



Quality of life of children treated for cleft lip and/or palate in a selected South African Population

by

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PREFACE

This study is a representation of original work by the author and has not been submitted to other universities in any form. The findings have been published in accredited journals in line with the thesis guidelines of the University of KwaZulu-Natal. Acknowledgement in the text has been made where the work of others was used.

The research described in this project was supervised by Prof L. Lazarus (Department of Clinical Anatomy, School of Laboratory Medicine and Medical Sciences, College of Health Sciences, University of KwaZulu-Natal, South Africa), Prof A. Madaree (Department of Plastic and Reconstructive Surgery, School of Clinical Medicine, College of Health Sciences, University of KwaZulu-Natal, South Africa) and was conducted in the above-mentioned institution (on the Westville Campus) and Inkosi Albert Luthuli Central Hospital, Durban, KwaZulu-Natal, South Africa.

DECLARATION

I, Mr Siyabonga Lembede, declare that:

- i. The work described in this thesis has not been submitted to the University of KwaZulu-Natal or other tertiary institutions for purposes of obtaining an academic qualification, whether by myself or any other party.
- ii. This dissertation does not contain another person's data, graphs, tables, or other information unless specifically acknowledged as being sourced from other persons.
- iii. This dissertation does not contain another person's writing unless specifically acknowledged as being sourced from other persons. Where other written sources have been quoted, the information used has been referenced accordingly.
- iv. The research reported in this thesis, unless where otherwise indicated, is my original work.

My contribution to the project was as follows:

- Development and design of research topic and protocol
- Conduction of research methodology
 - Collection and analysis of data
 - Interpretation of data obtained.
 - Formulation of manuscript
- Write-up of final thesis

- v. The contribution of others to this project was as follows:

Prof L Lazarus (Supervisor), Prof A Madaree (Co-Supervisor) and

- Development and refining of the research design and plan
- Assistance with the analysis of data and statistical analysis
- Review of the manuscript and thesis before submission


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DEDICATION

In loving memory of MaNgcobo, who witnessed the beginning of this journey but did not live to see its completion. Your wisdom, love, and strength continue to guide and inspire me each day. “*Awukho umshika-shika ongenanzuzo*,” which translates to “*no effort is ever in vain*.” Mom, these words have sustained and motivated me throughout this journey, reminding me that perseverance always bears fruit. In moments of doubt and exhaustion, they reminded me that perseverance, faith and hard work always yield purpose. I will forever cherish your faith in me and the values you instilled

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LIST OF ACRONYMS AND ABBREVIATIONS

ANOVA	Analysis of Variance
BCLP	Bilateral Cleft Lip and Palate
BREC	Biomedical Research Ethics Committee
CL	Cleft Lip
CP	Cleft Palate
IALCH	Inkosi Albert Luthuli Central Hospital
NRF	National Research Foundation
OME	Otitis Media with Effusion,
PI	Principal Investigator
QoL	Quality of-Life
SAS	Statistical Analysis System
UCLP	Unilateral Cleft Lip and Palate
WHO	World Health Organisation
DoH	Department of Health
UKZN	University of KwaZulu-Natal

ABSTRACT

Background

Cleft lip or palate are regarded as the most prevalent congenital anomalies of the head and neck, occurring on the lips and both the hard and soft palates. These clefts are associated with complications that affect patients' quality of life (QoL) by impairing their eating, communication, hearing, and physical appearance in both adolescence and adulthood. Maxillofacial surgeons commonly perform surgical repairs for clefts, yet some challenges may persist even after treatment. These ongoing issues might go unnoticed without a QoL assessment. Thus, this study aimed to evaluate how surgical correction of cleft lip or palate impacts the QoL of patients with orofacial clefts.

Methods

Fifty patients who came for cleft lip or palate repair surgery at Inkosi Albert Luthuli Central Hospital's Craniofacial Clinic were included in this study. A questionnaire was employed as the data collection instrument to evaluate the QoL of these patients.

Results

Participants with a cleft lip only exhibited low QoL scores specifically in the social health domain, at 63.5%. Those with unilateral cleft lip and palate had decreased scores in the psychological health domain, while patients with bilateral cleft lip and palate scored lower in the physical health domain, with percentages of 57.1% and 71.1%, respectively. In contrast, children with cleft palate only displayed higher QoL scores across all health domains. Female participants showed elevated scores in both the psychological domain (61.5%) and the physical domain (85%). Importantly, children aged 10 to 13 years recorded the lowest scores across all health domains.

Conclusion

QoL was higher in patients with cleft palates than in those with other cleft subtypes. Those within the 1-3 age group had much higher QoL scores than older age groups, and females had a higher QoL than males.

Keywords: QoL, Cleft lip, cleft palate, health domains

CHAPTER 1

1.1 Introduction

Orofacial clefts are congenital malformations that primarily present as a cleft lip, which may occur with or without an accompanying cleft palate, and also include isolated cleft palates (Shkoukani *et al.*, 2013). Cleft lip or palate are facial abnormalities affecting the orofacial area and continue to pose a major public health issue (Elmouden *et al.*, 2020). Globally, about 303,000 newborns pass away within the first month of life due to congenital defects. (Hlongwa *et al.*, 2019). Cleft lip or palate has a complicated aetiology that appears from the fourth through the seventh week of embryonic growth, this is the period of organogenesis, which has the greatest period of sensitivity (Moodley *et al.*, 2018). These defects can occur separately, in various combinations, or in conjunction with other congenital malformations (Vyas *et al.*, 2020).

The occurrence of cleft lip or palate varies based on biological sex, population affinity and socio-economic status (Hlongwa *et al.*, 2019). Although the specific etiology of cleft lip or palate remains unknown, maternal intrauterine hormone patterns have been proposed as a possible contributing factor. Some studies suggest that maternal hormone concentrations at the time of conception may partially influence the sex of the offspring (Ács *et al.*, 2019; Hapsari *et al.*, 2024). It has therefore been hypothesised that the hormonal profiles implicated in the development of clefts may overlap with those involved in determining foetal sex (James *et al.*, 2000; Pedersen, 2002; Burg *et al.*, 2016). Burg *et al.* (2016) further noted that the increased occurrence of cleft palate in females may be linked to the timing or the process of palatal shelf fusion during female embryonic development, which occurs approximately one week later than that of male embryos.

Previous studies conducted on orofacial clefts revealed the global incidence of oral clefts to be 1 in 700 births (Mossey and Modell, 2012; Hlongwa *et al.*, 2019; Putri *et al.*, 2024). In South Africa, the public sector reported an estimated prevalence of orofacial clefts of 0.3 per 1000 live births, with provincial variations ranging from 0.1/1000 to 1.2/1000 (Hlongwa *et al.*, 2019). The highest prevalence was observed in the Free State Province and the lowest in the Eastern and Northern Cape Provinces. Although Gauteng Province recorded the majority of cases, its estimated prevalence rate was 0.5 per 1000 live births, showing provincial variations from 0.1/1000 to 1.2/1000. The distribution of clefts was as follows: 35.3% for cleft palate, 34.6% for cleft lip and palate, 19.0% for cleft lip, and 2% for other cleft anomalies (Hlongwa *et al.*, 2019).

Clefts not only affect the patient's physical health but also cause major psychological and socio-economic challenges for both the individual and their family. These impacts include disturbances in psychosocial functioning and a reduction in overall quality of life (QoL) due to emotional difficulties, social barriers, and financial strain associated with ongoing treatment and care (Shkoukani *et al.*, 2013). Orofacial clefts cause considerable health problems for children, create substantial financial challenges for their families, and

contribute to social difficulties (Emeka *et al.*, 2017). They are associated with speech difficulties, challenges with feeding, middle ear issues, hearing impairment, dental irregularities, and accompanying social and psychological problems. (De Cuyper *et al.*, 2019). Individuals born with a cleft lip or palate often face high rates of bullying over their facial appearance. (Hunt *et al.*, 2005; Kelly *et al.*, 2020). While patients with clefts usually experience aesthetic issues, it has been reported that a considerable number of children have clinically significant behavioural, emotional and cognitive problems (Endriga *et al.*, 1999; Shkoukani *et al.*, 2013; Berman *et al.*, 2021; Branson *et al.*, 2022).

QoL refers to a patient's evaluation of their current functional status and their satisfaction with it, compared to their perception of an ideal state (Emeka *et al.*, 2017). It is a multidimensional and subjective concept that is always changing (Elmouden *et al.*, 2020). The study of QoL can be used to assess the daily impact on a person's life with a cleft lip or palate before and after they have undergone surgery (Elmouden *et al.*, 2020). It is crucial in assessing the effectiveness of the repair surgery and the satisfaction of the patient and the surgeon with the results (Elmouden *et al.*, 2020). Health-related QoL measures are being used more frequently to assess aspects of health that are not examined by other indicators, such as psychological and social factors (Emeka *et al.*, 2017). The importance of QoL is becoming more widely recognised as a significant health outcome in individuals who have had surgery for conditions that can be treated (Emeka *et al.*, 2017).

QoL brings together several distinct branches of multidisciplinary care, such as physical appearance, speech, craniofacial development, and social-psychological functioning (Elmouden *et al.*, 2020). Additionally, what matters is understanding how these different aspects might transform as individuals progress from childhood development into adult life. Questionnaires for individuals with cleft lip or palate are able to assess areas of significance and be aware of any changes in QoL aspects as the child matures. Designed for people with cleft lip or palate, these questionnaires can evaluate important areas and track changes in QoL dimensions as the child develops (Elmouden *et al.*, 2020).

Orofacial clefts additionally result in significant clinical and psychological implications (Akinmoladun *et al.*, 2017). Therefore, how they are treated will have a considerable effect on patient QoL and overall well-being (Akinmoladun *et al.*, 2017). Due to various constraints in the developing environment, including limited resources, infrastructure and workforce shortages, cleft care in the developing world has been found to be behind that of the Western world (Akinmoladun *et al.*, 2017). One of the most widely established patterns in social science research is the relationship between physical appearance, social stereotyping and societal expectations (Foo *et al.*, 2012). Patients with clefts have anxiety and depression rates that are twice as high, according to reports (Foo *et al.*, 2012). Depression has been linked to dissatisfaction with one's

appearance in subjects with clefts; literature indicates that certain aspects of social life, such as social participation, satisfaction with appearance, psychological stress, mood disorders, and family functioning, may be affected (Foo *et al.*, 2012). Little attention has been given to general health-related QoL and oral health implications for individuals with clefts, and those studies that exist have lacked the methodology necessary to adequately summarise the QoL of orofacial clefts, especially after treatment (i.e., post-surgery).

Given that no reliable, objective way to measure aesthetic outcomes from treatments, questionnaires have become useful for evaluating subjective perceptions of facial aesthetics (Menon et al., 2019). Existing measures, such as the CLEFT-Q, Youth QOL-Facial Differences (YQOL-FD), Psychosocial Assessment Tool-Craniofacial (PAT-Craniofacial), Cleft Evaluation Profile (CEP), COHIP, PedsQL, SF-36/SF-12, and others, have been applied to evaluate cleft populations across diverse demographics. However, these instruments were not specifically designed for children/young adults who have completed cleft treatment (Klassen et al., 2012; Menon et al., 2019). A further limitation is that existing patient-reported outcome measures of sufficient quality were predominantly developed for Western populations, where cultural values, healthcare systems, socioeconomic conditions, and social structures differ substantially. Due to the significant sociodemographic differences between the target audience of these measures and the population examined in this study, there is a clear need for measures that are capable of adequately assessing QoL among patients treated cleft lip and palate from developing countries and lower socioeconomic backgrounds. Hence, this study sets out to assess the QoL of patients (children) who underwent cleft lip or palate treatment within a select South African Population.

1.1.1. Aims

The study aimed to evaluate the impact of cleft lip and palate surgical reconstruction on patients' quality of life.

1.1.2. Objectives

- To evaluate the QoL of individuals treated for cleft lip and/or palate across physical, psychological and social domains
- To analyze variations in QoL scores of individuals treated for cleft lip or palate based on cleft type, biological sex and age.

1.1.3. Research question

How does reconstructive surgery for cleft lip or palate affect the physical, psychological and social aspects of quality of life in treated individuals, and to what extent do these outcomes vary by cleft type, biological sex and age?

1.2. Literature Review

1.2.1 Gross anatomy

The lips are mobile, musculo-fibrous tissues that border the mouth and travel from the nasolabial sulci and nares laterally and superiorly, toward the mentolabial sulcus below (Moore *et al.*, 2013). They are coated internally by a mucous membrane and externally by skin (Moore *et al.*, 2013). The lips contain the orbicularis oris muscle, which consists of fibers that circle the mouth (*Figure 1*) (Drake *et al.*, 2009; Moore *et al.*, 2013). Some of these muscle fibers have their origin near the midline, originating from the maxilla above and the mandible below, while others originate from the buccinator muscle of the cheek and from a number of other muscles that act on the lips (Drake *et al.*, 2009). It attaches to the skin and mucous membrane of the lips, as well as to itself (Drake *et al.*, 2009). The orbicularis oris muscle functions as the valve for the oral fissure by regulating entry and exit from the mouth, as well as the upper digestive system and respiratory tracts (Moore *et al.*, 2013). Its contraction narrows the mouth and brings the lips together (Drake *et al.*, 2009)

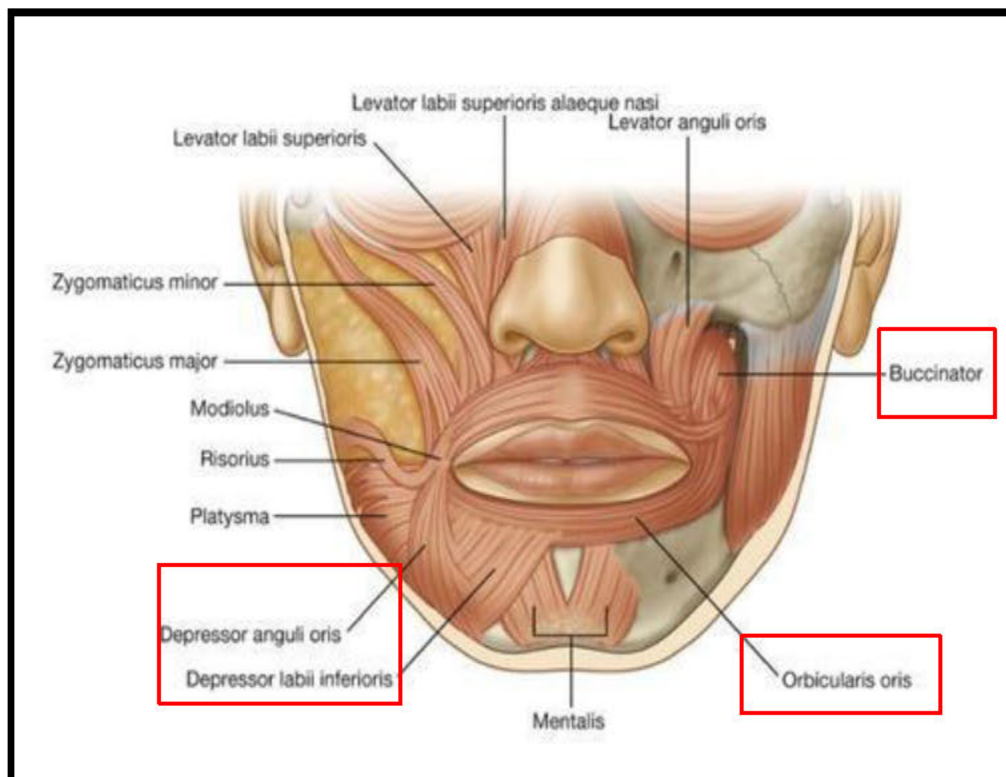


Figure 1: Oral group of facial muscles

(Adapted from Drake *et al.*, 2009)

The palate forms the floor of the nasal cavity as well as the roof of the curved oral cavity (Moore *et al.*, 2013). It consists of two regions, viz. the anterior two-thirds formed by the hard palate and the posterior one-third formed by the soft palate (*Figure 2*) (Moore *et al.*, 2013). The palatine processes of the maxillae and the horizontal plates of the palatine bones form the hard palate, while the soft palate is a movable portion hanging from the posterior border of the hard palate (Drake *et al.*, 2009; Moore *et al.*, 2013). Although the soft palate lacks a bony skeleton, the anterior portion receives structural support from the palatine aponeurosis, which is thick in the anterior region and thin in the posterior region, where it combines with a posterior muscular component called the uvula (Moore *et al.*, 2013). The lower (oral) aspect of the palate is lined with oral mucosa, which contains densely packed glands that assist in secreting essential substances and provide sensory capabilities for detecting temperature, touch, pain, and taste. The upper (nasal) surface is lined with respiratory mucosa containing hair-like projections called cilia that move mucus-entrapped particles such as smoke or pollen away from the nasal cavity (Moore *et al.*, 2013).

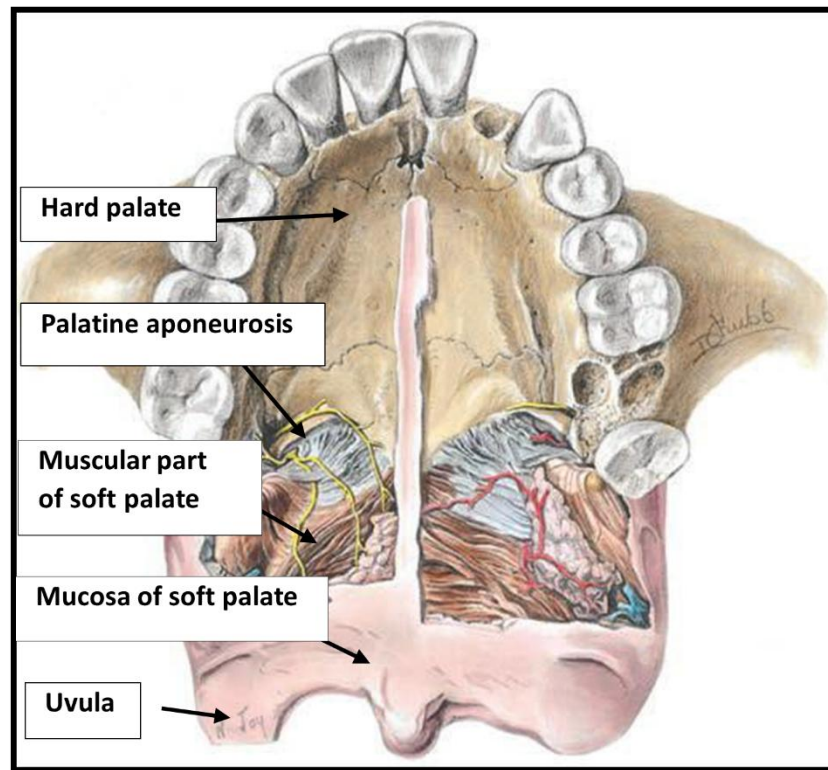


Figure 2: Anatomical structures of the hard and soft palate (Adapted from Moore *et al.*, 2013)

1.2.2. Embryology

Facial prominences develop at the end of week four, primarily from the first pharyngeal arches and neural crest-derived mesenchyme (Afshar *et al.*, 2012). Mandibular prominences can be seen caudal to the stomodeum, while maxillary prominences lie lateral to it. The frontonasal prominence, formed by mesenchymal proliferation ventral to the brain vesicles, forms the superior boundary of the stomodeum. (Singh *et al.*, 2014). The ventral portion of the forebrain causes nasal placodes (which are small thickenings of the surface ectoderm) to develop on both sides of the frontonasal prominences (Singh *et al.*, 2014).

During week five, the nasal placodes invaginate to create nasal pits (Singh *et al.*, 2014). As a result, there is a tissue build up along the edges of each pit, giving rise to the nasal prominences (Sadler *et al.*, 2012). The medial nasal prominences are on the inner edge of the pits, whereas the lateral nasal prominences are on the outside edge (Sadler *et al.*, 2012).

The maxillary prominences undergo continuous morphological enlargement throughout the following two weeks. While growing medially, they compress the medial nasal prominences in the direction of the midline (Singh *et al.*, 2014). Subsequently, the cleft that separates the medial nasal prominence from the maxillary prominence is lost, and the two prominences eventually fuse. Therefore, the upper lip is formed by the fusion of two medial nasal prominences and two maxillary prominences. (Sadler *et al.*, 2012). There is no involvement of the lateral nasal prominences in the development of the upper lip. Fusion of the mandibular prominences along the midline produces the lower lip and jaw (Figure 3) (Singh *et al.*, 2014)

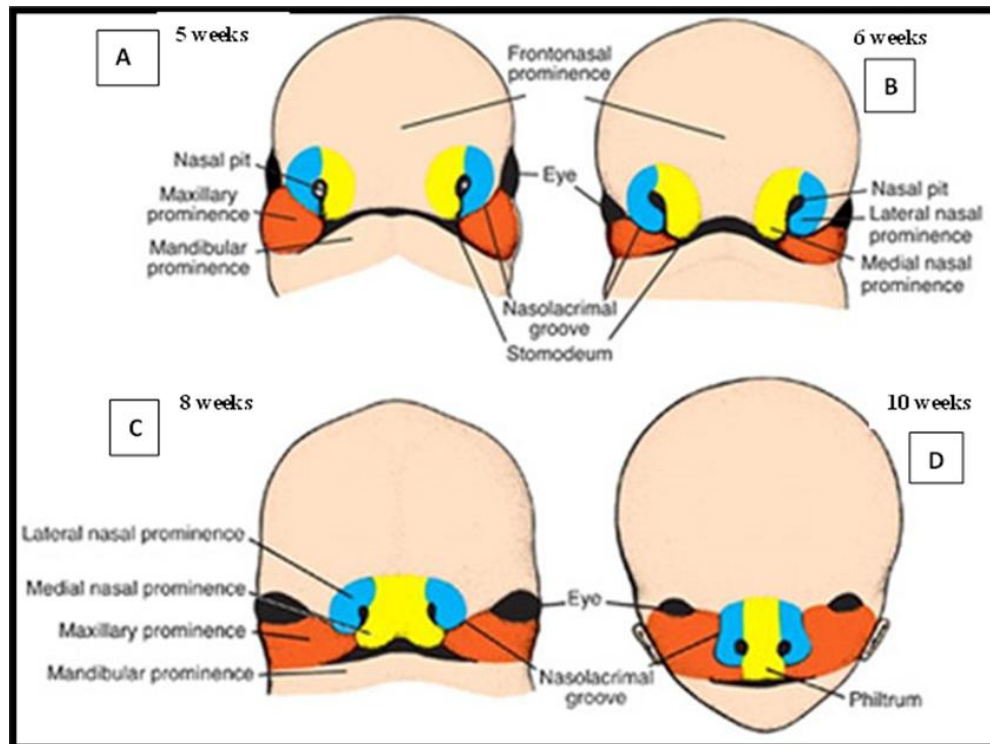


Figure 3: Development of the face (Adapted from Ferguson, 1995)

Five facial prominences make up the nose: the bridge originates from the frontal prominence, the crest and tip develop from the united medial nasal prominences, and the sides (alae) arise from the lateral nasal prominences. (Sadler *et al.*, 2012).

As the maxillary prominences grow medially, they push the two medial nasal prominences together, causing them to join both on the surface and underneath on a deeper level (Sadler *et al.*, 2012). The intermaxillary segment arises from the fusion of these two prominences. It is made up of three parts, viz., a labial part that contributes to the philtrum of the upper lip, a component of the upper jaw that contains the four incisor teeth and a component of the palate that creates the triangular primary palate (Sadler *et al.*, 2012). The anterior aspect of the nasal septum, which is formed by the frontal prominence, is continuous with the intermaxillary segment (Sadler *et al.*, 2012).

While the intermaxillary segment forms the primary palate, two shelf-like outgrowths from the maxillary prominences form the main part of the definitive palate (Afshar *et al.*, 2012). The palatine shelves, which are outgrowths that are pointed obliquely downward on either side of the tongue, first arise during the sixth week of development (Sperber, 2002; Hammond & Dixon, 2022). The secondary palate develops only during week seven, when the palatine shelves shift horizontally above the tongue and fuse (Sadler *et al.*, 2012). The shelves join with the triangular primary palate anteriorly, and the incisive foramen marks the transition between the primary and secondary palates. (Sadler *et al.*, 2012). As the palatine shelves merge, the nasal septum also extends down and connects with the top portion of the forming palate. (Figure 4) (Sadler *et al.*, 2012).

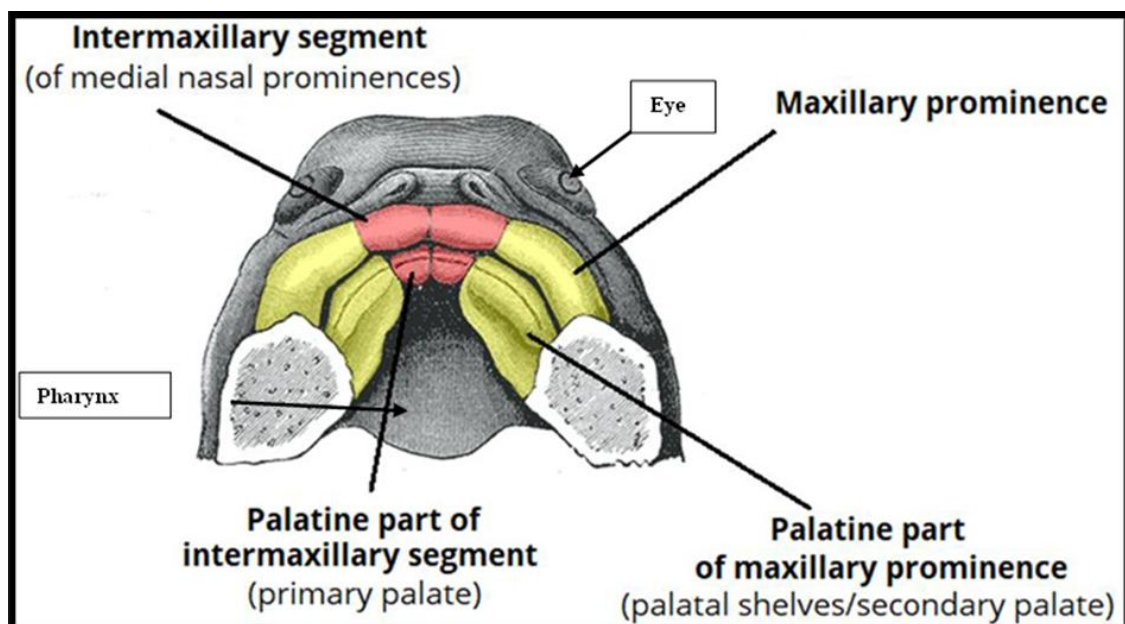


Figure 4: Development of the palate from the intermaxillary segment and maxillary prominences

(Adapted from Ahmed *et al.*, 2017)

Cleft lip and/or cleft palate are common congenital anomalies that affect the appearance of the patient and hinder speech (Sadler *et al.*, 2012). The incisive foramen is the dividing point for anterior and posterior cleft deformities. Those anterior to the incisive foramen are cleft upper jaw and cleft between the primary and secondary palates. Such congenital anomalies are caused by the partial or complete failure of the maxillary prominence to fuse with the medial nasal prominence in one or both sides (Sadler *et al.*, 2012). Those that lie posterior to the incisive foramen are cleft of the secondary palate. cleft palate is caused by the absence of fusion of the palatine shelves, which may be attributed to the small size of the shelves, failure of the shelves to elevate, prevention of the fusion procedure itself, or failure of the tongue to drop between the shelves (Sadler *et al.*, 2012). The third group (cleft lip and palate) is made up of a combination of clefts that lie anterior as well as posterior to the incisive foramen (Sadler *et al.*, 2012).

1.2.3. Classification of clefts

Syndromic clefts exhibit additional structural defects such as lip pits, hypodontia and ankyloglossia, whereas non-syndromic clefts do not have these associated deformities (Watkins *et al.*, 2014; Singh *et al.*, 2020). Clefts may develop unilaterally or bilaterally and can extend into the alveolus or palate (Table 1) (Shkoukani *et al.*, 2013). An incomplete cleft does not penetrate the nasal floor, while a complete cleft is characterised by a separation of the alar base and the medial labial element. (Vyas *et al.*, 2020).

Table 1: Classification of clefts

Type of Clefts	Description	Illustration /Sample Image
Unilateral cleft lip	A cleft lip is caused by a lack of fusion between the frontonasal and maxillary processes, leading to a cleft in the lip, alveolus, and nasal floor (Vyas <i>et al.</i>, 2020). A unilateral cleft lip affects only a single side of the upper lip [AB]. The extent of a cleft lip ranges from a minor philtral groove to a severe cleft affecting the primary palate, alveolus, and nasal floor (De Cuyper <i>et al.</i>, 2019). A unilateral cleft lip usually has a noticeable nasal defect. Typically, the inferior and lateral surfaces of the lower lateral cartilage are twisted and flattened (Azzaldeen <i>et al.</i>, 2015). The short columella frequently bends and displaces the septum, resulting in a flattened dome shape with a widened horizontal nostril on the affected side (Abu-Hussein <i>et al.</i>, 2019). This disruption can cause difficulties in speaking, eating and drinking.	 Figure 5: Unilateral cleft lip (Adapted from <i>What Is Cleft Lip and Palate - Operation Restore Hope</i>, 2020)

Bilateral cleft lip	In a bilateral cleft lip, the orbicularis muscle is affected on both the left and right sides, and portions of the prolabium are extruded [AB] and [CD] (Abu-Hussein <i>et al.</i>, 2015; Azzaldeen <i>et al.</i>, 2019). The nasal deformity is similar to that of the unilateral defect, having a small columella, a bilaterally horizontal nose and a dome that is flattened on both sides (Azzaldeen <i>et al.</i>, 2017). Due to the lack of muscle continuity, individuals with this condition may experience difficulty with clear speech and feeding.	 Figure 6: Bilateral cleft lip (Adapted from <i>What Is Cleft Lip and Palate - Operation Restore Hope</i>, 2020)
Cleft palate	Cleft palate arises from incomplete fusion of the palatal shelves of the maxillary processes, producing defects in the hard or soft palate (Vyas <i>et al.</i>, 2020). A cleft palate can have a soft tissue-only bifid uvula or involve the entire hard and soft palates, including both bony and soft tissue. A cleft will form in the hard palate if this occurs in front of the incisive foramen (Felman <i>et al.</i>, 2022). A cleft develops in	

The soft palate, if this occurs posterior to the incisive foramen. The severity of a cleft palate can also vary (Felman *et al.*, 2022). A cleft palate can appear as a little gap at the back of the mouth, or it might divide the sides of the palate from the front to the back of the mouth [AB] (Felman *et al.*, 2022). The primary palate is the part of the palate located anterior to the incisive foramen. A cleft from the incisive foramen through the alveolus is known as a primary palate cleft; such clefts are typically associated with clefts of the lip (Azzaldeen *et al.*, 2018). Secondary palate clefts result from the failure of medial growth of the palatal shelves. As a result, there is a cleft or opening on one or both sides of the lip that can extend from the nose to the back of the palate (De Cuyper *et al.*, 2019).



Figure 7: Cleft Palate (Adapted from *What Is Cleft Lip and Palate - Operation Restore Hope*, 2020)

1.2.4. Quality of life

QoL is a multidimensional construct that encompasses an individual's overall well-being and satisfaction across various life domains. The three core health domains include: physical health which assesses functional capabilities and bodily wellbeing, psychological health which evaluates emotional and mental wellbeing and lastly social health which examines interpersonal relationships and social functioning. QoL reflects both objective and subjective assessments of one's circumstances and experiences. It is measured using standardized tools which help quantify these subjective experiences and track changes over time, particularly important in evaluating treatment outcomes, chronic disease management, and healthcare interventions. QoL recognizes that health extends beyond mere absence of illness to include holistic human flourishing and perceived life quality from the individual's own perspective.

The goals of primary cleft lip repair include restoring normal lip structure and function, fixing the nasal deformity, creating the nasal floor, and properly aligning the maxillary segments (Bassuk *et al.*, 2012). Cleft palate surgery primarily aims to restore normal palate anatomy and function. This includes creating a separation between the oral and nasal cavities and stopping food and secretions from refluxing into the nose. Another goal is to re-establish velopharyngeal function by ensuring adequate palate length so the nasopharyngeal port can close properly during speech and swallowing (*Figure 8*) (Tibesar *et al.*, 2009). Finally, realigning the soft palate musculature to improve eustachian tube function is also a goal of surgical repair (Tibesar *et al.*, 2009). Additionally, even after undergoing successful treatment, some patients who have been cured and long-term survivors may still experience issues. Without a QoL assessment, these late issues can go unnoticed (Haraldstad *et al.*, 2019).

A substantial amount of research indicates that numerous children face significant challenges due to their visible differences, difficulties with speech and language, as well as social isolation (Lockhart, 2003). Psychological wellness is significantly determined by perceptions of physical appearance and how well they can communicate verbally (Kelly *et al.*, 2020; Yang *et al.*, 2025). In 2005, an assessment of the QoL in a Children's Hospital in Seattle compared the QoL between children with facial deformities and those without. The study found that children with facial deformities experienced lower QoL than children without such conditions. However, it also showed that patients with orofacial clefts had better family relationships than those without.

Sahoo *et al.* (2023) compared patients with orofacial clefts against a control group and found that all areas, such as self-image, educational or workplace environment, functional wellness, and social and emotional wellness, revealed lower scores. When compared to controls, research has found that parents and teachers rate children with cleft deformities as being more depressed, less socially competent and reclusive

(Lockhart, 2003). The social isolation of children with clefts has been investigated, and there appears to be a myriad of causes. For instance, some children withdraw to avoid peer rejection, while others have been discovered to lack social skills (Murray et al., 2009; Crerand et al., 2017; Martínez et al., 2022). Children with clefts are more likely to have intellectual impairments, especially when the cleft is associated with a syndrome.

Regarding functional well-being, individuals with cleft lip or palate reported statistically significantly lower scores when responding to questions regarding pronunciation and difficulty articulating particular words (Payer et al., 2022). The quality of speech is a crucial consideration after lip and palatal reconstruction and forms the basis for surgical decision-making regarding revision procedures (Bickham et al., 2017). Speech poses significant challenges for these children. The issue with speech can be categorised into two aspects, viz. difficulty articulating specific words and experiencing hypernasality while speaking (Zeraatkar et al., 2019). According to two qualitative studies, hearing difficulties, ear infections and otitis media with effusion (OME) were believed to have a detrimental effect on learning in a school setting (Tierney et al., 2015). This is due to the fact that secondary cleft palates often result in speech difficulties like hypernasality and, in particular, velar insufficiency (Aravena et al., 2017). These findings coincided with those from studies by Chetpakdeechit et al. (2009) and Aravena et al. (2017). They stated that individuals with cleft lip or palate felt distinct from others due to their speech difficulties. This is because of the cleft of the soft palate, which is a crucial component of the palate that affects pronunciation and how loudly particular sounds are emphasised.

Zeraatkar et al. (2019) measured QoL according to the caregivers' observations and found that children's functional well-being was unsatisfactory; they are less capable of performing their daily tasks. Ardouin et al. (2020) stated that the majority of patients (74.8%) said they could breathe both via their nose and mouth, while just 25.3% said they could only do so through their mouth. Approximately 47.8% of individuals with cleft lip or palate reported that it was at least occasionally difficult for them to breathe. At the same time, 44.6% of participants described ongoing hearing challenges. 48% of this group believed the issues were related to their cleft lip or palate, while 45.8% reported not knowing (Ardouin et al., 2020). Approximately 49.1% of the participants said that they frequently experienced uncomfortable symptoms during feeding. These included nausea, pain, nasal regurgitation, shortness of breath, reflux, coughing/choking, and general discomfort (Ardouin et al., 2020).

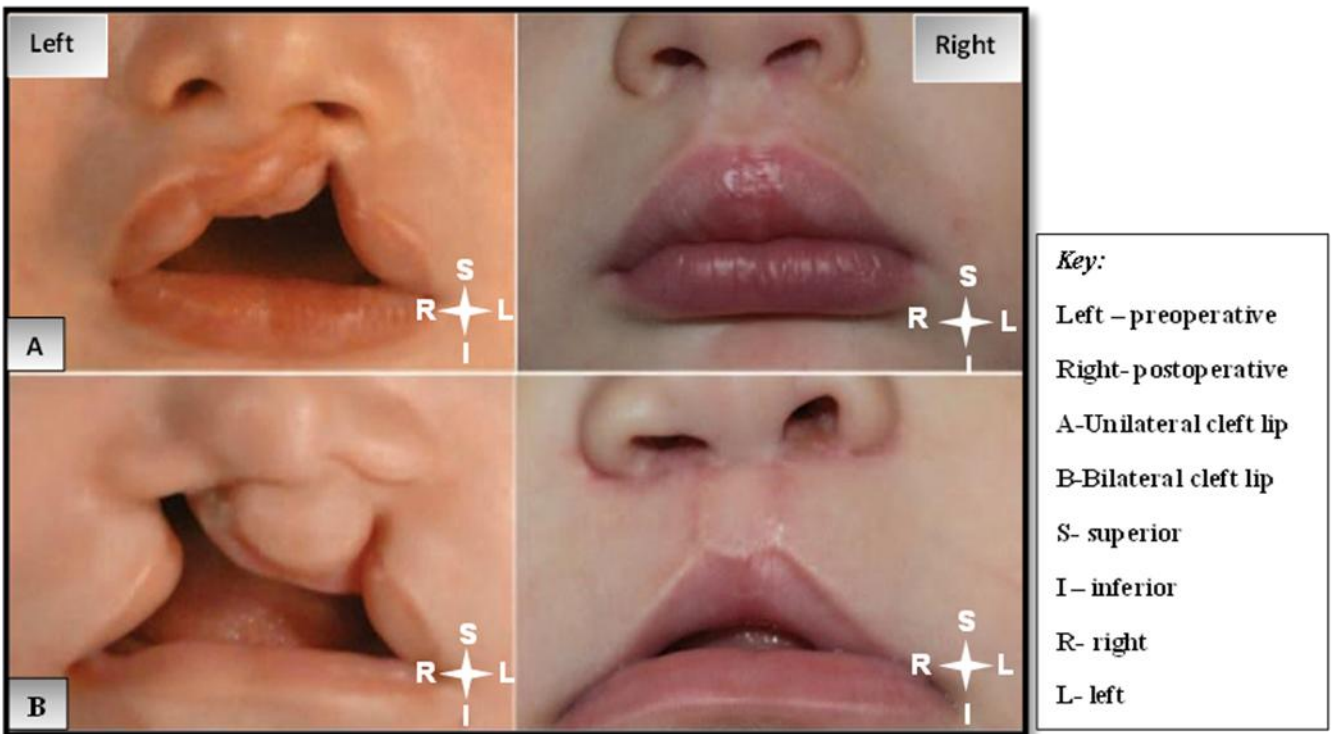


Figure 8: Goals of surgical repair (Adapted from Gatti *et al.*, 2017) (Left = preoperative, right = postoperative)

1.2.5. Epidemiology

Globally, orofacial clefts occur in approximately 1.5 out of every 1000 live births (about 220,000 new occurrences each year), with considerable variations between geographic areas, ethnic groups and the type of cleft itself (Tables 2, 3, 4) (Allam *et al.*, 2014). For example, Native Americans and Asians (China, Japan) had the highest reported incidence rates of cleft lip and/or palate, whereas Africans and Southern Europeans had the lowest rates (Pereira *et al.*, 2018). According to Burg *et al.* (2016), the prevalence rates per 10,000 live births were highest among non-Hispanic Whites (7.60), followed by Asian/Pacific Islanders (4.90), Hispanics (4.79), non-Hispanic Blacks (4.12) and Native Americans (2.11).

A study by Gatti *et al.* (2017) found that the majority of patients with orofacial clefts were identified as Caucasian (82%), followed by Asian (13%), Latino (3%), and African American (2%) individuals. The highest prevalence rates per 10,000 live births were reported in British Columbia (25.31), Finland (14.31) and Malta (14.13), whereas the lowest rates were observed in South Africa (1.93), Colombia (1.69) and Cuba (1.35) (Burg *et al.*, 2016). Overall, the incidence of orofacial clefts tends to be highest among Asians (0.82–

4.04 per 1,000 live births), intermediate among Caucasians (0.9–2.69 per 1,000 live births) and lowest among Africans (0.18–1.67 per 1,000 live births) (Vanderas *et al.*, 1987; Mossey, 2023; Wright *et al.*, 2023; Putri *et al.*, 2024).

It has been reported that African populations have the lowest prevalence of orofacial clefts, at approximately 1 in 2,500 live births, compared to about 1 in 1,000 among European populations (Emeka *et al.*, 2018). In contrast, Asian and Native American populations exhibit the highest recorded prevalence, reaching up to 1 in 500 live births (Emeka *et al.*, 2018).

Most African countries lack active, population-based surveillance programs and prevalence data are largely derived from hospital-based studies (Hlongwa *et al.*, 2019). Reported prevalence rates across Africa range from 0.2 to 1.7 per 1,000 live births, with Kenya showing the highest rate (1.7 per 1,000) (Hlongwa *et al.*, 2019), followed by Nigeria (0.5 per 1,000) (Butali *et al.*, 2014) and Ethiopia (0.2 per 1,000) (Eshete *et al.*, 2017). In South Africa, Singh *et al.* (2020) reported prevalence rates ranging from 0.1 to 0.4 per 1,000 live births.

Overall, studies across the continent consistently demonstrate a comparatively low prevalence of orofacial clefts, which may reflect underreporting due to inadequate data collection systems and limited health record infrastructure (Moodley *et al.*, 2018).

The most prevalent kind of cleft in South Africa was isolated cleft palate, followed by cleft lip and palate, and then cleft lip (Hlongwa *et al.*, 2019). Cleft lip is consistently more common in South African males than females, with a 2:1 ratio (James *et al.*, 2000; Hlongwa *et al.*, 2019). Cleft palate is more frequent in females than in males at a 2:1 ratio (James *et al.*, 2000). It has been proposed that certain maternal hormones responsible for offspring sex determination also promote the development of orofacial clefts. (James *et al.*, 2000; Ács *et al.*, 2019; Hapsari *et al.*, 2024).

The Free State had the highest prevalence rate for orofacial clefts (1.2 per 1000 live births), followed by the Western Cape (1.0 per 1000 live births), while the Northern Cape and Eastern Cape had the lowest prevalence rates (0.1 per 1000 live births). The prevalence rate in KwaZulu-Natal was 0.2 per 1000 live births, which was the same as in Limpopo and the North West provinces (Hlongwa *et al.*, 2019).

Table 2: Incidence of cleft lip in different countries

<i>Author</i>	<i>Sample Size (n)</i>	<i>Geographic Location</i>	<i>Incidence n (%)</i>
Van Wyk <i>et al.</i> , 1987	260	South Africa	59 (22.7%)
Tolarova <i>et al.</i> , 1998	2732	United States of America	718 (26.28%)
Shapira <i>et al.</i> , 1999	278	United States of America	6 (2.15%)
Manyama <i>et al.</i> , 2011	240	Uganda	118 (49.2%)
Chowdhury <i>et al.</i> , 2017	300	India	89 (29.70%)
Emeka <i>et al.</i> , 2017	94	Nigeria	62 (65.97%)
Gatti <i>et al.</i> , 2017	752	Italy	215 (28.59%)
Moodley <i>et al.</i> , 2018	383	South Africa	93 (24.2%)
Pereira <i>et al.</i> , 2018	701	Portugal	165 (23.5%)
Hlongwa <i>et al.</i> , 2019	699	South Africa	133 (19.03%)
Elmouden <i>et al.</i> , 2020	40	Morocco	12 (30%)
Ruiz-Guillen <i>et al.</i> , 2021	60	Spain	10 (17%)

Table 3: Incidence of cleft palate in different countries

<i>Author</i>	<i>Sample Size (n)</i>	<i>Geographic Location</i>	<i>Incidence n (%)</i>
Van Wyk <i>et al.</i> , 1987	260	South Africa	70 (26.6%)
Tolarova <i>et al.</i> , 1998	2732	United States of America	784 (28.70%)
Shapira <i>et al.</i> , 1999	278	United States of America	31 (11%)
Manyama <i>et al.</i> , 2011	240	Uganda	28 (11.7%)
Chowdhury <i>et al.</i> , 2017	300	India	4 (1.3%)
Emeka <i>et al.</i> , 2017	94	Nigeria	10 (10.6%)
Gatti <i>et al.</i> , 2017	752	Italy	202 (26.86%)
Moodley <i>et al.</i> , 2018	383	South Africa	115 (30%)
Pereira <i>et al.</i> , 2018	701	Portugal	249 (35.5%)
Hlongwa <i>et al.</i> , 2019	699	South Africa	247 (35.34%)
Oner <i>et al.</i> , 2020	1229	Turkey	436 (35.6%)
Ruiz-Guillen <i>et al.</i> , 2021	60	Spain	14 (23.3%)

Table 4: Incidence of cleft lip and palate in different countries

<i>Author</i>	<i>Sample Size (n)</i>	<i>Geographic Location</i>	<i>Incidence n (%)</i>
Van Wyk <i>et al.</i>, 1987	260	South Africa	131 (50.4%)
Tolarova <i>et al.</i>, 1998	2732	United States of America	1217 (44.55%)
Shapira <i>et al.</i>, 1999	278	United States of America	197 (71%)
Manyama <i>et al.</i>, 2011	240	Uganda	94 (39.2%)
Chowdhury <i>et al.</i>, 2017	300	India	207 (69%)
Emeka <i>et al.</i>, 2017	94	Nigeria	22 (23.4%)
Gatti <i>et al.</i>, 2017	752	Italy	335 (44.55%)
Moodley <i>et al.</i>, 2018	383	South African	175 (45.8%)
Pereira <i>et al.</i>, 2018	701	Portugal	287 (40.9%)
Hlongwa <i>et al.</i>, 2019	699	South Africa	305 (43.63)
Elmouden <i>et al.</i>, 2020	40	Morocco	28 (70%)
Ruiz-Guillen <i>et al.</i>, 2021	60	Spain	36 (60%)

1.2.6. Aetiology

The aetiology of orofacial clefts is multifactorial (Singh *et al.*, 2020). Although genetic and environmental factors play a role in syndromic cleft lip or palate, it is still unclear what causes the more prevalent non-syndromic types (Yaqoob *et al.*, 2013). Cleft lip and palate can be caused by factors grouped as:

A. Non-genetic

: This includes a range of environmental (teratogenic) risk factors that might cause cleft lip or palate. Factors such as vitamin insufficiency, particularly folic acid deficiency, maternal smoking, alcohol intake, drug usage and chemical exposure have all been linked to the development of cleft lip and palate (Oner *et al.*, 2020).

B. Genetic:

These include:

Syndromic: In this case, the cleft is associated with another abnormality, such as Van der Woude syndrome, Treacher Collins syndrome or Pierre-Robin sequence. It is usually caused by a single gene abnormality (monogenic or Mendelian) (Lakhanpal *et al.*, 2014).

Non-syndromic: The cleft presents predominantly as an isolated defect, comprising roughly 70% of cleft lip or palate cases. This type doesn't represent a known malformation pattern, and the underlying cause cannot be determined (Lakhanpal *et al.*, 2014).

1.3. Materials and Methods

This study employed a cross-sectional design involving 50 patients (African- 40; Asian - 9; Caucasian- 1) presenting with non-syndromic clefts aged from 1 to 13 years. It was conducted at the Inkosi Albert Luthuli Central Hospital located in Durban, South Africa.

1.3.1. Inclusion criteria

Patients presenting with non-syndromic orofacial clefts who required surgical reconstruction.

1.3.2. Exclusion criteria

Patients presenting with syndromic cleft and oblique craniofacial clefts.

1.3.3. Ethical approval

The Biomedical Research Ethics Committee at the University of KwaZulu-Natal provided institutional ethical approval for this study (BREC/00004708/2022) [Appendix A].

1.3.4. Gatekeeper's permission

Relevant gatekeeper permissions were provided by the departmental head of Plastic & Reconstructive Surgery at Inkosi Albert Luthuli Central Hospital, along with approval from the KwaZulu-Natal Department of Health in South Africa [Appendix B & C].

1.3.5 Consent

As the study population consisted of minors below the age of 18, assent forms were provided to participants for completion. [Appendix D]. Thus, informed consent forms were also disseminated to parents or guardians [Appendix E].

1.3.6 Sample size determination

Using G-power software, the following statistical parameters were used to arrive at a minimum sample size with a statistical power of 90% with an effect size equal to 0.49. Type 1(Alpha) error equal to 0.05 (this is the false positive), Type 2 (Beta) error equal to 0.1 (this is the false negative), and statistical power = $1 - \beta = 0.9$ (which means a statistical power of 90%). Based on the above statistical parameter, a minimum sample size of 36 patients was determined; however, 50 patients were used to increase the statistical power of the study.

1.3.7 Data collection Tool

To measure the quality of life, a comprehensive questionnaire was designed (Appendix F). This questionnaire was adapted from the work of Menon et al. (2019). This questionnaire was adapted due to its being condition-specific, particularly for individuals with cleft lip or palate. The questionnaire consisted of four sections that addressed socio-demographic data, physical health, psychological health, and social health, following the conceptual framework developed by Klassen. et al (2012) (Figure 9). Section A focused on socio-demographic factors, gathering information on participants' age, biological sex, cleft laterality, and type of cleft. Section B focused on physical health, capturing data on physical capabilities like feeding, breathing, and speech. Section C covered psychological health, including assessments of how satisfied individuals were with their appearance, their level of psychological distress, and their self-

perception. Section D focused on social health, with items assessing social functioning and support systems, such as interactions with family members and peers. Sections B, C, and D utilized a four-point Likert scale where participants indicated the frequency of these experiences, with ratings as follows:

- 4 = No
- 3 = Uncertain
- 2 = Occasionally
- 1 = Yes

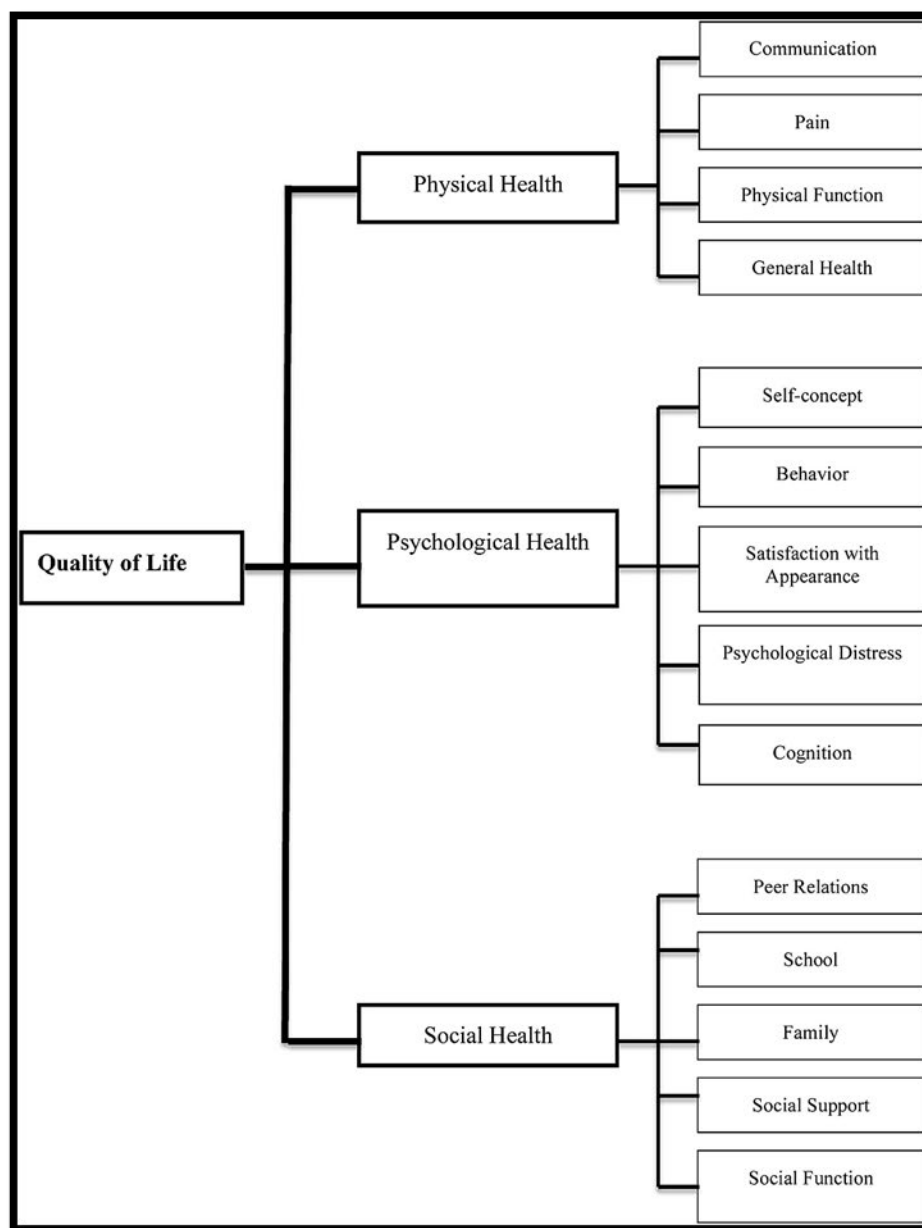


Figure 9: Domains of quality of life (Klassen *et al.*, 2012)

1.3.8. Data collection

The study interviews were carried out at Inkosi Albert Luthuli Central Hospital (IALCH) in Durban, South Africa. Fifty patients ranging from 1 to 13 years of age with non-syndromic cleft lip or palate who had been treated with primary or secondary reconstructive surgery at the Craniofacial Clinic between December 2022 and May 2023 were recruited on routine visits to the centre. Written informed consent from parents or guardians was obtained for each patient prior to study enrolment, as all subjects were minors under 18 years of age. Prior to enrolment, parents or guardians received detailed information and a thorough

explanation of the study. During the consent procedure, parents or guardians were able to ask questions and get clarification. The right to withdraw at any stage without being subjected to victimization was communicated to all parents or guardians. Where required, the principal investigator provided explanations of certain terms in one of the local South African languages. Given that all study subjects were under 18, responses were given by their guardians. The interviews were conducted by only one investigator, and they took approximately twenty minutes to complete; follow-up interviews were not needed. Following respondents' consent, the interviews were documented, anonymized and stored on an external hard drive accessible only to the researcher and supervisor. The supervisor will securely retain the data for five years in accordance with university policy.

1.3.9. Validity and Reliability of Questionnaires

The questionnaires were designed in collaboration with a biostatistician and then submitted to the supervisors for face and content validation. Cronbach's alpha reliability analysis was employed to validate the questionnaire. This measure assesses internal consistency or reliability. The test determines the consistency of surveys with multiple-item Likert scales that evaluate underlying dimensions like a person's awareness, anxious feelings, or honesty. Cronbach's alpha coefficients range from 0 to 1, with higher coefficients indicating greater reliability. A value of 0.70 or greater is commonly regarded as satisfactory for research purposes, although this standard may vary depending on the specific situation. The internal consistency reliability coefficients, as measured by Cronbach's alpha, demonstrated acceptable values across all assessed domains: physical health ($\alpha = 0.74$), social health ($\alpha = 0.77$), and psychological health ($\alpha = 0.72$). A pilot study was also conducted on five patients using the questionnaire to check its reliability. The aim was to ensure that when the questionnaire was used in the main study, the patients would find it easy to comprehend without stress due to unclear wording or concepts. In addition, it was required to make the questionnaire reliable in gathering pertinent feedback for each question.

1.3.10. Statistical Analysis

Data analysis was carried out using R Statistical software, version 3.6.3 (R Core Team, 2020). To evaluate QoL score variations, participants were classified into four categories: bilateral cleft lip and palate, unilateral cleft lip and palate, cleft lip only, and cleft palate only. Demographic data such as cleft type, laterality, age, and biological sex were compiled using SAS statistical software. QoL scores across different cleft subtypes were compared using Analysis of Variance (ANOVA). The relationship between sex and

QoL scores was examined using the Chi-square test of independence. Additionally, ANOVA was applied to analyze QoL scores across different age groups. QoL scores were calculated by summing up all the scores for each patient; high scores on each health domain imply a higher QoL. The QoL scores were determined by adding together all scores for each participant, higher scores across each health domain represent a better. **Determination of QoL:** The Median-Based Cut-off method was used, and a benchmark of 50.5% was considered; scores falling below or close to this mark represented low QoL, while those that exceeded this number represented high QoL.

1.4 Structure of the thesis

This master's thesis was prepared according to the guidelines outlined by the College of Health Sciences, University of KwaZulu-Natal, South Africa. The structural outline of the thesis is as follows:

1.4.1 Chapter 1: Introduction

This chapter supplied insight into cleft lip and/or palate, anatomy, embryology, and aetiology, as well as a comprehensive literature review and an overview of the study. This chapter includes the aims, objectives, research question and detailed methodology.

1.4.2 Chapter 2: Scientific manuscript

This chapter comprises an original scientific manuscript entitled: Quality of life of children treated for cleft lip or palate in a selected South African population: a questionnaire-based survey of guardian/parent perspectives. This manuscript analysed the physical, psychological and social impacts the clefts have on patients. The manuscript was structured and formatted according to the guidelines of the respective scientific journal.

1.4.3 Chapter 3: Synthesis and conclusion

This chapter discusses the findings of Chapter 2. It provides a synthesis of findings on the types of clefts, age and biological sex relations, as well as the effects of clefts on the quality of life of patients in relation to the three domains (physical, psychological and social). Following Chapter 3 are the appendices used in this study.

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Interface

Chapter 1 provided insight into the anatomy, embryology and aetiology of cleft lip and/or palate, as well as a comprehensive literature review on the quality of life of patients living with clefts and an overview of the study. The aims, objectives, research question, and detailed methodology were also discussed in this chapter.

Contributions of Chapter 2

This chapter comprises an original scientific manuscript entitled “Quality of life of children treated for cleft lip or palate in a selected South African population: a questionnaire-based survey of guardian/parent perspectives.” This manuscript analysed the physical, psychological, and social impacts that clefts have on patients. The manuscript was submitted to Oral and Maxillofacial Surgery on 23rd July 2025, accepted on 12th September 2025, and published online on 15th October 2025.

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CHAPTER 2
SCIENTIFIC MANUSCRIPT

**Quality of life of children treated for cleft lip or palate in a selected South African population: a
questionnaire-based survey of guardian/parent perspectives**

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Quality of life of children treated for cleft lip or palate in a selected South African population: a questionnaire-based survey of guardian/parent perspectives

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Abstract

Background Cleft lip or palate are defects that affect the orofacial region and continue to be a serious public health challenge impacting the quality of life of affected patients. Surgical repair of the cleft lip or palate has been the most effective treatment for correcting these facial defects. This study aimed to evaluate the quality of life of children treated for cleft lip or palate in a selected South African population.

Methods Fifty patients aged 1 to 13 years, diagnosed with non-syndromic cleft lip or palate, were evaluated six months post-surgery. The QoL of children with cleft lip and/or palate was assessed through parent-reported Likert scale ratings across physical, psychological, and social health domains.

Results Patients with cleft lip only reported lower QoL scores in the social health domain (63.5%). Those with unilateral cleft lip and palate showed reduced scores in the psychological health domain (57.1%), while patients with bilateral cleft lip and palate had lower scores in the physical health domain (71.1%). In contrast, children with cleft palate only demonstrated higher QoL scores across all health domains. Female participants reported higher scores in both the psychological (61.5%) and physical (85%) health domains. Notably, children aged 10–13 years had the lowest scores across all domains of health.

Conclusion Patients with a cleft palate only showed an increase in QoL than the other cleft subtypes. Females had an increased QoL than males, and children in the 1–3 age group exhibited higher QoL scores than older age groups.

Keywords Cleft lip · Palate · Quality-of-life · Physical · Psychological · Social health

Introduction

Cleft lip and palate are the most common congenital malformations of the head and neck, observed on the lips, hard and soft palates [1]. Most African countries lack active population-based surveillance programs for the screening of clefts. Prevalence is determined by using hospital-based data [2]. Only a few studies have been done in South Africa

to ascertain the epidemiology of clefts [3]. A prevalence rate of 0.3 per 1000 live births was reported in South Africa [4]. Cleft lip or palate are linked to several complications that impact patients' quality of life (QoL) in the physical, functional, and psychological domains, compromising their ability to eat, communicate, hear, and maintain their physical appearance [5]. These factors affect patients' well-being and self-esteem, which in turn have a direct impact on their social interactions and relationships [6]. Individuals born with clefts ideally receive multidisciplinary care that includes several surgical procedures, hospital stays, and repeated follow-up appointments throughout their childhood [6].

In 1947, the World Health Organization (WHO) first described QoL as a "state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity" [7]. The WHO's definition has expanded over time to encapsulate an individual's perspective of their position

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in life as situated within the cultural and ethical frameworks that form their world regarding their goals, expectations, standards, and concerns [7]. It is a broad concept that encompasses the complex integration of an individual's physical health, psychological state, level of independence, social connections, personal beliefs, and their relationships to key aspects of their environment [8].

Children with cleft lip or palate experience significant challenges associated with being visibly different, having speech and language difficulties, and social isolation [9]. An individual's psychological well-being is highly influenced by their perception of their facial attractiveness and their ability to communicate verbally [10]. Orofacial clefts may also often be linked to severe clinical and psychological consequences like anxiety, depression, and low self-esteem [11]. As a result, their management will significantly impact the patient's QoL and general well-being [11]. Cleft care in developing nations demonstrably lags behind that of high-income, well-resourced countries, primarily due to significant constraints such as limited financial resources, inadequate healthcare infrastructure, and critical shortages in the specialized workforce required for comprehensive cleft management [11].

Through various studies, social science research has continued to point out a strong bond between body appearance, stereotypes that people start to form, and the expectations that are consequently cultivated [12]. Social media platforms are widely accessible and significantly influence users' decision-making processes concerning various life domains, including health-related behaviors. However, most social media platforms create a serious risk of encountering misinformation [13]. Knowledge of this, in essence, cyclically flows back to demonstrate the extent to which appearance plays in shaping social perception and expectations of what certain physical looks or features signify [12]. Patients with clefts reportedly experience rates of anxiety and depression that are twice as high as those of the general population [12]. Depression in individuals with clefts has been associated with dissatisfaction regarding their appearance. The literature further suggests that various aspects of social functioning—including appearance-related satisfaction, anxiety, depressive symptoms, and family dynamics—may be adversely impacted [12].

Having the patients report their own perception of their QoL is very helpful in recognizing which measures can be taken and in what ways treating and caring should be improved; otherwise, the treatments may be those through which the patients derive just minimal benefits [14]. QoL is used to highlight the different hardships that can affect individuals. If patients are given this information, they will be able to anticipate and understand the outcomes of the deformity and its treatment [14, 15]. Difficulties can persist in

individuals born with clefts even after treatment. These late problems may not be detected without a QoL assessment. Since QoL is both a major prognostic factor and a predictor of response to treatment, good or bad, it will also become crucial for making medical decisions [14].

Treating cleft lip or palate is a comprehensive process that starts at birth and extends into adolescence and adulthood. Maxillofacial surgeons routinely perform surgical reconstruction for clefts, addressing lip repair around 4–6 months of age and palate repair between 8 to 14 months, and beyond, while clinical psychologists focus on psychological rehabilitation [16, 17]. Ongoing care involves regular clinic visits to manage health issues such as mid-facial growth deficiency, hearing challenges, ear infections, speech impairments, dental anomalies, and alveolar bone defects [17, 18]. The prolonged nature of these multidisciplinary treatments places a considerable psycho-emotional and financial burden on both the patient and their family, often impacting social relationships and coping mechanisms [17]. Accordingly, a questionnaire for individuals with cleft lip or palate could be able to address areas of importance and be aware of any changes in QoL aspects as the child matures. The current research, therefore, aimed to determine the effect of surgical repair of cleft lip or palate on the QoL in patients with orofacial clefts in a South African population, according to types of clefts, age, and sex.

Materials and methods

Study design

This is a cross-sectional study done at a Central Hospital in Durban, South Africa, with 50 patients between the ages of 1 to 13 years suffering from non-syndromic cleft lip or palate who underwent primary or secondary surgical repair within six months prior to the study.

Ethical approval

Institutional ethical approval for this study was obtained from the Biomedical Research Ethics Committee (BREC/00004708/2022) at the University of KwaZulu-Natal. Informed and written consent was obtained from the participants and their guardians.

Consent

As the participants in this study were younger than 18 years of age, an assent form was provided to their parent/guardian, after which an informed consent form was also requested to be completed.

Sample size determination

Using G-power software, the following statistical parameters were used to arrive at a minimum sample size with a statistical power of 90% with an effect size equal to 0.49. Type 1 (Alpha) error equal to 0.05 (this is the false positive), Type 2 (Beta) error equal to 0.1 (this is the false negative), and statistical power = $1 - \beta = 0.9$ (which means a statistical power of 90%). Based on the above statistical parameter, a minimum sample size of 36 patients was determined; however, 50 patients were used to increase the statistical power of the study.

Data collection tool

A structured questionnaire adapted from Menon et al. [19] was utilized for this study. This questionnaire was adapted because it is more disease-related, specifically to cleft lip/palate, as used by Menon et al. [19] in the South Indian population. The questionnaire was structured into four sections, covering socio-demographic information, physical health, psychological health, and social health, following the conceptual framework developed by Klassen et al. [20] (Fig. 1).

Section A was the socio-demographic information section, which included particulars of participants like age, sex, type of cleft, and side of cleft. Section B was the physical health section, and it comprised items on physical functioning, such as feeding, breathing, speech, etc. Section C was the psychological health component and included satisfaction with appearance, psychological distress, and self-concept items. Section D focused on the social health component. It consists of items on social functioning and social support, including peer and family relations. Sections B, C, and D included a four-point Likert scale on which participants were asked to rate how frequently these events occurred, where:

- 4 = No
- 3 = Do not know
- 2 = sometimes
- 1 = Yes

Validity and reliability of questionnaires

The questionnaire was drafted in consultation with a biostatistician and subsequently presented to the supervisors for face and content validation. The questionnaire was validated using the Cronbach's alpha reliability analysis test. Cronbach's Alpha is a measure of reliability, or internal

consistency. It evaluates the consistency of surveys using multiple-question Likert scales, which assess underlying variables such as an individual's awareness, feelings of anxiousness, or honesty. Cronbach's Alpha ranges from 0 to 1, where a higher value reflects greater internal consistency. Generally, a value of 0.70 or higher is considered acceptable for research. The Cronbach's Alpha value was calculated to be above 0.72 for all three health domains. A pilot study was carried out using 20% of the total sample size intended for the main research to check for the reliability of the questionnaire.

Method of data collection

Upon arrival at the Craniofacial Clinic, the principal investigator verbally explained the study details to each participant. Subsequently, each participant received an information sheet, and those who agreed were enrolled consecutively. As all participants were under 18 years old, parents or guardians provided responses on their behalf. When necessary, the principal investigator explained certain terms in one of South Africa's local languages. Following respondents' consent, the interviews were documented. The principal investigator conducted all interviews individually, and no follow-up interviews were required for any participant. On average, each interview lasted approximately 10 min.

Statistical analysis

Statistical data analysis was conducted using the R Statistical computing software of the R Core Team, 2020, version 3.6.3. To assess differences in QoL scores, participants were categorized into four subgroups: bilateral cleft lip and palate, unilateral cleft lip and palate, cleft lip only, and cleft palate only. SAS statistical software was employed to compile demographic data such as cleft type, laterality, age, and sex. Analysis of Variance (ANOVA) was employed to compare QoL scores across different cleft subtypes. The Chi-square test of independence was used to examine associations between QoL scores and sex. Additionally, ANOVA was applied to analyze QoL scores across different age groups. QoL scores were calculated by summing up all the scores for each patient; high scores on each health domain imply a higher QoL.

Determination of QoL The Median-Based Cut-off method was used, and a benchmark of 50.5% was considered; scores falling below or close to this mark represented

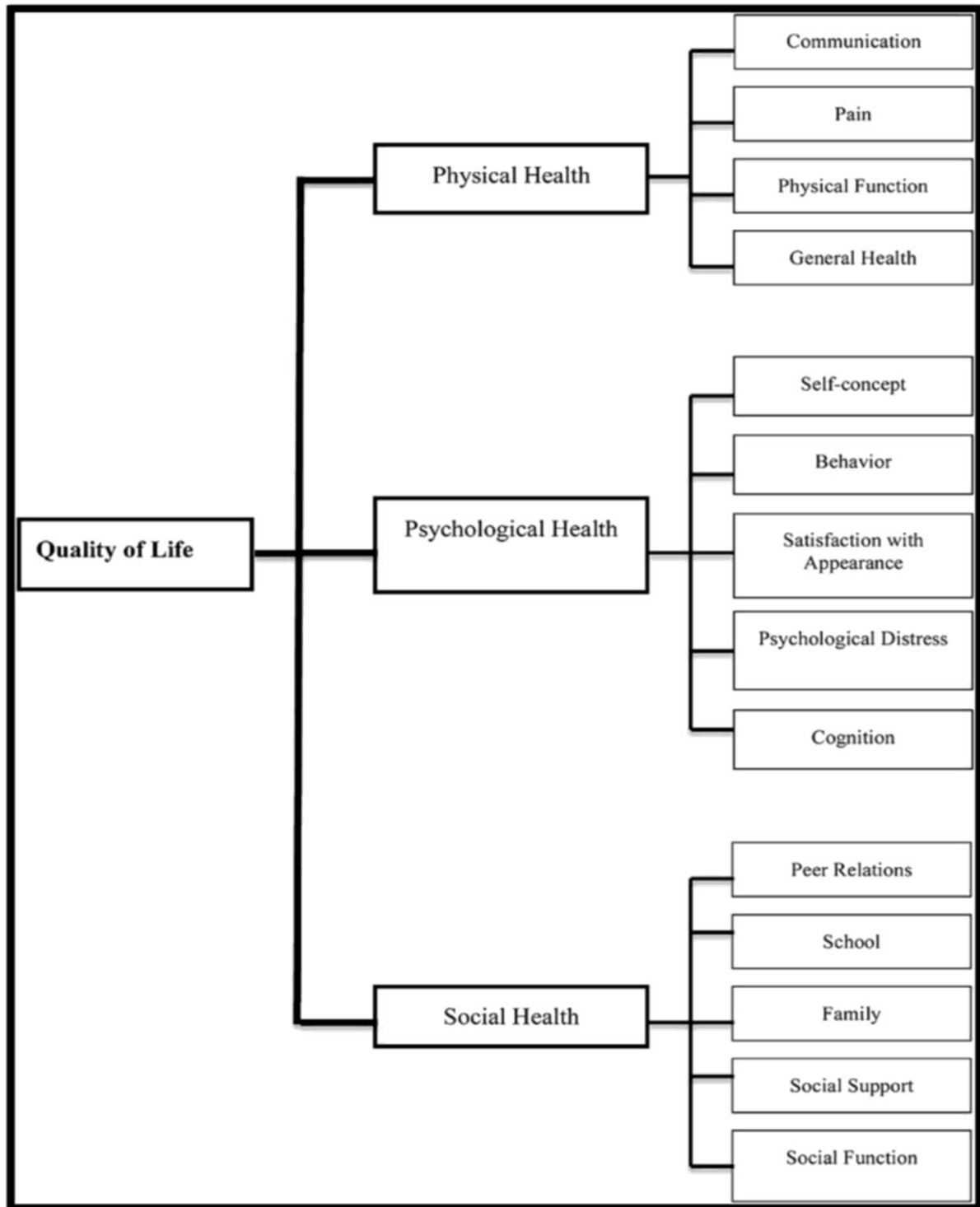


Fig. 1 QoL health domains (Adapted from Klassen et al., 2012)

low QoL, while those that exceeded this number represented high QoL.

Results

Demographics

A total number of 50 participants were included in this study. The median age of the participants was 3.00, with an interquartile range of 2.00 to 3.00 (Table 1).

Physical health domain

The majority of the participants' guardians (76%) reported that their children experienced feeding difficulties and a preference for soft or chopped foods. Only a small proportion (8%) experienced swallowing difficulties. Over 30% reported having difficulties breathing through the nose and hypernasality during speech, while more than 40% reportedly had challenges pronouncing certain words, which necessitated repeating themselves to be understood (Fig. 2).

Psychological health domain

Over 90% of parents reported satisfaction with the surgical outcomes, indicating that the results met their expectations and that they would recommend lip or palate repair surgery to others. Half of the respondents indicated that they had spent an excessive amount of time in hospitals, with 14% reporting that their children had undergone an excessive number of surgeries and 24% expressing a desire for additional surgical interventions. Only 4% of parents expressed regret regarding the decision to proceed with the procedure (Fig. 3).

Table 1 Participants' demographics

Type of Cleft <i>n</i> (%)	Lateral-ity <i>n</i> (%)	Age <i>n</i> (%)	Sex <i>n</i> (%)	Eth-nicity <i>n</i> (%)	Attending regular/spe-cial school <i>n</i> (%)
Bilateral lip; Palate 4 (8.0)	Left 18 (36.0)	Median (Q1-Q3) 3.00 (2.00–3.00)	Female 25 (50.0)	African 40 (80.0)	Not applicable 26 (52.0)
Lip 8 (16.0)	Left & Right 3 (6.0)	3.00 (2.00–7.00)	Male 25 (50.0)	Asian 9 (18.0)	Regular 21 (42.0)
Lip & Palate 25 (50.0)	Middle 10 (20.0)	<i>n</i> (Min-Max) 50 (1.00–13.00)		Cauca-sian 1 (2.0)	Special 3 (6.0)
Palate 13 (26.0)	Right 19 (38.0)				

Social health domain

More than 80% of guardians reported that their child found it easy to speak in groups, with new people, or in public settings, suggesting the ability to maintain healthy social relationships. Ten percent perceived that their child was treated differently from others, while 8% reported experiences of bullying or teasing. Over 20% indicated that their child avoided smiling in public, 36% noted that others made comments about their child, and 12% stated that their child hesitated to go out due to being stared at by others (Fig. 4).

QoL outcomes

Overall, physical health QoL scores were uniformly high across all cleft types, with values exceeding 70.0, while psychological health QoL scores were relatively lower for each cleft type, approximating values near 50.0 (Fig. 5).

Social scores were high for individuals with cleft palate only and low for those with cleft lip only; however, this difference was not statistically significant ($p=0.218$). A statistically significant difference was observed between participants with cleft lip only and those with cleft palate only, where psychological scores were low for the cleft lip group and high for the cleft palate group ($p<0.05$). Physical scores were low for participants with unilateral cleft lip and palate, bilateral cleft lip and palate, and cleft lip only, while those with cleft palate had higher scores; however, no statistically significant differences were observed ($p=0.173$) (Table 2).

No statistical significance was detected in social scores between males and females, as the values were equal ($p=0.863$) (Table 3). Psychological scores were slightly higher in females than in males, but this difference was not significant ($p=0.415$). Physical scores were higher in females compared to males, but this difference was not significant ($p=0.534$).

There is a decrease in the social score with increasing age across age groups; however, this decrease was not significant. ($p=0.380$) (Table 4).

Discussion

The concept of QoL has won the attention of academics and practitioners alike and is now recognized as an essential domain of study and practice in the field of health and medicine [14]. QoL is integral for symptom relief, care delivery, and patient reintegration [15]. In the last few decades, significant advancements in medical care, including technological innovations, new medications, and enhanced understanding of disease mechanisms, have led to a substantial

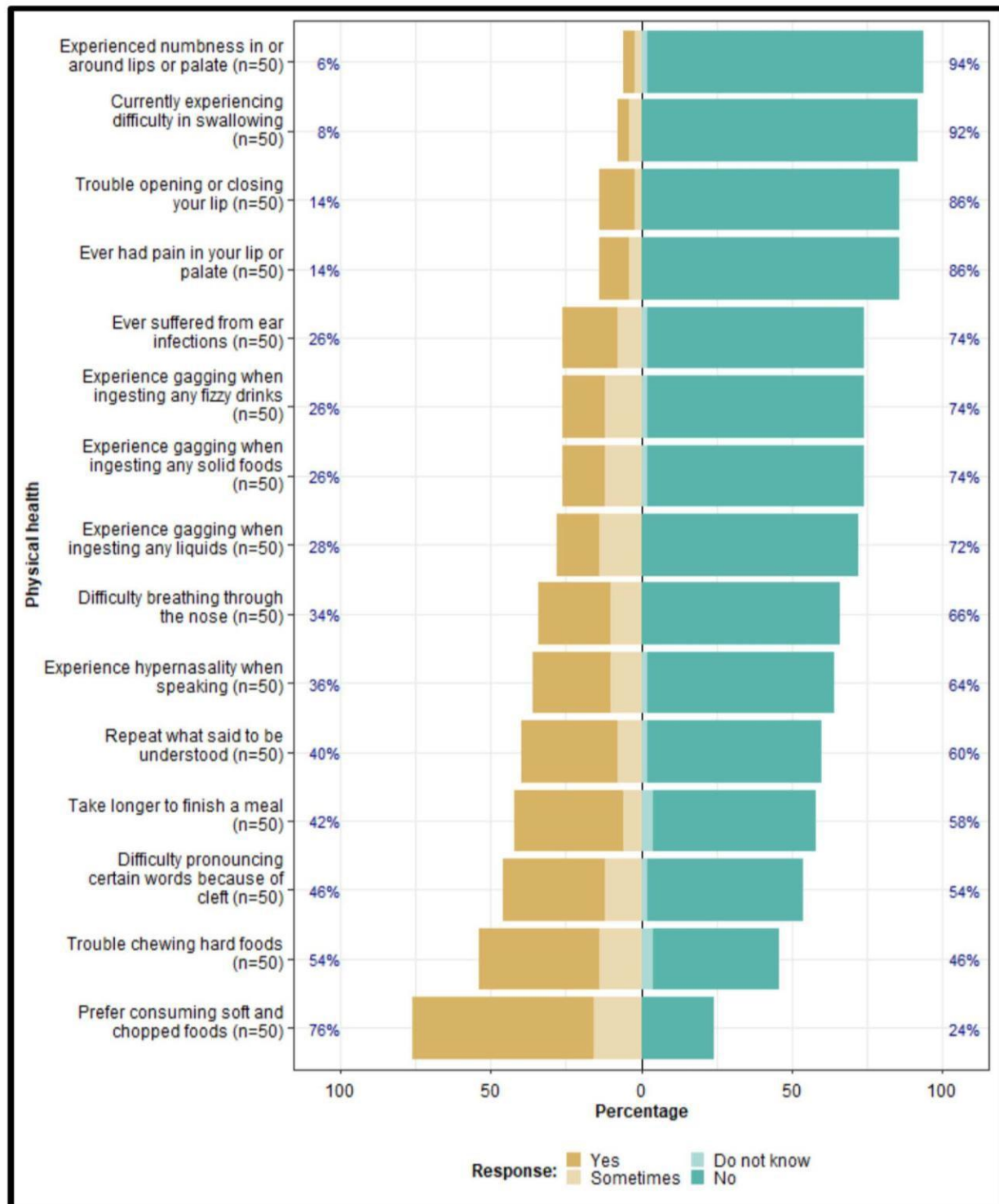


Fig. 2 Physical health domain

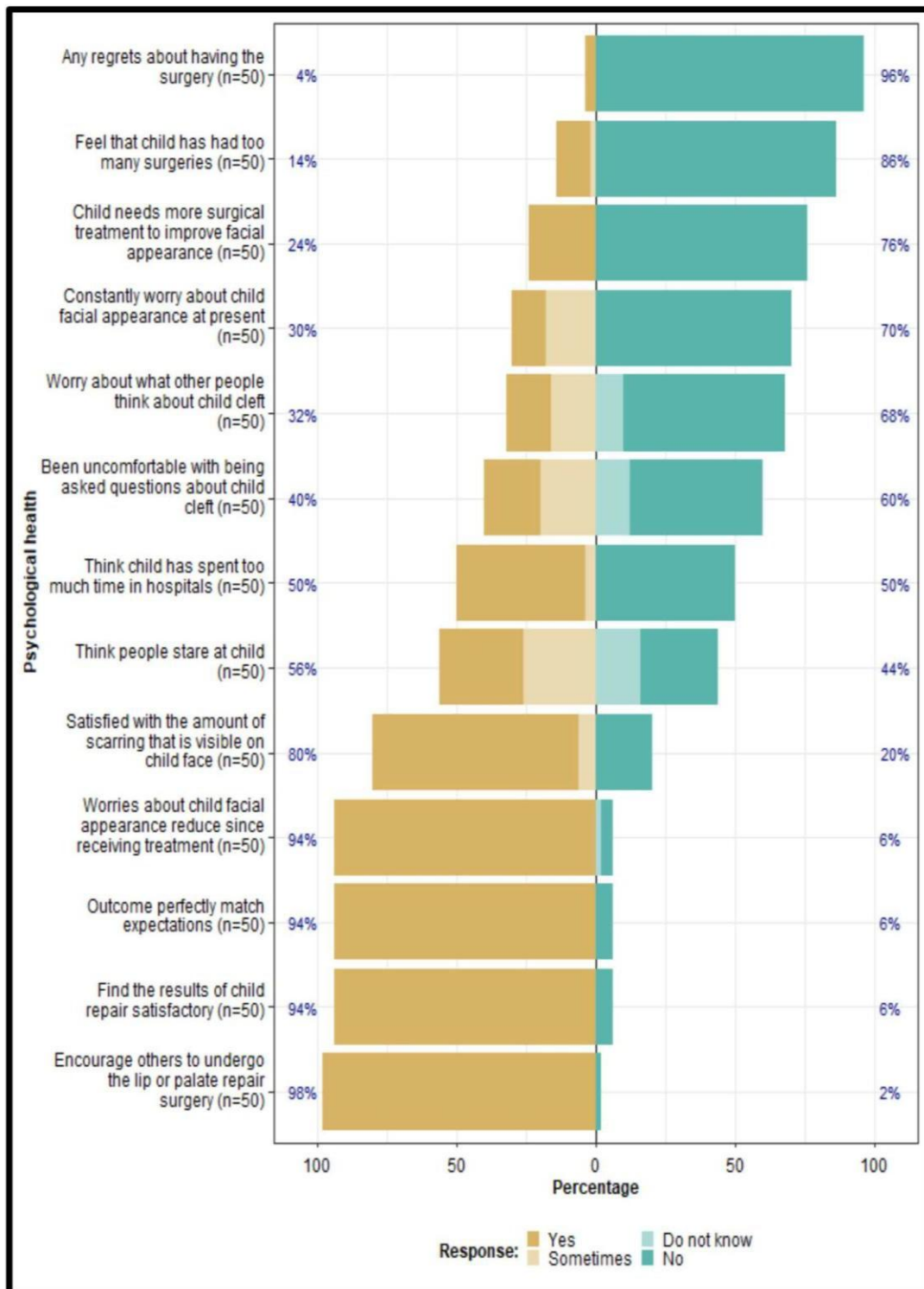


Fig. 3 Psychological health domain

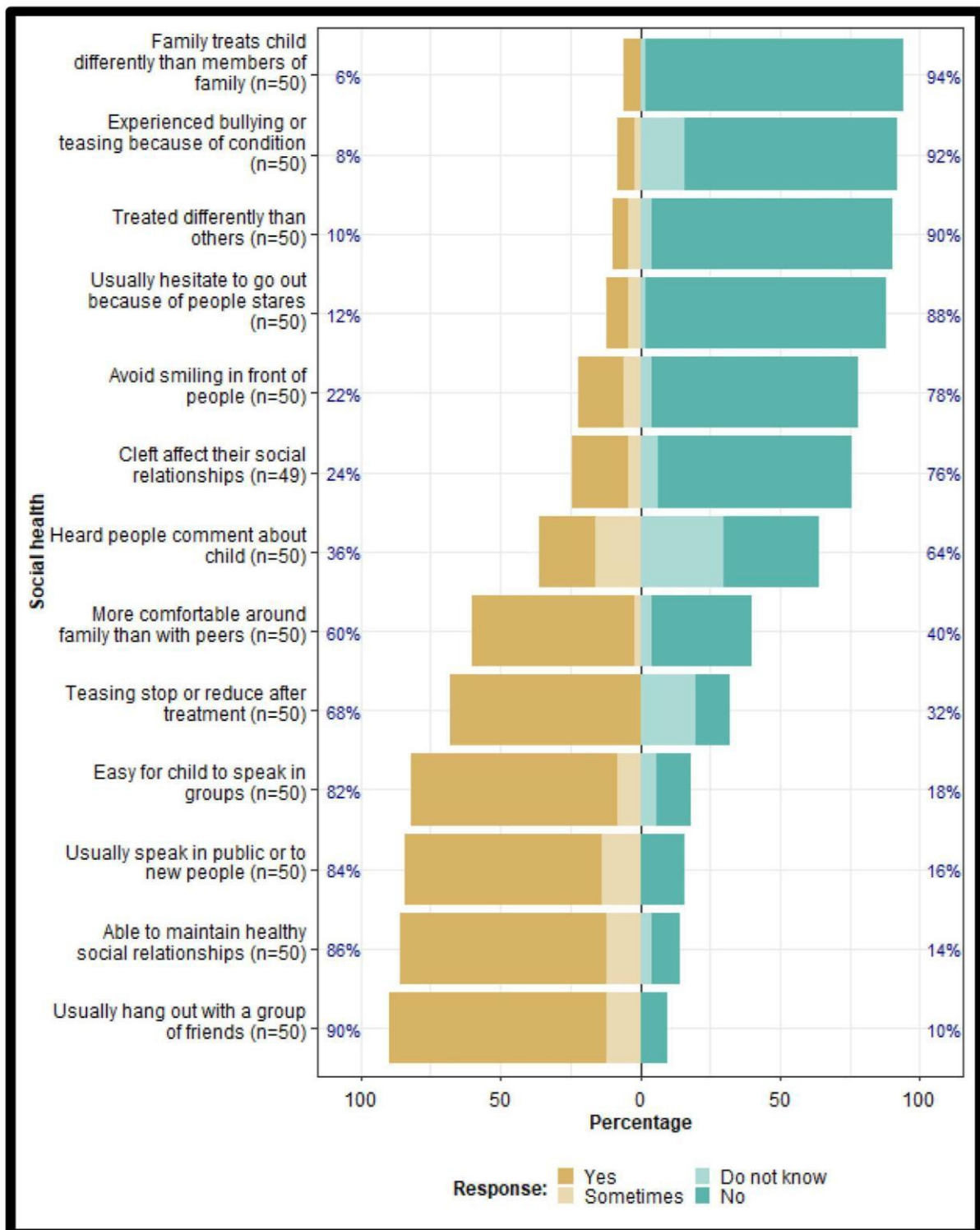


Fig. 4 Social health domain QoL Scores

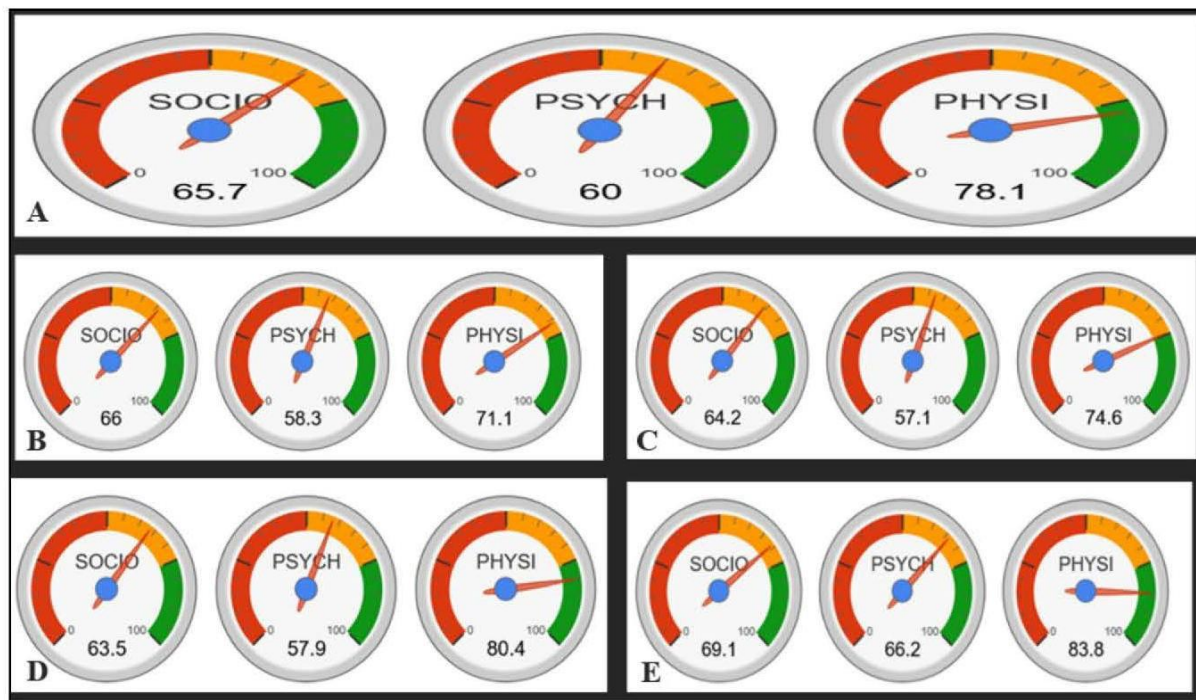


Fig. 5 QoL scores for all types of clefts: A) overall QoL scores for all types of clefts, B) bilateral cleft lip and palate, C) unilateral cleft lip and palate, D) cleft lip only, E) cleft palate only

Table 2 QoL scores of patients post-surgery categorized by the type of cleft

TYPE OF CLEFT	UCLP	BCLP	CL	CP	P-VALUE
PHYSICAL SCORE	74.6	71.1	80.4	83.8	0.173
SOCIAL SCORE	64.2	66.0	63.5	69.1	0.218
PSYCHOLOGICAL SCORE	57.1	58.3	57.9	66.2	0.004*
OVERALL QoL	65.3	65.13	67.27	73.0	0.273

UCLP, Unilateral cleft lip and palate; BCLP, Bilateral cleft lip and palate; CL, Cleft lip; CP – Cleft palate. * $p < 0.05$ is significant

Table 3 QoL scores of patients post-surgery categorized by sex

SEX	FEMALE	MALE	P-VALUE
PHYSICAL SCORE	85.0	78.3	0.287
SOCIAL SCORE	65.4	65.4	0.892
PSYCHOLOGICAL SCORE	61.5	59.6	0.415
OVERALL QoL	70.6	67.8	0.123

Table 4 QoL scores of patients post-surgery categorized by age

AGE GROUPS	1–3	4–6	7–9	10–13	P-VALUE
PHYSICAL SCORE	81.3	26.2	25.5	23.1	0.398
SOCIAL SCORE	67.0	23.0	22.4	19.7	0.380
PSYCHOLOGICAL SCORE	59.4	20.7	20.3	20.3	0.416
OVERALL QoL	69.2	23.33	22.7	21.0	0.393

increase in the average life expectancy of patients [21]. However, improvements in life expectancy do not always translate into improvements in QoL. Thus, it is imperative that all medical professionals put patients' QoL first [22].

Physical health domain

Children with this condition face a variety of functional and aesthetic challenges. These challenges include feeding complications since birth due to issues with oral sealing, swallowing, nasal regurgitation, and hearing problems due to abnormalities in the musculature of the palate, as well as speech defects due to problems in nasal escape, articulation, and dental matters [23]. While 76% of the participants reported that they preferred consuming chopped foods even after surgery, only 8% stated that they currently experience difficulties when swallowing, and 26% still experienced regurgitation. A notable difference was reported between males and females in this domain, with females reporting more improvements to their QoL as opposed to males. However, this difference was not statistically significant ($p = 0.287$).

Social health domain

Professionals caring for patients with clefts indicate that many individuals experience social effects due to the condition [24]. In a qualitative study by Tiemens et al. [25], participants indicated that having a cleft lip resulted in increased shyness and reduced confidence [25]. In this study, only 12% of the participants reported that they avoided going out because people stared at them. Using social isolation and distraction as methods for coping led to poor social experiences and poor adjustment [18]. According to previous studies, children with cleft lip or palate have a greater percentage of school dropouts and are less likely to participate in clubs and groups than their peers [26, 27]. The results of the present study differ in that 84% of participants reported that they usually speak in public or in their respective groups. This was supported by 8% of the participants who reported that they had been bullied. There was no notable difference between males and females in this domain, as both groups showed similar improvements in their QoL ($p=0.892$).

Psychological health domain

Anxiety and depression have been reported to be twice as prevalent among individuals with clefts compared to normal control patients [28]. Dissatisfaction with facial appearance has been found to be a predictor of depression among subjects with cleft [29]. According to a study by Noor and Musa [30], many patients stated that the cleft had influenced or "greatly impacted" their self-confidence [30]. In the present study, although over half of the participants stated they had spent too much time in hospitals and thought people stared at them, the overall perception showed that most (94%) were very satisfied with the outcome of their repair surgery. Also, their concerns about their facial appearance decreased after treatment. This is consistent with other studies in which children with cleft lip or palate achieved higher scores in terms of self-image compared to control patients [10, 31]. While it is common in other studies that females with cleft lip or palate are more dissatisfied with their appearance than males [29, 32, 33], females in this study were more satisfied with the amount of scarring visible on their faces, which led to a relatively higher QoL than males.

Overall QoL

Efforts have been undertaken to measure the impact of dental and oral disorders on daily life and overall well-being, as well as their influence on clinical care outcomes, such as the effectiveness of treatment interventions [34]. Patients with cleft lip or palate are very conscious of how others perceive

them because their condition may be hard to conceal and could evoke negative feelings.

Considering the nature of the cleft, Payer et al. [35] reported that patients with cleft lip only showed the highest QoL score, followed by those with cleft palate only, those with a unilateral cleft lip and palate, and lastly those with a bilateral cleft lip and palate [35]. Similar studies done by Kramer et al. [36] and Sahoo [37] had the same results, with patients who were treated for cleft lip only having the highest QoL scores, followed by the cleft palate only group, and lastly, the unilateral cleft lip palate group [36, 37]. A study conducted by Bos et al. [32] also reported that patients treated for cleft lip only had high QoL scores. However, this group was followed by those with bilateral cleft lip and palate, unilateral cleft lip and palate, and cleft palate only [32]. Unlike the previous studies, results of this present study revealed minor differences in patients treated for cleft palate only, scoring the highest on QoL, followed by patients with cleft lip only, then unilateral cleft lip and palate, and lastly, patients with bilateral cleft lip and palate. It is necessary to note that different types of clefts require different treatment methods. These facts may clarify, at least partially, the differences reported.

Furthermore, regarding sex, previous studies report that female cleft patients are less satisfied with their facial appearance and have lower health-related QoL when compared with their male counterparts [29, 33–38]. Defabianis et al. [5] found QoL scores to be higher for males than females in an Italian population [5]. These findings are comparable to those of Bos et al. [32], who evaluated the quality of life of males and females and found males to have higher scores than females [32]. This observation is supported by the fact that females usually worry more about their body image and are more susceptible to the stigma associated with cleft repair than males [39]. This contradicts the results of the present study, which found females to have higher scores than males; however, it agrees with Eslami et al. [40], who examined the oral health-related QoL among Iranian patients and reported that females scored higher than males [40], these differences could also be due to the small sample size and the fact that surgical procedures required for each patient with cleft lip and palate will vary depending upon the type and severity of the deformity. In a similar study, Nolte et al. [41] provided an overview of QoL sex differences and indicated that females scored higher than males, which is similar to the works of previous authors [35, 36, 41, 42].

Some attention has been paid to variation with age. According to a review by Hunt et al. [10], age does not seem to have any significant influence on the QoL of cleft participants [42]. However, there are some exceptions to this, with increasing reports of more challenges as the child grows.

This can be seen in the decreasing QoL scores of participants over the age of 12. Previous authors have compared QoL of children in the age groups 8–12 and 12–15 and have found the latter to have significantly lower scores [5, 32, 35]. The present study had similar results, with participants in the 1–3 age group having higher QoL scores than the 10–13 age group. The observed variations may be attributed to the limited capacity of young children to accurately self-report due to cognitive and communication challenges, whereas patients aged 12 and above typically demonstrate greater self-reflection, observational skills, and improved ability to communicate their concerns to their parents. This developmental difference likely explains the age-related disparities identified in the present study. An additional consideration is that the participants in this study were treated by different surgical teams, which may produce variable results.

Conclusion

This study evaluated whether QoL increases in children with cleft lip or palate after surgical treatment. Although with a limited sample size of fifty, the present study reported high QoL scores among patients affected by cleft lip and palate. However, even after surgery, some domains of physical, psychological, and social health remain affected. Patients affected by bilateral and unilateral cleft lip and palate have considerably lower QoL scores compared to individuals affected by cleft palate only. Females were less affected by the clefts, as their QoL scores were higher than those of males. Additionally, participants aged 1 to 3 reported the highest quality of life scores when compared to those in older age groups.

Limitation

One of the limitations of this study is the absence of a control group, which could have allowed for comparison with QoL scores of unaffected patients. Another limitation to consider is that cleft lip and palate repair can be performed using a variety of procedures. Also, every surgeon incorporates their own modification to make it a variation.

Recommendation

Further investigations with larger sample sizes for each cleft type, along with the inclusion of a control population, are necessary to produce more robust and convincing results. This approach would facilitate meaningful comparisons across different cleft types, populations, and age groups. To improve the assessment for patients with orofacial clefts, it is crucial to develop and validate condition-specific

questionnaires with defined cut-off values for the various QoL domains being evaluated.

Authors' contributions S.L., A.M., and L.L. conceptualized the study; S.L. and A.M. collected and analyzed data; S.L., O.S.A., and L.L. wrote and edited the manuscript.

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Data availability The data that support the findings of this study are available from the corresponding author upon request.

Declarations

Conflict of interest The authors declare no competing interests.

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Interface

Chapter 2 analysed the quality of life of children treated for cleft lip or palate, including the distribution of clefts by type, biological sex and age.

Contributions of Chapter 3

This chapter integrates and critically analyses the findings presented in Chapter 2 in relation to the existing literature. The discussion focuses on how surgical repair of cleft lip or palate affects the quality of life (QoL) of children across physical, psychological and social domains. These results are contextualised within the broader South African healthcare environment and related global findings. The chapter also highlights the implications of these findings for clinical practice, multidisciplinary care and future research.

CHAPTER 3

SYNTHESIS AND CONCLUSION

3.1. Synthesis

This study provided valuable insights into how different cleft types, demographic factors, and developmental stages influence quality of life outcomes in children who have undergone cleft repair. The research highlights the multidimensional nature of QoL in this population and reveals patterns that have significant clinical and theoretical implications. While reconstructive surgery remains a crucial step toward restoring function and aesthetics, the persistence of reduced QoL in some domains suggests that surgery alone does not address all aspects of patient well-being. This finding aligns with previous studies, which emphasise that post-surgical patients may continue to experience physical, emotional, or social challenges despite successful anatomical correction (Klassen et al., 2012; Gosain et al., 2011).

This study is underpinned by the biopsychosocial model of health, which conceptualises quality of life (QoL) as the dynamic interaction between biological, psychological and social factors. Within this framework, cleft lip and/or palate is not viewed solely as an anatomical defect requiring surgical correction, but as a condition that influences multiple interconnected domains of a child's development and lived experience. The physical domain reflects biological functioning and surgical outcomes (e.g., feeding, speech and breathing), the psychological domain captures emotional wellbeing, self-perception and appearance-related distress, while the social domain reflects interpersonal relationships, peer interactions and societal responses to visible difference. By adopting this multidimensional perspective, the study moves beyond a purely surgical evaluation of success and instead interprets QoL outcomes as shaped by developmental stage, gender dynamics and social context within the South African setting. This theoretical lens strengthens the interpretation of findings by explaining why surgical repair, although essential, may not uniformly translate into optimal psychosocial or social wellbeing, thereby reinforcing the importance of multidisciplinary and context-sensitive cleft care.

Building on the biopsychosocial framework outlined above, the relationship between normal anatomy, cleft pathology, surgical reconstruction and quality of life (QoL) outcomes can be understood as a continuum linking structure to lived experience. Normal lip and palatal anatomy supports essential functions such as feeding, speech articulation, breathing and facial symmetry, all of which contribute to psychological confidence and social participation. In cleft pathology, disruption of these anatomical structures compromises both physiological performance and facial aesthetics, thereby influencing emotional

wellbeing and interpersonal interactions. Surgical repair seeks to restore anatomical continuity, muscular integrity and structural alignment; however, the findings of this study demonstrate that anatomical reconstruction does not uniformly translate into optimal psychosocial or social outcomes. Interpreting QoL scores as indicators of the broader impact of anatomical restoration therefore reinforces the importance of evaluating surgical success not only in structural terms, but also in relation to functional recovery and the child's overall developmental and social wellbeing.

Creating an extensive QoL study for patients with clefts is challenging because it needs to take into account specific factors like speech, appearance, facial development, social implications and how these aspects change in complexity and significance as the patient grows through childhood (Klassen *et al.*, 2012). In frequently examined QoL evaluations, results typically depend on multiple factors and may vary according to the questionnaire types and variables assessed. (Kramer *et al.*, 2009; Shkoukani *et al.*, 2013). However, it is essential to acknowledge the limitations of patient-reported outcomes in measuring QoL, as they can significantly contribute to identifying the aspects of QoL that require the most improvement (Gosain *et al.*, 2011).

3.2. Quality of life

3.2.1 Physical health

Physical health represents the foundational component of QoL in children with clefts. It encompasses vital orofacial functions such as breathing, swallowing, chewing, and speech, which are integral to daily living and social participation (Bakke *et al.*, 2007; Schimmel *et al.*, 2021). The current study revealed that patients with cleft palate only exhibited higher scores in the physical domain compared to other subtypes. This may be attributed to the relatively less visible nature of palate clefts, requiring less complex surgical operations and the greater functional improvement that can be achieved after repair. Children with bilateral cleft lip and palate demonstrated the poorest physical health scores (71.1), indicating that despite surgical intervention, these children continue experiencing substantial functional limitations in speech production, feeding, breathing, and hearing six months post-operatively. This persistent impairment suggests current surgical techniques incompletely restore normal anatomical function in the most complex cases. These findings suggest that surgical correction alone is insufficient for many patients, particularly those with bilateral clefts. These patients require comprehensive, sustained functional rehabilitation addressing speech, feeding, hearing, and respiratory function that extend well beyond the immediate post-operative period.

3.2.2. Social health

The social health domain measures the child's ability to engage and communicate within their environment. Participants with cleft lip only, which is the least anatomically severe defect, recorded lower social scores (63.5). This finding demonstrates that visible facial difference drives social outcomes more than functional severity. Despite having normal speech, feeding, and hearing, children with residual lip scarring or subtle facial asymmetry face substantial peer acceptance challenges and social exclusion. Children with isolated cleft palate, whose defects leave no visible facial evidence after repair, demonstrated the highest social health scores, possibly due to fewer visible stigmata. From these findings we can conclude that surgical excellence in aesthetic outcomes is not merely cosmetic, it also provides social rehabilitation. Surgical interventions for patients with cleft lip only may include scar revision, lip symmetry optimization, and nasal reshaping. However, medical intervention alone cannot solve social health problems, no surgical technique eliminates all visible evidence of cleft history. Therefore, social support requires non-medical strategies such as anti-bullying education in schools, social skills training for affected children, peer support groups and community education to reduce stigmatisation.

3.2.3. Psychological health

The psychological dimension of QoL is closely linked to a child's perception of self and satisfaction with appearance. The present study found lower psychological scores in patients with unilateral cleft lip and palate (57.1), these patients face both visible facial differences and speech issues, which together creates psychological risk that exceeds the separate impacts of each condition. This is supported by previous research showing reduced emotional well-being, such as increased rates of anxiety, elevated depressive symptoms and body image dissatisfaction among cleft patients (Sinko *et al.*, 2005; Hunt *et al.*, 2006, 2007; Mani *et al.*, 2010; Yusof *et al.*, 2023; Feragen *et al.*, 2017). Nevertheless, the persistence of psychological challenges highlights the importance of integrating psychosocial support, such as counselling and peer engagement programmes, into long-term cleft management. Furthermore, psychological support must be proactive rather than reactive. Waiting for psychological problems to manifest means intervening after damage has occurred. Teaching resilience, coping strategies, and positive identity development may prevent rather than remediate the psychological decline documented during ages 10-13.

3.2.4. Cleft type

Different types of clefts represent distinct clinical entities and require individualised rehabilitation and treatment approaches (Agnew *et al.*, 2017). Previous research has shown that cleft type can influence QoL outcomes (Wehby *et al.*, 2006; Damiano *et al.*, 2006; Lin *et al.*, 2020). Children with isolated cleft palate consistently showed the highest QoL across physical, psychological, and social domains, suggesting that less visible defects or those requiring less extensive surgical intervention produce better overall outcomes. The domain-specific vulnerabilities associated with different cleft types reveal important patterns. Children with cleft lip only experienced their greatest challenges in the social health domain (63.5% scoring lower), indicating that visible facial difference, even after surgical repair continues to impact peer relationships and social participation. This suggests that residual scarring or subtle aesthetic differences carry social consequences that persist beyond surgical correction.

Unilateral cleft lip and palate cases showed their lowest scores in the psychological health domain (57.1%), suggesting that the combination of visible facial difference and functional impairments (speech, feeding) creates particular psychological vulnerability. The burden of aesthetic and functional concerns may severely affect self-esteem issues and emotional wellbeing.

Notably, bilateral cleft lip and palate as the most severe anatomical defect demonstrated lowest scores in the physical health domain (71.1). This indicates that despite surgical intervention, children with bilateral

clefts continue experiencing functional limitations affecting feeding, breathing, speech production, and possibly hearing. The physical complexity of bilateral defects appears to exceed what current surgical techniques fully restore, leaving residual functional impairments that impact daily physical functioning.

3.2.5. Sex

The literature consistently notes biological sex differences in the occurrence of orofacial clefts based on traditional classification categories; however, there is no widely accepted explanation for these variations. While some studies have explored biological sex differences in satisfaction with cleft treatment outcomes, the relationship between biological sex and QoL among patients with cleft lip or palate remains insufficiently understood (Mani *et al.*, 2010). In this study Females demonstrated higher scores in both psychological (61.5%) and physical (85%) health domains compared to males. This finding contradicts much Western literature where females with facial differences typically report lower QoL due to greater societal emphasis on female appearance. This reversal suggests that gender effects on quality of life are not universal but culturally constructed, varying according to local cultural values, gender role expectations, and social structures.

3.2.6. Age

The use of a structured, validated questionnaire allowed for systematic assessment of QoL. However, since all participants were under 18 years of age, data were collected from the perspectives of parents or guardians. Although this approach ensured reliability, it may have introduced perception bias, as parental evaluations might not fully capture the child's subjective experiences. Additionally, the study's hospital-based setting may limit the generalisability of findings to the broader South African population, especially in rural areas where access to specialised surgical and psychological care remains limited.

The age-related decline in QoL scores represents one of the study's most clinically significant findings. Children aged 1-3 years exhibited the highest QoL scores, with a progressive decline through middle childhood, and children aged 10-13 years showing the lowest scores across all domains. This pattern reveals several important dynamics. High QoL scores in early childhood (1-3 years) reflect Low self-awareness of differences, as there is little peer comparison, protective family environment, and parental optimism after a recent successful surgical intervention. Children at this developmental stage have not yet experienced severe social stigma, and functional limitations might not yet be completely obvious or socially relevant

The progressive decline in middle childhood (ages 4 to 9) can be related to school enrollment, increasing

peer contact, self-awareness development, and growing acceptance of being unique. As verbal communication becomes essential to classroom engagement and peer connections, speech impairments become more socially noticeable. Bullying and teasing usually start throughout these years.

The lowest QoL scores in the 10-13 age group (pre-adolescence) are a result of multiple developmental challenges coming together. Peer acceptability and self-concept are more influenced by physical appeal. Awareness of physical differences is heightened by increased self-consciousness and social comparison. The need for clear speech is increased by educational obligations. The difference in timing between surgical care (which is most common in early childhood) and psychosocial vulnerability (which is highest in late childhood and teens) suggests that current care models may inadequately address evolving patient needs.

3.3. Conclusion

This study demonstrated that although surgical repair significantly improves QoL in patients with cleft lip or palate, disparities persist across domains, particularly in psychological and social well-being. Female patients reported marginally better QoL scores than males, and children in the 10–13 age group showed the lowest scores overall. These findings reaffirm the necessity of comprehensive, multidisciplinary cleft care that extends beyond surgery to include psychological and social support.

The study contributes to the growing body of African-based evidence on QoL outcomes in cleft populations and provides a foundation for developing targeted interventions within resource-constrained healthcare systems.

3.4. Limitations

A limitation of this investigation is the absence of a control group, which would have enabled comparison of QoL scores between affected patients and healthy individuals. Additionally, variability in cleft lip and palate repair techniques, including surgeon-specific modifications, introduces heterogeneity that may affect the outcomes. The inclusion criteria in this study limited the sample size, but the final sample used was effective in detecting 90% power.

3.5. Recommendations

Future research should consider including a control group and focus on individuals aged 18 years and above to reduce reliance on parent-proxy questionnaires. Additionally, there is a need to create and validate a robust, cleft-specific, multidisciplinary quality of life measurement tool. There is also a need to implement routine QoL screening post-surgery to identify ongoing challenges. It is recommended that multidisciplinary cleft

care teams, including surgeons, speech therapists, psychologists and social workers, are established. Furthermore, family counselling and community-based support to reduce stigma are also proposed. It is also recommended that studies be expanded to include diverse South African populations to enhance representativeness.

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3.7. APPENDICES

3.7.1. Appendix A-Ethical Approval



28 August 2023

Mr Siyabonga Welcome Lembede (218000996)
School of Laboratory Medicine & Medical Science
Westville

Dear Mr Lembede,

Protocol reference number: BREC/00004708/2022
Project title: Quality of Life of Children Treated for Cleft Lip and/or Palate
Degree: Masters

EXPEDITED APPLICATION: APPROVAL LETTER

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application.

The conditions have been met and the study is given full ethics approval and may begin as from 28 August 2023. Please ensure that any outstanding site permissions are obtained and forwarded to BREC for approval before commencing research at a site.

This approval is valid for one year from 28 August 2023. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on RIG on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2020) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be noted by a full Committee at its next meeting taking place on 12 September 2023.

Yours sincerely,



Prof D Wassenaar
Chair: Biomedical Research Ethics Committee

Biomedical Research Ethics Committee

Chair: Professor D R Wassenaar
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INSPIRING GREATNESS

3.7.2 Appendix B- IALCH Gatekeeper permission letter



health

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28 August 2022

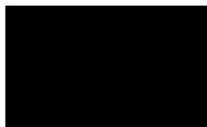
Dr Linda Mtshali
Medical Manager
Medical Service
Inkosi Albert Luthuli Central Hospital

RE: PERMISSION GRANTED TO CARRY OUT RESEARCH WORK AT IALCH – SIYABONGA LEMBEDE

This letter serves to notify you that permission is granted to Siyabonga Lembede to carry out research in Masters in Medical Science entitled “Quality of life of children treated for cleft lip and/or palate ” at the Inkosi Albert Luthuli hospital.

The research will have no cost implication to the IALCH institution.

Yours sincerely



PROF ANIL MADAREE
Head of Department, Plastic & Reconstructive Surgery

uMnyango Wezempilo . Departement van Gesondheid

3.7.3 Appendic C- DoH Permission



health

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DIRECTORATE:

Health Research & Knowledge
Management

NHRD Ref: KZ_202212_004

Dear Mr S Lembede
(UKZN)

Approval of research

1. The research proposal titled 'QUALITY OF LIFE OF CHILDREN TREATED FOR CLEFT LIP AND/OR PALATE' was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central hospital.

2. You are requested to take note of the following:
 - a. **Kindly liaise with the facility manager BEFORE your research begins.**
This is to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
 - b. All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.
 - c. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
 - d. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za
 - e. Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.

For any additional information please contact Dr. G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge

Chairperson, Provincial Health Research Committee

Date: 10/11/2022

Fighting Disease, Fighting Poverty, Giving Hope

3.7.8 Appendix D- Participant consent form

UKZN BIOMEDICAL RESEARCH ETHICS COMMITTEE

APPLICATION FOR ETHICS APPROVAL

For research with human participants (Biomedical)

INFORMATION SHEET AND CONSENT TO PARTICIPATE IN RESEARCH

Date: _____

Dear Potential Participant

My name is Siyabonga Lembede from the Department of Clinical Anatomy, UKZN: Westville Campus (Cell: 081 921 7700; Email: 218000996@stu.ukzn.ac.za)

You are being invited to consider participating in a study that involves a patient's quality of life pre and post cleft lip/palate repair surgery. Patients presenting with unilateral and bilateral cleft lip and/or cleft palate as well as combined cleft lip and palate will be interviewed.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BREC/00004708/2022). Kindly note that the supervisors of this study is Professor A. Madaree and Prof L Lazarus.

I _____, have been informed about the above study entitled "" by Mr. Siyabonga Lembede.

- I understand the purpose and procedures of the study.
- I have been allowed to ask questions about the study and have had answers to my satisfaction.
- I declare that my participation in this study is entirely voluntary and that we may withdraw at any time without affecting any treatment or care that we would usually be entitled to.
- If I have any further questions/concerns or queries related to the study, I understand that I may contact the researcher at provided details.
- If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

This survey is voluntary and anonymous. Withdrawing will not cause the participant to incur any negative consequence/s. There are no direct benefits of participation. Your participation is greatly appreciated.

Signature of Participant

Signature of Witness

Date

Date

3.7.9 Appendix E- Parental Consent Form

UKZN BIOMEDICAL RESEARCH ETHICS COMMITTEE

APPLICATION FOR ETHICS APPROVAL

For research with human participants (Biomedical)

INFORMATION SHEET AND CONSENT TO PARTICIPATE IN RESEARCH

Date: _____

Dear Potential Participant

My name is Siyabonga Lembede from the Department of Clinical Anatomy, UKZN: Westville Campus (Cell: [REDACTED] Email: 218000996@stu.ukzn.ac.za)

Your child is being invited to consider participating in a study that involves a patient's quality of life post cleft lip/palate repair surgery. Patients presenting with unilateral and bilateral cleft lip and/or cleft palate as well as combined cleft lip and palate will be interviewed.

This study has been ethically reviewed and approved by the UKZN Biomedical research Ethics Committee (approval number BREC/00004708/2022). Kindly note that the supervisors of this study is Professor A. Madaree and Prof L Lazarus.

I _____, have been informed about the above study entitled "" by Mr. Siyabonga Lembede.

- I understand the purpose and procedures of the study.
- I have been allowed to ask questions about the study and have had answers to my satisfaction.
- I declare that my child's participation in this study is entirely voluntary and that we may withdraw at any time without affecting any treatment or care that we would usually be entitled to.
- If I have any further questions/concerns or queries related to the study, I understand that I may contact the researcher at provided details.
- If I have any questions or concerns about my child's rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

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KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

This survey is voluntary and anonymous. Withdrawing will not cause the participant to incur any negative consequence/s. There are no direct benefits of participation. Your participation is greatly appreciated.

I hereby give permission for my child's responses to be recorded and published.

Signature of Parent/Guardian

Date

Signature of Witness

Date (Where applicable)

Signature of Translator

Date (Where applicable)

3.7.10. Appendix F- Questionnaire

Type of cleft:	
Side/laterality:	
Age:	
Sex:	
Population group:	
Attending a special or regular school:	

Please mark with an X where appropriate

TO BE FILLED BY THE PATIENT/ GUARDIAN	1 (Yes)	2 (Sometimes)	3 (Don't know)	4 (No)
PHYSICAL HEALTH				
1. Ever had pain in your lip/palate?	Yes	Sometimes	Do not know	No
2. Have you experienced numbness (a loss of sensation) in or around your lips/palate?	Yes	Sometimes	Do not know	No
3. Have you had trouble opening or closing your lip?	Yes	Sometimes	Do not know	No
4. Had trouble chewing hard foods e.g., apples, firm meat?	Yes	Sometimes	Do not know	No
5. Do you currently experience difficulty in swallowing?	Yes	Sometimes	Do not know	No
6. Do you prefer consuming soft and chopped foods?	Yes	Sometimes	Do not know	No
7. Do you experience gagging when you ingest any liquids?	Yes	Sometimes	Do not know	No
8. Do you experience gagging when you ingest any solid foods?	Yes	Sometimes	Do not know	No

9. Do you experience regurgitation when you ingest any fizzy drinks?	Yes	Sometimes	Do not know	No
10. Do you take longer to finish a meal?	Yes	Sometimes	Do not know	No
11. Have you ever suffered from ear infections?	Yes	Sometimes	Do not know	No
12. Do you have difficulty breathing through the nose?	Yes	Sometimes	Do not know	No
13. Do you experience hypernasality when speaking (occurs when too much sound vibrates in the nasal cavity during speech, causing the patient to sound as if they are talking through the nose)	Yes	Sometimes	Do not know	No
14. Had difficulty pronouncing certain words because of your cleft?	Yes	Sometimes	Do not know	No
15. Do you usually have to repeat what you say to be understood?	Yes	Sometimes	Do not know	No

PSYCHOLOGICAL HEALTH				
1. Do you find the results of your child's repair satisfactory?	Yes	Sometimes	Do not know	No
2. Did the outcome perfectly match your expectations?	Yes	Sometimes	Do not know	No
3. Do you have any regrets about having the surgery?	Yes	Sometimes	Do not know	No
4. Are you happy with the current appearance of your child's face?	Yes	Sometimes	Do not know	No
5. Are you satisfied with the amount of scarring that is visible on your child's face?	Yes	Sometimes	Do not know	No
6. Do you think your child needs more surgical treatment to improve their facial appearance?	Yes	Sometimes	Do not know	No
7. Would you encourage others to undergo the lip/palate repair surgery?	Yes	Sometimes	Do not know	No
8. Do you think people stare at your child?	Yes	sometimes	Do not know	No
9. Do you constantly worry about your child's facial appearance at present?	Yes	Sometimes	Do not know	No

10. Have your worries about your child's facial appearance reduced since you received treatment?	Yes	Sometimes	Do not know	No
11. Do you think your child has spent too much time in hospitals?	Yes	Sometimes	Do not know	No
12. Do you feel that your child has had too many surgeries?	Yes	Sometimes	Do not know	No
13. Do you worry about how what other people think about your child's cleft?	Yes	Sometimes	Do not know	No
14. Have you ever been upset/uncomfortable with being asked questions about your child's cleft?	Yes	Sometimes	Do not know	No
SOCIAL HEALTH				
1. Do you usually speak in public/to new people?	Yes	Sometimes	Do not know	No
2. Do you usually hang out with a group of people?	Yes	Sometimes	Do not know	No
3. Do you usually hesitate to go out because of people's stares?	Yes	Sometimes	Do not know	No
4. Have you heard people comment about you?	Yes	Sometimes	Do not know	No
5. Do you think you are treated differently than others?	Yes	Sometimes	Do not know	No
6. Does your cleft affect your social relationships?	Yes	Sometimes	Do not know	No
7. Do you think your family treats you differently than other members of your family?	Yes	sometimes	Do not know	No
8. Are you more comfortable around family than with peers?	Yes	Sometimes	Do not know	No
9. Have you been teased/bullied because of your condition?	Yes	Sometimes	Do not know	No
10. Has the teasing stopped/reduced after your corrective treatment?	Yes	Sometimes	Do not know	No
11. Do you feel confident when speaking in groups?	Yes	Sometimes	Do not know	No
12. Have you avoided speaking/reading in class because of your cleft?	Yes	Sometimes	Do not know	No

13. Do you avoid smiling in front of people?	Yes	Sometimes	Do not know	No
14. Do you consider yourself a person with good social relationships?	Yes	sometimes	Do not know	No

3.7.11. Turnitin

Match Overview

12%

1	Siyabonga Lembede, O...	6%	>
2	etd.uwc.ac.za	1%	>
3	www.ncbi.nlm.nih.gov	1%	>
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ABSTRACT

Background

Cleft lip or palate are regarded as the most prevalent congenital anomalies of the head and neck, occurring on the lips and both the hard and soft palates. These clefts are associated with complications that affect patients' quality of life (QoL) by impairing their eating, communication, hearing, and physical appearance in both adolescence and adulthood. Maxillofacial surgeons commonly carry out surgical repairs for clefts, yet some challenges may continue even after treatment. These ongoing issues might go unnoticed without a QoL assessment. Thus, this study aimed to evaluate how surgical correction of cleft lip or palate impacts the QoL of patients with orofacial clefts.

Methods

Fifty patients who came for cleft lip or palate repair surgery at Inkosi Albert Luthuli Central Hospital's Craniofacial Clinic were included in this study. A questionnaire was employed as the data collection instrument to evaluate the QoL of these patients.

Results

Participants with a cleft lip only exhibited low QoL scores specifically in the social health domain, at 63.5%. Those with unilateral cleft lip and palate had decreased scores in the psychological health domain, while patients with bilateral cleft lip and palate scored lower in the physical health domain, with percentages of 57.1% and 71.1%, respectively. In contrast, children with cleft palate only displayed higher QoL scores across all health domains. Female participants showed elevated scores in both the psychological domain (61.5%) and the physical domain (85%). Importantly, children aged 10 to 13 years recorded the lowest scores across all health domains.