



“Psychosocial Interventions for Parents of Infants with Cleft Conditions: A Systematic Review (Narrative Synthesis)”

Deepthi T. B.¹

¹Assistant Professor, Aswini College of Nursing, Thrissur, Kerala, India

¹PhD Scholar, Malwanchal University, Indore, Madhya Pradesh, India

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Abstract: Cleft lip and/or palate (CL/P) is among the most common congenital craniofacial conditions and presents families with a complex and prolonged pathway of treatment and adaptation. Although advances in surgical and multidisciplinary care have improved clinical outcomes, the psychosocial needs of parents of infants with cleft conditions may remain inadequately addressed. Parents may experience anxiety, depression, guilt, self-blame, fear regarding feeding and surgery, uncertainty about the child's future, and difficulties establishing early parent-infant bonding. These emotional challenges may influence feeding practices, treatment adherence, family functioning, and engagement with healthcare services. This paper presents a systematic review with narrative synthesis of psychosocial interventions for parents and caregivers of infants with cleft lip and/or palate. The review focuses on intervention characteristics, psychological outcomes, family outcomes, clinical benefits, barriers to implementation, research gaps, and nursing implications. The interventions identified include psychological counselling, cognitive behavioral therapy, stress-management interventions, online support groups, in-person peer support, nurse-led education, and multidisciplinary counselling. Across the reviewed literature, psychosocial interventions were associated with reductions in parental anxiety and depression, improved parenting confidence and coping, better emotional adjustment and parent-infant attachment, improved feeding practices, greater clinical knowledge, treatment adherence, and family communication. The synthesis indicates that early intervention, continuity of support, education, peer connection, and multidisciplinary collaboration are central to effective family adaptation. Nurses are positioned as a continuous thread of care, providing psychological assessment, first aid, feeding education, pre-operative counselling, care coordination, home-based education, telephone follow-up, and referral. Important limitations include small sample sizes, methodological heterogeneity, limited randomized controlled trials, inconsistent outcome measures, inadequate long-term follow-up, limited access to mental health professionals, rural disparities, financial barriers, and sociocultural stigma. Future research should prioritize standardized culturally adapted protocols, multicenter randomized trials, routine psychosocial screening, nurse-led programmes, telehealth, cost-effectiveness evaluation, and long-term outcome measurement.

Keywords: cleft lip and palate, parents, psychosocial support, parental anxiety, depression, family-centered care, nursing, counselling, peer support, narrative synthesis

1. Introduction

The birth of an infant with a cleft condition can represent a significant emotional and practical challenge for parents and families. Cleft lip and/or palate affects the structure and function of the lip and palate and may require multiple stages of treatment, including surgical procedures, feeding support, dental and orthodontic management, speech and language intervention, and long-term multidisciplinary follow-up.

While advances in cleft surgery and multidisciplinary clinical management have improved the physical outcomes of affected children, the emotional experience of parents can receive comparatively less attention. The diagnosis may be unexpected, and parents may immediately confront questions about feeding, surgery, appearance, speech, development, social acceptance, and the long-term well-being of their child.



The source document identifies cleft lip and/or palate as occurring in approximately 1 in 500 to 1,000 live births worldwide and emphasizes that family-centered psychosocial care is essential from diagnosis through treatment.

Parental psychological distress may include anxiety, depression, guilt, self-blame, fear concerning feeding and surgery, and uncertainty regarding the child's future. When these needs remain unaddressed, emotional distress may extend beyond the parent and affect the broader caregiving environment.

The psychosocial well-being of parents is therefore not a secondary issue. It is closely connected with the family's capacity to adapt to the child's condition, understand treatment requirements, participate in care, and maintain effective parent-infant relationships.

This paper presents a systematic review with narrative synthesis of psychosocial interventions designed for parents of infants with cleft conditions. It examines the intervention approaches described in the source document, their psychological and family-related outcomes, clinical implications, barriers to implementation, and the role of nurses in providing continuous family-centered psychosocial support.

2. The Clinical Reality: When Diagnosis Becomes a Family Crisis

The diagnosis of a cleft condition can initiate a cascade of emotional responses. Parents may experience shock, anxiety, sadness, guilt, self-blame, fear, and uncertainty.

For some families, the diagnosis may also generate concerns regarding social acceptance and stigma. Parents may worry about how relatives, peers, teachers, and the wider community will perceive their child.

Feeding is an immediate practical concern. Infants with cleft conditions may experience difficulties with effective feeding, and parents may feel anxious about whether their baby is receiving adequate nutrition. The need for specialized feeding techniques can increase parental workload and emotional strain.

Surgery represents another major source of anxiety. Parents may fear anesthesia, operative risks, pain, complications, and the child's experience during hospitalization.

These concerns can accumulate.

The source document conceptualizes the process as a cascading impact:

Unaddressed psychosocial needs → emotional distress → compromised feeding practices → impaired parent-infant bonding → reduced treatment adherence → strained family functioning.

This pathway demonstrates why psychosocial care should begin early rather than being introduced only after severe distress becomes evident.

3. Psychosocial Needs of Parents

Parents of infants with cleft conditions may have diverse psychosocial needs depending on the timing of diagnosis, severity and type of cleft, available social support, financial circumstances, cultural environment, and access to specialist care.

3.1 Anxiety and Depression

Anxiety and depressive symptoms may develop as parents adjust to the diagnosis and anticipate the child's treatment pathway.

Repeated appointments, surgery, feeding challenges, and uncertainty about future outcomes can contribute to sustained emotional pressure.

3.2 Guilt and Self-Blame

Parents may question whether they did something that caused the condition. Such thoughts can become a significant source of psychological distress.

Appropriate counselling and education can help parents understand the condition and reduce inappropriate feelings of personal responsibility.

3.3 Fear of Feeding Difficulties

Feeding is among the earliest practical challenges faced by families. Parents need accurate information and hands-on support to develop confidence in caring for their infant.

3.4 Fear Regarding Surgery

Anticipation of surgery can produce substantial anxiety. Parents may need clear, developmentally appropriate



explanations regarding procedures, preparation, postoperative care, and expected outcomes.

3.5 Parent-Infant Bonding

Emotional distress can interfere with confidence and early attachment. Psychosocial interventions therefore need to support not only the parent's emotional health but also the parent-infant relationship.

3.6 Family Functioning

The demands of prolonged treatment may affect communication, finances, family roles, and relationships. Psychosocial care should consequently extend beyond the individual parent and consider the family as a unit.

4. Aim of the Review

The source document presents four principal objectives:

1. To identify psychosocial interventions for parents of infants with cleft conditions.
2. To describe the characteristics of these interventions.
3. To examine psychological and family outcomes.
4. To identify research gaps and nursing implications.

The review is framed as a systematic review with narrative synthesis.

The population consists of parents or caregivers of infants with cleft lip and/or palate. The intervention focus is psychosocial rather than purely surgical.

Quantitative, qualitative, and mixed-methods studies are relevant to the review framework.

The source identifies databases including PubMed, CINAHL, Web of Science, and the Cochrane Library.

Adult cleft patients, purely surgical interventions, and non-English publications were identified as exclusion areas within the source framework.

5. Psychosocial Intervention Landscape

The review identifies a diverse toolkit of psychosocial interventions.

These include:

- Psychological counselling
- Cognitive behavioral therapy
- Stress-management programmes
- Nurse-led education

- In-person peer support groups
- Online support groups
- Multidisciplinary counselling

The interventions vary considerably in their delivery format and level of professional involvement.

Some are primarily peer-led, while others are professionally or clinically led. Some occur face-to-face, whereas online support groups create opportunities for connection without requiring physical attendance.

This diversity is important because parents do not have identical needs.

A parent experiencing significant anxiety may require professional psychological counselling. Another parent may primarily require practical education regarding feeding and surgery. A third may benefit from peer connection with another family who has experienced a similar treatment pathway.

The most effective care model may therefore involve **multiple complementary forms of support rather than a single intervention.**

6. Psychological Outcomes of Psychosocial Intervention

The narrative synthesis identifies several important psychological outcomes.

6.1 Reduction in Anxiety and Depression

Psychosocial interventions are associated in the reviewed evidence with significant reductions in parental anxiety and depression.

This finding reinforces the importance of treating parental emotional health as a meaningful component of cleft care.

6.2 Improved Parenting Confidence

Education and structured support can increase parental confidence in caring for an infant with a cleft condition.

Confidence is particularly important during feeding and peri-operative periods, when parents may feel uncertain about what to do.

6.3 Improved Coping

Coping refers to the ability to manage emotional and practical challenges associated with the child's condition.



Psychological interventions and peer support can provide parents with strategies for managing stress and adapting to changing treatment demands.

6.4 Emotional Adjustment

Support can assist parents in moving from an initial period of shock and uncertainty toward greater acceptance and adaptation.

6.5 Parent-Infant Attachment

By reducing emotional distress and increasing parental confidence, psychosocial support may facilitate healthier parent-infant interaction and attachment.

The improvement in parental emotional well-being can therefore have implications extending beyond the parent to the child's broader developmental environment.

7. Systemic and Clinical Benefits

The benefits of psychosocial interventions are not limited to psychological outcomes.

The source identifies several systemic and clinical benefits.

Improved Feeding Practices

Education and emotional support can help parents approach feeding with greater confidence. Improved parental understanding may contribute to safer and more effective feeding practices.

Increased Clinical Knowledge

Nurse-led education and multidisciplinary counselling can improve parents' understanding of cleft conditions, treatment requirements, and home care.

Knowledge reduces uncertainty and can strengthen participation in treatment.

Increased Clinic Attendance

Parents who feel supported and informed may be more likely to remain engaged with specialist services.

Improved Treatment Adherence

Long-term cleft care requires sustained participation. Psychosocial support can help families manage the emotional and practical burden associated with repeated treatment.

Improved Family Communication

Family-centered support can encourage communication between parents and other family members and improve overall treatment satisfaction.

These findings reinforce the idea that psychosocial care is not separate from clinical care. It can influence how effectively families participate in the clinical pathway.

8. The Narrative Synthesis: The Web of Care

The source document presents a particularly important conceptual model: **The Web of Care**.

This framework identifies five interconnected elements:

Early intervention

Continuous support

Multidisciplinary teams

Empowerment through education

Connection through shared experience

Together, these elements create a network of support around the family.

8.1 Early Intervention

Early psychosocial support can reduce initial parental distress.

The period immediately following diagnosis is a critical window. Parents are attempting to understand the condition while simultaneously adjusting emotionally to unexpected information.

Psychological first aid and early assessment can therefore establish a supportive foundation.

8.2 Continuous Support

The source emphasizes that long-term threading throughout treatment is more valuable than one-time counselling.

Cleft care is rarely completed in a single encounter. Families may require support across infancy, surgery, feeding, speech development, dental care, and other stages.

Psychosocial care should therefore follow the treatment journey.

8.3 Multidisciplinary Teams

Integrated approaches appear to produce better family adaptation.

Cleft care requires collaboration among surgeons, nurses, psychologists, speech professionals, dental specialists,



social workers, and other professionals depending on individual needs.

Psychosocial support should be embedded within this team.

8.4 Empowerment Through Education

Knowledge directly contributes to parental confidence.

When parents understand the condition and know what to expect, uncertainty may decrease.

Education should be practical, accessible, culturally appropriate, and repeated at different stages of treatment.

8.5 Connection Through Shared Experience

Peer support provides an opportunity for parents to connect with people who have lived through similar experiences.

Such connections can reduce feelings of isolation and create a sense of community.

9. Nursing as the Continuous Thread of Care

Nurses occupy a distinctive position in cleft care because they can interact with families across multiple stages of the treatment pathway.

The source conceptualizes nurses as the **continuous thread of care**, moving from assessment to education to long-term coordination.

9.1 At Diagnosis

The nurse can provide psychological first aid and conduct an early emotional assessment.

This involves recognizing distress, providing reassurance, identifying immediate needs, and determining whether referral to a mental health professional is appropriate.

9.2 During Early Infancy

Nurses can provide feeding education, home visits, and parent education programmes.

This stage is particularly important because parents are developing practical caregiving skills.

9.3 During the Peri-Operative Period

Pre-operative counselling and care coordination can reduce uncertainty and help families prepare emotionally and practically for surgery.

The nurse can reinforce information provided by the multidisciplinary team and ensure that parents understand the expected care process.

9.4 After Discharge and Long-Term Follow-Up

Telephone follow-up, integration into support groups, and referral to psychologists or social workers can extend support beyond hospitalization.

This continuity is particularly valuable because psychosocial needs may change as treatment progresses.

10. Barriers to Effective Psychosocial Care

Despite evidence supporting psychosocial interventions, several barriers can prevent families from receiving adequate support.

10.1 Limited Access to Mental Health Professionals

Many cleft services may not have dedicated psychologists or other mental health professionals integrated into routine care. This can result in psychological needs being recognized but not adequately treated.

10.2 Rural and Geographic Disparities

Families living in rural or geographically isolated areas may face significant difficulties accessing specialized cleft services and psychosocial care.

Travel requirements can increase financial and emotional burden.

10.3 Financial Burden

Cleft treatment often requires prolonged engagement with healthcare services. Transportation, accommodation, lost workdays, and other expenses can add to family stress.

10.4 Sociocultural Stigma

Congenital anomalies may be associated with deeply rooted cultural beliefs and stigma.

Parents may experience shame, social isolation, or inappropriate blame from others.

Psychosocial interventions therefore need to be culturally adapted rather than simply translated from one setting to another.

10.5 Lack of Standardized Interventions

Different studies use different interventions, durations, providers, and outcome measures.

This methodological heterogeneity makes it difficult to determine which intervention components are most effective.

11. State of Current Evidence



The source identifies both momentum and friction within the current evidence base.

Strengths

There is a growing international research base.

Across diverse studies, psychosocial interventions generally report positive outcomes.

There is also increasing multidisciplinary involvement in cleft care.

These trends suggest that psychosocial support is increasingly recognized as an important component of comprehensive cleft management.

Limitations

However, several limitations remain.

The source identifies a scarcity of randomized controlled trials, substantial diversity in intervention methods, variable outcome measures, limited standardized psychosocial protocols, and inadequate evaluation of long-term intervention durability.

Small sample sizes further restrict the generalizability of findings.

These limitations indicate that the field requires stronger methodological consistency.

12. Moving from One-Time Counselling to Longitudinal Support

A key message emerging from the narrative synthesis is that psychosocial care should not be treated as a single event.

A parent may receive counselling immediately following diagnosis, but new emotional challenges may emerge before surgery, during hospitalization, after discharge, or during later developmental stages.

Longitudinal support therefore needs to be integrated into the cleft treatment pathway.

A family-centered model can be represented as:

Diagnosis → emotional assessment → education → feeding support → peri-operative counselling → surgical care → discharge support → peer connection → long-term follow-up.

At each stage, psychosocial needs should be reassessed.

This approach recognizes that parental adaptation is dynamic rather than static.

13. Telehealth and Digital Psychosocial Support

The source recommends expanding telehealth counselling to address rural and financial barriers.

Telehealth can potentially reduce travel requirements and make psychological support more accessible to families who live far from specialist centers.

Online support groups can also provide opportunities for peer connection.

However, digital delivery should not automatically replace face-to-face care.

Some parents may require direct psychological assessment, crisis support, or intensive counselling that cannot be adequately provided through remote platforms.

Telehealth should therefore be considered as part of a flexible care model.

A blended approach may include:

Face-to-face specialist care + telehealth counselling + telephone follow-up + online peer support + home-based nursing education.

14. Research Imperatives

The source proposes a dual-track blueprint combining research priorities with clinical implementation.

14.1 Routine Psychosocial Screening

Psychosocial screening should be implemented routinely for parents of infants with cleft conditions.

Screening provides an opportunity to identify anxiety, depression, stress, and other concerns early.

14.2 Integration into Standard Cleft Services

Psychological care should be formally integrated into cleft services rather than treated as an optional additional service.

This would support a truly multidisciplinary model.

14.3 Nurse-Led Intervention Programmes

The development and funding of dedicated nurse-led psychosocial intervention programmes could expand access and strengthen continuity.

Nurses are well positioned to deliver education, assess emotional needs, coordinate referrals, and maintain follow-up.

14.4 Large Multicenter Randomized Controlled Trials



Large multicenter RCTs are needed to establish stronger evidence concerning intervention effectiveness.

Such studies could compare different intervention models and identify the most effective components.

14.5 Standardized Outcome Measures

The use of standardized outcome measures would improve comparability across studies.

Outcomes should include both psychological and family-related measures as well as relevant clinical and adherence outcomes.

14.6 Culturally Adapted Protocols

Interventions should be adapted to local cultural contexts.

A psychosocial programme developed in one country may not be directly transferable to another because attitudes toward congenital anomalies, family roles, mental health, and healthcare utilization vary.

14.7 Cost-Effectiveness

Cost-effectiveness studies are required to determine how psychosocial programmes can be sustainably integrated into hospital and community services.

This is particularly important in resource-constrained settings.

15. The Holistic Care Model

The overall synthesis supports a holistic care model in which psychosocial interventions are treated as a necessary component of comprehensive cleft care.

The source presents a direct relationship:

Psychosocial interventions → optimal family adaptation → treatment success.

This model recognizes that successful cleft treatment depends not only on surgical correction but also on the family's capacity to participate in the treatment process.

Family adaptation can influence feeding, appointment attendance, treatment adherence, emotional well-being, parent-infant interaction, and long-term satisfaction.

The holistic model therefore places the family alongside the infant at the center of care.

16. Implications for Nursing Practice

The findings have several important implications for nursing practice. Nurses should incorporate psychosocial

assessment into routine cleft care and provide structured education rather than relying solely on informal explanations. Assessment of feeding-related concerns and parental confidence during early infancy is also essential, along with the provision or coordination of appropriate pre-operative counselling. Nurses should maintain communication with families after discharge to support continuity of care and facilitate timely referral to psychologists, social workers, and other professionals when required. Connecting families with peer-support resources can further enhance coping, confidence, and social support. Nurses should also advocate for psychosocial care as a standard component of cleft services. The nursing role is therefore both clinical and coordinative, encompassing direct patient and family care, education, psychosocial support, care coordination, referral, follow-up, and advocacy.

17. Implications for Multidisciplinary Practice

Psychosocial support should be embedded within multidisciplinary cleft teams.

Surgeons address surgical needs. Nurses provide continuity and education. Psychologists address emotional and behavioral needs. Speech and language professionals address communication-related concerns. Dental and orthodontic professionals contribute to long-term structural and functional management. Social workers can assist with financial, social, and community resources.

The effectiveness of this model depends on communication among professionals.

A family should not have to repeatedly explain its emotional and practical challenges to different providers. Shared documentation, coordinated care planning, and clear referral pathways can improve continuity.

The multidisciplinary team should therefore function as a coordinated network rather than a collection of independent professionals.

18. Discussion

The findings of this narrative synthesis support the proposition that psychosocial interventions are an essential component of family-centered cleft care.



The clinical journey associated with cleft conditions can be prolonged and emotionally demanding. Parents may experience distress at diagnosis, uncertainty during infancy, anxiety surrounding surgery, practical difficulties with feeding, and continuing concerns as the child progresses through treatment.

A one-time counselling session is unlikely to address all these needs.

The strongest conceptual message emerging from the source is therefore the importance of **continuity**.

Early intervention reduces initial distress. Education improves confidence. Peer connection reduces isolation. Multidisciplinary care integrates psychological support with clinical management. Long-term follow-up maintains the therapeutic relationship.

Nurses are particularly suited to maintaining this continuity.

At the same time, the evidence base requires strengthening. Positive outcomes across studies are encouraging, but methodological heterogeneity, small samples, limited RCT evidence, and inadequate long-term follow-up restrict certainty about which interventions produce the greatest and most durable effects.

Future studies should therefore focus not only on whether psychosocial interventions work, but also on:

- Which interventions work best?
- For which parents?
- At what stage should they begin?
- How frequently should they be delivered?
- Who should deliver them?
- How long do benefits last?
- Which approaches are culturally acceptable?
- Can telehealth improve access?
- Are nurse-led programmes cost-effective?
- Which outcomes are most clinically meaningful?

Answering these questions would help transform psychosocial support from a desirable addition into a standardized component of cleft care.

19. Conclusion

Psychosocial interventions for parents of infants with cleft conditions represent an essential component of

comprehensive family-centered care. Although surgical advances remain fundamental, the emotional and practical experiences of parents can significantly influence the family's ability to adapt to the child's condition and participate effectively in treatment.

The narrative synthesis identifies a diverse range of interventions, including psychological counselling, cognitive behavioral therapy, stress management, nurse-led education, peer-support groups, online support, and multidisciplinary counselling.

Across the reviewed evidence, these interventions are associated with reductions in parental anxiety and depression, improved coping and parenting confidence, better emotional adjustment and parent-infant attachment, improved feeding practices, greater clinical knowledge, increased treatment adherence, and improved family communication.

The evidence also demonstrates that psychosocial care should begin early and continue throughout the treatment pathway. The concept of the **Web of Care** captures this principle: early intervention, continuous support, multidisciplinary collaboration, education, and peer connection should operate together.

Nurses have a central role in this model. They provide the continuous thread linking diagnosis, emotional assessment, education, feeding support, peri-operative counselling, discharge planning, telephone follow-up, support-group integration, and referral.

However, important barriers remain. Limited access to mental health professionals, rural disparities, financial burden, sociocultural stigma, methodological heterogeneity, small sample sizes, and inadequate long-term evaluation all restrict the widespread implementation and evaluation of psychosocial care.

A dual-track blueprint is therefore required. Clinically, services should implement routine psychosocial screening, integrate psychological care into standard cleft programmes, develop nurse-led interventions, and expand telehealth. Research should prioritize large multicenter randomized trials, standardized outcomes, culturally adapted protocols, long-term follow-up, and cost-effectiveness evaluation.



Ultimately, psychosocial interventions should not be viewed as optional support added to surgical care. They are part of the care itself.

Comprehensive cleft care begins not only with repairing the cleft, but also with supporting the family that will walk the entire treatment journey with the child.

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