JHWCR JOURNAL OF HEALTH, WELLNESS AND COMMUNITY RESEARCH 3007-0570

https://doi.org/10.61919/22jy7r98

Original Article

Parental Experiences of Managing Pediatric Dysphagia in Children with Cerebral Palsy

Sana Ali[1], Anum Ashraf[2], Ruqqia Bano[3], Areej Tahir[4]

[1] MS Speech and Language Pathology and Hearing Sciences, University of Lahore, Lahore, Pakistan
[2] Assistant Professor, Department of Rehabilitation Sciences, University of Lahore, Lahore, Pakistan
[3] House Officer, Ghurki Trust Teaching Hospital, Lahore, Pakistan
[4] Senior Speech Therapist, Lahore, Pakistan

***Corresponding author: Sana Ali, 70143557@student.uol.edu.pk**

"Cite this Article" Received: 07 January 2026; **Accepted**: 09 February 2026; **Published**: 15 March 2026
Author Contributions: Concept: SA and AA; Design: SA and AA; Data Collection: SA and RB; Analysis: SA and AT; Drafting: SA, AA, RB, and AT. **Ethical Approval**: University of Lahore, Lahore, Pakistan. **Informed Consent**: Written informed consent was obtained from all participants; **Conflict of Interest**: The authors declare no conflict of interest. **Funding**: No external funding; **Data Availability**: Available from the corresponding author on reasonable request; **Acknowledgments**: N/A.

ABSTRACT

Background: Pediatric dysphagia is a clinically important complication in children with cerebral palsy and may affect feeding safety, nutrition, respiratory health, growth, and family routines. Although clinical management of dysphagia has been widely discussed, less attention has been given to how caregivers experience daily feeding challenges, emotional stress, home-based adaptations, and access to professional support. Objective: To explore mothers' experiences of managing pediatric dysphagia in children with cerebral palsy, with attention to mealtime challenges, safety concerns, feeding adaptations, caregiver burden, and perceived support needs. Methods: This interpretative qualitative study included 14 mothers of children with cerebral palsy and dysphagia recruited through purposive sampling from hospital and rehabilitation settings in Lahore, Pakistan. Data was collected using semi-structured interviews and analyzed through thematic analysis. Demographic characteristics were summarized descriptively. Results: Six themes were identified: mealtime stress and disruption of daily life, safety concerns related to choking and aspiration, home-based feeding adaptations, nutritional management and food texture modification, caregiver burden and financial strain, and professional guidance and support needs. Mothers described feeding as prolonged, stressful, and shaped by fear of choking, aspiration, poor nutrition, and weight loss. They used texture modification, posture support, special utensils, distraction-free spaces, and frequent meals, but these strategies increased time, financial, and emotional burden. Conclusion: Mothers experienced pediatric dysphagia as a multidimensional caregiving challenge requiring practical feeding support, affordable multidisciplinary services, caregiver education, and emotional support. The findings should inform family-centered dysphagia care for children with cerebral palsy. Keywords: Cerebral palsy; pediatric dysphagia; feeding difficulties; caregiver experience; mothers; qualitative research; thematic analysis.

INTRODUCTION

Cerebral palsy is one of the most common childhood neurodevelopmental conditions and is characterized by persistent disorders of movement, posture, and muscle tone that may be accompanied by communication, feeding, nutritional, respiratory, and functional difficulties (1,2). Among the clinically important complications associated with cerebral palsy, pediatric dysphagia has particular relevance because safe and efficient swallowing is essential for nutrition, hydration, growth, respiratory protection, and quality of life. Children with cerebral palsy may experience impaired oral-motor control, poor coordination of swallowing, drooling, coughing during meals, prolonged feeding time, food refusal, recurrent chest infections, aspiration risk, and difficulty maintaining adequate dietary intake (3–6). These difficulties are not limited to the child's clinical condition but extend into daily family routines, caregiver responsibilities, emotional wellbeing, and access to rehabilitation services.

Most available literature on pediatric dysphagia in cerebral palsy emphasizes clinical assessment, therapeutic management, feeding modification, and prevention of complications such as malnutrition, aspiration, and pneumonia (3,5–8). While these clinical concerns are essential, they do not fully capture the lived experience of families who manage feeding and swallowing difficulties at home. Parents and primary caregivers are often responsible for preparing modified food textures, positioning the child during feeding, monitoring choking episodes, attending repeated therapy sessions, and making decisions about feeding safety in the absence of continuous professional support. These responsibilities can create anxiety, fear, guilt, fatigue, financial strain, and social restriction, particularly when caregivers have limited access to multidisciplinary dysphagia services or community-based support (9–12).

A qualitative approach is needed because parental experiences of pediatric dysphagia involve meanings, emotions, coping strategies, family roles, financial pressures, service expectations, and perceived gaps in professional guidance that cannot be adequately understood through clinical outcomes alone. Using a PICo framework, the population of interest comprises parents or primary caregivers of children with cerebral palsy and dysphagia; the central interest is their experience of managing feeding and swallowing difficulties; and the context is care-seeking and home-based management in hospital and rehabilitation settings in Lahore, Pakistan. Alternatively, through a SPIDER framework, the sample consists of caregivers of children with cerebral palsy and dysphagia, the phenomenon of interest is daily dysphagia management, the design is qualitative interviewing, the evaluation focuses on perceived emotional, practical, nutritional, financial, and service-related challenges, and the research type is qualitative thematic inquiry.

In resource-limited settings, caregiver experience is especially important because professional dysphagia services, specialized feeding equipment, dietetic guidance, and multidisciplinary rehabilitation may not be consistently available or affordable. Understanding caregiver perspectives can help clinicians identify unmet needs, strengthen family-centered counseling, improve caregiver training in safe feeding practices, and design support systems that address both the child's swallowing needs and the caregiver's emotional burden. Therefore, this study aimed to explore the experiences of parents or primary caregivers of children with cerebral palsy and pediatric dysphagia, with specific attention to mealtime challenges, choking and aspiration concerns, nutritional management, home-based adaptations, emotional and financial burden, access to professional support, and perceived recommendations for improving dysphagia care.

MATERIALS AND METHODS

This study was designed as an interpretative qualitative inquiry using semi-structured interviews to explore the experiences of parents or primary caregivers managing pediatric dysphagia in children with cerebral palsy. The qualitative design was considered appropriate because the study sought to understand caregiver perceptions, emotional responses, practical feeding challenges, coping strategies, and perceived service gaps rather than to test a statistical association or measure treatment effectiveness. The study was conducted over a period of 12 months after approval from the Departmental Research Committee. Participants were recruited from clinical and rehabilitation settings in Lahore, including the University of Lahore Teaching Hospital, Children's Hospital Lahore, Mayo Hospital, and Combined Military Hospital; where applicable, any additional recruitment sites such as PSRD or Sheikh Zayed Hospital should be retained only if confirmed from the final study records.

The study population comprised parents or primary caregivers of children diagnosed with cerebral palsy and pediatric dysphagia. Participants were selected through purposive sampling because the study required information-rich participants with direct experience of feeding and swallowing management in daily care. Eligible participants were caregivers of children with a diagnosis of cerebral palsy and feeding or swallowing difficulty who were directly involved in the child's mealtime care and were willing to share their experiences through an interview. Caregivers who did not provide routine feeding care or

were unable to participate in an interview were not included. The final sample consisted of 14 caregivers. Since all respondents reported in the current dataset were mothers, the manuscript should use "mothers" or "female primary caregivers" consistently unless fathers or other caregiver groups were also interviewed and added to the final analysis.

Participants were approached in the relevant clinical or rehabilitation settings after identification according to the eligibility criteria. The recruitment process should be reported transparently in the final manuscript by specifying who approached the participants, whether treating clinicians were involved, whether any eligible caregivers refused participation, and whether recruitment continued until thematic saturation or information sufficiency was achieved. If saturation was assessed, the manuscript should state how it was monitored, at which interview no substantially new codes were identified, and whether additional interviews were conducted to confirm saturation. If saturation was not formally documented, the study should describe the sample as purposive and information-rich and acknowledge the absence of formal saturation assessment as a limitation.

Data were collected using a semi-structured interview guide developed to explore caregiver experiences of pediatric dysphagia, including feeding difficulties, choking or aspiration concerns, nutritional challenges, food texture modification, mealtime routines, emotional burden, financial constraints, professional support, and perceived recommendations for service improvement. The manuscript currently states that the interview guide was developed through a Delphi technique; this claim should be retained only if the Delphi process can be fully described, including the number and expertise of panel members, number of Delphi rounds, criteria for item retention, and how consensus was defined. If these details are unavailable, the method should instead state that the guide was developed after literature review and expert review by relevant rehabilitation professionals. The interview guide should also be reported as having been piloted if piloting was actually performed.

Interviews should be described in sufficient detail to allow methodological appraisal. The final manuscript should specify the language of the interviews, whether interviews were audio-recorded with permission, whether field notes were taken, the approximate duration of each interview, the interview location, whether privacy was maintained, and whether any non-participants were present during the interview. If interviews were conducted in Urdu or another local language and later translated into English, the translation process should be reported, including whether translation was checked for accuracy. Participant quotations should be presented with clear identifiers, such as "Mother, P1," and may include the recruitment site or child age group if this does not compromise anonymity. Quotations should be either verbatim or translated faithfully and lightly edited only for readability without changing meaning.

All interview data were to be handled confidentially. Audio recordings, notes, transcripts, and translated files should be de-identified before analysis by removing participant names, child names, hospital identifiers where necessary, contact details, and other potentially identifying information. Each participant should be assigned a unique code. Data storage procedures should be reported, including who had access to the files and how confidentiality was maintained. Demographic information, such as caregiver relationship, child age group, and child sex, may be summarized descriptively; however, inferential statistics, p-values, confounder adjustment, and missing-data imputation are not appropriate unless a separate quantitative component is formally included.

Data should be analyzed using thematic analysis rather than SPSS as the main analytic method. The analysis process should include familiarization with transcripts, generation of initial codes, grouping of related codes into subthemes, development of broader themes, review of themes against the dataset, and refinement of theme names and definitions. The manuscript should specify whether coding was inductive, deductive, or both; how many researchers coded the transcripts; whether a codebook was developed; how disagreements were resolved; and whether any qualitative software was used. If coding was conducted manually, this should be stated. If more than one coder was involved, the manuscript

should describe the consensus process rather than reporting statistical intercoder agreement unless such agreement was formally calculated. An audit trail of coding decisions, theme development, and representative quotations should be maintained to strengthen dependability and confirmability.

Reflexivity should be explicitly addressed because researcher background, clinical training, and prior assumptions about dysphagia management may influence interviewing and interpretation. The final manuscript should report the role and professional background of the interviewer, whether the interviewer had any prior relationship with participants, and how potential bias was minimized. Bias mitigation strategies may include use of a semi-structured guide, reflexive notes after interviews, discussion of emerging codes among researchers, and careful separation of participant accounts from researcher assumptions.

Trustworthiness should be reported using credibility, dependability, confirmability, and transferability. Credibility may be supported through the use of participant quotations, prolonged engagement with transcripts, peer discussion among researchers, or member checking if it was actually performed. Dependability may be strengthened through a consistent interview guide, documented coding steps, and maintenance of an audit trail. Confirmability may be supported by reflexive memoing and team-based review of coding decisions. Transferability may be enhanced through thick description of the study setting, participant characteristics, child feeding context, and service-access environment. Triangulation may be claimed only if multiple data sources, participant groups, investigators, or methods were actually used.

Ethical approval was obtained before data collection from the relevant departmental or institutional review body and should be reported with the exact committee name and approval number if available. Written or verbal informed consent should be described clearly, including consent for participation, audio recording if used, use of anonymized quotations, and voluntary withdrawal. Participants should be assured that refusal or withdrawal would not affect the clinical care of their child. Because interviews may involve emotionally distressing experiences related to choking, feeding fear, guilt, and caregiver burden, the manuscript should also state whether participants were offered support, referral, or guidance if distress occurred during or after the interview.

RESULTS

A total of 14 mothers of children with cerebral palsy and dysphagia participated in the study. All respondents were female primary caregivers. The children included eight boys and six girls. Seven children were aged 1–5 years, five were aged 6–10 years, and two were aged 11–16 years. The qualitative analysis generated six interrelated themes describing the mothers' experiences of managing pediatric dysphagia: mealtime stress and disruption of daily life, safety concerns related to choking and aspiration, home-based feeding adaptations, nutritional management and food texture modification, caregiver burden and financial strain, and perceived gaps in professional and community support. Because participant-level site labels and formal theme-frequency tallies were not available in the current dataset, the strength indicators in the theme matrix are based only on recurrence across the available coded extracts and should be interpreted descriptively rather than statistically.

Table 1. Theme Matrix Showing Major Themes, Subthemes, Participant Group, and Strength of Evidence

Theme	Subthemes	Participant group represented	Evidence across available coded extracts	Illustrative quote IDs
Mealtime stress and disruption of daily life	Slow feeding, prolonged mealtime, anxiety, tantrums, reduced daily routine	Mothers / female primary caregivers	Frequent across available extracts	P1, P5, P8, P10, P12
Safety concerns related to choking and aspiration	Fear of choking, aspiration risk, pneumonia, safety during feeding	Mothers / female primary caregivers	Frequent across available extracts	P1, P7, P11, P13
Home-based feeding adaptations	Distraction-free space, special utensils, special chair, posture support, prolonged feeding routine	Mothers / female primary caregivers	Frequent across available extracts	P1, P5, P8, P11, P13
Nutritional management and food texture modification	Semi-liquid food, grinded/chopped food, thickened liquids, frequent meals, moisture modification	Mothers / female primary caregivers	Frequent across available extracts	P1, P2, P5, P6, P9, P13, P14
Caregiver burden and financial strain	Time burden, neglect of siblings, therapy expenses, adaptive equipment cost, restricted family life	Mothers / female primary caregivers	Moderate to frequent across available extracts	P1, P4, P8, P12, P13, P14

Theme	Subthemes	Participant group represented	Evidence across available coded extracts	Illustrative quote IDs
Professional guidance and support needs	SLP/dietitian support, oral-motor exercises, lack of trained professionals, awareness seminars, low-cost services	Mothers / female primary caregivers	Moderate to frequent across available extracts	P1, P2, P5, P7, P9, P10, P13, P14

The theme matrix shows that mothers described dysphagia as a daily caregiving challenge rather than only a clinical swallowing problem. Mealtime stress, choking concerns, feeding adaptations, and nutritional management appeared repeatedly across the available coded extracts. The strongest recurring pattern was the link between feeding difficulty and caregiver vigilance: mothers described meals as prolonged, emotionally stressful, and shaped by fear of choking, aspiration, and inadequate nutrition. Financial strain and professional-support gaps were also prominent, particularly where mothers described the cost of therapy, dietetic consultation, adaptive feeding utensils, and specialized seating. No defensible comparison by district, hospital, or recruitment site could be made because participant-level site identifiers were not provided.

Table 2. Representative Quote Table Linking Subthemes to Participant Accounts

Theme	Subtheme	Representative quotation	Participant label
Mealtime stress and disruption of daily life	Slow feeding and prolonged mealtime	"We have to face many challenges such as slow feeding and limitation in swallowing preferences which impact the life style severely. Mealtime is stressful and consuming huge amount of time or leading towards tantrums."	Mother, P12
Mealtime stress and disruption of daily life	Anxiety during feeding	"Our child has experience eating and swallowing difficulties which affects their daily routine badly, leading to a lot of tantrums… His physical health has also been affected with weight loss and nutritional deficiencies. In short, mealtime is a source of anxiety and stress for us."	Mother, P1
Safety concerns related to choking and aspiration	Fear of choking	"Being a parents, when we first notice, our child has swallowing difficulties, we were worried. Our major concern that good health and safety and choking free mealtime because sometime choking can be life threatening condition."	Mother, P13
Safety concerns related to choking and aspiration	Aspiration and nutrition concerns	"We were worried their nutrition and hydration, when I first notice to feeding problem and our major concern was his safety and risk of aspiration."	Mother, P11
Home-based feeding adaptations	Distraction-free feeding environment	"We have modified our home environment by creating a calm and distraction free eating space feeding routine include small, frequent meal."	Mother, P5
Home-based feeding adaptations	Adaptive utensils and posture support	"We have introduce specialized utensils and adaptive furniture like special chair to maintain their posture, and to make meal time easier."	Mother, P11
Nutritional management and food texture modification	Modified food consistency	"We have use different food texture like semi liquid or grinded food for fulfill their nutrition needs accordingly."	Mother, P9
Nutritional management and food texture modification	Thickened liquids and feeding plan	"We have working with a nutritionist and speech language pathologist develop personalized feeding plan that ensure by child gets the necessary nutrient while accommodating there swallowing limitation. We have also introduced thicken liquid pureed food to reduce the risk if choking and supplement their diet with vitamin and minerals as needed."	Mother, P5
Caregiver burden and financial strain	Financial cost of dysphagia management	"We have feel financial burden to administrate their unique needs such as, we have spent a lot of expenses for working with dietionist and speech language pathologist to develop feeding plan that ensure by child gets the necessary nutrient while accommodating their food preference."	Mother, P12
Caregiver burden and financial strain	Neglect of siblings and time burden	"We face many difficulties to modified our home environment that we can't look after my other children the rest of the day, they are neglected because most of the time spend in preparing modified food for them and after that she consume my enough time during mealtime."	Mother, P8
Professional guidance and support needs	Oral-motor exercises and SLP support	"We have work with the speech pathologist to develop oral motor skills plan which include exercises to strengthen their oral musculature such as: lips, tongue, cheeks and jaw. The SLP also recommended me to use of vibratory brush to increase their oral stimulation, which will be helpful to improve their feeding abilities."	Mother, P9
Professional guidance and support needs	Awareness and affordable services	"The Government should needs to promote awareness seminars and workshops, for parents or caregivers of children with dysphagia, on free of cost. Also provide related services to CP and dysphagia on cheap prices, which will be helpful in dysphagia management and every person could access these services the most."	Mother, P7

Mothers consistently described mealtime as a stressful and time-consuming activity. This pattern was reflected in accounts of slow feeding, prolonged meals, child tantrums, and caregiver anxiety. These experiences suggest that dysphagia affected not only swallowing safety but also the structure of daily family life. The emotional burden was particularly visible where mothers described mealtime as a source of anxiety because of the possibility of choking, aspiration, weight loss, or nutritional deficiency.

Safety concerns formed a central part of the mothers' narratives. Several participants described their first recognition of swallowing difficulty as frightening because feeding was associated with choking, aspiration, pneumonia, and potential life-threatening events. These concerns shaped how mothers approached each meal, with feeding described as an activity requiring constant vigilance. The accounts suggest that caregiver anxiety was closely linked to uncertainty about whether the child could swallow safely and whether professional help would be available if complications occurred.

Home-based adaptation was another recurring theme. Mothers described creating calm and distraction-free feeding environments, modifying feeding routines, using small and frequent meals, introducing

specialized utensils, and using adaptive chairs to support posture. These adaptations show that mothers were actively modifying the home environment in response to dysphagia-related needs. However, these adjustments also created additional caregiving demands, particularly when mothers had to spend extended time preparing food, supervising feeding, and managing behavioral responses during meals.

Nutritional management was closely connected to food texture modification. Mothers reported using semi-liquid, grinded, chopped, pureed, thickened, or moisture-enhanced foods to reduce choking risk and improve intake. Some mothers described receiving guidance from speech-language pathologists and dietitians, while others appeared to rely on practical trial-and-error strategies. Across these accounts, the main caregiving goal was to balance adequate nutrition with swallowing safety. The findings indicate that food modification was not a simple dietary preference but a daily clinical and practical strategy used to manage aspiration risk, feeding tolerance, and nutritional adequacy.

Caregiver burden was expressed through financial, emotional, and family-level strain. Mothers described the cost of therapy, feeding consultations, adaptive utensils, special seating, and repeated healthcare visits as difficult to manage. Some accounts also indicated that the time required for feeding and food preparation affected care for other children and limited routine family functioning. These findings suggest that pediatric dysphagia management can redistribute household time, attention, and financial resources toward the affected child, increasing pressure on mothers as primary caregivers.

Professional guidance and support needs were repeatedly emphasized. Mothers valued input from speech-language pathologists, dietitians, occupational therapists, and other rehabilitation professionals, particularly for oral-motor exercises, feeding plans, posture, and food consistency. At the same time, participants identified gaps in awareness, limited availability of trained professionals, high treatment costs, and poor access to adaptive feeding resources. The findings suggest a need for structured caregiver education, affordable multidisciplinary dysphagia services, awareness seminars, support groups, and community-based rehabilitation models for families managing cerebral palsy and dysphagia.

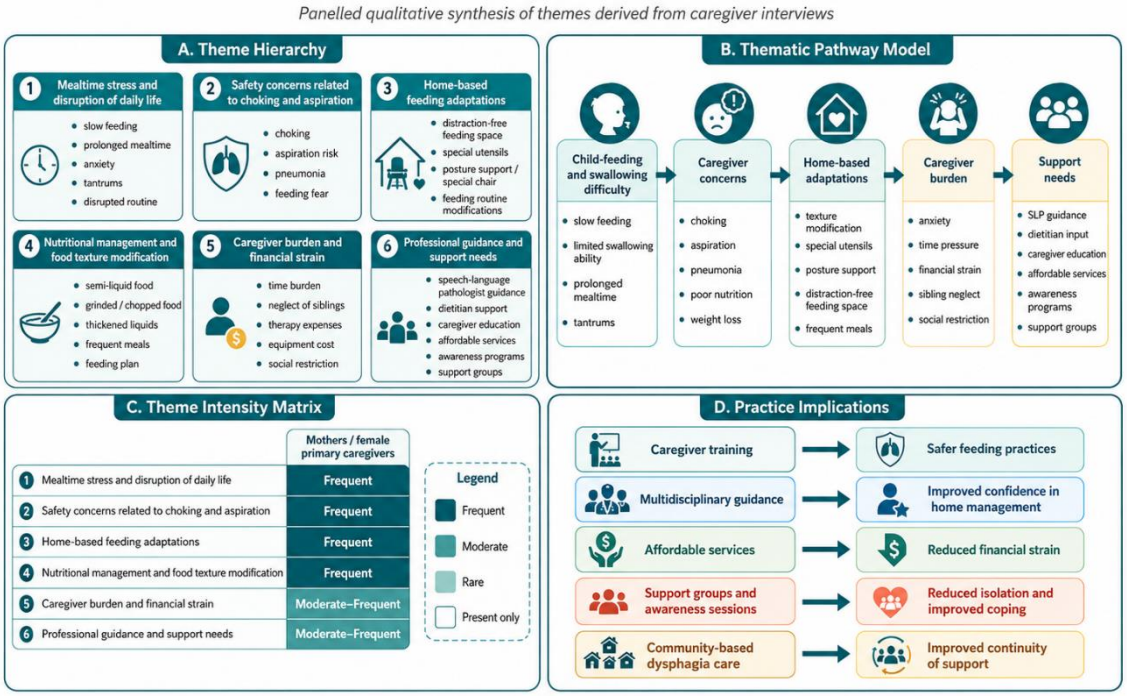

Figure 1. Panelled qualitative synthesis of mothers' experiences of managing pediatric dysphagia in children with cerebral palsy. Panel A presents the thematic hierarchy derived from coded interview extracts. Panel B illustrates the perceived pathway from feeding and swallowing difficulties to caregiver concerns, home-based adaptations, burden, and support needs. Panel C summarizes theme recurrence among mothers/female primary caregivers using qualitative intensity categories. Frequent indicates repeated representation across several coded extracts; moderate indicates representation in multiple but less consistent extracts; rare indicates isolated representation. If formal frequency coding is not available, intensity should be replaced by

presence/absence only. Panel D translates the qualitative findings into practice implications for caregiver education, multidisciplinary support, affordability, and community-based dysphagia care.

The panelled figure summarizes pediatric dysphagia as a multidimensional caregiving experience rather than a swallowing problem alone. Mothers described feeding difficulty as producing persistent safety concerns, especially fear of choking, aspiration, pneumonia, poor nutrition, and weight loss. In response, they modified food texture, feeding routines, posture, utensils, and the home environment, but these adaptations increased emotional, financial, and time-related burden. The figure also highlights that caregiver support needs were concentrated around practical dysphagia education, access to speech-language pathology and dietetic guidance, affordable adaptive resources, and structured family support. Because the findings are qualitative, the visual model should be interpreted as a synthesis of reported experiences and perceived needs, not as evidence of causal effects or population-level prevalence.

DISCUSSION

This qualitative study explored the experiences of mothers caring for children with cerebral palsy and pediatric dysphagia. The findings show that dysphagia was experienced not only as a swallowing disorder but as a persistent caregiving challenge that shaped mealtime routines, emotional wellbeing, household responsibilities, financial demands, and interactions with health services. Mothers described feeding as slow, prolonged, stressful, and frequently accompanied by fear of choking, aspiration, pneumonia, poor nutrition, and weight loss. These accounts are consistent with the clinical understanding that children with cerebral palsy may experience oral-motor dysfunction, impaired swallowing coordination, prolonged feeding time, aspiration risk, and nutritional compromise (1–6). However, the present study adds an experiential perspective by showing how these clinical risks are translated into daily maternal vigilance, anxiety, and adaptive caregiving practices.

A central finding was that mealtime became a site of emotional stress and continuous safety monitoring. Mothers repeatedly described fear of choking and aspiration, suggesting that feeding was not perceived as a routine domestic activity but as a high-risk event requiring constant attention. Previous literature on pediatric dysphagia and cerebral palsy has emphasized the medical consequences of unsafe swallowing, including respiratory complications, malnutrition, and growth concerns (3–6). The present findings extend this evidence by highlighting the caregiver's psychological burden, particularly the way mothers anticipated danger during meals, modified food textures, and adjusted the home environment to reduce perceived feeding risk. This indicates that dysphagia care should address caregiver confidence and emotional preparedness in addition to child-level feeding safety.

The mothers' accounts also showed that home-based adaptation was a major component of dysphagia management. Participants described using semi-liquid, grinded, chopped, pureed, thickened, or moisture-enhanced foods, as well as special utensils, adaptive seating, posture support, distraction-free spaces, small frequent meals, and individualized feeding routines. These strategies are consistent with contemporary dysphagia management principles, which commonly include texture modification, positioning, adaptive feeding techniques, and multidisciplinary input from speech-language pathologists, dietitians, pediatricians, occupational therapists, and rehabilitation professionals (4,7,8). However, in this study, such adaptations were not presented as simple technical adjustments. Mothers described them as time-consuming, financially demanding, and difficult to sustain, especially where professional services, feeding equipment, or dietetic support were limited or costly.

Financial and family-level burden emerged as another important theme. Mothers reported expenses related to therapy sessions, specialist consultations, feeding plans, adaptive utensils, and special chairs. Some also described the indirect burden of spending prolonged time preparing modified meals and feeding the child, which affected attention to other children and restricted normal family routines. This is consistent with caregiver-focused literature showing that feeding and swallowing disorders can affect family functioning, social participation, emotional wellbeing, and quality of life (9–11). In the present study, the caregiving burden appeared intensified by the mothers' role as primary caregivers. Since all

participants in the current dataset were mothers, the findings should be interpreted as maternal caregiver experiences rather than generalized parental experiences. This distinction is important because fathers, grandparents, and other caregivers may experience dysphagia management differently and may contribute differently to decision-making, finances, transport, and care-seeking.

The study further identified perceived gaps in professional guidance and community support. Mothers valued speech-language pathology and dietetic input when available, particularly for oral-motor exercises, feeding plans, food consistency, posture, and swallowing safety. At the same time, they reported limited awareness, lack of trained professionals, expensive treatment, and insufficient availability of adaptive feeding resources. These findings suggest that family-centered dysphagia care should include structured caregiver education, practical demonstrations of safe feeding techniques, low-cost feeding modification guidance, locally feasible adaptive strategies, and referral pathways for children at risk of aspiration or poor nutrition. Training should not only provide information but also build caregiver confidence through repeated counseling, visual instructions, supervised practice, and follow-up support.

The implementation implications of these findings are clinically relevant. First, speech-language pathologists and rehabilitation teams should develop caregiver-oriented dysphagia education modules covering signs of unsafe swallowing, choking response, feeding posture, texture modification, meal pacing, and warning signs requiring referral. Second, multidisciplinary services should be strengthened so that feeding plans integrate swallowing safety, nutrition, growth monitoring, respiratory risk, and caregiver feasibility. Third, affordable access to adaptive feeding utensils, supportive seating, and dietetic guidance should be prioritized, particularly for families with limited financial resources. Fourth, support groups or caregiver counseling sessions may help reduce isolation, normalize caregiver distress, and improve confidence in home-based care. Finally, community-based rehabilitation models may improve continuity of care by reducing the need for repeated hospital visits and by making dysphagia support more accessible to families.

Trustworthiness should be considered when interpreting these findings. Credibility was supported by the use of participant quotations that directly reflected mothers' experiences of feeding stress, choking concerns, food modification, financial burden, and support needs. However, the current manuscript requires stronger reporting of the data collection and analysis process, including interview language, audio recording, transcription, translation, number of coders, coding consensus, audit trail, and reflexivity. Dependability and confirmability would be strengthened by documenting how codes were developed, how themes were refined, and whether coding decisions were reviewed by more than one researcher. Transferability would be improved by providing richer contextual detail about recruitment sites, child severity, feeding status, socioeconomic background, and access to rehabilitation services.

This study has several limitations. The sample was small and included only mothers or female primary caregivers, limiting the transferability of findings to fathers, grandparents, or other family decision-makers. Recruitment from hospital and rehabilitation settings may have included caregivers already connected to services, potentially excluding families with poorer access to dysphagia care. The manuscript does not currently provide a formal saturation statement, so the completeness of theme development cannot be fully assessed. If interviews were translated into English, some meaning may have been affected by translation or editing of quotations. Social desirability bias is also possible, particularly if participants were interviewed in clinical settings or by researchers linked to rehabilitation services. Finally, because this was a qualitative study, the findings should not be interpreted as evidence of prevalence, treatment effect, or causal improvement in feeding outcomes.

Overall, the findings suggest that pediatric dysphagia in children with cerebral palsy produces a multidimensional caregiving burden involving emotional vigilance, safety concerns, nutritional management, home modification, financial strain, and dependence on professional support. The study supports the need for integrated, family-centered dysphagia care that recognizes mothers as active

partners in feeding management while also addressing their emotional, educational, and practical support needs.

CONCLUSION

This qualitative study suggests that mothers caring for children with cerebral palsy and pediatric dysphagia experience feeding as a demanding, emotionally stressful, and safety-sensitive part of daily life. Mothers described persistent concerns about choking, aspiration, pneumonia, poor nutrition, and weight loss, and they responded by modifying food texture, feeding routines, posture, utensils, and the home environment. These adaptations reflected strong caregiver commitment but also created time pressure, financial strain, social restriction, and reduced attention to other family responsibilities. The findings indicate that effective dysphagia care should extend beyond child-focused clinical management to include caregiver education, emotional support, affordable multidisciplinary services, practical training in safe feeding strategies, and community-based support systems. Because the study is qualitative and based on a small sample of mothers, the findings should be interpreted as reported experiences and perceived needs rather than population-level estimates or evidence of causal effects.

REFERENCES

1. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007;109:8-14.

2. Gulati S, Sondhi V. Cerebral palsy: an overview. Indian J Pediatr. 2018;85(11):1006-1016.

3. Benfer KA, Weir KA, Bell KL, Ware RS, Davies PSW, Boyd RN. Oropharyngeal dysphagia and cerebral palsy. Pediatrics. 2017;140(6):e20170731.

4. Lawlor CM, Choi S. Diagnosis and management of pediatric dysphagia: a review. JAMA Otolaryngol Head Neck Surg. 2020;146(2):183-191.

5. Tutor JD, Gosa MM. Dysphagia and aspiration in children. Pediatr Pulmonol. 2012;47(4):321-337.

6. Rogers B, Arvedson J, Buck G, Smart P, Msall M. Characteristics of dysphagia in children with cerebral palsy. Dysphagia. 1994;9(1):69-73.

7. Novak I. Evidence-based diagnosis, health care, and rehabilitation for children with cerebral palsy. J Child Neurol. 2014;29(8):1141-1156.

8. DeFabrizio ME, Rajappa A. Contemporary approaches to dysphagia management. J Nurse Pract. 2010;6(8):622-630.

9. Silva CSRD, Palladino RRR, Machado FP, Baldrighi EMG. Emotional aspects of parents of children with dysphagia. ABCS Health Sci. 2023;48:e023303.

10. Follett AM, Rumbach AF, Ward EC, Marshall J, Dodrill P, Lewindon P. Dysphagia and feeding difficulties post-pediatric ingestion injury: perspectives of the primary caregiver. Int J Pediatr Otorhinolaryngol. 2017;103:20-28.

11. Stewart A, Smith CH, Govender R, Eaton S, De Coppi P, Wray J. Parents' experiences of feeding children born with oesophageal atresia/tracheo-oesophageal fistula. J Pediatr Surg. 2022;57(12):792-799.

12. Kamal RM, Ward E, Cornwell P. Dysphagia training for speech-language pathologists: implications for clinical practice. Int J Speech Lang Pathol. 2012;14(6):569-576.

13. Duncan DR, Cohen A, DiLorenzo C, Larson K, Rosen R. A prospective study of parental experience with thickening feeds for children with oropharyngeal dysphagia and gastroesophageal reflux. J Pediatr. 2023;260:113510.

14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349-357.

15. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.