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ROLES AND EXPERIENCES OF HEALTHCARE PROFESSIONALS IN CARING FOR PERSONS WITH CLEFT LIP AND/OR PALATE AT THE KOMFO ANOKYE TEACHING HOSPITAL, KUMASI, GHANA

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ABSTRACT

The specific roles and experiences of healthcare professionals in caring for CL/P patients are investigated. A case study of the qualitative approach was used. The study setting was the Multidisciplinary Cleft Clinic at the Komfo Anokye Teaching Hospital (KATH). Eleven healthcare professionals participated in the study. The study employed in-depth interviews to obtain rich, lived experiences of the participants. Themes identified included multi-disciplinary approach to care, patient and family centered care, collaboration with external organizations, longevity and experience in the field, patient reception and psychological support, financial and procedural counseling, building supportive relationship, geographic distribution and relocation of parents, psychological impact of CL/P on parents, emotional transformation, societal stigma and misconception, financial strain, social and emotional implications. The analysis of the roles and experiences of healthcare professionals highlights the importance of a comprehensive approach involving surgeons, paediatricians, orthodontists, nurses, nutritionists, social workers and representatives from the Ghana Cleft Foundation and Smile Train. This multi-disciplinary strategy addresses not only surgical aspects but also pre- and post-surgical care, genetics research, nutritional support, orthodontic care, speech therapy, and psychological assistance. The study confirms that holistic treatment and care for CL/P go beyond general medical care. This study emphasises the need for a multidisciplinary approach to CL/P care, accentuating that treatment extends beyond surgery to include nutrition, speech therapy, psychological support, financial assistance, and social integration. Establishing consistent collaborations among healthcare professionals, government, and philanthropic organisations is crucial in ensuring access to comprehensive cleft care.

Keywords: Healthcare professionals, experiences, roles, cleft, palate, patients, multidisciplinary, Komfo Anokye.

INTRODUCTION

Cleft lip and/or palate are the most common congenital craniofacial abnormalities (Mitchell and Wood 2000). Patients with cleft lip and/or palate need synchronised treatment and care involving numerous disciplines from birth throughout adolescence and adulthood (Hamdan *et al.* 2022). According to Lewis *et al.* (2017), persons with CL/P should receive their speciality cleft-related care from a multidisciplinary cleft or craniofacial team with sufficient patient and surgical volume to promote successful outcomes. The role of primary healthcare professionals is vital in enabling the provision of care and treatment for persons with CL/P, who every so often have several healthcare requirements. These healthcare requirements include chronic ear infections, feeding difficulties, speech disorders, and dental and orthodontic challenges (Mitchell and Wood 2000). The emotional issues of persons with CL/P and their families are noteworthy and hence, require the services of a multidisciplinary team to manage these complexities (Stock *et al.* 2024). The roles and experiences of healthcare professionals are therefore to provide a stable source of support for these patients and their families to assist in coordinating care and treatment for the countless physical and emotional problems they may face with. Mitchell and Wood (2000) in their study explain that the principal role of the cleft team is to provide integrated case management to ensure quality and continuity of patient care and longitudinal follow-up. This paper seeks to explore the specific roles and experiences of healthcare professionals at the KMCC as they provide treatment and care for persons with CL/P and their families.

LITERATURE REVIEW

Cleft lip and/or palate has been described as one of the most common congenital anomalies, causing many problems such as impaired suckling, defective speech, chronic ear infections, facial deformity, and severe psychological problems (Kaul *et al.* 2017). Even though the etiology of CL/P is still largely unknown, most clefts of the lip and palate are believed to have a multifactorial etiology with several genetic and environmental factors interacting to shift the complex process of morphogenesis of the primary and secondary palates toward a threshold of abnormality at which clefting can occur (Shi *et al.* 2008, Loenarz *et al.* 2010, Babai and Irving 2023). This anomaly thus requires a multidisciplinary approach from an interdisciplinary team. The management of persons with cleft lip and/or palate according to studies (Agbenorku *et al.* 2011, Paradowska-Stolarz *et al.* 2022), has scores of challenges but also several rewards. Inasmuch as the team approach to management of CL/P offers many advantages to the patient, the patient's family and the health care professionals, problems can also occur if the individual roles are not clearly defined within the team. Although the advantages of the team approach far outweigh any disadvantages, Dixon-Wood *et al.* (1991) explain that there are some common inherent problems associated with interdisciplinary teams. One factor that can affect the function of the team is the perceived or ascribed status of various team members relative to other members (Jones 2023, Watted *et al.* 2020, Wogden *et al.* 2019). This can be based on characteristics such as age, gender, discipline, experience, or accomplishments. According to (Hodgkinson *et al.* 2005), the presently accepted model for cleft care in the most appropriate way is by a multidisciplinary cleft team. This team is made up of individuals with diverse specialist backgrounds who work meticulously together, not only to bring each specialist's particular expertise to the patient in the optimum way, but also to develop

an understanding of the necessities and specialist skills of the other team members to enhance the delivery of a holistic outcome. It is worth noting that such an approach to cleft care enables each individual specialist within the team to function in an interdisciplinary way to ensure that all aspects of health care required by persons with CL/P are carried out as unified as much as probable (Hodgkinson *et al.* 2005). With this model, according to Watted *et al.* (2020), there exists collaboration, interaction, communication, and cooperation amongst the various specialists who are involved in the patient's care and treatment. This multidisciplinary approach has an international consensus spanning from multidisciplinary teamwork, centralisation, high-volume care, team continuity, long-term treatment planning from birth to adulthood, standardised protocols, documentation, evaluation, follow-up studies, research, training and quality assurance (Azzaldeen *et al.* 2017), and the Komfo Anokye Teaching Hospital has steadily developed its services along these lines. Usually, the multidisciplinary cleft team includes an orthodontist, a maxillofacial surgeon, a plastic surgeon, a prosthodontist, a speech therapist, an audiologist (ENT specialist), a psychologist, and a paediatrician (Sharp 1995). Inasmuch as the aims of treatment of a child with a cleft lip and/or palate include repairing the birth defect (lip, palate, and nose), attaining regular speech, language, hearing, functional occlusion, and good dental health, it augments the psychosocial and developmental results (Watted *et al.* 2020).

Roles of healthcare professionals in a multidisciplinary care system

Nurses: The nurse's role on the team is to assess the child's overall physical development. The nurse can determine if the child is growing normally and is in good general health (Peng *et al.* 2021). The nurse is often the professional who assists the family in developing compensatory feeding techniques (Perry *et al.* 2013). Finally, the nurse is typically the professional who counsels the family concerning surgical procedures and answers their peculiar inquiries (Watted *et al.* 2020).

Paediatrician: When a child is born with CL/P, the parents/caregivers are usually faced with shock, fear and despair (Stock *et al.* 2024, Dapaah *et al.* 2021, Hlongwa 2019). The paediatrician is responsible for assessing the patient's overall medical health, growth, and development. The paediatrician determines whether other aspects of medical care should be done prior to surgical intervention (Robin *et al.* 2006). The paediatrician member of the multidisciplinary cleft team is confronted with their immediate questions about what could have happened and what could be done. It is the duty of the paediatrician to positively influence the parents'/caregivers' attitudes toward their child born with CL/P and the management of the problem at hand. The knowledge, reassurance, and counselling that the paediatrician provides at such a critical stage go a long way to alleviate the uncertainties and anxieties of parents/caregivers of children with CL/P (Stock *et al.* 2024).

Nutritionist: Most children with incomplete cleft lip do not have feeding problems with bottles (Martin and Greatrex-White 2014, Bessell *et al.* 2011). However, the negative intraoral pressure that needs to be generated for suction cannot be created in complete cleft lip babies especially in the bilateral situation (Miller and Madhoun 2016). The best and economical way that this problem is dealt with is to use squeezable plastic milk bottles with enlarged teat hole (Agbenorku *et al.* 2011). The babies with clefts also need to be fed by a spoon or a syringe. This is to ensure that the baby learns these two alternative ways of feeding. It is the responsibility of the

Nutritionist to ensure that parents/caregivers of children with CL/P are equipped with this new knowledge of feeding their child with cleft lip and/or palate.

Oral Surgeon: The oral surgeon is the specialist who does bone grafts to the alveolar cleft areas when there is deficient bone in the line of the cleft (Stasiak *et al.* 2019). This specialist also performs the orthognathic surgeries, including maxillary expansions and mandibular setbacks, to normalise the occlusion between the maxillary and mandibular arches (Strong and Buckmiller 2001, Katzel *et al.* 2009)

Orthodontics: Dental problems associated with cleft lip and/or palate involve irregularity around the cleft, such as supernumerary incisors, rotation, and malformation of the lateral incisors and malocclusion (Lasota 2020). Orthodontic treatment, such as alignment of the teeth and their underlying supporting structures, is used to intervene at almost any age from birth to adolescent years. According to Dibart (2020), treatment is limited to discrete episode of treatment that contributes to the result, for example, presurgical dentofacial orthopaedics vase of a dental plate to align the maxillary segments before initial lip and palate repair. The orthodontist treats dental and skeletal malocclusion and promotes normal jaw relationships (Breeze and McLeod 2019). The orthodontist is responsible for aligning misplaced teeth and adjacent tissues to improve the dental and facial aesthetics and to improve the function of the dentition (Abu-Hussein 2008).

Otolaryngologist: The otolaryngologist, also known as the ear, nose, and throat specialist (ENT), is responsible for monitoring middle ear function and hearing, and treating middle ear disease, which is common in children with a history of cleft or craniofacial anomalies (Rickert 2023). The otolaryngologist also assesses the structural aspects of the oral cavity, oropharynx, nasal cavity, and upper airway-and treats anomalies, including Aden tonsillar hypertrophy, pharyngeal masses, or vocal fold abnormalities (Strong and Buckmiller 2001). The otolaryngologist may be the surgeon involved in the nasal and oral repairs and reconstruction. The otolaryngologist also manages upper airway obstruction, which is particularly common in infants with Pierre Robin sequence (Salyer 2001).

Speech and Language Therapist: According to (Nagarajan *et al.* 2009), children born with cleft lip and/or palate are at risk of developing abnormal speech patterns. Moghe *et al.* (2013) explains that most of non-syndromic cleft children who had palate repair before 18 months of age did not require speech and language therapy. The aetiology of speech disorder is often multifaceted and complex in nature with numerous structural and non-structural factors potentially interacting to cause speech challenges (Hodgkinson *et al.* 2005, Quigley *et al.* 2023). Etiologic factors include abnormal oronasal structure and function, such as velopharyngeal insufficiency, nasal airway deviations, hearing and ENT issues, residual clefts and oronasal fistulae, and abnormal oronasal structure and growth. The speech-language diagnostician counsels the parents/caregivers concerning what to expect with communication skills and how to accelerate normal development at home. The speech-language diagnostician assesses feeding and swallowing, general development, speech, language, resonance, and velopharyngeal function, and makes proposals for treatment when problems are detected. The speech-language diagnostician provides therapy for communication problems and syndromes of feeding or swallowing

Plastic Surgeon: It is the responsibility of the plastic surgeon to provide surgical repair of

the lip, palate, and facial anomalies, and is also responsible for the surgery for correction of velopharyngeal dysfunction (Bhuskute *et al.* 2017, Guerrerosantos *et al.* 2004). This surgeon may also perform cranial surgery, bone grafts, and orthognathic surgery on the jaws. Again, the plastic surgeon is responsible for not only the repair of the defects but also for the improvement through surgery of the patient's overall facial aesthetics, feeding function, and speech (Salyer 2001).

Prosthodontics: The branch of dentistry that deals with the restoration of natural teeth and the replacement of lost teeth is Prosthodontics (Zhao and Wang 2014, Jokstad *et al.* 1998). The prosthodontist can develop prosthetic devices to replace or improve the appearance of surrounding oral and facial structures. The prosthodontist can also manufacture and fit devices to assist with feeding and with velopharyngeal closure (Shprintzen and Bardach 1995).

Psychologist: It is the duty of the psychologist to assess the patient's psychosocial needs and assist the patient and family in dealing with the medical, social, and emotional challenges that arise due to the patient's anomalies. The psychologist often assists the physician in determining the preparedness of the patient for each surgical procedure (Bardach and Morris 1990).

Social Worker: The social worker helps families to deal with the countless problems accompanying the child's anomalies (Bennett 2011). The social worker sometimes is the one to manage appointments and may also assist the families in dealing with insurance and other funding sources. The social worker may help the family manage their stress and emotional reactions to the many challenges and issues associated with the child's treatment and care (Sommerlad 1994).

METHODOLOGY

This study employed a qualitative approach to investigating the roles and experiences of healthcare professionals at the Okomfo Anokye Teaching Hospital's Multidisciplinary Cleft Clinic in Kumasi. In-depth interviews were conducted among eleven (11) healthcare professionals to understand their roles and experiences as they provide care and treatment for people with CL/P. Consent to record responses was sought from the participants. All eleven tapes were transcribed into text and analysed using NVivo version 14 statistical software. On average, each interview lasted for 30 minutes. The total number of hours of interview recording obtained was 330 minutes (5 hours, 30 minutes). Common codes were identified and grouped for the presentation of results based on the study participants' responses. Two healthcare professionals at the KATH multidisciplinary cleft lip clinic were used to pilot the interview guide. The clarity of the questions was evaluated, and appropriate corrections were effected. Validity and reliability were ensured using multiple coders. Patterns of inconsistencies in the data were identified and corrected, and recurring ideas across responses were analysed to ensure consistency. Participants were given pseudonyms to fulfil the anonymity part of the consent form. The researcher was deeply involved in the data collection and analysis to ensure the Calibration of the Data Capturing Tool. Demographic information of healthcare professionals was captured, and the results are presented in Table 1. Thematic analysis was used for the objective of the study and was supported with theoretical and empirical evidence, as well as direct quotes of participants in quotation marks. Using Rosenstock & Hochbaum's classical version of the Health Belief Model (Gakuru 2004) to analyse the roles and experiences of healthcare professionals in CL/P care highlights the complexity of their work

and the decisions taken to provide holistic treatment and care for their patients.

RESULTS

The roles and experiences of healthcare providers are very crucial in the treatment and care of cleft lip and/or palate. The complexities of cleft lip and/or palate require the expertise of healthcare providers specifically trained to handle such congenital conditions. The study thus sought to find out the specific roles and experiences of these healthcare providers as they provide the needed treatment and care for children with the cleft lip and/or palate condition and its latent and manifest implications on parents/guardians. The roles and experiences that were brought to bear according to the study were; multi-disciplinary approach to cleft care, patient and family centred care, collaboration with external organisations and support systems, longevity and experience in the field, patient reception and psychological support, financial and procedural counselling, building supportive relationship, geographic distribution and relocation of parents/guardians, psychological impact of CL/P on parents/caregivers, emotional transformation, societal stigma and misconception, financial strain, social and emotional implications and medical and healthcare challenges.

Demographic Information of Healthcare Professionals

Table 1 presents the demographic characteristics and professional backgrounds of the 11 healthcare professionals. The results show that most participants (36%) are between the ages of 46 and 50 years. The other common age categories include 30-35, 36-40, and 41-45, with 18% each of the individuals, while those at 51 and above form 9%. On the basis of gender, males in the group constituted 64% whilst females constituted 36%. This genuinely reflects a composition dominated by male professionals. The majority (35%) of healthcare professionals had 3-5 years of experience, which is followed by 13+ years (27%). Year groups 6-9 years and 10-12 years had 18% each. The data provided is spread across many types of specialisations. The highest specialisation is Oral and Maxillofacial Surgeon, which has approximately 36%. Other specialities included Genetics (9%), Nurse (9%), Rep. Smile Train (9%), Social Worker (9%), Nutritionist (9%), Orthodontist (9%), and Plastic Surgeon (9%).

On the number of repairs done, the data points to a mixed contribution level among the professionals. The majority of them have carried out an uncountable number of repairs or have done "so many." Another 18% have conducted repair work described as "several scores" or "a lot," while another 9% have completed a "quiet number" of repairs. The data presents a picture of a group with varying years of experience yet predominantly male professional diversity. Most are aged 46-50, and experience years and specialties are being distributed in such a way as to demonstrate the depth of the group. The various levels of repair, illustratively capture to some extent the impact and dedication that these professionals bring to their respective fields.

Table 1: Demographic information of healthcare professionals

Demographics	Frequency	Percent (%)
Age		
30-35	2	18
36-40	2	18
41-45	2	18
46-50	4	36
51+	1	9
Sex		
Male	7	64
Female	4	36
Years of Experience		
3-5 years	4	36
6-9 years	2	18
10-12years	2	18
13+ years	3	27
Specialty		
Genetics	1	9
Nurse	1	9
Rep. Smile Train	1	9
Oral and Maxillofacial Surgeon	4	36
Social Worker	1	9
Nutritionist	1	9
Orthodontist	1	9
Plastic Surgeon	1	9
Number of repairs		
Several scores	2	18
A lot	2	18
Quiet a number	1	9
Uncountable	3	27
So many	3	27

Multi-disciplinary approach to cleft care

The data highlights a cohesive and multi-disciplinary approach to cleft care, underscoring the involvement of various specialists at different stages of patient life. Surgeons, paediatricians, orthodontists, nurses, nutritionists, and social workers contribute to a holistic care model.

The emphasis extends beyond surgical interventions, incorporating pre- and post-surgical care, genetics research, nutritional support, orthodontic care, speech therapy, and psychological assistance. This data accentuates the comprehensive nature of cleft care, emphasising the importance of a collaborative and multi-faceted strategy.

> *"I am part of the surgeons involved in the preparation of the patients before, during and after surgery. So mainly, we do the repairs. And then after that we make sure the wound has healed well, then we do the assessment to see whether the surgery was successful or not". (Dr. Larry)*

Patient and family-centred care

The data indicate that the multi-disciplinary cleft lip clinic provides patient and family-centred care, emphasising the consideration of patients' overall well-being, family background, and personal circumstances. The creation of patient folders with specialised sheets for different specialists illustrates a personalised approach to care. The inclusion of counselling and efforts to calm patients before procedures underscores the significance of addressing emotional and psychological aspects. Social workers play a crucial role in assessing social and psychological needs, highlighting a holistic approach that recognises the unique circumstances of each patient and their family.

Collaboration with external organisations and support systems

As part of the roles of healthcare providers, there is collaboration with external organisations and support systems, with a notable example being Smile Train. This international organisation provides financial support for surgeries and essential care, emphasising sustainability and local models. Social workers also contribute to psychological support, demonstrating the importance of external support systems beyond medical interventions. Plastic surgery, depicted as a problem-solving discipline, addresses not only congenital anomalies but also trauma and reconstructive aspects, emphasising a broader perspective on patient well-being.

The analysis unveils a comprehensive and collaborative paradigm in cleft care, encompassing various specialists and external organisations. The patient-centric approach emphasises personalised care, considering individual and familial circumstances. Collaboration with external organisations reflects a broader recognition of socio-economic and psychological factors influencing patients and families dealing with cleft conditions. This interpretation underscores the significance of a holistic, multi-faceted approach to ensure effective and sustainable cleft care.

> *"First of all, Smile Train is an international organisation that focuses on organization with sustainable and local model for supporting surgery and other forms of essential care. When I talk of essential care, after the surgery, the local partners, that is the doctors and nurses that Smile Train trains in Africa and other places, provide speech therapy, psychological support, nutritional service, orthodontics, and other essential forms of care to ensure that children with clefts have everything they need. Not everything in totality, but survives to some extent". (Miss Adu)*

Longevity and experience in the field

The data reveals a varying level of experience among practitioners. Some individuals have been practising for extended periods, exceeding 10 years, indicating a wealth of experience in the field. This suggests a mix of seasoned professionals contributing their knowledge and expertise to the practice.

This highlights the inclusion of both relatively new practitioners and those with extensive experience in the specialised field of cleft care. The varying time frames contribute to a dynamic and balanced team with a combination of fresh perspectives and seasoned insights.

The analysis suggests a well-rounded and dynamic team of practitioners in the specialised field of cleft care. The presence of both experienced professionals with over a decade of practice and newer practitioners with a few years of experience contributes to a diverse and collaborative environment. The commitment of individuals who have practised for an extended period indicates a sense of dedication to the field, fostering continuity and the accumulation of specialised knowledge over time. Overall, the analysis portrays a balanced blend of experience levels, promoting a comprehensive and evolving approach to cleft care.

"Oh, for the past 5 years, I have been with the cleft clinic". (Dr. Akosua)

'This is my fifteenth year with the cleft clinic, and I would say it's been adventurous and fulfilling knowing that I am able to make these children smile. (Dr. Larry)

Patient reception and psychological support

Reactions of parents and caregivers at the cleft clinic were noticed from the data. It is highlighted that the initial interaction varies depending on whether the patient is from the hospital's database or coming from outside. In either case, the first step is registration using the mother's name due to potential societal stigma. Importantly, the data emphasisesemphasise the critical role of psychological support and counselling for parents. The multidisciplinary clinic is seen as a supportive community where experienced mothers share their stories, providing comfort and reassurance to newcomers. This psychological support is considered an integral part of the healing process.

"So, as nurses, when the patient passes through the system, ideally when the patient comes, takes the card at the records, then goes to oral diagnosis and goes to pedodontics. So, the Pedodontists refer to Maxillofacial. Once they are in the system, we have their names in the system and then we start with the whole process. Because it is a multidisciplinary care, we make a folder for them (lymph). In the folder are different colours of sheets for the various specialists that they will see. On the form, we take their biodata. This helps us to get some information such as their family background, age, marital status, known traits in the family, alcohol use, whether they accessed traditional medicine at any point in time from them, after which we counsel them to calm them down for the process." (Nurse Sandra)

Financial and procedural counselling

The data indicates that a significant number of parents inquire about the cost during their first visit. The reassurance that the surgery is free is noted to have a positive impact on the parents, alleviating a burden. The process involves detailed counselling sessions explaining the surgical procedures, including the timing of surgeries based on the type of cleft. Additionally, the data reveals that some parents may only become aware of the free services after the surgery, showcasing the importance of financial transparency and the role of the foundation in covering expenses.

"We first talk to the people before they come to the clinic and usually, we have a fair idea of what they are going through so some of them will tell you, their problems. Some of them will tell you they don't have

transportation and some of them will tell you they don't even have food, so we get to know all of this. Sometimes too, when the doctors are taking care of the patients, they ask the mothers where they are coming from, and that gives us an idea of who to support." (Dr. Larry)

Building a supportive relationship

The data also highlights the establishment of a supportive and open relationship between the clinic staff and parents/caregivers. The clinic aims to create a familial atmosphere, acknowledging the emotional challenges that parents face. Reassuring parents that the cleft condition is not their fault and providing educational materials, including images, helps demystify the condition. These findings also underscore the importance of ongoing communication, both one-on-one and in group sessions, to educate parents about cleft conditions and create a sense of community among families facing similar challenges.

"Well, this builds a very cordial, friendly relationship with the clients and their relatives because then they become a part of a family union that we are forming. So, we open up to them, and they also open up to us. So, it becomes a family relationship sort of. We have a very cordial relationship, so that we can understand the clients and their caregivers' perspective very well and then we also explain the perspective of our management and care to them. (Dr. Osbourn)

The analysis reveals a holistic approach to patient reception at the cleft clinic. Beyond the procedural aspects, the clinic places significant emphasis on psychological support, financial transparency, and building relationships with parents and caregivers. This approach recognises the emotional and social dimensions of caring for children with cleft conditions, contributing to a more comprehensive and compassionate healthcare experience. The findings underscore the importance of integrating counselling, community-building, and transparent communication into the overall care framework for families dealing with cleft conditions.

Geographic distribution and relocation

The geographic distribution of parents and caregivers seeking services at the cleft clinic was analysed. The majority of patients, approximately 70%, predominantly come from the Ashanti Region. However, it is noteworthy that some families, particularly those from regions like the Western region, may relocate to Kumasi to conceal the cleft condition due to societal stigma. This relocation is driven by a desire to avoid the judgment and scrutiny associated with the visible birth defect. The data suggests that Kumasi has become a central location for these families, providing both anonymity and accessibility to the clinic's services. While cases from regions like Accra are not uncommon, the concentration of patients from the Ashanti Region and the phenomenon of relocation indicate the multifaceted challenges faced by families dealing with cleft conditions.

The data also emphasises the diverse regional representation of parents and caregivers seeking assistance at the cleft clinic. The data reveals that families travel from various parts of the country, including the Eastern, Western, Northern, Central, and Greater Accra regions. This wide regional representation underscores the clinic's importance as a national centre for cleft care. Families from areas, such as Obuasi, Tamale, and some communities in the Bono region, highlight the widespread reach of the clinic's services. The findings suggest that the clinic serves as a crucial resource

for families dealing with cleft conditions, attracting patients from both nearby and distant regions across the country.

"In terms of statistics, I will say that about 70% of our patients come from the Ashanti region. Sometimes they will come and tell you they are from Kumasi, but in actual fact, they are not from Kumasi. The reason being that when they are from the Western region and they have a baby with cleft, because they don't want the family and other people to see the defect, they relocate to Kumasi so they will get the Kumasi address. so, whenever you ask them 'where are you coming from?', they will tell you 'Ooo, I'm from Kumasi'. But we know that because of the stigma attached to such defects, some mothers will relocate and again since they have to attend clinic almost every week, it is better for them to look for somewhere in Kumasi or a close relative to live with. We sometimes get cases from even Accra and all over the country, but like I said, about 70% of the cases are from the Ashanti region". (Dr. Akosua)

"Most of our patients are from the Ashanti Region and its environs, but we have some of them coming from the Eastern Region, as far as Accra and the Western Region. In fact, we have patients coming from all over the country". (Dr. Ziblim)

"You know, most of these parents come from various parts of the Ashanti Region and other parts of the country. We have people coming from the Western region, Northern region, Central region, Eastern and even Accra'. (Dr. Sam)

The analysis reveals a dual perspective on the geographical dynamics of patient origins at the cleft clinic. The concentration of patients from the Ashanti Region and the associated phenomenon of relocation speak to the local challenges of stigma and the need for accessibility to specialised care. Simultaneously, the wide regional representation indicates the clinic's national significance, drawing families from various parts of Ghana. This dual perspective highlights the clinic's role not only as a local support hub but also as a vital national resource for families navigating the complexities of cleft conditions. Understanding geographic dynamics is crucial for tailoring support and services to the diverse needs of the family seeking assistance at the clinic.

Psychological impact of CL/P on parents/caregivers

The psychological impact on parents when they first bring their babies with cleft lip/palate (CL/P) to the clinic were commonly noticed by healthcare providers. The reactions are characterised by shock, disbelief, and emotional distress. Mothers, in particular, often face a significant psychological burden, exacerbated by societal stigma and, at times, blame from their spouses. The data highlights a prevalent trend where husbands may distance themselves, attributing the condition to the mother's actions. The clinic plays a crucial role in providing counselling and education to dispel myths, explaining the genetic and developmental aspects of CL/P. The multidisciplinary clinic serves as a supportive environment, helping parents realise they are not alone and fostering understanding of the condition.

"The normal trend is that most of them are broken from the initial visit, probably because they have not seen such a child with a cleft, so they come with anxiety and fear, but when they get to the clinic and realise they are not the only ones with children with the defect, then they become a bit relieved. There are some of the children who are born with very severe or extreme cleft and for such parents, you really will notice that they are very broken". (Dr. Mansah)

Emotional Transformation - Post-Surgery

The data explores the emotional transformation of parents after their babies undergo surgery for CL/P. The initial breakdown, fear, and disappointment give way to overwhelming joy and relief as they witness the positive changes post-surgery. Mothers express a desire to hug and carry their babies without the burden of concealing a visible defect. The societal pressure and impact on marriages are discussed, emphasising the toll the condition takes on family dynamics. Surgery becomes a catalyst for emotional healing, restoring confidence, and, in some cases, preventing marital breakdowns. The clinic serves as a pivotal point in this transformation, offering hope and support during this challenging journey.

> *"So, you see, before surgery, these mothers are broken, torn, displaced, and you name it. And after the surgery, when we bring their babies to the recovery room, some of them want to hug you and carry you, and the excitement is so great. In our part of the world, you know that when one has a baby, they want to show it to everyone and in fact, everyone wants to see the baby, and imagine you have a baby, but you cannot show her/him to everyone because there is a defect? It is not a pleasant experience, and it does take a toll on the parents, especially the mother". (Dr. Festus)*

Societal Stigma and Misconceptions

The analysis of the qualitative data indicates that parents frequently face societal judgment, with some cases mentioning the association of cleft babies with negative superstitions like being river children or victims of witchcraft. The reactions of families, including instances of rejection, hiding, or even sacrificing the child for rituals, highlight the deeply ingrained misconceptions within the community. The clinic not only addresses medical aspects but also undertakes the crucial task of dispelling societal myths and fostering acceptance, emphasising that CL/P is a developmental error, not a result of personal actions or divine punishment.

> *"They come and they start crying that they've never seen it before, and their husbands are rejecting them, leading to divorce and all that. So, our initial meetings are very emotional, but because I want them to really get the advice I'm giving them, I really don't go into their personal life because the moment you go into their private life they start crying and when it happens like that you just have to let them go and reschedule. So, I just don't go there but rather reassure them and remind them of the fact that there are other children with similar defects or even worse". (Dr. Yinni)*

The analysis underscores the multifaceted challenges parents encounter when facing the diagnosis of CL/P in their infants. The initial psychological impact, emotional transformation post-surgery, and societal stigma collectively paint a comprehensive picture of the complex journey these families navigate. The clinic emerges as a beacon of support, offering not only medical interventions but also crucial counselling, education, and a sense of community. This is pivotal for healthcare professionals to tailor interventions that address the holistic needs of parents and caregivers throughout the cleft care continuum.

Financial strain

The data highlights the multifaceted economic challenges, including transportation costs for frequent clinic visits, accommodation expenses for those travelling from distant locations, and the impact on employment as mothers often need to quit their jobs or take extended leaves. The financial implications

extend to the purchase of expensive food supplements, laboratory investigations, and potential complications such as diarrhoea, further adding to the economic strain. The interviews underscore the intricate relationship between financial difficulties and the ability to access necessary care, creating barriers to timely interventions and exacerbating the overall challenges faced by these families.

"Financial burden is one of the challenges of having a child with a cleft. Some of them share their dilemma, which involves transportation fares, the cost of feeding the baby and themselves, etc. Some of them have to quit their jobs and businesses just to take care of their child with cleft lip/palate". (Dr. Sumah)

Social and emotional implications

The data reveal that the social and emotional repercussions of having a child with CL/P were one of the challenges faced by parents. Stigma and societal misconceptions contribute to strained family dynamics, with instances of blame, abandonment, and emotional distress evident in the narratives. The impact on relationships, particularly the strain on marriages and neglect by some fathers, further exacerbates the emotional toll on mothers. The interviews highlight societal attitudes that associate cleft babies with superstitions, witches, and negative perceptions. The emotional strain extends to parents, caregivers, and even the affected individuals themselves, as evidenced by one case of a 28-year-old contemplating suicide due to the persistent stigmatisation and speech difficulties resulting from delayed surgery.

"Oh, cleft has a lot of implications on the mother, the child and sometimes the family. For instance, as I have indicated earlier, some men neglect the women and the baby, claiming that it is not their fault, leaving the mothers with some emotional and psychological burdens. The financial burden alone is something that can also contribute to some emotional issues. and you know, some of these children grow and have confidence issues because of their scars or their speech". (Dr. Osbourn)

Medical and healthcare challenges

The medical and healthcare challenges associated with CL/P are challenges faced by parents. The discussions touch on the complexities of surgical procedures, the high cost of treatment, and the need for comprehensive care involving speech therapists, orthodontists, and other specialists. The data underscores the intricate nature of addressing cleft conditions, which go beyond surgical interventions to include long-term orthodontic care, speech therapy, and potential psychological support. Challenges in feeding, breathing, and speech, as well as the potential for long-term dental and facial complications, are highlighted. The data suggests a need for a holistic approach that not only focuses on the physical correction of the cleft but also addresses the broader healthcare and emotional needs of individuals and their families.

"The main problem is how to latch the babies to breastfeed. Most mothers feel their babies are not having enough breastmilk, so the moment the baby starts crying, they feel the baby is hungry, so sometimes they prepare porridge in addition and usually, the porridge is even lighter than the breastmilk. The only way a child can communicate with the mother is through crying. We tell them and sometimes they feel that the moment the nipple gets into the mouth of the child, milk should start flowing. For some, transport fares are such a problem so with such a patient and maybe she is not getting enough

breastmilk, and within a week, a child can consume almost 2 tins of formular, and this has a financial implication. Financial difficulties in feeding the CL/P child are also something that parents/guardians battle with. Genuinely, there are some you have to come in to help". (Dr. Bilkis)

The analysis reveals the interconnected challenges faced by families with children diagnosed with CL/P, emphasising the need for a comprehensive and multidisciplinary approach to address financial, social, emotional, and medical aspects. The economic strain emerges as a significant barrier to accessing timely and appropriate care, potentially leading to delays in surgery and exacerbating the overall impact on affected individuals and their families. Additionally, the social and emotional implications underscore the importance of community education to dispel misconceptions and reduce societal stigma surrounding the cleft conditions. These findings underscore the imperative for healthcare systems to provide not only surgical interventions but also holistic support services that address the diverse needs of individuals and families affected by CL/P.

DISCUSSION

The qualitative analysis of cleft lip and/or palate care highlights the significance of a multidisciplinary, comprehensive approach which aligns with the key constructs of the Health Belief Model (HBM). The multidisciplinary cleft care team at the Komfo Anokye Teaching Hospital (KATH), Kumasi-Ghana, fosters a dynamic and progressive approach to treatment. This diversity ensures that patients benefit from a range of expertise, enhancing the quality of care and strengthening parents/caregivers' self-efficacy, their confidence in managing their child's condition. This approach involves various specialists, including surgeons, paediatricians, orthodontists, nurses, nutritionists, social workers, and personnel from organisations such as the Ghana Cleft Foundation and Smile Train. From an HBM perspective, parents/caregivers' engagement with CL/P care is influenced by their perceived susceptibility to complications, such as feeding difficulties or speech impairments, and their perceived severity of the condition's impact on their child's future. Furthermore, financial constraints, logistical challenges, and societal stigma serve as perceived barriers that may deter caregivers from seeking timely treatment. To counter these barriers, patient and family-centred care emerges as a critical strategy, ensuring that treatment plans are personalised to fit each family's unique circumstances. The presence of multidisciplinary care enhances perceived benefits, reassuring families that treatment is effective and holistic, addressing not only surgery but also pre- and post-operative care, nutritional support, orthodontic interventions, speech therapy, and psychological well-being.

Healthcare professionals are known to contribute tremendously to the comprehensive care of individuals with cleft lips and/or palates. Not only are they involved in prenatal diagnosis, but their responsibilities extend through the long-term follow-up care, involving a multidisciplinary team. Healthcare professionals' recognition of the prevalence and serious implications of CL/P drives their commitment to early detection and intervention, and this aligns with Perceived Susceptibility and Severity of the HBM. For instance, prenatal counselling and ultrasound diagnosis are critical components of care, enabling timely surgical planning and support for affected families. The importance of a multi-disciplinary approach and patient-centred care in cleft management has been reported in several scholarly works (Harrison *et al.* 2023, Stock

et al. 2024). The data underscored the involvement of various specialists, including surgeons, paediatricians, orthodontists, nurses, geneticists, speech therapists, nutritionists, plastic surgeons, and social workers, highlighting the comprehensive nature of cleft care (Frederick *et al.* 2022). These shared experiences help alleviate perceived severity by demonstrating successful treatment outcomes, while also reducing perceived susceptibility to social isolation. By fostering a sense of community, the MCC enhances parents/caregivers' psychological well-being and resilience, warranting that CL/P care extends beyond biomedical treatment to address emotional and social well-being. This aligns with literature emphasising the necessity of addressing not only the surgical aspects but also the psychosocial and nutritional needs of patients with cleft conditions (Feragen and Stock 2016). The emphasis on patient and family-centred care, as evidenced by the personalised approach to care and the inclusion of counselling and psychological support, resonates with literature advocating for holistic care models that consider the unique circumstances and needs of each patient and their family (Feragen and Stock 2016, Sischo *et al.* 2017). The study's findings highlight the importance of collaboration with external organisations and support systems, such as Smile Train and the Ghana Cleft Foundation, in providing essential care and addressing socio-economic and psychological factors influencing patients and families dealing with cleft conditions (Choudhry *et al.* 2016). Collaboration with external organisations, such as the Ghana Cleft Foundation and Smile Train, plays a crucial role in reducing perceived barriers to CL/P care by providing financial assistance and essential services (Odoi-Agyarko 2024). These partnerships enhance the sustainability and ease of access of CL/P care, emphasising perceived benefits of seeking treatment while ensuring that families receive comprehensive support. By leveraging peripheral support systems, healthcare facilities can extend their capacity to address the diverse medical, financial, and emotional needs of children with CL/P and their parents/caregivers. These findings align with the Perceived Benefits of HBM by providing an understanding of the positive outcomes of comprehensive, multidisciplinary care that motivates healthcare professionals to engage in collaborative practices (Dankoly *et al.* 2021). Organisations like Smile Train offer training programs that enhance surgical skills and interdisciplinary coordination, leading to improved patient outcomes. These training programs, organised by Smile Train can be signified as Cues to Action as stipulated in the HBM. Furthermore, the training and professional development opportunities will enhance healthcare professionals' confidence in their ability to deliver effective CL/P care. And this will be attributed to the Self-Efficacy component of the Health Belief Model.

Additionally, the varying levels of experience among practitioners, ranging from seasoned professionals with extensive experience to newer practitioners, reflect the dynamic and evolving nature of cleft care teams. This diversity in experience contributes to a balanced and collaborative environment, fostering continuity and the accumulation of specialised knowledge over time (Stock *et al.* 2020).

Furthermore, the study's recognition of the critical role of psychological support and counselling for parents and caregivers aligns with literature emphasising the importance of addressing emotional and psychological needs alongside medical interventions (Sischo *et al.* 2012). Healthcare providers, according to the findings, usually form strong bonds with parents/caregivers and their children with CL/P following the long-term nature of cleft care, which lasts years and sometimes

decades (Talesh and Motamedi 2013, Sharma 2020). This continuous care is likely to lead to profound emotional connections, as healthcare providers witness the patient's progress. For most healthcare providers, it is to see the transformation in the lives of their patients with cleft lip and/or palate, from overcoming initial feeding challenges to achieving clear speech and a positive self-image (Kappen *et al.* 2019, Moi *et al.* 2020). Again, the study's exploration of medical and healthcare challenges, such as difficulties in feeding, breathing, and speech, echoes existing literature emphasising the need for comprehensive care involving multiple specialities beyond surgical interventions (Sischo *et al.* 2016). Providing healthcare for persons with CL/P necessitates a high level of empathy and compassion, as providers must often assist families in navigating the emotional and social challenges associated with the CL/P condition.

Notwithstanding, healthcare providers sometimes experience clinical and surgical challenges of performing delicate procedures that require precision to ensure both functional and aesthetic outcomes for their patients with cleft lip and/or palate (Reddy and Fanan 2020, Sharma *et al.* 2012). The quest to achieve optimal results, knowing the impact on a child's self-image is key and these healthcare providers will go to all lengths to achieve just that (Cawthorn *et al.* 2022). The data underscore the importance of a holistic approach that addresses not only the physical correction of the cleft but also the broader healthcare and emotional needs of individuals and their parents/caregivers. This aligns with literature advocating for multidisciplinary care models that encompass speech therapy, orthodontic care, and psychological support to optimise outcomes for patients with cleft conditions (Stock and Feragen 2016)

CONCLUSION

This study highlights the necessity of a holistic, patient and family-centred approach in CL/P care, as viewed through the lens of the Health Belief Model. By examining the perceived severity, susceptibility, barriers, and benefits of treatment, as well as the role of cues to action and self-efficacy, the research emphasises the need for multidisciplinary collaboration, financial and social support, and ethical commitment from healthcare professionals. The findings reinforce that CL/P care extends beyond surgery to include emotional, psychological, and social support, which is crucial for fostering resilience among caregivers and improving patient outcomes. Collaboration with external organisations, peer support networks, and the active engagement of healthcare professionals contribute significantly to mitigating financial, social, and emotional challenges. Ultimately, this study adds to the discourse on comprehensive paediatric care by demonstrating that a holistic, ethically driven approach can enhance both medical outcomes and overall well-being. These insights can inform future healthcare policies, strengthen multidisciplinary interventions, and improve the long-term support systems available to families navigating the complexities of cleft lip and/or palate treatment.

REFERENCES

Abu-Hussein, M. (2008) Cleft Lips and Palates; The Roles of Specialists. *The Internet Journal of Dental Science,* **7**(1).

Agbenorku, P., Ansah, S., Acheampong, A., Sabbah, D., Bankas, D., Adu, E., Plange-Rhule, G., Adiyiah, Y. & Donkor, P. (2011) Komfo anokye teaching hospital multidisciplinary cleft clinic. *Journal of Craniofacial Surgery,* **22**(2), 532-536.

Azzaldeen, A., Mai, A. & Muhamad, A.-H.

(2017) Genetics and Dental Disorders–A Clinical Concept. Part; 1. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS),* **16**(11), 35-42.

Babai, A. & Irving, M. (2023) Orofacial clefts: genetics of cleft lip and palate. *Genes,* **14**(8), 1603.

Bardach, J. & Morris, H.L. (1990) Multidisciplinary management of cleft lip and palate. *(No Title)*.

Bennett, R.L. (2011) *The practical guide to the genetic family history,* John Wiley & Sons.

Bessell, A., Hooper, L., Shaw, W.C., Reilly, S., Reid, J. & Glenny, A.M. (2011) Feeding interventions for growth and development in infants with cleft lip, cleft palate or cleft lip and palate. *Cochrane Database of Systematic Reviews,* (2).

Bhuskute, A., Skirko, J.R., Roth, C., Bayoumi, A., Durbin-Johnson, B. & Tollefson, T.T. (2017) Association of velopharyngeal insufficiency with quality of life and patient-reported outcomes after speech surgery. *JAMA facial plastic surgery,* **19**(5), 406-412.

Breeze, J. & McLeod, N.M. (2019) *Vivas for the Oral and Maxillofacial Surgery FRCS,* Oxford Higher Specialty Training.

Cawthorn, T.R., Todd, A.R., Hardcastle, N., Spencer, A.O., Harrop, A.R. & Fraulin, F.O. (2022) Optimizing outcomes after cleft palate repair: design and implementation of a perioperative clinical care pathway. *The Cleft Palate-Craniofacial Journal,* **59**(5), 561-567.

Choudhry, F.R., Mani, V., Ming, L.C. & Khan, T.M. (2016) Beliefs and perception about mental health issues: a meta-synthesis. *Neuropsychiatric disease and treatment,* **12**, 2807.

Dankoly, U.S., Vissers, D., El Farkouch, Z., Kolasa, E., Ziyyat, A., Rompaey, B.V. & Maamri, A. (2021) Perceived barriers, benefits, facilitators, and attitudes of health professionals towards multidisciplinary team care in type 2 diabetes management: a systematic review. *Current diabetes reviews,* **17**(6), 50-70.

Dapaah, J.M., Addo, B. & Effe, J.P. (2021) Mothers' reactions to seeing their children with cleft for the first time: A qualitative study in Ghana. *The Cleft Palate-Craniofacial Journal,* **58**(7), 854-863.

Dibart, S. (2020) *Practical Advanced Periodontal Surgery,* John Wiley & Sons.

Dixon-Wood, V.L., Williams, W.N. & Seagle, M.B. (1991) Team acceptance of specific recommendations for the treatment of VPI as provided by speech pathologists. *The Cleft Palate-Craniofacial Journal,* **28**(3), 285-292.

Feragen, K.B. & Stock, N.M. (2016) Risk and protective factors at age 10: psychological adjustment in children with a cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal,* **53**(2), 161-179.

Frederick, R., Hogan, A.C., Seabolt, N. & Stocks, R.M.S. (2022) An ideal multidisciplinary cleft lip and cleft palate care team. *Oral diseases,* **28**(5), 1412-1417.

Gakuru, P.W. (2004) *HIV testing in the 15–49 age bracket in Kenya: A test of the health belief model,* Arizona State University.

Guerrerosantos, J., Chicas, M. & Rivera, H. (2004) Palatopharyngeal lipoinjection: an advantageous method in velopharyngeal incompetence. *Plastic and reconstructive surgery,* **113**(2), 776-777.

Hamdan, U.S., Rogers-Vizena, C.R., Vyas, R.M. & Sommerlad, B.C. (2022) *Interdisciplinary Cleft Care: Global Perspectives,* Plural

Publishing.

Harrison, C., Apon, I., Ardouin, K., Sidey-Gibbons, C., Klassen, A., Cano, S., Wong Riff, K., Pusic, A., Versnel, S. & Koudstaal, M. (2023) The development, deployment, and evaluation of the CLEFT-Q Computerized Adaptive Test: a multimethods approach contributing to personalized, person-centered health assessments in plastic surgery. *Journal of medical Internet research,* **25**, e41870.

Hlongwa, P. (2019) Epidemiology and care of individuals with cleft lip and palate in South Africa. *Johannesburg: University of the Witwatersrand*.

Hodgkinson, P., Brown, S., Duncan, D., Grant, C., McNaughton, A., Thomas, P. & Mattick, R. (2005) Management of children with cleft lip and palate: a review describing the application of multidisciplinary team working in this condition based upon the experiences of a regional cleft lip and palate centre in the United Kingdom. *Fetal and maternal medicine review,* **16**(1), 1-27.

Jokstad, A., Ørstavik, J. & Ramstad, T. (1998) A definition of prosthetic dentistry. *International Journal of Prosthodontics,* **11**(4).

Jones, T.A. (2023) The Role of Caregiver's Perception of Their Child's Cleft Lip/Palate on Treatment Engagement: An Analysis of Culturally-Bounded Barriers to Healthcare at a Craniofacial Center. Wheaton College.

Kappen, I.F., Bittermann, G.K., Stock, N.M., Mink van der Molen, A.B., Breugem, C.C. & Swanenburg de Veye, H.F. (2019) Quality of life and patient satisfaction in adults treated for a cleft lip and palate: a qualitative analysis. *The Cleft Palate-Craniofacial Journal,* **56**(9), 1171-1180.

Katzel, E.B., Basile, P., Koltz, P.F., Marcus, J.R. & Girotto, J.A. (2009) Current surgical practices in cleft care: cleft palate repair techniques and postoperative care. *Plastic and reconstructive surgery,* **124**(3), 899-906.

Kaul, R., Jain, P., Saha, S. & Sarkar, S. (2017) Cleft lip and cleft palate: Role of a pediatric dentist in its management. *Int J Pedod Rehabil,* **2**(1), 1-6.

Lasota, A. (2020) Dental abnormalities in children with cleft lip with or without cleft palate. *Journal of Pre-Clinical and Clinical Research,* **15**(1), 46-49.

Lewis, C.W., Jacob, L.S., Lehmann, C.U., Krol, D., Gereige, R., Karp, J., Fisher-Owens, S., Braun, P., Jacob, L. & Segura, A. (2017) The primary care pediatrician and the care of children with cleft lip and/or cleft palate. *Pediatrics,* **139**(5).

Loenarz, C., Ge, W., Coleman, M.L., Rose, N.R., Cooper, C.D., Klose, R.J., Ratcliffe, P.J. & Schofield, C.J. (2010) PHF8, a gene associated with cleft lip/palate and mental retardation, encodes for an N ε-dimethyl lysine demethylase. *Human molecular genetics,* **19**(2), 217-222.

Martin, V. & Greatrex-White, S. (2014) An evaluation of factors influencing feeding in babies with a cleft palate with and without a cleft lip. *Journal of Child Health Care,* **18**(1), 72-83.

Miller, C.K. & Madhoun, L.L. (2016) Feeding and swallowing issues in infants with craniofacial anomalies. *Perspectives of the ASHA Special Interest Groups,* **1**(5), 13-26.

Mitchell, J.C. & Wood, R.J. (2000) Management of cleft lip and palate in primary care. *Journal of pediatric health care,* **14**(1), 13-19.

Moghe, G., Mauli, S., Thomas, A. & Obed, V.A. (2013) Bridging the gap: addressing challenges toward improvement of cleft

teamwork in a tertiary care center in north India: a pilot study. *The Cleft Palate-Craniofacial Journal,* **50**(4), 473-480.

Moi, A.L., Gjengedal, H., Lybak, K. & Vindenes, H. (2020) "I smile, but without showing my teeth": The lived experience of cleft, lip, and palate in adults. *The Cleft Palate-Craniofacial Journal,* **57**(7), 799-807.

Nagarajan, R., Savitha, V. & Subramaniyan, B. (2009) Communication disorders in individuals with cleft lip and palate: An overview. *Indian Journal of Plastic Surgery,* **42**(S 01), S137-S143.

Odoi-Agyarko, A. (2024) Parental Experiences and Health Education Perceptions Raising Children With Orofacial Clefts. Walden University.

Paradowska-Stolarz, A., Mikulewicz, M. & Duś-Ilnicka, I. (2022) Current concepts and challenges in the treatment of cleft lip and palate patients—A comprehensive review. *Journal of Personalized Medicine,* **12**(12), 2089.

Peng, Y., Hao, X., Guo, Y., Zhang, X., Li, Y., Ma, Y. & Wang, J. (2021) High quality nursing based on childlike interest in children with cleft lip and palate: application assessment after operation. *BMC oral health,* **21**, 1-7.

Perry, L., Hamilton, S., Williams, J. & Jones, S. (2013) Nursing interventions for improving nutritional status and outcomes of stroke patients: descriptive reviews of processes and outcomes. *Worldviews on evidence-based nursing,* **10**(1), 17-40.

Quigley, N., Mistry, S.G., Vasant, D.H. & Vasani, S. (2023) Practical multidisciplinary framework for the assessment and management of patients with unexplained chronic aerodigestive symptoms. *BMJ Open Gastroenterology,* **10**(1), e000883.

Reddy, S.G. & Fanan, A. (2020) Complications in Cleft Lip and Palate Surgeries. *Complications in Cranio-Maxillofacial and Oral Surgery*, 3-32.

Rickert, S.M. (2023) Otolaryngology considerations in cleft and craniofacial care. *Cleft and Craniofacial Orthodontics*, 196-205.

Robin, N.H., Baty, H., Franklin, J., Guyton, F.C., Mann, J., Woolley, A.L., Waite, P.D. & Grant, J. (2006) The multidisciplinary evaluation and management of cleft lip and palate. *Southern medical journal,* **99**(10), 1111-1121.

Salyer, K.E. (2001) Excellence in cleft lip and palate treatment. *Journal of Craniofacial Surgery,* **12**(1), 2-5.

Sharma, G. (2020) Orthodontic management of cleft lip and palate patients. *Current Treatment of Cleft Lip and Palate*, 19-33.

Sharma, V., Bella, H., Cadier, M., Pigott, R., Goodacre, T. & Richard, B. (2012) Outcomes in facial aesthetics in cleft lip and palate surgery: a systematic review. *Journal of plastic, reconstructive & aesthetic surgery,* **65**(9), 1233-1245.

Sharp, H.M. (1995) Ethical decision-making in interdisciplinary team care. *The Cleft palate-craniofacial journal,* **32**(6), 495-499.

Shi, M., Wehby, G.L. & Murray, J.C. (2008) Review on genetic variants and maternal smoking in the etiology of oral clefts and other birth defects. *Birth Defects Research Part C: Embryo Today: Reviews,* **84**(1), 16-29.

Shprintzen, R.J. & Bardach, J. (1995) Cleft palate speech management: a multidisciplinary approach. *(No Title)*.

Sischo, L., Chan, J.W., Stein, M., Smith, C., Van Aalst, J. & Broder, H.L. (2012) Nasoalveolar molding: prevalence of cleft centers offering NAM and who seeks it.

The Cleft palate-craniofacial journal, **49**(3), 270-275.

Sischo, L., Clouston, S.A., Phillips, C. & Broder, H.L. (2016) Caregiver responses to early cleft palate care: A mixed method approach. *Health Psychology,* **35**(5), 474.

Sischo, L., Wilson-Genderson, M. & Broder, H. (2017) Quality-of-life in children with orofacial clefts and caregiver well-being. *Journal of dental research,* **96**(13), 1474-1481.

Sommerlad, B.C. (1994) Management of cleft lip and palate. *Current Paediatrics,* **4**(3), 189-195.

Stasiak, M., Wojtaszek-Słomińska, A. & Racka-Pilszak, B. (2019) Current methods for secondary alveolar bone grafting assessment in cleft lip and palate patients—a systematic review. *Journal of Cranio-Maxillofacial Surgery,* **47**(4), 578-585.

Stock, N.M., Blaso, D. & Hotton, M. (2024) Caring for a Child with a Cleft Lip and/or Palate: A Narrative Review. *The Cleft Palate Craniofacial Journal*, 10556656241280071.

Stock, N.M. & Feragen, K.B. (2016) Psychological adjustment to cleft lip and/or palate: a narrative review of the literature. *Psychology & health,* **31**(7), 777-813.

Stock, N.M., Hammond, V., Hearst, D., Owen, T., Edwards, Z., Ridley, M. & Rumsey, N. (2020) Achieving consensus in the measurement of psychological adjustment to cleft lip and/or palate at age 8+ years. *The Cleft Palate-Craniofacial Journal,* **57**(6), 746-752.

Strong, E.B. & Buckmiller, L.M. (2001) Management of the cleft palate. *Facial plastic surgery clinics of North America,* **9**(1), 15-25, vii.

Talesh, K.T. & Motamedi, M.H.K. (2013) Cleft lip and palate surgery. In *A Textbook of Advanced Oral and Maxillofacial Surgery*IntechOpen.

Watted, A., Watted, N. & Abu-Hussein, M. (2020) Multidisciplinary treatment in cleft lip and palate patients. *Int J Dent Res Oral Health,* **2**, 1-12.

Wogden, F., Norman, A. & Dibben, L. (2019) Treatment choice in adolescents with cleft lip and/or palate: The importance of shared decision-making. *The Cleft Palate-Craniofacial Journal,* **56**(9), 1220-1229.

Zhao, J. & Wang, X. (2014) Dental prostheses. In *Advanced ceramics for dentistry*Elsevier, pp. 23-49.