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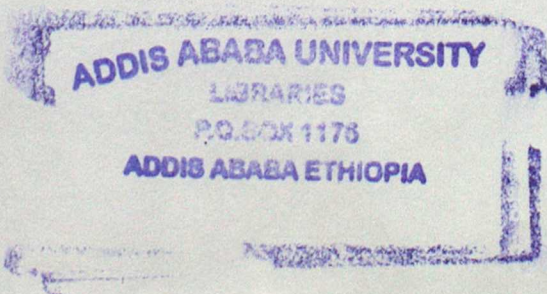
**PSYCHOSOCIAL EXPERIENCES OF CHILDREN WITH
REPAIRED CLEFT LIP AND PALATE:
AN INVESTIGATION OF FOUR CASES**

BY

TEHETENA WOLDETENSAE AREGAY



**JULY 2010
ADDIS ABABA**



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**A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF
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REQUIREMENTS FOR THE DEGREE OF MASTER OF ARTS IN SPECIAL
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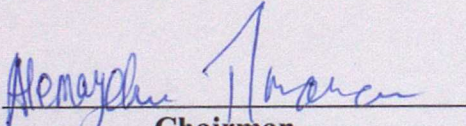
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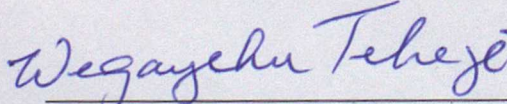
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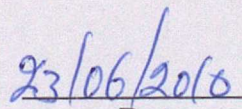

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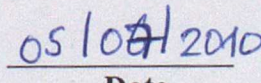
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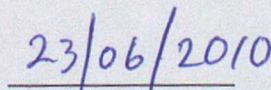
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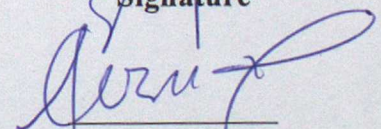

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I dedicate this study to all children with cleft lip and palate.

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I thank God for “through Him” all things were made. And it goes without saying that a work like this could not have been brought to its end without the support of many people.

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List of Abbreviations and Acronyms

CECH - Cure Ethiopia Children's Hospital

CLP - Cleft Lip and/or Palate

CPO - Cleft Palate Only

GO - Governmental Organization

MOLSA - Ministry of Labor and Social Affairs

NGO - Non-Governmental Organization

ABSTRACT

Children with repaired cleft lip and/or palate encounter a range of physiological, social, and psychological stresses associated with the cleft. Even though they have gone through surgical treatments, they have appearance and functional differences that potentially compromise their psychosocial functioning. In view of this, this study aimed to explore the psychosocial experiences of children with repaired cleft lip and/or palate, with the goal of addressing their social experiences, psychological functioning, learning and achievement and factors associated with these variables. A qualitative case-study design method was employed to attain the objective. In-depth open-ended interviews were conducted with 4 children aged 12 to 16 with repaired cleft lip and/or palate, their parents and teachers. In addition, focus-group discussions were undertaken with other groups of parents and teachers of children with repaired cleft lip and/or palate. The focus was the subjective interpretation of the children's experiences. The interviews were transcribed and analyzed using a qualitative case description and cross-case approach with emphasis on thematic analysis. The major findings of the study were that difference in facial appearance coupled with speech deficits made the children with repaired cleft lip and/or palate experience teasing in their day-to-day lives, which impacted their social and psychological wellbeing. The psychosocial problems the children experienced were mainly characterized by frequent teasing and insult, social anxiety; feelings of dissatisfaction with facial appearance and speech, insecurity, guilt, frustration, anger, sadness, worry, withdrawal, and other symptoms of depression. A case of aggressive and disruptive behaviors at school were also reported. Furthermore, some of the children had poor academic performance and achievement. The findings further showed that parents of these children had themselves gone through higher degrees of personal stress, which had influenced the children's current psychosocial functioning and achievement in academics. In addition, speech and language deficits paired with lower expectations led them to lower educational aspirations. The results suggest the importance of timely interventions on social, psychological, and family factors.

CHAPTER ONE

1. Introduction

1.1 Background of the study

This study intends to explore the subjective perceptions and values of children with repaired cleft lip and/or palate (CLP), particularly with regard to their psychosocial functioning.

A cleft is an opening or a split in the upper lip, the roof of the mouth (palate) or both which can occur anytime between the 6th and 12th week of pregnancy. Scientists have not been able to pinpoint the exact cause of the cleft, but they know that both hereditary and environmental problems are involved (Abramowicz, Cooper, Bardi, Weyant & Marazita, 2003; Schoenbrodt, 2004).

It is evidenced that amongst the various craniofacial developmental abnormalities, CLP occur most commonly, affecting one in 700 live births worldwide (Turner, Rumsey & Sandy, 1998). Research shows that learning to live with a change in appearance of one's face as a result of injury or disease is a difficult task (Bilboul, Pope, & Synder, 2005). Even though the cleft of the lip and palate could be repaired by reconstructive surgery, which improves appearance and speech, individuals with the condition may face a range of anatomical and psychosocial problems due to the complications created by the cleft (Millard & Richman, 2001; Lockhart, 2003; Berger & Dalton, 2009).

The intent of this study, therefore, is to explore the psychosocial experiences of these individuals with only non-syndromic repaired CLP, emphasizing on their social experience, psychological functioning, academic achievement, and factors related to these variables. To understand the situation better, it is important to see the management of CLP in Ethiopia.

1.2 Cleft care in Ethiopia

There are no written documents on how cleft care has started in Ethiopia. However, it has been recalled that cleft care in Ethiopia was first run by an expatriate plastic surgeon who had been in the faculty of medicine at Tikur Anbessa Hospital for three decades until he retired in 2005 G.C. Otherwise interested individual surgeons, mainly foreigners were the ones doing surgery for group of individuals with CLP. Then Yekatit 12 Hospital in Addis Ababa started up the Burn Project in 2000 G.C. in collaboration with the Department for Plastic and Reconstructive Surgery at Haukeland University Hospital of Norway. In 2002, an additional project proposal was approved for establishing a multidisciplinary CLP team on the same premises and also at ALERT Hospital (Y. Demissie, Personal communication, October 28, 2009).

The CURE Ethiopia Children's Hospital (CECH) is another major institution where cleft care is provided. The hospital is a pediatric orthopedic teaching hospital in Addis Ababa. CECH fills a critical need for an orthopedic and trauma care residency program in Ethiopia. The hospital provides modern medical and surgical care to children with physical disability in Ethiopia, in collaboration with Smile Train (Cure Ethiopia, 2010).

The other major project on cleft is Project Harar, a health outreach charity that secures professional surgical treatment and after-care for children and young people with severe facial disfigurements from remote and very poor areas of Ethiopia. Founded in 2001, they treat conditions like CLP, noma (a devastating facial infection), tumors and accidental injuries (Project Harar, 2009).

According to the information given by Project Harar, there are just eight plastic and reconstructive surgeons and forty dentists in the whole of Ethiopia, serving a population of over 85 million. They are virtually all based in the capital, Addis Ababa. As a result, there is a dramatic lack of accessible cleft care, especially outside the main city. Babies who are born with this condition in developed countries are operated on soon after birth, but it is ignored here due to poverty. The routine operation which rectifies the cleft is too expensive for most families in Ethiopia. Project Harar, Cure Ethiopia, and Yekatit 12 Hospital Burn Project, with collaboration of the Smile Train help the poorest and most

isolated people because they face the greatest barriers to accessing the surgical care they need.

As reported by Project Harar, (2009), many people with facial disfigurements in Ethiopia experience discrimination and social exclusion. Often individuals with a facial 'difference' are ostracized by their communities, denied their right to a school-place and in some cases are forced to become street-children. The physical anomaly together with the unfavorable societal responses has a potential effect on the psychosocial functioning of children with cleft condition.

Therefore, if the ultimate goal of rehabilitation for children evaluated by cleft/craniofacial teams is to improve the quality of their lives and to help them realize their potential, then not only providing surgical service but also assessing the individuals' psychosocial status is essential. The management of a child with CLP may appear to be a complicated process, which calls for comprehensive assessment of the impact of the cleft on development areas. Thus, it is indispensable to identify the overall effects of the condition to provide appropriate intervention.

1.3 Problem statement

Recent studies of psychosocial functioning reveal that young adults with CLP experience poor psychosocial functioning due to the speech abnormalities and facial appearances present in them (Hunt, Burden, Hepper & Stevenson, 2005; Synder, Bilboul, & Pope, 2005). Children with repaired CLP are also at an elevated risk for developing psychosocial problems especially those relating to self concept, peer relationships, and appearance (Schoenbrodt, 2004; Acta, 2009). These literatures regarding psychosocial status among children with CLP have identified areas of psychosocial risks in this population.

It was also identified that the treatment of cleft deformities often lasts from infancy into adolescence, and parents are intimately involved in the treatment process (Kapp-Simon, 2004). This time and financial, and health implications can be a burden to those with cleft

and to all family members. In view of the complex disease modality of CLP, it is important to investigate whether the children's psychosocial wellbeing is affected by the condition.

The field work for this study has not been able to trace any previous study on the subject of CLP with reference to psychosocial functioning in Ethiopia. This gap in knowledge created the need to have a systematic assessment to explore the psychosocial functioning of children with CLP. Thus, this research tried to answer the following leading questions:

1. How do children with repaired cleft lip and/or palate function socially?
2. How do children with repaired cleft lip and/or palate function psychologically?
3. How do they perform and achieve academically?
4. What factors contribute to the children's current psychosocial functioning, and learning and achievement?

1.4 Significance of the study

The study is significant in the following ways:

- Various social and psychological problems occur among children with CLP. However, not all pediatric reconstructive surgery teams consider this as a major issue in rehabilitating the children with cleft. It is likely that psychosocial problems are higher in incidence than literature actually suggests. Hence, this study is very essential to help the surgical team identify such cases and maximize positive outcome of their surgery and rehabilitation program,
- The effects of CLP are not well understood in Ethiopia. It is within this context that the knowledge of CLP and its impact on psychosocial functioning should be set. Therefore, the researcher believed that this study fills the knowledge gaps about the psychosocial issues revolving around children with repaired CLP, and

- It is important for counselors, teachers, parents, and for those involved in the issue to set up possible mechanisms and strategies that contribute to the better implementation of intervention programs.

1.5 Operational definition of variables

Children: refers in this study to individuals aged 10 to 16

Psychosocial functioning: underlines both the ideas of social and psychological factors interacting together in the lives of children with repaired CLP
Social functioning, such as interpersonal relationships, social behaviors that influence psychological make up
Psychological functioning, such as self and parental reported experiences that reflect internalizing and externalizing patterns of behavior

Speech problem: any difficulty that hinders an individual's oral communication by means of spoken words

Academic achievement: competence related to educational studies

1.6 Organization of the paper

This paper has six chapters. This introductory chapter comprises an overview of CLP together with the problem statement, significance of the study and operational definitions of the variables used. The second chapter encompasses the review of related literature. The methodology of the study is dealt in chapter three. In this chapter, the study design, the participants, the instruments used, the data collection and analysis procedures are discussed. Chapter four is devoted for the presentation of the cases as they are reported and narrated. The focus of chapter five is on the discussion of the findings and finally, chapter six deals with conclusion and implications of the findings.

CHAPTER TWO

2. Review of related literature

2.1 Overview of cleft lip and palate

CLP are facial and oral malformations that occur very early in pregnancy, while the baby is developing inside its mother. The size of the cleft lip may range from small notch in the upper lip to an opening that extends into the base of the nostril. The cleft may be single sided or occur on both sides. A cleft palate may involve only the hard palate or soft palate or a combination of both (Richard, 2009). Clefts commonly occur as isolated birth defects, but they are also associated with many genetic conditions.

Cleft lip

A cleft lip is a physical split or separation of the two sides of the upper lip and appears as a narrow opening or gap in the skin of the upper lip. This separator often extends beyond the base of the nose and includes the bones of the upper jaw and/or upper gum (Ryeme, 2009). In most cases clefts occur only in the upper lip, they do not affect the lower lip. With a unilateral cleft lip, a gap appears under one nostril. The nose might tilt slightly or look lower than normal. With a bilateral cleft lip, a deep split might extend from the lip into both nostrils, causing the nose to look broader and shorter than normal.

Clefts can be complete or incomplete. A complete cleft involves the entire lip, and typically, the alveolar arch (part of the jaw bone that holds the teeth). An incomplete cleft involves only part of the lip (Roberet & Cheryl, 2006).

Cleft palate

A cleft palate is a split or opening in the roof of the mouth. Cleft palates can extend from the front of the mouth (hard palate) to the throat (soft palate). Cleft palates are less noticeable than cleft lips as the palate is inside the mouth.

CLP can occur on one or both sides of the mouth. Because the lip and the palate develop separately, it is possible to have a cleft lip without a cleft palate; a cleft palate without a cleft lip, or both a cleft lip and a cleft palate together (Tonn, 2009).

2.2 Causes of cleft lip and palate

As with many physiological traits, no single cause can explain clefting. Congenital malformations, including clefts may be due to genetic, chromosomal, environmental, multi-factorial or unknown causes. However, both genetics and environmental factors may predispose an individual to CLP (Wood & Shell, 2006; Johansson & Ringsberg, 2004).

In both single gene and chromosomal disorders, a CLP is often one potential trait in a series of traits that generally characterize a disorder or syndrome. There appears to be a great chance of clefting in a new born if a sibling, parent or relative has had the problem. Both fathers and mothers can pass on a gene or genes that can contribute to the development of CLP (Bartoshesky, 2008). As stated by Wood and Shell (2006), biological children of a parent with cleft have a 4 to 6 percent chance of also having clefts. There is an explanation that when a child has a cleft but neither biological parent has a cleft, there is a 2 to 8 percent chance that biological siblings of the child also will have clefts. When a parent and a biological child both have clefts, the chances are even greater that the parent's future children will have clefts.

Maternal use of alcohol and cigarettes, both appear to be linked to an increased risk of clefts in offspring. Additionally, intake of anticonvulsant drugs used to treat epilepsy and use of retinoid (vitamin A) drugs also appear to increase the risk of clefts. Researchers have also investigated maternal diet and vitamin intake as potentially related to clefts in offspring. Particularly, folic acid deficiency during pregnancy appears to be linked to a decrease in embryonic cell propagation, with resulting congenital malformations such as clefts (Shprintzen & Baradach, 1995). Cleft may occur as a result of exposure to viruses or chemicals while the fetus is developing in the womb. In other situations, CLP may be part of another medical condition.

2.3 Incidence of cleft lip and palate

Oral-facial clefts, including cleft lip with or without cleft palate, are among the most common visible birth defects occurring in 1 of every 500 to 1000 live births worldwide (Berk, Cooper, Liu & Marazita, 2001). The incidence of CLP varies by race, with the highest rate among American Indians, 3.74 cases per 1000 live births and the lowest rate among Africans with 0.18 to 1.67 cases per 1000 live births (Michael, 2009).

Robert and Cheryl, (2006) stated that cleft lip occurs more frequently in males and cleft palate alone occurs more frequently in females. The majority of children born with CLP are otherwise normal with no associated syndromes.

In Ethiopia, the study of incidence of CLP was undertaken by Mekonnen, Chil, Egil, Topstad and Sisay, (2006), which was the first incidence study in the country. The study included a population size of 39,554 live births taken from 5 hospitals and 2 health centers in Addis Ababa. Accordingly, the incidence rate of clefts is found to be 1.74 per 1000 live births or 1 in 574 live births (The female to male ratio being 1.31:1). As stated by Mekonnen et al. (2006), there has not been relevant study of CLP in Ethiopia, no system of registration and follow-up for children born with this anomaly. Therefore, further studies would be conducted in the future.

2.4 Treatment of cleft lip and palate

The successful management of the child born with a CLP requires improvement or restoration of the initial impairment and preservation of all other anatomical, social and psychological attributes of the child. The initial impairment, which occurs in uterus results in a cascade of events after birth that have impact on the child's physical development and psychosocial outcome. Problems are compounded by possible facial growth aberrations, communication abnormalities involving speech and hearing, extensive dental needs, and psychosocial and developmental problems (Bzoch, 2004). Therefore, a health care team that specializes in CLP is ideal.

The cleft team consists of multiple specialists including a plastic surgeon, speech therapist, dentist, orthodontist, otolaryngologist, audiologist, geneticist, pediatrician and feeding specialist. Team members will work closely with families and children to determine the best treatment plan. The care of an infant with CLP begins at birth with accurate diagnosis, identification of the child's needs and the location of a proper treatment center.

Treatment involves surgery to repair the defect and therapies to improve any related conditions. Children with cleft lip should have surgery between birth and 3 months. Children with cleft palate should have surgery during the first 12 months of life. Following the initial cleft repair, health professionals may recommend follow-up surgeries to improve speech or improve the appearance of the lip and nose (Cleft Palate Foundation, 2006). Additional treatments may be recommended based on continuing assessment of the child's speech, developmental and cognitive abilities. These may include speech and psychological therapies.

One of the problems in the treatment of CLP is that the definitive results of treatment are not visible until two decades after primary surgery. Because the physical development and level of cooperation of children with the condition may vary, the final outcome cannot be predicted when the treatment is started. It was stated that the final result can be assessed only when the individual is about 20 years old (Sinko, Jagsch, Prechtel, Watzinger, Hollmann & Baumann, 2005).

2.5 Speech and language development of children with CLP

Speech most often emerges in young infants even before they learn to walk and run well. According to Bzoch, (2004), language is now so ingrained in the human brain; therefore the development of speech and language skills is dependent only in part on the complete physical integrity of the many physical structures composing the speaking mechanisms of the body. However, cleft palate is one of the few physical differences that always affect speech development directly and adversely.

Since a cleft lip is usually repaired early in infancy, no speech effects generally result. In some cases, however, a repaired lip (particularly if the cleft was bilateral) may be too short for the appropriate production of bilabial sounds (/b, p, m/). However, affected individuals usually substitute labio-dental productions with little perceptual effect on speech production. Rather, most speech problems associated with clefts are related to clefts of the palate (Shprintzen & Baradach, 1995; Rosanowski & Eysholdt, 2002).

A cleft interferes with making the sounds of our language. The child's speech delay may continue even after the first surgical repair of the cleft because the child may have learned bad speech habits. These habits do not automatically change when the mouth has been repaired. This implies that speech and oral language communication disorders in individuals with CLP emerge due to both organic (physical) and functional (learned) factors (Bzoch, 2004).

2.5.1 Major organic factors

Bzoch defined organic factors as diagnosable structural abnormalities that when corrected by physical management results in direct measurable improvement in speech behavior or hearing. Three major organic problems usually underlie defects of speech and oral language communication in individuals with CLP: (a) velopharyngeal insufficiency, (b) dental or occlusal abnormalities, and (c) hearing loss.

Velopharyngeal Insufficiency

When speech is produced correctly, the soft palate lifts and moves toward the back of the throat, separating the nasal cavity from the mouth so that air and sound can be directed out of the mouth. A child with cleft palate has difficulty in speaking clearly because air escapes through the gap in the roof of the mouth and out of the nose. This inability to block off the nasal cavity from the mouth so that air flows through the mouth is called velopharyngeal incompetence (Shoenbrodt, 2004; Richard, 2009). This limits the child's ability to build up air pressure and control airflow to produce certain sounds. Therefore, individuals with cleft palate are at obvious risk for articulation disorders. Articulation is the way we make speech sounds. Children with existing palatal cleft or fistula have

articulation disorders such as nasal emission, weak-pressure consonants, compensatory articulation and other articulation problems.

Another condition associated with velopharyngeal insufficiency in children with palatal cleft is resonance. Resonance is often used to refer to a perceived quality of the voice that results from vibration of sound in the pharyngeal, oral and sometimes nasal cavities during speech. The most common resonance disorder associated with cleft palate is hyper-nasality. The inability to seal off the nasal cavity from the mouth (velopharyngeal incompetence) may give the voice a "nasal twang". Degree of perceived hyper-nasality will depend to some extent upon size of the opening into the nasal cavity (Kummer, 2001).

As stated by Kummer, another resonance disorder that can be associated with cleft palate is hypo-nasality. Here, the normal nasal resonance is not heard due to a partially occluded or blocked nasal passage. A type of hypo-nasality called cul-de-sac resonance is sometimes heard in individuals with a history of cleft palate. Cul-de-sac resonance occurs when acoustic energy is trapped in a pouch with an entrance but no outlet.

Some children develop a hoarse voice quality because they are straining to control the air flow. Other children may use a soft voice because they feel that when they use a louder voice, more air escapes through the nose (Shoenbrodt, 2004). After cleft palate repair, most children may require speech therapy or another surgery when they are older to improve their articulation.

Dental or occlusal abnormalities

A child with a cleft palate or a cleft through the gum line may have missing or abnormally shaped baby and permanent teeth. In addition, the upper jaw may not grow as far forward as the lower jaw, necessitating corrective surgery later in life (Richard, 2009). In addition, the front portion of the roof of the mouth is often narrow or collapsed. As stated by, Shprintzen and Baradach, (1995), teeth grow irregularly, with many spaces in

between. Because of these dental problems, the child may place his/her tongue in these spaces and distort the production of sounds.

Hearing loss

Any child with cleft palate is at risk of developing frequent middle ear infections, which may sometimes cause hearing problems. According to the explanation given by Richard, (2009), the Eustachian tube, which drains the middle ear, malfunctions causing persistent fluid build up in the middle ear. A combination of fluid and repeated ear infections can cause scarring of the tympanic membrane (eardrum) and hearing loss.

These usual Eustachian tube abnormalities leading to frequent otitis media may affect early speech and language learning directly. This problem alone has been shown to be causally related to speech and language and otological disorders (Bzoch, 2004).

2.5.2 Functional factors

Functional factors can be considered as all other presumed learning, speech, articulation, and voice production habits, developmental motor skill, and psychosocial factors related to speech production not treatable by physical management.

Several functional factors can negatively affect the speech and language development of children with clefts. These include (a) bonding problems with parents and siblings after the shock of having a baby born with facial disfigurement, (b) the possible altered parenting and lowered expectation levels for early language skill on the part of parents, (c) the frequent lack of reinforcement of developing receptive language skills due to the substitution of gesture communication by an infant whose early expressive language efforts (speech) are difficult to understand by busy parents, and (d) the habituation of modified speech patterns with effort through glottal-initiated syllables in early speech, leading to unintelligible speech (Bzoch, 2004).

These developmental problems can usually be managed through counseling, teaching, and treatment in a team approach. According to Bzoch, good early speech and language skills enable human infants and preschool children to quickly learn from the experiences of past generations. Language cultures are passed on to all new members of human societies through speech. If cleft palate team management does not emphasize early treatment focused on preventing delayed language and speech development, language development often remains markedly delayed for children born with cleft palate.

2.6 Psychosocial issues in cleft lip and/or palate

Children and young adults with CLP may have appearance and functional differences that can potentially compromise their psychosocial adjustment. Although surgical correction may help minimize breathing and feeding problems, and allow the individual to look more normal, even the most advanced surgical techniques may not result in a normalized appearance. Furthermore, speech disabilities may remain after surgical correction (Alice & Heather, 2005).

A range of social problems (Berk, Cooper, Liu & Marazita, 2001), behavioral problems (Hunt, Burden, Hepper, Stevenson & Johnston, 2006), emotional difficulties (Kasuya, Sawaki, Ohno & Ueda, 2000), problems with low self-esteem (Berk et al., 2001), anxiety and depression (Marcusson, Paulin & Ostrup, 2002) and learning difficulties (Millard & Richman, 2001) have all been reported in the literature regarding the psychosocial development of children and young adults with CLP.

Social and psychological functioning of children with repaired CLP are discussed in what follow.

2.6.1 Social Functioning

According to professionals involved in cleft care, many are socially affected as a result of having a cleft (Hunt, Burden, Hepper & Johnston, 2005). In terms of social skills, Berk et al., (2001) found out that, individuals with CLP possess the necessary social interaction skills, but their social interactions can be adversely affected by the speech defect and

facial deformity they have. In addition, some parental issues also influence the social behaviors of children with CLP.

Speech difficulties

Children with CLP are not only confronted with aesthetic problems; they are also in jeopardy for speech and language development. Concerns regarding speech rank highly in aspects which are likely to attract teasing. In support of this, Bzoch, (2004), stated that CLP are often associated with speech problems, particularly hyper-nasality; which often elicit negative responses.

Stigma and facial disfigurement

Individuals with altered appearance generally have altered social experiences. Being different implies being perceived by others as less than complete, limited or otherwise reduced (Bzoch, 2004). Bzoch explains that the bodily signs of being different, known as stigma, carry a moral evaluation, usually a negative one. Goffman's (1963) work cited by Bzoch provided a theory of stigmatization useful in understanding the social responses to human differences and health conditions. Goffman described how first impressions, on meeting strangers are based on observations of attributes that are transformed into "normative expectations" and then into firmly held roles and responsibilities.

Individuals with CLP experience being seen as deviant when judged by cosmetic norms or communicative standards. An imperfect appearance may initiate overt teasing, bullying and unwanted questioning. This is mostly because the appearance of the face and oral area is often immediately observable by others and is the target of attention in interpersonal interaction. Turner, Rumsey and Sandy, (1998) stated that social responses may also take the form of more subtle changes in normal patterns of verbal and non-verbal interaction such as facial expression. These unfavorable social responses are the results of stigma, where outsiders subconsciously judge individuals negatively because of their imperfect appearance.

A study on parent reports conducted by Hunt et al. (2006) states that it is not necessarily the presence of CLP itself that causes psychosocial problems, but the experiences that often accompany the condition, such as teasing. The fact that teasing (which most often took the form of teasing about facial appearance or speech) was a predictor for most of the psychosocial outcomes in the study, suggests that children with cleft receive negative feedback from others about their appearance. It is likely that with society's increasing preoccupation with facial appearance, individuals who deviate from preconceived notions of normal and attractive will experience ever-increasing levels of negative feedback.

Being physically attractive appears to be an advantageous trait regardless of age. According to Sawyer and Magee, (2006), physical attractiveness has shown to play a significant role in social set ups like developing relationships during various stages of life, school, courtships, work etc. Social acceptance often depends on one's physical look. These associations between physical beauty and social acceptability indicate the difficulties for CLP affected individuals because of the intense stigma attached to perceived unattractiveness.

Parental Issues

Having a child with a CLP creates unique medical, social, financial, and emotional stressors on families. It has been reported that elevated stress levels in mothers correlated with reduced social skills in their children (Hunt et al., 2005). During childhood, the child's self-image is largely developing based upon the parents' behaviors and attitudes. Stressors to the child and family continue through the toddler and pre-school years. These stressors may impact the parent-child relationship which may in turn impact the child's psychosocial wellbeing.

The birth of a child with a cleft usually leads parents, especially mothers to strong crisis reactions, including feelings of shock, confusion, grief, guilt and mourn (Turner et al., 1998) due to the abnormal appearance of the child and breast-feeding difficulties. If the mother's self-concept is negative, she might see the child as confirmation of her negative self-concept. In addition, breast-feeding is disturbed when a child with cleft is born. As a

result, it may be difficult for her to develop a warm bonding to the child. This consequently affects the psychosocial development of the child as he/she may not have good emotional attachment and relationship with the parent.

Furthermore, most parents do not have adequate information about the anomaly and its treatment. Due to this, parents may not give special support and treatment for their child. Lack of knowledge, therefore, hinders the child's physiological and psychological treatment.

A warm, accepting, and supportive parental behavior ensures the positive development of the socio-emotional competence of the child. The attitudes, expectations and degree of support shown by parents can influence a children's perception of their cleft impairment. Experts suggest that parents should receive adequate information on how to give care to their children with CLP. In addition, parents should discuss with their children ways to handle negative social situations related to their CLP (Hunt et al., 2005). A child who is entering school should learn the proper (and age-appropriate) terms related to the cleft. The ability to confidently explain the condition to others may limit feelings of awkwardness and embarrassment and reduce negative social experiences.

Generally, social rejection from outsiders is predicted and noticed by individuals with CLP. Fearful anticipation of these antisocial responses within these individuals will affect how they function socially. These fears may result in psychological problems because unfavorable responses are recalled at the next encounter (Turner et al., 1998).

2.6.2 Psychological Functioning

Children as a result of poor social functioning may develop psychological problems. Problems of self-concept, social anxiety and depression, behavioral problems, dissatisfaction with facial appearance and speech are among the major ones.

Self-concept

Nutrition and communication difficulties are the primary early challenges for children with CLP. Low self-concept poses a secondary risk because cleft often involves visual facial impairment as well as expressive language deficits.

The importance of having a good self-concept is universally accepted. Appearance or attractiveness is regarded as a major component of self-concept. Research has shown that during the early preschool years, children with cleft tend to have a self-concept that is similar to their peers without cleft. However, as they grow older and their social interactions with other children increase, they tend to report more dissatisfaction with peer relations and higher levels of social anxiety (Berk et al., 2001). This is mostly due to the associated stigma of visible deformities and speech abnormalities. Facial disfigurement and hyper-nasality elicit negative interpersonal responses. Consequently, children with cleft could be expected to have a negative self-concept.

However, a research study on psychological characteristics of children with cleft showed that the self-concept of these children is relatively good although there is a suggestion of situational concern related to appearance, especially with females (Persson, Aniansson, Becker & Svensson, 2002).

Social anxiety

"Social anxiety has been defined as anxiety that occurs as a result of one's being concerned about others' evaluation and perception of him or her" (Berk et al., 2001, p.127).

Physical appearance has been found to be related to social anxiety, with individuals who perceive themselves as being unattractive having more social anxiety. As cited by Berk, Buss (1980) described the importance of the body in self-consciousness: "As a social stimulus, the body's most obvious and important characteristic is its appearance" (p.127). Highly attractive individuals have been found to elicit more favorable social impressions, responses, and interactions. This shows that physical attractiveness is a major

determinant of social expectations. Individuals with physical deformities are more prone to being avoided by others who may be uncomfortable with or insensitive to the anomaly. Such experiences have been linked to inhibition in social interaction behavior.

Furthermore, fearful anticipation of these antisocial responses within the individual will affect how they function socially. These fears may result in psychosocial adjustment problems (Turner et al., 1998). In the study of Berk et al., (2001), aversive attention, such as teasing or staring behavior, has been identified as a causal factor in social anxiety. It was also explained that if discomfort, lack of familiarity, or insensitivity at the sight of an individual with a craniofacial anomaly leads to such responses; individuals with oral-facial clefts would be more predisposed to high levels of chronic social anxiety than unaffected counterparts.

Behavioral problems

Behavioral problems have been reported among children with CLP. These problems, such as a tendency to have higher than average levels of internalizing behavior, are considered to be risk factors for developing anxiety disorders (Hunt et al., 2005; Hunt et al., 2006). In another study by Slifer, Amari, Diver, Hilley, Kane and McDonnell, (2003), parents of children with clefts have described their children as having more externalizing behavioral problems compared with parents of children without clefts. It has been suggested that parents with a child who has cleft may feel that they are in some way responsible for the condition and may over-compensate by failing to place appropriate limits on their child's bad behavior (Hunt et al., 2006).

Satisfaction with facial appearance

There are many researches showing attractiveness has an important effect on psychological development (Coy, Speltz & Jones, 2002; Topolski, Edwards & Patrick, 2005; Sinko et al., 2005; Synder et al., 2005). In recent years, researches have examined the relationship between perceptions and facial deformity (Bzoch, 2004; Synder et al., 2005). In the case of cleft, some features specifically associated with cleft lip, such as the

nose and teeth are considered less than satisfactory and may result in problems with body image.

According to Hunt et al., (2005), many express dissatisfaction and desire further treatment to improve their appearance. A visible scar appears to be of most concern, even to those with speech and hearing difficulties. Bzoch, (2004) refers to a study that explains youth ranging from age 10 to 20 affected by a cleft with visible impairments were more dissatisfied with their facial appearance than were subjects with invisible impairments. Another study of self reports by Hunt et al., (2006) revealed that children with CLP were significantly less happy with their facial appearance than were subjects who did not have CLP. This study clearly demonstrated that subjects with cleft had concerns regarding facial features specially related to the condition, namely their noses, lips teeth and scars. This greater dissatisfaction may reflect the increasing importance that society has placed on facial appearance and attractiveness in recent years.

An individual's perception of his/her facial attractiveness has an important influence upon an individual's psychological wellbeing. How we perceive ourselves is influenced by how others respond to us socially. A negative response from outsiders, actual or perceived, may be interpreted as a form of social unacceptability which may reduce our feelings of self-worth and may adversely affect our own self-image.

In addition, the negative attitudes, behaviors, and responses because of their facial difference that children receive from other people may lead them to think that their appearance is unacceptable and internalize the idea that they are aesthetically inferior to others (Bilboul et al., 2005). It is therefore, not surprising that children with cleft may be at greater risk for negative self-evaluations of appearance.

However, a recent study by Berger and Dalton, (2009) found out a higher level of satisfaction with appearance (except for ratings of the adolescents' lips) compared with peers who are not facially disfigured, considering the different contexts in which responses were given by adolescents and their parents.

Satisfaction with speech

Researches have indicated that few adolescents and young adults with CLP are dissatisfied with their speech. However, those with concerns regarding facial appearance are also more likely to have concerns regarding speech. Children with cleft have been shown to have poorer conversational skills compared with controls (Hunt et al., 2006). Difficulties with articulation may cause frustrations because of not being understood. Peer relationships would be more limited for youngsters who have greater articulation problems. However, there is a need for further study of the relationship between articulation disorders and psychological conflicts.

Satisfaction with surgical results

CLP irregularities vary greatly in terms of width of the cleft and other characteristics. Treatment modalities also differ, depending on the date of surgery and the techniques of reconstruction. For obvious reasons, the region where this deformity occurs (i.e. the face) is a very sensitive region of the body. In the long term, the treatment of cleft should provide good aesthetic and functional results (Jeffery & Boormann, 2001; Marcusson et al., 2002).

Surgery for disfigurement usually results in increased self-esteem, and satisfaction with appearance, irrespective of whether an objective improvement is noticed by the independent observers. High level of satisfaction with surgical results has been reported (Turner et al., 1998), while large proportion of individuals says that they desire further treatment (Berger et al., 2009). The high level of expressed satisfaction may be attributable to a need for families to justify their emotional and sometimes financial investment in treatment. On the other hand, unrealistically high expectations for surgical improvement may end in dissatisfactions with post-surgical results.

One of the most relevant measures of success of treatment of a cleft is the individual's facial appearance. The individual may have a scar in the lip, a nasal deformity, a missing tooth, poor occlusion in a retruded maxilla, a nasal voice or a combination of these phenomena. All these features are often the focus for dissatisfaction. Females may be

more affected by the stigma of a repaired cleft because of the importance given to physical attractiveness (Sinko et al., 2005). As a result, females seek to improve their appearance after cleft repair.

2.7 Academic achievement

A number of studies have reported learning problems among children CLP (Millard & Richman, 2001; Hunt et al., 2005; Hunt et al., 2006). These studies also suggest that a number of factors may place children with CLP at higher risk for academic difficulties than non-cleft peers.

These potentials for school achievement difficulty in children with CLP may be due to high incidence of middle ear pathology with accompanying hearing loss, speech and language difficulties, and facial disfigurement. In addition, intelligence, the presence or absence of learning disabilities, self-concept, social adjustment to school and expectations of peers, parents, and teachers interact to affect achievement in school. However, there is little objective research data on the subject.

2.7.1 Major factors affecting school achievement

Speech and language difficulties

Many factors such as hearing loss associated with otitis media may impact language acquisition. In addition, more subtle psychosocial factors, such as multiple hospitalizations, lack of adequate stimulation, and even social isolation may also influence language development. Articulation limitations may impact phonological development.

There is strong association between language difficulties and low achievement. Delayed language acquisition results in delayed start of school. Furthermore, these children may have reading and writing difficulties which may adversely affect their education. Children with cleft palate are more likely to have serious reading disabilities. However, children with a history of cleft may lack self-confidence reading aloud in class, which

may adversely affect teacher evaluations and thus stigmatize students as reading disabled (Kummer, 2001).

Facial disfigurement and expectations of others

Facial disfigurement does seem to influence a teacher's perception of the child with CLP. It has been suggested that teachers may have a stereotyped view that physical unattractiveness is related to lower intellectual ability (Turner et al., 1998). Teachers also perceive children with cleft to be inhibited in the classroom which may lead to underachievement. In addition, both teachers and parents may have lower expectation of their academic attainment. This may result in lower academic aspirations for the child and less favorable evaluations by the teachers.

Generally, children with clefts achieve below expectations academically when achievement is compared to intellectual skill level (Shprintzen & Baradach, 1995). As mentioned above, this may be due to several interacting factors. It is therefore imperative that assistance should be provided to the child and family to maximize the possibility of the child functioning optimally in the family, school and community.

CHAPTER THREE

3. Methodology

This part of the paper deals with the research design of the study, the participants, data collection instruments, procedure of data collection, analysis, and interpretation; ethical considerations and how the quality of the study has been addressed.

3.1 Research design

The intention of this study was to collect data specific to the psychosocial functioning of children with repaired CLP. In order to meet this purpose, qualitative case-study design was employed. Fossey, Harvey, McDermott, & Davidson, (2002) describe the aims of qualitative research as being directed at providing an in-depth and interpreted understanding of the social world of research and participants by learning about their social and material circumstances, experiences, perspectives and histories. The emphasis of some qualitative research is on the participants' lived experience and is well suited for uncovering the meanings people place on the events, processes, and structure of their lives (Miles & Huberman, 1994; p. 10).

Qualitative research tends to focus on exploring, in as much detail as possible, smaller number of instances or examples which are seen as being interesting or illuminating, and aims to achieve 'depth' rather than 'breadth' (Blaxter, Hughes, & Tight, 2008). Therefore, qualitative case study approach was employed in order to "constitute a specific way of collecting, organizing, and analyzing data" (Patton, 2002; p.447). To develop understanding and more powerful explanations as stated by Miles and Huberman, (2004), cross-case analysis of the results was also made.

3.2 Participants

The participants of this study included 4 children with repaired CLP, their respected parents and teachers, and other 5 parents of children with the same condition, who were

all purposely selected. Qualitative inquiry typically includes samples that are small in scale and purposely selected. Patton (2002) stated the relevance of purposive sampling as: "the logic and power of purposeful sampling lie in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry" (p.230). Therefore the study encompasses small number of information-rich participants for in-depth study.

Though there are different strategies for purposely selecting information-rich cases, this study used criterion sampling strategy to review and study the cases that meet some predetermined criterion of importance. Therefore, the participants who met the following preset criteria were selected:

- They were aged between 12 and 16. This is because the researcher assumed that these groups would understand the purpose of the study, express themselves in depth, and become cooperative.
- They were with repaired CLP, as this is the focus of the study.
- They were expected to be free of any other syndromic condition (like mental retardation, van der woude syndrome, and others) associated with cleft for the reason that the results may be different.

Criteria for selecting the parents for FGD

- They were parents of children with the same condition mentioned above.

As a result, the major sources of the data were 4 children, a boy and 3 girls, who were purposely selected, based on the above criteria from hospital clinical records, their 4 respected mothers and 8 teachers, and other 5 mothers of children with repaired CLP, which in all made 21 participants.

The purpose of selecting the parents of these children was with the assumption that they could be more reliable in assessing the psychosocial well-being which the children might be unwilling to reveal. Parents can usually provide more information about their children than any other single source and therefore, their reports were important. Mothers of the

children were selected in all except one of the cases, as they were believed to be more close to their children and had intimate knowledge about them.

The teachers of the children were key informants with regard to their learning and academic achievements. Therefore, homeroom and teachers of different subjects were selected.

The following tables show the general demographic information of the participants.

Table 1 Background information of the children and their parents

S. No	Cases	Sex	Age	Cleft Condition (repaired)	Grade Level	School Type	Parental Education	Economic Status
1	Helen	F	14	Bilateral CLP	9	Government	Father - Diploma Mother - Grade 12	Middle class
2	Abdi	M	12	Bilateral CLP	4	Private	Both - Grade 10	Middle class
3	Saba	F	12	Bilateral CLP	6	Government	Both – Non educated	Low class
4	Alem	F	13	Complete CP	5	Government	Both – Non educated	Low class

Table 2 Background information of teachers

	Sex		Position		Educational Background			Experience in Years		
	M	F	Unit Leader	Teacher	Certificate holders	Diploma holders	Degree holders	0 - 5	5-10	10-15
No. of personnel	4	5	1	8	4	2	3	5	3	1
Total	9		9		9			9		

Table 3 Background information of (other groups) mothers of children with CLP

S. No	Age	Child's Cleft Condition (repaired)	Parental Education	Occupation
1	43	Bilateral CLP	Non-educated	Cleaner
2	38	Complete CPO	Grade 8	House-wife
3	32	Complete CPO	Certificate	Business woman
4	45	Bilateral CLP	Non-educated	House-wife
5	40	Bilateral CLP	Grade 6	House-wife

3.3 Data collection instruments

Qualitative research is not a single method but rather a set of tools and approaches that can be selected for their fit according to the nature of a particular research question (Flick, 2006; Cresswell, 2007). Therefore, this study employed interview, focus-group discussion, and document analysis as tools for data gathering.

3.3.1 Interview

Qualitative interviews can yield rich accounts from participants' own perspectives of their views, experiences, perceptions and beliefs (Green & Thorogood, 2004). Therefore, in-depth interviews were made with the participants. All the interview questions were translated and conducted in Amharic language to make communication easier.

Interviews were conducted using semi-structured and open-ended questions, to enable the respondents address matters in their own terms. Three interview guides were prepared for the children, parents and teachers. The interview guides were prepared by the researcher, based on the intention to investigate the psychosocial functioning of the children with repaired CLP.

Accordingly, the interview items for the children with CLP revolved around their overall social, psychological, and academic functioning and experienced problems. The interview items for the parents included their overall perception about the children's psychosocial development, their relationship with their children, and related issues. The interview items for the teachers focused on their students' social and academic competence, such as peer relationship, participation, attendance, achievement, and so on. All the interviews were audio-taped, except in one situation where the participant refused to be audio-taped.

3.3.2 Focus group discussion

Focus group discussion (FGD) was found to be useful for exploring issues in groups, where attention to group dynamics and to discussion content allows participants to interact and co-create the research data (Nelson, 2009).

Therefore, the FGD was undertaken for two major reasons: first, to cross-check and supplement the information gathered through interview regarding their psychosocial and educational experiences and second, to explore if there are any behavioral differences that those children exhibit at school and at home, and to elucidate reasons for some of the psychosocial issues.

The FGD guide contains a list of guiding questions that were developed by the researcher, based on the objectives of the study. The group participants were organized into two groups each composed of 5 mothers of children with cleft and 6 teachers of the children. These participants were chosen with the intention to collect data on children's psychosocial and educational issues.

All the FGD were facilitated by the researcher and were undertaken in a hospital and school compounds, which were chosen for their convenience.

3.3.3 Document Review

The clinical records of the subjects were reviewed to get reliable information on their overall health conditions. In addition, the academic achievements of the participants were assessed using the overall scores achieved in the terminal examination in the previous academic year, as well as the scores in individual subjects, in addition to the interviews conducted with their teachers.

3.4 Procedure of data collection

At first, a pre-visit was made to hospital CLP project workers for initial contact. Then, the aim of the research was explained to prospective participants to maintain their willingness for cooperation. Next, the children with CLP were selected based on the preset criteria with the help of the hospital record keepers. The selected children and their parents were then contacted and notified about the purpose of the research and their willingness to participate in the study was obtained. Later, teachers of the children were contacted in person to secure their consent of participation in the study.

Pilot study

Pilot study was necessary to ascertain the instruments' validity. Therefore, prior to data gathering, a pilot study was conducted with participants with similar conditions, who attended treatment at CECH. This helped to improve and finalize the sequence of items, to modify and accordingly minimize misunderstanding and ambiguity.

Main study

Having modified the instruments after the pilot study, appointment was arranged according to convenient time schedule and each participant was contacted for data collection through interview. The interviews were held for six weeks using tape-recorder and note-taking. Each interviewee was contacted for more than 3 times, each interview session taking a time ranging 30 minutes to an hour.

The interview guide listed guiding questions to ask each participant, which were put each question into the researcher's own words for each participant, depending on the flow of the conversation. In support of this idea, Fossey et al., (2002) stated that interview guides usually contain a list of questions and prompts designed to guide the interview in a focused, yet flexible and conversational manner.

The interview guide was dynamic in that questions were added to it and ideas for different probing and follow-up questions were generated as additional interviews took

place. In fact the changes were made after a participant brought up a key point that was felt important enough to ask of all the participants.

Focus group discussions were carried out for two days, each lasting for an hour, with the researcher being the facilitator. The discussions were tape-recorded.

3.5 Procedure of data analysis

All the data obtained from the participants were transcribed, classified, and organized into a case record. Then, in-depth case histories were described in a complete but manageable manner to make the reader understand all the necessary information about the case.

Then the transcripts were read thoroughly to get familiarized with the information, before the process of coding began. Coding, as described by Miles and Huberman, (1994), is reviewing a set of information and dissecting them meaningfully, while keeping the relations between the parts intact. Accordingly, certain codes (tags or labels), initially derived from the key variables that the study was intended to explore, were developed and were assigned to the note by marking in the margins. Then similar phrases from different participants, relationships between various codes and common patterns in responses were noted.

The codes within each participant were closely studied for similarities, differences and recurring patterns. Pattern analysis helped to reduce the amount of data into more manageable units and laid the groundwork for analysis across cases. As the units were thoroughly examined, larger patterns, or themes, were developed. These themes reflected a broader perspectives or concepts. Then the themes were analyzed, where the analysis sought to relate and make sense of the different patterns and themes, which had initially been identified by the coding. Finally, comparisons were made, meanings were extracted from the data, and conclusions and implications were drawn.

3.6 Ethical consideration

This research was conducted by taking all ethical issues of a research into consideration. Participants of the study were firstly briefed about the purpose of the study and asked for their informed consent to participate in the study. The interviews were conducted separately and in private. The issue of confidentiality was also assured to the participants of the study and was implemented accordingly. Tape-recording of the interview was also based on consent. Informants were also informed that they could withdraw from participating in the study at any time.

3.7 Addressing quality of the study

"Credibility of qualitative research is dependent upon the rigorous methods used for conducting an inquiry that yields high-quality data" (Patton, 2002, p.553). Rigor was established in this study by having prolonged exposure to the data (listening to the recorded interviews, and reading every transcript in its entirety at least twice before coding), and using the interview guide to systematically record participants' views on similar topics. In addition, the participants were asked at the end of each session if the information received was what they really meant (as a form of member-checking). Moreover, triangulation was utilized to enhance the quality of the data by gathering information from different sources and using various methods.

Validity refers to the correctness or precision of the research (Ritchie & Lewis, 2003). In this study, there was not a known bias in the recruitment of the participants for the study. They were selected purposely, with preset criteria. The participants were also told that they have the right to refuse to answer any questions. This was done to create a free environment where they feel free to express themselves. Great effort was made to establish rapport with the participants prior to the interview. In addition, careful attention was paid to the expression of the participants as interviews were transcribed. Internal validation was also achieved by constantly comparing and checking codes within and across transcripts.

CHAPTER FOUR

4. Case Presentation

This section of the paper presents the histories of the children with repaired CLP. A comprehensive case history is written up based on the information obtained from the children, parents and teachers.

The case histories were developed in a way that they could give in-depth information about the children's early childhood experience of having a cleft, their surgical treatments and the outcomes, social life, emotional issues, and school experiences. To give more realistic information, some sensitive issues are presented in informants' own words, other issues being reported. In addition, the researcher's personal reflections were included in the form of observer's comment (O.C.).

All the names used in case presentations are pseudonyms and the exact appearance and living place of the informants are not described here (even if these things are noted by the researcher). This is due to the delicate nature of the issue and for some ethical reasons.

Case 1 - Helen

Helen was a second child to her family. She had 2 sisters and no brother. Helen, 15 years old, was attending her education at a government high school - she was in grade 9.

O.C: Helen was a lively child who looked beautiful with her smiling face, even with the visible scars she had on her upper lip and little deformity she had on her face.

The initial contact with this girl was made through the phone (after securing her parents' agreement to participate in the study by Hospital coordinators). Then arrangement was made to meet her the time she preferred and the first contact was made in a cafeteria around her home. The researcher then made explanation on the purpose of the study and created rapport with the girl. Then, another appointment was arranged.

The second contact was made a couple of days after at Helen's home. That time the researcher met Helen's mother and the rest of the family members. The researcher had to make contact with Helen for 4 times, each time taking more than 45 minutes of interview sessions and two of which were undertaken in a near by hotel.

O.C: The first interview session with the girl took place at her home - this actually made Helen to feel free and talk without limitation. Helen was an open girl, through all the interviews, she had no feeling of boredom rather she had been cheerful. It was noticed that her words were nasalized and she omitted some sounds when she spoke.

Helen's father, who was a government employee, was a diploma holder and her mother, a housewife, completed grade 12. Her two sisters were students. Helen's mother was interviewed in 2 interview sessions which took place at her house with the first interview session taking about an hour long, the other taking shorter period. The mother had no hesitation to take part in the study when she was asked to do so rather she mentioned that she would be glad to inform anything regarding her child's situation since the study would benefit those with cleft. She was extremely open that she talked some other topics (which were irrelevant to this study) and sometimes she talked almost to herself.

However, only the relevant ones have been transcribed here. She expressed her earlier experiences with her child as follows:

I gave birth to my second child in the house and I was very shocked when I saw my baby with strange facial appearance at first as I was expecting a cute one. Everybody who was there also felt the same to see a baby with the upper lip torn apart. I thought what in heaven's name have I done to have a baby like that. I have never seen such kind of thing before. Then we immediately went to the hospital and the doctor said that it was a small defect and can be repaired when the child reaches 8 months. He then briefed us how to feed the baby and sent us home.

Helen was born with bilateral cleft lip accompanied by a complete cleft palate. She had also little facial deformity where her upper jaw was occluded. However, her condition was non-syndromic. After birth, the doctors diagnosed the baby's condition as cleft lip and palate. Some advices were also rendered to the mother on how to feed the baby with spoon since the cleft on the mouth made it not to roll around the nipples to suck breast milk.

The mother was shocked when she first saw her baby, so was everybody. She used to hide her and refused to show her to anyone. In addition, she said that she had difficulty in feeding the baby. She said:

I wished that nobody visited me and knew about my baby's condition but couldn't stop people from coming. Those who saw her used to give me advices to take the baby to different places. But my husband and I decided to take her to the hospital for surgery when the time comes. We really had hard times especially during feeding - she usually choked when she ate, sometimes to death. That was really terrible. Her father usually got away when she started choking. But he felt sorry for her - all of us felt sorry for her. Even though she wasn't attractive, I used to hold her out of pity.

She grew up and underwent her first surgery. But after the operation, it was quite a shock somehow when her face was swollen and somehow when I saw that she reacted immediately when I came in and then it sort of happened that I cried terribly (tears well up in her eyes). But on the other hand we were so happy with the surgery outcome - I thought her lips would be left apart forever. But let's say that it was the most difficult moment of all.

According to her medical report, at 8 months of age, the child underwent her first surgery to repair the cleft on the lip. Then at the age of 1 year and 8 months, she underwent her second surgery for the cleft palate.

Helen did not begin to speak until she was 3 years old. When she started to produce words, she left out many of the sounds and was not producing as many sounds or words as she should. Although her parents attributed this to lasting trauma from her early surgery, they assumed that Helen would eventually learn the sounds. At the age of 5, Helen entered a pre-school.

Then when she was 11 years old, she underwent her third surgery (secondary to her palate) for some corrections. That time, the surgery was complicated that it made her voice worse. Sometimes later, her parents were urged to take her to another hospital for further treatment. After a close analysis, another surgery was needed to correct the previous surgery and minimize the space the scar covered. Two years later, she underwent another surgery for her nose and palate correction, jaw adjustment and overall for correction of other facial disfigurements that she had. Then she was referred to speech therapy which she took for 3 months.

There is no doubt that the family, especially the mother had a difficult time in adapting to the baby earlier. But then, the situation got much better. Now she felt that she loved her but she had strong feeling of guilt for being a cause for the cleft of the child. She said that at the time she started to think about her baby as her own child, she also started to think about the cleft:

I really had passed through difficult times with my baby. But then, I begun to realize that it might be the medications that I used to take when I was pregnant that made my baby like that. I was suffering from asthma and other diseases and took different medications since my first month of pregnancy. That was a mistake but I had no choice. When I started to think of Helen as my child, I then started to think that I have caused it and it is my fault that she has the cleft...then I thought that sort of with her having the cleft that she is otherwise good but she has this cleft.

Helen, after having undergone through all those surgeries, looked happy with her voice that she said had improved a lot. However, when it comes to her facial appearance, even though there were changes, she said there would be much to be done with her face.

Helen expressed her experience as follows:

I never knew till I reach the age of 11 years that my condition was a severe one. By that age, I underwent surgery on my palate to repair a fistula of the palate. However, the surgical treatment was not effective that it left my voice hoarser than before. For about 2 years, I became very quiet because my voice was terrible. When I spoke, air leaked out through my nose and I had to speak out the words with high pressure. But it was only breath that came out of my mouth instead. I preferred to be quiet, especially at school. In the house, I usually used signs to communicate with my family - they used to understand me. But I never dared to answer phone calls. This was the terrible time I have passed through and the time I realized that I had a serious problem which prohibited me from sharing my ideas with others, it was really terrible. And, I worried a lot about my voice and some sort of thought came to my mind – as I felt I was different, and I felt I was an inferior creature.

Helen recalls her early childhood as good time of her life with only exception of 'bad memories' that she experienced due to her unsatisfactory speech and language.

My mother told me that I used to speak so uniquely when I was a child that many people who heard my voice were eager to hear more when I spoke. But I remember my early school years...my teachers, when they asked me questions and I tried to answer, they made me repeat what I had said many times as they didn't understand my words. And it had been other students who used to 'translate' what I said to the teachers. It was embarrassing - seeing confused looks in teachers and students was really embarrassing. When this occurred repeatedly, I preferred not to say a word in the class and eventually became a quiet girl. Some teachers understood my problem and others used to be furious because of my silence when they talked to me. Since then, I never tried to participate in the class.

...There were times, especially when we transited to the next grade level, many classmates got confused with my voice when they first heard it. I noticed some teased me and others laughed at me. But what could I do? When I went home, I usually told everything to my mom and sometimes got angry and cry terribly. There were also times when I refused to go to school in fear of teasing. It was my father who advised and encouraged me to go again. However, after sometimes, when they got used to me, they minimized staring at me strangely and then I felt a little bit relieved. I appreciate my friends in this regard - they usually tried to explain my problem as it was innate that could happen to anybody. They usually defended me. We spend our times together playing and studying - my school friends meant a lot to me.

Helen was very happy with her elementary school friends' attitude towards her. She said that they had understood her condition and they were always there to support her. She liked going to school because of them. She described that she wouldn't appear in the schools environment without her friends. She also said that her parents support her to continue her education. During the time of interview, she was attending her grade 9 education, which she joined the academic year 2009/10. She described her high school experiences as follows:

I have now joined the high school. I am thankful to my parents for their ceaseless support which made me to be what I am now today. Without their support I could have quit my education. Now in high school, I am experiencing new life - new environment, new teachers, new friends. Those who came close to me asked for explanation about my voice and face even there has been a lot of improvement. I was glad that they looked for explanation than getting lost with assumptions.

...However, out of the class, more eyes stare on me. I see students staring and then talking about me. This makes me feel ashamed of my appearance. I cannot hide my face. Had it been on other part of my body, I could have covered it with clothes. But it is on my face (eyes full of tears). I don't know why God made me look different from others. This is the time, when I entered high school that I realized very deeply that I am different from others and that this difference is seen greatly. Before, even if people looked at me with confusion, it was never touching like this. It is now terrible so that I feel sorry about it. Especially, what I notice from male students' reaction is frustrating. I used to get satisfied with the surgery treatments I had undergone but now realized that much has to be done on my nose and lips. I wish I was born in developed countries where there are special instruments and specialized surgeons - my situation would have been greatly different. However, I have to live with it, what else can I do?

There were 48 students in Helen's class. She sat around the middle area of the class with two friends of her. Helen's Homeroom and English language teachers were interviewed by the researcher in two different sessions in the school compound. The focus was on Helen's overall class activities and academic achievement. In addition, her interaction with other classmates and their reaction towards her were the issues.

O.C: However, it was noticed that those high school teachers were never concerned about such individual issues. Therefore, they couldn't respond to the interview questions

raised to them. They just give lecture on the lesson and leave the class. However, they gave some information about her class activities.

Helen was an average student. However, she never participated in the class. Her teachers stated that neither of them saw her saying anything - they considered her as a quiet girl. One of them stated that even in group presentations, she never took part rather others cover up for her. Due to this, they considered her as shy and inhibited. It is a pity that neither of them knew her condition, nor tried to find out why she behaved like that, and therefore, they made no attempt to help her. However they witnessed that she had good interaction with those who sat around her. They also had no complaints on her regarding completion of assignments.

Helen's grade 8 progress report showed that she got a year average of 82% and her grade 9 first semester results 78%. Her English teacher said that she had little difficulty on English language that she still had to work more on language (60%). Otherwise, they commented that her results were satisfactory for a grade 9 student. However, she had to put more effort for better results.

Helen, regarding her class activity said that she was very quiet in fear of teasing:

In the class as I am very quiet, there is no room for others to tease me. Teachers here do not push students to participate as they do in elementary school. This somehow made me feel fine in the classroom. I and my friends usually study together when we have spare times and do group works, but I never do presentations in front of the class. I found really good friends in my class who understand my condition and give me support and encouragement. At times when I feel sad, they try to advise me not to give attention to what others say and sometimes they confront others for me.

Helen was also quiet in the house. Her mother said that Helen was a person who liked listening than talking. She usually spent time doing her home works and watching films. Sometimes she said that she noticed bad moods in her child and tried to discuss the matter with her. She said:

Helen is quiet in the house. Sometimes we don't even notice her presence. We have open relationship that I am well informed about whatever happens to her. In her early childhood, she used to play with neighbors - but not for long. She

usually ended up with quarrels. She came and told me everything what the children did to her that they made fun of her voice and nose. She used to cry a lot and I always tried to make her feel fine. We, her father and I, to the best of our ability try to make her happy and now she's happy in the house except sometimes she comes with a bad mood from school. At times, she comes from school - closes her door and lies on her bed. She even doesn't respond when we call her for tea and sometimes she stays all night there in locked room.

Helen was a cheerful girl. What made her angry was an unfair reaction towards her facial condition and voice. Alone, she began to reflect on why this happened to her, why to her and not someone else.

When I was in elementary school, some students used to insult me saying 'anchi nefnafa' (meaning you who speak with the nose) and others 'zirtit afincha' (meaning flat nose). These words were offensive to me that I would rather die than being called 'nefnafa'. Not only in the school, but those boys, who stand along my way, also usually insult me by saying the same words. When they do so, I usually tell my mother and elder sister what happens but what they can do is saying 'It's Ok'. Sometimes I go to my room and pray to God in tears. And I hope that someday in the future, my situation will be changed.

Helen's parents, as reported by the mother, did not talk to their child about the cleft condition she had – they think the child herself did not want the issue to be raised, so they did not want to disturb her. Her mother said:

Helen used to ask me about her lips, nose, and voice persistently. But how could I explain that to her – did I have to tell her that I caused it or that God made that to her? Whenever she raised such issues, I usually switched the topic as I had nothing to say. She is now tired of questioning.

Helen said that she felt happy and relieved as she was describing her past experience and feelings - she said nobody was interested to talk about such kind of issue.

O.C: It was noticed that Helen, during the interview, has been happy to talk about her cleft condition as nobody initiated her to talk about the issue before.

Helen's mother, regarding the support rendered to and needed by Helen said that they tried to make her cleft condition better through surgery, which, as she stated, has been the most difficult time to them and to the child. The speech therapy, which Helen took for 3 months, was not effective enough. Apart from this, they always tried to fulfill her

material needs as possible. However, she had never received any psychological support either from the hospitals or from her parents.

Helen's mother said that she noticed her child becoming more anxious towards her appearance. She said Helen was never satisfied by the surgery outcomes she had undergone. Helen usually had complains about her lips and nose - the mother said that her appearance was the most sensitive thing she had.

She sometimes says that she wishes she wasn't born. And sometimes she looks through the mirror and says 'I am the ugliest girl on earth', touches her nose and says 'had this been like this (holding her one side of nose up), it would have been fine'. To tell the truth, she is not ugly, rather attractive - she has got bright eyes, even the deformity on her nose is not noticeable unless you deliberately see it. But she is never happy with her facial appearance. Now that she is growing up, she is giving more attention to her beauty.

Helen usually spent time with her elder sister. They did their home works together but they did not go to the same school. Helen did not need help academically; she usually got on her own. And her results also were satisfactory.

Her mother added, "I think she will succeed in the future if she keeps on like this. I wish the best of everything to her and I thank God that she is now grown up".

Case 2 - Abdi

Abdi was a 12 years old boy, who was born with bilateral complete cleft lip and palate. He lived with his family. He had 2 elder step-brothers and elder sister - he was the youngest in the family.

The first interview took place at a public park nearby his house. The father was contacted by phone to receive his consent to participate in the study (the mother was abroad). First he said that he would not have much to tell, because he had not any problems with his son. The researcher then explained that extra-problematic cases in particular were not the focus and that the very fact that somebody had not had any problems was of equal importance for this study. Then he agreed to take part and got on well with the researcher. The second and third interviews with the father and the son took place at the same place, each taking one hour for both. The last contact was made with the child and his so called aunt in their house for some missed points.

O.C: During all the interview sessions, Abdi had been sincere and enthusiastic to talk about every issue raised. He was much more interested in talking about the 'adventures' he made.

When I first met him, he was a little bit upset by some children who hit his back with ball (made of pieces of clothes) when they played. He said, he then picked up and threw the ball away across the road. This happened some minutes earlier before we met, but he was still upset and was murmuring with anger.

O.C: When he spoke, he was lively and told stories as if they were current events. His talks were accompanied by hand signs - he moved both his hands each time he spoke.

Abdi's family was economically stable. His parents were agents to one of the Arab countries. During the time of interview, his mother was there and worked with her husband - Abdi's father. The father also had a business here in Addis Ababa. However, both of his parents did not go beyond grade 10 in their education.

According to the information given by the father, their home served as a guest-house and was usually crowded with people who underwent their processes abroad. Abdi's father was a very busy person - left home early in the morning and got home late in the evening. His two elder step-brothers also had their own businesses to run. Abdi's elder sister was a student in a private school.

O.C: It seemed that Abdi and his sister had nobody to take care of them. They had only the house maid to cook their food and wash their clothes. Abdi was a boy with repaired lip and palate. The scars on his lips somehow changed the normal appearance of his face. When he spoke, he had problems in speaking loud and omitted some speech sounds. His voice was hyper-nasal.

Abdi was born in a small town South of Addis Ababa. When he was 2 years old, his family moved to Addis Ababa. He then underwent his first surgery for the lip and palate repair at the age of 2. The surgery was successful in closing the gap between his lips and palate. However, the child did not stop producing strange gargling and spitting sounds when he spoke. Abdi's father described his early experience as:

Abdi was born in a small health center found in the town. When he was born, the mid-wife told me that the baby had a cleft lip and palate and that we wouldn't be shocked because it was rather ugly looking. It was really a shock to see a baby like that but it was more on the mother. We have passed through hard times feeding and nursing the baby.

Abdi did not have the access to undergo surgical treatment at early age due to lack of health care services in the town he was born. His father added:

It was after 2 years when we moved to the city that we took him to a hospital and they appointed him to undergo a surgery for his lips at first and palate later. This was the most difficult moment - treating a baby with surgical wounds was really difficult. At first, we all thought his condition wouldn't change. But from time to time, it has become normal. I always thank my god when I look at him and now that he has grown up.

Abdi's father also said that Abdi started talking when he was 5 years old. But before, he used to produce some limited sounds which they couldn't understand. When he talked, he had problems in producing sounds and most of his words were difficult to understand. It was only his mother who could understand him better and translated what he said to others.

At the age of 9, he underwent his second surgery for lip revision. A year after, his palate made a fistula and therefore was taken to hospital for his third surgery for fistula repair. This time he was assessed and diagnosed to have a severe articulation disorder. It has been noted that Abdi omitted stop, fricatives and affricate sounds. However, no intervention was rendered to him.

O.C: Abdi still had the inability to produce high pressure consonants due to leakage of air into the nasal cavity.

Abdi also described his early experience and the condition he had as follows:

"When I was a little boy, I usually asked my mother why I have scars on my lips and my nose was so flat. And her responses were that it was my nature. Then I wondered why I was the only person who has such condition. I began to realize that I had a split upper lip when I saw the scars which reached from lip to nose. I wanted to know more about the scars, but no body would be able to explain that to me - even my mother - she used to tell me not to be angry about it because one cannot change nature. I do have also a problem when I speak. I have to put high pressure to produce sounds and cannot pronounce some sounds. But the biggest problem lies on my palate - I never have a comfortable feeling on it. I usually choke when I eat or drink, choke till tears cover my face".

Regarding his speech and social interaction, Abdi said the following:

I have no problem interacting with my family - they got used to my speaking style and can understand me easily. I have two friends near by who usually play with me. But sometimes when we disagree with something, they insult me saying 'tebtaba' (meaning who does not speak properly) and tease me by speaking just like me. However, they won't dare saying anything to me when they are near because they know what I will do - I beat them when I get very angry.

Abdi's aunt said that he had friends whom he usually played with, however, they usually ended up in quarrel or fight. She said, whenever she went to their house to visit, she met

neighbors who complained about Abdi's behavior. Due to this, she said, he usually spent time at home playing games and watching movies.

Concerning this his father said that Abdi was very aggressive by nature. But unless he was insulted or teased by somebody, he was a calm boy. He remembered an occasion when Abdi was accused of beating by some neighbors:

Once I got a call from one of my neighbors when I went home from work in the evening. When I went there, they told me that Abdi beat a boy very terribly on the head and that the boy was taken to a hospital. I was very shocked to hear that and went back home to talk to Abdi. He had slept but I woke him up and asked him to tell me why he did such a thing. He was sobbing when he told me that the boys insulted him saying 'a curse from God' and that they teased and ridiculed him. He was very angry - he brought a big stone and hit one of the boys on the head".

The father also added that Abdi was a very sensitive boy. He did not want anybody to talk about the cleft condition he had. If so, he did not hesitate to confront that. At home, he usually got on well with his brothers and sisters. They all knew his behavior. They rather cared for him.

Abdi entered his pre-school at the age of 6. He had passed through four schools till he reached his current grade level - 4. The reason reported for this was the inconvenience of the schools' environment for the child. The researcher managed to interview Abdi's teachers and the unit leader at his school. They were so cooperative in informing the child's situation. Interviews were made with each and his previous and current achievement records were reviewed.

Regarding his behavior, Abdi's teachers reported that he was very aggressive at school. The unit leader also reported that Abdi was usually accused of physical violence by other children in the school. They said they tried to work this out and counseled Abdi many times. But he always related his faults with his cleft condition, that he beat them because they insulted him. However, the children always said that it was with other reasons but not by insult that they quarreled. The school personnel also tried to talk with his father about this and other problems but they could not meet the father.

Nevertheless, Abdi was a cheerful boy. He sometimes got depressed and felt guilty of his condition. He said:

I miss my mother. Had she been near to me, my situation would have been different. Sometimes when I couldn't get along with my friends, I get home and look for someone to talk to. But nobody is there except the maid and others who I do not know. I usually sleep or play video games to forget what happens. Sometimes I wait for my father until mid-night and tell him what has happened to me. He feels very sad and advises me not to get angry. But I wonder when this situation will change - unless I am born again healthy.

...My neighbors, knowing that I am an ill person, they attack me verbally saying 'nefnafa', 'tebtaba'. I have gone through a lot of suffering due to my cleft and yet these people add more to me – this is really unbearable.

Abdi's mother started her job she when Abdi was 2 years old. She has no fixed visit to her family. She came to visit when the time was convenient for her. Abdi always missed his mother even though she frequently met him through phone. His father was always there to fulfill the material needs of his children - he had no reservation to buy anything they wanted. He thought that his child's condition created depression which should need attention. Therefore, he tried to make his child happy by doing whatever he liked. By doing so, he assumed that the child would not have chance to think of his cleft condition and become depressed.

At school, Abdi had lower performance. During the time of interview, he was in grade 4, which he repeated. He has passed through four schools before he joined the current school.

O.C: Even though the reason for frequent change of schools was not clear, it was suspected that this could be because of his unfavorable behavior.

His homeroom teacher said:

Abdi never sits calm in the class. His seat is around the middle area and disturbs others who sit surrounding him. Even sometimes he pulls or pushes those who sit a desk ahead or back to him. You see him sometimes laying on the desk during lesson or doing something else. He doesn't obey teachers' orders neither does he interact with others well.

The school's unit leader also added that:

Not only students have complaint on him but also teachers. They usually accuse him of disturbing others (by insult or harm) and the whole class with the mobile phone he brings to class. He sometimes tends to speak through mobile phone during lesson. We see many different expensive mobile phones with him and tried to talk to his father about that.

The school's management had used different mechanisms to control such habits of the child but the situation seemed out of control. They tried to reach the father many times however they could not meet him. But once the father came to the school for the same reason and explained that his child had a health problem and he did not want to stress him with education and that he sent him to school not for learning, seemed for fun. And the reason he gave him mobile phones was not to miss his mother when she called. He said:

I don't want my child to feel sad about anything. He has gone through many health problems which he suffered a lot from. I want him to feel free and live happily. So I never prohibit him from doing or giving what he likes to do or have, nor push him to do what he doesn't want to.

Abdi hardly participated in class discussions in fear of teasing. Regarding this he said:

Some children used to laugh when I spoke in the class. I know I have a unique voice but that made me angry and beat them when the class was over. Since then, they never laugh but I still see some feelings on students when I read a text or answer questions. Sometimes the teachers do not understand me, too. It is better to be quiet than get insulted, so I choose that.

...I like Math from all subjects and I am good at it. But I hate English and Amharic subjects - I never understand English and I feel sleepy at those periods.

One of Abdi's teachers said that he did not participate in the class or showed interest to learn at all. Whenever he was called upon to say something, his answer was 'I don't know'. His results of first semester of this academic year (2009/2010) also showed that Abdi had an average of 53 with 3 failing subjects (less than 50). The teachers said that they were trying their best to upgrade his performances on behalf of the school through tutorial classes (which he never participated) but he needed serious supervision and support from home.

Case 3 - Saba

Saba, 12 years old, was a girl born with complete cleft lip and palate, with upper jaw deformity. She was a grade 6 student at a governmental school. She lived with her family.

The first interview took place in a hotel with the child and her mother after securing their consent of participation in the study through a phone from a hospital.

O.C: Both the child and the mother were easy to talk to and had no reservation to share their experiences.

Then after having discussed on basic issues, an appointment for another interview was made and departed. The second and third interviews were undertaken in their house and the last one in the child's school compound.

O.C: All the interview sessions were interesting and they were happy to talk about the issue.

Saba was the youngest child in the family with three brothers and a sister. Her parents were married. They lived in a small rented house. Her father was retired and her mother was a street vendor. The eldest brother worked in a garage and supported the family. Her other brothers and sister were students. According to the mother, there was no cleft history in their background, nor any other related problems. She related her child's condition with the traditional medicines that she used to take to abort the baby when she was pregnant. She described her early experience as follows:

I was about to be employed in an organization when I knew I was pregnant. They wouldn't accept a pregnant woman so I had to do something. You know we were poor, my husband's salary was not enough even for our food. So my friends advised me to abort the baby and went to a place where I was given different kinds of medicines to take. I took all of them (laughter) but nothing happened. So I had to give away the job.

...She was born in a hospital. But then I saw the doctors were looking at my baby...I knew that I did something wrong and felt that the baby too had something wrong. Then they told me that the baby had a cleft-like thing on the mouth, which they couldn't even describe. When I saw it, it was terrible

looking...I had never seen a new born baby like that. At first, I felt shocked, I thought she was ugly and I felt terrible seeing her, and had a feeling that I didn't want to touch. She had no upper mouth at all, her upper jaw being rolled upon her nose, oh God, she looked terrible. I felt at one moment, and even wished her death. I remembered it immediately and it came to me that I thought it was something that caused it, but certainly no one, even my husband, knew about that. I felt guilty, and still feel it because first I couldn't give birth to a healthy baby and then I couldn't feel towards her properly.

...In the beginning, I hated her and then I somehow or other or I don't know if I really hated her but somehow I avoided her. For a long time afterwards, I have thought that I quite consciously left her so that I didn't even touch her, always when I took care of her, I looked in the other direction, because she was so awful.

Saba then underwent her first surgery. The doctors managed to put the lips and jaw back to the proper position. Then after a year, they joined her lips. A year later, she underwent her third surgery for her palate. However, the palatal surgery was not effective enough - it was torn apart after some time so her parents had to take her again to hospital for another surgery. Due to this, she started speaking when she was five years old. She still has difficulty in speaking and choking disturbed her whenever she ate or drank because she had a fistula in her palate. The doctors in the previous hospital told them that they would call them when specialists come from abroad and they were still waiting.

Saba and her parents were happy with the surgical outcome she had gone through. Especially the mother has no words in expressing her satisfaction about the lip surgery. She said she thought of teeth would grow on her gum which was on her nose and her child would seem some kind of 'monster'.

The mother used to hide the child when she was a baby and afterwards she did not let her go out of the house - people used to talk about her child. They used to say 'she gave birth to a child with no mouth'. In fear of this, she did not even let her take vaccination nor have christening. She did not even want her own family members see her. Then everything was changed except some deformities seen on the mouth and her front teeth being rotated. Now it seemed that it was such an old issue that one can not talk about it. The mother now felt that she loved her daughter, but she had strong feelings of guilt for not having been a good enough mother for her.

O.C: Saba had a strange look - she had many visible scars on her nose and mouth. Her nose was flattened. Her teeth pushed her mouth out and made protruded. However, she looked happy and seemed less concerned with her facial appearance. When she spoke, she nasalized sounds and substituted one sound for the other. And some sounds were difficult for her to pronounce. However, one could understand her if she spoke loud.

In the house, Saba interacted well with her sister and brothers. She spent most with her sister and other children from neighboring houses - they played together. But when they quarreled, they insulted her. She said:

I had friends – we used to play together after school. But sometimes they made group and isolated me. They used to insult me 'difitit' (meaning flat nose). They came to my nerves when they say this to me. So I used to run away home, cry and tell my mother what has happened. She always said 'don't worry, they themselves are 'difitit', it is only that they want to make you sad - don't be sad and make them angry'. But someday one of our neighbors came out of her house and insulted me taking side to her daughter. She said 'You, torn apart - I will tear off your sewed face!' I felt so terrible that I couldn't even tell to my mother except crying and sobbing. But then when I told her she immediately went to the woman and they were about to fight, oh that was because of me, and because of my condition. That time on, I stopped playing with villagers and usually stay at home.

According to her mother, Saba was a decent girl. She felt very angry when she was insulted or if someone teased her. Otherwise, she was good and sociable - easy to be with. Sometimes she said she felt sorry about her nature:

I remember most vividly what others said about me concerning my face and voice. Then I think of myself...just a kind of why me...that why couldn't it go well and of course I keep thinking that what did I do at certain times. And finally, I come to a point that God made this happen, so I should accept it.

Saba was in grade 6. She was one of the outstanding students in her class of 52 students. Her homeroom and English language teachers were interviewed regarding her academic performance and interaction with peers. The interview sessions took place in the school compound. The teachers knew Saba very well because as they said she was active in the class and was very clever. Above all, she could be easily identified by the cleft condition

she had. Her year and half progress reports were also reviewed. When she was in grade 5, her year average was 92% and 90.5% the academic year 2009/2010. One of her teachers commented:

I know Saba for two years. She is one of our best students. She is very much enthusiastic in her studies and scores high marks. During lesson, she has no reservation to participate in discussion. Even when some volunteer reading is needed, she is always the first to raise her hand. She is really a model, even to those with disability, I can say.

Saba also said that she liked her education above all things. She enjoyed learning and studying. She said she did not want to lose her rank position, so she studied hard. Her sister, too, was a rank student in grade 7, same school. Saba and her sister studied together, they helped each other in their studies.

Her parents were also very happy with Saba's school performance. They said that they did not push her to study because she had a difficult condition. But she was self-motivated towards her studies. She has been outstanding since her early years of school. They said they would support her in any aspect regarding her education mentioning that it was the only way that could brighten her future. They seemed proud of her.

Saba had friends in her school. They too, studied together, she liked them. However, according to her, there were also some indecent students who usually teased her in the class and school compound:

At times, some students sitting at the back laugh at me when I answer questions or when I read a text. And some make me angry by speaking just like me. Sometimes, teachers warn these students. I remember once one of my teachers punished the student who teased me and made him say 'sorry' to me, and he did.

...I feel I'm different at times, and many times I feel shock when I think of the surgeries and my family's worries and insults and so on...sometimes, it comes a feeling that I can't bear all those things and terrible feelings and a need come to my mind - a need to accept my own crisis and the anomaly. I feel 'why does this have to happen to me and a kind of jealousy when I see healthy children. But I make myself go on, to somehow manage pass a certain point.

O.C: Saba, regardless of the condition she had, was optimistic about her future.

She wanted to become an engineer. She knew she had to put much effort in her education. The only thing that bothered her was her palatal fistula, which she was waiting for another surgical treatment. Her lips, as the doctors said, would be corrected when she developed physically after some years.

Case 4 – Alem

Alem was a girl with complete cleft palate only. She was 13 years old. Initially, her mother was contacted through phone to secure their consent to participate in the study. The first physical contact with her and her mother was made in a hotel near by their home. The researcher then introduced the overall aim of the research and secured some basic information about the child. The second contact was made at a hospital compound (chosen for its convenience) and the interviews lasted for about 45 minutes each with the child and her mother. The last interview session took place at their home after a week.

O.C: Alem and her mother were very happy to take part in the study. They both were very open and honest to talk about even very difficult issues.

Alem and her family lived in a small, old house. Her parents were married and she had two elder sisters. She was the youngest in the family. Both her sisters were students in high school. Her father and mother were both non-educated. Her father worked in a government organization and her mother was a house-wife but she did anything that could make money. She served as a cook for wedding celebrations, and sold paper bags (made at home) for small stores, so on.

O.C: It seemed that the family has low economic status.

According to her mother, when Alem was born, she was cute with no visible defect on her face. But the problem appeared during feeding. Feeding the baby was problematic for the mother. At the hospital, the nurses tried to help her to breast feed the baby, but breast feeding did not succeed. The mother did not get any information on what the problem was and on how to feed her baby, and the baby lost weight. Then the situation got better when she fed her milk with spoon even though she used to be disturbed by terrible choking.

It was when the child was 9 years old that she was diagnosed to have a complete cleft of the palate, when she was taken to a hospital for treatment of fever. Then after some time she underwent palatal surgery at a hospital.

She remembered her early experience with her child as follows:

I never forget the time that I used to breast feed my baby during her early years. She choked and cried all the time and nobody could understand her problem. I usually left her with my sister who used to live with us not to hear such a noise. It was really hard time. I was anxious, I cried a lot too and was depressed because I had no information and I started wondering if there might be something wrong with her.

... Then when she began to speak, she used to produce only same sounds repeatedly. We thought it was because she was a baby. But as she grew up, at age of 4, no improvement was there – she wouldn't produce any words, except some strange sounds. I and her father thought that our daughter was dumb and felt very sorry for her. But we had to accept that it was God's will and could do nothing about it. However with age, she began to speak a little, had difficulty in speaking out, with some sort of sound, I mean she seemed as if she was speaking through her throat. It was then when she was 9 years old when she got sick of Tonsillitis that we took her to a hospital where she was diagnosed having a cleft palate. She then underwent surgery. Then I began to think of the problems she had in feeding and speaking. I blamed myself for not knowing her problems... when she cried a lot, when she choked frequently and when she was not able to speak... you know, if you are stupid, you are stupid.

Alem's mother was guilty of not only giving birth to such a child but also not knowing her child's problem. She considered her child's condition as a curse from God. She never heard of such a condition earlier, nor did the father. After the surgery, Alem's condition seemed improved. The doctors advised the mother to teach her child say some basic sounds and let her practice every time. But the mother didn't have the tolerance to do so. She said that the child herself didn't want to practice because she became tired of producing such sounds.

Alem joined a government school at the age of 6. She described her school experience:

I don't like schooling, it is not a place where I get peace of mind, I mean I don't. Children make fun of my voice; they try to imitate my voice to tease me. Some insult me saying 'nefnafa' (who speak through the nose). Sometimes elder students come to me and ask me to say some difficult words, and when I say the word in fear of them, they laugh. Also in the class, when teachers ask me questions and when I keep quiet, they tell teachers that I deliberately keep quiet to make them angry. And when I begin talking to explain, they laugh at me. But now-a-days teachers seem to understand my problem – that I have a problem in

speaking and have low voice. But no body tried to find out what really happened to me. Only my two friends, who sit with me have positive attitude towards me, we understand each other and they always try to help me in all aspects.

Alem's teachers were interviewed in the school compound on her academic and class participation issues. They witnessed that she was very quiet in the class. In fact, they did not know the problem she had in her mouth. It was a government school with more than 50 children in each class. Therefore, according to them, they had no chance to find out the needs of each student except referring to their progress reports and comment on it.

O.C: Alem, when she spoke, it was difficult to understand her; otherwise one should get used to her unique nasalized wordings to understand her easily. She had a very low and breathy voice and takes break frequently while speaking. She said she had to put much pressure to speak out which makes her tired. The researcher also had to make her repeat what she said during interview so as to make sure that what was heard was what she meant.

She underwent her secondary surgery for palatal fistula she had a year before, but her condition has not improved yet. Due to this, she said she was afraid of speaking and playing in groups at school. Her teachers also reported that she usually stayed in the class when others went out for recess.

Alem was also quiet in the house. Her mother said:

We all want her to improve her speaking skill so everybody talks to her, but her responses are too short and she shows no interest in talking at all. At times she says she gets tired when she speaks. Every time I see her, I see her depressed. She is lonely, has no friends among the neighbors. Even in the house, when everybody is there, she's lonely. She usually cries and becomes disturbed with no reason. I also become very disturbed seeing her like that and try to be with her. Sometimes, when she is in a good mood, she plays with her sisters and helps me in the house works.

When at home, Alem liked to help her mother in making paper bags. She had no friends around, played with her sisters. She did not enjoy talking, she was a good listener. She was kind and obedient to her mother, even to neighbors. But at times, she became aggressive with no reason. She complained of frequent head aches but refused to go to a clinic. She preferred laying on a bed for long. She sometimes blamed her family for all the condition she had and for not providing the support she deserved. Alem spoke:

I know I have a defect in my palate, a defect in my speech. I don't want people know this... you know, nobody understands you, even family members. When I sometimes get angry with something, nobody tries to find out what has happened to me. I don't have anybody to talk to...I mean share my feelings to and understands me. I just cry and cry and sometimes I just don't feel like going to school or even go out from home.

Alem needed her speech to improve badly. But she was not trying even to speak out and practice. She preferred keeping quiet. She believes a more specialized surgical treatment would result better. She seemed unhappy with her previous surgical outcomes because she said she did not see any improvement on her speech. Alem had no other serious health problem except that she sometimes had an ear infection, which she said, was painful. She never visited a psychiatrist or did take any counseling from the cleft treatment team. Her mother was also informed from a hospital that they would call upon her when specialized cleft team comes from abroad, and she was waiting for that.

Academically, Alem did not perform well. She repeated grade 4 once and was in grade 5. She said, "I have difficulty in Math and English subjects. Especially English, I don't understand it at all. I feel even going out of the class on English period. I try my best to improve but I always fail. No one supports me in school or at home".

Alem's parents were also not happy with the school outcome of their child. Her father once said:

I don't think she would succeed academically. She doesn't even show any interest in her education. I never saw her doing homework or studying as her elder sisters do. I know she will give up someday and will be fired from school and stay at home.

Her mother also said that her sisters were always willing to help her, but she did not have the interest. She also reported that she had never been called from her school regarding her education. However, her English and homeroom teachers reported that they told the child to call upon her parents to school to discuss the problem. It was because Alem did not do her home works regularly and came to class without exercise books or books and that she did not perform well. One of the teachers also said that Alem sometimes slept in the class and the reason she gave (as her peers explained for the teacher) for this and for

not doing her assignments was that she was busy at home making paper bags that her mother sold.

Her grade 4 and grade 5 (1st semester) results also showed that Alem scored below passing point in main subjects, which she had to do more to be promoted to the next grade level.

Regarding Alem's educational matters, the researcher managed to take her mother to her school to discuss the issue with the teachers. After having discussion, they agreed to follow up the child at school and at home and help her improve her performance.

4.1 Cross-case Analysis

In the following table, attempt was made to show characteristics of each case under the major themes of this research. This was done after full understanding of individual cases before combining them thematically. This, according to Miles and Huberman, (1994) helps the reader to deepen understanding and explanation.

Table 3 Cross-case display

Cases	Cleft condition & related problems	Psychosocial issues	Learning and achievement	Contributing factors
Helen	- Repaired complete CLP - Facial deformity - Speech and voice problem	- Experienced frequent insult and tease - Embarrassed about voice and speech - Unhappy, feels shame of her facial appearance - Social inhibition - Feeling of anger, unhappiness, frustration, worry, worthlessness	- No class or group participation - No support from teachers - Studied at home - Achieved average (low in English subject)	- Fear of teasing and insult - Dissatisfaction with facial appearance and speech - Lack cleft knowledge and of support from family
Abdi	- Repaired complete CLP with palatal fistulae - Frequent choking - Flattened nose - Speech and voice problem	- Experienced frequent insult and teasing - Considered himself as unhealthy - Felt lonely, angry, sad - Disturbed in the class, disobeyed teachers, beat others frequently	- Changed school frequently - Repeated grade 4 - Inattentive in the class - Didn't like learning - No support from family or teachers - Achieved poor	- Fear of teasing and insult - Lack of early language stimulation - Lack of control of behavior and knowledge of cleft - Lack of educational and psychological support - Continued hospitalization
Saba	- Repaired complete CLP with palatal fistulae - Teeth occlusion - Deformity around the mouth - Speech & voice problem	- Experienced frequent insult and teasing - Felt different, isolated, sad - Jealous of others' appearance - Self-motivated, optimistic	- Participated actively - Enjoyed learning - Needed no support - Outstanding achievement	- Fear of teasing - Lack of early language stimulation - Lack of cleft knowledge and support from family
Alem	- Repaired complete CPO - Speech, voice and language problem	- Experienced frequent teasing and insult - Felt anger, loneliness, worthlessness, unhappiness with speech - Exhibited avoidance behavior, socially inhibited - Cried with no reason, complains for aches	- Never participated in class - Didn't like schooling - Repeated grade 5 - No support from teachers and family - Achieved poor	- Fear of teasing and insult - Lack of early language stimulation - Dissatisfaction with speech - Lack of psychological and educational support - Lack of cleft knowledge and support from family

The above table, in summary, shows the overall cleft condition, psychosocial functioning, learning and achievement, and factors that contribute for the current psychosocial and academic functioning of the four cases. An attempt was made to demonstrate the major findings in each theme, which helps the reader to have the overall individual picture of the cases presented and to see the similarities and differences across cases.

The cleft condition that the children had created various aesthetic and functional problems to them. The three cases were with repaired complete CLP, two of them having deformities around middle face and mouth. Moreover, all of them had significant speech, voice and language disorders. Besides, two of them suffer from frequent choking due to palatal fistula. These children also were victims of frequent surgical treatment due to the nature of their cleft. All these conditions have made the cases to have various forms of aesthetic and functional limitations.

The cases in this study also went through various psychosocial concerns due to their cleft anomaly. A range of psychosocial problems, such as teasing, insult, feeling of shame and different, unhappiness, anger, loneliness, frustration, frequent crying, worry, avoidance behavior, and withdrawal have been reported in the cases. Externalized behavioral problems, such as disruptive behavior and physical violence have also been reported in one of the cases. These psychosocial problems were mainly the results of the impairment that the cleft caused and other factors related to their families and the society as a whole.

All of the cases were found to have different levels of aesthetic and functional impairments as a result of their cleft. These impairments in turn have brought to them stigmatization by the society. They were inhibited from social settings in fear of teasing and verbal attacks. Lack of positive responses towards these children resulted in placing them into impaired psychosocial functioning. In addition, the cases have not received any emotional support from families or any other. This has been attributed to parents' previous background, early interruption of mother-child bonding, lack of ability to cope with stress and lack of knowledge of the cleft anomaly. Parents reported that they have gone through various emotional situations due to the birth of a baby with a cleft anomaly. This, to some extent, has deteriorated the mother-child bonding during early stages. Poor

interpersonal relations at this early stage have resulted in poor psychosocial functioning. As a result, the attitudes, expectations and degree of support shown by most parents were consistently low, which were likely to have an enormous negative influence on the children's perception of their cleft impairment and psychosocial adjustment.

The children's learning and achievement have also been influenced by the cleft impairment they had. As shown in the table, three of the cases have refrained themselves from classroom active participation, which in turn affected their competence in their academic performance. Repetition of classes has been observed in two cases, who were poor achievers. In these cases, no support from teachers and family was reported. However, in one of the cases, outstanding achievement has been reported. These situations have been attributed to various factors. The major ones were the children's functional limitations such as speech and language. In two cases, these limitations have hindered the children's learning and therefore made them have low motivation and academic competence. Lack of early language stimulation (after the first surgery) due to lack of knowledge of the condition has been reported in most cases to be the causal factor for their speech and language impairment.

The mother-child bonding at early developmental stages was also interrupted in three of the cases due to the cleft condition they had. This, as a result, contributed to lack of early language stimulation and various emotional problems. These children, due to teasing of their speech and language have withdrawn class participation. Not only because of their functional problems but also their aesthetic concerns has made them lag behind in their learning and achievement. Two of the cases did not take part in the teaching-learning activities in the classroom due to fear of stigma. In addition, the teachers were not aware of the cleft condition of these children and therefore have provided no special support for them. Parents also did not have knowledge on how to motivate and provide support to these children, rather, in two cases, they reported that they did not expect much from their children's educational outcome. All these factors contributed to the low academic achievement of the cases under the study.

Generally, it was found out that most of the features related to psychosocial functioning of the children were found in common. In addition, the contributing reported factors to such behaviors were similar.

4.2 Summary

The aim of this study was to explore the psychosocial experiences of children with repaired CLP. In order to understand the complexity of the issue under investigation, qualitative case study approach was employed. Accordingly, participants were purposely selected which included four children with repaired CLP, their respective parents, and teachers and other five parents of children with repaired CLP. A total of 21 individuals participated in the study. Interviews were made with the children, parents and teachers, whereas the other groups of parents and teachers participated in FGD. The children's clinical and academic reports have also been reviewed.

As a result, the following have been identified as major findings:

- The children with repaired CLP had difficulties with speech and language. They have gone through multiple surgeries, but have never received speech therapy after surgical treatment except one of them, who received therapy for a short period of time.
- The children experienced frequent tease and insult from neighbors, class and school-mates and strangers – the features directly related to the cleft were the focus of teasing. Teasing mostly occurred when meeting strangers and at specific turning points in the children's lives such as starting in a new school, new class... They reported teasing worried them a lot.
- Most of them reported that they did not participate in social activities and class activities because of fear of teasing.
- The children were not satisfied with their cleft surgical results. They reported dissatisfaction with facial appearance and speech.
- The teachers perceived them as more inhibited (withdrawn) in the classroom than other children.

- Behavioral manifestations, such as internalizing (sadness, unhappiness, shame, guilt, frustration, loneliness, worry) and externalizing behaviors (aggressiveness, disruptive behaviors) have been reported.

Other related findings are the following:

- Early mother-child bonding have been interrupted due to the babies' facial appearance and cleft impairment.
- The children started pre-school being delayed in their age, i.e. after the age of 5, due to speech and language development delay.
- Teachers were unaware of the cleft problem that the children had and have given no support.
- Most parents did not exceed in their education and had lower expectation of the children's academic outcome.
- The families rarely discussed the cleft anomaly, or issues surrounding the cleft.

CHAPTER FIVE

5. Discussion

In the previous section, an attempt was made to offer the reader a possibility to enter into the life-worlds of the children with repaired CLP; their subjective experiences as they were told by the children, parents and their respected teachers. These cases differed from each other in their interpretation of the cleft problem they had, and showed the variation of the interpretation possibilities in the whole of its extent. Now is the time for providing a synthesis of the meanings of their experiences, that is attaching significance to what was found, making sense of findings, offering explanations and drawing conclusions as stated by Patton, (2002).

Therefore, this chapter focuses on discussing the major research themes through figuring out possible patterns of behavior. These are major psychosocial problems that children with repaired CLP experience and overall learning and academic achievements with identifying the contributing factors.

5.1 Major psychosocial issues

The results of this study revealed that children with repaired CLP suffer from a range of psychosocial problems. The most prominent one was that they were socially challenged with respect to social competence and confidence.

The everyday social interactions of these children was strained, that is, in their course of everyday social interaction, they were not accorded the same social respect as individuals without a facial deformity. Not only their facial appearance, but also the speech defect they had made them to receive negative responses from others.

The participants reported that they received negative responses from outsiders, which in turn had negative effect on them. Helen described that at school, many got confused with her way of speaking and she noticed some teasing at her. She also said that she felt embarrassed and shame in reaction to the confused looks of teachers and students. Due to

this, Helen did not want to speak in front of others in fear of negative responses so she preferred to be quiet all the time. Alem, in the same way, said that she did not want to speak because she did not want others to know about her speech problem – if they did so, as to her, they would ridicule her. Saba also said that she always thought about what others would react to her speech and facial appearance. These children were subject to the social burden of stigmatization. Besides, they experienced feelings of powerlessness with respect to social interaction, and the experience of loneliness and social isolation. To this effect, many of them were seen to withdraw socially.

Social rejection from outsiders is predicted and noticed by people with CLP. Facial and oral area of appearance is often observable immediately by others. Regarding this, Bzoch (2004) indicated that facial differences are quickly perceived in social discourse in that the face is the initial focus of the gaze – it is the principal target of attention in interpersonal interaction. Therefore, an imperfect appearance, according to Turner et al., (1998) may initiate overt teasing, bullying and unwanted questioning. As a result, the children importantly lack their privacy. Helen described, “I see students and people staring and talking about me”. Regarding this, Frances Macgregor (1990) stated:

“In their efforts to go about their daily affairs, they are subject to visual and verbal assaults and a level of familiarity from strangers...(including)...naked stares, startle reactions, ‘double takes’, whispering, remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, laughter, ridicule, or outright avoidance. Whatever form the behaviors may take; they generate feelings of shame, impotence, anger and humiliation in their victim (p.250).

The findings suggested a relationship between speech and facial attractiveness associated with the development of interpersonal relationships. Speech defects coupled with a craniofacial anomaly in this study have been found to compound negative reactions from others. These links between speech and physical beauty with social acceptability underlay the potential disadvantage for these children to have social skills and positive body image.

Such experiences have also been linked to inhibition in social interaction behavior. All the children in this study reported that they preferred to be quiet than interact with others.

Saba and Alem also said that they had no intimate friends or friends to play with. Alem once said that she did not want others to know about her speech problems because of fear of teasing so she avoided social contact. Some parents' reports in the FGD also revealed that their children were usually engaged in the household chores rather than playing with neighbors. In two situations, they also reported that their children did not even want to go to visit their relatives or participate in social activities like get together and so on. It has also been mentioned in the FGD that most parents themselves did not want their children with cleft to have a social relation, especially with strangers. This was due to their fear of having their children depressed as a result of the negative social responses. Therefore, it can be said that it is not only the children's preference to be inhibited from social relations but also the parents' influence that has put them into having impaired social development.

These findings of elevated rates of social difficulties are consistent with two recent reports on population with cleft (Hunt et al., 2006; Hunt et al., 2007), where interestingly, poor emotional and behavioral adjustments were found to be largely a function of poor social relationships.

The unfavorable social responses may be interpreted as forms of social unacceptability, which may induce feelings of self-worth within these children. They thought that they were different in that they had unsatisfactory speech and unattractive facial appearance. This perception was the result of others' responses to them. The negative attitudes, behavior and responses the children received from other people led them to think that they were aesthetically and functionally inferior to others, which put them at risk for negative self-evaluation. This is evidenced by a study which emphasizes that the unpleasant social reactions at an early age result in a self-evaluation that is more fundamentally negative for some children with craniofacial anomalies, whereby they may internalize a more global view of themselves as deficient or devalued (Bilboul et al., 2006).

Physical appearance has been found to be related to social anxiety, with individuals who perceive themselves as being unattractive having more social anxiety (Berk et al., 2001).

Helen, when people stared at her, felt shame of her appearance and wished if she could hide her face. She said, "...had it been on other part of my body, I could have covered it with clothes...but it is on my face". There is no doubt that this girl has been distressed in social situations, which involve body evaluations of the face, which can not be camouflaged by clothing. In support of this idea, Berk suggests that social anxiety can be a pervasive and persistent experience for individuals with physical anomalies. At the same time, aversive attention, such as teasing or staring behavior experienced by the children has been identified as a causal factor in social anxiety (Buss, 1980 in Berk, 2001). He further explained that if discomfort, lack of familiarity, or sensitivity at the sight of an individual with cleft leads to such responses, individuals with oral-facial clefts would be more predisposed to high levels of chronic social anxiety than their unaffected counterparts. An individual's self-perception is also a contributory factor in the experience of social anxiety. Children in this study were aware of the social risk of being different as a result of their facial appearance. As a result, they have become more disadvantaged with respect to social affiliation and adaptation.

It has been noted that this situation is cyclic – the higher levels of inhibition is a potential for social anxiety and the reverse is also true. The children's situation can be seen from both directions, that is, unfavorable social responses caused inhibition and limited social experiences; and inhibition functioned to prevent further aversive social interaction and the unfavorable reactions of others. The findings showed that the children were disadvantaged from social interactions and consequently were less inclined to engage in them. On the other way round, they were inhibited in order to avoid negative social responses. This view is supported by Baumeister and Tice, (1990), who reviewed the potential benefits of anxiety secondary to its cognitive consequences when anxiety serves, a protective mechanism that enables individuals to prepare or adapt to potentially threatening situations. The cumulative effect of this interactional phenomenon is detrimental with respect to their social wellness. The socially anxious or shy person avoids the anxiety of rejection but at the cost of a chance of forming social bonds.

The study has also found relationship between satisfaction with facial appearance and depression. Three of the cases have reported that they needed further corrective surgical treatment. Helen said that had she been living in developed nations where she could find specialized surgical treatment, she would have looked better. She said she was ashamed of her appearance. Parents of Helen and Saba also reported that their children were usually of concern about their facial appearance and that they were looking for corrective surgeries. Helen's mother said, "...she wishes she wasn't born...she looks into the mirror and says 'I am the ugliest girl on earth', touches her nose and says 'had this been like this (holding her one side of nose up), it would have been fine'...she is never happy with her face". Saba also said, "I feel jealous of others' appearance", and that she had concerns with her mouth and nose. Her mother mentioned that even if she was happy with her child's previous surgical results, a more corrective one would be needed to fulfill Saba's needs of being 'good-looking' as others. Most of the parent participants of the FGD also mentioned that their children were not happy with the surgical outcomes even though the parents did not complain. This dissatisfaction with facial appearance has been found to be a predictor of depression among subjects with cleft (Marcusson et al., 2002). As a result of this, the children have experienced continued worry, sadness, frustration, shame, loneliness and guilty feelings. Some also usually cried with no reason.

Dissatisfaction with speech is also found to be a factor to develop depressive symptoms. The children perceived their speech as unsatisfactory and therefore were withdrawn from social interactions. This, in turn has put them in a situation where they developed feeling of anger, worry and loneliness. In the case of Alem, it was her dissatisfaction with her speech that has made her lonely – she had no friends around, felt sad and anger, and cried with no reason. She also made complaints of aches, which she refused to get them treated. This is attributable to her possible, yet not expressed, feelings of distress. Her experiences of aches could be explained as psychological problems that children experience when they are in stressful condition.

Frequent and prolonged hospitalization also had an effect on the children's psychological wellbeing. Abdi considered himself as an ill person because of his frequent hospitalization. This might be one of the factors which made him have most of the above

depressive symptoms. In support of this, Hunt et al., (2007) made a speculation that children with cleft consider their condition to be an illness, which may partly explain the increased level of depressive symptoms. In the rest of the cases, though not described, it can also be said that frequent hospitalization and the surgical treatment at this age also brought distress to them.

There were contrasting reports regarding the externalizing behavioral problems among the cases in this study. For instance, Alem and Helen were very shy, socially inhibited whereas Abdi was very aggressive. Abdi's father and teachers reported that he was usually accused of beating and being hard on others. In addition, according to his teachers, he was restless in the class. The reason for this, as described by Abdi, was that other children insulted, teased, or called his name. But, according to the unit leader and the teachers, none of the students did those things to him. As he has repeated the grade he is in, he was older and physically bigger than his classmates. Due to this he usually threatened and beat them if he saw any kind of unfavorable condition in them. This was his mechanism to avoid teasing before happening and to cover up the aesthetic and functional differences he had. Such kind of behavior, according to the school's management, was intolerable and that the management was on the way to decide on other measures than counseling. It has also been noted that Abdi had gone through four schools before he entered the current one. The reason, even though not mentioned, can be related to his bad behavioral manifestations.

The above experiences of the children in this study have also been greatly influenced by familial issues other than the cleft anomaly itself and the social responses. A family is a basic social unit that influences children's early psychosocial development. The kind of relationship the children have with their parents and family members has effects on the children's later personality. The parents' feelings about their child's cleft defect are thought to be paramount in developing the child's self-esteem. The birth of a baby with a cleft anomaly is rarely predicted, so the expectation is always for a normal birth. Therefore, parents usually go through emotional reactions, such as shock, confusion, grief, guilt, and mourn. The parents of the children in this study have also gone through such emotional reactions after they gave birth to their children with cleft. Even though

they have handled the reactions, it has been noted that the children's facial appearance and cleft palate have interfered with early mother-child bonding, which is thought to be an important determinant of personality and adjustment in later life. To support this idea, Pruzinsky, (1992), and Turner et al., (1998) stated that mothers of children with CLP may not form as positive attachment with their children as do mothers of children without cleft. As a result, the children are placed at serious risk for a wide range of emotional problems. This has also influenced the children's speech and language ability through lack of early stimulation.

Another related explanation is that parents, in shaping their children's development of self-concept, provide the understanding of the impairment and its relevance. The self-concept of these children is influenced by the parents' ability to understand the disability and seek information about it, by loving and respecting the children, and by having a positive outlook towards their future. However, due to lack of knowledge on how to support the child, parents of the children in this study provided no support for their children in how to handle their cleft impairment and improve their speech and language skills. These children (and of course those with any other disability) could have achieved good self-concept if parents have had a positive outlook towards them.

To put it in a nut shell, the current study has found out that the children with repaired CLP have been going through various psychosocial problems. They often dealt with threats to their quality of life for multiple reasons including multiple surgeries, unsuccessful social relationships, and a range of psychological problems. In attempting to go about their daily lives, these children were susceptible to negative verbal commentaries and stares. The offensive remarks, unpleasant stares, stunned reactions, and outright avoidance that this group experienced have been traumatic.

5.2 Learning and achievement

The findings in this study showed that the cases had difficulties in speech and language, social, and academic performances. Studies on general intellectual functioning of individuals with cleft report IQ levels within the average range; but significantly lower

scores than non cleft control groups (McWilliams, Morris & Shelton, 1990; Broder, Richman & Matheson, 1998). On average, children with clefts appear to have mental abilities that are not different from those of other children (Shames, Wiig & Secord, 1998). However, a number of studies have reported increased frequency of speech and learning problems (Millard & Richman, 2001), as well as lower IQ scores for verbal and language deficiency compared to normative data (Turner et al., 1998). They also are more likely to have serious reading disabilities (Richman & Millard, 1997).

In this study, the data obtained about the cases' learning and achievement were only from the interview, FGD, and document review, which, in fact did not show the children's overall intellectual abilities. Besides, the teachers of these students have failed to give full account of information about the children's academic performance at school (there was no close supervision). However, it can be said that they had speech and language difficulties and their academic achievement, in case of Abdi and Alem, was consistently low as shown in their progress records. Therefore, such data must be interpreted with caution.

It has also been found out that a range of interacting factors contributed to the academic achievement of the children. These were general speech and language deficiency, facial disfigurement, expectations on the part of teachers, parents, and the children themselves, and socialization issues.

Early language delays may comprise a child's ability to communicate to others and may be a precursor of intellectual delays and difficulties in reading and writing. The cases in this study, due to their facial disfigurement in early stages (in the case of Abdi, and Saba) and the cleft of the palate (in case of Alem) might have been detached from their mothers, which has put them to have speech and language problems. Parents and caregivers play a vital role in a child's speech and language development. However, these children were deprived of such kind of attachment and therefore lacked early speech and language stimulation. Even after their first surgical repair, due to lack of information, these children did not receive any kind of speech and language therapy. (However, Helen received speech therapy but after her 3rd surgery, which was not effective). Speech and

language ability is necessary for adequate reading, and for overall academic competitiveness. Thus, it is believed that general speech and language difficulty have resulted in academic failure in especially two of the cases (Abdi and Alem).

Facial disfigurement did also seem to influence the academic performances of the children in this study. It was not clearly stated in the findings, though, the facial appearance of these children might have resulted in negative perception of their academic abilities, which resulted in lack of adequate educational stimulation, thus reducing their opportunity to maximize their cognitive potential. The children, as stated in FGD, have received little or no support from parents or teachers regarding their education. No teacher has reported that they tried to find out the children's actual problems. It has also been noted that parents did not expect much from the academic performances of these children. Moreover, the children were delayed in starting pre-school (after age 5) because of their language difficulty and two of them repeated grades in schools. These children, due to their facial differences, also have been responding to negative social responses by teachers and peers, which in the classroom environment, where independence and competitiveness are necessary for achievement, might have resulted in diminished academic performances.

Teachers of Helen and Alem perceived them as more withdrawn and inhibited in the classroom than other children. (This is consistent with parents' perception of the children at home). These children have learned to avoid situations which gave rise to negative responses by others. As a result, in the classroom environment, which requires a degree of independence and competitiveness for successful achievement, these inhibited children have been less successful than their peers. Kummer (2001), in support of this idea stated that children with a history of cleft may lack self-confidence reading aloud in class, which may adversely affect teacher evaluations and thus stigmatize students as reading disabled.

In contrast to others, teachers of Saba perceived her as attentive in the classroom. She participated well in all activities and seemed to ignore the negative responses of peers. She had also an outstanding performance in her studies. It is possible that children

employ benign defenses that enable them to reduce the impact of stigmatization, negative feedback, and social rejection. The point is on the meaning that Saba attributed to the symptoms. She viewed herself within a range of mild illness, rating cleft close to the concept of a headache (even if she experienced frequent teasing). This showed that she had perceived her disability in a benign way.

Parental literacy has also its own influence in the children's educational lives. Most of the parents in the study did not exceed in their education, while others were found to be non-educated. In consequence, they did not provide support and encouragement to their children to succeed in their education.

Generally, it can be said that, the children's learning and achievement were affected by a number of interacting variables, such as speech and language difficulty, facial disfigurement, lower expectations of teachers and parents, and social inhibition.

It is therefore imperative that assistance to these children and their families should be provided to maximize the possibility of the children functioning optimally.

CHAPTER SIX

6. Conclusion and Implications

6.1 Conclusion

Children with CLP usually experience multiple difficulties starting from birth. Their appearance and functional differences can potentially put their psychosocial functioning in question. Although surgical correction may help minimize breathing and feeding problems, and help to close the cleft of the lip and palate, it may not result in normalized appearance. Moreover, speech and language disabilities may remain after surgical correction. Therefore, children with repaired CLP are at risk of developing psychosocial difficulties. Findings of this study reveal that the functional and facial differences of these children have initiated overt teasing. Stigmatizing social responses have led them to negative self-perceptions of competence and physical attractiveness. This in turn has put them into developing psychosocial problems. It is therefore evidenced that the impact of teasing is a significant problem among the subjects.

Having a child with cleft has also put emotional stressors on the parents of these children. The parents were found to have experienced negative feelings towards their children during early stages due to the cleft condition they have and lack of appropriate knowledge on how to give care and support. This has resulted to have a negative influence on the parent-child relationship at early and later ages, which results to impact the psychosocial wellbeing of the children.

Even though minimal empirical data exists to explain the presence of learning disorder and underachievement in children with cleft, two points were raised in this study. First, speech and language delays or deficits preclude the acquisition of effective reading and academic skills, and competitiveness. The other is parents; teachers and the children themselves have lower academic expectations, which made them not be encouraged to excel in their academics. The evidence is less positive regarding achievement, language development, and parent and teacher expectations, which have affected level of aspiration in especially two of the subjects.

It would be incorrect to suggest that the results of this study indicate that all children with repaired CLP need psychological help. However, the overall findings showed that due to factors related to speech and language, facial appearance, and parental support and expectations, the children have been going through a range of internalizing and externalizing behaviors; internalizing behaviors being the elevated ones. Therefore, from the study, it can be concluded that teasing is a significant problem that leads the children to poor psychosocial functioning. Further, speech and language deficits, coupled with lower support and expectations in school outcome, lead the children to have lower educational aspirations and achievement.

Finally, it is important to point out that descriptive studies such as this one are valuable in beginning to improve understanding about which, areas of psychosocial experience are likely to be more problematic for children with CLP. As this study has limited evidence to suggest that children may encounter psychosocial problems as a result of having a CLP, more comprehensive studies, along with more varied methodological strategies are needed to ascertain this hypothesis. Of course, this study is not without limitation. A potential limitation of this study is that the subjects were 3 girls and a boy, due to availability problem, which might have influenced the findings as girls are usually more concerned with facial appearance than boys.

6.2 Implication of the study

The findings of this study call for early identification and treatment of the problems the children with repaired CLP encounter. Therefore, the following implications are worth mentioning:

1. Unlike the developed nations where CLP are managed by a multi-disciplinary team, treatment issues in Ethiopia are managed mainly by the pediatric and/or plastic surgeons in some hospitals. As a result, the defects are sometimes closed leaving patients with residual speech, hearing, facial structural, and therefore, psychosocial impairments. These problems have to do with the serious lack of specialized medical

personnel, ignorance and poverty. A child with cleft needs a range of specialists for successful rehabilitation, starting from birth till he/she is physically grown, typically around age 18 - 20. Therefore, there is a call for the government, medical associations, cleft care centers, and other NGOs for enhancing team approach that performs a comprehensive, coordinated evaluation of the whole child for successful intervention.

2. Parents should receive adequate information from health care professional after birth about the cleft problem and how to take care of the baby. The information should be given in a positive way; the positive prognosis for complete rehabilitation should be emphasized (with a rapid start during the first months). One of the most important responsibilities of the health care professionals working with families that have a child with cleft is providing emotional and medical support. If parents get the support they need, the psychosocial problems on both themselves and the children related to the cleft can be reduced.

Parents need support to be able to achieve successful parenting. Most parents are anxious about their child's ability to communicate and may have misconceptions about what to expect. By making their feelings of stress explicit as a part of what parents may have to learn to cope with, they can also be taught how to care for their children. An organized and planned effort, by MOLSA, MOH, and GO and NGO would facilitate the adaptation process so that the parents will be capable of successful parenting and to have a beneficial impact on the children. Furthermore, to facilitate language skills of the children, informing about how to stimulate age-appropriate language skills and making suggestions for activities to do at home can be helpful and reassuring.

3. A family is of paramount importance and indispensable for the proper psychosocial development of children in any context. The child's relationship with parents and other family members has an impact on the child's personality development. Therefore, the family environment is an important factor in the rehabilitation of a child with a cleft. Parents must give focus on the needs of the child – material and

psychosocial supplies that nourish and nurture their minds and spirits. It is important that parents talk to their child and encourage him or her to practice appropriate speech behaviors. It is important that the child feels successful about his or her speech.

4. There is an implication for the development and delivery of trainings for teachers and other school personnel. It is obvious that the needs of school personnel differ according to their roles and the degree to which they come in contact with children with CLP. Teachers had limited experiences with these children. Therefore, it is important to suggest for educational bureaus and schools that increased efforts on awareness programs and in-service training in the area of CLP are needed for school professionals. Such efforts may help prepare school personnel in meeting the needs of children with CLP.

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APPENDICES

APPENDIX A

ADDIS ABABA UNIVERSITY SCHOOL OF GRADUATE STUDIES DEPARTMENT OF SPECIAL NEEDS EDUCATION

Ethical consideration

(To be discussed with the research participants before conducting the interview or FGD)

Dear informants,

You are requested for your assistance with a research study that is being conducted by me in partial fulfillment of a Master Degree. The purpose of this research is to explore the psychosocial experiences of children with repaired cleft lip and/or palate. In order to maintain this, interview and FGD will be conducted with the participants. The interview and discussion will focus on your experiences and thoughts which you describe, with the following ethical considerations:

- Your personal identity will be kept anonymous and pseudonyms (if necessary) will be used in the report.
- You will have the option to refuse to answer any question and your responses will be kept strictly confidential.
- Tape recording is through permission, it will not be used for other purposes.
- Your decision to participate or not is completely voluntary.

Your cooperation is highly appreciated.

The researcher

APPENDIX B

INTERVIEW GUIDE FOR CHILDREN WITH REPAIRED CLP

I. DEMOGRAPHIC CHARACTERISTICS

- Sex
- Age
- Grade level
- Type of school
- Cleft condition
- Cleft medical history
- Living condition
- Family background

II. PSYCHOSOCIAL EXPERIENCES

1. How do you spend your spare time?
2. Do you have friends? If yes, how many?
 - 2.1 How often do you spend time with them?
 - 2.2 Does it make you happy to play and be with others? Why or why not?
3. How do you interact with parents, brothers and sisters (if any)?
4. How do you describe your cleft condition?
5. Do you discuss your health condition with your parents? If yes, how often?
6. Do you feel that having a cleft lip and palate has in any way affected your life?
Describe.
7. What treatments have you received for the cleft lip and palate?
8. What improvements have you seen in your speech and facial appearance?
9. Are you satisfied with your speech and appearance?
10. What feature(s) (if any) do you like or dislike about your appearance?
 - 10.1 Do you desire a change in your appearance?
11. How do you describe the attitude and treatment of parents, siblings, teachers, friends towards you?
12. How do such treatments make you feel?
13. Do you feel that having a cleft has made social interaction difficult for you? Describe.
14. What makes you happy?
15. What unfortunate times have you had?

- 15.1 Are there occasions when you are disappointed with people? Describe.
16. How do you cope up with the problems you face?
- 16.1 Who do turn to when you feel bad?
17. What would you like to become in the future?

III. SCHOOL EXPEREINCES

1. Do you attend school regularly? If no, what is the reason?
2. How do you get along with classmates in and out of your classroom?
3. What problems have you encountered during your stay in the class/school?
4. How do you perceive your performance academically?
5. In what ways do you participate in class activities?
6. Describe your favorite subject.
7. What areas do you think you need support?
8. What supports have you received form teachers?
9. What do you expect in your school outcome?

APPENDIX C

INTERVIEW GUIDE FOR MOTHERS OF CHILDREN WITH REPAIRED CLP

I. DEMOGRAPHIC CHARACTERISTICS

- Age
- Educational background
- Economic background
- Living condition (marriage)
- Cleft history
- Current occupation

II. PSYCHOSOCIAL FUNCTIONING OF THEIR CHILDREN

1. Describe your early experience of having a child with cleft lip and/or palate.
2. Describe your child's medical history.
3. What did your early relationship with your child look like?
 - 3.1 How does your current interaction with the child look like?
4. Do you feel having a child with cleft has brought any change (in any way) to your life, and the family's life as a whole? If yes, describe.
5. How does your child behave in the house? Describe.
 - 5.1 What do you think are the factors that contribute to the child's such behaviors?
6. How and with whom does your child spend his/her leisure time?
7. How does your child get along with siblings (if any)?
8. What kind and how much support does your child need from you?
 - 8.1 How do you support him/her?
9. What do you think are the neighbors' attitude towards you and your child?
- 10 What is your expectation regarding your child's health and education outcome?

APPENDIX D

INTERVIEW GUIDE FOR TEACHERS OF CHILDREN WITH REPAIRED CLP

I. DEMOGRAPHIC CHARACTERISTICS

- Sex
- Age
- Educational background
- Special education training
- Teaching experience

II. ABOUT THE CHILDREN WITH CLP

1. Are you aware of the condition of the child?
2. How does the child interact with peers in and out of the class?
 - 2.1 How does the general social behavior of the child compare with that of others?
3. How does the child behave in the class?
 - 3.1 What do you think are the reasons for such kinds of behavior?
4. What kind of difficulties do you think the child exhibits?
5. What difficulties have you experienced working with such children?
6. Does the child attend school regularly? If no, what is the reason?
7. How do you think the academic potential of the child compares with the others?
8. In what areas does he need support?
 - 8.1 How do you provide support to him/her in or out of the class?
9. What do you expect in relation to the child's education?
10. What additional information do you need to serve the child adequately?

APPENDIX E

FGD GUIDE FOR MOTHERS OF CHILDREN WITH REPAIRED CLP

I. DEMOGRAPHIC CHARACTERISTICS OF MEMBERS

- Age
- Educational background
- Occupation
- Child's condition

II. MAJOR ISSUES OF DISCUSSION

- Children's interaction with the family
- Children's interaction with the neighbors
- General behavioral manifestation of children at home
- Kinds of support rendered to the children
- Educational aspirations of the children and parents expectations
- Parents' and children's satisfaction and expectation of surgical treatment

APPENDIX F

FGD GUIDE FOR TEACHERS OF CHILDREN WITH REPAIRED CLP

I. DEMOGRAPHIC CHARACTERISTICS OF MEMBERS

- Age
- Educational background
- Position
- Teaching experience

II. MAJOR ISSUES OF DISCUSSION

- Awareness of cleft condition
- General perception of the children with CLP
- Social interaction with classmates
- Behavioral manifestations in the class
- Academic performance and achievement
- Support needed and provided
- Any difficulties they exhibit

AMHARIC VERSION OF INTERVIEW QUESTIONS AND FGD ITEMS

አዲስ አበባ ዩኒቨርሲቲ
የድህረ ምረቃ ትምህርት ፕሮግራም
የልዩ ፍላጎት ትምህርት ክፍል

የቃለ-መጠይቁ ዋና ዓላማ

ይህ ቃለ-መጠይቅ የተዘጋጀው የሁለተኛ ዲግሪ ማሟያ ዕሉፍ ለማዘጋጀት የሚረዳ መረጃ ለማሰባሰብ ታስቦ ነው። ስለዚህ በመቀጠል በዝርዝር ለሚቀርቡት ጥያቄዎች ተገቢውን ምላሽ በመስጠት የጥናቱን ሥራ የተሟላ በማድረግ እንዲተባበሩ በትህትና እጠይቃለሁ።

በቃለ-መጠይቅ ወቅት፡

- የሚሰጡት መረጃና ማንነትዎ በሚስጥር የሚያዝ ይሆናል።
- መቅረፁ-ድምፅ መጠቀም በፈቃድዎ ይሆናል።
- በማንኛውም ጊዜ በጥናቱ ውስጥ ያለዎትን ተሳትፎ በፈቃድዎ ማቋረጥ ይችላሉ።

ስለትብብርዎ በቅድሚያ አመሰግናለሁ።

አዘጋጁ

ቅጽ ሰ

ከንፈር/ላንቃ መሰንጠቅ ለደረሰባቸው ልጆች የተዘጋጀ ቃለ-መጠይቅ

I. የግል ታሪክ

- | | |
|--------------|-----------------|
| - ያታ | - የከንፈር/ላንቃ ሁኔታ |
| - እድሜ | - የጤና ሁኔታ |
| - የክፍል ደረጃ | - የእናገር ሁኔታ |
| - የት/ቤት ዓይነት | - የቤተሰብ ሁኔታ |

II. ማህበራዊና ስነልቦናዊ ሁኔታ

1. ትርፍ ጊዜህን/ሽን እንዴት ታሳልፋለህ/ታሳልፈዋለሽ?
2. ጓደኞች አሉህ/ሽ? ካሉ ስንት?
- ምን ያህል ጊዜ አብራችሁ ታሳልፋላችሁ?
- ከሌሎች ጋር መጫወትና አብሮ መሆን ያስደስትዋል/ሻል? ለምን?
3. ከቤተሰብህ/ህ ጋር እንዴት ታሳልፋለህ/ህ?
4. የከንፈርህን/ሽን ሁኔታ እንዴት ትገልጽዋለህ/ትገልጫለሽ?
5. ከወላጆችህ/ሽ ጋር ስለጤናህ/ሽ ሁኔታ ትወያያላችሁ? መልሱ አዎ ከሆነ ምን ያህል?
6. የከንፈር/ላንቃ መሰንጠቅ በህይወትህ/ሽ ላይ ያመጣው ለውጥ አለ? አብራራ/ራ::
7. ለከንፈር/ላንቃ መሰንጠቅ የወሰድከው/ሽው ህክምና ምንድን ነው?
8. ከህክምና በኋላ በገፅታህ/ሽ እና በንግግርህ/ሽ ላይ የታየ ለውጥ ምንድን ነው?
9. በፊት ገፅታህ/ሽ እና በንግግርህ/ሽ ደስተኛ ነህ?/ሽ?
10. ከፊት ገፅታህ/ሽ የምትወደው/ጂው ወይም ቅር የሚልህ/ሽ ነገር ምንድን ነው?
 - 10.1 በፊት ገፅታህ/ሽ ላይ ለውጥ የሚያስፈልግ ይመስልዋል/ሻል?
11. የቤተሰቦችህን/ሽን፣ የአስተማሪዎችህን/ሽንና የጓደኞችህን/ሽን በአንተ/ቺ ላይ ያለ አመለካከት እንዴት ትገልጽዋለህ/ትገልጫለሽ?
 - 11.1 ከላይ በጠቀስኳቸው/ሻቸው አመለካከቶች ምን ይሰማሃል/ሻል?
12. የከንፈርህ/ሽ/የላንቃህ/ሽ መሰንጠቅ በማህበራዊ ኑሮህ/ሽ ላይ የመጣው ችግር አለ? ካለ አብራራ/ራ::
13. ምን ማድረግ ያስደስትዋል/ሻል?
14. የተከፋህበት/ሽበት ጊዜ ካለ አብራራ/ራ::
15. ከሰዎች ጋር ያልተስማማሽበት ጊዜ አለ? ካለ አብራራ/ራ::
16. የሚገጥሙህን/ሽን ችግሮች እንዴት ትወጣቸዋለህ/ለሽ?
 - 16.1 መጥፎ ስሜት በሚሰማህ/ሽ ጊዜ ከምን ጋር ትወያያለህ/ሽ?
17. ወደፊት ምን መሆን ትፈልጋለህ/ትፈልጊያለሽ?

III. የትምህርት ሁኔታ

1. ትምህርትህን/ሽን በአግባቡ ትከታተላለህ/ትከታተያለሽ? ካልሆነ ለምን?
2. በክፍል ዓደኞችህ/ሽ ጋር ያለህ/ህ ግንኙነት ምን ይመስላል?
3. በክፍል/በትምህርት ቤት ውስጥ ያጋጠሙህ/ሽ ችግሮች አሉ? ካሉ አብራራ/ራ።
4. በትምህርትህ/ሽ ላይ ያለህን/ሽን ችሎታ እንዴት ትገልጻለህ/ትገልጫለሽ?
5. በክፍል ውስጥ ያለህ/ሽ ተሳትፎ ምን ይመስላል?
6. የምትወደው/ጂው የትምህርት ዓይነት ምንድን ነው? ለምን?
7. በየትኛው የትምህርት ዓይነት እገዛ ትፈልጋለህ/ትፈልጋለሽ?
8. ከመምህራኖችህ/ሽ የተደረገልህ/ሽ እገዛ አለ? ካለ አብራራ/ራ።
9. ከትምህርትህ/ሽ ምን ትጠብቃለህ/ትጠብቂያለሽ?

ስእናቶች የተዘጋጀ ቃለ-መጠይቅ

I. የግል ታሪክ

- ዕድሜ
- የትምህርት ሁኔታ
- የኢኮኖሚ ሁኔታ
- የኑሮ ሁኔታ
- የከንፈር/ላንቃ መሰንጠቅ ሁኔታ
- የሥራ ዓይነት

II. የልጆች ማህበራዊና ስነልቦናዊ ሁኔታ

1. ከንፈር/ላንቃ የተሰነጠቀ ልጅ መውለድ ምን ይመስላል? አብራሩ::
2. የልጅዎን የጤና ሁኔታ አብራሩ::
3. ከልጅዎ ጋር የቀድሞ ግንኙነትዎ ምን ይመስል ነበር?
- ከልጅዎ ጋር አሁን ያለዎት ግንኙነት ምን ይመስላል?
4. ከንፈር/ላንቃ የተሰነጠቀ ልጅ መውለድ በእርስዎና በቤተሰብዎ ህይወት ላይ ያመጣው ለውጥ አለ? ካለ አብራሩ::
5. ልጅዎ በቤት ውስጥ ባህሪው/ዋ ምን ይመስላል?
 - 5.1 ከላይ ለጠቀሱት ባህሪ መኖር ተፅዕኖ ያሳደሩ ነገሮች ምንድን ናቸው ብለው ያስባሉ?
6. ልጅዎ ትርፍ ጊዜውን/ዋን የሚያሳልፈው/የምታሳልፈው እንዴትና ከማን ጋር ነው?
7. ልጅዎ ከወንድሞችና ከእህቶች ጋር ምን ዓይነት ግንኙነት አለው/አላት?
8. ልጅዎ ከእርስዎ የሚፈልገው/የምትፈልገው እገዛ ምንድን ነው? አብራሩ::
- በምን ዓይነት መልኩ እገዛ ያደርጉለታል/ያደርጉላታል?
9. የጎረቤቶችዎ በልጅዎ ላይ ያላቸው አመለካከት ምን ይመስላል?
10. ከልጅዎ የጤናና የትምህርት ሁኔታ ምን ውጤት ይጠብቃሉ?

ስመምህራን የተዘጋጀ ቃለ-መጠይቅ

I. የግል ታሪክ

- ፆታ
- ዕድሜ
- የትምህርት ደረጃ
- የልዩ ፍላጎት ትምህርት ስልጠና
- የማስተማር ልምድ

II. የተማሪዎች ማህበራዊ፣ ስነልቦናዊና ትምህርትዊ ሁኔታ

1. ስለተማሪው/ዋ የጤና ሁኔታ ምን ግንዛቤ አለዎት?
2. በክፍልና ከክፍል ውጪ ተማሪው/ዋ ከሌሎች ጋር የሚያደርገው/የምታደርገው ግንኙነት ምን ይመስላል?
- የተማሪው/ዋ ማህበራዊ ሁኔታ ከሌሎች ጋር ሲነፃፀር ምን ይመስላል?
3. ተማሪው/ዋ በክፍል ውስጥ ምን ዓይነት ባህርይ ያሳያል/ታሳያለች?
- ከላይ ለጠቀሱት ባህሪያት መኖር ተፅዕኖ ያሳደሩ ነገሮች ምንድን ናቸው?
4. በተማሪው/ዋ ላይ ያዩት ችግሮች ምንድን ናቸው?
5. እነዚህን ልጆች በማስተማር ሂደት ላይ ያጋጠምዎት ችግሮች አሉ? ካሉ አብራሩ።
6. ተማሪው/ዋ ትምህርቱን/ቷን በሚገባ ይከታተላል/ትከታተላለች? ካልሆነ ለምን?
7. የተማሪው/ዋ አጠቃላይ የትምህርት ችሎታ ከሌሎች ጋር ሲነፃፀር ምን ይመስላል?
8. ተማሪው/ዋ በምን የትምህርት ዓይነቶች እገዛ ይፈልጋል/ትፈልጋለች?
- በምን ዓይነት መልኩ እገዛ ያደርጉለታል/ያደርጉላታል?
9. ከተማሪው/ዋ ትምህርት ምን ውጤት ይጠብቃሉ?
10. እርስዎ ተማሪውን/ዋን በአግባቡ ለመርዳት ምን ዓይነት መረጃ ያስፈልግዎታል?

ቅፅ ሆ

ለእናቶች የተዘጋጀ የቡድን ውይይት

I. የግል ታሪክ

- እድሜ
- የትምህርት ደረጃ
- የሥራ ዓይነት
- የልጅ ከንፈር/ላንቃ ሁኔታ

II. ዋና ዋና የመወያያ ሃሳቦች

- ልጆች ከወላጆቻቸው ጋር ያላቸው ግንኙነት
- ልጆች ከጎረቤቶቻቸው ጋር ያላቸው ግንኙነት
- ልጆች በቤት ውስጥ የሚያሳዩአቸው ባህሪያት
- ለልጆች የተደረጉ እገዛዎች
- ልጆች ለትምህርት ያላቸው ፍላጎት/ችሎታ እና የወላጆች አስተያየት
- ወላጆች በቀዶ ጥገና ላይ ያላቸው እርካታና የሚጠብቁት ውጤት

ቅፅ ፭

ስመምህራን የተዘጋጀ የቡድን ውይይት

I. የግል ታሪክ

- እድሜ
- የትምህርት ደረጃ
- የሥራ ዓይነት
- የማስተማር ልምድ

II. ዋና ዋና የመወያያ ሃሳቦች

- ስለተማሪዎቹ የክንፈር/ላንቃ ሁኔታ ግንዛቤ
- ስለተማሪዎቹ ያላቸው አጠቃላይ ግንዛቤ
- ተማሪዎቹ በክፍል ውስጥ ከሌሎች ጋር ስላላቸው ግንኙነት
- ተማሪዎቹ በክፍል ውስጥ የሚያሳዩአቸው ባህሪያት
- የተማሪዎች ትምህርት ክትትልና ውጤት
- ተማሪዎች የሚያስፈልጓቸውና የተደረጉላቸው እገዛዎች
- ከተማሪዎቹ ጋር በተያያዘ የተከሰቱ ችግሮች

Declaration

I, hereby declare that this Thesis is my original work and has not been presented for degree in any other Universities and relevant sources of materials have been duly acknowledged.

Name Tehetena Woldetensae

Signature 

Date of Submission 5th July 2010

This Thesis has been submitted for examination with my approval as University advisor.

Name Alemayehu Teklemariam

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Date of Approval _____