

**KNOWLEDGE AND ATTITUDES OF CARETAKERS OF CHILDREN SUFFERING
FROM BRAIN TUMORS. LESSONS FROM MULAGO NATIONAL
REFERRAL HOSPITAL.**

BY

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Abstract

This study investigated the knowledge and attitude of Caretakers of children suffering from Brain tumors focusing on Mulago Hospital, Kawempe division, Kampala, Uganda. A cross-sectional study design was used, respondents were determined by adapting a Krejcie and Morgan Table 1970, and convenient sampling was used to select 50 respondents including 16% fathers, 56% mothers, 20% grandparents, and 10% others. The specific objectives of the study were a) to assess caretakers' knowledge of brain tumors in children in Mulago Hospital and (b) to evaluate the attitude of Caretakers towards the management of brain tumors in children in Mulago Hospital. Data was collected using a self-administered questionnaire and entered, analyzed using SPSS, and exported to an Excel program for analysis. Results were presented in both tabular and graphic forms. The study found that 46% of caretakers had fair knowledge and the majority had negative attitudes toward brain tumors. The study concluded that caretakers had fair knowledge related to medicine names, painful procedures, side effects and duration of treatment and further showed majority of caretakers had negative attitudes, especially about procedures and side effects of treatment hence more Brain tumors, Knowledge, caretakers.

Keywords: Brain Tumors; Caretaker Knowledge; Caretaker Attitude; Pediatric Oncology

Declaration

I **Musiimenta Sandra** do declare that the content in this research work is proved to be my own authentic work and has never been published by anyone in any academic sphere.

Signature.....

Date.....

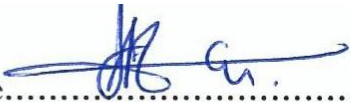
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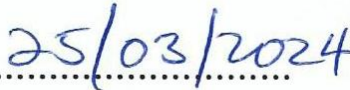
Researcher



Approval Sheet

This dissertation has been done under my supervision and it is ready for submission to King Ceasor University authorities with my approval as a university supervisor.

Signature.....
Dr. Amos Ronald Kalukusu
(Supervisor)

Date.....



Dedication

I dedicate this work to my family and friends who sacrificed a lot of time and money to support me do this work.

Acknowledgement

I wish to thank the almighty lord for having enabled me write this research and also helping me finish the entire course of bachelors of Science in nursing.

I also want to thank the management of king Ceasor University. Lecturers and the entire staff more especially my supervisor for his good work and time.

Appreciation goes to my classmates, colleagues, friends for the wonderful time they offered to me while I was writing this research report. May God bless them abundantly.

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List of Abbreviations

CNS : central nervous system

DNA : Deoxyribonucleic acid

DEFINITION OF TERMS

Attitudes:	Responses on hope of curability, satisfaction with treatment, anxiety regarding child's future, studies and play.
Caretaker:	An individual who is predominantly responsible for an individual who is unable to care for themselves. The caretaker may be a father, mother, family member or volunteer engaged in their care
Craniopharyngioma:	Non-cancerous brain tumors that usually form near the pituitary gland and hypothalamus
Gliomas:	Growth of cells that start in brain or spinal cord
Knowledge:	Caretakers understanding of child's condition, Means understanding or awareness of an individual
Medulloblastoma:	Fast growing type of cancer that form in cerebellum
Pilocytic astrocytoma:	Slow growing type of primary central nervous system tumors
Tumor:	Abnormal growth of cells

CHAPTER ONE: INTRODUCTION

1.1 Introduction

Brain tumors are the leading cause of death from cancer in children. They are abnormal growth or mass of cells in or around the brain (Butowski, 2015). Tumors of Central Nervous System(CNS) account for 20% of childhood cancers making them second only to Leukemia in frequency (Stanić et al., 2021). They are caused by changes in DNA inside the cell. Brain tumors are classified into Supratentorial and Infratentorial (Subramanian & Ahmad, 2018). They can be malignant (cancerous) or benign (non-cancerous) and are categorised as Primary tumors or glial (develop from the brain) and Secondary tumors or non-glial (develop from outside the brain), one-third of brain tumors are cancerous (Seunggu, 2022).

Globally, the incidence of pediatric brain tumors varies by country, ranging from 1.15 to 5.14 cases per 100,000 children. In Sub-Saharan Africa, the incidence of pediatric cancer was reported to at 3,101 cases whereas in a cross sectional study conducted in Kenya hospital showed that 88 brain tumor pediatric patients were recorded and records retrieved (Mutua et al, 2019). In Uganda, 121 children had brain tumors as stated in a case study conducted by Victoria et al (2023) at Mulago hospital from may 2019 to march 2023 . These findings were likely underestimated due to the lack of proper diagnosis and cancer registration. A retrospective series conducted in Uganda found various histologic types in children with brain tumors, including Pilocytic astrocytoma, Ependymoma, Craniopharyngioma, choroid plexus papilloma, medulloblastoma, and supratentorial tumors. Children with brain tumors typically present with symptoms such as headaches, nausea, vomiting, sleepiness, vision or hearing changes, personality changes, balance problems, seizures, and increased head size (Loughan et al., 2019).

Currently, treatment varies according to the tumor whether Benign or malignant for treatment can be palliative care or surgery or chemotherapy. The impacts include lower self-esteem, depressive symptoms and more severely compromised quality of life than other types of pediatric cancer survivors (Cheung et al., 2019; Pancaldi et al., 2023). Therefore, these children require a lot of supportive care.

“When a child is diagnosed with cancer, the whole family is diagnosed” (Jones, 2012). Care takers play a very significant role in the management of children with brain tumours for example they can be involved in management of treatment, attend clinic visits, hospital stays, and other treatment related tasks (Jibb et al., 2021).

As caretakers come to terms with the fact that their child has been diagnosed with cancer, they also need to gain new knowledge to ensure the safe care of their child in the home environment. (Rodgers et al., 2018). Caretakes undertake difficult medical procedures, oversee patients, make decisions, address challenges, offer emotional assistance, and manage the coordination of healthcare (El-Sawy et al., 2013).

There is scarcity of studies that investigated the caretaker’s knowledge, attitudes and practices of their children’s brain tumours. Good knowledge has been reported in some studies a (Nair et al., 2017). Also, moderate knowledge has been reported among patients and caregivers. A study conducted in India reported that most of cancer patients had moderately adequate knowledge (Aweke et al., 2017). Another study from Mexico exploring the current knowledge of childhood cancer among parents and caregivers reported that 41.6% of the respondents were knowledgeable of childhood cancer (Uribe-Ortiz et al., 2022). Poor knowledge has likewise been reported among communities. For example, in a community based cross-sectional study

assessing brain cancer among women of child bearing age in Hossana town, Southern, Ethiopia reported that 46% of the participants had poor knowledge (Aweke et al., 2017).

Regarding attitudes positive attitudes have been reported in several aspects regarding cancer diagnosis and treatment, hope for cure and good communication (Naghavi et al., 2023).

Anecdotal data from Mulago National Referral Hospital reveals a concerning situation where caretakers of patients lack vital information about their loved ones' conditions. This information gap leads to heightened anxiety, stress, and even depression among caregivers. Many are in the dark about the appropriate course of action and the treatments available for their patients. When new patients arrive at the hospital, a series of crucial steps are undertaken to determine the most suitable approach to their care. This includes patient registration, gathering their medical history, conducting assessments, and performing blood work and radiology investigations. The results of these investigations help in determining whether the patient requires surgery, counseling, or chemotherapy. Following this, the patient is admitted to either the pediatric neurosurgical ward or the pediatric oncology ward, depending on their specific needs.

The treatment options offered to these children suffering from brain tumors encompass chemotherapy, surgical procedures, or palliative care, depending on the severity and nature of their condition. However, despite these essential steps in patient care, there is a significant gap when it comes to educating and supporting the caretakers. The absence of a formalized process for educating caretakers further exacerbates the difficulties faced by these individuals. This lack of understanding and support hampers the quality of care that can be provided to the patients. In light of these issues, the primary goal of this study is to assess the knowledge and attitude of caretakers of children suffering from brain tumors at Mulago National Referral Hospital. The

results of this study will serve as valuable insights to inform future interventions and improve the support system for these caretakers, ultimately enhancing the overall quality of care provided to the young patients at the hospital.

1.2 Problem Statement

A paediatric brain tumor diagnosis impacts an entire family unit from diagnosis through curative treatment and into survivorship or bereavement (Robinson et al., 2019). Evidence in a study conducted among caregivers of adolescents showed that only 45% accounted in caregiver competence (Deatrick et al., 2014) and another study showed that 81% mother's reported high levels of anxiety while 66% mother's worried regarding painful procedures (Srivastava & Srivastava, 2022). Presently in Uganda, there is scanty literature of knowledge of caretakers on brain tumors due to the lack of proper diagnosis, uncertainty of epidemiology childhood cancer registration, (Stagno et al., 2014). Caretakers are the first line involved in daily management of patients. Therefore, having inadequate knowledge on this condition puts the patient at high risk of morbidity and death and also puts that family to more anxiety and stress. Mulago National Referral Hospital is the only National Referral Hospital for brain tumor management Centre which also partners with CURE children's Hospital of Uganda. Health talks, family conferences are provided to caretakers daily from Monday to Friday for those who attend out-patient clinic. The health talks mostly cover manifestation, signs and symptoms, chemotherapy, counseling, prognosis and what brain tumor means to the children. Despite the family conferences, caretakers still continue to face stress and anxiety; role conflict, role strain and parental quality of life are still the greatest challenges. This study sets out to assess the knowledge and attitude of caretakers regarding the management of brain tumors in children.

1.3 Purpose of Study

To explore the knowledge and attitudes of caretakers toward the management of brain tumors in children in Mulago hospital.

1.4 Specific Objective

- 1) To assess the caretakers knowledge of brain tumors in children in Mulago hospital.
- 2) To evaluate the attitude of caretakers towards the management of brain tumors in children in Mulago National Referral Hospital.

1.5 Research Question

- 1) What was the level of knowledge of caretakers toward the management of brain tumors in children in Mulago National Referral Hospital?
- 2) What was the attitude of caretakers toward the management of brain tumors in children in Mulago National Referral Hospital?

1.6 Justification

It was found and documented that high knowledge and attitude were required for effective management of brain tumors. Assessment of knowledge and attitude of caretakers who were the first line of care for patients was urgently required. The literature on knowledge levels regarding brain tumors was almost non-existent or scanty among the caretakers and general population. This study therefore aimed to assess knowledge and attitudes of caretakers towards the management of brain tumors in children in Mulago National Referral Hospital. This would inform policy makers to make informed decisions and design evidence-based interventions that would improve the management and quality of life of patients with brain tumors.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The impact of a child's diagnosis with a brain tumor extends beyond the medical realm, affecting the psychosocial well-being of both the afflicted child and their caretakers. This literature review aims to explore the existing body of knowledge regarding the knowledge and attitudes of caretakers of children diagnosed with brain tumors.

2.3 Brain Tumor

Understanding the prevalence and demographics of brain tumors in children is crucial for contextualizing the challenges faced by caretakers. Studies suggest that brain tumors are one of the most common solid tumors in pediatric oncology, necessitating an in-depth exploration of the associated caregiver burden.

A brain tumor is an abnormal and uncontrolled growth of cells within or around the brain. These cells can originate in the brain itself (primary brain tumor) or spread to the brain from other parts of the body (metastatic or secondary brain tumor) (Subramanian & Ahmad, 2018). Brain tumors can be benign (non-cancerous) or malignant (cancerous) and can vary in size, location, and aggressiveness. They are caused by changes in DNA inside the cell. Brain tumors are classified into Supratentorial and Infratentorial (Subramanian & Ahmad, 2018).

Globally, the incidence rate of paediatric brain tumors varies among different countries ranging from 1.15 to 5.14 cases per 100,000 children (Subramanian & Ahmad, 2018) with the highest being in the United States which accounts for 5.3 cases per 100,000 with a number of 16,044 incident tumors (PLGA foundation, 2015). In Sub-Saharan Africa, an estimated 5-year

prevalence of cancers in 2018 for children 14 years and below was 606,982 and paediatric cancers was 103,016 with brain and nervous system accounting for 3,101(Ndlovu et al., 2019).

In a retrospective operative series conducted in Uganda on 172 children at CURE children's hospital showed that children presented with many histologic types like Pilocytic astrocytoma(23.3%), Ependymoma (16.3%), Craniopharyngioma (9.9%), choroid plexus papilloma(9.3), medulloblastoma (8.1%), supratentorial tumor (62.2%) but this was underestimated due to lack of proper diagnosis and childhood cancer registration. Pediatric brain tumors have a unique and profound impact on children and their families. The effects of these tumors can be particularly challenging due to the developmental stages and vulnerabilities of young patients. The impacts include lower self-esteem, depressive symptoms, more severely compromised quality of life than other types of pediatric cancer survivors (Cheung et al., 2019; Pancaldi et al., 2023).

2.3 Knowledge on Brain Tumors among Caretakers.

Parents of children newly diagnosed with cancer need to acquire knowledge and skills to effectively care for their child at home. To facilitate this, a standardized education checklist has been proposed, categorizing topics into primary, secondary, and tertiary areas. Primary education topics are vital before the initial hospital discharge, covering aspects like diagnosis communication, when to seek help, medication management, and appointment schedules. Secondary topics, to be discussed within the first month after diagnosis, include cancer overview, treatment effects, and practical considerations. Tertiary topics, meant to be addressed before completing therapy, encompass various aspects like vaccinations, emotional support, coping strategies, and financial resources. This structured approach aims to empower parents and

caregivers with the necessary tools to navigate the challenges of pediatric cancer care (Rodgers et al., 2018).

Caretakers' knowledge about brain tumors significantly influences their ability to cope with the diagnosis and contribute to the child's well-being. Research indicates that caretakers often lack comprehensive information about the nature of brain tumors, treatment options, and potential outcomes. Enhancing caretakers' knowledge is essential for fostering informed decision-making and improving the overall quality of care provided to the child.

Understanding the level of knowledge among caretakers is critical for providing effective care to children with cancer. Studies have consistently emphasized the importance of caretakers' awareness of cancer symptoms, treatment modalities, and potential side effects (Smith et al., 2018). A study by Johnson and Brown (2019) highlighted that knowledge gaps among caretakers can lead to delays in seeking medical attention and hinder optimal treatment outcomes. Educational interventions targeted at caretakers have been shown to improve their understanding of childhood cancer, resulting in better-informed decisions regarding treatment options (Clark et al., 2020).

Good knowledge has been reported in some studies. A study conducted in India showed out of 43 mothers (88%) knew the name of their child's cancer, 34 mothers (79%) knew the type of treatment received by child, and 39 mothers (90%) were aware of the approximate duration of treatment. 40/43 mothers (93%) knew that their child would be subjected to painful procedures such as lumbar puncture (LP)/bone marrow examination and 35 mothers (81%) were aware that these procedures would be repeated multiple times during the course of treatment. All parents were aware of the common side effects of treatment such as nausea, vomiting, and hair loss and

36 mothers (84%) reported knowing about serious side effects such as bleeding or life-threatening infection (Nair et al., 2017).

Also, moderate knowledge has been reported among patients and caregivers. A study conducted in India reported that most of cancer patients had moderately adequate knowledge (Aweke et al., 2017). Another study from Mexico exploring the current knowledge of childhood cancer among parents and caregivers reported that 41.6% of the respondents were knowledgeable of childhood cancer (Uribe-Ortiz et al., 2022).

Poor knowledge has likewise been reported among communities. For example, in a community based cross-sectional study assessing cancer among women of child bearing age in Hossana town, Southern, Ethiopia reported that 46% of the participants had poor knowledge (Aweke et al., 2017). Similarly, other studies conducted in Northwestern Ethiopia (Getahun et al., 2013). The following factors have been associated poor knowledge; a negative attitude, not having health seeking behavior for cervical cancer, not having received information about cancer and its prevention, not actively seeking health information.

2.4 Attitudes of Caretakers Toward Brain Tumors in Children

Caretakers' attitudes significantly impact the overall care and support provided to children with cancer. Positive attitudes are associated with better adherence to treatment regimens, increased engagement in psychosocial support programs, and improved emotional well-being for both the child and caretaker (Jones & White, 2017). Conversely, negative attitudes may contribute to increased stress levels and potential challenges in adhering to complex treatment plans. Research by Williams et al. (2019) highlighted the need for psychological support for caretakers, emphasizing the impact of their attitudes on the overall quality of care provided to children with

cancer. The psychological impact of caring for a child with a brain tumor is profound and often leads to emotional distress, anxiety, and depression among caretakers. Exploring the attitudes of caretakers towards the diagnosis, treatment modalities, and prognosis is crucial for developing targeted interventions that address their emotional and mental well-being.

Positive attitudes have been reported in several aspects regarding cancer diagnosis and treatment. In a study that determined the perception of symptom burden early in treatment and assess attitudes toward early integration of palliative care in pediatric oncology patient-parent, most parents and children were comfortable with the integration of palliative care and did not consider it to be intrusive, interfere and cause loss of hope (Levine et al., 2017).

In another study conducted in India that assessed parents' knowledge and attitudes regarding their child's cancer, a high percentage of mothers (90%) expressed a positive attitude toward the potential cure with treatment and satisfaction with the current treatment. However, a substantial number of mothers (81%) reported being preoccupied with thoughts about their child's disease, accompanied by high levels of anxiety. Specific concerns were identified, with a majority of mothers expressing worry about painful injections (62%) and procedures (66%), while a smaller percentage (20%) reported concerns about nausea and vomiting related to chemotherapy. Interestingly, a portion of parents (25%) felt that their child was aware of their cancer, but none of them desired their child to be informed about it. Reasons cited included fear, potential depression, non-cooperation with treatment, or difficulty in handling the situation.

In regards to communication of the diagnosis, participants affirmed the patient's right to be informed about the diagnosis and prognosis, expressing a personal desire for the same

transparency if they were facing a cancer diagnosis. However, a significant portion of caregivers reported not having discussed the illness with the affected patient (Naghavi et al., 2023).

Conclusion

This literature review provides a comprehensive overview of the knowledge, attitudes, and practices of caretakers of children suffering from brain tumors. It underscores the need for targeted interventions to enhance caretakers' knowledge, address their emotional well-being, and improve the overall support provided by healthcare systems. Future research should focus on developing and evaluating innovative strategies to empower caretakers and optimize the care and outcomes for children with brain tumors.

CHAPTER THREE: METHODOLOGY

3.1. Introduction

This chapter presents the research methodology used in the study. This includes; description of the study design and rationale, description of study setting and rationale, study population, sample size determination, sampling procedures, inclusion criteria, definition of variables, research instruments, data collection procedure, description of data analysis and management, ethical consideration, study limitations and dissemination of results.

3.2. Study Design and Rationale

A cross sectional study and quantitative method of data collection were used. This was to allow describe the elements in the study and data collection to be taken in the shortest period of time.

3.3. Study Setting and Rationale

The study was conducted in Mulago Specialised Referral Hospital Oncology and Neurological wards. Mulago National Referral Hospital located in Kampala the capital city of Uganda, in Kawempe division, a teaching hospital with a bed capacity of 1,790 patients. Two wards and one out-patient clinic handle brain tumors being paediatric oncology ward and paediatric neurology ward. Mulago being the only Referral center for people with brain tumors at national level also offers surgical, orthopedic and paediatric services as well as immunization and outpatient services.

3.4 Study Population

This study includes caretakers of children with brain tumors from paediatric - oncology ward, paediatric- Neurology unit and out- patient clinic.

3.4.1 Sample Size Determination

50 respondents were determined from all caretakers having children with brain tumors from units where these children are catered for and this was to get a good representation of the population by adapting Krejcie and Morgan Table 1970 to determine the sample size. (See Appendix VII)

3.4.2 Sampling Procedure

Convenient sampling was utilized to select the participants because it was simple and efficient to implement and Caretakers of children below 18 years of age were the participants.

3.4.3 Eligibility Criteria

Inclusion

Caretakers from oncology unit that is Pediatric oncology ward 5A and those who attended out- patient clinic from Monday to Friday

Caretakers from pediatric neurology unit that 3A surgical pediatric Neuro- spine ward and those who attend outpatient clinic on Mondays

Caretakers of children below 18 years suffering from Brain tumors who signed an informed consent and are on Neuro- oncology units

Exclusion

Caretakers who had not signed the informed consent form and were not attending Neuro- oncology units

Caretakers of patients suffering from Brain tumors and who were above 18 years of age who didn't attend Neuro-oncology units.

Caretakers who had children suffering from other cancers not brain tumors like leukemia and other solid tumors though they attended Neuro-oncology units

Caretakers from other wards especially those attending to children suffering from other illnesses not brain tumors and were admitted to other wards like medical wards

3.5 Definition of Variables

Knowledge was measured by responding to questions concerning the condition/cancer, pain management, side effects, type of treatment given, duration of treatment, knowledge about painful procedures, side effects of medication and risk of relapse

Attitudes: was assessed using responses on hope of curability, satisfaction with treatment, anxiety regarding child's future, studies and play.

Dependent variable: Children with brain tumors

3.6 Research Instruments

We adapted a research questionnaire developed by Nair et al., (2017). The questionnaire was divided into four parts;

The first part covered the social demographic characteristics of caretakers.

The second part right consisted of knowledge and attitudes of caretakers with children having brain tumors and each interview took 10-15minutes.

3.7. Data Collection Procedures

An introductory letter was acquired from King Ceasor University which was then presented to the research committee of Mulago and after approval was presented to the Heads of Departments Neurology and Oncology for permission to collect data.

Informed consent was sought from caretakers.

All interviews were conducted in privacy and caretakers were assured confidentiality of all information got was only be for academic purposes and only the researcher accessed the data collected.t.

Serial numbers were used to identify information; no names were recorded in the questionnaires or anywhere.

3.7.1 Data Management

The data collected from the caretakers was kept anonymously in two separate files edited and stored on a flush disk.

3.7.2 Data Analysis

Data was entered using SPSS and exported to excel program for analysis. Data analysis was based on objectives and all variables were presented in the conceptual framework that is social demographic characteristics of caretakers, knowledge and factors. Descriptive statistics were applied to describe caretakers' characteristics i.e. percentages, proportions, mean, medium and standard deviation (SD). Knowledge and attitudes were analysed by adding up the scores and categorizing them in good (score 50 and above) or poor (score between 0-49).

3.8 Ethical Approval

King Ceasor University research committee approved the proposal.

The research was approved by Mulago hospital research and ethics committee.

An introductory letter was acquired from King Ceasor University ethical committee.

During data collection, an informed consent was sought from the respondent/ participants and anonymity was ensured. The study posed no risks/harm to caretakers. It was voluntary and no threat posed to them especially those who choose not to participate. The data collection was used for the intended purpose which was purely academic.

All sensitive information such as name and other particulars of caretakers including the addresses were treated confidentially during the analysis and reporting process.

The university approved the final work for publication.

3.10 Dissemination of Results

The results of this study will be disseminated through a research report to be submitted to King Ceasor University, Mulago Research and Ethics Committee, Neurology and Paediatric - Oncology unit. Information obtained from the study will be shared with the head of department to improve on the services provided. Findings will also be shared with Cure hospital. A manuscript will be written and published in an appropriate journal.

CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.0 Introduction

This chapter presents results of this study and it shows demographic and perception of Caretakers on the brain tumor in children. A total of 50 Caretakers who have children suffering from Brain tumors from Neuro- oncology units in Mulago Hospital were studied. 15(30%) of brain tumor patients were aged between 6-10 years of age, 28(56%) patients were male, Gliomas were the commonest type of tumors covering 17(34%) in children, mothers were the primary Caretakers taking 28(56%), 16(32%) Caretakers were aged between 25-34 years, 23 (46%) completed primary school education and 45(90%) reported no family history of cancer.

4.1 Demographic Information

4.1.1 Distribution of Children's Age

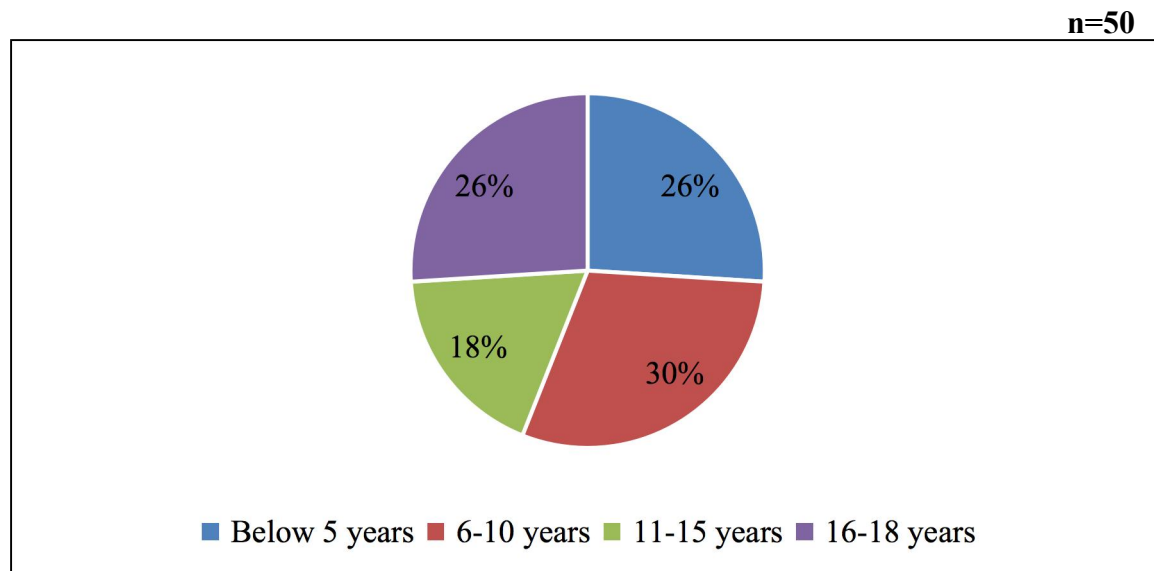


Figure 1: Age of Children Suffering from Brain Tumors in Years.

Source: Primary Data 2024

13 (26%) were below five years of age, 14 (30%) were children aged between 6-10 years, 9(18%) children were aged between 11-15 years and 13 (26%) children were aged 16-17 years.

n=50

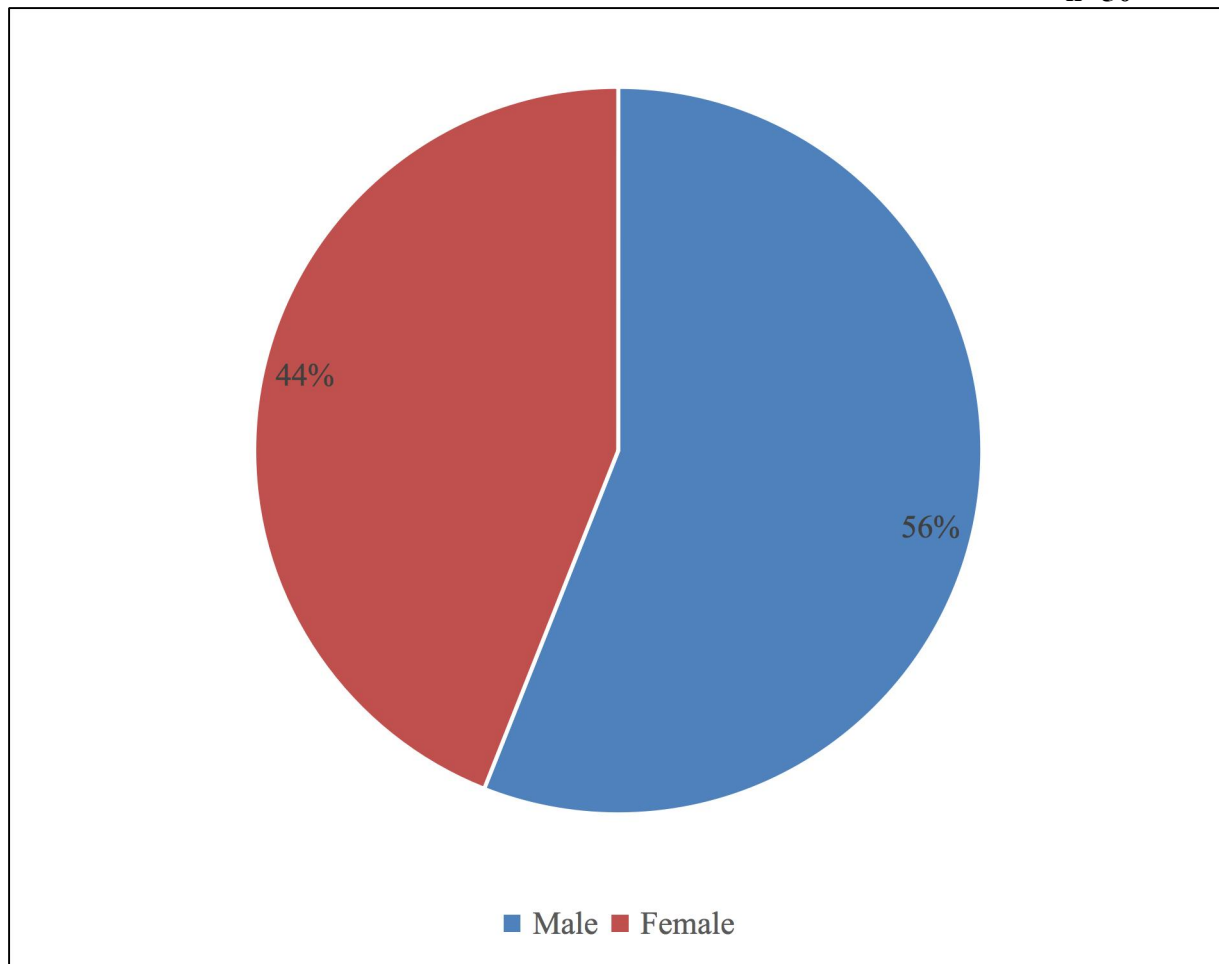


Figure 2: Gender of Children Suffering from Brain Tumors.

Source: Primary Data 2024

Majority 28 (56%) of the children suffering from Brain tumors were males while minority 22 (44%) were females.

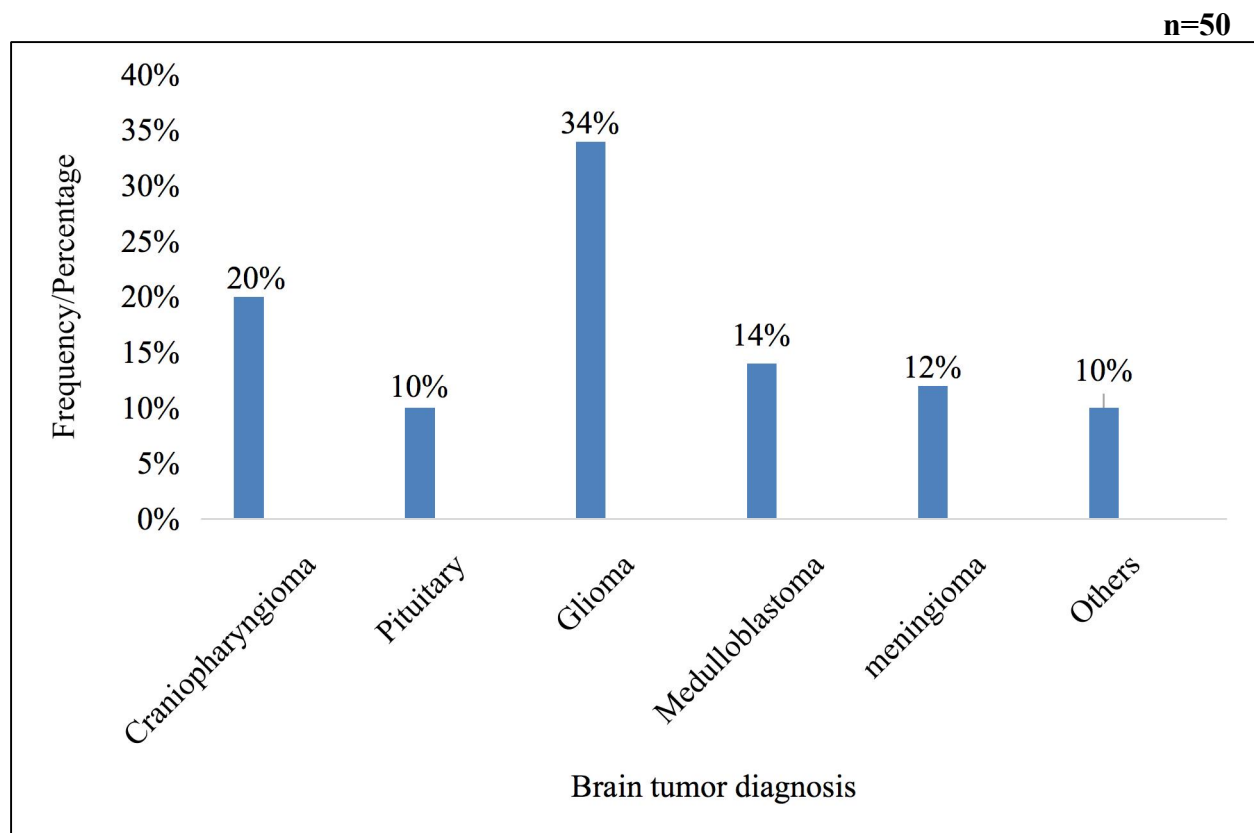


Figure 3: Brain Tumor Diagnosis

Source: Primary Data 2024

10(20%) of the children were diagnosed with craniopharyngioma, 5(10%) had pituitary tumors, 17 (34%) children had Gliomas , 7(14%) had medulloblastoma, 6 (12%) had meningiomas and 5 (10%) were diagnosed with others tumors like suprasellar and posterior fossa brain tumors.

n=50

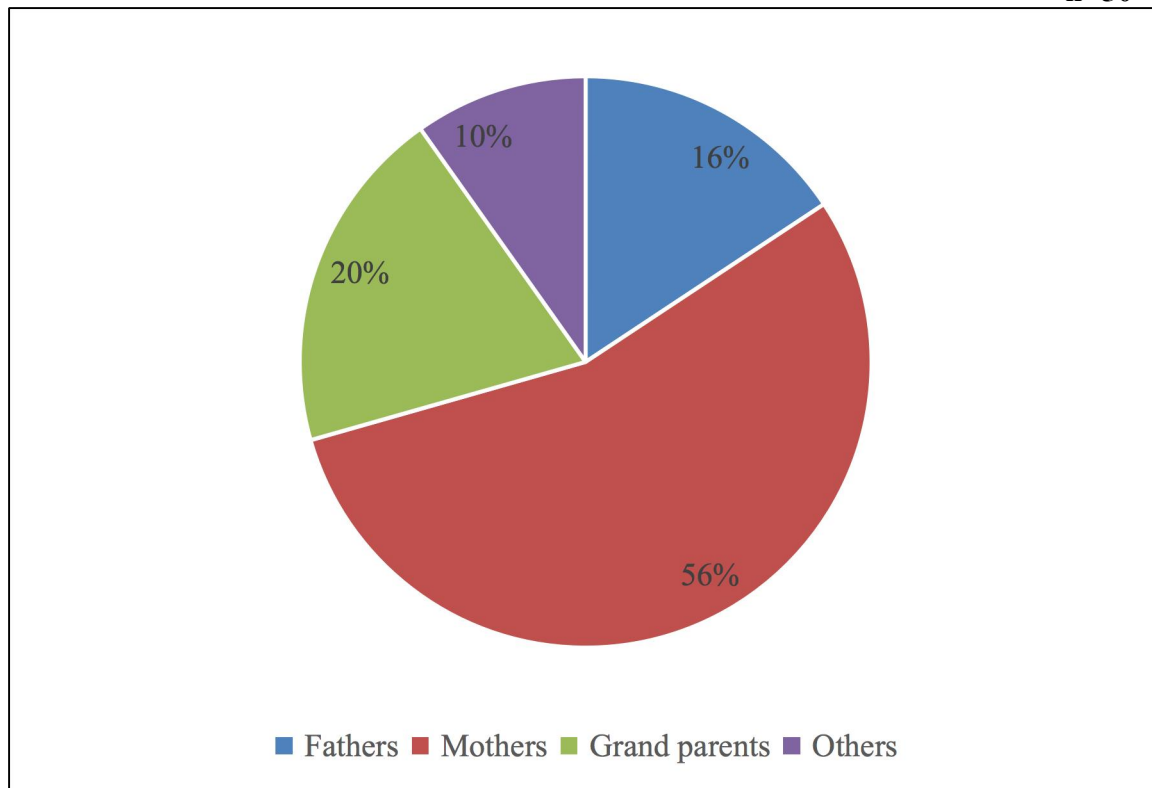


Figure 4: Primary Caretakers

Source: Primary Data 2024

Majority of the primary caretakers were mother's being 28(56%), 8 (16%) respondents were fathers, 10(20%) respondents were grandparents and 5(10%) respondents were others.

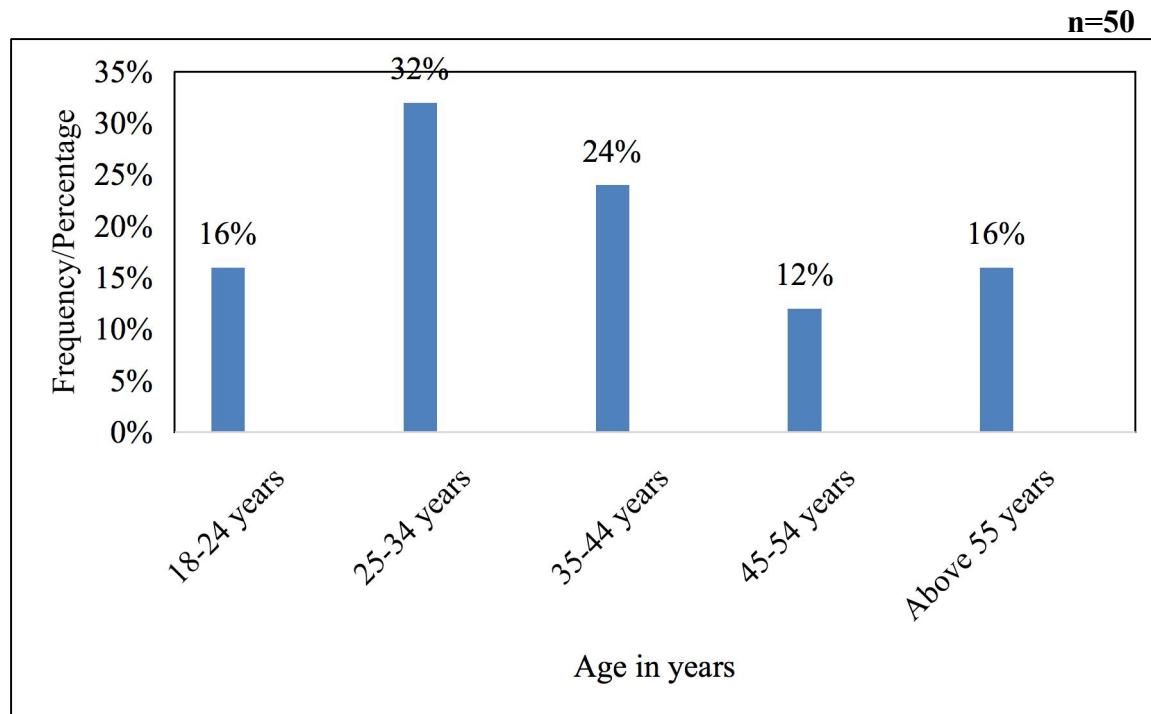


Figure 5: Respondents Age in Years.

Source: Primary Data 2024

8 (16%) respondents were aged between 18-24 years of age, 16 (32%) respondents were aged between 25-34 years, 12 (24%) respondents were between ages of 35-44 years, 6 (12%) respondents were aged between 45-54 years and only 8 (16%) were above 55 years.

n=50

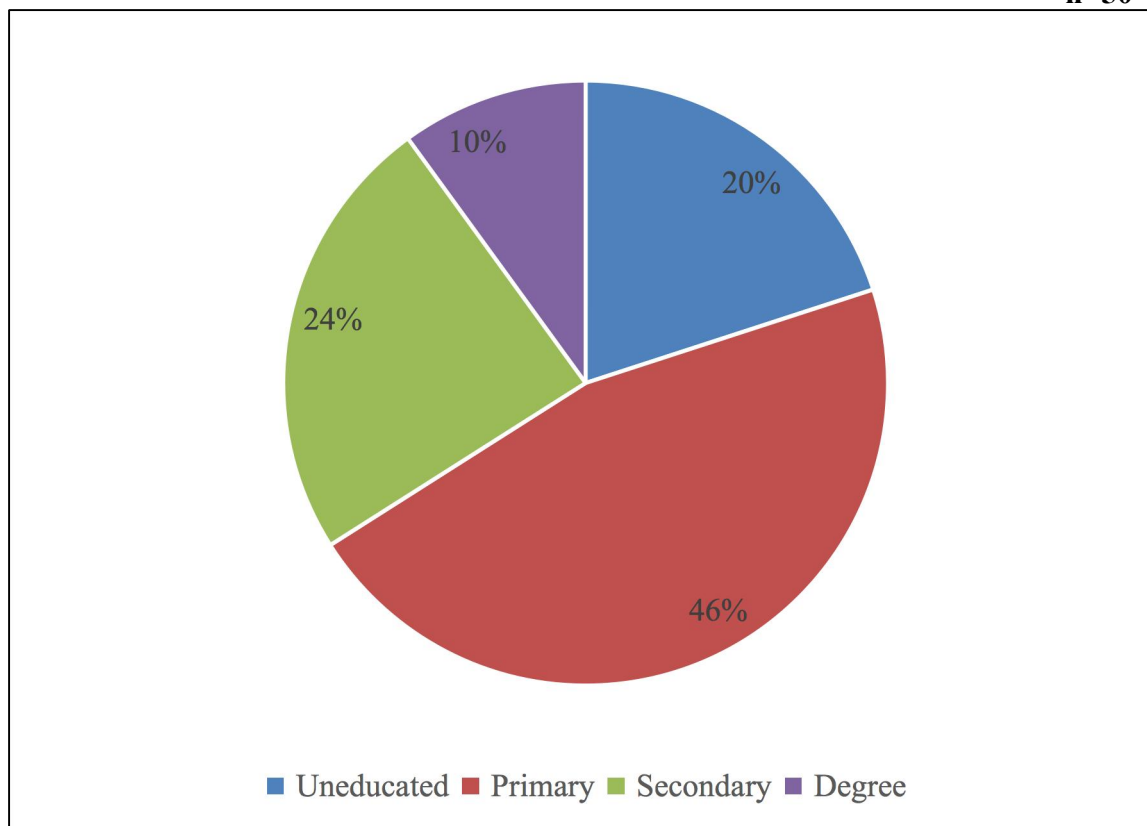


Figure 6: Respondent's Level of Education.

Source: Primary Data 2024

10(20%) respondents were not educated, majority 23(46%) respondents had completed primary education, 12 (24%) respondents had completed secondary education and minority 5(10%) had graduated with degrees.

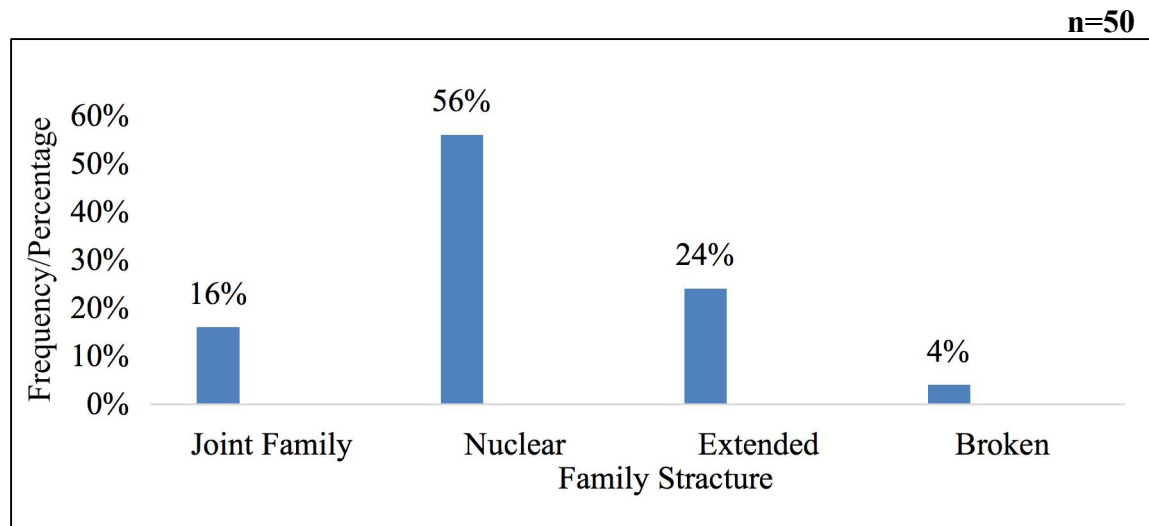


Figure 7: Respondents Family Structure.

Source: Primary Data 2024

8(16%) respondents were from joint families, 28 (56%) respondents were from nuclear families, 12 (24%) respondents were from extended families and only 2 (04%) were from broken families

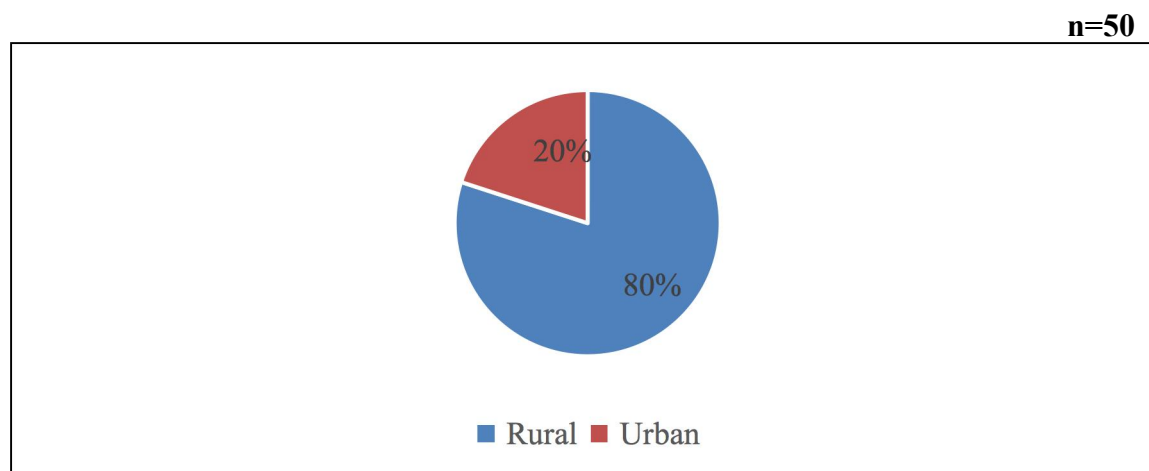


Figure 8: Respondents Domicile.

Source: Primary Data 2024

Majority 40 (80%) respondents were from rural areas while minority 10 (20%) respondents were from urban areas.

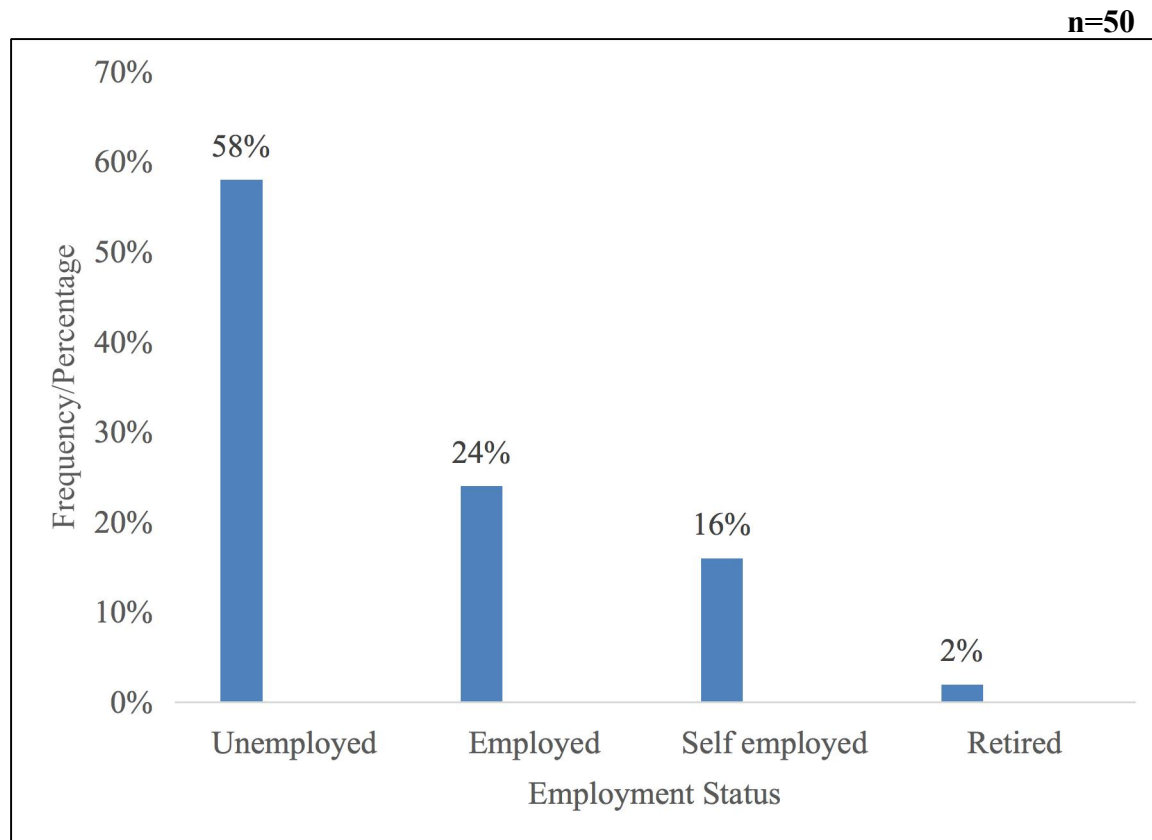


Figure 9: Respondents Employment Status.

Source: Primary Data 2024

Majority 29 (58%) respondents were unemployed, 12 (24%) respondents were employed, 1 (02%) respondent was retired and 7 (14%) respondents were self-employed.

n=50

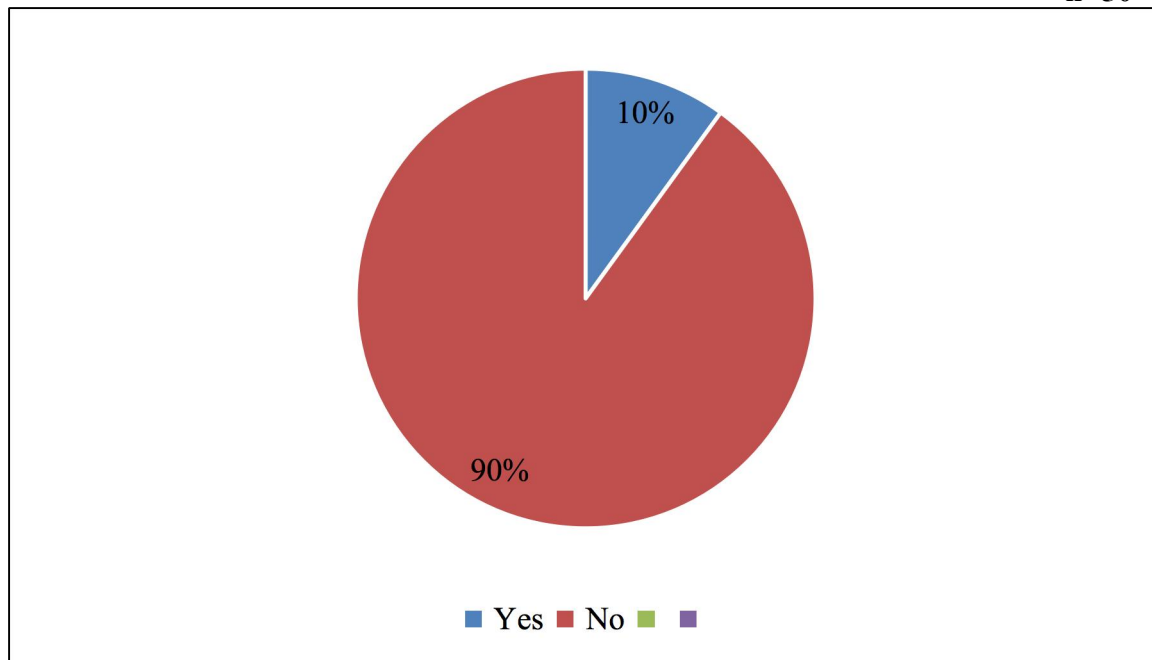


Figure 10: Family History of Cancer

Source: Primary Data 2024

Minority 5 (10%) respondents reported family history of cancer while majority 45 (90%) respondents reported no family history of cancer.

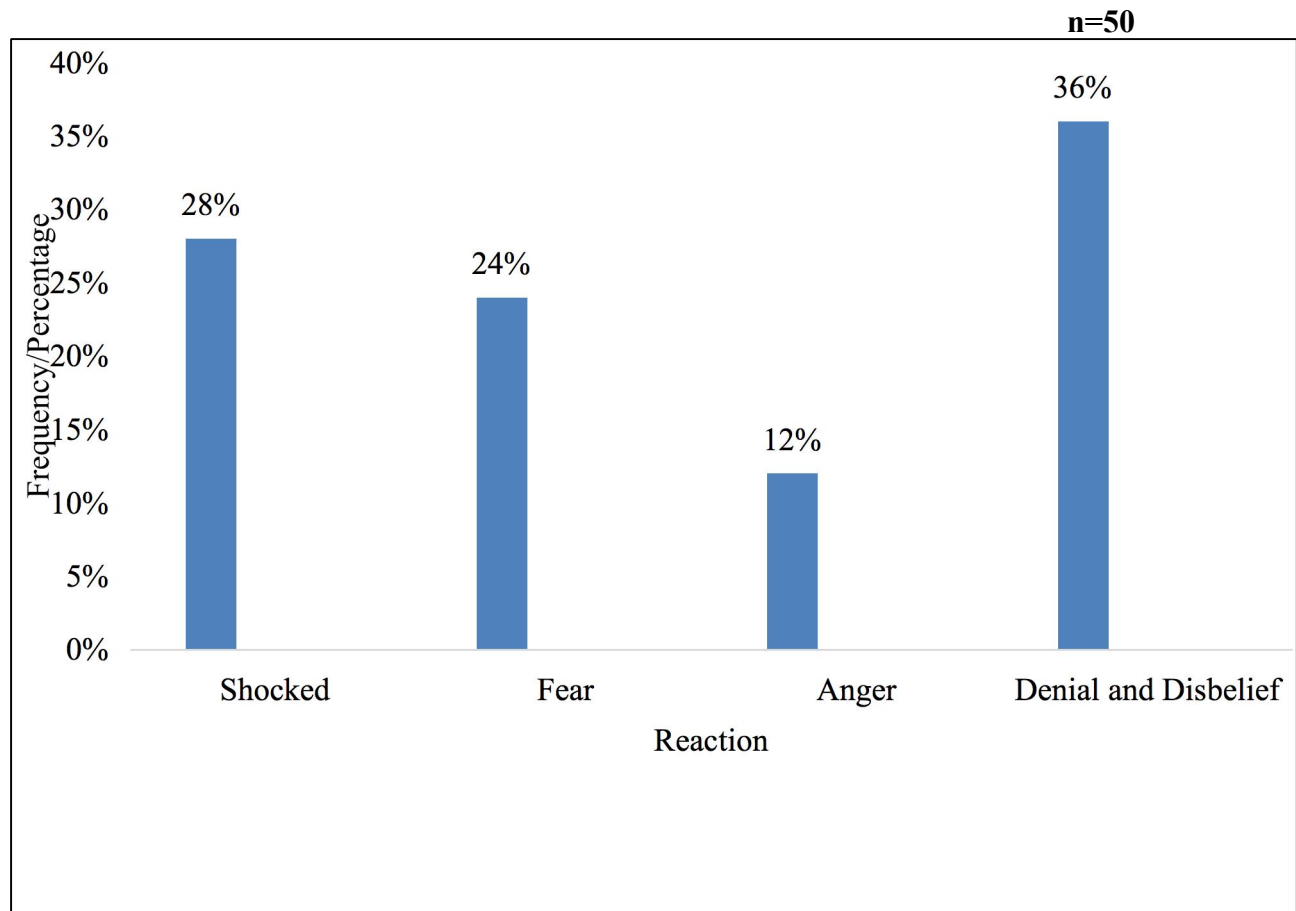


Figure 11: Respondents Reaction to Child's Diagnosis.

Source: Primary Data 2024

14 (28%) respondents were shocked on receiving child's diagnosis, 12 (24%) respondents reported fear, 6(12%) respondents reported anger and 18(36%) respondents were in denial and disbelief with child's diagnosis.

n=50

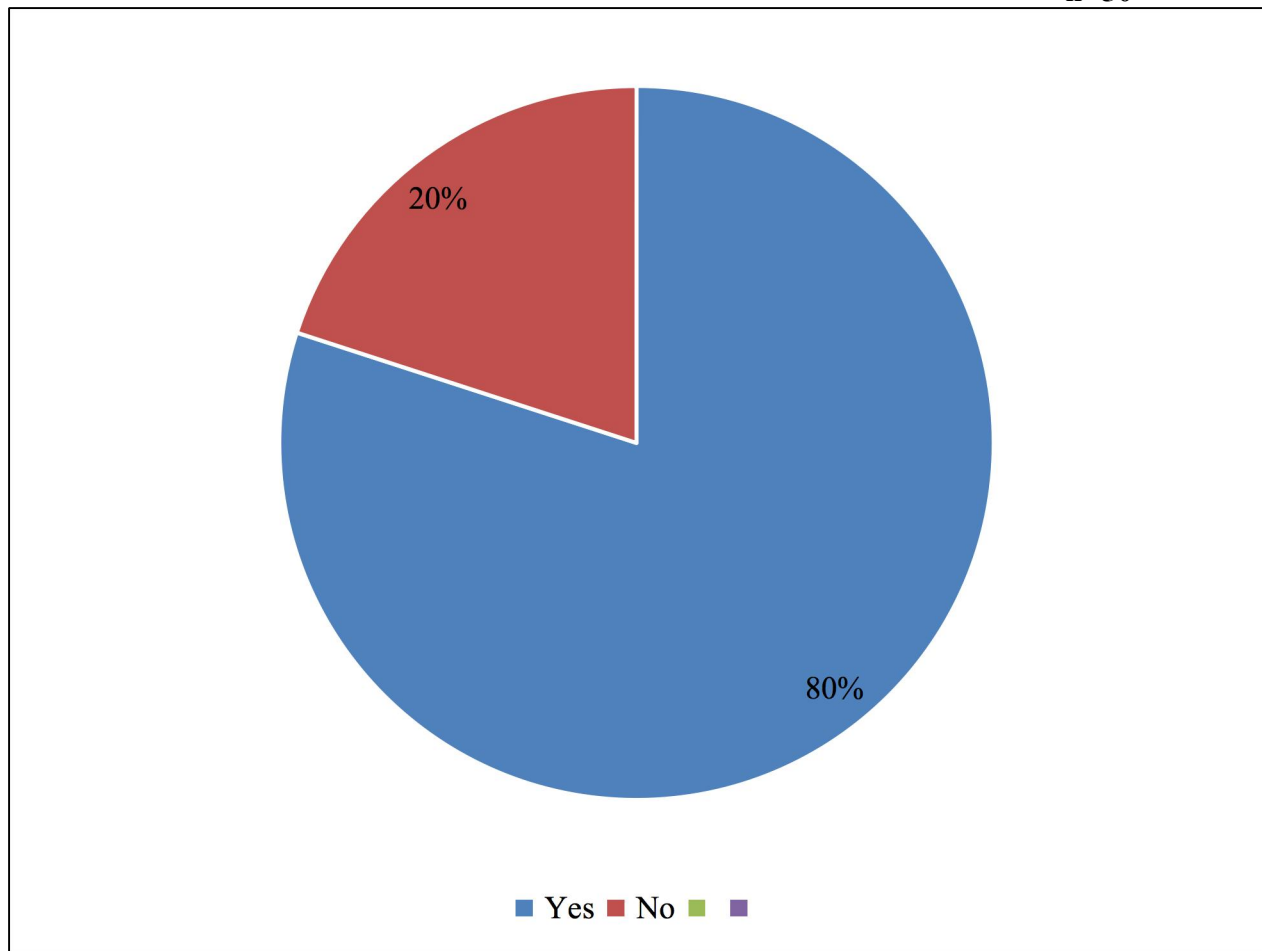


Figure 12: Respondents Urgency Seeking Medical Consultation.

Source: Primary Data 2024

Majority 40 (80%) respondents reported delay consulting doctors after onset of problems while 10(20%) respondents sought immediate consultation with doctors.

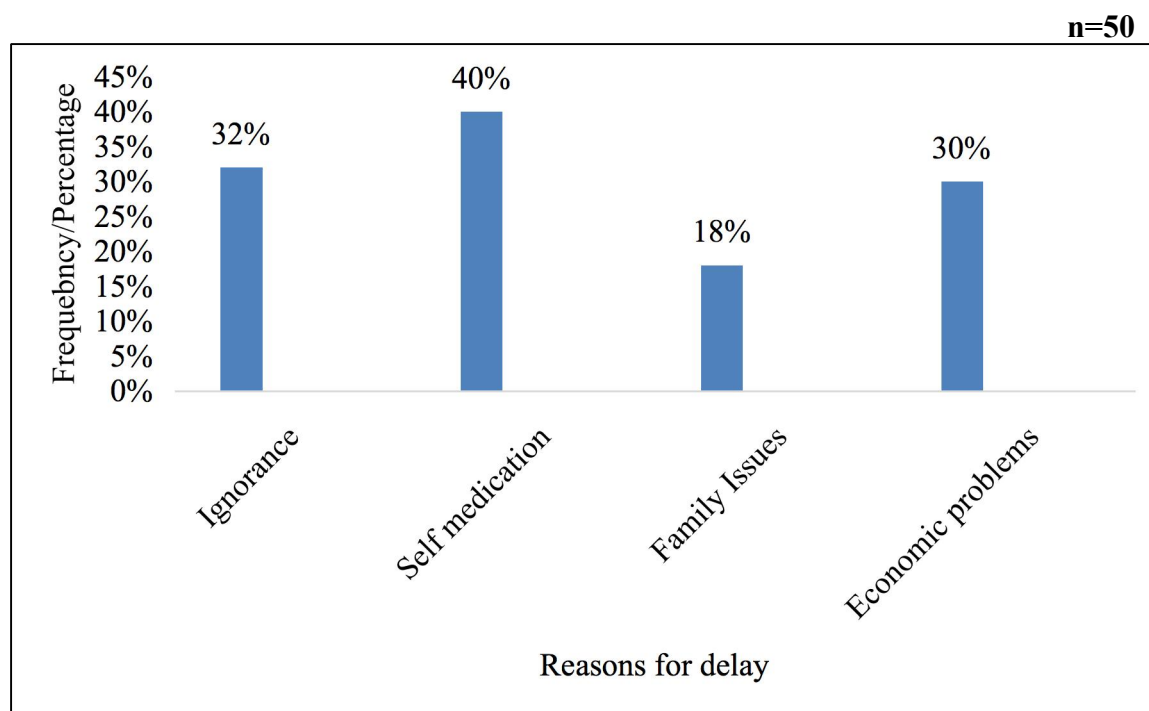


Figure 13: Respondents Reason for Delay

Source: Primary Data 2024

16 (32%) respondents reported ignorance as reason of delay seeking health care, 20 (40%) respondents reported self medication as reason for delay, 9(18%) respondents reported family issues and 15 (30%) respondents reported economic problems as reason for delay .

4.2 Knowledge of Caretakers on Brain Tumor

In this study, knowledge had 13 items and they were rated as good, fair , poor and results were as follows: Fifteen (30%) of respondent's were knowledgeable and there score was good (71- 80), Twenty three(46%) respondent's had fair knowledge and their score was fair (50 - 70) and Twelve(24%) had poor knowledge and scored (0-49). Individual test items were scored as shown in the table below.

Table1: Respondents Knowledge about Brain Tumors

Variables	Category	Frequency	Percentage (%)
Knows medical name of child's brain tumor.	Yes	15	30
	No	35	70
	Total	50	100
Knows about names of medicines (at least some)	Yes	20	40
	No	30	60
	Total	50	100
Knows about duration of treatment	Yes	10	20
	No	40	80
	Total	50	100
Knows about painful procedures	Yes	40	80
	No	10	20
	Total	50	100
Knows about curability with treatment	Curable	20	40
	Incurable	30	60
	Total	50	100
Knows that tumor can recur	Yes	23	46
	No	27	54
	Total	50	100
Knows about the common side effects of treatment (nausea, vomiting, disability, loss of speech, loss of sight, etc)	Yes	22	44
	No	28	56
	Total	50	100
Knows about serious side effects (bleeding, major organ dysfunction, infection)	Yes	22	44
	No	28	56
	Total	50	100
Do you have difficulty in understanding the information received?	Yes	35	70
	No	15	30
	Total	50	100
Do you think that the child knows about the disease?	Yes	20	40
	No	30	60

	Total	50	100
Should child be told about the disease?	Yes	20	40
	No	30	60
	Total	50	100
If yes, who should tell him/her?	Doctor	10	20
	Nurse	06	12
	Parents	04	08
	Total	20	40
If no, give reason	May get frightened	06 17	12 34
	May get depressed	04	08
	May not cooperate with treatment	03 30	06 60
	May become unmanageable		
	Total		

About knowing the medical name of the brain tumor of their children , only 15(30%) respondents knew the medical name of child's tumor and 35(70%) respondents didn't know the brain tumors medical name. 20(40%) respondents knew at least some names of medicine while the 30(60%) respondents didn't know any names of the medicine received by the child. Majority40 (80%) respondents didn't know the duration of treatment, only 10(20%) knew their child's treatment duration.

40(80%) respondents knew about the painful procedures like Lumber puncture, bone marrow, shunting, tapping, surgery) and only 10(20%) didn't know about the painful procedures. 20(40%) respondents knew their child's brain tumor were curable and 30(60%) respondents knew their children tumors were incurable. 23(46%) respondents knew about re occurrence of brain tumor while 27(54%) didn't know that the brain tumor could re-occur.22(44%) respondents knew about

the common side effects of treatment like nausea, vomiting, disability, loss of speech and loss of sight while 28(56%) respondents didn't know about the common side effects of treatment.

22(44%) respondents knew about the serious side effects that is bleeding, major organ dysfunction, infection while 28(56%) respondents didn't know about the major side effects.

35(70%) respondents reported having difficulty understanding the information received while only 15(30%) understood the information given to them. Only 20(40%) respondents agreed to children knowing about the disease while 30(60%) respondents said their children didn't know about the disease.

20(40%) respondents agreed to children being told about the diagnosis while 30(60%) respondents didn't want their children to know about the disease.10 (20%) of respondents who agreed to their children being told about the disease wanted doctors to be the ones to tell the children, only 03(06%) respondents wanted nurses to tell their children about the disease and 07(14%) respondents wanted parents to be the ones to tell their children about the disease. The majority respondents who disagreed children being told about the disease reported06(12%) responded that children would get frightened, 17(34%) responded that children would be depressed, 04(08%) respondents said children may not cooperate with treatment and 03(06%) respondents said children may become unmanageable.

4.3 Attitudes of Caretakers on Brain Tumors

Table 2: Attitudes of Respondents on Brain Tumors

Variables	Category	Frequency	Percentage
Do you feel anxiety about needle pricks/ pain ?	Yes	45	90
	No	05	10
	Total	50	100
Do you feel anxiety about biopsy/bone marrow test?	Yes	45	90
	No	05	10
Do you worry about child's disease?	Most of the time	40	80
	Sometimes	10	20
	Not very often	00	00
Do you worry that treatment is not working?	Most of the time	10	20
	Sometimes	35	70
	Not very often	05	10
Do you worry about medicines side effects?	Most of the time	30	60
	Sometimes	10	20
	Not very often	10	20
Do you worry that child's cancer will come back?	Most of the time	10	20
	Sometimes	22	44
	Not very often	18	36
Are you afraid of letting child play/ run?	Yes	30	60
	No	20	40
Are you afraid of sending child to school?	Yes	30	60
	No	20	40
Are you afraid that other siblings will get tumor?	Yes	15	30
	No	35	70
Are you worried about future of the child?	Yes	40	80
	No	10	20
If Yes, specify	Studies	00	00
	Marriage	00	00
	Disease recurrence	33	66
	Social stigma	10	20
	Hereditary	07	14
Do you think that you know all the necessary information about your child's illness and treatment?	Yes	05	10
	No	45	90
If No, what additional information would you like?	About disease	10	20
	About medicine	20	80
	About child's education	00	00
	About child's marriage	00	00

Would you like to have written information about child's disease and treatment?	Yes	30	60
	No	20	40
Are you satisfied with present hospital treatment?	Yes	45	90
	Partially	04	08
	No	01	02
If not Yes, give reason	Receiving different information from different staff	01	02
What do you do when you have doubts?	Ask doctor	27	54
	Ask staff	11	22
	Ask other parents	15	30
	Ask relatives	00	00
	Consult internet	07	14
What gives you more relief when you feel stressed?	Praying to God	20	
	Seeking help from family members	04	
	Talking to staff	06	
	Talking to other parents	14	
	Support of friends	06	
	Considering as fate	00	

45(90%) and 5(10%) respondents felt anxious about needle pricks. 45(90%) and 5(10%) respondents felt anxious about biopsy/ bone marrow tests. 40(80%) respondents worried most of the time about the child's disease, 10(20%) respondents sometimes worried about child's disease. 10(20%) respondents worried most of the time, 35(70%) respondents worried sometimes and 5(10%) respondents didn't worry often that treatment wasn't working.

30(60%) respondents worried most of the time about medicine side effects, 10(20%) respondents worried sometimes about medicines side effects and 10(20%) respondents didn't worry often about medicine side effects. 10(20%) respondents worried most of the time that child's cancer would come back, 22(44%) respondents worried sometimes and 18(36%) respondents didn't worry often about child's cancer coming back. 30(60%) respondents were afraid to let their children play while 20(40%) respondents were not afraid to let their children to play. 30(60%)

respondents were afraid to send their children to school while 20(40%) were not afraid to send their children to school. 15(30%) respondents were afraid that other siblings would get tumors while 35(70%) respondents were not afraid. 40(80%) respondents worried about future of child while 10(20%) respondents were not worried about future of the child that is 10(20%) respondents were worried about social stigma, 33(66%) respondents worried about disease recurrence and 7(14%) respondents worried about heredity. 5(10%) agreed to knowing all necessary information about the child's illness while 45(90%) respondents didn't know all the information about child's illness reporting 10(20%) respondents didn't know about the disease, 40(80%) respondents didn't know about the medicines. 30(60%) respondents wanted to have written information about child's disease and treatment while 20(40%) respondents didn't want written information. 45(90%) respondents were satisfied with present hospital treatment while 4(8%) were partially satisfied and 1(2%) respondents weren't satisfied with present hospital treatment reporting getting different information about the child's illness from different medical staff. 27(54%) respondents said they pray when in doubt, 11(22%) respondents said they talk to staff, 15(30%) respondents ask other parents and 7(14%) respondents consult the internet when in doubt. 10(20%) respondents prayed to God, 2(4%) respondents sought help from family members, 3(6%) respondents talked to staff and 7(14%) respondents talked to other parents and 6(12%) respondents got support from friends and this is how they got relief when stressed respectively.

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents results and interpretation of significant findings on this study which are stated as follows:

Most brain tumors were affecting male gender 28(56%) children, aged between 6-10 years of age and Gliomas were the commonest brain tumors affecting children, this was in agreement with a study on diagnosis and management of paediatric brain tumors in sub Saharan Africa, a case study of Uganda conducted by Katasi et al (2023) which stated that 121 children had brain tumors were 38% children had Gliomas and 57% were males .

Majority 28(56%) primary Caretakers were mothers, most caretakers had completed primary school as their highest level of education and 40(80%) reported delay seeking medical assistance reason being 16(32%) ignorance, 20(40%) self-medication, 9(18%) family issues and 15(30%) economic problems this was in agreement with a study by John and brown(2019) which highlighted that knowledge gaps among caretakers can lead to delays in seeking medical attention and higher treatment outcomes.

The knowledge section had 13 items and 15(30%) respondents knew name of child's tumor, 20(40%) respondents knew names of medicine, 10(20%) knew duration of treatment, 40(80%) knew about common side effects of treatment and serious side effects which is in contrast with a study conducted in India by Nair et al (2017) which showed 43(88%) mother's knew medical name of child's cancer, 39(90%) mothers knew approximate duration of treatment, 93% knew their children would be subjected to painful procedures such as biopsy, tapping , all parents were

aware of treatment side effects such as nausea, vomiting, hair loss and 84% reported knowing about serious side effects such as bleeding. This study showed that 23(46%) respondents had fair knowledge on brain tumors which is in contrast with a study conducted in Mexico exploring the current knowledge of childhood cancer among parents and caregivers by Uribe- Ortiz et al (2022) reported 41.6% of respondents were knowledgeable.

The attitude item consisted of (18) questions on Attitude of Caretakers on child's brain tumor; majority 45(90%) respondents felt anxious about needle pricks/ pain, 45(90%) felt anxiety about biopsy/ bone marrow tests, 40(80%) respondents worried about the child's disease most of the time and some 20(40%) were aware of their brain tumor disease though their caretakers didn't want them to know stating that 6(12%) would be afraid, 17(34%) would be depressed, 3(06%) would not cooperate with treatment, this was in agreement with a study conducted in India which stated that 81% mother's had preoccupied thoughts about child's disease accompanied by high levels of anxiety showing specific concerns with 25% having concern that their children knew about the disease though none desired them being informed and reasons were fear, potential depression, noncooperation with treatment and difficult handling.

5.2 Conclusion

This study showed that 46% caretakers had fair knowledge and majority had negative attitude towards brain tumor disease. Therefore knowledge and attitude need to be improved among caretakers.

5.3 Recommendations

Based on the results of the findings of the study, the investigator recommends the following:

- a) Government of Uganda should establish and invest in specialised pediatric oncology centers equipped with necessary diagnostic and treatment facilities for brain tumors and also integrate palliative care services into the health care system to support caretakers in managing pain , symptoms and address emotional and spiritual needs in children and families.
- b) Ministry of Health should conduct community outreach programs to raise awareness about brain tumor myth and misconceptions, create easily accessible online resources such as websites or mobile apps with reliable information about brain tumors and caregiving tips and also partner with nongovernmental organizations and support organisations specialising in oncology.
- c) Mulago Hospital should sponsor health care providers for advanced training in Pediatric oncology in different hospital across the world so as to improve on care and services
- d) Neuro-oncology unit conducted monthly CME's so as to keep informed and be up-to-date with current management and also distribute educational material to health care providers and caregivers.

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APPENDICES

APPENDIX I: CONSENT FORM

Title of study

Knowledge and attitudes of caretakers of children suffering from brain tumors in Mulago National Referral Hospital.

Principal investigator

Musiimenta Sandra, a student of King Ceasor University.

Purpose of study

The study seeks to assess caretaker's knowledge and attitude on brain tumors in children.

Study procedures

All participants will be recruited after signing an informed consent. The participants will be then given a questionnaire whereby they will be required to fill in all the information required in the form. The process may take 20 minutes depending on the participant.

Possible benefits

There are no immediate and direct benefits in for participating in the study but your participation will help in improving interventions.

Risk/ Discomfort

Minimal risks may accompany the study. May be participants may be inconvenienced in the aspect of time. The prospected participants may choose whether to participate or not.

Confidentiality

The information got will be used for academic and research purposes only. The questionnaires do not entail your personal information like name, address and so forth.

Alternative/Rights to refuse of withdrawal

Your participation in this study is entirely voluntary and you are free to take part or withdraw at any time without any penalty. There is no loss to benefits entitled to you for refusal to participate in this study.

Compensation for participants in the study

You will be given a bottle of Soda as a token of appreciation for the time, effort and inconvenience caused for your participation in this study.

In case of questions on this study

In case of questions related to this study, you can contact the principal investigator on 0781442432. OR you can contact my supervisor in case of questions to your rights as a participant in this study 0781457183, Mr. Kalukusu Amos Ronald OR the chairperson- IRB- Mulago National Referral Hospital 0772618111, Dr. Nakibuka Jane.

Statement of consent

Ihave been requested to participate in this study.

I have read, been explained and understood the above information and willingly accept to participate in the study with no coercion.

Participant

Name.....Date..... Signature.....

Investigators/Designee

Name.....Date..... Signature.....

APPENDIX II: QUESTIONNAIRE

KNOWLEDGE AND ATTITUDE OF CARETAKERS OF CHILDREN SUFFERING FROM BRAIN TUMORS IN MULAGO NATIONAL REFERRAL HOSPITAL.

1. Name of child:
2. Age: _____ Male/Female: _____

Diagnosis:

General information:

3. Primary caretaker: Mother/father/grandparent/aunt/uncle/elder sibling/others
4. What age group do you belong?(Years)
 - a) 18-24
 - b) 25-34
 - c) 35-44
 - d) 45-54
 - e) 55 and above
5. What is your marital status?
 - a) Single
 - b) Married
 - c) Divorced
 - d) Separated
 - e) Widowed
6. What is the highest level of education you have completed?
 - a) Uneducated

- b) Primary level
 - c) Secondary level
 - d) Degree level
7. Family structure: _____ Joint/nuclear/extended/broken
8. Place of domicile: _____ Rural/urban
9. Employment of parent:
_____unemployed/unskilled/skilled/semi.professional/professional
10. Family history of cancer: _____ Yes/No
11. What was your first reaction on hearing the diagnosis?
- a) Shocked
 - b) Fear
 - c) Denial and Disbelief
 - d) Anger
12. Was there any delay in consulting the doctor after onset of illness?
- Yes/No
- If yes, reason for delay:
- a) Ignorance
 - b) Tried self-medication
 - c) Family issues
 - d) Economic problems

PARENTS' KNOWLEDGE ABOUT THEIR CHILD'S DISEASE AND TREATMENT:

13. Knows medical name of child's brain tumor _____ Yes/No
14. Knows about names of medicines (at least some): _____ Yes/No
15. Knows about duration of treatment: _____ Yes/No
16. Knows about painful procedures (LP, bone marrow, shunting, tapping, surgery):
_____ Yes/No
17. Knows about curability with treatment: _____ curable/incurable
18. Knows that tumor can re-occur: _____ Yes/No
19. Knows about the common side effects of treatment (nausea, vomiting, disability, loss of speech, loss of sight, etc) _____ Yes/No
20. Knows about serious side effects (bleeding, major organ dysfunction, infection):
_____ Yes/No
21. Do you have difficulty in understanding the information received? _____ Yes/No
22. Do you think that the child knows about the disease? _____ Yes/No
23. Should child be told about the disease? _____ Yes/No
24. If yes, who should tell him/her? _____ Doctor/nurse/parents/others
25. If No, give reason _____ may get frightened/may get depressed/may not cooperate with treatment/may become unmanageable

ATTITUDE RESPONSES

26. Do you feel anxiety about needle pricks/pain? _____ Yes/No
27. Do you feel anxiety about biopsy/ bone marrow tests? _____ Yes/No
28. Do you worry about child's disease? _____ Most of the time/sometimes/not very often

29. Do you worry that treatment is not working? _____ Most of the time/sometimes/not very often
30. Do you worry about medicine's side effects? _____ Most of time/sometimes/not very often
31. Do you worry that child's cancer will come back? _____ Most of time/sometimes/not very often
32. Are you afraid of letting child play/run? _____ Yes/No
33. Are you afraid of sending child to school? _____ Yes/No
34. Are you afraid that other siblings will get tumor? _____ Yes/No
35. Are you worried about future of the child? _____ Yes/No
36. If Yes, specify: _____ Studies/marriage/social stigma/disease recurrence/hereditary
37. Do you think that you know all the necessary information about your child's illness and treatment? _____ Yes/No
38. If No, what additional information would you like? _____ About disease/about medicines/about child's education/about child's marriage, etc
39. Would you like to have written information about child's disease and treatment?
_____ Yes/No
40. Are you satisfied with present hospital treatment? _____ Yes/Partially/No
41. If not yes, give reason _____
42. What do you do when you have doubts?
43. What gives you more relief when you feel stressed?

APPENDIX III: INTRODUCTORY LETTER



"Moral Rearmament, Wealth Multiplication"

P.O Box 88, Kampala, Plot 30/33 King Ceasor Road, Bunga Hill Main Campus,

Email: amoskalukusu@kcu.ac.ug

DIRECTORATE OF RESEARCH

1st August 2023

*The Executive Director,
Mulago national Hospital,
Kampala, Uganda.*

**RE: RECOMMENDATION FOR RESEARCH DATA COLLECTION OF:- Ms.
MUSIIMENTA Sandra (Index No. 2021AP/BNS/1172) Tel; 0759293944;
Email: smusiimenta21ap@student.kcu.ac.ug**

I write to recommend the above named student who is pursuing a Bachelor of Nursing from King Ceasor University, in Uganda.

Ms. MUSIIMENTA Sandra is now in her third year of study (3.2) and now expected to write her research dissertation as part of the requirements for the award of her degree. She is working on the topic given as follows:

"Knowledge, attitudes & practices of caretakers of children suffering from Brain Tumors: Lessons from Mulago National Referral Hospital, Uganda".

The purpose of this letter is to request that you allow her undertake data collection from your hospital facility which will assist her to fulfil the requirements of the university. The results of her research can be shared with you upon the successful completion of her study.

In any correspondence, use the address given herein. Looking forward to hearing from you.

Sincerely,

**Amos Ronald Kalukusu (PhD Fellow, Public Health).
Assoc. Director for Research.
Email: amoskalukusu@kcu.ac.ug Tel: 0781457183**



CC: DVC Academic Affairs; Cc: Academic Registrar; Cc: Ms. MUSIIMENTA Sandra

APPENDIX IV: APPROVAL LETTER

TELEPHONE: +256-41554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug



MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

IN ANY CORRESPONDENCE ON THIS
SUBJECT PLEASE QUOTE NO.....

18 March 2024.

Ms. Sandra Musiimenta
Principal Investigator
King Ceasor University.

Dear Ms. Musiimenta,

Re: Approval of Protocol MHREC 2693: "Knowledge and Attitudes of Caretakers of Children Suffering from Brain Tumors; Lessons from Mulago National Referral Hospital".

The Mulago Hospital Research and Ethics Committee reviewed your proposal referenced above and granted approval of this study on 18 March 2024. The conduct of this study will therefore run for a period of one (1) year from 18 March 2024 to 17 March 2025.

This approval covers the protocol and the accompanying documents listed below;

- Consent form
- questionnaire

This approval is subjected to the following conditions:

1. That the study site may be monitored by the Mulago Hospital Research and Ethics Committee at any time.
2. That you will abide by the regulations governing research in the country as set by the Ugandan National Council for Science and Technology including abiding to all reporting requirements for serious adverse events, unanticipated events and protocol violations.
3. That no changes to the protocol and study documents will be implemented until they are reviewed and approved by the Mulago Hospital Research and Ethics Committee.
4. That you provide quarterly progressive reports and request for renewal of approval at least 60 days before expiry of the current approval.
5. That you provide an end of study report upon completion of the study including a summary of the results and any publications.
6. That you will include Mulago Hospital in your acknowledgements in all your publications.

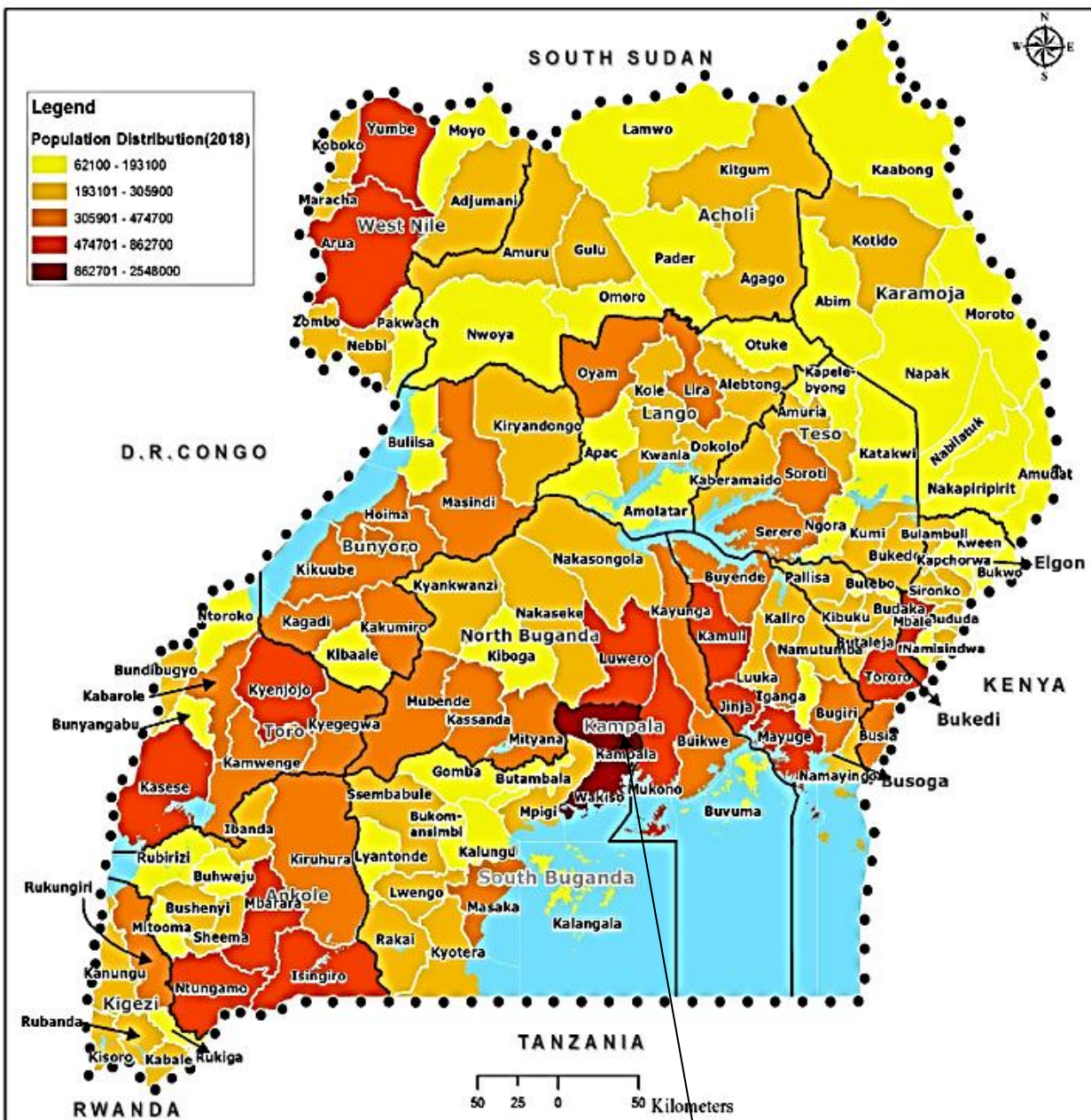
I wish you the best in this Endeavour.

DR. JANE NAKIBUUKA
CHAIRPERSON- MULAGO HOSPITAL RESEARCH & ETHICS COMMITTEE.

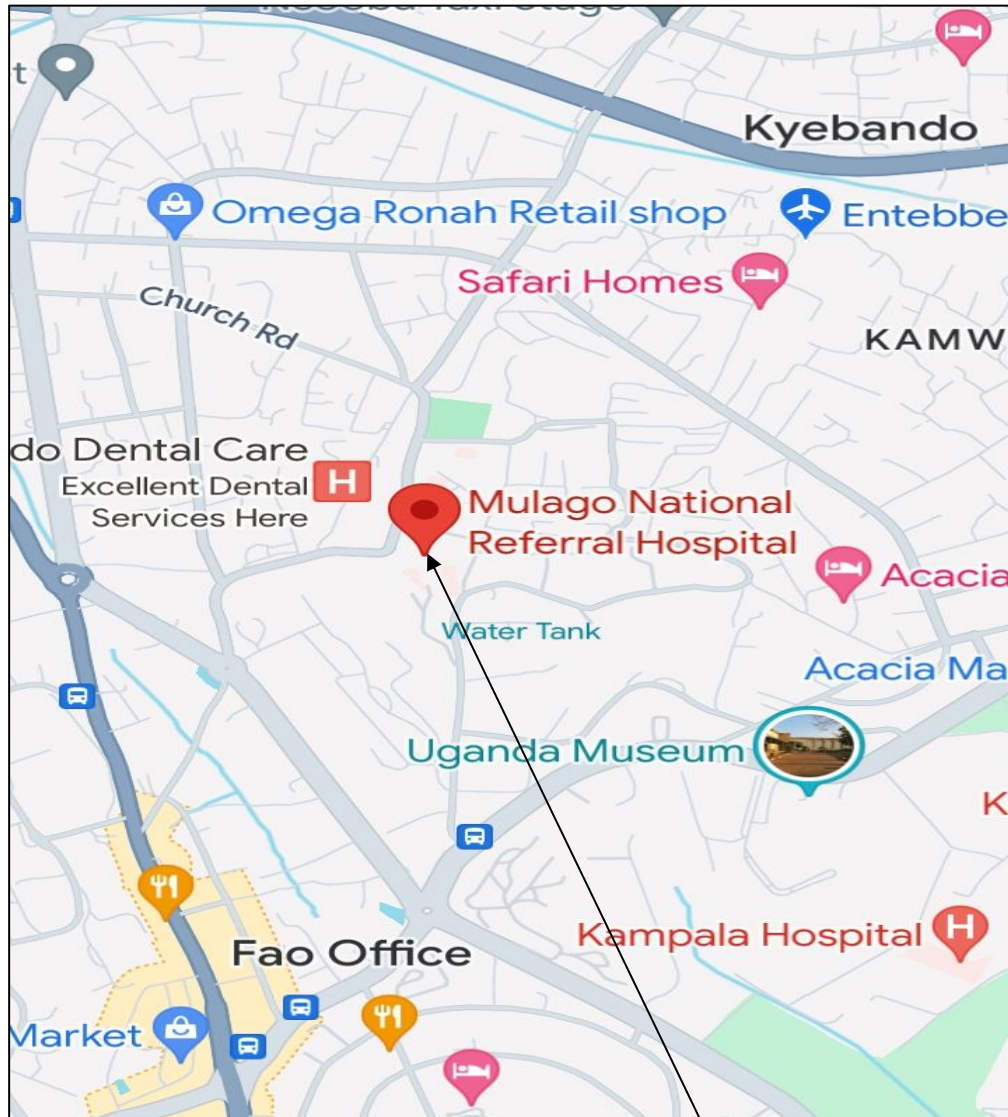


Vision: "To be the leading centre of Health Care Services"

APPENDIX IV: MAP OF UGANDA SHOWING KAMPALA DISTRICT

**KAMPALA DISTRICT**

APPENDIX V: MAP SHOWING MULAGO NATIONAL REFERRAL HOSPITAL



STUDY AREA

APPENDIX VI: APPENDIX VII: KREJCIE AND MORGAN

N	S	N	S	N	S	N	S	N	S
10	10	100	80	280	162	800	260	2800	338
15	14	110	86	290	165	850	265	3000	341
20	19	120	92	300	169	900	269	3500	246
25	24	130	97	320	175	950	274	4000	351
30	28	140	103	340	181	1000	278	4500	351
35	32	150	108	360	186	1100	285	5000	357
40	36	160	113	380	181	1200	291	6000	361
45	40	180	118	400	196	1300	297	7000	364
50	44	190	123	420	201	1400	302	8000	367
55	48	200	127	440	205	1500	306	9000	368
60	52	210	132	460	210	1600	310	10000	373
65	56	220	136	480	214	1700	313	15000	375
70	59	230	140	500	217	1800	317	20000	377
75	63	240	144	550	225	1900	320	30000	379
80	66	250	148	600	234	2000	322	40000	380
85	70	260	152	650	242	2200	327	50000	381
90	73	270	155	700	248	2400	331	75000	382
95	76	270	159	750	256	2600	335	100000	384

Note:

“N” is population size

“S” is sample size