

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY,

KUMASI, GHANA

KNUST
DETERMINING SOCIAL CHALLENGES OF CHILDREN WITH CLEFT LIP AND OR
PALATE AS PERCEIVED BY PARENTS OR CARETAKERS AT KOMFO ANOKYE
TEACHING HOSPITAL IN KUMASI METROPOLIS IN ASHANTI REGION, GHANA

BY

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DECLARATION

I hereby declare that this thesis for the award of MSc. Health Education and Promotion at Kwame Nkrumah University of Science and Technology, Department of Health Promotion and Education is submitted by me and has not been previously submitted to this university or to any tertiary educational institution. This is my own work in design and execution and all references contained in there have been dully acknowledged.

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DEDICATION

This research is dedicated to parents/caretakers of children with cleft lip and or palate and their children with the condition.

KNUST



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ABSTRACT

Introduction

Cleft lip and or palate is a congenital malformation in which there is failure of the lip or roof of the mouth to close leaving a gap in the lip or roof of the mouth. Most people affected with this malformation suffer discrimination, stigmatization and ostracism from non-affected people. Also, they do not receive enough attention from policy makers. As a result they have social challenges in education, finding employment and a life partner. This study aimed at finding out the proportion of children with cleft lip and or palate in KATH and the social challenges they could face as perceived by their parents or caretakers.

Methods

A descriptive cross- sectional study was used to conduct the study and the study population included parents or caretakers of children with cleft lip and or cleft palate and children with the condition.

Data was gathered using standard information extraction sheet and structured questionnaire. The extraction sheet was used to gather data from 272 folders of children with CLP and the structured questionnaires were administered to 224 caretakers/parents of children with CLP.

Data was entered into Microsoft word 2007 and was transported to Stata version 12.0 for analysis. Statistical significant was set as 0.05.

Results

The results indicated that cleft lip was the most occurring cleft type; 43.8% for 2013 and 46.9% for 2014 and 0.4% of parents of cleft children had cleft themselves. Only 10.7% of children with cleft were in school and the difference in perception on cleft affecting future job prospect was statistically significant (p - value=0.01). However, the

difference in perception on future marriage opportunities of CLP children was not statistically significant (p- value=0.69).

Most parents/caretakers (68.3%) suggested public education on cleft could minimize the social challenges that confront people with CLP.

There was a relationship between socio-demographic characteristics of caretakers and their perceived social challenges. The relationship between occupation of caretakers (pvalue=0.00) as socio-demographic characteristic and education and marriage as perceived social challenges was statistically significant. Also, there was statistical difference between religion of caretakers (p-value=0.00) as socio-demographic characteristic and employment as perceived social challenge.

Conclusion and recommendation

Most parents/caretakers were not aware of the challenges that would confront them when they give birth to a child with cleft lip and or cleft palate. This study therefore recommends that parents/caretakers of children with cleft should be given education on cleft lip and or cleft palate by health workers of Komfo Anokye Teaching Hospital.

ABBREVIATIONS AND ACRONYMS

CL.....Cleft lip

CLP.....Cleft lip and or palate

CP.....Cleft palate

KATH.....Komfo Anokye Teaching Hospital

KNUST.....Kwame Nkrumah University of Science and Technology

NHIS.....National Health Insurance Scheme

OFC.....Orofacial Cleft

PSS.....Psychosocial Support

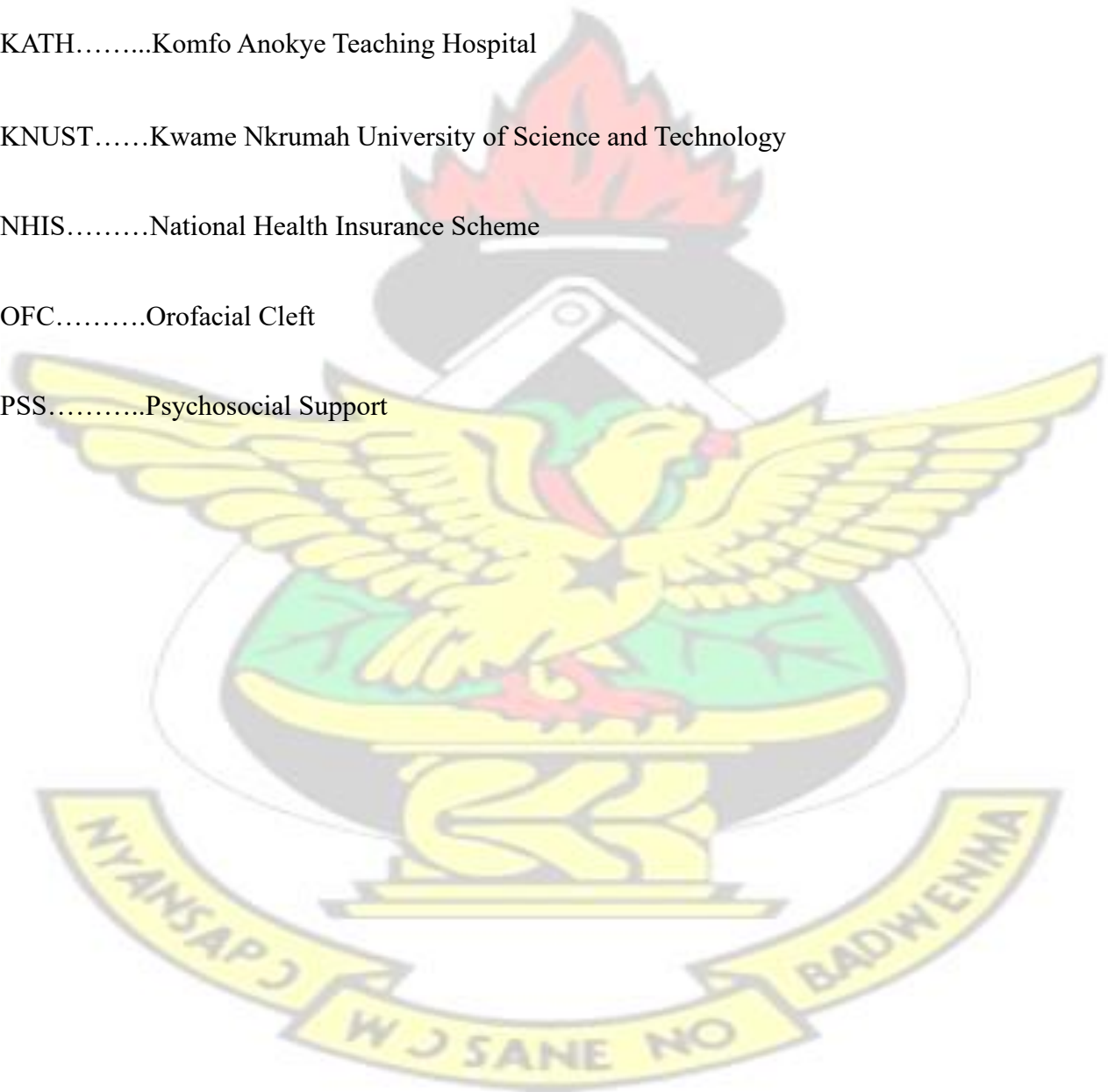


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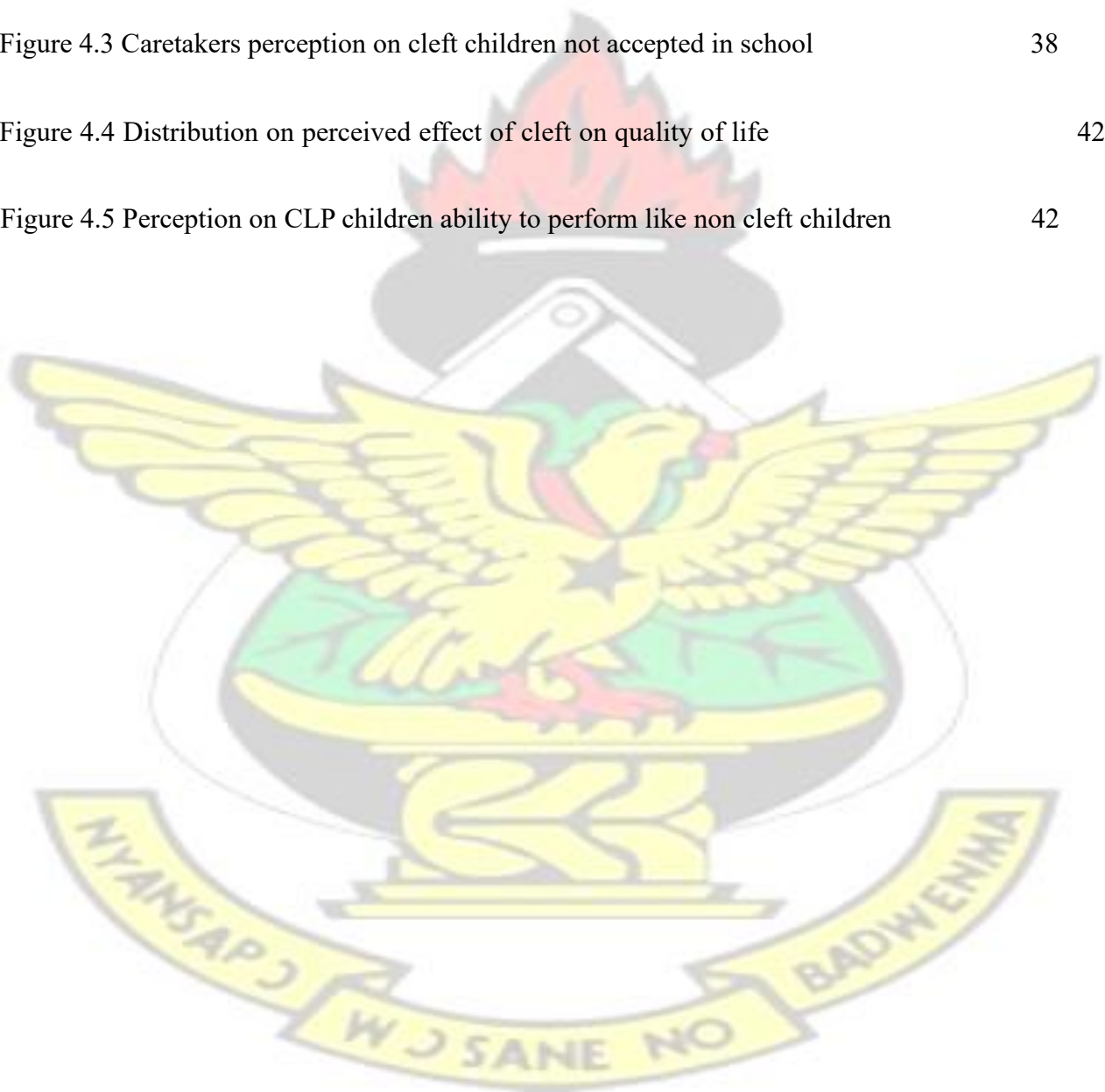
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CHAPTER ONE: INTRODUCTION

1.1 Background to the Study

Cleft lip and or palate (CLP) is a congenital defect which can affect anybody irrespective of one's colour or social status. The CLP refer to abnormal opening of the lip and or the roof of the mouth (Revesez *et al.*, 2013). The condition can affect one side of the lip (unilateral) or both sides of the lip (bilateral) and can cause deformity (Rumsey and Harcourt, 2003; Reilly *et al.*, 2013). People with deformity may have low self-esteem especially in situation where the site of deformity can be seen by everybody as in the case of cleft lip. Discrimination against such people will rather compound their situation since they can function just as any other person. Rumsey and Harcourt (2003) emphasized that most facial anomalies are not associated with deficits in brain function but rather link with physical features. They added that cleft affected children are more likely at risk than their non cleft peers for elevated anxiety, unhappiness, and self doubt in relation to interpersonal relationships. Therefore discrimination will just increase their anxiety or unhappiness level.

Seeing CLP individuals as sub-human and not given them that sense of love and care to the extent that most of them remain single and do not get married make them feel society has rejected them (Akhare *et al.*, 2013). Meanwhile associating with people with disfigurement has proven to be helpful. This is confirmed by Chan *et al* (2006) who indicated that increase contact with people with disfigurement tends to result in more positive attitude.

Cleft lip and palate is one of the most prevalent congenital orofacial deformities. Across the globe, children born with cleft condition is rising steadily, every one (1) out of 500 to 1000 live births in the world has cleft lip and or palate (Loh & Ascoli, 2011; Selvia *et al.*, 2009). In Europe the

prevalence is 1 in 700 (Peterson-Falzone *et al.*, 2001). In Africa the prevalence of CLP is 0.7 per 1000 live birth (Loh & Ascoli, 2011) and , in South Africa, from 1993 to 1997 there were 119 babies born with cleft lip out of 336,331 births (WHO 2003). In Ghana, a study conducted in eleven selected health facilities in Kumasi recorded 36 orofacial anomalies out of 27,449 live births from October 2009 to September 2010 (Agbenorku *et al.*, 2013).

A lot of researches have been conducted among people with CLP but not much is known about the perceived social challenges and how these impact on their life style. This research therefore focuses on the social challenges confronting children with CLP as perceived by their caretakers/parents since they are likely to be with the children most of the time.

1. 2 Statement of the Problem

People with deformity are perceived as less human (Umweni *et al.*, 2009). They are perceived as incapable and branding them as disabled. However, they have their own strengths. They may be challenged one way or the other but they have their own capabilities. Societal discrimination alone create gap between the physically challenged or the person with deformity and the so called 'normal' human beings. Discrimination is detrimental to people with disabilities and may impede the fulfillment of their life goals. In India, a study conducted among hundred subjects of CLP indicated that 29% were not allowed to draw water from the local well whiles 38% were not allowed to join school by the village elders (Akhare *et al.*, 2013). Even those expected to know better also discriminate against people with CLP. This is evident in China where teachers were found misjudge the intelligence of students with CLP when studies had disapproved of that misconception (Rumsey and Harcourt, 2003). In the light of pervasive emphasis in current society on body appearance, we will compound their situation by discriminating. They are denied love and care by society (Umweni *et al.*, 2009). Sometimes the discrimination is so deep that even

children's attitude towards similar age peers with any degree of facial disfigurement may reflect a low preference for social interaction. In other instances, employers react negatively to prospective employees with cleft palate (Chan *et al.*, 2006). These discriminations among the individuals indirectly or directly affect their socio-economic life and invariably affect their health.

In Ghana many studies have been conducted on cleft lip and or palate. Most of these studies focus on the incidence of cleft (Agbenorku *et al.*, 2013) but not much is known about their social challenges. Therefore, there is the need to determine the social challenges of children with CLP as perceived by their parents or caretakers as a lesson learning to inform future policy direction.

1.3 Rationale of the Study

The outcome of this study will provide relevant information on social challenges for children with CLP as perceived by caretakers or parents. This will provide a good source of knowledge and information for human rights activists; Ministry for Gender, Children and Social Protection, government, non-governmental agencies, benefits societies and all those who have the marginalized in society at heart. The people with CLP will have a sense of feeling that society is beginning to recognize them and for that matter address their problems which can serve as a morale booster for them. In addition, this research is to help stakeholders to know the proportion of children with CLP and therefore make provisions for them when formulating policies.

1.4 Conceptual Framework

A number of social challenges are perceived by parents or caretakers to be encountered by children with CLP as indicated in figure 1.1. Some of these perceived social challenges include stigmatization, discrimination, marginalization and even ostracism of people with CLP. These

social challenges are perceived to be encountered by the children with CLP because of their deformity. The outcome of these perceived social challenges if not well managed may lead to anxiety, low self-esteem, social interaction problems, depression, body image concerns and many others.



Deformity (Clip lip and or Palate)

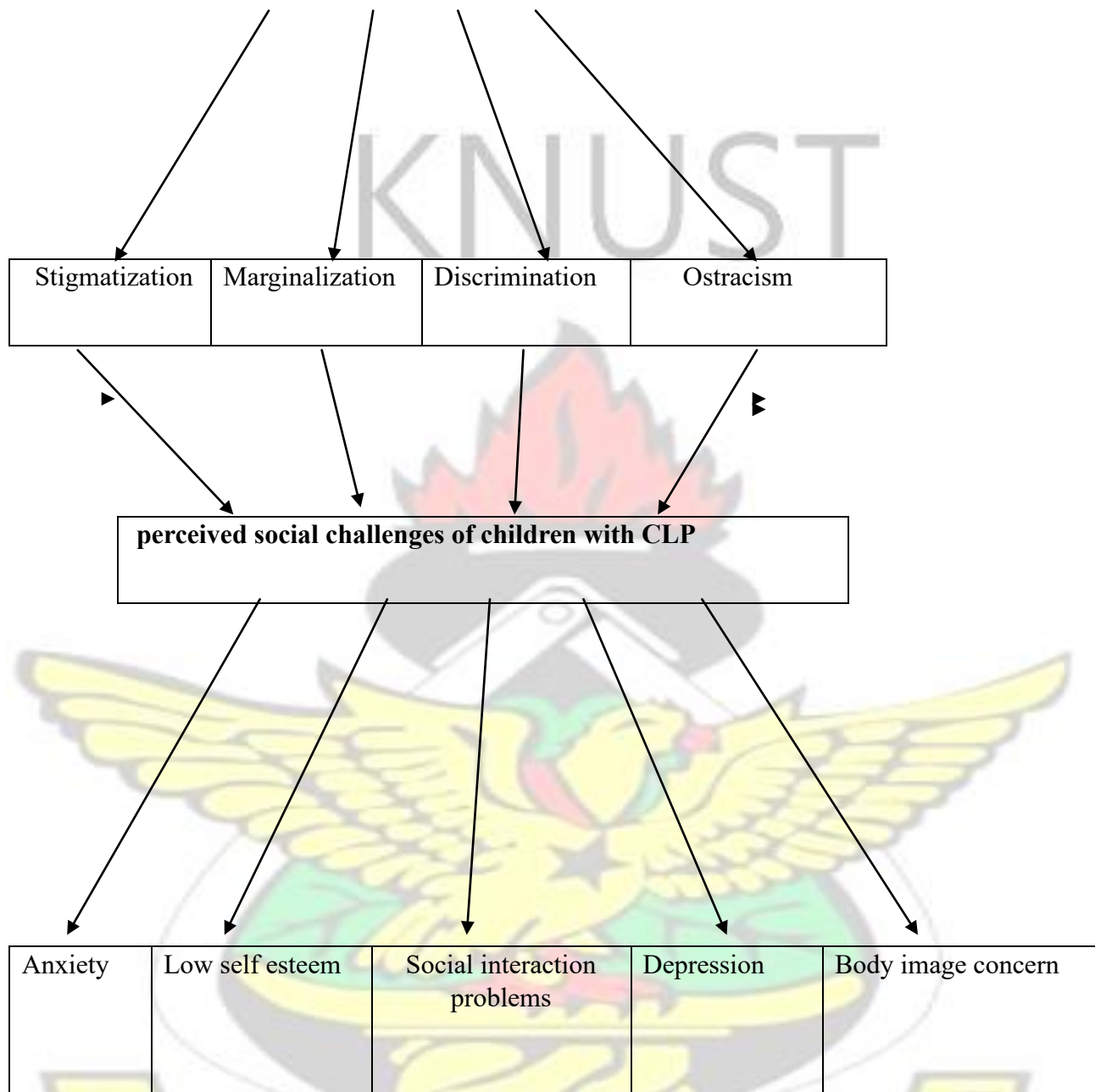


Figure 1.1: Perceived social challenges of children with cleft lip and or palate

Source: Health survey 2014

1.5 Research Questions

1. What is the proportion of children with CLP in KATH?

2. What are some of the social challenges confronted by children with CLP as perceived by parents or caretakers?
3. How can these social challenges be minimized?
4. Are there any relationship between social challenges perceived by the parents or caretakers and their socio-demographic background?

1.6 Objectives of the Study

1.6.1 General Objectives

To determine the proportion of children with CLP and social challenges confronting them as perceived by their parents or caretakers at KATH.

1.6.2 Specific Objectives

1. To compare the proportion of children with CLP at KATH in 2013 and 2014.
2. To determine the social challenges faced by children with CLP as perceived by their parents or caretakers.
3. To identify suggestions to overcome the social challenges based on parents or caretakers perspective.
4. To establish any relationship between the perceived social challenges and sociodemographic characteristics of the parents/caretakers.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter review related literature on the subject matter and present on general overview of cleft lip and palate, prevalence of cleft lip and palate in the world, self-concept of people with

cleft lip and or palate, challenges faced by people with cleft lip and palate and how to deal with these challenges.

2.2 General Overview of Cleft Lip and Palate

According to Centers for Disease Control and Prevention (2014), cleft lip and cleft palate are birth defects that occur when a baby's lip or mouth do not form properly during pregnancy. These birth defects commonly are called "orofacial clefts". In decades past, the condition was sometimes referred to as harelip, based on the similarity to the cleft in the lip of a hare, but that term is now generally considered to be offensive (Tessier, 1976). These birth defects happen early during pregnancy. A baby can have a cleft lip, a cleft palate, or both.

A cleft is a fissure or opening. It is the non-fusion of the body's natural structures that form before birth (Broyles, 2008). Approximately 1 in 700 children born have a cleft lip or a cleft palate or both (Hutchinson et al., 2011). Cleft means a gap or split between two things. A "cleft lip" is a split in the upper lip. This can happen on one or two sides of the lip, creating a wider opening into the nose. Additionally, Murray *et al* (1997), reveal that a "cleft palate" is a split in the roof of the mouth. This leaves a hole between the nose and the mouth. Sometimes a cleft lip and cleft palate occur together. Cleft lip and cleft palate are very common and occur in about 1 or 2 of every 1,000 babies born in the United States each year. This happens while a baby is developing. Normally the mouth and nose of a baby develop between the first 6 and 12 weeks of growth inside the mother (Murray *et al.*, 1997). In some babies, parts of the lips and roof of the mouth do not grow together. All because the lips and the palate develop separately, it's possible to have cleft lip alone, cleft palate alone, or both together.

It is believed by scholars that cleft lip happens if the tissue that makes up the lip does not join completely before birth (Ekvall & Ekvall, 2005). This results in an opening in the upper lip. The opening in the lip can be a small slit or it can be a large opening that goes through the lip into the nose. A cleft lip can be on one or both sides of the lip or in the middle of the lip, which occurs very rarely (Centers for Disease Control and Prevention, 2014). Children with a cleft lip also can have a cleft palate (Kim *et al.*, 2010; Tessier, 1976). On the other hand, the roof of the mouth (palate) of an unborn child is to be formed between the sixth and ninth weeks of pregnancy. Cleft palate happens if the tissue that makes up the roof of the mouth does not join together completely during pregnancy. For some babies, both the front and back parts of the palate are open. For other babies, only part of the palate is open (Yuzuriha & Mulliken, 2008). A cleft palate is a split or opening in the roof of the mouth. A cleft palate can involve the hard palate (the bony front portion of the roof of the mouth), and/or the soft palate (the soft back portion of the roof of the mouth) (Broyles, 2008; Agbenorku *et al.*, 2013).

A cleft lip is a physical split or separation of the two sides of the upper lip and appears as a narrow opening or gap in the skin of the upper lip. This separation often extends beyond the base of the nose and includes the bones of the upper jaw and/or upper gum (Tollefson *et al.*, 2011).

Even though, there is no consensus on the real cause of cleft lip and palate, there are still some causes of this developmental deformity. For instance, WebMD (2014) stresses that in most cases, the cause of cleft lip and cleft palate is unknown. These conditions cannot be prevented. Most scientists believe clefts are due to a combination of genetic and environmental factors. There appears to be a greater chance of clefting in a newborn if a sibling, parent, or relative has had the problem. (Black *et al.*, 1998; Mossey and Little, 2009; Aronson and Bless, 2009). Another potential cause may be related to a medication a mother may have taken during her pregnancy. Some drugs

may cause cleft lip and cleft palate. Among them: anti-seizure/anticonvulsant drugs, acne drugs containing Accutane, and methotrexate, a drug commonly used for treating cancer, arthritis, and psoriasis (DeLong & Burkhart, 2013; Broyles, 2008; Mossey & Little, 2009).

Cleft lip and cleft palate may also occur as a result of exposure to viruses or chemicals while the fetus is developing in the womb (Hill, 2001; Sloan, 2000).

In addition to the above expositions, Centers for Disease Control and Prevention (2014) reported on important findings from research studies about some factors that increase the chance of having a baby with an orofacial cleft:

- 1 Smoking—Women who smoke during pregnancy are more likely to have a baby with an orofacial cleft than women who do not smoke (Little *et al.*, 2004).
- 2 Diabetes—Women with diabetes diagnosed before pregnancy have an increased risk of having a child with a cleft lip with or without cleft palate, compared to women who did not have diabetes (Correa *et al.*, 2008).
- 3 Use of certain medicines—Women who used certain medicines to treat epilepsy, such as topiramate or valproic acid, during the first trimester (the first 3 months) of pregnancy have an increased risk of having a baby with cleft lip with or without cleft palate, compared to women who didn't take these medicines (Margulis *et al.*, 2012; Werler *et al.*, 2011).

Even though, the point had been made that the exact cause of orofacial clefts among most infants cannot be determined off hand, some children have a cleft lip or cleft palate because of changes in their genes (Dixon *et al.*, 2011). Besides, cleft lip and cleft palate have been seen to be caused by a combination of genes and other factors, such as things the mother comes in contact with in her

environment, or what the mother eats or drinks, or certain medications she uses during pregnancy as deduced from the scholarly views surveyed.(Mossey & little, 2009).

2.3 Prevalence of cleft lip and palate in the world

According to International Perinatal Database of Typical Oral Clefts (IPDTC, 2011), orofacial clefts (OFC) represent a heterogeneous group of defects with a considerable range of dysmorphological severity. It explains that the challenges in understanding the health impact of OFC include the lack of data in large areas of the world and poor-quality or incomplete data, often missing information on important variables such as gender and dysmorphological severity, in many other areas. In spite of this, there is adequate literature on individual countries in studies that have been undertaken to describe the prevalence at birth of OFC, which, at first glance, suggest very considerable international variation. However, the possibility cannot be excluded that this variation is, in substantial part, accounted for by differences among regional infrastructures for health care, and hence ascertainment, which may vary over time. Therefore, there is a need for data collected in a standardized and systematic manner to facilitate 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 highest prevalence rates for (CL ± P) 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 (Rivron, 1989; Karen, 1998)

The revelations in the last paragraph is given credence by Hutchinson *et al* 2011; Newman and Agbenorku 2014, which show that Cleft lip, either as a sole malformation or coupled with cleft palate occur 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.

According to a study conducted by Butali and Mossey (2009), it was indicated that reports of birth prevalence of orofacial clefts from different African populations vary widely, from as low as 0.3/1,000 reported in Nigeria to 1.65/1,000 reported in Kenya (Iregbulem, 1982). Determining the exact prevalence of orofacial clefts in Africa is important for public health reasons as the prevalence rates will help identify cluster areas and possible etiological factors, which will in turn help governments plan strategies for preventive measures and treatment (Butali & Mossey, 2009).

In support of the earlier submissions, Agbenorku *et al* (2011) affirm that the prevalence rates reported for live births for CL±P and CPO vary within different ethnic groups. They also state that the highest prevalence rates for CL±P are reported for Native Americans (3.74/1,000) and Asians (from 0.82/1,000 to 4.04/1,000). Consistently, it seems that prevalence rate of CL±P in

Africans is low compared to other races across the world. In Malawi, Msamati, Igbibi and Chisi (2000) as cited in Agbenorku et al (2011) reported that there is low prevalence rate for CL±P, which is 0.7 per 1,000 per live births. Another African scenario as contained in the report of Suleiman et al (2005) as cited in Agbenorku *et al* (2011) indicates that the prevalence rate of clefting among a group of Sudanese hospital newborns in the city of Khartoum is 0.9 per 1,000 live births.

In Ghana, Agbenorku, *et al* (2007) found out in a study in the Wudoaba communities in the Volta Region revealed a CL/CP prevalence of 5.0 per 1,000 people. Also, a retrospective review of CL and palate operations carried out at the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana by Donkor *et al* (2007) found that a total of 344 patients were operated for CL and palate during a 5-year period. This goes to confirm the assertion by Butali and Mossey (2009) that most prevalence reports on CL/CP had their data from hospitals, with relatively few studies done in communities such as the one conducted by Agbenorku *et al* (2007) in Ghana.

2.4 Self concept of people with cleft lip and palate

When it comes to self-concept, individuals with cleft lip and palate seem to perceive themselves differently depending on age. Studies on children have shown diverging results with both a lowered self-concept (Broder *et al.*, 1989; Kapp-Simon, 1986) and a medium to high selfconcept (Brust *et al.*, 1991).

Compared with children, adolescents with cleft lip and palate consistently show an average to high self-concept (Brust *et al.*, 1991; Kristovich *et al.*, 1992)

The degree of inhibition or introversion is significantly correlated to the degree of psychological maladjustment, and may thus depend on the individuals with cleft lip and palate behaviour and

social skill (Kristovich *et al.*, 1992). These qualities are at least partly determined by the acceptance an individual with cleft lip and palate will experience in the environment. However, people in general may be hesitant or even negative towards individuals who do not display normal human features or behaviours. Regarding the operated individual with cleft lip and palate, the appearance is actually considered less friendly and popular and not so intelligent and attractive compared with the normalized appearance achieved by photographs (Tobiasen , 1987). It is therefore not surprising that an individual with cleft lip and palate often is concerned about facial appearance. In childhood and adolescence, this correlates with an increased social inversion and may also be accompanied by poor self-concept and anxiety (Pertschuk *et al.*, 1985 ; Richman , 1983) Meanwhile with treatment, most children with orofacial clefts do well and lead a healthy life. Some children with orofacial clefts may have issues with self-esteem if they are concerned with visible differences between themselves and other children. Parent-to-parent support groups have proved to be useful for families of babies with birth defects of the head and face, such as orofacial clefts (American Cleft Palate-Craniofacial Association, 2009).

2.5 Challenges faced by children with CLP

There is no doubt that people who have been affected by CLP face a couple of challenges which could be psychological and social. These challenges can be termed psychosocial effects of CLP. In fact, several studies have been conducted to verify these challenges. For instance, it has been observed generally that facial appearance is regarded as an important prerequisite for healthy psychosocial development (Cole, 1998; Rumsey & Harcourt, 2005). This assumption is supported from three directions. Firstly, evolutionary theories indicate that symmetric faces imply physical health, including a well-functioning immune system, the absence of illness or a relative lack of environmental insults during development (Buss, 2008). Secondly, the theories emphasize that the

beauty and attractiveness may depend upon the face's symmetry and a relatively large interocular distance. Thirdly, social psychologists stress that social interactions largely rely upon perception and interpretation of facial expressions (Hubbard, 2001; Vigil, 2009) and evaluations of attractiveness (Feingold, 1992).

In addition to the above, Sousa et al (2009) emphasized that various physiological and socio cultural factors contribute in the development of psychosocial issues among individuals with any form of facial anomaly in general. Research has also shown that attractive children are seen by others as brighter, having more positive social behavior and receive more positive treatment than their less attractive counterparts (Dion *et al.*, 1972; Videbeck, 1960).

Also, Hunt *et al* (2005) affirm that research has shown that attractive children are seen by others as brighter, as having more positive social behaviour and receive more positive treatment than their less attractive counterparts. Many children with cleft lip and palate (CLP) may have a less attractive facial appearance or speech than their peers. A high incidence of teasing over facial appearance is reported among those with CLP (Bernstein & Kapp, 1981; Noar, 1991; Turner *et al.*, 1997). The general assumption that follows is that children with CLP must experience some kind of psychosocial distress as a result of their condition (Hunt *et al.*, 2005).

Furthermore, some studies have come out with these social challenges that are associated with children and adults who have CLP deformity. Largely, studies have been cited in Hunt et al (2005). In the first instance, Noar (1992) reveal that professionals who are involved in caring for patients with clefts confirmed that, many of the patients are socially affected as a result of having a cleft. On their part, some other scholars have found out that self-reports of adults with CLP indicate a number of social problems (McWilliams & Paradise, 1973; Peter & Chinsky, 1974). Also, there is

an observation that differences have been established between young people with CLP and controls, such as those with CLP dropping out of school more frequently and being less likely to belong to social clubs and societies in the school (McWilliams & Paradise, 1973; Peter & Chinsky, 1975). Moreover, it has been found in some studies that a larger proportion of young people with CLP indicate no aspiration for further education when compared with controls (Peter & Chinsky, 1974b), and they are more frequently unemployed with a significantly lower income aspiration than controls (Peter et al., 1975). It is therefore not surprising that Marcusson *et al* (2001) concluded that adults with OFC had significantly lower scores for quality of life, family life, private economy, global life, as well as having disturbance to life, well-being, and social contacts.

Besides the above, two areas of social functioning appear to differentiate those with CLP from those without CLP: marriage and friendships. Fewer adults with CLP marry (McWilliams & Paradise, 1973; Broder *et al.*, 1994), and even when they do, marriage occurs later in life (Peter & Chinsky, 1974; Broder *et al.*, 1994; Ramstad *et al.*, 1995). This is similar to a study by Danilo *et al* (2005) that investigated 82 French adults with repaired CLP and found that, compared to adults without CLP, people with CLP did marry later, displayed a delay in scholarship, had a lower income, and reported a significant delay in their independence process from their parents

In the same vein, Peter and Chinsky (1974) had found that childless marriages occur more frequently in subjects with clefts than among controls. Some studies have suggested that children and young adults with CLP have fewer friends than non-cleft people (Noar, 1991; Ramstad et al., 1995; Bressman *et al.*, 1999), with only one study suggesting that children with clefts have more friends than control children (Broder *et al.*, 1994). However, the authors of that study urged caution when interpreting the unusual finding.

In a study conducted by Tyl *et al* (1990), it was found that children with cleft lip and palate suffer from social stigmatization and specific disorders of self-evaluation. In these children problems associated with adaptation in the child community, manifestations of depression, low self-esteem, impaired ego identity and a tendency of a negative attitude to the world were recorded. These phenomena increase with the severity of the damage and the visibility of the defect. Another study conducted by Umweni *et al* (2009) and which focused on the social effects of CLP found that stigmatization and discriminations were related by the respondents as a common experience.

Furthermore, according to Zebrowitz (1997), Western society is very focused on the aesthetics of the human body. Those people who are objectively rated as beautiful or attractive are more frequently attributed with personal qualities such as intelligence and trustworthiness. On their part, Lefebvre and Barclay (1982) indicate that people with facial disfigurements who do not meet idealised standards of attractiveness are more likely to be stigmatised socially. It has been assumed that as a consequence of this process the more severe a person's disfigurement, the poorer their psychosocial adjustment will be. However, other studies have challenged this assumption and argue that many people born with a cleft lip and/or palate will demonstrate psychosocial adjustment within the normative range (Robinson, 1997; Walters, 1997). Despite a substantial number of studies over the past twenty years there remains a lack of clarity about what distinguishes those who adapt well from those who do not. Although the aetiology of adaptation is unclear, there is a general consensus that a sub-group of people with clefts are more anxious, more socially withdrawn, are at higher risk of suicide, have fewer friends and have fewer social contacts (Herskind *et al.*, 1993; Slifer *et al.*, 2003).

Also, it is important to note that preference for attractive individuals subsequently influences self esteem, social competence, and future ratings of attractiveness (Sawer & Magee, 2006).

Moreover, being physically attractive appears to be an advantageous trait regardless of age. Physical attractiveness has shown to play a significant role in social set ups like developing relationships during various stages of life, school, courtships, work etc. Social acceptance often depends on one's physical look. These associations between physical beauty and social acceptability indicate the difficulties for cleft lip and palate affected individuals (Turner *et al.*, 1997). In fact a study by Brand *et al* (2009) showed that children and adolescents with CLP were six times more likely to report difficulties in interactional competencies compared to controls without CLP. Stigma experiences, social problems, symptoms of anxiety and depression, dissatisfaction with facial appearance are some other problems faced by people with CLP (Snyder *et al.*, 2005; Patrick *et al.*, 2007).

2.6 Dealing with the Psychosocial Challenges of children with CLP

In view of the several challenges that children with CLP go through, there is a need to find ways of managing the situation to ensure that such children are integrated properly into normal societal lives. It is the basis of this that several scholars have come up with how such conditions could be managed effectively.

Hodgkinson *et al* (2005) affirm that the management of children with cleft lip and palate presents many challenges but also many rewards. They intimated that their involvement with children with CLP conditions and their families often began before birth and extended into late adulthood. Affected individuals present a multiplicity of problems and effective management involves a wide range of specialists. The currently accepted model for delivery of this care in the most appropriate way is the multidisciplinary cleft team. This is a group of individuals from different specialist backgrounds who work closely together, not only to bring each specialist's particular expertise to

the patient in the optimum way, but also to develop an understanding of the requirements and specialist skills of the other team members to enhance the delivery of the total package. It has been suggested that such an integrated system of delivery of care enables the individuals within the team to function in an interdisciplinary way so that all aspects of health care for the cleft condition can be delivered in as seamless a way as possible.

From another perspective, the University of Iowa Children's Hospital (2014) accepts that fact that most of the time, children with facial differences will not have a lot of psychological reaction to questions about their scars or differences in their appearance until they are roughly age six. But after this point, there may be more feelings attached to questions about the difference in their appearance and many times it is necessary for the parents to educate students and teachers at school as to exactly what a cleft palate is. The Iowa Children's Hospital authorities indicate there are studies in the medical literature that show that children with cleft lip or palate grow up essentially psychologically normal. There are also studies that show that children with cleft lip or palate have more problems psychologically than their peers who do not have this condition. At Iowa Children's Hospital, they talk to a number of patients who are in their 40s and older and have had the opportunity to look back over their lives to see what impact having cleft had to them. One consistent factor in the patients who were well adjusted was that they had extremely supportive families and felt that they had a safe and comfortable place to talk about their condition and get their questions answered. An important part of the overall care and treatment of these children has to involve the parents and their commitment to maintain such an environment while their children are growing up. This has been supported by Rumsey and Harcourt (2004) that Partners and families of people with disfigurement are likely to be the sole providers of support. This is in line with report by Chetpakdeecheit *et al* (2009) who found that

young adults with OFC and receiving recognition from others reported higher self-esteem and greater ability to cope with their social lives. Meanwhile, Eide *et al* (2006) said, birth defect including OFC, was not unfavourably associated with adult intellectual performance.

Apart from all the medical interventions and management principles of cleft lip and palate conditions, the next important thing to do is psychosocial support and counseling services. Accordingly, it has been stated that psychosocial support (PSS) is a set of interventions used to meet a person's emotional, social, mental, and spiritual needs (Bantwana.org, 2014). PSS is very important for the healthy development of all children and critical for orphaned and vulnerable children (OVC). As part of a comprehensive care approach, PSS provides vulnerable children with the necessary tools for good health and positive development (Bantwana.org, 2014).

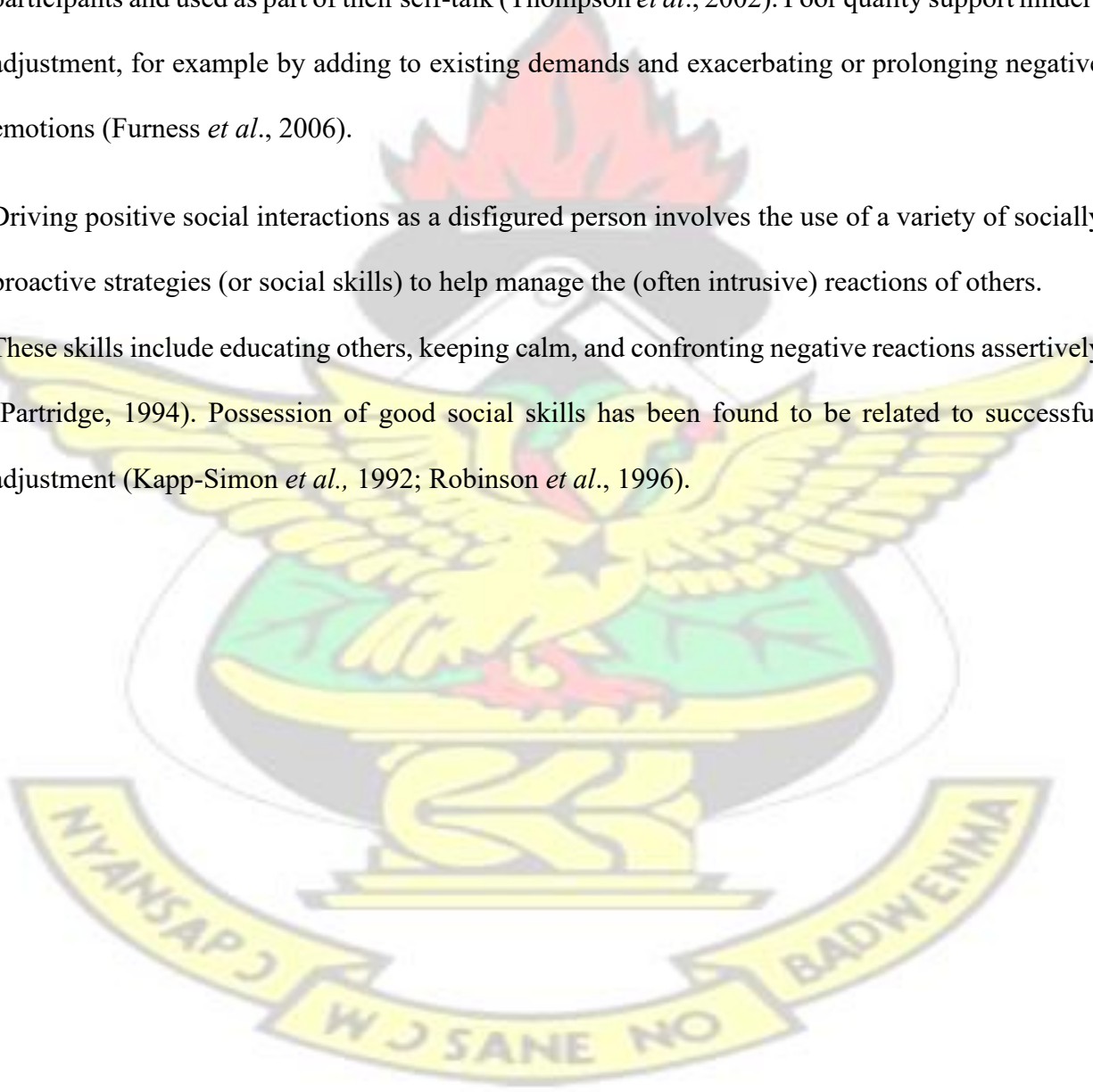
May be the most important copying mechanism for facial deformity is positive social interactions. On this score, a study done by Gallaher (2010) has come out with some suggestions. Cobb (1976) as cited in Gallaher (2010) stresses that social support has been defined as information leading people to believe that they are cared for and loved, esteemed, and a member of a network. Accordingly, social functioning is often the ultimate goal for both biomedical and psychosocial interventions for disfigurement (Ong *et al.*, 2007), and the use of avoidance and concealment illustrates the overriding concerns of social exclusion among the disfigured (Goffman, 1963). Ong *et al* (2007) suggest that successful adjustment in disfigurement lies in the ability to interact with other people at various levels, from meeting people for the first time to enjoying an intimate relationship.

Also, Gallaher (2010) citing the views of several scholars, indicates that the quality of perceived social support has been found to be particularly important to adjustment in a number of studies (Baker, 1992; Blakeney *et al.*, 1990; Browne *et al.*, 1985). High-quality social support is a

powerful resource aiding adaptation. Reported benefits of social support include encouragement to enter anxiety-producing settings, reassurance of acceptance regardless of appearance, and the development of adaptive cognitions. Carver and Scheier (1981) as cited by Gallaher (2010) found that social support can serve to facilitate the development of problem-focused and emotion-focused coping strategies. Helpful comments from friends and relatives were internalized by participants and used as part of their self-talk (Thompson *et al.*, 2002). Poor quality support hinders adjustment, for example by adding to existing demands and exacerbating or prolonging negative emotions (Furness *et al.*, 2006).

Driving positive social interactions as a disfigured person involves the use of a variety of socially proactive strategies (or social skills) to help manage the (often intrusive) reactions of others.

These skills include educating others, keeping calm, and confronting negative reactions assertively (Partridge, 1994). Possession of good social skills has been found to be related to successful adjustment (Kapp-Simon *et al.*, 1992; Robinson *et al.*, 1996).



CHAPTER THREE: METHODOLOGY

3.1 Profile of Study Area

3.1.1 Study Site

The study was conducted at Komfo Anokye Teaching Hospital (KATH) in Kumasi the regional capital of Ashanti Region of Ghana. The hospital was formally known as Kumasi Central Hospital. It was established in 1955. It gained a teaching hospital status in 1975 for the training of medical students from Kwame Nkrumah University of Science and Technology. KATH is the second largest hospital in Ghana under the auspices of Ministry of Health and has a bed capacity of 1000. A newly-established state of ultra modern Accident and Emergency Centre with a bed capacity of 120 was built in 2009. KATH is accessible to about 80% of the population of Ghana: Northern, Western, Central, Brong/Ahafo and neighbouring countries such as La Cote d'Ivoire, Burkina Faso, and Togo due to its strategic location in the middle belt of Ghana. The nurses' strength is 796 which are made up of all categories of nurses (Anon, 2009).

3.1.2 Departments

The hospital has 12 directorates and 15 units. The Directorates Include, Accident and Emergency, Anaesthesia and Intensive Care, Child Health, Dental, Ear, Eye, Nose and Throat (DEENT), Diagnostics, Domestic, Medicine, Obstetrics and Gynaecology, Oncology, Polyclinic, Pharmacy and Surgery. The Units Include Chaplaincy, General Administration,

Health Insurance, Human Resource, Information Technology, Internal Audit, Planning, Public Relations, Quality Assurance, Research and Development, Security, Social Welfare, Supply

Chain Management, Transfusion Medicine, and Technical Services (Anon, 2009).

This study, was conducted at Dental, Ear, Eye, Nose and Throat (DEENT), specifically at Dental unit. This place was chosen as a result of its mandate to handle all cleft lip or palate cases in northern sector of the country.

3.1.3 Top ten causes of admission

The top ten causes of admission included abortion and its complication, eclampsia/ preeclampsia, neonatal sepsis, preterm/ low birth weight, birth asphyxia, malaria, tuberculosis, cardiovascular accidents (stroke), pneumonia and neonatal jaundice (KATH Annual Report, 2012).

3.2 Study Design

This study is purely quantitative and the design that was employed was descriptive cross sectional study. A descriptive cross-sectional study is a survey in which measurement or data collections are done as a single observation like a snapshot, it is set out to describe a situation (Araoye, 2003). Descriptive cross sectional study was employed in this study because the researcher has a short time for the study and wanted to collect data on each study participant at a single point in time. The study started on 13th August 2014 and ended on 22nd October 2014.

3.3 Study Population

The study population included parents/caretakers whose children have cleft lip and or cleft palate and visited KATH for treatment at the time of the study. Also, data were extracted from folders of children with CLP

Inclusion criteria

Parents or caretakers whose children were six (6) years or less and have cleft lip, cleft palate, or cleft lip and palate. The cleft of the child included unilateral and bilateral cases and involved both repaired and unrepaired cases.

Exclusion criteria

Parents of children with cleft who do not visit KATH and those whose children were above six (6) years were excluded from the study

3.4 Sample size and sampling methods

3.4.1 Sample size

An anticipated proportion of 50% of parents/caretakers having children with CLP with 95% confidence level was used to calculate the sample size.

The formula used to calculate the sample size is:

$$N = \frac{z^2 pq}{d^2}$$

Where N = sample size

Z= reliability coefficient with 95 percent confidence level;

P=the proportion of children with CLP perceived to have social challenges;

q= the proportion of children with CLP perceived not to have social challenges;

d= the desired or required standard error allowed.

If the value of p is 0.5 and the desired standard error chosen to be 0.05 with reliability coefficient

of 95% certainty $z=1.96$ then $N = \frac{(1.96)^2 (0.5 * 0.5)}{(0.05)^2}$

$$(0.05)^2$$

Therefore $N = 384.16$

The sample size for the study was 384 but to allow room for non respondents the sample size was increased to 400.

3.4.2 Sampling methods

Purposive sampling technique was employed in selecting parents or caretakers of children with CLP. This is because of inadequate number of parents/caretakers of children with CLP.

3.5 Data collection techniques and tools

Two main data were collected; secondary data and primary data. Standardized data extraction sheet was used to collect the necessary secondary data from the children with CLP folders. This was done by researcher and two trained research assistants at KATH dental unit record office. The data collected with the extraction sheet included demographics of the study population and the various types of cleft that they had as well as the location of their cleft. In all, 272 folders were used to collect data.

The primary data were collected using quantitative structured questionnaire. This was also done at the dental unit of KATH by researcher and two trained research assistants. Every parent/caretaker who visited the cleft clinic was given information sheet of the study, those who agreed to participate were given consent form to sign or thumb print after which questionnaire was administered to them.

Data were collected on Socio demographic characteristics of the caretakers/parents, the perceived social challenges of the children and how these social challenges could be minimized.

The data were collected from 224 parents or caretakers of children with CLP.

3.6 Data analysis

Data collected from both patients' folders and parents/caretakers were entered into Microsoft Access 2007 database and transported to Stata version 12.0. The data were presented using statistical tools such as frequencies and charts. The statistical significance for all testing was set as 0.05.

Describing the background of parents/caretakers of children with CLP

Descriptive statistics of demographic variables such as age of caretaker or parent, relationship between caretaker and the child, marital status of caretaker/parent, educational level of mother and father of the child, religion of caretaker as well as occupation of mother and father were reported.

Describing background of the children with CLP

Descriptive statistics of demographic variables such as age, sex, and the region where they were referred from were reported.

Proportion of children with cleft lip and or palate

Descriptive statistics was used to determine the proportion of children with CLP in 2013 and 2014. The variables used included age of child, sex of child and region where child was referred from. In addition type of cleft, cleft repaired or not, want cleft to be repaired or not, whether child would give birth to cleft lip and or cleft palate child in future or not were also reported.

Social challenges of children with CLP as perceived by their parents/caretakers in terms of education, employment and marriage.

Descriptive statistics was used to assess the social challenges of children with CLP as perceived by their parents or caretakers. The variables used included education, employment and marriage.

Suggestions to overcome or minimized perceived social challenges

Descriptive statistics was used to determine suggestions to overcome or minimize perceived social challenges. The variables used included; assistants caretakers expect from health workers, from civil society and from the government and caretakers suggestion to minimize perceived challenges.

Relationship between perceived social challenges and socio- demographic characteristics of caretakers

A chi- square test was used to establish any relationship between socio-demographic characteristics of parents/caretakers and perceived social challenges. The variables considered included the socio demographic characteristics of caretakers such as relationship between caretaker to child, age group of caretaker, marital status of caretaker and education level of caretaker. In addition religion

of caretaker and occupation of caretaker were also considered and perceived social challenges in terms of education, employment and marriage.

3.7 Ethical Consideration

Prior to the conduct of the study, the study was registered at the Research and Development Unit of KATH and subsequently sought ethical approval from Committee on Human Research, Publication and Ethics of KNUST. Permission was also sought from the management team of the dental unit of KATH. A written information sheet and informed consent of all participants was administered before they were interviewed. Participation in the study was purely voluntary.

During the interview confidentiality and anonymity of participants were ensured

3.8 Pretesting

Prior to the data collection, the questionnaire was pretested on one patient at Pima Clinic, a private clinic in Buokurum, a suburb of Kumasi to ensure the validity and reliability of the information that were going to be generated from the study. The pretesting was done on only one patient because it is uncommon to find cleft patients in other hospitals apart from KATH.

3.9 Limitation

1. The sample size was statistically calculated as 400. However, only 224 caretakers or parents of children with CLP were available at the time of the study.
2. Since KATH is a referral centre, some of the patients came from the other nine regions of Ghana which might influenced the proportion of CLP in KATH.
3. The study documented the social challenges as perceived by caretakers/parents of children with CLP. These challenges might not be the perception of the children with CLP

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter is organized based on the background of the respondents, social challenges of children with cleft as perceived by parents or caretakers, suggestions by caretakers to eradicate or minimize perceived social challenges on people with cleft lip and or palate and the relationship between the perceived social challenges and socio demographic characteristics of the caretakers .The responses are presented in tables and graphs.

4.2 Background of the study participants

This session presents background characteristics of parents/caretakers of children with CLP as well as background characteristics of children with CLP

4.2.1 Background of caretakers or parents

Table 4.1 below shows details of the background characteristics of the parents or caretakers and covers their age, marital status, educational level, occupation and religion. Out of two hundred and twenty-four (224) respondents interviewed, majority of them (79.5%) were biological mothers of the children with cleft lip and or palate. Biological fathers formed 11.6% and other relation put together were 8.9%. Most of the parents or caretakers (49.1%) were below 30 years followed by those aged from 30 – 39 years(40.2%).Majority of the caretakers interviewed were married (72.7%) whilst a few of them (2.2%) were divorced. Majority of the mothers (82.6%) with cleft children had attained some level of education and 17.4% of them had never been formally educated. Over fifty two percent had attended middle school (primary and junior high),

9.8% secondary school and 20.6% tertiary education. Similarly, greater percent of fathers (87.1%) with cleft children had attained some level of education whilst 12.9% had never been educated formally. Over thirty two percent of them (32.1%) had attended middle school, 31.3% secondary school and 23.7% tertiary education. Out of the 224 caretakers or parents, 69.6% of them were Christians and 23.2% of them were Muslims. The occupation of mothers included traders (40.6%), civil/public servants (18.8%), farmers (14.7%) and artisanship (12.5%). Also the occupation of fathers with cleft children included farmers (27.7%), artisanship (18.7%), civil/public servants (18.3%), traders (11.2%) and other occupation (20.1%). Four percent (4.0%) of fathers and 13.4% of mothers with cleft children were unemployed.

4.2.2 Background of children with cleft lip and or palate

Table 4.1 presents the age distribution of the cleft lip and or palate children. Out of the 224 caretakers with CLP children, 38.0% of the children were aged from 1 month to 6 months (4 –26 weeks) and 31.2% of them were more than 1 year but less than 6 years (more than 52 weeks), 25.9% were 7 months to 1 year. A few of the children (4.9%) with cleft were aged less than one month (less than 4 weeks). From Figure 4.1, female formed 55.9% of the cleft children whilst the male children were 44.1%. The regions where these children were referred from included Ashanti region (46.7%), Upper East region (10.3%), Brong Ahafo region (8.5%), Greater Accra (1.1%), Central region (6.6%), Eastern region (8.1%), Western region (8.5%), Volta region (2.9%), Northern region (5.9%) and Upper West region (1.5%).

Table 4.1: Background characteristics of parents or caretakers of cleft children

Variable	Frequency (N=224)	Percentage %
Relationship between caretaker and child		
Mother	178	79.5
Father	26	11.6
Other	20	8.9
Age group of caretakers (in years)		
<30	110	49.1
30-39	90	40.2
40-49	19	8.5
≥50	5	2.2
Age group of CLP children <4 weeks		
11	4.9	
4-26 weeks	85	38.0
27-52 weeks	58	25.9
>52 weeks	70	31.2
Marital status of caretaker		
Married	162	72.7
Divorced	5	2.2
Single, living with partner	16	7.2
Single	40	17.9
Education level of mother		
Middle school	117	52.2
Secondary	22	9.8
Tertiary	46	20.6
None	39	17.4
Education level of Father		
Middle school	72	32.1
Secondary	70	31.3
Tertiary	53	23.7
None	29	12.9
Religion of caretaker		
Christian	156	69.6
Muslim	52	23.2
Traditional	6	2.7
None	10	4.5

Source: Author's field data 2014

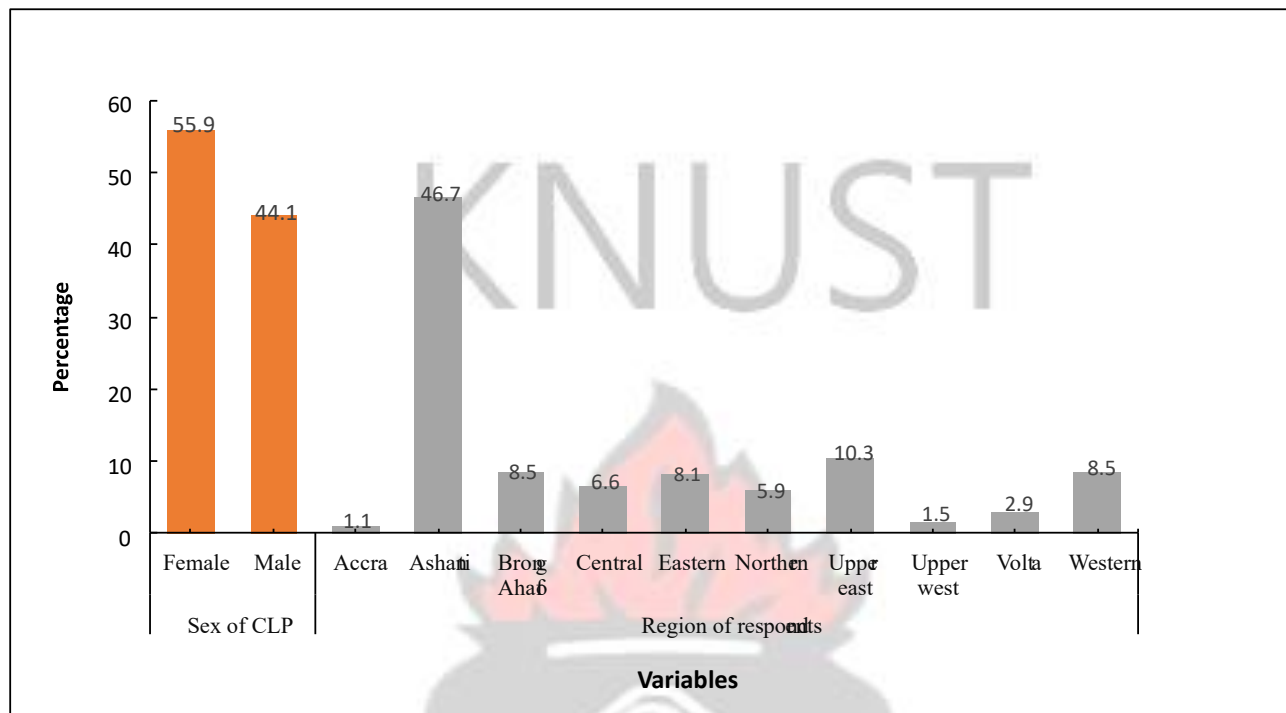


Figure 4.1: Background of cleft Lip and or Palate children

Source: Author's field data 2014

4.3 Proportion of Children with Cleft Lip and or Palate

The proportion of children with CLP was determined for the year 2013 and 2014. Table 4.2 presents the proportion of children with cleft at Komfo Anokye Teaching Hospital in 2014 and figure 4.2 presents proportion of children with CLP in 2013.

The most occurring type of cleft for 2014 was children with cleft Lip (46.9%), followed by children with both cleft Lip and Palate (37.9%) and children with cleft Palate (15.2%). From these categories of cleft types, 29.9% (67) of these cleft children were fully repaired whilst 70.1% (157) were not. Among the 70.1% cleft children not fully repaired, 14.7% (33) of the children were partially repaired and 55.4% (124) were not repaired at all. However, all the caretakers or parents of children whose cleft were not fully repaired would want their children to be fully repaired.

Majority of the caretakers (83.5%) perceived that children with cleft condition would not give birth to children with CLP, 7.6% perceived children with cleft condition have the possibility of giving birth to children with same cleft condition in future whilst 8.9% were not on either side. As shown in figure 4.2, the most occurring type of cleft was cleft lip (43.8%), followed by cleft lip and palate (29.4%) and cleft palate (26.8%). From these categories over ninety percent (90.1%) of the cleft children were fully repaired, 7.7% not repaired at all, and 2.2% partially repaired. Classifying the location of cleft, 48.2% were bilateral, 23.2% were located on the left, 14.7% located on the right, and 14.0% had no specific location. All the cleft children (100%) had no siblings with cleft condition. Also, 99.6% of the parents of these cleft children had no cleft condition whilst 0.4% of the parents had cleft condition as seen in figure 4.2.

Table 4.2: Proportion of Children with Cleft

Variable	Frequency N=224	Percentage %
Type of cleft Lip		
Palate	105	46.9
Lip and Palate	34	15.2
Cleft been repaired	85	37.9
Yes	67	29.9
No	124	55.4
Partially	33	14.7
Want cleft repaired if not repaired		
Yes	157	100.0
No	0	0.0
Child give birth to cleft lip and or palate in future		
Yes	17	7.6
No	187	83.5
Don't know	20	8.9

Source: Author's field data (2014)

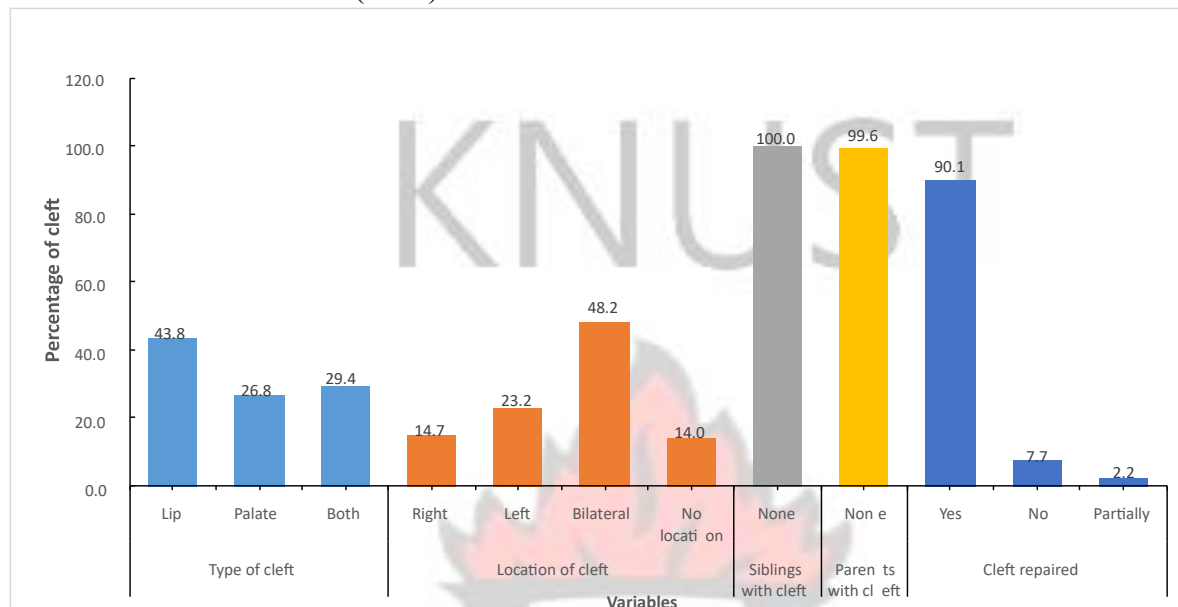


Figure 4.2: Proportion of Cleft children

Source: Author's field data 2014

4.4 Perceived social Challenges faced by children with CLP

The social challenges faced by children with CLP as perceived by their caretakers or parents were assessed in terms of education, employment and marriage.

4.4.1 Education

Table 4.3 presents education as a social challenge faced by children with CLP as perceived by their parents or caretakers. Out of the 224 children with cleft, 10.7% of them were already in school, 42.0% of them were not in school and the rest (47.3%) were not of school going age. However, the difference was not statistically significant ($\chi^2=4.96$; $p\text{-value}=0.27$). Among children who were not already in school, 97.0% of parents/caretakers intended to take their wards to school whilst (1.5%) were not willing to do so and the rest (1.5%) had no idea on what they would do. Majority of them (93.3%) perceived that their children with cleft would be accepted in school whilst 6.7%

perceived that their children would not be accepted in school. The difference in perception on educational acceptance for children with CLP was statistically significant ($\chi^2=16.2$; p -value=0.00). The reasons provided by caretakers or parents to justify why their children with CLP would be accepted in school are detailed in table 4.3 as; normal human beings (45.0%), live normal life after repair (22.0%), Ghana FCUBE policy (13.4%), brain not affected (11.0%), and early education promotes community acceptance (8.6%).

However, the difference in reasons offered were not statistically significant ($\chi^2=7.71$; $p=0.46$). The reasons provided by caretakers or parents to justify why children with cleft would not be accepted in school are indicated in figure 4.3. These were; cleft not repaired (50.0%), children feeling ashamed (25.0%) and perception that cleft is a bad condition (25.0%). Majority of the parents/caretakers (78.1%) perceived their wards to study up to tertiary level whilst 1.8% perceived their wards to attain only basic education. Under the challenge of harassing cleft children in schools, 19.2% perceived their children to be harassed in school, 65.6% disagreed and 15.2% were indifferent. However, there was no statistical difference in terms of whether child would be harassed or not ($\chi^2=4.01$; $p=0.41$)

Table 4.3: Perceived social challenges on education

Variables Category	Type of cleft n (%)			Total	Percentage%	F-test (p-value)
	Both	Lip	Palate			
Child go to school						4.96 (0.27)
Yes	8 (9.4)	11 (10.5)	5 (14.7)	24	10.7	
No	42 (49.4)	37 (35.2)	15 (44.1)	94	42.0	
N/A	35 (41.2)	57 (54.3)	14 (41.2)	106	47.3	
Intend taking the child to school						4.60 (0.33)
Yes	75 (97.4)	90 (95.7)	29 (100.0)	194	97.0	
No	2 (2.6)	1 (1.1)	0 (0.0)	3	1.5	
N/A	0 (0.0)	3 (3.2)	0 (0.0)	3	1.5	
Child accepted in school						16.12 (0.00)
Yes	76 (89.4)	105 (100.0)	28 (82.4)	209	93.3	
No	9 (10.7)	0 (0.0)	6 (17.6)	15	6.7	
Reasons why child will be accepted						7.71 (0.46)
Brain not affected	4 (5.3)	15 (14.3)	4 (14.3)	23	11.0	
Early education	7 (9.2)	8 (7.6)	3 (10.7)	18	8.6	
Ghana policy	11 (14.5)	11 (10.5)	6 (21.4)	28	13.4	
Normal humans	34 (44.7)	50 (47.6)	10 (35.7)	94	45.0	

Normal life after repair	20 (26.3)	21 (20.0)	5 (17.9)	46	22.0
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Source: Author's field data (2014)

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Table 4.3: Perceived social challenges on education cont.

Variables Category	Type of cleft n (%)			Total	Percentage%	F-test (p-value)
	Both	Lip	Palate			
Perceived level of education CLP child can attain						7.51 (0.28)
JHS	0 (0.0)	4 (3.8)	0 (0.0)	4	1.8	
SHS	11 (12.9)	12 (11.4)	6 (17.6)	29	13.0	
Tertiary	70 (82.4)	81 (77.1)	24 (70.6)	175	78.1	
None	4 (4.7)	8 (7.6)	4 (11.8)	16	7.1	
Child will be harassed at school						4.01 (0.41)
Yes	22 (25.9)	16 (15.2)	5 (14.7)	43	19.2	
No	51 (60.0)	72 (68.6)	24 (70.6)	147	65.6	
Don't know	12 (14.1)	17 (16.2)	5 (14.7)	34	15.2	

Source: Author's field data (2014)

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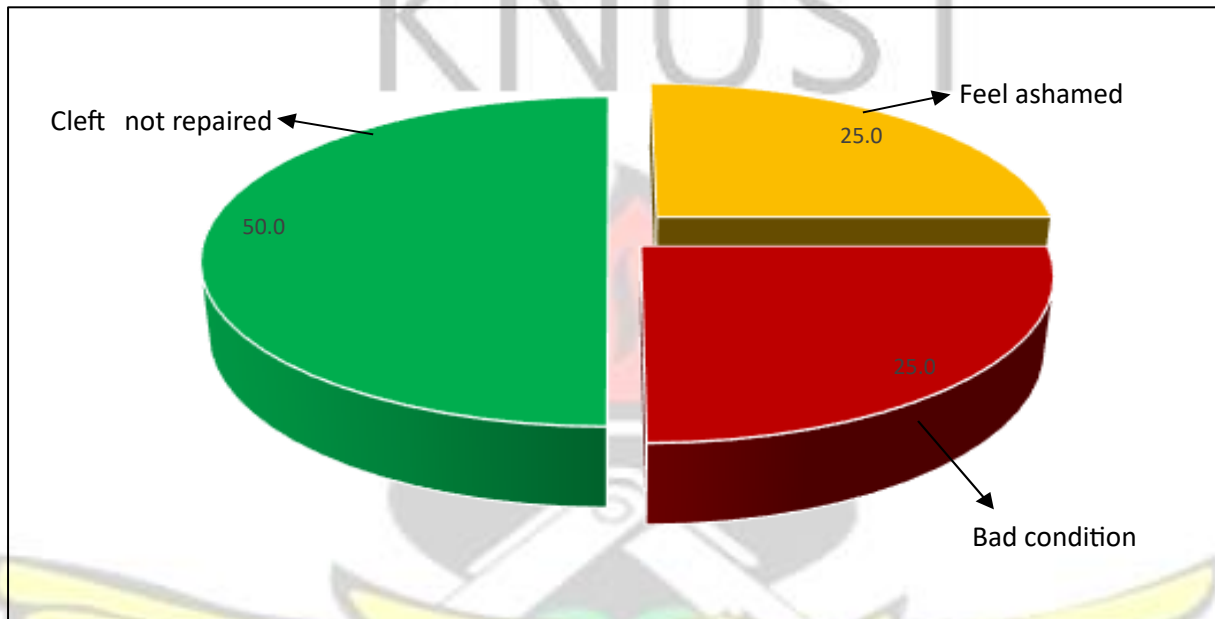


Figure 4.3: Caretakers perception on cleft children not accepted in school

Source: Author's field data (2014)

4.4.2 Employment

Table 4.4 below presents perception of parents or caretakers as far as future employment of children with CLP is concerned. Out of 224 caretakers or parents, 95.1% (213) perceived their children with CLP would be employed in future whilst 1.3% (3) perceived their children would not be employed. However, the difference in perception on future employment opportunities was not statistically significant ($\chi^2=5.51$; $p\text{-value}=0.24$). In response to cleft condition influencing future jobs prospect,

35 of the caretakers (15.6%) perceived cleft can affect future job prospect, 150 of them (67.0%) rejected this perception, and 39 of them (17.4%) were indifferent. The difference in perception on cleft affecting future job prospect was statistically significant ($\chi^2=13.77$, $p\text{-value}=0.01$). Under the kind of job opportunities, 86.9% perceived cleft children would qualify to work in formal jobs (white colour jobs), 3.2% perceived they would qualify for

informal jobs (manual works) and 9.9% perceived they would qualify for other kinds of jobs. The specific future job opportunities as perceived by caretakers or parents of the children with CLP included; doctors (35.3%), nurses (26.3%), teachers (10.3%), lawyers (9.4%), bankers (4.9%) and other occupations (4.5%). Outlining quality of life from perspective of caretakers or parents, majority (73.7%) perceived cleft condition would not affect quality of life whilst 12.9% opposed to this perception claiming cleft condition can affect the quality of life of CLP children.

The difference in perception on cleft affecting quality of life is not statistically significant ($\chi^2=8.3$, $p\text{-value}$ 0.08). The reasons provided by caretakers or parents to justify the above are detailed in figure 4.4. In response to a question of caretakers or parents employing children with unrepaired CLP or with repaired CLP if they had the opportunity to do so, 63.8% of them agreed to employ unrepaired cleft children, 36.2% of them disagreed to employ unrepaired cleft children, 96.0% of them agreed to employ children with repaired cleft and 4.0% disagreed to employ children with

repaired cleft. The difference in terms of employing children with repaired or unrepaired cleft was statistically significant ($\chi^2=5.19$, $p\text{-value}=0.00$; $\chi^2=6.73$, $p\text{-value}=0.03$).

Caretakers or parents perception on ability of children with CLP either repaired or unrepaired to perform and behave like other children without CLP is depicted in figure 4.5. Caretakers or parents perceived over sixty percent (61.9%) of unrepaired cleft children to perform normal, 38.1% of unrepaired children to perform abnormal, 97.8% of repaired children to perform normal and 3.2% of repaired children to perform abnormal.

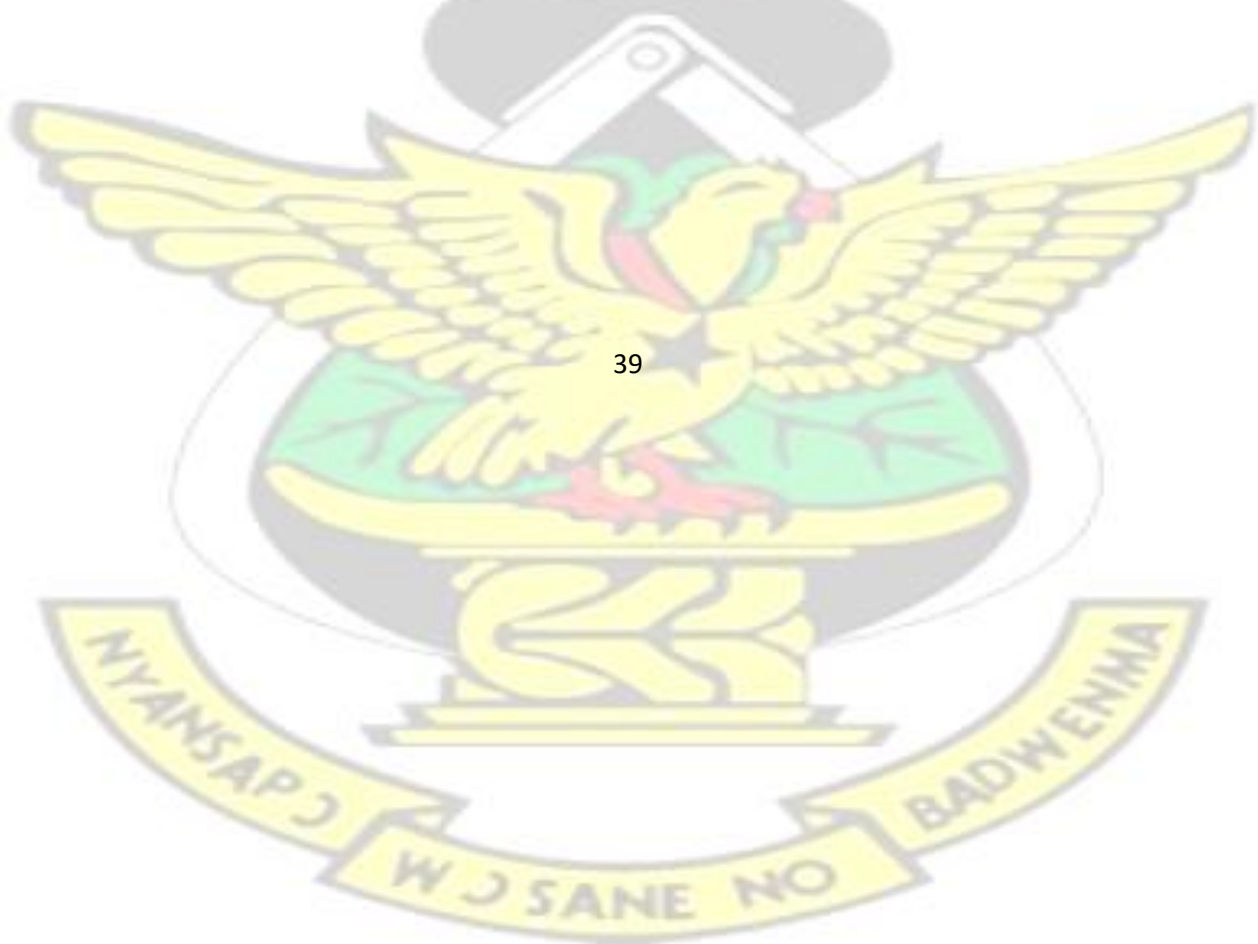


Table 4.4: Perceived social challenges on employment

Variables Category	Cleft Repaired n (%)			Total	Percentage %	F-test(p-value)
	Yes	No	Partially			
Ward can be employed in future						5.51 (0.24)
Yes	63 (94.0)	120 (96.8)	30 (90.9)	213	95.1	
No	2 (3.0)	1 (0.8)	0 (0.0)	3	1.3	
Don't know	2 (3.0)	3 (2.4)	3 (9.1)	8	3.6	
Condition influence future job prospect						13.77 (0.01)
Yes	2 (3.0)	27 (21.8)	6 (18.2)	35	15.6	
No	55 (82.1)	75 (60.5)	20 (60.6)	150	67.0	
Don't know	10 (14.9)	22 (17.7)	7 (21.2)	39	17.4	
Kind of work						2.92 (0.57)
White colour job	58 (87.9)	105 (85.4)	30 (90.9)	193	86.9	
Manual work	1 (1.5)	6 (4.9)	0 (0.0)	7	3.2	
Other work	7 (10.6)	12 (9.8)	3 (9.1)	22	9.9	
Perceived specific job in future						16.11 (0.19)
Lawyer	9 (13.4)	9 (7.3)	3 (9.1)	21	9.4	
Doctor	28 (41.8)	41 (33.1)	10 (30.3)	79	35.3	
Nurse	16 (23.9)	33 (26.6)	10 (30.3)	59	26.3	

Teacher	0 (0.0)	19 (15.3)	4 (12.1)	23	10.3
Banker	5 (7.5)	5 (4.0)	1 (3.0)	11	4.9
Other	4 (6.0)	4 (3.2)	2 (6.1)	10	4.5
Don't know	5 (7.5)	13 (10.5)	3 (9.1)	21	9.4

Source: Author's field data 2014

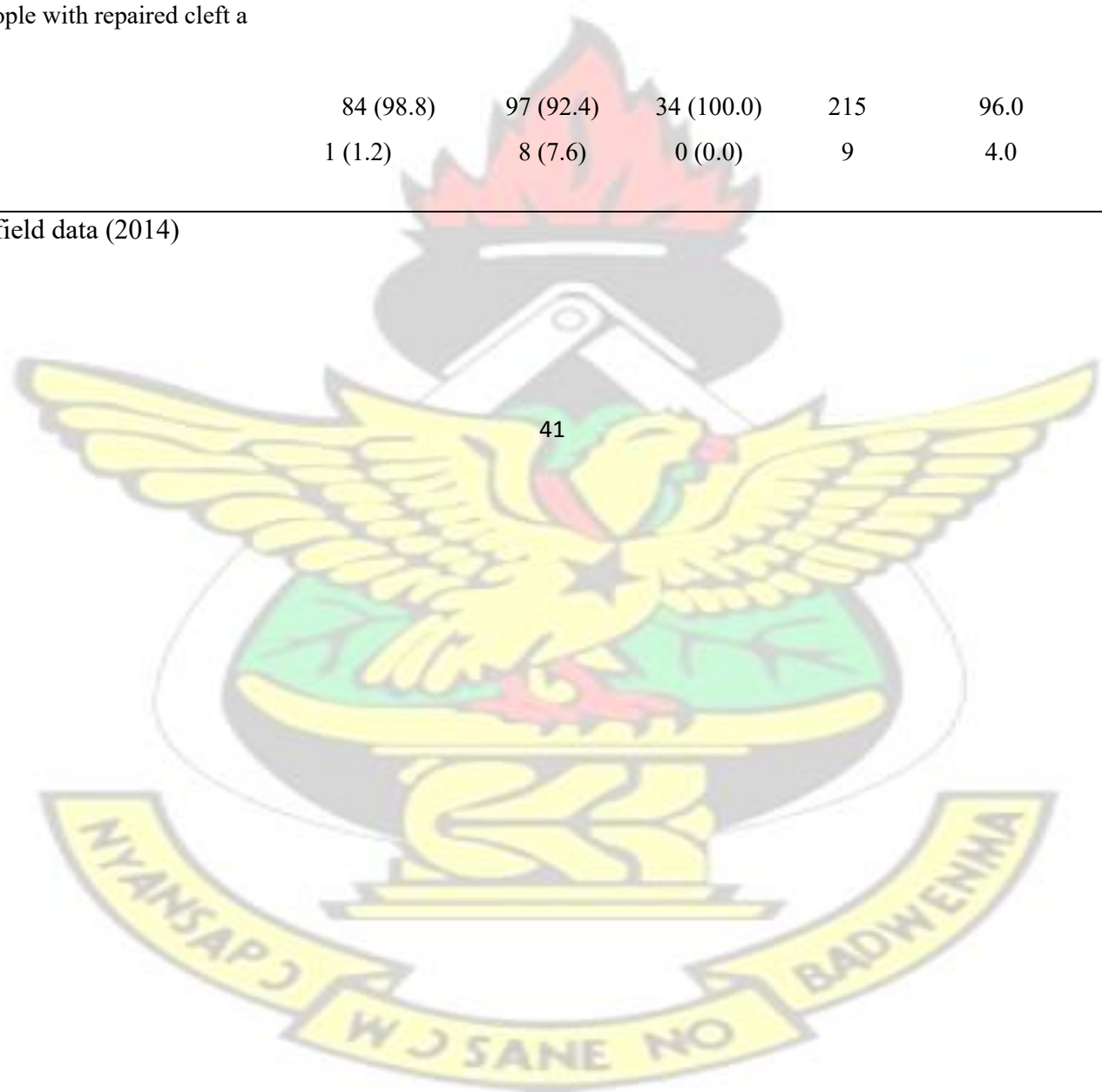
40

Table 4.4: Perceived social challenges on employment cont.

Variables	Cleft Repaired n (%)			Total	Percentage %	F-test(p-value)
Category	Yes	No	Partially			
Condition affect quality of life						8.30 (0.08)
Yes	3 (4.5)	23 (18.5)	23 (9.1)	29	12.9	
No	55 (82.1)	85 (68.1)	25 (75.8)	165	73.7	
Don't know	9 (13.4)	16 (12.9)	5 (15.1)	30	13.4	
Assumptions on Employment	Type of Cleft n (%)					
	Both	Lip	Palate			
Caretaker employ people with unrepaired cleft in a company/firm						5.19 (0.00)

Yes	59 (69.4)	59 (56.2)	25 (73.5)	143	63.8
No	26 (30.6)	46 (43.8)	9 (26.5)	81	36.2
Caretaker employ people with repaired cleft a company/firm					6.73 (0.03)
Yes	84 (98.8)	97 (92.4)	34 (100.0)	215	96.0
No	1 (1.2)	8 (7.6)	0 (0.0)	9	4.0

Source: Author’s field data (2014)



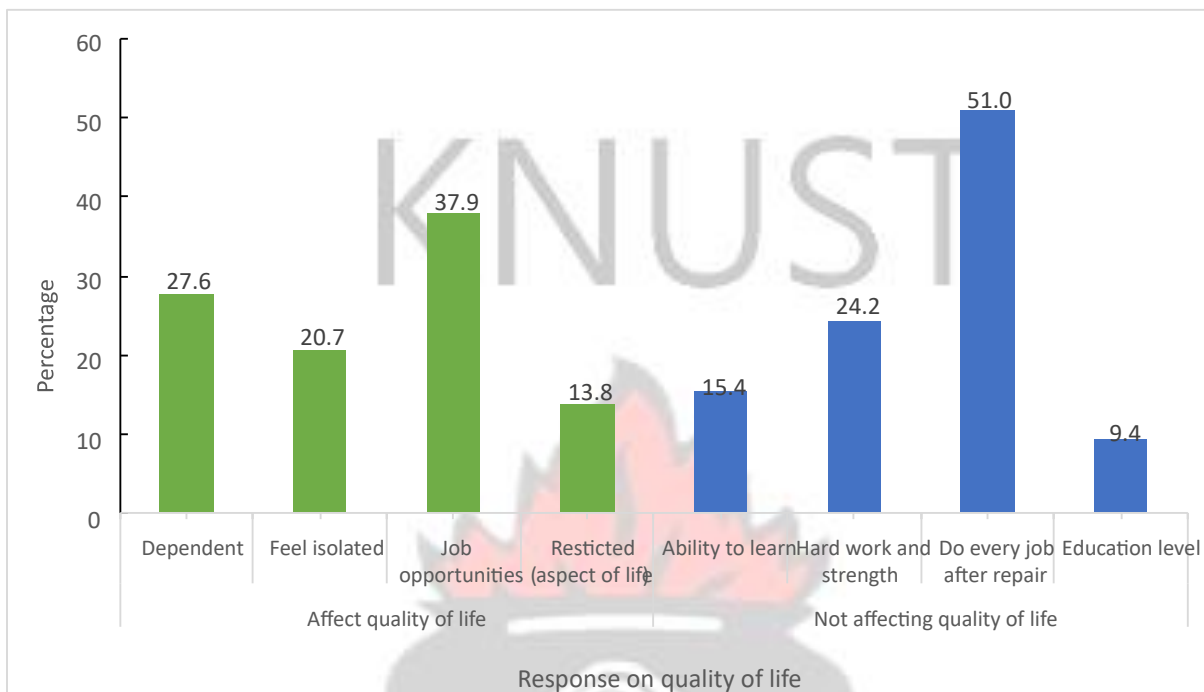


Figure 4.4: distribution on perceived effect of cleft on quality of life

Source: Author's field data (2014)

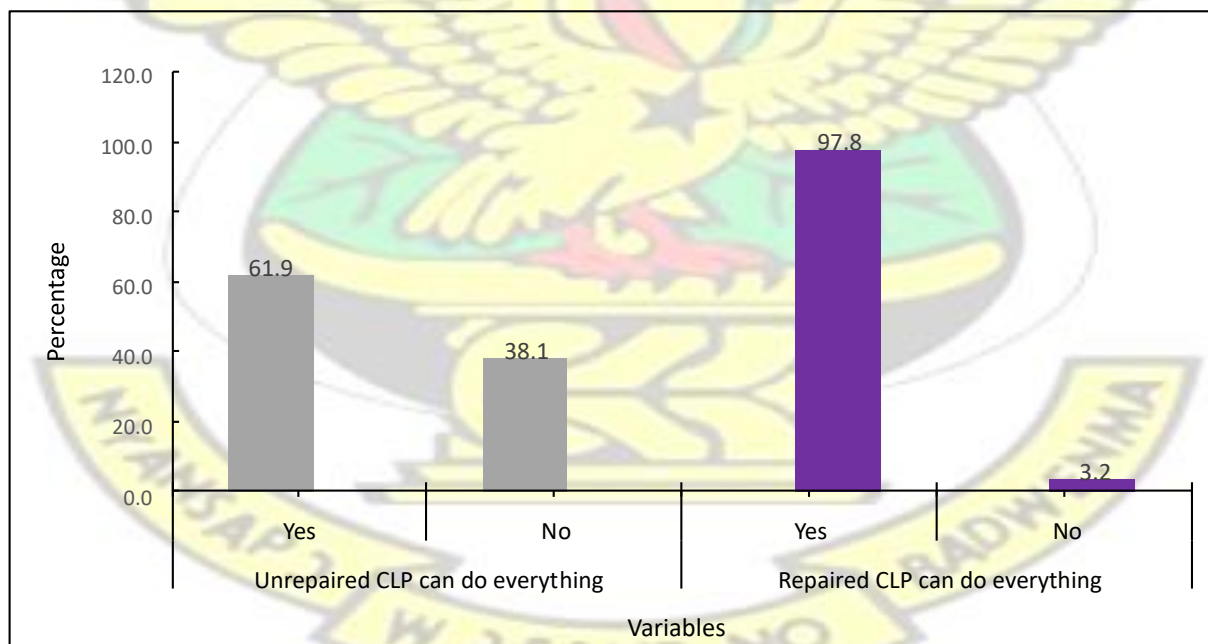


Figure 4.5: Perception on CLP children ability to perform like non CLP children

Source: Author's field data (2014)

4.4.3 Marriage

Table 4.5 below presents perception of parents or caretakers as far as future marriage of children with CLP is concerned. Out of 224 caretakers or parents interviewed, 96.0% (215) perceived that their children would have the chance of being in intimate relationship in future whilst 3.6% (8) were indifferent. However, the difference in perception on future intimate relationship opportunities of children with CLP was not statistically significant ($\chi^2=1.46$; $p\text{-value}=0.48$). With respect to the responses on getting married, 96.0% of them perceived CLP children have the possibility of getting married, 0.4% of them perceived CLP children have no chance of getting married in future, and 3.6% of caretakers or parents were indifferent. The difference in perception on future marriage opportunities of CLP children was not statistically significant ($\chi^2=2.28$; $p\text{-value}=0.69$). In response to a question of caretakers or parents getting married to a person with unrepaired CLP or with repaired CLP, 56.2% agreed to marry a person with unrepaired CLP, 43.8% disagreed to marry a person with unrepaired CLP, 91.5% agreed to marry someone with repaired cleft, and 8.5% disagreed to marry someone with repaired cleft. The difference in terms of caretakers or parents getting married to someone with repaired or unrepaired cleft was statistically significant ($\chi^2=6.04$; $p\text{-value}=0.00$; $\chi^2=11.11$; $p\text{-value}=0.00$).

Table 4.5: Perceived social challenges on marriage

Variables	Cleft Repaired n (%)			Total	Percentage %	F-test (p-value)
Category	Yes	No	Partially			
Child can be in intimate relationship						1.46 (0.48)
Yes	64 (95.5)	118 (95.2)	33 (100.0)	215	96.0	
No	0 (0.0)	1 (0.8)	0 (0.0)	1	0.4	
Don't know	3 (4.5)	5 (4.0)	0 (0.0)	8	3.6	
Child can get married						2.28 (0.69)
Yes	64 (95.5)	118 (95.2)	33 (100.0)	215	96.0	
No	0 (0.0)	1 (0.8)	0 (0.0)	1	0.4	
Don't know	3 (4.5)	5 (4.0)	0 (0.0)	8	3.6	
Assumptions on marriage	Type of Cleft n (%)					
	Both	Lip	Palate			
Caretakers marry someone with unrepaired cleft						11.11 (0.00)
Yes	56 (65.9)	52 (49.5)	18 (52.9)	126	56.2	
No	29 (34.1)	53 (50.5)	16 (47.1)	98	43.8	
Caretaker marry someone with repaired cleft						6.04 (0.00)
Yes	77 (90.6)	97 (92.4)	31 (91.2)	205	91.5	
No	8 (9.4)	8 (7.6)	3 (8.8)	19	8.5	

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Source: Author's field data (2014)

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4.5 Overcoming perceived social challenges base on parents or caretakers perspective

Table 4.6 below presents parents/caretakers perception on how perceived social challenges against children with CLP could be minimized or eradicated. Out of the 224 caretakers/parents, education of the public on cleft condition (68.3%) was the leading suggestion to eradicate or minimize perceived social challenges against children with CLP. Other suggestions included; public acceptance (15.2%), financial support for treatment (11.6%) and early repair as treatment (4.9%). Also, caretakers/parents suggested support from the health workers, society and government to minimize or eradicate social challenges against children with CLP. On the part of the health workers, majority of the caretakers/parents (51.3%) suggested complete treatment support from health workers, 27.2% suggested assistance from health workers for feeding children with cleft condition and 8.5% suggested health workers educating parents with cleft children. On support from the society, over forty-six percent (46.9%) suggested societal acceptance of children with CLP, 25%, suggested societal love and encouragement for children with CLP and 21% suggested financial support for treatment. The support suggested by caretakers/parents from the government included; free treatment (54.0%), creating more cleft clinics (15.6%) and general education for Ghanaians on cleft (14.7%).

Table 4.6: Suggestions to overcome perceived social challenges against children with CLP

Suggestions and assistance	Frequency N=224	Percentage %
Category		
Suggestions to minimize perceived social challenges on cleft		
Acceptance from public	34	15.2

Financial support from public	26	11.6
Early repair treatment	11	4.9
Public education on cleft	153	68.3
Assistance from health workers		
Educate parents with cleft children	19	8.5
Educate society	15	6.7
Gentle to patients	14	6.3
Help in feeding	61	27.2
Support to complete treatment	115	51.3
Assistance from society		
Accept condition	105	46.9
Assist in education	16	7.1
Financial support for treatment	47	21.0
Love and encouragement	56	25.0
Assistance from government		
Assist with artificial feed	6	2.7
Create more cleft clinics	35	15.6
Education on cleft	33	14.7
Provide medical care for cleft	29	13.0
Support in cost of treatment	121	54.0

Source: Author's field data (2014)

4.6 Relationship between Perceived social challenges and socio-demographic characteristics

4.6.1 Perceived educational challenges and socio-demographic characteristics

From table 4.7 below, among 209 (93.3%) caretakers who perceived CLP children to be accepted in school, 166 (79.4%) were biological mother, 24 (11.5%) were biological fathers, and 19 (9.1%) were other relationship. The difference in perception on accepting CLP children in school across the various relations of caretakers was statistically not significant ($\chi^2=0.13$; $p=0.93$). Similarly, the difference in perception on accepting CLP children in school across age group, marital status, and religion of caretakers or parents were statistically not significant ($\chi^2=0.82$, $p=0.66$; $\chi^2=4.13$, $p=0.25$; $\chi^2=1.47$, $p=0.69$) respectively. However, the difference in perception on accepting CLP children in school across educational level of caretakers was statistically significant ($\chi^2=9.49$; $p=0.04$). Also the difference in perception of accepting CLP children in school across occupations of caretakers or parents was statistically significant ($\chi^2=20.05$; $p=0.00$).

Table 4.7: Relationship between education as perceived challenge and socio-demographic characteristics

Variables Category	Distance in school n (%)		Total	Percentage %	F-test(p-value)
	Yes	No			
Relationship to child					0.13 (0.93)
Mother	166 (79.4)	12 (80.0)	178	79.5	
Father	24 (11.5)	2 (13.3)	26	11.6	
Other	19 (9.1)	1 (6.7)	20	8.9	
Age group					0.82 (0.66)
<30	101 (48.3)	9 (60.0)	110	49.1	
30-39	85 (40.7)	5 (33.3)	90	40.2	
≥40	23 (11.0)	1 (6.7)	24	10.7	
Marital status					4.13 (0.25)
Married	149 (71.6)	13 (86.6)	162	72.7	
Divorced	4 (1.9)	1 (6.7)	5	2.2	
Single, living with partner	16 (7.7)	0 (0.0)	16	7.2	
Single	39 (18.8)	1 (6.7)	40	17.9	
Education level of caretaker					9.49 (0.04)
Middle school	108 (51.7)	9 (60.0)	117	52.2	
Secondary	25 (12.0)	0 (0.0)	25	11.2	
Tertiary	41 (19.6)	5 (33.3)	46	20.5	

None 35 (16.7) 1 (6.7) 36 16.1

Source: Author's field data (2014)

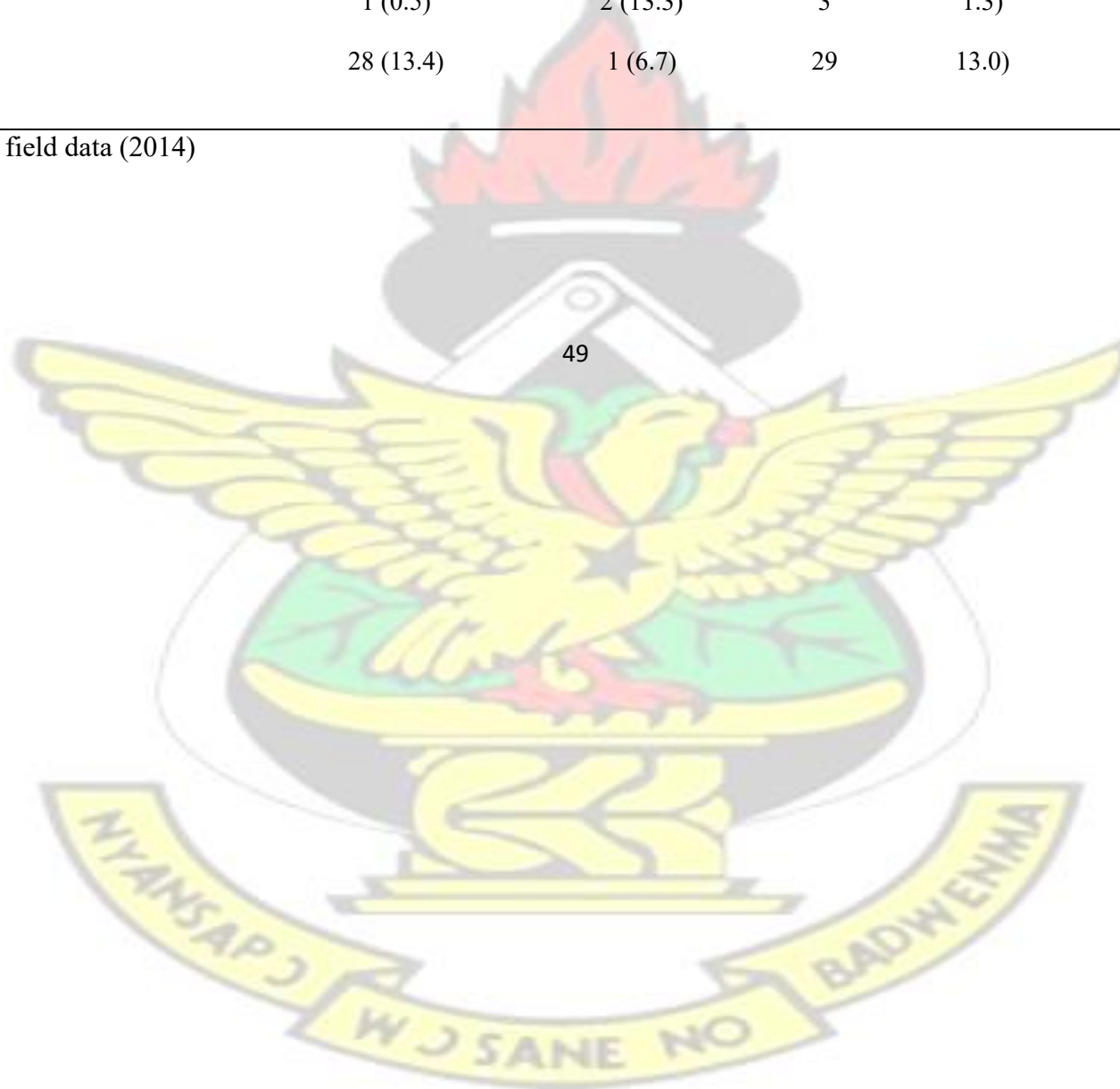
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Table4.7: Relationship between education as perceived challenge and socio-demographic characteristics cont.

Variables Category	CLP child Acceptance in school n (%)		Total	Percentage %	F-test(p-value)
	Yes	No			
Religion of caretaker or parent					1.47 (0.69)
Christian	114 (68.9)	12 (80.0)	156	69.6	
Muslim	49 (23.4)	3 (20.0)	52	23.2	
Traditional	6 (2.9)	0 (0.0)	6	2.7	
None	10 (4.8)	0 (0.0)	10	4.5	
Occupation of caretaker or parent					20.05 (0.00)
Civil servant	36 (17.2)	1 (6.7)	37	16.5	
Trader	80 (38.3)	6 (40.0)	86	38.4	

Artisans	29 (13.9)	1 (6.7)	30	13.4
Farmer	35 (16.7)	4 (26.6)	39	17.4
Other	1 (0.5)	2 (13.3)	3	1.3)
Unemployed	28 (13.4)	1 (6.7)	29	13.0)

Source: Author’s field data (2014)



4.6.2 Perceived employment challenges and socio-demographic characteristics

Table 4.8 below describes the relationship between perceived social challenges in terms of future employment opportunities for CLP children and the socio-demographic characteristics of caretakers or parents. Generally, 213 (95.1%) perceived that CLP children have an equal chance of being employed in future as non CLP children, 3 (1.3%) perceived that they may not be employed, and 8 (3.6%) were indifferent. However, the difference in perception on future employment opportunities was not statistically significant ($\chi^2=3.68$; $p\text{-value}=0.45$). Also the difference in perception on future employment as a social challenge across age group, marital status, educational level, and occupation of caretakers were not statistically significant ($\chi^2=2.34$, $p\text{-value}=0.67$; $\chi^2=2.17$, $p\text{-value}=0.90$; $\chi^2=14.01$, $p\text{-value}=0.08$; $\chi^2=12.30$, $p\text{-value}=0.42$) respectively. However, the difference in the perception of future employment opportunity of CLP children across religious background of caretakers or parents was statistically significant ($\chi^2=19.94$; $p\text{-value}=0.00$).

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Table 4.8: Relationship between employment as a perceived challenge and socio-demographic characteristics

Variables	CLP child future employment opportunity n (%)			Total	Percentage %	F-test (p-value)
Category	Yes	No	Don't know			
Relationship to child						3.68 (0.45)
Mother	168 (78.9)	2 (66.7)	8 (100.0)	178	79.5	
Father	25 (11.7)	1 (33.3)	0 (0.0)	26	11.6	
Other	20 (9.4)	0 (0.0)	0 (0.0)	20	8.9	
Age group						2.34 (0.67)
<30	105 (49.3)	2 (66.7)	3 (37.5)	110	49.1	
30-39	86 (40.4)	1 (33.3)	3 (37.5)	90	40.2	
≥40	22 (10.3)	0 (0.0)	2 (25.0)	24	10.7	
Marital status						2.17 (0.90)
Married	153 (72.2)	3 (100.0)	6 (75.0)	162	72.7	
Divorced	5 (2.4)	0 (0.0)	0 (0.0)	5	2.2	
Single, living with partner	16 (7.5)	0 (0.0)	0 (0.0)	16	7.2	
Single	38 (17.9)	0 (0.0)	2 (25.0)	40	17.9	
Education level of caretaker						14.01 (0.08)
Middle school	114 (53.5)	1 (33.3)	2 (25.0)	117	52.2	
Secondary	22 (10.3)	1 (33.3)	2 (25.0)	25	11.2	

Tertiary	46 (21.6)	0 (0.0)	0 (0.0)	46	20.5
None	31 (14.6)	1 (33.3)	4 (50.0)	36	16.1

Source: Author's field data (2014)

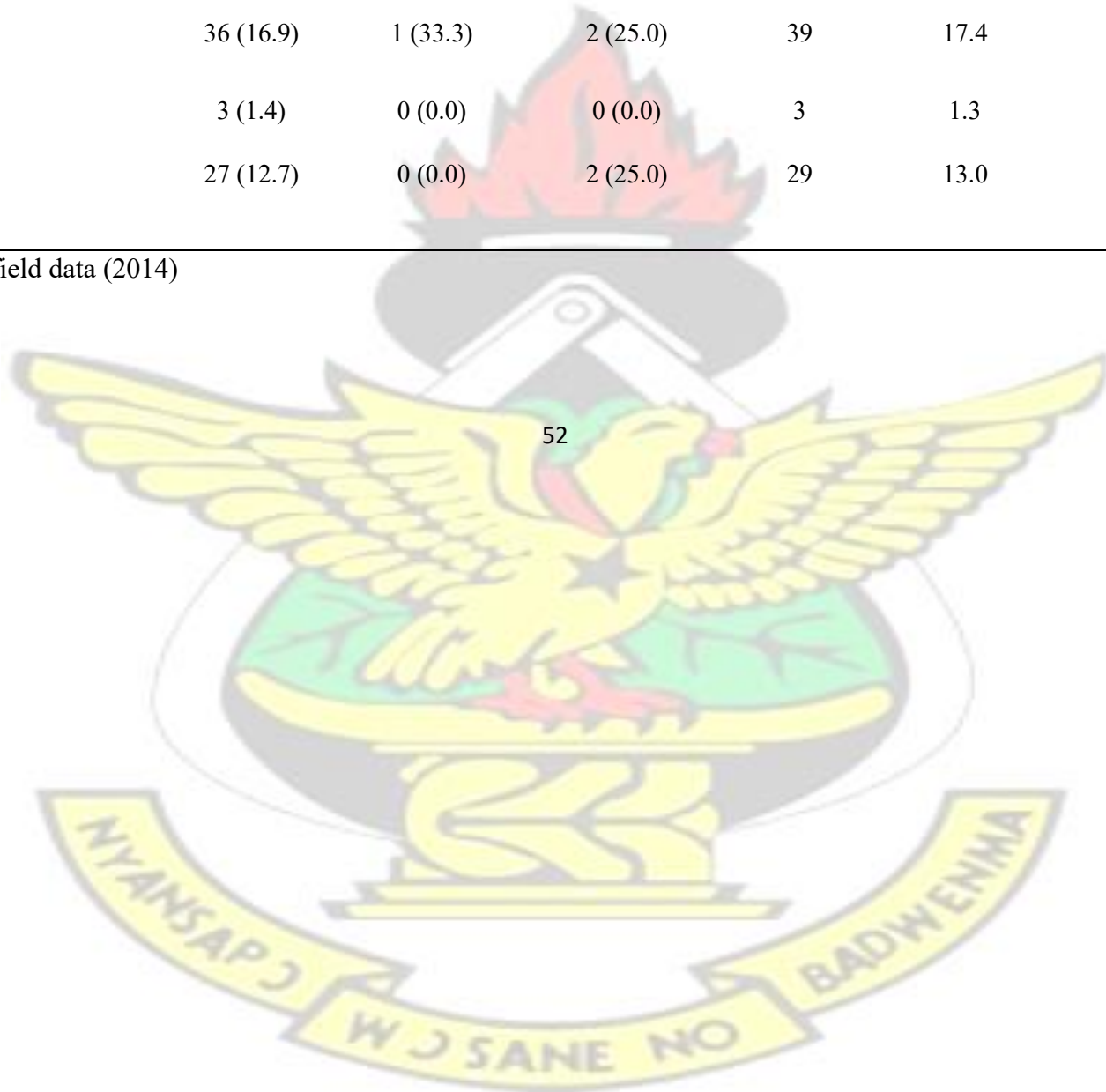
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Table4.8: Relationship between employment as perceived challenge and socio-demographic characteristics cont.

Variables Category	CLP child future employment opportunity n (%)			Total	Percentage %	F-test (p-value)
	Yes	No	Don't know			
Religion of caretaker or parent						19.94 (0.00)
Christian	150 (70.4)	2 (66.7)	4 (50.0)	156	69.6	
Muslim	50 (23.5)	0 (0.0)	2 (25.0)	52	23.2	
Traditional	5 (2.3)	1 (33.3)	0 (0.0)	6	2.7	
None	8 (3.8)	0 (0.0)	2 (25.0)	10	4.5	
Occupation of caretaker or parent						12.30 (0.42)
Civil servant	37 (17.4)	0 (0.0)	0 (0.0)	37	16.5	

Trader	81 (38.0)	2 (66.7)	3 (37.5)	86	38.4
Artisans	29 (13.6)	0 (0.0)	1 (12.5)	30	13.4
Farmer	36 (16.9)	1 (33.3)	2 (25.0)	39	17.4
Other	3 (1.4)	0 (0.0)	0 (0.0)	3	1.3
Unemployed	27 (12.7)	0 (0.0)	2 (25.0)	29	13.0

Source: Author’s field data (2014)



4.6.3 Perceived marriage challenges and socio-demographic characteristics

Table 4.9 presents the relationship between marriage as a perceived social challenge and caretakers socio-demographic characteristics. Generally, 215 (96.0%) perceived CLP children would have an equal chance of getting married in future, 1 (0.4%) perceived they would not be married in future and 8 (3.6%) perceived indifferently. The difference in perception was statistically significant ($\chi^2=10.99$; p -value=0.03). Similarly, the difference in the perception on CLP children future marriage prospect across marital status of caretakers was statistically significant ($\chi^2=17.86$; p -value=0.01). Also the difference in the perception on CLP children future marriage prospect across occupation of caretakers was statistically significant ($\chi^2=30.37$, p -value 0.00). However, the difference in perception on cleft children getting married across age group of caretakers, educational level of caretakers and religion of caretakers were statistically not significant ($\chi^2=3.97$; p -value=0.41, $\chi^2=11.09$; p -value=0.20, $\chi^2=4.96$; p -value=0.55) respectively.

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Table 4.9: Relationship between marriage as perceived challenge and socio-demographic characteristics

Variables	CLP child future marriage opportunity n (%)			Total	Percentage %	F-test (p-value)
Category	Yes	No	Don't know			
Relationship to child						10.99 (0.03)
Mother	171 (79.5)	0 (0.0)	7 (87.5)	178	79.5	
Father	25 (11.6)	0 (0.0)	1 (12.5)	26	11.6	
Other]	19 (8.9)	1 (100.0)	0 (0.0)	20	8.9	
Age group						3.97 (0.41)
<30	104 (48.4)	0 (0.0)	6 (75.0)	110	49.1	
30-39	87 (40.5)	1 (100.0)	2 (25.0)	90	40.2	
≥40	24 (11.1)	0 (0.0)	0 (0.0)	24	10.7	
Marital status						17.86 (0.01)
Married	158 (73.8)	0 (0.0)	4 (50.0)	160	72.7	
Divorced	5 (2.3)	0 (0.0)	0 (0.0)	5	2.2	
Single, living with partner	13 (6.1)	1 (100.0)	2 (25.0)	16	7.2	
Single	38 (17.8)	0 (0.0)	2 (25.0)	40	17.9	
Education level of caretaker						11.09 (0.20)
Middle school	111 (51.6)	0 (0.0)	6 (75.0)	117	52.2	
Secondary	24 (11.2)	1 (100.0)	0 (0.0)	25	11.2	

Tertiary	44 (20.5)	0 (0.0)	2 (25.0)	46	20.5
None	36 (16.7)	0 (0.0)	0 (0.0)	36	16.1

Source: Author's field data (2014)

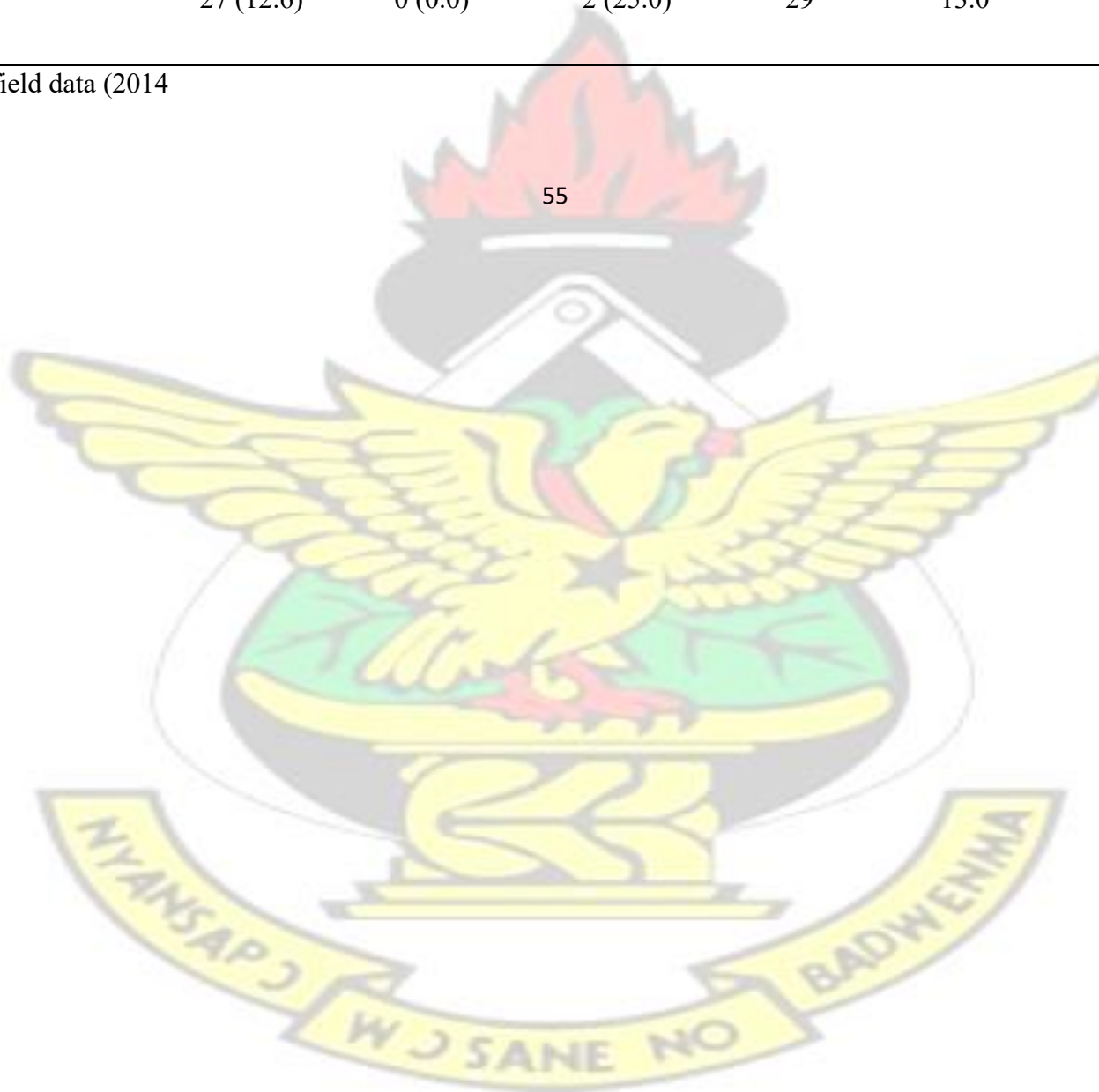
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Table 4.9: Relationship between marriage as perceived challenge and socio-demographic characteristics cont.

Variables Category	CLP child future employment opportunity n (%)			Total	Percentage %	F-test (p-value)
	Yes	No	Don't know			
Religion of caretaker or parent						4.96 (0.55)
Christian	151 (70.2)	1 (100.0)	4 (50.0)	156	69.6	
Muslim	49 (22.8)	0 (0.0)	3 (37.5)	52	23.2	
Traditional	5 (2.3)	0 (0.0)	1 (12.5)	6	2.7	
None	10 (4.7)	0 (0.0)	0 (0.0)	10	4.5	
Occupation of caretaker or parent						30.37 (0.00)
Civil servant	35 (16.3)	0 (0.0)	2 (25.0)	37	16.5	
Trader	83 (38.6)	1 (100.0)	2 (25.0)	86	38.4	
Artisans	30 (13.9)	0 (0.0)	0 (0.0)	30	13.4	

Farmer	37 (17.2)	0 (0.0)	2 (25.0)	39	17.4
Other	3 (1.4)	0 (0.0)	0 (0.0)	3	1.3
Unemployed	27 (12.6)	0 (0.0)	2 (25.0)	29	13.0

Source: Author’s field data (2014)



CHAPTER FIVE: DISCUSSION

5.1 Introduction

In this chapter of the study, the results are discussed within the context of existing literature on the subject matter.

5.2 Background of study participants (caretakers and children with CLP)

University of Iowa Children's Hospital (2014) indicated that the important part of the overall care and treatment of CLP children has to involve the parents and their commitment to maintain such an environment while their children are growing up. The results of the study indicated that the children with CLP were aged from less than 4 weeks to 52 weeks and above, with those aged from 4-26 weeks dominating (38.0%) as shown in Table 4.1. This implies that most of the children were babies and children in this age group had to be taken care by their mothers. This might explain why 79.5% of caretakers interviewed were biological mothers followed by 11.6% being biological fathers. In rare circumstance other family relatives (8.9%) like aunties and grandmothers would stand in for the mother and father as indicated by Table 4.1. One consistent factor in the CLP children who adjusted well with social environment is that they had extremely supportive parents and families and felt that they had a safe and comfortable place to talk about their condition and get their questions answered (University of Iowa Children Hospital, 2014).

This then confirms that parents (married couples) are well needed in taking care of children with OFC. This is evident in the study as greater percentage of caretakers (72.7%) was married as indicated in table 4.1. Parent-to-parent support groups have proved to be useful for families of babies with birth defects of the head and face, such as orofacial clefts (American Cleft Palate-Craniofacial Association, 2009).

Driving positive social interactions as a disfigured person involves the use of a variety of socially proactive strategies (or social skills) to help manage the (often intrusive) reactions of others. These skills include educating others, keeping calm, and confronting negative reactions assertively (Partridge, 1994). This implies that accepting people with CLP condition requires education and the parents and caretakers of these children also need to have education on the condition. Educating the caretakers to be able to educate teachers and students on proper way of taking care of children with CLP and avoiding discrimination might be easiest since majority of the mothers (82.6%) and fathers (87.1%) have attained some level of education at least up to the middle school level and at most up to tertiary level as shown in table 4.1 . Therefore, training them to undertake education might be easier and more acceptable as evident in a study conducted in the United States (University of Iowa Children's Hospital, 2014). About 20.6% mothers and 23.7% of fathers were tertiary institution graduates and this partly accounted for why 18.8% of mothers and 18.3% of father were working as civil servants. Most women in Ghana are into petty trading and this emerges in the study as most mothers (40.6%) were traders compared to other occupations as shown in Table 4.1. Also 63.4% fathers were middle school and secondary school (SHS) leavers and this partly might have accounted for 27.7% of them being farmers and 18.7% being artisans. Some mothers (17.4%) and fathers (12.9%) were uneducated and this could partly account for 13.4% of the mothers and 4.0% of the fathers unemployment situation (REF: Table 4.1). The study was conducted at Komfo Anokye Teaching Hospital (KATH) which is located in the middle belt of Ghana and the second largest hospital in Ghana under the auspices of Ministry of Health (Anon 2009). The strategic location of the hospital attract patients from all 10 Regions in Ghana and this might explain why caretakers were from Ashanti region, Upper East region, Brong Ahafo region, Greater Accra, Central region, Eastern region (8.1%), Western region, Volta region, Northern

region, Upper East and Upper West region. In the case of religious affiliation of caretakers, it was seen that 69.6% of them were Christians and

23.2% were Muslims as detailed in. Table 4.1 This virtually explains the religious distribution of Ghanaians where there are more Christians than Muslims, especially considering the Ashanti region where the study took place (Mundi, 2014)

5.3 The Proportion of Children with CLP in KATH

Cleft lip and cleft palate are birth defects that occur when the lip or mouth of a baby do not form properly during pregnancy and these birth defects are commonly called “orofacial clefts” (Centers for Disease Control and Prevention, 2014). The results from the study revealed that the dominant orofacial clefts (OFC) was cleft lip (46.9%) comparing to cleft lip and palate (37.9%) and only cleft palate (15.2%) (REF. Table 4.2). . The trend as revealed in this study is contrary to the study conducted by Jagomagi et al (2010) that involved 583 children with cleft lip and or palate at the Tartu University Hospital, Estonia. The study revealed that 19.0% of the patients had a cleft lip (CL), 39.0% of the patients had a cleft palate (CP), and 42.0 % of the patients had a cleft lip and palate (CLP). The ratio for the different cleft types CL: CLP: CP was 1:2:2. The inconsistencies with the trend of different ratio in terms of cleft types support the argument that the proportion reported for cleft lip with or without cleft palate and cleft palate alone varies around the world due to substantial variability related to geographic origin, ethnicity, and socioeconomic conditions (Mossey & Little, 2002; Lozano 2012).

Cleft lip and palate is very treatable. However, the kind of treatment to be adopted depends on the type and severity of the CLP condition. Most children with a cleft condition are monitored by cleft

lip and palate team or craniofacial team through young adulthood (Bristow and Bristow, 2007). This explains why some of the CLP children (29.9%) were completely treated, others (55.4%) were not treated or repaired and few of them (14.7%) were partially repaired (REF: Table 4.2). Bristow and Bristow (2007) further explained that CLP care process is a lifelong one. Treatment procedures vary between craniofacial teams and explained why some of the CLP individuals were not treated during the study. For example, Bristow and Bristow further explained that some teams wait on jaw correction until the child is aged 10 to 12 (argument: growth is less influential as deciduous teeth are replaced by permanent teeth, thus saving the child from repeated corrective surgeries), whilst other teams correct the jaw earlier (argument: less speech therapy is needed than at a later age when speech therapy becomes harder). These raised comments are subjected to the notion that treatment differs between individual cases depending on the type, severity of the cleft and availability of specialized teams and equipment. With over 90% of CLP children seen at KATH in 2013 fully repaired as shown in Figure 4.2 presupposes that some of the basic condition and equipment for treating CLP were available. This might explain why the main concern of all caretakers (100%) whose wards were not fully repaired was to get their children cleft lip and or palate completely repaired (REF: Table 4.2)

The perception on the causes of cleft lip and palate differs across individuals. Even though, there is no consensus on the real cause of cleft lip and palate, there are still some causes of this developmental deformity. Most scientists believe clefts are due to a combination of genetic and environmental factors. None (0%) of the CLP children who visited KATH in 2013 had immediate siblings with cleft condition and this conforms to WebMD (2014) argument that in most cases, the cause of cleft lip and cleft palate is unknown and cannot be prevented. However, the parents of very few (0.4%) of these CLP children seen at KATH in 2013 had cleft condition as showed in

Figure 4.2. This might explain why some caretakers (7.6%) perceived their CLP children would give birth to children with CLP condition in future as supported by Black et al (1998).

5.4 Perceived social challenges faced by children with CLP

The social challenges of cleft lip and palate are discussed with respect to perceived educational, employment and marriage challenges.

Perceived educational challenges for children with CLP

The acceptance of children with CLP and other orofacial deformities to the various schools is the major concern to discuss. The results revealed that over forty percent (42.0%) of the CLP children in school going age were not in school as indicated in Table 4.3. Stigmatization and teasing of these orofacial cleft children might prevent caretakers from taking their wards to school. This is because a high incidence of teasing over facial appearance is reported among those with CLP in schools (Bernstein & Kapp, 1981; Noar, 1991; Turner *et al.*, 1997). As a result, children with CLP experience some kind of psychosocial distress in school as a result of their condition (Hunt *et al.*, 2005). However, with all these educational challenges stated earlier, the study revealed that some of the CLP children (10.7%) were already in school and a significant proportion of caretakers intend to take their children to school which includes those who are not in school (42.0%) and children who are not in school going age (47.0%) (REF: Table 4.3). This looks promising and conform with the UN obligation for all parents and caretakers to take their school going age children to school to attain basic education which starts from kindergarten to Junior High school (JHS) (UN, 2008).

Also, a significant proportion of caretakers (93.3%) perceived that their CLP children would be accepted in school. This is probably because caretakers are optimistic their children might not be

discriminated and stigmatized. This is in line with a study conducted in United State of America which indicated that children with clefts have more friends and accepted in school than control children (Broder et al., 1994). The various reasons mentioned by significant proportion of caretakers in accepting CLP children into school include Ghana's Free Compulsory Basic Education policy (FCUBE), early education, brain of the child not affected, and normal life after repair as shown in Table 4.3. This reason(s) are not different from that of Rumsey and Harcourt (2004) emphasizing that most facial anomalies are not associated with deficits in brain function but rather link with physical features. Among caretakers who perceived that CLP children would not be accepted in school mentioned harassment as the major challenge and the feeling of being ashamed of the condition (REF: Figure 4.3). This perception is supported by similar perception in India where some community leaders refused to take children with CLP to school (Alkhare *et al.*, 2013).

Perceived employment challenges for children with CLP

Western society is very focused on the aesthetics of the human body. People who are objectively rated as beautiful or attractive are more frequently attributed with personal qualities such as intelligence and trustworthiness (Zebrowitz (1997). Attractive people are seen by others as brighter, having more positive social behavior and receive more positive treatment and favour than their less attractive counterparts when it comes to employment

(Dion *et al.*, 1972; Videbeck,1960). It is therefore in no doubt that facial appearance is acknowledged as a qualification criterion in certain category of jobs. As a result, some caretakers (4.9%) perceived that their CLP children have no chance of being employed in future. This is because individual with cleft lip and or palate are less regarded qualified aspirant by employers.

This is evident in a study conducted by Peter *et al* (1975) which indicated that people with cleft lip and palate deformities were more frequently unemployed with a significantly lower income. This is because people with CLP are mostly employed in informal jobs. This is confirmed in a study conducted by Danino *et al* (2005), that in the 21st century people with CLP are less likely to hold high profile jobs, rather they seek positions in skilled trade occupations. This is evident in the study as 15.6% of caretaker perceived that the CLP children will have no chance of holding high profile job in future as shown in Table 4.4. In reality, one will agree that in certain occupation like front desk officer, marketers and client service executive, employers will be interested in people who are very attractive. However, greater percent of caretakers (95.1%) perceived CLP children to be employed in future as indicated in Table 4.4. This is because getting employment in the formal sector depends on one's educational level. Certainly, higher education comes with specialized competences and skills that make one more employable. Besides, from perspective of these caretakers, white colour jobs, manual work, and other artistic work were mentioned as job categories for individuals with CLP. This implies that people with CLP have the chance of being employed in the formal sector for those who are able to be educated up to higher levels or learn a skill to be employed in an informal sector. This might explain why over ninety percent of caretakers (95.1%) perceived their CLP children have the chance of being employed in future (REF: Table 4.4). Also, medical doctor, nurse, teacher, lawyer, and banker were among the specific formal professions which caretakers and parents perceived that their CLP children can be equipped to become in future. All these mentioned professions can be achieved when these cleft lip and palate children are able to study up to higher level towards that dream. This positive thinking might explain why a greater proportion of caretakers (97.8%) indicated that people with repaired CLP have the ability to do everything in life and are normal human being as compared to those without

CLP. Therefore, these caretakers (67.0%) perceived that individuals with cleft condition have equal chance as those with no cleft condition in holding high profile jobs. This perception is highly supported in United Kingdom, where the Disability Discrimination Act prevents employers from discriminating against employees because of their appearance (Rumsey and Harcourt 2004).

Caretakers were asked to assume the role of employers to examine their personal capacity and willingness to hire people with CLP condition. The percentage of caretakers (63.8%) willing to employ people with unrepaired cleft and percentage of caretakers (96.0%) willing to employ people with repaired cleft was both highly significant (REF: Table 4.4). This might explain why 73.7% of caretakers indicated that quality of life of children with CLP is not affected by facial attractiveness as asserted by Baker (1992) but rather the ability to learn, education level, health treatment (repair), and hard work and strength as the possible factors which can affect the quality of life of these CLP children as shown Figure 4.4.

Perceived marriage challenges for children with CLP

Friendship and courtship are activities preceding marriage. McWilliams & Paradise (1973) and Broder *et al* (1994) outlined friendship and marriage as two areas of social functioning which appear to differentiate those with CLP from those without CLP. People with facial disfigurement would have challenges having any better attraction to people, they stay in complete isolation (Noar, 1991) and this is evident in the study as 4.0% of caretakers perceived that people with cleft lip and palate have no chance of getting married. This might explain why less than fifty percent (43.8%) and less than ten percent (8.5%) of caretakers were not willing to marry adult with unrepaired and repaired CLP respectively. This is further supported by a study conducted by Broder *et al* (1994) which indicated that fewer adults with CLP marry and among the few that marry, it occurs in their

later life and childless marriage is common among them. Similarly Danilo *et al* (2005) undertook a study that investigated 82 French adults with repaired CLP and found that, compared to adults without CLP, people with CLP did marry later, displayed a delay in scholarship, had a lower income, and reported a significant delay in their independence process from their parents.

Of those who are willing to marry people with CLP condition, their major reason is that selecting a marriage partner depends on love, attitude and choice but not physical appearance (Danilo *et al.*, 2005). This might explain why a high proportion of caretakers (96.0%) perceived children with CLP to marry in future as indicated in Table 4.5. As a result, majority of the caretakers were willing to marry adults with repaired (91.5%) and unrepaired (56.2%) CLP as detailed in Table 4.5

5.5 overcoming/minimizing perceived social challenges

It has already been established that children and adults with CLP condition face a couple of social challenges. The results of the study outlined suggestions from parents and caretakers, and needed assistance from health personnel, society and government to mitigate and/or minimize educational, employment and marriage social challenges.

Most parent/caretakers (68.3%) suggested educating the general public on cleft lip and palate will help to mitigate and minimize social challenges of OFC. meaning the awareness of OFC in Ashanti Region and Ghana as whole is undoubted not encouraging. This could explain why (15.2%), (7.1%), and (14.7%) of parents/caretakers considered education as one of the assistance they expect from health workers, civil society and Government respectively. The need for education on cleft to help minimize stigmatization of individuals with OFC has been expressed by caretakers to all stakeholders (REF Table 4.6). This is supported by Akhare *et al* (2013) that problems faced by cleft patients and their parents in developing countries are as result of lack of

knowledge and certain beliefs present in these developing countries. To help reduce discrimination of individuals with OFC, 15.2% of caretakers or parents suggested the public should accept individuals with OFC as normal humans. This could be why 46.9% of caretakers or parents considered civil society can assist minimizing social challenges of OFC by accepting the condition (REF Table 4.6) and Gallaher (2010) did, indicate that social support and acceptance is particularly important to adjustment or adaptation of people with CLP condition. This is because the major challenges and rejection people with OFC encounter are mainly from the society (Zebrowitz (1997), therefore if all people living in the society come to consensus to accept children and adults with orofacial deformities as normal humans, the perceived social challenges in education, employment and marriage can be minimized to some degree.

Another suggestion from parents/caretakers (11.6%) to help minimize the social challenges was financial support. This could be the reason why 54.0% of the caretakers think government should bear the cost of cleft treatment and 21.0% think civil society should provide financial support (REF. Table 4.6). The cost of health care is very alarming in developing countries. Not all parents and caretakers can afford the cost of treatment in cleft lip and palate (Haakonsen 2012). She added that in most countries the funding for treatment of CLP comes from health insurance, federal and state sources, private and non-profitable agencies. The situation in developing countries like Ghana is different from developed countries as Kummer (2008) confirmed that in developing countries, parents of CLP children may not have the opportunity to rely on third party payers for their children medical care and therefore caretaker rely on the government to intervene as indicated by 54.0% of caretakers in this study.

The University of Iowa Children's Hospital (2014) accepts that fact that most of the time, children with facial differences will not have a lot of psychological reaction to questions about their scars

or differences in their appearance until they are roughly age six therefore early CLP treatment as suggested by 4.9% of parents or caretakers (REF Table 4.6) was highly recommended. It is therefore in place when 51.3% of parents or caretakers indicated that they need assistance from health workers to complete treatment. Treatment procedure for CLP comes in different dimension. Hodgkinson *et al* (2005) affirm that the support and management of children with cleft lip and palate presents many challenges but also many rewards. The currently accepted model for delivery of this treatment in the most appropriate way is the introduction of multidisciplinary cleft team. Multidisciplinary cleft team consist of Audiologists, Geneticists, Nurses and nurse practitioners, Orthodontists, Ear, nose and throat surgeons, Pediatricians, Pediatric dentists, Pediatric plastic surgeons, Prosthodontists, Psychologists, Speech-language pathologists, social worker/care coordinators. Therefore health personnel have major role to play in treating children with CLP. Apart from assistance needed from health worker 25% of parents/caretakers indicated civil society should show love and encouragement to people with CLP. In fact Gallaher (2010) stresses that showing love, support, caring for, and encouragement to people with orofacial deformities enhance excellent self-esteem, reduces anxiety, and development of adaptive cognitions

5.6 Relationship between perceived social challenges and socio-demographic characteristics of caretakers

The perception of caretakers on CLP is influenced by many factors of these parents and caretakers. The perceived social challenges in education, employment and marriage by parents or caretakers is discussed to outlined the significant influence the demographic characteristics which includes; relation to child, age, marital status, education background, occupation and religion of parents and caretakers affect their perception on cleft lip and palate.

5.6.1 Relationship between perceived educational challenges and socio demographic characteristics of caretaker

Generally 93.3% of these caretakers perceived their CLP children to be accepted in school and 6.7% of them perceived negatively in the survey (REF. Table4.3). The status of family relation of caretakers (mothers, fathers and others) had no significant influence on perception on accepting CLP children in school compared to the perception on not accepting these children in school (REF: Table 4.7). Rumsey and Harcourt (2004) and Baker (1992) indicated that partners and families of people with disfigurement are likely to be the sole providers of support and this might have accounted for indifference in the perception of accepting CLP children in school. Similarly the age group of caretakers, marital status, religious background, had no significant relationship on their perception on accepting CLP children in school. However, education level of caretakers made significant difference in the perception on the acceptance of CLP children in school. From the study, 63.4% of caretakers had education up to secondary school, 20.5% were tertiary graduates, (REF. Table 4.7). Their level of knowledge and understanding on the importance of education might have accounted for the significant difference in the perception of accepting children with CLP in school. Education and occupation are related; parents with good education background could be financially sound and therefore can afford the tuition of their children to higher level. This is evident in the study as the occupation of caretakers made significant difference in the perception on accepting CLP children in school (REF: Table 4.7). Schultz (2008) did confirm that higher education, financial support, and good social support enables the parent of CLP child to adjust faster and to cope better with CLP situation. In contrast lower education and less income and social support parents appear to experience more depression.

5.6.2 Relationship between perceived employment challenge and socio demographic characteristics of caretaker

Based on responses from parents and caretakers, generally 95.1% of these caretakers perceived their CLP children have the chance of being employed in future and 4.9% of them perceived otherwise (REF. Table 4.4). The caretaker relation, age group of caretakers, marital status, education and occupation of caretakers had no significant relationship on the perception on employing the CLP children in future compared to the perception on CLP preventing these children from being employed in future as shown in Table 4.8. However, the religious affiliation (Christians, Muslims, traditionalist and none as seen in Table 4.1) of caretakers made significant difference in the perception on employing the CLP children in future. This is consistence with the Chamorro culture of the Mariana Island where someone with CLP is viewed as a gift from God (Cheng 1990) and therefore employing people with CLP is a blessing.

5.6.3 Relationship between perceived marriage challenges and socio demographic characteristics of caretakers

The percentage of caretakers (96.0%) perceiving that the CLP children have chance of getting married in future (REF. Table 4.5) compared to that of caretakers who perceived differently was significantly influenced by relationship existing between caretakers and CLP child as well as marital status of these caretakers as shown in Table 4.9. Married caretakers with experience in marriage might want their children with CLP condition to also have the chance of getting married. They see the choice of selecting married partner in a different perspective which could be influenced by love and care they have for the children. Again caretakers 7.6% (REF; Table 4.2) who perceived their CLP children have the chance of giving birth to CLP children (Mossey and Little, 2009) may have different perception on marriage therefore perceived that children have no chance of getting married in future. Similarly the occupation of caretakers made significant

difference in the perception on CLP children getting married in future. Parents and caretakers who are financially sound as a result of their occupation can afford the treatment of cleft lip and palate and with treatment, most children with orofacial clefts do well, lead a healthy life and live a normal life (Richman, 1983). When the cost of treatment is readily available by caretakers, children with CLP can live a normal life and therefore perceive them to marry in future. In contrast, parents and caretakers who cannot afford treatment as a result of their occupation perceived their CLP children would not have chance of getting married in future. However, age group of caretakers, education and religion of caretakers had no significant influence on the perception on future marriage opportunity of these CLP children in future as shown in Table 4.9.

CHAPTER SIX: CONCLUSION AND RECOMMENDATION

6.1 CONCLUSION

The findings gathered in this study had the following conclusions drawn based on specific objectives of the study.

Background of participants

Most of the caretakers/parents of cleft children were biological mothers (79.5%) and had attained some level of education (82.6%). Most of the children with CLP were between 1month and 6months (38.0%) and were females (55.9%). More than half (53.3%) of CLP cases were referred from other regions.

Proportion of children with cleft lip and or palate

The proportions of children with CLP in 2013 were; cleft lip (43.8%), cleft palate (26.8%) and cleft lip and palate (29.4%). In 2014, the proportions were; cleft lip (46.9%), cleft palate (15.2%) and cleft lip and palate (37.9%)

Perceived social challenges faced by children with CLP

On education, only a few (10.7%) of the CLP children were in school and majority of the caretakers (97.0%) intended to take their children with CLP to school. However, a few (6.7%) of the caretakers perceived that the children with CLP would not be accepted in school. The reasons provided by caretakers to justify why children with CLP would not be accepted in school included; cleft left not repaired, children would feel ashamed and the perception that cleft is a bad condition.

On employment, a significant proportion of caretakers (67.0%) perceived that cleft condition would not affect future job prospects of children with CLP. The perceived future job prospects as stated by caretakers included; formal jobs (86.9%), informal jobs (3.2%) and others (9.9%). However, a few of the caretakers would not employ adults with CLP either repaired or not repaired.

Finally on marriage, majority of the caretakers (96.0%) perceived their cleft children would be married in future. However, a few of the caretakers would not marry adult with CLP either repaired or not.

Overcoming perceived social challenges based on parent/caretaker perspective

Suggestions given by parents/caretakers to overcome the perceived social challenges of people with cleft included; public education (68.3%), acceptance from the public (15.2%), financial support from the public (11.6%) and early repair treatment (4.9%).

Any Relationship between perceived social challenges and socio- demographic characteristics of caretakers

There was a relationship between perceived social challenges and socio-demographic characteristics of caretakers. The relationship between socio-demographic characteristics such as educational level of caretakers ($p\text{-value}=0.04$) and occupation of caretakers ($p\text{-value}=0.00$) and education as perceived social challenge was statistically significant. However, the relationship between socio-demographic characteristics such as caretakers' relationship to child ($p\text{value}=0.93$), age group ($p\text{-value}=0.66$), marital status ($p\text{-value}=0.25$), religion ($p\text{-value}=0.69$) and education as perceived social challenge was not statistically significant.

On employment, the relationship between socio-demographic characteristic such as religion ($p\text{value}=0.00$) and employment as perceived social challenge was statistically significant. However the relationship between socio-demographic characteristics such as relationship to child ($p\text{value}=0.45$), age group of caretaker ($p\text{-value}=0.67$), marital status of caretaker ($p\text{-value}=0.90$), educational level of caretaker ($p\text{-value}=0.08$), occupation of caretaker ($p\text{-value}=0.42$) and employment as perceived social challenge was not statistically significant.

Finally on marriage, the relationship between socio-demographic characteristics such as relationship of caretaker to child ($p\text{-value}=0.03$), marital status of caretaker ($p\text{-value}=0.01$) and occupation of caretaker ($p\text{-value}=0.00$) and marriage as perceived social challenge was statistically significant. However the relationship between socio-demographic characteristics such as age group of caretaker ($p\text{-value}=0.41$), educational level of caretaker ($p\text{-value}=0.20$), religion of caretakers ($p\text{-value}=0.55$) and marriage as perceived social challenge was not statistically significant

6.2 RECOMMENDATION

The following recommendations are made for health workers, civil society and the Government of Ghana.

Health workers of KATH

1. Health workers of KATH should educate parents/caretakers of children with CLP, on the various stages of care until complete treatment is achieved. This will help parents to be informed of the task ahead of them as long as achieving complete treatment is concern.
2. Health workers of KATH should organize outreach programmes to educate the general public that there is treatment for CLP and that individuals with the condition can leave normal life after completing treatment. This can be done through community health nurses who go into the communities regularly. It is therefore important to update such staff knowledge on the condition.
3. Health workers of KATH must educate the public on possible risk factors for giving birth to a child with CLP so that people can take the necessary precaution. For example, partners who have cleft history in their respective families should not marry since they stand the risk of giving birth to a child with cleft.

Civil Society; (family members, church members, community members)

1. Good support from family members, church members or community members will urge people with CLP to complete their treatment since strong support system is very important when people are down hearted especially with certain conditions which need long term for complete treatment.

2. Community members should avoid stigmatization, discrimination or ostracism of families with CLP child since it compound the emotional trauma /stress that they go through and further demoralize them. Accept them and show love to them.
3. Traditional leaders should be educated on the condition so that they do not see such children as cursed children or think it is abominable to keep children with CLP in their communities.

Government of Ghana

1. Government of Ghana should create cleft clinic in at least every regional hospital to shorten the travelling distance by those who stay far from KATH or Korlebu Teaching Hospitals to encourage completion of treatment since the long distance and its accompany high transport cost can deter people seeking for treatment and do not have money.
- 2 Government of Ghana should include cleft care in the NHIS so that bill for cleft care can be taken care of by the NHIS.
3. Government of Ghana should train more health personnel on cleft management so that in the interim they can go on outreach programmes and create awareness that cleft lip and or palate can be repaired.

Recommendation for further studies

Further studies can be carried out on the social challenges faced by individuals with CLP based on their own perspective.

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APPENDICES

APPENDIX I

INFORMATION SHEET AND CONSENT FORM

Information Sheet For Study Participants

You are being invited to take part in a study that aimed at assessing the perceived social challenges of cleft lip and or palate patients at Komfo Anokye Teaching Hospital, Kumasi. Before you decide to participate, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the information carefully and discuss it with others if you wish. Ask the researcher if there is anything that is not clear or if you would need more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Who is conducting this study?

The study is being conducted by Mercy Larnyoh, a student being supervised by Dr Kofi Akohene Mensah of Kwame Nkrumah University of Science and Technology, Department of community Health, Kumasi.

What is the purpose of the study?

The study is determining the perceived social challenges of people with cleft lip and or palate at KATH so that the necessary recommendation for these unfortunate ones to receive the necessary attention from authorities and or policy makers. We will use information extraction sheet and questionnaire. The field work for this study begins on 6th August to 29th October 2014 (on Wednesdays only).

Why have you been selected?

You have been selected to represent views of parents/caretakers of children with cleft lip and or Palate.

What would be involved?

You will answer a questionnaire at the cleft lip and palate clinic on your clinic days (Wednesday). This is for your convenience. You will be guided to answer a questionnaire and your privacy will be ensured. It will not last more than twenty-five (25) minutes. The questions will be asked on social challenges you perceived your ward to experience with regard to his/her condition and your recommendations on how well you can be helped out.

What happen next?

If you are interested in participating in this study, then a consent form will be given to you to sign to affirm your willingness to participate in the study.

Do I have to take part?

The choice is yours to decide to participate or not. If you do decide to participate you will then be given this information sheet to keep and be asked to sign a consent form. If you decide to participate you are still free to withdraw at any time and without giving reason.

What are the benefits of taking part?

There may be no direct benefits of being participant. However, you will be providing useful and important information, which will enhance and strengthen the support provided by benevolent society and government in addressing the needs of people with cleft lip and or palate.

What are the disadvantages of participating?

You will be asked of anticipated social challenges of your ward which might disturb you psychologically, but you can choose not to answer a particular question if you so wish.

Will my participation in this study be kept confidential?

All information provided about you during this study will be kept strictly confidential. You will be identified by a code number and no names will be recorded. This cannot be linked to you in any way and your name or any identifier will not be used in any publication or report of this study. However your participation is purely voluntary.

What will happen to the results?

The study is for an MSc Health Education and Promotion and the results will be presented at scientific meetings and published in academic journals. If you want a copy of the published results, you can contact Mercy Larnyoh. You will not be identified in any report or publication.

Who is organizing and funding this research?

The research is being conducted by Mercy Larnyoh, a student at Kwame Nkrumah University of Science and Technology under supervision from Dr Kofi Akohene Mensah, an academic lecturer. The student is funding this research.

CONSENT FORM

Title of the project: Determining the social challenges of children with cleft lip and or palate as perceived by parents or caretakers at Komfo Anokye Teaching Hospital Kumasi.

Name of Researcher: Mercy Larnyoh

1. I confirm that I have read and understood the information sheet dated version.....

for the above study and have had the opportunity to ask questions

☐

2. I understand that my participation is voluntary and that I am free to opt out at any time, without given a reason without any legal rights being affected.

☐

3. I agree to take part in the above study. ☐

Name of subject Date Signature/thumbprint

Name of person taking consent Date Signature (If different from researcher)

Researcher: Mercy Larnyoh Date Signature

APPENDIX II

QUESTIONNAIRE

TOPIC

DETERMING SOCIAL CHALLENGES OF CHILDREN WITH CLEFT LIP AND OR PALATE AS PERCEIVED BY PARENTS OR CARETAKERS AT KOMFO ANOKYE TEACHING HOSPITAL CODE:

SECTION A: SOCIO-DEMOGRAPHIC CHARACTERISTICS OF STUDY

PARTICIPANTS

1. Relationship between caretaker and child

Mother ☐ father ☐ Others specify.....

2. Age of the mother/ caretaker

3. Age of the child.....

4. Marital status of the mother/caretaker

Married ☐ divorced ☐ single but living with a partner ☐ single
others specify.....

5. Educational level of the mother/caretaker

Primary school ☐
Junior high school ☐
Senior high school ☐
Tertiary education ☐
None ☐

6. Educational level of the father

Primary school ☐
Junior high school ☐
Senior high school ☐
Tertiary education ☐
None ☐

7. Religion of the mother

Christian ☐
Muslim ☐
Traditionalist ☐
None ☐

8. Religion of the father Christian

Muslim

☐

Traditionalist

☐

None

☐

9. Occupation of the mother

☐

Civil servant

☐

Self employed

☐

Trader

☐

Apprentice artisan

☐

None

☐

Others specify.....

10. Occupation of the father.

Civil servant

☐

Self employed

☐

Trader

☐

Apprentice artisan

☐

None

☐

Others specify.....

SECTION B; PROPORTION OF CHILDREN WITH CLEFT LIP AND OR PA

11. Type of cleft.

Lip

☐

palate

☐

12. Has the child's cleft been repaired?

Yes ☐ No ☐

13. If no, do you want your child's cleft be repaired

Yes ☐ No ☐

14. Do you think your child can give birth to a child /children with cleft lip and or palate?

Yes ☐ No ☐ Don't know ☐

SECTION C: PERCEIVED SOCIAL CHALLENGES FACED BY CHILDREN WITH

CLEFT LIP AND OR PALATE

EDUCATION

15. Does the child go to school?

Yes ☐ No ☐ Not applicable ☐

16. If no, do you intend taking the child to school?

Yes ☐ No ☐ Not applicable ☐

17. If yes to question 15, what challenges do you think the child will face at school?

Will feel isolated ☐ will be bullied ☐ not be respected ☐

Others specify

18. Do you think your child will be accepted in school?

Yes ☐ No ☐

19 .If yes, why?

20. If no, why?

21. Which level of education do you think your child can reach/attain?

Primary school

☐

Junior high school

☐

Senior high school

☐

Tertiary education

☐

None

☐

22. Do you think your child will be harassed when he goes to school?

Yes

☐

No

☐

Don't know

☐

EMPLOYMENT

23. Do you think your ward can be employed in future?

Yes

☐

No

☐

Don't know

☐

24. If yes what kind of work?

White color job

☐

Manual work

☐

Others specify

.....

25 If no, why.....

26 What do you want your child to become in future?

Lawyer ☐

Doctor ☐

Nurse ☐

Teacher ☐

Banker

Others specify

27. Assuming you own a company/firm, will you employ people with unrepaired cleft lip and or palate? Yes ☐ No ☐

28. Assuming you own a company/firm, will you employ people with repaired cleft lip and or palate? Yes ☐ No ☐

29. Do you think people with unrepaired CLP can do anything that everybody can do?

Yes ☐ No ☐

30. Do you think people with repaired CLP can do anything that everybody can do?

Yes ☐ No ☐

31. Do you think the child condition can influence his future job prospect?

Yes ☐ No ☐ Don't know ☐

32. If Yes, how?

33. If No, why?

34. Can the condition affect the quality of life of your ward?

Yes ☐ No ☐ Don't know ☐

35. If Yes, how?

36. If No, why?

MARRIAGE

37. Do you think your child can be in intimate relationship when he/she grows up?

Yes ☐ No ☐ Don't know ☐

38. Do you think your ward can get married in future?

Yes ☐ No ☐ Don't know ☐

39. Assuming you are young unmarried man/woman, will you marry somebody with unrepaired

CLP? Yes ☐ No ☐

40. Assuming you are young unmarried man/woman, will you marry somebody with repaired

cleft lip and or palate? Yes ☐ No ☐

SECTION D; SUGGESTIONS AND ASSISTANCE TO MINIMIZED SOCIAL CHALLENGES AS PERCEIVED BY PARENTS/CARETAKERS.

41. What suggestions do you have to minimized perceived social challenges

.....

42. What assistance do you expect from the health workers?

.....

.....

43. What assistance do you expect from civil society?

.....

...

.....

44. What assistance do you expect from the government?

.....

.....

THANK YOU



APPENDIX III

INFORMATION EXTRACTION SHEET

TOPIC

DETERMINING SOCIAL CHALLENGES OF CHILDREN WITH CLEFT LIP AND ORPALATE AS PERCEIVED BY PARENTS OR CARETAKERS AT KOMFO ANOKYE TEACHING HOSPITAL

CODE;

SECTION A: SOCIODEMOGRAPHIC CHARACTERISTICS OF CHILD WITH CLEFT LIP AND OR PALATE

1. Age of the child.

2. Sex: male female

☐☐

3. Place of residence.....

4. Hometown.....

SECTION B: PROPORTION OF CLEFT LIP AND OR PALATE IN KATH

5. Types of cleft

lip

☐

palate

☐

6. Location of cleft lip:

right

☐

left

☐

bilateral

☐

7. Does any of his/her direct siblings has

Cleft lip ☐
Cleft palate ☐

Cleft lip and palate ☐

None ☐

8. Does any of the parents has cleft?

Yes ☐

No ☐

9. If yes, who? Mother

☐ father ☐

10. Has the child's cleft been repaired?

Yes ☐

No ☐

