UNIVERSITY OF GHANA  
COLLEGE OF HUMANITIES  
DEPARTMENT OF SOCIAL WORK

EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CLEFT LIP  
AND/OR PALATE RECEIVING TREATMENT AT THE  
RECONSTRUCTIVE PLASTIC SURGERY AND BURNS CENTER OF  
THE KORL-BU TEACHING HOSPITAL

BY  
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LEGON IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE  
AWARD OF MPHIL SOCIAL WORK DEGREE

JULY, 2018
DECLARATION

I, Fatimah Anderson, do hereby declare that with the exception of the references duly cited, this thesis titled “Experiences of caregivers of children with cleft lip and/or palate” was entirely conducted by me in the Department of Social Work, University of Ghana, Legon under the supervisions of Prof. Mavis Dako-Gyeke and Dr. Doris A. Boateng. This work has never been presented in part or full to any other Department or Institution for any academic activity.

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(SUPERVISOR)
DEDICATION

I dedicate this work to God Almighty for leading my way and to all caregivers of children with congenital birth defects.
ABSTRACT

Globally, the issue of cleft lip and/or palate is a growing concern in many developed and developing countries. This study explored the experiences of caregivers of children with cleft lip and/or palate receiving treatment at the Reconstructive Plastic Surgery and Burns Center of the Korle-Bu Teaching Hospital in the Greater Accra Region of Ghana. The objectives of the study were to (a) explore caregivers’ beliefs about the causes of cleft lip and/or palate (b) identify the challenges faced by caregivers caring for a child with cleft lip and/or palate (c) ascertain the coping strategies adopted by caregivers caring for a child with cleft lip and/or palate and (d) find out support services available to caregivers of children with cleft lip and/or palate. Using a qualitative research design, twenty-five participants were purposively recruited for this study. Key informant and in depth interviews were conducted to gather data for the study and the findings were analyzed thematically. The findings of the study revealed that cleft lip and/or palate was caused by factors such as abnormalities or heredity in pregnancy, supernatural causes, abuse of drugs and food. Moreover, some of the challenges faced by caregivers of children with cleft lip and/or palate included work/financial challenges, child care and negative reactions from family and health professionals. Furthermore, the findings indicated that support services were provided by government, NGOs, families and friends but some of the caregivers were not aware of the formal support services available to them. In addition, the study further indicated that caregivers in dealing with their challenges adopted strategies such as isolation, self-encouragement and motivation. From the findings of the study, it is recommended that sensitization of pregnant women and the general public on cleft and palate by social workers and health professional should be encouraged to reduce the negative reactions and stigmatization that caregivers face.
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# TABLE OF CONTENTS

DECLARATION...................................................................................................................................................... ii  
DEDICATION................................................................................................................................................................ iii 
ABSTRACT................................................................................................................................................................ iv  
ACKNOWLEDGMENT ....................................................................................................................................................... v  
TABLE OF CONTENTS ................................................................................................................................................ vi  
LIST OF ABBREVIATIONS ........................................................................................................................................ ix  
CHAPTER ONE .......................................................................................................................................................... 1  
INTRODUCTION.......................................................................................................................................................... 1  
1.1 Background to the Study ........................................................................................................................................... 1  
1.2 Problem Statement .................................................................................................................................................. 5  
1.3 Objectives of the Study .............................................................................................................................................. 6  
1.4 Research Questions ................................................................................................................................................... 6  
1.5 Significance of the Study ............................................................................................................................................ 7  
1.6 Definition of Terms .................................................................................................................................................... 7  
1.7 Organization of the Study ........................................................................................................................................... 8  
CHAPTER TWO .......................................................................................................................................................... 9  
LITERATURE REVIEW AND THEORETICAL PERSPECTIVE .................................................................................. 9  
Introduction .................................................................................................................................................................. 9  
2.1 Caregivers’ Beliefs about CL/P ................................................................................................................................. 9  
2.2 Challenges Faced by Caregivers ............................................................................................................................. 15  
2.3 Coping Strategies Adopted by Caregivers ................................................................................................................ 24  
2.4 Support available to Caregivers .............................................................................................................................. 28  
2.5 Theoretical Perspectives ........................................................................................................................................... 32  
2.5.1 Adult Personal Resilience Theory (Robert Taormina, 2015) ............................................................................. 32  
2.5.2 Stress, Appraisal and Coping Theory (Richard Lazarus and Susan Folkman, 1984) ....................................... 35  
2.5.3 Justification for using Two Theories .................................................................................................................... 39  
CHAPTER THREE ........................................................................................................................................................ 40  
RESEARCH METHODOLOGY ..................................................................................................................................... 40  
3.0 Introduction ............................................................................................................................................................. 40  
3.1 Research Design ....................................................................................................................................................... 40  
3.2 Study Site ................................................................................................................................................................. 41
3.3 Target Population and Study Population ................................................................. 41
3.5 Sampling Technique ............................................................................................... 42
3.6 Sample Size ............................................................................................................. 43
3.7 Source of Data ......................................................................................................... 43
3.8 Method of Data Collection ...................................................................................... 43
3.9 Data Handling and Analysis .................................................................................... 44
3.10 Trustworthiness ...................................................................................................... 45
3.11 Ethical Considerations ............................................................................................ 45
3.12 Limitations of the Study ........................................................................................ 46

CHAPTER FOUR .............................................................................................................. 47
PRESENTATION OF FINDINGS AND DISCUSSIONS ..................................................... 47
4.1 Introduction ................................................................................................................ 47
4.2 Demographic Information of Participants ............................................................... 47
  4.2.1 Sex and Relationship of Caregivers to a Child with CL/P ................................. 47
  4.2.2 Age of Caregivers .............................................................................................. 48
  4.2.3 Level of Education ............................................................................................ 48
  4.2.4 Marital Status ..................................................................................................... 49
  4.2.5 Religious Affiliation of Caregivers ..................................................................... 49
  4.2.6 Occupation of Caregivers .................................................................................. 49
  4.2.7 Ages of Children with CL/P .............................................................................. 49
  4.2.8 Demographic Information of Key Informants ................................................... 50
4.3 Beliefs about Cleft Lip and/or Palate ....................................................................... 50
  4.3.1 Abnormalities in Pregnancy/ Heredity ................................................................. 50
  4.3.2 Awareness / Supernatural Cause ........................................................................ 52
  4.3.3 Abuse of Drugs and Food .................................................................................... 54
4.4 Challenges faced by Caregivers .............................................................................. 55
  4.4.1 Work/Financial Difficulties ................................................................................ 55
  4.4.2 Poor Caregiver- Community Relationship ....................................................... 57
  4.4.3 Problems Associated with Child Care ............................................................... 59
  4.4.4 Negative Reactions from Family and Health Professionals ............................... 60
4.5 Coping Strategies Adopted by Caregivers .............................................................. 62
  4.5.1 Support from Family and Friends ...................................................................... 62
  4.5.2 Self-Encouragement and Motivation ................................................................. 63
4.5.3 Isolation..................................................................................................................................... 63
4.6 Support available to Caregivers .................................................................................................... 64
  4.6.1 Formal support.......................................................................................................................... 65
  4.6.2 Support from Friends and Relatives ......................................................................................... 66
4.7 Measures to Address Challenges ............................................................................................... 67
4.8 Discussion of Findings .................................................................................................................. 68

CHAPTER FIVE ........................................................................................................................ 76
SUMMARY OF FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS ........... 76
  5.0 Introduction.................................................................................................................................. 76
  5.1 Summary of Findings ................................................................................................................... 76
  5.2 Conclusions................................................................................................................................. 77
  5.3 Recommendations....................................................................................................................... 78
  5.4 Implications for Social Work Practice ......................................................................................... 80

REFERENCES............................................................................................................................... 82
APPENDIX 1 ................................................................................................................................. 94
APPENDIX 2 ................................................................................................................................. 96
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CL/P</td>
<td>Cleft lip and/or palate</td>
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<tr>
<td>KBTH</td>
<td>Korle-Bu Teaching Hospital</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>NAM</td>
<td>Naso-alveolar Molding</td>
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<tr>
<td>NHIS</td>
<td>National Health Insurance Scheme</td>
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<td>OPD</td>
<td>Out Patient Department</td>
</tr>
</tbody>
</table>
CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Globally, the issue of cleft lip and/or palate (CL/P) which is a medical condition has been of growing concern in many developed and developing countries. The condition CL/P is one of the most common Oro-facial deformities and discernible birth defects worldwide (Cooper, Ratay & Marazita, 2006). It involves an abnormal opening of the lip or the roof of the mouth (Revesz, Newman & Holtsberry, 2013). Cleft lip and/or palate can be unilateral or bilateral (Reilly, Reid, Skeat, Cahir, Mei & Bunik, 2013). Cleft lip is said to be unilateral when there is a gap or slit in the upper lip while bilateral cleft lip involves two gaps or slit in the upper lip (Reilly et al., 2013). Cleft palate however, occurs when there is failure of fusion of palatal shelves, resulting in an opening in the crown of the mouth into the nasal region (Costello & Ruiz, 2004). CL/P is the commonest craniofacial birth defects following Club foot in the incidence of major birth anomalies (Arosarena, 2007).

Deformities experienced during the formation of the fetus are known as birth defects, congenital malformation, congenital disorders or congenital birth defects (World Health Organization [WHO], 2016). The structure or function of the human body may be affected by different types of birth defects (Swanson & Sinkin, 2013). Congenital birth defects are the leading cause of infant mortality, causing twenty percent of all infant deaths (Matthews, MacDorman & Thoma, 2015) and also the most prominent cause of disabilities in the world (Tusano, 2015). It is estimated that about 303,000 new-borns die annually due to congenital birth defects globally (WHO, 2016). There are over 4,000 different types of congenital birth defects which range from
minor ones that do not need treatment to severe ones that lead to disabilities or require medical or surgical attention (Ricci & Kyle, 2009). Some examples of congenital birth defects include but not limited to Albinism, Club Foot, Cleft Lip and/or Palate, Congenital Heart Disease, Cyclopia, Down Syndrome, Cerebral Palsy, Ectopia Cordis, Bladder Exstrophy, Fetal Alcohol Syndrome, Goldenhar Syndrome, Hirschsprung’s disease, Haemophilia, Imperforate Anus, Katz syndrome (WHO, 2016).

Cleft lip and/or palate constitutes one of the common congenital birth defects and each year 250,000 babies have this condition worldwide (Adeyemi, 2015; Nelson, Glenny, Kirk & Caress, 2011). It can affect anybody regardless of colour or social status. An incidence of CL/P is 1.7 in every 1000 live births worldwide (Hakonsen, 2012). The prevalence of CL/P varies due to factors such as race, ethnic group, geographical location or gender (Mossey & Little, 2009). The prevalence of CL/P is high especially in Asian populations, Native Americans and Caucasians (Behrman, Kliegman & Jenson, 2007). In Asia, the prevalence of CL/P is 1.57 per every 1000 live births, 1.55 in every 1000 live births in Europe and 0.99 per every 1000 live births in South America (Panamonta, Pradubwong, Panamonta & Chowchuen, 2015).

The prevalence of CL/P in Africa is low (Behrman et al., 2007), with countries like Malawi and Uganda, recording a prevalence rate of 0.7 and 0.73 per 1000 live births respectively (Dresie, Galiwango & Hodges, 2011; Msamati, Igbibi & Chisi, 2000) and 0.9 per 1000 live births among groups of new births in Sudan (Suleiman, Hamzah, Abusalab & Samaan, 2005). Cleft lip occurs commonly in males than in females as compared to Cleft palate, which is common among females than males (Khan et al., 2012). In Ghana, estimates show that 6.3 per 1000 live births in the Volta Region suffered from CL/P (Agbenorku et al., 2011) while 1.30 per 1000 live birth suffered from CL/P in the Ashanti Region (Agbenorku, Yorke, Danso, & Turpin, 2013). Again
1000 cases of CL/P was recorded at the Korle-Bu Teaching Hospital (KBTH) between 2003 and 2015 in the Greater Accra Region of Ghana (KBTH, 2015).

Beliefs about the causes of CL/P are enormous and vary from one society to the other and have been linked to environmental and genetic factors (Murray, 2002). It is perceived that lack of vitamins and folic acid deficiencies, excessive alcohol consumption, smoking and self-medication by pregnant women may result in the birth of a child with CL/P (Chuangsuwanich, Aojanepong, Muangsombut & Tongpiew, 1998). Furthermore, women who before pregnancy are diagnosed with diabetes have greater risk of bringing forth a child with a CL/P as compared to women who are diabetes-free at the time of pregnancy (Correa et al., 2008). In India, the cause of CL/P is linked to the eclipse (Naram et al., 2013) whiles in Nigeria, CL/P is perceived to occur when parents abuse traditional religious beliefs (Oginni, Asuku, Oladele, Obuekwe & Nnabuko, 2010). Similarly, in Ghana, CL/P is perceived to be caused by evil spirits (Antwi-Kusi et al., 2015).

Children with CL/P usually have related dental problems, especially with the shape, size and position of the teeth (Costello & Ruiz, 2004). Some common features of these children include facial deformities, speech disorders, ear infections and feeding difficulties (Costello & Ruiz, 2004). The deformation in the physical appearance of these children results in low self-esteem, anxiety, discrimination and unhappiness in relation to social relationship which in turn affect the quality of life of caregivers (Rumsey & Harcourt, 2005). Cleft lip and/or palate in Ghana may result in perinatal death (Agbenorku et al., 2011). Although children with CL/P experience many challenges, their experiences in relation to that of their caregivers have not been explored much (Klein, Pope, Getahum & Thompson, 2006).
Generally, caregivers, especially mothers’ frustration starts immediately they receive report on the prenatal diagnosis or news of the child’s condition right after delivery (Tordal & Kjoll, 2010). The care of children with CL/P could pose challenges, ranging from financial constraints to problems associated with care giving which may eventually affect the wellbeing of caregivers and children (Adeyemo et al., 2009). According to Razera, Trettene, Tabaquam and Niquerito (2017), providing care for a child with CL/P could be challenging as the gap in the lip or palate poses significant difficulties in breastfeeding because of anatomical issues that make lip-sealing more intricate and also obstruct the development of the negative intraoral. This hinders the pressure that is vital for efficient suckling and could result in a range of complexities for the child: exhaustion throughout breastfeeding; lengthened feeding; development can be compromised leading to weight loss, iron deficiency or anemia. These challenges compound the concerns of the caregiver or mother as it gives them that feeling of being incapable of providing care for their children (Razera et al., 2017).

Furthermore, there seem to be circumstances whereby, caregivers are not aware of the treatment options available for them. The limited number of available specialized services could also lead to delayed surgical treatment of CL/P. All these factors can lead to an increase in caregivers’ frustrations and uncertainty about the future (Schwarz & Khadka 2004). In addition, people caring for children with CL/P could experience a range of emotional and psychological challenges (Lockhart, 2003). In an attempt to deal with the frustrations and challenges faced by caregivers of children with CL/P, some of them resort to infanticides, which have implications for human rights (Hutchinson, Wellman, Noe & Kahn, 2011).
1.2 Problem Statement

In many cultures, the birth of a child is usually greeted with excitement, but when a child is born with some kind of deformity, such as cleft lip and/or palate, families and society at large are likely to express feelings, which may range from minor disappointment to outright rejection of the child. Also, due to certain sociocultural beliefs about the causes of congenital birth defects, it is common for caregivers of children with CL/P to experience depression and hopelessness (Allen & Vessey, 2004) and these tend to hinder their ability to take good care of the child and understand his/her needs. This could make the care and management of the child difficult and often could lead to stigmatization, psychosocial stress and poor self-image of caregivers. There could also be the risk of future pregnancies, especially among mothers of such children as these mothers fear that, future pregnancies may result in another child with CL/P.

Even though philanthropists like Transforming Faces Worldwide come to Ghana yearly to perform surgeries on children with CL/P, not everyone gets to hear about them or have the opportunity to be operated on because they stay for short periods of time, while other caregivers may not seek medical help at all due to their sociocultural beliefs. Furthermore, few studies that have been conducted on CL/P in Ghana have concentrated on the endemicity of the condition in a rural community in the Volta Region of Ghana, (Agbenorku, Agbenorku, Sefenu, Mantondo & Osei, 2007), incidence of orofacial cleft care (Agbenorku et al., 2013), as well as the perception mothers of children with CL/P have about aetiology, social reaction and treatment of cleft (Antwi-Kusi et al., 2015) in Kumasi. To help bridge this gap of accessibility to wider information about the state of CL/P in Ghana, this study sought to explore the experiences of caregivers of children with CL/P at the Reconstructive Plastic Surgery and Burns Center at the Korle-Bu Teaching Hospital (KBTH), by highlighting the lived experiences of caregivers of
children with CL/P. This is important because, it has been detailed that cases of CL/P is increasing at the Korle-Bu Teaching Hospital in the Greater Accra Region of Ghana (KBTH 2015) and this may lead to an increase in the incidence of depression and hopelessness among the caregivers if nothing is done to address their concerns.

1.3 Objectives of the Study

The objectives of the study were to:

1. Explore caregivers’ beliefs about the causes of CL/P.

2. Identify the challenges faced by caregivers caring for a child with CL/P.

3. Ascertain the coping strategies adopted by caregivers caring for a child with CL/P.

4. Find out support services available to caregivers of children with CL/P.

1.4 Research Questions

The following research questions guided the conduct of the study:

1. What are the beliefs of caregivers about CL/P?

2. What are the challenges faced by caregivers caring for a child with CL/P?

3. What are the coping strategies adopted by caregivers caring for a child with CL/P?

4. What supports services are available to caregivers of children with CL/P?
1.5 Significance of the Study

This study will provide useful information for human rights activists, Ministry for Gender, Children and Social Protection, Ministry of Health, Government and Non-Governmental Organizations on the challenges faced by caregivers providing care for persons with CL/P in particular and other disabilities in general. Again, findings of the study will inform medical practitioners, social workers and the general public about the realities of the challenges caregivers encounter and the need for they themselves and their children to get the needed support. This will aid in designing appropriate policies and programs to support caregivers and children with CL/P.

Furthermore, social workers could use findings from this study to educate the general public on the various causes of CL/P as this will help reduce the negative beliefs people have about the causes of CL/P and thereby reduce the associated stigma and discrimination meted out to children with the condition and their caregivers. This study will also provide important information that will contribute to existing literature in the field of CL/P, as well as disability by serving as a guide for researchers who would want to undertake similar studies on CL/P in other parts of the country. The study will help Foundations and NGOs on CL/P to secure funds from donor agencies to aid in reconstructive surgery and provision of other medical needs of children with these conditions.

1.6 Definition of Terms

**Congenital Abnormalities:** Refers to physical, metabolic or anatomic divergence from normal growth that is obvious at birth or noticed during the first year of life (Harry & Karpawich, 2007).
Cleft Lip and/or Cleft Palate: Refers to birth defects that takes place when a baby’s lip or mouth and top crown of the mouth do not fuse properly during pregnancy (Agbenorku et al., 2011).

Perceptions: Is the personal expression of how one views the world that is made up of many socio-cultural elements (McDonald, 2012).

1.7 Organization of the Study

The study was organized under five main chapters. The first chapter of the study was the background to the study, statement of problem, objectives of the study and research questions. The chapter also discussed the significance of the study and provided definition of terms. Chapter two covered the related literature review and theoretical framework that underpinned the study. The third chapter outlined the methodology for the study. This chapter comprised of the research design, sampling techniques, target and study population. The chapter also discussed the sources of data and how data handling and analysis was done. Ethical consideration, organization of the study and limitations were also considered in this chapter. The fourth chapter centered on presentation and discussion of the findings. Chapter five comprised of the summary of findings, conclusions, recommendations and implications for Social Work practice.
CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL PERSPECTIVE

Introduction

The chapter presents a review of relevant literature on the following themes: caregivers’ beliefs about the causes of CL/P, challenges faced by caregivers of children with CL/P, coping strategies adopted by caregivers of children with CL/P and support available to caregivers of children with CL/P. The chapter also describes the Adult Personal Resilience Theory and the Stress, Appraisal and Coping Theory which were the theories underpinning the study.

2.1 Caregivers’ Beliefs about CL/P

In both developed and developing countries, people hold different beliefs about the causes of CL/P. According to Langlois, Kalakanis, Rubenstein, Larson, Hallam and Smoot (2000), an individual’s appearance may unconsciously be used to attribute negative and positive qualities due to the beliefs held by other individuals. People’s beliefs thus eventually may affect how they relate among themselves. In a pilot study to assess the perceptions, expectations and reactions to cleft lip and palate surgery in some rural communities in India, Weatherley-White, Eiserman, Beddoe and Vanderberg (2005) used a 15-item questionnaire to elicit parents’ general knowledge concerning cleft lip and/or palate, beliefs regarding its causation, and expectations of what surgery would accomplish to identified some of the causes of CL/P. The findings of the study revealed that majority of respondents attributed the cause of CL/P to an act of God. In addition, some of the respondents revealed that CL/P was a punishment due to sins committed by parents or family members in the past. The study further revealed that the causes of CL/P were diverse
and others attributed it to solar eclipse and starvation that occurred in the village during pregnancy.

Similar to the study by Weatherley-White, Eiserman, Beddoe and Vanderberg (2005), Ross (2007) explored the beliefs and practices of South African Muslim and Hindu traditional healers regarding cleft lip and/or palate. The study employed individual interviews, which was complemented with a secondary data. The study recruited four Hindus and twelve Muslims who viewed the issue of CL/P from social and religious perspectives. The study revealed that if a pregnant woman handled a sharp object during an eclipse, her infant could be born with a cleft. Also, the Hindu healers who participated in the study indicated that CL/P could be attributed to karma. The study further reported that during eclipse, pregnant women who ate and drank suffered complications after the eclipse had disappeared (Ross, 2007). It was not surprising that the respondents attributed CL/P to spiritual issues because of their religious background.

In a study which employed an exploratory-descriptive, qualitative research design, Dagher and Ross (2004) found some of the causes of CL/P. The researchers recruited fifteen African traditional healers who had been practicing for at least one year. It was revealed in the study that traditional healers included in the study had treated one to six persons with cleft lip, cleft palate or both. Many of the informants believed that CL/P was caused by ancestors, spirits and witchcrafts. The study further revealed that the causes of CL/P were associated with abortion thus women who gave birth to children in this condition are considered as witches. As a result, the traditional healers used a variety of plant and animal products to treat these conditions and were augmented by spiritual resources from ancestors.

Olasoji, Ugboko and Arotiba (2007) conducted a study to find out the perceptions of mothers on CL/P from two Nigerian ethnic groups who had children with CL/P at the Obafemi Awolowo
University Teaching Hospital. The researchers recruited sixteen mothers from Yoruba ethnic group and twenty from the Hausa/Fulani ethnic group who were interviewed over an eight month period. The study revealed that thirteen out of the sixteen Yoruba group members who participated in the study, attributed the causes of CL/P to supernatural forces (evil spirits and ancestral spirits), while sixteen of the twenty Hausa/Fulani parents who participated in the study attributed the cause of CL/P to the will of God. However, it was further revealed that twelve out of the sixteen Yoruba parents had consulted traditional healers for treatment before they went to the hospital. Based on the works of Dagher and Ross (2004) and Olasoji et al. (2007) it can be noted that, the perceptions of the cause of CL/P held by people in Nigeria were not different from those of South Africa.

Venkatesan (2015) researched on socio-cultural dimensions of cleft lip and palate in India. The study relied mainly on secondary data form empirical studies conducted over the world. The study revealed that results from available body of western literature, as well as the sparsely available details on CL/P in India have failed to provide a coherent picture. According to Venkatesan (2015) the reason for this may be because various investigators had used different measures, non-representative and/or small samples. Venkatesan (2015) noted that, there were several myths surrounding persons with CL/P and suggested that children with CL/P is possibly the consequence of a curse placed on them, due to their own actions in their previous lives. However, the researcher added that these children could be holy and gifted with special powers to inspire people and that is the reason they had been affected by the condition. Similarly, Dagher & Ross (2004) indicated that children with CL/P were believed to have supernatural powers that were critical for families and communities.
El-Shazly, Bakry, Tohamy, Ali, Elbakry, Brown and Weatherley-White (2010) conducted a study on the attitudes toward children with clefts in rural Muslim and Hindu societies. The researcher adopted a questionnaire which was administered to fifty families of children with cleft lip and/or palate seeking care at Operation Smile missions. The study found that almost all the respondents blamed the birth of CL/P child on a curse or an act of evil spirits. This led to individuals blaming the birth of a child with CL/P as evidence of witchcraft, collusion with the devil or as a result of the sins of parents. The attitudes and beliefs of people about the cause of cleft lip and/or palate tend to influence the health seeking behaviour of respondents.

The causes of CL/P were varied and the attitude that people in Africa held was different from people in Europe. Clark, Mossey, Sharp and Little (2003) in a study on the socio-economic status and orofacial clefts in Scotland attributed the cause of CL/P to medical conditions. The study comprised of Eight hundred thirty-four live births with OFC born between January 1, 1989, and December 31, 1998, ascertained from the nationwide register of the Cleft Service in Scotland, compared with the total 603,825 live births in Scotland in that period. The study revealed that in Scotland, areas with higher growing proportion of local authority housing involving young families, increase in unemployment and high unskilled workers have a higher incidence of CL/P. The study further indicated that it is possible that there is an association between deprivation and risk factors for CL/P, most likely smoking during pregnancy.

Emordi and Osifo (2018) examined the challenges of congenital malformations in Africa and reported that several factors come to play in issues of congenital malformation such as CL/P. They indicated that nutritional factors such as vitamins and minerals deficiencies, viral infectious diseases like syphilis in pregnancy, neural tube defects, among others have been found to cause CL/P in newborns. It was also revealed that the age at which a mother gives birth to a child could
increase her risk of having a baby with congenital malformations or abnormalities such as Down-syndrome. According to Emordi and Osifo (2018), maternal exposure to chemicals, usage of some types drugs, infections during pregnancy and malnutrition are all attributed to the condition of CL/P.

In a study on awareness and causal beliefs of cleft lip and palate: perspectives from Filipino parents and caregivers, Bondoc and Ligot (2015) found some causal beliefs of cleft lip and/or palate. Using a convenience sampling, eighty-four parents and caregivers from two institutions that offer surgical, dental, and speech interventions for children with CL/P participated in a pilot study. The study indicated that hereditary, effect of medicine intake during pregnancy and effects of chemicals (zonrox, acid, smoke) were some of the causes of cleft lip and palate. The study further found that effect of foods craved for during pregnancy, accident/travelling fatigue, lack of good nutrition during pregnancy (folic acid), unsuccessful abortion, curse and even God’s will were some of the factors identified.

Agbenorku et al. (2011) examined cleft lip and/or palate in a community in the South Eastern part of Ghana. The study was to detect the prevalence of CL/P in the Wudoaba community and to investigate the factors associated with the causes of this malformation in the area. Two different interview-based questionnaires were designed to collect data over a period of 3 days from March 27 to 29, 2006. The study which adopted a purposive and accidental random sampling technique found that genetic homogeneity and vitamin deficiencies in this community may be some causal factors for the high prevalence of CL/P.

Additionally, risk factors such as tobacco smoking during pregnancy contributed to CL/P (Clark et al., 2003). Similar to this finding was a study by Honein et al. (2007) which found a direct
association between smoking and orofacial clefts and indicated that there are specific phenotypes that are affected when a woman smokes during pregnancy. According to Little et al., (2004), women who smoke during pregnancy are more likely to have children with CL/P than women who do not smoke. In many developing countries, people with less access to prenatal care associate the causes of CL/P to religion and folklore than to biomedical explanations (Hutchinson et al., 2011). For instance, as mentioned earlier, South Indian Muslims and Hindus believe that when a pregnant woman handles a sharp object during an eclipse, it causes a child to have CL/P (Ross, 2007).

In an ethnographic study using focused informants to describe the perceived causes of CL/P in Philippine, Daack-Hirsch and Gamboa (2010) found several causes of CL/P. Their study revealed that most of the participants attributed CL/P to the trauma resulting from a pregnant woman falling, slipping or being startled during pregnancy as well as other genetic related issues (Daack-Hirsch & Gamboa, 2010). Additionally, women who use medicines such as valproic acid and topiramate during the first trimester of pregnancy have a higher risk of giving birth to children with CL/P than women who do not take these medicines (Margulis et al., 2012).

Even though there are no specific factors that have been outlined as the main causes of CL/P among children, some scholars attribute CL/P to mutation of genes (Dixon, Marazita, Beaty & Murray, 2011). Also, a combination of genes and other factors that the pregnant woman is exposed to in her environment such as what the mother eats and drinks, certain medications she uses during pregnancy are some of the causes of CL/P among children (Mossey & little, 2009). In addition, mutant genes, chromosomal abnormalities and interactions between genes and environmental factors could cause CL/P (Butali et al., 2011). According to Laureta and Macapagal (n.d.), although the exact cause of CL/P is not known, it is generally believed to have
been caused by genetic and environmental factors. Alkuraya, Saadi, Lund, Turbe-Doona, Morton and Massa (2006) also points out that a number of genes have been identified as being responsible for causing CL/P, however, such genes and how they interact are yet to be identified.

In 2009, Chuacharoen, Ritthagol, Hunsrisakhun and Nilmanat studied the needs of parents caring for infants with cleft lip and/or palate in Thailand. They revealed in their study that ‘caregiver parents’ of children with the condition of cleft lip and palate especially fathers felt less worried about the condition of their children because of their experience with the condition. Some fathers had previous knowledge about the condition of cleft lip and palate and perceived it to be a malformation that could occur in birth.

**2.2 Challenges Faced by Caregivers**

Zeytinoglu (2014) examined the experiences of couples who have a young child with cleft lip and palate, comparing prenatal and postnatal diagnosis groups. The study was designed to describe the experiences of both mothers and fathers who were currently caring for an infant or young child who was born with cleft lip and/or palate. In the study which adopted a convenient sample consisting of seventeen couples (ten prenatal and seven postnatal) found that the timing of the CL/P diagnosis, the birth and initial stages after birth were reported as the most challenging periods for both prenatal and postnatal couples. The study further revealed that the initial stages (i.e. immediately following the birth) were reported as more stressful for the postnatal diagnosis group because they had no time to prepare. Moreover, the cost of treatment and feeding coupled with social stigma were reported as the major source of stress and challenges faced by all the seventeen couples. This indicates that the challenges faced in caring for a child with cleft are not only experienced by the mother but the father as well.
It has also been observed that cleft lip and/or palate conditions have great impact on caregivers who provide assistance to these children. However, the challenges escalate when these parents have to cater for twins with cleft lip and palate. Fernihough (2011) discussed the experiences of mothers of twins born with congenital facial deformity. The study was qualitative and sought to explore the unique experiences of these mothers. The study reported that the participants face emotional challenges such as shock, disbelief, denial and sadness due to the condition. The author observed that many mothers experience loss of control of their lives, changed their career goals because of additional demands when faced with a child with any form of birth defect. According to Fernihough (2011), all the participants indicated that raising a child with a cleft lip and palate had a strain on their marital relationship. This could lead to many marital break-down especially if these challenges are not given the needed attention and managed well.

Nelson et al. (2011) in a study on parents’ experiences of caring for a child with a cleft lip and/or palate: a review of the literature found some challenges faced by parents in caring for children with cleft and palate. The review brought together for the first time the existing qualitative and quantitative research evidence based on secondary literature. The review identified a lack of comparable research in the cleft field to examine parents’ experiences and needs at different stages of their children’s life. Thus, the need for this current study. The study further revealed that caring for a child with cleft and palate impacted on the emotion lives of caregivers. To the researchers, other challenges commonly mentioned by the participants included stigma and other social challenges in seeking support for their children.

Hakonsen (2012) investigated cleft lip and/or palate in Ethiopia: a qualitative study of Ethiopian mothers’ experiences with raising a child who has cleft lip and palate. The study recruited six biological mothers who were interviewed. Using a semi-structured interview guide as a tool, the
author elicited in-depth information from the informants. The study revealed that mothers raising a child with clefts lip and/or palate faced financial challenges and difficulties in feeding their baby. Notwithstanding, some of the mothers indicated that their husbands, mothers and fathers in-law were worried and ashamed about the child’s condition. This is evident that cleft lip and/or palate impacted not only on the caregiver but other relations of the child.

Razera, Trettene, Tabaquim and Niquerito (2017) examined the burden among caregivers of children with cleft lip and palate. A total of one hundred caregivers whose children were in the perioperative period of cheiloplasty and/or palatoplasty, were interviewed using the Scale Burden Interview. The data of the study were analysed quantitatively and it was found that 100% of participants reported their children depended on the same caregiver, while 73% reported that, in general, they felt overloaded in taking care of the child, and 67% indicated that, because of the time they spent providing care to the child, they did not have enough time to take care of themselves. Additionally, 59 percent stated that they felt stressed, having to provide care to the child along with other family responsibilities and work.

Although many studies have focused on the challenges faced by mothers in giving care to children with CL/P, fathers’ experiences have been neglected despite the important role fathers play in the well-being and development of their children. Zeytinoglu, Davey, Crerand and Fisher (2016) investigated the impact of cleft lip and palate on fathers. The study adopted a descriptive qualitative study with a convenience sample of seventeen fathers and the findings were analyzed thematically. The study revealed that cost of treatment, feeding and social stigma were major source of stress for all fathers.
Nelson, Glenny, Kirk & Caress (2011), examined parent’s emotional and social experiences of caring for a child through cleft treatment. The researchers conducted in-depth interviews with thirty-five parents with children between the ages of twenty weeks and twenty-one years to explore their experiences through the treatment program. The data was analyzed using a constructivist grounded theory approach. The study found that throughout childhood and adolescence, parents experienced conflicting emotions about their child’s emotions, uncertainty about cleft treatment and stigmatizing attitudes. Although parents attempted to manage emotional tensions by pursuing cleft treatments, the interventions could themselves be a source of conflict for them (Nelson et al., 2011). Similarly, Venkatesan (2015) indicated that caregivers especially parents go through different emotional troubles for instance shock, disappointment, guilt, denial despair, shame and depression.

People’s beliefs about CL/P resulted in few parents exercising some constraints and keeping their children totally isolated and not permitting them to leave the house or attend school (Weatherly-White, Eiserman, Beddoe & Vanderberg, 2005). Pelchat, Lefebvre, Proulx and Reidy (2004) conducted a study to examine the parental satisfaction with an early intervention program in Canada. Their study implemented an early family prevention program for Canadian parents who gave birth to children with CL/P and Down syndrome. The study found that parents fought each other while caring for the child with CL/P due to misunderstandings therefore causing them to withdraw from each other (Pelchat et al., 2004).

Benson, Gross and Kellum (1999) in a research conducted in Mississippi found that the birth of and care of a child with CL/P created tension between couples and hampered the development of the child. Furthermore, Benson et al. stressed that caring for a child with CL/P resulted in disagreements between couples due to the variations in parenting strategies. This led to blame on
each other and affected the development of the child (Benson et al., 1999). Furthermore, caregivers especially couples ended up having conflicts and suffering violence due to the issues pertaining to the provision of care for a child with CL/P (Awoyale et al., 2016). These incidents subsequently led to miscommunication among family members in addition to feelings of stigma in the community.

In Sweden, mothers of children with CL/P revealed unmet nutritional needs of their children due to inadequate support from health professionals with regards to the feeding of their children (Lindberg & Berglund, 2013). A mix-method research conducted by Awoyale et al. (2016) in Lagos State, Nigeria revealed that challenges encountered by some caregivers of children with CL/P were breastfeeding difficulties. Caregivers also lacked adequate information about proper breastfeeding of the child with CL/P and as a result they encountered stress and shock (Awoyale, 2016).

Feeding has been identified as a major challenge some mothers caring for children with CL/P face, this involves either giving solid food to the child or breastfeeding the child (Kalland, 1995). According to Kalland, some mothers fail in an attempt to breastfeed the child with CL/P. They usually resort to bottle feeding which also comes with challenges. This results in disappointments for these parents (Kalland, 1995). Mothers who are able to breastfeed their children with CL/P do so while avoiding scenes of people to overcome social pressure (Kalland, 1995). In addition, Kalland reveals that some mothers face the challenge of bonding with the child as they have disappointments and frustrations giving birth to a child with the condition of CL/P. In assertion to this is a study by Collett, Leroux and Speltz (2010) who reported that feeding of the child with cleft lip and/or palate is distressing and disrupts the bonding that should
exist between the child and his or her parents. Parents’ reaction to a child with CL/P or childhood disabilities could be similar to the grief associated with the loss of a child.

Allen and Vessey (2004) in a study on primary care of the child with a chronic condition revealed some of the challenges faced by parents of children with CL/P. To them, the feeling of depression and hopelessness is common among parents of appearance-impaired children. Furthermore, parents of children with CL/P tend to be anxious about the reaction of the peers of the child at school going age and issues of the implication of the development defects on the child (Collett, Leroux & Speltz, 2010). In a study to assess the parental diagnosis of facial clefts and the evaluation of specialized counseling, Rey-Bellet and Hohlfeld (2004) found that, the feeling of guilt, fear and sadness were common among parents who gave birth to children with CL/P. It is important to note that parents who discovered that their children have CL/P at antenatal or at the time of the delivery go through similar emotions and feelings (Rey-Bellet & Hohlfeld, 2004).

Pope, Tillman & Snyder (2005) conducted a study in Jamaica and found that parents who care for children with cleft lip and palate encounter challenges relating to self. Such people have self-doubt about their parenting capacity. Besides, they go through persistent stress. Parents of children with cleft lip and/or palate go through different emotional troubles that destabilize their family (Kapp-Simon & Krueckeberg, 2000). Some of these emotional troubles include shock, grief sadness, fear and guilt. Some experience severe emotional troubles during their first experience of having a child with the condition of cleft lip and palate (Kapp-Simon & Krueckeberg, 2000). According to the author, in addition to these emotional troubles, parents of children with CL/P also encounter difficulties in feeding the child as well as integrating the baby into the family (Kapp-Simon & Krueckeberg, 2000).
Relating to emotional and psychological challenges, Nelson et al. (2011) assert that anxiety, depression and poor psychological adjustment termed as ‘emotional strain’ are some of the challenges caregivers of children with cleft lip and palate encounter as they provide care for such children. Apart from that, family resources are seriously affected as parents provide care for children with cleft lip and/or palate. The long and frequent visits to health facilities for treatment negatively affect the family (Nelson et al., 2011). Furthermore, mothers of children with cleft lip and palate have indicated their feelings of hatred for reactions from friends and family in addition to the verbal abuse they suffer at the hands of some section of the public. (Nelson et al, 211). In the long run these emotional and psychological troubles affect the interactions between the parents and their children with the condition leading to anger towards other children (Venkatesan, 2015). According to Nelson et al. (2011) parents who give birth to CL/P children have little information about the condition, and are scared that people will only see their child’s deformity and not the worth and dignity of the child as human. People give positive attributes to people with no deformity and negative attributes to people with facial and other developmental defects (Nelson et al., 2011). Psychosocial problems have been identified to be some of the challenges caregivers of children with CL/P encounter (Cerand, Kapa, Litteral, Pearson, Eastman & Kirschner, 2018).

Emordi and Osifo (2018) are of the opinion that increased parental stress, marital strain, lack of family acceptance and stigmatization are some of the numerous problems caregivers of children with CL/P face while providing care for a child with the condition. Likewise, a survey conducted in the USA by Strauss et al. (2007) found that perceived stigmatization was common among children with CL/P and their parents or caregivers. Children and their caregivers experience stigmatization and societal rejection because of the effects of CL/P on the appearance of the
child (Rumsey & Harcourt, 2005). CL/P condition influences the emotions of parents, which could result in conflict and divorce (Locker, Jokovic, Stephens, Kenny, Thompson & Guyatt 2002).

In Malaysia, Noor and Musa (2007) conducted a mix method study with the aim to assess the levels of satisfaction of patients of cleft lip and palate and their caregivers with treatment and revealed that with regards to the treatment of their children, about 18 percent of caregivers were saddened by the fact that health providers did not include them in the process of decision making that affected their children. Another concern of some caregivers was the fact that during sessions with healthcare providers, their children with cleft lip and/or palate, the consulting rooms are usually overcrowded and this inconveniences caregivers.

Contrary to the fact that some regretted for not been involved in the decision making process that affected their children, Noor and Musa’s (2007) findings showed that some parents of children with cleft lip and/or palate were shy of discussing problem concerning their children with health specialists. Waiting for longer periods to be attended to by health specialists have been stated as being challenging for some caregivers of children with cleft lip and/or palate (Noor & Musa, 2007). The findings further revealed that caregivers travelled long distance to health facilities to seek care which is compounded by the longer waiting periods within the health facilities for care (Noor & Musa, 2007). Some parents have difficulty adjusting to the needs of the child.

Hasanzadeh, Khoda, Jahanbin and Vatankhah (2014) conducted a qualitative study in North-Eastern Iran assessing the psychological distress among mothers of patients with non-syndromic cleft lip and palate, the study revealed that caregivers of children with cleft lip and/or palate face challenges relating to severe psychological distress. In addition, families were also drained in terms of their financial resources due to the provision of care for children with CL/P
What worsen the burden of caregivers is that most of them especially mothers are left alone to handle the stress associated with caring for a child with CL/P such as frequent visits to the health facilities, feeding and other daily care provisions for the child (Hasanzadeh et al., 2014).

The effects of CL/P influence the functionality of parents or caregivers and the family as a whole. The effects are common especially during the first three months of the child’s life (Locker et al., 2002). In a study to investigate family impact of child oral and oro-facial conditions, Locker et al. (2002) indicated that, parents and caregivers of children with CL/P normally take time off work as the child requires extra attention, this resulted in financial difficulties, heightened feeling of guilt among parents as well as distress because of the child’s condition. In the findings of a research conducted in Nigeria, it was observed that a large majority of caregivers of children with CL/P reported of their social lives being negatively affected as a result of being burdened with the responsibility of caring for a child with CL/P (Emeka, Adeyemo, Ladeinde & Butali 2017). It was asserted that before surgery, all families of children with bilateral cleft lip and cleft palate reported that their finances were negatively impacted by caring for the cleft children but, after the child’s condition was corrected only few caregivers, (15 percent) reported deterioration in financial capacity (Emeka et al., 2017). Concerning the distance travelled to health facilities to seek treatment, Sandy et al (1998) observed that parents expressed discomfort in travelling long distances to health facilities to seek care for their children with CL/P.

Many parents also experience verbal and non-verbal distasteful expressions by friends and other family members in public, which makes them shun social gatherings and associations to avoid being seen as different and ridiculed (Johansson & Ringsberg 2004). Coy, Speltz and Jones
(2002) indicated that caregivers spend less time with the child and also demonstrate less sensitivity during interaction which is critical in identifying the basic needs of the child. To the authors, factors such as maternal depression and the worry over not getting an ideal baby could hinder attachment between parents and the child with CL/P.

2.3 Coping Strategies Adopted by Caregivers

Baker, Owens, Stern and Willmot (2009) examined the coping strategies and social support in the family impact of cleft lip and palate and parents’ adjustment and psychological distress. The researchers recruited one hundred and three parents of children or young adults with CL/P from families attending a multidisciplinary cleft lip and palate clinic. The study which employed questionnaire as an instrument found that parents caring for children with CL/P adopted approach oriented (seeking support, problem solving, logical analysis, positive appraisal) rather than avoidance orientated (cognitive avoidance, acceptance, alternative rewards, emotional discharge) dominant coping strategies. It is interesting to note that some mothers in an attempt to deal with the pressure of caring for a child with CL/P, chose to laugh or wear smiles rather than worrying about the situation.

Similar to this finding is a quantitative study by Hasanzadek, Khoda, Johanbin and Vatankhah (2014) in Iran. The study findings show that mothers of children with CL/P employed approach oriented coping strategies. The findings further indicated that, this strategy used by mothers of children with CL/P was geared towards problem solving and managing the issue by obtaining needed resources to tackle the problem. In the same vein, Gibson (2016) also reported that in the United Kingdom, caregivers of CL/P adopted better use of approach coping than avoidance coping strategies. The author also stated that the positive approaches caregivers employed include: acceptance, seeking guidance, problem solving and cognitive avoidance. Other
caregivers in their bid to reduce their problems related to living with a child with the condition of cleft lip and/or palate resort to avoidance and emotion oriented style of coping which have been identified as negative strategies that further increases the burden. Previous contact with patients of cleft lip and/or palate by some caregivers have been noted to be a strong coping strategy for some caregivers because, they realize that the problem is not peculiar to their children (Chuacharoen et al., 2009).

According to Nelson et al. (2011), caregivers of children with cleft lip and/or palate overcome the stressful life of caring for a child with cleft lip and/or palate by acknowledging their personal strength, they attach importance to their relationships and have good intentions. The authors further added that caregivers of children with CL/P adopt tolerance as a strategy to cope with challenges (Nelson et al., 2011). Besides they also have a sense of communal belonging and sense of good hope for the future (Nelson, et al., 2011). Cognitive problem focused coping strategies have been also identified as a useful coping method adopted by some caregivers to do away with some challenges or stress associated with providing care for CL/P children, it is reported that caregivers resort to having discussions with school staff regarding the condition of the child. This exercise is noted to bring some sort of relief to the parent (Nelson et al., 2011).

In a study to analyze the use of the resiliency model of family stress, adjustment and adaptation by a rehabilitation counselor, Frain, Lee, Tansey, Tschopp & Chronister (2007) identified how rehabilitation counselors can help families coping with a disability. The study found that helping the family identify existing resources and educating the family about the rehabilitation process, procedures, and realistic time frames for each treatment procedure were important. According to the researchers, to help couples and families prepare, adapt, and cope with the intrusive medical procedures their children with CL/P will require, it is vital to inform them about the treatments
that will be needed, such as ongoing surgical procedures, dental treatment, and speech therapy during different developmental stages of the child’s life. Nelson, Glenny, Kirk and Caress (2011) indicated that coping strategies used by caregivers of children with CL/P have not been a priority.

Studies that have treated coping strategies as a variable have found that coping strategies include cognitive or problem-focused strategies such as discussing a child’s needs with school administrative staff and teachers to think of ways to help them establish some social bonds which will prevent teasing from colleague students (Klein, Pope, Getahun, & Thompson, 2006). Similarly, Johansson and Ringsberg (2004) found that caregivers made use of emotional-focused strategies such as maintaining a hopeful attitude for the future and having confidence in themselves.

Similar to findings from the study by Frain et al. (2007) was a study by Sischo, Clouston, Phillip and Broder (2016) to understand caregiver’ response to early cleft lip and/or palate care for their infants. This study employed a mixed method multicenter longitudinal approach with a sample size of one hundred and eighteen participants in the United States. Each participant belonged to one or two treatment group(s) - the traditional care (traditional surgical cleft treatment) only or naso-alveolar molding (NAM). NAM is a nonsurgical therapy that uses molding plates to reduce cleft size and reshape the infant’s nose prior to lip surgery (Grayson & Maull, 2004) plus traditional care. They looked at responses from the beginning of treatment (less than one month of age), pre-lip surgery (between three-five months of age) and post-palate surgery (twelve to thirteen months of age) and found that, the first year was demanding for all caregivers but the onset of NAM was more stressful. However, caregivers used a hopeful attitude, problem-solving behaviour, and social support to cope with this stress. The authors further revealed that
caregivers adopted problem solving as a way of coping with their child’s condition by investigating and learning about CL/P and its treatment options. Findings of the study also revealed that caregivers of CL/P coped with the situation by comparing their children’s condition with others and getting the understanding that CL/P has no long term effect on the child, rather, it is purely a cosmetic defect (Sischo et al., 2016).

Gibson (2016) conducted a research in Vancouver, Canada assessing caregivers of children with CL/P’s burden and coping strategies. He revealed that caregivers relied on avoidant coping while others were motivated through their resilience. Again, caregivers used emotional discharge to overcome certain bad times while caring for a child with CL/P. The study further explained that seeking guidance similar to keeping a confidant was also reported to have been adopted by caregivers in their attempt to deal with stressful moments (Gibson, 2016). In the same vein social support has been highlighted as being useful in the process of coping, as well as perceived support from professionals involved in caring for a child with CL/P (Emeka et al., 2017). Besides, support from friends and family has been linked to lower distress, better adjustment, and less negative family impact, possibly due to social support providing greater feelings of belonging, self-esteem, a positive outlook, and a greater sense of value (Emeka et al., 2017).

Stock and Rumsey (2015) researched on the experience of parents with clefts and palate. The study employed individual telephone interview eliciting qualitative data. The data was analyzed thematically and it was reported that unlike other new parents with no experience of CL/P, parents with CL/P themselves had firsthand experience and unique feelings about what it means to grow up with a cleft. Discussing such feelings with his or her partner may be difficult, and the partner may struggle to understand. The study further revealed that supporting couples to communicate these feelings may be a useful way of strengthening the parents’ relationship and
helping them to cope with their child’s diagnosis together. On the contrary, Awoyale et al. (2016) revealed that caregivers of children with the condition of CL/P in order to cope with the pressure of caring for the child resorted to avoidance of people through excuses. The authors further stated that some caregivers in their bid to cope covered the faces of their babies when they went to public places.

2.4 Support available to Caregivers

Due to the challenges and the burden of caring for a child with CL/P, it is vital for caregivers to receive some kind of support to help improve their overall well-being. This support could be formal or informal depending on the information that the caregiver has. According to Adeyemo et al. (2009), in Nigeria, all caregivers and patients with CL/P receiving treatment in the Department of Oral and Maxillofacial Surgery in Lagos University Teaching Hospital received the support of an American Non-Governmental Organization through subsidies in the cost of the treatment. Even though the support was not enough, participants indicated that they could not have done without the support.

Furthermore, counseling has been reported in many studies as a form of support available to caregivers of children with CL/P (Hlongwa & Rispel, 2018; Snyder & Lyon, 2013). Parents of children with CL/P in the United States of America are provided with counseling by social workers and counselors as this has a positive effect on having their emotional and social support needs met (Snyder & Lyon, 2013). Similarly, a study by Hlongwa and Rispel (2018) in South Africa revealed that, mothers providing care to children with CL/P received information about their children’s condition and counseling from health professionals specifically doctors and this helps in accepting their children’s condition.
In a study conducted in the United States, Kaye, Lybrand and Chew (2018) revealed that Social Workers provided interventions for caregivers of children with CL/P. As part of these interventions, children with CL/P and their caregivers received counselling as well as temporary financial assistance, provision of nutritional diets and other non-related assistance such as helping them in legal cases (Kaye et al., 2018). In addition, Zeytinoglu, Davey, Crerand, Fisher and Akyil (2016) assessed the experiences of couples caring for a child born with CL/P and also emphasized that mothers of children with CL/P received emotional support from their husbands by having open communication and being affectionate towards each other. Likewise, extended family members as well as friends provide emotional support to families with children with CL/P by encouraging them (Zeytinglu et al., 2016).

In Ghana, Antwi-Kusi et al. (2015) revealed that both nuclear and extended family relations provided moral and financial supports to mothers of children with CL/P. The findings of a study by Hakonsen (2012) in Ethiopia found that extended family relations were involved in providing practical support in the form of looking for information for treatment, financial support and emotional support to mothers of children with CL/P. Mothers of children with CL/P also receive assistance and advice from other mothers with children with CL/P who have been in or are in similar situation (Hakonsen, 2012).

Parents of children with CL/P in the United Kingdom receive social support from people in the form of tangible support (accessibility of financial resources and services), appraisal support (for instance, availability of a confidant), and belonging support (availability of someone with whom to socialize) (Baker, Owens, Stern and Willmot, 2009). Awoyale (2016) noted that in Nigeria there are advocacy groups as well as women organizations that extend support to caregivers of children with CL/P. They suggested that a range of supportive services designed could help
caregivers in caring for a child with CL/P. Such services included provision of information to
caregivers, education and training on the use of technology to enhance knowledge about CL/P,
counselling and support groups in addition to financial support. Johns, Gutierrez, Nicolaou,
Garcia, Cespedes-Knadle & Bava (2017) researched into caregivers of children with CL/P
experiences in the United States. They revealed that support available for caregivers to enable
them cope with the difficulties of caring for a child with CL/P include skill enhancement,
provision of aid and family support through interventions.

In Uganda, services developed to support mothers caring for babies with CL/P in CL/P treatment
facilities include providing advice on use of nutritious food, provision of food supplements and
insecticide treated nets to caregivers (Hodges, Wilson & Hodges, 2009). Moreover, Singh (2009)
observed that in India, Smile Train in their bid to support caregivers, formed a team that
routinely visited the homes of children with CL/P and their caregivers to interacted with them as
a strategy to give them confidence and see to their well-being. In addition, outreach programs
were organized in communities in India with the assistance of social workers to help sensitize
caregivers about the condition of CL/P (Singh, 2009).

Camps for caregivers were also organized to assist caregivers in providing adequate care for
children with CL/P, within the camps, some amenities such as taps, cooking facilities and
lavatories were made available for caregivers while going through education and receiving
treatment for their children with CL/P (Singh, 2009). Moreover, Singh emphasized that to ease
movement from their homes to the CL/P treatment centers and camps, caregivers were provided
with transportation in order to be able to visit the centers. Materials such as clothing, toys shoes,
milk and other food products were also received at the facilities. Furthermore, the broad range of
support given to caregivers of children with CL/P include: engaging caregivers in vocational
training programs while receiving treatment for their children with CL/P in the facilities (Singh, 2009).

According to Pope et al., (2005), support systems available to caregivers of children with cleft lip and/or palate include networking with parents and caregivers who also care for children with the condition. This connection has been identified to be helpful for caregivers and help reduce their stress. The study reports that this group of caregivers come together to determine the well-being of themselves and their children (Pope et al, 2005). Noor and Musa (2007) are of the view that in Malaysia, the Cleft Care Team has been supportive and friendly to caregivers of children with cleft lip and/or palate. In assessing the impact of the Smile Train Alleviating programs around the world, Poenaru (2012) emphasized that Smile Train is the world’s leading charity organization that provides support and care for cleft lip and/or palate patients. Providing around 700,000 surgical supports in about 84 countries, the organization trains medical professionals mostly national surgeons to assist CL/P patients (Poenaru, 2012).

Poenaru in his findings also adds that Smile Train provides funding for local surgeons to support CL/P patients. Among the regions of the world that have benefited largely from the support of Smile Train, South East Asia and the Western Pacific with 87% is noted to have received larger support (Poenaru, 2012). Though the earliest continent to receive surgical interventions for CL/P patients from Smile Train, Africa has the lowest CL/P repair (Poenaru, 2012). Elsewhere in Thailand, Patjanasontorn, Pradaubwong, Rogbuttsri, Mongkholtanwornchai and Chowchuen, (2012) also revealed that CL/P patients and their caregivers were covered under the Thailand Universal Coverage Healthcare System which is the most commonly registered healthcare system in Thailand. The healthcare system is free for patients and caregivers without any
deductible income, in addition, the care covers the cost of surgery, dental, speech therapy and development assessment (Patjanasoontorn et al., 2012).

The cost identified to be incurred by caregivers of children with cleft lip and/or palate is only their transportation costs (Patjanasoontorn, 2012). Moreover, counseling has also been identified as part of the support systems available for caregivers of children with cleft lip and/or palate. The authors further state that children with the condition of CL/P receive cognitive behavior therapy to reduce anxiety and stress (Patjansoontorn et al., 2012). Chuacharoen et al. (2009) identified that support for caregivers of children with CL/P is from family and relatives in relation to the provision of financial and morale support. In addition, they stress that caregivers receive the Thailand government insurance support.

2.5 Theoretical Perspectives

This section provides a description of the theories that guided the study. The study was guided by the adult personal resilience theory by Robert Taormina (2015) and Stress, Appraisal and Coping Theory by Richard Lazarus and Susan Folkman (1984).

2.5.1 Adult Personal Resilience Theory (Robert Taormina, 2015)

The Adult Personal Resilience theory posits that adults become resilient to adverse conditions through cognitive and physical processes. The process of adult’s resilience to difficult conditions has been categorized into four different dimensions by Taormina (2015) and these comprise; determination, endurance, adaptability, and recuperability which enables individuals to resist adverse situations.
2.5.1.1 Determination

According to the author, individuals recover from difficult situations by having the willpower, firmness and the decision to succeed. This process mainly involves a cognitive and conscious process adopted by an individual to overcome an adverse situation. This could mean that, when caregivers come in contact with a child with CL/P, they may be shocked or disappointed but need to develop the willpower, firmness and a decision to succeed in order to come to terms with the child’s condition. Adults who are unable to develop determination tend to either abandon the child with CL/P or give them to others to be cared for.

2.5.1.2 Adaptability

Adaptability involves the cognitive effort of an individual to withstand adverse and changing environments by adjusting themselves to fit into that changing environment. This resilience process involves more cognitive efforts in changing ones thinking towards an adverse condition rather than changing ones physiological structure to adapt to a difficult situation. In this regard, caregivers of children with CL/P may have to constantly adjust to changing conditions of the child with CL/P since the treatment of CL/P starts from birth to adulthood until facial development stops.

2.5.1.3 Endurance

Endurance as a form of resilience involves the individual using his or her cognitive and physical strength to withstand an unpleasant situation. During difficult moment the person adjusts his/her thinking to deal with the situation. For caregivers of children with CL/P, it is important to make cognitive and physical efforts to withstand unpleasant situations, such as stigma and
psychosocial stress that come along with caring for a child with CL/P due to some socio-cultural beliefs.

2.5.1.4 Recuperability

Taormina (2015) notes that, recuperability enables adults to recover physically and cognitively from difficulties in order to return to one’s usual condition. Recuperability means adults ability to recover physically and cognitively from difficulties in order to return to one’s self prior to having a child with CL/P. As such, as children go through treatments, caregivers would have to develop the ability to recover from all the stress they may have encountered in caring for the child with CL/P. Caregivers who are able to develop these traits (Determination, Adoptability, Endurance and Recuperability) may be are able to cope better with the condition of their children.

2.5.1.5 Application of the Theory to the Study

The adult personal resilience theory helped the researcher to understand the experiences of caregivers of children with CL/P. Furthermore, the theory helped to comprehend how caregivers withstood the difficulties of living with and caring for children with CL/P. Additionally, insight was gained as to whether caregivers adopted a cognitive or physical approach to overcome adverse conditions in relation to caring for and living with children with CL/P. Again, the theory helped the researcher to understanding how caregivers of children with CL/P endured the stigma associated with CL/P.
2.5.2 Stress, Appraisal and Coping Theory (Richard Lazarus and Susan Folkman, 1984)

The stress, appraisal and coping theory was developed by Richard and Folkman (1984). The theorists argued that stress is not defined as a stimulus or a response but as a person-environment relationship that is perceived as exceeding a person’s resources (Folkman, 1984; Lazarus, 1993). When the individual is faced with a stressful situation, he/she will evaluate its significance and impact on the goals of the individual. This process is known as primary appraisal (Lazarus & Folkman, 1984). The theorists also identified a secondary appraisal process which is identified as the individual’s ability to evaluate the controllability of the stressor and his/her resources and opinions available to them.

According to Lazarus and Folkman (1984) effective coping requires a fit between situational appraisals and choice of coping responses. Also, coping strategies that are effective for one individual might not be effective for another person in the same encounter. In general terms, coping efforts aim at ameliorating the source of stress (or the related emotions and appraisals) and distress, but it may sometimes provoke more stress and distress, depending on the pertinence of the strategy used by the person to face demands. Folkman and colleagues further indicated that coping focuses on what the person thinks and does in a specific problem encounter.

The different stress appraisals adopted by the individual can lead to diverse coping responses. Coping is defined as the cognitive and behavioral efforts employed by an individual to deal with the demands that are created by the stressful person-environment transaction (Lazarus, 1993). From Lazarus and Folkman’s (1984) perspective, there are two main types of coping strategies: those aimed at resolving the stressful encounter (problem-focused) and those utilised to regulate the unpleasant emotions that arise during the encounter (emotion-focused). They further pointed out that problem and emotion focused coping strategies included (a) confronting (b) distancing...
(c) self-control (d) seeking social support (e) accepting responsibility (f) escape avoidance (g) planful problem solving (h) positive reappraisal. Some coping strategies are inherently not better than others.

2.5.2.1 Confronting

The first coping style, confronting, refers to directly and consciously facing the stressor. This explains aggressive efforts by the person experiencing the stressful situation to alter the situation and suggests some degree of hostility and risk taking. In this study, some of caregiver sometimes beat the child or abandon them as a strategy to express their hostility towards the stressor.

2.5.2.2 Distancing

When people perceive a threat, a common approach is to distance themselves from it, by physically, mentally and emotionally moving away from the threat. Distancing describes efforts by the caregiver to detach himself/herself from the stressor in order to develop a positive outlook. According to Lazarus and Folkman (1984) such acts include refusing to think too much about the issue or by trying to forget about it while consciously focusing on the bright side of it. It was evident from review of literature that some of the caregivers abandoned their child with CL/P as a way of distancing themselves from the stressor and others tried to forget the challenges associated with providing care for the child by having a positive outlook for the future.

2.5.2.3 Self-Control

Self-control is an emotion-focused strategy which describes efforts to regulate one's feelings and actions. Individuals who adopt this strategy try to keep others from knowing how difficult things are and try not to act hastily. The stigmatization and discrimination experienced by caregivers
caused them to hide their children from family and community members who did not know about the condition of the child.

2.5.2.4 Seeking Social Support

This is a coping strategy that describes efforts to seek support from people in the form of information, tangible support (food and money) and emotional support. This support may be solicited from family members, friends, community members and governmental as well as nongovernmental organizations. Many caregivers explained that support from family, friends and organizations were instrumental in the provision of care to their children with cleft lip and/or plate.

2.5.2.5 Accepting Responsibility

This strategy indicates that the individual confronted with a stressful situation acknowledges his or her own role in the problem with a related effort of trying to put things right. For instance, a caregiver accepting that her negligence led to the problem and doing everything fix it.

2.5.2.6 Escape Avoidance

This coping mechanism explains wishful thinking and behavioral efforts to escape or avoid the problem. Individuals confronted with the stressful situation may resort to behaviors such as drinking, smoking, isolation and sleeping to avoid the stressor. In order to deal with the challenges associated with caring for children with CL/P, caregivers could resort to behaviors like taking pills to help them sleep and forget their problems. Additionally, caregivers who have intentions to give birth again, may choose to take their medications well to avoid giving birth to another child with CL/P.
2.5.2.7 Planful Problem Solving

This mechanism describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem. This involves making deliberate plans, establishing objectives and developing actions to deal with the problem. As a result of planful problem solving, caregivers may plan and raise money to undertake surgery for the child with CL/P. Such decision may help repair the CL/P for the child to restore his or her social functioning.

2.5.2.8 Positive Reappraisal

This coping strategy describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension and this may include praying and having hope in God to help change the situation. Literature reviewed indicates that, many caregivers develop a hopeful attitude once they visit the hospital and when they come in contact with other families with children with CL/P. Once surgery commences, many caregivers become highly optimistic about their child’s condition.

2.5.2.8 Application of the Theory of Stress, Appraisal and Coping to the Study

The theory is applicable to the study because caregivers of children with cleft lip and/or palate face stressful situations in the provision of care which could affect their social and health functioning. The birth of a child with CL/P comes as a surprise to many caregivers. Thus, many of the caregivers are not prepared for the condition and have limited information and knowledge about CL/P, its causes and ways of treating it. This could intensify the stress that caregivers go through in caring for these children. This theory also helped the researcher to understand how caregivers of children with CL/P evaluate or assess the challenges in care provision and how
their choice of coping is informed by these appraisals. Given that in the face of these stressful situations caregivers adopted strategies to deal with the stress and challenges they faced, the theory enabled the researcher to contextualize the internal and external support systems that they used to deal with the stress and challenges they faced.

2.5.3 Justification for using Two Theories

The study employed stress, appraisal and coping theory to complement the adult personal resilience theory by Taormina (2015). The theory of adult personal resilience theory enabled the researcher to understand how caregivers of cleft and plate recover quickly from the difficulties they faced in providing care to their children. Also, the theory provided insight into how caregivers of children endured the challenges associated with CL/P. While both theories look at adults’ ability to cognitively deal with and overcome their problems, the adult personal resilience theory views other theories such as those that define social support as helping to overcome difficulties as weak because according to the author such social support as a form of resilience is external to the individual. The stress, appraisal and coping theory apart from the individuals going through personal mental processes to cope with stressful situations considers external support as a means for individuals to cope with stressful situation. Furthermore, the adult personal resilience theory is limited in explaining the support services adopted by individuals in a stressful situation to be resilient enough to recover from the situation. In addition, the theory is restricted in explaining the specific coping strategies that caregivers adopted to be resilient in tackling their challenges.
CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter discussed the research design, the study site and method of data collection. The sampling technique, sample size and the source of data for the study were also discussed. In addition, the chapter captured the methods for analyzing data and ethical considerations.

3.1 Research Design

The study employed a qualitative research design. A qualitative research design was appropriate because, this study sought to emphasize the qualities, processes and meanings that caregivers of children with CL/P have and these could not be experimentally examined or measured in terms of quantity, amount or frequency (Denzin & Lincoln, 2011). Furthermore, the research design helped the researcher to gain a deeper insight into the experiences of caregivers of children with CL/P at the Reconstructive Surgery and Burns Center at the Korle Bu Teaching Hospital.

Qualitative design helped to explore and obtain in-depth information from participants regarding their experiences, but not to generalize even though findings can be applied to similar settings. Also, the design allowed research participants to feel comfortable in their natural setting when sharing their experiences and this made them open up on their experiences in caring for children with CL/P (Denzin & Lincoln, 2011).
3.2 Study Site

The study site was the Reconstructive Plastic Surgery and Burns Centre of the Korle-Bu teaching hospital at Korle-Bu in the Greater Accra Region of Ghana. The Centre is dedicated to the treatment of burns and offers reconstructive plastic surgery for congenital or acquired deformities of which CL/P is a part of (Korle-Bu Teaching Hospital [KBTH], 2015). The Centre also handles cases of ulcers, injuries and cosmetic problems. Since KBTH is a referral hospital, CL/P cases from other health facilities are referred there for reconstructive surgery. Furthermore, Non-Governmental Organizations such as Transforming Faces Worldwide and Smile Train have been collaborating with the Reconstructive Plastic Surgery and Burns Centre of the Korle Bu Teaching Hospital to provide free surgeries to people with CL/P. This gesture has increased the patronage of this group of people to the health facility.

3.3 Target Population and Study Population

The target population for this study was all caregivers of children with CL/P and key informants from the Korle-Bu Teaching Hospital. The study included caregivers of children with CL/P receiving treatment at the Reconstructive Plastic Surgery and Burns Center at the Korle Bu Teaching Hospital and health professionals providing treatment for children with CL/P at the Centre. The researcher recruited caregivers for the study because they had frequent and direct contact with children with CL/P. Health professionals were recruited as key informants because they are responsible for clinical assessment of children with CL/P and they are also members of Cleft Lip and Palate Management Foundation.
3.5 Sampling Technique

Purposive sampling was used to recruit participants for the study. Purposive sampling attempts to select participants according to criteria determined by the research purpose (Tuckett, 2004). Purposive sampling is the deliberate choice of an informant due to the qualities he or she possesses (Tongco, 2007). This sampling technique allowed the researcher to decisively select participants due to the qualities they have while satisfying the criteria determined by the purpose of the research (Denzin & Lincoln, 2011). The researcher, therefore, selected caregivers purposively because they have experiences regarding provision of care for children with CL/P.

Caregivers for the study were recruited through a panel clinic session organized at the Korle-Bu Reconstructive Plastic Surgery and Burns for children with CL/P. The panel clinic sessions consist of a team health professionals who come together to assess patients of CL/P and make recommendations for further treatment when necessary. The panel is made up of eight to twelve medical professionals which includes a plastic surgeon, dentist, ear-neck-throat specialist, ward nurse, theater nurse, public health nurse, nurse matron, dietician and a speech therapist. Through the health professionals of the center, the purpose of the study was explained to the caregivers during a panel clinic session to obtain their permission to be recruited for the study. Furthermore, key informants consisting of health professionals from the center were recruited for the study. The contact details of research participants were collected after they had agreed to be part of the study.

Inclusion Criteria

Caregivers who were responsible for the day-to-day upkeep, had been providing care for and had direct experience with children with CL/P for more than three months were recruited for the
study. Furthermore, the caregivers had to provide care for CL/P children who received treatment at the Reconstructive Plastic Surgery and Burns Center in the Korle Bu Teaching Hospital. Health professionals who had worked at the Reconstructive Plastic Surgery and Burns Centre for at least one year and had been consistent on the panel for at least three months were included in the study.

3.6 Sample Size

A total of twenty-five participants were sampled for the study. The participants were twenty caregivers of children with CL/P and five health professionals made up of doctors and nurses at the Korle-Bu Reconstructive Plastic Surgery and Burns Center. Twenty-five participants were sampled as the number enabled the researcher to gather rich data. This number was decided on as it seemed manageable to work with considering the time frame available for the study. Again Creswell (1998) noted that sample size for a qualitative study should range from five to twenty-five participants to reach saturation. Francis et al. (2010) also suggest that data saturation may be reached when no new information is gained from research participants and as such when no new information was forth coming, data collection came to a halt.

3.7 Source of Data

Data for the study was collected solely from a primary source. This included interviews with the research participants.

3.8 Method of Data Collection

Primary data was collected from participants from 11th January to 14th February 2018 through in-depth interviews with the aid of an interview guide developed by the researcher. There were two
separate interview guides developed for the caregivers and the key informants. The in-depth interviews allowed research participants to express themselves freely on the phenomenon under study and aided the researcher to ask open ended questions. The interview guide was used to solicit information from twenty-five participants through a one-on-one interview session. The interview guide allowed research participants to provide information that was relevant to the study. The interview guide was designed in English Language as English is the Lingua Franca of Ghana. However, interviews with research participants were conducted in English and Twi because these were the languages the research participants were familiar and comfortable with. Research participants voluntarily decided either to use English or Twi during the interview. Each interview lasted approximately forty-five minutes. The In-depth interviews were audio-recorded with permission from participants. Interviews with caregivers were conducted at the conference room where assessments are conducted while that of the key informants were held in their offices at the KBTH.

3.9 Data Handling and Analysis

The audio recorded data from the interviews were saved on a computer. The data was also saved on Google drive to serve as a backup. The recorded data was transcribed from audio to a text format. The data was analyzed using thematic analysis based on Braun and Clarke (2006) six steps in analyzing qualitative data. The first step is familiarization with the data. The researcher read and re-read the data to immerse herself in and become familiar with the data. The second step which is coding involve generating labels for important features of the data that is important to the research question(s). After familiarization, the themes that emerged were identified and labelled. For example, unawareness and supernatural causes were some of the themes that emerged.
The next step involved searching for themes. This included looking for coherent and meaningful patterns in the data that were relevant to the research questions. As such I started searching for common patterns in the data that were relevant to the research questions. The fourth step involved reviewing themes. At this point, themes in relation to both the coded extracts and full data set were checked for by cross checking the data with the research objectives. The fifth step is defining and naming themes. This required the researcher to write and conduct detailed analysis of each theme that emerged. I went through all the themes that emerged and selected the final set of themes that would be used to present the findings. The sixth step is writing up the report. This involves weaving together the analytic narrative and data extracts for a coherent and persuasive story about the data, and contextualizing it in relation to the literature reviewed. Themes were linked and discussed to make a meaningful report.

3.10 Trustworthiness

To ensure trustworthiness of the study, peer debriefing was employed. This was done by requesting supervisors to review the data and make their input. According to Creswell and Miller (2000), peer debriefing is the evaluation of the information and research process by an individual who is well known in the study being investigated.

3.11 Ethical Considerations

Participants were informed about the purpose of the study, the benefits, the risks involved and their choice to either participate in the study or not. Participants signed an informed consent before taking part in the study. To ensure confidentiality of participants, pseudonyms were used in place of actual names and all information they provided were kept confidential. In addition, plagiarism was avoided by acknowledging all secondary information that were used in the study.
3.12 Limitations of the Study

The study sought to explore the experiences of caregivers receiving treatment at the Reconstructive Plastic Surgery and Burns Center but did not include caregivers who did not seek medical care due to some sociocultural beliefs. As such, views that have been presented by participants may have been limited to individuals who sought medical help for their children. Furthermore, data loss may have occurred when interviews were being translated from the local language to English language but was reduced by using words closest in meaning.
CHAPTER FOUR

PRESENTATION OF FINDINGS AND DISCUSSIONS

4.1 Introduction

This chapter presents the findings and discussions of the study. The chapter captures the demographic information of participants followed by the presentation of findings which are based on the objectives of the study. Caregivers ‘beliefs about cleft lip and/or palate (CL/P), and challenges faced by caregivers of children with CL/P are discussed. The chapter concludes by identifying the coping strategies adopted by caregivers of children with CL/P and the various forms of support available to caregivers. Findings are presented under themes and sub-themes.

4.2 Demographic Information of Participants

The demographic information of the caregivers and key informants enabled the researcher to put the study into perspectives. This section considered the age, sex, education and the work experience of key informants and caregivers.

4.2.1 Sex and Relationship of Caregivers to a Child with CL/P

This study consisted of 25 participants made up of 20 caregivers of children with CL/P and 5 health professionals as key informants. Out of the total number of caregivers sampled, eighteen were females and two were males. All of the eighteen females were biological mothers of children with CL/P. With regards to the two males, one was the biological father of a child with CL/P while the other one was the grandfather of the child with CL/P. All caregivers interviewed indicated they cared for only one child with CL/P.
4.2.2 Age of Caregivers

Five of the caregivers were between the ages of 26 and 30, two were between the ages of 31 and 35 years and three were between the ages of 36 and 40 years. Also, five each of the caregivers were between the ages of 41 and 45 and 46 and 50 respectively. With respect to the age of mother at the birth of a child with CL/P, the demography showed that, one caregiver was between ages of 21 to 25 and five caregivers were between the ages of 26 to 30 at the time of delivery. In addition, five mothers were between 31 and 35 years at the time of delivery while two and three caregivers respectively gave birth to a child with CL/P between ages 36 and 40 and 41 and 45. Four caregivers did not state the age at which their child with CL/P was born.

Attention was paid to the ages of the mothers at the time they gave birth to a child with CL/P as some studies reported some relationship between the ages of parents and the chance of a child being born with CL/P. A study by Bille, et al. (2005) reported that, older ages of mother and father was associated with increased risk of bearing a child with CL/P. It is interesting to note that, at the time of the interviews, 18 out of the 20 caregivers were biological mothers of children with CL/P, while one caregiver was the father of a child with CL/P and the other was the maternal grandfather of a child with CL/P.

4.2.3 Level of Education

The educational background of caregivers showed that three had attained Tertiary level education, five had Senior High School (SHS) education, one had attained commercial level education, six had completed Junior High School level (JHS) and three had attained primary level education. Two caregivers, however, had had no formal education.
4.2.4 Marital Status

Marital status was considered to help find out how marital relationship was affected by caring for a child with CL/P. In terms of marital status, seventeen caregivers were married, two were divorced and one had never married.

4.2.5 Religious Affiliation of Caregivers

Religion was considered to help understand how religious beliefs informed caregivers’ beliefs about the causes of CL/P and also how these beliefs affected the care provided by these caregivers. Out of the twenty caregivers, eighteen were Christians while two were Muslims.

4.2.5 Occupation of Caregivers

The occupation of caregivers was also considered to enable the researcher understand how participants’ respective occupations influenced the care being provided by caregivers as well as to find out how the stress of caring for these children affected their occupation. Occupation of participants showed that six were traders, two were health workers, one was a cleaner, one was a pastor and one happened to be a herbalist. The rest were two famers, three seamstresses, one cobbler and three unemployed adults.

4.2.6 Ages of Children with CL/P

Regarding the ages of the children who were being cared for by caregivers in this study, two babies were four and eight months, eight children were between 1 and 5 years, six were between 6 and 10 years and one child between 11 and 15 years. One was an adult of eighteen years and two did not state the ages of their children. According to Adeyemi (2015) treatment of CL/P may
span from birth to adulthood when facial growth is complete. Based on this reason the ages of children receiving treatment at the Reconstructive Plastic Surgery and Burns Center was considered during the study.

4.2.7 Demographic Information of Key Informants

The ages of the five health professionals interviewed were, thirty-four, forty-one, forty-nine, fifty-nine and sixty years respectively. In terms of their occupations, two were plastic surgeons, one was a speech and language therapist, and there were two nurses but one doubles as a counselor. With regards to the number of years they worked, two health professionals had worked for 11 years, one had worked for 17 and the other two had worked for 20 years.

4.3 Beliefs about Cleft Lip and/or Palate

The beliefs regarding causes of cleft and/or palate varied from one participants to the other while others had similar opinion. Some caregivers were of the view that CL/P was an abnormality in pregnancy while others as well as some health professionals (before they became health professionals) pointed out that the condition resulted from a curse or spiritual attack. Others noted that CL/P could result from over indulgence in drugs, alcohol beverages and even food.

4.3.1 Abnormalities in Pregnancy/ Heredity

Complications during pregnancy could lead to cleft lip and/or palate in many children. Some of the caregivers and health professionals revealed that when pregnant women acquire some diseases during pregnancy, it could lead to cleft lip and/or palate. More so, some of the participants explained that these abnormalities could be as a result of genetic predisposition. Thus, there is likelihood for a child to be born with CL/P if someone in his family had had the
condition before. The health professionals also explained that, during the formation of the fetus there could be problems with the genes which could result in CL/P as reflected in the following voices:

   I don’t have any belief that this condition was caused by something or a deity. I just saw it as an abnormality that might have occurred during my pregnancy (Mother C).

   I had seen this condition before since my elder brother had it so I knew it was a medical condition. When I saw my child with this condition I was very disturbed and scared. I did not attribute this to any cause. When I first saw it I knew it was a sickness because I have an elder brother who has this condition so my child might have inherited it from my family (Mother D).

   I believe it is a natural phenomenon and not anything relating to evil. She came with it so I can’t blame anyone. Before I even gave birth, as a nurse I believed it was a form of malformation (Mother L).

Some of the health professionals who attributed the abnormality to genetic or environmental factors and deficiencies noted:

   As a surgeon and a scientist, I know about how the face develops and what can possibly go wrong that can give rise to all sorts of defects including cleft lip and/or palate. I also know that it’s a balance between hereditary and environmental factors. Hereditary where a child might be born with it because the parent has it (Plastic surgeon one).

   Before becoming a doctor, I don’t remember seeing one of these conditions but I first got to know of it at the medical school. It’s usually genetic; we are taught how the face and the lips form and anything that interrupts that but commonly nothing has really been pinpointed out as the cause of cleft. However, some things such as vitamin and folic acid deficiencies and some diseases in the first week of pregnancy have been associated with it. There are also some syndromes that
always come with cleft. Syndromes are usually genetic; they are passed on from parents to children (plastic surgeon two).

One of the health professionals had this to say:

CL/P is something that the cause is actually not known but studies have shown that it could be either hereditary or environmental. If a pregnant mother is malnourished and lacks folic acid and some essential vitamins, the child may end up with a defect like CL/P (Surgical nurse three).

As clearly indicated in the voices captured above, both health professionals and some caregivers alike do agree that, CL/P may be caused by infections or diseases affecting the mother during her pregnancy or by some changes in the genetic makeup of the baby which could be inherited or mutated.

4.3.2 Awareness / Supernatural Cause

Some participants indicated they had no knowledge about the causes of cleft lip and/or palate, but attributed causes of CL/P to supernatural causes. Some caregivers attributed spiritual attack and curse against the pregnant woman as the cause of CL/P while other participants disclosed that when a pregnant woman is cursed for perpetrating evil deeds, it could lead to CL/P or an attack by witches from the families of these caregivers could lead to the condition. However, some participants attributed the cause of cleft lip and/or palate to an act of God and considered children with the condition as being part of God’s creation:

The first time I saw my child with this condition I was surprised because I asked myself ‘how come? Because I already have five children and none of them has any challenges, so I was really scared. But I did not have any negative belief about the condition (Mother A).
Initially, my belief was that someone was behind this. I don’t have any problem with anyone but I really didn’t have any knowledge about it that is why I thought it was spiritual (Mother E).

I had the belief that it can happen through birth and also something from God and it is only through God’s mercy that a person would not have that condition (Mother F).

I honestly didn’t know about it before becoming a doctor. I didn’t think about this condition, but I have one in my house. A relative of mine’s son had cleft palate and the other boys and girls teased him as speaking like a ghost so we knew that was the problem the boy had but then I didn’t think of how he got it whether by witchcraft or any reason. As a doctor then but now a plastic surgeon I considered it as one of the defects a child may have (Plastic surgeon one).

I first saw the condition when I was in the secondary school. My belief was that it was something that was associated with a curse or something evil that a family had done and that served as the reason why that family was having children of cleft lip and palate (Surgical nurse three).

For many of the caregivers, their beliefs about the condition changed when they visited the health facility to interact with health professionals and seeing others having a child with the condition. The voices below affirms some of the beliefs caregivers held on the causes of cleft lip and/or palate being congenital, hereditary and being a cause from God Almighty had changed:

Initially, my belief was that someone was behind this. I thought it was a spiritual attack but when I came to the hospital and realized that many people were affected by this condition, I started thinking this was part of God’s creation (Mother E).

When I saw my child with this condition I said to myself this is something from God. But I found out that it is a normal problem when I came to Korle-Bu Hospital (Mother N).
My belief has changed because first, the problem that caused me not to be able to send my child out to the public is no more because her lip has been repaired. Even though the inside is yet to be sealed, I know God will make it for me. Secondly I also believe that it is God who has put my child in that state. I also believe that my child’s condition is a medical condition and the doctors can help her recover (Mother E).

4.3.3 Abuse of Drugs and Food

Abuse of drugs and eating of some food that did not support the health of pregnant women was believed to be some of the cause of cleft lip and/or palate. Some of the participants highlighted that CL/P in a child could result from the lifestyle that the mother led during pregnancy such as excessive drugs, alcohol and food abuse. One of the caregivers highlighted that:

It could also result from alcohol consumption or cigarette smoking. But I don’t live all these lifestyles and that made me a little anxious when I first saw the condition of my son (Mother B).

I don’t really know but the lady whose child I saw first with this condition in my neighborhood used to drink alcohol so may be that was the cause of her child’s condition (Mother P).

One of the caregivers who attributed this to an abuse of drugs highlighted that:

My belief about CL/P was that may be it resulted from the food we eat or the self-medications we take in during pregnancy (Mother S).

Health professionals also asserted that abuse of drugs and some life styles could cause CL/P and this is what they had to say:
...so drugs have been blamed, alcohol, tobacco and the mother having infections while pregnant. I know two women who drank heavily and all two ended up giving birth to children with cleft of the palate (Plastic surgeon one).

Some things have been associated with the cause of CL/P such as vitamins and folic acid deficiencies and some diseases in the first week of pregnancy (Plastic surgeon two).

Drugs intake during pregnancy, x-rays and chemical exposure and if a pregnant mother is malnourished and lacks folic acid can cause CL/P. The structures of the face are formed at the early stage of pregnancy before the woman realizes that she is pregnant the formation has been done. Alcohol and smoking too are part (Surgical nurse three).

It was revealed by the caregivers and key informants that the abuse of drugs and food was a common cause of cleft lip and/or palate. The participants attributed these problems to excessive intake of drugs, alcohol and food components that were not beneficial to the health of the pregnant woman.

4.4 Challenges faced by Caregivers

Challenges that caregivers encountered in their day to day activities were also explored. Majority of the caregivers indicated that they were faced with varied challenges that affected their ability to properly care for their children with CL/P. The study found that caregivers faced challenges related to financial difficulties, poor caregiver-community relationship, health issues, problems with stress and frustration and negative reaction from family and health professionals.

4.4.1 Work/Financial Difficulties

Financial difficulties were identified as one of the major challenges caregivers faced while providing care for children with CL/P. Many of the participants attributed their financial
difficulties to their inability to work due to the time they spent caring for the child with CL/P. To some of them, they could not get money to support themselves, their children and adequate healthcare for that child with CL/P. Some of the participants disclosed that:

_Hmm! the challenges are a lot. The challenge I encounter is financial problems. I sometimes don’t have money for my child to go to school due to the frequent hospital visits_ (Mother D).

_The problem I have is regarding my work because where I come from is a village and work there is very slow. Currently, I don’t even have the time to work because of this child. When they call us to come to the hospital then money becomes the problem for me_ (Mother E).

_Because of caring for this child I am limited in doing certain things especially in doing my work. I no longer could go to work the way I wanted… When I got divorced by my husband as a result of having this child, things became very difficult especially caring for this child because I did not have money. I cried a lot of the times in the house_ (Mother J).

One of the male caregivers had this to say:

_Even sitting here now is one of the challenges am facing because by now I should have gone to work to find money to support my family but am sitting here to receive care for the child. This sometimes could be time consuming and affects my ability to work and get money for survival_ (Father Q).

Some of the health professionals revealed that some caregivers had financial issues that needed urgent attention. Evidence of this is reflected in these voices:

_The child cannot also suck and because of that they have to support it with artificial foods which most of them cannot afford. So there are financial implications_ (Surgical nurse three).
Some may not even go to work especially those who sell in the market because people will see their child. Some have financial problems because of stigma and their inability to secure better and proper job (OPD nurse four).

As clearly indicated in the interviews captured above some caregivers mentioned financial difficulties as a problem in their provision of care to their children. The provision of care has made it difficult for them to work thus, making it difficult for them to raise money for their day to day activities.

4.4.2 Poor Caregiver- Community Relationship

Poor relationships among caregivers and community members was a challenge faced by some of the caregivers. Some of the participants explained that they had difficulties socializing with community members because of caring for a child with CL/P. This was because, some were given derogatory remarks and stigmatized by these community members. These actions by some community members affected caregivers of children with CL/P psychologically. In addition, some of the health professionals were of the opinion that caregivers of children with CL/P could not socialize due to pressure from family and in-laws. This they explained that, in-laws and family members who usually make caregivers and for this study mostly mothers’ life miserable believe these mothers are the reasons for, or the cause of the child having CL/P. Some of the participants lamented that:

For other people they did not see the child because I usually did not take the baby to the public scene. I did not also inform any of my friends (Mother F.)

I did not take the child outside to the public because I did not want anyone to talk about him in a way that will hurt me, but the people in my house saw him. Some of them who saw the baby refused to talk to me because they feared talking to me could make them to give birth to same (Mother G).
My child fought with another woman’s child in my house and when I tried to intervene the woman told me that my child is from the spiritual world. But people from outside don’t get to see my child because when I return to the house, I stay in my room and hardly do I go outside of the house with this child (Mother K).

One market woman who had lost many customers because she had a child with CL/P had this to say:

I was a market woman with many customers but I lost them when I gave birth to this child. Many customers and market women said I was a witch and decided not to buy anything from me. I have suffered financially and ever since I have not had my peace (Mother H).

One of the caregivers who previously had problems with her in-laws and other family members indicated that:

With my in-laws, the first time they saw the child with the condition there was a fight between us. Because they always told me I was disrespectful and so blamed me for the child’s condition. But now that it has been operated on, there is peace in the house now. Even with that there are still some members in my family who do not talk or interact with me (Mother D).

Some of the health professionals had this to say:

Stigma is a big issue to the parents especially the mothers. Women can be unkind to each other, they say all sort of words to each other especially those in the compound houses (Plastic surgeon one).

And the worst of all is the person’s family and cultural reactions. The society also pressures the mothers and because of that some go early for prenatal care and leave early or go very late and leave late all to avoid people seeing them. Some may not even go to work especially those who sell in the market because people will see their child (Surgical nurse 3).
People keep their babies indoor because they don’t want other people to see the defect their babies have and sometimes because of what these people will say about them in the community (OPD nurse four).

If someone had a child with cleft, all events that were supposed to happen would never happen. So the naming ceremony won’t come on so a whole lot of things wouldn’t come on and those are social issues and affect a lot of parents (Speech therapist five).

The voices from the participants revealed that some of the participants had to face poor community relationship because they care for a child with CL/P. This had resulted in many of them been rejected by their friends and some family members.

4.4.3 Problems Associated with Child Care

Some of the participants in the study acknowledged that they went through frustrations and stress in caring for their babies. The participants attributed these stress and frustrations to the long periods spent in feeding the baby, training the child to speak and prolonged time spent at the health facility during visits which called for halting other activities they were engaged in. Some of the participants lamented that:

The other challenges I face has to do with the feeding process which is tedious as compared to the other children who don’t have the condition. Feeding the child also takes a lot of time. I have to also give much attention to this baby so that the baby will not fall and hurt the mouth further (Mother H).

She finds it difficult to pronounce the letter ‘M’, she pronounces with the sound of letter ‘V’. I am trying to teach her how to pronounce it. Apart from that her feeding and everything is normal (Mother L).

Other participants revealed that:
Feeding this child is also a problem because the child reacts in a difficult manner when we about to feed him. This worries my wife a lot but I assist her because I know how to do all these things (Father Q).

I face challenges because when am feeding her she cries, shouting and the food is always coming out from the nose and consequently every ten to fifteen minutes she wants to eat and it’s still coming out. They said I shouldn’t give her any solids but I should give her liquids so I started with the Non and it’s consuming all the money left behind so I stopped and started preparing Tom Brown and other liquid foods for her but she still didn’t like it (Mother S).

One of the participants explained the frustrations she went through after the surgery of her baby’s cleft lip:

*After the surgery the challenge I encountered was how to now properly feed the child because the surgery was fresh and the child could not breastfeed so feeding the child was very tedious* (Mother N).

From the voices indicated above, it was obvious that some of the participants faced challenges with child care provision. They had difficulties with feeding the child, training the child to speak and prolonged time spent in the health facilities.

**4.4.4 Negative Reactions from Family and Health Professionals**

Upon giving birth to a child with cleft lip and/or palate, some caregivers noted that they received negative reactions from either family relations or other friends. Some caregivers were of the opinion that they were divorced by their husbands because they gave birth to children with CL/P while others mentioned that their family remained silent upon seeing they had a child with CL/P. Some caregivers mentioned that, they received negative reactions from some health professionals and this was confirmed by some of the key informants in the study. Caregivers had this to say about negative reactions they experienced due to caring for a child with CL/P:
...but the father of the child told me that he doesn’t want the child because he did not request for a child with cleft lip. The child’s uncle also told me that he didn’t know where I picked the condition from and brought it into their family. My child’s father has married another woman and that woman has given birth so he called me to come and have a look at the child because that child does not have any condition. So it was as if he was teasing me (Mother B).

When I took the child home my husband asked where the new born child got that condition from because it was unknown in his family. I denied him letting us have another child because I wanted to see this child’s condition repaired before having another child. He then refused to provide financial support to me and divorced me because of that (Mother J).

I nearly stopped going to the hospital at some point in time. One day I was just humiliated by a nurse when I took my child to the hospital. I was really embarrassed and said to myself why this problem. I received some encouragement from friends and parents and that has kept me moving (Mother K).

Other participants indicted that:

What happened was that I delivered at the Ridge Hospital and soon as the baby was born, the nurse raised the baby up and she shouted and said ‘aah! ’so you have also given birth to this kind of baby’, so I asked what had happened to the child, she asked me to raise my head and look at the baby’s face. When I saw that the child has cleft lip I became very disturbed and I went back to sleep. I gave birth at 7am but they did not attend to me until afternoon when the next badge of nurses came in before the child was cleansed from the blood but before that I bleed a lot and finally they attended to me as well as covered my baby too in a piece of cloth. (Mother N).

When I delivered at the hospital the child was not sucking, I called the nurse and she came and stood there watch me breastfeed the child and she said I should force her to suck and I said oh am forcing but then I had not realized the mouth so
I was forcing her to suck but because the nurse felt I was disturbing her she got angry and left (Mother S).

Some health professional who confirmed the negative reactions caregivers experience at certain health facilities had this to say:

*Some health professionals are generally not kind* (Plastic surgeon one).

....but if you take that away and they came through the general hospital then am afraid you know we are not friendly as Ghanaians to each other and it doesn’t matter whether it is the hospital environment (Speech therapist five).

### 4.5 Coping Strategies Adopted by Caregivers

In order to deal with the challenges faced by caregivers, they adopted some coping strategies. From this study, it was found that caregivers used coping strategies to overcome some of the challenges they encountered while caring for children with CL/P. The coping strategies adopted by caregivers included support from family and friends or by isolating themselves.

#### 4.5.1 Support from Family and Friends

Some of the caregivers sought support from family and friends as coping strategies. According to some of participants, they resorted to borrowing from friends. Taking loans were some of the strategies some caregivers adopted to deal with their financial challenges. Some of the participants had this to say:

*Frankly speaking as am sitting here I do not have even ten pesewas in my name in the house but because my child’s date was due today to attend the hospital I approached someone to borrow some amount so that when I come back home I will find something to do and pay her back* (Mother D).

*I also have a younger sister who has been very helpful to me. She washes some of my clothes for me. People who visited me extended some help to us in cash and in kind* (Mother N).
I resort to borrowing from people to overcome the problem of finance and when this fails I fall on my family members for all the support that I need (Mother E).

4.5.2 Self-Encouragement and Motivation

In addition, other caregivers noted that in order to overcome problems relating to the caring of a child with CL/P, they developed close intimacy and extreme love for the child with CL/P while others comforted themselves with the other children who did not have the condition. A man caring for a child with CL/P stated that he became strong in order to face challenges in caring for such a child.

Even though I didn’t have money to take good care of my child I was happy with my child because of the intimacy that I developed for her. So the love I have for my child keeps me very happy. I have also gotten a lot of moral and material support from my family members (Mother O).

Others had this to say:

I get over this problem that my child has because the other twin brother keeps me happy all the time because he likes to be played with (Mother P).

I have been able to cope with this child’s situation because I am a man and as a man I must face difficulties. I also became strong when I came to the hospital and the Non-Governmental Organization (NGO) said they will take part of the cost of surgery as well as seeing that other children with this condition have been repaired so I went and found money to come and pay for the remaining cost of the surgery (Father Q).

4.5.3 Isolation

Isolation was one of the coping strategies adopted by caregivers in dealing with the challenges they face. Some of the participants explained that they avoided the pain of negative remarks from
people by locking themselves and staying indoors. Others stated that they resorted to listening to motivational songs when they were alone:

If I got discouraged and I started to think about my baby girl’s condition, I sometimes locked myself in the room and cry. I am restricted in fighting back people who offend me because they may make derogatory remarks about my child. Another woman in my house also mimicked my child’s sound which I did not like (Mother J).

To overcome my tears I have a Nigerian song that talks about keeping happy in the midst of difficulties so I listen to the song alone in my room with my baby in my hands then I forget about all the negative thoughts on my mind (Mother K).

Others hide the babies in the room. They don’t take the babies out for immunization let alone social gatherings. From my experience here, most of the babies brought here were abandoned by their parents and they have been brought in by their grand-parents. Others come for treatment ones and they don’t come again and when we follow up we realize the child has been abandoned or they tell you the baby died. People keep their babies indoor because they don’t want other people to see the defect their babies have and sometimes because of what these people will say about them in the community. Some even say the mother had gone to fornicate and so they even hide them. They are shy having that baby (OPD nurse four).

4.6 Support available to Caregivers

The availability of support services to caregivers could facilitate the care they provide to children with CL/P. In all cases the caregivers and key informants explained that there were formal and informal support services available to caregivers in Ghana. From the findings, the three main support services available to caregivers were support from friends and relatives, provision of resources by government and support from non-governmental organization. However these
supports had stopped or were inadequate. In terms of the support available to caregivers, caregivers and health professionals alike made mention of the fact that the current support caregivers of children with CL/P received was from government provided through the National Health Insurance Scheme (NHIS) even though they indicated the support was woefully inadequate.

4.6.1 Formal support

The study found that formal support included support from the Government through the NHIS and Non-Governmental sources through The Smile Train, Operation Smile and the Cleft Lip and Palate Management Foundation. Some of the key informants stated that the Operation Smile had run out its course and were no more providing support to caregivers and children with CL/P at the time of the interview. Smile Train however, provided financial support to cover sessions for speech and language therapy during speech camps and the Multi-Disciplinary Team under the Cleft lip and palate Management Foundation made up of health professionals provided support through their monthly panel clinic assessments:

The Cleft lip and Palate Management Foundation has been in existence for about three years. It’s a foundation that came about to provide comprehensive multi-disciplinary care to parents and children of this condition. Children born with cleft lip/palate have numerous problems apart from the stigma, they have problems with feeding, hearing, speech, they have problem with the teeth, problem with the facial development, there are numerous problems and no one doctor can treat all. So we need a team that can look at each child’s problem and treat that child (Plastic surgeon One).

For governmental relief there is the NHIS but how much NHIS pays for each cleft surgery is woefully inadequate. So that is the Governmental support and we wish
they could look at that by paying full for those with cleft lip/palate and that will go a long way to help care givers (Plastic surgeon Two).

One participant revealed that:

...I mentioned the MDT’s (Multi-Disciplinary Teams), they work as some kind of support. ...I worked for one speech and hearing center and we have a contract with Smile Train to provide speech therapy for people with CL/P when they attend the speech camp (Speech therapist five).

Some of the caregivers confirmed the words of the health professionals by stating that:

The initial support provided to us is no more available and should be reinstated. Some of the drugs could be made available because the medicines are very costly. A drip costs 45 Cedis and they take three drips a day when we come here during surgery (Mother J).

The government through the NHIS is also helping us after we renewed it but we have to pay an extra GH5 Cedis before other things get done (Mother S).

At first they used to give us some money and food when we came to the hospital. But that does not happen anymore because they told us the sponsors are no more there. Now the Smile Train Agency is the one that provides us with something but that only comes when we go to camp. When we go there the children learn how to make sounds. Apart from that they also feed us when we go for camping which lasts for three days (Mother B).

4.6.2 Support from Friends and Relatives

From the interviews conducted, other support available that emerged was the support from friends and relatives. Some of the participants explained that these supports came mainly from their friends, close family members and church members as indicated:

The family support is what we mostly rely on and I mean support from my husband who provides more for us (Mother I).
Another participant revealed that her mother and other siblings have been very instrumental in the provision of care to her child:

My sister who is a health worker also saw it and said it was a pregnancy disorder. My mother and my other siblings are also aware of it and they have been very supportive especially my elder sister who got a baby seat for me that I put the baby in when am feeding her (Mother P).

4.7 Measures to Address Challenges

It was also suggested by caregivers of children with cleft lip or palate and health professionals who participated in this study that some measures such as fundraising, education of caregivers on proper feeding of children with CL/P, sensitization programs in the media, counseling from some organizations and groups such as churches could help donate to support persons caring for children with CL/P.

There should be education on proper ways of feeding these children because it is very tedious to do that. Women with these children should be encouraged always to keep them strong because some mothers may be frustrated with caring and living with children with cleft and may end up harming the child (Mother J).

I would suggest that health professionals learn to know more about disability because when the person has the idea about it he or she will understand and do properly what is required. Media sensitization will also help a lot because it is not everyone who has this problem (Mother L).

I think educating the pregnant women about this condition is very important. It should be part of the routine education at the hospital so that when it happens the mother would not be surprised (Mother N).

Other participants had this to say:
Education is also important. Now there is this thing called supervised delivery which is very high in Ghana which means there is a health worker or if not there is a trained traditional birth attendants who assist so a high percentage of births are now supervised. So if there is a program and information is disseminated through these health workers that if a person delivers a child that looks abnormal they should inform them that, it is a problem that could be fixed for the child to look normal and function normally (Plastic surgeon Two).

My general recommendation is, there should be general education to the entire public about what cleft lip and/or palate is and if it is possible people can donate to support cleft lip and palate programs that will also help. We have a fund here people can donate into that is the Cleft Lip and Palate Management Foundation (OPD nurse four).

4.8 Discussion of Findings

The purpose of this study was to explore the experiences of caregivers of children with cleft lip and/or palate. Different experiences and opinions were shared by study participants regarding their belief about CL/P. The findings indicated that some caregivers of children with CL/P as well as some health professionals did not have any form of idea about the condition of CL/P until they gave birth to a child with CL/P or became health professionals. Furthermore, other caregivers were of the view that they came to know of the condition at the health facility. Moreover, from the findings, participants of this study believed CL/P resulted from causes such as congenital defects, lack of essential vitamin in the body during pregnancy and heredity. This affirms the work of Dixon et al. (2011) that even though there are no specific factors that have been outlined as the main causes of CL/P among children, some scholars attribute CL/P to changes in genes. The findings of this study seem to be in agreement with Mossey & Little
(2009), who reported that mutant genes, chromosomal abnormalities and interactions between genes and environmental factors could cause CL/P.

As evident from the findings, some caregivers also affirmed that CL/P could result from evil or spiritual attacks on the family or the pregnant woman. This supports the assertion by El-Shazly et al. (2010) in a study among the rural poor, illiterate and unemployed in India where almost all the respondents blamed the birth of CL/P child on a curse or an act of evil spirits. Dagher and Ross (2004) also indicated that in some cultures in Africa, the cause of CL/P is associated with abortion and witchcraft. Thus, women who give birth to children in this condition are considered as witches. Contrary to the belief of spiritual attacks, others were of the opinion that cleft lip and/or palate was an act of the Almighty God. However, caregivers of children with CL/P upon visiting the Reconstructive Surgery and Burns Center, changed their negative mindset about the cause of CL/P, the Adult Personal Resilience Theory by Taormina (2015) emphasizes that adults recover from difficult moments through the process of adaptability by adjusting to changes in the environments to withstand adverse conditions.

Additionally, it was found from the study that some of the participants associated the cause of cleft lip and/or palate with lifestyle led by the mother during pregnancy such as uncontrolled diet, alcohol, smoking and excessive drug intake during pregnancy. The findings are in agreement with Clark, et al. (2003) who found in Scotland that risk factors such as tobacco smoking during pregnancy contributed to CL/P. The lack of education on the part of some pregnant women contributed to the abuse of drugs and alcohol. However, from this current study, caregivers who were aware of the effects of abuse of drugs and alcohol explained that they did not engage in these acts to avoid trouble for themselves and future children.
It is important to note that some caregivers of children with CL/P received encouraging and derogatory remarks from some family members as well as from other people mainly friends and neighbours. The findings revealed that two caregivers were divorced by their husbands because they had given birth to a child with CL/P. In line with this finding, it was revealed that CL/P condition influence the emotions of parents, which could result in conflict and divorce (Locker et al., 2002). Also, some experienced negative remarks from neighbors that hurt their feelings and because of the need to avoid such negative remarks, some did allow their children to mingle with others. In the same vein, Nelson, et al. (2011) found that parents who give birth to children with CL/P have very scanty information about the condition, and they are afraid that people will only see their child’s deformity and not the worth and dignity of the child as human.

From the study, it was evident that caregivers faced multiple challenges resulting from their personal attributes and actors in their environment. Some of the participants in this study revealed that financial difficulties, poor caregiver-community relationship, problems with child care, frustration and negative reactions from family and health professionals were some of the challenges in care provision. It was unfortunate that caregivers of children with CL/P faced certain challenges which further compounded their problems. Some could not effectively go about their businesses as a consequence of the need to be fully available to accompany the child during hospital visits and also the associated stigma they receive from the public, due to which they became financially constrained. This is consistent with Locker et al. (2002) whose study revealed that caregivers of children with CL/P normally take time off work because of the child requiring more attention, financial difficulties and parental feeling of guilt as well as distress because of the child’s condition.
Also, besides the financial challenges faced by caregivers, some also revealed that they had poor relationships with community members. They further revealed that they were stigmatized and humiliated because of the care they provided to children with CL/P. Others indicated that they have lost some family relationships especially their husbands simply because they gave birth to a child with CL/P. This finding corroborates the findings of Collett, Leroux and Spletz (2010) that feeling of depression and hopelessness is common among parents of appearance-impaired children. They attributed this problem to the poor relationship that existed between caregivers and community members.

In addition, participants mentioned problems with stress and frustration as some of the challenges they face in the provision of care. Caregivers of children with CL/P faced challenges with child care. These challenges were in relation to feeding the child which they indicated was very time consuming and tedious considering the child’s condition. Some of the caregivers revealed that they sometimes spend the whole day at the medical facility just to seek assistance for their children. They further lamented that it was very stressful and frustrating which makes it difficult for them to even pay attention to their own personal lives.

Health challenges were one of the challenges that were revealed by the caregivers. Participants indicated that they have had experiences with chronic cough and body pains as a result of caring for the child with CL/P. Others indicated that they never had blood pressure until they gave birth to a child with cleft lip and/or palate. They attributed these health implications to carrying the child every day, the frustration they go through every day and the stress associated with caring for these children. According to some of the participants this makes life very difficult for them because they have to raise money to cater for the health of their child and themselves. From the current study, the participants indicated that the initial stage is a period where the child needs
much attention which could be very stressful. This supports the assertion by Zeytinoglu (2014) that the initial stages immediately following the birth of a child with CL/P were reported as more stressful for the postnatal diagnosis group because they had no time to prepare.

Another issue frequently discussed was negative reaction from family and health professionals which affected their interaction. Caregivers explained that they received poor treatments from some health professional which influenced their health seeking behaviour. This situation was stressful because it changed the perceptions of some of the caregivers on health care systems in Ghana. Although some of the caregivers commended some of the health professionals, others lambasted them because of the negative attitudes towards them. Some of the participants disclosed that they received negative reactions from their family members especially from their in-laws which made caring for their children very difficult. They were regarded as witches because they had given birth to a child with CL/P. This confirms the findings of Rumsey and Harcourt (2005) and Nelson et al. (2011) that children and their caregivers experience stigmatization and societal rejection because of the effects of CL/P on the appearance of the child. This was not surprising as some caregivers remained lonely and found it difficult to socialize with other community members. This is related to escape avoidance which is described as wishful thinking and behavioral efforts to escape or avoid the problem (Lazarus & Folkman, 1984).

The study found that in the face of challenges, caregivers resorted to coping strategies for survival in their communities. The caregivers used strategies such as self-encouragement and motivation as well as support from friends and families to cope with the challenges they faced. Evidence from this current study indicated that self-encouragement and motivation was a major coping strategy adopted by caregivers to deal with frustrations, stress and negative reactions
towards them from the community. According to some of the participants, they developed more affection and attachment to the child with CL/P whereas some also comforted themselves with other children they had aside the child with cleft lip or palate or both. In the midst of frustrations some participants also saw the need to be confident and move on. This relates to the adult personal resilience theory by Taormina (2015) which states that in the midst of difficult circumstances, individuals decide to persevere in order to overcome difficult situations without giving up. Lazarus and Folkman (1984) in the stress, appraisal and coping theory also explained that, individuals adopt different coping strategies in the midst of stressful events. According to them, individuals can adopt a problem focused strategy or an emotional focused strategy which involves distancing or isolating one’s self, exercising self-control, accepting responsibility, seeking social support or having a positive attitude towards the stressor. Similarly, Johansson and Ringsberg (2004) found that parents of children with cleft lip and/or palate adopted strategies such as maintaining a hopeful attitude for the future and seeking of confidence in their own competence as parents.

Evidence from the study also showed that caregivers resorted to isolation as a form of strategy to overcome challenges. This coping strategy was imperative as some of the participants explained that they lacked support services in the provision of care to their children. Isolation is an internal coping strategy that participants resorted to in the absence of support. Some of the participants revealed that locking up self in the room was very effective for a participant while another listened to motivational songs to move on. Moreover, some caregivers in coping with the stigma they received as a result of caring for a child with CL/P used isolation or distancing themselves from the public while others used self-encouragement. This relates to the stress, appraisal and coping theory that individuals in the face of a stressful event regulate the unpleasant emotions
that arise during the encounter. Also, individuals in a stressful situation detach themselves from the situation in order to have a positive outlook (Lazarus & Folkman, 1984).

Health professionals and caregivers suggested some measures if adopted would ensure that caregivers’ challenges are reduced. Isolation was resorted to in order to deal with the poor caregiver and community relationship as well as stigmatization. Caregivers resorted to this strategy to avoid the trouble of being ridiculed by community members and false accusations by some family members. Furthermore, support services from government, non-governmental organizations, friends and relatives were useful for the caregivers in caring for their children. The frustration and stress as well as emotional challenges associated with care of children with CL/P suggests that care support services are critical for caregivers. As part of the support services, government provided subsidies on Out Patients Department (OPD) consultation cost through the national health insurance scheme (NHIS) even though this is woefully inadequate. Also, the Cleft Lip and Palate Management Foundation Team provided caregivers counselling services to help them overcome the trauma they experienced in caring for their children. The counselling service could have the potential to encourage and motivate caregivers to continue with the support they provide for their children.

As found in studies by Hlongwa & Rispel, 2018; Kaye at al., 2018 and Snyder & Lyon, 2013, the provision of services and resources by local and international non-governmental organizations were critical to caregivers to deal with the financial challenges they faced. In addition to counselling and OPD costs, some NGOs also subsidized the cost of surgery, paying of transportation fares and feeding for some of the caregivers. Some of the participants expressed concerns that the support met them half way and they could not have survived without it. That was why it became a great source of worry since they could not get any of these forms of support
anymore. The support provided by these organizations enabled some of the caregiver to save some amount of money instead of using everything for the surgery. Unfortunately, the NGO that provided that support had out run its course, even though the provision of these support such as transportation fare enabled some of the caregivers to frequently visit the hospital with their wards for the necessary treatment and care it still remains woefully inadequate, as mentioned earlier.

The support from family and relatives was one of the important services for caregivers. Above all, some family members especially parents of caregivers were very supportive to their daughters and grandchildren with cleft lip and/or palate. Some family members showed no reactions upon hearing that their daughters and in-laws gave birth to children with cleft lip and/or palate. Consequently, some of these reactions had positive effects on the role of some caregivers of children with CL/P. The support from friends and families in the form of material resources, prayers and advice encouraged caregivers to continue with their roles. This is related to seeking social support which states that in the face of stressful situation, individuals make effort to seek emotional, informational and material support from friends, family members and organizations to deal with the challenge (Folkman & Lazarus, 1984).

In spite of the considerable efforts by the government and NGOs, some of the caregivers indicated that they had not received any support services and the few who had mentioned receiving support said that it met their needs half way. It was evident from the study that even though there were support services available to the care givers, these services were accessed by only a few of the caregivers. The caregivers who received support services explained that these support enabled them to meet some of their day to day challenges. Thus, support from government agencies, and non-governmental agencies could help caregivers to reduce the challenges they face.
CHAPTER FIVE
SUMMARY OF FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

5.0 Introduction

This chapter comprises the summary of the findings, conclusions drawn from the study and some suggestions to help improve the conditions of caregivers of children with CL/P. Also, the chapter provides information on the implications of the findings of the study for social work practice, policy and future research.

5.1 Summary of Findings

The study explored the experiences of caregivers of children with cleft lip and/or palate. The findings of this study indicated that some caregivers had no idea or any sort of belief about cleft lip/or palate before they gave birth to a child with one or became caregivers of a child with CL/P. Some of the participants were of the view that cleft lip and palate are caused by (a) abnormalities in pregnancy (b) supernatural cause and (c) abuse of drugs and food.

Also, the study found that the care for children with CL/P posed some challenges for caregivers. Many of the children with CL/P had related health issues, which affected their ability to breathe, hear, feed, speak and socialize, which made their care difficult and stressful. Key challenges encountered by caregivers in the provision of care included financial challenges, poor caregiver-community relationship and problem with child care. Other challenges were stress and frustration, as well as negative reaction from family and health professionals.
Furthermore, it was found that caregivers who provided care for children with CL/P adopted coping strategies to deal with their problems. The coping strategies adopted by caregivers, included seeking support from friends and relatives and isolation. Also, others resorted to strategies, such as self-encouragement and motivation to build themselves up in the face of adversities.

In addition, participants revealed that formal and informal support services available to them were provided by friends and relatives, governmental organizations and non-governmental organizations. Specifically, these resources and services were provided in the form of counselling, money for transportation, free surgery for the child. Others revealed that they were provided with food anytime they went for camp meetings. The caregivers who received the support were able to visit the medical facility regularly to seek medical care for their children.

5.2 Conclusions

The study found that some caregivers had no belief about cleft lip or palate before they gave birth to a child with one. Some of the participants perceived the condition to be an abnormality associated with pregnancy while others indicated that it could result from lifestyle of pregnant woman such as alcohol intake, uncontrolled diet or lack of vitamins. Some believed the condition of cleft was a cause from evil attacks with others contrary indicating it was the creation of God Almighty. The study therefore concludes that many people through the stage of pregnancy to the birth of child have no idea about condition of cleft lip/or palate. This resulted in caregivers being shocked, surprised and disappointed when they came in contact with a child with CL/P.

The study further found that some caregivers of children with cleft lip or palate received some positive and negative reactions from some family members and neighbors. Based on this it
concluded that because some people lack the knowledge about cleft lip or palate, they reacted strangely and gave negative interpretations to the condition and this affected caregivers emotionally and psychologically which eventually affected their overall wellbeing.

In addition, caregivers experienced some challenges caring for a child with cleft lip/or palate and these include: financial challenges, poor caregiver-community relationship, problem with stress and frustration. Conclusively, care and support provided by family and institutions to caregivers of children with cleft lip or palate is inadequate and as such some caregivers resorted to doing menial jobs, borrowing and falling on family and friends for support. Furthermore, poor caregiver-community relationship coupled with stress and frustration caused caregivers to isolate themselves and CL/P children they cared for from engaging in social activities.

From the findings, some caregivers resorted to seeking support from friends, acquiring bank loans and doing menial jobs to overcome financial challenges. Isolation was also used as a strategy to overcome the stigma. In accordance, this study concludes that in addition to the institutional support caregivers receive, they also find some ways to overcome some of their challenges.

5.3 Recommendations

In line with the findings of this study, some recommendations have been made to help improve the conditions of caregivers of children with CL/P and the children with CL/P in Ghana. The study found that some caregivers had no knowledge about CL/P before they gave birth to a child with CL/P or became a caregiver while some believed the condition of CL/P was a curse from evil attacks with others contrary indicating it was the creation of God Almighty. This study therefore recommends that the Ghana Health Service in collaboration with the Ministry of Health
and other stakeholders should collaborate with each other to form a strong force to intensify the education on CL/P and other congenital diseases through the media and in community programs. This could help reduce the negative perceptions people have on the cause of CL/P.

Also, some caregivers of children with CL/P received negative reactions from some family members, neighbors and health professionals which affected their role in providing care. The Ministry of Health and the health directorate of health institutions should organize workshops and seminars for health professionals on the best ways to handle caregivers of children with CL/P. This will help reduce the negative reactions they have towards caregivers and the children with CL/P. Furthermore, health professionals could also organize workshops that is aimed at training caregivers on appropriate ways to care for a child with CL/P or other congenital diseases. Moreover, community members should be educated on CL/P to reduce the rate of stigmatization and stereotyping.

In addition, caregivers experienced some challenges because of caring for a child with CL/P some of which include: financial challenges. In order to reduce the challenges caregivers of children with CL/P face, this study recommends that health institutions and churches organize fundraising events in the community to solicit for funds to support caregivers and children with CL/P. The Government of Ghana could also assist caregivers through the NHIS to cover part of the cost of surgery and other medical expenses.

The Cleft Lip and Management Foundation in Ghana could be supported with resources from government and non-governmental organizations to effectively carry out their services to children with cleft lip or palate and their caregivers.
Furthermore, the study found that some of the caregivers coped with the challenges they faced by resorting to isolation. Counseling programs would be very effective to support caregivers of children with CL/P. Besides the Panel Clinics that are organized for caregivers in the cleft units in hospitals, counseling programs could be extended to take place within every health facility where pregnant women deliver to provide initial counseling for those who give birth to children with CL/P before they are transferred to Korle-Bu or any other referral health facility.

5.4 Implications for Social Work Practice

As at the time conducting this study, Counseling at the Reconstructive Plastic Surgery and Burns Center was provided by the OPD nurses. Social workers at KBTH could liaise with these OPD nurses to provide support services for caregivers outside the hospital setting. They could assist the caregivers to form support groups and link them to resources such counseling, emotional support and some financial assistance to enhance the care they provide to children with the condition.

Social Workers as advocates could do a lot of advocacy work to ensure children with the condition of cleft lip and/or palate as well as their caregivers receive the maximum support of government through the NHIS and other benefits.

Social Workers could also liaise with the health organizations such as the Cleft and Management Foundation to raise funds for the support of children with cleft lip or palate and their caregivers. In the same way, they could link caregivers to available support groups such as churches and other outreach groups in order for them to be provided with resources to enhance the care they provide to their children with the condition. It is also vital that as part of their educational campaigns, Social Workers do extensive education and sensitization about the
condition of cleft lip and palate through the media houses to create extensive awareness on the condition. Furthermore, Social workers as educators can engage in further research on CL/P to increase the understanding of the condition of CL/P to help improve the care of children with CL/P.
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APPENDIX 1

INTERVIEW GUIDE FOR CAREGIVERS OF CHILDREN WITH CLEFT LIP AND/ OR PALATE (CL/P)

Demographic Information

a) What is your age?

b) What is your level of education?

c) What is your marital status?

d) What is your religious affiliation?

e) What is your occupation?

f) How many children with CL/P do you take care of?

g) What is/are the age(s) of the child/children with CL/P?

h) Can you tell me about the condition of the child (cleft lip/ cleft palate/ cleft lip and palate)?

i) What was the age of the mother during the child’s birth?

Caregivers Belief about CL/P

1. What is your belief about CL/P?

2. How did you come about this belief about CL/P?

3. Do other people share in your belief about CL/P?

4. How do you know people share your belief about CL/P?

5. Has your belief about CL/P changed overtime?

6. How has your belief changed over time?
Challenges Caregivers Face in Caring for Children with CL/P

1. What are the reactions you experience from family due to your role as a caregiver for a child/children with CL/P?

2. What are the reactions you experience from other people due to the provision of care for a child/children with CL/P?

3. How do these reactions affect your role in the family?

4. Tell me about the reactions you experience from health professionals at the health facility?

5. Do you encounter challenges from health professionals at the health facility?

6. If yes, what are the challenges?

7. Describe the challenges you encounter in providing care for a child/children with CL/P?

Coping Strategies Adopted to Overcome the Challenges

1. How do you deal with the challenges you encounter in caring for a child/children with CL/P?

2. In your opinion, what do you think can be done to address the challenges caregivers encounter?

Support Services Available to Caregivers of Children with CL/P

1. Are there any support systems available to you as a caregiver of a child/children with CL/P?

2. If yes, tell me about the support available for you in providing care for the child/children with CL/P.

3. How is the support provided?

4. Who provides the support?
APPENDIX 2

INTERVIEW GUIDE FOR KEY INFORMANTS

Demographic Information

1. What is your age?
2. How many years have you worked at the health facility?

Caregivers Belief about CL/P

1. What is your belief about CL/P?
2. How did you come about this belief about CL/P?
3. Do other people share in your belief about CL/P?
4. How do you know people share your belief about CL/P?
5. Has your belief about CL/P changed over time?
6. How has your belief changed over time?

Challenges Caregivers Face in Caring for Children with CL/P

1. What do you think are the reactions you receive as a caregivers of children with CL/P receive from health professionals at the health facility?
2. Do you think caregivers face challenges at the health facility?
3. If yes, tell me about these challenges?

Coping Strategies Adopted to Overcome the Challenges

1. In your opinion how can caregivers overcome their challenges?
2. How can you help caregivers overcome the challenges?
Support Available to Caregivers of Children with CL/P

1. What support are available for caregivers of children with CL/P?

2. How is the support provided?

3. Who provides the support?