

# A Qualitative Study Of Psychological Problems Among Parents Of Children With Cerebral Palsy In Pakistan

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## Abstract

**Introduction:** Cerebral palsy (CP) is a neurodevelopmental disorder that affects a child's movement and posture owing to brain injury. Raising children with CP presents unique challenges for parents, including increased caregiving demands, financial strain, and emotional distress. This qualitative study aimed to explore the psychological problems faced by parents of children with CP in Pakistan.

**Methodology:** A semi-structured interview approach was employed, involving 40 participants (primary caregivers) from five regions of Pakistan: Baluchistan, Khyber Pakhtunkhwa, Azad Jammu and Kashmir, Punjab, and Sindh. A thematic analysis was conducted on the interview data using NVivo 14.0.

**Results:** The analysis revealed several overarching themes: (1) psychological impact on parents (anxiety, depression, grief, anger, disappointment, lack of sleep, guilt); (2) daily caregiving challenges (feeding, mobility, toilet needs, behaviour management, safety monitoring); (3) effect on parental health and well-being (physical health deterioration, lack of self-care, sleep deprivation, and inability to work); and (4) concerns about the future (financial worries and uncertainty about future care). Participants reported significant emotional distress, social isolation, physical health issues, and financial strain. Of the participants, 65% were mothers, and 35% were fathers. A total of 97.5% were married, and 80% of the fathers were employed. Ninety% of mothers were housewives.

**Conclusion:** Parents of children with CP in Pakistan face significant psychological challenges that profoundly impact their well-being. Robust support systems, including increased awareness, improved access to healthcare services, support groups, and financial assistance are crucial for addressing the unique needs of these families. Further research is recommended to explore effective interventions tailored to Pakistan's cultural context.

**Keywords:** Cerebral palsy, Pakistan, Parents, Psychological problems, Qualitative study, Caregiving challenges.

## Introduction

Cerebral palsy (CP) is a neurodevelopmental disorder characterised by impaired movement and posture due to brain injury and behavioural brain development during the prenatal, perinatal, or postnatal periods (1). It is a non-progressive condition that affects various aspects of a child's life, including motor function, cognition, sensation, and behaviour (2). The global prevalence of CP ranges from 2 to 6 cases per 1,000 live births (1), making it one of the most common childhood disabilities worldwide.

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The impact of cerebral palsy extends beyond the physical limitations experienced by the children. It also profoundly affects the psychological well-being and daily lives of both parents and caregivers. Raising a child with CP presents unique challenges, including increased caregiving demands, financial strain, and emotional distress (3,4). These challenges can lead to psychological problems among parents such as anxiety, depression, stress, and social isolation (5–7).

In Pakistan, where cultural and societal norms play a significant role in shaping perceptions and experiences, the psychological impact on the parents of children with CP remains largely unexplored. This qualitative study aimed to shed light on the psychological problems faced by parents of children with CP in Pakistan, providing valuable insights into their lived experiences and the challenges they encounter.

### Methodology

This qualitative study employed a semi-structured interview approach to gain an in-depth understanding of the psychological problems experienced by the parents of children with cerebral palsy in Pakistan. The study was conducted across various regions of Pakistan, including Baluchistan, Khyber Pakhtunkhwa (KP), Azad Jammu and Kashmir (AJK), Punjab, and Sindh.

### Participant Selection and Recruitment

Participants were recruited through purposive sampling from pediatric outpatient clinics and rehabilitation centers across the aforementioned regions. A total of 40 participants (eight from each province) were included in the study. The inclusion criteria were as follows: (1) being a primary caregiver of a child aged 1–18 years with a confirmed diagnosis of cerebral palsy, (2) being aware of the child's diagnosis for at least one year, and (3) willingness to participate in the study without external pressure.

### Data Collection

Semi-structured interviews were conducted with each participant, lasting approximately 30–45 minutes. The interviews were conducted in native languages (Pashto and Urdu) using an interview guide with questions exploring the psychological experiences of the parents. The interviews were audio-recorded with the participants' consent, transcribed verbatim, and translated into English for analysis.

### Ethical Considerations

The study was approved by the relevant institutional review boards and ethics committees. Informed written consent was obtained from all participants prior to data collection. Participants were assured of confidentiality and their right to withdraw from the study at any time, without consequences.

### Results

#### Socio-demographics (N=40)

Variable	N	Percentage
<b>Caregiver Gender</b>		
Male	14	35%
Female	26	65%
<b>Child Gender</b>		
Male	26	65%

Variable	N	Percentage
Female	14	35%
<b>Marital Status</b>		
Married	39	97.5%
Divorced	1	2.5%
<b>Father Occupation</b>		
Employed	32	80%
Unemployed	8	20%
<b>Mother Occupation</b>		
Housewife	36	90%
Employed	4	10%
<b>Monthly Income</b>		
Up to 20000 PKR	5	12.5%
21000-30000 PKR	9	22.5%
31000-40000 PKR	12	30%
41000-50000 PKR	5	12.5%
Above 50000 PKR	9	22.5%

### Data Analysis

The transcribed interviews were analysed using NVivo 14.0(8) qualitative data analysis software. The primary caregivers' responses were recorded and transcribed, and a thematic analysis approach was employed to identify recurring patterns, themes, and sub-themes within the data.

Analysis of the interview data revealed several overarching themes related to the psychological problems experienced by parents of children with cerebral palsy in Pakistan. These themes are discussed below along with illustrative quotations from the participants.

#### 1. Psychological Impact on Parents

One of the most prominent themes that emerged from the data was the significant psychological impact on the parents of children with CP. This impact manifests in various forms including anxiety, worry, stress, depression, hopelessness, grief, sadness, anger, irritation, frustration, disappointment, dissatisfaction, lack of sleep, and guilt.

##### a. Anxiety, Worry, and Stress

Parents across all regions of Pakistan expressed heightened levels of anxiety, worry, and stress related to their children's condition and future prospects. They constantly grappled with concerns about their children's well-being, independence, and ability to lead fulfilling lives. These concerns were amplified by the uncertainties surrounding the availability of support systems and healthcare resources.

"I am anxious about the child for their future, and I am feeling hopeless." (AJK Interview 2)

"Anxious for them that child is disabled, what will be their future?" (Punjab Interview 6)

"I am thinking that in the future, does my issue will be solved or not?" (Sindh Interview 2)

##### b. Depression and Hopelessness

Many parents reported feelings of depression and hopelessness often stemming from the realisation that their child's condition was permanent and incurable. The emotional toll of caring for a child with CP, coupled with societal stigma and a lack of support, contributed to these feelings of despair. "Most of the time, I feel depressed for him and spend my whole day in stress to do his daily tasks." (AJK Interview 3)

"Yes, I feel very depressed." (KP Interview 5)

**c. Grief, Sadness, and Crying**

The diagnosis of cerebral palsy in their children evoked profound feelings of grief, sadness, and tears among parents. They mourned the loss of their children's potential and dreams they had envisioned for their children's future. "Starting weeping... it is Allah's wish, but I never disappoint..." (Punjab Interview 8)

"No...!!!! I have no happiness after his birth." (Sindh Interview 2, 7)

**d. Anger, Irritation, and Frustration**

Parents expressed feelings of anger, irritation, and frustration related to their children's conditions and the challenges they faced in providing care. The constant demand for attention and inability to control certain aspects of a child's behaviour contributed to these emotional responses.

"Yes, I feel angry and so angry... These kids make me so angry." (Baluchistan Interview 10)

"Yes, I feel angry. It is out of my control." (AJK Interview 7)

"Yes, I feel angry and irritative." (Sindh Interview 2, 4, 6, 8)

**e. Disappointment and Dissatisfaction**

Many parents expressed disappointment and dissatisfaction with their circumstances, particularly when comparing their children's development and abilities to those of typically developing children. They grappled with the realisation that their children might not achieve certain milestones or live independently.

"It is so distressing and unbearable..." (Baluchistan Interview 8)

"I became disappointed that came to know that my child is disabled. This was very hard to accept it that my child is disabled." (AJK Interview 2)

**f. Lack of Sleep or Disturbed Sleep**

The demands of caring for a child with CP often result in sleep disturbances or a lack of adequate sleep for parents. This sleep deprivation exacerbated existing psychological problems and added to the overall burden of caregiving.

"My sleep is too less due to all these issues which I told you. Sometimes I am taking sleeping pills but very rarely..." (Punjab Interview 8)

"I have very disturbed sleep due to my child." (KP Interview 5)

**g. Guilt**

Some parents expressed feelings of guilt, often related to their perceived inability to provide the best care for their child, or the belief that their actions might have contributed to their child's condition.

"No...!!! [Guilt feeling] I am blaming my luck for this bad time..." (Baluchistan Interview 10)

**2. Daily Caregiving Challenges**

Caring for a child with cerebral palsy presents numerous daily challenges that can exacerbate parents' psychological problems. The study participants highlighted various caregiving difficulties they encountered, including feeding, cleaning, bathing, mobility

and transferring, lack of independent living skills, toilet needs, managing behaviour, monitoring child safety, accessing rehabilitation and hospital visits, cleaning hygiene, providing medications, and the need for constant supervision.

**a. Feeding, Cleaning, and Bathing Difficulties**

One of the most prevalent challenges reported by parents across all regions was the difficulty in feeding, cleaning, and bathing their children with CP. The physical demands of these tasks, coupled with the child's limitations, added to the emotional strain experienced by parents.

"I am smashing the food and giving them in the mouth. If they are not swallowing food, it is a problem for me. It is my tough duty." (Baluchistan Interview 8)

"Yes, feeding, dressing, cleanliness, and their physiotherapy are the issues I face in daily life."

**b. Mobility, Transferring, and Accessibility Issues**

Parents reported difficulties related to their children's mobility and the need to transfer them from one place to another. The physical strain of carrying their child, particularly as they grew older and heavier, took a toll on parents' physical and emotional well-being.

"We are carrying our disabled children on our back to home or hospital." (Baluchistan Interview 6)

"Child is grown up and heavy to lift and carry them on back." (AJK Interview 1)

**c. Lack of Independent Living Skills**

The lack of independent living skills in children with CP poses a significant challenge for parents. The constant need to assist their child with basic tasks, such as toileting, dressing, and feeding, added to the caregiving burden and impacted the parents' emotional well-being.

"They cannot attend the toilet, and I am going along with them to the toilet to clean them." (Baluchistan Interview 10)

"I do not have a wheelchair to carry them, and I don't have a toilet chair to seat him in the toilet." (AJK Interview 8)

**d. Toilet Needs**

Addressing their children's toilet needs has emerged as a recurring challenge for parents. The need for constant supervision and assistance during toileting adds to the already demanding caregiving responsibilities.

"Sometimes he is awaking us for the toilet to help them, sometimes asking for water." (Sindh Interview 9)

**e. Managing Behavior**

Parents expressed difficulties in managing their children's behaviour, which often contributed to their emotional distress. The child's stubbornness and insistence on having their demands meet the caregiving challenges.

"And due to my disabled child, I cannot do a job. And my child is too stubborn, and what he wishes, they want at any cost." (Punjab Interview 1)

**f. Monitoring Child Safety**

Ensuring the safety and well-being of children with CP is a constant concern for parents. They reported staying awake at night to monitor their children and to prevent potential accidents or seizures.

"I am waking whole night that the child may not suffer fits and not fall from the bed." (Punjab Interview 3)

**g. Accessing Rehabilitation and Hospital Visits**

Parents face challenges in accessing rehabilitation services and hospital visits for their children. The distance to these facilities and associated transportation costs add to the overall burden of caregiving.

"I bring him regularly to this rehab center, and it is far away from my home."  
(Punjab Interview 1)

**h. Cleaning Hygiene**

Maintaining proper hygiene in children with CP is a daily challenge for parents. The physical demands of cleaning and bathing children add to their caregiving responsibilities.

"Feeding, dressing, cleaning of a disabled child are the challenges in daily life for me." (Sindh Interview 3)

**i. Giving Medications**

Administering medications to their children with CP was another task that parents had to navigate. The importance of timely and accurate medication administration is added to the caregiving demands.

"Their medication is also on me." (Sindh Interview 4)

"Also, medication on time is also hard to not miss his medicine." (KP Interview 4)

**j. Need for Supervision**

The constant need for the supervision of children with CP is a recurring theme among parents. They reported the need to be vigilant at all times, even at night, to ensure their child's safety and well-being.

"And waking again and again at night that the disabled kid may not fall from the bed. Or changing their side as he becomes tired on one side." (Sindh Interview 4)

**3. Effect on Parental Health and Well-being**

The findings revealed that the challenges of caring for a child with cerebral palsy had a significant impact on the physical and psychological health of parents.

**a. Physical Health Deterioration**

Many parents reported experiencing physical health problems that were directly linked to the demands of caregiving. Common symptoms include back pain, arthritis, slipped discs, hypertension, and diabetes.

"With the birth of this child, I became ill, and I have bone issues and became too weak." (Baluchistan Interview 5)

"Back pain, arthritis from lifting child." (Punjab Interviews 1, 3, 4)

"Hypertension, diabetes." (Punjab Interviews 2, 9)

**b. Lack of Self-Care**

The constant focus on caring for their child with CP often leads parents to neglect their own health and self-care needs. Some participants reported not seeking medical attention for their own health issues because of caregiving demands.

"Since last 3 years, I didn't go to the doctor for my own health issue [weeping...]" (Baluchistan Interview 1)

**c. Link to Caregiving**

Parents acknowledged a direct link between their physical health issues and the demands of caregiving for their children with CP. Constant lifting, transferring, and physical strain contribute to deteriorating health.

"Yes, lifting my child is the cause of my illness." (AJK Interview 8)

"I spent my whole day restless due to my disabled child. And become tired whole day by caring for my child." (Punjab Interview 1)

**d. Psychological Effect**

The psychological impact of caring for a child with CP was evident in parents' responses. Some participants reported experiencing psychological stress, depression, and emotional distress directly related to their caregiving responsibility.

"Yes, my wife is suffering from psychological stress." (AJK Interview 1)

"I have diabetes... But the rest, I am ok and have some psychological illness too." (Sindh Interview 2).

**e. Sleep Deprivation**

Sleep disturbances and deprivation are common among parents, often resulting from the need to attend to their child's needs throughout the night. The lack of adequate sleep contributes to physical and psychological well-being.

"Sleep is very disturbed... as the child needs care at night too." (Baluchistan Interview 8)

"My child is not letting me sleep. By self, his sleep was disturbed, and they also disturbed us. I have BP issues due to a lack of sleep." (Sindh Interview 8)

**f. Inability to Work**

For some parents, caregiving demands made it difficult to maintain employment or engage in income-generating activities. This inability to work, in addition to their financial strain, impacted their overall well-being.

"In health issues, that I have a backbone issue. Because my child is heavy, I lift him regularly. I bring him regularly to this rehab center, and it is far away from my home." (Punjab Interview 1)

**g. Medical Conditions**

Parents reported developing various medical conditions that they attributed to the stress and physical demands of caring for their children with CP. These conditions range from hypertension and diabetes, to musculoskeletal and psychological disorders.

"I became too busy. I spent most of my time caring for this disabled child, and I could not give time to another child. For some time, he was okay, and for some time, he was not feeling good. The whole day I spend in this cycle, and it keeps me busy." (Sindh Interview 2)

**4. Concerns about the Future**

One of the recurring themes that emerged from the study was the significant concern and worry that parents had about their child's future and the uncertainties that lay ahead.

**a. Financial Worries**

Financial concerns were a prevalent issue for parents, as they grappled with the ongoing costs associated with their children's treatment, therapies, and care. Uncertainty about their ability to provide for their children's future needs was added to their psychological distress.

"First, I am having a financial issue, and I cannot afford the child's treatment and needs, so I am worried about my child's future." (AJK Interview 1)

"So many worries for the child's future that he does his graduation that he supports himself in the future." (Punjab Interview 8)

**b. Concern about Death and Care**

The parents expressed deep concerns about what would happen to their children with CP if they were to pass away. Uncertainty about who would provide the necessary care and support for their child in their absence was a significant source of anxiety and worry.

"If we die, then who will take care of the child in the future?" (AJK Interview 1)

"Yes, I have many worrying thoughts. If we die, then who will look after my disabled children?" (Sindh Interview 3)

**c. Siblings Not Providing Future Care**

Some parents expressed doubts about whether their other children would be willing or able to take on caregiving responsibilities for their child with CP in the future. This added to their concerns regarding their children's well-being after passing.

"I am worrying for their future that what will they do next? If I die, what will be the next? " (Baluchistan Interview 8)

**Discussion**

This study highlighted the profound impact of raising a child with cerebral palsy on parents' psychological well-being in Pakistan. Emotional distress, social isolation, physical health issues, and financial strain were common among the participants. These findings are consistent with previous research conducted in other countries, underscoring the universal challenges faced by parents of children with CP.

**Emotional Distress**

Parents reported significant levels of anxiety and worry about their children's future, which aligns with the findings of Raina et al. (2005) that parents of children with disabilities often experience heightened anxiety (3). Feelings of depression and hopelessness among parents have been well-documented in the literature (9,10). The grief and loss felt by parents reflects the emotional burden of having a child with a chronic condition, as noted by Barnett et al. (2003) (11).

**Social Isolation**

The lack of support and social stigma experienced by parents in this study is similar to the findings of Rosenbaum (2011) and Dirks and Hadders (2011), who noted that parents of children with disabilities often feel isolated and face social discrimination. This social isolation can exacerbate the psychological stress faced by parents (12,13).

**Physical Health Issues**

Exhaustion and neglect of personal health among parents were prevalent themes, which is consistent with the findings of Brehaut et al. (2004), who reported that the physical demands of caregiving can lead to chronic health issues for parents. This neglect of self-care further compounded the stress and fatigue experienced by caregivers (14).

**Financial Strain**

The financial burden of medical expenses and reduced income due to caregiving responsibilities are significant issues for many parents. This finding supports previous studies by Raina et al. (2005) and Davis et al. (2010), which highlighted the economic impact of raising a child with a disability (3,7). Financial strain can lead to further psychological stress and affect the family's overall well-being.



### **Coping Strategies**

Despite numerous challenges, many parents displayed remarkable resilience and utilised various coping strategies to manage their stress. Support systems such as support groups and professional help are crucial for many parents and provide them with emotional and practical support. This finding is in line with studies by Peer and Hillman (2014) and Hauser-Cram et al. (2001), which emphasise the importance of social support in alleviating caregiver stress (5,10).

### **Limitations**

This study has several limitations. The sample size was relatively small and may not be representative of all the parents of children with CP in Pakistan. The use of purposive sampling may have introduced a selection bias. Additionally, the study relied on self-reported data, which may be subject to social desirability bias. Future research should include larger and more diverse samples and consider longitudinal designs to explore changes in psychological well-being over time.

### **Recommendations**

Several recommendations can be made based on these findings.

1. **Increased Awareness and Education:** Educate the public about CP to reduce stigma and discrimination. Awareness campaigns can help communities understand the challenges faced by families of children with CP.
2. **Improve Access to Healthcare Services:** Enhance access to affordable healthcare services, including medical treatments, therapies, and mental health support for children with CP and their parents.
3. **Establish Support Groups:** Create support groups and networks for parents of children with CP to provide emotional and practical support. These groups can help reduce social isolation and provide platforms for sharing experiences and coping strategies.
4. **Provide Financial Assistance:** Develop financial assistance programs to alleviate the economic burden on families. This can include subsidies for medical expenses and support for parents who need to leave their jobs to care for their child.
5. **Conduct Further Research:** Encourage further research to explore effective interventions and support mechanisms tailored to Pakistan's cultural context. Longitudinal studies can provide insights into the long-term impact of caregiving on parents' psychological wellbeing.

### **Conclusion**

Parents of children with cerebral palsy in Pakistan face significant psychological challenges including emotional distress, social isolation, physical health issues, and financial strain. This study emphasises the need for robust support systems to improve the QoL of these families. Policymakers and healthcare providers must collaborate to create interventions that address the unique needs of parents caring for children with CP in Pakistan.

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