



“Healing Beyond the Smile: Psychosocial Challenges and Coping Strategies among Parents of Children with Cleft Lip and Palate — A Nursing Perspective”

Deepthi T B¹

¹Assistant professor

Community Health Nursing Department
Aswini College Of Nursing
Thrissur, Kerala, India

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Abstract: Children born with cleft lip and/or palate (CL/P) face not only surgical and developmental challenges but also psychosocial implications that extend deeply into family life. Parents of these children experience a complex mix of emotional, social, and practical challenges that demand understanding and support from healthcare professionals. This review explores the psychosocial difficulties encountered by parents of children with CL/P and the coping strategies they employ, highlighting the crucial role nurses play in supporting families through the child's developmental and treatment journey. Literature indicates that parents often face initial emotional turmoil, persistent anxiety, social stigma, and financial strain, which can affect family functioning and quality of life. However, coping strategies such as active participation in care, information seeking, emotional acceptance, and reliance on social and spiritual support help parents adapt over time. Nursing interventions—through early assessment, psychosocial counselling, education, and peer connection—have shown to mitigate stress and strengthen resilience. The article concludes with implications for nursing practice, policy, and research, emphasizing the need for family-centred and culturally sensitive psychosocial care for parents of children with CL/P.

Keywords: *cleft lip and palate, parental stress, coping strategies, psychosocial adaptation, family-centred nursing, caregiver resilience, emotional support, congenital anomalies, pediatric nursing, holistic care.*

Introduction

Cleft lip and palate (CL/P) are among the most prevalent congenital anomalies affecting craniofacial development worldwide. While surgical interventions have significantly advanced, the psychosocial dimensions of this condition remain challenging. For parents, the diagnosis of CL/P in their child is not merely a medical issue—it is an emotional and social event that redefines family life. Parents often encounter distress, fear, and uncertainty as they navigate repeated surgeries, speech therapy, and concerns about social acceptance. Nursing professionals, who interact closely with both the child and family, are uniquely positioned to provide psychosocial support, education, and counselling. Understanding parental emotions and coping mechanisms allows nurses to tailor interventions that foster resilience, emotional well-being, and better outcomes for

the family. This review examines the psychosocial challenges and coping mechanisms of parents of children with CL/P and explores the nursing implications for holistic care.

Background and Rationale

The birth of a child with a facial deformity can be a life-altering experience for parents. The diagnosis, whether prenatal or postnatal, often triggers intense emotions such as grief, guilt, and anxiety. Beyond the physical concerns, parents grapple with the stigma attached to visible differences, frequent hospital visits, and uncertainty about their child's future. The psychosocial burden of care can influence family relationships, affect parental self-esteem, and alter caregiving capacities. Nursing science recognizes that optimal outcomes for children with congenital



anomalies depend not only on clinical management but also on the psychosocial adjustment of caregivers. Hence, assessing and supporting parental well-being becomes a cornerstone of holistic pediatric and mental health nursing.

Psychosocial Challenges Faced by Parents

Emotional Reaction and Parental Guilt

The initial discovery of a cleft—whether during antenatal screening or after birth—commonly elicits feelings of shock and disbelief. Many parents describe a sense of mourning for the “perfect” child they expected. Emotional responses such as guilt and self-blame are frequent, particularly in mothers who may internalize societal beliefs linking birth defects to personal wrongdoing. Research reveals that many parents feel helpless and anxious during the early months following diagnosis. These emotions, if unaddressed, can evolve into chronic stress or depressive symptoms. Nurses play a pivotal role during this sensitive period by offering empathetic communication, reassurance, and counselling that can alleviate guilt and normalize parental emotions.

Parental Self-Image and Self-Esteem

Parents of children with CL/P often struggle with feelings of inadequacy or social judgment. In cultures where physical perfection is highly valued, mothers and fathers may feel stigmatized or fear being blamed for their child's condition. Studies indicate that nearly 40% of such parents report diminished self-esteem, particularly when societal attitudes reinforce shame. Reduced self-esteem can limit parental engagement in care and hinder bonding with the child. Nursing interventions that emphasize acceptance, empowerment, and self-efficacy can help restore parental confidence and facilitate healthy parent-child interactions.

Persistent Anxiety and Uncertainty

Parenting a child with CL/P involves continuous exposure to uncertainty regarding surgical outcomes, speech development, and long-term social integration. Parents frequently report heightened anxiety levels during the surgical phase and while awaiting developmental milestones. Both mothers and fathers express concerns about how their child will be perceived by others. Some studies note that mothers experience greater anxiety related to caregiving, while fathers express stress over financial and social responsibilities. By maintaining open communication and providing clear, honest information,

nurses can reduce ambiguity and strengthen parental trust in the healthcare process.

Social Stigma and Isolation

Stigma remains a major psychosocial challenge for families affected by visible deformities. Parents may face intrusive questions or discrimination from relatives and community members. The child's appearance and speech difficulties can invite teasing or bullying, which indirectly distress parents and lead them to withdraw socially. This isolation can erode social support networks, further compounding stress. Community-based nurses and health visitors can play a critical role in combating stigma by providing awareness programs and connecting families to peer groups, thereby fostering inclusion and empathy.

Financial and Logistical Burden

The treatment of CL/P involves multiple surgeries, orthodontic care, and speech therapy over several years. These cumulative medical expenses, travel requirements, and caregiving responsibilities impose financial strain. Parents, especially mothers, often reduce working hours or leave employment to attend medical appointments. The resulting financial pressure and loss of personal independence may contribute to marital tension and family conflict. Nurses, by facilitating access to social services, charitable support, and governmental schemes, can help alleviate the financial burden on families.

Impact on Family Functioning and Quality of Life

The psychosocial consequences of CL/P extend to the entire family unit. Couples may experience stress due to differing coping styles or blame dynamics. Siblings may feel neglected or embarrassed about their brother or sister's appearance. The family's overall functioning may decline as attention and resources are concentrated on the affected child. Studies comparing families with and without children with CL/P reveal lower quality of life scores in the former group. Family-centred nursing approaches that involve both parents and siblings can mitigate these disruptions and enhance collective resilience.

Coping Strategies among Parents

Problem-Focused Coping

Many parents cope by actively engaging in their child's care and seeking information about the condition. This proactive approach includes learning about treatment options, feeding techniques, and postoperative management.



Information-seeking not only reduces uncertainty but also empowers parents to participate meaningfully in decision-making. Parents who actively collaborate with healthcare professionals tend to experience a stronger sense of control and lower stress levels. Support groups, both physical and virtual, serve as important venues for sharing experiences and acquiring practical advice. Research shows that parents who use active, approach-oriented coping strategies report less family impact compared to those who rely on avoidance. Nurses can encourage such proactive behaviors by providing accessible information and connecting families to credible resources.

Emotion-Focused Coping

Emotional adaptation is a vital element of long-term resilience. Parents often transition from denial or grief to acceptance over time. Some reframe their experiences positively, perceiving their child's condition as an opportunity for personal growth and deeper family bonds. Spirituality and faith frequently act as protective factors, offering meaning and hope amidst adversity. Expression of emotions through counselling, storytelling, or parent forums allows families to release internalized distress. Many parents adopt the philosophy of "normalizing" their child's life—focusing on strengths rather than limitations. Nurses can support this process by encouraging positive reframing, facilitating spiritual support if desired, and modelling acceptance through non-stigmatizing care practices.

Social and Community Support

The role of social support cannot be overstated. Friends, extended family, and peer networks provide emotional reassurance, practical assistance, and validation. Parental engagement with organizations specializing in craniofacial conditions often enhances coping. Nurses can strengthen these support systems by promoting community awareness, initiating family clubs, and advocating for inclusive social policies. Integrating social work and nursing services ensures that families receive comprehensive psychosocial assistance beyond hospital walls.

Nursing Perspective and Implications for Practice

Nursing care for families of children with CL/P must move beyond biomedical treatment to encompass psychosocial assessment, education, and sustained emotional support. Nurses act as a consistent point of contact for parents

throughout the child's treatment trajectory, making them ideal agents for psychosocial intervention.

Assessment and Early Intervention: Upon diagnosis, nurses should assess the parent's emotional response, support networks, and coping resources. Early screening for anxiety, depression, and social isolation allows timely referral to mental health professionals. Involving both parents during counselling sessions helps address gender-specific emotional needs and prevents unequal burden distribution.

Education and Empowerment: Educational interventions remain central to nursing care. Providing clear, culturally sensitive information about feeding, surgical stages, and rehabilitation reduces fear and builds confidence. Teaching parents practical caregiving skills and including them in postoperative care fosters a sense of mastery and partnership. Education should extend beyond medical details to include information on psychosocial adaptation and community resources.

Psychosocial Counselling and Support: Nurses can lead individual or group counselling sessions aimed at stress management, self-esteem enhancement, and emotional regulation. Integrating mental health principles into routine nursing care ensures that psychosocial needs are addressed holistically. Encouraging parents to express their emotions and validating their experiences reduces isolation and guilt.

Peer and Family Support Facilitation: Creating platforms for parent-to-parent interaction offers shared understanding and mentorship. Experienced parents who have navigated the treatment process can guide new families, demonstrating that adaptation and happiness are achievable. Involving siblings and extended family members in educational sessions fosters empathy and cohesive family functioning.

Collaboration and Continuity of Care: Nurses serve as vital links within multidisciplinary teams that include surgeons, psychologists, speech therapists, and social workers. Coordinated care ensures that parents receive consistent messages and integrated support. Nurses can maintain follow-up communication through phone calls or community visits to monitor parental well-being across different treatment stages.

Cultural Sensitivity and Advocacy: In many cultures, facial deformities carry moral or spiritual stigma. Nurses



must provide culturally competent care that respects beliefs while gently challenging misconceptions. Advocacy for inclusion, public awareness campaigns, and family education can help reduce stigma and foster acceptance within the community.

Implications for Nursing Education and Policy

To adequately address psychosocial dimensions, nursing curricula should incorporate training on congenital anomalies, family systems theory, and resilience promotion. Skills in communication, empathy, and counselling are as essential as clinical expertise. Hospital policies should institutionalize psychosocial screening for caregivers of children with congenital anomalies and allocate time for nurses to provide counselling. Health institutions must also support continuing education programs to keep nurses updated on family-centred care models.

Policies at national and institutional levels can promote interdisciplinary collaboration, integrating psychological services into pediatric surgery units. Establishing structured parent education modules and mentorship networks can further institutionalize support. Nurses, as advocates, should lobby for public insurance schemes or social aid programs to assist families burdened by the long-term financial cost of CL/P care.

Research Directions and Gaps

Despite growing literature on the psychosocial experiences of families affected by CL/P, several gaps remain. Most research focuses primarily on mothers, overlooking fathers and extended caregivers. Future studies should adopt inclusive designs capturing family diversity. Longitudinal research is needed to explore parental adaptation from infancy through adolescence, identifying phases of heightened vulnerability. Moreover, few controlled trials evaluate the impact of nursing-led psychosocial interventions such as resilience training, mindfulness programs, or digital peer support. Developing standardized, culturally validated assessment tools for parental distress and coping specific to CL/P populations remains a priority. Research in low- and middle-income countries, where stigma and resource constraints are more pronounced, will add valuable insight to global nursing practice.

Integrating a Nursing Framework for Parental Support

A conceptual nursing framework for psychosocial care of parents of children with CL/P can be visualized in six interrelated stages.

Early engagement involves assigning a nurse liaison at the time of diagnosis to establish rapport and assess psychosocial needs.

Structured education at key treatment milestones—such as pre-surgery, post-surgery, and speech therapy—ensures that parents are informed and empowered. Peer support integration provides opportunities for group learning and emotional sharing.

Periodic psychosocial screening allows nurses to detect evolving stressors over time and intervene early. Family inclusion in counselling sessions ensures that siblings and partners also adapt healthily. Finally, feedback and evaluation mechanisms help refine services and strengthen trust between healthcare providers and families.

This model, rooted in family-centred nursing, encourages continuous collaboration and resilience-building as part of the care continuum.

Illustrative Case Example

Consider a young mother whose newborn is diagnosed with cleft lip and palate shortly after delivery. Initially overwhelmed, she expresses guilt and refuses to show her baby to visitors. A nurse trained in family-centred care provides nonjudgmental support, explains the condition and treatment plan, and introduces her to a parent group. Over the following months, the mother learns feeding techniques, attends counselling sessions, and gradually gains confidence. After the child's first surgery, she begins mentoring new parents in the support group. Her anxiety diminishes, and her relationship with her partner strengthens. This case underscores the profound role nurses play not only in clinical recovery but also in nurturing parental resilience and empowerment.

Conclusion

Parenting a child with cleft lip and palate is a journey that challenges emotional endurance, social identity, and family stability. The psychosocial challenges—ranging from initial shock and guilt to long-term anxiety, stigma, and financial



stress—are profound but manageable with appropriate support. Parents demonstrate remarkable resilience when equipped with accurate information, emotional validation, and community connection. Nursing professionals, through consistent, compassionate, and holistic care, can bridge the gap between medical treatment and emotional healing. Emphasizing psychosocial assessment, empowerment, and family inclusion transforms nursing care into a partnership that strengthens the invisible bond between parent and child. By integrating evidence-based psychosocial interventions into routine practice, nurses can help families move from distress to adaptation—truly healing beyond the smile.

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