDGEMENTS

First and foremost, I am grateful to God for all that he has done to me during my entire training, and my research project. He gave me the strength, courage, and endurance to complete this study. Without him I would have not done anything, Glory to God, my everlasting father.

I am grateful and appreciative for the help given to me by my Supervisors; Dr. Anna Sanyiwa and Dr. Suzan Mosenene, they were always there and guided me patiently throughout my dissertation work.

I am truly thankfully to all my teachers Prof. Milka Mafwiri, Dr. Celina Mhina and Dr. John Kisimbi, for their supportive feedbacks and to all members of the Ophthalmology department at Muhimbili National Hospital (MNH) for their assistance.

I would like to sincerely appreciate my family for their endless support and acknowledge the sacrifice that my wife Dorice and my daughter Noreen had to make during the hours I spent to make this research a success.

I would like to thank all the parents/caregivers and the children with retinoblastoma as well for the precious time they spent with me, they allowed me to search for answers and made my study a success.

I would also like to deeply appreciate the help and support I received from Dr. Dickson Mkoka (Lecturer ,School of Nursing, MUHAS), Dr. Edith Tarimo (Lecturer, School of Nursing Muhas) Happiness Mdangu (Nurse specialized in critical care, MNH), Dr. Frank Macha(Lecturer, MUHAS, School of Public Health) for their endless efforts, they helped me so much with my qualitative research part of the study, all the nurses and staffs in Pediatric oncology wards and Eye pediatric ward, without forgetting all my Colleagues (Ophthalmology MMed students at MUHAS) during the study period.

I would also like to thank my sponsors, CCBRT Hospital for their support to make this research project a success.

DEDICATION

I dedicate this work to my beloved wife Dorice and my lovely daughter Noreen, who have been there for me, endured all for the time I was not home or was home but busy working on my dissertation.

To my parents, Mr. and Mrs. Chaula, my young brother Elieza Chaula, and to my late grandfather Mr. James Chaula, who always believed in me and encouraged me to do well in my studies.

To Dr. Anna Sanyiwa my supervisor, whose passion to retinoblastoma patients inspired and encouraged me to do this study, she has been with me all the time, her help was priceless.

To Dr. Cyprian Ntomoka and Dr. William P. Sellar, their kindness, trust and help, made it possible for me to continue with my training in ophthalmology and pursue my dream.

To all the, parents, caregivers and the adorable children involved in the study for their generosity, they allowed me to enter into their private lives and obtain all the crucial information. It is my hope that my research findings will help them and other affected patients in the best possible way.

ABSTRACT

Background

Parental refusal for enucleation is a major challenge in management of retinoblastoma patients, and it is associated with low survival rates. Knowing and addressing factors leading to parental/caregiver refusal will help improve the survival rates of children with retinoblastoma.

Aim: To determine the factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma at Muhimbili National Hospital.

Materials and Methods: A descriptive hospital based cross sectional study was conducted from June to December 2019. The study employed both quantitative and qualitative methods. A total of 50 participants were recruited using non-probability consecutive technique. Ten in-depth interviews were conducted by purposive sampling technique. A questionnaire with closed and open-ended questions and verbatim interviews were used to collect data. Statistical Package for the Social Sciences (SPSS) version 23.0 and systematic thematic approach were used to analyze data. Ethical approval was obtained.

Results: This study involved 50 parents/caregivers of children with retinoblastoma who attended Muhimbili National Hospital during the study period. More than two thirds of the participants were females (78%) with a mean age of 33.3yrs,had a primary level education, peasants, had 2-4 children (60%) and most children had unilateral retinoblastoma (83%).The proportion of refusal for enucleation was (24%), advanced stages of the disease was associated with refusal for enucleation of more than 3months in 25%.Majority of parents/caregivers refused enucleation because of low level of education, family and economic challenges, lack of employment, traditional and religious beliefs, perception towards appearance of the child after eye removal and the associated social stigma.

Conclusions: The proportion of refusal for enucleation is high, it hinders timely and proper management of children with retinoblastoma and a barrier to their survival. Most parents/caregivers refused enucleation because of their perception towards appearance of the child after enucleation, low level of education traditional and religious beliefs, poor socioeconomic status. Refusal for enucleation was associated with disease progression and eventual death.

Recommendations: 1. Provision of ocular prosthesis and protective glasses is encouraged to all children after eye removal to improve appearance and reduce the social stigma.

2. The hospital needs to help all children with retinoblastoma to get access to free medical care or pay a minimal contribution of health services through health insurance coverage.

3. There is a need to increase awareness and knowledge about the nature of the disease to the community, through campaigns, media etc.

TABLES OF CONTENTS

CERTIFICATION i
DECLARATION AND COPYRIGHT ii
ACKNOWLEDGEMENTS iii
DEDICATION iv
CHAPTER ONE 1
1.0 INTRODUCTION 1
1.1 Background 1
1.2 Literature review 3
1.3 Problem statement 5
1.4 Rationale 6
1.5 Research questions 6
1.6 Conceptual framework 7
1.6 Objectives 8
1.6.1 Broad objective 8
1.6.2 Specific objectives 8
CHAPTER TWO 9
2.0 MATERIALS AND METHODS 9
2.1 Study design 9
2.2 Study setting 9
2.3 Study population 11
2.4 Sample size and selection 11
2.5 Sampling procedure 12
2.6 Data collection tools and methods 13
2.7. Data analysis 15
CHAPTER THREE 16
RESULTS 17
CHAPTER FOUR 28
4.0 DISCUSSION 28
CHAPTER FIVE 35
5.0 CONCLUSION AND RECOMMENDATIONS 35
5.1 Conclusions 35
5.2 Recommendations 35
REFERENCES 35
APPENDICES 39
APPENDIX 1: QUESTIONAIRE ENGLISH VERSION 39
APPENDIX I I: DODOSO LA KISWAHILI 43
APPENDIX 2: CONSENT FORM 48
Appendix i: Consent Form (English Version) 48

LIST OF TABLES

Table 1: Parent/caregivers demographic characteristics 17
Table 2: Children demographic characteristics 18
Table 3: Parental refusal for enucleation by background characteristics. 19
Table 4: Association between laterality and refusal for enucleation 20
Table 5: Logistic regression analysis of the factors associated with parental refusal to child enucleation among attendees of muhimbili national hospital 20

LIST OF FIGURES

Figure 1: Conceptual framework for decision making towards refusal or acceptance of enucleation. 7

Figure 2: Map of Tanzania showing regions..... …… ….11

Figure 3: Proportion of refusal for enucleation. 18

Figure 4: The CT image of a child who died showing stages on first admission and at readmission after refusal. 20

Figure 5: Refusal for enucleation by likert scale 22

LIST OF ABBREVIATIONS

AC	Anterior chamber
CT	Computed tomography
ECHO	Echocardiogram
ECG	Electrocardiography
FBC	Full Blood Count.
EUA	Examination under anesthesia
HCD	Horizontal cornea diameter
ICRB	Intraocular Classification of Retinoblastoma
IRSS	International Retinoblastoma Staging System
LFT	Liver Function Test
MNH	Muhimbili National Hospital
RB	Retinoblastoma
RFT	Renal Function test

DEFINITION OF KEY TERMS

Acceptance of enucleation is an act of consenting to undergo removal of the eye.

Duration of refusal is defined as the time taken from the initial refusal to the time the parents/caregiver accepted enucleation.

Enucleation is the removal of the eye leaving behind the conjunctiva, extraocular muscles and other orbital contents

Horizontal cornea diameter is the horizontally measured diameter of the cornea which averages 10mm in infancy and 11mm in adults.

Intraocular pressure is the fluid pressure inside the eye

Refusal is defined as a decision to avoid recommended elective treatment

Retinoblastoma is a primary malignant neoplasm of the retina that arises from immature retinal cells.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Retinoblastoma is the most common childhood intraocular malignancy that accounts for 2.5-4% of all pediatric cancers in developing countries, with a high prevalence in Sub-Saharan Africa (1). It affects 1:20000 live births and 90% of these are diagnosed before the age of five years (2, 3).

According to an unpublished report on the prevalence of retinoblastoma among pediatric cancers admitted in the oncology ward at MNH was 23% in 2016.This was conducted as a baseline study in evaluating the retinoblastoma program which started in 2016 at MNH.(4).

Enucleation is a surgical removal of the eye leaving behind the extraocular muscles and orbital contents and it is curative in more than 95% of patients with unilateral retinoblastoma (5). Indications includes unilateral tumors that are still confined within the eye with no hope of vision, or for bilateral tumors in the severely affected eye with no visual potential, which are unresponsive to other treatment modalities like chemotherapy(5,6).

Surgery aims at preventing the risk of extraocular spread, metastasis and death. This makes enucleation as a definitive cure before the tumor has spread extraocularly and the procedure offers complete cure without further risks of frequent examination under anesthesia or adjuvant treatment if there was no high histopathological risk features like optic nerve involvement or scleral involvement (5, 7, 8).

Despite the fact that primary enucleation has been reported to be curative in >95% of children with retinoblastoma (5), the rate of parental/caregivers refusal of enucleation is still high in African countries compared to developed countries (9). The initial refusal rate has been reported to be up to 100% in developing countries compared to 25% developed countries (9, 10).

Refusal for enucleation has been reported to increase the delay of treatment with accompanied extraocular spread, proptosis, metastasis and **6.3** times increased risk of death (7). A delay of more than six month is associated with 70% mortality rate, but for a rapidly growing tumor with a disease stage suggesting enucleation as a sole modality of treatment even a delay of 2 months is enough to cause death (7, 12).

During the period of refusal, parents/caregivers choose to go back home and try other treatment remedies (11).This has been reported to contribute to the significant difference in survival rates between developed and developing countries with a survival rate of 95% and as low as 6.8% respectively at 5yrs survival rate respectively(11). Generally the survival rate is fairly good for those who accepted enucleation compared to those who refused (70% vs 20%) (9).

Factors leading to parental/caregiver refusal for enucleation are not well known in Tanzanian context. No study has been done in our settings to find out these factors and because it is important to know and address them, this study was conducted to investigate the factors associated with refusal for enucleation among parents and caregivers of children with retinoblastoma attending Muhimbili National Hospital. Knowing these factors and addressing them is crucial for improving the survival rates of retinoblastoma patients.

1.2 Literature review

Proportion of refusal for enucleation

Globally the rate of refusal of enucleation is higher in developing countries compared to developed countries, 100% initial refusal rate versus 0-25%, this has been reported by a global study done in Canada which interviewed physicians from low income and high income countries (10).

Various studies done in Asian countries have shown different rate of refusal for enucleation, one study done in Indonesia showed that among 165 patient who attended the hospital, 82 refused enucleation and among those, 50 temporally refused while the rest refused definitely (9).Refusal rate for enucleation was also reported to be 13.7% and 31.0% by studies done in Taiwan and Malaysia respectively, while a study done in India has reported a refusal rate of 20% (6, 19, 20).

Refusal for enucleation is still a big challenge in management of children with retinoblastoma especially in African countries. In a study done in Ibadan, Nigeria the rate of refusal was reported to be 70% and only 21.4% accepted enucleation. In a follow up study also done in Nigeria, Onitsha reported refusal rate of 42.0%. (13, 21)

Factors associated with refusal for enucleation

1. Family and Social-economic factors

Family and social-economic factors plays a pivotal role in refusal for enucleation among retinoblastoma parents/caregivers. This was reported by a study done in Indonesia on the effect of refusal against medical advice in retinoblastoma patients. The study reported lack of financial support and local accommodation, lack of belief in the proposed treatment and parents giving up on their children as they would die anyway were among the commonly reported family and social-economic factors. (9).

Appearance of the child prior to and after enucleation has been reported to be an important factor in allowing or refusing enucleation. Parents were found to be unlikely to refuse enucleation mostly if the child presented with proptosis, but the fear of appearance of the child after enucleation made some parents/caregivers refuse enucleation (6, 9).

A global study done in Canada on retinoblastoma, which interviewed physicians from low and high income countries on the reasons associated with refusal for enucleation, showed that social beliefs, beliefs in traditional medicine and fear of social stigma as factors associated with their decision to refuse enucleation. These were more reported by physicians from low income countries. Those from high income countries reported that irrational fear that the child won't be able to adjust after the procedure as the main reason for refusal, as well as beliefs that in the future there could be more treatment option apart from removing the eye and thought that it could be better to wait. Similar findings were also reported in countries like Taiwan where parents/caregivers opted for traditional healers first and only decided to go back to the hospital after the tumor had advanced more (10,14).

Studies have reported that fathers and grandparents were more influential in decisions to accept or refuse enucleation compared to the mothers and other relatives .Another study reported that socio-cultural beliefs and role of other family members as having a great influence in refusing enucleation and delaying treatment (9,10).

II. Institutional factors

Regarding institutional factors, a study done in Canada reported that parents who initially refused enucleation reversed their decision after the practitioners spent adequate time in counselling and explaining about enucleation. Time spent with parents was reported to be very crucial in managing children with retinoblastoma (6, 10).

Most developed centers offers ocular prosthesis to these children after enucleation to provide cosmetic support but this is usually not the case in developing countries where these services are mostly not available. This leads to eventual refusal of enucleation, because parents might perceive their children differently after removal of the eye without further supportive measures to help the children cope (6, 10).

The cost of surgery and treatment in general at many centers in developing countries has led parent/caregivers to choose the cheaper traditional treatments instead of the assured expensive services at the hospital. This is mostly explainable by the fact that most families of children with retinoblastoma are financially unstable and are not covered by medical insurance, which makes it difficult to get all the offered services by the hospitals (9, 22).

Effects of refusal for enucleation on the stage of disease.

Refusal for enucleation leads to delay in treatment, which is associated with progression of the disease from intraocular stage to extraocular stage. A study done in Indonesia on the effects of refusal against medical advice in retinoblastoma patients reported that the rate of intra-ocular tumors at first admission was 69.2% and decreased to 15.4% at readmission and 30.8% of patients had extra-ocular tumors at first admission which increased up to 73. 1% at readmission. (9).The study also showed that 28 out of 36 children who refused therapy progressed from intraocular to extraocular stage (9).

Metastasis of the tumor usually follows after refusal because of delays in treatment, and has been reported to occur within 4month of diagnosis. Death can follow within a year of metastasis spread. Similarly a study done in Indonesia, showed that a significant number of children died after refusal and 19 out of 28 children progressed from an intraocular stage to extraocular stage during that period. Had enucleation been done at the right time it would have prevented these deaths from occurring (9, 23).

Management of children with retinoblastoma at an advanced stage is even more challenging, considering the economies of developing countries. In this setting the economic status of parents and caregivers is low and lack health insurance. Management of advanced disease stages of the disease changes from primary to secondary enucleation after chemotherapy and sometimes they may even need radiation therapy. Such modalities of treatment are possible only at a tertiary center requiring transportation and higher treatment costs. Additionally these treatment options have a lot of side effects including the increased risk of secondary malignancy for example osteosarcoma. (9, 17, 24).

1.3 Problem statement

In developing countries children usually present late to the hospital and most of them have advanced manifestation of the disease. This leads to a limited number of options and makes enucleation as a sole modality of treatment for children with retinoblastoma (17).

One of the challenges in managing children with retinoblastoma is parents/caregivers refusal for enucleation with high rates of refusal in Africa compared to Europe,49.7% vs 0.8-2.2% respectively, yet factors associated with such huge difference are poorly understood and unreported in African countries(9). Refusal for enucleation is associated

with low survival rate, a delay of treatment for more than six month is associated with 70% mortality (9, 12). Further delays usually occurs when parents refuse enucleation and seek treatment remedies elsewhere and return to the hospital when the tumor has progressed to extraocular stage or has intracranial metastasis (11,12).

However, factors leading to parental/caregiver refusal of enucleation are not well known in Tanzanian context. In light of this knowledge gap this study sought to investigate factors associated with refusal of enucleation among parents and caregivers of children with retinoblastoma attending Muhimbili National Hospital.

1.4 Rationale

Findings from this study would help the community to understand the consequences associated with refusal for enucleation and address their fears concerning the surgical procedure**.**

Findings from this study would help the community and institutions to understand the factors associated with refusal for enucleation, and upon addressing them, the complications associated with refusal for enucleation will be reduced.

1.5 Research questions

1. What is the proportion of parents/caregivers of children with retinoblastoma at Muhimbili National Hospital who refused enucleation between Jan to Dec 2019?
2. What are the family-social factors associated with refusal of enucleation among parents/caregivers of children with retinoblastoma at Muhimbili National Hospital?
3. What are the institutional factors associated with refusal of enucleation among parents/caregivers of children with retinoblastoma at Muhimbili National Hospital?
4. What are the effects of parents/caregivers refusal for enucleation on the stage of disease of disease among children with retinoblastoma at Muhimbili National Hospital.?

1.6 Conceptual framework

The decision to accept or refuse the enucleation is usually surrounded by many factors. These factors may range from belief of the patients/parents about the procedure, experience of outcome of the procedure probably from other children, role of other relatives in decision-making, appearance of the child after the procedure, value of life over appearance of the child, role of medical practitioners in counseling and explaining about the procedure, and socioeconomic barriers. All these factors might determine on whether these parents or caregivers will agree to the procedure or not. This conceptual framework is based on the theory of reasoned action in which an individual will act according to the pre-existing attitudes and this will determine the decision that person is going to take and this is usually to the best interest of the actor.

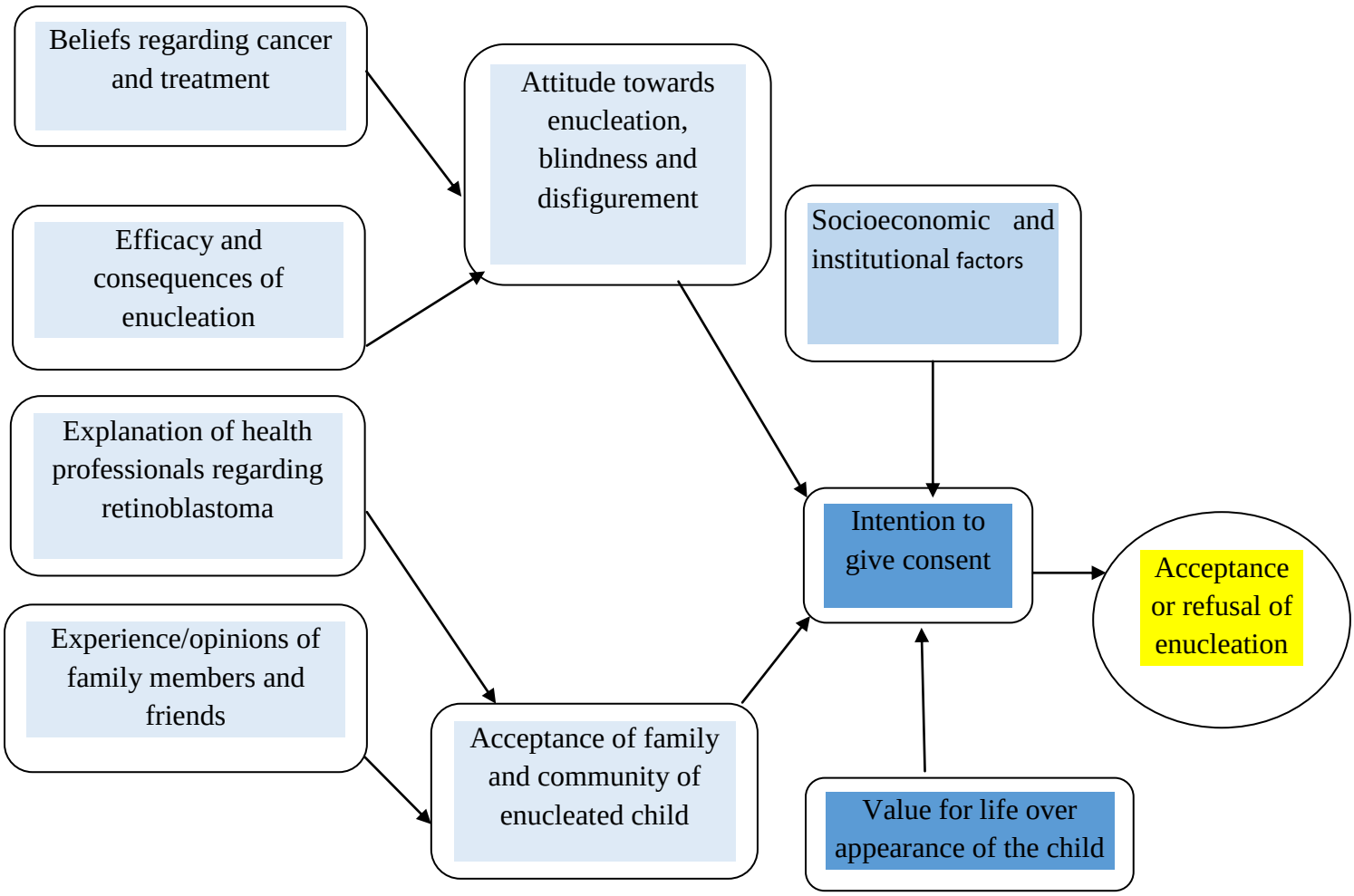


Figure 1: Conceptual framework for decision making towards refusal or acceptance of enucleation. (Adopted from Martin fschbein and Icek Arjen 1980 (16)

1.6 Objectives

1.6.1 Broad objective

To determine factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma attending MNH between Jan to Dec 2019.

1.6.2 Specific objectives

1. To determine the proportion of refusal for enucleation among parents/caregivers of children with retinoblastoma attending Muhimbili National Hospital.

2. To investigate the family-social factors associated refusal for enucleation among parents/caregivers of children with retinoblastoma.

3. To determine the institutional factors associated with refusal for nucleation among parents/caregivers of children with retinoblastoma.

4. To determine the effect of parents/caregivers refusal for enucleation on stage of disease at start of treatment among children with retinoblastoma.

CHAPTER TWO

2.0 MATERIALS AND METHODS

2.1 Study Design

This was a hospital based cross sectional study which employed a mixed method approach. This approach involved data collection both quantitatively and qualitatively. Quantitative method was used to determine factors of refusal for enucleation from parents/caregivers of children with retinoblastoma and to get more insight on the factors for refusal. Qualitative exploratory design was also used for parents or caregivers who refused enucleation.

2.2 Study setting

The study was conducted at Muhimbili National Hospital, located in Dar es Salaam city, Ilala region in Upanga along United Nations road. Muhimbili National Hospital is a National center for management of Retinoblastoma and the program started in 2016. Retinoblastoma has a prevalence of 1:150000-20000 live births, and with the population of Tanzania it is expected to have around 120 cases of retinoblastoma per year. Two thirds of these children are usually attended at MHN. An audit revealed that retinoblastoma prevalence of 23% among other pediatric oncology cases, which was around 72 children with retinoblastoma per year. Data was collected from the pediatric oncology and eye pediatric ward where patients with retinoblastoma are admitted and attended. About 60-80 new children with RB are expected to be referred to MNH for treatment as it was evidenced by the clinical audit of cases from Jan 2016 to 2018.

MNH is one of the retinoblastoma treatment centers in Tanzania and it receives about ¾ of all new cases in Tanzania because it is the most well equipped to manage early and late cases. Other centers are Kilimanjaro Christian Medical College, Bugando and Mbeya Referral Hospital. The pediatric oncology ward has two units which are Tumaini and Upendo wards with 83 bed capacity .Usually these children are admitted in the wards for basic investigations which includes Full Blood Count, Liver Function Test, Renal Function Test Computed Tomography Scan of orbit and brain, Echocardiogram, Electrocardiogram, are done as prerequisite work up for EUA and chemotherapy when needed.

Explanation and counselling about the disease of the child and the available modality of treatment based on the staging are usually given to the parents/caregivers prior to any procedure.

Once the basic investigations for safe examination under anesthesia are ready all children suspected to have Retinoblastoma are taken to theatre to be examined under general anesthesia, during examination intraocular pressure, horizontal cornea diameter, extent of tumor invasion are examined and documented, and proper staging of the disease is done. Each eye is grouped using the International Classification of Retinoblastoma. Enucleations, and local therapy which includes Transpupillary thermotherapy, cryotherapy or local carboplatin maybe done to the affected eye if the parents agreed to the proposed treatment. Average of at least one enucleation is done out of about 7 examinations under anesthesia per week. For those who have refused on first counselling, further counselling is usually done and if they definitely refuse they are usually managed symptomatically and allowed to go home. But contacts of those who accepted/refused are always kept for proper follow up and for reminding those who have refused and see if they have changed their opinion on the proposed procedure.



Figure 2: Map of Tanzania showing regions

Source: Google map

2.3 Study population

The study population in this study were parents/caregivers of children with retinoblastoma attending MNH who had indications for enucleation and either accepted or refused enucleation between Jan to Dec 2019. Specifically parents/caregivers involved were those who are involved directly in the decision making concerning treatment of the child. This is important because not all caregivers who bring these children to hospital or clinic are involved in decision making concerning treatment especially when it comes to delicate issue like removing the eye or any major surgery.

2.4 Sample size and selection

Quantitative: Sample size was estimated using the calculation of sample size for prevalence studies as follows:

$$n = \frac{[Z^2 P (100\% - P)]}{d^2}$$ Where

n = Minimum required sample size

Z= percentage point of normal distribution corresponding to the level of confidence (95% 0f C.I =1.96)

d= Maximum likely error/ margin of error (5%).

p= expected proportion with the characteristic of interest in percentage (Prevalence of retinoblastoma 4%).

$$n = \frac{1.96 \times 1.96 \times 3(100-3)}{5 \times 5} = 58$$

N= 58 parents/caregivers of children with retinoblastoma

Inclusion Criteria: All parents/caregivers of children with retinoblastoma attending MNH who either accepted or refused enucleation between Jan to Dec 2019.

Exclusion Criteria: All parents/caregivers of children with retinoblastoma attending MNH who were not involved in decision making towards enucleation from Jan to Dec 2019.

Qualitative: The principle of data saturation was used to determine the sample size in the qualitative method of the study. This is the principle of deciding sample size for qualitative study and is reached when no new insight is generated from subsequent interview, and the study participants provides maximum information on the phenomenon explored (17). This means, the sample size for this study was not be predetermined, instead, the interviews stopped when the researcher noticed repetition of the earlier gained information with little or no new information in regards to the research questions.

2.5 Sampling procedure

Quantitative: Non-probability consecutive sampling was used, all parents/caregivers of children with retinoblastoma attending eye clinic (retinoblastoma or general pediatric eye clinic or admitted in the ward) at MNH whose children were indicated for enucleation and whether they accepted or refused the surgical procedure during the study period.

Qualitative: Purposively sampling was used to select participants in this part of the study design. Only participants who refused enucleation were involved in the qualitative part of the study, these were followed up after the quantitative data collection so as to gain more insight into their reasons of refusal. The study participants were selected by choosing the most potential participants who were thought to be informative and with adequate and useful details and seemed more likely to open up and give more information.

2.6 Data collection tools and methods

Quantitative

The initial data collection included demographic data, laterality, number of children the participant has, occupation, marital status, relationship with the child and occupation. Information about stage of the disease were obtained in the patients files. Further data was collected using Likert scale, where by participants were supposed to give response to the structured statement whether they agree or not to the particular statement.

Study subjects were parents/caregivers of children with retinoblastoma who were admitted in the Oncology or Pediatric eye ward or those attending clinic for follow up, between Jan 2019-Dec 2019 who had enucleation for the first eye or second eye for those with bilateral disease and these were consecutively recruited. Only the participants who fulfilled the inclusion criteria were recruited in the study and all participants were informed about the study by the principal investigator. After agreeing to participate in the study, they signed a written consent form.

Qualitative

The qualitative part of the study was conducted at the pediatric eye clinic. All parents/caregivers of children with retinoblastoma who refused enucleation from Jan to Dec 2019 were recruited by purposefully sampling technique. Ten In-depth interviews (IDI) were conducted. During the interview the researcher explained about the research question and what was expected from the participants. Those who agreed signed a written consent for participating in the study. The day for the interview was scheduled depending on both the principal researcher and participants' convenience but within the appropriate study period. The interviews lasted between 20 to 40 minutes. Open-ended questions were used to obtain all the information required in the study and allowed participants to discuss

their opinions, views, and experiences in full details. The interview was recorded using an audio recorder and appropriate themes identified for further review when needed.

The interviews were conducted in Swahili language, directed by the semi-structured open-ended questions with probing points, follow up questions and exit questions. The participants were not following any structured pattern, probing was used merely to guide the researcher throughout the interview and also to clarify areas which were not clear, and the interviews were recorded.

To ensure privacy during the interviews, a room in the eye department was used and the interview was audio recorded and no names were mentioned during the interviews instead their responses were coded as P1, P2 (Participant 1etc). The interviewer remained open to other new emerging issues. Preliminary analysis of data was done upon completion of the first interview. This process was useful in generating insight and preliminary sub-themes, which was used later to employ emergent design and modification of the interview guide for subsequent interviews. The researcher used one research assistant who assisted in taking notes during interviews which were useful to get some non -verbal data which was missed from tape recorder and helped during analysis.

2.7 Trustworthiness

Trustworthiness refers to the degree of confidence in the collected data, its interpretation, and methods used to ensure the quality of a study. A number of measures were taken to increase trustworthiness of the findings, to ensure credibility of the findings, during the in-depth interviews prolonged engagement with the participants was emphasized. The research assistant was also used to make sure all the non-verbal actions were documented and were reviewed later during the transcription process. Also to increase the credibility of the findings method triangulation was used and similar findings were obtained by using both methods. Data was analyzed and interpreted by the researcher and shared with the supervisor who has extensive knowledge in qualitative research. This was important for minimizing researchers influence on the data and it helped with confirmability of the research findings. To increase confirmability, findings were presented verbatim with quotes from participants.

To ensure transferability of the study findings, the study setting was described in detail, which enabled the generalization of the study findings to other settings with similar context.

To ensure dependability, a notebook was used to record all activities that happened during the study and decisions about aspects of the study such as whom to interview. Furthermore, dependability was increased by employing emergent design, meaning that the interview guide was reviewed after each interview, and modified based on the reflection of the new emergent issues and insight generated.

2.8 Data analysis

Quantitative: Data was transferred from the hand-written data forms into a data spreadsheet and analyzed with Statistical Package for the Social Sciences (SPSS) version 23.0. Mean, standard deviations, frequencies and percentages was selected according to the level of measurement of each of the key variable of interest. Each associated factor for refusal was analyzed in terms of how frequent the participants responded, proportion of participants who gave the same answer. Chi-square test and p-value were used to assess the level of statistical significance. Associations between dependent and independent variables of $p<0.05$ was considered significant.

Qualitative: Thematic analysis approach was used to analyze data, this approach helped in identifying themes or patterns in the data and choosing the interesting and significant ones to address the research objectives. Data was obtained from the interviews and to ensure accuracy and completeness daily review of data was done. The recorded audio was checked and re-checked against the written data to ensure that nothing important is missed or missing. Verbatim transcription of the recorded data was done and then translation to English language was performed. To ensure quality of the translated scripts double checking of the data against the original data was done. The English transcripts was analyzed by the researcher with guidance and help from the supervisor.

Theoretical or deductive thematic analytic approach was used, which means pre-determined themes or questions was used to analyze data. For this particular study analysis was be based on one research question (i) What are the family-social factors associated

with refusal for enucleation among parents/caregivers of children with retinoblastoma attending Muhimbili National Hospital?

Steps of thematic analysis were followed; first, the transcripts were read and re-read to become familiar with the data. Second, generation of initial codes from the transcripts followed. Because deductive thematic analysis approach was used, the coding framework was the one research question which are related to the family-social factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma attending Muhimbili National Hospital so as to guide the thematic analysis process. Third, generated codes were reviewed so as to identify the pattern of the data set that corresponds to the research question. Similar codes which relate to the preset research question were grouped to form subthemes and similar sub-themes was merged to form a theme grounded from the data. Fourth, the emerged themes were reviewed and defined and then shared with supervisor and discuss their relevance with the research question.

2.9 Ethical considerations

Ethical clearance was sought from Senate Research and Publications Committee of Muhimbili University of Health and Allied Sciences (MUHAS) and the Directorate of Research and Publications of Muhimbili National Hospital (MNH). Informed consent were taken from the parents and caregivers after fully explanation about the procedure and consent to record audio was obtained from participants. All patients who did not give consent were excluded from the study. File numbers and not names appeared in the study for confidentiality purposes. Anonymity of research subjects and confidentiality was highly maintained by using numbers instead of names in the questionnaire. The researcher had no conflict of interest. Participants were free to withdraw from the study, and they were allowed to do so at any time. There was no payment to participants, no any risk in participating in the study; however no direct benefit to participants but findings of the study if implemented can improve eye care services in the future.

CHAPTER THREE

RESULTS

PART A: QUANTITATIVE DATA.

This study involved 50 parents/caregivers of children with retinoblastoma who attended Muhimbili National Hospital during the study period. Most participants were females, aged between 19-29 years, married and had primary level education.

Table 1: Parent/caregivers demographic characteristics (n=50)

Overall	**Frequency**	**Percent (%)**
Age (years).		
19-29	24	48%
30-39	15	30%
40+	11	22%
Mean=33.3, SD=10.8, Min=19,Max=73yrs		
Sex		
Male	11	22%
Female	39	78%
Education level		
Secondary/College education	12	24%
Primary education	29	58%
No formal education	9	18%
Occupation		
Peasant/Farmer	33	66%
Petty business	12	24%
Employed	5	10%
Relationship with the child		
Father	10	20%
Mother	38	76%
Guardian	2	4%
Number of children		
1	8	16%
2	15	30%
3-4	15	30%
5+	12	24%
Place of residence		
Central zone	7	14%
Coastal zone	16	32%
Lake zone	10	20%
Northern zone	5	10%
Southern zone	4	8%
Western zone	5	10%
Zanzibar	3	6%

Table 2: Children demographic characteristics (n=50).

Overall	**Frequency**	**Percent (%).**
Age(months)		
0-23	20	40%
24-48	**21**	**42%**
>48	9	18%
Sex		
Male	**27**	**54%**
Female	23	46%
Laterality		
Unilateral Retinoblastoma	**43**	**86%**
Bilateral retinoblastoma	7	14%

Most children were males and aged between 0-48months, had unilateral retinoblastoma (Table 2).

24% of the participants refused enucleation (Figure 3).

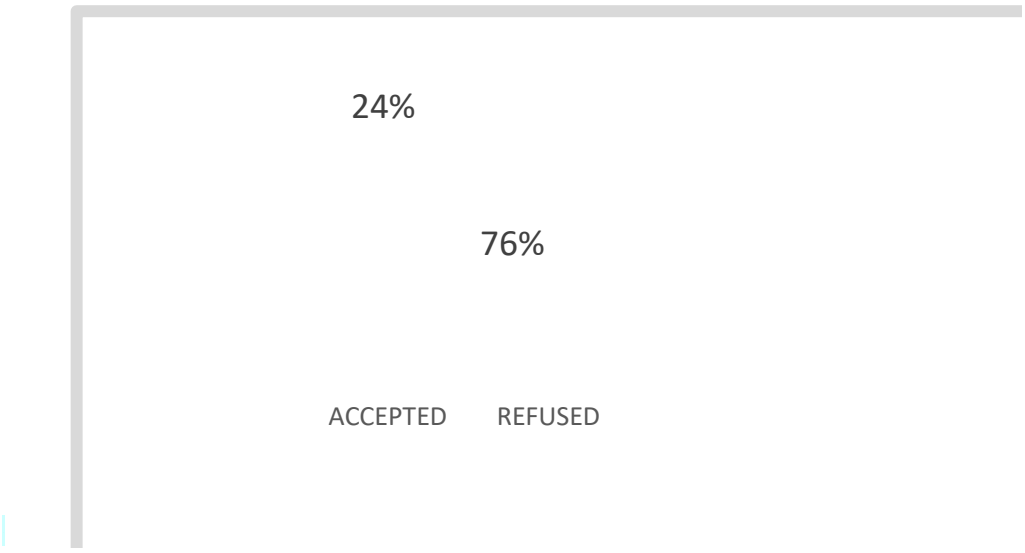


Figure 3: Proportion of refusal for enucleation.

Table 3: Parental refusal for enucleation by background characteristics. (n=12).

Overall	**% of refusal for enucleation. 24% (n=12).**	**P-Value**
Children characteristics		
Age (months).		0.987
0-23months	41.7% (5)	
24-48months	41.7% (5)	
>48months	16.6% (2)	
Sex		0.497
Male	58.3% (7)	
Female	41.7% (5)	
Parents/caregivers characteristics		
Marital status		0.627
Married	83.3%(10)	
Not married	16.7%(2)	
Sex		0.472
Female	83.3%(10)	
Male	16.7%(2)	
Age		0.323
19-29yrs	66.7%(8)	
30-39yrs	16.7%(2)	
40+yrs	16.7%(2)	
Education level		0.280
No formal education	41.7% (5)	
Primary education	50.0% (6)	
Secondary/College	8.3% (1)	
Occupation		0.874
Peasant/farmer	75 %(9)	
Petty business	16.7 %(2)	
Employed	8.3% (1)	
Relationship with the child		0.660
Father	16.7 %(2)	
Mother	83.3 %(10)	
Number of children		0.050
1 Child	41.7%(5)	
2 Children	25.0%(3)	
3-4 Children	25.0%(3)	
5+	8.3%(1)	
Place of residence		0.968
Central zone	16.7%(2)	
Eastern zone	16.7%(2)	
Lake zone	8.3%(1)	
Northern zone	16.7%(2)	
Southern/Southern highlands	16.7%(2)	
Western zone	16.7%(2)	
Zanzibar	8.3%(1)	

Most participants who refused enucleation had 1 child and majority of children had unilateral retinoblastoma. (Table 3).

Table 4: Association between laterality and refusal for enucleation (n=50).

		Enucleation			
		Accepted	**Refused**	**Total**	**P-value**
Laterality	**Unilateral**	36(83.7%)	7(16.3%)	43(100%)	0.006
	Bilateral	2(28.6%)	**5(71.4%)**	7(100%)	
	Total	38(76%)	12(24%)	50(100%)	

A higher proportion of parents and caregivers of children with bilateral retinoblastoma refused enucleation (of the second eye) than those with unilateral. The association between having a child with bilateral retinoblastoma and refusal for enucleation was statistically significant. (**Chi-square 10.038, p-value=0.006) (Table 4).**

Table 5: Duration and stage of disease after refusal for enucleation. (n=12.)(IRSS).

Duration refusal	**Number of participants**	**Stage on first admission**	**Stage on admission after refusal.**
<2weeks	6	Stage I, Stage II	Stage I,II
2weeks-1Months	3	Stage I	Stage I
>3months	3	Stage I, Stage II	Stage III, IV.

Longer duration of refusal was associated with advanced stages of the disease. (Table 5).

***Note**: One child among those who refused enucleation for more than three months died.*



Figure 4: The CT image of a child who died showing stages of disease at first admission (image 1) and at readmission after refusal (image 2). Image 2 shows massive proptosis of the left eye.

Table 5: Logistic regression analysis of the factors associated with parental refusal to child enucleation among attendees of Muhimbili National hospital (n = 50)

	Univariate Models			Multivariate Mode		
	Crude Odds Ratios (cOR)	95% Confidence Interval (CI)	*p*-value	Adjusted Odds Ratios (aOR)	95% Confidence Interval (CI)	*p*-value
Covariate	-	-	-	-	-	-
Age (months)						
0-24months	**1.00**	**—**	**—**	**—**	**—**	**—**
24-48months	**0.94**	**0.23-3.90**	**0.929**	**—**	**—**	**—**
>48months	**0.86**	**0.13-5.56**	**0.872**	**—**	**—**	**—**
Sex						
Male	**1.00**	**—**	**—**	**1.00**	**—**	**—**
Female	**0.79**	**0.21-2.95**	**0.730**	**0.24**	**0.02-2.64**	**0.246**
Child's Parent/caregiver characteristics	-	-	-	-	-	-
Marital status						
Married	**1.00**	**—**	**—**	**—**	**—**	**—**
Not married	**1.07**	**0.19-6.14**	**0.942**	**—**	**—**	**—**
Age (years)						
19-29 years	**1.00**	**—**	**—**	**1.00**	**—**	**—**
30-39 years	**0.31**	**0.06-1.71**	**0.178**	**3.89**	**0.20-77.31**	**0.373**
40+ years	**0.44**	**0.08-2.56**	**0.364**	**13.9**	**0.45-425.6**	**0.131**
Sex of the parent/caregiver						
Male	**1.00**	**—**	**—**	**—**	**—**	**—**
Female	**0.64**	**0.12-3.50**	**0.611**	**—**	**—**	**—**
Education level						
Secondary/college	**1.00**	**—**	**—**	**1.00**	**—**	**—**
Primary education	**2.09**	**0.22-20.09**	**0.524**	**24.3**	**0.46-1280.2**	**0.115**
No formal education	**5.71**	**0.53-61.41**	**0.150**	**427.7**	**2.66-68656.2**	**0.019**
Occupation						
Peasant/farmer	**1.00**	**—**	**—**	**1.00**	**—**	**—**
Petty business	**0.53**	**0.10-2.92**	**0.469**	**0.09**	**0.01-1.26**	**0.074**
Employed	**0.67**	**0.07-6.79**	**0.732**	**0.01**	**0.0001-0.86**	**0.043**
Relationship with the child						
Father	**1.00**	**—**	**—**	**—**	**—**	**—**
Mother	**1.33**	**0.24-7.35**	**0.741**	**—**	**—**	**—**
Number of children						
1 child	**1.00**	**—**	**—**	**1.00**	**—**	**—**
2 children	**0.15**	**0.02-1.01**	**0.052**	**0.01**	**0.0001-0.38**	**0.016**
3-4 children	**0.15**	**0.02-1.01**	**0.052**	**0.01**	**0.0004-0.58**	**0.024**
5+ children	**0.05**	**0.004-0.66**	**0.022**	**0.002**	**0.00001-0.37**	**0.019**

Parents with higher level of education, employed and high number of children were less likely to refuse enucleation.

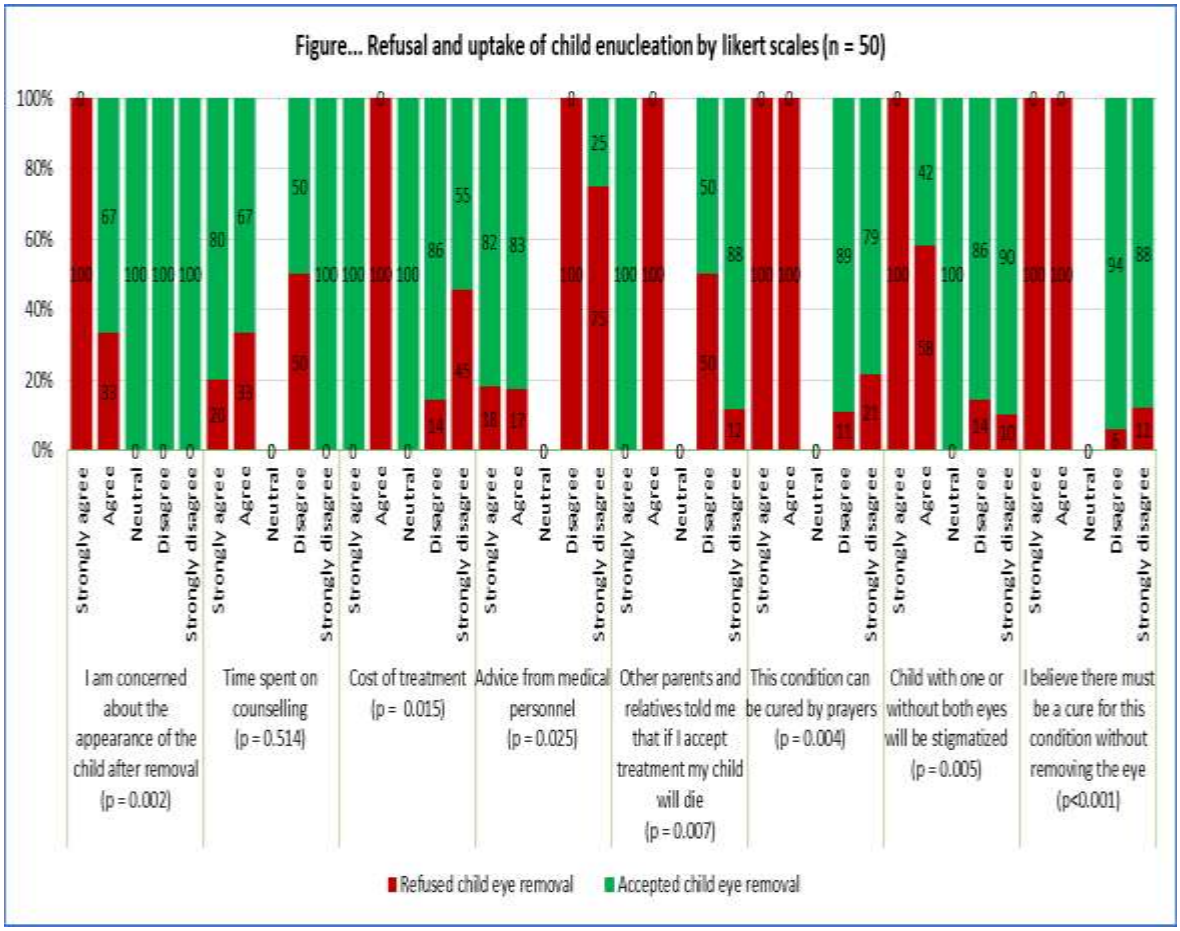


Figure 5: Refusal for enucleation by Likert scale

***Note**: Concern about appearance of the child after enucleation, high cost of treatment, belief that the condition can be cured by prayers and fear of social stigma were highly associated with refusal. These factors were also reported by parents during In-depth interviews.*

PART B: QUALITATIVE ANALYSIS

The qualitative part of the study aimed at investigating the family –social and economic factors associated with refusal for enucleation. Ten In-depth interviews were conducted, analysis of the interviews described factors associated with refusal for enucleation among the participants from the family-social and economic aspect. Three cross-cutting themes emerged which described perception towards the appearance of the child after enucleation, family and social challenges and influence of social beliefs affected decision making towards enucleation.

THEME I: Perception towards appearance of the child and associated social stigma after enucleation.

This theme provided a broader perspective of participants on their perception towards the appearance of the child and social acceptance after enucleation. Most of the participants were concerned about social stigma which might increase with the appearance of their children after enucleation. During in-depth interviews when parents/caregivers expressed concerns about appearance of their children after eye removal and this emerged as one of the main reasons of refusal for enucleation in nearly all interviewed participants. Most participants thought it was unimaginable for their children to live without one eye or both eyes ***"I cannot allow my child to live without one eye" (IDI 2).***

Parents/caregivers didn't want to consent for the procedure, mainly because they had the impression that their children would appear ugly after eye removal and considered appearance as a very important thing. One parent said

> ***"Appearance matters you know, when I looked at my child, even though they told me that she had cancer, initially it didn't look that bad, So the idea of removing the eye at that time was not appealing to me".(IDI 1)***.

Parental perception towards appearance of the child after enucleation is out of proportion compared how the children actually look with an ocular prosthesis in-situ after enucleation, maybe due to lack of experience in caring for a child without one or both eyes.

Some parents could not allow eye removal surgery because the child was a girl, this was substantiated by one parent who said,

> ***"I cannot allow enucleation for my baby girl, how will she look like with one eye?, she can now accept because she doesn't understand the implications of it, but when she grows up she will look ugly and will start asking me why did I allow her eye to be removed?"(IDI7).***

Apart from the perception of bad appearance after eye removal, parents feared that their children might not adjust well after eye removal because of social stigma

> ***"I know in our society there is stigma towards people with one eye, if I allow the eye to be removed, he will be disabled, and the society might not accept him and even when playing with other children they might stigmatize him" (IDI 3).***

THEME II: Influence of social beliefs on refusal for enucleation.

This theme described participant's perspectives on the influence of social beliefs on refusal for enucleation. Social beliefs emerged as one of the main reasons for parental/caregiver's refusal for enucleation, as most parents refused the surgery and went back home to traditional healers and churches for prayers. Some believed that their children have been bewitched **"AMEROGWA"** simply because the child was not born with the disease, these parents couldn't understand how is it possible for the child to be born normal and then to be later told that the child had an eye cancer, one of the parents said

> ***"My child was born without any eye problem, but when he reached around one year and six month, they told me that your child has eye cancer! I asked them, what could be the cause of this cancer? I thought he might be bewitched, so I decided to go to a traditional healer" (IDI 4).***

Parents/caregivers who believed that their children was bewitched refused enucleation and went on to seek help from traditional healers, ***"I went to a traditional healer, he told me that your child is bewitched"*** **(IDI 4).** These beliefs led to the default of treatment and further delays of treatment which is usually associated with disease progression and unavoidable death from metastasis.

Religious beliefs was another reason of refusal for enucleation that emerged during the in-depth interviews. Parents/caregivers believed that the disease can be cured by prayers, they refused enucleation and sought help from local church leaders, some of them even went to more than one church in search for help, as reported by one parent

> ***"My husband agreed to the eye removal operation, but I was not ready. I decided to consult one of my sisters who advised me to go for prayers. I went for prayers in different churches for about 8months but with no improvement"***

All interviewed participants believed in God, and they believed that God is the number one helper for any problem including cancer. They believed that the child can be cured by God, this not only led to refusal but the associated delay to treatment was significant **"*I believed only God can cure her*".** And the influence of this belief also came from significant others who encouraged them to seek help from church leaders ***"My aunt advised me to seek help from one church at home" (IDI 5).*** This showed the influence of other family members and society as well, who believed in miracles or prayers and perhaps had the experience in the past that any disease can be cured through prayers.

Parental/caregivers social beliefs in relation to refusal of treatment, stems from the lack of experience and knowledge about the nature of the disease itself. Some perceived it as just a small problem, one parent who refused enucleation said

> **"*They told me that my baby had cancer, but the eye didn't look that bad by then. So the idea of removing the eye at that time was not appealing to me" (IDI 1).***

Even when these parents were told about the eye cancer, because in its early stages the tumor was still intraocular, children were feeding well and with good general health, most of the parents thought it was not a big problem. These parents ended up delaying by attending at different churches for prayers and they returned to the hospital when the disease had progressed to extra ocular stage with obvious proptosis.

THEME III: Family-social and economic challenges are barriers to parental/caregivers acceptance for enucleation.

This theme described the role of family, social and economic challenges in parental refusal for enucleation. It showed that family-social and economic challenges were barriers to parental acceptance of enucleation. Most interviewed participants came from middle or low income families, and lack of family or social support and financial constraints emerged as one of the factors of refusal for enucleation. Various issue emerged from the family and at society level. Factors like lack of family and community support, lack of health insurance coverage emerged. Some participants were abandoned by husbands and close

relatives and were left alone to take care of the children at home and while admitted in the ward. They had no one to supply their basic needs which made it difficult for them to continue with treatment as was evidenced by one of the parents who said

> ***"My husband abandoned me because of our sick child. I was left alone with three young children and he never called even once to ask about them".***

This parent was also abandoned by other close relatives who did not offer support to the mother and the sick child ***"No one bothered to come to the hospital to see me or the child for the whole time that I have been admitted"***.

At the society level problems were also noted, this mother who was abandoned by the husband and relatives, reported the issue about the sick child to the ward executive officer, who opted to give her work, and she worked for five months to collect enough money for her to travel from Kigoma to Dar es salaam which is approximately 1240kms by road. The mother reported **"*I was paid twenty thousand per month, I had to work for five month to get the fare to travel from Kigoma to Dar es Salaam"***.

Another factor associated with refusal was observed specifically in parents who had children with bilateral retinoblastoma when enucleation was the best option for the second eye. Parents were concerned about how to take care of the child who has lost both eyes, they were worried that having a child at home who doesn't have both eyes and needs help for everything would interfere with their carrier and daily activities. The future and education of the blind child was also a concern. One parent said ***"How will I be able to earn money and take care of my family if you decide to remove both eyes of my child, while there is no one else at home to take care of him"*** Another parent was worried about education of her child due to lack of schools for the blind children in her community, she said

> ***"What about her studies Dr.! Will it be possible for her to continue with school without both eyes? Because I have not heard about schools for the blind children in our district"*** the parent from Sumbawanga. (Southern, Tanzania)

Nearly all interviewed participants lacked health insurance coverage for their children, and this was because most of them were peasants and of low socioeconomic status so they

couldn't afford to pay for the health insurance. Some of the parents refused enucleation because of the cost of treatment and along with its long hospital stay. Some requested to go home for a couple of days or weeks in search of money for insurance coverage and other necessary basic needs

> **"*When I arrived at the hospital, I was told that my child needs admission. I disagreed because I had no money, no health insurance and wondered who will cater for my hospital needs. So I requested to go home and look for money to get health insurance which took me more than six months to return back to the hospital"***

Long hospital stay was another reason of refusal for enucleation, usually the minimum duration is 3weeks for those undergoing primary enucleation without chemotherapy and 12months for those with bilateral disease or extraocular disease. These parents were concerned about their daily hospital needs, and some of them were concerned about their young children they had left at home with no one to take care if the hospital stay is long. They thought treatment will take longer and apart from their concern about their young children left at home. Some were worried about their husbands would engage in extramarital affairs if the hospital stay is long. One parent said

> **"I *heard other women in the ward saying, when they went back home after a long stay at the hospital, they found their husbands with extramarital affairs or married another wife"***

often we have received reports from our parents when they come for follow up, unfortunately some husbands abandon these women with their the sick child and marry another women.

CHAPTER FOUR

4.0 DISCUSSION

Refusal for enucleation has been reported to be one of the major barriers to survival of children with retinoblastoma in Tanzania and Africa at large. Results from this study showed a refusal rate of 24%, which is comparable to results from studies done in India and Malaysia which reported the refusal rates of 20% and 31% respectively(19, 20). However, some African countries have reported a higher refusal rate for enucleation compared to results from this study. Studies done in Nigeria have shown a refusal rates of 42% and 70%. (13, 26). The lower rate of refusal in our study compared to other African countries could be attributed to the existence of an Integrated Retinoblastoma treatment program at the hospital which started in 2016, and the availability of well-established pediatric oncology services which have increased awareness about retinoblastoma and its possible treatment options. Additionally access to supportive services, ocular implants and the use of prosthetic after enucleation reduce the stigma of the affected children. Parents whose children have been enucleated and fitted with prosthetic eyes are also involved to give support to parents of newly admitted patients.

In African societies, mothers are responsible for taking care of children, especially when they are sick and they may have significant influence on the decision of treatment of the sick child. The rate of refusal for enucleation was high among mothers compared to fathers, this can be explained by the fact that most children were brought by their mothers who were also the majority in this study and they were the sole decision makers for acceptance or refusal for enucleation. The study done by Rolando et al on psychosocial factors associated with refusal for enucleation, showed that in decision making concerning eye removal it is very important to convince the mother because her decision is most valuable. This finding was also evidenced by one parent when asked about the influence of other relatives in her decision of refusal for enucleation, she said

> ***"they are just relatives but I am the one who bears the pain of my child's condition and I am the one who takes care of her and not them"***.

This shows that even when the main decision maker in the family has already agreed, there is still more to do to convince the mother as well, this will reduce or prevent delays

associated with refusal. This was also substantiated by another mother who said ***"my husband agreed for eye removal surgery but I was not ready".*** These findings differ from the study done by Cristina et al which showed that the main decision makers were fathers and grandparents, and they were the main reason for the refusal. (6, 10).

Findings from this study suggests that, the number of children the parent/caregivers had, affected their decision towards enucleation, those who had five children or more were less likely to refuse enucleation compared to those who had one child . This can be explained by the fact that most parents with a single child involved in this study were young and inexperienced, and had one child, it seemed difficult for them to consent for the surgery. Some thought that if they consented for the surgery they might end up losing the child, one participant who refused enucleation said ***"I didn't want my child to be operated because I was afraid he might die during the operation".*** However those who had many children were likely to accept enucleation, this could be explained by the fact that they had other children at home and they would have liked a minimum stay at the hospital so that they can go back home to take care of the other children.

This study showed that, there was an association between having a child with bilateral retinoblastoma and refusal for enucleation. Parents of children who had bilateral retinoblastoma refused enucleation of the second eye, because they believed the remaining eye could still see. They were concerned about the future of their children, their education, and appearance of the child without both eyes. They were worried about raising a child without both eyes, who is going to need their care and attention all the time, but at the same time they have to leave home so that they can work and earn to sustain the whole family. One parent said ***"How will I be able to earn money and take care of my family if you decide to remove both eyes of my child, while there is no one else at home to take care of him".*** Another parent was concerned about education of her child, she understood that if you remove both eyes the child will be blind and there were no local schools for the blind at her community ***"What about her studies Dr.! Will it be possible for her to continue with school without both eyes?*** Said one parent from Sumbawanga (Southern highlands, Tanzania). This finding echoes the importance of integrating special education

needs to the local government education system to the lower level where majority of these poor parents come from.

Parental concern about appearance of their children after eye removal was associated with refusal for enucleation, and this was reported by all parents/caregivers who refused enucleation. Similar findings were reported by a study done in Philippine's by Rolando et al. on psychosocial factors associated with refusal for enucleation, which reported that parents perceived that an enucleated eye is not acceptable to their children (6, 9). Patients' perception towards the appearance of their children after eye removal matters more to them as one parents who refused said

> ***"I cannot allow enucleation for my baby girl, how will she look like without one eye? When she grows up she will look ugly and will start asking me why did I allow her eye to be removed?"***

The availability of prosthesis at our hospital has helped to relieve some parents of their concern towards appearance of the child after enucleation, because all children are usually given ocular prosthetics after enucleation. Refusing parents are encouraged to join special retinoblastoma clinic where they can interact with survivors and meet the fellow parents as part of efforts to support them clear their concerns.

Fear of social stigma was another reason of refusal for enucleation reported by parents/caregivers of children with retinoblastoma in this study. It was also reported by a global study on enucleation refusal for retinoblastoma by Cristina et al, the study showed that physicians from low income countries, reported that some parents refuse enucleation because of the fear that the child will be stigmatized in the society after eye removal (10). One parent refused enucleation because she feared that the community will not accept the child after eye removal

> ***"I know in our society there is stigma towards people with one eye and even when playing with other children they might stigmatize him" (IDI 3).***

This emphasizes the importance of educating the community about the disease, and to embrace those who suffered rather than stigmatize them. These findings is a wakeup call for the program to refocus the awareness campaigns to include issues related to enucleation.

Social beliefs were found to influence parental/ caregiver's decision towards enucleation, this study showed that parents/caregivers refused to consent for enucleation because they believed the disease can be cured through prayers or traditional methods. Majority of the parents/caregivers who refused enucleation believed that there must be other ways of treating the child without removing the eye. Beliefs in alternative treatment was also reported by a study done by Rita S et al on effects of refusal against medical advice, where parents sought traditional treatment and only to be readmitted once the condition has worsened (6, 9).Beliefs in traditional healers was also noted during in-depth interviews, whereby participants reported to have refused enucleation and sought help from a traditional healer, one parent said

> ***"When I was referred here for further treatment and being told the eye of my child will be removed, I did not agree, so I decided to go to a traditional healer"***

Parents had this belief in traditional healers because they believed that the child might be bewitched. One parent pointed out that she thought her child is bewitched, because he was born without any eye problem, she couldn't understand why a child who was born normal could possibly get eye cancer later on in life

> ***"My child was born without any eye problem, but when he reached around one year and six month, they told me that your child has eye cancer! I thought he might be bewitched, so I decided to go to a traditional healer"***.

It is extremely important to clearly explain and educate the community about the nature of the disease and make them understand, that it is not necessarily for the disease to be evident immediately after birth, but it can occur even after a year or years after birth. Most importantly they should know that the cause of the disease is not witchcraft, this will reduce the time these parents spent in search for other treatment alternatives, and hence the need of public awareness cannot be more emphasized.

Religious beliefs, where participants believed that the disease can be cured through prayers was another reason of refusal for enucleation. These parents/caregivers had firm belief in their religion and wondered from one church to another in search for help. Similar findings were also reported by a global study on refusal for enucleation among Retinoblastoma patients which was done in Canada by Cristina et al. In that study parents from low income

countries believed that **"*the disease does not pose any danger and even monks can cure the disease"* (10).** This belief was also reported by study done in Philippines by Orlando et al where one out of ten participants interviewed opted to go to faith based healers (6). Parents defaulted treatment after being informed about enucleation and decided to go for prayers, one of the parents defaulted treatment for more than six month and when she came back her child had already progressed to a more advanced stage**, *" I went for prayers in different churches for about 8months but with no improvement"* (6, 9, 10).** This belief poses a great challenge in managing these children because it leads to delay of treatment and its associated complications notably disease progression, and even death. Parents need to be told and understand that retinoblastoma is deadly disease and there is no alternative for a timely intervention to prevent progression of the disease.

Findings from this study suggests that parental/ caregivers' level of education influenced their decision towards enucleation. We found that the higher the level of parents/caregiver education the more favorable decision towards enucleation, parents/caregivers who had secondary level of education or higher were more likely to accept enucleation compared to those with no formal education. Similar findings were reported by a study done by Wei Xiao et'' al in china, which showed that fathers who had more than nine years of school were less likely to default treatment compared to those with lesser school experience (25,26). Most parents with higher level of education had good jobs and possibly had better socioeconomic status, and could afford to pay for services, as well as health insurance coverage, but also they were more likely to access proper information concerning the nature of the disease and treatment options.

Treatment costs in general, which included hospital stay and surgery, was another reason of refusal for enucleation, similar findings were also reported by several studies which highlighted the poor socioeconomic status, lack of insurance coverage as reasons for refusal against medical advice in developing countries, therefore these parents chose cheaper options like going for prayers or traditional healers (9, 22, 25, 26).The same reasons was also found during in-depth interviews. Some parents refused enucleation in order to go back home and look for money for health insurance which took longer than anticipated. One parent who refused enucleation due to poor socioeconomic status said

> ***"When I arrived at the hospital, I was told that my child needs admission. I disagreed because I had no money, no health insurance and wondered who will cater for my hospital needs. So I requested to go home and look for money to get health insurance which took me more than six months before I went back to the hospital"***

There is a need to increase the health insurance coverage to the society, in order to help children with retinoblastoma to access appropriate services in time. The overall treatment cost for enucleation and admission is around 500,000 Tanzanian shillings which is usually very high for most families. Considering the fact Tanzania has a policy of free medical services (exempted by policy) for some of the chronic conditions including HIV, retinoblastoma could be added to this list. These measures will decrease the delay to treatment associated with the lack of necessary economical support, which always leads to advanced manifestation of the disease.

Refusal for enucleation is always associated with delays in initiating timely and proper treatment, when proper treatment is delayed, disease progression, metastasis and death cannot be avoided (9). Findings from this study showed that 25% (3) of children whose parents/caregivers refused enucleation, they progressed from an intraocular stage (stage I) to extraocular stage (stage II), and one child among these died (Stage IV-CNS metastasis) from the complications of the disease associated with late treatment. These parents defaulted treatment for more than three month due to various reasons as shown by this study. Similar findings were also reported by a study done in Indonesia on the effects of refusal against medical advice in retinoblastoma patients, the study reported that the rate of intra-ocular tumors at first admission was 69.2% and decreased to 15.4% at readmission and 30.8% of patients had extra-ocular tumors at first admission which increased up to 73.1% at readmission.(9).The study also showed that death occurred to 67.9% of all children who progressed to extraocular stage (9,23).It is clearly evident that refusal for enucleation leads to disease progression and death which could have been prevented. It also increases treatment cost because with advanced manifestations of the disease these children will need chemotherapy and a much longer hospital stay. Keeping in mind that most of these parents have low socioeconomic status, the increase in treatment cost and a longer hospital stay will further complicate their situation and affects everyone around them. If these parents/caregivers had agreed to the surgery death would have been

prevented. More efforts are necessary to increase parental/caregivers' compliance for enucleation, in order to save lives and decrease cost of treatment as well.

Studies have shown that there is an association between time spent by the health care providers during counselling and decision towards enucleation, the longer the time spent during counselling ,the greater the likelihood of parental acceptance of the recommended procedure or treatment(10). However findings from this study showed that there might be other factors of refusal for enucleation, because almost all participants who refused enucleation, with exception of one parent, agreed that time spent during counselling was adequate. This tells us that our health care workers usually spend enough time in counselling these parents at the hospital, because some parents are usually counseled more than once and on different occasions. Parents who are under treatment are also around and can help in counselling other parents. But this also shows us that we need to keep this up and put more emphasis on tackling other factors associated with refusal for enucleation evidenced in this study. The factors to work on are improving their appearance after enucleation, helping them cope with social stigma and improving their access to health insurance schemes, etc.

CHAPTER FIVE

5.0 CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSIONS

A quarter of patients indicated for enucleation for retinoblastoma at MNH refused enucleation. This proportion is high, and hinders timely and proper management and this is the barrier to survival of children with retinoblastoma. Most parents/caregivers refused enucleation because of their perception towards appearance of the child after enucleation, social and religious beliefs, poor socio-economic status and lack of health insurance coverage were among the contributing factors for refusal. Refusal for enucleation was associated with disease progression and eventual death.

5.2 RECOMMENDATIONS

1. Provision of ocular prosthesis and protective glasses is encouraged to all children after eye removal to improve appearance and reduce the social stigma.
2. The hospital needs to help all children with retinoblastoma get access to free medical care or pay a minimal contribution of health services through health insurance coverage.
3. There is a need to increase awareness and knowledge about the nature of the disease to the community, through campaigns, medias etc.

5.3 STUDY LIMITATIONS AND MITIGATIONS.

This study described only a snapshot of the factors associated with refusal for enucleation among parents/caregivers of children with retinoblastoma attending Muhimbili National Hospital hence results cannot be generalized for the whole community. However, it is a tertiary hospital which receives patients referred from different parts of the country, this will increase the generalization of our findings.

REFERENCES

1. Stiller C, Parkin D. Geographic and ethnic variations in the incidence of childhood cancer. Br Med Bull 1996; 52:682 - 703.
2. Rodrigues KE, et al. Delayed diagnosis in retinoblastoma. *J Pediatr (Rio J)* 2004; 80: 511–16.
3. Pendergrass TW, Davis S. Incidence of retinoblastoma in the United States. Arch Ophthalmol. 1980; 98: 1204-10.
4. Jack N. Retinoblastoma: Clinical picture and grouping at the time of first presentation in patients attending Peadtric oncology ward at Muhimbili National Hospital. 2016:22 (Unpublished).
5. Murali C, Patricia C, Evelyn A.P, Sharon E. P et al. Retinoblastoma: Review of Current Management. The Oncologist 2007; 12:1237–1246
6. Rolando E D, Maria S W, Beverley V L. Psychosocial Factors Influencing Parental Decision to Allow or Refuse Potentially Lifesaving Enucleation in Children with Retinoblastoma. *Asia-Pacific Journal of Oncology Nursing* •2017; 4 :5-6
7. Zhao J, Dimaras H, Massey C, et al. Pre-enucleation chemotherapy for eyes severely affected by retinoblastoma masks risk of tumor extension and increases death from metastasis. *J Clin Oncol 2011; 29: 845 -51*
8. Dimaras H, Kimani K, Dimba EA, et al. Retinoblastoma. *Lancet* 2012; 379:1436–1446.
9. Rita S, Pandu R, Annete C et al. The Effect of Therapy Refusal against Medical Advice in Retinoblastoma Patients in a Setting Where Treatment Delays are Common. *Article in Ophthalmic Genetic.* 2009 ;30(1):31-6
10. Cristina O, Helen D. Enucleation refusal for retinoblastoma: A global study, *ophthalmic genetics early online. 2014: 1–7.*
11. Nyaywa M, Chipalo-Mutati G, Chintu. C .Modes of Presentation, Management and outcome of Retinoblastoma Treatment at University Teaching Hospital. *Medical Journal of Zambia, 2016;43 (4): 216 - 223*
12. Nyamori JM, Kimani K, Njuguna MW, Dimaras H. "The incidence and distribution of retinoblastoma in Kenya." British Journal of of ophthalmology. 2012; 96 (1):141-142.

13. Bekibele CO, Ayede AI, et al. Retinoblastoma: the challenges of management in Ibadan, Nigeria. *J Pediatr Hematol Oncol* 2009; 31:552–555.
14. Kao LY, Su WW, Lin YW. Retinoblastoma in Taiwan: Survival and clinical characteristics 1978-2000. *Jpn J Ophthalmol* 2002; 46:577-80.
15. Fischbein M, Azjen I et al. Theory of reasoned action as applied to moral behavior-A confirmatory analysis. Journal of Personality and Social psychology. January 1992. DOI:10.1037//0022-3514.62.1.98
16. Menon BS, Alagaratnam J, Juraida E, et al: Late presentation of retinoblastoma in Malaysia. Pediatr Blood Cancer 2009:52:215-217
17. Rodriguez-Galindo C, Wilson MW, Chantada G, et al: Retinoblastoma: One world, one vision. Pediatrics 2008;122:763-770
18. Chen YH, Lin HY, Hsu WM, Lee SM, and Cheng CY: Retinoblastoma in Taiwan: incidence and survival characteristics from 1979 to 2003.Eye (London) 2010; 24: 318–322.
19. Menon BS, Alagaratnam J, Juraida E, et al: Late presentation of retinoblastoma in Malaysia. Pediatr Blood Cancer 2009; 52: 215–217.
20. Kodilinye HC: Retinoblastoma in Nigeria: problem of treatment. Am J Ophthalmol 1967; 63: 469-448
21. Robert M. Lukamba Jean-Jacques A. Yao Theophile A. Kabesha et al Retinoblastoma in Sub-Saharan Africa: Case Studies of the Republic of Côte d'Ivoire and the Democratic Republic of the Congo. J Glob Oncol 2018;4:1
22. Jemal Zeberga S, Alemayehu Mekonnen et al .Presenting signs of retinoblastoma at a tertiary level teaching hospital in Ethiopia. Pan African Medical Journal. 2017; 28:66.
23. Usha Singh, Deeksha Katoch, Savleen Kaur a et al. Retinoblastoma: A Sixteen-Year Review of the Presentation, Treatment, and Outcome from a Tertiary Care Institute in Northern India. Ocul Oncol Pathol 2018; 4:23–32

24. Chantada G, Fandino A, Manzitti J et al. Late diagnosis of retinoblastoma in a developing country. Arch Dis Child. 1999; 80:171–74.

25. Wei Xiao, Huijing Ye, Huiqi Zeng, et al. Associations among Socioeconomic Factors, Lag Time, and High-Risk Histopathologic Features in Eyes Primarily Enucleated for Retinoblastoma. Current eye research 2019:44:1144–1149.

26. Sebastian N. N. Nwosu, Nonso E. Okpala, Chinasa A. et al. Retinoblastoma in Onitsha, Nigeria. Guinness Eye Center, Onitsha, Nigeria. Niger J Ophthalmol 2019; 27:8-11.

APPENDICES

APPENDIX 1: QUESTIONAIRE ENGLISH VERSION

FACTORS ASSOCIATED WITH REFUSAL FOR ENUCLEATION AMONG PARENTS/CAREGIVERS OF CHILDREN WITH RETINOBLASTOMA ATTENDING MUHIMBILI NATIONAL HOSPITAL.

PATIENT IDENTIFICATION…….
QUESTIONNAIRE
SERIAL NUMBER…….
HOSPITAL REGISTRATION NUMBER…….
RECRUITMENT DATE……..
PART A: DEMOGRAPHIC CHARACTERISTICS

1. Sex of the child

a) Male b) Female

2. **Age of the child……..**

3. Gender of the parent or caregiver

a) Male b) Female

4. Age of the parent/caregiver……..

5. Occupation

a) Peasant/Farmer b) Petty business c) Employed d) Student e) Business

6. Marital status

a) Married b) Single c) Divorced d) Widow e) Widower

7. Education level

a) No formal education b) Primary education c) Secondary education d) College or university education

8. **Residency (Fill district and region), Tribe……..**

9. Relationship with the child

a) Father b) Mother c) Uncle/Aunt d) Guardian or other…..Specify

10. How many children do you have?.....

11. Did you know that your child has/had an eye cancer? If yes proceed to the next question

a) Yes b) No

12. How did you come to know that your child has an eye cancer?

a) Just observed some abnormalities in the eye(s) of the child
b) Told by relatives
c) Told by the healthcare workers
d) Local healers told me

13. Was enucleation (eye removal surgery) proposed to you by the doctors as the only treatment option to save your child's life?

a) Yes
b) No

14. Did you agree to the eye removal surgery the first time it was proposed to you? If no proceed to the next qn, if yes proceed to likert scale…..

a) Yes

b) No

15. How long did it took for you to agree?

a) Within two weeks

c) Within two weeks and month

d) More than 3months

QUANTITATIVE PART PARTI: LICKERT SCALE FOR QUANTITATIVE DATA (5-point traditional Likert scale)

Parents/caregivers will be supposed to respond whether they agree or not to the posed statement. Here attitudes, beliefs and experiences of these parents and caregivers will be measured. Family and social economic factors as well as institutional factors associated with refusal of enucleation will be measured.

QN	**STATEMENT**	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1.	Your child has eye cancer called Retinoblastoma					
2.	This eye cancer is very dangerous, it can kill your child					
3.	Decisions and advice given by family members and friend matters more than health care workers advice.					
4.	Am concerned about the appearance of the child after eye removal					
5.	The child without one or both eyes will be stigmatized in our community					
6.	I believe(d) there must be treatment for this condition without removing the eye					
7	Traditional healers in our community can treat this child without removing the eye.					
8.	This condition like many other conditions can be cured by just prayers from our religious leaders					
9	It’s a taboo to remove any organ from the child					
10	Our religion prohibits us from					

	removing any organ from the child even if it was recommended at the hospital.					
11.	It’s a curse to have a child without one or both eyes I would rather let him/her die with both eyes intact.					
12	I was afraid I will be divorced, if had agreed to the eye removal surgery.					
13.	There was enough medical tools and equipemnts at the hospital to support the child prior and after the surgery					
14.	Cost of treatment and surgery as well was high at the hospital we couldn’t afford it					
15.	The medical personel spent enough time on counselling me about eye removal surgery					
16.	It is important to listen and follow advice given by health workers concerning eye removal.					
17	Other parents/relatives of children in the ward/hospital told me the child will die if agree to eye removal surgery.					

PART C: QUALITATIVE PART

SECTION I: IN-DEPTH INTERVIEW OF PARENT /CAREGIVERS.

FAMILY AND SOCIO-ECONOMICAL FACTORS ASSOCIATED WITH REFUSAL.

1. Can you share with me briefly about yourself and the child?
2. What is your experience in caring this child since he/she developed this disease?

- What are your views about this disease? Do you think this is a fatal disease)??

-What made you seek health care?

-How do you feel about raising a child with this disease?

-How is your relationship with your spouse/relatives since you started caring for the child?

-Can you tell me about your experience of care at MNH?

-Was there any challenges you faced when you thought medical care, what bothered you more?

3. Have you ever sought any other treatment modality for this condition?
4. When did you receive the information that your child s eye is supposed to be removed as a necessary part of treatment?

Please explain if it was immediately on the day of admission or days later…….

5. What was your response to the option proposed by the medical practitioner? Please explain in detail on what led you to give your answer. Was there any other specific reason/reasons apart from the ones you have already mentioned for you to give such an answer?
8. Did you discuss with anyone before deciding to give your answer? Explain more if there was someone more important who was involved in your decisions and why did you listen to him/her?

APPENDIX I I: DODOSO LA KISWAHILI
SABABU ZINAZOPELEKEA MIONGONI MWA WAZAZI/ WALEZI WA WATOTO WENYE RETINOBLASTOMA WANAOHUDHURIA KATIKA HOSPITALI YA TAIFA YA MUHIMBILI KUKATAA WATOTO WAO KUFANYIWA UPASUAJI WA KUTOA JICHO/MACHO.

NAMBARI YA DODOSO YA MGONJWA…….
NAMBA YA USAJILI YA MGONJWA……
TAREHE YA KUHOJIWA……..

SEHEMU YA KWANZA: TAARIFA ZA MGONJWA.

1. Jinsia ya mtoto
a)Kike b)Kiume
2. Umri wa mtoto……..
3. Jinsia ya mzazi/ mlezi
a) Kike b) Kiume
4. **Umri wa Mzazi/ mlezi……..**
5**. Shughuli/ kazi ya mzazi/ mlezi**
a) Shughuli ndogo ndogo/Kilimo b)Biashara ndogo c)Mwanafunzi d) Mwajiriwa e 6. **Hali ya ndoa ya mzazi/ mlezi wa mtoto**
a) Ameoa/kuolewa b)Ameachika c) Amefiwa na mke d) Amefiwa na mume

7. Elimu ya mzazi/ mlezi wa mtoto

a) Hajasoma kabisa b) Elimu ya msingi c) Elimu ya sekondari d) Elimu ya chuo

8. Mahali unakoishi. Jaza Mkoa,Wilaya, na Kabila……..

9. Uhusiano wako na mtoto
a)Baba b) Mama c) Dada/ Kaka/ Shangazi/ Mjomba d) Mlezi **e)** Mwingine eleza
10. Idadi ya watoto ulionao……..
11. Je ulijua kwamba mtoto wako ana saratani ya jicho?
a) Yes b) No
12. Ulijuaje kwamba mtoto wako ana saratani ya jicho?
a) Nilimtazama na kuona tu ana shida kwenye macho/jicho lake

b) Ndugu waliniambia

c) Niliambiwa na wahudumu wa afya

d) Watu wa tiba asilia kijijini kwetu aliniambia.

13. Je uliambiwa kuondoa jicho ndio njia pekee ya kuokoa maisha ya mtoto wako?

a) Ndio

b) Hapana

14. Je ulikubaliana na upasuaji wa kuondoa jicho la mtoto kwa mara ya kwanza tu uliposhauriwa? Kama ndio endelea na likert scale,kama hapana endelea swali linalofuata

a) Ndio

b) Hapana

15. Ilikuchukua muda gani mpaka kukubali?

a) Wiki mbili hadi mwezi

b) Mwezi mmoja hadi miezi mitatu

c) Zaidi ya miezi mitatu

SEHEMU YA PILI

SEHEMU YA KUTUMIA LIKERT SKELI

Mzazi/ Mlezi atatakiwa kujibu kuwa anakubaliana au hakubaliani na swali au kipengele cha maelezo aliyopewa. Hapa vinaangaliwa mtazamo, Imani na uzoefu walio nao wazazi au walezi wa watoto wenye saratani ya retinoblastoma.

SL	Sentensi	Nakubali kabisa	Nakubali	Yote sawa	Sikubali	Sikubali kabisaa
1.	Mtoto wako ana saratani ya jicho iitwayo Retinoblastoma.					
2.	Saratani hii ni hatari inaweza kumuua mtoto wako					
3.	Maoni na ushauri unaotolewa na familia na ndugu ni muhimu Zaidi kuliko ninaopata kwa wataalamu wa afya.					
4.	Nina wasiwasi mtoto hatoonekana vizuri baada ya kutolewa jicho/macho.					
5.	Mtoto asiye na jicho moja au macho yote atanyanyapaliwa kwenye jamii.					
6.	Ninaamini(nili) kutakuwa na tiba nyingine mbadala wakuondoa jicho la mtoto					
7.	Watu wa tiba asilia kwenye jamii yetu wanaweza kumtibu mtoto bila kuondoa jicho (macho).					
8.	Tatizo la mwanangu linaweza kutibika kwa maombi tu kama magonjwa mengine					
9	Ni mwiko kabisa katika mila zetu kuondoa kiungo cha mtoto					
10.	Dini yetu hairuhusu kabisa kuondoa jicho la mtoto hata kama wataalamu wa afya walishauri hivyo					
11.	Ni laana kuwa na mtoto asiye na jicho(macho) ni bora nimwache afe na macho yake yote mawili					
12.	Ningeachana na mwenzi wangu kama ningeruhusu mtoto atolewe jicho					
13.	Kulikuwa na vifaa tiba vya					

	kutosha kumsaidia mtoto baada na kabla ya upasuaji wa kuondoa jicho.					
14.	Gharama za matibabu na upasuaji zilikuwa kubwa tulishindwa kulipia					
15.	Wataalamu wa afya walitumia muda wa kutosha kabisa kunishauri kuhusu upasuaji wa kuondoa jicho la mtoto.					
16.	Ni muhimu kufuata na kusikiliza ushauri wa wataalamu wa afya kuhusu matibabu ya mtoto.					
17.	Wazazi wa watoto wengine wodini/hospitalini waliniambia kuwa nikikubali mtoto atolewe jicho atakufa					

PART C: QUALITATIVE PART
SEHEMU YA I: WAZAZI/WALEZI
A. FAMILIA NA SABABU ZA KIJAMII-KIUCHUMI

1. Unaweza kunieleza kwa ufupi kuhusu wewe na huyu mtoto?

2. Tafadhali naomba unieleze uzoefu wako na uliyoyapitia tangu umeanza kumuuguza huyu mtoto.

-Ni upi mtazamo wako kuhusu ugonjwa huu wa mtoto?

-Je ni jambo gani lilikufanya utafute tiba ama umpeleke hospitali?

-Na unajisikiaje kumlea mtoto mwenye tatizo hili?

-Tafadhali niambie je mahusiano yako na mwenzi wako yamekuwaje tangu ulipoanza kuuguza mtoto huyu?

-Unaweza kunieleza zaidi kuhusu yote uliyokutana nayo hapa Muhimbili hospitali kipindi hiki cha tiba ya mtoto?Ni changamoto zipi ulipitia?

3. Je umewahi kutafuta njia nyingine ya tiba?Kama ndio tafadhali nieleze ilikuwaje mpaka ukaenda na matokeo yake yalikuwa ni yapi kama ulipata msaada au la?

4. Je ni lini ulipata taarifa kuwa jicho la mtoto wako litatakiwa kutolewa?

Tafadhali eleza kama ilikuwa nimara tu baada ya kulazwa au ni baada ya siku kadhaa.

5. Ulishauriana/ kujadili na mtu yeyote kabla ya kutoa jibu lako kuhusu upasuaji wa kutoa jicho la mtoto? Tafadhali eleza ulishauri na nani, alikuleza nini na nikwanini ulifuata ushauri wake.

5. Je ni kwanini kukataa ushauri uliotolewa na mtaalamu wa afya? Tafadhali eleza kwa kina sababu zilizopelekea kutoa jibu lako.

6. Kulikuwa na sababu nyingine zilizopelekea wewe kujibu hivyo mbali na hiyo uliyo kwisha kuitoa?



APPENDIX 2: CONSENT FORM

APPENDIX I: CONSENT FORM (ENGLISH VERSION)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS

ID-NO……

CONSENT TO PARTICIPATE IN THE STUDY

My name is Dr. Nicholaus Benedicto; I am conducting a study on factors associated with acceptance or refusal of enucleation among parents/caregivers of children with retinoblastoma attending MNH.

STUDY PURPOSE

This study is conducted to determine the factors associated with acceptance or refusal of enucleation among parents/caregivers of children with retinoblastoma attending MNH. It is also conducted as a partial fulfilment for the completion of Mmed Ophthalmology .Findings from this study will help to create awareness in the community on the effects or late hospital presentation as well as complications associated with refusal of treatment.

HOW TO BE INVOLVED

The patients who will agree to participate in this study will be required to sign the consent form, then interviewed after that.

CONFIDENTIALITY

The information obtained from you will be confidential. No name will appear on any document of this study instead Identification numbers will be used.

PARTICIPATION AND RIGHT TO WITHDRAW

Involvement in this study is voluntary. You can participate or refuse to participate from this study. Refusal to participate from this study will not interfere with the treatment of your child.

BENEFITS

The information that you will provide, will help in addressing the factors associated with refusal hence form proper measures to eliminate them, this inturn will improve the survival rates of these children.

For any concern please, contact me personally or to any of the following

If you ever have questions about this study, you should contact the Principal Investigator, Dr. Nicholaus Benedicto, Muhimbili University of Health and Allied Sciences, P. O. Box 65001, Dar es Salaam.Tel. **+255689692125.**OR in case you have questions about your rights of participation in this study you may contact Dr.Bruno Sunguya Diretor of Research and publications P. O. Box 65001 DSM. Telephone**: +255 022 2152489.**

Dr. Anna Sanyiwa who is the supervisor of this studyTel. **+255 784717461.**

Participant agreement.

I ……. have read the contents in this form. My questions have been answered. I am willing to participate in this study.

Signature of participant ……Date…….……

Signature of Researcher …….Date…….

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

Appendix ii: Consent Form (Swahili Version)

CHUO KIKUU CHA SAYANSI ZA AFYA MUHIMBILIKURUGENZI YA TAFITI NA UCHAPISHAJI

FOMU YA RIDHAA

Namba ya utambulisho ----------

RIDHAA YA KUSHIRIKI KWENYE UTAFITI

Naitwa Dkt. Nicholaus Benedicto, nafanya utafiti kuhusu sababu zinasosababisha wazazi/ walezi wa watoto wenye retinoblastoma wanaohudhuria katika Hospitali ya Taifa Muhimbili, kukukubali au kukataa watoto wao wasifanyiwe upasuaji wa kutoa jicho/macho.

DHUMUNI LA UTAFITI

Dhumuni la utafiti huu ni kutaka kujua sababu zinazopelekea miongoni mwa wazazi wenye watoto wenye retinoblastoma wanaohudhuria katika Hospitali ya taifa Muhimbili kukubali au kukataa watoto wao wasifanyiwe upasuaji wa kutoa jicho au macho.

Dhumuni jingine la Utafiti huu ni pamoja na kutimiza sehemu ya matakwa ili kutunukiwa shahada ya uzamili wa matibabu ya Macho ya Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili.

Matokeo ya utafiti huu yatasaidia katika kuleta hamasa na mwamko katika jamii yetu kuhusu kuwahi kwenda Hospitali na kukubali tiba zinazopendekezwa na wataalamu wa afya ya macho, hii itasaidia katika kupunguza vifo vya watoto wenye saratani ya Retinoblastoma.

JINSI YA KUSHIRIKI

Ukikubali kushiriki katika utafiti huu, utasailiwa alafu utatakiwa kujibu maswali kutoka kwenye dodoso lililo andaliwa na mtoto wako ataendelea na tiba kama kawaida.

USIRI

Taarifa zote zitakazo kusanywa kupitia dodoso hili zitakuwa ni siri. Jina lako halitatumika badala yake tutatumia namba yako ya utambulisho.

UHURU WA KUSHIRIKI NA HAKI YA KUJITOA

Kushiriki kwenye utafiti huu ni hiari. Unaweza kushiriki au kukataa kushiriki na hii haita muondolea mtoto wako haki yake ya kupata matibabu.

MAWASILIANO

Kama una maswali kuhusiana na utafiti huu, wasiliana na mtafiti mkuu, Dkt. Nicholaus Benedicto, Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili, S. L. P. 65001, Dar es Salaam. Simu**+255789692125** Dr. Bruno Sunguya, Mkurugenzi wa Utafiti na Uchapishaji, **S.L.P 65001, Dares Salaam. Simu+255 022 2152489** au msimamizi wa utafiti huu Dkt Anna Sanyiwa Simu +**255 784717461**

Kama umekubali kushiriki weka sahihi

Mimi..... nimesoma maelezo ya fomu hii nimeyaelewa na nimekubali kushiriki katika utafiti huu.

Sahihi ya mshiriki……Tarehe ya kutia sahihi…….....

Sahihi ya mtafiti…….Tarehe ya kutia sahihi……