

Cleft lip and palate in Ethiopia

*A qualitative study of Ethiopian mothers
experiences raising a child with cleft lip
and /or palate*

Hanna Abebe Håkonsen



Masteroppgave i spesialpedagogikk
Institutt for spesialpedagogikk
Det utdanningsvitenskapelige fakultet

UNIVERSITETET I OSLO

Høst 2012

Cleft lip and/or palate in Ethiopia

A qualitative study of Ethiopian mothers experiences raising a child with cleft lip and/or palate

Written by Hanna Abebe Håkonsen

Master in Special Needs Education

2012

University of Oslo

Faculty of Education

Department of Special Needs Education

06.12.2012

© Hanna Abebe Håkonsen

2012

Cleft lip and/or palate in Ethiopia -A qualitative study of Ethiopian mothers experiences
raising a child with cleft lip and/or palate

<http://www.duo.uio.no/>

Print: Reprosentralen, Universitetet i Oslo

Abstract

This study was aimed to discover Ethiopian mothers` experiences raising a child with cleft lip and/or palate (CL/P). To date, little research has looked at the Ethiopian mothers` experiences raising a child with CL/P. This study`s focus is not only to reflect the experiences of the mothers`, but also to provide an in-depth understanding of the children`s unique situation.

A qualitative approach and design was used as the instrument to collect the data. Six biological mothers were interviewed using a semi-structured interview guide. The interview guide was designed to elicit in-depth information from the informants.

The major findings in this study were that the Ethiopian mothers` experienced tremendous challenges in raising a child with CL/P. The mother`s emotional wellbeing was overshadowed by the child`s needs. This study emphasized the need for specific attention to be given to the mother`s emotional state.

Mothers reported a lack of sufficient information from health professionals regarding feeding, the child`s condition, and availability of treatment. The informants were thankful for the treatment received, but it was not sufficient to meet their needs and the child`s needs. The lack of coordination of professional services was one of the strongest barriers met by these mothers and their children.

Acknowledgement

My thanks and appreciation goes to all the mothers who agreed to be part of this study. Thank you for offering your time and sharing your personal stories with me.

I would also like to say thank the CL/P team in Ethiopia, especially the speech therapy unit for your assistance and help in recruiting participants. Dr. Almayehu Tekelemariam, thank you for your help in reviewing my interview guide in Amharic.

My advisor Miriam D. Skjørten, thank you for your patience, precious time, constructive comments and criticism which were sincerely appreciated.

I would like to thank Klara Ulveseter for being a wonderful Norwegian teacher for many years.

I would like to say thank you to Anders Holmefjord who sparked my interest to these field and your remarkable support and encouragement through this long journey.

Getu Abebe and Solomon Abebe, your love and guidance have allowed me to fulfill my dream of becoming a speech therapist. Getu, I would not be here today without your sisterly and motherly love.

I must thank my friend Haimanot Mulatu Walter for your support in this study, for your love and humor which sustained me when I lost motivation.

Danby Whitmore thank you, for your time to go through my thesis gave correction the English grammar.

Last but not least, my husband Emil Håkonsen, words cannot express how much I appreciate your support. Emil, you always let me know that you believe in me and you are proud of me at every stage of this journey. Your love and motivation has enabled me to complete this thesis.

Table of contents

1	Introduction	1
1.1	Country profile	1
1.2	Background of the study	2
1.3	Objective	3
1.4	Problem statement	3
1.5	Structure of the thesis	4
2	Theoretical background.....	6
2.1	Cleft lip and/or palate	6
2.2	The cause of CL/P	7
2.3	Causation beliefs in different cultures	7
2.4	Discloser of diagnosis.....	8
2.5	The mother's emotional reaction to the child's condition	8
2.6	Information about CL/P	9
2.7	Stages of emotional reactions	10
2.7.1	The stage of shock.....	11
2.7.2	The stage of denial	11
2.7.3	The stages of sadness, guilt, and anger.....	11
2.7.4	Reorganization and adjustment	12
2.8	Mother and child relationship	13
2.8.1	Facial appearance	13
2.8.2	Bonding	14
2.8.3	Feeding difficulties.....	14
2.9	CL/P surgery	16
2.10	Factors impacting children with CL/P	17
2.10.1	Speech and language development	17
2.10.2	Hearing difficulties.....	18
2.10.3	Dental problems	18
2.10.4	The role of stigma	18
2.11	Multidisciplinary team	19
2.12	Financial burden to parents of children with CL/P	20
2.13	Coping strategies	21

2.14	Chapter summary	21
3	Methodology	23
3.1	Research approach: Qualitative.....	23
3.2	Design - Case study	23
3.3	Qualitative interview	24
3.3.1	Interview	24
3.3.2	Semi-structured interview.....	24
3.3.3	Interview guide	25
3.4	Two pilot interviews.....	26
3.5	Purposive sampling	26
3.5.1	Criteria for selection.....	27
3.6	Research procedure	28
3.6.1	Approaching the mothers.....	28
3.6.2	Description of mothers	28
3.6.3	Interview site.....	29
3.6.4	Interview procedure.....	29
3.7	Data organization, presentation, and analysis	30
3.7.1	Transcription and translation of the interview	30
3.7.2	Organization of data	30
3.7.3	Data analysis	31
3.8	Ethical considerations.....	32
3.9	Validity and reliability	33
3.10	Summary	34
4	Presentation of data.....	35
4.1	Theme one: Demographic data	35
4.2	Theme two: Discovery of the child's condition.....	36
4.3	Theme three: Information about CL/P	38
4.4	Theme four: Mother's emotional reactions	39
4.5	Theme five: The family's reaction	41
4.5.1	The father's reaction to the child's condition	41
4.5.2	Extended family's response to the child's condition	42
4.6	Theme six: Feeding difficulties.....	43
4.7	Theme seven: Facial appearance and speech difficulties	44

4.7.1	Facial appearance	45
4.7.2	Speech and speech stigma	46
4.8	Theme eight: The mother's experience before, during, and after surgery	47
4.9	Theme nine: Financial burden.....	50
4.10	Theme ten: Beliefs on cause of CL/P	51
4.10.1	Mothers belief on the cause of CL/P	51
4.10.2	Society beliefs on causation of cleft lip and palate	52
4.11	Theme eleven: Coping strategies.....	54
4.11.1	Spiritual and treatment seeking.....	54
4.11.2	Meeting other mothers in the same condition.....	54
4.12	Theme twelve: Recommendations from the mothers	55
5	Discussion of findings.....	57
5.1	Discloser of diagnosis.....	57
5.2	Information about CL/P.....	58
5.3	Maternal emotional reactions.....	59
5.3.1	Emotional reactions	59
5.3.2	Stages of emotional reaction.....	59
5.4	Bonding and attachment	61
5.5	Feeding	61
5.6	Informal support.....	62
5.6.1	Family support	62
5.6.2	Meeting mothers in the same situation.....	63
5.7	Formal support	64
5.8	Mother's belief on the cause of CL/P.....	64
5.9	Society beliefs on the cause of CL/P.....	65
5.10	Surgical treatment.....	65
5.11	Facial appearance.....	67
5.12	Speech difficulties.....	67
5.13	Financial burden	68
5.14	Recommendations from the mothers	69
6	Conclusion.....	71
6.1	Factors to be considered	71
6.1.1	Mothers' emotional well-being.....	71

6.1.2	Health professional qualifications	72
6.1.3	Cooperation within the country's health system.....	72
6.2	Study strengths	72
6.3	Study limitations	73
6.4	Further research.....	73
	References.....	74
	Appendix.....	84
	Appendix 1: Cover letter.....	84
	Appendix 2 : First telephone contact	85
	Appendix 3: Home visit	86
	Appendix 4: Interview guide.....	87
	Appendix 5 : Interview guide translated into Amharic	89

List of Tables

Table 1: List of mothers with age and their children with age and diagnosis	28
---	----

1 Introduction

The focus of this study is on maternal experiences of raising a child with cleft lip and/or palate (CL/P) in Ethiopia. This chapter is the introductory part of the thesis, including country profile, background of the study, the study objective, the problem statement and key terms that are used throughout this thesis. At the end of this chapter, there is an outline of the structure of this thesis.

1.1 Country profile

Ethiopia is situated in northeast Africa, a location that is known as the Horn of Africa. The population of Ethiopia is estimated to be over 79.2 million, with an annual population growth rate of 2.7%. Ethiopia is one of the poorest countries in the world. It ranks 169 out of 177 on the Human Development Index (World Health Organization, 2009).

The health system in Ethiopia is weak. The country faces great challenges concerning preventable, communicable, and nutritional diseases. Both communicable and nutritional diseases are related to the low socio-economic development in the country. The infrastructure is underdeveloped, especially in the rural areas. There is a great variation in access to health facilities. There is also a huge difference in the quality of health service provided in the different regions of the country. About 94 % of women in Ethiopia give birth at home. Many women live in distant rural areas that are too far from a road, and even farther away from any health facility that could provide sufficient care (Chaya, 2007). The epidemic of the preventable communicable diseases such as HIV, TB, and malaria places great demands on the health system. Due to these overwhelming health challenges and the low socio-economic development, CL/P is given little attention in the country. To this date the prevalence of cleft is yet not accurately determined. However, one study by Eshete, Graven, Topstad and Beviko (2011) estimate that 1.49/1000 live births are born with cleft. These figures may not represent the whole population since the study was conducted in only within Addis Ababa.

1.2 Background of the study

Becoming a mother is a unique experience for most women, usually followed by emotions of happiness and joy. But the birth of a child with CL/P is often perceived as loss of the “perfect” child. The birth may have a negative impact on the mother (Land, 1998).

I became aware of maternal challenges in raising a child with CL/P during the 8 weeks I served as a volunteer in a governmental hospital in Addis Ababa in the winter 2009. During that time, I joined the multidisciplinary team to work as an assistant speech therapist. As part of the team I had possibility to talk with mothers and give some guidance regarding feeding and treatment. Because of the limited treatment available, mothers were coming to this hospital from the whole country. During my stay, I became more interested in assessing the unique experiences these mothers had and the challenges they faced in raising a child with CL/P. When I talked with these mothers, I became aware of the enormous struggle they faced on daily basis that often went unrecognized. According to my knowledge existing research concerning maternal experiences of raising children with CL/P in Ethiopia is rare. Since maternal experiences have not been researched widely in Ethiopia, there is limited knowledge for health professionals, so they may not give attention to the emotional strain that mothers encounter.

The reason I chose mothers in this study is that growing up in Ethiopia I have seen mothers carry great responsibility in taking of caring their children. They are also considered to be subordinate to their husbands. Taking this into account, I started to ask how it might be to be a mother of a child with a special condition. During my time in Addis Ababa in 2009, I met several mothers of children with CL/P. They came to the hospital several months after child birth. I observed that some of the children were well-fed and healthy, while others were underweight and sick. What caused this difference among those children? Why were some of the children healthy, while others were not? Did the mothers of the healthy children do something different than the mothers of sick and underweight children? These questions led me to become interested in hearing about their experiences taking care of their cleft-affected children.

My attention was more drawn to this theme when I attended the Pan African Association of Cleft Lip and Palate Conference in Addis Ababa in 2009. During the conference, I got a deeper understanding of the treatment availability in Western World for cleft-affected

children and the limited treatment available for the cleft population in Ethiopia. In addition, meeting the Ethiopian multidisciplinary team and experiencing their commitment to give a better life to this population was very encouraging. I started to think about what I could do as a future speech therapist in Ethiopia to contribute to their work.

1.3 Objective

Previous researchers have had a limited focus on maternal experiences of raising children with CL/P (Speltz, Endringa, Fisher, & Mason, 2005). The present study is aimed at exploring the experiences of mothers raising children with CL/P in Ethiopia. This study has not only looked into the maternal experience of raising a child with CL/P, but also explored the topic within the context of the Ethiopian culture and community.

I hope to share the information obtained, thereby providing more knowledge to the health professionals working with mothers raising children with CL/P in Ethiopia. Finally, it may serve as a stepping stone for further studies.

1.4 Problem statement

The problem statement for this thesis is:

What are maternal experiences raising a child with cleft lip and /or palate in Ethiopia?

The present study was designed to find out the experiences of mothers of children with CL/P in Ethiopia. To gain a deeper understanding into maternal experiences the interview guide covered these main areas:

- Discovery of the child's condition
- Maternal emotional reactions
- Challenges that the mothers faced
- Treatment

The phrase ‘cleft lip and/or palate’ (CL/P) is used throughout this thesis, so it requires explanation, as follows:

- “Cleft is an abnormal opening or a fissure in an anatomical structure that is normally closed.”
- “Cleft lip is the result of failure of parts of the lip to come together early in the life of a fetus.”
- “Cleft palate occurs when the parts of the roof of the mouth do not fuse normally during fetal development, leaving a large opening between the oral cavity and the nasal cavity.” (Kummer, 2008, p. 37)

Another phrase that is used frequently in this thesis is ‘child’s condition’. This phrase is used because other expressions such as facial deformity and congenital deformities may evoke negative feelings among the readers and among persons born with CL/P.

The expression ‘multidisciplinary team’ is also used throughout the thesis. A multidisciplinary team consists of: health professionals within the fields of surgery, orthodontics, as well as ear-nose and throat, speech therapy and psychology (Kjøll & Tørdal 2010).

1.5 Structure of the thesis

The thesis is organized into six chapters:

Chapter one: Introduction

Chapter two provides a review of previous relevant literature on CL/P and maternal experiences. It will provide a theoretical background and understanding of what CL/P is, as well as the challenges faced by both children and their caregivers. The literature review covers specific literature that addresses the maternal emotional strains of raising a child with CL/P. But due to limited research available on this theme, related research materials were also included in the search.

Chapter three deals with the methodology for this research study. This chapter deals with the qualitative approach and design, the semi-structure interview used to gather data, the target

population, the analysis and presentation, the ethical concerns, validity and reliability are presented here.

Chapter four presents the findings of the study. The presentation is organized according to the themes of the interview guide, and according to new themes that emerged during the transcribing of the data.

Chapter five discusses the findings in relation to the literature presented in chapter two.

Chapter six is the final chapter that summarizes the thesis and presents recommendations for further research.

2 Theoretical background

This chapter is aimed to cover a theoretical background for the thesis. It presents theories and research to get insight into the experiences of mothers of children with CL/P. The aim is to get an updated review of all aspects of the maternal experience of raising a child with CL/P.

2.1 Cleft lip and/or palate

Cleft lip and/or palate is a common congenital birth defect (Nelson, Glenny, Kirk, & Caress, 2011). The prevalence of CL/P is approximately 1.7 per 1000 live birth worldwide. However, different studies show that prevalence of CL/P varies due to ethnic group, racial, geographical locations or gender (Mossey, Little, Monger, Dixon, & Shaw, 2009). In Norway, the incidence is approximately 2 in 1000 live births (Tørdal & Kjøl, 2010). Among the Asian population, the prevalence is 2.7 per 1000 live births, while for the Ugandan population it is estimated to be 0.73 in 1000 live births (Dreise, Galliwango, & Hodges, 2011).

The only study on the occurrence of CL/P prevalence in Ethiopia shows that the prevalence in Ethiopia is approximately 1.49/1000. This estimate is based on hospital births. So it could be on the lower end, as many Ethiopian babies are born outside of the hospital and some succumb to death from malnutrition following birth. Further, the research was restricted to 7 health institutions within the capital city Addis Ababa. Therefore, it is difficult to accurately estimate the prevalence in Ethiopia (Eshethu et al., 2011).

CL/P is a structural deficit occurring early in the first trimester of the pregnancy, which is present at birth. Facial structures and formations occur very early in pregnancy, between weeks 5 and 11. CL/P refers to a split or separation in the lip, alveolus and palate resulting incomplete fusion between the oral and nasal cavity. CL/P may occur separately or together (Kummer, 2008).

Cleft lip is a split in the upper lip between the mouth and the nose. It can occur as a complete cleft where the opening extends in to the nose, or incomplete, which may result in a small split in upper lip (Kummer, 2008).

Cleft palate can occur in both the soft palate and hard palate (separately or together) and in combination with different types of cleft lips. The soft palate is located at the at the back of

the mouth (muscular tissue) and the hard palate is located at the front of the mouth (made of bone). Each category can be divided into unilateral (on one side) or bilateral (on both sides) and complete or incomplete (Kummer, 2008).

2.2 The cause of CL/P

The causes of CL/P are unknown. However, it is widely accepted that the causes of cleft are multifactorial. Both genetic and environmental factors have been reported as possible cause of CL/P (Martin & Suri 2004).

Genetic factors have been studied for their role in the formation of cleft lip and palate. The family history is regarded as relevant. However, results have been inconsistent, showing that most children of parents who have CL/P do not have cleft themselves (Martin & Suri, 2004).

Environmental factors starts during the embryologic development. Environmental factors that may contribute to cleft during the first trimester include smoking, alcohol consumption, poor nutrition, viral infection, the use of particular medications, deficiency of folic acid and other vitamins. (Mossey et al., 2009).

2.3 Causation beliefs in different cultures

Beliefs have significance in how society accepts a child born with CL/P. In most cultures, physical appearance plays a great role in social perceptions. Facial attractiveness is associated with positive characteristics (Kiyar & Rechmuth, 2002).

There are stigmas against deformities and inadequate functioning in many societies. Deformities such as CL/P have been associated with shame, 'the wrath of God' and some forms of divine punishment. Bradbury and Habel (2008) described that in some societies such a child is considered to be a changeling creature. In Norway, for example, until the twentieth century pregnant women were told they should not be exposed to seeing a hare, as people believed that if a pregnant woman saw a hare, her baby would be born with a cleft (Sæther, 1996).

2.4 Discloser of diagnosis

Ultrasound is utilized in pregnancy evaluation. This is a part of prenatal care in most Western countries. Today's detailed scans provide certainty about what is present or absent in the unborn child. The assessment of fetal anatomy by ultrasound increases the detection rate of any malformation (Tørdal & Kjøl, 2010).

Professionals describe prenatal diagnosis as beneficial for the mother. Usually a prenatal diagnosis is followed up with a meeting by the mother with a multidisciplinary CL/P team for counselling and helpful guidance. According to Robbins et al., (2010) prenatal diagnosis gives opportunity to the mother to digest the news and to prepare herself for the needs of the child.

Usually CL/P is diagnosed right after birth. For cases such as cleft palate the diagnosis may be delayed hours to weeks, and even for years in a case of sub-mucous cleft palate. In order to detect cleft palate, health professionals must get a clear view of the palate by examining it with spatula and torch when the infant is crying (Habel, 2004).

The time of diagnosis disclosure did not appear to change the initial reaction of the mother. Many mothers report similar reactions, whether the diagnosis disclosure was received prenatally or post-natally (Robbins et al., 2010).

In countries such as Ethiopia, a great number of women live in remote rural areas with limited infrastructure concerning both roads and health service facilities. According to Chaya (2007) just 6 % of the women give birth at hospitals or health stations, while 94 % of the women give birth at home. This makes it hard for pregnant women to access proper prenatal care.

2.5 The mother's emotional reaction to the child's condition

The mother's immediate reaction may start when she receives the prenatal diagnose disclosure, or in the delivery room right after the child is born and she receives the news of her child's condition (Tørdal & Kjøl, 2010). Due to lack of professional training in the handling of children with CL/P, health care professionals may show a visible reaction towards the child's disfigurement. The mother's experience is influenced by these reactions. The

actions of the professionals, their decisions, and their facial expressions in the delivery room shape the first reaction of the mother (Hodgkinson et al., 2005). Well trained and qualified health professionals can alleviate the difficult emotional and stressful situation for the mother (Clifford, 1987). Even though a mother may get emotional support from health professionals, research show that most mothers pass through different stages of emotional reactions (Nelson et al., 2011; Despars, Peter, & Borghini, 2009).

2.6 Information about CL/P

When a child is born with CL/P, the health professionals are in the position of having to share this difficult news with the parents regarding the health of their newborn. The content of the information provided and the manner in which the information is given will have a long-term effect on parental ability to adjust to the situation (Tørdal & Kjøl, 2010). Those who deliver the news to the parents have the opportunity to positively or negatively impact the parents' experience (Young, O'Riordan, Goldstein, & Robin, 2001; Amstalden-Mendes et al., 2011).

Parents who did not receive information about the child's condition right after the birth and parents who left the hospital without information tend to have high anxiety. It has been indicated that it is essential to fulfil the desire of parents to be fully informed immediately after child birth (Young et al., 2001).

The parents desired basic information before leaving the hospital, such as accurate diagnosis, the nature of the structural defect, how to feed the child, breast feeding, time and type of surgery available, and likely treatment pathway. As parents are often very shocked by the news, they are not able to easily absorb the conveyed information, so discussing these matters must be at the parents' own pace and time, and should be repeated later (Young et al., 2001; Hodgkinson et al., 2005).

Both Young et al.,(2001) and Hodgkinson et al., (2005) underline that the information shared in this manner may help parents to understand the nature of the CL/P, facilitating an earlier bonding process and lowering anxiety. One of the most important parental needs is complete information that can facilitate the process of parental adaption to the child's condition.

In Norway, new mothers of a child with CL/P meet the multidisciplinary team as soon as possible. There is a one-day course offer, where there is a possibility to talk with a health

professional and with a mother or father who has experienced the same situation. Health professionals strive to support these mothers by giving them adequate information. The information is overwhelming, so it is a challenging task for the professional who discloses the devastating news. The health professional's view and reaction towards the child's diagnosis has significant impact on the mother's reaction (Tørdal & Kjøll, 2010).

Health professionals must meet mothers with respect. Sufficient information involves providing information of the child's condition, as well as what can be done to improve her/his condition. It should also involve techniques for feeding the child properly, thus empowering the mother to take good care of her child. Another crucial factor is to understand the mother's situation and realize the need for support. The mother needs access to medical and psychological advice, both in regards to her child and her own well-being. Even though the situation is stressful for the mother, she needs to know what she can do to help her child. The professionals must give the information in a supportive manner. The people who deliver the news should have knowledge about the particular child's condition and give support in the early stages following diagnosis. For the new mother with a cleft-affected child, this information is important for developing later coping strategies. Regardless of who is in charge of giving information, that person must listen to the mother. The mother must be given room to ask questions and express her feelings (Hodgkinson et al., 2005; Clifford, 1987). Most mothers with children born with a CL/P do not know anything about cleft. Most of them have never seen an unrepaired cleft. They have limited knowledge about what having a child with cleft involves. Therefore it is necessary to provide the mothers with a quick professional response, giving sufficient information (Tørdal & Kjøll, 2010).

2.7 Stages of emotional reactions

The loss of the ideal child is a crisis situation (Despars et al., 2009). Mothers must deal their emotional upsets by letting go of the child they dreamed of, and generate a new dream to raise the child they have (Clifford, 1987).

A variety of negative emotional reactions by the mothers towards this trauma or loss has been reported. Most mothers undergo the different stages of shock, denial, sadness, anger, anxiety, reorganisation, and adjustment. These stages of emotional reactions are observed in most mothers of children with CL/P, however not everybody experiences all these stages (Kalland,

1995). Even though these mothers share similar feelings, each mother may have different reactions and the reaction may vary in length and intensity. Some may remain in certain stages longer than others. Others might not experience some of these stages at all (Bradbury & Bannister, 2004).

2.7.1 The stage of shock

The shock happens when the mother learns that her child has a cleft. This reaction usually appears as no reaction at all, or it can happen with tears and loud crying. Unexpected news can take some time to understand. The mother can be confused about what the diagnosis means. The length of this stage varies from a few hours to days. At this stage, the mother may not fully grasp the implications of the news of her child's condition (Nakanii, 2010; Kalland, 1995).

2.7.2 The stage of denial

Mothers react in different ways after hearing the first bad news about the child's condition. They feel unprepared and out of control. One form of reaction in this stage may be to ignore the reality and not believe the information received (Nelson et al., 2011). This is a defence mechanism that is set into motion when the parents learn about their child's condition when they are unable to cope with the situation. They fear for the uncertain future, fear for the child's future, fear the impact the child will have on their life, on their family, and on their social networks (Young et al., 2001).

2.7.3 The stages of sadness, guilt, and anger

When the reality of the child's condition is fully acknowledged by the mother, this may lead her into the state of sadness. Her sadness stems from the loss of the hope and expectation of having the ideal child. Subsequently, guilt may be a part of the grieving process. Guilt may occur because the mother may think that she is to blame for her child's condition by not taking care of her health during pregnancy (Vanz & Ribeiro, 2011). The mother has encountered a significant loss, and she may want to take it out on something or someone. The anger can be turned against the healthcare professionals, relatives, the child, or themselves. The mother wants to know and ask repeatedly: "Why me?" She tries to find the cause, and struggles to find it (Tørdal & Kjøl, 2010). At this stage she also tries to mobilize her

resources and is prepared to do anything about the situation. She may force herself to make a major change within herself and her environment (Bradbury & Bannister, 2004; Kalland, 1995).

2.7.4 Reorganization and adjustment

At this stage, the mother has matured into an emotional acceptance of her loss. She is ready to take responsibility for the needs of her child. The mother learns to recognize that her loss is real, and to acknowledge her task of leading her child on to a good life. However, the process of adjustment is not an immediate event. The emotional reactions that the mother has encountered will not disappear in short period of time. At this stage, even though a mother might have manageable control of her emotional reaction, some of the feelings may re-emerge again and again. It is noticed that with some mothers, two or more emotional states occur at the same time. Unfortunately, there is way to predict how long it will take for a mother to develop acknowledgment of her loss (Bradbury & Bannister, 2004; Kalland, 1995).

Adjusting to having a child with a deformity is a process. Besides the challenging parental task, mothers experience emotional vulnerability. In the process of adjustment, a mother's response is as unique as every loss is unique. Mothers may react in a variety of ways. There is, however, some similarity in the nature of the emotional reaction of the mothers (Nelson et al., 2011).

In her early work with terminally ill patients Elisabeth Kübler Ross outlined the five stages of the grief cycle that a dying patient passed through before death: shock, denial, guilt, anger, shame and depression. In her work as volunteer at Chicago's Light house for the Blind, she came to realize that these stages could also be applied to the way humans deal with other types of loss. Kübler-Ross discussed further that those who were able to express themselves were better able to manage their condition, while those who were unable to externalize their feelings, frustration, and guilt, would remain in them. That does not mean they would not able to move forward in dealing with their child's condition, rather that they need a longer period of time to reach that stage (Kübler- Ross, 1969).

Mothers of children with deformities adjust themselves daily through this process. Each of the stages helps the mother to deal with the impact of their loss, changing the mother's views about her situation. The intensity of feelings in relation to having a child with deformity can

be somehow reduced as the mother undergoes these stages. At this period of time, some of the mothers identify their situation and generate their own strength and look for opportunity to acquire skills to cope with their child's condition (Klein, Pope, Getahun, & Thompson, 2006).

2.8 Mother and child relationship

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

2.8.1 Facial appearance

As it is mentioned earlier in this chapter, having a child with CL/P may be an immense emotional strain on the mothers. One important factor that increases this emotional strain tends to be the facial appearance of the child (Bradbury & Bannister 2004; Lemvik, 2003). Mothers of these children may experience lowered self-esteem and emotional distress for the loss of an ideal child (Ainsworth & Bowlby, 1991; Rees, 2007). In the first months following the birth, the mother may have difficulties adjusting to her child's facial appearance, so the mother may be less involved in facial interaction (Chuacharoen, Ritthogal, Hunsrisakhun, & Nimanat, 2008).

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

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

2.8.2 Bonding

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

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

Risk factors such as maternal depression, lack of social support, bereavement over the loss of the ideal baby and the infant's temperament are considered to hinder attachment between the infant with CL/P and the mother. To enhance infant attachment security, the cleft lip team can have a role to help the mother to establish sensitivity and responsiveness to her child.

However, most studies seem to suggest that infants with cleft lip and palate have little effect on attachment, but it still emphasizes disruption on interaction may occur (Coy et al., 2002; Speltz et al., 1997).

2.8.3 Feeding difficulties

Feeding difficulties is one of the immediate challenges parents with a child with CL/P will face (Miller & Kummer, 2008). Feeding difficulties among these children differs according to

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

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

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

Most researchers believe breast feeding is best for infants. Breast feeding is recognized as the optimum form of nutrition for infants. Breastfeeding is protective. It also has a range of benefits that are important for infant health, growth, immunity, and development. Breast milk provides the infant with immune protection, a lower risk of infections, and minimizes allergies. Also the act of breast feeding creates a good mother and baby bonding (Owens, 2008). Cleft palate can also alter the swallowing of milk or food. The infant may have a problem to grip the nipple itself (Berkowitz, 2006). So infants may not get adequate nutrition and gain the appropriate weight. The goal of feeding an infant with a CL/P is the same as infants without cleft. In developed countries, breast pumps are available so the infants can get

the benefits of breast milk. The first priority is to provide optimal nutrition for the infant's daily growth, with weight maintenance being of primary concern both for parent and professionals (Berkowitz, 2006; Martin, 2004).

2.9 CL/P surgery

Surgical treatment often starts shortly after birth for children with CL/P. Surgery to repair the CL/P tends to happen within the child's first year and continuing to late adolescence. The goal of the surgery is to gain anatomic condition for normal breathing and feeding, to normalize the face with scars that are hardly visible, a nose that is symmetrical, teeth that are aligned and a palate that is intact, facilitating normal speech development (Berkowitz, 2006).

Surgery is a traumatic time. The parents are concerned about the induction of anaesthesia and the postoperative recovery. Therefore they require assistance and encouragement from the health professionals during this period (Bradbury & Bannister, 2004).

Cleft lip repair can start at about three to six months age, although this can vary according to the child's weight and general health (Berkowitz, 2006). Studies conducted by Cassell, Daniels, and Meyer (2009) on the timing of surgery show that when the repair is done at an earlier age, the results were the most beneficial.

Surgery is a main concern for parents. Their concern intensifies as surgery gets closer. In a study in Thailand, Chuacharoen et al., (2009) reported that the main parental concerns about their child surgery were: when it would happen, how long it took, recovery time, side effects, care for their infants after surgery, techniques used, outcomes of surgery and pain. A retrospective study on parental experience by Johansson and Ringsberg (2004) indicates that parental anxiety during surgery particularly concerned the anaesthetic. Furthermore, this study shows that parental concerns involve risks of infection, the possibility that surgery would not be successful, and concern for the child's appearance after surgical repair. According to Stone et al., (2010) surgery is one of major factors that influence the child quality of life. Further, that study indicates the major elements that were important during surgery, such as communication with professionals, empathy, expectations of surgery, preparation for surgery, postsurgical care, and discharge.

2.10 Factors impacting children with CL/P

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

2.10.1 Speech and language development

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

Children with CL/P in developing countries may be living in poverty, without access to sufficient health care. In some of these countries, maternal child care and cleft care services are not enough to meet their needs. Therefore, in developing countries such as Ethiopia, children with cleft are at additional risk for delayed speech and language development (Lemvik, 2003). Lemvik highlighted that children with unrepaired cleft can exhibit nasal speech, making them a laughing stock in the public. Children with isolated cleft lip have fewer speech difficulties than those with cleft palate. The children with isolated cleft lip often find compensatory ways of producing the sounds following lip-closure surgery (Berkowitz, 2006).

2.10.2 Hearing difficulties

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

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

2.10.3 Dental problems

Dental anomalies are commonly present among children with CL/P. CL/P can have an effect on both primary (baby) teeth and permanent teeth. This involves the number, size, shape, cross bite, and position of the teeth, both in early age and later in adult life. Many children with CL/P have missing permanent teeth, or may have an increased number of teeth compared to the normal. Combined with the cleft, this can affect speech, chewing, and swallowing. The esthetic look of dentation is an important part of an individual's facial appearance. Extensive dental orthodontic treatment is often required (Campbell, Dock, & Kummer 2008).

2.10.4 The role of stigma

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

human interaction (Hutchinson, Wellman, Noe, & Kahn 2011; Sousa, Devari, & Ghanshani, 2009; Turner et al., 1998).

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

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

2.11 Multidisciplinary team

Management of children with CL/P should go through a multidisciplinary team. Children with CL/P need several, long-term treatments requiring input from different professionals (Tørdal & Kjøll, 2010). Children with CL/P need a long-term follow up by health professionals. The frequency of the multidisciplinary team visits will depend on the child’s need. The cleft team usually includes craniofacial surgeons, plastic surgeons, orthodontists, ear nose and throat specialists, speech language therapists, audiologists, paediatricians, dieticians, and social workers. Right after diagnosis (before or after birth) the family should meet the multidisciplinary team. The multidisciplinary team provides care to the child with CL/P and family throughout the stages of the child’s life. Treatments include feeding, counselling, and cleft surgery help for hearing impairment, orthodontic treatment, and speech therapy, which

are often start at an early age and continue as the child gets older. The multidisciplinary team works together to meet the needs of the growing child with CL/P. Although the treatment journey for these children is often similar, variations do occur. Many developing countries face the challenge of coordination of the team and the availability of professionals to staff it. Non-profit organizations such as Smile Train work to alleviate the challenges by providing free treatment (SmileTrain, 2012).

The multidisciplinary team approach for children with CL/P was introduced to Ethiopia in 2003 by a project called “Capacity Building on Management of children with Cleft Lip and Palate in Ethiopia”. It was funded by NORAD and administered by Haukeland University Hospital, Bergen, Norway. Thanks to this effort, there is a multidisciplinary team providing service free of charge for the cleft-affected population in Ethiopia. The Ethiopian multidisciplinary team in this project includes plastic surgeons, speech therapists, orthodontists, ENT surgeons, social workers, and coordinators (Tsegaye, 2011).

2.12 Financial burden to parents of children with CL/P

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

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

The financial burden is even more overwhelming in developing countries such as Ethiopia where the per capita income is as low as 120 US dollars and 60% of the population lives under the poverty line. Lack of economic prosperity means limited infrastructure for health care, creating an inaccessible health care system. It is estimated that some 2 million disabled children live in Ethiopia, with only 3,000 of those getting some form of care. It is easy to understand that children with CL/P are not getting the basic medical care they need in a timely manner. In recent years, nongovernmental organizations have made a major advance in

medical care, including CL/P treatment, but the magnitude of the problem still remains high to be addressed (Fekadu, 2001).

2.13 Coping strategies

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

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

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

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

2.14 Chapter summary

In this chapter, an in-depth review of literature was carried out to describe parental and maternal experiences with having/ raising a child with CL/P. Many studies have been

conducted about parental experiences with having/ raising a child with CL/P. Not so many have been conducted that focus only on the mother, as mentioned in the introduction. In order to understand the effects of the birth of a child with CL/P on mothers, the above review facilitated the understanding of maternal challenges in having/ raising a child with CL/P. From the above review, it is evident that the mother, as one of the parents, often experiences emotional strain in having/raising a child with CL/P. The literature on parenting a child with CL/P, indicates that it is stressful experience. In contrast, some literature states that the experience of parenting a child with CL/P has led to positive outcomes in the parent's lives.

The following chapter will outline the methodology of this study.

3 Methodology

This chapter describes the research method used in this study. It discusses the qualitative approach and design, the instrument that is used to collect the data, and the process of finding informants. Then it describes the collection of information, the transcribing process, the organization of data, as well as its presentation and analysis. The ethical concerns, validity and reliability of this study are discussed at the end of this chapter.

3.1 Research approach: Qualitative

Qualitative research offers useful insights into social and emotional phenomena from the perspectives of the informants in their social world (Patton, 2002). Qualitative research provides the possibility for understanding a phenomenon by allowing informants to express their experiences in their own terms. In other words, the researcher learns about a particular phenomenon by listening to the informant. Qualitative research is an inductive research strategy that provides rich descriptive data. The aim of this study was to understand and present the experiences of Ethiopian mothers raising children with CL/P as is the experience is 'lived' and 'felt'. In order to accomplish this, a qualitative approach was used, with the interview as the main method (Creswell, 2007; Postholm, 2005).

3.2 Design - Case study

According to Yin (2003), case studies are detailed investigations of individuals, groups, institutions, or other social units. The purpose of the case study is to focus on individual cases and not the whole population. Yin (1994) defined a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (p. 139).

A researcher may use a case study to explore a specific case of an individual or a group of people to gain holistic understanding of the phenomena. To achieve the goal, the researcher can use multiple sources of data including interviews, direct observation, video, and audio tapes (Yin, 1994).

A case study design was used to collect detailed information from the Ethiopian mothers. This design was preferred because the experience of Ethiopian mothers in raising a child with CL/P has had little attention; their situation is poorly understood (Leedy & Ormod, 2001).

3.3 Qualitative interview

Qualitative research is increasingly being used in the field of social science. It can be defined as “involving the collection and analysis of non-numerical data through a psychological lens” (Coyle, 2007, p.11). Qualitative research aims to gather data through various methods. One such method is the interview: interviewing individuals or groups about their daily activities or life experience (Kvale, 2007).

3.3.1 Interview

This study sought the meaning of the lived experience of mothers raising a child with CL/P. The interview was a suitable approach for this study, as it explores experiences of mothers and their description of individual experiences. Interviews involve a direct conversation or face-to-face meeting with the informants based on a list of questions or topics that the interviewer needs to cover during a session. The nature of interactivity during the interview is particularly useful to enabling the informants to construct their worlds and explore the meanings they attach to their experiences (Larsen, 2007).

A qualitative researcher who uses interview as a method is interested in acquiring in-depth information. I asked probing questions, then listened attentively, thought, and then asked more probing questions to gain deeper understanding of the informant’s perspective. Further, each informant was handled professionally as a unique individual (Larsen, 2007).

3.3.2 Semi-structured interview

According to Kvale (2007), the semi-structured interview is a common method for obtaining description of an individual experience. Kvale (2007) defines the semi-structured interview as “A planned and flexible interview with the purpose of obtaining descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena.” (p. 149).

A semi-structured interview is a useful tool for obtaining specific details about the topic of study. In the semi-structured interview, a set of questions is established beforehand or fairly specific topics are prepared that need to be covered. The main objective is to allow the informants the freedom to talk about what they believe to be important, and take different paths to explore their thoughts and feelings in a normal conversation setting. The interviews for this study did not always follow the order of the prepared questions and in the way they were outlined. Rather, open-ended and non-directive questions were used, which allowed the informants to talk freely and at length. Each topic encouraged the informants to open up and describe their experiences in their own way by their own words (Johannessen, Tufte, & Kristoffersen 2006; Postholm 2005). This provided room to follow new leads, to explore the interviewee's views by asking clarification to obtain new information while also covering the prepared questions (Larsen, 2007).

3.3.3 Interview guide

Developing a semi-structured interview guide was an important step in the data collection process. According to Kvale and Brinkmann (2009), the interview guide is a valuable aid that offers a pathway for the researcher to generate adequate data (Kvale & Brinkmann, 2009). For this study, an interview guide was developed by first reviewing relevant theoretical concepts. In the beginning of the research, adequate time was allotted for review of literature and the preparation of interview questions. The literature reviewed helped to identify themes useful for the study, what kind of questions to ask, and their logical order (Larsen, 2007). In order to establish the correct focus and type of questions for the semi-structured interview guide, I discussed it with my adviser several times.

The interview guide was structured into nine broad thematic areas. Each theme was systematically designed to investigate the various aspects of maternal experiences raising a child with CL/P. The interview guide had three stages. The introduction covered an overview of the process and aimed to build trust between the informants and myself. Gradually I moved to questions that included demographic information and to specific topics that are more sensitive and controversial. The final part of the interview allowed the mothers to add more information and express their reactions to the interview.

3.4 Two pilot interviews

Two pilot interviews were conducted to determine if there were any questions that the mothers may not understand or any questions that could make mothers uncomfortable. Further this pilot interview allowed me to polish up my interview skills. The pilot interview assisted me in conducting the interviews in a manner that encouraged rich and detailed dialogue and data. The adequacy of the interview questions was tested before the questions were used in the actual data collection process. If any deficiencies were observed, necessary corrective changes were made. For this purpose, I used my husband to interview me and I took the role of the mother. Subsequently I interviewed my husband and took the role of the researcher. This process helped me to refine the interview questions.

The interview questions were initially prepared in English; however it was necessary to translate them into Amharic, one of the official languages in Ethiopia (see Appendix 5). Most of the interviewees spoke Amharic as their mother tongue. It was important to conduct the interview in the language they are able to express their thoughts freely. A professor at the Department of Special Needs Education at Addis Ababa University reviewed my interview guide in Amharic to ensure that it was correctly translated.

The next step was doing a pilot test in Amharic. I asked my friend who has two children if she would be interested in being an interviewee. My friend agreed and chose a place where she felt comfortable to hold an interview. This experience was used to further refine the interview questions and see their relevance in the Amharic language, culture and from an Ethiopian mother's context. This was done to strengthen the reliability of the study.

3.5 Purposive sampling

According to Patton (2002) a qualitative researcher chooses participants to ensure adequate, rich, and varied information to answer his/her research question (Patton, 2002).

In a qualitative inquiry, the actual number of participants is flexible, with the need to explore the meaning of the lived experiences in an in-depth manner being positively linked to the smaller sample size.

A purposive sampling method was used in this study. Mothers were selected on the basis that they would be the most representative of the population. This ensures that the mothers would be able to provide the data that would answer the research question.

3.5.1 Criteria for selection

These are the criteria for selecting informants:

- The mothers had to reside in Addis Ababa. Comment: Addis Ababa was chosen for practical reasons since a majority of the CL/P patients get treatment there.
- Mothers with children diagnosed with CL/P
- The children had to be not more than 6 years old
- Two mothers who have a child with cleft lip only
- Two mothers who have a child with cleft palate only
- Two mothers who have a child with CL/P.
- All mothers had to speak Amharic.
- Mothers had to be willing to reflect on their experiences raising a child with CL/P.
- Mothers had to be able to participate in face-to-face interviews lasting between 45 to 90 minutes.
- Mother had to be willing to have the interview audio taped.

A speech therapy assistant gathered the address and telephone number for each of the mothers. I contacted the mothers that fulfilled the criteria by telephone and explained the purpose of the study and the procedure for the interview and the manner in which it would be conducted. The informants were told that the study would require face-to-face meetings. After their willingness to participate was obtained, I asked them to suggest a quiet place where they would feel comfortable to meet and talk (see Appendix 2).

The mothers who did not meet these criteria were excluded from the study. In addition, mothers with a history of mental illness or depression were excluded. It was assumed that all of the mothers would be able to speak fluent Amharic. There are 80 different languages in Ethiopia. However, Amharic is one of the most widely spoken languages in the area where the research took place.

The plan was to interview two mothers from each group as mentioned above in the criteria. This turned out to be not possible because of lack of detailed information of the patient and the telephone network problems in the country. I interviewed six biological mothers without regard to their ethnic, cultural, and religious background. However, they were all Amharic speakers who were located in the city of Addis Ababa. I limited the number of mothers to six, due to limitations concerning time and resources.

Table 1: List of mothers with age and their children with age and diagnosis

Number	Mother fictive name	Age of the mother	Child fictive name	Age of the child	Diagnose
1	Tigest	32	Saba	5 years	Cleft lip and palate
2	Tesfa	Don't know	Leah	6 years	Cleft lip and palate
3	Mekelit	26	Salam	7 months	Cleft lip and palate
4	Fatuma	28	Abdi	1 year	Cleft lip only
5	Alem	28	Mimi	1 year	Cleft lip only
6	Helen	38	Hirut	3 ½ years	Cleft palate

3.6 Research procedure

3.6.1 Approaching the mothers

Informants were selected from the patient population at a bigger hospital in Addis Ababa. Because there was no direct access to potential participant contact details, the recruitment procedure was carried out by the speech therapy assistant in the hospital. Mothers were selected from the hospital database. The initial approach to the mothers was made by phone (See Appendix 2). This was designed to ensure that mothers would feel comfortable when they came for the interview.

3.6.2 Description of mothers

With the help of an assistant speech therapist nurse, I was able to obtain a list of telephone numbers for twelve mothers with CL/P children. Out of these twelve mothers, four could not be reached because of network problems. Two did not meet the criteria because their children

were older than 6 years of age. Of the six mothers selected, the first three had children with CL/P. One had lip surgery and was waiting for the palate surgery, while another child had completed surgical treatment and speech therapy treatment. The third child had not started any surgical treatments, due to age and weight gain. One mother had a child with cleft palate only and her child had also completed the surgical treatment. The last two mothers had children with cleft lip only. Both children had finished their surgical treatments. Incidentally, none of these mothers in the study had shared their experiences with raising a child with CL/P prior to their participation in this study.

3.6.3 Interview site

After explaining the content of the interview, the informants were asked to suggest a place to hold an interview where they would feel comfortable. Most had no past interview experience and were reluctant to suggest a place. But when asked if participants would feel comfortable to hold the interview in their homes, most were very happy with the suggestion. As it is not usual for health professional to visit people at home, the mothers were very thankful and hospitable. Consequently, five of the mothers were interviewed at their homes (without their children) so that they could focus entirely on what they wished to express. In some of the cases, their children were present and talked to me in the beginning of the interview. One mother was interviewed at her office during a quiet time of day.

3.6.4 Interview procedure

The initial plan was to meet with each informant two times. But most of the informants found this difficult due to time constraints. Therefore, the initial plan was changed to suit to the mothers' situations. Instead of two meetings, a single meeting was planned with each mother. Before each interview began, 20 to 45 minutes were spent getting acquainted with each mother and engaging them with simple conversation, drinking coffee or having a small meal. In this way, the participants were put at ease. The purpose of the study was then explained to them and the mothers were asked if they had any questions or concerns about the study. During the interview the mothers were allowed to speak freely about their experiences without interruption. The questions were not necessarily presented in the order described in the schedule. Instead, I have followed the mother's lead and when necessary asked follow-up questions. Notes were made on questions to ask, so as to not disturb the flow of the interview.

This was to elaborate the statements or words they used in order to ensure brief understanding. Each mother was asked the same questions. A slightly different interview guide was used for the mothers of a child with cleft lip only. All interviews were recorded.

3.7 Data organization, presentation, and analysis

Data organization, presentation, and analysis ensure that the huge amount data, field notes, and other material would be managed in a manner that facilitated systematic understanding to the reader (Corbin & Strauss, 2008).

According to Patton (2002), the analysis of data is the process of bringing order to the data obtained during the study and then organizing this ordered data into patterns, categories, and basic descriptive units (Patton, 2002).

This study focuses on maternal experiences of raising a child with CL/P. The mothers' stories provided an overview of their experiences, starting with the discovery of the child's condition, and proceeding to their reaction to the child's condition, the reaction of others to their child's condition and their journey to treatment and recovery.

3.7.1 Transcription and translation of the interview

In order to ensure credibility, all interview data was transcribed in Amharic - the language in which the interviews were conducted - and then the interviews were translated into English. During the transcription process, I listened to the interview tapes several times, taking notes about the tone of voice used by mothers when they described their experiences. This requires special skill and patience. It helped bring me closer to the data. All interviews were carefully transcribed with all words, pauses, silences and non- verbal expressions used by the interviewees.

3.7.2 Organization of data

I listened to each recording at least two times. The transcript was re-read several times. The next stage was to organize the data into significant and manageable categories. These categories were coded with different colours. Certain important statements were selected, highlighted, and grouped into thematic categories. The participants' descriptions of events

were used as they appeared in the interview, so as not to lose the original meaning (Corbin & Strauss, 2008). During the transcription, twelve major overarching themes were derived from this research. Most of the themes are derived intentionally from the semi-structured interview protocol, while others emerged from the data itself. The themes that emerged were listed chronologically and then moved around to form clusters of related themes. The whole semi-structured interview protocol can be found in Appendix 4.

The themes are:

- Demographic data
- Discovery of the child's condition
- The mother's emotional reactions
- Information about CL/P
- The family's reaction
- Feeding difficulties
- Facial appearance and speech difficulties
- Surgery
- Financial burden
- Belief on cause of CL/P
- Coping strategies
- Mothers' recommendations

3.7.3 Data analysis

Analysis of meaning was utilized to obtain a coherent understanding of maternal experiences of raising a child with CL/P. In the analysis phase of the study, the interview transcriptions revealed aspects of how mothers made sense of their experience through thematic organization. This was followed by looking for patterns between the cases to discover the diversity of the experiences among the mothers. This was achieved by drawing up a list of themes for the group and clustering these into master themes. The mothers' transcripts were interpreted to find meaningful information that indicated how their child's condition had influenced their lives (Larsen, 2007).

3.8 Ethical considerations

Qualitative research methods usually require in-depth investigation of the issue, so good interaction with the informant is necessary. For this reason, ethical considerations are very important. For this study, all required approvals were obtained before research commenced. During research, the appropriate ethical precautions were taken to ensure that the interests of the informants were not compromised (Kvale, 2007).

Permission for the study was obtained from the Norwegian Data Inspectorate. A formal letter for carrying out the research in Ethiopia was obtained from the University of Oslo, Department of Special Needs Education. Both of these documents were instrumental in facilitating the study and securing support from the speech therapy unit at the hospital in question in Ethiopia. Beside these letters, a letter to the hospital administration was written to give insight into the research study (see Appendix 1).

Postholm (2005) states that adequate information can reduce misunderstandings. All efforts were employed in advance to make sure that informants would not be surprised during the conduct of the interview. First, all selected informants were contacted by telephone. I introduced myself and explained how I obtained their telephone numbers. Then the objectives of the study were explained to the informants. I also explained how long it will take and that I would use a tape recorder. Further, I also explained that the study would not affect their medical care or that of their children. The principles of anonymity, confidentiality, and right of withdrawal were conveyed to each participant (Postholm, 2005).

All informants were informed that there were no primary or immediate material benefits from the study. Rather, they were informed of the long-term benefits of the study and its possible potential to help mothers in similar circumstances to alleviate the emotional stress of raising a child with CL/P.

After fully informing each mother, permission was obtained from each participant to take part in the study. Oral informed consent was obtained from all participants. Everyone agreed to have their interviews tape recorded. This enabled me to stay focused on the conversation, follow interesting leads and probe when needed.

During an interview, memories could be evoked, which were accompanied by emotions. Under such circumstances, I provided sufficient time and emotional support for the mother to allow expression of her emotions. After the episode, I made sure that the mother was willing to continue the interview.

3.9 Validity and reliability

To determine if a research finding is valid or not is essential in all research. In the social sciences validity is concerned with the issue if a method investigates what it intends to investigate (Kvale, 2007). “Validity is often defined by asking a question: Are you measuring what you think you are measuring?” (Kerlinger, 1979, p. 138).

For this study, necessary steps were taken to ensure the validity of findings. The research questions were developed with strong theoretical basis, while also making them understandable enough for their target audience. The questions were checked and rechecked for completeness, appropriateness, and for their ability to address the research problem. It was crucial to look at the procedures in this manner to meet the goal of the research. As an Ethiopian who grew up in the place where the research took place, I used my cultural knowledge and sensitivity in developing in the interview guide. While conducting the pilot test with my Ethiopian friend, I had to change some words in some questions that did not give the proper meaning when translated from English to Amharic. Amharic is my mother tongue. I conducted the all interviews myself without an interpreter. During the interview, I could easily detect any unclear answers and ask for further explanation straight away. Having an inside knowledge of the culture, I was able to understand and decode non-verbal communication, and thus asking the mothers follow up questions according to the way the question was answered. In Ethiopia, a professional seldom visits patients in their home. I conducted the interviews in their home, which enabled me to be closer with them than I would have been if the interviews had been conducted in the hospital. The mothers appreciated that I came to visit them and this enabled them to be more open with me. They accepted me as a family member and talked freely with me.

Reliability is the extent to which a measurement procedure yields the same results no matter how many times it is carried out (Kirk & Miller, 1986). It refers to the extent to which results are consistent over time and replicable by other researchers.

This research has employed the following strategies of data collection to ensure reliability. I believe that usage of the participant's own words can serve to illustrate the meanings derived from the interviews. To ensure that the real words of the participants were captured, a tape recorder was used during the interviews, and all transcriptions of the interviews were directly taken from the recorded data. I believe that the study and its results can be effectively replicated by others following the data collection processes followed in this study.

This study is limited to interviewing six Ethiopian mothers. This research shed light on the Ethiopian maternal experience raising a child with CL/P. The findings are not meant to be generalized for all mothers of children with CL/P, but to give insight concerning the impact of a having a child with CL/P and maternal coping strategies in a developing country.

3.10 Summary

This chapter described the research methods that were employed in this study. It includes a description of the research progress undertaken in the conduct this study, decisions made relating to sampling size and recruitment, the interview process, data collection method, ethical consideration relating to informed consent, privacy, and confidentiality, as well as the management of the large amount of data, and the methods used to analysis. Reliability and validity of the data is insured. The next chapter is chapter four, which presents the findings of this study.

4 Presentation of data

This study focused on the maternal experience of having a child with CL/P. This chapter will outline the data collected from interviews with six mothers of children diagnosed with CL/P.

The themes are: Demographic data, discovery of the child's condition, information about CL/P, the mother's emotional reactions, the family's reaction, feeding difficulties, facial appearance and speech difficulties, surgery, financial burden, belief on cause of CL/P, coping strategies and mothers' recommendations.

4.1 Theme one: Demographic data

A brief description of each mother is presented below. This will provide the background of the informants. Any identifiable information has been eliminated or changed. The mothers and children were given pseudonyms to prevent them from being identified.

1. Tigest and child Saba

Tigest is 32 years old. She is from the southern part of Ethiopia, but has lived in Addis Abeba more than 17 years. Tigest has completed 5th grade. She is married and the mother of five children. She works in an organization weaving traditional clothes.

Saba is five years old and her 4th daughter. She was diagnosed with cleft lip and palate at birth. At the age of nine months Saba had her lip surgery. She is in the waiting list for her palate closure.

2. Tesfa and Leah

Tesfa is in her mid-forties. She is from Addis Abeba. Tesfa has an 11th grade high school education. She is married and has four children. Tesfa is a housewife.

Leah is six years old. She was diagnosed with cleft lip and palate at birth. Leah has had her lip and palate surgery completed. Leah has also had speech therapy training.

3. Meklit and child Selam

Mekelit is 26 years old. She is from southwest Ethiopia. Mekelit has a 6th grade education. She is divorced. Meklit has one child. She is not working at the moment.

Selam was seven months old at the time of the interview. He was diagnosed with cleft lip and palate. The interview was conducted before any surgery.

4. Fatuma and child Abdi

Fatuma is 28 years old. She is from southern Ethiopia, but has lived in Addis Abeba for 15 years. Fatuma is married and has two children. She is a housewife.

Abdi is one year old. He diagnosed with cleft lip only at birth. He has got his lip closure.

5. Alem and child Mimi

Alem is 28 years old. She has finished high school and completed some college level studies. Alem is married and they have one daughter. Alem owns and manages her own business.

Mimi is one year old. She was diagnosed with cleft lip only. She has had her lip closure.

6. Helen and child Hirut

Helen is a 38 years old. Helen is originally from northern Ethiopia but she has lived in Addis Ababa for more than 15 years. She is married and has two children. She works fulltime at a souvenir shop.

Hirut is 3 1/2 years old. She was diagnosed with cleft palate only at the age of 3 years. She has had her palate closure.

4.2 Theme two: Discovery of the child's condition

Four mothers reported they learned about their child's condition at birth. One mother knew her child's condition at the year of three. Another mother knew there was something wrong with child during pregnancy. In this section the mothers describe how they discovered their child's condition.

Tigest: I gave birth to my daughter at home. I was planning to go to hospital but my neighbours persuaded me to give birth at home like I have done with my other children. It was my neighbour and a traditional midwife who helped me during delivery. As soon as I gave birth I heard them shouting in the name of God. I was shocked to hear that. I asked them why they shout in the name of God. But they said do not worry nothing happened. When I heard the shouting, I knew that something had happened. I thought I had delivered a disabled baby (baby without arm or blind or etc.) and I felt sad, I was worried about the kind of baby I had given birth to.

Tesfa: I gave birth to my child at the hospital. (...) I was unconscious when the baby was delivered and I was bleeding during delivery. After delivery I slept for some hours. When I woke up, they told me I have a baby girl. They also told me I had a normal delivery, but she was born with some problem on her face. When they first said it, it was like hearing a noise from a far place. It was like it was not real. When I saw her I asked the nurse if they had injured her during delivery.

The nurse convinced me that this occurred sometimes. She told me that one out of hundred is born like this. I was confused when I saw her. I didn't know what I could do with her. I thought there would be nothing anyone can do to help her. I asked the nurse if it was alright to leave her there. I told them to take her away and do whatever they can. I couldn't view her in full because I was feeling something terrible.

Meklit: I had a week labour until I finally gave birth through operation. After I woke up from a long sleep, I asked my sister to show me the baby. She told me to wait and relax before to see the baby. I waited for two days. I asked to see the baby, but she refused to show me. When I asked if the baby had a problem, my sister told me that it was a minor issue. The doctors were also telling me that it was treatable. I cried a lot and insisted that I see the baby and finally they showed me.

Fatuma: I gave birth to my child in a health station. They told me that he had a cleft lip and I should take him to one of the biggest hospital. I was not in panic when I saw him. Even though they were saying different thing I was not shocked. The reason that I reacted this way, was because I had a childhood friend with the same condition when I grew up. She had open cleft all of her life. She got a treatment recently. I was familiar with it.

Alem: I had a cold or flu and got medicine. I told the doctor that I was a month and week pregnant. He warned me not take any medicine other than the one prescribed by him. Taking other medication could have a possible consequence on the fetus. He mentioned CL/P. His assistant gave me antibiotics. It turned out to be the wrong medicine. I knew something would happen before I gave birth. I searched on the Internet to find out what kind of damaged it caused. You don't find the exact answer on the Internet, but it makes me ready for something unknown. When I saw her I was shocked and I asked the midwife if it happened during delivery.

Helen: When she became 3 years old, I started my work again and I got her to join a kindergarten. After being in kindergarten one week, the kindergarten refused to have her there and they told me she is not talking like her peers. I was shocked and took her to a private clinic.(...) The doctor asked her to open her month and discovered that she had a little hole in her palate.

4.3 Theme three: Information about CL/P

All of the mothers conveyed that the initial information offered about CL/P was not sufficient and they were referred to a big hospital to get more information. The mothers got very different kinds of information about their child's condition and what could be done.

Tigest: At the hospital the nurse looked at my daughter and asked us different questions such as if we have a child with similar condition? Or if there is any family member with similar problem and she also mentioned to us what the cause could be. The nurse warned me not to breast feed her. They told me that she could die.

Tesfa: Before I was discharged from the hospital, the nurse told me that it is very common to see children born in unusual circumstances. The nurse convinced me that it occurred naturally. She also told me that it is treatable and told me which hospital I should go to. I was calmed after I realized she will be treated, I got the strength to accept whatever she turns out to be.

Meklit: After that a nurse came and explained everything to me about the situation because I never thought that it was treatable. She told me to go to a bigger hospital. She repeatedly said it is treatable.

Fatuma: The nurse in maternity ward encouraged me and told me it would be fixed in this hospital.

Alem: Right after her birth, the doctor told me it is not that complicated since her palate was fine. I was not worried that much since it was only her lip. I have been reading about it and was actually prepared for that.

Helen: The doctor didn't know the problem very well. He said it was very simple. As a result, I never took it seriously though I was glad to discover about it. I never saw it seriously because the doctor told me that those who have severe palatal problem have also got a hearing defect, drinks came out of their nose and they usually get choked. Since I have not seen these problems in her, I took it easy. I assumed if I go to the big hospital, they would tell me it doesn't require surgery.

4.4 Theme four: Mother's emotional reactions

Giving birth to a child with CL/P usually results in emotional reactions by the mother.

Tigest: I cried until I saw the baby. I asked them frequently what kind of problem the baby has. I was devastated. I was wondering what kind of problem it was. They told me to wait and gave me a shower. I never saw the baby till I took a shower and got on the bed.

When they told me that I had given birth to a baby with an open mouth, I started to give thanks to God because he had given me healthier children earlier. So the traditional midwife handed me the baby. I felt moved when I looked at her.

Nevertheless it was a very big relief when I saw her. I was thinking she was disabled, like she couldn't walk, she couldn't see or expected much worse than this. I thanked God that it was not even worse than it was.

Tesfa: I couldn't believe that she is born like that. It felt like looking at a crushed-boiled potato (It was disgusting). She didn't look like a human being. When I was about to see her, I closed my eyes. Her skin and everything was different, I was not able to look at her. The nurses saw I struggled to see her and they said to me it is better that I don't see her till I calm down. Then they took her to another room. They brought her and put her by my side after I calmed down. I didn't see her for one day. I felt so broken

and complained to God. It took away all my happiness. I recalled all bad experiences earlier in life, and now it felt like I had become a mockery among my neighbours.

Meklit: When I saw him I was shocked. I have never seen a child with the same condition. At that moment I hated my life. I'd rather die than live. I was scared and sick when I looked at him. In fact I couldn't hold my baby for 45 days. My sister took care of him. I myself couldn't bear to see his face. She even turned his face from me when he slept on the bed.

Fatuma: Since I knew that there was treatment available I was not panicking. To tell you the truth I was happy before the treatment, I am not saying this not because it was eventually repaired. It was my belief while it was still open. This is the work of Allah, and I should not interfere with his work. You can't complain, mourn or regret over the situation. All you have to do is endure it. We should not worry with anything that happens. As we might be exposed to something worse, we have to be thankful for whatever happens to us.

Alem: My pregnancy time was not easy for me. I was worried and want to give birth to my child as soon as possible to see if my child had any problem, to see what kind of complication she could have. I gave birth to my child at the hospital. I knew this would happen before I gave birth.

(...)I had a long labour, and I gave birth through an operation. When I saw her, I was shocked. When I saw her, I was shocked and ask them what they can do. I never thought there was treatment for her problem. It was hard to believe even though I was prepared for something. I felt sad when I first saw her. It is unbelievable. They said, "This is easy. God has saved you from things worse than this. They said her palate was well."

Helen: I was very sad to hear that she was lesser than her peers. I believe it was not difficult for her to stay in school. I was displeased that she was rejected just because she had a speech problem. The statement I heard from the teacher which stated "she does not speak like a 3-year-old girl" makes me very sad.

4.5 Theme five: The family's reaction

4.5.1 The father's reaction to the child's condition

The mothers informed about the father's reaction towards their child's condition as follows.

Tigest: My husband was so worried and ashamed because of her. He used to ask me if I had anything to do with it. He thought I had sinned in some way or another. He used to grumble over the situation and say, "who knows what you have done? How could this happen without sin?" I would say in response "Have mercy, God!" He used to think that it was because of some kind of curse that this thing happened. He complained that he would have died instead of having a baby like that.

Mekelit: After the hospital my brother and sister asked me to stay with them. They saw my situation and they took me to their house. I stayed there 45 days and my sister helped me in feeding him and encouraged me. After 45 days I return home and then I was in for another big shock. My husband left me. He sold every item in the shop and ran away secretly because he never liked the child born.

Comment: After relating this story, Mekelit started to cry. I stopped the tape recorder and comforted her. After a break I asked if she wanted to continue the interview. She agreed and we finished the interview.

My husband left me because he thought it was hereditary. My argument is not with him but God. There have been a lot of challenges after I had given birth to my child.

Fatuma: My husband didn't say anything. As I was calm so he was just like me.

Alem: My husband didn't say much, we both knew it will be fixed. During the diagnosis some asked me if I have done something during pregnancy, some says it is a curse, but my husband didn't believe in any of this. He didn't react very much as well.

Helen: My husband was not in town at the time of diagnosis. He was sad when he heard that she is not at kindergarten, but he was far away and left all the responsibility on me.

4.5.2 Extended family's response to the child's condition

When asked about the response of their extended family, mother, mother-in-law, grandmother, sisters and brothers:

Tigest: My father was present during the delivery. He couldn't believe what he was looking at and talked to my aunt, but never said anything to me. My mother-in-law was very shocked when she heard the news. She came to visit me and cried a lot. She even said it is her who brought the punishment on us.

Tesfa: My mother was with me until I got stronger and emotionally stable. Even in the hospital she was the first to see my baby. I was located in one room with many other women. We were many in the room. My mother hid my daughter in another room because she didn't want her to be seen by others. I, for my part, had hope, since the nurse had told me it was treatable. My mother felt that it might have been hereditary but couldn't clearly know from whose side it came. I told her it had nothing to do with heredity and that it was the will of God.

Meklit: My mother-in-law came to see me only once. After that she phoned and asked if the child was treated or not. She had always a reason why she did not visit us, but I believed she was lying.

Fatuma: My family lived far from Addis Ababa. I phoned them and told them about my child's condition. My childhood friend who had the same problem was also known by my family and they were aware the condition. It was not big news for them at all.

Alem: I was sharing to my husband, family and friends that I have been sick and given wrong medicine early in my pregnancy. All of my family knew about my worry. I have talked to my husband and my family a lot before she was born. We have been discussing about the consequence of the medicine I was given, and all of them were aware of her condition. They were encouraging me.

Helen: Right after the time of diagnosis, all of my family was involved in searching treatment to her. (...) My father never wanted the surgery. He said let her grow like this as it might change through time. My brother said it is not safe to have medical treatment in Ethiopia and advised us to take her to another country. He said it is unwise to have her

operated at this age and suggested that we took her to Bangkok. I never agreed with him and never wanted to delay the operation.

4.6 Theme six: Feeding difficulties

The mothers of children with CL/P conveyed their struggle to feed their children.

Tigest: The nurse warned me not to breast feed her. She said it would hurt the baby. I bought her a baby's bottle and powdered milk and fed her. I used to buy her powdered milk. She finished it very fast. I had very little money because I have small children that I had to take care of. I started to make her traditional drink (containing wheat and sugar). However she was not healthy and had a severe cough. When I fed her, the drink came out her nose and it was very difficult. On the other hand she was continuously crying. I was tired and weak because I was not fed well.

Comment: In Ethiopian culture it is recommended that mothers and their newborn babies stay at home for 40 days. This practice facilitates time for rest and repair for the mothers by providing them special food such as porridge. The principle behind this practice is essentially to establish breastfeeding. It is also believed that at this time mother and newborn are vulnerable to evil spirits so they should stay at home for these days.

Tesfa: After some days I took her to the bigger hospital to seek treatment. I thought it would be taken care of immediately, but they told me I have to wait until she gained some weight. They also told me how to feed her, but I already knew those methods. The only new things that the nurse told me was to hold her up while feeding.

I used to milk my breast and give it to her with a bottle cap. However my breast dried soon. I was also giving her milk and making it thinner with water and giving her drops of it. Even though I did all this I felt inadequate to meet her nutritional needs. I was not sure how much food she got because her nose and mouth were open, food came out of her mouth and nose. It was wide open, you know, and even when she cried we were not able to distinguish her voice, because we couldn't hear her crying or babbling.

Meklit: (...) They also explained to me feeding was not possible. You know it is all open, and I had no milk, the other problem was he couldn't hold my breast at all. His mouth and

nose were all open. The first days when we were in the hospital, my sister was feeding him by syringe. She used to drop the milk with a syringe at the back of his mouth. Breast feeding was not possible at all. I went to one non-profitable organization and they gave me the equipment to feed him.

Fatuma: After the doctor and the nurses told me to breastfeed him on one side of the mouth where there is no opening, so that he doesn't get any problem. I used to feed him on both sides of the mouth. He had no problem with it.

I did not face any feeding problem. Actually, he weighed heavy when he was born. Because of this he had the surgery on his seventh month.

Alem: She was not breastfed. I start working after one months and fifteen days. I never took care of her very long. She is more attached to her babysitter than me.

Helen: My daughter was sick right after she was born. I took her to the hospital and they gave me some medicine and she got better but she was thin and weak. My daughter was never breastfed. I had no milk in my breast. I tried but there was nothing. For three days it had no milk. She was crying hard. She was hungry and I started gave her powder milk.

After I gave her the powder milk in bottle, she refused to be breastfed. She was not breastfed even though I believed that breastfeeding brings maternal affection and it is a good nutrition for the child, she refused it. So I always tried to have her suck my breast while she is asleep. Though she didn't suck it, I just put it in her mouth. Since breastfeeding is healthier for the child, I tried my best but she refused. I didn't know she had problem in her palate but I tried her with bottle, so she started to suck and get enough milk.

4.7 Theme seven: Facial appearance and speech difficulties

The mothers reported their different experiences to show their child in public.

4.7.1 Facial appearance

Tigest: In the beginning I hid my daughter by a blanket from people who came to see me. I always lied to them that she was sleeping. Only the two women who helped me during delivery knew about her condition and I was afraid that they would talk about the situation to the neighbours.

(...) I debated with myself “how long could I hide my daughter from other people?” So I decided to show her whenever they asked me to see her.

(...) Before I meet the cleft lip and/or palate team at the hospital, and saw other children with the same condition I had never showed her to people. I was thinking that it happened only to me.

Tesfa: Showing her to other people was my biggest fear. I always covered her and try to sit alone if I took buss or taxi. I choose the last seat in the bus so that people didn't see her. But I couldn't manage to hide her all the time, sometimes people would see.

Meklit: There are few people who knew about my child's condition right after birth, like the house owner.

When people come to visit me, I am always troubled because they ask me to see the baby. I cover him and tell them that he is sleeping, because they presume me guilty. People make you feel guilty and judge you as if you brought this thing on yourself. I don't want to hear that I have caused this thing to my son.

Nobody saw my son until he was one to two months old, because I always covered him. Now he wants to be free and doesn't want to be covered so when I used taxi or bus. He removes the cover to see his surroundings so people also see him. I don't want him to be seen but I can't control him anymore.

Fatuma: My problem was nothing compare to others. I have seen a child without hands and legs when I was pregnant, and when some people grown up with open cleft. I feel my problem is smaller than others when I look at the others.

Comment: Alem and Helen didn't talk about their child facial appearance.

4.7.2 Speech and speech stigma

Three of the mothers have children at the age of three and six. The mothers reported that their children experienced speech difficulties. These children had been stigmatized of their speech by other people around the village.

Tigest: Her palate is not yet fixed. She is on a waiting list for surgery, and as she grows I have noticed that she has problem with her speech. She doesn't talk very much with her peers. They say she speaks in her nose. Some say that when she speaks they don't understand what she is trying to say. That makes her unhappy. There is no problem with the family understanding her speech and even the near neighbours understand her.

I feel bad for her when children or a grown up laugh at her. One day I heard a woman in the neighbourhood mimicking her speech and the others were laughing. I was very sad and talked to that woman. I told her that she is a little girl and she should not be teased by an adult. This is God's work. My daughter did not choose to be like this I told this to the woman.

Tesfa: She is very clever at school, but she doesn't speak much. She has better marks than her classmates. However, she feels sorry because she has not been rewarded for class participation.

(...) She has difficulty in spelling the sounds "T" and "D" but after her speech therapy, she is able to pronounce them well. I recently found out she had some toothache. I took her to the hospital again. She was very scared and asked me several times what the doctor will do to her teeth. I think she also remembered her painful surgery. Luckily they told us we have to wait for her teeth regulation and she was so happy for that.

Once daughter of a close friend of mine was playing with my child and insulted her. She said "Nefnafa" to my daughter. (Comment: This is a negative expression in Amharic for people who have nasal speech) It never hurt her because she was just a child. But as she grows up, it can cause serious problem to her self-esteem. I talked to this girl and told her not to do this again. (After a pause) Children need love. I would be happy if they are not discriminated and treated properly.

Helen: Since she started to talk, we noticed that she had a nasal speech, but we believed that she will grow out of it.

I believe it was not difficult for her to stay in school. I was displeased that she was rejected just because she had a speech problem. The statement “she does not speak like a 3-year-old girl” makes me very sad.

Comment: One child is only seven months old and he has CL/P. The mother did not notice any speech difficulty yet. Two of the mothers have children with cleft lip only and they will likely not face any speech difficulties in the future.

4.8 Theme eight: The mother’s experience before, during, and after surgery

Mothers reported that they were informed about the availability of treatment in the country and where to go right after birth. All mothers mentioned that they were referred to the bigger hospital to get surgical treatment for their children. Some of the mothers went to the referred hospital immediately, while others took time to adjust. The children got their treatment when they weighed 8–10 kg. In one case the child was diagnosed at the age of three, so she was treated three months after diagnosis. The mothers in this study conveyed their different experiences concerning information before and during surgery:

Tigest: While we were in the hospital, she got better. She was so happy and always laughing and playing. All the nurses called her “pop-corn” (*a word that expresses happiness*).

One morning they told me she will have a surgery and when they told me this I was alone. My husband was away for work. I was not prepared for anything and I was nervous. The time came and we entered the operating room and the nurses told me to take off her clothes so I gave her to the nurse naked. I was embraced when I see she was naked. They told me to wait outside of the room.

“UUUU” I can’t forget that. They shut the door of the operating room. She was only 9 months old, I cried bitterly because I thought I will not get her back. I cried because I was thinking I will not see her again. I was all alone and there was no one beside me to give comfort. I was afraid she would be wounded more or may die under treatment. But thanks be to God it went well.

Comment: When Tigist described her experience of surgery, she was looking down and to the side trying not to make eye contact with me.

They closed only her lip. (...) Her palate is still open. I am happy they closed her lip. After she got her lip closure and she started to walk and play outside. Some neighbours started to question her scar at the lip. I would tell them she got injured playing with the children. It looks like she got injured and got a surgery.

Tesfa: After some months she gained weight and I took her to the hospital to make an appointment. They gave me an appointment and she was admitted to the hospital. One morning the nurse came and told me that she will have her surgery today. So we took her to the operating room and I left the room.

When she was in the operation room I was alone outside waiting. There was no one to talk to. I walked all alone in the compound. It was a very bad time. I felt sad, crying and praying, I was wondering whether she would be back alive or not (I didn't know what I was doing as I cried and prayed). An hour was like a year! They closed her lip and her palate after some years.

I was glad for her to have an operation though it was painful. Although she was the one who is operated, it was me who felt the pain. (She uttered the next statement with tears) "We suffered severely!"

I never saw her after they took her to the operating room. I was all alone till they finished and gave me. I was wondering whether she would be back alive or not. Time is flying and she is a big girl now. She attends school and is doing very well at school.

Fatuma: I was prepared that he would have the operation one day but they came early in the morning and they told us he would have the surgery today. They changed his cloth [nappie] and took him. They told us to wait outside. I was crying hard. I thought I would never see him again. Since he was just a kid, I thought he couldn't bear the anesthesia.

It was raining heavily and we were waiting outside the operation room. It was an unforgettable day. My husband was with me. He was crying even worse than me. He was crying even after the operation. We did not sleep the whole night looking after the baby. The baby was crying, I was crying, and the father was crying. I cried because of

my son's pain but I never complained at all. The boy was sick and crying hard. I am happy it is over. Thanks to Allah.

Comment: Staring at some place, she had tears in her eyes as she talked about the event.

The operation was quite painful, but the doctors had done their best for me. I won't forget that day. I am satisfied with their treatment. You never expected such good treatment from a governmental hospital and for free. We heard a lot of things how bad governmental hospitals were, even some advised us not to take him there. But their treatment was wonderful. The doctors had done a terrific job. Allah blesses them! Now my son is recovered completely and better looking. People think he injured himself falling. For us it is a big change. Seeing at the scar nobody knows what happened to him except the doctors.

Alem: After a month and fifteen days, I took her to the hospital. They told me to come back after 3 months, and then they told me to wait till the baby weighs 8 kg. When they told me to wait, I suggest we should go to a nearby clinic for a possible fix. My husband told me to wait. In the meanwhile she gained weight very fast. They fixed her lip. I was worried when her surgery was near, I was thinking of her age and the anesthesia, but it went well. I am planning to come again because her lip is not properly closed. The stitch was loosened and needs a new repair. I was happy but I never thought it would be treated. We got her full treatment for free as well.

Comment: Alem did not mention the lack of emotional support during surgery.

It looks incredible now. It had changed her facial appearance completely. She looked like her father before she had the treatment but now she looks like me.

Comment: Alem laughed whilst saying this sentence.

Helen: I heard that there was not a safe medical treatment in governmental hospitals. However, I found it to be contrary. It was clean. It is not only about the treatment. They were also professional, polite and friendly. My sisters and I were asking them about how it was going and they treated us well. We talked about hospitals with my neighbour and I was always in favour of them. God bless them all.

They were profession, polite and friendly and the treatment was for free. My sisters and I were asking them about how the surgery was going. They treated us well. After her surgery I could clearly hear her speech progress. She used to be nasal but now I could clearly hear her through the phone. That is a big change.

Comment: Meklit's son has not undergone surgical treatment at the time of the interview.

4.9 Theme nine: Financial burden

The mothers mentioned the extra expenses having/raising a child with CL/P.

Tigest: When the nurse warned me not to feed her my breast, I used to buy her powdered milk. She finished it very fast. I had very little money so I started to make her traditional drink. I had no money to buy her three, four bottles. My income limited me. I took her several times to the clinic. I used what I have to her medicine food and transportation.

Tesfa: I have never had any jobs that gave me salary. I take care of all the activities in the home. Sometimes I work with my husband a few days when he takes contracts to build houses. That improves our monthly income. When I got my daughter, I put all my effort on her need. I was with her all the time, I couldn't do anything else. Milk was very expensive, so I couldn't afford it. I could not help my husband like before.

Meklit: When his father disappeared I felt it was difficult to be alone with a sick child. I have suffered a lot since my son's birth. I got no job because I have closed my shop, and I am separated from my husband. I felt so sad because I lost everything. Even to buy milk to my son I went to the hospital and told them to help me. I got some help from mother Teresa home.

I have tried a number of times to give him to an orphanage but they told me to wait. Gradually, I changed my mind and now I do whatever it takes to help him grow up. I will never give him to anyone. I feel compassionate towards him now. I suffered, but I only care for my child now. I feel relieved when I see him happy and healthy. There is nothing more pleasing than seeing him joyous. I believe I will also be happier when I see him treated.

Fatuma: When my first son was born I used to work in one café. I had baby sitter to look after my son, while I was pregnant for my second son. My plan was to go back to work. When I found out that he has cleft lip I decided to stay home with him. My husband works and we have enough income but it is not the same as it was before

Alem: After I gave birth, I wanted to be home to look after her but I am the one who runs this business. (...). I start working after one months and fifteen days.

Helen: After three months I was suppose go back to work. I had my own business it was closed for some times after her birth. After I got back to work, a baby sitter took care of her. Once she was very sick. Since then she has been under weight. For this reason, I gave up my job.

4.10 Theme ten: Beliefs on cause of CL/P

4.10.1 Mothers belief on the cause of CL/P

The mothers conveyed different view on the cause of CL/P.

Tigest: I was always sure that it never came to me because of sin. As I told you before when we were in the hospital for the first time the nurse asked us if there was anyone in the same condition in our family and I know in my husband's family, there was someone with a similar condition. And you know she is still living with an open cleft. I have no doubt this is heredity but I have never said it aloud as I am afraid that I will hurt my husband.

Tesfa: I felt I had become a mockery around my village. People thought I had done something that did not please God. That makes me sad even today. I and my husband were separated. He went away from home and had an affair with a Muslim woman. But later on we were reconciled by local church elders. After that I became pregnant. I believe it is a curse from God for my husband's sin.

Meklit: I went to hospital after some days to seek treatment. The nurse asked me about my pregnancy months. As I told her that I had taken a medicine, she assured me that it was the cause of the cleft. She told me that was the cause. I felt sad again that I had

caused the problem by taking the medicine. I wouldn't be into all these problems if I didn't take that medicine.

Fatuma: I asked the doctor what could be the cause and he told me that it occurs either by taking medicine during early pregnancy or hereditary. I know there is no-one with the same problem in the family, but I thought it could be from the medicine I took during pregnancy. When I was a two- months pregnant I was sick and had taken a traditional medicine without knowing that I was pregnant. They told me my sickness was demonic and they gave me a traditional medicine with honey. I didn't know what kind of medicine it was, but it was traditionally made at home. I think it was the medicines that cause this problem but I never regret taking it.

Alem: I had a cold or flu and got medicine. I told the doctor that I was a month and week pregnant. He prescribed a medicine for me, but the assistant gave me the wrong medicine. I am sure that caused the cleft lip on my daughter.

Helen: I met the doctor before the operation and the doctor told me the cause to be smoking or chewing chat. He even asked me if I have such experiences. I told him before I move to Addis Ababa, if there is nothing to do after work, we chewed chat with friends for fun, but it was not dangerous for our health. Though I neither smoked nor chewed chat when I was pregnant, I was worried that it would be the cause.

4.10.2 Society beliefs on causation of cleft lip and palate

The mothers conveyed their experiences on society beliefs on cause of CL/P.

Tigest: One day one elderly woman came to bless me and my daughter. She wanted to hold the child, and then I was forced to show her my daughter. When she saw her, she was shocked and she did the sign of the cross. She asked me very boldly if I had laughed at anyone before. I replied to her I hadn't laughed and I told her I believe that it was the work of God. I had no right to meddle. I told her I might have unknowingly done it and brought this curse upon the family.

Neighbours came to congratulate me and some of them saw my daughter. A few of them had an open discussion with me about her condition. Some thought if she was born at the hospital, it wouldn't have happened. (...) People gave different

explanations of why and how it happened. They believe that this condition happens when a mother laughs at anyone with any disability or defect. Even some believe that a sin in the family brought this condition upon the child or that I had done something that displeased God. They didn't say this to me directly but I could understand that from their discussion.

Tesfa: (...) I have been living in this area for 21 years. When I came home from the hospital my neighbours came to visit me. People around here have different types of beliefs. Some of them they told me they have seen such problem before and it was normal. Some say I had laughed at people with the same situation. The priest told me that it could be treated at one of the biggest hospitals.

Meklit: Nobody saw my son when he was one to two months because I always covered him. Now he wants to be free and doesn't want to be covered so when I used taxi or bus he removes the cover to see his surroundings so people also see him. I don't want him to be seen, but I can't control him anymore. Some say that it is treatable and others ask the cause of the problem. People didn't say thing to me, but you hear rumours like I have been cursed, some say it is heredity. In our society things are difficult; they are fast to blame you. It is good to understand the problem fully before judging others. They started a show on TV now, I am happy that they started such a program. This helps everyone to understand and brings awareness.

Fatuma: After the birth my friends and neighbour came to visit me and they also gave their comment. Some say it happened if the mother laughed at people with the same condition. I never laughed at anybody and I didn't believe it to be a cause.

Alem: Some of my friends asked me one or two times what would be the cause of my child's condition, and what I have done to help the child. I told them I have taken medicine at early pregnancy, and that is the cause of my child's condition. They never believed me when told them this. Some of them asked me if I had taken a medicine to abort the baby.

Helen: Most people believe the cause to be spiritual and if there is a mess at home, they say it is a curse.

4.11 Theme eleven: Coping strategies

4.11.1 Spiritual and treatment seeking

Mothers in this study reported various mechanisms they use to cope with their child's condition. Some turns to their spiritual belief; others seek treatment.

Tigest: I used to ask in prayer why did you give me this child. I believe she is a gift of God and she has some purpose in my life.

Tesfa: I believe she has a bright future. She has got a lot of opportunities and there is something special about her. She is a blessing for me and perhaps that is the reason she has suffered a lot. I gave full control to God and I always pray for her.

Meklit: (...) My argument is not with him [the husband] but God. There have been a lot of challenges after I had given birth to my child.

Fatuma: I shouldn't interfere with the work of Allah. In our religion, you don't interfere in the work of Allah. You can't complain over the work of Allah. You can't mourn or regret over a situation. All you have to do is endure it. We shouldn't worry with anything that happened. As we might be exposed to something worse, we have to tolerate whatever happens to us. Allah might be displeased.

Alem: Right after her birth the doctors told me it is not that complicated since her palate was fine. I was not worried that much since it was only her lip, I didn't ask much. I have been reading about it on the internet and was actually prepared for that. The operation was also very easy.

Helen: For my first child I had so many problems. I am thankful we found her problem. I was over all in Ethiopia to find medicine to my son. I even visited *Tenqoye* [witch craft] people to get him well. I don't complain for what she has and she has got treatment. Thank God!

4.11.2 Meeting other mothers in the same condition

Mothers stated that meeting others in the same condition was helpful.

Tigest: After I quarrelled with a neighbourhood woman I decided to take her to the hospital again for her palate. When I took her to the hospital, I saw some children in the same condition. I learned that it is common, and I saw the pictures before and after treatment. I felt guilty that I hid my child in the beginning. I saw a nurse with the same condition and I was more encouraged that my daughter also will have bright future.

Tesfa: When I came to the hospital I saw many children with cleft lip and palate with their mothers, and I found that very strengthening. It helped me keep on track. I saw some children who have got treatment. I got new hope.

Meklit: As I went to hospital, I met many in the same condition. I became strong and even encouraged them. When I am there, I forget things that bother me and know I am in a better position living in Addis where treatment is available. I meet other mothers in my situation who come from far away and teach them how to bottle-feed their child.

Comment: Three mothers did not mention any feelings in meeting others with same problem.

4.12 Theme twelve: Recommendations from the mothers

One of the final questions asked concerned whether mothers have any recommendation to mothers in similar condition and to the health professionals. They gave the following recommendations.

Tigest: What I want to say to other mothers who have a child with cleft lip: seek out treatment! Don't hide your sick child. I have neighbour who has a child with a hearing problem. I encouraged her to seek treatment for this child as there might be a solution for her child's problem.

Tesfa: My message is not only for mothers in similar situations, but to all Ethiopian mothers: mothers must look after themselves! We don't have this habit traditionally, but a woman has to care for herself, taking nourishing meals and keeping her beauty during pregnancy. She has to take responsibility to give birth to a healthier offspring as much as she can.

Meklit: Above all, when I see pregnant women, I am eager to counsel them not to take medicines during pregnancy and tell them they must look after themselves.

Fatuma: For the mothers in the same condition, they should seek treatment. I knew one woman who has a child with same condition. She always covered her daughter. I encouraged her to seek treatment and told her where to go.

Alem: In our country most women go to the hospital during pregnancy. They get medicine and taking it without any question. I will suggest health professionals give awareness to the community, especially to mothers about medication that can affect their pregnancy.

Helen: I have been to school, but I never understood about my daughter's problem. Others like me don't see the problem very well because they only look at the way the child look like. They don't even know that cleft palate will bring a speech problem. Then the child will grow with the problem, even when it was easy to have it treated. Our society needs awareness, teaching mothers both in health station and by mass media.

If it is announced in a church and mosque, it will ease the tension and they will take their children to hospital. Because of parental negligence, the children will find it difficult to attend to school at an older age.

It should be seriously dealt. Professionals should be sent to raise awareness about the situation. All these children must come and get treatment. City people don't have problem, but people in the countryside don't have the access. The treatment is simple but out of ignorance, children grow up with an open cleft lip and palate.

This chapter gave insight of the lived experience of the Ethiopian mothers by their own words concerning their experience of having/raising a child with CL/P. The next chapter will discuss the findings with the relevant theory.

5 Discussion of findings

The purpose of this study was to gain deeper understanding and describe the unique experience of Ethiopian mothers raising a child with CL/P. Six biological mothers participated in face-to-face semi-structured interviews that were categorized and presented in chapter four. In this chapter, there is a discussion of the findings of the study in relation to the theoretical framework presented in chapter two and the findings of other researchers.

The topics discussed in this chapter are: Discloser of diagnosis, information about CL/P, maternal emotional reactions, bonding and attachment, feeding difficulties, informal support, formal support, mothers' belief on the cause of CL/P, society's belief on the cause of CL/P, surgical treatment, speech difficulties, financial burden, and recommendations from mothers.

5.1 Discloser of diagnosis

Except for one mother, all of the informants reported that they discovered their child's condition at birth. Even though they gave birth at the hospital or health station, they did not obtain an exact diagnosis from the medical professionals in the immediate time following the birth. Mothers mentioned that it was mainly the midwife or nurse who was the first to disclose the child's condition. This person gave the initial diagnosis and referred them to the bigger hospital for an exact diagnosis and treatment procedure.

One mother gave birth at home with a traditional midwife. She was not allowed to see her child immediately after birth. After some time, this mother sought help from a local health station and was referred to the bigger hospital for an exact diagnosis and treatment procedure.

These mothers learned about the child's condition at birth. None of them got a prenatal diagnosis.

There was only one mother who discovered her child's condition later in childhood. Her child was the only one in this study who had a cleft palate only. In such cases, the palate is hidden from view for everybody. Even though the child was sick several times, did not breastfeed at all, failed to gain weight and had a speech difficulties, her condition was not discovered until the age of three.

According to Habel et al. (2004), a delayed detection of cleft palate is not uncommon. In such cases, the cleft palate can be hidden from view and might only be identified later in childhood. The result of this study supports this finding, as this mother stated her daughter's problem was discovered as a result of her speech difficulties at the age of three. However, Habel et al. (2005) suggest that trainee doctors and midwives should be instructed to use a torch and a tongue depressor during infant screening to identify the cleft palate. Such results reinforce the need for attention to infant screening methods and the evaluation of doctors in Ethiopia.

5.2 Information about CL/P

The findings of this study reveal that the mothers who delivered their child at the hospital did not receive adequate information while on the maternity ward. There was no clear information provided regarding the treatment procedure, no training offered about how to take care of the newborn with cleft. It is apparent from their stories that there is limited knowledge among health professionals concerning how to handle such cases. This finding correlates with Lemvik (2003), whose study shows that there is a limited knowledge among professionals. Mothers were confused and stressed and did not know what they could do with their cleft affected child. Limited information was given by professionals to assist the mother to cope with the child's condition. Mothers reported that they had to acquire skills concerning how to take care of the child by themselves.

The health professionals could do better in providing the mothers with essential information to alleviate maternal emotional stress. The mothers sought their help, not only because they are experts and the first ones to be in contact, but also because the mothers rely on them as professionals. The little information that the health professionals delivered to the mothers about the availability of treatment reduced maternal anxiety about the child's future. This study's finding, as well as the findings of Hodgkinson et al., (2005) reveal that the health professional has a vital role in delivering important information. By providing thorough information, the mother is able understand the nature of CL/P, which lowers the level of anxiety and worry.

Informants reported that they gave birth either at hospital, health station or at home with the traditional midwife. None of my informants got information about the child's condition

immediately after birth. The findings reinforce the need for training health professionals in handling such cases in a manner that will provide support to the mothers. This is in accordance with the study by Young et al. (2001), which explored the needs of information to the mothers.

5.3 Maternal emotional reactions

5.3.1 Emotional reactions

Each mother provided a rich description of the child's delivery and their own intense emotional reactions during the initial hours, days, and weeks after the discovery of the condition.

Although there is a difference among mothers in how the mother was given the news of the newborn's condition, the similarity of the maternal emotions experienced was striking. None of these mothers were prepared to have a child with CL/P (Young et al., 2001). The ideal picture of the baby was flushed away and most mothers experienced distress, shock, and mourning. Regardless of where and what the mothers were told about the child's condition, their stories illustrated that the news was devastating. Every part of each mother's world was affected by her child's diagnosis of CL/P. After the news of the child's condition, the mother must find her new role as a mother of an atypical child. This study found that the informants experienced strong emotions in reaction to receiving the news about the child's condition. The finding from this study as well as those found in research by Despars et al. (2009) and Owens et al. (2010) reveal that the news can be devastating.

5.3.2 Stages of emotional reaction

The findings in this study indicate that mothers went through some of the emotional stages in relation to mothering a child with CL/P.

One of the stages that the informants mentioned was shock as they received the news. On receiving the diagnosis the mothers in this study were left in state of shock, and their first reaction was 'Why me?' The mothers reported that soon after receiving the news of the child's diagnosis they experienced feelings of confusion, disorganization, and helplessness.

Another stage that was experienced by the mothers was denial. This was seen in the majority of the mothers in this study. For most of the mothers, denial or disbelief seems to appear shortly after they learned the child's condition. Two of the mothers wanted their infant immediately institutionalized and adopted. They also described that they had difficulty seeing the infant for a period of time.

An emotional stage of grief, anger, guilt, and sadness are feelings that my informants experienced. This was generally directed at close family members. These feelings were experienced by the majority of the mothers. Some of the mothers asked 'why' questions and bargained with God. They asked God for what reason they got a child with this condition. One mother believed that the cause of the child's condition was a punishment from God. She blamed her husband for the cause of the cleft. Several of the mothers were concerned that they themselves had caused the problem by their actions during pregnancy (taking traditional medicine, chewing chat). Mothers searched their past actions to find out what they did during pregnancy that might have caused the cleft. Young et al., (2001) noted how mothers of children with CL/P reacted when they received the news of the child's condition. Receiving the child's diagnosis is devastating news, and the mother may go through a period of mourning. This is supported by the findings of this study, since four of the mothers disclosed that their initial reaction to their child was a period of mourning.

It seemed that some of the informants made quick progress in helping their child and accepting the child's condition. They said that in order to help their child live, they had to find means of improving the child's situation. They faced great challenges due to the child's condition. The mothers took full responsibility for the child's condition, which created a time of closeness between mother and child. Besides this, they used support from the nurses and doctors, seeking treatment, praying, seeking spiritual reasons and forming a relationship with the actual child rather than the idealized child. Several of the mothers highlighted that their child is a gift from God, giving a purpose in their life. The mothers reported that they had the opportunity to express their emotions for the loss of their ideal child, which helped them adapt to their new life situation. This is in accordance with Kübler-Ross (1969), who wrote that healthy mourning involves a new orientation from sorrow to problem solving.

5.4 Bonding and attachment

Several of the mothers in this study revealed that their primary bonding with their child was impaired, due to the facial appearance of the child.

Two of the mothers described that the facial appearance of the child had an impact on the mother-child bonding and attachment process. The ideal picture of the child was flushed away and they struggled to adjust with the child's condition, feeling depressed and in a state of mourning. This finding correlates with the findings of Coy et al. (2002) and Speltz et al. (1997) that several factors including maternal depression, lack of social support and mourning over the loss of the ideal child are considered to decrease the bonding between the mother-child.

Nevertheless, in this study, when the mothers were told by a professional that treatment was available, the mothers were encouraged and their feelings of connectedness with their child were strengthened. The findings of this study show that providing even a limited amount of information had a positive impact on mother-child attachment. This study shows that health professionals (preferably working in a multidisciplinary team) can play a vital role in the establishment of strong mother-child attachment through counselling and providing information. This was mentioned by (Lemvik 2003), who described the need of multidisciplinary team in Ethiopia.

5.5 Feeding

The informants stated that the feeding process were stressful both for themselves and their children. The mothers did not know how to establish a good feeding method, and did not get information from the midwife, nurse, or staff at the hospital right after birth. In addition, there were no special feeding bottles available on any of the maternity wards or at the health stations. Special feeding bottles were even not available on the market. Mothers reported that due to lack of feeding materials and support from health professionals, they failed to establish a good feeding pattern. This created a considerable maternal anxiety, due to the child's sickness and failure to gain weight. Several of the mothers mentioned that their children struggled to acquire adequate nutrition for growth and weight gain. This shows that feeding caused considerable maternal anxiety, which correlates with other studies that found that

feeding is one of the major concerns of mothers (Bannister, 2004; Miller & Kummer, 2008). The mothers in this study tackled the feeding problem by themselves and with the help of family. Their dedication to help their child and to tackle the challenges they faced by themselves was impressive. Professional help was not sufficient to alleviate maternal anxiety. The mothers had to take their own measures to improve the child's feeding situation.

5.6 Informal support

5.6.1 Family support

Overall findings in this study revealed that a birth of a child with CL/P generates a range of emotional responses within the child's family.

All mothers reported that they felt responsible for the child, for providing for most of the child's needs. The mothers perceive care giving for the child as a burden.

The mothers in this study reported their family's involvement by the family's sharing of emotional and practical burdens and by their support and encouragement. This support included seeking information for treatment, financial support and emotional support. The families of the mothers felt obligated to help the child. They made an effort to meet the child's need in terms of time, money, and finding treatment. The husbands, brothers, sisters and parents of the mothers were involved in providing practical and emotional support. This had a positive effect on maternal self-esteem. The mothers were thankful for the support from extended family members. This finding supports the finding by Baker et al. (2008), which highlights that family support creates a sense of belonging, psychological, and physical well-being.

However, one mother stated that her marriage had fallen apart as a result of the birth of the child with CL/P. When the child was 45 days old, her husband left her. This greatly affected her situation, so she has difficulties coping with her child's condition. Lack of family support led this mother into depression, thus making the process of adaptation to the child's condition slower than it would have been if she had good social support. This is further emphasized by Schultz (2008), who reported that mothers with lower social support appear to experience more depression.

5.6.2 Meeting mothers in the same situation

Many mothers indicated that their social support came from other mothers they met at the hospital or other mothers with who have a child with cleft. In this context, the relationships or meetings with other mothers of children with CL/P is beneficial, which proved to be a resource for several of the mothers. Other mothers of children with CL/P have been in, or are in a similar situation and can help by providing support and advice. The mothers also see how the other children have been treated and the results of that treatment. Mothers in this study realized that they were not alone and there are others that have had the same experience. Even meeting the other children helped the mothers to feel not ashamed. They recognized that their children are not the only ones in the community with this condition and that there is hope, despite the child's condition. This finding is consistent with that of Davies (2004), who emphasized that meeting mothers in the same situation greatly reduce maternal emotional stress.

It was apparent from the mothers interviewed that each mother had her own experience and concern about the child. They were particularly concerned about the child's facial appearance, and how the family and others would react to the child. They asked themselves: 'why did this happen to me?' They felt inadequate in meeting the child's nutritional needs, and struggled to cope with all the challenges they faced. These challenges could be tackled by the new mothers. It is therefore important establishing a group of mothers. As the mothers in this study had gained a lot of experience through raising their child with CL/P, this knowledge and experience would be beneficial for new mothers in a similar situation. This is also highlighted by Tørdal and Kjøl (2010), who mention that one way of helping a new mother could be by meeting mothers who have older children with cleft and sharing experiences with them. For example, most of the mothers in this study had tried various ways of giving the child milk or other types of drinks and had overcome the problem of feeding. This practical knowledge would help new mothers to cope with frustration and exhaustion during the early months of having an infant. In this group they can also share emotional reactions. This may provide new others with the opportunity to realize that it is not unusual to have these feelings.

5.7 Formal support

Formal support is defined as the provision of assistance by the multidisciplinary team who are experts in the area of the child CL/P. All mothers have had an overall good experience with the service and treatment they received from the multidisciplinary team. They also commented that the treatment was free of charge, which made them very happy since most of them had a limited income. The opportunity for free treatment also has a positive impact on maternal coping strategies. The cost of treatment can pose an additional challenge for mothers from a low-income household. Mothers valued the fact that they escaped the financial pressure that they had encountered during hospitalization. This revealed that the free service provided in Ethiopia considerably reduces the financial burden encountered by the mothers. This finding emphasizes the vital role played by non-profit organizations in helping the cleft-affected population. This finding is similar to what was found by Lemvik (2003), who stressed the importance of non-profit organization intervention in assisting the cleft-affected population in Ethiopia.

5.8 Mother's belief on the cause of CL/P

Interpretations of the beliefs of the mothers regarding the child's condition revealed that the mothers in this study held both environmental/medical and traditional beliefs as the cause of CL/P. Before these interviews took place, all of the mothers had talked with health professionals and discussed possible causes of CL/P. Specific explanations on the cause of CL/P had been provided by health professionals after the delivery of the child. Some of them leaned towards the environmental and medical view held by the health professionals, while others did not.

Environmental and medical causes were identified by the mothers. Several of them used medication during the first period of their pregnancy. One of them recalled that she had been chewing chat before pregnancy. Another mother believed that the cause of CL/P was genetic. They were all informed by health professionals that these environmental and medical factors might be the cause of CL/P. These findings emphasize the causes of clefts can be both environmental factors and genetic factors. This is also mentioned by Martin and Suri (2004) as possible causes of CL/P.

Even though one mother used traditional medicine during early pregnancy, she still believed there was a divine reason for the child's condition. She believed it was the work of Allah. Another mother strongly believed that the child's condition was a punishment from God, because her husband had an affair with another woman. This finding supports the findings by Lemvik (2003).

During the interviews, it was apparent that the mothers were still searching for the cause of the CL/P. They asked what the possible cause could be, as several of them still were not content with the answer given to them by the health professionals. It was apparent that they still felt guilty because they took medicine during pregnancy. When they were told the possible cause of CL/P, they were felt somehow relieved that the child's condition might not be their fault.

5.9 Society beliefs on the cause of CL/P

The questions of what caused the CL/P were central among the informants in this study. The society beliefs on cause colour all aspects of the mother's relationship to the child with CL/P.

One of the most widespread beliefs in Ethiopia on causation of CL/P has a spiritual association. Everything that happens is an expression of justice, so mothers are largely to blame for the presence of the cleft.

Most of the mothers said society believed it is a curse or the mother had mocked someone with the same condition. These beliefs, that some past failure causes cleft, has a pervasive effect on marriage, religious functions, and interpersonal relationships. This is also underlined by Lemvik (2003), who found that the Ethiopian society believes that the child's condition was caused by the mother's wrong deeds in her past.

5.10 Surgical treatment

The findings of this study show that the mothers experienced a wide range of emotional strain during the child's hospitalization. None of the mothers were informed about the upcoming procedure and were unprepared for the child's surgery. There was a distant relationship between the health professionals and the mothers; the mothers felt they had no control at the time of surgery. Four of the mothers highlighted the experience concerning the child's

anesthesia. Their biggest concern was whether the child would bear the anesthesia and if they would ever see the child again. As the mothers mentioned, they feared the unknown. They were anxious about the anesthesia and surgery.

The mothers tentatively experienced what the child went through during the surgery. They struggled with intense emotions of grief and loneliness. Even after the child was admitted to hospital, the mothers did not know when the surgery would take place and how long it would take.

Some of the health professionals were not concerned with the mother's emotional state during the operation, whilst others took the emotional concern of the mother seriously.

Nevertheless, the mothers' stories show the need for communication with health professionals and for more awareness by health professionals concerning the mother's emotional state during the child's surgery. This is underlined in a study by Stone et al., (2010), which indicates the importance of providing information during surgery.

Good preparation could help these mothers to cope, relieving the fear of hospitalization. None of the mothers were present during induction of anesthesia. To alleviate the stressful anesthetic experience, the child's mother could assist the health professional by being with the child during induction of anesthesia. Mothers felt vulnerable when the child was taken to surgery. Even though these mothers did not directly mention a need for information at the time of the child's hospitalization, their experiences indicated that need. They needed to know what the child would go through, with practical and emotional preparation for the surgery. These findings coincide with the study by Johansson and Ringsberg (2004) and Chuaharoen et al. (2009), which highlight the importance of providing information during surgery. Moreover, one should bear in mind that a mother's emotional stability can have a positive impact on the child's recovery, by helping the mother to be more focused and prepared to meet the needs of her child during hospitalization than she would have been otherwise.

Mothers in this study may at least have had a positive experience of staying at the hospital. They were allowed to stay at the hospital during the child's treatment. The mothers were allowed to hold the child right after the surgery and to spend as much time as possible in hospital with the child. This policy must be encouraged, as it has a positive impact both on mother and child. It also helps the child to cope better with treatment.

5.11 Facial appearance

Mothers reported that immediately following the birth of the child with CL/P, they had difficulty engaging in social activities. They hid the child inside the house for fear of other people's negative attention, judgment and expressions of pity. The mothers were concerned about how other people would react to the child's appearance. The mothers in this study reflected to some degree the belief that society still stigmatized people with visible defects. This belief resulted in fear and maternal discomfort about being seen in public. Several mothers tried to hide the stigmatic condition of the child. They gave example of covering the child and not allowing visitors to see the child.

The informants of Lemvik (2003) also used some of these methods (hiding and covering the child from public view) to reduce the stigma of the child's condition.

After surgery, several of the mothers reported that this changed and now they felt safe and dared to take the child out in public

In Ethiopian society, facial appearance is more important than other challenges that are faced by children with CL/P, so getting surgical treatment as quickly as possible is very important for the mothers because of the stigmatization and maternal emotional strain caused by the visible defect.

5.12 Speech difficulties

Speech difficulties were reported by three of the mothers in this study. These children were diagnosed with cleft lip and palate. Mothers reported their children speech difficulties were noticed by others and mocked by their speech difficulties. They described that the children speech production were nasal. This limited the children participation in the public and even among the family. This finding is in line with the finding by Lemvik (2003) who underlined the stigma of speech difficulties in Ethiopia.

One mother said that her daughter impairment speech was the turning point for further assessment and treatment. The kindergarten rejected her child because of her indistinct speech. This finding is similar with the finding by Lemvik (2003) who found that children with cleft lip and palate in Ethiopia were not seen as being fit for a regular school and kept

home isolated. This is due to the lack of knowledge among the teacher and the student, the child with such condition may be stigmatized.

Two mothers reported that their daughters were teased by other people due to speech difficulties. One of them said that speech therapy given to her child after the cleft palate surgery considerably improved her daughter's speech. According to the information acquired during interviews with the mothers, the speech therapist has an important task in Ethiopia. As of this date there are no trained speech therapists in the country to help children with speech problems.

One of the children was five years old at time of interview and she was still waiting for her palate closure. Her open palate caused speech difficulties. This finding coincides with Lemvik (2003) who stated that in some cases patients after lip closure do not return to the hospital for further treatment. This is due to lack of understanding of later speech problem. It could be also that the lip closure removed the stigma of facial appearance. Another reason could be that in a developing country such as Ethiopia, children can grow and live with an open palate for years due to lack of early intervention and treatment. This again can add the risk for delayed speech and language development.

5.13 Financial burden

It is obvious that there were expenses that these mothers must cover. Raising a child with cleft lip and/ or palate placed additional demand on mothers. Weather they were employed or had their own business, these mothers stopped working or shift their role and devoted them self to look after their children.

All of the mothers noted that there are costs related to a child with CL/P, including, milk, bottles and other additional expenses. Two of the mothers were unemployed, but they took full responsibility for all aspects of the child's demands while their husbands supported them financially. Two informants left their paid employment or business to become a full-time mother. One had her own business, and had to rush back to work six weeks after the birth of her child to sustain her business. One mother experienced that her income disappeared because her husband left with all her belongings.

The mothers in this study did not mention treatment expenses because treatment is given free of charge. The study's findings show that non-profit organizations help reduce the financial strain on the mothers. Again, as Lemvik (2003) emphasizes, the help provided by non-profit organizations is vitally important until the country is fully capable of addressing this problem. Even though the treatment was free of charge, the mothers struggled financially to buy feeding bottles and equipment for feeding the child. Providing free bottles and supplement feeding equipment can reduce the financial strain on a family that has a child with CL/P.

5.14 Recommendations from the mothers

At the end of the interview the mothers were asked if they had any suggestions or recommendations for mothers in the similar situations or for health professionals. Most of the mothers were thankful for the treatment given to the child. They appreciated that the treatment was free of charge.

One mother underlined the importance of active involvement by churches and mosques in the creation of positive awareness about CL/P. She stated that by creating a positive awareness, society will gain better understanding and acknowledge the children's condition. This would benefit children with CL/P.

All mothers mentioned that society is often unaware of the child's condition. This leads to stigmatization. Public awareness is important for minimizing stigmatization and maintaining positive attitudes towards children with CL/P. Two of the informants mentioned that they saw a TV program where health professionals raised awareness of treatment possibilities for people with CL/P. Both highlighted the importance of public awareness to alleviate the stigma of cleft. There is still a great deal that needs to be done in raising awareness of CL/P in Ethiopia.

All of the mothers stated that they encourage other mothers in similar situations to take their children to the hospital. They also mentioned that they encourage mothers to seek professional help immediately. The mothers said that after seeking treatment they had got a better understanding of the child's condition and the possible cause. The information gained from health professionals helped to raise their self-esteem.

It was apparent that it is not always the CL/P condition, but the way the condition is interpreted by society that impacts maternal experience. These mothers reported that being not aware of the cause of the child's condition and the treatment available led them to hide the child from the community. After being at the hospital, most of them maintained a positive awareness as a result of increased knowledge about the child's condition.

From the above recommendations, it was evident that raising awareness is vital. This encourages mothers of children with this condition to seek professional help. Subsequently, this can also reduce the stigmatization of people with CL/P.

6 Conclusion

This study sheds light on the experience of Ethiopian mothers raising a child with CL/P. It reveals a number of themes related to the mother's experience raising a child with CL/P. Mothers experienced emotional strains having a child with CL/P. This is particularly true in Ethiopia where the health infrastructure is limited. The mother's emotional reaction was aggravated because society largely blamed them as the cause of the child's condition. The impact of social norms had a significant consequence for these mothers with the result that several of them isolated themselves and the child before the treatment. Having the child stigmatized due to either facial appearance or speech difficulties created an additional emotional burden for the mothers.

At the time of diagnosis, the news was devastating to the mothers. They described various emotional reactions immediately following receiving the diagnosis of the child. Some of the mothers took a longer time accepting the child's diagnosis before they felt ready to move forward.

6.1 Factors to be considered

Study findings indicate that the following factors need to be considered to give better the health service to these mothers and their children.

6.1.1 Mothers' emotional well-being

The findings highlight that it was essential to provide emotional support for mothers when the child's diagnosis is disclosed to the mother. At that time, the mother's emotional well-being was overshadowed by the need of the child. Specific attention needs to be given to address the mother's needs concerning her emotional well-being. Since the mother is the main caregiver for the child, this will help the child, too. When the mother is emotionally stable, she is in a better position to provide for the needs of her child.

6.1.2 Health professional qualifications

The mothers encountered a lack of knowledge about CL/P among health professionals. This led additional emotional distress for the mother who had to figure out feeding methods and to seek for treatment for the child.

Information is essential for mothers during diagnosis and treatment. The mothers were not given much guidance concerning how to feed the child. There was no material available on the maternity wards to equip the mother to feed her child. The mothers did not meet the multidisciplinary team until a long time after the time of diagnosis. This made the situation more difficult for the mothers. Some mothers were given information, while others searched by themselves for ways to feed the child. This finding emphasizes the lack of knowledge among professionals and the need of more training. The information provided could prepare the mother to face challenges, to give her hope to see positive future with her child, and alleviate emotional distress.

6.1.3 Cooperation within the country's health system

The study's findings indicate that health stations, governmental hospitals and non-governmental hospitals provide individual service to the population. It is apparent that there are limited connections among these various institutions. I believe it is beneficial to establish links and cooperation between local health stations, different governmental hospitals, and non-governmental hospitals as pre-requisite for providing good health service to these mothers and their children. Establishing a link to the existing multidisciplinary team may help the team to reduce their work load in some extent, and benefit the mothers, too.

6.2 Study strengths

I believe this study has numerous strengths. This study brings the unheard voice of the mothers from Ethiopia out into the open. The unique experience that is faced by these mothers in raising a child with CL/P was discussed. The study gives insight into the experience of the mothers who needs more support in various areas.

6.3 Study limitations

This study was limited by the fact that interviews were conducted with just six mothers, therefore a broad generalization cannot be made from the study. Rather it should be considered as starting point for further research. The samples for this study were mothers from the same city, who speak Amharic. I therefore cannot be certain that the sample is representative of the population of Ethiopia at large. However, knowing the Ethiopian culture and the conditions of health care in Ethiopia, it is possible that the experience of the mothers from other parts of the country would not result in a significantly different outcome. In addition to this it would also be important to hear the fathers' voices , they were not represented in this study. Although the majority of the informants described the experience of the child's father, I have not heard the experiences related directly from the fathers themselves.

6.4 Further research

I believe it would be worthwhile to replicate this study in Ethiopia with a larger sample with additional time , including mothers from other parts of the country, particularly rural areas where there is limited availability of treatment. This will broaden the overall understanding of the phenomena. I also believe research focusing on socio-economic status in relation to the child's condition. Does a low socio-economic status increase or decrease emotional strain for mothers of children with CL/P? Further research may increase the understanding concerning this population and strengthen the professionals, enabling them to give better service both to mothers and children.

References

- Ainsworth, M. D. S. & Bowlby, J. (1991). An ethological approach to personality development. *Journal of American Psychologist*, *46*(4), 333–341.
- Amstalden-Mendes, L. G., Xavier, A. C., Antunes, D. K., Ferreira, A. C. R. G., Tonocchi, R., Fett-Conte, A. C., et al. (2011). Time of diagnosis of oral clefts: a multicenter study. *Journal de Pediatria*, *87*(3), 225–230. doi:10.2223/JPED.2084
- Baker, S. R., Owens, J., Stern, M., & Willmot, D. (2009). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *The Cleft Palate-Craniofacial Journal*, *46*(3), 229–236.
- Bannister, P. (2004). Feeding a baby with cleft palate. In V. Martin & P. Bannister (Eds.) *Cleft Care: A Practical Guide for Health Professionals on Cleft Lip and Palate* (pp. 45–47). Wiltshire, England: APS.
- Berkowitz, S. (2006). *The Cleft Palate Story*. Thorofare, NJ: Slack.
- Bowlby, J. (1977). The making and breaking of affectional bonds. I. Aetiology and psychopathology in the light of attachment theory. An expanded version of the fiftieth Maudsley Lecture, delivered before the Royal College of Psychiatrists, 19 November 1976. *British Journal Psychiatry*, *130*, 201–210.
- Bowlby, J. (1980). *Attachment and Loss: Volume 3. Loss: Sadness and Depression*. London: Hogarth.

- Bradbury, E. & Bannister, P. (2004). Prenatal, perinatal and postnatal counselling. In A. C. H. Watson, D. A. Sell, & P. Grunwell (Eds). *Management of Cleft Lip and Palate* (pp. 117–222). London: Whurr.
- Bradbury, E. & Habel, A. (2008). Psychological and social aspects of CL/P in the developing world, including implications of late surgery or no surgery. In M. Mars, D. Sell, & A. Habel (Eds.). *Management of Cleft Lip and Palate in the Developing World*. (pp. 159–172). Chichester, England: John Wiley & Sons.
- Britton, L. (2004) Speech and language difficulties associated with cleft palate. In V. Martin & P. Bannister (Eds.) *Cleft Care: a Practical Guide for Health Professional on Cleft Lip and/or Palate* (pp. 95–103). Wiltshire, England: APS.
- Campbell, R., Dock, M., & Kummer, A.W. (2008). Dental anomalies associated with cleft lip/palate: effects on speech. In A. W. Kummer (Ed.) *Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance* (2nd ed.), (pp. 238–278). Clifton Park, NY: Delmar Cengage Learning.
- Cassall, C. H., Daniels, J., & Meyer, R. E. (2009). Timeliness of primary cleft lip/palate surgery. *The Cleft Palate-Craniofacial Journal* 46(6), 588–597.
- Chaya, N. (2007). *Poor Access to Health Service: Ways Ethiopia is Overcoming It*. Washington, DC: Population Action International. Retrieved from http://populationaction.org/wp-content/uploads/2012/01/Health_Services.pdf
- Chuacharoen, R., Ritthogal, W., Hunsrisakhun, J., & Nimanat, K. (2009). Felt needs of parents who have a 0 to 3 month old child with a cleft lip. *The Cleft Palate-Craniofacial Journal*, 46(3), 252–257.

- Clifford, E. (1987). *The Cleft Palate Experience: New Perspectives on Management*.
Springfield, IL: Charles C. Thomas Pub.
- Corbin, J. & Strauss, A. (2008). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory* (3rd ed.) Thousand Oaks, CA: Sage.
- Collett, B. R., & Speltz, M. L. (2006). Social-emotional development of infants and young children with orofacial clefts. *Infants and Young Children, 19*(4), 266–291.
- Coy, K., Speltz, M. L., & Jones, K. (2002). Facial appearance and attachment in infants with orofacial clefts: a replication. *The Cleft Palate-Craniofacial Journal, 39*(1) 66–72.
- Coyle, A. (2007). Introduction to qualitative psychological research. In E. Lyons & A. Coyle (Eds.), *Analysing Qualitative Data in Psychology*. (pp. 9–29). London: Sage.
- Creswell, J. W. (2007). *Qualitative Inquiry and Research Design. Choosing among Five Traditions* (2nd ed.). Thousand Oaks, CA: Sage.
- Davies, G.(2004). The role of parent support groups. In A. C. H. Watson, D. A. Sell, & P. Grunwell (Eds.). *Management of Cleft Lip and Palate* (pp. 379–385). London: Whurr.
- Despars, J., Peter, C., Borghini, A., Pierrehumbert, B., Habersaat, S., Müller-Nix, C., et al. (2011). Impact of a cleft lip and/or palate on maternal stress and attachment representations. *The Cleft Palate-Craniofacial Journal, 48*(4), 419–424.
- Dreise, M., Galiwango, G., & Hodges, A. (2011). Incidence of cleft lip and palate in Uganda. *The Cleft Palate-Craniofacial Journal, 48*(2), 156–160.
- Endriga, M. C. & Speltz, M. L. (1997). Face to face interaction between infants with orofacial clefts and their mothers. *Journal of Pediatric Psychology, 22*(4), 439–453.

- Eshete, M., Graven, P. E., Topstad, T. K., & Befikadu, S. (2011). The incidence of cleft lip and palate in Addis Ababa, Ethiopia. *Ethiopian Medical Journal*, 49(1), 1–4.
- Fekadu, Z. (2001). An alternative approach to prevent child welfare problems. In P. S. Klein (Ed.), *Seeds of Hope. Twelve Years of Early Intervention in Africa* (pp.159–172). Oslo: Unipub forlag.
- Garcias, G., L. & Schüler Faccini, L. (2004). The beliefs of mothers in southern Brazil regarding risk-factors associated with congenital abnormalities. *Genetics and Molecular Biology*, 27(2), 147–153. Retrieved from <http://www.scielo.br/pdf/gmb/v27n2/a03v27n2>
- Grunwell, P. & Sell, D. A. (2004). Speech and cleft palate/velopharyngeal anomalies. In A. C. H. Watson, D. A. Sell, & P.Grunwell (Eds.). *Management of Cleft Lip and Palate*, (pp. 68–86). London: Whurr.
- Habel, A. (2004). The role of the paediatrician. In A. C. H. Watson, D. A. Sell, & P. Grunwell (Eds.). *Management of Cleft Lip and Palate* (pp. 23–136). London: Whurr.
- Harcourt, D. & Rumsey, N. (2008). Psychology and visible difference. *The Psychologist*, 21(6), 486–489.
- Harper, D. C. & Peterson, D. B. (2001). Children of the Philippines: attitudes toward visible physical impairment. *The Cleft Palate-Craniofacial Journal*, 38(6), 566–576.
- Hodgkinson, P. D., Brown, S., Duncan, D., Grant, C., McNaughton, A., Thomas, P., & Mattick, C. R. (2005). Management of children with cleft lip and palate: a review describing the application of multidisciplinary team working in this condition based upon the experiences of a regional cleft lip and palate centre in the United Kingdom. *Fetal and Maternal Medicine Review*, 16(1), 1–27.

- Hutchinson, K., Wellman, M. A., Noe, D. A., & Kahn, A. (2011). The psychosocial effects of cleft lip and palate in non-Anglo populations: a cross-cultural meta-analysis. *The Cleft Palate Craniofacial Journal*, 48(5), 497–508.
- Johannessen, A., Tufte, P. A., & Kristoffersen, L. (2006). *Introduksjon til samfunnsvitenskapelig metode* (3. utg.) [Introduction to Social Scientific Methods (3rd ed.)]. Oslo: Abstrakt forlag
- Johansson, B. & Ringsberg, K. C. (2004). Parents' experience of having a child with cleft lip and palate. *Journal of Advanced Nursing* 47(2), 165–173.
- Kalland, M. (1995). *Psychosocial Aspects of Cleft Lip and Palate. Implications for Parental Education*. Helsinki: University of Helsinki, Department of Teacher Education.
- Kerlinger, F. N. (1979). *Behavioral Research*. New York: Holt, Rinehart & Winston.
- Kirk, J. & Miller, M. L. (1986). *Reliability and Validity in Qualitative Research*. Newbury Park, CA: Sage.
- Kiyak, H. A. & Reichmuth, M. (2002). Body image issues in dental medicine. In T. F. Cash & T. Pruzinsky (Eds.), *Body Image. A Handbook of Theory Research and Clinical Practice* (pp. 342–350). New York: Guilford Press.
- Klein, T., Pope, A. W., Getahun, E., & Thompson, J. (2006). Mother's reflections on raising a child with a craniofacial anomaly. *The Cleft and Palate-Craniofacial Journal* 43(5), 590–597.
- Kummer, A. W. (2008). *Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance* (2nd ed.). Clifton Park, NY: Delmar Cengage Learning.
- Kübler-Ross, E. (1969). *On Death and Dying*. London: Tavistock.

- Kvale, S. (2007). *Doing Interviews. The Sage Qualitative Research Kit*. Thousand Oaks, CA: Sage.
- Kvale, S. & Brinkmann, S. (2009). *Interviews. Learning the Craft of Qualitative Research Interviewing* (2nd ed.). Thousand Oaks, CA: Sage.
- Land, G. H. (1998). Reconstructing motherhood in the age of “perfect” babies: Mothers of infants and toddlers with disabilities. *Signs: Journal of Women in Culture and Society*, 24(1), 69–99.
- Larsen, A. K. (2007). *En Enklere Metode. Veiledning i Samfunnsvitenskapelig Forskningsmetode* [A Simpler Method: Guidance in Social Scientific Research Methods]. Bergen: Fagbokforlaget
- Lazarus, R. S. & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York: Springer
- Leedy, P. & Ormrod, J. (2001). *Practical Research: Planning and Design* (7th ed.). Upper Saddle River, NJ: Prentice-Hall.
- Lemvik, J. S. (2003). *Jeg Tok Han ikke ut Blant Andre - Om Nye Muligheter for Etiopiske Barn Født med Leppe-Ganespalte* (Hovedoppgave i Spesialpedagogikk) [I Didn't Take Him Out in Public - About New Possibilities for Ethiopian Children Born with Cleft Lip/Palate (thesis in Special Education)]. Oslo: Universitetet i Oslo.
- Loh, J. & Ascoli, M. (2011). Cross-cultural attitudes and perceptions towards cleft lip and palate deformities. *World Cultural Psychiatry Research Review*, 6(2), 127–134.
- Martin, V. (2004). Classification of cleft. In V. Martin & P. Bannister (Eds.). *Cleft Care: A Practical Guide for Health Professionals on Cleft Lip and Palate* (pp. 7–20). Wiltshire, England: APS.

- Martin, V. & Suri, M. (2004). Development of the face and palate and clinical implications. In V. Martin & P. Bannister (Eds.) *Cleft Care: A Practical Guide for Health Professionals on Cleft Lip and/or Palate* (pp. 21–30). Wiltshire, England: APS.
- Miller, C. K. & Kummer A.W.(2008). Feeding problems of infants with cleft lip/palate or craniofacial anomalies. In A.W. Kummer (Ed.) *Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance* (2nd ed.) (pp. 120–153). Clifton Park, NY: Delmar Cengage Learning.
- Mossey, P.A., Little, J., Munger, R. G., Dixon, M.J., & Shaw, W.C. (2009). *Cleft Lip and Palate*. Retrieved from: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(09\)60695-4/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)60695-4/fulltext)
- Murray, L. Hentges, F., Hill, J., Karpf, J., Mistry,B., Kreutz, M., et al. (2008). The effect of cleft lip and palate, and the timing of lip repaired on mother-infant interaction and infant development. *Journal of Child Psychology and Psychiatry*, 49(2), 115–123.
- Nakanii, M. (2010). Negative events experienced by mothers raising a child with cleft lip and palate. *Kawasaki Journal of Medical Welfare*, 16(1), 43–49. Retrieved from: http://www.kawasaki-m.ac.jp/soc/mw/journal/en/2010-e16-1/43-49_NAKANII.pdf
- Nelson, P., Glenney, A.-M., Kirk S., & Caress, A.-L. (2011). Parents’ experiences of caring for a child with a cleft lip and/or palate: a review of the literature. *Child: Care, Health and Development*, 38(1), 6–20, doi:10.1111/j.1365-2214.2011.01244.x
- Owens, J. (2008). Parent’s experiences of feeding a baby with a cleft lip and palate. *British Journal of Midwifery*, 16(12), 778–784.
- Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.) Thousand Oaks, CA: Sage.

- Postholm, M. B. (2005). *Kvalitativ metode. En innføring med fokus på fenomenologi, etnografi og kasusstudier* [Qualitative Methods: An Introduction with Focus on Phenomology, Ethnography and Case Studies]. Oslo: Universitetsforlaget.
- Ress, C. (2007). Childhood attachment. *British Journal of General Practice*, *57*(544), 920–922. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2169321/>
- Robbins, J., M., Damiano, P., Druschel, C., M., Hobbs, C. A., Romitti, P. A., Austin, A. A., et al. (2010). Prenatal diagnosis of orofacial clefts: association with maternal satisfaction, team care, and treatment outcomes. *Cleft Palate Craniofacial Journal*, *47*(5), 476–481.
- Sank, J. R., Berk, N. W., Cooper, M. E., & Marazita, M. L. (2003). Perceived social support of mothers of children with clefts. *The Cleft Palate-Craniofacial Journal* *40*(2), 165–171.
- Schultz, J. R. (2008). Psychosocial aspects of cleft lip/palate and craniofacial anomalies. In A. W. Kummer (Ed.) *Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance* (2nd ed.) (pp. 279–296). Clifton Park, NY: Delmar Cengage Learning.
- Smiletrain (2012). *Ethiopia. A Country that has seen Much Sorrow, but Promises a Brighter Future*. Retrieved from: <http://www.smiletrain.org/around-the-world/ethiopia.html>
- Sousa, A. D., Devare, S., & Ghanshani, J. (2009). Psychological issues in cleft lip and palate. *Journal of Indian Association of Pediatric Surgeons*, *14*(2), 55–58. doi: 10.4103/0971-9261.55152
- Speltz, M. L., Endringa, M. C., Fisher, P. A., & Mason, C. A. (1997). Early predictors of attachment in infants with cleft lip and/or palate. *Child Development*, *68*(1), 12–25.
Retrieved from

<http://www.jstor.org/discover/10.2307/1131921?uid=3738744&uid=2129&uid=2&uid=70&uid=4&sid=21101297310591>

Stone, M. B., Botto, L. D., Fedkamp, M, L. Smith, K. R., Roling, L., Yamashiro, D., & Alder, S. C. (2010). Improving quality of life of children with clefts, perspective of parents. *Journal of Craniofacial Surgery*, 21(5). 1358–1364.

Strauss, R. P., Ramsey, B. L. J., Edwards, T. C., Topolski, T. D., Kapp-Simoin, K. P., Thomas, C. R., et al. (2007). Stigma experiences in youth with facial differences: a multi-site study of adolescents and their mothers. *Orthodontic & Craniofacial Research*, 10(2), 96–103.

Sæther, I. L.(1996). Behandlingstilbudet for Mennesker Født med Leppe-Kjeve-Ganespalte i Norge. (Doktoravhandling) [Available Treatment for People Born with Cleft Lip and Palate in Norway (PhD Dissertation)] Oslo: Universitetet i Oslo.

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

Tsegaye, T. (2011). *A Manual for Speech and Language Therapy Assistants Training. Specifically for Cleft Lip and Palate (CLP)*. Informal publication. Yekatit 12 University Hospital: Addis Ababa.

Turner, S. R., Rumsey, N., & Sandy, J. R. (1998). Psychological aspects of cleft lip and palate. *European Journal of Orthodontics* 20(1998) 407–415. Retrieved from: <http://ejo.oxfordjournals.org/content/20/4/407.full.pdf>

Tørdal, I. B. & Kjøll. L. (2010). *Talevansker hos Barn med Leppe- Kjeve- Ganespalte* [Speech Difficulties of Children with Cleft Lip and Palate]. Oslo: Bredtvet Kompetansesenter.

Vanz, A. P. & Ribeiro, N. R. R. (2011). Listening to the mothers of individuals with oral fissures. *Revista da Escola de Enfermagem da USP*, 45(3), 595–601. Retrieved from: http://www.scielo.br/pdf/reeusp/v45n3/en_v45n3a07.pdf

World Health Organization (2009). WHO Country Cooperation Strategy 2008–2011. Ethiopia. Brazzaville, Republic of Congo: WHO Regional Office for Africa. Retrieved from: <http://www.afro.who.int/en/ethiopia/country-cooperation-strategy.html>

Yin, R. K. (1994). *Case Study Research: Design and Methods Applied Social Science Research Method Series, Volume Five* (2nd ed.). Thousand Oaks, CA: Sage.

Yin, R. K. (2003). *Case Study Research: Design and Methods* (3rd ed.). Thousand Oaks, CA: Sage.

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

Appendix

Appendix 1: Cover letter

_____ Hospital Ethiopia
The Cleft Lip and Palate Team
Addis Ababa

Dear Sirs/Madam,

My name is Hanna Abebe Håkonsen

I have been a volunteer with the multidisciplinary cleft lip and palate team 3 years ago at your Hospital working in the speech therapy department. I am working on my master thesis in at the Department of Special Needs Education, Faculty of Education, University of Oslo, Norway. I am writing my master thesis on mothers experience and reaction when they get a child with cleft lip and /or palate.

I would like to interview 6 mothers of children with cleft lip and palate and who received service at you hospital.

I will arrive in Addis Ababa the 17th of February and will stay until the 17th of March. Due to my limited time, I kindly ask you to help me select participants for my study.

Criteria for selecting participants are as follows:

- 6 mothers of children with cleft lip and palate who have been treated in your hospital.
- The children should be under 6 years old.
- The mothers must be Amharic speakers so that it will be possible for me to communicate directly with them.
- The mothers must be living in Addis Ababa because I plan to conduct the interviews at their home.

I would like to inform you that I will record the interviews in order not to miss important details and in order to establish and keep a good interaction with the mothers. I assure you that I will be the only person who will have access to the tapes. After finishing the thesis these recordings will be destroyed. The identity of the mothers and the children will not be exposed through my writing.

After finishing my thesis I will prepare a summary of my findings so that the participants will be able to review my work if interested. I would be grateful if you could be so kind as to respond to my letter as soon as possible.

Thank you for your cooperation on this matter.

Sincerely yours

Hanna Abebe Håkonsen

Appendix 2 : First telephone contact

Hello

My name is Hanna Abebe Håkonsen.

I was given your name and telephone number by the staff member of the _____ hospital. I heard that your child was having a treatment at _____ hospital.

Reminding of the goal:

I am doing research addressing mothers experience raising a child with cleft lip and/or plate.

Obtain her permission:

Are you interested to share your experience having a child with cleft lip and / or plate? (If yes)

Schedule:

Schedule an appointment and agree where the interview will be held. Ask if it is comfortable to have the interview at the mothers' home. This is because home will be natural, confidential, comfortable and easy accessible to the mother.

If the answer is yes: ask for their address and when to meet

Where do you live?

Address:

Interview length:

The two sessions:

The first session will be the introductory part

The second session will be the continue of the first session

All in all the two session will take 60 to 90 min.

Ask for permission for the second contact the participant to confirm the date and places.

Thank you for your time

Appendix 3: Home visit

Introduction

My name is Hanna Abebe Degeffie

I am Married

I have 4 brothers and one sister

I am pre-school teacher and studying to be a speech therapist

I love to work with children and their parent and have 2 years' experience working with kids.

Topic I must take before interview.

- Before I start the interview I must Explain the goal of the study
- The objective of this study will focus on the strategies that the mothers are using adjusting their situation having a child with non syndromic cleft lip and/or palate. This study underlines their main methods of coping to the challenges, to encourage the project team in both hospitals, explore the extent of the problem to The Health Minister in Ethiopia, to improve the life quality of the citizens.
- Remind anonymity, confidentiality and rights of withdrawal.
- Remember to remind the participant is a representative of a mother who raise a child with non syndromic cleft lip and palate.

I want to assure you that the information I receive from you will remain confidential. I will make a document that has a number on; your identity will not revealed through my writing. The number I assign to you will replace you.

At any time of interview you wish to withdraw you are free to do that. You just let me know and any information you have provided up to that point will be destroyed and will not be used in this study.

Ask about recording of the interview and their willingness to this. If refused, note will be taken instead.

I have few questions that might feel sensitive and I want to remind you that you don't need to answer if you feel they are not comfortable.

Ask if there is anything that is not clear.

Thank you for your interest for sharing your experience having a child with cleft lip and/or palate

Appendix 4: Interview guide

1. Information about the mother

- 1.1 Can you please tell me about yourself?
- 1.2 Tell me also about your family?

2. Discovery of the child's condition

- 2.1 How did you find that there was something different with your child?

3. Mother's reaction and feelings

- 3.1 What were your feelings when you learn that (cite the child's name) had a cleft lip and palate?
- 3.2 Why do you think you respond the way you did?

4. Coping strategies and caring for the child

- 4.1 Can you please tell me about your child (ren)?
- 4.2 Is there anyone beside you helping to take care of your children? (example grandmother, other family members or house maid)
- 4.3 How did it feel to give birth to your child (ren)?
- 4.4 Can you please tell me about life after discovering that something is different of (cite the child's name)?
- 4.5 How did you feed (cite the child's name)?
Did you play with your child?(cite the child's name) How?

5. Family response to the child's condition

- 5.1 How did your family get to know about your child's condition? (cite the child's name)
- 5.2 What was their reaction?
- 5.3 How did you respond to their reaction?
- 5.4 Did your family life changed after you had (cite the child's name)? How

6. Social response

- 6.1 How long have you been living in this area?
- 6.2 Do you visit your neighbors? How often?
- 6.3 Do your neighbors visit you?
- 6.4 What kind of issues do you discuss when you are together with your neighbors?
- 6.5 Have you ever talked about your child's condition with your neighbors?
- 6.6 Are you a member of social- or religious group? What is their reaction to (cite the child's name) condition?

7. Treatment and outcomes

7.1 When did you find out that (cite the child's name) could get help?

7.2 What kind of information did you get at the hospital?

7.3 From whom did you get this information?

7.4 Can you please tell me how you felt when you first found out your child can get help?

7.5 What kind of changes occurred in your life after (cite the child's name) got help?

8. The future

8.1 Can you please tell me your thoughts about (cite the child's name) future?

What would you like to say or what are your recommendations

a) For other mothers who have a child with condition?

b) Society?

9. Anything else you would like to tell me?

Thank you!

Appendix 5 : Interview guide translated into Amharic

ለ እናቶች የተዘጋጀ የ ቃለ መጠይቅ ማመሳከሪያ

የ መጠይቅ ርዕስ ማመሳከሪያ

1. የ ተሳታፊ መረጃ

1.1 እባክዎን ስለ ራስዎ ቢነግሩኝ?

1.2: እባክዎን ስለ ቤተሰብ ቢነግሩኝ?

2. የ ህጻኑን ሁኔታ መገንዘብ

2.2 በልጅት ላይ አንድ የተለየ ነገር እንዳለ እንዴት ተገነዘቡ?

3. በእናቶች ዘንድ የነበረው የ መጀመሪያ ስሜትና አቀባበል

3.3 ልጅዎት የከንፈር ወይም የላንቃ ስንጥቅ እንዳለው ሲገነዘቡ ምን ነበር የተሰማዎት?

3.4 እንደዚህ ዓይነት ስሜት የተሰማዎት ለምን ይመስልዎታል?

4. እናቶች ለህጻናቶቹ ያደረጉት እንክብካቤዎች እና ችግሩን ለመቋቋም የተጠቀሟቸው ስልቶች

4.1 እባክዎን ስለ ልጆቻዎ ትንሽ ቢነግሩኝ?

4.3 ልጆቻዎን በመንከባከብ የሚረዳዎት የቅርብ ሰው አለ? ለምሳሌ አያት፣ አክስት፣ ወይም ደግሞ የቤት ወስጥ ሰራተኛ?

4.4 ልጅን ለመጀሪያ ጊዜ እንዴት ነበር ያጠቡት?

4.5 ልጅ ህጻን በነበረ ጊዜ ከልጅ ጋር ይጫወቱ ነበር? ምን ዓይነት ጫዋታዎችን ነበር የምትጫወቱት?

4.5 እባክዎን ልጅዎን ከወለዱ በሆላ ስላለው ህይወት አጫወቱኝ?

5. ቤተሰብ ስለ በሽታው ያላቸው ግንዛቤ

5.1 ቤተሰብ ስለ ልጅት ህመም እንዴት ነበር ያወቁት?

5.1 ምላሻቸው ምን ነበር?

5.3 ለቤተሰብ ምላሽ የእርሶ ምላሽ ምን ነበር?

5.4 በልጅ ምክንያት የቤተሰብ ህይወት ተለወጥቷል ይላሉ? እንዴት?

6. ህብረተሰቡ ስለ በሽታው ያለው ግንዛቤ

6.1 በዚህ አካባቢ ለረጅም ጊዜ ኖረዋል?

6.2 ከጎረቤቶቹ ጋር የቀረበ ግንኙነት አልዎት?

ጎረቤቶችን ይጠይቃሉ? እንደው በግምት ስንት ጊዜ?

6.3 ጎረቤቶቻችን እርሶን ይጎበኛታል?

6.4 ከጎረቤቶቹ ጋር ሲገናኙ የምትወያዩበት ነጥብ ነገር ምንድን ነው?

6.5 ስለ ልጁ ሁኔታ የተወያይታችሁበት ወቅት ነበር?

6.6 የእድር ወይም ደግሞ የዕቁብ አባል ናት? የሃይማኖት ማህበር አባል ናት?

አባላቱ ስለ ልጅ ምን ይላሉ? የሃይማኖት መሪዎች ስለ ልጅ ምን ይላሉ?

7. ህክምና እና ወጤቱ

7.1 መቼ ነበር ልጅ የህክምና እርዳታ እንዲያሟገዝ ያወቁት?

7.2 ከሆስፒታል ምን ዓይነት መረጃ ነበር ያገኙት?

7.3 ይህንን መረጃ ከማን ነበር ያገኙት?

7.4 እባክዎን ለመጀመሪያ ጊዜ ለልጅ የህክምና እርዳታ እንዳለ ሲገነዘብ የተሰማዎትን ስሜት ቢገልጽልኝ?

7.5 ከህክምና ወስን በሆነ በህይወትዎ ወስጥ የተከሰተ ለውጥ ይኖር ይሆን?

8. የወደፊቱ ህይወት ጉዞ

8.1 እባክዎን ስለ ወደፊት ህይወት ምን እንደሚያስቡ ያጫወቱኝ?

ተሳታፊዎቹ ሊያነሱዎቻቸው የሚፈልጓቸው ሌሎች ነጥቦች

ሀ: በተመሳሳይ ሁኔታ ለሚገኙ እናቶች የሚሉት ነገር ይኖሮታል?

ለ: ለህብረተሰብ ስለ የሚሉት ይኖሮታል ይሆን?

ግሌላ ሃሳብ ወይም አስታያ የት አለዎት?

አመሰግናለሁ!