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Parents' Experiences of Having a Child with Cleft Lip and Palate in the West Bank/ Palestine: A Qualitative Study

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Dedication

I dedicate this work to the one with sincere prayers and a pure spirit. To the soul of my beloved grandmother, this achievement is first and foremost for her; may God have mercy on her.

To the source of safety and support that surrounds me, to the greatest of people, to the one who struggled for my comfort and success, my beloved father.

To the foundation of my strength and my existence in life, to the one who gave me hope — my beloved mother.

To the unknown soldier in my life, my big supporter, Nancy.

To those whose presence in my life I am grateful for, my siblings Ibrahim, Omar and Hamza.

To the one in whose eyes I see the reflection of my love, my beloved grandfather.

To my beloved grandparents, who hold a special place in my heart

To who came into my life to complete this beautiful work with me, Wael.

To my beloved family, whose presence fills my life with joy — Aunt Maha, Ruba, Zaid, Bashar, Jamila, and Taleen.

To my dear ones, Fatima and Abd.

To my dear friends who supported me throughout my academic journey.

I dedicate this work to all children with cleft lip and palate in Palestine.

I dedicate this work to the parents of the children who shared their experiences with me and placed their trust in me.

Declaration

I certify that this thesis submitted for the degree of master, is the result of my own research, except where otherwise acknowledge, and that this thesis (or any part of the same material) has not been submitted for a higher degree to any other university or institution.

Signed: 

Aysheh Mohammad Ibrahim Abbad

Date: 3/1/2026

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Researcher: Aysheh Mohammad Abbad

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Abstract

Background: Cleft lip and palate (CLP) are the most common congenital anomalies affecting the mouth and related structures. Children born with congenital craniofacial defects, as (CLP), require long-term, multidisciplinary therapeutic approaches, which makes parents experience a range of emotions, including helplessness, guilt, uncertainty, pain, and even depression.

Aim: This study aimed to explore the lived experiences of parents who have children with cleft lip and palate in Palestine

Methods: A qualitative descriptive approach was utilized to investigate the experiences of parents with children who have cleft lip and palate in the West Bank/Palestine. Purposive sampling was employed to recruit these parents through the Operation Smile organization in Hebron. Data collection involved conducting semi-structured, face-to-face interviews with the parents, which continued until data saturation was achieved. The interview guide comprised five main questions, along with supplementary probe questions. Eleven interviews were conducted, audio-recorded, transcribed verbatim, and analyzed thematically.

Results: The experiences of parents with children who have cleft lip and palate in Palestine are profoundly challenging and can be categorized into three major themes and eight subthemes. The three major themes included facing the hardship with dedication to their child care, concerns during the complex surgical journey, and social stigma and gaps in family and healthcare support. Overall, these findings provide an in-depth understanding of parent adaptation, resilience, and coping within Palestinian sociocultural and structural settings.

Conclusion: Parents of children with cleft lip and palate in Palestine face significant emotional, social, and practical difficulties influenced by cultural, economic, and healthcare system limitations. These findings highlight the necessity for family-oriented, culturally attuned support services and enhanced professional guidance during the treatment process.

Keywords: Cleft Lip, Cleft Palate, Parents' Experiences, Operation Smile Institution, Palestine.

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List of Abbreviations

Abbreviation	Meaning
CLP	Cleft Lip & Palate
CL	Cleft Lip
FCC	Family-Centered Care
SMCP	Submucous Cleft Palate
NICU	Neonatal Intensive Care Unit
VCFS	Velocardiofacial Syndrome

Chapter One

Introduction

1.1 Introduction

Cleft lip and palate (CLP) are the most common congenital anomalies affecting the mouth and related structures. These conditions can occur independently or in conjunction with other syndromes (Morsi et al., 2023). Cleft lip (CL) arises from the failure of fusion between the frontonasal and maxillary processes, leading to a cleft of varying severity that can extend through the upper lip, alveolus, and nasal floor (Vyas et al., 2020). Conversely, a cleft in the hard and soft palate is the result of the failure of fusion of the palatal shelves of the maxillary processes, commonly referred to as cleft palate.

The global prevalence of cleft lip and palate (CLP) shows significant variation across different regions, with an estimated occurrence of 0.45 per 1,000 live births (Putri et al., 2024). Despite this variation, the overall incidence remains notable. Various environmental and genetic risk factors associated with CLP have been identified, including parental age, income, educational attainment, and gender (Putri et al., 2024). Other contributing factors include Consanguinity, which is defined as marriages between relatives (Rochmah et al., 2024). Lower rates of prenatal folic acid supplementation (Kruppa et al., 2022) and the ongoing use of certain medications during pregnancy, such as anticonvulsant drugs (Rezaallah et al., 2019), are important risk factors. In Palestine, the prevalence of CLP is estimated at 1.01 cases per 1,000 live births, with 63 percent of affected infants being male (Shrestha et al., 2022).

Children born with congenital craniofacial defects, such as cleft lip and palate (CLP), require long-term, multidisciplinary therapeutic approaches. These approaches include dental, surgical,

dietary, medical, speech, ethical, and psychosocial interventions (Adawy et al., 2023). Consequently, the birth of a child with CLP can create ongoing anxiety for both the affected children and their families (Imani et al., 2020). Families often encounter a range of challenges, including psychosocial and economic difficulties. Additionally, they may face social stigma or taboos related to having a child with congenital abnormalities that affect speech, eating, and even teething (Zhang et al., 2023). The psychosocial burden on parents begins at the time of birth or upon receiving a CLP diagnosis and persists throughout the entire treatment process (Opriș et al., 2022).

Parents of children with CLP may experience a range of emotions, including helplessness, guilt, uncertainty, pain, and even depression. These parents are urged to collaborate in sharing responsibilities and making significant decisions concerning their child's care (Morsi et al., 2023). Recently, the approach to caring for children with CLP has been shifting toward family-centered care (FCC), which emphasizes the involvement of both parents and children in the care process and decision-making (Bennett et al., 2020). This model of care shows how important it is for patients, their families, and healthcare providers to work together and be partners. Key elements of Family Centered Care (FCC) include recognizing and valuing the diverse perspectives of patients and families, fostering open communication, and integrating their values and preferences into the decision-making process to ensure the delivery of comprehensive and standardized care (Pfeifauf et al., 2020).

The existing literature on children with cleft lip and palate (CLP) and their families in the unique Palestinian context is limited. The experiences of families and the responses of parents to diagnoses, childbirth, and the overall treatment process are not well understood. To gain insight into these aspects, it is essential to gather information about parents' experiences, as well as their knowledge, feelings, and needs throughout the caregiving process. Therefore, this study is meant to examine the experiences of parents who have a child with cleft lip and palate in Palestine.

1.2 Problem Statement

Cleft lip and palate (CLP) are complex congenital conditions that require prolonged and multidisciplinary treatment. They represent the most common craniofacial anomalies affecting the oral cavity and associated structures (Albustani et al., 2022). Having a child with CLP can significantly impact both the physical and psychosocial well-being of children and their families, as parents often encounter considerable challenges in meeting their child’s needs while enduring social, economic, and psychological pressures (Morsi et al., 2023; Arias-Urueña et al., 2023; Aslan et al., 2018).

Although previous research has primarily concentrated on clinical aspects such as prevalence, treatment options, feeding difficulties, and quality of life (Salari et al., 2022; Sander et al., 2025; Opriș et al., 2022), limited attention has been given to parents' lived experiences, particularly within the Palestinian context, where cultural and structural healthcare challenges may exacerbate their burden. Therefore, an in-depth exploration of parents’ experiences in

raising children with CLP is essential, as these experiences have significant implications for caregiving practices, treatment adherence, and overall child outcomes. How parents emotionally respond, provide care, and cope with the associated physical and psychosocial demands remains insufficiently understood. Gaining insight into these emotional and practical realities is crucial, as many parents experience persistent anxiety, stress, and ongoing concerns regarding their child's health, treatment trajectory, and future well-being.

In Palestine, approximately 40% of marriages are consanguineous, a factor that increases the likelihood of congenital anomalies among offspring, including CLP (Zawahrah et al., 2019). Consequently, many families face substantial emotional distress, including anxiety, fear, uncertainty, and stress related to their child's health status, surgical journey, and long-term quality of life. Cultural expectations, limited availability of specialized healthcare services, financial pressures, and insufficient psychosocial support may intensify these challenges. Despite this considerable emotional and social burden, parents' lived experiences remain largely underexplored.

Understanding parents' emotions and coping strategies is essential for guiding healthcare professionals and developing culturally appropriate support interventions. Addressing this knowledge gap is crucial to inform family-centered care approaches, enhance parental support, and ultimately improve health and psychosocial outcomes for children with cleft lip and palate and their families. Therefore, this study seeks to answer the following main research question that defines the problem under investigation:

"How do parents experience having children with cleft lip and palate in Palestine?"

1.3 Significance of the study

Cleft lip and palate are significant congenital anomalies that affect a child's overall health and development. Children with these conditions often face feeding and breathing difficulties, delayed speech and language development, and an increased risk of ear infections, hearing loss, and dental problems (Mossey, 2023). Therefore, the crucial role of these children's parents in promoting the children's health should not be neglected. In the Palestinian context, little is known about Parents' experiences when having a child with cleft lip and palate. Their knowledge, attitudes, and health-seeking behaviors are not well understood.

This study explores the challenges faced by parents of children with cleft lip and palate, focusing on social issues, caregiving responsibilities, economic difficulties, and psychological experiences related to the stigma associated with having a child with this condition. Additionally, the study may help parents, policymakers, and communities identify gaps or barriers that could hinder the implementation of essential therapeutic measures. Furthermore, it emphasizes the experiences of parents caring for a child with a facial condition (cleft lip and palate), which may encourage parents to share responsibilities and tasks in their child's care.

1.4 Aim of the Study

This study aimed to explore the lived experiences of parents who have children with cleft lip and palate in Palestine

1.4.1 Specific Objectives

- To describe the lived experiences of parents of children with CLP.
- To explore parents' perceptions about having a child with CLP.
- To describe psychosocial, economic, and therapeutic challenges that parents of children with CLP might face.

1.5 Research Questions

The research's main question is "**How do parents perceive and experience the status of their children with cleft lip and palate in Palestine?".** Thus, the sub-questions of the study are as follows:

- How do parents perceive the conditions and aspects related to their children with CLP children in Palestine?

- How do parents experience their CLP children's psychological, social, economic, and medical status?

- What are the challenges faced by the parents of children with cleft lip and palate?

1.6 Feasibility of the Study

This study is considered feasible due to its subject, which has not been investigated in Palestine yet. This establishes a track for future research in Palestine taking into consideration other variables and issues related to children with CLP. In addition, this study has practical feasible means of providing results that might benefit healthcare institutions toward improvements in their healthcare services.

Chapter Two

Literature Review

2.1 Introduction

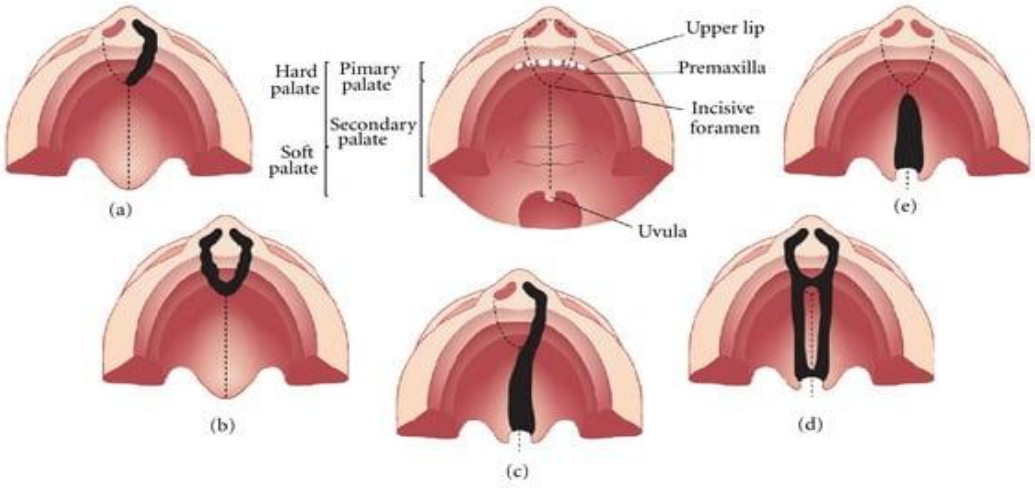
This chapter displays a review and a presentation of the previous studies related to the subject of the current study, in addition to the summary of the literature review, and then the conceptual definitions of the terms used in this study.

2.2 Cleft Lip & Palate

A cleft of the hard and/or soft palate results from the failure of the palatal shelves of the maxillary processes to fuse together. Clefts arises during the fourth developmental stage. The precise locations at which the fusion of different facial processes failed to occur determine where they appear, and this in turn depends on the stage of embryologic life at which some interference with development occurred (Salari et al., 2022).

A cleft lip is an opening or gap in the upper lip that can be as tiny as a notch or as wide as an orifice that juts into the nose. The front or rear of the palate may be affected by a cleft palate, which is a gap or opening in the roof of the mouth that varies in size. A cleft lip is a congenital defect that affects the primary palate which is located before the incisive foramen. The primary palate may happen either unilaterally, bilaterally, fully, or partially (Gulomovna & Kizi, 2023).The primary palate buildings are composed of structures preceding the incisive foramen. These structures include the upper lip, premaxillar which is a triangle-shaped bone harboring the alveolar ridge. The secondary palate is made of structures located behind the incisive

foramen. Some of these structures include the uvula, velum, soft palate, and hard palate (Gulomovna & Kizi, 2023).



Resource: Brito, L. A., Meira, J. G. C., Kobayashi, G. S., & Passos-Bueno, M. R. (2012). Genetics and management of the patient with orofacial cleft. Plastic Surgery International.

Palate clefts are submucous or superficial. An oral observation shows an apparent aperture between the palate and the mouth floor that is referred to as an overt palatal cleft. The submucous cleft palate (SMCP) has an intact oral mucosa; however, the underlying velar muscle mass has failed to be attached at the centre. The cleft is not easily visible and often it disappears when examined intraorally. The three signs of an SMCP include a bifid uvula, a bony notch felt at the margin of the soft palate, and zona pellucida, or a blue discoloration brought about by the diastasis of levator veli palatini muscle in the midline (Paradowska-Stolarz et al., 2022).

Another type of SMCP, an occult (hidden) SMCP, does not produce any oral symptoms, but may only be diagnosed through magnetic resonance imaging or by direct observation in the operating room. The nasal endoscopy may show a flat or concave nasal surface of the palate may indicate that there is a possible diastasis or absent muscle of the palate, musculus uvulae (Babai and Irving, 2023).

The number of cases of orofacial clefts in the world amounted to 237, 258 cases (95% CI: 155, 983-364, 211 cases) in 1990, and since 2019, it was 192, 708 (95% CI: 125, 226-294, 619 cases), a 19% decrease (1990 cut-off -2019 Similarly, it was estimated that the global Age-Standardized Rate of Incidence of Orofacial Clefts dropped at 2.98 (95% CI: 1.93–4.55) per 100,000 in 2019 as compared to 3.61 (95% CI: 2.37–5.54) per 100,000 in 1990 at an estimated annual percentage change of -0.69 (95% CI: -0.81 to -0.58) (Wang et al., 2023).

One of the most common congenital defects is cleft lip and palate(Alaviyan, 2025). This condition affects one baby out of every 700 births. According to a systematic study by Salari et al. in 2022, the rates of cleft lip, cleft palate, and cleft lip and palate were 0.33, 0.3, and 0.45 per 1000 live births, respectively. An epidemiological study in Iran reported 1.03 cases of cleft lip and palate per 1,000 live births. Although the exact cause of cleft lip and palate is unknown, teratogenic agents and genetic predictors appear to be internal and external variables that contribute to the disorder's occurrence.

Many health issues, such as speech and feeding difficulties, middle ear complications, hearing loss, and dental abnormalities, are common in children with this genetic condition, particularly in cases of cleft palate (Almeida et al., 2016). While these challenges often lead to satisfactory functional and aesthetic outcomes, they necessitate complex collaborative therapies, multiple referrals, and surgical procedures that begin shortly after birth (Osses & Spuler, 2021).

2.3 Feeding mechanisms

When the feeding bottle with its soft nipple is placed in the newborn's mouth, the mechanism of feeding begins. The infant compresses the nipple to release the milk, then suction creates a negative pressure to keep the milk flowing. In order to prepare and regulate the food for swallowing, the infant's tongue works in tandem with the oral and perioral muscles as well as the hard and soft palate (Alirhayim & Mohammed, 2022).

Due to their incapacity to generate the suction required for efficient breastfeeding or bottle feeding, infants born with this syndrome frequently face severe feeding challenges. Nasonal regurgitation causes the avoidance of direct breastfeeding during this period and bottle or palatal spoon-feeding is encouraged. Because breastfeeding is associated with the progression of oral musculature, feeding problems can hamper normal growth and disrupt connection processes (Pawar et al., 2025). Additionally, there is also a risk that milk can enter the nasal passages because of the gap between the oral canals and the nasal ones, increasing the threat of aspiration and endangering the nutritional intake of the baby (Mohapatra et al., 2023).

Feeding position

Many research efforts have been dedicated to the significance of the posture of the infant during the feeding process, which suggests that this can be a decisive aspect in the process of assisting CLP newborns with feeding (Fadnis, 2023). To successfully carry out the feeding process, the CLP newborn should be placed in the most favorable way. To influence the gravity role in posterior fluid flow and swallowing, it is usually dependent on having the correct head support, with the arms in front, the trunk in the mid line with the hips flexed, and at least 60 degrees upright (Pawar et al., 2025).

Palatal obturators

To enhance the proficiency of CLP infants in initiating intraoral negative pressure in the feeding process, as well as reduce food regurgitation into the respiratory tract, a prosthetic device known as a palatal obturator is crafted in an attempt to isolate the oro-nasal cavities in such infants (Ragulakollu et al., 2020).

The appliance is an infant feeding obturator when the cleft baby cannot take food in case of breast or bottle-based feeding. There are no restrictions. Larger palatal abnormalities prevent infants from producing the same amount of suction as minor faults. Before undergoing surgery to fix the cleft lip and/or palate, the baby must consistently gain weight. Feeding obturators will improve the infant's ability to suction and help provide proper nourishment (Ueki et al., 2023).

Blocking out the palatal malformation is the aim of the obturator. This makes it possible for the baby's tongue to express the liquid by applying the right amount of force to the nipple of the bottle. There must be space left for the newborn to breathe while eating, even if the palate cleft must be shut off. Palatal defect sealing permits appropriate sucking and keeps the tongue from protruding into the defect (Reddy et al., 2023).

Types of feeding obturators

The undercut portions of the palate are sometimes lined with soft, elastic material that is subsequently molded to the fault area. Feeding obturators are typically composed of auto-or heat-polymerized acrylic resin (Alirhayim & Mohammed, 2022).

Obturators take several intricate procedures to fabricate because they are held in place by intricate extraoral devices or soft materials that engage the undercuts. In an effort to make the fabrication process simpler, less costly, and more effective, numerous authors have embraced the idea that the feeding appliance can be made from vacuum-formed materials made of ethylene-vinyl soft materials that are frequently used to make mouth guards for athletes. This process can be completed quickly, safely, and without putting the infant in danger (Pawar et al., 2025). Furthermore, the obturator can be delivered concurrently with the impression-making session, typically within 45 minutes of the patient's attendance at the dental office (Mohapatra et al., 2023).

Benefits of feeding obturator

The effectiveness of feeding obturators has been demonstrated. Choking, nasal discharge, and the amount of time needed to complete the feeding session can all be decreased with obturators. The parent's noted reduction in anxiety during feeding was very remarkable. Reduced feeding time, increased volume intake, and the infant's healthy development were all associated. Breastfeeding mothers who use an obturator have higher milk volume intake and reduced baby fatigue. One of the many benefits of palatal obturators for children with cleft lip and palate is

that they give a sturdy, sound palatal vault that allows the baby to release milk and squeeze their nipple (Ragulakollu et al., 2020). The baby has a higher probability of creating the negative pressure required to keep the liquid flowing when the obturators are present during the feeding procedure. In addition to the normal feeding process that supplies the infant's body with the necessary nutrition and elements for normal growth and development, obturators may play a crucial role in the development and growth of the palate, jaws, and associated musculature by keeping the tongue in its normal position and preventing it from entering the defect area, which are key factors in normal stimulation of the muscles and jaw bones for growth (Fadnis, 2023).

Also, palatal obturators are important in aiding in decreasing the duration of time spent on feeding time, enhancing the volume of milk consumed, reducing the respiratory tract and nasal cavity infection rates and cases of otitis media through the prevention of choking and the regurgitation of milk into the nasal cavity (Alirhayim and Mohammed, 2022).

Baton with standard acrylic velar extension- Type I

An advanced modified OwE, the Baton with standard acrylic velar or dorsal extension is fastened to the forehead with an increased velar extension size and an anterior pre-formed facial-extension wire framework. Neonates with and without a cleft of the hPsP (in ±88%) or sP (in ±12%), staging with glossoptosis and apnea, are treated with this modified obturator. Neonates with PRS are the main users of this gadget. Because the maxillary sulci are too shallow for retention, the additional retention applied to this facio-oro-pharyngeal device to the forehead is necessary to ensure the additional tongue force and movement applied to this posterior acrylic extension (Prinsloo & Bütow, 2024).

This kind of obturpaedic device aims to overcome glossoptosis with upper airway blockage by releasing the tongue, which is mostly a microglossia, from the cleft into a more anterior position and preventing it from occluding against the naso-oro-pharynx wall. This is especially crucial for patients with PRS and occasionally other syndromic cleft and non-cleft conditions. Anaesthesia and nursing are still at risk during this pre-reconstruction phase if a glossopexia, neonatal mandibular distractions, or tracheostomy are chosen as surgical alternatives. Although the acrylic velar extension is a conventional design, its width can be narrowed or shortened after it is manufactured. It is not possible to alter the superior-inferior dimension. After placement in relation to the tongue's posterior surface, modifications to this extension are subjective (Reddy et al., 2023).

Baton with modified velar with wire extension and small acrylic foot plate-Type II

With two wires firmly and securely fastened to a little acrylic footplate, this Baton has a bendable modified velar extension. This extension, placed in the oro-pharynx against the tongue's posterior side, allows for adjustments in all dimensions, particularly superior-inferior

and anterior-posterior. A preferred position at the back of the tongue can be accommodated by immediately moving the footplate after the device is placed (Prinsloo & Bïow, 2024).

Baton device with modified facial extension-Type III

The final alteration to the Baton device entails making precise changes to the extra-oro-facial extension wires to facilitate oxygen delivery and nasogastric feeding tubes. This adaption is essential for neonates requiring prolonged care in the NICU. This update is applicable to both Baton type I and type II devices (Mohapatra et al., 2023).

The dorsal foot plate modification for the Type II device is more advanced, while the external facial modification is suitable for the Baton-type II. The intra-oral impression process stays the same as for the OwE and Baton kinds I and II appliances. The external superior-inferior measures are similar, with the distinction that the external facial wire extension requires an excentric bend to avoid interference with nasogastric and/or nasotracheal tubes (Prinsloo & Bütow, 2024).

2.4 The challenges faced by Children with Cleft Lip and Palate

2.4.1 Feeding Issues

Mothers with children with cleft lip and palate have substantial feeding issues as a result of their child's inability to establish efficient suction due to the cleft, which causes nasal regurgitation, extended feeding times, and exhaustion. These issues not only impede the baby's nutritional intake, but also cause significant emotional and psychological stress for the moms. The effect of the cleft means that the baby is not able to form a negative force needed to suck the breast or ordinary bottle. This leads to such problems as nasal regurgitation, when food or liquid is forced out of the nose, excessive air intake, which is uncomfortable, fatigue due to more serious feeding efforts, and the risk of aspiration, which is critical health risks (Eltayeb et al., 2022).

Due to all these feeding difficulties, there is often an increase in the levels of anxiety and stress among mothers. This may be in the form of inadequacy, especially in cases when they are unable to breastfeed as planned, which adversely affect their confidence in raising a child, parental self-efficacy. This emotional disturbance could result in maladaptive feeding habits such as coercive feeding habits which would unwillingly create an unhealthy feeding behavior in the kid. The complete feeding difficulties may turn into desperation among some mothers, as they fear their child might die (Ville et al., 2022).

Mothers often seek specialized feeding products and guidance to address the challenges of feeding their infants. Specially designed bottles, nipples, and feeding plates—referred to as obturation devices—are crucial for effectively separating the nasal and oral cavities during feedings. Feeding specialists, including clinical nurse specialists, should provide support for using these devices. Effective strategies for managing infant feeding include holding the baby in an upright position, limiting feeding sessions to no more than 30 minutes to reduce fatigue, and using soft bottles to aid in milk expression (Oluwafemi Adeagbo et al., 2025). These approaches help ensure that infants receive adequate nutrition while also alleviating some of the emotional stress that mothers experience.

2.4.2 Breathing difficulties

Children born with cleft lip and/or palate (CL/P) face a range of respiratory challenges throughout growth, from infancy into childhood, largely due to alterations in the structure and function of the upper airway. Anatomically, the maxilla and mandible are often underdeveloped or retruded in CL/P, and nasal deformities are common, contributing to reduced airway patency and increased resistance to airflow. These craniofacial differences predispose children with CL/P to upper airway narrowing and resultant obstructive breathing patterns, particularly during sleep (Budihardja & Nathania, 2025).

A major clinical concern in this population is sleep-disordered breathing (SDB), which includes conditions such as snoring, intermittent airway obstruction, and obstructive sleep apnea (OSA). Several studies have reported that children with CL/P exhibit a significantly higher risk of SDB relative to peers without clefts. For instance, routine screening using validated questionnaires indicates that a substantial proportion of children with CL/P score positively for SDB risk, often correlating with maxillary retrusion and Class III occlusion patterns (Budihardja & Nathania, 2025).

The impact of palatoplasty (surgical repair of the cleft palate) on breathing is multifaceted. While surgical closure of the palate is crucial for feeding and speech, it may initially exacerbate upper airway obstruction by restricting the already altered airway space. A longitudinal study observed that children with cleft palate exhibited an increased prevalence of snoring and possible OSA in the early postoperative period, and a high frequency of persistent snoring remained at later follow-ups. These findings suggest that postoperative changes in airway dynamics could contribute to ongoing breathing challenges (Prado et al., 2019).

Moreover, children with syndromic conditions or associated sequences, such as Pierre Robin Sequence (PRS), often have concomitant micrognathia that further constricts the airway and increases the severity of SDB and OSA after cleft repair compared with nonsyndromic populations, highlighting the heterogeneity of respiratory risk within cleft cohorts (Poupore et al., 2023).

Beyond the immediate respiratory mechanics, SDB in children with CL/P has broader implications for behavior, attention, and quality of life. In a sample of preschool-aged children with cleft palate, symptomatic SDB and moderate to severe OSA (as confirmed by PSG) were associated with elevated behavioral concerns including inattention, hyperactivity, and social difficulties. Families also reported lower emotional well-being and reduced quality of life measures, emphasizing that untreated sleep breathing disorders contribute to psychosocial and developmental burdens (Moraleda-Cibrián et al., 2021)

In summary, breathing challenges in children with cleft lip and/or palate arise from structural airway compromise that increases the propensity for snoring and obstructive sleep apnea. These respiratory issues begin early, may persist or temporarily worsen after surgical intervention, and are linked with significant behavioral and quality-of-life consequences. Early, multidisciplinary assessment including clinical screening and, when indicated, polysomnography is recommended to identify and manage SDB in this vulnerable population.

2.5 Risk Factors Associated with Cleft Lip and Palate

Velopharyngeal dysfunction is the cause of speech issues in patients with cleft palates. Air passes through the nose rather than the oral cavity when the soft palate cannot rise higher to make touch with the nasal cavity. Hypernasality speech is the term used to describe this disorder. Surgery to provide velopharyngeal closure can be used to treat this situation. Sphincter pharyngoplasty and pharyngeal flap are regarded as the most effective procedures for treating velopharyngeal deficiencies in patients with cleft lip and palate (Branson et al., 2024).

An accumulation of fluid in the middle ear, known as otitis media, can lead to an ear infection. The tensor veli palatine and levator veli palatine muscles are responsible for the aberrant action of the Eustachian tube opening. As a result, fluid builds up inside the middle ear and the middle ear chamber is not adequately ventilated. During the first six months of life, this problem manifests in children with cleft palates (Mirashrafi et al., 2021).

Furthermore, dental issues include irregularities in the size and shape of the teeth. For instance, the permanent lateral incisor exhibits irregularities in the size and shape of the cleft side, irregularities in the position of the teeth, and delays in the eruption and formation of permanent teeth (Wu et al., 2023).

Babies with cleft lip and palate have trouble feeding because they can't sucking from a bottle or their mother's nipple. As a result, the baby's weight and growth are impacted since there is insufficient food or milk for growth. A number of techniques, including the use of disposable syringes, spoons, cups, and prosthetic obturator devices, allow the infant to feed and reach a normal weight (Srivastav et al., 2021).

In addition to their cosmetic issues, cleft lip patients have trouble making labial noises. When attempting to make contact between their upper and lower lips, babies with cleft lips struggle

(Kelly & Shearer, 2020). In addition to the psychological side of a patient with cleft lip is affected by all of the aforementioned issues; they experience anxiety, depression, and low self-esteem, and they are unable to interact with their classmates at school. Additionally, some individuals experience anxiety as a result of other people's emotions and worry about social gatherings (Branson et al., 2024).

Socially, a connection between a lower socioeconomic status and a higher incidence of orofacial clefts has also been suggested by recent research. The evidence is contradictory, nonetheless, as other studies have found no link between the likelihood of orofacial clefts and a lower socioeconomic class (Malic et al., 2020). The minimal number of studies, their small-scale or regional nature, and the existence of confounders all further reduce the strength of the evidence. Understanding the link between socioeconomic position and the occurrence of orofacial clefts is crucial since a cleft diagnosis may result in diminished employability and prolong the poverty cycle if left untreated (Lian, Li, Su, & Wang, 2024).

The prevalence of orofacial clefts is generally substantial, despite regional variations in the incidence rate, which illustrates the importance of risk factor identification and prevention. Previous research has indicated that several demographic characteristics, including parental age, sexual inequalities, wealth, and educational achievement, are associated with risk factors. A strong scientific foundation for preventive actions will be provided by examining the association between these risk variables and the incidence of orofacial cleft (Putri et al., 2024).

2.6 Family Centered Care Approach toward the Children with Cleft Lip & Palate

Children with clefts frequently undergo surgical procedures during their first year of life. Early surgical treatment is often recommended for these children to reduce complications and enhance their quality of life. A multidisciplinary team is necessary for the management of children born with cleft lip and palate, contingent upon the complexity of the case (Alinezhad et al., 2025). This team, primarily composed of experts in dentistry, speech therapy, psychology, nutrition, nursing, social work, and pedagogy, must collaborate effectively to provide comprehensive care (Kumar et al., 2024).

Families of these children should actively participate in their care alongside the multidisciplinary team. To ensure comprehensive treatment, the multidisciplinary team must collaborate effectively, emphasizing interaction, communication, and the sharing of expertise among professionals from various disciplines while including families in the care process (Morsi et al., 2023). The prognosis for children with cleft lip and palate has significantly improved due to the involvement of patients and their families in designing and prioritizing therapeutic and rehabilitation procedures, as this condition impacts the entire family unit (Ueki et al., 2025).

Therefore, the participation of the family in the planning, delivery, and assessment of care under the Family-Centered Care (FCC) paradigm is essential. Further, healthcare providers must respect the patients and their family members' choices, including their values and beliefs,

to implement this care approach (Mori et al., 2024). To encourage adherence to therapeutic methods, it is essential to deliver information in an impartial and transparent manner (Manohar et al., 2025).

2.7 Surgical therapy options available for a child with a cleft lip and palate

The surgical management of the child's cleft lip and palate consists of a series of primary and secondary surgical procedures undertaken to respond to functional and aesthetic issues. The primary procedures involve cheiloplasty, which is the surgery of the cleft lip usually carried out at the age of three months. The surgery involves moving the lip muscles and closing the lip defect, often simultaneous with correcting the symmetry of the nose. Palatoplasty, usually undertaken between six and eighteen months, is cleft palate surgery. Z-plasty or push-back palatoplasty and other methodologies are adopted to close the cleft, relocate the oral and nasal areas, and properly separate both spaces (Oh & Kim, 2023).

Apart from the basic repairs, other surgical procedures may also be required within the surgical plan. Ear tubes are often carried out together with the palate surgery, where tubes are implanted into the eardrums to ensure fluid does not accumulate, potentially causing hearing loss. Bone grafting of the alveolar ridge takes place by inserting bone into the gum line, usually performed before the canine tooth erupts into the oral cavity and may also be used to close any fistula, if existing. The aim of fistula repair is to close any existing anomalies, especially those occurring within the oral and respiratory cavities, following palate repairs (Sander et al., 2025).

In order to support the child's speech development, the pharyngeal flap procedure can be used, whereby the child will benefit from the creation of a flap in the throat. The secondary surgeries may range from nose and lip surgery, which aims at improving the aesthetic look as the child will now have undergone the primary surgeries. Last, orthognathic surgery takes place during adolescence, at either twelve or eighteen years, and aims at improving the face by restoring jaw positioning and symmetry (Noorsaeed et al., 2022).

2.8 Complications Occurred after Surgery

The most frequent side effects after cleft palate surgery include sleep apnea, palatal fistula, and chronic velopharyngeal insufficiency. The incidence of fistulas vary greatly depending on the manner of surgery and the surgeon. Some claim that the Von Langenbeck repair, which has a greater rate than Furlow palatoplasty and intravelar veloplasty, has a lower rate of fistula formation than the Veau-Wardill-Kilner repair. Fistula rates are considerably higher in bilateral and wide clefts. Whether the time of repair affects the establishment of fistulas is unknown. Typically, fistulas are identified early in life (Paradowska-Stolarz et al., 2022).

VPI and other speech disorders are frequently not assessed until a kid is between the ages of 5 and 6, at which point they are able to participate during a speech test. Speech therapy, palatoplasty revision, or another compensatory operation such a pharyngoplasty or pharyngeal

flap may then be recommended (Garland et al., 2022). Persistent VPI affects 5 to 20% of patients and is probably influenced by the surgical method and the experience of the surgeon (Pitkanen et al., 2025).

Maxillary growth seems to be more impacted by primary palate repair than secondary palate repair. Age at operation should be carefully examined, with a balance struck between the need for healthy speech development and minimizing growth disturbance of the midface (Hattori et al., 2023). Patients with Pierre Robin sequence are generally more affected by sleep apnea than those without syndromic cleft palate. To check for sleep apnea symptoms, these patients must be closely monitored. In some patients, cleft palate repair might have to wait until mandibular distraction or tongue-lip adhesion is used to relieve airway impairment. In general, people with velocardiofacial syndrome (VCFS) have fewer favorable results. This is thought to be caused by a number of things, such as the oropharynx's anatomical form and weak muscles (Öztürk et al., 2024).

2.9 Parents' Experiences toward their Children with Cleft Lip and Palate

When a kid is born with a cleft, the family has to cope with the diagnosis of this deformity and the difficulties of caring for the infant, which can cause psychological problems such as shock, anxiety, and melancholy. Long-term multidisciplinary treatments that include medical, dietary, surgical, speech, aesthetic, and psychosocial interventions also cause a great deal of stress for parents. Parents have to deal with potentially uncomfortable reactions from friends, family, and the general public, and a lack of understanding about how to handle these circumstances can make parents feel more alone. Long-term impacts on the parents' mental health, the family dynamic, and their ability to adjust to the child's condition can result from such emotional and psychological strains.

According to an Iranian study by Alinezhad et al. (2025), time was linked to the diagnosis theme. Initial reactions, social pressure, the child's future in the community, hiding from family, feeling guilty about the oddity, and couples' relationships were among the main issues under the psychosocial experience's topic. The daycare theme's challenges included cleft procedures, financial difficulties, and feeding issues. Primary awareness and the significance of understanding how to care for the child were incorporated in the information acquisition theme. Gaining awareness, seeing the issue as God's plan and destiny, downplaying the importance of the child's cleft, and receiving support were the coping themes. Parents were worried about telling their children about their condition. According to a recent study by Lian, Li, Su, & Wang (2024), the parents' worries were grouped into three themes: need for assistance and support; attitudes regarding parental involvement in surgical decision-making; and the status of parental involvement in surgical decision-making.

Within the child who is born with CL/P, the parents of the child are also impacted. How parents adjust and cope is influenced by when their child is diagnosed. Prenatal diagnosis makes it

possible for experts to provide parents with proactive assistance, which may enhance the child's treatment and improve the patient's and family's quality of life.

When a child with CL/P is born, parents may experience a range of emotions, including shock, sadness, fear, grief, guilt, concern, and anger, according to the literature. These reactions can have an impact on the lives of the families involved. At the time of the diagnosis, parents may want to talk to specialists with experience about their sentiments and expectations. This will help them deal with these emotions and reorganize to meet the requirements of their affected kid.

The qualitative study conducted by Costa et al. (2021) highlighted the impact of the COVID-19 pandemic on parents' stress and concerns related to having a child with cleft lip and palate (CLP). Delays in surgery heightened uncertainty for parents. Changes in the healthcare situation, isolation, and lack of contact with their child increased their worries and underscored their need for social support. Kimotho and Macharia (2020) also reported the challenges that parents of children with CLP experience, including emotional difficulties, caregiver burdens, concerns about public and friend reactions, stigmatization, and the need for social support. The challenges faced by parents of children with cleft lip and palate have been further summarized in six major themes by Alinezhad et al. (2025). These themes include diagnosis, psychosocial experiences, childcare challenges, information acquisition, coping strategies, and informing the child about their condition.

Parents' emotional reactions were influenced by the diagnosis's timing, and childcare issues—particularly those related to feeding and treatment expenses—were prevalent. Parents frequently relied on unofficial networks for information and support because they lacked prior expertise. Coping mechanisms differed, but shared experiences and faith were important. To ensure awareness, the majority of parents planned to tell their child about the disease (Salari et al., 2022).

The social and emotional challenges faced by parents of children with clefts, including anxiety, sadness, and poor psychological "adjustment," have been the subject of numerous studies. Studies examining the experiences of parents and/or caregivers of children with CL/P in Palestine are still lacking, nonetheless. Consequently, taking into account that a long-term treatment plan typically has an impact on parents in the areas of psychology, emotions, and society.

2.10 Critical Synthesis

The literature consistently establishes cleft lip and palate (CLP) as a complex congenital condition rooted in early embryological disruption, with the timing and location of failed fusion determining the anatomical presentation and severity of the defect. While embryologic explanations and classifications of primary and secondary palate clefts are well described (Salari et al., 2022; Gulomovna & Kizi, 2023), much of this work remains descriptive, offering limited insight into how embryologic variability translates into differential functional outcomes.

Genetic and environmental contributions are widely acknowledged, yet the precise mechanisms and interactions remain insufficiently clarified, highlighting an ongoing gap between developmental biology and clinical prediction.

Epidemiological evidence demonstrates a global decline in the incidence of orofacial clefts over recent decades; however, CLP remains one of the most common congenital anomalies worldwide, with marked regional variation (Wang et al., 2023; Alaviyan, 2025). While population-level studies quantify prevalence and trends, fewer investigations critically address disparities in access to care, long-term outcomes, or survival-adjusted quality of life, particularly in low- and middle-income settings. This limits the applicability of global statistics to localized healthcare planning and policy development.

Feeding difficulties emerge as one of the earliest and most pervasive challenges for infants with CLP, driven primarily by the inability to generate adequate intraoral negative pressure. The literature strongly supports the effectiveness of feeding strategies such as upright positioning, specialized bottles, and palatal obturators in improving nutritional intake and reducing aspiration risk (Pawar et al., 2025; Ragulakollu et al., 2020). However, most studies focus on short-term feeding efficiency and weight gain, with limited longitudinal evidence on how early feeding interventions influence later oral-motor development, speech outcomes, or caregiver infant bonding. Moreover, while obturators are widely promoted, their availability, cost, and feasibility in resource-constrained settings are not consistently addressed.

Respiratory challenges, particularly sleep-disordered breathing and obstructive sleep apnea, are increasingly recognized as significant but underdiagnosed complications in children with CLP. Structural airway compromise, compounded by surgical interventions such as palatoplasty, places this population at sustained risk for breathing disturbances that can persist into childhood (Budihardja & Nathania, 2025; Prado et al., 2019). Although evidence supports routine screening and multidisciplinary monitoring, implementation remains inconsistent, and standardized clinical pathways for respiratory surveillance are lacking, especially for syndromic cases such as Pierre Robin sequence.

The reviewed literature also highlights the cumulative burden of associated morbidities, including speech disorders, recurrent otitis media, dental anomalies, and growth disturbances. While surgical and therapeutic advances have improved functional and aesthetic outcomes, complications such as velopharyngeal insufficiency, fistula formation, and maxillary growth restriction remain prevalent and variably reported. This variability underscores the influence of surgical timing, technique, and provider expertise, yet comparative, high-quality studies remain limited.

Beyond clinical outcomes, a critical theme across studies is the profound psychosocial impact of CLP on families, particularly parents. Parents commonly experience shock, guilt, anxiety, and chronic stress, intensified by feeding difficulties, prolonged treatment trajectories, financial

strain, and social stigma (Alinezhad et al., 2025; Kimotho & Macharia, 2020). While qualitative studies provide valuable insight into parental experiences and coping strategies, there is a notable lack of culturally specific research, especially in Palestine, examining parental information needs, decision-making involvement, and access to psychosocial support. This gap limits the development of contextually appropriate family-centered interventions.

The family-centered care (FCC) approach is widely endorsed as best practice, emphasizing parental involvement, multidisciplinary collaboration, and transparent communication. Evidence suggests that FCC improves adherence, satisfaction, and overall outcomes (Morsi et al., 2023; Mori et al., 2024). However, much of the existing literature focuses on theoretical frameworks rather than evaluating the real-world effectiveness of FCC models across different healthcare systems. The extent to which families are genuinely empowered, as opposed to passively included remains insufficiently examined.

In summary, the body of literature portrays CLP as a lifelong condition with intertwined biological, functional, and psychosocial dimensions. While advances in surgical care and supportive interventions have improved outcomes, significant gaps persist in understanding long-term trajectories, parental experiences, and culturally responsive care delivery.

Chapter Three

Methodology

3.1 Introduction

This chapter presents the methodology for conducting the study. The components of the methodology consist of the study design, target population, sampling technique, settings of the study, inclusion and exclusion criteria, tool of the study, and data collection and analysis methods.

3.2 Study design

This study utilized a qualitative approach to examine the lived experiences of parents of children with cleft lip and palate in the West Bank/Palestine. This research method involves describing and clarifying human experiences using natural language, incorporating both narrative and explanatory forms of expression. Given the study's focus on understanding the experiences of parents of children with cleft lip and palate, the qualitative method is essential for elucidating the phenomenon and interpreting its various dimensions.

This scientific approach takes place in natural settings, requiring the researcher to collect data and observe events before conducting inductive analysis. The focus is on understanding meanings and connotations, which allows for clear and persuasive articulation of findings, ultimately enhancing understanding and awareness (Edwards, 2020, p. 19). This approach entails gathering and analyzing substantial amounts of data in a manner that is neither strictly statistical nor merely descriptive, aiming for a deep comprehension of the specific phenomenon. By utilizing this method, the study aims to gather rich and nuanced information, allowing the researcher to present qualitative results that are pertinent to the phenomenon being investigated. As a result, this methodology empowers the researcher to deliver comprehensive and analytical responses to the research questions.

3.3 Target population

The study's population included parents of children with cleft lip and palate who visited the Operational Smile Institute in Hebron Governorate, representing all West Bank governorates. In total, the Operational Smile Institute provided services to 500 children with CLP during the year 2025.

3.4 Study Settings

The Operation Smile institution is an international humanitarian organization registered as a non-profit, non-political, non-sectarian entity based in Virginia, USA. For nearly 40 years, it has provided free surgical care for patients with cleft lip and palate conditions in 35 countries around the world. Operation Smile-Palestine is a branch of Operation Smile International, established in 2021 through a cooperation agreement with Al-Ahli Hospital of the Association of Patient Friends Society in Hebron.

Operation Smile offers both surgical treatment and non-surgical care for cleft patients born with facial birth defects, specifically cleft lip and cleft palate. The organization also emphasizes social and psychological rehabilitation to enhance the quality of life for these individuals and promote their integration into society. The mission of Operation Smile focuses on delivering surgical and non-surgical care for cleft patients through a team of credentialed volunteers. This team includes surgeons, anesthesiologists, pediatricians, dentists, orthodontists, speech and language pathologists, nurses, social workers, psychologists, and statisticians, who collaborate to provide the following services:

· Surgical and plastic surgeries for cleft patients.

· Dental and orthodontic treatments.

· Speech and language therapy.

· Feeding and nutrition consultation.

· Psychological support for cleft children and their families.

3.5 Sampling Methodology

Purposive sampling was employed to investigate the experiences of parents who have children with cleft lip and palate in Palestine. To facilitate contact with potential participants, the researcher reached out to the Operation Smile Institute, which assisted in identifying parents of children with cleft lip and palate who were eligible and willing to take part in the study. Parents of children with CLP were purposefully recruited to ensure diversity in age, educational background, and place of residence across different districts in the West Bank. Selection also

aimed to include a wide range of cleft lip and palate types, associated challenges, and levels of severity.

3.6 Sample Size

There is no consensus or clear criteria to guide researchers in determining the appropriate sample size for qualitative research (Mocănașu, 2020). A sample of 15 participants was selected based on the concept of data saturation, which refers to the point at which no new data or themes emerge. The researcher conducted a total of 11 interviews. Four interviews included both the mother and father, six interviews involved mothers only, and one interview featured the father alone. The characteristics of the participants were as follows:

Table 3.1: Socio-Demographic Characteristics of the Participants

Socio-Demographics	Categories	No.	Percentage
Mother Age	22-29	5	50.0%
	30-39	3	30.0%
	40-49	2	20%
Father Age	22-29	0	0
	30-39	2	40.0%
	40-49	3	60.0%
Child Gender	Male	4	36.0%
	Female	7	64.0%
Place of Residency	Urban	7	64.0%
	Rural	4	36.0%
Educational Level of Mother	Primary	6	60.0%
	High School	1	10.0%
	University	3	30.0%
Educational Level of Father	Primary	3	60.0%
	High School	2	40.0%
	University	0	0
Income Level	Less than 2000	7	64.0%
	2000-3500	3	27.0%
	More than 3500	1	9.0%
District	Hebron	7	64.0%
	Bethlehem	1	9.0%
	Nablus	2	18.0%
	Jericho	1	9.0%

Eleven interviews were conducted. According to Table 3.1, the average age of the mothers and fathers ranged from 24 to 48 years. The ages of the children, which included seven girls and four boys, varied from four months to seventeen years. The study involved parents of eight

children with cleft lip and palate and three with cleft palate. Additionally, two couples of the participating were relatives, and only five mothers reported having a detailed ultrasound.

During the first months of pregnancy, three of the mothers were medicated. Six parents resided in Hebron, two in Nablus, one in Bethlehem, and one in Jericho. At the time of the interview, the child's parents were married and living together.

3.7 Inclusion Criteria

Parents of children with cleft lip and palate, without any other comorbidities or additional diseases or syndromes, who visit the Operational Smile Institute in the Hebron Governorate from various West Bank governorates, will be included in this study.

3.8 Exclusion Criteria

Parents with children with cleft lip and palate and who are born with other diseases or syndromes.

3.9 Instrument of the study (semi-structured interview)

The study employed a semi-structured interview guide as the primary data collection tool, a widely accepted method in qualitative research for exploring participants' perspectives in depth. The use of open-ended, pre-planned questions aligned with the study objectives allowed participants to freely express their knowledge and experiences (Stuckey, 2013), while giving the researcher flexibility to probe further and clarify responses as needed (Alamri, 2019). This approach facilitated a rich understanding of complex phenomena through participants' narratives and explanations, enhancing the accuracy and relevance of the findings.

The interview guide began with an introduction explaining the study's purpose and included questions addressing participants' demographic and socioeconomic characteristics. The questions were developed based on existing literature and reviewed by subject-matter experts to strengthen credibility and content validity. Expert feedback was incorporated to refine the interview questions, ensuring their alignment with the research goals and the quality of the data collected, as shown in table 3.2:

Table 3.2: Open-ended questions of the semi-structured interview guide

Main Questions	Sub-Questions
Please describe your feelings after you found out that your child has cleft lip and palate	How did these feelings begin? when did you start experiencing the situation of having a child with cleft lip and palate?
	What you feel exactly can you describe these feelings, please?
	What are the difficulties and challenges you faced since that time?
	How did you come to understand that you had a child with cleft lip and palate? who helped you understand it? How did this experience affect you?
How did you seek help and therapy for your child? and what was the benefit?	What type of treatment did your child receive? Explain to me, please, your experience with the treatment of your child?
	What type of treatment do you prefer and feel better following? What about your ability to determine the appropriate treatment for a child?
	How did this treatment help your child to be treated?
	"What about counseling? Who gave you advice, and who discussed your child's treatment with both of you?"
	What obstacles may prevent both of you from asking for help of any kind for the treatment of your child?
Describe your feelings towards the period of treatment of your child.	How do you feel about your child?
	Tell me about how your child's condition has affected their overall health, including breastfeeding, nutrition, weight, or any other illnesses?
	Tell me how were the feelings of your child? Did your child face challenges obstacles, or bullying from society? Please tell me where, how, and when. (This question applies to children aged four years or older)
	How difficult is it to have a child with cleft lip and palate?
	How has your child's interaction with the family been, and how has their condition affected their interaction with peers at school? (This question applies to children aged four years or older).
How were you able to face the feelings that you described, and what were the methods of confrontation that were useful to alleviate the feelings of having child with cleft lip and palate?	Did you feel that the steps of treatment that your child passed on were helpful for him/her in his/her social life?
	When did you start to feel that your child will be better during his/her treatment?
Can you describe the reaction of people around you as close family members, relatives or neighbors?	Tell me about the reaction and feelings of your partner, family, parents, and neighbors?
	How can you explain their feelings against your child?
	Give me details about their reaction toward your child?
	How were they able to provide you with support and assistance when needed?

3.10 Data Collection

Ethical approval for the study was obtained from Al-Quds University, ensuring compliance with the university's ethical standards and guidelines. Permission letters were sent to Operation Smile in Hebron, detailing the study's objectives, methodology, and ethical considerations to secure its accreditation. Following the acquisition of the necessary approvals, a meeting was scheduled with the Operation Smile institute to introduce the study, including its title, significance, and purpose. Additionally, the institute was asked to provide authorization to conduct research within the organization, as well as the contact information of parents whose children have cleft lip and palate and meet the study's criteria.

After receiving the approvals, frequent visits to the Operation Smile institute were conducted, and collaboration with the organization's staff was established to reach out to eligible parents. The researcher specifically sought contact information for parents whose children had undergone surgical or therapeutic interventions related to cleft lip and palate, all while adhering to ethical standards, maintaining the confidentiality of information, and ensuring that informed consent was obtained from the parents.

The institution communicated with the parents to arrange meeting dates based on their preferences. The interviews were conducted face-to-face in a semi-structured format, lasting between 30 and 70 minutes. Informed consent was obtained from all participants before data collection. Consent was obtained in written & verbal forms after providing parents with a clear explanation of the study's purpose, procedures, potential benefits, and their right to withdraw at any time without consequence.

To ensure confidentiality and data protection, all interview data were anonymized, with identifying information removed and replaced by codes. Audio recordings, transcripts, and related documents were stored on password-protected devices accessible only to the research team. Hard copies of data, where applicable, were kept in locked storage, and access was restricted to authorized personnel. Data were used solely for research purposes and handled in accordance with ethical guidelines for qualitative research.

Each session with the participating parents began with a warm-up. Informed consent was obtained before the interviews commenced. Most interviews were conducted face-to-face, with two exceptions that took place over the phone due to safety concerns in certain areas, as the roads were not secure for the researcher or the participating parents during the data collection period. The interviews were recorded using an iPad, allowing for multiple listenings to ensure that all necessary information was accurately documented. All data and recordings were saved in a single file. Before starting the thematic analysis method, the audio recordings were transcribed into a Word document, which aided in organizing the data. This process included translating the information from Arabic to English and coding it in a separate file, facilitating

classification and code extraction. The interviews were conducted in Arabic, the participants' native language, to ensure comfort, clarity, and accurate expression of their experiences. Following data collection, participants' responses were translated from Arabic into English for the purposes of analysis and reporting. To preserve the original meaning and cultural context of participants' narratives, the translation process was carried out carefully and systematically. The researcher, who is fluent in both Arabic and English, performed the initial translation. Particular attention was given to maintaining semantic equivalence, emotional tone, and culturally specific expressions. When literal translation was insufficient to convey meaning, conceptual translation was used to ensure accuracy and clarity.

To enhance the credibility of the translated data, selected transcripts were reviewed and cross-checked to confirm consistency between the Arabic and English versions. Any ambiguities or discrepancies were resolved through careful comparison with the original recordings. Participants' quotations presented in the findings were anonymized and translated in a way that retained their intended meaning while ensuring confidentiality. This approach helped ensure that the English translations faithfully represented participants' lived experiences while minimizing the risk of misinterpretation or loss of meaning.

Throughout the interviews, some parents expressed feelings of fear and hesitation. Occasionally, parents became emotional and cried, necessitating a temporary pause in the interview to allow them time to calm down before continuing. Additionally, psychiatrist Dr. Tawfiq Salman (Tel: 0599676031) was available to provide support to any participating parents who experienced psychological distress during the interviews.

Reflexivity was an integral component of this qualitative study, as the researcher acknowledges that personal background, professional experience, and social positioning can influence the research process, particularly during data collection and interpretation. The researcher's role as the primary interviewer required continuous self-awareness to minimize bias and ensure that parents' experiences were represented authentically and respectfully.

The researcher has a professional background in the healthcare field, with experience in caring for children with congenital conditions, including cleft lip and palate. This background provided valuable contextual understanding of medical terminology, treatment pathways, and the challenges faced by affected families. However, it also carried the potential risk of preconceived assumptions regarding parents' knowledge, coping strategies, and emotional responses. To address this, the researcher consciously adopted an open, non-judgmental stance during interviews, allowing parents to guide the discussion and articulate their experiences in their own words.

The researcher shares cultural and social familiarity with the Palestinian context of the West Bank, including awareness of local healthcare structures, cultural beliefs, and family dynamics.

This positionality facilitated trust-building and rapport with participants, enabling open and honest communication. At the same time, the researcher remained attentive to the possibility that shared cultural assumptions could lead to overlooked explanations or taken-for-granted meanings. Reflexive practices, such as reflective note-taking after interviews and ongoing critical self-examination, were employed to mitigate this risk.

Throughout the interview process, the researcher sought to balance empathy with analytical distance, avoiding leading questions or interpretations that might shape participants' responses. Regular reflection on interview dynamics, emotional reactions, and emerging interpretations was undertaken to ensure that the findings reflected the parents' lived experiences rather than the researcher's perspectives. This reflexive approach enhanced the credibility, trustworthiness, and ethical rigor of the study.

3.11 Data Analysis

Data collected in this study were analyzed by use of thematic analysis. This approach is considered to be simple, easy to use, and can be used to summarize the large data set, as it underlines the main attributes of the data, which can be of importance to the research question. Nevertheless, thematic analysis also has shortcomings such as possibility of biasing and it is important to heed the data to make sure that the data is able to produce the themes and not the researcher (Braun and Clarke, 2006).

In this paper, the researcher followed the defined steps of the thematic analysis:

1 Getting acquainted with the Data: Reading and rereading the transcripts in order to get a deep feel of the content.
2 Extracting Codes: Identifying and coding important features in the dataset systematically.
3 Theming: Organizing the related codes into one theme that has some significant pattern in the data.
4 Themes: Revising and verifying themes so that they reflect the data.
5 Naming Themes: Deciphering the nature of each theme and giving it concise and informative names.
6 Report writing: This was done by presenting the themes in a sequential manner in a manner that answered the research question.

The transcribed records of all recorded interviews were done in their verbatim form which helped to explore the meanings embedded in the experiences of the study participants in-depth. The researcher read the transcribed narratives several times. Meaning units were separated into texts and these units could be in form of words, sentences or paragraphs. These were then cut down, abstracted and coded. The trustworthiness of my qualitative research was established through:

Dependability: regular discussions were held between the researcher and the supervisor(DR Maha).
Confirmability: Supported by detailed documentation of data collection and analysis processes.
Credibility: Member checking (participant validation), Staff validation (Operation Smile staff), and Peer debriefing with an independent qualitative researcher enhanced rigor
Transferability: Facilitated through thick descriptions and purposeful sampling, allowing findings to apply to similar research settings.

Throughout the analysis process, the researcher and supervisor consistently reviewed transcripts and the coding scheme to ensure confirmability and reliability. Consensus was reached during the interpretation process, and codes were systematically organized into themes and subthemes.

3.13 Ethical Considerations

Al-Quds University's public health faculty received the necessary approvals for this study. Additionally, the researcher obtained permission from the Operation Smile institution in Hebron to conduct the study and collect data from parents utilizing the services offered by the institution. The parents were told they could leave the study at any time, but they signed a consent form to join. The researcher was also committed to maintaining the confidentiality of the parents' responses. Parents were told the study's purpose and that their interviews would be recorded for research. A psychologist accompanied the researcher during the interview sessions to help parents manage any psychological issues that might arise.

Chapter Four

Results of the Study

4.1 Introduction

This chapter presents the results of the study, derived from the analysis and interpretation of the raw data collected from parents who have children with Cleft Lip and Palate in Palestine. The findings are presented according to the objective of the study and the themes extracted from the thematic analysis, which has been conducted after gathering data using the interview.

4.2 Results

A total of eleven interviews were conducted; four interviews included both the mother and father, six interviews involved mothers only, and one interview featured the father alone. Each interview lasted approximately 30 to 70 minutes. The parents' ages ranged from 24 to 48 years. The participating children included seven girls and four boys, aged between four months and seventeen years. Among them, eight children were diagnosed with cleft lip and palate, while four had cleft palate only. Two of the fathers were consanguineous relatives of their wives. Five mothers reported undergoing detailed ultrasound examinations during pregnancy, and three mothers had taken medication during the first trimester. Regarding place of residence, six families were from Hebron, two from Nablus, one from Bethlehem, and one from Jericho. All parents were married and cohabiting with their children at the time of the interview.

The thematic analysis conducted in this study identified three main themes and eight subthemes, which are outlined in Table 4.1. In the subsequent text, the letter "M" followed by a number denotes quotes from mothers, while the letter "F" followed by a number indicates quotes from fathers.

Table 4.1: Themes and Sub-themes conducted from the thematic analysis

Themes	Sub themes
1. Facing the hardship with dedication to their child care.	**1. Psychosocial and emotional hardship in response to the anomaly.**
	2. Feeding and caregiving-related hardships.
2. Concerns during the Complex Surgical Journey.	**1. Emotional concerns in response to Surgery.**
	2. Critical Concerns related to Insufficient Knowledge.
	3. Concerns about the Financial and logistical cost.
3. Social Stigma and Gaps in Family and Healthcare Support.	**1. Facing the social stigma of a child's anomaly**
	2. Insufficient family support.
	3. Insufficient professional support.

Theme One: Facing the hardship with dedication to their child care

Participants in this study reported experiencing a range of complex and often distressing emotions. Initially, they described feelings of shock and profound sadness, frequently accompanied by self-blame or guilt. Even parents who were informed of their child's condition through antenatal screening initially struggled with denial and found it challenging to accept the diagnosis. These findings underscore the emotional difficulties associated with receiving unexpected or adverse information. Over time, however, many parents gradually progressed toward acceptance, understanding, and expressions of affection for their children.

The parents' experiences of hardship and dedication to the child are reflected in the following subthemes:

1.1 Psychosocial and emotional hardship in response to the anomaly

Parents in this study expressed feelings of stress, shock, and self-blame during the early stages of having a baby with a cleft lip. They also reflected on their emotional transformation and the

profound love they developed for their child. They were taken aback when they first saw their child. One mother shared:

"I was shocked. I did not know what this meant. What did a cleft lip and a cleft palate mean? I had no previous knowledge about this defect" (M1).

This challenge was also significant for the fathers, most of whom had not received any information before the baby's birth. One father remarked:

"I did not know about a cleft lip, and I had never heard of it until I saw the child. It was an entirely new experience for me. Then we started to learn about it. We experienced very difficult days" (F5).

Some mothers reported experiencing shock, fear, and psychological pressure during pregnancy due to the information they received from their detailed ultrasound. They described feeling caught between fear and hope as they tried to emotionally prepare for what lay ahead. One mother shared:

"Honestly, I was really shocked, because I had never experienced something like this in the family. I was so surprised and disoriented until I got close to giving birth. I cried continuously throughout the day until I entered my last month of pregnancy. I started to program my mind that I would accept the situation no matter what" (M8).

Parents in this study expressed various concerns about having a child with a cleft lip and palate, particularly regarding breastfeeding and the child's future health and well-being. One mother shared her distress, stating:

"I was very shocked. I was saying, 'How can I breastfeed her? Does she live normally?" (M1).

They also voiced worries about societal perceptions of children with congenital abnormalities, such as a cleft lip. One mother remarked:

"The most difficult thing is society, and we are living in a village where perceptions of abnormality are challenging. Even if she becomes healthier and people are aware of her improvements, they will still view her as having a defect and being deformed" (M2).

Some parents expressed ongoing concern and fear about their child's future and development, as a mother said:

"I was particularly worried that my son might develop speech difficulties, and that worry persists even after he turns two years old" (M5).

The emotional and psychological impact of having a child with a cleft lip and palate, particularly on mothers, has been extensively reported. This impact extended beyond the postpartum period and influenced mothers' perspectives on future pregnancies and childbirth. As a mother shared:

"I refused to have children. I refused for four years because I was afraid of having a child like her" (M4).

Some mothers in the study felt guilty and blamed themselves for taking certain medications during the early months of their pregnancies, believing they were responsible for causing the anomaly, as a mother reported:

"I blamed myself a lot because I had gestational diabetes and also because of the medications. I kept asking, "Why, my God, is it like this? But thank God" (M8).

Mothers shared that their feelings of love for their child deepened as they provided essential care, and their attachment to their child with a cleft lip grew stronger. One mother noted:

"I loved her since the delivery. Once, when she was bathing, the girl fell and hit her head on the ground. I cried a lot, and from that moment, she entered my heart and became a part of me" (M6).

Despite the parents' initial feelings of sadness and shock, they expressed their unconditional devotion to their child through words of love, acceptance, and care. One mother said:

"At first, I experienced a significant amount of self-blame because of my gestational diabetes and the medications I was using. I kept questioning, 'Why, my God, is it like this?' However, I am grateful that I have come to accept her circumstances. I now see her as the most beautiful girl in the world" (M8).

1.2 Feeding and caregiving-related hardships

The parents who were interviewed discussed the daily challenges and struggles they faced with their children regarding feeding, daily care, difficulties with breastfeeding, challenges in formula feeding, and issues related to using special feeding tools. They also addressed the impact these factors have on their child's weight and the difficulty of achieving a normal weight gain. The parents expressed feelings of frustration due to these challenges.

Mothers emphasized the importance of being attentive to the child's position during feeding, as it requires careful handling due to the child's sensitivity and the complexities of breastfeeding. As a mother said:

"He should always be sitting while feeding so that he does not choke. Any wrong movement will cause him to choke, and he will not be able to breathe" (M5).

Parents shared the challenges of the daily tasks associated with their children. One mother mentioned that she struggles to change her child's diaper because the child's position could lead to suffocation or milk regurgitation. As a mother shared:

"Even when I want to change her diaper and put her on the floor, all the milk in her mouth might come out, and she might choke and aspirate because of the cleft palate" (M2).

Mothers shared their fears regarding the daily care and attention required for a child with a cleft lip and palate:

"It's a big responsibility; I was overwhelmed with fear. Anxiety and horrible thought, 'How am I going to bathe her and feed her?' I was scared" (M4).

Many mothers concurred that breastfeeding presented one of the most significant challenges they encountered, as it is often perceived as an emotional experience that strengthens the maternal bond. They voiced their sadness over their inability to breastfeed. As a mother expressed:

"I really wanted to breastfeed, but it didn't work out. Bottle feeding was also quite challenging. I had to use a syringe to feed her, which created significant difficulties" (M9).

The challenges of breastfeeding and using a special feeding bottle for children with cleft lip and palate have negatively affected the child's health and weight. As a mother said:

"Everything is difficult. I struggle a lot with feeding issues, and I am afraid my child might choke. It is tough, and feeding her takes a long time," she explained, but despite these efforts, her child has not gained weight" (M7).

And another mother said:

"My baby stayed in the hospital for a month. She frequently choked during feedings, and her weight did not increase. This heightened my fears of losing her when we returned home" (M9).

Most of the participating mothers highlighted their need for training and education on feeding children with cleft lip and palate. They stressed the importance of follow-up care to help them manage their child's feeding and to protect against choking and its associated risks. As a mother shared:

"The feeding issue is a challenge for me. The bottle leads to choking and aspiration. I preferred to use syringe feeding" (M9).

And another mother expressed:

"Despite my desire to breastfeed my baby, it was very difficult. I felt exhausted and worried about my infant's health and weight until I started using a special bottle provided by the institution that supports these children and their families." (M8).

Theme Two: Concerns during the Complex Surgical Journey

The parents' journey with surgical therapy and management of the child with a cleft lip and palate has been exhausting. It affects them physically, psychologically, emotionally, and financially. They have expressed significant concerns, primarily related to a lack of sufficient knowledge

Parents articulated their fears and anxieties concerning the surgical operations, the potential complications, and their effects on the child's appearance. They also conveyed their concerns about the length of the treatment period, the possibility of needing multiple operations, the challenges following the surgeries, the difficulties of caring for children during recovery, and the overall impact of the child's treatment journey on their own psychological well-being.

2.1 Emotional concerns in response to Surgery.

Parents felt overwhelmed by emotional stress and concerns regarding the complex surgical procedures needed for their child with a cleft lip and palate. Their primary worry centered on the child's weight gain, which was necessary before the surgical intervention could take place. As a mother shared:

"Postponing the operation was our major concern. The doctor informed us that the child needed to gain weight, but achieving this goal proved challenging within a few months… She gained only 400 grams in four months" (M2).

Additionally, parents expressed concerns about the child's appearance following the surgical procedures. One parent stated:

"The only thing that matters to me is that she will return healthy and will not have undesirable marks on her face. She's a girl" (F2).

The parents experience constant anxiety and concerns related to the multiple surgeries, which is a serious issue, especially when some have failed. The child's multiple procedures and failed surgeries exhaust the parents. As a mother said:

“She had about seven operations on her nose, ear tubes, a lip operation, and three surgeries on the roof of her mouth” (M6).

In addition, another mother stated:

“The last two surgeries weren’t good—the last one failed” (M4).

Parents have expressed their fear that their children might suffer complications from unsuccessful surgeries and the need to repeat them. As a mother said:

“My child stayed in the hospital for 27 days and caught a bacterial infection. Thank God, God was kind to her" (M6).

Parents faced challenges in providing care for their child during the recovery period after surgery. The child's need for continuous care was overwhelming and exhausting for the parents, impacting their physical and psychological health. They expressed fears about their ability to meet the child's needs. One mother shared:

“Following the surgery, we were particularly worried about the child's health, especially when he was unable to eat. We offered him only milk, but introducing solid food, such as cereal or mashed foods, proved to be a challenge” (F5).

Caring for the surgical wound and preventing the child from touching the operation area was another challenge for parents of children with cleft lip and palate. Parents expressed that the child needs constant care and attention, as a father expressed:

"It was difficult for the child to be left alone we have to stay very close to detect any problems that might arise” (F5).

The serious condition of the child, along with the significant need for continuous care and careful handling after the operation, affected the entire family, especially the siblings. Some parents expressed feelings of guilt for neglecting their other children while concentrating solely on the child with a cleft lip and palate. They noted that the entire family might require psychological, physical, and moral preparation. As a result, the family became exhausted, and their emotional state was overwhelming. As a mother said:

“This situation completely disrupted my life. I was a typical mother who worked at home and raised my three daughters. I was expecting twins—both boys and girls. I left those four and devoted myself solely to one boy. I didn’t know how to move forward or do anything” (M7).

Parents expressed the importance of the palatal obturator that sealed the palate temporarily. This device helped reduce the psychological burden on parents concerning feeding their child,

even though children often find the palatal obturator bothersome. The installation of the obturator was sometimes challenging for the parents, yet its presence provided some comfort. As a mother reported:

"She improved a lot, and I felt comfortable with the device, although she is not currently accepting it. She keeps removing it. When she was younger, it was easier. I used to put it in only when she was feeding, and after I finished feeding, it would come out of her mouth and onto her tongue. Although I used to secure it with adhesive, she still pulled it out. I am still talking to the doctor. I need a way to secure it because the operation is close to her lip" (M8).

Despite the psychological and emotional challenges experienced by parents of children with cleft lip and palate, many report feeling deeply satisfied with the noticeable improvements in their children following surgical interventions. These enhancements in their child's appearance have helped alleviate much of the parents' anxiety and fear. Several parents expressed gratitude and relief after the palate repair surgery, which allowed them to discontinue using the palatal obturator. One parent shared:

"We kept renewing the cleft palate obturator until he had the lip surgery at six months old. After that, everything changed. The surgery allowed us to stop using the device, and he began feeding without it"(M3).

Another parent remarked:

"The operations and treatment really helped her. I mean, Israa's face used to look very frightening—her lips were split on both sides, and her mouth was only at the edges. The roof of her mouth was missing. She improved in appearance and in every way" (M6).

For many families, the surgical procedure represents a major milestone for both the child and the parents. The intervention directly facilitates the child's daily feeding and reduces the problem of milk leaking from the nose. As one parent explained:

"The food used to come out of her nostrils, and she often choked, but after the palate surgery, her condition improved" (M1).

2.2 Critical Concerns related to Insufficient Knowledge

Parents in this study expressed deep feelings of anxiety and fear, largely stemming from a lack of information, guidance, and, at times, inadequate professional handling of their child immediately after birth. They described a general absence of medical education about cleft lip and palate, which left them feeling uncertain and insecure about their child's condition. Many parents reported confusion regarding the timing and nature of surgical interventions, as well as practical challenges in caring for their infants - such as difficulties with breastfeeding, the

unavailability of specialized feeding bottles in hospitals, and limited access to medical services specifically designed for children with cleft lip and palate. As a mother shared:

"In the hospital after giving birth, I was eager to learn how to care for my baby, but none of the nurses provided any guidance. Until the pediatrician arrived, I felt as though they just wanted to obtain rid of me. Every time I asked for help, they simply responded, "We don't know" (M8).

Parents expressed dissatisfaction with the lack of health education provided in hospitals following the birth of a child with a cleft lip and palate. They explained that this absence of guidance sometimes led to preventable medical complications that could have been avoided if proper information and support had been available to help them care for their child appropriately. As a parent said:

"I tried to feed her by the bottle, with no success, and she developed jaundice. I think they didn't teach me how to use the bottle properly" (M10).

One of the most pressing challenges reported by all participating parents was the lack of special feeding bottles for infants with cleft lip and palate in hospitals, as well as the difficulty in obtaining them elsewhere. Parents expressed deep concern about the absence of guidance on how to feed and care for their newborns immediately after birth. As a father expressed:

"When our son was born, I went looking for a bottle, but there was none in the hospital, and no one helped" us" (F3).

Some parents were compelled to seek information on their own. As a mother stated:

"I went online, searched for the name of the special bottle, and learned how to feed my baby and how to position her. Eventually, I managed to feed her properly—at least 30 cc. I had to teach myself because no one guided me" (M10).

And another mother shared:

"I always have my phone in my hand, continuously reading about the situation and looking at various cases. I am keen to learn as much as possible so I can effectively care for my daughter, especially before and after the operation - how to feed her and how to help her sleep. I explore all these topics and consider the potential long-term effects on her health" (M8).

Parents expressed concerns about the shortage of doctors specializing in cleft lip and palate in both government and private hospitals. They noted that most surgeries on their children were performed by foreign doctors, which left them feeling anxious and fearful.

Additionally, parents connected their anxiety and stress to delays in surgical appointments. Their children were suffering from recurring infections, such as ear infections and respiratory issues, along with difficulties in gaining weight. The repeated postponement of surgeries intensified the families' worries about their children's futures. As a father expressed:

"Honestly, I'm scared because we do not have specialized doctors in Palestine, and we are waiting for a group of foreign doctors to perform surgery on our children. This situation has caused delays in therapy and may have increased the risk of unexpected complications" (F2).

Another parent expressed frustration, stating:

"The surgery for our child was not performed at the expected time because his weight is low, and he can't tolerate surgery. He frequently experiences inflammation in his ears" (M5).

2.3. Concerns about the Financial and logistical costs.

The majority of parents expressed their concerns related to the financial and logistical costs of the treatment journey for their children with cleft lip and palate, especially the costs related to surgical operations and the need for their children to undergo repeated surgical operations. Since surgical operations require a very high cost, and the costs of special supplies that children need, which vary between special feeding bottles, which are considered somewhat expensive, and orthodontic devices like obturators that the child needs in the preparatory period that precedes the surgical treatment stage. Sometimes parents were forced to delay treatment due to the financial situation, and parents were concerned about the negative impact of the war on their financial situation, which made them neglect the treatment of their children.

Treatment and surgical care for children with cleft lip and palate are often costly, creating significant financial challenges for many families. As a mother shared:

"I faced financial obstacles with my child's therapy. We are fortunate to have an institution (the Cleft and Craniofacial Unit at Caritas Baby Hospital) that supports children with cleft lip and palate, as well as their families—whether by helping cover the cost of surgery or by coordinating with visiting medical delegations from abroad" (M7).

The parents expressed that essential supplies for children, such as special feeding bottles and obturators, are unavailable in hospitals and government facilities. Instead, these items must be purchased from pharmacies and private clinics at exorbitant prices, placing a significant financial burden on them.

Additionally, government institutions do not provide the necessary milk or devices for children promptly, further exacerbating the financial strain on parents and intensifying their feelings of neglect and helplessness, according to a father, who said:

"The milk that the doctor requested for our infant was expensive, and it was not provided by the government health centers, where they told me to come back after 15 days" (F3).

The constant need to renew the obturator and periodically measure the child's palate adds to the parents' stress due to increased costs and financial burden. As a mother shared:

"Frequent changes of the obturator are expensive, and it requires a significant amount of time to measure the palate and regularly change the device" (M3).

The financial burden significantly impacts the psychological well-being of parents, often forcing them to make tough decisions, such as abandoning or delaying critical aspects of their children's treatment due to financial constraints. They mentioned that they sometimes had to prioritize essential procedures, like surgery, while canceling others, such as orthodontic work or speech therapy sessions. As a mother said:

"We couldn't afford the surgery when my child was young, and the surgeries were done when she turned 16 years old" (M1).

The transportation needs of parents seeking medical and surgical therapy for their children with cleft lip and palate were another concern that burdened their financial capacity, daily expenses, and ability to support the family. They also expressed the impact of unemployment and the cumulative effects of the war over the past two years. As a father declared:

"In the beginning, there weren't many obstacles, but now there are financial challenges due to the war, lack of work, transportation issues, and associated costs. While the institution covers many expenses, there are still additional costs to consider" (F3).

Theme Three: Social Stigma and Gaps in Family and Healthcare Support

The results of this study, which involved interviews with numerous parents, indicated that they faced significant social stigma and psychological challenges from society. Some parents said they would rather not take their child out of the house because they were afraid of what other people, even family members, would say or think. Additionally, parents reported gaps in family and health care support.

3.1Facing the social stigma of a child's anomaly:

Parents in this study were concerned about society's perception of their child. They felt that the child's gender contributed to the social stigma of having a child, particularly if the child is a girl. These difficulties intensified their anxieties about the child's future as she grows older. One mother reported:

“My little girl was standing by the door, playing with her cousins, when she occasionally spat on the ground….” She heard these sarcastic words from a neighbor: “Oh, so now you have a mouth, and you know how to spit!” Then she started to cry and said, "Why am I different?" (M7)

Little girls have a fondness for makeup, and one day, my daughter chose to apply some lipstick. Once again, she heard these teasing words from a relative: “So now you have a mouth, and you’re even applying lipstick!” (M6).

3.2 Insufficient family support:

Parents of children with cleft lip and palate reported experiencing psychological pressure and feelings of loneliness in caring for their child. They felt unsupported by family members and lacked the necessary assistance, as a mother declared:

"I received no support. No one offered to help me. I felt isolated and carried a heavy burden while caring for the baby and using the required device on her palate" (M6).

Parents expressed that the family was not a source of security for their children and that their children faced bullying not only from the outside community but also from within the family, which lowered the family’s self-confidence. Bullying of the child included mocking the tone of speech, the child’s voice, and the shape of the mouth and nose. In some cases, some families used hurtful words towards the child. As a mother said:

“Her grandfather kept insulting her and calling her “rabbit lip” and “hole in the roof of your mouth. I was angry, but I couldn’t do anything” (M1).

Some parents shared their experiences of rejection within their families when it came to their child with a cleft lip and palate deformity. This rejection manifested in various ways, such as not accepting the child, not visiting, or not holding them. Such rejection led to a breakdown in family support. For example, one parent noted:

“My father-in-law doesn’t accept carrying her or playing with her. He doesn’t go out with her. He has barely seen her. They didn’t even help me” (M10).

Additionally, some parents described their families as sources of judgment and blame rather than support. This dynamic heightened the stress and psychological burden on the parents, leading to feelings of insecurity and guilt regarding their children. One parent stated:

“Honestly, my father-in-law blamed me so much for giving birth to such a child, which made my husband cry. I am upset by these reactions, but I do not force anyone to love my daughter or speak to her” (M8).

Regardless of the difficulties encountered by the parents of children with cleft lip and palate, it did not diminish their determination towards their children and their pursuit of continuity and treatment. They did not give up for the sake of their children, as they expressed their strong attachment to them and their refusal to abandon them for the sake of society. As a mother believed:

"I must be strong and support my son. He will be better in the future. I will not neglect his needs; my son still has a life ahead of him" (M5).

3.3 Insufficient professional support:

Parents reported that their primary support came from an institution dedicated to serving children with cleft lips and their families. They expressed significant gratitude toward this institution, as the government does not provide any assistance.

Parents described the challenges they encountered in accessing help and managing their child's care for cleft lip and palate. They received no guidance from the hospitals where their children were born and eventually found their way to the supportive institution with help from their community members. As a mother shared:

"I needed to arrange an appointment with the cleft lip institution; the hospital did not help me or provide any information" (M8).

Some mothers faced difficulties during pregnancy after receiving a diagnosis of having a baby with a cleft lip and palate. The hospital refused to admit them for delivery due to concerns regarding the pre-birth diagnosis, according to a father:

"The hospital in my town refused to admit my wife for delivery, despite the report we provided, because of concerns regarding the baby, and they did not offer us any assistance" (F3).

Chapter Five

Discussion and Recommendations

5.1 Introduction

This chapter reports findings from the current qualitative study, which examined how parents coped with children who had cleft lip and palate (CLP) in the West Bank, Palestine. Analysis places the research findings within the context of existing research and theory. The primary purpose was to elaborate on how parents cope, both emotionally, socially, and pragmatically, with the realities of raising a child with CLP within the war-zoned and resource-deprived setting. There was also identification of the three overarching themes, namely: (1) surviving with dedication to child-rearing, (2) concerns through the escalating surgical journey, and (3) stigma and inadequacy with regards to both family and medical systems. Overall, these findings provide an in-depth understanding of parent adaptation, resilience, and coping within Palestinian sociocultural and structural settings.

5.2 Discussion

The findings of this study can be explained at the link of Four general theoretical frameworks: Stress and Coping Theory (Lazarus & Folkman, 1984), Ecological Systems Theory (Bronfenbrenner, 1979), and Stigma Theory (Goffman, 1963), and Hazel Markus Theory.

Parents' emotional transformations - between shock and acceptance - illustrate the dynamic cognitive process of appraisal and coping. Parents originally saw CLP as a risk-taking threat that stimulated stress responses such as denial, guilt, and anxiety. Over time, they utilized coping mechanisms, including problem-focused coping (seeking information, calling agencies) and emotion-focused coping (spiritual acceptance, love, and meaning-making). This process illustrates psychological resilience and adaptive capability in culturally relevant situations of religion and family values (Lazarus & Folkman, 1984).

These interpenetrating systems are environmental systems whose orientations shaped the experiences of parents. In the microsystem, family life was tense with the responsibilities of care giving. The disconnection between the hospitals and support agencies at the mesosystem level violated the continuity of care. The ecosystem included healthcare policies and institutional constraints, and the cognizant parental stress and resilience were determined by sociocultural values of the macro-system, economic insecurity, and political strife. According to this ecological approach, parenting coping is not psychological but rather much contextual (Bronfenbrenner, 1979).

The reaction of social stigma to the facial difference is observed to have a profound influence on the family identity as well as the social interaction. Parental hiding behavior, self-blame and defiance is all comprehensible as reactions to the perceived social devaluation. The cultural norms of physical normality and gender discrimination were used to enhance the stigma and place the family experience in the larger social structures that lay the foundation of discrimination against visible difference (Goffman, 1963).

Interpreting Findings within Hazel Markus Theory

The findings from the study strongly support the Self-Schema Theory (Markus, 1977) and the Cultural Models of the Self (Markus and Kitayama, 1991) developed by Hazel Markus. Markus believed that persons construct their experiences by using self-schemas, that is, cognitive structures that are directed by societal norms and relationship patterns. However, in collectivist cultures, for example, in Palestinian society, people normally form interdependent self-construals.

The parents, through their experiences, illustrated how the process of caring for a child alters their existence by modifying their self-schemas. Feelings of guilt, shame, and self-blame, triggered by the disturbance in parental identity and societal notions of normality, were predominant in the initial phase. However, through their interacting process, the parents were also able to recreate themselves around the themes of dedication, resilience, and moral duty, resonating well, in the words of Markus, with ‘self-schema adaptation.’ The transformation, from feeling distressed to becoming accepting, aptly expresses how ‘love, caregiving, or parent-child interaction is sometimes used by people to restore a coherent sense of self.’

Furthermore, the ideas that emerged, i.e., stigma and the absence of support, also shed light on how the interdependent self might become victimized by the judgment of the society. The attempts that the parents carried out to protect their children prove that self-evaluation was influenced by the social validation. Nevertheless, the gestures that were provided by the social acceptance and support were basically a re-created definition of self which depended on instinctual, as opposed to social validation, but that which Markus has labeled as self-expansion.

Generally, the theory developed by Markus is useful in interpreting how the process of caring of the child with CLP, who is not only emotionally, but also deeply self-defining, can be related to the cultural identity, social belief and personal meaning in developing resilience and adaptation.

Theme One: Facing the Hardship with Dedication to Child Care

Psychosocial and Emotional Hardship

In this study, parents said they struggled with emotion shock of receiving the notification that his or her child has clefts, with feelings of denial, sadness, grief and self-blame, which eventually resulted to acceptance and affection. The direct response of the parents who were at a loss for words in expressing distress, grief, and self-blame shows that the CLP diagnosis of the child was seen as a major upset in the way the parents expected the child to be born. To most of the respondents, the birth of a child with a facial anomaly was a test of their control and went against their cultural beliefs of having a perfect newborn baby. Mothers talked about the never-ending crying, lack of sleep, and guilt, which implied the content of the moral aspect of their sufferings. Many of them would believe that they had not done everything to save their child and especially those who associated the anomaly to drug use or some disease in the course of pregnancy.

This self-deprecation is a demonstration of the fact that parental identity is linked to moral responsibility, which corresponds to the results of other qualitative studies on congenital anomalies (Al-Khalaf et al., 2014; Mori et al., 2024). Nonetheless, emotional experiences were transformed toward hopelessness to acceptance to love. This shift shows the transformative nature of being a caretaker: parents who got increasingly involved in taking care of their child started to feel the anxiety fade slowly, and acceptance became one of the crucial sources of emotional survival. Love was now more than a natural reaction but an active-coping mechanism, an active re-conceptualization of situations that led to the creation of hope and purpose.

This feeling is best captured by one of the mothers saying that she saw her as the prettiest girl in the world, as it implies that emotional healing was accomplished through the reworking of the views on difference. This is a process of emotion that is similar to the Stress and Coping Theory of Lazarus and Folkman (1984), which refers to stress as a type of interaction between the person and the environment. The parents went through the diagnosis with a high threat

(primary appraisal) initially and emotion-oriented coping responses with a resultant contribution to emotional adaptation. These are the findings that are similar to previous studies across the globe. Similar results were also observed by Nelson et al. (2012) and Adawy et al. (2023) who concluded that most of the parents of children with craniofacial anomalies suffer parallel grief responses as the bereavement. Mothers in particular experience extreme guilt and self-blame whenever they view their behavior in the prenatal period as the cause of the anomaly (Stock & Ridley, 2018). The current study internalized guilt in Palestinian mothers that were either medicated or had some health issues during pregnancy, which corresponds with the conclusion of Imani et al. (2020) that maternal self-blame is a holistic emotional response to congenital diagnoses.

As time went on, however, the prevailing majority of parents in the present study terminated as accepting and verbally connected with their children. Such an emotional adjustment is in line with meaning-biased coping whereby parents transform adversity by means of spirituality, religion, and unconditional affection (Ueki et al., 2025). Spirituality and religious gratitude (Alhamdulillah) are typically applied as effective emotional regulators in the Palestinian culture, and a study by Al-Khalaf et al. (2014) involving Saudi Arabian Arab families proved this.

Feeding and Caregiving-Related Hardship

The most distressing problems of the day included parental feeding and daily care problems. Mothers cited fear of choking, difficulties with special bottles, emotional distress at the inability to breastfeed, which is a symbolic and emotive marker of maternal identity. Kruppa et al. (2022) and Kumar et al. (2024) discovered that feeding issues are not only physical but also upsetting as they ruin the feeling of competence and attachment in a mother.

There was practical and symbolic meaning in feeding problems. In real life, they were tussles we fought day in day out together having to be very vigilant and creative and physical. Symbolically, they broke the usual mother-child bond, since the culturally symbolic exercise of nurturance, breastfeeding, could barely be done. The agency and resilience against structural constraints are indicated through the reported mechanisms of adaptation to syringe feeding, special bottles and specific feeding positions by parents. Feeding was a moral act a reinstatement of love, in spite of social and medical barriers, a daily reinstatement of self-worth of parents and their child.

The Family Systems Theory (Bowen, 1978) has it that tensions experienced by a single member of a family will compel the whole system to alter. Fatigue of mothers, financial strain of fathers and neglect of siblings observed in this research are some of the ripple effects on Palestinian families in the system. Local hospitals also contributed to the level of parental anxiety with poor professional training in infant feeding practices (Almeida et al., 2016; Al-Dabass et al., 2019).

These implications are also indicative of structural inequalities. These problems lack specialized feeding equipment in the hospital and the need of the family to travel between cities to access help are characteristic of systemic healthcare shortcomings. Viewing the issue of micro-level caregiving problems among such mothers through the prism of the Ecological Systems Theory by Bronfenbrenner (1979), macro-level institutional failure and economic instability contribute to the micro-level problems, proving how the environment significantly affects parental adjustment.

Theme Two: Concerns During the Complex Surgical Journey

Emotional Concerns About Surgery

Parents described the surgical experience as an emotionally exhausting one that was full of fear, uncertainty and frequent hospitalization. Mothers expressed concerns on the success of surgery, scarring and how the child will look like in future. Similar results could be observed in Morsi et al. (2023), Salari et al. (2022), and Stock & Ridley (2018) who also reported that surgical uncertainty and repeated surgeries are the significant stressors in CLP caregiving.

The surgery was both shown as an assurance of a solution and a cause of unending pain simultaneously. The procedure was not only a medical intervention but also the possibility of social sanity and repeated failure. Feelings of powerlessness by parents were enhanced by the ambivalence in relation to surgical outcome. This is due to the endless hospitalization and the care after the operation that caused chronic distress that redefined life in the family with mothers playing constant care giver and fathers playing constant financial provider.

The descriptions of parents taking care of the child when it comes to surgery, the vigil of constant watch, watching feeds, watching to protect the wound, can be regarded as the examples of how surgery did not point to a conclusion but a start of new task. These experiences can be described as typical of a protracted process of relief and fear processes, in which one challenge is met ends up casting the shadow of another challenge that comes in. Emotionally, the surgery itself was a test of patience, in which one had to endure and survive through endurance and patience (Shrestha et al., 2020).

The cyclic character of the surgeries contributes to burnout and anxiety in the parents. The Theory of Sense of Coherence (SOC) by Antonovsky (1987) explains this dynamic very well. Parents who gave meaning to the course of treatment to the child by either religious or selfless values, most often, were more resilient. The ones who lacked a clear medical command by them, on the contrary, generated reduced levels of comprehensibility and manageability, and were psychologically drained.

Critical Concerns Related to Insufficient Knowledge

Lack of professional leadership and post-natal medical education was one of the major themes. Most parents said that hospital staff did not know much about CLP and therefore resorted to the internet or generalist sources to find information. This omission created medical insecurity and confusion an outcome that is consistent with Mori et al. (2024) and Wehby et al. (2012) who found that poor healthcare communication exacerbated parental distress.

The stories of poor medical information and poor communication by the health facilities are pointers to the bigger theme of disempowerment. The systemic deficit is indicated by confusion of the parents over the protocols of feeding, surgical dates, and postoperative treatment, and make the families feel abandoned. The fact that some of the respondents were over reliant on the internet is indicative of the desperate clinging to power by those institutions that have been unable to provide institutional leadership. This lack of communication not only proves lack of proper education, but also uneven power balance in these healthcare systems (Wehby et al., 2012).

Such ignorance is most evident in conflict or low resource environments. Alinezhad et al. (2025) stated that parents with underdeveloped backgrounds turn to non-professional sources because of the lack of effective experience at the systems level of patient education. The healthcare system of Palestine is further degraded by political instability and institutional weakness whereby the healthcare system is not able to provide routine parental counseling.

Financial and Logistical Concerns

One theme was the cost of the further surgeries, special bottles, and transportation. The parents talked about delaying or foregoing treatment because of cost, which is consistent with Wehby et al. (2012), and Kummer et al. (2016) finding socioeconomic status to be a major factor in CLP treatment adherence. In Palestine where the poverty and unemployment are aggravated by war, the economic strain over time does not allow families to get further medical attention.

It was not only an economic problem but a moral and emotional problem of financial difficulty. Even when parents could not afford specialist feeding equipment or surgeries it was explained in terms of guilt and failure implying that financial constraints were internalized as a personal failure. These economic burdens are what we mean by structural injustices at the societal level with regard to healthcare. The economic situation in Palestine - where there is no work, and freedom of movement is a luxury - makes the medical treatment a permanent negotiation of love, care and low chances.

These results are consistent with the ecological theory developed by Bronfenbrenner, which demonstrates how the conditions of the macro-system, i.e. Political instability and institutional support, are converted into family experience. It is the interplay between individual coping (micro-level) and structural constraints (macro-level) which determine the specific problems Palestinian parents encounter throughout the treatment process of their children.

Theme Three: Social Stigma and Gaps in Family and Healthcare Support

Social Stigma

The strongest psychosocial burden was the stigma. Parents have said that they had to go out of their way to shun social places, feared being judged, and in two instances were even shunned by their extended families. The Stigma Theory developed by Goffman (1963) can be applied to explain these experiences. Goffman hypothesized outward physical variations as spoiled identities that seek social isolation and prejudice.

The accounts of stigma given by parents reveal the effect of the visible difference on disrupting not only the social identity of the child, but also the collective family reputation. The stigma is relational so as to prevent going to the public places or hide the child due to stigma affecting the entire family. According to the parental testimonies, the difference of the body is transformed into the place of social judgments based on the cultural standards of beauty and family prestige. Stigma was also gendered because mothers cared more about the future of daughters and associated deformity with lower chances of marriage (Zhang et al., 2024; Al-Khalaf et al., 2014).

However, at the moment, some of the parents talked about not being afraid to openly disobey social opinion and accepting their children. These rebellious performances represent a re-arrangement on ethical terms - disgrace to pride - and indicate that acceptance is no longer an emotional experience but a social statement of opposition to stigma.

Some studies support these observations. Al-Dabass et al. (2019) and Nelson et al. (2012) stated that stigma based on facial difference is deeply ingrained in the appearance-based culture and as a result, parents tend to hide their children or keep them out of social life. Stigma can be more severe in Arab cultures, where family respect and social status are highly cultural values, especially among girl children (Al-Khalaf et al., 2014). The mothers in this research showed an increased anxiety as to the way their daughters will be married in future, a female anxiety which is indicative of patriarchal societal frameworks.

Faced with stigma, parents opposed social judgment and recovered the value of their children. This acts as an antithesis to work by Stock & Ridley (2018), which determined that acceptance and advocacy would be probable to develop as adaptive responses to persistent social exclusion. Parents restructured society in terms of employing religion and motherly love and put caregiving into perspective.

Insufficient Professional and Family Support

Parents themselves also protested of the lack of expertise in hospitals and insufficient support of extended family members. The anomaly was blamed on mothers by relatives or they refused to associate with the child further contributing to emotional distress. Such rejection by family

members is corroborated by the research of Berk et al. (2013) and Al-Dabass et al. (2019) who reported the accelerating burden on caregivers through low family cohesion.

This was a deep-rooted emotional wound of lack of family support. Isolation of parents was aggravated by rejection or blame by the family members, particularly in-laws. The inability of the extended families to take part in the process of empathy showed that disability can ruin the solidarity of the kinship in the cases when the values of perfection and pride come in conflict with it. In the meantime, the absence of professional and institutional assistance made families resort to NGOs. Such organizations were deemed to occupy long-standing gaps in care, but due to their intermittent nature, they also signified the instability of care systems in resource limited environments.

The families were too dependent on non-governmental organizations (NGOs) to be supported, which was proven to be ineffective as Vyas et al. (2020) discovered that community-based organizations tend to balance the deficiencies of failed state healthcare systems. Insufficiency highlights an acute policy lack of support in Palestinian health infrastructure to the extent of full service multi-disciplinary CLP care facilities including surgical, psychological, and educational support.

Through all three of these themes, the meaning points to an underlying narrative: parental resilience through moral commitment in the face of social, emotional, and system adversity. Trajectories of parents were not only marked by adversity but by rich meaning-making. Caregiving for a CLP child was transformed into a language of love, faith, and moral duty redefining being a 'good parent.' Psychologically, parents converted suffering into meaning; socially, they dealt with stigma by subtle revelation and activism; structurally, they accommodated limited resources with creativity and grit. Resilience thus arises as a process dynamic out of love, faith, and necessity.

5.3 Conclusion

The findings of this study add a contextually grounded, parent-centered understanding of what it means to raise a child with cleft lip and palate in the West Bank, Palestine, extending beyond clinical descriptions to reveal the intersecting emotional, social, financial, and healthcare-system challenges parents endure. While existing literature acknowledges parental stress and caregiving burden, this study deepens understanding by illustrating how these challenges unfold longitudinally, beginning at diagnosis and continuing through feeding, surgery, and long-term care, within a fragile health and social context.

First, the results illuminate the emotional trajectory of parents, characterized by an initial phase of shock, grief, guilt, and self-blame often persisting even when the diagnosis is known antenatally followed by gradual acceptance and deepened parental attachment. This progression highlights parents' resilience and dedication, demonstrating that emotional suffering and

unconditional love coexist rather than replace one another. The findings add nuance by showing how maternal guilt is frequently internalized and linked to pregnancy-related factors, reinforcing the need for early psychological support and accurate counseling to prevent long-term emotional distress.

Second, the study contributes rich insight into feeding and daily caregiving hardships, emphasizing feeding as not only a technical challenge but also an emotionally charged experience that shapes parental identity and anxiety. The data underscore how inadequate feeding support, fear of choking, and poor weight gain compound parental stress and threaten infants' health. Importantly, parents' narratives reveal a critical gap between clinical recommendations and real-world implementation, particularly the lack of structured training and follow-up for caregivers. The role of palatal obturators emerges as both a practical and psychological aid, reducing parental fear despite challenges in use, thereby extending current knowledge on their psychosocial value.

Third, the results provide a detailed account of the surgical journey as a prolonged and exhausting process, rather than a single corrective event. Parents' fears surrounding delayed surgeries, failed procedures, postoperative care, and repeated hospitalizations highlight the cumulative emotional toll of long-term treatment plans. The study adds to existing literature by showing how surgical success is not measured solely by clinical outcomes but by parents' relief, restored hope, and reduced daily caregiving burden, particularly in relation to feeding and appearance.

Fourth, the findings expose critical gaps in healthcare knowledge, communication, and service availability, which significantly intensify parental anxiety. Parents' reliance on self-directed learning, social media, and informal networks reflects systemic deficiencies in postnatal education, specialized services, and professional support. The shortage of local cleft specialists and reliance on visiting foreign medical teams introduce delays and uncertainty, adding a unique geopolitical and structural dimension that is rarely addressed in cleft research.

Fifth, this study adds strong evidence of the financial and logistical burden faced by families, demonstrating how treatment costs, repeated procedures, transportation, unemployment, and the effects of ongoing conflict directly influence care decisions. Unlike studies that mention financial strain in general terms, these findings show how economic hardship leads to postponed surgeries, interrupted therapies, and forced prioritization of care, thereby shaping long-term outcomes for children.

Finally, the results highlight the pervasive impact of social stigma and insufficient family support, revealing how negative societal attitudes, gender expectations, and intra-family rejection amplify parents' psychological distress. The findings extend existing knowledge by showing that stigma is not limited to the broader community but can also originate within the family unit, undermining parents' sense of security and belonging. Despite this, parents

demonstrated remarkable determination and advocacy for their children, resisting social pressure and committing to their child's future.

Overall, this study adds a holistic, culturally situated perspective that integrates emotional resilience, caregiving labor, systemic healthcare gaps, and social adversity. It underscores the urgent need for family-centered care models, improved parental education, psychosocial support, and equitable access to specialized cleft services particularly in resource-limited and conflict-affected settings such as Palestine.

5.4 Recommendations

According to the results and conclusions, the study recommends the following:

1. Strengthen Psychosocial Support Services: Develop accessible psychosocial programs within hospitals and community centers to support parents from the moment of diagnosis through long-term care. This includes counseling, peer-support groups, and culturally sensitive interventions grounded in local norms and faith-based coping practices.

2. Enhance Clinical Training and Healthcare Capacity: Provide specialized training for healthcare professionals, especially specialists, nurses, and frontline staff, on communicating diagnoses, managing parental distress, and delivering coordinated care for children with cleft lip and palate. Investment in multidisciplinary teams would help reduce systemic fragmentation.

3. Implement Community-Based Stigma Reduction Initiatives: Design and distribute public awareness campaigns that normalize cleft conditions, challenge misconceptions, and emphasize successful treatment outcomes. Collaboration with community leaders, religious figures, and local media can make these campaigns more impactful within a collectivist culture.

4. Improve Financial and Structural Support for Families: Introduce or expand funding mechanisms subsidies, insurance coverage, or transportation support to ease the economic burden on families. Streamlining referral pathways and improving service accessibility in remote areas could help mitigate structural barriers.

5. Foster Policy Integration for Holistic Care: Encourage governmental and NGO stakeholders to adopt an integrated model of care that aligns medical, psychological, and social services. Policy frameworks should acknowledge the influence of political instability and economic hardship on family adjustment.

5.5 Orientation for Future Research

This study focuses on the experiences of parents with children who have cleft lip and palate in Palestine. It is recommended that future research include a longitudinal study that accounts for the various developmental stages of these children. Additionally, conducting qualitative studies to investigate the experiences and attitudes of fathers and siblings and their

psychosocial changes is advised. Furthermore, examining the impact of political and economic instability in Palestine on the long-term resilience of families with children who have cleft lip and palate is also suggested.

5.6 Limitations of the Study

1. The sample individuals may lack motivation to participate in the study. Consequently, it is anticipated that parents will decline to take part in the study to protect their children's privacy concerning cleft lip and palate.
2. Findings may not be fully generalizable to all Palestinian parents who have children with cleft lip and palate due to variations in the situations surrounding each family.

3. The study sample members may show bias in their opinions about their experiences with children with cleft lip and palate, which may affect the study's results. In addition, The researcher is encouraged to acknowledge that recruiting participants via Operation Smile may limit the diversity of experiences represented.

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Appendices

Appendix #1: Approval Letter from Public Health Faculty in Al-Quds University

Al-Quds University
Jerusalem
School of Public Health

جـامـعـة الـقـدس
القدس
كلية الصحة العامة

التاريخ: 9/3/2025
الرقم: REF.18/25

عزيزتي الطالبة عائشة عباد المحترمة
برنامج ماجستير السياسات والادراة الصحية

الموضوع: موافقة لجنة اخلاقيات البحث العلمي

قامت اللجنة الفرعية لأخلاقيات البحث التابعة لكلية الصحة العامة بمراجعة مشروع الرسالة بعنوان:
"Parents' experiences of having children with cleft lip and palate in West Bank, Palestine"

المقدم من (مشرف البحث/د.مهى نحال).
يعتبر مشروعك مستوفيًا لمتطلبات أخلاقيات البحث في جامعة القدس.
نتمنى لكم كل التوفيق في تسيير المشروع.
ملاحظة: في حالة الحاجة الى موافقة من اللجنة المركزية في الجامعة، تستطيع التقدم باستخدام هذه الموافقة على الرابط. https://research.alquds.edu/en/ethics/48-how-to-apply.html

رئيسة اللجنة الفرعية لاخلاقيات البحث
كلية الصحة العامة
د. نهى الشريف

نسخة/ أعضاء لجنة البحث
نسخة/ الملف

Jerusalem Branch/Telefax 02-2799234
Gaza Branch/Telefax 08-2644220 -2644210
P.O. box 51000 Jerusalem

فرع القدس / تلفاكس 02-2799234
فرع غزة / تلفاكس 08-264420-2644210
ص.ب. 51000 القدس

Appendix #2: Research Ethics Committee's Decision Letter

Al-Quds University
Jerusalem
Deanship of Scientific Research

بسم الله الرحمن الرحيم

جامعة القدس
القدس
عمادة البحث العلمي

Research Ethics Committee
Committee's Decision Letter

Date: May 4, 2025
Ref No: 554/REC/2025

Dears Dr. Maha Nahal, Mr. Aysheh Abbad,

Research ethics application. After reviewing your submission titled: "Parents' experiences of having children with cleft lip and palate in West Bank/ Palestine", the Research Ethics Committee (REC) at Al-Quds University confirms that your application aligns with our ethics guidelines, which are based on the principles outlined in the Declaration of Helsinki.

Please note that this approval does not replace other required permissions, such as for sample shipment or data sharing. We also request a copy of your final report or publication when available.

This approval is valid for two Years. If your research extends beyond this period, a renewal request will be necessary. The approval remains valid as long as there are no changes to the research protocol.

Sincerely,

Suheir Ereqat, PhD
Associate Professor of Molecular Biology

Research Ethics Committee Chair

Cc. Prof. Hanna Abdel Nour - President
Cc. Members of the committee
Cc. file

Abu-Dies, Jerusalem P.O.Box 20002
Tel-Fax: #970-02-2791293
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Appendix #3: Researcher's Task Facilitation Letter

بسم الله الرحمن الرحيم

Al-Quds University
Jerusalem
School of Public Health

جامعة القدس
القدس
كلية الصحة العامة

Date: 19/3/2025

To: Operation Smile Management

[Hebron-Palestine-al Ahili hospital-al sadeya building f2]

Subject: Official Request for Access to Patient Data for Research Purposes

Al-Quds University, Faculty of Public Health, is pleased to support the research efforts of our graduate student, Ms. Aysheh Mohammed Ibrahim Abbad, who is currently conducting her master's thesis titled "Parents' Experiences of Having Children with Cleft Lip and Palate in West Bank, Palestine."

The primary objective of this study is to explore the experiences of parents raising children with cleft lip and palate in Palestine. To facilitate the research, we kindly request your cooperation in providing non-confidential patient data, particularly contact details of parents who might be willing to participate in interviews. The study's sample size consists of 20 parents, and all collected data will be handled with the utmost confidentiality, by ethical research guidelines and university policies.

We would like to emphasize that this research has been reviewed and approved by the Al-Quds University Ethics Committee, ensuring that all ethical considerations and confidentiality standards are strictly followed.

Sincerely yours,

Hazem Agha, M.P.H, PhD
Dean, School of Public Health

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تجارب الوالدين في تربية أطفال مصابين بالشفة الأرنبية وشق الحنك في الضفة الغربية/فلسطين دراسة نوعية وصفية

اعداد: عايشة عباد

اشراف: د. مها نحال

الملخص

الخلفية والهدف: تعدُّ الشفة الأرنبية وشق الحنك (CLP) من أكثر التشوهات الخلقية شيوعًا التي تؤثر على الفم والبنى المرتبطة به. غالبًا ما يمرّ آباء وأمهات هؤلاء الأطفال بمجموعة من الصعوبات النفسية والاجتماعية، مثل الشعور بالعجز والذنب وعدم اليقين والألم وحتى الاكتئاب. وعليه، هدفت الدراسة إلى استكشاف تجارب الوالدين لأطفال مصابين بشق الشفة والحنك في فلسطين.

المنهجية: تم استخدام منهج وصفي نوعي لاستقصاء تجارب الآباء والأمهات لأطفال يعانون من الشفة الأرنبية وشق الحنك في الضفة الغربية. وتم توظيف أسلوب العينة القصدي لاختيار المشاركين من خلال منظمة "عملية الابتسامة" في الخليل. تم جمع البيانات من خلال مقابلات شبه مُنظمة وجهًا لوجه مع الأهالي، واستمرت المقابلات للوصول إلى تشبّع البيانات. وقد شمل دليل المقابلة خمس أسئلة رئيسية بالإضافة إلى أسئلة استيضاحية. وتم إجراء (11) مقابلة، وتسجيلها، ثم تفريغها حرفيًا وتحليلها موضوعيًا.

النتائج: كشف التحليل عن ثلاثة محاور رئيسية تتضمن ثمانية محاور فرعية. تمثلت المحاور الرئيسية في: مواجهة الصعوبات مع الإخلاص في رعاية الطفل، المخاوف خلال الرحلة الجراحية المعقدة، والوصمة الاجتماعية والفجوات في دعم الأسرة والرعاية الصحية. وبصورة عامة، توفر هذه النتائج فهمًا معمقًا للتكيف والمرونة وآليات المواجهة لدى الأهالي ضمن السياقات الاجتماعية–الثقافية والبنيوية الفلسطينية.

الاستنتاجات: يواجه الآباء والأمهات لأطفال مصابين بالشفة الأرنبية وشق الحنك في فلسطين تحديات عاطفية واجتماعية وعملية كبيرة، تتأثر بالعوامل الثقافية والاقتصادية وبقيود النظام الصحي. تؤكد هذه النتائج الحاجة إلى خدمات دعم موجهة للأسرة ومراعية للثقافة المحلية، إضافة إلى تعزيز الإرشاد المهني أثناء مسار العلاج.

الكلمات المفتاحية: الشفة المشقوقة، الحنك المشقوق، تجارب الوالدين، مؤسسة عملية الابتسامة، فلسطين.