



Psychological Coping Mechanisms of Parents of New-born Babies with Cleft Lip and Palate-during Feeding and Naso Alveolar Molding Therapy—A Systematic Review

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Abstract

Orofacial clefts are one of the most common and major congenital anomalies occurring all over the world. The parents or caretakers face many financial, social, and psychological challenges. In addition to the critical concerns related to issues like aspiration, infections, and the impaired growth and development of the affected child, the family grapples with emotional challenges. Their emotional resilience and ability to navigate the challenges associated with cleft lip and palate treatment profoundly impact the outcomes. Many parents tend to take proactive and problem-solving approaches to manage the situation. The Quality of parents' family and social support system is positively associated with their coping and psychosocial functioning. A widely adopted approach for treating cleft lip and palate in infants is the 'Presurgical Nasoalveolar Molding Appliance'. Parents consider this as a problem-focused coping strategy and associate it with positive factors such as effective feeding, increased empowerment, self-esteem, and bonding with their babies. Aim: This review aims to explore and synthesize the existing literature on the psychological coping mechanisms employed by parents of newborns diagnosed with cleft lip and palate undergoing Nasoalveolar Molding (NAM) therapy. Methods: A comprehensive search was conducted in electronic databases, including PubMed, web of science, Scopus, google scholar, grey literature. The search strategy involved a combination of keywords such as "cleft lip and palate," "newborn," "parents," "psychological coping," and "Nasoalveolar Molding therapy." The inclusion criteria encompassed original research articles, qualitative and quantitative studies, and systematic reviews that focused on the psychological coping experiences of parents generally and during NAM therapy. Exclusion Criteria: Articles written in a language other than English, conference proceedings. Results: The initial search yielded 1243 articles, of which the final 67 most relevant ones were considered for this study. The included studies were diverse in design, ranging from qualitative interviews to quantitative analysis. Conclusion: Parents of newborns with cleft lip and palate undergoing NAM therapy employ various psychological coping mechanisms to navigate the challenges associated with their child's condition. Understanding these coping strategies is crucial for healthcare professionals to provide tailored support and interventions. Future research should aim to develop evidence-based interventions that enhance coping mechanisms and promote the well-being of parents during the NAM therapy process.

Keywords: Psychology, cleft lip, and palate, coping skill, caregiver coping, Nasoalveolar molding

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1. Introduction

Cleft Lip and Palate (CLP) is one of the most common craniofacial anomalies occurring all over the world. Worldwide, oral clefts in any form are found in approximately one in every 1,000–1,500 live births [1, 2]. Unilateral cleft lip is more common than bilateral cleft lip. Left-sided cleft lip is more common than right-sided cleft lip [3]. Based on ancestry, the highest incidence rates were observed amongst the Asian population (0.82–4.04/1000 live births), intermediate rates amongst Caucasians (0.9–

2.69 / 1000 live births), and the lowest rates amongst the African population (0.18–1.67/1000 live births) [4]. The management of a patient with cleft lip and palate involves a multidisciplinary approach involving surgery for cleft lip and palate closure, rhinoplasty, pharyngo veloplasty, speech therapy, orthodontic treatments, and psychological counseling at various stages of life. Reconstructing the lips, palate, and nose to their normal anatomy is a challenging task for surgeons.

To aid in surgical management, Presurgical Infant Orthopedics (PSIO) was developed. Based on Matsuo's

cartilaginous molding concept, Grayson and Cutting introduced the "Presurgical nasoalveolar molding appliance (PNAM/NAM)" as a method in PSIO [5, 6]. Pnam therapy offers several advantages, including 1. Reducing the size of the cleft by approximation of the cleft segments, to facilitate further surgeries. 2. Providing effective feeding assistance, whether it is through breastfeeding, bottle feeding, or other means. 3. Minimizing the risk of aspiration during feeding. 4. Reducing or eliminating the need for secondary nasal reconstruction. [6]. Different countries follow different protocols for cleft treatment [7-9]. American cleft palate and craniofacial association have included NAM/ presurgical orthopedics as part of their treatment parameters NAM is the most popular PSIO technique (68%) in North American cleft centers, suggesting that the nasal molding component of PSIO is of critical influence on current treatment practices [7]. 61% of Korean institutes with plastic surgery training programs were using presurgical orthopedics before cleft repair, and applied presurgical nasoalveolar molding as the most common method [8].

In Nigeria, adhesive tapes were employed by 63.7% of cleft surgeons for managing the protruding premaxilla [9]. Studies conducted to find the effectiveness of NAM therapy show a positive trend towards its application [10-13]. Although treating the child with cleft lip and palate condition is crucial, it is also important to support the parents or caregivers. They face physical, financial, and psychological challenges when caring for their child. The experience of seeing their child suffering from this condition can initially be traumatic for these individuals. They undergo a train of emotions such as confusion, distress, and guilt, loss of control, helplessness, and even depression [14, 15]. To manage their emotions, parents use different coping mechanisms, and understanding these mechanisms can help healthcare specialists develop a more family-oriented care approach that emphasizes the psychosocial needs of parents, children, and their families. This paper aims to investigate and analyze different psychological coping mechanisms employed by parents of newborns with cleft lip and palate during Nasoalveolar Molding therapy

2. Objectives

1. Identify and analyze studies on the psychological coping mechanisms of parents during NAM therapy.
2. Evaluate the impact of psychological coping strategies on parental well-being.
3. Explore any variations in coping mechanisms based on cultural or demographic factors.

3. Methodology

A comprehensive search was conducted in electronic databases, including PubMed, web of science core collection, Scopus, google scholar and grey literature from inception to the present date (Figures 1-2). The search strategy involved a combination of keywords such as "cleft lip and palate," "newborn," "parents," "psychological coping," and "Nasoalveolar Molding therapy." The inclusion criteria encompassed original research articles, qualitative and quantitative studies, and reviews that focused on the psychological coping experiences of parents during NAM

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therapy. Exclusion Criteria: Articles written in a language other than english, book contents, conference proceedings. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for study selection and data extraction.

4. Results and discussion

Finally, 67 articles met the inclusion criteria. The included studies were diverse in design, ranging from qualitative interviews to quantitative surveys. Common psychological coping mechanisms identified in the literature included social support networks, information-seeking behaviors, emotional: expression, and resilience strategies.

4.1 Psychological challenges faced by parents

Psychological challenges faced by the parents of children with cleft are well discussed in the recent literature [16-18]. The diagnosis of CLP prenatally can be stressful, causing more anxiety throughout the pregnancy. Parent experience conflicting emotions regarding their child's condition, uncertainty associated with treatment, and stigmatizing attitudes at various stages of life [19]. A gender difference may exist in the psychosocial adjustment of the child's condition, with mothers experiencing more psychosocial problems than fathers [20]. The majority of the mothers feel self-blame, coping difficulties, and anxiety about their child's cleft condition [21]. Ramstad et al.'s study showed that mothers experience a higher degree of personal stress and family conflict, with less family cohesiveness than non-cleft families [22]. Martin et al. studied the effects of maternal self-esteem and different feeding bottles and teats on cleft babies in terms of weight, velocity, and feeding behavior, and observed that poor weight gain was associated with a mother's low perception of herself and her child, and her tendency towards depression [23]. Fathers may react and cope differently compared with mothers in response to their child's health condition, specifically in that the father adopts a supportive and information-seeking role [24, 25]. Nidey et al. found that fathers had higher self-esteem than mothers and were less concerned about being negatively judged by others [20] while fathers in Stock and Rumsey, 's study felt stressed not only because of the shock of the cleft condition but the insensitive way in which this information was delivered.

The immediate offer of termination following antenatal diagnosis was a prominent and distressing memory for some fathers, particularly because they had received no information about what a cleft was or what it may mean for their child's future [18]. Having a younger child and/or a child with medical problems in addition to Cleft lip and palate had a greater impact on the family both financially and psychologically [26]. Parents may be concerned about the risk of having another affected child and may modify their fertility behaviors subsequent to the birth of an affected child, which could further affect their psychosocial status. [27]. Many mothers experience concern about feeding their children [28] as feeding is one of the most immediate post-natal concerns in a newborn. Infants with clefts cannot produce an effective intra-oral negative pressure due to their inherent clinical condition, so feeding them is very challenging. This also acts as a source of considerable stress

for parents and can potentially negatively affect the parent-infant bonding process [29].

4.2 Coping Strategies

Every human cope with his challenges differently. Coping can be described as a set of cognitive and behavioral techniques employed to handle situations perceived as overwhelming or beyond one's capabilities, to mitigate negative emotions and stress-induced conflicts [30]. As many stressors exist, coping strategies are as diverse as they are numerous. Some are avoidant and attention coping, some are active and passive, and some are behavioral and cognitive. According to Lazarus and Folkman, there are two general coping strategies: Problem-focused and Emotion-focused. Problem-focused is aimed at problem solving or doing something to alter the source of the stress, which includes confrontative coping and seeking social support. Emotion-focused coping is aimed at minimizing or managing the emotional distress that is associated with the stressful situation, by self-control, seeking social support, distancing, positive appraisal, accepting responsibility, and escape/avoidance [31]. Carver and Weintraub added dysfunctional coping to Lazarus's list. It focuses on, venting of emotions, denial, behavioral disengagement, mental disengagement, and alcohol/drug use [32].

They identified 13 dimensions of coping with five interpreted as sub-dimensions of problem-focused coping (i.e., active coping, planning, suppression of competing activities, restraint coping, seeking social support for instrumental reasons), and another five as sub-dimensions of emotion-focused coping (seeking social support for emotional reasons, positive reinterpretation and growth, acceptance, denial, turning to religion); the remaining three were classified "less useful" strategies (focus on and venting of emotions, behavioral disengagement, mental disengagement). To measure these 13 coping strategies they developed the COPE inventory, which has now been extended to include two additional scales: humor and substance use [32]. Parker and Endler noted that problem-focused coping strategies were associated with a task orientation, whereas emotion-focused ones reflect a person's orientation [33]. Many coping models added a third basic dimension—avoidance-oriented coping, involving both task-oriented and person-oriented strategies [33, 34]. Roth and Cohen conceptualized coping in terms of the direction of the responses to the threat or stressor, as an approach or avoidance coping. Approach coping is any behavioral, cognitive, or emotional activity that is directed toward a stressor (e.g., problem-solving or seeking information). Avoidance is any behavioral, cognitive, or emotional activity directed away from a stressor (e.g., denial, withdrawal). Generally, applying more of an approach-coping strategy and less of an avoidance-coping strategy is associated with better outcomes [34].

4.3. Coping with CLP

4.3.1 Family

Family functioning and stress management have been shown to serve as coping factors. Higher levels of support were predictive of less family impact, lower psychological distress, and more positive adjustment to having a child with a craniofacial condition [35]. Family resilience refers to the capacity of a family to withstand and adapt to difficult and potentially harmful situations that may arise in life. According to Walsh, positive adaptation to adversities requires a process that enables individuals and families to effectively react to difficulties and grow through them. She highlights three key processes that determine the effective functioning of a family and its resilience. These processes help to reduce stress and vulnerability in high-risk situations, promote healing, and predispose families to grow because of a crisis. The three processes include the family's shared belief systems (strongly influencing how they perceive and respond to the crisis), organizational patterns (flexibility and adaptability to existing requirements), and communication processes (clear, consistent messages and a high level of trust [36]).

Furthermore, the family resilience theory suggests that when a family overcomes adversity, they not only return to their previous level of functioning but also experience growth and transformation as individuals, as well as in the relationships between them [37]. In a family with a child with having cleft lip and palate condition, the father's resilience is linked to coping, job status, and medical payments, while the mother's resilience is associated with hope, perceived social support, and the age of the patient. High resilience is also connected with more frequent use of problem-focused and emotion-focused coping strategies and a lower preference for dysfunctional strategies [38]. The well-being of the parents, particularly the mother, plays a crucial role in predicting a child's psychological outcomes [39]. Hasanzadeh's study on mothers of patients with CLP confirmed this and further pointed out that positive coping strategies, such as approach-oriented techniques, can improve not only the mother's psychological status but also parent-child behavior. Mothers who use avoidant coping strategies report a greater impact of cleft lip and palate on their family. Mothers with children between 13 and 18 years old with CLP tend to use problem-solving coping strategies more frequently than younger mothers. They also reported that the greatest impact of CLP was on their family's financial status and parental emotions [16]. Frey et al. found that having a non-critical family network and positive belief systems could reduce psychological distress in mothers and improve family adjustment [40]. Aleman et al. observed that during prenatal and birth stages, parents used emotion-focused strategies. A few hours to a week after birth, they used problem-focused strategies, which led them in search of treatment. Some parents used avoidance strategies during periods of social interaction before surgery, and formal education [41].

Table 1. Global prevalence rates vary with types of cleft

Cleft type (live births)	Prevalence rate
Oral clefts-	1/1000-1500
Cleft lip	1/3000-3300
Cleft palate	1/1500-3000
Cleft lip and palate	1/1500-2000

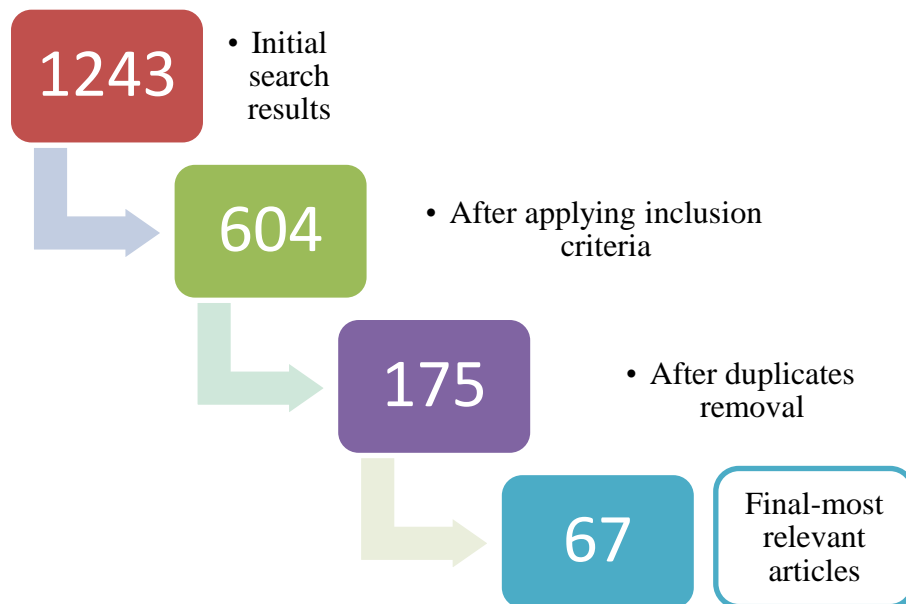


Figure 1. Article search results

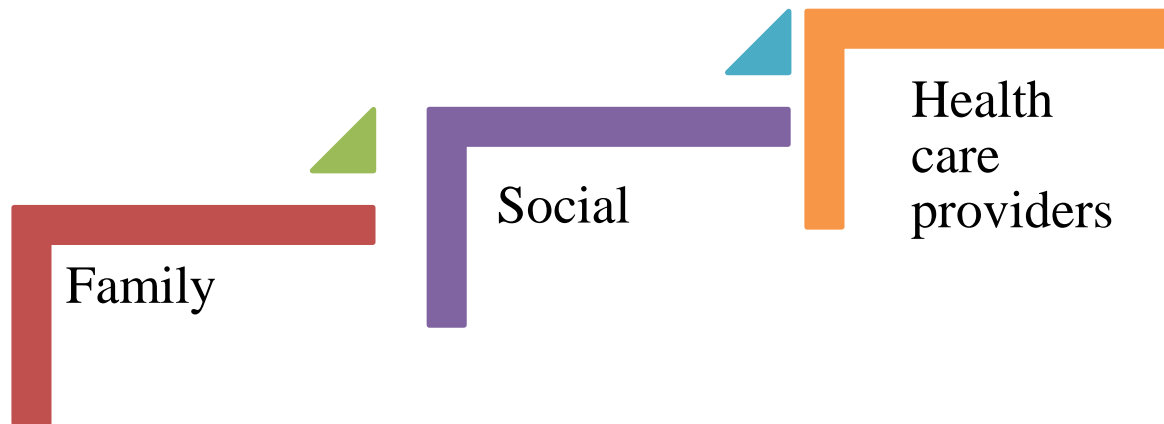


Figure 2. Levels of Support System

4.3.2. Social Support

Several studies have investigated the impact of social support on stress and emotional/physical problems [42-46]. McKinney and Peterson identified peer support as one of the most important factors in predicting stress levels [42]. Dunst et al. observed that parents who were more satisfied with their social support systems reported fewer emotional and physical problems [43]. Raina et al. showed that the quality of a parent's social support system was positively linked to their ability to cope with challenges and their overall psychological well-being [44]. In particular, parents of children with cleft who relied on problem-focused coping strategies and had high levels of social support reported less family impact and better adjustment to their child's condition than those who used avoidance-oriented strategies and had lower levels of social support [26]. In Alexis' study, parents reported high levels of social support and preferred approach-oriented coping strategies.

They also found that having more support from friends and family was associated with less negative family impact, lower psychological distress, and better adjustment [21]. As Stewart et al., explain, peer support can be a valuable coping resource for parents or caregivers as it helps them feel a sense of shared identity and experience [45]. The knowledge that they are not alone in their situation can help reduce feelings of loneliness and provide a greater sense of belongingness, self-esteem, and value. Ultimately, this can have a positive impact on the well-being of caregivers and the people they care for [46]. The three types of social support - tangible

support (e.g., availability of financial resources and services), appraisal support (e.g., availability of a confidant), and belonging support (e.g., availability of someone to socialize with) - were all found to be important forms of support for parents of children with a cleft [26].

4.3.3. Health care providers

Psychological coping strategies of parents begin when a cleft condition is diagnosed prenatally. Prenatal diagnosis and counseling can assist mothers in preparing themselves mentally for the arrival of a child with a cleft condition [47]. Having prior knowledge of their child's condition helps them to come to terms with the situation, seek support and counseling, and prepare themselves for matters such as feeding and therapeutic options for correcting the defects [48]. Sreejith et al. and O'Hanlon et al. noted specific patterns of adaptation in mothers, which were associated with the etiology of the child's disability and the amount of information available to the parents regarding the condition [49, 50]. Therefore, healthcare providers should ensure that parents have access to proper information at all times. It is also important to involve parents or caregivers in the discussion of treatment plans and provide them with information about the various stages of treatment and options available at each stage. Clinical assessments should include screening both mothers and fathers for signs of depression and anxiety during their child's initial evaluation. This would allow clinicians to start a conversation with parents about how their symptoms might affect their child's treatment outcomes. Incorporating psychosocial assessments of parents

can be readily performed in settings that follow a team-based approach to treating children with oral clefts with psychosocial expertise as part of the team [43]. Healthcare providers should include the assessment of risk factors in their evaluation and treatment planning process. Immediately after birth and during infancy, feeding is a common, and a most important concern for the parents. Comprehensive guidelines should be available regarding feeding strategies, maternal guidance, and the management of potential complications. Mothers may receive training in adopting certain modifications such as the modified football hold and the dancer hand position to promote successful breastfeeding.

5. Coping strategies during feeding and NAM therapy

The goal of feeding intervention for a child with CLCP is to ensure adequate and efficient intake for appropriate hydration and nutrition, for growth and development, and for adequate medical status prior to surgery [51]. An important additional goal is to ensure that feeding is a low-stress experience for the infant and their family as it has been documented as a source of considerable stress for parents and can have a potentially negative effect on the parent-infant bonding process. [29, 51]. Obturators are simple feeding plates that can help with feeding infants with cleft. They serve several purposes such as closing the cleft for normal suckling, creating negative intra-oral pressure, preventing tongue protrusion into the defect, and protecting from food aspiration into the nasal cavity. They can be used with any feeding method, including breastfeeding or bottle-feeding. A PNAM appliance functions as an obturator very effectively. Jones's study showed that using an obturator during feeding can decrease choking, nasal discharge, and the time required to complete feeding. Most importantly, the study reported that parents felt less anxious during feeding [52]. Turner found that using an obturator with proper instructions, along with a Haberman bottle, led to shorter feeding times, increased volume intake, and improved infant growth. Mothers who breastfed and who elected to use an obturator were found to have an increased milk intake in their infants and the infants experienced less fatigue as well [53]. Trenouth et al., evaluated feeding methods followed by the mothers of 25 neonates with cleft lip and palate and found that most parents had problems in feeding their babies. More than half of the mothers found the acrylic feeding plate to be helpful [54].

Goyal et al. suggest that a combination of feeding interventions, such as a palatal obturator, Haberman feeder, breast milk pump, and lactation education, may be necessary to meet the feeding needs of both mothers and children and achieve effective weight gain [55]. In a study conducted by Britton et al., 26% of parents reported their infants using pre-surgical appliances, with 70% rating them highly for aiding in feeding their babies [56]. Similarly, Zajac et al. reported improved feeding with the use of a PNAM appliance [57]. D Albustani et al. observed the attitudes, perceptions, and experiences of mothers of children with cleft undergoing presurgical orthodontic treatment and found that the majority of mothers expressed that the appliance improved their infant's feeding, along with improving the aesthetics of the infant's facial appearance and allowing for prompt surgical repair [58]. Alperovich et al. observed that the duration of

NasoAlveolar Molding prior to cleft lip repair had no effect on the length of breast milk feeding length. [59]. Sischo et al. observed that NAM-associated activities served as a problem-focused coping strategy for many parents or caregivers. Initially, while undergoing NAM therapy, most of them expressed apprehension and anxiety about the burden of care. However, during follow-up visits, they were able to interact with children and other caregivers who had completed various treatment levels such as NAM therapy, lip and palate surgeries, and revision surgery (nose), which further motivated them to continue with NAM. They were clear that the tasks associated with NAM were temporary and that the benefits, such as their child's treatment result, outweighed the cost and effort. Additionally, NAM was found to contribute to the parents/caregiver's positive identity construction, leading to increased empowerment, self-esteem, and bonding with their child. These positive effects minimized the impact of the burden of undergoing NAM [60]. A study by Nur Yilmaz et al. found that NAM therapy increased parental satisfaction by enabling them to stay in contact with the cleft team and other families, and by giving them an active role in the treatment process [61]. Murthy J claimed that the role of NAM was to support surgeons if they were not capable of handling wide clefts and that improvement in the skills and knowledge of surgeons would reduce the major burden of care of NAM therapy [62]. Abd. El-Ghafour et al. observed that additional high-quality research was needed to determine the degree of parents' acceptance of NAM therapy [63]. AL Anazi et al. found that more than 80% of patients would recommend NAM therapy to other parents [64].

Similarly, a study by Roth et al. found that all parents strongly agreed that NAM therapy was beneficial not only for their children but also for their well-being, as it provided them with an approach-oriented coping strategy to deal with their child's cleft situation [65]. According to Alqadi et al, the majority of parents (80%) in their study found the treatment to be useful for their child. They also reported an improvement in their child's feeding after undergoing NAM. Additionally, most parents (95%) expressed their satisfaction with the treatment and stated that they would recommend it to other parents of children with orofacial clefts [66]. According to Broder et al., caregivers in high-volume cleft centers reported 'molding' therapy resulted in better post-surgery outcomes in their infants compared with caregivers who belonged to, the no-molding CLP infants' group, particularly in relation to the appearance of the nose [67]. Alfonso et al. claimed that Nasoalveolar molding had been indiscriminately associated with the burden of care in the literature. They concluded that psychosocial advantages outweighed any physical limitations [68]. Similarly, the results of the Hopkins et al. found that parents remained committed to nasoalveolar molding treatment despite encountering challenges they expressed that the advantages of the treatment outweighed any additional effort it required. Enhancing education and offering support can significantly alleviate the challenges faced by parents during the NAM process. This further reinforces the critical role the parents play in ensuring successful outcomes for nasoalveolar molding [69].

6. Suggestions

A good understanding of how parents manage their child's craniofacial condition could aid caregivers in cultivating a more family-centered care approach that addresses the psychosocial needs of parents, children, and their families with greater sensitivity.

- Implementing educational programs for healthcare as well as non-healthcare professionals, routine pediatric follow-up, and the involvement of specialized multidisciplinary teams, has the potential to enhance nutritional intake and expedite the scheduling of surgical procedures.
- There is a need for an individualized care plan and contact point to psychologically support families of a child with a cleft
- Social support is beneficial for both the psychological and physical health of the parents. The government or charitable organizations should provide financial assistance to alleviate the financial strain of caring for a child with a cleft lip and palate condition. Equally important is the need to increase public awareness about this issue.

7. Conclusion

Positive mental health helps in combating any illness. It is beneficial to integrate psychological well-being techniques into all treatment approaches to enhance the overall well-being of both the patient and their family. NAM not only contributes to reducing cleft deformities but also supports parents of children with clefts in adopting approach-oriented coping strategies.

References

- [1] N. Salari, N. Darvishi, M. Heydari, S. Bokae, F. Darvishi, M. Mohammadi. (2022). Global prevalence of cleft palate, cleft lip and cleft palate and lip: A comprehensive systematic review and meta-analysis. *Journal of stomatology, oral and maxillofacial surgery*. 123 (2) 110-120.
- [2] World Health Organization. (2022). Oral health.
- [3] World Health Organization. (2022). Global status report on physical activity.
- [4] E. Allam. (2014). Cleft lip and palate: etiology, epidemiology, preventive and intervention strategies. *Anatomy and Physiology*. 4 (3) 1.
- [5] K. Matsuo, T. Hirose, T. Tomono, M. Iwasawa, S. Katohda, N. Takahashi, B. Koh. (1984). Nonsurgical correction of congenital auricular deformities in the early neonate: a preliminary report. *Plastic and reconstructive surgery*. 73 (1) 38-51.
- [6] B.H. Grayson, P.E. Santiago, L.E. Brecht, C.B. Cutting. (1999). Presurgical nasoalveolar molding in infants with cleft lip and palate. *The cleft palate-Craniofacial journal*. 36 (6) 486-498.
- [7] S.P. Avinoam, H.R. Kowalski, B.F. Chaya, P.R. Shetye. (2022). Current presurgical infant orthopedics practices among American cleft palate association-approved cleft teams in North America. *Journal of Craniofacial Surgery*. 33 (8) 2522-2528.
- [8] J.S. Eom, T.J. Lee. (2011). Changing trends in cleft lip and palate management taught in training programs in Korea. *Journal of Craniofacial Surgery*. 22 (2) 430-433.
- [9] V. Akinmoladun, S. Ademola, A. Ademola. (2017). Management of cleft lip and palate in Nigeria: A survey. *Nigerian Journal of Clinical Practice*. 20 (11) 1355-1359.
- [10] B.H. Grayson, J. Craniofac Surg. (2015). 26 (1) 71-5.
- [11] B.I. Aslan, A. Gülsen, K. Findikcioglu, D. Uzuner, N. Üçüncü. (2018). Effects of nasoalveolar molding therapy on alveolar and palatal cleft deformities in unilateral and bilateral cleft lip and palate. *Journal of Craniofacial Surgery*. 29 (2) 179-184.
- [12] S. Peanchitlerkajorn, A. Mercado, J. Daskalogiannakis, R. Hathaway, K. Russell, G. Semb, R.E. Long Jr. (2018). An intercenter comparison of nasolabial appearance including a center using nasoalveolar molding. *The Cleft Palate-Craniofacial Journal*. 55 (5) 655-663.
- [13] J.S. Garfinkle, T.W. King, B.H. Grayson, L.E. Brecht. (2011). A 12-year anthropometric evaluation of the nose in bilateral cleft lip-cleft palate patients following nasoalveolar molding and cutting bilateral cleft lip and nose reconstruction. *Plastic and reconstructive surgery*. 127 (4) 1659-1667.
- [14] C. Rey-Bellet. (2004). Prenatal diagnosis of facial clefts: evaluation of a specialised counselling. *Swiss medical weekly*. 134 (4344) 640-644.
- [15] M. Dölger-Häfner, A. Bartsch, G. Trimbach, I. Zobel, E. Witt. (1997). Parental reactions following the birth of a cleft child. *Journal of Orofacial Orthopedics/Fortschritte der Kieferorthopädie*. 58 124-133.
- [16] N. Hasanzadeh, M.O. Khoda, A. Jahanbin, M. Vatankhah. (2014). Coping strategies and psychological distress among mothers of patients with nonsyndromic cleft lip and palate and the family impact of this disorder. *Journal of Craniofacial Surgery*. 25 (2) 441-445.
- [17] N.O. Carvalho, M.F.S. Matos, I.F.C. Belchior, M.B. Araújo, C.T. Rocha, B.G. Neves. (2021). Parents' emotional and social experiences of caring a child with cleft lip and/or palate. *Pesquisa Brasileira em Odontopediatria e Clínica Integrada*. 21.
- [18] N.M. Stock, N. Rumsey. (2015). Starting a family: the experience of parents with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*. 52 (4) 425-436.
- [19] P.A. Nelson, S.A. Kirk, A.L. Caress, A.M. Glenney. (2012). Parents' emotional and social experiences of caring for a child through cleft treatment. *Qualitative health research*. 22 (3) 346-359.
- [20] N. Nidey, L.M. Moreno Uribe, M.M. Marazita, G.L. Wehby. (2016). Psychosocial well-being of parents of children with oral clefts. *Child: care, health and development*. 42 (1) 42-50.

- [21] A.L. Johns, J.A. Hershfield, N.M. Seifu, K.A. Haynes. (2018). Postpartum depression in mothers of infants with cleft lip and/or palate. *Journal of Craniofacial Surgery*. 29 (4) e354-e358.
- [22] T. Ramstad, E. Ottem, W.C. Shaw. (1995). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate II. Self-reported problems and concerns with appearance. *Scandinavian journal of plastic and reconstructive surgery and hand surgery*. 29 (4) 329-336.
- [23] V. Martin, S. Greatrex-White. (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.
- [24] E. Ahmann. (2006). Family matters. Supporting fathers' involvement in children's health care. *Pediatric Nursing*. 32 (1).
- [25] K. Deeney, M. Lohan, J. Parkes, D. Spence. (2009). Experiences of fathers of babies in intensive care. *Nursing Children and Young People*. 21 (1).
- [26] S.R. Baker, J. Owens, M. Stern, D. Willmot. (2009). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *The Cleft Palate-Craniofacial Journal*. 46 (3) 229-236.
- [27] G.L. Wehby, K.A. Nyarko, J.C. Murray. (2014). Oral cleft recurrence risk and subsequent maternal fertility preferences and behavior in Brazil. *Birth Defects Research Part A: Clinical and Molecular Teratology*. 100 (1) 48-56.
- [28] R. Chuacharoen, W. Ritthagol, J. Hunsrisakhun, K. Nilmanat. (2009). Felt needs of parents who have a 0-to 3-month-old child with a cleft lip and palate. *The Cleft palate-craniofacial journal*. 46 (3) 252-257.
- [29] C.K. Miller. (2011). Feeding issues and interventions in infants and children with clefts and craniofacial syndromes. In *Seminars in speech and language*. 32 (2) 115-126.
- [30] S.M.S. Baqutayan. (2015). Stress and coping mechanisms: A historical overview. *Mediterranean Journal of Social Sciences*. 6 (2 S1) 479.
- [31] R.S. Lazarus, S. Folkman. (1987). Transactional theory and research on emotions and coping. *European Journal of personality*. 1 (3) 141-169.
- [32] C.S. Carver, M.F. Scheier, J.K. Weintraub. (1989). Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*. 56 (2) 267.
- [33] J.D. Parker, N.S. Endler. (1992). Coping with coping assessment: A critical review. *European Journal of personality*. 6 (5) 321-344.
- [34] S. Roth, L.J. Cohen. (1986). Approach, avoidance, and coping with stress. *American psychologist*. 41 (7) 813.
- [35] P. Sloper, S. Turner. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of child psychology and psychiatry*. 34 (2) 167-188.
- [36] F. Walsh. (2003). Family resilience: A framework for clinical practice. *Family process*. 42 (1) 1-18.
- [37] J. Ledesma. (2014). *Conceptual frameworks and research models on resilience in leadership*. Sage open. 4 (3) 2158244014545464.
- [38] D. Czajeczny, M. Matthews-Kozanecka, K. Piórkowska, M. Ziarko, E. Mojs, D. Hojan-Jezińska, A. Matthews-Brzozowski. (2021). Psychological correlates of affect in parents of children with cleft lip and/or palate. *European Review for Medical & Pharmacological Sciences*. 25 (18).
- [39] J. Despars, C. Peter, A. Borghini, B. Pierrehumbert, S. Habersaat, C. Müller-Nix, J. Hohlfeld. (2011). Impact of a cleft lip and/or palate on maternal stress and attachment representations. *The Cleft palate-craniofacial journal*. 48 (4) 419-424.
- [40] K.S. Frey, M.T. Greenberg, R.R. Fewell. (1989). Stress and coping among parents of handicapped children: a multidimensional approach. *American Journal of Mental Retardation: AJMR*. 94 (3) 240-249.
- [41] R.M. Aleman, M.G. Martinez. (2023). Thematic Analysis of Coping Strategies Used by Parents of Children with Cleft Lip and Palate in El Salvador. *The Cleft Palate Craniofacial Journal*. 60 (3) 336-343.
- [42] B. McKlnney, R.A. Peterson. (1987). Predictors of stress in parents of developmentally disabled children. *Journal of Pediatric Psychology*. 12 (1) 133-150.
- [43] C.J. Dunst, C.M. Trivette, A.H. Cross. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American journal of mental deficiency*. 90 (4) 403-417.
- [44] P. Raina, M. O'Donnell, H. Schwellnus, P. Rosenbaum, G. King, J. Brehaut, E. Wood. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC pediatrics*. 4 1-13.
- [45] D.K. Wells, K. James, J.L. Stewart, I.M.K. Moore, K.P. Kelly, B. Moore, B. Speckhart. (2002). The care of my child with cancer: A new instrument to measure caregiving demand in parents of children with cancer. *Journal of pediatric nursing*. 17 (3) 201-210.
- [46] M. Stewart, A. Barnfather, A. Neufeld, S. Warren, N. Letourneau, L. Liu. (2006). Accessible support for family caregivers of seniors with chronic conditions: From isolation to inclusion. *Canadian Journal on Aging/La Revue canadienne du vieillissement*. 25 (2) 179-192.
- [47] A. Davalbhakta, P. Hall. (2000). The impact of antenatal diagnosis on the effectiveness and timing of counselling for cleft lip and palate. *British journal of plastic surgery*. 53 (4) 298-301.
- [48] P. Hlongwa, L.C. Rispel. (2018). "People look and ask lots of questions": caregivers' perceptions of healthcare provision and support for children born with cleft lip and palate. *BMC public health*. 18 (1) 1-10.
- [49] V.P. Sreejith, V. Arun, A.P. Devarajan, A. Gopinath, M. Sunil, M. (2018). Psychological effect of prenatal diagnosis of cleft lip and palate: a

- systematic review. *Contemporary clinical dentistry*. 9 (2) 304.
- [50] K. O'hanlon, P.M. Camic, J. Shearer. (2012). Factors associated with parental adaptation to having a child with a cleft lip and/or palate: the impact of parental diagnosis. *The Cleft palate-craniofacial journal*. 49 (6) 718-729.
- [51] J. Reid. (2004). A review of feeding interventions for infants with cleft palate. *The Cleft palate-craniofacial journal*. 41 (3) 268-278.
- [52] J.E. JONES, L. HENDERSON, D.R. AVERY. (1982). Use of a feeding obturator for infants with severe cleft lip and palate. *Special Care in Dentistry*. 2 (3) 116-120.
- [53] L. Turner, C. Jacobsen, M. Humenczuk, V.K. Singhal, D. Moore, H. Bell. (2001). The effects of lactation education and a prosthetic obturator appliance on feeding efficiency in infants with cleft lip and palate. *The Cleft palate-craniofacial journal*. 38 (5) 519-524.
- [54] M.J. Trenouth, A.N. Campbell. (1996). Questionnaire evaluation of feeding methods for cleft lip and palate neonates. *International Journal of Paediatric Dentistry*. 6 (4) 241-244.
- [55] M. Goyal, R. Chopra, K. Bansal, M. Marwaha. (2014). Role of obturators and other feeding interventions in patients with cleft lip and palate: a review. *European Archives of Paediatric Dentistry*. 15 1-9.
- [56] K.F.M. Britton, S.H. McDonald, R.R. Welbury. (2011). An investigation into infant feeding in children born with a cleft lip and/or palate in the West of Scotland. *European Archives of Paediatric Dentistry*. 12 250-255.
- [57] D.J. Zajac, O.L.D. Vallini. (2017). Feeding the newborn. Evaluation and management of cleft lip and palate: A developmental perspective. 113-127.
- [58] S.H. Albustani, A. Dziezic, M. Abid. (2022). The Perception and Experience of Parents of Children with Cleft Lip and Palate Concerning the Use Pre-Surgical Infant Orthopedics: A Questionnaire-Based Cross-Sectional Survey. *Children*. 9 (7) 1054.
- [59] M. Alperovich, J.D. Frey, P.R. Shetye, B.H. Grayson, R.M. Vyas. (2017). Breast milk feeding rates in patients with cleft lip and palate at a North American craniofacial center. *The Cleft Palate-Craniofacial Journal*. 54 (3) 334-337.
- [60] L. Sischo, H.L. Broder, C. Phillips. (2015). Coping with cleft: a conceptual framework of caregiver responses to nasoalveolar molding. *The Cleft Palate-Craniofacial Journal*. 52 (6) 640-650.
- [61] R.B.N. Yilmaz, D.G. Çakan, E.T. Uyar. (2019). Maternal and paternal well-being during nasoalveolar molding and primary surgery periods. *Journal of Craniofacial Surgery*. 30 (7) 2227-2232.
- [62] V. Bajpai, N. Singh, H. Sardana, S. Kumari, B. Vettiyil, A. Saraya, F. Ventrini. (2019). Burden of care: management of cleft lip and palate. *Indian Journal of Plastic Surgery*. 52 (03) 343-348.
- [63] M. Abd El-Ghafour, S.A. Elkordy, M.M.S. Fayed, A.R. El-Beialy, F.H.K. Eid. (2020). Parents' acceptance to alveolar and nasoalveolar molding appliances during early cleft lip and palate care: A call for high-quality research. *Open Access Macedonian Journal of Medical Sciences*. 8 (F) 58-64.
- [64] F.N. AlAnazi, W.A. AlHayyan, S.C. Pani. (2020). Impact of presurgical nasoalveolar molding on the parental perceptions of oral health-related quality of life of children with cleft lip and palate. *J Contemp Dent Pract*. 21 (2) 152-155.
- [65] M. Roth, D. Lonic, F.D. Grill, L.M. Ritschl, D.J. Loeffelbein, K.D. Wolff, L.J. Lo. (2021). NAM—help or burden? Intercultural evaluation of parental stress caused by nasoalveolar molding: a retrospective multi-center study. *Clinical Oral Investigations*. 25 5421-5430.
- [66] S. Alqadi, A. Qazali, R. Altamimi, R. Altamimi, I. Abdouh, A. Othman, F.D. Abdulhameed. (2023). Perception and Attitude of Parents of Children With Orofacial Clefts Regarding the Use of Presurgical Orthopedics and Feeding Obturators. *Cureus*. 15 (9).
- [67] H.L. Broder, R.L. Flores, S. Clouston, R.E. Kirschner, J.S. Garfinkle, L. Sischo, C. Phillips. (2016). Surgeon's and caregivers' appraisal of primary cleft lip treatment with and without nasoalveolar molding: A prospective multicenter pilot study. *Plastic and reconstructive surgery*. 137 (3) 938.
- [68] A.R. Alfonso, E.P. Ramly, R.S. Kantar, M.M. Wang, B.S. Eisemann, D.A. Staffenberg, R.L. Flores. (2020). What is the burden of care of nasoalveolar molding?. *The Cleft Palate-Craniofacial Journal*. 57 (9) 1078-1092.
- [69] E.E. Hopkins, E. Gazza, M.L. Marazita. (2016). Parental experience caring for cleft lip and palate infants with nasoalveolar moulding. *Journal of Advanced Nursing*. 72 (10) 2413-2422.