# Psychosocial Challenges Faced by Mothers of Children with Speech and Swallowing Difficulties in Non-Progressive Neurological Disorders: A Phenomenological Analysis

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## *Abstract*

*Non-progressive neurological conditions such as cerebral palsy, childhood stroke, brain tumors, and traumatic brain injury commonly impair movement, balance, posture, speech, and swallowing, with speech and swallowing difficulties affecting up to 80% of children with developmental delay. These complex clinical conditions place a significant burden on children and their caregivers, leading to long-term physical, psychological, social, and economic challenges that markedly reduce quality of life. This qualitative study aimed to explore the psychosocial experiences of mothers caring for children with speech and swallowing difficulties associated with non-progressive neurological disorders in Pakistan. Face-to-face semi-structured interviews were conducted with 25 purposively selected mothers enrolled in the Person with Disability Program at the Helping Hand Institute of Rehabilitation Sciences, Mansehra. Interviews lasted approximately 45 minutes, were audio-recorded with informed consent, and analyzed using interpretative phenomenological analysis. The findings highlight that mothers experience extensive psychosocial difficulties, often compounded by inadequate family and societal support. The study concludes that caregivers of children with speech and swallowing difficulties in a developing country context face multidimensional challenges, underscoring the need for comprehensive, family-centered rehabilitation and psychosocial support programs to enhance caregiver well-being and improve child care outcomes.*

**Keywords:** Non-Progressive Neurological Disorder; Speech & Swallowing Difficulties; Psychosocial Challenges; Caregivers; Qualitative Study.

## Introduction

The non-progressive neurological conditions like cerebral palsy, childhood stroke, brain tumor, and traumatic brain injury affect a person's ability to move, maintain balance and posture, and also cause difficulty in speech and swallowing. It is the most common diagnosis causing motor disability in childhood and usually arises as a result of a combination of events either before, during, or after birth (Moen, 2020). Stroke, traumatic brain injury, or other non-progressive neurological conditions cause dysarthria, which is one of the disorders of speech (Mitchell et al., 2017). Dysarthria affects

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or weakens the muscles that are involved in communication (Mitchell et al., 2017; Yorkston, 1996). Non-progressive neurologic disorders also affect the person's ability to swallow (Daniels, 2006). The nervous system comprises neurons; if neurons become damaged or die, they do not regenerate. This condition of the nervous system affects the muscles of the body, including those of speech and swallowing (Giliter et al., 2022).

There are many children with speech and swallowing difficulties. The estimated prevalence of speech and swallowing difficulties is 25% and 45%, respectively, in normally developing children (Lefton et al, 2007). The prevalence of speech and swallowing difficulties increased in developmentally delayed children up to 80%. Developmentally delayed children are at more risk of developing speech problems (Lefton-Greif & Arvedson, 2008). The causes of speech and swallowing difficulties in children include premature birth, low birth weight, cardiorespiratory disorders, and any neurological trauma. These are the conditions responsible for the increased speech and swallowing problems in children (Arvedson, 2008; Lefton-Greif & Arvedson, 2007; Miller & Willging, 2003). The severity of speech and swallowing difficulties varies because it is a developing condition (American Speech-Language Hearing Association, 2001).

### Psychosocial Challenges Faced by Mothers

The complex clinical conditions due to neurological diseases seriously burden children, their families, and caregivers with disabilities, including communication and eating-swallowing disorders, which are difficult to cope with and have both a high prevalence and substantial impact on quality of life (Nasios, 2022).

There are some social and psychological challenges that are experienced by mothers of children with disabilities. The social challenges include insufficient support from family, spouse, and other societal members (Ambikile & Outwater, 2012). Fear of rejection from society is a psychological issue (Vijesh & Sukumaran, 2007). The prolonged health care of children with neurological impairment causes financial constraint to the families as well. (Lawal et al., 2014). Every day care of children with neurological disorders has been created to be a burden as well. Parents often feel burdened by their child's care (Wallander & Varni, 1998; Rodenburg et al., 2007). The negative relationship may occur between the child and the mother due to negative behaviors. A parent may feel guilt when they experience a negative experience. That is the reason a higher stress is found in mothers of children with neurological disorders, further lowering the quality of the parent-child relationship. Although these deficits affect millions of patients worldwide, their impact and management have not yet been fully investigated or appreciated in clinical settings. This underestimation of speech and eating-swallowing disorders in neurological diseases led us to investigate the current special issue. Therefore, it is significant to investigate the challenges faced by mothers of children with non-progressive neurological disorders suffering from speech and swallowing issues.

## Literature Review

Children with non-progressive neurological disorders cause a psychological and social burden on caregivers (Jessop & Stein, 1985). In terms of daily care, the children with neurological disorders have also been found to be a burden on the family (Wallander & Varni, 1998; Rodenburg et al, 2007).

Researchers found that the families or parents of children with prolonged illness or disability experience an increased stress level. The level of stress is directly related to the high need for healthcare of the children with neurological disorders (Strauss & Cassell, 2009). It has been reported

that the caregivers of children with craniofacial abnormalities may experience difficulties in accessing the healthcare system for their child (Strauss & Cassell, 2009). It was described by the researchers that children with neurological disorders need a high level of care, and parents tried to give an optimum level of care to their children in order to overcome their disability, which could lead parents toward parenting stress. Parents of epileptic children described parental stress along with some other factors and stated that the child's lower functional status and high parenting stress are directly related to a poor parent-child relationship. Parents cannot provide a warm, safe, and affectionate environment for their children, and their parental support declines when they are under stress (Rodenburg et al., 2007). The stressed parents of children with neurological disorders cannot give proper health care to their children; hence, children experience difficulties in their activities of daily living (Parkes, 2009). The physical health and social wellbeing of parents are severely affected by stress (Davis et al., 2010; Parkes et al., 2011). Children who need prolonged health care cannot access the healthcare system due to societal attitudes and changes in the system, leading them to stay at home with family rather than go to an institution for better care.

Research has shown that chronic illnesses damage the quality of life. The neurological disorder has negative social and psychological outcomes. This pressure could lead to separation and a decrease in self-esteem (Ekberg et al., 2002). Ekberg et al. (2002) reported that speech was often the center of social interactions, holidays, and family gatherings. Not being able to fully participate could lead to embarrassment and a loss of dignity. Numerous families with dysphagia children did not trust that they could be facilitated. The negative belief led the families not energetically talk to doctors about their child's issue. It caused the isolation and psychological burdens in the child and the parents. It has been found that the length of social and psychological problems was the reason for depression. For that reason, the presence of neurological problems has a significant effect not only on the life of a child but also on their family. Despite different etiologies, caregivers of people with neurological problems have reported bad effects on their daily lives. The management of food and appropriate meals created pressure for parents. Therefore, the parents of a child with swallowing and speech difficulties were under the social and psychological burden ( Nund et al, 2014 ).

In developed countries, a wide range of support resources is available to parents and children. In underdeveloped countries like Pakistan, significant differences exist between urban and rural environments. Our study seeks to explore the psychosocial problems experienced by the mothers of children with speech and swallowing difficulties in non-progressive neurological disorders.

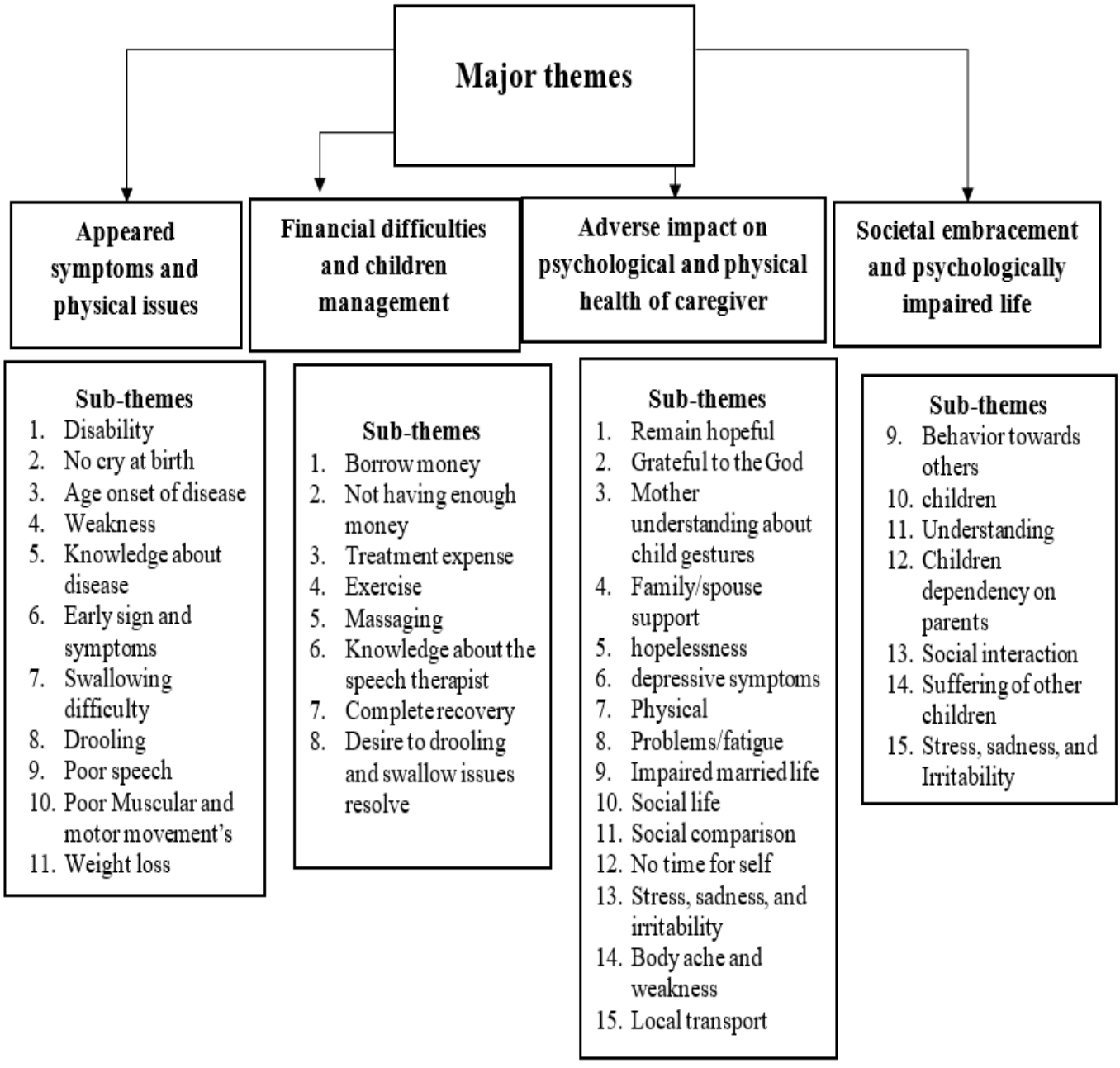
### Objectives

The aims of the study were to investigate the psychosocial challenges faced by the mothers of children with non-progressive neurological disorders and suffering from speech and swallowing difficulties.

## Methodology

In this study, we used a qualitative methodology. This allows participants to consider their experience unique. Semi-structured interviews were used to collect the data. Face-to-face interviews were used because they have been shown to increase openness and honesty, particularly when discussing sensitive topics. The maximum interview time was 45 mins.

**Figure 1: Major themes**




**Participants**

25 participants were recruited after providing consent. Participants were the mothers of children with non-progressive neurological disorders who had drooling, speech, and swallowing difficulties. Participants were selected from the Persons with Disability Program (PWDP) of Helping Hand Institute of Rehabilitation Sciences (HHIRS), Mansehra.

**Sampling**

Participants were selected purposively from a cluster of persons with disabilities program (PWDP)**.**

**Procedure**

Consent to participate in the study was obtained from the participants. Participants were called into the speech-language pathology assessment room. Informed consent was obtained from all mothers after providing an appropriate explanation about the purpose of the study and the nature of the research. Their permission was obtained before using tape for data recording. To build rapport with the participants, some initial informal conversation was held. Research interviews lasted approximately 45 minutes. A recording was made after each interview.

**Analysis**

Data were analyzed using interpretative phenomenological analysis, and the collected data were clustered into themes and sub-themes.

## Results

**Table 1: Thematic findings of research participant's response about Appeared symptoms and physical issu**

| | Sub-theme | Verbatim |
|---|---|---|
| Societal embracement and psychologically impaired life | Behavior towards other Children | *"Nai jab bachi ko dekhti hai to roti hai. Jab koi bacha k rha ho na to koshish krti hai k m b woi krn, jb nai kr pa rona sherou kr daiti hai".* |
| | | *"Bachu kheiltey hen to un ko dekh kr khush hoti hail lakin b ho jati hai k m nai khel sakti. Zahir hai, un k sath chl t sakti. Phr gussa ata hai. Unpr gussa krti hai. K meri trf a unko maro"* |
| | Understanding | *Kbi ye dmag sai hota hai to phr bolta hai thora sa.* |
| | | *"Apni koi baat smjani ho to wo b total bolta hai, mgr apni smja laita hai.kbi kici ko btanay m ni smj skta k mjy kia ta hai"* |
| | Children dependency on parents | *"He can't do anything himself, I have to do everything"* |
| | | *"I feed her, I change her clothes, She can't do anything"* |
| | Social interaction | *"Khush hota hai, m kahi jati hun to bolta hai, k mjy lay kr* |
| | | *Dostiyan bnata hai.khush hota hai".* |
| | | *"Bol nai sakti mgr smjdar hai. Chezo ko smj laity hai. Ja yad koi ata hai, to mble hath m lay gi k mjy baat krwao".* |
| | Suffering of other children | *"My other children are school going but I can't look after as my all time is occupied with this child"* |
| | | *"I can't manage to give time to other children"* |
| | | *Nai rakhti hun doosru ko* |
| | | *Other ki tenshion ki waja se baqi chezain maintain nai kr bachu ko time nai dai sakti* |
| | Stress, sadness, and Irritability | *to isko sahanbalna bhot muskil hota hai.* |
| | | *Normal bachy ko sahnbalna mushkil hota jai.to aisy bachy zayada hoga.* |
| | | *" To us ki waja se dil khafa rehta hai.* |

| | | |
|---|---|---|
| | Social embracement | *Ghar se yahan atey huvey 2 se 3 bar kaprey change krti Ur warzish k waqt b isy ulti ho jaati hai, phr is kay ka tabdeel krti hun.* |
| | | *q k local gaari m jab jaati hun to ur b log hotey hen,unhy kr bhot zayada rota hai. Gaari m is kay kaaprey change kr phr us ki ultiyan sahanbalna bhot mushkil hota hai.kbi kb ganty se b zayada time lg jata hai.* |

In order to answer the research question, this section focused on the major themes that are categorized under appeared symptoms and physical issues, financial difficulties, and children management, adverse effect on psychological and physical health of caregiver, and societal embracement and psychologically impaired life.

Table 1 shows the societal embracement and psychologically impaired life as a major theme and related to major theme, sub-themes show behavior towards others children, understanding, children dependency on parents, social interaction, suffering of other children, stress, sadness, and irritability, and social embracement.

**Table 2: Thematic findings of research participant's response about Adverse impact on psychological physical health caregiver**

| Theme | Sub-theme | Codes in term of responses | Verbatim |
|---|---|---|---|
| Adverse impact on psychological and physical health caregiver | Positive | Remain hopeful<br>Grateful to the God | *Being a mother I was said that my daughter wa like normal kids. She could not walk easily but happy now that though she cannot walk properly am grateful that I am having her and I am pretty she will be fine soon.* |
| | | Mother understanding about gestures | *"Only I can understand what he is saying."*<br>*"Other people can't understand him what h saying."* |
| | | Family/spouse support | *Yes, by the grace of Allah, my husband is very co and so is my mother-in-law.*<br>*In my family I have my mother and supportive bro* |
| | Negative | Hopelessness depressive symptoms | *pareshani rai,bhot rona ur takleef rehti thi.dunu b ka khercha jethani e krti hai.is ka khercha m ee hun.*<br>*I have difficulty in managing him at home, seco bring him here is really difficult. My muscles started to ache my arms and my back hurt and w* |
| | | Physical Problems/fatigue | *have him in my lap at home my kidneys ache.*<br>*raat ko jb atey hen. Mjy is halat m dekh kr ur bach dekh kr, ghussa to aa ee jata hai.aksar hamari l ho jati hai.* |
| | | Impaired married life | |
| | | Social life | *"Yes, My social life is badly effected as I don anywhere due to the disable baby."*<br>*"People ask why he don't speak, walk, or play other baby of his age."*<br>*"I avoid social gatherings."* |

| | | |
|---|---|---|
| | Social comparison | *"M chahti hun k ye b doosrey bachu ki tra khe dorray",*<br>*"doctor ne btaya hai k ye thk ni ho sakti baqi chec kmaz km normal bachu ki tra to ho na."* |
| | No time for self | *"My personal life is no more, I all the time look of this kid."*<br>*"Never got time for myself."*<br>*"Due to look after of this child all day, I got so r tired."*<br>*"Fade off all my own wishes."* |
| | Stress, sadness, and irritability | *to isko sahanbalna bhot muskil hota hai.*<br>*Normal bachy ko sahnbalna mushkil hota jai.to bachy k our zayada hoga.* |
| | Body ache and weakness | *is ko uthany se qamar m dard hota hai. Patthay k ho gahy hen, jorro m dard rehta hai.*<br>*"m khud b thek ni rehti, "* |
| | Local transport | *G local gaari m aati hen.kbi kbar booking kr k ac hun*<br>*M khud ly kr jati hun, kafi maslay hotey hen aty j*<br>*Nai, gaari nai hai. Local gaari pr ati hai*<br>*. Aaney jaaney ka masla hota hai* |

Table 2 shows the adverse impact on psychological and physical health caregiver as a major theme and related to major theme, sub-themes show positive and negative impact on psychological and physical health caregiver. The response of caretaker is in positive sub-theme is, remain hopeful, grateful to the god, mother understanding about child gestures, and family/spouse support. In negative sub-themes show hopelessness, depressive symptoms, physical problems/fatigue, impaired married life, social life, social comparison, no time for self, stress, sadness, and irritability, body ache and weakness, and local transport.

**Table 3: Thematic findings of research participant's response about financial difficulties and chil management**

| Theme | Sub-theme | Codes in term responses | Verbatim |
|---|---|---|---|
| Financial difficulties children management | Financial difficulties | Borrow money | *Yes, I try my best to do the best for him, his fa also tries his best, and even if we have to bo money, we do only in order to meet his need difficult for me because my monthly income* |
| | | Not having enough money | *money is an issue, arranging for transport issue.*<br>*1500 gari waley ko daitey hen.* |
| | | Treatment expense | *"k hospital ka ana jana, bhot khercha o hai.hospital ki dawa"*<br>*"Wapsi m hmy taxi e krna prti thi q k hmary koi gaari nai jaati thi to wapsi pr taxi ka kar bhot mushkil hota tha"* |
| | Treatment management | Exercise | - *"m is ki exercise krti hun jis se muh ka paani bhot km ata hai, han agr kci* |

| | | |
|---|---|---|
| | | *masrufieat yak ci waja se na kr pao, to phr paani zayada ata hai".*<br>*"raat ko baba speech b krty hen".*<br>*"G improvement aa rai hai,kuch masaj wagaira unhu ne btahey hen.* |
| | Massaging | *"I did oil massage"*<br>*"Doctor asked that do the massage regularly it will be fine"* |
| | Knowledge about the speech therapist | *"Nai, mjy nai pta.*<br>*"G han,m speech thropist k pas lay kr gai"*<br>*"Klay kr to ni gai,lakin doctor ne btaya hai to abi ly kr jahy gay, suna hai, k us se b kafi asr ho sakta hai"* |
| | Complete recovery | *"M chahti hn k ye khud ko sahnbal lay.basic ye bolay, itna ho k bethay, iski mohtaji khtam ho. Khana peena……"*<br>*"M to chati hun k saarey masly hal ho jay"* |
| | Desire to drooling and swallow issues resolve | *"M to itna chati hun k is k muh se paani ana band ho jahy, q k paani ki waja se usko yahan infection ho jata hai".*<br>*bs yai k khana peena ka msla hal ho jaahey to baqi cheezay sath rehti hen.* |

Table 3 presents the financial difficulties and children management as a major theme, with sub-themes including borrowing money, not having enough money, treatment expenses, exercise, massage, knowledge about the speech therapist, complete recovery, and a desire to resolve drooling and swallowing issues.

## Discussion

The study was conducted in light of Pakistan's cultural settings and unique social situations. A total of 25 participants were recruited for the subject research. The aims of the subject research were to investigate the psychosocial challenges faced by the mothers of children with non-progressive neurological disorders and suffering from speech and swallowing difficulties. Post-study analysis uncovered a broad range of psychosocial issues. Post-study analysis uncovered a broad range of psychosocial issues.

Results from this study indicated that mothers of children with non-progressive neurological disorders and suffering from speech and swallowing difficulties faced psychosocial challenges in the present society of Pakistan. The current study revealed that mothers were faced with societal embarrassment and psychologically impaired life, stress, sadness, irritability, and social embarrassment. The result was supported by the work of Rodenburg et al (2007), parents' views of the extent to which day-to-day activities of a child are affected due to an underlying health condition, or the association of an epileptic child's condition with higher levels of parenting stress (Rodenburg et al., 2007). Lower parental/caregiver observation of functional status also affected the relationship between a child with asthma and the primary caregiver (Bleil et al., 2000). Another research pilot in Iran concluded that the prevalence and severity of depression in caregiver/mother was correlated with having a child with cerebral palsy (Sajedi et al., 2010). In another research done in the United Kingdom, when compared to parents of normally developed children, parents of the children with a higher degree of intellectual/functional disabilities scored higher in anxiety and depression

screening. A sizeable part of this group of caregivers/parents met criteria for clinical depression and anxiety as well (Gallagher et al., 2008).

The outcomes from the current study indicate that the adverse impact of psychological and physical health is a major theme, and sub-themes showed positive and negative impacts of psychological and physical health on mothers of children with speech and swallowing difficulties. The responses of mothers in the positive sub-theme included remaining hopeful, being grateful to God, understanding motherhood, and family/spouse support. Negative sub-themes showed hopelessness, depressive symptoms, physical problems/fatigue, impaired married life, social life, social comparison, no time for self, stress, sadness, irritability, body ache and weakness, and local transport. In a study conducted on children with chronic conditions in Canada, it was revealed that the primary caregivers of such children reported a number of health issues, with back pain being the main issue (Brehaut et al., 2004). A similar finding was reported in a study by Lachet et al (2009). They found that back pain was the second most frequently reported illness by parents/caregivers of children with advanced neurodegenerative disorders; however, they also found that caregivers of such children were quite healthy if they received support from their partner. In another study, caregivers of children with developmental disabilities were found to have a poor sleep quality (Gallagher et al., 2010).

The results of the current research show that financial difficulties are a major source of anxiety for mothers of children who suffer from speech and swallowing difficulties. It was found that the family is significantly impacted, with increased economic burden and greater care needs. Similar results were reported by Davis et al. (2010). The study reported an increase in physical problems among mothers with increasing child age and weight. The other issues related to the caregiver included difficulty in maintaining social relationships, disturbed sleep, financial pressure on parents, effect on the mother's employment status, and inadequate support services.

This phenomenological study highlights the substantial psychosocial challenges experienced by mothers of children with speech and swallowing difficulties due to non-progressive neurological disorders. The findings indicate that persistent caregiving demands, particularly related to feeding, communication, and physical assistance, place considerable physical and emotional strain on mothers. From the perspective of stress and coping theory, these challenges often exceed available coping resources, resulting in chronic stress and psychological distress.

Financial hardship emerged as a significant concern, as ongoing medical care and rehabilitation costs frequently disrupt family stability. This finding is supported by family systems theory, which explains how childhood disability alters family roles and economic functioning, thereby increasing caregiver burden. Additionally, mothers reported feelings of social isolation and emotional distress, largely driven by societal stigma and lack of support. Social stigma theory helps explain how negative cultural attitudes toward disability contribute to withdrawal, fear of rejection, and reduced social participation.

Overall, the findings suggest that limited social support intensifies caregiver stress, consistent with the social support buffering model. These results emphasize the importance of family-centered, culturally appropriate interventions that address both child rehabilitation and maternal psychosocial well-being to improve long-term care outcomes.

**Implications of the study**

The focus of future research may be on prognostic factors related to the impact of speech and swallowing issues on the family. Examples of prognostic factors may include, but are not limited to, the number of children in the family, family behavior management, and the nature of the underlying speech and swallowing disorder. When looking at the effects of child speech and swallowing issues

on the family, the coping mechanisms of families could be an important factor. Another factor shown to lower levels of parenting stress is family cohesion (Rodenburg et al., 2007), and could be a family- or parenting-stress impact level predictor of speech and swallowing disorders. The knowledge from the present research was also important for developing effective therapies for parents to manage their social and psychological issues.

## Conclusion

This phenomenological study concludes that mothers of children with speech and swallowing difficulties associated with non-progressive neurological disorders experience profound and multidimensional psychosocial challenges. The findings demonstrate that continuous caregiving responsibilities, particularly related to feeding, communication, and physical assistance, lead to sustained physical fatigue, psychological distress, social isolation, and financial strain. These difficulties are further intensified by limited family support, societal stigma, and inadequate access to rehabilitation and mental health services in a developing country context. The study underscores that caregiving extends beyond managing the child's medical condition and significantly affects maternal well-being, family functioning, and quality of life. Addressing these challenges is essential for improving both caregiver resilience and the effectiveness of long-term care and rehabilitation for children with speech and swallowing difficulties.

**Recommendations**

1. Family-Centered Rehabilitation Programs: Healthcare and rehabilitation services should adopt family-centered approaches that actively involve and support mothers in decision-making and care planning.
2. Psychosocial Support Services: Counselling, support groups, and stress management programs should be integrated into paediatric rehabilitation services to address maternal mental health needs.
3. Financial and Policy Support: Government and non-governmental organizations should provide financial assistance, subsidies, or insurance coverage to reduce the economic burden on families.
4. Community Awareness and Education: Public awareness campaigns are needed to reduce stigma, promote social acceptance, and encourage community support for families of children with disabilities.
5. Training for Caregivers: Structured programs focused on feeding, communication strategies, and coping skills should be provided to empower mothers and enhance their caregiving competence.

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