

EXPLORE THE LIVED EXPERIENCES OF PARENTS OF SPECIAL NEEDS CHILDREN

Muhammad Dawood Alvi, Hafiza Tuba Qamar

Department of Psychology, Forman Christian College (A Chartered University)

Abstract

Aims. The aim of the study was to explore the essence of the lived experiences of parents of special-needs children in Pakistan. The study aimed to investigate the perspectives and real-life situations that parents of differently abled children encounter. **Methods.** A qualitative phenomenological methodology was employed to examine the real-world challenges parents face while trying to access and make use of resources such as healthcare, education, and other necessities. The sample included 7 parents of differently abled children. The in-depth interviews were conducted individually to explore each parent's experiences, and purposive sampling was done. **Results.** The following main themes emerged from a thematic analysis of the data: discrimination in society, financial stress, lack of guidance, balancing daily responsibilities, sources of support, and parents' views. **Conclusions.** This study has broad implications that will help develop better policies, educational plans, and healthcare delivery methods that are adapted to the requirements of families with children who have special needs. The results can help community organizations develop more effective support systems, increase public awareness and support, and create an empathetic environment in society. Furthermore, by confirming their experiences, the study gives parents more power and establishes the foundation for future studies aimed at continuously enhancing support systems.

Keywords: Special Needs Children, Parenting Experiences, Phenomenological Approach, Social Support Systems

1.1 Introduction

Parenting children with special needs presents unique challenges and profound experiences that impact every facet of family life. Parents often navigate a complex landscape of caregiving, advocacy, and emotional resilience to support their children's developmental, social, and educational needs. The lived experiences of these parents reflect a blend of joy, stress, and uncertainty shaped by the interaction between personal circumstances and societal structures. Studies have documented the significant physical, emotional, and psychological demands placed on parents of special needs children, as well as their adaptive strategies to enhance family well-being (Dobrea, 2025; Dlamini & Chang, 2025).

In addition, societal perceptions and institutional frameworks can influence how parents of children with disabilities access resources, participate in inclusive education, and foster their children's social integration (Kareem & Khanna, 2025). These experiences underscore the importance of understanding their narratives to develop more inclusive policies and targeted support systems. Recent research has highlighted the dynamic interplay between caregiving and broader societal factors. For example, Weimann-Sandig et al. (2025) explored how the COVID-19 pandemic amplified existing caregiving challenges, revealing the fragility of support systems for families with special needs children.

Similarly, research by Supratiwi and Yuwono (2025) underscores the transformative role of parental competencies in fostering social interaction skills among children with disabilities. These studies reflect the growing recognition of the need for holistic approaches that consider the voices and perspectives of parents to enhance policy and service design. Despite advances in research and

advocacy, parents of special needs children continue to face systemic barriers, including inadequate access to healthcare, education, and social services. These challenges often result in feelings of isolation, caregiver burnout, and financial strain, which exacerbate the complexity of caregiving.

Moreover, existing support structures frequently overlook the unique cultural, socioeconomic, and individual circumstances that shape parental experiences. As a result, there remains a gap in understanding the lived realities of these parents, particularly how they navigate caregiving challenges and leverage resilience strategies within their social and cultural contexts (Santana et al., 2025; Onsjö, 2025). Research efforts are needed to explore these lived experiences in depth, enabling policymakers and practitioners to design interventions that are culturally sensitive, equitable, and aligned with the specific needs of families. A deeper understanding of parents' narratives will not only enrich academic discourse but also foster community-based solutions that prioritize empowerment and inclusivity. By addressing these gaps, future research can contribute to building a more supportive and understanding society for parents and children with special needs.

2. Method

2.1 Research Design

This study used a qualitative research design because it incorporates an explanatory, naturalistic perspective. A phenomenological approach and constructivist framework were used to explore the experiences of parents with special needs' children. Phenomenology was chosen to understand the lived experiences of parents interpreting the essence and significance from their point of view. This facilitated us to explore how parents decode and understand the meaning of their personal experiences, also highlighting the practical, social, and emotional challenges they encountered. According to the research, the possible factors influencing parents' experiences may include cultural background, socioeconomic status, support systems, and positive or negative societal experiences. Through the use of the constructivist paradigm, we were able to explore the parents' perceptions and interpretations of their experiences with children with special needs, recognizing their subjectivity. And if this is further explored through the lens of constructivism, we attempt to understand the multi-faceted perspectives of parental role while always acknowledging that participants' observations were subjective and ever-changing.

2.2 Sample and Sampling Strategy

The sample of the seven parents of special needs children was accessed through purposive sampling. One father and six mothers were part of the study. We reached out to parents through the help of local support groups and special education networks using social media platforms (Facebook and Instagram). This strategy was quite helpful because we were able to retrieve in-depth interviews that provided an understanding of their different kinds of experiences. The objective of our study was clear, and thus we had an inclusion criterion as follows. Each participant was a parent of diagnosed special needs children who had been providing care for at least one year and was willing to give an audio-recorded interview.

2.3 Procedure

This study conducted semi-structured, in-depth interviews for data collection. This approach best suited the research purpose of exploring different aspects of parents' social, emotional, and other unique experiences. This study considered all ethical concerns during the interview process. This approach contributed to gaining in-depth, rich information while providing the liberty of using flexibility in interviews. The current study recorded seven interviews with varying time durations, from a minimum of 30 minutes to a maximum of an hour. Researchers ensured they provided adequate support to the participant during the interview. All interviews were conducted with privacy, prioritizing the comfort of the participant. The interviews were completed effectively, and

endured that the participant is satisfied and comfortable. All interviews were transcribed by the researchers for further thematic analysis.

3. Results

This study conducted 7 in-person interviews with the parents of differently abled children. Following the thematic analysis, the current study generated 7 superordinate themes, which in turn comprised the following sub-themes.

Table 1. *Superordinate and subordinate Themes*

Superordinate themes	Subordinate themes
Societal Discrimination	Harassment Bullying Discrimination by Educational Institutions Facing insensitivity of society
Financial Strains	
Lack of Guiding Channels	
Effect on Parent's life	Balancing Everyday Responsibilities
Inadequate facilities	Doctor's Negligence
Sources of Support	Disappointment in Medical and other facilities Guidance
Parent's Perspective	Religious Support Support from friends and family Strong Determination Hopelessness Confidence in Child's ability Message to society

Table 2. *Themes and Participants checklist*

Superordinate themes	Participants						
	1	2	3	4	5	6	7
Societal Discrimination	✓	✓	✓	✓	✓	✓	✓
Financial Strains	✓	✓	✓	✓		✓	✓
Lack of guiding channels	✓				✓		
Effect on parents' life	✓	✓	✓	✓		✓	✓
Inadequate facilities	✓	✓	✓			✓	✓
Sources of support	✓	✓	✓	✓	✓		✓
Parents' perspectives	✓	✓	✓	✓	✓	✓	✓

Social Discrimination

This theme involves the attitude and behaviour of society towards special needs children as perceived by their parents. At various instances, society marginalizes or treats them differently based on their differently abled characteristics. This discrimination was manifested in multiple

ways, including a lack of accessibility or limited opportunities for resources like education, health care or employment facilities.

Harassment

Participants shared their perspectives on the harassment that their differently abled children experience. One of the participants explained how her son faced serious sexual harassment by the workers of a factory.

Bullying

The participants explained how their differently abled child faced the intentional act of intimidation or exclusion from various people. Another participant highlighted how a girl in the school used to deceive her child for money.

Discrimination by Educational Institutions

Most of the participants faced discrimination while advocating for their child's right to education. One of the participants highlighted how lacking the ability to walk was causing trouble in school admission for their child.

Facing Insensitivity of Society

Not only did the participants face discrimination from the schools, but they also faced discrimination from their respective family members and other people around them. They heard insensitive words from society, adding to the emotional strain of these parents. One of the participants encountered discrimination from their neighbors.

Financial Strains

The parents of children with special needs experienced high financial pressure while they sought valuable care and education for their children. They faced the financial burdens, including exploitative educational expenses, medical expenses for treatment, as well as the cost of professional services.

Lack of Guiding Channels

The absence of proper guiding channels creates hurdles for parents. One of the themes identified by the interview with three participants was the lack of guidance to make them aware of the situation. Parents of differently abled children faced challenges because of a lack of information and the absence of platforms providing guidance. One of the participants did not know anything about differently abled children. Another participant expressed that many challenges and doubts arise because of a lack of any authentic guidance. She mentioned the need for developing institutes where parents can satisfy their doubts and get clear directions and insights into the situation.

Balancing Daily Responsibilities

Balancing everyday responsibilities is a difficult task, especially for the parents of children with special needs. Parents faced the unique challenges that required significant adjustments in their lives. One of the participants shared the struggle she faced while carrying her 10-year-old child, which showed the importance of being around and available for their child at all times.

4. Discussion

All the participants of the study expressed that they faced societal discrimination for being a parent of a special needs child, which has impacted their lives (Mabel Oti-Boadi, 2017). The societal attitudes toward the differently abled child affect the social lives of the parents; similar findings have been mentioned in the literature as well (Deniel et al., 2021). The literature also reveals that child with special needs face societal stigma, bullying, and harassment (Ahmad et al., 2021). Six participants expressed having financial pressure while they were looking for care and education for their child. Participants revealed that the public sector has limited institutions, and private sector institutions are costly, which adds to the stress level of parents with special needs children.

This was also found in various studies conducted by Robinson et al., 2023, who talked about the medical expenses that parents have to take care of and Yaacob et al., 2021, shed light on financial constraints being a huge barrier for getting adequate services for autistic children. Participants expressed that they have to face challenges due to a lack of information and the absence of guiding platforms. Due to lack of awareness, participants were not able to get proper treatment on time. Similar findings have been found in literature that mothers were not able to access vital information about their child (Lamba et al., 2022; Nawaz & Bushra, 2019). Five parents revealed that managing everyday responsibilities was a major challenge they had to face. This phenomenon was also highlighted in a study conducted by Goh et al. (2021), which also found a major theme called change in lifestyle among parents (Qamar & Ibrahim, 2024).

The experiences of parents are greatly shaped by their surroundings, as noted by Latour et al. (2010) and McGarty et al. (2020). The study contributed to this by presenting personal examples of parents who had to make big changes in their lives, such as leaving their jobs or organizing their whole schedule according to their child's needs. Furthermore, they underlined how much commitment and dedication are required when looking after a child with special needs. Participants mentioned the issue of negligence in medical care and their overall dissatisfaction with inadequate services, including ramps at public places for children with physical impairment. The study showed that insufficient medical care, which is represented by incorrect diagnosis and inefficient treatments, has a negative influence on the parents' and child's well-being.

The results matched those of Oti-Boadi's (2017) study, which talked about similar situations involving mothers of children with special needs and how a lack of medical knowledge had caused them to be constantly stressed and in pain. The perspectives of parents in the study aligned with the findings of Lamba et al. (2022). Both studies highlighted the need for improving medical professionals' training and expanding their services. Various sources of support added to the positive experiences of parents. The provision of guidance and information regarding special needs children was helpful for parents. Religious support was the greatest support among the families. Participants said that religious acts like praying and worshipping have helped them deal with their problems. They also talked about how their chosen participants have talked about their disability from a religious point of view and how they can use religious acts like praying and worshipping as ways to deal with their problems (Shah & Samana, 2010; Borah & Gogoi, 2020).

A study explored the crucial role that families play as a support system for parents of differently abled children, which aligns with the findings of our study. In times of confusion and distress, any light of guidance was encouraging for parents (Riasat, 2012). Every parent strove to provide the best possible upbringing for their differently abled child. The exploration of parents' perspectives demonstrated that having confidence in the abilities of children played a significant role in acceptance. Second, the research (Syalviana & Syahrul, 2024) further elucidates the common negative feelings parents often experience when raising differently. The research explains that parents often prioritize the weaknesses of special needs children over their strengths, leading to increased stress due to a lack of acceptance and understanding. explained that parents tend to parents particularly expressed feelings of support for all parents who are currently confused about understanding their child's condition.

They said that it is important for parents to accept and have confidence in their child, fostering positivity and self-confidence in children. The study has highlighted the role of society in shaping the experiences of parents. It is recognized that there is a dire need for attention towards managing the existing problems and concerns of the parents of special needs children. The research has provided important implications by recognizing various aspects that require effective policy design and implementation. Moreover, it has shown that what individual role one can play for providing support and reducing the faced discrimination for differently abled individuals and their parents. While designing policies for better education, guiding channels, and the requirement of adequate facilities, the perceived challenges, sources of support, and perspectives must be considered.

This has highlighted the importance of having properly designed guiding institutions and plans for parents. The findings contribute to empowering parents by validating their experiences. Parents will feel confident while advocating for required resources, as the study provides validation of their experiences by understanding those of others in similar situations. The research fosters empathy in society by making them understand the lived experiences of parents of differently abled children. Awareness and discussions further contribute to creating a safe and compassionate environment for children with special needs. The study provided significant insights by exploring the messages parents sent to society. All parents have expressed the importance of accepting their children's unique abilities, highlighting positive aspects, and fostering confidence in them.

Conclusion

This research explored various aspects of the experiences of parents of special needs children through phenomenology, framed in social constructivism. The findings showed that these challenges are multifaceted and encompassed societal discrimination, financial issues, lack of guiding channels, and changes in parents' lives. We urge more awareness and application toward these issues, emphasizing social acceptance and the recognition of parents' determination and dedication in parenthood. Furthermore, they should get easy access to basic facilities that include healthcare centres and educational institutions. Although there was indigenous literature available in Pakistan, it lacked sufficient coverage of parents' perspectives within Pakistan's culture. Therefore, this study served to bridge the gap in the literature, highlighting the significance of fostering compassion and understanding within Pakistani society. This can help individuals globally to support and understand the perspectives and feelings of parents in a better manner. With increased awareness and compassionate hearts, more efficient ways and methods can be considered to significantly improve the lives of differently abled children and their families, creating a more inclusive and supportive society.

References

1. Ashiq, R., & Ahmad, A. C. (2021). Experiencing and coping with social stigma: Stories of mothers of disabled children in south Punjab, Pakistan. In *Proceedings The 4th International Conference on Special Education*. (pp. 610–618). Zenodo. <https://doi.org/10.5281/ZENODO.6910022>
2. Bahador, R. S., Farokhzadian, J., Nasab, F. R. S., & Abbasi, M. (2023). Experiences of family caregivers of people with intellectual disabilities from rural areas in southeastern Iran: a qualitative study. *BMC Psychiatry*, 23(1). <https://doi.org/10.1186/s12888-023-05077-0>
3. Borah, S., & Gogoi, S. (2020). Parental stress in raising children with special needs (CWSN). *Asian Journal of Home Science*, 15(1), 12–16. <https://doi.org/10.15740/has/ajhs/15.1/12-16>
4. Chang, M. D. D. & Y. (2025). Caregiver Burden in Caring for Children with Cerebral Palsy: A Concept Analysis. *International Journal of Health, Medicine and Nursing*

- Practice, CARI Journals Limited*, vol. 7(1).
<https://ideas.repec.org/a/bhx/ijhmn/v7y2025i1p1-23id2465.html>
5. Chin, W., Chang, H., & Chao, K. (2023). Exploring coping strategies of parents of children with autism spectrum disorder in Taiwan: a qualitative study. *the journal of Nursing Research/the journal of Nursing Research*, 31(3), e278.
<https://doi.org/10.1097/jnr.0000000000000553>
 6. Daniel, J. A., Okefenam, E. C., Ugorji, T. N., Agbasi, P. U., Onyido, D. C., Odoh, I. O., Fakorede, S. O., & Egbujo, S. M. (2021). Challenges faced by Nigerian parents with disabled children in caring for them. *Open Journal of Social Sciences*, 09(10), 201–212.
<https://doi.org/10.4236/jss.2021.910015>
 7. Dobrea, L. (2025). Exploring Joint Manifestations in RASopathies: A Prospective Survey. *Digital Commons at Liberty University*.
 8. Faraji-Khiavi, F., Zahiri, M., Amiri, E., Dindamal, B., & Pirani, N. (2021). The Experiences of Families Raising Autistic children: A Phenomenological Study. *Journal of Education and Health Promotion*, 10(1), 78. https://doi.org/10.4103/jehp.jehp_837_20
 9. Khanna, R., & Kareem, J. (2025). Voicing Out Parental Experiences of Schooling Their Children with Learning Disabilities: A Qualitative Study of Inclusive Government Schools of India. *International Journal of Educational Reform*, 0(0). <https://doi.org/10.1177/10567879241309355>
 10. Latour, J. M., Goudoever, J. B. van, Schuurman, B. E., Albers, M. J. I. J., Dam, N. A. M. van, Dullaart, E., Heerde, M. van, Verlaat, C. W. M., Vught, E. M. van, & Hazelzet, J. A. (2010, November 10). A qualitative study exploring the experiences of parents of children admitted to seven Dutch Pediatric Intensive Care Units - *Intensive Care Medicine*. *SpringerLink*. <https://link.springer.com/article/10.1007/s00134-010-2074-3>
 11. McGarty, A. M., Westrop, S. C., & Melville, C. A. (2020). Exploring parents' experiences of promoting physical activity for their child with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 34(1), 140–148. <https://doi.org/10.1111/jar.12793>
 12. Nawaz, M. Y. and Bushra, G. (2019) Problems faced by the parents of autistic children: a qualitative study in Punjab, Pakistan, *Org.pk*. <https://www.rmj.org.pk/fulltext/27-1524761207.pdf?1713274434>
 13. Onsjö, M. (2025). Children Subjected to Family Violence: A Retrospective Study of Life Situation and Trauma-Focused Treatment. *University of Gothenburg Publications*.
 14. Oti-Boadi, M. (2017). Exploring the lived experiences of mothers of children with intellectual disability in Ghana. *SAGE Open*, 7(4), 215824401774557. <https://doi.org/10.1177/2158244017745578>
 15. Ott, L. (2015). Families with special needs children and stress: *Research review*. Eric.ed.gov. <https://files.eric.ed.gov/fulltext/EJ1230692.pdf>
 16. Padmashree, T. (2019). Role of parents of special needs children: A qualitative study. *Pramanaresearch.org*. <https://www.pramanaresearch.org/gallery/prj-p889.pdf>
 17. Riasat, A. (2012) *A study of problems faced by mothers of disabled children in rural areas of district Faisalabad*, *Globaljournals.org*. Available at: https://globaljournals.org/GJHSS_Volume12/3-A-Study-of-Problems-Faced-by-Mothers.pdf
 18. Qamar, T., & Ibrahim, N. (2024). A Quasi-Experimental Clinical Trial of the Detached Mindfulness Group Therapy for Married Women with Major Depressive Disorder. *Revista De Gestão Social E Ambiental*, 18(7), e07137. <https://doi.org/10.24857/rgsa.v18n7-113>
 19. Robinson, T. L., Bowman, E. B., & Barker, B. A. (2023). Exploring the stories of parents' experiences with infant hearing-loss screening and diagnosis in the United States. *Ear and Hearing*, 44(3), 518–529. <https://doi.org/10.1097/aud.0000000000001294>
 20. Santana, V.O., Ramos, A.C., Cogo-Moreira, H. et al. (2025). Sex-specific association between maternal childhood adversities and offspring's weight gain in a Brazilian cohort. *Sci Rep* 15, 2960 (2025). <https://doi.org/10.1038/s41598-025-87078-5>

21. Shah, S. (2010). *Listening to the experiences of second-generation Pakistani Muslim parents of children with special educational needs: an interpretative analysis*. University of Sheffield.
22. Supratiwi, M., Gunarhadi, & Yuwono, J. (2025). Parental competencies in developing social interaction skills in children with special needs. *Multidisciplinary Science Journal*. <https://malque.pub/ojs/index.php/msj/article/view/7328>
23. Syalviana, E., & Syahrul Syahrul. (2024, March 31). Positive Parenting Training for Increasing Self-Acceptance of Parents with Special Need Children in Sorong... ResearchGate; *Springer Nature*. https://www.researchgate.net/publication/379458663_Positive_Parenting_Training_for_Increasing_Self-Acceptance_of_Parents_with_Special_Need_Children_in_Sorong_City
24. Weimann-Sandig, Nina & Schneiderat, Götz & Völlger, Aileen. (2025). Navigating Crisis: The Transformative Impact of COVID-19 on Family Support Services in Germany. *In: Journal of Mental Health Disorders*. Journal of Mental Health Disorders. <https://www.researchgate.net/publication/388194334://>
25. Yaacob, W. N. W., Yaacob, L. H., Muhamad, R., & Zulkifli, M. M. (2021). Behind the Scenes of Parents Nurturing a Child with Autism: A Qualitative Study in Malaysia. *International Journal of Environmental Research and Public Health/International Journal of Environmental Research and Public Health*, 18(16), 8532. <https://doi.org/10.3390/ijerph18168532>
26. Yousafzai, A. K., Farrukh, Z., & Khan, K. (2011). A source of strength and empowerment? an exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. *Disability and Rehabilitation*, 33(12), 989–998. <https://doi.org/10.3109/09638288.2010.520811>

Article received 2025-02-10