UNIVERSITY OF GHANA

SCHOOL OF PUBLIC HEALTH

COLLEGE OF HEALTH SCIENCES

AWARENESS, KNOWLEDGE AND ATTITUDE TOWARDS CLEFT LIP/PALATE AMONG ANTENATAL ATTENDEES AT THE MAMPROBI POLYCLINIC

BY

MERCY SAGWALA
(10637006)

THIS DISSERTATION IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF A MASTER OF PUBLIC HEALTH (MPH) DEGREE

JULY, 2018

DECLARATION

I do hereby declare that apart from people's knowledge that I have acknowledged, this Dissertation is the result of my dedication hard work under supervision in accordance with the procedures laid down by the University of Ghana. I take full responsibility for this work.

…… ……..

Mercy Sagwala Date

(Student)

…….. ……..

Dr. Emmanuel Asampong Date

(Supervisor)

DEDICATION

I humbly dedicate this work to the Almighty God whose faithfulness and mercies have brought me this far. It is also dedicated to Madam Rose Baniba, my family and close friends for their love and immense support during my course of study.

ABSTRACT

Background: Children with cleft lip/palate suffer major functional morbidity such as restricted maxillofacial growth, speech anomalies, swallowing and feeding difficulties, hearing impairment/or recurrent ear infections. Cleft lip/palate are generally not life-threatening, living with cleft evokes a notable health burden. **Objective:** To assess the awareness and knowledge of pregnant women attending Mamprobi polyclinic on cleft lip and or palate.

Methods: A cross-sectional study design adopting quantitative methods in collecting data from 239 pregnant women seeking antenatal care at Mamprobi Polyclinic was used. Descriptive statistics were presented using tables and charts. Chi square test was used to assess the association between knowledge and the respondents' characteristics of interest as well as the association between awareness and the characteristics of respondents. Logistic regression analysis was used to model the association between knowledge and the significant characteristics.

Results: The proportion of respondents who had high knowledge on cleft lip/palate was 53.7% and the proportion of those who were aware of these conditions was 37.9%. The level of education was significantly associated with level of knowledge (COR= 5.61, 95% CI: 1.67, 18.87). Of all respondents, 45.74% (102/223) believed that cleft lip/palate has no evil connotation. Also, 51.89% (110/212) of the women believed cleft lip/palate is not a condition contracted as a curse from gods; 54.72% (116/212) believed the condition is not gotten from witchcraft. Regarding attitude, 95.4% were interested in knowing more about cleft lip/palate, 79.2% would be willing to touch a child with cleft lip/palate.

Conclusion: Pregnant women attending the Aantenatal clinic at the Mamprobi polyclinic had low level of knowledge about cleft lip/palate. The beliefs about cleft lip or palate were

generally unfavourable while their attitude towards it was largely favourable. Pregnant women showed a low awareness of cleft lip/palate.

ACKNOWLEDGMENT

Firstly, I express my gratitude to the Almighty God for his goodness and mercy. I couldn't have come this far without his grace and guidance. For 'except the lord build the house, they labor in vain that build it: except the lord keep the city, the watchman wake but in vain (Psalm127:1). To Him be the glory and honor.

My genuine appreciation goes to my supervisor Dr. Emmanuel Asampong, Department of Social and Behavioural Science, School of Public Health, for his counsel, patience and encouragement and correcting my work at no cost, Dr. Samuel Dery of the Department of Biostatistics for his unrelenting encouragement and correcting my work.

I would like to thank staff of the antenatal unit of the Mamprobi polyclinic for their cooperation and the good working environment they created. My sincere thanks to Mr., Enoch Akyeampong for his great work done in preliminary editing.

Lastly, I say a big thank you to my family, friends and loved ones especially Jennifer Korley for the support, prayers and encouragement and to all and sundry I might not have mentioned, I say God bless you all.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

ANC	Antenatal Care
AOR	Adjusted Odds Ratio
CDC	Centre for Disease Control
CI	Confidence Interval
CLP	Cleft Lip and Palate
KATH	Komfo-Anokye Teaching Hospital
OFC	Orofacial cleft
SD	Standard deviation
UOR	Unadjusted Odds Ratio
WHO	World Health Organization

DEFINITION OF TERMS

Antenatal attendees'	pregnant women who seek care at the clinic
Awareness	Recognition of the condition
Cleft lip and palate	an opening in both the lip and the roof of the mouth
Cleft lip	an opening or a division on the lip
Cleft palate	an opening or a split in the roof of the mouth

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

In times past, diagnosing cleft lip/ palate was made upon delivery of a baby. However, in recent times, it can be identified and diagnosed through advanced technology while the baby is still in the womb (Phil, 2002). Cleft lip or palate are considered one of the most common birth defects that possess significant medical, psychological, social, and financial implications on the affected individuals and families (Allam, Windsor, & Stone, 2014).

According to Allam et al., (2014), some of the risk factors that contribute to the development of clefts include lack of folic acid consumption, age of the mother, and smoking when pregnant. In addition to the notable defect, a child with cleft lip/palate suffers some huge functional complications such as limited facial growth, speaking difficulty, swallowing and feeding difficulties, hearing loss and/or recurrent ear infections.

The facial growth is stepwise process involving complex structural events and increased reproduction, and therefore can be affected by physical, chemical, natural and hereditary factors, resulting in the high incidence of anomalies of the face. The shape of the embryo's head is formed during the first six to eight weeks of pregnancy. Hereditary factors that contribute to cleft lip and or palate formation have been observed for some syndromic and non-syndromic cases, but knowledge about genetic factors that contribute to the more common isolated cases of cleft lip/palate is still unknown (Agbenorku et al., 2011). According to the World Health Organization and the National Institute of Dental and Craniofacial Research, cleft lip and or palate (CLP) are ranked as the fourth most prevailing congenital defect globally, occurring about once per every 500 to 700 live births (WHO, 2013).

About 70% of conditions are non-syndromic and do not include other birth defects associated with it (Cronin, Brauer, & Palate, 2017). The emotions associated with having a child with cleft lip and or palate can be very devastating especially in developing countries such as Ghana where peoples way of life is guided by traditional belief system(Antwi-kusi, Addisson, Oti, & Amuasi, 2015).

The facial appearance stirs up emotions in family members and other people. Feeding during the first thirty days of life can be very challenging (Antwi-kusi, *et al*.(2015). Peoples reaction and attitude towards children with the condition can be associated with their religion, cultural beliefs and demographic differences (Owotade et al., 2014). Superstitious belief often accompanies the birth of a child with orofacial cleft with a higher prevalence of such attitudes in rural and less educated areas (Olasoji, Ugboko, &Arotiba,2007). For example, there is a belief among parents in Africa that CLP is caused by supernatural forces that have expressed their thirst for blood through the baby's 'deformity'. Others consider CLP to be retribution from past sins or crimes (Loh & Ascoli, 2011). One school of thought concerning myths of CLP has it that children are struck with the anomaly as a result of worms within the stomach when women are starved during pregnancy. Another school of thought has it that pregnant women give birth to children with CLP when they laugh at a patient with CLP. Also, pregnant women can give birth to children with CLP when they go out during an eclipse (Loh & Ascoli, 2011).

International estimates that are limited to cleft lip with or without cleft palate range from 7.94 to 9.92 per 10,000 live births (Mastroiacovo et al., 2011). The occurrence rate of orofacial clefts varies by race. Overall, higher prevalence have been documented in Asians and American Indians while lower prevalence been reported in African-derived populations (Kesande, Muwazi, Bataringaya, & Rwenyonyi, 2014).

1.2 Problem statement

Globally the prevalence for cleft lip/palate is1 per 700 births (Mossey & Modell, 2012). The prevalence is high among Asians,Causcasians being the intermediary and then low in African population. (Conway et al., 2015). Cleft lip/palate is an issue of public health concern. It is referred to as a physical abnormality that can be attributed to the environment or genetics and is present at the time of birth (Kalisya, Nyavandu, Machumu, & Kwiratuwe, 2015). Center for disease control (CDC) recently estimated that, each year in the United States, about 2,650 babies are born with a cleft or palate and 4,440 babies are born with a cleft lip with or without a cleft palate (CDC, 2016). Studies have shown that in Africa the distribution and incidence of cleft varies widely among publications. While the epidemiology of orofacial clefting in Africa has been studied, results vary widely between publications. The population in Africa is distinct and not just with a low incidence (1/2,500), but also in the way by which different types of cleft are distributed (Conway et al., 2015). In Ghana, it is estimated that on average, about one in every 500–750 live births results in a cleft (Agbenorku et al., 2011).

Due to the deformity and the demands of care, parents usually become disappointed and hence caring for such children is tedious as well as emotional, particularly to mothers in poor resource countries (Oshodi & Adeyemo, 2015). In addition to the emotional impact, sociocultural interpretations and perceived stigma add stress to the mothers of such infants (Adebola, Bamgbose, & Adeoye, 2014). Also, parental attitudes and expectations towards children with CLP affect the social and emotional development of patients, thus, a negative attitude has been linked with increased mental and social stress, leading to a lower quality of life for people with CLP (Chan, McPherson & Whitehill, 2006).

Few studies have been done on this phenomenon in Ghana. For example, a study conducted at the Komfo-Anokye Teaching hospital sought to understand the satisfaction that parents will derive from the surgical correction that will be provided. (Oti, Obiri-Yeboah, & Donkor,

2014). Anecdotal evidence shows that orofacial disorders specifically cleft lip and or palate are not mirages but real conditions, although research and studies on the situation is rare in Ghana. It is in this direction that this study seeks to assess the awareness, knowledge and attitude towards cleft lip/palate among antenatal attendees at the Mamprobi Polyclinic.

1.3 Justification of the study

Understanding the causes, signs, symptoms and treatment of cleft lip or palate is a very important component if education is given during antenatal care (Antwi-kusi et al., 2015). In most developing countries for example giving birth to a child with cleft lip/palate causes emotional and traumatic experiences for parents, especially because myths and beliefs play a huge role in health seeking behaviors (Olasoji et al., 2007). This emotional and psychological trauma can be eliminated if parents (especially mothers) are well informed about cleft lip/palate and its management. In some cases, educating family members however, will go a long way to address issues of misconceptions about cleft lip/palate. It will also help in identifying strategies that will help increase awareness about cleft lip/palate among antenatal attendees at the Mamprobi Polyclinic. It will again contribute to existing literature from the Ghanaian perspective on the phenomenon under study.

1.4 Research questions

1. What is the awareness on cleft lip/palate among antenatal attendees at Mamprobi Polyclinic?

2. What is the knowledge level among antenatal attendees on cleft lip/palate at Mamprobi Polyclinic?

3. What are the attitudes of pregnant women towards cleft lip/palate at the Mamprobi Polyclinic?

1.5 Objectives

The objectives of this study are divided into general and specific. These have been indicated below.

1.5.1. General objective

The general objective of the study is to assess the awareness, knowledge and attitudes pregnant women have towards cleft lip/palate at the Mamprobi polyclinic.

1.5.2. Specific objectives

The specific objectives of the study have been outlined as:

1. To assess the awareness on cleft lip/palate among pregnant women.
2. To assess the knowledge pregnant women have on cleft lip/palate.
3. To explore the attitude and beliefs of pregnant women towards cleft lip/palate.

1.6 Conceptual framework

Behavioural and Proximate Determinants model was modified to arrive at the conceptual framework for the study. According to the Berman et al., (1994) model, the socio-demographic environement which includes income, work, wealth and education influence the level of awareness and knowledge and hence, health seeking behaviour.

Health system factors such as health services, proximity of health institutions e.t.c have an influence also on the health seeking behaviour.

Health care provider-related factors, such as physician communication, attitude of staff, the hospital environment (infrastructure and basic facilities), waiting time, health education e.t.c influence the health seeking behaviour of pregnant women. Cultural factors such as perception of community, belief systems and taboos on cleft lip/palate influences knowledge and awareness and attitude.

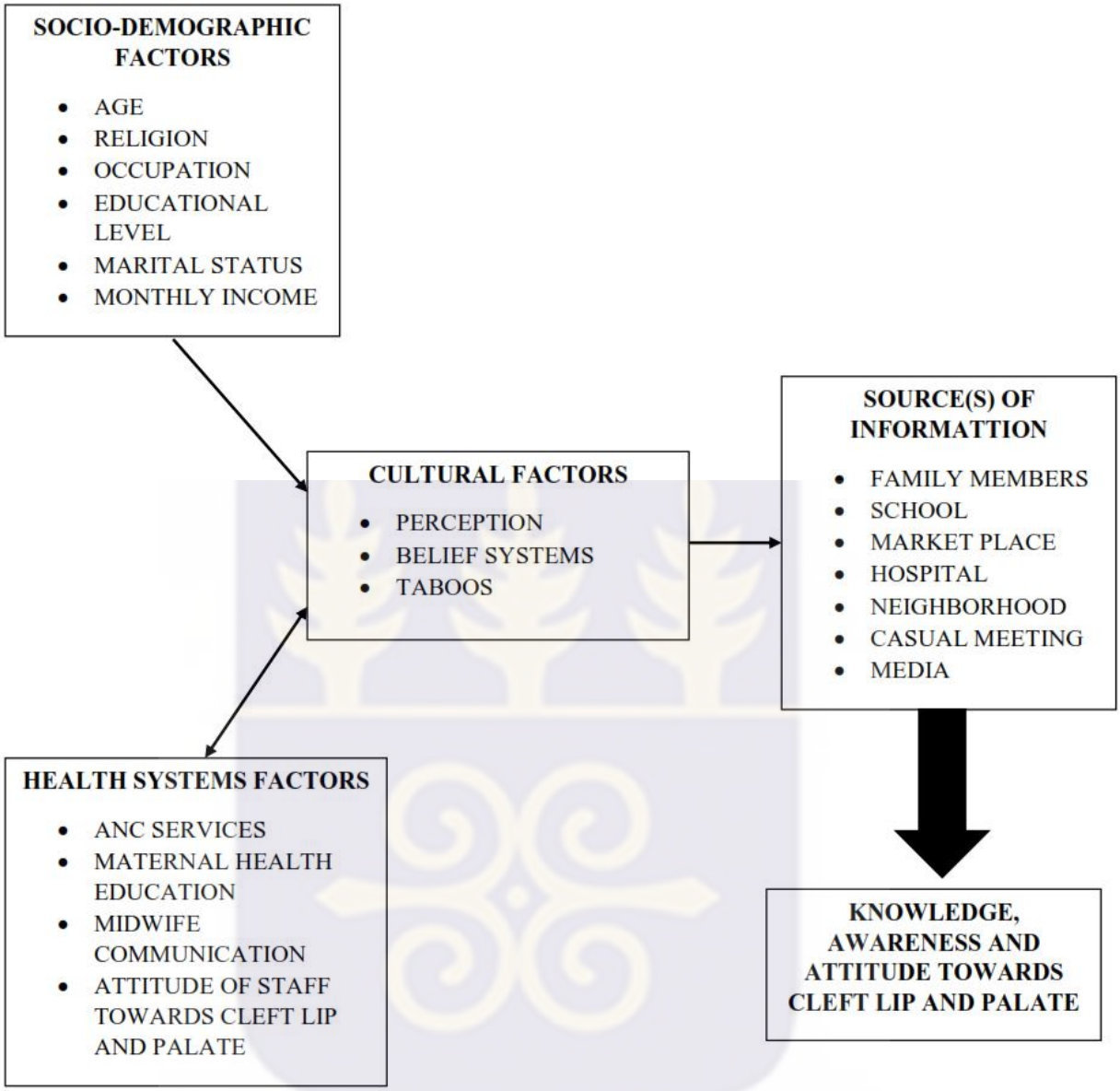


Figure 1 Conceptual Framework Adapted from the Behavioural and Proximate Determinants model (1994).

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The chapter reviewed literature related to the topic under study. The chapter was divided into five main sections. Section 2.1 reviewed literature on the embryonic development of cleft lips/palate, classification of cleft lip/palate and etiology of cleft lip/palate. Section 2.2 presented information on epidemiology of cleft lip/palate. Section 2.3 reviewed literature on knowledge, awareness and perception on cleft lip/palate. Section 2.4 touched on ante-natal care and cleft lip/palate and section 2.5 presented psychosocial factors affecting mothers of cleft lip/palate babies.2.6 presented relationship between mothers and children with cleft lip/palate.2.6.1 reviewed facial appearance.2.6.2 talked about bonding with babies suffering from cleft lip and palate2.6.3 looked at feeding difficulties.2.6.4 reviewed the financial burden on parents.2.7 examined factors impacting cleft lip/palate.2.7.1 analyzed speech and language development.2.7.2 assessed hearing difficulty.2.7.3 reviewed dental problems.2.7.4 explained the role of stigma on cleft lip/palate and 2.8 evaluated the coping strategies that are employed.

2.2 Embryonic development of cleft lips/palate

During the fourth week of gestation there is an improved development of facial structures, which is attributed to the migration of neural crest cells from the dorsum of the anterior neural tube with subsequent merger with mesodermal cells to create the first part of the facial cells. (Moore et al. 2015). The cells and nerves that constitute the face are made up of frontonasal prominence, two maxillary and two mandibular prominences. The forehead and the nose are formed from the frontonasal prominence (Carstens, 2008). There are prominences in the maxillary and mandibular, which are bilateral. The lateral stomodeum is

formed in the maxillary and the mandibular prominences and it houses the caudal growth of the stomodeum. The lower cheek region and the lower lip are formed in the fourth week of pregnancy when the middle ends of the mandibular protuberance join (Moore et al. 2015).

The maxilla protuberance also increases and develops together with the nasal cavity. When the nasal cavity joins together it forms the primary palate and that is when the segments of the intermaxillary develops. The side of the upper lip develops when the already indicated region joins to the maxillary cavity (Steding, 2009). In the sixth week of pregnancy the secondary palate starts to develop. The palatal shelves lie side by side on either side of the tongue. With development of the mandible, the tongue migrates caudally, and the median edges of the palatal shelves, swing in a horizontal arch to meet in the midline. Subsequent mesenchymal penetration enables fusion to form the secondary palate. By the twelfth week, the soft palate and the uvula fuse to complete formation of the fetal palate. When there is lack of fusion in the structures that form the mouth and the nose they produce clefts. (Gorlin et al. 2010).

2.2.1 Classification of clefts lip/palate

Clefting results from failure of the structures of the lip and palate to properly fuse during the first twelve weeks of pregnancy (Pearson & Kirschner 2011). Among most of conditions of the face and the nose cleft lip and palate are most common. While there have been a lot of efforts to group clefts, deformities of the face, neck, jaw and head are most comprehensive as examined by Tessier (1976) with 14 meridians of craniofacial cleft. Numbers are given to the various grouping of cleft a this denotes the seriousness and the area of the cleft in key areas like eye socket, the oral and the nasal cavity. Cleft lip and palate as identified by Tessier can be group into four depending on their position. The middle is known as the meridian and is denoted with 0. cleft in the midline fall in the 0 and 14 position, Paramedian clefts occurs in

the first, second, twelfth and thirteenth position, while the orbital cleft happens the third, fourth, fifth, ninth, tenth and eleventh position and the lateral cleft develop in the sixth, seventh and eighth positions. Hence cleft lip or palate develops where two meridians are positioned according to Tessier's classification. Kernaghan and Strak (1958) as cited in Lithovius, (2015) explained the stripped Y classification that was argued about for being too complicated and difficult and to use.

Kriens (1989) as cited in Lithovius, (2015) explained the LAHSHAL system for classification of clefts in which L for lip, H for hard and S for soft palate. The left-hand letters (LASH) depicts clefts that are right sided and the letters on the right (SHAL) represents a left sided cleft. Small letters are used when reference is being made to submucosal clefts and bifid uvula.

Tolarová and Cervenka (1998) as cited in Lithovius, (2015) Orofacial clefts have been classified under nine major groups considering factors such as diagnosing separately or correct estimate of the causative agent: single cleft abnormalities, series of primary defect, missing chromosomes, inherited disorders, results of known physical abnormalities, associations, multiple congenital abnormality of which causes are not known and babies who are joined together physically when they are born.

Currently, clefts of the face and nose are the two major forms of cleft. Oral and nasal clefts can present as either a cleft lip, separately without a cleft palate or with a cleft palate. The International Classification of Diseases (ICD) is used worldwide for epidemiology, health management and diagnostic purposes and its utilisation has made it easier for clefts to be grouped. ICD-10 is made up of congenital deformation such as different cleft types. Group Q35 is made up of cleft of the palate, Q36 shows cleft of the lip and Q37 represents cleft of the lip and palate (ICD-10, version: 2015).

According to (Mossey et al. 2009) variations in orofacial cleft are determined by their intensity and magnitude, ranging from small hole in the lip to the clefts that goes beyond the alveola ridge of the maxilla and spreads to the base of the nose and palate. Because the primary palate and the lip undergoes various formation in the germinal stage than the secondary palate, further divisions of clefts are (CLP) and (CP) where the lip is not fragmented. Cleft palate can also occur on both the hard and soft palate. (Figure 2.1).

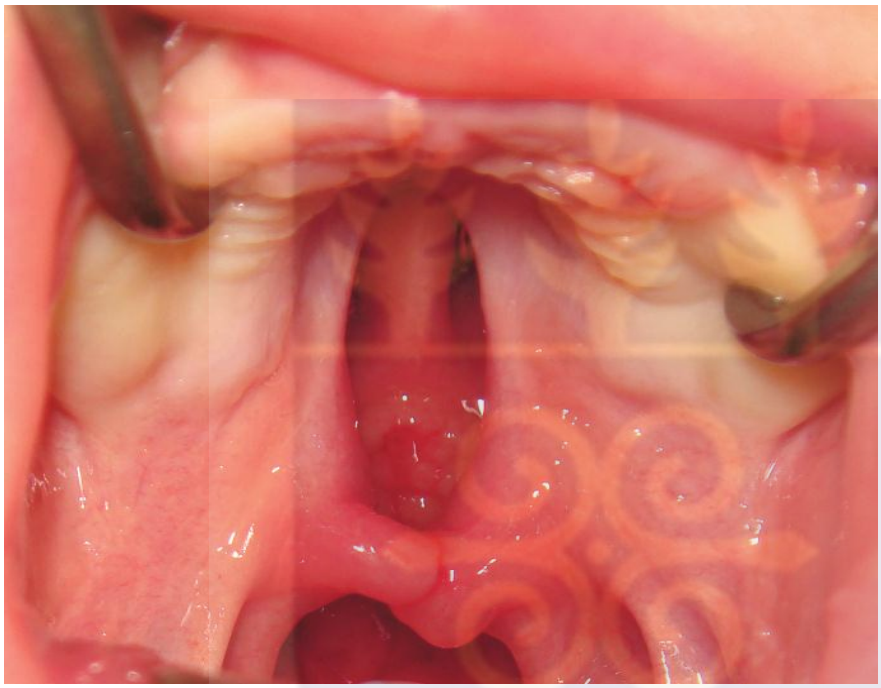


Figure 2: Cleft of hard and soft palate (Isolated)

Cleft palate in its slightest form, otherwise known as bifid uvula is an indicator of submucosal cleft palate (SMCP). This is medically concealed beneath the oral mucosa. Some of the other indicators comprise reaching behind margin of the hard palate in the middle part of the palate because of a separation of the palate muscles. (Goodacre & Swan 2008, Klockars et al. 2010) (Figure 2.2).

Figure 3: Submucosal cleft palate

Unilateral CLP Occurs when the fusion between the medial nasal prominence and the maxillary prominence fails on only one side. (Figure 2.3) or can be referred to bilateral CLP (Figure 2.4) usually when two sides are included. In addition, clefts can be separated as complete or incomplete. Cleft lip and palate can be termed as incomplete when it involves the lip and the front part of the maxilla as well as both the soft and hard palate (Mossey et al. 2009). Clefts can also be grouped as forme fruste which may include minimal muscle dehiscence (Goodarce & Swan 2008).

Figure 4: cleft lip and palate(unilateral)

Figure 5: cleft lip and palate (bilateral)

2.2.2 Etiology of cleft lip and or palate

The etiology of cleft lip and palate is described as heterogeneous with both genetics and environmental contributions (Allam et al., 2014). With the emergence of genetic technology and progress in both quantitative and molecular analysis techniques, there has been great advancement in the identifying the causative genetic mutations and possible associations underlying syndromic forms of cleft lip and palate. Meanwhile, there is currently little headway in identifying and understanding the genetic etiology of isolated (non- syndromic) cleft lip and or palate cases (Dixon, Michael J. Marazita, Mary L. Beaty, Terri H. Murray, 2011).

According to (Allam et al., 2014) a wide range of genetic factors have been measured in population based studies and candidate genes studies. Results have suggested a role for genes responsible for growth factors (e.g. TGFα, TGFβ3), transcription factors (e.g. MSX1, IRF6, TBX22), factors which influence xenobiotic metabolism (e.g. CYP1A1, GSTM1, NAT2), nutrient metabolism (e.g. MTHFR, RARA), and immune response (e.g. PVRL1, IRF6). TGFα and MTHFR genes have been amongst the most widely investigated variants over the years (Allam et al., 2014).

Cleft lips and or palates are medical conditions that are easily recognizable (Antwi-kusi et al., 2015). Even though not a major cause of mortality in developed countries, it does cause notable medical problems to affected children and imposes a substantial financial risk as well as psychosocial burden for families (Agbenorku et al., 2011). Relatively, it has been established that most of the cleft lip and or palate epidemiologic studies support a role for environmental factors in its etiology(Care, 2010). Maternal exposure to tobacco products, alcohols, nutritional deficiencies, some viral infections, medications, and teratogens in the workplace or at home in early pregnancy have been identified as some of the most recurrent risk factors (Roux, 2013).

2.3 Epidemiology of cleft lip/palate

According to International Perinatal Database of Typical Oral Clefts 2011, orofacial clefts (OFC) represent a heterogeneous group of defects with a considerable range of dysmorphological severity. In understanding the challenges of the health impact on OFC it has been maintained that lack of data, poor-quality or incomplete data often missing information on important variables such as gender and dysmorphological severity are contributing factors in many areas in the world. Scarce data on OFC has made it very difficult to understand and appreciate the severity of the condition. Despite this, there is adequate literature on individual countries in studies that have been undertaken to describe the rate at birth of OFC, which, at first sight, imply very considerable international differentiations. However, it is not possible to rule out these differentiations as it is a substantial part accounted for by differences among geographical infrastructures for health care, and hence ascertainment, which may change over time. Therefore, there is a need for data to be collected in a logical way to enhance meaningful assessments of the regional variation of the birth prevalence and time trends for OFC. For example, in Europe, where protocols to enhance comparability of data have been implemented for some time, there is a fivefold variation in the prevalence at birth of cleft lip with or without cleft palate (CLP) and a threefold variation in isolated cleft palate (CP) across surveillance registries (Mossey & Little, 2002).

The data available to Lozano 2012) indicates that the prevalence rates reported for live births for cleft lip with or without cleft palate and cleft palate alone varies within different ethnic groups and this caused about 4,000 deaths globally in 2010 down from 8,400 in 1990. With specific reference to the United States of America, the prevalence rate for Cleft lip and or palate are reported for Native Americans and Asians. It was seen that children of African descent have the lowest prevalence rates in the United States (Cervenka & Shapiro, 2008).

Also, the rate of occurrence of CPO is similar for Caucasians, Africans, North American natives, Japanese and Chinese. In effect the prevalence of "cleft uvula" has varied from 0.02% to 18.8% with the highest numbers found among Chippewa and Navajo and the lowest generally in Africans

The revelations in the last paragraph is given credence by Hutchinson et al (2011); Newman and Agbenorku (2014), which show that Cleft lip, can occur solely as a malformation or together with cleft palate which is reported in approximately one in 700 live births. Boys are twice as likely to have a cleft lip with or without an associated cleft palate. On the other hand, girls are more likely to have a cleft palate alone (those not associated with a cleft lip malformation). Ethnic background has been shown to affect the frequency of clefts. Children of Asian, Latino, or Native American ancestry are more frequently affected when compared to those of Caucasian background.

Cleft lip and cleft or palate occurrence varies in frequencies among different cultures and races as well as countries (Agbenorku et al., 2011).Typically, there is an average of one in every 500-750 live births that produces a cleft. The Centre for Disease Control (CDC) revealed that in the United States of America, the prevalence of cleft lip and or palate is 2.2 to 11.7 per 10,000 births. Cleft palate alone results in a prevalence rate of 5.5 to 6.6 per 10,000 births (CDC, 2013).

Prevalence rates reported for live births for Cleft lip and palate and cleft palate only vary within different ethnic groups (Kesande et al., 2014). There are high prevalence rates for cleft lip and or palate among Native Americans 3.74/1,000 and Asians from 0.82/1,000 to 4.04/1,000. Africans from 0.18/1,000 to 1.67/1,000 have the lowest prevalence rates (Agbenorku et al., 2011).

The frequency of cleft lip/palate also differs by sex and laterality. There is a 2:1 male to female ratio for clefts involving the lip and approximately a 1:2 male to female ratio for clefts of the palate only; and there is a 2:1 ratio of left to right sided clefts among unilateral cleft lip cases (Dixon, Michael J. Marazita, Mary L. Beaty, Terri H. Murray, 2011).

Malawi recorded a low prevalence rate for Cleft lip or palate, 0.7 per 1,000 live births According to a study done in Khartoum city in Sudan revealed that there is prevalence of 0.9 per 1000live births of clefting among newborns (Kesande et al., 2014). In Ghana, a prevalence of 5.0 per1000 people was reported after a survey done in Wudoaba communities (Agbenorku et al., 2011). According to a retrospective review executed at the Komfo-Anokye Teaching Hospital (KATH) in Kumasi on cleft lip and palate, Ghana reported a total of 120 patients. Out of the number 66.0% had complete unilateral cleft lip while 34% had incomplete unilateral cleft lip (Oti et al., 2014). Most prevalence reports on cleft lip and or palate had their data from hospitals, with relatively few studies done in communities. In Ghana, the only community based study on cleft was reported by Agbenorku et al., (2011).

2.4 Perception, knowledge and attitude towards cleft lip/palate

Negative expression and feelings associated with the condition can be eliminated if there is enough recognition and understanding of the cleft lip and palate deformity. (Owotade et al., 2014). Like many African communities, myth and superstition commonly accompany the birth of a physically defective child (Antwi-kusi et al., 2015). The birth of a congenitally deformed baby is usually unexpected and provokes mixed feelings of shock, shame, anxiety, confusion, guilt, inadequacy, rejection, depression, disappointment, anger, hopelessness and stigmatization for the parents, especially the mother (Collett, Cloonan, Speltz, Anderka, & Werler, 2012). Religion and beliefs are one of the factors that affect the social perception and

the reaction to any health problem as well as the utilization of the health services (Olasoji et al., 2007).

However, the passionate feelings shows the negative perception about cleft lip and or palate is understood based on spiritual, traditional and socio-economic differences in many communities(Mba & Onah, 2017).

Several studies have been published attempting to describe the relation between Cleft lip and or palate and the influence of cultural perception in many countries (Umweni, 2009). The phenomena, depending on the culture of the people could be attributed to solar life, curse, transgressions of the ancestor's rules or rituals, God's will or punishment, certain behaviors during pregnancy such as fishing, laughing on somebody with cleft, and eating rabbit meat among others (Dagher & Ross, 2004).

The direct impact on such false etiology results in negative social feedback. This transforms the individual's psychological development into anxiety, lower self-esteem, or even results in lowering the family position in some societies (Mba & Onah, 2017). Furthermore, in some cultures, ostracism and shame are brought to the individual together with his family. In some cases, the public presentation of the child is avoided while in some extreme cases, infanticide is practiced as a cultural obligation (Olasoji et al., 2007).

A systematic review conducted by Loh and Ascoli revealed a general belief across three different cultures (Chinese, African, and Indian) that the mother is responsible for the occurrence of cleft lip and or palate (Oshodi & Adeyemo, 2015).

In Madagascar for example, religion and beliefs have obvious influences on health seeking behaviour. Circumcision, for example, is done for religious and cultural reasons, and not for health-related reasons (Randriamiharisoa et al., 2015).

In this regard, there is the need to boost education mostly in the rural communities where sensory experience support the fact that babies are still being eliminated because they are believed to be children of the gods and are associated with bad luck to the community (Antwi-kusi et al., 2015).

2.5 Ante-natal care and cleft lip/palate

In the management of health problems that affect mothers and babies during pregnancy, antenatal care (ANC) is essential for the provision of adequate care for women before birth and parenthood as well as prevent problems for pregnant women, mothers and babies through early detection (Fagbamigbe & Idemudia, 2015). The functioning and operationalized continuity of care together with affordability, accessibility and high quality of care is the center for any successful antenatal care service. (Dickson, Darteh, & Kyereme, 2017). According to WHO (2015) antenatal care helps in the early identification and treatment of conditions that may threaten the health of the mother and foetus and helps a pregnant woman approach pregnancy and birth successfully (Mbai, 2015).Implementation of Antenatal care (ANC)has a potential to drastically reduce morbidities such as cleft lip/palate as it continues to be one of the Safe Motherhood interventions (Oladapo & Osiberu, 2009). Antenatal care services also educate the pregnant woman on good nutrition, importance of exclusive breastfeeding and proper position of breastfeeding. It also informs them of the danger signs to note during pregnancy such as bleeding, hyperemesis gravidarum, symptoms of malaria, effects of self-medication, alcohol and tobacco use throughout pregnancy and cleft lip/palate among others (Lambon-Quayefio & Owoo, 2014). Lack of antenatal care however, denies the pregnant woman of these benefits and results in major risk factors for development of negative pregnancy outcomes such as cleft lip and or palate (Dixon, Tenkorang, Luginaah, Kuuire, & Boateng, 2014).

2.6 Psychosocial factors affecting mothers of cleft lip/palate babies

In a study conducted by reactions (Hsieh, Chao, & Shiao, 2013) giving birth to a "perfect" baby is most often at times a dream shared by expectant mothers. Mothers tend to have mixed feeling and reactions when they know of the diagnosis. Most often lose their sense of self value and are frightened by baby's health or guess the baby will be unhealthy after delivery after realizing the diagnosis of cleft lip and or palate (Roux, 2013). Mothers often admit to culpability (self-blame) and attribute the condition to heredity or as a curse put on the family (Olasoji et al., 2007). They end up hiding the child from society and in some cases, the children are rejected by their fathers (Umweni, 2009).

Knowledge of foetus facial deformity results in anxiety, especially when mothers are less informed about condition (Olasoji et al., 2007). Mothers are sometimes burdened with concerns about potential disadvantaged status (Cassell et al., 2007). The expectant mother must struggle to handle with the stance of husband, family and friends. This poses a lot of burden on her psychologically (Umweni, 2009). Although Western medicine has made it possible to correct cleft lips and or palates, there still exists the perception that children born with such are defects are physically and spiritually deficient especially in our part of the world (Olasoji et al., 2007).

2.7 Relationship between mothers and children with cleft lip/palate

Mothers of children with CL/P face immediate challenges after birth, such as adjusting to the facial appearance of the child and bonding to the child. Most of the children with CL/P face feeding difficulties. This becomes an instant distress for the mothers.

2.7.1 Facial appearance

Having a child with CL/P may be an immense emotional strain on the mothers. One important factor that increases this emotional strain tends to be the facial appearance of the

child (Bradbury & Bannister 2004; Lemvik, 2003). Mothers of these children may experience lowered self-esteem and emotional distress for the loss of an ideal child (Rees, 2007). In the first months following the birth, the mother may have difficulties adjusting to her child's facial appearance, so the mother may be less involved in facial interaction (Chuacharoen, Ritthogal, Hunsrisakhun, & Nimanat, 2008).

Society is orientated towards physical attractiveness. Individuals who are less attractive get negative response to their physical appearance, while individuals who are more attractive tend to have easier positive interactions with others (Tobiasen, 1987). Appearance is one of the most obvious concerns among individuals with CL/P. Appearance may have an impact on the psychosocial development, attachment, and social relationships to others (Harper & Peterson, 2001).

Studies that focus on facial appearance and social development indicate that individuals with CL/P experience stigma associated to their appearance (Strauss et al., 2007; Turner, Rumsey, & Sandy, 1998). The impact of visible differences depends upon the type of cleft and its severity, and upon which part of the face is affected and how extensive scar tissue is (Harcourt & Rumsey, 2008; Berkowitz, 2006). Tørdal and Kjøll (2010) and Lemvik (2003) described mothers of children with CL/P who hide their children from other people's view.

2.7.2 Bonding with babies suffering from cleft lip/palate

The relationships of infants and their primary caregiver (usually defined as the mother) during the first years is critically important for infants to grow into emotionally and psychologically healthy children and adults. Bowlby (1980) believed that infants need the mother for meeting basic physiological needs. According to Bowlby (1977) optimal attachment occurs when a mother recognizes and responds to the infant's signals and meets the infant's needs both emotionally and physically; unconditional love is required to adjust

emotionally and socially in adulthood. Infants born with CL/P elicit different emotions from their caregivers. Inadequate maternal responses may have an adverse psychological effect on children with CL/P, delaying the attachment process between mother and child. On the other hand, some mothers may overprotect their children. This creates a safe bonding (Coy, Speltz, & Jones, 2002). Yet Coy et al. (2002) mentioned other studies that have discovered that mothers of children with attractive infants are more compassionate and attached to their infants than mothers with less attractive children. These findings can imply that bonding between a mother and infant with an unrepaired CL/P may be negatively affected. A mother may particularly have trouble playing face to face with her child. Mothers of infants that had early lip repair may find it easier to engage in responsive play with their child. The mother of an infant with CL/P might spend less time playing with the infant and exhibit less sensitivity during parent/child interaction and less engagement in facilitating the child basic needs (Coy et al., 2002).

Risk factors such as maternal depression, lack of social support, bereavement over the loss of the ideal baby and the infant's temperament are considered to hinder attachment between the infant with CL/P and the mother. To enhance infant attachment security, the cleft lip team can have a role to help the mother to establish sensitivity and responsiveness to her child. However, most studies seem to suggest that infants with cleft lip and palate have little effect on attachment, but it still emphasizes disruption on interaction may occur (Coy et al., 2002; Speltz et al., 1997).

2.7.3 Feeding difficulties

Feeding difficulties is one of the immediate challenges parents with a child with CL/P faces (Miller & Kummer, 2008). Feeding difficulties among these children differs according to the type of cleft and severity of the condition. For instance, a single cleft lip is a visible defect,

but may not cause a major feeding difficulty for the infant. Infants with cleft lip only can establish feeding and they may not have difficulties with feeding, since they can create adequate suction that is needed (Miller & Kummer, 2008).

Children with CL/P often have an impaired ability to breast-feed. Infants with cleft of hard and soft palate have problems feeding, due to air leakage through the nose. The problem is severe for an infant with isolated cleft palate because he/she may be unable to create enough pressure to produce the suction required to take in milk, and in some cases food escapes through the nasal passageway (Endriga & Speltz, 1998). Therefore, they are rarely able to breast feed because of their difficulty creating a vacuum. There are devices available to overcome this obstacle. A very minor modification can resolve these feeding problems (Miller & Kummer, 2008). For instance, children with CL/P can be fed using bottle that needs less pressure to squeeze the milk into the oral cavity. They can also be fed with a soft plastic bottle with one crosscut to widen the nipple, thereby easing the feeding process. These children may have a problem with poor oral suction, inadequate volume intake, lengthy feeding times, nasal regurgitation, excessive air intake, coughing, or choking. Due to this problem, the mother may experience anxiety, may feel stress regarding feeding and her relationship with her infant (Bannister, 2004; Miller & Kummer, 2008).

Mothers need to establish basic strategies for effective feeding. Professionals need to give special attention to the matter to reduce anxiety and stressful interaction between mother and infant. This can be done by giving the parents a feeding guide, making sure that the parents do not leave the hospital without knowing what to do (Miller & Kummer, 2008; Berkowitz, 2006).

Most researchers believe breast-feeding is best for infants. Breast-feeding is recognized as the optimum form of nutrition for infants. Breastfeeding is protective. It also has a range of

benefits that are important for infant health, growth, immunity, and development. Breast milk provides the infant with immune protection, a lower risk of infections, and minimizes allergies. Also, the act of breast-feeding creates a good mother and baby bonding (Owens, 2008). Cleft palate can also alter the swallowing of milk or food. The infant may have a problem to grip the nipple itself (Berkowitz, 2006). So, infants may not get adequate nutrition and gain the appropriate weight. The goal of feeding an infant with a CL/P is the same as infants without cleft. In developed countries, breast pumps are available, so the infants can get the benefits of breast milk. The priority is to provide optimal nutrition for the infant's daily growth, with weight maintenance being of primary concern both for parent and professionals (Berkowitz, 2006; Martin, 2004).

2.7.4 Financial burden on parents

Treatment of CL/P often involves medical, surgical, dental, speech, and psychological treatments. The entire treatment process can last a long time. In most countries, the funding for treatment comes from health insurance, federal and state sources, private and non-profitable agencies, and services organizations (Kummer, 2008).

In developing countries, parents may not have the opportunity to rely on third-party payers for their child's medical care. In rare cases, they may get some form of support from governmental hospitals, but even then, they still need to cover the non-medical expenses by themselves (Kummer, 2008).

The financial burden is even more overwhelming in developing countries such as Ghana where the per capita income is as low as 120 US dollars and 60% of the population lives under the poverty line. Lack of economic prosperity means limited infrastructure for health care, creating an inaccessible health care system. It is easy to understand that children with CL/P are not getting the basic medical care they need in a timely manner. In recent years,

nongovernmental organizations have made a major advance in medical care, including CL/P treatment, but the magnitude of the problem remains high to be addressed (Fekadu, 2001).

2.8 Factors impacting children with CL/P

Children born with cleft lip and palate are at the risk for impaired hearing and speech difficulties as well as dental problems. Being born with CL/P is also associated with social stigma.

2.8.1 Speech and language development

Children with CL/P have physical abnormalities from birth on their vocal organs. The dysfunction of the vocal organ affects the ability to suck, chew, swallow, and breathe initially, and then affects the production of speech (Berkowitz, 2006). Vocal organ dysfunctions include both hard and soft palate. These children may have problems generating enough air pressure to produce certain sounds. Speech difficulties are caused by anatomic and physiological abnormalities and dysfunction among the cleft population (Kummer, 2008). They may have delay in early language acquisition (Tørdal & Kjøll, 2010). This is related to various factors including hearing loss, lowered parental expectations and disrupted parent-child interaction. The characteristic speech problem for children with CL/P is related to articulation and resonance. Resonatory dysfunction results in hypernasality or more hypo nasality, while articular problems mostly relate to production difficulties in plosives and fricatives. Due to these factors, the speech of a person with a cleft can have reduced intelligibility. Early cleft palate repair helps the children to acquire normal speech development (Kummer, 2008; Grunwell & Sell, 2004).

Children with CL/P in developing countries may be living in poverty, without access to sufficient health care. In some of these countries, maternal child care and cleft care services are not enough to meet their needs. Therefore, in developing countries such as Ghana,

children with cleft are at additional risk for delayed speech and language development (Lemvik, 2003). Lemvik highlighted that children with unrepaired cleft can exhibit nasal speech, making them a laughing stock in the public. Children with isolated cleft lip have fewer speech difficulties than those with cleft palate. The children with isolated cleft lip often find compensatory ways of producing the sounds following lip-closure surgery (Berkowitz, 2006).

2.8.2 Hearing difficulties

Children with CL/P also can experience hearing problems. Muscles of the soft palate (tensor velipalatini) are responsible for the correct opening and closing of the Eustachian tube. The Eustachian tube equalizes the pressure within the middle ear and aids in drainage of mucous secretion. The muscles that open the Eustachian tube are affected when a child is born with CL/P, due to an insufficient opening, which leads to accumulation of fluid and poor ventilation. This leads to a decreased ability to equalize air pressure and to a decreased ability for secretion. This results in the risk of middle-ear infections and mild hearing loss (Martin, 2004).

Hearing is an essential component for speech and language development. As mentioned above, children with CL/P are more susceptible to ear infections, which may have a negative impact on their speech and language development (Murray et al., 2008).

2.8.3 Dental problems

Dental anomalies are commonly present among children with CL/P. Cleft lip/palate can influence both primary (baby) teeth and permanent teeth. This involves the number, size, shape, cross bite, and position of the teeth, both in early age and later in adult life. Many children with CL/P have missing permanent teeth or may have an increased number of teeth compared to the normal. Combined with the cleft, this can affect speech, chewing, and

swallowing. The esthetic look of dentation is an important part of an individual's facial appearance. Extensive dental orthodontic treatment is often required (Campbell, Dock, & Kummer 2008).

2.8.4 Role of stigma

Because of their facial appearance, reduced speech quality, and hearing impairment, children with CL/P may be negatively perceived negatively by society. They are stigmatized, which may lead to them being stared at as something strange or to being ignored (Schultz, 2008). Beliefs have a strong influence on how society accepts the deformity of a child with CL/P. In most cultures, physical appearance plays a great role in social perceptions. Facial attractiveness is associated with positive characteristics. On the other hand, a facial deformity such as CL/P may be viewed as bad. Additionally, facial interaction plays a central role in human interaction (Hutchinson, Wellman, Noe, & K,ahn 2011; Sousa, Devari, & Ghanshani, 2009; Turner et al., 1998).

Many societies hold stigma against deformities and inadequate functioning. Deformities such as CL/P have been associated with shame, 'the wrath of God', and other forms of divine punishment (Loh & Ascoli, 2011; Gracias & Schüler-Faccini, 2003). These stigmas affect the mother's place in family and society. Because of the stigma associated with her child's condition, she may seek refuge at home until her child gets surgical treatment. Thus, in many cases, her child deformity may limit her from certain activities that she used to do before and may make her feel uncomfortable in daily society. She may feel guilt, shame, and sorrow (Tørdal & Kjøll, 2010; Nakanii, 2010). Cleft lip children can also suffer from limited social interaction and be shamed from being seen in public (Sank, Berk, Cooper, & Marazita, 2003). Lack of explanation concerning the causation of cleft lip plays a huge role in compounding these problems. Eradication of traditional beliefs can have an immediate relevance in improving attitudes towards the deformity (Tørdal & Kjøll, 2010).

In the research by Lemvik (2003) in Ethiopia, children with CL/P are stigmatized because of their impaired speech and facial appearance. Lemvik described that these children being compared to pigs due to the nasality in their speech production. In an Ethiopian religious context, pigs are unclean. For a mother of a child with CL/P, this can create sorrow and unwillingness to interact in society for both mother and child (Lemvik, 2003).

2.9 Coping strategies

Lazarus and Folkman (1984) defined coping as "constantly changing cognitive and behavioural efforts to manage specific internal/or external demands that are appraised as taxing or exceeding the resources of the person" (p. 141).

Parents of children with CL/P may indeed experience different emotional and stressful events, but many of them adjust well to the new life situation and manage their lives effectively. In fact, the stressful event may have positive outcomes, such as having a more empathic towards others, a willingness to help others, and adopting a new way to face problems and challenges in life (Baker et al., 2009). For new parents of children recently diagnosed with CL/P, the primary coping strategies may be gathering information about their child's condition, learning to how feed their child, and having an appropriate and effective interaction with professionals (Hodgkinson et al., 2005; Young et al., 2001).

Gathering information enables parents to feel empowered so that they understand the diagnosis and its implication. During this time, professional help is important. Parents may easily develop trust in and get help from the multidisciplinary team, which helps parents to become less depressed. Experts can also help parents to learn new skills such as feeding the child, reducing additional stress events (Hodgkinson et al., 2005; Young et al., 2001). Sharing experiences with other mothers in the same situation may benefit them and enable them to adjust easier in their new life situation (Davies, 2004).

Social support has been widely acknowledged as being essential for coping. Good support from the family, friends, along with higher education enables the mother to adjust faster and to cope better with the situation. In contrast, mothers with lower education and less social support appear to experience more depression (Schultz, 2008).

2.10 Chapter summary and conclusion

The chapter reviewed literature on awareness, knowledge and attitude of pregnant women on cleft lip/palate. A lot more studies have done on awareness, knowledge and attitude among mothers of children with CL/P, however, studies on awareness, knowledge and attitude among pregnant women was lacking. There was contrasting perceptions on clefts/palate. Parents of children with cleft lip/palate are drained emotionally, psychologically and financially.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter sought to describe methods and procedures that were used to achieve the research objectives. It included the study design, research area, study population, inclusion and exclusion criteria, sample size and sampling techniques, collection instruments and procedure data analysis techniques**.**

3.2 Study design

A cross-sectional study was conducted using quantitative approach to assess the awareness, knowledge and attitude of antenatal attendees on cleft lip/palate.

3.3 Study area

The study was conducted at the Mamprobi Polyclinic. It can be located at Mamprobi in the Ablekuma Sub-Metropolitan District. The district shares boundary with Odododiodio constituency to the East, Weija to the west, Gulf of Guinea to the South and Ablekuma Central and North constituencies. The Polyclinic serves a population of about 200,000 (GHS, 2010). It serves about eight suburbs within the District; Gbenu, Mampong, Okai, Mamprobi, Korle Gono, Korle bu, Chorkor, Mamsralor and New-Mamprobi. The polyclinic caters for about 65% of pregnant women in the Ablekuma Sub-Metropolis and due to the free and focus antenatal care the clinic has high patient's turnover. The polyclinic has a fifty-three (53) bed capacity. It is a Government facility established in 1992.It is operating as a polyclinic under the management of Ghana Health Service, Ministry of Health. It recorded a total of 24,254 pregnant women at the antenatal clinic and 4,216 deliveries were attended to in the year 2011(Annual report of Ablekuma sub-metro 2011).

3.4 Study population

The study targeted women who attend antenatal clinic at the Mamprobi Polyclinic.

3.5 Sampling technique

A systematic sampling based on the projected daily attendance at the antenatal clinic and a list of expectant mothers who had registered with the antenatal clinic was used. The average weekly antenatal attendance was 523.The daily attendance was between 90 to 110. To get the sampling interval, the total number of patients attending antenatal clinic per day was divided by the estimated sample size. The register was used to select every 3rd person on the list to arrive at the sample size. Detailed explanations on the study were provided to the pregnant women to get their approval to become participants.

3.5.1 Sampling size determination

The sample size was determined using the Yamane's (1967) formula.

$$n = \frac{N}{1+N(e)^2}$$

n = sample size

N = population

e = margin of error (0.05)

Substituting, n = $\frac{523}{1+523\ (0.05\times0.05)}$

$= \frac{523}{2.3075}$

= **226.65 approximately 227**

Using a 5% non-response rate, n= 239

3.6 Inclusion criteria

All expectant mothers who attended the antenatal clinic at the Mamprobi Polyclinic

3.7 Exclusion criteria

All pregnant women who could not speak or hear (deaf), were in serious condition and had a mental health condition.

3.8 Study variables

The variables to be measured in the study were categorized into dependent and independent variables.

3.8.1 Dependent variable

The dependent variable was level of knowledge, awareness and attitude towards cleft lip/palate among antenatal attendees.

3.8.2 Independent variable

The independent variables for the study include; socio demographic variables (age, religion, tribe, marital status); level of awareness (high. low); cultural factors (taboos, beliefs) and sources of information (school, hospital, market place, family members)

3.9 Data collection tools

Data was collected using an interviewer-administered questionnaire. The questionnaires were designed in English, but the questions were asked in the local dialects, which mostly included Ga and Twi for better understanding of participants who were not educated. Structured questionnaire-containing questions that relate to socio demographic factors, mothers' level of

awareness and their attitude towards cleft lip and or palate, cultural factors, sources of information as well as level of knowledge on cleft lip and or palate was administered.

3.10 Training of research assistants

Three research assistants were engaged in this study. They were trained intensively for two days on the techniques of questionnaire administration for quantitative data collection, on the ethical guidelines. They had a minimum qualification of certificate in Health care. They assisted in administration of the questionnaires and the collection of data.

3.11 Pretesting

Pretesting was done at the Korle-Bu polyclinic antenatal unit because the respondents had the same characteristics as the targeted population. The developed questionnaire was pre-tested at Korle-Bu Polyclinic. Twenty Questionnaires were pretested. The aim was to test for validity and reliability of the instruments that were 0.8 and 0.9 respectively. Identified anomalies in the questionnaire on attitude towards cleft lip /palate were corrected before the final data collection.

3.12 Ethical consideration

Approval of the study was sought from Ghana Health Service Ethics Review Committee (GHS-ERC). Permission was obtained from the Greater Accra Regional Health Directorate and from the Mamprobi Polyclinic. Informed consent was obtained from all the participants after the objectives and the methodology of the study has been explained.

3.12.1 Participant consent

Every respondent was approached to express consent prior to participation. Before participants were interviewed, each was given a consent form to read and sign. For individuals who could not read, the purpose of the study was explained to them and when they accepted to partake, their thumbprints were taken.

3.12.2 Confidentiality

All respondents were given assurance that any information they provided was strictly be used solely for academic purposes and was not disclosed to anyone without the participants permission. Personal information that made a participant identifiable was not included in the questionnaire. A convenient place was provided for answering the questionnaire therefore privacy and confidentiality was ensured.

3.12.3 Risk and benefit

There was no major risk associated with participating in the study. However, some participants who were emotional on seeing pictures of cleft lip babies were given time to compose themselves before the interview continued. Respondents were assured that the research came to them at any risk or cost except their precious time that they used to fill the questionnaire.

3.12.4 Compensation

Respondents were compensated with a 500grams of Omo washing powder to make up for their time wasted. Questionnaires were administered on a one on one basis – they were interviewer-administered. Each questionnaire was administered between 20 and 40 minutes.

3.13 Data Analysis

Pre-coded data was entered and cleaned in Excel Spreadsheet and analyzed using STATA version 15.0. The scores of all questionnaire items related to knowledge on cleft lip or palate were coded either 1 for appropriate responses or 0 for inappropriate responses. All the item scores were summed for each observation to obtain composite scores; out of a possible 29 the composite scores ranged from 4 to 20. The mean composite score was 13.51, thus, all observations with composite scores equal to or less than 13.51 were categorized as low level of knowledge while all composite scores above 13.51 were categorized as high level of knowledge. Awareness was measured based on whether respondents had heard of cleft lip/palate or not. Tables and charts were used to present summary statistics. Chi square test statistic was used to describe the association between knowledge on cleft lip/palate and participants' demographics. Also, chi square test was used examine the association between awareness on cleft lip/palate and participants background characteristics and the association between level of knowledge and the background characteristics. Logistic regression was used to determine the odds ratio between level of knowledge and educational level.

3.14 Study limitations

It is imperative to note that this study had several limitations, while conceding the importance of this study. One strength of this study is that it sought to provide data on a rare and less often researched topic in the Ghanaian health community. Regarding the limitations, given that the present study was undertaken in one polyclinic, the findings may not be generalizable to populations beyond the hospital. Also, the possibility of information bias must be mentioned since respondents may have provided or refused to provide some responses to keep up an appearance. Furthermore, some sets of questions contained in the questionnaire was not answered, thus, reducing the sample size of the study.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter focuses on the presentation of the findings of the research concerning the awareness, knowledge and attitude of antenatal attendees towards cleft lip/palate at the Mamprobi polyclinic. This is guided by the objectives of the study.

4.2 Characteristics of study participants

Responses were received from 239 study participants resulting in a response of 100%. However, 10 observations, which had at least 6 missing values, were dropped. The background characteristics of respondents are described in Table 1. The median age of respondents was 28 (IQR: 24 – 32) with majority of them (48.3) aged between 25 and 32. About 3 out of 10 of respondents were less than 24 years (29.85%). About highest educational level, most of the respondents (44.1%) had secondary school education, 31.7% had primary school education and 7.9% had no formal education. A little above a quarter of respondents (77.3%) were employed. While 62.8% were married (142/226), 23.9% had never married (54/226) and 11.1% were cohabiting with their partners (25/226). Christians formed the majority of respondents with a proportion of 77.7% (178/229) while the proportion of Muslims was 22.3% (51/226). No persons of other religious affiliations were recorded.

Table 1: Background characteristics of respondents

Variables	Median (IQR)	Number of respondents	Percent (%)
Age in years (n= 228)	28 (24 - 32)		
18 – 24		68	29.8
25 – 32		110	48.3
33 – 40		44	19.3
> 40		6	2.6
Educational level (n= 227)			
No education		18	7.9
Primary		72	31.7
Secondary		100	44.1
Tertiary		30	13.2
Vocational		7	3.1
Occupation (n= 229)			
Unemployed		52	22.7
Employed		177	77.3
Marital status (n= 226)			
Single		54	23.9
Married		142	62.8
Separated		5	2.2
Co-habitation		25	11.1
Religious affiliation (n= 229)			
Christian		178	77.7
Muslim		51	22.3
Awareness (n= 226)			
Yes		108	47.8
No		118	52.2

IQR= Inter-quartile range

4.2 Assessment of awareness on cleft lip/palate among pregnant women

Table 2 contains detailed information on the awareness of cleft lip/palate among pregnant women. It was observed that married women had low awareness of cleft lip/palate 68.67% (57/217) compared to single women 14.46% (12/217). There was a significant association between marital status and women awareness on cleft lip/palate (p=0.040). Nonetheless, there was no association between age of women and level of awareness on cleft lip/palate (p=0.647), educational level of women and level of awareness on cleft lip/palate (p=0.009); occupation of women and level of awareness on cleft lip/palate (p=0.205).

No significant association was further observed between the number of children of women and awareness on cleft lip/palate (p=0.504) and women religious affiliation and awareness on cleft lip/palate (p=0.774).

Table 2: Bivariate analysis of association between demographic variables and awareness of cleft lip/palate among antenatal attendees at Mamprobi Polyclinic

Variables	Awareness of cleft lips/palate		χ2	p-value
	No	Yes		
Age			1.664	0.647**
18-24	45 (33.09%)	21 (25.30%)		
25-32	61 (44.85%)	43 (51.81%)		
33-40	26 (19.12%)	17 (20.48%)		
41-45	4 (2.94%)	2 (2.41%)		
Educational level			13.139	0.009**
No education	8 (5.88%)	9 (10.84%)		
Primary	46 (33.82%)	23 (27.71%)		
Secondary	52 (38.24%)	45 (54.22%)		
Tertiary	23 (16.91%)	6 (7.23%)		
Vocational	7 (5.15%)	0 (0.00%)		
Occupation			1.604	0.205
Unemployed	33 (24.09%)	14 (16.87%)		
Employed	104 (75.91%)	69 (83.13%)		
Marital status			8.123	0.040**
Single	38 (28.26%)	12 (14.46%)		
Married	81 (60.45%)	57 (68.67%)		
Separated	4 (2.99%)	1 (1.20%)		
Co-habitation	11 (8.21%)	13 (15.66%)		
Religious affiliation			0.082	0.774
Christian	105 (76.64%)	65 (78.31%)		
Muslim	32 (23.36%)	18 (21.69%)		

** Fishers exact column total

4.3 Assessment of knowledge level on cleft lip/palate among pregnant women

Some responses provided by respondents on cleft lip/palate are presented in Table 3. Of all respondents, 83% (190/229) rightly knew that avoiding alcohol would contribute to keeping pregnancy safe from cleft lip or palate. Three quarters (75.5%) rightly knew that avoiding smoking could contribute to preventing cleft lip or palate in their babies and a little less than two-thirds (63.3%) knew they had to avoid self-medication to keep their pregnancy safe from cleft lip or palate. About 9 out of 10 of the pregnant women interviewed knew that feeding is a problem or challenge that people with cleft lip or palate may have. A similar proportion (91.1%) knew speech was a challenge people with cleft lip or palate could be faced with. While two-thirds of respondents (66.2%) knew people with cleft lip or palate could have dental problems, 72.8% knew people with cleft lip or palate could have hearing challenges. Describing the signs and symptoms of cleft lip, about half of respondents (49.7%) reported that it is "a small notch in the lip", about 4 out of 10 (41.3%) reported that it is "an opening in the lip from mouth to nose" and about 1 out of 10 (9%) reported that it is "A split on both sides of the lip". While 41.7% believed cleft palate is "opening in the throat", 32.6% believed feeding difficulty is a sign or symptom of cleft palate and 1.1% reported that hearing loss was a sign or symptom of cleft palate. The proportions of respondents who thought mouth breathing, nasal congestion and snoring could be signs or symptoms of cleft palate were 12.6%, 6.3% and 5.7% respectively.

Table 3: Responses related to knowledge on cleft lip/palate

	Number of respondents	Percent (%)
What should a pregnant woman avoid during pregnancy to keep her pregnancy safe from cleft lip/palate* (n= 229)		
Alcohol	190	83
Smoking	173	75.5
Self-medication	145	63.3
Don't know	17	7.4
Feeding is a problem/challenge that people with cleft lip or palate may have (n= 213)		
Yes	190	89.2
No	23	10.8
Speech is a problem/challenge that people with cleft lip or palate may have (n= 213)		
Yes	194	91.1
No	19	8.9
People with cleft lip or palate may have dental problems/challenges (n= 213)		
Yes	141	66.2
No	72	33.8
People with cleft lip or palate may have hearing problems/challenges (n= 213)		
Yes	58	72.8
No	155	27.2
Signs and symptoms of cleft lip (n= 202)		
A small notch in the lip	100	49.7
An opening in the lip from mouth to nose	83	41.3
A split on both sides of the lip	18	9
Signs and symptoms of cleft palate (n= 175)		
Opening in the throat	73	41.7
Mouth breathing	22	12.6
Nasal congestion	11	6.3
Snoring	10	5.7
Hearing loss	2	1.1
Feeding difficulty	57	32.6

*Multiple responses possible

Further responses related to cleft lip or palate knowledge are provided in Table 4. The proportion of respondents who knew people with cleft lip or palate was 82.5%. While about three-quarters of respondents (74.4%) rightly knew that cleft lip or palate could be prevented, about 1 out of 5 (21.2%) reported that they did not know if these conditions could be corrected. Of the respondents who were of the opinion the conditions could be corrected, 94.1% reported that it could be corrected surgically while 9.5% reported that it could be corrected using medication and 0.6% (1/169) reported it could be corrected by an herbalist. According to majority of respondents (72.7%), cleft lip or palate could be prevented. Asked about the risk factors of cleft lip or palate, 77% identified smoking, 74.5% identified alcohol intake, 52.2% identified unprescribed medication and 40.7% said it could be hereditary.

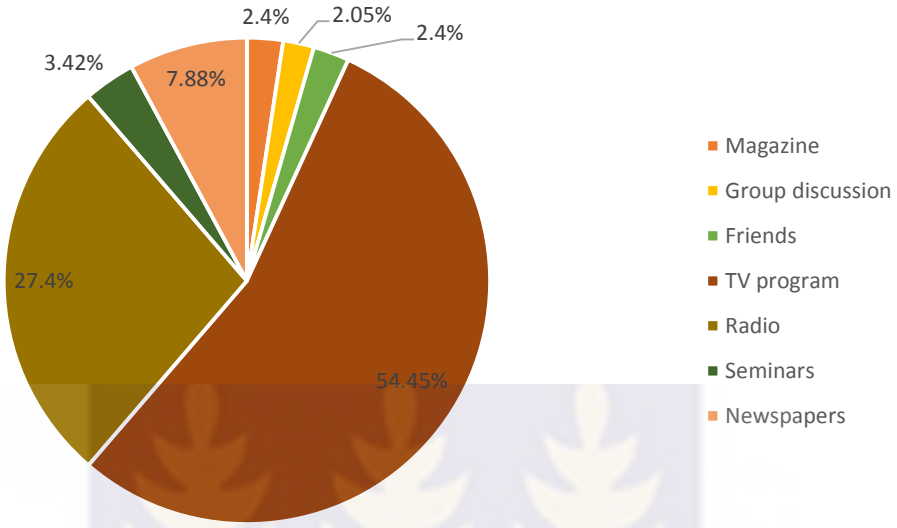
Table 4: Additional responses related to knowledge of cleft lip/palate

	Number of respondents	Percent (%)
Know anyone with this condition (n= 228)		
Yes	40	17.5
No	188	82.5
Can these conditions be corrected? (n= 227)		
Yes	169	74.4
No	10	4.4
Don't know	48	21.2
How can they be corrected? * (n= 169)		
Surgical	159	94.1
Medication	16	9.5
Prayer camp/prayer will heal the baby	0	0
Herbalist	1	0.6
Can cleft lip/palate be prevented? (n= 227)		
Yes	165	72.7
No	1	0.4
Maybe	17	7.5
Don't know	44	19.4
Risk factors associated with cleft lip/palate* (n= 226)		
Smoking	174	77
Alcohol	169	74.5
Hereditary	92	40.7
Congenital	65	28.8
Unprescribed medications	118	52.2
Eating certain foods	39	17.3

*Multiple responses possible

Details on the source of information on cleft lip/palate among pregnant women seeking treatment at Mamprobi polyclinic is shown in Figure 6. The common source of information on cleft/palate is TV program 54.45% (159/292).

Figure 6: Sources of information on cleft lip/palate among pregnant women seeking care at Mamprobi polyclinic



The bivariate analysis of the level of knowledge and the factors of interest is summarised in Table 5. The proportion of respondents with no formal education who had low knowledge on cleft lip or palate was 5.9% (12/203) while the proportion that had high level of knowledge was 2.0% (4/203). Those with secondary education who had low level of knowledge formed 15.3% (31/203) of all respondents while those in the same category who had high level of knowledge formed 28.6% (58/203) of respondents. There was a statistically significant association between level of knowledge and educational level (p= 0.01). There was no statistically significant difference between the level of cleft lip or palate knowledge and age (p=0.407), occupation (p=0.29), marital status (p=0.252), religious affiliation (p=0.0.561) and cleft lip or palate awareness (p=0.888).

Table 5:Bivariate analysis of level of knowledge with characteristics of interest

Variables	Level of knowledge		*P*-value
	Low	High	
Age in years			0.407
18 – 24	33 (16.2)	27 (13.2)	
25 – 32	43 (21.1)	57 (27.9)	
33 – 40	16 (7.8)	22 (10.8)	
> 40	2 (1.0)	4 (2.0)	
Educational level			0.01**
No education	12 (5.9)	4 (2.0)	
Primary	36 (17.7)	31 (15.3)	
Secondary	31 (15.3)	58 (28.6)	
Tertiary	13 (6.4)	11 (5.4)	
Vocational	2 (1.0)	5 (2.5)	
Occupation			0.29
Unemployed	23 (11.2)	20 (9.8)	
Employed	72 (35.1)	90 (43.9)	
Marital status			0.252
Single	26 (12.90	19 (9.4)	
Married	55 927.2)	72 (35.6)	
Separated	1 (0.5)	4 (2.0)	
Co-habitation	12 (5.9)	13 (6.4)	
Religious affiliation			0.561
Christian	71 (34.6)	86 (42.0)	
Muslim	24 (11.7)	24 (11.7)	
Awareness			0.888
Yes	47 (23.3)	54 (26.7)	
No	48 (23.8)	53 (26.2)	

The logistic regression of educational level on level of knowledge showed a statistically significant model (LR $\chi 2$ (4) = 13.27, p= 0.01). Pregnant women with secondary school education had 5.6 times greater odd of having high knowledge compared with those who had no formal education (COR= 5.61, 95% CI: 1.67, 18.87). Those with tertiary level education were 2.5 times more likely to have high knowledge that those without any formal education but this association was not statistically significant (COR= 2.54, 95% CI: 0.63, 10.17). the odds of a pregnant woman who had vocational education having high knowledge was 7.5 times higher compared to those who had no formal education (COR= 7.5, 95% CI: 1.02, 55).

Table 6: Logistic regression model of level of knowledge and educational level.

Educational level	COR (95% CI)	*p*-value
No education	1	
Primary	2.58 (0.76, 8.83)	0.13
Secondary	5.61 (1.67, 18.87)	0.005**
Tertiary	2.54 (0.63, 10.17)	0.188
Vocational	7.50 (1.02, 55)	0.047*

** $p<0.01$ *$p<0.05$

4.4 Beliefs of pregnant women towards cleft lip/palate

Details of pregnant women beliefs towards cleft lip/palate are presented in Table 7. Largely, the women had a good belief towards cleft lip/palate. Specifically, 45.74 (102/223) of the women believed cleft lip/palate has no evil connotation. Also, 51.89% (110/212) of the women believed cleft lip/palate is not a condition contracted as a curse from gods; 54.72% (116/212) believed the condition is not gotten from witchcraft (M=7.094; 0.668).

It was observed that 51.69% (107/207) of the women believed the condition is not contracted as a punishment from the gods. Again, 52.13% (110/211) of the women believed that the condition is not God's will for an innocent baby, while 52.0% (104/200) of the women believed cleft lip/palate is not a condition contracted by an innocent baby from sins committed by their parents in their past lives.

Table 7: Belief towards cleft lip/palate among antenatal attendees at Mamprobi Polyclinic

	n (%)
Cleft lip/palate is as a result of evil spirit	
Agree	81 (36.32)
Disagree	102 (45.74)
Neutral	40 (17.94)
Cleft lip/palate is caused by witchcraft	
Agree	61 (28.77)
Disagree	110 (51.89)
Neutral	41 (19.34)
Cleft lip/palate is as a result of curses	
Agree	58 (27.36)
Disagree	116 (54.72)
Neutral	38 (17.92)
Cleft lip/palate is a result of punishment from the gods	
Agree	60 (28.99)
Disagree	107 (51.69)
Neutral	40 (19.32)
Cleft lip/palate is gotten by the will of God	
Agree	64 (30.33)
Disagree	110 (52.13)
Neutral	37 (17.54)
Cleft lip/palate is as a result of sins committed in past lives	
Agree	63 (31.50)
Disagree	104 (52.0)
Neutral	33 (16.50)

4.5 Attitude of pregnant women towards cleft lip/palate

Details of pregnant women attitude towards cleft lip/palate is presented in Table 8 Generally, respondents had a good attitude towards cleft lip/palate. That is, 95.35% (205/215) were interested in knowing more about cleft lip/palate while 79.20% (179/226) were willing to hold and or touch a child suffering from cleft lip/palate with 88.4% (199/225) ready to let the 'world' know about their child condition should they suffer from cleft lip/palate.

Table 8: Attitude towards cleft lip/palate among antenatal attendees at Mamprobi Polyclinic

	N (%)
Interested in knowing more about Cleft lip/palate	
Yes	205 (95.35)
No	10 (4.65)
Touch a child with Cleft lip/palate	
Yes	179 (79.20)
No	47 (20.80)
Allow people to know about child with Cleft lip/palate	
Yes	199 (88.44)
No	26 (11.56)

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The study sought to assess the awareness and knowledge of pregnant women attending Mamprobi polyclinic on cleft lip/palate. It had specific objectives to describe the knowledge pregnant women have on cleft lip and or palate, it also sought to ascertain the awareness on cleft lip and/or palate among pregnant women and to explore the attitude and beliefs of pregnant women towards cleft lip/palate.

5.2 knowledge level among pregnant women

The level of high knowledge among the pregnant women was quite low (53.7%) and the level of awareness was even lower (37.9%). This is comparable to studies by Owotade et al. (2012) in Nigeria where knowledge on cleft lip and palate was low. Similarly, a study in Nepal found low levels of knowledge among pregnant women and showed that this lack of knowledge about CLP treatment was the most common reason for late presentation of the patients (Schwarz, Bhai & Khadka, 2004). However, the study findings are different to one by Alnujaim et al (2017) who found good knowledge on cleft lip/palate among pregnant women in Saudi Arabia.

In relation to knowledge on the risk factors, most of the women knew 1 or 2 but were ignorant of the others. The implication is that they may avoid those they know but will remain at risk since they may not consciously avoid the others they see as not being risky. Generally, the knowledge on the signs and symptoms of both cleft lip and palate was low since less than half could identify anyone of the signs and symptoms. This must be addressed as a matter of urgency in order that if mothers were to give birth to children with cleft palate (since that may not be as obvious as cleft lip) they could identify and seek early medical

attention. Since most women identified TV programs as their main source of knowledge acquisition, that avenue provides a good opportunity to address this shortfall in knowledge.

It is of concern that about a quarter of pregnant women seeking care at the Mamprobi polyclinic did not know these conditions could be corrected or wrongly thought that it could not be corrected. Much more worrying was that fact only 72.7% knew that these conditions could be prevented. As was found by Owotade et al. (2014) such low levels of knowledge facilitates the proliferation of negative attitudes and beliefs. Deliberate efforts must be made to remedy this.

Because of education, women are willing to embrace their babies no matter the outcome. With marital status, it is easier to attend antenatal for married women compared to unmarried women. These women are socially embraced and provided with enough knowledge during antenatal compared with unmarried women.

While being formally educated does not necessarily translate into knowledge on a rare condition such as cleft lip or palate, the results suggest an association between them. Secondary school graduates and those vocationally trained were more likely to have high knowledge on cleft lip and palate. This may be the case because higher education enhances the open-mindedness that encourages people to know more about things that may not be common in their societies. Interestingly, however, being a graduate from a tertiary institution did not show any influence on level of knowledge.

Being pregnant for the first time provides the avenue to be immersed with knowledge. First time pregnant women more likely attend antenatal clinics where they are educated on varied topics including birth defects. One's religious affiliation could translate into the cleft lip/palate being is spiritual than medical. Such women would assign spiritual interpretations to cleft lip/palate.

5.3 Awareness of cleft lip/palate among pregnant women

The inadequate awareness on the condition is because of the low incidence of the condition. That is, the condition is rare among babies. The findings agree with an old but relevant study by Middleton et al (1986) who found that more than half (54.8%) of participants had not heard of cleft lip/palate and cleft lip/palate-related awareness of the public was found less than adequate, suggesting the need for public awareness and information programs. This low awareness both in the current study and in the one by Middleton et al (1986) is of concern as the earlier study conducted approximately 30 years earlier found an even marginally higher rate of awareness than the current study. This requires prompt, effective and targeted action on the part of health educators and all health workers.

However, the low proportion of awareness among pregnant women could be attributed to the setting of the study, as polyclinics have less teaching programs to spread awareness. A few researches have described a significant gap in the awareness of cleft lip/palate and its influence on parents and their children. A Nigerian study reported that half of the women (50.5%) had seen or heard about cleft lip/palate and that many respondents had neither read an article on cleft lip/palate nor participated in any public enlightenment program. The study by Owotade et al. (2014) suggests that the more educated a respondent was, the more aware and knowledgeable they were about cleft lip/palate. Contrary to this, the present study found that there is no statistical relationship between the two.

5.4 Attitude of cleft lip/palate among pregnant women

The attitude generally was favourable among pregnant women on cleft lip/palate. With the advent of technology especially television, efforts embarked on by governmental and non-governmental agencies as well as individuals to re-engineer mind-set on medical conditions are yielding dividends. They mostly disagreed with the opinion that children with cleft lip/palate should be hidden from the public.

Traditional beliefs believed to be associated with congenital malformations may still be pervasive as a lot of them could not conclusively say they believed it had nothing to do with witchcraft (48.1%), curses (45.3%), punishment from the gods (48.3%) or the will of God (47.9%). While this finding disagrees with a study by White (2005) who found that 84% of respondents attributed cleft lip and palate to "God's will", whereas 10% thought it was because of sins that were committed in past lives, the proportions from the current study are quite high and significant if it's considered that almost half of respondents had these unfavourable beliefs.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

Antenatal clinic attendees studied in Mamprobi polyclinic generally had low knowledge on cleft lip/palate. This poses significant risk to both mother and child. Pregnant women showed an inadequate awareness of cleft lip/palate. The level of awareness and knowledge varied from the beliefs and attitudes of the pregnant women. The level of education is a predictor of the level of knowledge on cleft lip and palate. In line with the low level of knowledge, the beliefs about cleft lip or palate were largely unfavourable, contrarily their attitude was generally favourable.

6.2 Recommendations

The Ghana Health Service (GHS) should increase public enlightenment/health education to increase awareness and subsequently help develop more positive attitudes toward children with cleft lip/palate. The Ministry of Health (MOH) should collaborate with other stakeholders to ensure awareness on the condition is adequate to improve access to health care. Non-governmental organizations should embark on educational programs to include distribution of pamphlets on cleft lip/palate at antenatal clinics, media campaigns on radio, TV. Also, cleft support groups should be established by non-governmental and professional organizations to shed more light on the condition.

The management of Mamprobi polyclinic should organize continuous in-service training for nurses and other health personnel especially those at the outpatient department for them to be abreast with the pattern of the changing health needs and trends of patients whose children are suffering from cleft lip/palate.

Nurses and or health professionals who exhibit good behaviour towards mothers with children suffering from cleft lip/palate should be rewarded to motivate them. Also, a complaint unit could be formed to address grievances and complaints of clients and relatives who visit the facility. The provision of education as part of focussed ANC should include information on cleft lip or palate.

The pregnant women at the Mamprobi polyclinic should be encouraged and empowered to read more as well as implore all media avenues that will help in assessing health information with regards to antenatal care.

REFERENCES

Adebola, R. A., Bamgbose, B. O., & Adeoye, J. B. (2014). Community Mobilization and Awareness Creation for Orofacial Cleft Services : A Survey of Nigerian Cleft Service Providers, *2014*.

Agbenorku, P., Agbenorku, M., Iddi, A., Abude, F., Sefenu, R., Matondo, P., & Schneider, W. (2011). A study of cleft lip / palate in a community in the South East of Ghana, 267–272.

Allam, E., Windsor, L. J., & Stone, C. (2014). Anatomy & Physiology Cleft Lip and Palate : Etiology , Epidemiology , Preventive and Intervention Strategies, *4*(3), 2–7.

Antwi-kusi, A., Addisson, W., Oti, A. A., & Amuasi, A. A. (2015). Mother ' s of Children with Cleft Lip and / or Palate , Perception about Aetiology , Social Reaction and Treatment of Cleft, (October), 98–101.

Baker, S. R., Owens, J., Stern, M., & Willmot, D. (2009). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. The Cleft Palate-Craniofacial Journal, 46(3), 229−236.

Bannister, P. (2004). Feeding a baby with cleft palate. In V. Martin & P. Bannister (Eds.) Cleft Care: A Practical Guide for Health Professionals on Cleft Lip and Palate (pp. 45−47).Wiltshire, England: APS.

Berkowitz, S. (2006). The Cleft Palate Story. Thorofare, NJ: Slack.

Bowlby, J. (1977). The making and breaking of affectional bonds. I. Aetiology and psychopathology in the light of attachment theory. An expanded version of the fiftieth Maudsley Lecture, delivered before the Royal College of Psychiatrists, 19 November 1976. British Journal Psychiatry, 130, 201−210.

Bowlby, J. (1980). Attachment and Loss: Volume 3. Loss: Sadness and Depression. London: Hogarth.

Bradbury, E. & Bannister, P. (2004). Prenatal, perinatal and postnatal counselling. In A. C. H. Watson, D. A. Sell, & P. Grunwell (Eds). Management of Cleft Lip and Palate (pp. 117−222). London: Whurr.

Campbell, R., Dock, M., & Kummer, A.W. (2008). Dental anomalies associated with cleft lip/palate: effects on speech. In A. W. Kummer (Ed.) Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance (2nd ed.), (pp. 238−278). Clifton Park, NY: Delmar Cengage Learning.

Care, O. F. (2010). Cleft Lip and Palate.

Carstens, M. H. (2008) Neural tube programming and the pathogenesis of craniofacial clefts, part I: the neuromeric organization of the head and neck. Handbook of Clinical Neurology 87(7): 247-276.

Cassell, C. H., Ph, D., Mendez, D. D., Ph, D., Strauss, R. P., & Ph, D. (2007). Maternal Perspectives : Qualitative Responses About Perceived Barriers to Care Among Children With Orofacial Clefts in North Carolina.

Chan, R.K.K, McPherson, B. Whitehill, T.L. (2006). Chinese attitudes toward cleft lip and palate: Effects of personal contact. Cleft Palate Craniofac J; 43: 731-739.

Chuacharoen, R., Ritthogal,W., Hunsrisakhun, J., & Nimanat, K. (2009). Felt needs of parents who have a 0 to 3 month old child with a cleft lip. Cleft Palate-Craniofacial Journal, 46(3), 252−257.

Collett, B. R., Cloonan, Y. K., Speltz, M. L., Anderka, M., & Werler, M. M. (2012). Psychosocial functioning in children with and without orofacial clefts and their parents. *Cleft Palate-Craniofacial Journal*, *49*(4), 397–405. http://doi.org/10.1597/10-007

Conway, J. C., Taub, P. J., Kling, R., Oberoi, K., Doucette, J., & Jabs, E. W. (2015). Ten-year experience of more than 35,000 orofacial clefts in Africa. *BMC Pediatrics*, *15*(1), 8.

Coy, K., Speltz, M. L., & Jones, K. (2002). Facial appearance and attachment in infants with orofacial clefts: a replication. The Cleft Palate-Craniofacial Journal, 39(1) 66−72.

Cronin, T. D., Brauer, R. O., & Palate, C. (2017). EC DENTAL SCIENCE Research Article Physical Impairments, Psychological Impact, and Risk Factors of Cleft Lip and Palate in Children from a Surgical Mission Project in Armenia, Colombia, *2*, 53–59.

Dagher, D., & Ross, E. (2004). Approaches of South African Traditional Healers Regarding the Treatment of Cleft Lip and Palate. *The Cleft Palate-Craniofacial Journal*, *41*, 461–469.

Davies, G. (2004). The role of parent support groups. In A. C. H. Watson, D. A. Sell, & P. Grunwell (Eds.). Management of Cleft Lip and Palate (pp. 379−385). London: Whurr.

Dickson, K. S., Darteh, E. K. M., & Kyereme, A. K.-. (2017). Providers of antenatal care services in Ghana: evidence from Ghana demographic and health surveys 1988–2014. *BMC Health Services Research*, *17*(1), 203.

Dixon, Michael J. Marazita, Mary L. Beaty, Terri H. Murray, J. C. (2011). Cleft lip and palate. Synthesizing genetic and environmental influences. *National Institute of Health*, *12*(3), 167–178.

Dixon, J., Tenkorang, E. Y., Luginaah, I. N., Kuuire, V. Z., & Boateng, G. O. (2014). National health insurance scheme enrolment and antenatal care among women in ghana: Is there any relationship? *Tropical Medicine and International Health*, *19*(1), 98–106.

Endriga, M. C. & Speltz, M. L. (1997). Face to face interaction between infants with orofacial clefts and their mothers. Journal of Pediatric Psychology, 22(4), 439−453.

Fagbamigbe, A. F., & Idemudia, E. S. (2015). Assessment of quality of antenatal care services in Nigeria: evidence from a population-based survey. *Reproductive Health*, *12*(1), 88.

Fekadu, Z. (2001). An alternative approach to prevent child welfare problems. In P. S. Klein (Ed.), Seeds of Hope. Twelve Years of Early Intervention in Africa (pp.159–172). Oslo: Unipub forlag.

Goodacre T, & Swan M.C (2008). Cleft lip and palate: current management. Pediatrics Child Health 18(6): 283-292.

Gorlin R.J, Cohen M.M, Hennekam R.C.M (2010). Orofacial cleft syndromes. In Gorlin RJ (ed). Syndromes of head and neck. Oxford University Press: 943-971.

Grunwell, P. & Sell, D. A. (2004). Speech and cleft palate/velopharyngeal anomalies. In A. C. H. Watson, D. A. Sell, & P.Grunwell (Eds.). Management of Cleft Lip and Palate, (pp. 68−86). London: Whurr.

Harcourt, D. & Rumsey, N. (2008). Psychology and visible difference. The Psychologist, 21(6), 486−489.

Harper, D. C. & Peterson, D. B. (2001). Children of the Philippines: attitudes toward visible physical impairment. The Cleft Palate-Craniofacial Journal, 38(6), 566−576.

Hodgkinson, P. D., Brown, S., Duncan, D., Grant, C., McNaughton, A., Thomas, P., & Mattick, C. R. (2005). Management of children with cleft lip and palate: a review describing the application of multidisciplinary team working in this condition based upon the experiences of a regional cleft lip and palate centre in the United Kingdom. Fetal and Maternal Medicine Review, 16(1), 1−27.

Hutchinson, K., Wellman, M. A., Noe, D. A., & Kahn, A. (2011). The psychosocial effects of cleft lip and palate in non-Anglo populations: a cross-cultural meta-analysis. The Cleft Palate Craniofacial Journal, 48(5), 497−508.

Hsieh, Y., Chao, Y. Y., & Shiao, J. S. (2013). A Qualitative Study of Psychosocial Factors Affecting Expecting Mothers Who Choose to Continue a Cleft Lip and / or Palate Pregnancy to Term, *21*(1), 1–9.

Kalisya, L. M., Nyavandu, K., Machumu, B., & Kwiratuwe, S. (2015). Patterns of Congenital Malformations and Barriers to Care in Eastern Democratic Republic of Congo, 1–10.

Kernahan DA, Stark RB (1958) A new classification for cleft lip and palate. Plast Reconstr Surg 22(5): 435-441. In Lithovius, R. (2015). Aspects of cleft lip and palate from Northern Finland.

Kesande, T., Muwazi, L. M., Bataringaya, A., & Rwenyonyi, C. M. (2014). Prevalence , pattern and perceptions of cleft lip and cleft palate among children born in two hospitals in Kisoro District , Uganda, 1–7.

Klockars T, Ala-Mello S, & Rautio J (2010). Chromosomal abnormalities in Finnish orofacial cleft patients: excess of Submucous cleft patients? Cleft Palate Craniofac J 47(4):352-358.

Kriens, O. (1989). Lashshal: A concise documentation system for cleft lip, alveolus and palate diagnoses. In Kriens, O. (ed): What is a cleft lip and palate? A multidisciplinary update Stuttgart. Georg Thieme: 30-34

Kummer, A. W. (2008). Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance (2nd ed.). Clifton Park, NY: Delmar Cengage Learning.

Lambon-Quayefio, M. P., & Owoo, N. S. (2014). Examining the Influence of Antenatal Care Visits and Skilled Delivery on Neonatal Deaths in Ghana. *Applied Health Economics and Health Policy*, *12*(5), 511–522.

Lazarus, R. S. & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer

Lemvik, J. S. (2003). I Didn't Take Him Out in Public - About New Possibilities for Ethiopian Children Born with Cleft Lip/Palate (thesis in Special Education); Oslo: University of Oslo.

Loh, J. & Ascoli, M. (2011). Cross-cultural attitudes and perceptions towards cleft lip and palate deformities: *World Cultural Psychiatry Research Review*, 6(2): 127-134.

Martin, V. & Suri, M. (2004). Development of the face and palate and clinical implications. In V. Martin & P. Bannister (Eds.) Cleft Care: A Practical Guide for Health Professionals on Cleft Lip and/or Palate (pp. 21−30). Wiltshire, England: APS.

Mastroiacovo, P., Maraschini, A., Leoncini, E., Mossey, P., Bower, C., Castilla, E. E., … Zhuchenko, L. A. (2011). Prevalence at birth of cleft lip with or without cleft palate: Data from the International Perinatal Database of Typical Oral Clefts (IPDTOC). *Cleft Palate-Craniofacial Journal*, *48*(1), 66–81.

Mba, U. C., & Onah, I. I. (2017). Tongue harmatoma in association with cleft palate : Case Report, 168–169.

Mbai, C. M. (2015). Factors influencing the utilization of antenatal care services among reproductive women: a case of Kibera, Nairobi county, Kenya.

Miller, C. K. & Kummer A.W. (2008). Feeding problems of infants with cleft lip/palate or craniofacial anomalies. In A.W. Kummer (Ed.) Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance (2nd ed.) (pp. 120−153). Clifton Park, NY: Delmar Cengage Learning.

Moore K.L, Persaud T.V.N, & Torchia M.G. (2015). Fourth to eight weeks of human development. In: Moore KL (ed): The developing human. Clinically oriented embryology. Elsevier: 69-88.

Mossey P.A, Little J, Munger R.G, Dixon M.J & Shaw W.C (2009). Cleft lip and palate. Lancet 374(9703): 1773-1784.

Mossey, P. A., & Modell, B. (2012). Epidemiology of Oral Clefts 2012: An International Perspective. *Cleft Lip and Palate*, *16*, 1–18.

Murray, L. Hentges, F., Hill, J., Karpf, J., Mistry,B., Kreutz, M., et al. (2008). The effect of cleft lip and palate, and the timing of lip repaired on mother-infant interaction and infant development. Journal of Child Psychology and Psychiatry, 49(2), 115−123.

Nakanii, M. (2010). Negative events experienced by mothers raising a child with cleft lip and palate. Kawasaki Journal of Medical Welfare, 16(1), 43−49.

Oladapo, O. T., & Osiberu, M. O. (2009). Do sociodemographic characteristics of pregnant women determine their perception of antenatal care quality? *Maternal and Child Health Journal*, *13*(4), 505–511.

Olasoji, H. O., Ugboko, V. I., & Arotiba, G. T. (2007). Cultural and religious components in Nigerian parents ' perceptions of the aetiology of cleft lip and palate :, *45*, 302–305.

Oshodi, Y. O., & Adeyemo, W. L. (2015). Psychological distress and perceived stress , among mothers of infants with orofacial clefts in a tertiary hospital in Lagos , Nigeria, 96–102.

Oti, A. A., Obiri-Yeboah, S., & Donkor, P. (2014). Aesthetic outcome and the need for revision of unilateral cleft lip repair at Komfo Anokye Teaching Hospital. *Ghana Medical Journal*, *48*(1), 20–3.

Owens, J. (2008). Parent's experiences of feeding a baby with a cleft lip and palate. British Journal of Midwifery, 16(12), 778−784.

Owotade, F. J., Ogundipe, O. K., Ugboko, V. I., Okoje, V. N., Olasoji, H. O., Makinde, O. N., & Orji, E. O. (2014). Awareness , knowledge and attitude on cleft lip and palate among antenatal clinic attendees of tertiary hospitals in Nigeria, *17*(1), 6–9.

Pearson G.D & Kirschner R.E. (2011) Surgery for cleft palate and velopharyngeal dysfunction. Semin Speech Lang 32(2): 179-190.

Phil, D. (2002). Mothers experiences when their infants were diagnosed with cleft lips andior palates liezel Ter Poorten, 56–67.

Randriamiharisoa, M. N., Kuhlman, A. R., Jeannoda, V., Rabarison, H., Rakotoarivelo, N., Randrianarivony, T., … Bussmann, R. W. (2015). Medicinal plants sold in the markets of Antananarivo, Madagascar. *Journal of Ethnobiology and Ethnomedicine*, *11*(1), 60.

Ress, C. (2007). Childhood attachment. British Journal of General Practice, 57(544), 920–922.

Roux, C. (2013). Pregnant women ' s perceptions and knowledge.

Sank, J. R., Berk, N. W., Cooper, M. E., & Marazita, M. L. (2003). Perceived social support of mothers of children with clefts. The Cleft Palate-Craniofacial Journal 40(2), 165−171.

Schultz, J. R. (2008). Psychosocial aspects of cleft lip/palate and craniofacial anomalies. In A. W. Kummer (Ed.) Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance (2nd ed.) (pp. 279–296). Clifton Park, NY: Delmar Cengage Learning.

Sousa, A. D., Devare, S., & Ghanshani, J. (2009). Psychological issues in cleft lip and palate. Journal of Indian Association of Pediatric Surgeons, 14(2), 55−58.

Steding, G. (2009). Endodermal organs in the head and neck. In: The anatomy of the human embryo. A scanning electron-microscopic atlas. Basel, Freiburg, Paris, London, New York, Bagalore, Bangkok, Shanghai, Singapore, Tokyo, Sydney. Karger: 123-196.

Strauss, R. P., Ramsey, B. L. J., Edwards, T. C., Topolski, T. D., ……. &Thomas, C. (2007). Stigma experiences in youth with facial differences: a multi-site study of adolescents and their mothers. Orthodonotic & Craniofacial Research, 10(2), 96−103.

Tobiasen, J. M. (1987). Social judgments of facial deformity. Cleft Palate-Craniofacial Journal 24(4), 323−327.

Tolarová M.M & Cervenka J (1998). Classification and birth prevalence of orofacial clefts. Am J Med Genet 75(2): 126-137.

Tørdal, I. B. & Kjøll. L. (2010). Speech difficulties of Children with Cleft Lip and Palate, Master dissertation, University of Oslo, Sweden.

Turner, S. R., Rumsey, N., & Sandy, J. R. (1998). Psychological aspects of cleft lip and palate. European Journal of Orthodontics 20(1998) 407−415.

Umweni, A. (2009). Social Analysis of Cleft Lip and Palate Abnormality in Nigeria, *3*(1), 1–19.

Young, J. L., O'Riordan, M., Goldstein, J. A., & Robin, N. H. (2001). What information do parents of newborns with cleft lip, palate, or both want to know? Cleft Palate-Craniofacial Journal, 38(1), 55–58.

APPENDICES

APPENDIX I

INFORMED CONSENT FORM

Title: AWARENESS, KNOWLEDGE AND ATTITUDE TOWARDS CLEFT LIP PALATE AMONG ANTENATAL ATTENDEES AT THE MAMPROBI POLYCLINIC

Principal Investigator: Mercy Sagwala

Address: **SCHOOL OF PUBLIC HEALTH**
DEPARTMENT OF SOCIAL AND BEHAVIORAL SCIENCES
UNIVERSITY OF GHANA, LEGON

Contact: **0243703741**

My name is Mercy Sagwala. I am a graduate student from the University of Ghana, School of Public Health undertaking a research on "knowledge and attitude towards cleft lip/palate among antenatal attendees at the Mamprobi polyclinic".

Some research assistants will be assisting in the study. The study seeks to find out how well informed pregnant women are on cleft lip/palate and their attitude towards cleft lip/palate.

Personal information that will make you identifiable will not be included in the questionnaire. Questionnaire that you will to will be anonymous (will not bear names of participants) so you will not be identified. You are free to be part of the study and decide to leave at any point you want. No one will be upset if you decide not to partake in the study. However, be assured that your privacy and confidentiality will be respected. Be assured that the research come at no risk and no cost except the precious time that they will used to fill the questionnaire. You can choose a place of convenience to answer the questions.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title "**AWARENESS, KNOWLEDGE AND ATTITUDE TOWARDS THE CLEFT LIP/PALATE AMONG ANTENATAL ATTENDEES AT THE MAMPROBI POLYCLINIC**" has been explained to me.

I have read or have had someone read all the above, asked questions, received answers regarding participation in this study, and am willing to give consent to participate in this study 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 nature and purpose of this study were read to the volunteer. All questions asked were answered satisfactorily regarding participation in this study, and volunteer gave consent to participate in this study.

_____ _____

Date Name and Signature or mark of witness

I certify that the nature and purpose in this research has been duly explained to the above individual.

_____ _____

Date Name and Signature of Person Who Obtained Consent

CONTACT INFORMATION

Questions, Concerns, or Complaints: If you have any questions, concerns or complaints about this research study, its procedures or risks and benefits, you should ask the research assistant.

Independent Contact: If you are not satisfied with how this study is being conducted, or your questions/ concerns etc. are not satisfactorily answered by the research assistant or if you have further concerns, complaints, or general questions about the research or your rights as a participant, please contact:

Hannah Frimpong

GHS-Ethical Review Committee
Research and Development Division
Ghana Health Service
P. O. Box MB 190
Accra

Office: 0302 681 109
Mobile: 024 451 6482
Email: Hannah.Frimpong@ghsmail.org

Or

Dr. Emmanuel Asampong (Supervisor)
School of Public Health
University of Ghana, Legon
Tel: 0244278453
e-mail: asampong2000@yahoo.com

Or

Mercy Sagwala
School of Public Health
University of Ghana, Legon
Tel: 0243703741
lagetmi@yahoo.com

APPENDIX II

(QUESTIONNAIRE)

QUESTIONNAIRE
This is a research on AWARENESS, KNOWLEDGE AND ATTITUDE TOWARDS CLEFT LIP/PALATE AMONG ANTENATAL ATTENDEES AT THE MAMPROBI POLYCLINIC. The study tries to find out the various factors that influence your knowledge, awareness and attitude towards cleft lip/palate.

SECTION A: **Personal Information**

Direction for interviewer: *Please tick the option that best represents the response Of the interviewee to the question you pose.*

A1. Age _____ (*enter actual age in 2 digits, e.g., 30, 35, 50)*

A2. What is your highest level of educational?

0. No Education [ ]

1. Primary [ ]

2. Secondary [ ]

3. Tertiary [ ]

4. Vocational [ ]

A3. What is your occupation?

0. Unemployed [ ]

1. Self Employed [ ]

2. Civil Servant [ ]

3. Private Job [ ]

4. Small sale business [ ]

Please Specify _____

A4. Marital status:

0. Never married/Single [ ]

1. Married [ ]

2. Separated/Divorced [ ]

3. Widower [ ]

4. Co-habitation [ ]

A5. How many children do you have? _____ (*enter actual number of children, e.g., 1, 2*)

A6. Religious Affiliation:

1. Christian [ ]

2. Muslim [ ]

3. Traditional Religion [ ]

4. No Religion [ ]

5. Others (specify) _____

SECTION B: Awareness and knowledge of Antenatal attendees on cleft lip/palate

B1. Have you ever heard of cleft lip and or palate?

1. Yes [ ]

0. No [ ]

B2. Have you ever seen a cleft lip/palate?

1. Yes [ ]

0. No [ ]

B3. If '**YES to B2 or B1**' what is cleft lip/palate?

1. opening in the lip/palate [ ]

2. defect in the lip/palate [ ]

3. Genetic problem [ ]

4. Others (*specify)* _____

99. Don't know [ ]

B4.What are some of the things a pregnant woman **should avoid** during pregnancy in order to keep her pregnancy safe from cleft lip/palate? *(To the interviewer: Please 'Tick' all that apply).*

1. Alcohol [ ]

2. Smoking [ ]

3. Self-medication [ ]

4. Others (specify) _____

99. Don't know [ ]

B5. What are some of the problems/challenges that people with cleft lip and palate may have?

(To the interviewer: Please 'Tick' all that apply).

1. Feeding yes [ ] no [ ]
2. Speech yes [ ] no [ ]
3. Dental yes [ ] no [ ]
4. Hearing yes [ ] no [ ]
5. Others (specify)_____

B6. What are the signs and symptoms of cleft lip/palate?

1. Cleft lip

1. A small notch in the lip [ ]

2. An opening in the lip from mouth to nose [ ]

3.A split on both sides of the lip [ ]

2. Cleft palate

1. Opening in the throat [ ]

2. Mouth breathing [ ]

3. Nasal congestion [ ]

4. Snoring [ ]

5. Hearing loss [ ]

6. Feeding difficulty [ ]

B7. What are your sources of information on cleft lip/palate? *(To the interviewer: Please 'Tick' all that apply).*

1. Family members [ ]
2. Casual meeting [ ]
3. Media [ ]
4. Health Facility [ ]
5. Neighborhood [ ]
6. School [ ]
7. Market place [ ]

B8. Have you read or discussed or been educated anything about cleft lip/palate before?

1. Yes [ ]
0. No [ ]

B9. If **YES TO B8** through which medium did you read or discuss? *(Tick all that apply)*

1. Magazine [ ]
2. Group discussion [ ]
3. Friends [ ]
4. TV program [ ]
5. Radio [ ]
6. Seminars [ ]
7. Newspaper [ ]
8. Health Facility [ ]
9. Market place [ ]
10. Information Van [ ]

B10. Do you know anyone with any of these conditions?

1. Yes [ ]
0. No [ ]

B11. Has any of your children or relative had cleft lip or palate?

1. Yes [ ]
0. No [ ]

B12. Do you think that these conditions can be corrected/treated?

1. Yes [ ]
0. No [ ]
99. Don't know [ ]

B13. If **YES TO B12** then how do you think it can be corrected? *(Tick all that apply)*

1. Surgical [ ]
2. Medication [ ]
3. Prayer camp/prayer will heal the baby [ ]
4. Herbalist [ ]

B14. Do you think it can be prevented?

1. Yes [ ]
0. No [ ]
2. Maybe [ ]
99. Don't know [ ]

B14. To what extent do you agree that these steps can help prevent cleft lip or palate?

Taking Folic acid

Taking Fersolate

Taking Iron supplement

Taking Vitamin B supplement

Attending regular antenatal clinic

1. Strongly disagree [ ]
2. Disagree [ ]
3. Neutral [ ]
4. Agree [ ]
5. Strongly Agree [ ]

B15. The condition can be associated with the following risk factors. (*Please 'Tick' all that apply*)

1. Smoking [ ]
2. Alcohol [ ]
3. Hereditary [ ]
4. Congential [ ]
5. Unprescribed medications [ ]
6. Eating certain foods [ ]

SECTION C: Attitude towards cleft lip/Palate

C1. To what extent do you think/believe these conditions are caused by evil spirit?

1. Strong disbelief [ ]
2. Disbelief [ ]
3. Neutral [ ]
4. Belief [ ]
5. Strong belief [ ]

C2. What do you think should be done to parents of a cleft lip/palate baby?

? *(To the interviewer: Please 'Tick' all that apply).*

0. Nothing
1. Ostracized and banished [ ]
2. Pacify the god(s) [ ]
3. Pay for their sins [ ]
4. Visit the hospital for medical attention [ ]
5. Seek spiritual and herbal treatment [ ]
6. Herbal treatment:_____

C3. What do you think parents should do in the event when their child has cleft lip/palate?

(To the interviewer: Please 'Tick' all that apply).

1. seek herbal and spiritual help [ ]
2. seek medical attention [ ]
3. Report to family head [ ]
4. Hide child from public [ ]
5. Not sure [ ]
6. Others (specify):_____

C4. To what extent do you agree that the following causes cleft lip or palate? Use the following

1. Strongly disagree
2. Disagree
3. Neutral
4. Strongly agree
5. Agree

	1	2	3	4	5
a. Curse from the gods					
b. Witchcraft					
c. Punishment from the God/gods					
d. God's will					
e. Sins committed in past lives					

C5. Do you have an interest in knowing more about cleft lip/palate?

1. Yes [ ]
0. No [ ]
99. Don't know [ ]

C6. If YES to **C5**, through which medium will you want to know about cleft lip/palate? *(To the interviewer: Please 'Tick' all that apply).*

1. Magazine
2. Group discussion
3. Friends
4. TV program
5. Radio
6. Seminars
7. Newspaper
8. Hospital
9. Market place
10. Information Van
11. What do you want to know:_____

C7. If a child had cleft lip/palate, would you hold/touch that child?

1. Yes [ ]
0. No [ ]
99. Don't know [ ]

C8. If your child or relative has cleft lip/palate, would you like people to know about it or you would hide it?

1. I would like people to know about it [ ]
0. I would hide it [ ]
99. I don't know [ ]

SECTION D: Health Systems Factors

D1. Are ANC (antenatal care services) available to you during pregnancy?

1. Yes [ ]

0. No [ ]

99. I don't know [ ]

D2. During ANC, do the healthcare worker/ midwife educate you on maternal health issues?

1. Yes [ ]

0. No [ ]

99. I don't know [ ]

D3. During ANC, do the healthcare worker/ midwife educate you on cleft lip/palate issues?

1. Yes [ ]

0. No [ ]

99. I don't know [ ]

D4. Are you able to freely discuss your difficulties with you midwife?

1. Yes [ ]

0. No [ ]

99. I don't know [ ]

End of interview. Thanks for your time

APPENDIX III

APPROVED CONSENT