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KNOWLEDGE AND PERCEPTION OF PATIENTS OF CHILDREN LIVING WITH CONGENITAL GLAUCOMA AT KOMFO ANOKYE TEACHING HOSPITAL, GHANA

BY

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DECLARATION

I, Dorinda Godson-Amamoo declare that this dissertation is my own work conducted under the supervision of Dr. Alfred Edwin Yawson. In places where other people's opinions or works have been cited as references, full acknowledgements have been given. This work has never been presented either in whole or in part to any institution for the award of degree, diploma or certificate.

DORINDA GODSON-AMAMOO (STUDENT)

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Date……

DR. ALFRED EDWIN YAWSON (SUPERVISOR)

Signature……..…

Date……

DEDICATION

I dedicate this work to the Almighty God for helping me to complete this work.

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My appreciation goes to Dr. Alfred Edwin Yawson for his constructive criticism and advice towards completing this work. I wish to also thank the entire staff of the Department of Social and Behavioral Science for their support.

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ABSTRACT

Congenital glaucoma is a major public health issue because visually impaired children have a lifetime of blindness ahead of them with its associated emotional, social and economic cost to the child, family and society. The study sought to assess the level of knowledge and perception of parents of children with congenital Glaucoma seeking care at the Komfo Anokye Teaching Hospital. The study was undertaken at Komfo Anokye teaching hospital. A mixed method design comprising of one hundred and twenty (120) respondents and twenty (20) guardians for focused group discussion was conducted. The purposive and convenient sampling methods were used respectively. A structured questionnaire and an interview guide were also used as the collecting tool. The chi-square analysis and ordinal logistic regression was used to test for associations between demographic characteristics level of knowledge and effect of factors on congenital glaucoma. Data obtained from the focused group was analyzed using thematic analysis. Results showed that more than half of the respondents (52%) had moderate level of knowledge on congenital glaucoma and 24% had low level of knowledge. Majority of the respondents 86.7% were of the view that congenital glaucoma can be treated with surgery. More than half of the respondents had their source of information from the media (58.3%), and (33.3%) from the hospital. The study found significant associations between level of knowledge on congenital glaucoma and religion ($p= 0.002$), ethnicity ($p=0.001$) and occupation ($p=0.001$) of respondents. Perception of respondents on congenital glaucoma was poor as most reported that it is caused by spiritual powers and it cannot be managed. The study observed an average level knowledge of parents/guardians on congenital glaucoma. Most guardians/caregivers did not have positive perception on congenital glaucoma and the primary sources of information to guardians were from the media and hospital. Ministry of health must place ophthalmic nurses at various antenatal and postnatal clinics for early identification and management of congenital glaucoma cases.

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LIST OF ABBREVIATIONS

GNECS	-	Ghana National Eye Care Secretariat
IOP	-	Intra-ocular Pressure
JOAG	-	Juvenile Open Angle Glaucoma
KATH	-	Komfo Anokye Teaching Hospital
NGO	-	Non – Governmental Organization
OPD	-	Out Patient Department
PCG	-	Primary Congenital Glaucoma
U5MR	-	Under 5 Mortality Rates
WHO	-	World Health Organization

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

According to Vijaya et al., (2014) the second commonest cause of vision loss worldwide aside cataract is glaucoma, such causes of vision loss related to glaucoma are usually irreversible. In developing countries, those affected with the disease condition are at a disadvantage, they report with a more advanced form of the illness, exposing them at higher risk and often have a greater occurrence of the disease than those in the developed nations. (Omoti, Osahon and Waziri-Erameh, 2006). The number of people with glaucoma globally is anticipated to increase from 64 million to 76 million in 2020 and 111 million in 2040, with Africa and Asia being affected more severely than the rest of the world (Tham et al., 2014; Quigley and Broman, 2006). Due to differences in expertise of measure, differences in definition and diagnostic equipment, glaucoma prevalence is difficult to ascertain. In 2014, an assessment on the incidence of worldwide Primary Open Angle Glaucoma among the elderly revealed an approximation of 4.20% in Africa,3.65% in Latin America and the Caribbean, and 2.31% in Asia (Than et al., 2014). Even though childhood blindness is quite uncommon as equated to blindness starting in adulthood, the number of blind years due to adult cataracts is almost equal to the number of blind years due to childhood blindness (Gilbert and Foster, 2001). Larger percentage of blindness in children have been observed in poorer countries and are more likely to be due to avoidable causes. (Koay et al., 2015).

Studies done in Ghana, Honduras, and India, 95% of caregivers revealed that it was essential for children to have eye exams, but 66% had never undertaken one (Rabiah, 2004). The commonest type of glaucoma that affects children in the world is primary congenital glaucoma (PCG)

although it is still quite uncommon with a prevalence of about 1 in 10,000 to 18,000 live births. Greater disease prevalence has been reported in cultures where consanguineous relationships are common (Papadopoulos et al., 2007; Moore, Tomkins and Ben-Zion, 2013). In a study from Ethiopia, advanced disease was common at presentation and they reported an average age of detecting primary congenital glaucoma is 3.3 years (Ben-Zion et al., 2011). This is different with the advanced countries, where the disease is detected in the first twenty-four months of life. For example, in two studies conducted in developed countries the average age detection is 4 and 11 months in Australia and Great Britain respectively (Fang et al., 2014; Ben-Zion et al., 2011).

Congenital glaucoma is a group of eye diseases in which there is increased in intra ocular pressure leading to optic disc cupping from birth (Sommer, 2006). Congenital and secondary glaucoma affect more than 3 million people in the Eastern Mediterranean region, including 500, 000 children and adolescents (Green, 2007). While glaucoma is not preventable, early detection and treatment can help to avoid serious damage to a person's vision. It accounts for 70 million blind persons globally (Bohn, 2007). In adult life, it is impossible to correct glaucoma, this underscores the urgency in treating childhood eye disease. Early detection and proper management of glaucoma can considerably improve the child's vision in future therefore pediatricians should play an important role in preventing blindness by early diagnosis and treatment of simple ocular ailments while identifying conditions requiring referral to the ophthalmologist.

Common presentations range from corneal haze due to stromal and epithelial edema secondary to raised intraocular pressure (IOP), lacrimation and blepharospasm. Signs include buphthalmos, enlarged corneal membrane (Kanski and Bowling, 2011). It's a relatively rare condition and hence is sometimes misdiagnosed or sub optimally treated leading to irreversible optic nerve

damage. In view of this, 18% of children in visually impaired institutions around the world is due to glaucoma and is responsible for 5% of blind children worldwide (Gilbert et al., 2012; Frick et al., 2005).

Surgery is almost always the most effective way to manage congenital glaucoma. To maximize pressure control after surgery, medical therapy is used only as a temporizing measure prior to surgery. Globally, childhood blindness exists as a huge problem. Meanwhile, accurate prevalence data are difficult to obtain due to the need of larger sample sizes for population-based surveys. However, prevalence of childhood blindness varies per socio-economic development as well as under-5 mortality rates (U5MR) (Gilbert, 2001).

The occurrence of congenital glaucoma in low income countries is 1.5 per1000 children, while in high-income countries with low U5MR, the occurrence is 0.3 per 1000 children (WHO, 2000). Several children with visual impairment, who present with chronic disorders not responsive to ophthalmic treatment, hence need visual rehabilitation, educational support as well as developmental interventions. It is projected that, in almost half of the children who are blind today, the underlying cause could be avoided or treated to preserve vision or restore sight (Gilbert, 2001).

Firstly, the number of blind years resulting from glaucoma in children is almost equal to the number of blind years attributable to cataracts in adults. Such children have a lifetime of blindness ahead of them, with all the accompanying psychological, social and financial costs to the child, the family, and society (Robert, 2009).

Nationally as at 2005, a total of only 300 specialists such as ophthalmologists, optometrists, ophthalmic nurses and optical technicians exist in Ghana according to the Ghana National Eye Care Secretariat (GNECS). This number per the eye patient load is very alarming.

Over the past several decades, researches repeatedly have shown that the Komfo Anokye Teaching hospital records quite a significant number of children with congenital glaucoma (GNECS, 2005). It is generally accepted that the mirror of a human's body is the eye and hence parents' ignorance of eye diseases that affect their child implies that children with eye conditions may be exposed to blindness due to delay in seeking medical care from the ophthalmologist. To safeguard the health of children with congenital glaucoma and to reduce blindness to the barest minimum, the perception, attitude and knowledge of parents with people with the condition needs to be ascertained, so that they can monitor their children with the view to finding solutions to health problems associated with congenital glaucoma. It is therefore imperative to determine the knowledge and perception of parents of children with congenital glaucoma**.**

1.2 Statement of problem

Globally, out of an estimated 285 million people who are visually impaired; 39 million are blind and 246 million have low vision. Majority of these people are blind due to treatable and/or preventable causes such as congenital glaucoma and cataract (WHO, 2010). Eighty per cent of these people live in the lesser developed countries where chronic deprivation is worsened by the added challenge of failing vision. If nothing is done, it is estimated that by the year 2020 the number of blind people may hit 76 million (Pizzarello, 2004). The increasing burden of blindness globally, especially in developing countries led to a global initiative for the elimination of avoidable blindness, VISION 2020: THE RIGHT TO SIGHT initiative in 1999 (WHO, 1999). Nonetheless, the mission of implementing VISION 2020 rests with governments of the countries

that have identified blindness and visual impairment as a public health problem, assisted by inter-governmental organizations such as the World Health Organization (WHO) and other international Non-Governmental Organizations (NGOs), which are collaborators (WHO, 2010).

In Ghana, both availability and accessibility of eye care services are highly limited coupled with the essential eye care provision (WHO, 2010). Studies have assessed level of access as well as utilization patterns of eye care services patterns in several developed countries but that of Ghana is absent. There is very little or no data on the prevalence of blindness and other eye conditions, particularly congenital glaucoma in Ghana (Resnikoff et al., 2004). Pascolini (2010), documented congenital glaucoma as a key public health problem that is unequally circulated among countries. Preventable cases constitute as high as 80% of the total global burden. Vision 2020 aims to eliminate avoidable blindness in the world by 2020 and targets the leading causes of avoidable visual impairment such as uncorrected refractive errors and glaucoma which form 43% and 33% respectively.

Some research works have been conducted on what the causes of blindness in children are such as congenital cataract and, refractive errors in developing countries like Ghana (Gilbert, 2001; WHO, 2000; Marrioti et al., 2009). However, most researchers have focused their studies on the causes rather than ascertaining the knowledge, awareness and perception of parents and guardians of children with the condition in Ghana. The prevalence of this eye condition and the capacity of these conditions to cause blindness usually have a deep root in the knowledge and awareness of parents.

Little study is known concerning knowledge and awareness of congenital glaucoma therefore creating a gap for investigation. From a policy perspective, parents' understanding and

awareness, and perception of congenital glaucoma are crucial to reduce the health problem associated with it.

1.3 Justification and significance of study

Congenital glaucoma is an important cause of blindness globally. Several of the sources are avoidable and can be treated at early on set. However, delays in detection of childhood eye disease can often lead to debilitating outcomes. There's inadequate distribution of ophthalmologists in different regions of the country compared to pediatricians transferring large portion of the initial care of children with eye diseases to pediatricians. Therefore, even though the ophthalmologist could provide specialized care for the children, early detection and appropriate referral to an ophthalmologist largely depends on the knowledge and perception of the parents of the child with the condition. Pediatricians therefore should play an important role in preventing blindness in children through routine vision screening evaluations. This would be both beneficial and cost-effective means to identify children that require care from an eye specialist (Kivela, 2009).

This study sought to identify the knowledge and perceptions of care givers that contribute to the late detection or non-detection of ocular illnesses in children. Lastly, there are little studies of congenital glaucoma reported in Ghana and hence the information acquired will add to the already existing data. It will also help inform health workers to organize workshops and for parents to know more about the various eye conditions so that they can immediately seek medical care for their children. This study would also help inform policy makers in developing policies, projects and programs aimed at reducing and eliminating childhood glaucoma and other related eye conditions among children in Ghana.

1.4 General objective

The researcher sought to assess the knowledge and perception of congenital glaucoma by parents of children living with congenital glaucoma seeking care at the Komfo Anokye Teaching Hospital, Kumasi, Ghana.

1.4.1 Specific objectives

- To assess the level of knowledge of parents on Congenital Glaucoma.
- To determine how parents/guardians perceive Congenital Glaucoma.
- To identify the sources of information of parents on Congenital Glaucoma.

1.5 Research questions

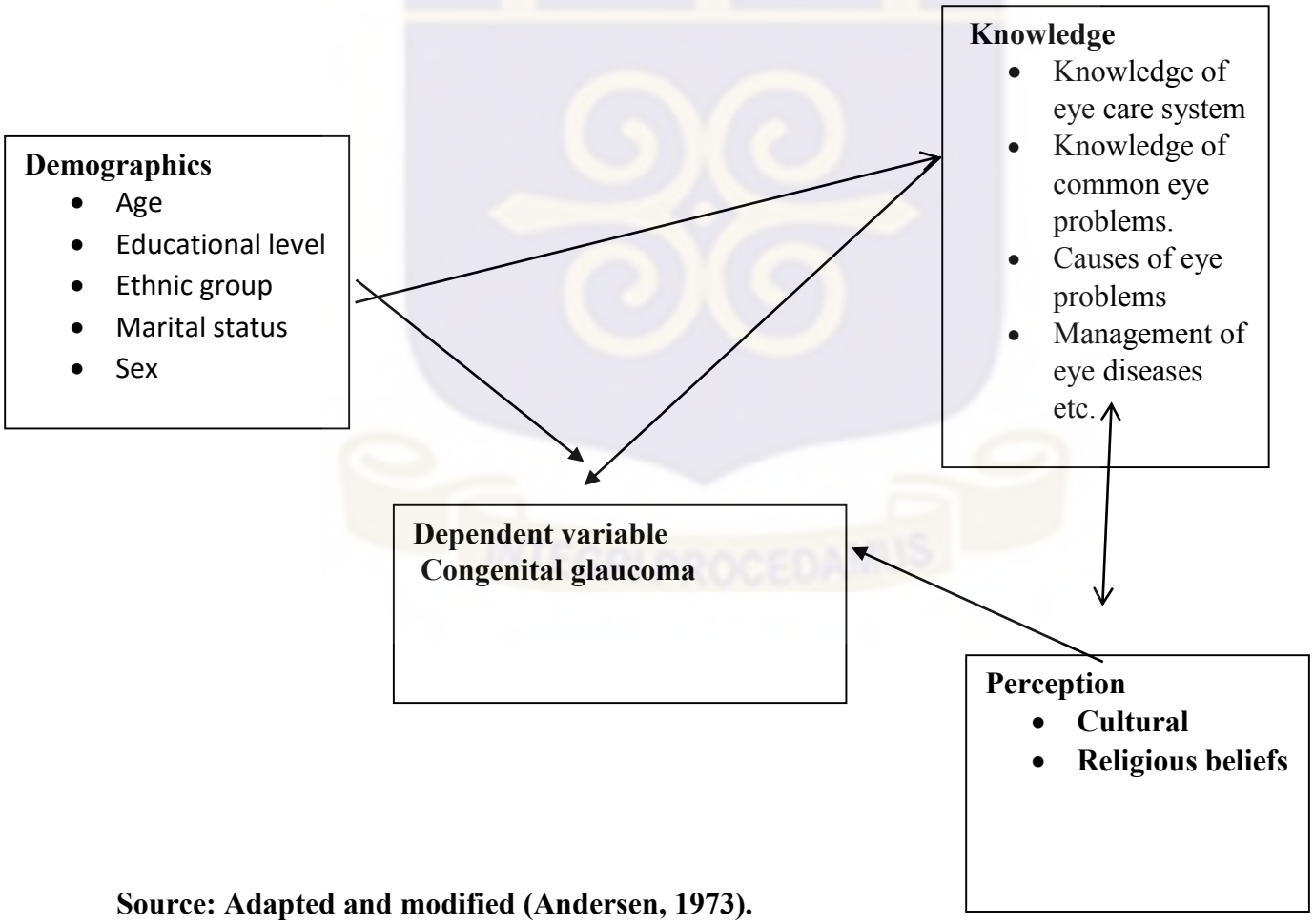
- How do parents perceive Congenital Glaucoma?
- What is the level of knowledge of parents on Congenital Glaucoma?
- What are the sources of information on Congenital Glaucoma?

1.6 Conceptual Framework

The Andersen and Newman Framework of Health Services Utilization is also known as the Andersen Newman model of health seeking behaviour was adopted for the study (Andersen and Newman, 1973). However, specific to this study it will be referred to only as the Andersen and Newman Framework of Health Services Utilization. This framework seeks to uncover conditions which expedite or obstruct utilization of health care services. The primary aim is to develop a behavioural model through knowledge and perception that provides measures of access to eye related medical care. A person's contact to and use of health services has three features specifically; need factors, enabling factors and predisposing factors. The predisposing factors include the social and cultural features of the individual that was present before the occurrence of

their illness such as secondary social structures including; social interactions, ethnicity, occupation, culture social networks, and education may also influence the individual's ability and perception not to report eye related condition for early treatment (Chopra et al., 2009). The enabling factors include health beliefs such as attitudes, values, and knowledge that people have concerning and towards the health care system and knowledge about the disease (Gilbert, 2001). Demographic characteristics such as age and gender may also influence ones knowledge and perception about eye related conditions (Iranzo et al., 2006).

Conceptual framework



Source: Adapted and modified (Andersen, 1973).

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

Globally, it is estimated that 285 million people are visually impaired; 39 million people are blind and another 246 million have low vision. Majority of these people are blind due to treatable and/or preventable causes (Pascolini et al., 2010). Congenital glaucoma is one of the major causes of childhood blindness globally. Consequently, it accounts for up to 18% of children in blind institutions around the world (Marriott et al., 2009).

The proportion of children with congenital glaucoma is 1out of every 10,000 births. In every 8 out of 10 cases the number of males affected are 7 in both eyes. The commonest cause of early blindness is of congenital origin of which 50% of these cases are from glaucoma.

Majority of the instances of congenital glaucoma are not genetic and does not run in families. Remarkably, in some families where there is glaucoma, the males are the one's affected, which is an uncommon trend in autosomal recessive heredity. Historically, Merin and Morin conducted a study comprising of 64 households, and the results revealed that inheritance has multiple effect on congenital and open-angle glaucoma. This result is in agreement with Demanais work in 1981 in identical twins, both is affected by congenital glaucoma, though Rajiv et al., (2010) described the case of a pair of monozygotic twins where only one was glaucomatous; this indicates a role of non-genetic factors. Whereas primary congenital glaucoma affects all persons despite their ethnic background, its occurrence, nevertheless, varies worldwide: 1:2,500 within the Middle East; 1: 5,000–22,000 in developed countries; population of Slovakia (1998);1:1,250 in the Rom

(Gypsy) 1:3,300 in the Indian state of Andhra Pradesh, where the disease accounts for approximately 4.2% of all childhood blindness (Dandona et al., 2001).

Congenital glaucoma is a rare disease which occurs within the first 24 months of life and transferred to the ophthalmologist in the initial two years of life. Primary congenital glaucoma is associated with an incorrect development of the drainage system at the level of the trabecular meshwork at birth leading to rise in intra ocular pressure (IOP), of the eyeball and also there is swelling of the cornea due to fluid retention. If not treated promptly it deteriorates very fast leading to severe destruction of the entire eyeball especially the optic fibre. PCG is a multifaceted illness, which is entirely unlike ordinary glaucoma in adults, due to the structure and functions of the eyes of the newborn. From its medical presentations, pathophysiology, and anatomopathological findings, its immediate cause is due to goniodysgenesis which is associated with a mal- development of the chamber angle. According to Plasilova 1998, infantile congenital glaucoma's and late congenital glaucoma's can be differentiated at 4 years of age, since from this age, the axial length stops developing because of elevated intra ocular pressure. Congenital glaucoma is the worst of all the glaucoma's, which requires immediate attention. Shaffer examined the children in the theatre room and seek the parents' consent to continue with surgery if the clinical conclusion was positive.

Many of the causes are either preventable or treatable with early diagnosis and treatment, however, early detection and appropriate referral to an ophthalmologist largely depends on the parent's knowledge and perception about the disease condition (Gilbert, 2012). Congenital glaucoma encompasses a diverse group of diseases that have one thing in common, raised intraocular pressure leading to optic disc cupping. Overall glaucoma is responsible for 5% of blind children worldwide (Gilbert et al., 2012).

Common symptoms of the disease include buphthalmos, enlarged corneal diameters breaks in Descemet membrane and optic disc cupping. (Kanski and Bowling, 2011). It is a relatively rare eye condition and thus sometimes misdiagnosed or sub optimally treated leading to irreversible optic nerve damage. PCG is almost always managed surgically. Medical therapy is only a temporal measure prior to surgery and to control IOP after surgery. Early recognition and appropriate therapy of the glaucoma can significantly improve the child's visual future (Edward et al., 2012). While glaucoma is not preventable, early detection and treatment can help to avoid serious damage to a person's vision (Rein et al., 2009). Wilson et al. (2002) confirmed that the aim of glaucoma treatment is to slow the rate of field loss by reducing intraocular pressure (Wilson, Kosoko, Cowan, 2002). Some simple methods of self-care are available to patients with glaucoma. For example, therapeutic nutrition such as foods rich in antioxidants (lutein and zeaxanthin), vitamins (C, E and A) and minerals (zinc and copper), and application of eye compresses can lower intraocular pressure and improves blood flow to the retina and optic nerve, preserve patients' vision and limit glaucoma-related vision loss (Belal, 2006; Danesh, 2009).

Congenital and secondary glaucoma, although sometimes difficult to detect, has a traumatic impact on individual's behavioural, knowledge, attitude, perception and psychosocial development (Clare, et al., 2012). A study conducted in Uganda about parent's knowledge and awareness on congenital glaucoma revealed that 12% of parents of children with the eye condition had satisfactory knowledge about glaucoma (Terry et al., 2010). This poor knowledge and awareness was attributed to lack of educational materials about glaucoma, lack of time for ophthalmologists and nurses to provide parents with proper information, patients' low educational status and the limited training of ophthalmologists and nurses who are the main source of information for patients.

2.2 Categories of childhood glaucoma

An understanding of categories of childhood glaucoma is unclear. There are many terms used to define the several categories of glaucoma in children in diverse forms and can be classified as follows;

2.2.1 Primary Childhood Glaucoma

Usually the cause of primary glaucoma is unknown. There are two categories of primary childhood glaucoma:

i. Primary Congenital Glaucoma (PCG): It normally presents with big eyes and often have corneal blurring. It consists of three subtypes based on the age of the child, late onset develops after 24 months of age, infantile onset develops between 1 month to 24 months of age, and neonatal, onset develops before 1 month of age

ii. Juvenile Open Angle Glaucoma (JOAG): This type of glaucoma develops after age 3 years, and is associated with absence of corneal clouding and normal size eyes.

2.2.2 Secondary Childhood Glaucoma

Glaucoma is classified as secondary if it results from an ocular birth defect or a syndrome, an eye injury, or other disease such as juvenile inflammatory arthritis. There are four categories of secondary childhood glaucoma:

i. Glaucoma following Cataract Surgery/Aphakic Glaucoma: Occurs in children who have undergone a cataract surgery

ii. Glaucoma Linked with Acquired Conditions. Occurs due to the presence of diseases such as ocular injury, inflammation or infection of the eye or corticosteroids use.

iii. Glaucoma Associated with Non-Acquired Systemic Disease or Syndrome: Refers to systemic disorders like Down syndrome, Marfan syndrome and Sturge-Weber syndrome that are congenital.

iv. Glaucoma Linked with Non-Acquired Ocular Anomalies. Occurs in ocular conditions present at birth. Examples are Aniridia, Axenfeld-Rieger anomaly or Peter's anomaly, among others (Glaucoma Research Foundation, 2010).

2.3 Knowledge and perception and sources of information of congenital glaucoma

Historically, client's knowledge on the value of constant eye care is noted as a key player in seeking eye care. Moreover, eye health education has also been identified as an aid to preventing blindness. Some studies have examined different eye diseases, such as glaucoma. In cases where authors have not scaled knowledge, the liberal definition is noted as "at least one correct answer represents some knowledge." Seemingly, no standardized method is used for assessing glaucoma knowledge since all studies are basically different. Some studies employed focus group discussions and in-depth interviews approaches to assess the knowledge and attitudes that make it difficult to quantify glaucoma knowledge levels (Cross et al., 2007; Ellish et al, 2007) Moreover studies which employed the questionnaire system used varied question types, length and depths of questions. All these factors must be taken into account when comparing the results. In view of this Costa et al. (2006) emphasized this challenge by investigating two different population from urban settings in Brazil and United States of America. He identified differences in knowledge of glaucoma among these two populations. This is evident in Costa's study (Costa et al., 2006) which assessed two different urban populations (one in Brazil and one in United States of America). In their study, knowledge of glaucoma varied significantly between the two areas.

Furthermore, it was noted that at the various stages of health education could be attributed to low knowledge in these. Juzych et al., (2008) study stated that low glaucoma knowledge is expected in people with low health literacy. Population-based studies, report low awareness (0.32%-2.4%) of glaucoma in rural India (Dandona et al., 2001; Krishnaiah et al., 2005), as high as 93% in Australia (Attebo et al., 1997; Lau et al., 2002) and 78% in Hong Kong (Hoevenaars et al, 2005). This brings to bare the essence of knowledge surveys for specific countries and populations. It is imperative for parents of children with glaucoma to have requisite knowledge as well as awareness of glaucoma and eye care to prevent future visual impairment (Bile, 2007).

He asserted that when adequate awareness is given to parents, it turns to influence their perception on the eye condition and help prevent childhood blindness.

In Brazil, 20% of parents with children with childhood ocular illness were not knowledgeable and aware about the disease as well as how to start treatment (Salomao et al, 2010). Additionally, in their study, only 53% were knowledgeable in the correct time of ophthalmologic evaluation. These findings were relational to their educational background and sources of information obtained from health care providers well as print and electronic media.

A study in Nigeria revealed that 75% of parents of children with glaucoma did not know the initial management of the disease and do not follow guidelines provided by health care providers due to religious and cultural believes. In the same study, 63% were reported not to be aware and did not know the classic symptoms of the eye condition due to lack of information. These lead to late referrals of children with glaucoma for treatment leading to childhood blindness (Clare, et al., 2012).

Another study (Edward, 2012) conducted on awareness of congenital glaucoma among parents of children with the condition in a tier two city of South India showed that 65.1% parents were aware of the disease. It was observed that, most parents got their sources of information on the diseases from their health care providers and television programs while 34.9% were not aware of the disease. About 39.8% answered that glaucoma was preventable, while 28.9% responded that it was not preventable. In the same study 41% of parents had no idea as to which part of the eye is affected while 45.8% did not know when glaucoma screening should be started. 51.8% however were aware that glaucoma is treatable with early diagnosis (Rewri and Karkka, 2014). The study also revealed that parents with higher educational status were more aware and had higher knowledge of congenital glaucoma compared to those with lower educational status.

In a study carried out on knowledge, attitude and practice of parents in respect of eye complications and care among children in Nepal, India, it revealed that Parents of children with congenital glaucoma do not follow guidelines for vision screening and referrals. The study revealed that two thirds of sampled parent population had poor knowledge, attitude and perceptions on the diseases. About one third did not begin visual acuity administration to their children due to religious and cultural believes. The study further revealed that those who did not have knowledge and poor perception attributed it to low level of awareness and lack of relevant information from health care providers about congenital glaucoma (Khandekar et al, 2010).

In a study by Islam et al., (2015), factors associated with lower awareness regarding common eye diseases were advancement in age, lack of formal schooling, and lower socioeconomic status. A lower proportion (57%) of people with no schooling compared to those who had attained at least secondary school certificate education (72%) reported that they knew that blindness could be

prevented. Overall 51% of people had heard of at least six (67%) out of nine items relating to awareness of common eye diseases.

A study done by Zhou et al., (2000). revealed that 89.6% of parents had been aware of their children's condition for more than a year. Only 49.8% of all parents had known for over a year that their children's eye disease could be treated. The major obstacles for those seeking eye treatments included residual functional vision (49.0%), financial problems (36.7%), no demand for the operation (8.8%), and skepticism about the operation (8.8%). Poor vision function grade and female gender were two significant factors associated with a longer awareness (>3 years) of the existence of cataracts. Patients with a history of eye disease and a longer awareness of eye disease were more likely to have known about the potential treatments for a longer period of time (>1 year).

In a related study by Baker and Murdoch (2008), they reported that knowledge of all the eye diseases assessed was poor. Subjects aged >30 years were significantly more aware of all eye diseases assessed except night blindness. Multivariate analysis revealed that women were significantly less aware of night blindness. Education played a significant role in awareness of these eye diseases. Study subjects of upper socioeconomic status were significantly more aware of night blindness and those belonging to upper and middle socioeconomic strata were significantly more aware of diabetic retinopathy. Muslims were significantly more aware of eye diseases and less aware of night blindness. The major source of awareness of the eye diseases was a family member/friend/relative suffering from that eye disease.

Research on the same topics in Australia found that awareness of glaucoma is satisfactory, but knowledge about the characteristics of the condition is poor (Livingston et al., 1998). Patients

with higher education showed greater awareness regarding the nature of the disease. This outcome is supported by previous studies (Krishnaiah et al., 2005). Therefore, education plays a vital role in addressing the situation and ensuring early diagnosis. The higher the level of education, more likely were the glaucoma patients to know the seriousness of glaucoma as a cause for blindness.

In a recent study by Rewri and Kakkar (2014), out of 5000 individuals enrolled in a survey, only 8.3% were aware of glaucoma and 1.89% qualified as having adequate knowledge about glaucoma. They reported that level of education correlation with awareness and knowledge of glaucoma.

In a related study conducted in China, on awareness of glaucoma in a multi-ethnic population in rural China. The researchers found that only 18% were aware of glaucoma and this was significantly associated with level of education. They also reported significant ethnic differences in the level of awareness of glaucoma among the population (Pan et al., 2016).

Sathyamangalam et al., (2009) reported in their study on awareness and attitude towards glaucoma, they reported a low awareness of 15.8% among 259 respondents. Their primary sources of information were visits to eye clinics and knowing someone with glaucoma. They reported that older participants, males and skilled workers were significant predictors of glaucoma.

Nkum et al. (2015) in their study on awareness and knowledge of glaucoma reported that, amongst the participants, 74% were aware of glaucoma. There was no significant statistical difference in the various age groups, sex, ethnic group or religion and their awareness of glaucoma. There were statistically significant differences between those who

had higher education and their awareness of glaucoma. Yet only 27% of these had accurate knowledge of glaucoma.

In Ghana, no study has been conducted on congenital glaucoma, however, a study conducted on awareness, knowledge and perception of glaucoma reported out of the 300 respondents surveyed majority 99.1% were aware of glaucoma. They observed significant associations of age and educational level with awareness and knowledge of glaucoma (De-Gaulle and Darko-Gyeke, 2016). Contrary to the above study, another study conducted in Ghana on awareness of glaucoma reported that 269 (56.0%) were aware of glaucoma and this was also significantly correlated with education, religious community, English language, male sex and older age. Their sources of information were television and radio (Deokule et al., 2016).

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This section presents the methodology used in answering the research objectives and questions. It comprises of the study site, study design, target population, sample and sampling methods, data collection tool and procedures as well as statistical analysis. Finally, the section describes validity, reliability and ethical issues are also presented in this section.

3.2 Study area

The study was undertaken at Komfo Anokye Teaching Hospital (KATH) Eye Clinic in the Ashanti Region, which is the second largest hospital in Ghana. It takes care of referrals from the Northern part of Ghana. The Komfo Anokye Teaching Hospital is in the Kumasi metropolis, Ashanti region of Ghana. The hospital was founded in 1954. It is under the care of Ghana health service /National Health Insurance Scheme. It is affiliated to Kwame Nkrumah University of Science and Technology, School of Medical Sciences. The Hospital has a bed capacity of 1,000. It is the second largest hospital in Ghana, the only tertiary health institution in the Ashanti Region and the main referral hospital for the Ashanti and Brong Ahafo regions in Ghana. The hospital is also accredited for post graduate training by the West African College of Surgeons in surgery, obstetrics and gynaecology, otorhinolaryingology, radiology and ophthalmology. The eye center is located near the Accident and Emergency Centre. The eye clinic sees about 31, 294 patients a year. The glaucoma clinic is run twice a week on Tuesdays and Thursdays (GHS, 2014). The eye center comprises of 16 rooms and is divided into outpatient's department, ward and theatre. There are 7 ophthalmic nurses, three general nurses, 7 ophthalmologists and 10 residents. There are 14 slit lamps, three auto refractors, A and B scans machines, biometry

machine, visual field analysis machine. The clinic runs specialist clinic. Namely, paediatric, cornea, glaucoma, retina and oculoplastic clinics. The OPD has 8 consulting rooms, one general room, one screening room, one procedure room, three rooms for refraction with three optometrists and a pharmacy shop. The ward is made up of two (male and female) wards. The female ward consists of 10 beds and four cots and the male has 7 beds. Theatre consist of the recovery room and three operating rooms. They have four microscopes and four operations tables and three anaesthetic machines. The recovery room has five beds with one anaethestic machine and three pulse meters.

3.3 Study design

This study used a mixed method study design. This design requires that the researcher combine qualitative and quantitative approaches for breadth and depth of understanding of a health outcome or condition. In this study, the convergent parallel type of mixed method was used. This required the collection of quantitative and qualitative data, analysis and interpretation at the same time and compared after completion. In this study, a cross-sectional descriptive survey was first conducted. This study design is most appropriate for describing patterns, associations and prevalence of most health outcomes. The design was chosen because it is fast, easy to implement and less expensive. Since, the researcher was limited by time and funds, this design was most appropriate under the circumstances. The design is however prone to bias and unable to determine cause and effect of dependent and independent variables. Participants were asked to provide information on congenital glaucoma using a questionnaire. The questionnaire comprised of three sections with knowledge on glaucoma as the main outcome variables.

For the second part of the study, focus group discussion was performed for the qualitative aspect. A focused group is a small but demographically diverse group of people whose reactions and

behaviors are studied in guided or open discussions. It consists of interviews in which a group of persons are asked to express their perceptions, opinions, beliefs and attitudes towards a health concept or health phenomenon. Interactive settings are used to ascertain participants' views and are free to talk with other group members. The focus group discussion was used to determine the perception of respondents on congenital glaucoma. An interview guide was used in the conduct of focus group discussion.

3.4 Study population

The population for this study consisted of parents or guardians of children who attend the eye clinic at the Komfo Anokye Teaching Hospital who were above 18 years. These people constituted the target group because they possessed characteristics that the researcher sought for and could provide answers to the research questions.

3.4.1 Inclusion Criteria

All parents/guardians who have children with Congenital Glaucoma and have given their consent to participate.

3.4.2 Exclusion Criteria:

All parents/guardians who have children with congenital glaucoma and are not willing to participate and are below 18 years.

3.5 Variables

The variables in the study were grouped into outcome/dependent variables and explanatory/ independent variables. The two-main outcome/dependent variables were knowledge on congenital glaucoma and perception on congenital glaucoma. The explanatory/independent variables included socio-demographic factors (age, gender, relation to child, occupation,

religion, educational level and ethnicity) and source of information. Knowledge on congenital glaucoma comprised of seven individual questions. Also, focus group discussion was used to measure the perceptions of parent/guardians on congenital glaucoma. The perception on congenital glaucoma comprised of a structured interview questionnaire bothering on perception and beliefs.

3.6 Sample size determination

A sample is a representative section of the population that meets the researchers' criteria. A minimum sample size was obtained using sample size calculation for proportion (formula as shown below).

$$n= \frac{Z \times Z \times PQ}{D \times D}$$

Where: n= desired sample size

Z= Reliability coefficient for 95% confidence level usually set at 1.96

P= the proportion in a target population estimated to have knowledge and perceptions about congenital glaucoma. As a rule of thumb 50% was used because there was no reasonable estimate available in literature.

Q=1-p (target population estimated not to have knowledge and perceptions about congenital glaucoma.

d=degree of accuracy desired set at 0.10 probability level.

Using the formula above a total sample size of 96 participants was estimated. A 10% error margin was allowed for non-responses bringing the total sample size to approximately 120 participants.

Twenty guardians/parents were conveniently selected to form 3 focus groups for the qualitative section. The groups comprised of 7; 7; and 6 parents/guardians.

3.7 Sampling Technique

The sampling method that was used to sample participants for the study was purposive sampling method. Purposive sampling requires that participants are selected based on their characteristics peculiar to the research problem. This is because of the lack of existing knowledge on the research problem and the experience of the researcher. In this study, the researcher first spoke to each consented parent/guardian to ascertain whether they had the characteristics required to be part of the study. They were asked if they could also speak English, Ewe, Twi or Ga before they were made to be part of the study. Characteristics such as their age were also verified from their folders. Finally, the researcher verified if they adequately understood the study as explained to them. All those who met these criteria were then recruited to be part of the study after they have duly consented.

3.8 Pretesting

Pretesting of the questionnaire was done a week before the commencement of the actual study. The questionnaire was pretested on twenty (20) parents/guardians of congenital glaucoma patients attending the eye clinic of Korle-bu Teaching Hospital. This ensured that ambiguities and inconsistencies were corrected before commencement of the study. Age groups were modified because of overlaps in some age groups. Questions 8 was reworded to reflect what

was intended. Question 15 was modified by replacing genetic with inherited.

3.9 Data collection Technique and tools

A quantitative data collection approach using structured questionnaire was used. The questionnaire was structured in both closed and open ended format. The questionnaire comprised of four sections. The knowledge section was scored and cumulative mean score determined. Mean values above the cumulative mean score was classified as adequate knowledge and mean score below the cumulative mean score as inadequate knowledge. For further assessment, Bloom's cut off points was used to categorize level of knowledge as follows: 80 - 100% as Good Knowledge; 60-79% as Moderate Knowledge and<60% as poor knowledge. The first two categories will be summed together as satisfactory knowledge in the analysis (Khandekar et al., 2012). Perceptions was also scored in similar manner. The questionnaire was administered after obtaining informed consent from the participants in the local or their preferred language of the participants by turn. Responses were checked and validated on at the study site. The researcher then collected the completed questionnaires and sealed them in an envelope. Focus group discussion was analyzed using the thematic analysis approach.

3.10 Data processing and Analysis

Initial data collected on the forms was cleaned and entered computer's Microsoft Office Excel spreadsheet (2010). Descriptive statistics such as means ± SD, cross-tabulations, tables, frequency and percentages were used to describe demographic characteristics of the study population. Analysis of the quantitative data was done using STATA version 14. Test of associations using the Pearson's Chi square test statistics was used to determine association between demographic characteristics and knowledge and perception. Stepwise binary logistic

regression was done to assess individual independent variable in relation to the knowledge attitude and perception and their Odds ratio determined. Statistical significance was accepted at less than 5 % probability level ($P \leq 0.05$).

Data analysis for the focused group was done concurrently with the interview. An editing analysis approach as described by Polit, Beck and Hungler (2001) was used to analyse the data of the current study. The recorded interview was listened to over and over again and transcribed word-for-word. After reading the interview transcripts several times in search of meaning and deeper understanding (Morse & Field 1995), significant statements were identified, line by line, without making any assumptions. The data was compared between researcher and another transcriber for similarities and also to determine differences in the codes. The data file was imported unto the computer; the Nvivo version 8.0. Data reduction was done by loading portions of the transcribed data unto the software, on the computer; codes and groupings were compiled in the form of nodes; a table was generated to display the codes after which the codes were printed and sorted according to the groupings. These statements were grouped according to the meaning derived from them. The most frequently occurring statements were considered strong and were therefore picked and themed. The loaded software helped me with easy access to quotations needed to support the findings. The final step, interpretation of findings was done and conclusion was drawn based on the frame of reference defined by the research questions.

3.11 Quality assurance and control

Quality assurance procedures and precautions was taken to ensure the reliability and validity of the data. This included the selection and training of two research assistants with a public health background. Responses were checked for mistakes and completeness before final entry into appropriate software for statistical analysis. Coding was done to prevent typographical errors.

Validity was ensured by using a validated questionnaire. A pretest was done using 20 respondents with similar characteristics as the study sample. Errors and omissions detected were discussed with the respective assistants and asked to go back and make the necessary corrections. All the data collected were entered and ensure data cleaning by a qualified biostatistician to ensure reliability and validity of the results.

3.12 Ethical considerations

Ethical clearance was obtained from School of Medical Sciences/Komfo Anokye Teaching hospital committee on human research, publication and Ethics review board. Consent was sought from all the study participants. An introductory letter was obtained from the School of Public Health and administration of the Hospital for the purpose of seeking permission to gain entrance into the research setting. Issues regarding informed consent, confidentiality, anonymity, risks and benefits, freedom to participate and withdrawal were addressed. The researcher explained the nature and purpose of the research to each participant and questions raised were duly answered, after which the "informed consent/assent form" was signed. To ensure that the participants have understood the information, they were made to complete the "Volunteer Agreement form. Respondents were informed that they had the right to withdraw from the study at any point of the study without giving reasons. The study participants were made to understand that participation in the study will be entirely voluntary. Their decision to decline to enter the study, failure to answer any question or termination of the interview was highly respected and considered by the principal researcher. To maintain anonymity, individual participants were given identity numbers and to ensure confidentiality as well. All documented information given by participants was stored under lock and key and passwords were used for soft copies. The data will be made available only to supervisor and possibly authorities from the KATH Ethical

Review Committee if required. Copies of the research will be made available to the school's library and KATH. The study will be published in a peer review journal pertaining to the field.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This section presents the results of the study. The results are presented in tables and charts. The data obtained are summarized as frequencies, percentages, means and standard deviations.

4.2 Characteristics of respondents

The study surveyed one-hundred and twenty (120) parents/guardians. Majority of the respondents 104 (86.7%) were above 30 years while none was within age group 16-20 years. There were more female parents/guardians 67 (55.8%) compared to males. Majority of the respondents 105 (87.5%) were Christians while 15 (12.5%) are were Muslim. More than half of the respondents 78 (65.0%) were Akan while 17 (14.2%) were Northerners. Close to half of the respondents 48 (40%) had tertiary level education, 46 (38.3%) had SHS/middle level education while only 8 (6.7%) had no formal education. Most respondents 37 (30.8%) were traders, 28 (23.3%) are civil servants, 14 (11.7%) are professionals while `16 (13.3%) are unemployed.

Table 1: Respondents' characteristics

	Frequency	Percent
Age group (years)		
16-20	0	0.0
21-25	16	13.3
30 above	104	86.7
Gender		
Female	67	55.8
Male	53	44.2
Religion		
Christian	105	87.5
Muslim	15	12.5
Traditionalist	0	0.0
Buddhist	0	0.0
Others	0	0.0
Ethnicity		
Akan	78	65.0
Ewe	9	7.5
Fante	12	10
Ga	4	3.3
Northerners	17	14.2
Level of education		
None	4	3.3

	Frequency	Percent
Primary	12	10
JHS	10	8.3
SHS/middle	46	38.3
Tertiary	48	40.0
Occupation		
Banker	8	6.7
Civil servant	28	23.3
Farming	8	6.7
Hairdresser	6	5.0
Mason	1	0.8
Professional	14	11.7
Tailors	2	1.7
Trading	37	30.8
Unemployed	16	13.3

4.3 Source of information

More than half of the respondents 58.3% head of congenital glaucoma from the media (television or radio), 33.3% from the health centers while only 0.8% obtained the information themselves.

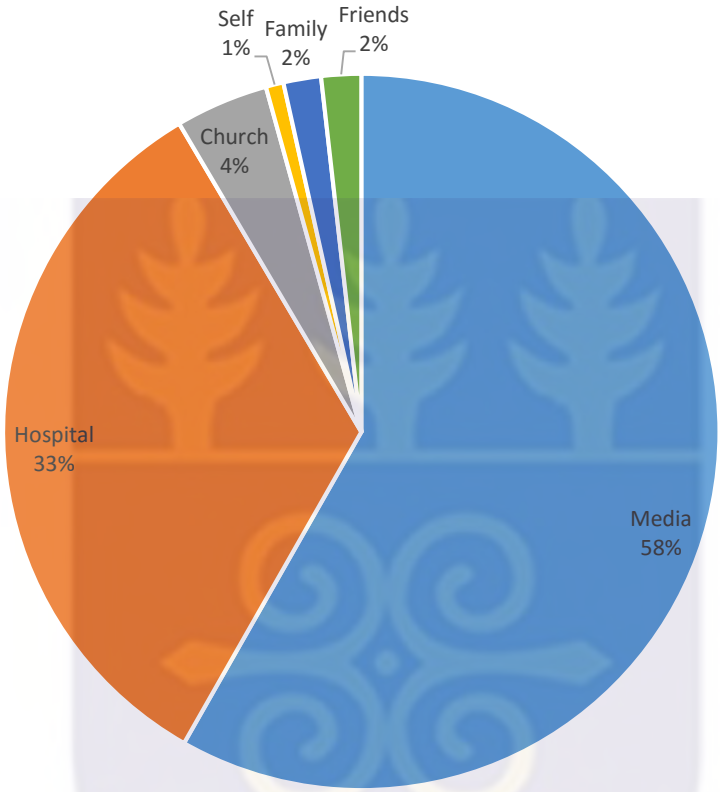


Figure 1: Respondents' source of information

4.3 Knowledge on congenital glaucoma

More than half of the respondents 68 (56.7%) have heard of congenital glaucoma. Most of the respondents 65 (54.2%) reported they know a little about congenital glaucoma while only 11 (9.2%) reported they know a lot about congenital glaucoma. However, 34 (28.3%) reported they do not know about congenital glaucoma. Most respondents in the study 83 (69.2%) reported congenital glaucoma as a disease of the eye that affect both adults and children while 26 (21.7%) reported not having an idea what congenital glaucoma is. Majority of the respondents 99 (82.5%) believe they do not know what causes congenital glaucoma. Approximately half 61 (50.8%) of the respondents did not have any idea about any signs or symptoms of congenital glaucoma. Only 3 (2.5%) reported poor vision as a sign of congenital glaucoma. Also, 26 (21.7%) reported white patch on the eye as a symptom of congenital glaucoma. Majority of the respondents 103 (85.8%) believe congenital glaucoma can be treated while 17 (14.2%) reported that they have no idea. Less than half of the respondents 54 (45.0%) reported that glaucoma can be inherited while a third 38 (31.7%) reported not having any idea. Only 13 (10.8%) of the respondent reported having a family history of congenital glaucoma. Majority of the respondents 92 (76.7%) reported that congenital glaucoma can lead to blindness. Most parents/guardians believe their child has an eye problem.

Table 2: Parent/guardians knowledge on congenital glaucoma

Knowledge factors	Frequency	Percent
Have you heard of congenital glaucoma before		
No	52	43.3
Yes	68	56.7
How well do you know about congenital glaucoma		
A Lot	11	9.2
A Little	65	54.2
I don't know	34	28.3
Quite a lot	10	8.3
What do you think congenital glaucoma is		
I have no idea	26	21.7
Is a disease of the eye that affect both adults and children	83	69.2
Is a disease of the eye that affects children only	11	9.2
Do you know the cause of congenital glaucoma		
No	99	82.5
Yes	21	17.5
What are some of the signs and symptoms of congenital glaucoma		
Beautiful big eyes	19	15.8
Excessive tearing	11	9.2
No idea	61	50.8
Poor vision	3	2.5

White patch on eyes	26	21.7
Do you think congenital glaucoma is treatable		
No	1	0.8
No idea	17	14.2
Yes	103	85.8
Can congenital glaucoma be inherited		
No	28	23.3
No idea	38	31.7
Yes	54	45.0
Do you have a family history of congenital glaucoma		
No	93	77.5
No idea	14	11.7
Yes	13	10.8
Can congenital glaucoma lead to blindness		
No	6	5
No idea	22	18.3
Yes	92	76.7
Do you know if your child has an eye problem		
No	18	15
No idea	3	2.5
Yes	99	82.5

This figure shows the level of knowledge of respondents on congenital glaucoma. Approximately a quarter of the respondents have high or low knowledge on congenital glaucoma.

Majority of the respondents 87% reported they have no idea what causes congenital glaucoma.

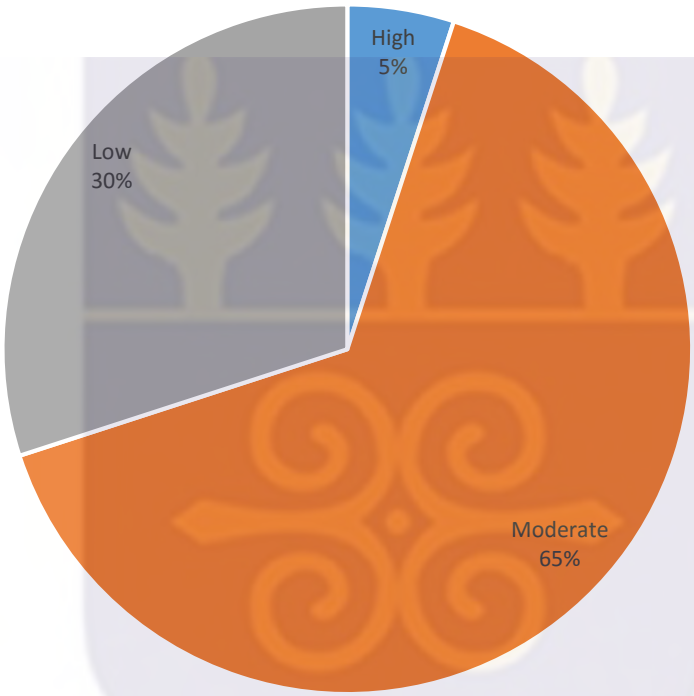


Figure 2: Level of Knowledge on glaucoma

Majority of the respondents 86.7% were of the view congenital glaucoma can be treated with surgery while only 5% had no idea of how it can be treated.

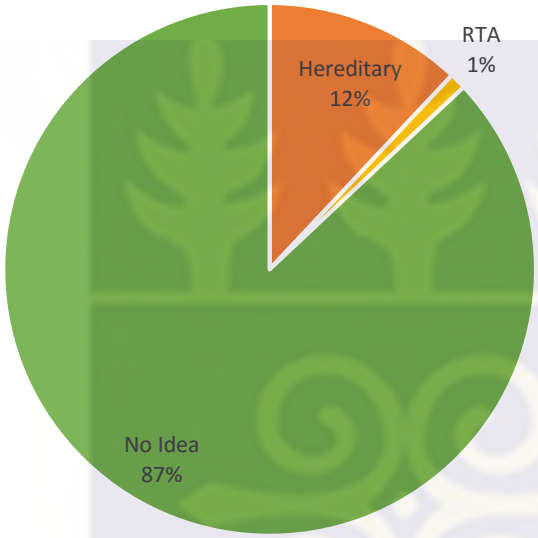


Figure 3: Perceived treatments for congenital glaucoma

Almost all respondents in the study 94% have sought treatment for congenital glaucoma available.

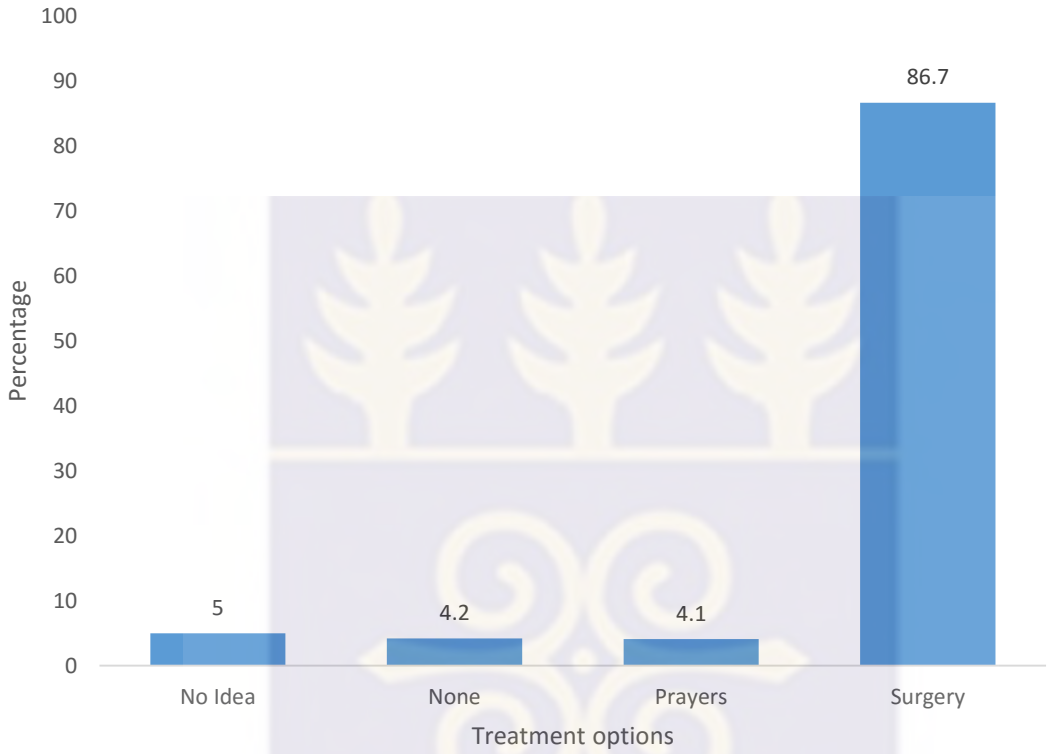


Figure 4: Respondents who have sought treatment

4.4 Perception of respondents on congenital glaucoma

Table 4.4 presents respondents' perception on congenital glaucoma. Most respondents 74 (61.6%) in the study could not tell whether their child needed eye check-up or not while 26 (21.7%) believe their child needs eye check-up. More than half of the respondents 68 (56.7%) do not know whether children develop serious eye disease that can cause blindness, however 27 (22.5%) believed that children do not get serious eye disease that can cause blindness. Only a fifth 20.8% believe that children's eye diseases are untreatable. A quarter 30 (25.0%) of the respondents feel eye hospitals do not have any facility to treat children and 69 (57.5%) don't know whether the hospitals can or cannot treat eye diseases of children. About a third 36 (30.0%) of the respondents have seen children going blind despite treatment and majority of the respondents 84 (70.0%) believe nothing can be done if the child goes blind.

Table 3: Respondents' perception on congenital glaucoma

Perception indicators	Frequency	Percent
I feel the child does not need eye check-up		
No	20	16.7
Yes	26	21.7
Don't know	74	61.6
In my opinion, children do not get serious eye disease that can cause blindness		
No	25	20.8
Yes	27	22.5
Don't know	68	56.7
If yes, have you ever sought treatment for the child's eye disease		
No	7	5.8
Yes	113	94.2
I feel children having eye diseases usually are untreatable		
No	19	15.8
Yes	25	20.8
Don't know	76	63.4
I feel eye hospitals do not have any facility to treat children		
No	21	17.5
Yes	30	25.0
Don't know	69	57.5

Perception indicators	Frequency	Percent
I have seen children going blind despite treatment		
No	15	12.5
Yes	36	30.0
No idea	69	57.5
Nothing can be done if the child is blind		
No	17	14.1
Yes	84	70.0
Don't know	19	15.8

4.5 Association between selected demographic characteristics and respondents' level of knowledge on congenital glaucoma

The study found significant association between level of knowledge on congenital glaucoma and religion (p=0.002); ethnicity (p=0.001) and occupation (p=0.001). Among those with higher level of knowledge on congenital glaucoma, most were Christians, Akans and Hairdressers. There were not significant associations between age group, gender, educational level and level of knowledge on congenital glaucoma

Table 4.4 Demographic characteristics and knowledge on congenital glaucoma

Characteristics	Low	Moderate	High		p-value
Age group					
16-24	0 (0.0)	0 (0.0)	0 (0.0)	5.257	0.072
21-25	6 (20.7)	4 (6.5)	6 (20.7)		
30 and above	23 ((79.3)	58 (93.5)	23 (79.3)		
Gender					
Male	13 (44.8)	31 (50.0)	9 (31.0)	2.953	0.288
Female	16 (55.2)	31 (50.0)	20 (69.0)		
Religion					
Christian	20 (69.0)	59 (95.2)	26 (89.7)	11.187	0.002*
Muslim	9 (31.0)	3 (4.8)	3 (10.3)		
Ethnicity					
Akan	18 (62.1)	46 (74.2)	14 (48.3)	27.96	0.001*
Ga	0 (0.0)	2 (3.2)	2 (6.9)		

Characteristics	Low	Moderate	High		p-value
Ewe	1 (3.4)	8 (12.9)	0 (0.0)		
Fante	2 (6.9)	2 (3.2)	8 (27.6)		
Northerners	8 (27.6)	4 (6.5)	5 (17.2)		
Level of education					
None	2 (6.9)	2 (3.2)	0 (0.0)	14.188	0.077
Primary	7 (24.1)	3 (4.8)	2 (6.9)		
JHS	3 (10.3)	6 (9.7)	1 (3.4)		
SHS/Middle	8 (27.6)	23 (37.1)	15 (51.7)		
Tertiary	9 (31.0)	28 (45.2)	11 (37.9)		
Occupation					
Banker	1 (3.4)	5 (8.1)	2 (6.9)	42.381	0.001*
Civil servant	7 (24.1)	17 (27.4)	4 (13.8)		
Farmer	1 (3.4)	2 (3.2)	5 (17.2)		
Hairdresser	0 (0.0)	0 (0.0)	6 (20.7)		
Mason	0 (0.0)	1 (1.6)	0 (0.0)		
Professional	3 (10.3)	10 (16.1)	1 (3.4)		
Tailor	14 (48.3)	18 (29.0)	5 (17.2)		
Trader	0 (0.0)	0 (0.0)	2 (6.9)		
Unemployed	3 (10.3)	9 (14.5)	4 (13.8)		

***Significant at 5%**

4.6 Factors influencing level of knowledge of congenital glaucoma

Level of knowledge on congenital glaucoma was significantly influenced by respondents being an Akan, Ga, having SHS, technical and tertiary level education and being a civil servant ($p<0.05$)

Table 4.5 Ordinal logistic regression

	Estimate	Std. Error	p-value	95% C.I.	
Age group (years)					
21-25	0.201	0.706	0.775	-1.182	1.584
30 and above	Reference	.	.	.	.
Sex					
Female	0.268	0.598	0.653	-0.904	1.44
Male	Reference	.	.	.	.
Religion					
Christian	3.985	1.21	0.001*	1.614	6.356
Muslim	Reference	.	.	.	.
Ethnicity					
Akan	-2.963	1.171	0.011*	-5.258	-0.669
Ewe	0.616	1.496	0.680	-2.315	3.547
Fante	-1.916	1.299	0.140	-4.461	0.63
Ga	-5.553	1.881	0.003*	-9.239	-1.866
Northerners	Reference	.	.	.	.

Educational level					
None	-24.786	81.819	0.998	-15.859	15.288
Primary	-4.154	1.235	0.001*	-6.575	-1.732
JHS/middle	-2.241	1.062	0.035*	-4.322	-0.16
SHS/secondary	-2.419	0.831	0.004*	-4.048	-0.79
Tertiary	Reference	.	.	.	.
Occupation					
Banker	-2.609	1.306	0.046	-5.17	-0.049
Civil servant	-2.965	1.152	0.010*	-5.223	-0.707
Farmer	21.387	81.819	0.998	-15.687	15.46
Hairdresser	24.481	83.589	0.998	-16.172	16.134
Mason	2.84	2.756	0.303	-2.561	8.242
Professional	-0.864	0.866	0.319	-2.561	0.834
Tailor	-0.763	0.715	0.286	-2.165	0.639
Trader	24.481	0.000	.	24.481	24.481
Unemployed	Reference	.	.	.	.

4.7 Qualitative results

Most respondents believed congenital glaucoma affected both children and adults and that it could be cured with a surgery. Most of them did not know if congenital glaucoma was hereditary and could not be treated. Although majority of the parents/guardians were seeking health care for their wards they did not believe the hospitals could cure or treat congenital glaucoma. Cultural and religious practices were seen to influence decision of parents to seek early management for their children

4.7.1 Perception of parents on Congenital Glaucoma

The participants described what their perception on congenital glaucoma was and how they perceived it.

G1 reported:

I think congenital glaucoma is a condition that affect the eye of both adults and children. But I think it is more common in children.

G2 said:

I know it is a disease that affects the eye, usually both eyes and can lead to blindness. It can affect both adults and children.

G3 also reported:

Congenital glaucoma is one of the common eye conditions of humans and is common in poor communities.

G12 explained:

I understand what congenital glaucoma is and I have some level of accurate information on the condition.

G8 recounted:

I know congenital glaucoma can be cured if detected early. However, treatment procedure and process are expensive and most people cannot afford.

G12 said:

Congenital glaucoma can be treated with herbal medicine and prayers. It is a spiritual illness that requires supernatural powers.

G9 explained:

Congenital glaucoma can be treated if diagnosed early. This can be done through surgery and medications.

4.7.2 Cultural and religious beliefs

Respondents commented on their religious and cultural beliefs about congenital glaucoma. **G14 said:**

I take my child for special prayers because I believe the almighty God can do something about it for me.

G5 explained:

I keep my child home because the neighbours believe she has a spiritual illness and they talk about her.

G7 recounted:

I send my child for special prayers every Sunday because I believe he can be healed through prayers.

G18 also said:

I believe congenital glaucoma can be cured by other means so I try other forms of treatment such as herbal, prayers etc.

CHAPTER FIVE

5.0 DISCUSSION

5.1 Introduction

This section discusses the findings of the study in relation to published review literature on congenital glaucoma. The study sought to assess the level of knowledge of parent/guardians of children with congenital glaucoma on congenital glaucoma. The findings are discussed in relation to stated research questions as follows: What is the level of knowledge of parents on Congenital Glaucoma? How do parents perceive Congenital Glaucoma? What are the sources of information on Congenital Glaucoma?

5.2 Characteristics of respondents

This study sampled one-hundred and twenty (120) parents/guardians who were attending the eye clinic of Komfo Anokye Teaching Hospital. A large proportion 87% of parents/guardians were above 30 years while none was found in age group 16-20 years. This age distribution reflects the expected distribution for parents/guardians. They are mostly above 18 years and are in their mid-thirties. Such age group also forms the active working population in Ghana. There more females than males in the study. A side the higher rate of females in the country as reported by the Ghana Statistical Service (2012), it is the norm and culture of Ghanaians that women take their children or grandchildren to the hospital for reviews. Majority of the respondents 87.5% were Christians while 13% were Muslims. This is a true reflection of the distribution of religious groups in Ghana as reported by the Ghana Demographic Health Survey in (2010). Some studies have reported some influence of religion on perception on a variety of health issues. This distribution may have therefore influence parents'/guardians' perception on congenital glaucoma. More than half of the parents were Akans while 14.2% were Northerners. This may be attributed to the fact

that the study was conducted in Kumasi is predominantly an Akan community. It also has a large proportion of Northerners around the northern part of the metropolis. Close to half of the respondents had tertiary education. Kumasi is the capital town of Ashanti region and most of the white color jobs in the region are situated in the town. It is therefore not surprising that clients attending the hospital have high educational level. Only, 12% of the parents/guardians did not have formal education. The level of education of parents/guardians have been shown in some studies to influence knowledge and perception on several health conditions. Most respondents 30.8% were traders and 23.3% were civil servants while `13.3% are unemployed. This distribution reflects the educational level of respondents in this study.

5.3 Level of knowledge of parents/guardians of children with congenital glaucoma on congenital Glaucoma

In terms of knowledge on congenital glaucoma among parents/guardians, only 5% had and overall high level of knowledge while 30% had low level of knowledge on congenital glaucoma. Similar studies conducted in Ghana reported high awareness and knowledge among respondents. Specifically, De-Gaulle and Darko-Gyekye (2016) reported 99.1%% of their respondents had adequate knowledge on glaucoma and Murduroch, Opoku and Murdoch (2016) reported 56% of their respondents had adequate knowledge on glaucoma. In spite these findings, more than half of the respondents have head of congenital glaucoma. This rate of awareness may be due to their frequent attendance to congenital glaucoma clinics for their children where health education is always conducted before clinic starts. Though parents/guardians were aware of congenital glaucoma, most believe they have little information on congenital glaucoma. Researchers have reported a disconnect between awareness and having knowledge. They opined that awareness does not always translate into having adequate knowledge. Almost a third of the parents/guardian

do not know about congenital glaucoma. In a related study conducted in Nigeria, Isawuni et al., (2014) in their study on awareness and attitude towards glaucoma, they reported a low awareness of 15.8% among 259 respondents. Their primary sources of information were visits to eye clinics and knowing someone with glaucoma. Most parents believe the disease affects both adults and children. Congenital glaucoma is usually born with the child and he/she grows with it to become an adult. This seems to underscore the need to provide clear and detailed health education on the condition to improve parents/guardians understanding of the condition. In a related study by Rajesh et al., (2001), they reported that knowledge of all the eye diseases assessed was poor. Subjects aged >30 years were significantly more aware of all eye diseases assessed except night blindness.

Parents/guardians knowledge on the causes of congenital glaucoma was poor as 83% reported they do not know what causes. Not having accurate knowledge on a disease condition can influence treatment and management choices as well as perception on the condition. In a related study conducted in China, on awareness of glaucoma in a multi-ethnic population in rural China. The researchers found that only 18% were aware of glaucoma (Pan et al. 2016). Signs and symptoms of disease condition are very important in ensuring early detection. In this study, half of the parents did not have any idea about the signs and symptoms of congenital glaucoma. White patch on the eye was the most commonly known symptom of congenital glaucoma. It was interesting to know that majority of the parents/guardians believe congenital glaucoma can be treated. Research on the same topics in Australia found that awareness of glaucoma is satisfactory, but knowledge about the characteristics of the condition is poor (Livingston et al., 1995). They reported surgery as a primary way of treating congenital glaucoma. This may positively influence their quest to seek early treatment. However, a third of the

parents/guardians could not tell if congenital glaucoma can be treated. In this study, only 13% reported having a family history of congenital glaucoma. This may have influenced the level of knowledge and awareness of such parents/guardians as they may be aware of the disease in the family in the past. Majority of the respondents 76.7% reported that congenital glaucoma can lead to blindness. Knowing that the condition can lead to blindness can influence the urgency of such parent/guardians to seek for early treatment. Most parents/guardians believe their child has an eye problem. Looking only at the population-based studies, the proportion who had heard of glaucoma was as low as 0.32% and 2.4% in rural India Dandona et al., (2001); Krishnaiah et al., (2005) and as high as 93% in Australia (Attebo et al., 1997; Lau et al., 2002) and 78% in Hong Kong (Hoevenaars et al, 2005). This highlights the importance of knowledge surveys for specific countries and specific populations within the same country.

The study found significant association between religion, ethnicity, occupation and level of knowledge on congenital glaucoma among parents/guardians of children with congenital glaucoma. Among those with higher level of knowledge on congenital glaucoma, most were Christians, Akans and Hairdressers. There were not significant associations between age group, gender, educational level and level of knowledge on congenital glaucoma. In a related study, Murdock, Opoku and Murdoch (2016) reported associations between educational level, religious community, English language, male sex and older age and level of knowledge on congenital glaucoma. Similarly, De-Gaulle and Darko-Gyeke (2016) also reported significant association between age, educational level and awareness and knowledge of glaucoma. Contrary to this finding, NKum et al. (2015) in their study on awareness and knowledge of glaucoma reported that, there was no significant statistical difference in the various age groups, sex, ethnic group or religion and their awareness of glaucoma. In a study by Islam et al., (2015), factors associated

with lower awareness regarding common eye diseases were increasing age, lack of formal schooling, and lower socioeconomic status.

5.4 Perception of parents/guardians of children with congenital glaucoma on congenital Glaucoma

In this study, overall perception of parents/guardians on congenital glaucoma was generally low. Most parents/guardians in the study could not tell whether their child needed eye check-up or not while only 21.7% believe their child needs eye check-up. Such perception may negatively influence parents'/guardians' decision to go for early treatment or even adhere to medication given to them at the hospital. More than half of the parents and guardians do not know whether children develop serious eye disease that can cause blindness. Only a fifth 20.8% believe that children's eye diseases are untreatable. Like the findings of this study, Gilbert, (2001), reported that perception among respondents was mainly negative and were not accurate. According to Resnikoff et al., (2004), parents do not normally believe the their children need regular eye checkup to manage their condition.

A quarter of the parents/guardians feel eye hospitals do not have any facility to treat children and 57.5% don't know whether the hospitals can or cannot treat eye diseases of children. Not having trust in hospitals capability of treating congenital glaucoma can lead to them looking for alternative sources such as herbal, tradition and religious. Or they might not adhere to instructions and medications given to them in the hospital. In a similar study, Marrioti et al., (2009) reported that most parents in the study did not believe the hospital has the capacity to treat their children.

About a third 30.0% of the parents/guardians have seen children going blind despite treatment and majority of the respondents 70.0% believe nothing can be done if the child goes blind. Most respondents believed congenital glaucoma affected both children and adults and that it could be cured with a surgery. Most of them did not know if congenital glaucoma was hereditary and could not be treated. Although majority of the parents/guardians were seeking health care for their wards they did not believe the hospitals could cure or treat congenital glaucoma. Cultural and religious practices were seen to influence decision of parents to seek early management for their children. In view of this perception, some take their children to pastors for regular prayers while other apply herbal medications. Herbal medications have been shown to be harmful to the human especially those of infants and children. Similar to the finding of this study, Pizzarello, (2004) reported that cultural and religious beliefs play a major role parents decision making in seeking health care for their children.

5.5 Sources of information on Congenital Glaucoma among parent/guardians of children with congenital glaucoma.

Having access to information can improve awareness and knowledge leading to better practice. The study revealed that parents/guardians source information is the media (television or radio) and the health centers while only 0.8% obtained the information themselves. The media and health education at health centers continue to provide rich source of information on important health issues. Parents/guardians having access to such important information can increase their awareness and knowledge and help them in making informed decision about congenital glaucoma. In a related study, Murdock, Opoku and Murdoch (2016), reported showed that primary sources of knowledge on glaucoma were television and radio. Pan et al., (2016) reported that significant ethnic differences in the level of awareness of glaucoma among the population.

Another study (Edward, 2012) conducted on awareness of congenital glaucoma among parents of children with the condition in a tier two city of South India showed that most parents got their sources of information on the diseases from their health care providers and television programs while 34.9% were not aware of the disease.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONs

6.1 Conclusion

The study showed that parents and guardians of children with congenital glaucoma have fairly moderate knowledge on the condition. However, a quarter of them had low knowledge about congenital glaucoma. Parents and guardians have the perception that their child's condition can be cured through other means such as spiritual and herbal. They also believed that cultural beliefs influence their seeking early treatment for the affected child. The media (radio and television) and hospitals were identified as important and efficient sources of information on congenital glaucoma for parents.

6.2 Recommendations

The findings of this study make provision for the under listed recommendations:

1. District and operational level eye care delivery can use this findings as basis for health education/promotion interventions

2. The Ministry of Health (MOH) must develop a policy to place ophthalmic nurses at both children and maternity blocks to identify congenital glaucoma as early as possible

3. Health facilities in collaboration with the Health Promotion Unit of the Ghana Health Service must make provision for health education on congenital glaucoma at the OPDs to create awareness and increase knowledge on the condition.

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APPENDICES

APPENDIX 1: CONSENT FORM

Title: KNOWLEDGE AND PERCEPTION OF PARENTS OF CHILDREN LIVING WITH CONGENITAL GLAUCOMA AT THE KOMFO ANOKYE TEACHING HOSPITAL, GHANA

Principal Investigator: DORINDA GODSON-AMAMOO

Address: School of Public Health, University of Ghana.

General Information

Dear Participant, This consent form contains information about the research on knowledge and perception of parents of children living with congenital glaucoma at the Komfo Anokye Teaching Hospital (Kumasi). In order to be sure that you are well informed of the research, the researcher is asking you to carefully read (or have it read and explained to you) this Consent Form. You will then be asked to sign or thump print the consent form after agreeing to participate in the research. This consent might contain some words that are unfamiliar to you. Please ask the researcher to explain or clarify anything you may not understand.

Why the study

Congenital glaucoma is an important cause of blindness globally. Many of the causes are either preventable or treatable with early diagnosis and treatment. However, delays in detection of childhood eye disease can often lead to debilitating outcomes. There's inadequate distribution of ophthalmologists in different regions of the country compared to pediatricians transferring large portion of the initial care of children with eye diseases to pediatricians. Therefore, even though the ophthalmologist could provide specialized care for the children, early detection and appropriate referral to an ophthalmologist largely depends on the knowledge and perception of the parents of the child with the condition

General Information and your part in the study

For you to qualify to be part of this study, you must be a parent/guardian who has children with congenital glaucoma attending the eye clinic at Komfo Anokye Teaching Hospital. I may contact you by phone if further information is needed.

Possible Risks and Discomforts

The researcher acknowledges that this research will course some psychological discomfort during the answering of some part of the questionnaire. However, the level of psychological distress will be minimal.

Possible Benefits

There are no direct benefits to you; however, findings of this study will help us to suggest improved ways of educating and creating of awareness to parents with children living with congenital glaucoma.

Confidentiality

Your identity and privacy will be protected; a number will be used to identify you instead of your name on anything that will be written about and the document bearing your name such as the consent form will be handled by the researcher and the supervisor only and these will be kept in safety.

Voluntary Participation and Right to Leave the Research

Your participation in this research is strictly voluntary and so, if you don't want to participate you are free to do so. You are not going to lose anything if you decide not to take part. If you participate and in the process you want to stop you will be allowed to do so.

Compensation

No compensation will be given to parents/guardians in the research, however their inputs will be recognized and appreciated.

Contacts for Additional Information

If you ever have any questions about the research study or study-related problems, you may contact Dorinda Godson-Amamoo

School of Public Health, +233-244-872-768 or Dr. Alfred Yawson,

+233-244-662-711

Your right as a Participant

This research has been reviewed and approved by the Kwame Nkrumah University of Science and Technology, School of Medical Sciences and Komfo Anokye Teaching Hospital. If you have any questions about your right as a research participant you can contact the IRB Office between the hours of 8am–5pm.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title knowledge and perception of parents of children living with congenital glaucoma at the Komfo Anokye Teaching Hospital, Ghana (KATH) has been read and explained to me. I have been given the opportunity to ask any question about the research and answer to my satisfaction. I agree to participate as a volunteer.

Date Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits; risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date Name Signature of Person Who Obtained Consent

APPENDIX II: QUESTIONNAIRE

UNIVERSITY OF GHANA – LEGON

KNOWLEDGE AND PERCEPTION OF PARENTS OF CHILDREN WITH CONGENITAL GLAUCOMA AT THE KOMFO ANOKYE TEACHING HOSPITAL, GHANA

Survey Interview Questionnaire 2017

Dear respondents,

I am a student of University of Ghana, Legon (School of Public Health), and researching on the topic Knowledge And Perception of Parents of Children with Congenital Glaucoma at the Komfo Anokye Teaching Hospital, Ghana.

This questionnaire is to gather data for Academic Purpose only. You will be contributing immensely towards the success of this study by responding to these questions. Kindly give adequate information to the under listed questions. Your identity will not be disclosed in any way. Participation is entirely voluntarily and will not affect any hospital health care services.

Please thick (√) in the boxes provided where necessary and write in the spaces provided where needed. Thank you for your cooperation.

QUESTIONNAIRE ID _____ **NAME OF FACILITY**_____

DATE OF INTERVIEW _____/_____/_____ **TIME**_____

SECTION A: DEMOGRAPHIC INFORMATION		
1.	Age	16-20yrs[ ] 21-25[ ] 30 above [ ]
2.	Gender	Male[ ] Female[ ]
3.	Religion	Christian[ ] Muslim[ ] Traditionalist[ ] Others (Specify)……
4.	Ethnicity	Ga[ ] Akan [ ] Ewe[ ] Northerners[ ] Others (specify)……
5.	Level of education	Primary[ ] JHS/Middle School [ ] SHS [ ] Technical/Vocational [ ] Tertiary[ ] None [ ]
6.	Occupation	Farming [ ] Trading [ ] Artisan [ ] Professional [ ] Civil servant [ ] Unemployed [ ] Others (Specify)…….
SECTION B: SOURCE OF INFORMATION		
7.	Where do you get health information?	Media [ ] Friend[ ] Hospital[ ] other(specify)……
8.	Have you heard of Congenital Glaucoma before?	Yes[ ] No[ ]

9.	If yes, where have you heard it from?	Media [ ] Friend[ ] Hospital[ ] other(specify)……
SECTION C: KNOWLEDGE ON CONGENITAL GLAUCOMA		
10.	How well do you think you know about Congenital Glaucoma?	A lot [ ] Quite a lot[ ] A little[ ] Don't Know[ ]
11.	What do you think Congenital Glaucoma is? Is a disease of the eye that affects children only? [ ] Is a disease of the eye that affects adults only [ ] Is a disease of the eye that affects both adults and children. [ ] I have no idea [ ] Others please specify ……	
12.	Do you know the causes of Congenital Glaucoma?	Yes [ ] No [ ]
13.	If Yes, What are some of the causes? Witchcraft[ ] (specify)……..	RTA[ ] Hereditary[ ] No idea[ ] others
14.	What are some of the signs and symptoms of Congenital Glaucoma?	Excessive tearing [ ] White patch on the eyes [ ]

	Beautiful big eyes [ ] No idea [ ] others (specify) ……..	
15.	Do you think Congenital Glaucoma is treatable?	Yes[ ] No[ ] Don't know[ ]
16.	If yes, What do you think is the best treatment .	Herbal medicine[ ] Eyedrops[ ] Surgery [ ] Prayers from religious leaders[ ] Others (specify)…….
17.	Can Congenital Glaucoma be inherited?	Yes[ ] No[ ] Don't know[ ]
18.	Do you have a family history of Congenital Glaucoma?	Yes[ ] No[ ] Don't know[ ]
19.	Can Congenital Glaucoma lead to blindness?	Yes[ ] No[ ] Don't know[ ]
20.	Do you know if your child has an eye problem?	Yes[ ] No[ ] Don't know[ ]
21.	If yes, have you ever sought treatment for the child's eye disease?	Yes[ ] No[ ] Don't know[ ]

SECTION D: PERCEPTION ABOUT CONGENITAL GLAUCOMA Code: 1=Yes 2=No 0=Don't know 3=No Response		
22.	I feel the child does not need eye check-up	[ ]
23.	In my opinion children do not get serious eye diseases that can cause blindness	[ ]
24.	I feel children having eye diseases usually are untreatable	[ ]
25.	I feel eye hospitals do not have any facility to treat children	[ ]
26.	I have seen children going blind in spite of treatment	[ ]
27.	Nothing can be done if the child is blind	[ ]

THANK YOU

APPENDIX III: INTERVIEW GUIDE

Introduction

I am going to ask you some question about your perception and belief on congenital glaucoma, take time in answering them and feel free to ask me to explain further if the question is not clear to you. You can skip question and return to it if you want to. If you don't want to comment on a question please say so. Please be assured that there are no wrong answers, so give me your honest response. Remember that whatever you share with me will not be identified with you but may be used as valuable information in the study.

1. Please tell me some few things about your self
2. Can you please tell me how old you are?
3. What work do you do?
4. In which part of Kumasi do you live?
5. What tribe do you belong to?
6. What is your religion?
7. Are you educated?
    - If yes (the level)
8. Please are you married?
9. Do you already have children?
    - How many children
    - Age and sex
10. Could you tell me something about the circumstances of child with congenital glaucoma?

11. Please describe what experience you have had with leaving with a child with glaucoma.

12. The care you received from health personnel do you believe it is helpful and can treat your child's condition?
13. Do you think the hospital is the best place for treatment of congenital glaucoma?
14. Can congenital glaucoma be cured?
15. Do you think other sources of treatment can help your child's condition?
16. Have you tried other source of cure/treatment or management for your child's condition?
17. Does cultural and religious belief play any role in your seeking treatment for your child?
18. How has this discussion been to you?
19. Is there anything else you would like to tell me about which you think would be important for me to know?

Closing

I am grateful for the time you have spent with me and the contribution you have made to the study. If you think now or in the next few days that our discussion has brought up things that needs to be talked about with the doctor or nurse please call me. I would be happy to send you the result of the study if you request for it. Thank you very much.

APPENDIX IV: ETHICAL CLEARANCE