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RESEARCH ARTICLE

Exploring The Lived Experiences of Parents Raising Children with Down Syndrome: A Qualitative Phenomenological Study

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Abstract: Raising a child with Down syndrome (DS) presents unique multidimensional challenges that profoundly impact parents' emotional, social, and financial well-being. While research exists in Western contexts, there is a scarcity of localized studies in India exploring these lived experiences in depth. This study aimed to explore and understand the lived experiences of parents raising children with Down syndrome in the Sangli-Miraj-Kupwad Corporation area of India. A qualitative phenomenological approach was adopted. Through non-probability purposive sampling, ten parents were recruited. Data were collected via in-depth, semi-structured interviews and analysed using Colaizzi's phenomenological method to identify significant themes and sub-themes. Thematic analysis revealed seven major themes: (1) Emotional Response and Adaptation (shock, denial, acceptance), (2) Communication Challenges (with child and professionals), (3) Financial Burdens and Constraints (therapy costs, employment loss), (4) Social Support and Societal Attitudes (stigma, isolation, mixed family support), (5) Psychological Well-being and Stress Management (anxiety, burnout, coping mechanisms), (6) Educational Barriers (admission denial, lack of inclusive facilities), and (7) Hopes and Future Aspirations (independence, social inclusion, security).Parents of children with DS navigate a complex journey marked by significant adversity but also demonstrate remarkable resilience. The findings underscore an urgent need for holistic, multi-sectoral support systems. Recommendations include implementing psychological counselling services, enhancing affordable and accessible healthcare/therapy, enforcing inclusive educational policies, and launching community awareness initiatives to reduce stigma and foster a supportive environment for these families.

Keywords: Lived Experiences, Down Syndrome, Parents, Qualitative Research, Phenomenology, India, Coping, Challenges, Support Systems.

INTRODUCTION

Down syndrome (DS), a genetic condition caused by trisomy 21, occurs in approximately 1 in 700 live births globally [1]. It is associated with intellectual disability, developmental delays, and distinctive physical features, necessitating lifelong support. While the child faces developmental challenges, the parents undertaking their care encounter a profound transformation in their lives, encompassing emotional turmoil, financial strain, social isolation, and systemic navigational challenges [2, 3].

Existing literature highlights a spectrum of parental experiences, from initial grief and chronic sorrow to post-traumatic growth and strengthened family bonds [4, 5]. However, these experiences are heavily influenced by cultural, socioeconomic, and support service contexts. In India, despite a significant population, there is a dearth of nuanced qualitative research capturing the lived realities of these parents, particularly in semi-urban settings like Sangli-Miraj-Kupwad. Societal stigma, inadequate access to specialized healthcare and inclusive education, and lack of financial safety nets compound parental stress [6, 7].

Understanding these lived experiences is crucial for nurses, policymakers, and community health workers to develop empathetic, effective, and culturally sensitive interventions. This study, therefore, sought to explore the in-depth lived experiences of parents raising children with DS in selected areas of Sangli-Miraj-Kupwad Corporation, India.

MATERIAL AND METHOD

Research Design: A qualitative research approach utilizing a phenomenological design was employed to gain a deep understanding of the essence of the parents' experiences.

Setting and Participants: The study was conducted in the Sangli-Miraj-Kupwad Corporation area. Participants were parents (primary caregivers) of a child diagnosed with DS for at least one year. Using purposive sampling, ten participants were recruited until data saturation was achieved.

Data Collection: After obtaining ethical clearance and informed consent, data were collected through audio-recorded, in-depth, semi-structured interviews between January 10th and 30th, 2025. The interview guide explored domains including emotional journey, communication, financial impact, social support, mental health, education, and future hopes.

Ethical Considerations: Ethical approval was granted by the Institutional Ethics Committee. Written informed consent was obtained, ensuring anonymity, confidentiality, and the right to withdraw. A protocol was in place to manage emotional distress during interviews.

Data Analysis: Interviews were transcribed verbatim and analysed using Colaizzi's seven-step method for phenomenological analysis [8]. This involved reading transcripts repeatedly, extracting significant statements, formulating meanings, clustering themes, developing an exhaustive description, and returning findings to participants for validation (member checking). Rigor was ensured through credibility, transferability, dependability, and confirmability.

RESULTS

Demographic Profile: The ten participants comprised mainly mothers (n=7) and fathers (n=3). The majority were aged 31-35 years (40%), held a graduate degree or above (50%), and were homemakers (40%). Most (60%) had received their child's diagnosis within the last 1-3 years.
Seven core themes emerged from the data analysis:

1. Emotional Response and Adaptation: Parents described a tumultuous journey beginning with *"shock," "fear,"* and *"disbelief"* upon diagnosis. This often evolved into a period of denial and self-blame before culminating in gradual acceptance and adaptation, fuelled by resilience and love for their child.

2. Communication Challenges: A significant source of stress was the dual challenge of their child's speech delays and difficult interactions with healthcare professionals who often provided inadequate guidance. *"Speech therapy is crucial, but it is very expensive"* (Participant 6).

3. Financial Burdens and Constraints: The high, ongoing costs of therapies, medical care, and special education were universally reported. This often led to job loss or reduced working hours, creating severe financial dependency and strain. *"I had to leave my job because there was no option to look after my child"* (Participant 3).

4. Social Support and Societal Attitudes: Experiences were polarized. While some received strong family support, others faced blame and stigma. Societal ignorance and negative perceptions led to social withdrawal and isolation. *"People still look at my child as if he is different"* (Participant 9).

5. Psychological Well-being and Stress Management: Parents reported chronic stress, anxiety, sleep disturbances, and emotional burnout. Coping mechanisms included relying on faith, seeking support from close family, and developing personal resilience, though many struggled immensely. *"There are times I am so stressed... but there is no alternative but to manage"* (Participant 5).

6. Educational Barriers: A paramount concern was the struggle to secure appropriate education. Mainstream schools often denied admission, while special schools were deemed expensive and/or inadequately equipped. *"I tried very hard to get admission in a normal school, but the teachers said they cannot manage"* (Participant 5).

7.Hopes and Future Aspirations: Despite the hardships, parents harboured strong hopes for their child's future independence, social acceptance, and happiness. A profound fear and uncertainty about the child's long-term security and care after the parents' lifetime was a pervasive underlying worry.

DISCUSSION

This study provides a rich, contextualized understanding of the challenges and resilience of parents of children with DS in Western India. The findings align with global literature on parental emotional adjustment [5, 9] and financial strain [10] but highlight acute disparities in resource access and pronounced societal stigma within this specific cultural context.
The intense emotional trajectory from shock to acceptance underscores the critical need for empathetic, continuous counselling from the point of diagnosis, a role where community health nurses can be pivotal. The financial hardships and employment sacrifices echo findings by Genereux et al. [10], emphasizing the need for governmental financial aid and supportive workplace policies for caregivers.
The pervasive communication barriers with professionals and the educational system point to a significant gap in provider training and institutional inclusivity. Nurses and doctors require better training in communication and counselling skills. Furthermore, the findings strongly advocate for the rigorous implementation of inclusive education policies in India.
The resilience and hope parents maintain, despite adversity, is a powerful testament to their strength. This hope can be harnessed by support groups and community networks, which were identified as a buffer but were largely absent or inaccessible for most participants.

CONCLUSION

The journey of parenting a child with DS is one of immense challenge and profound love. This study concludes that parents require a robust ecosystem of support encompassing:

- **Emotional & Psychological:** Integrated mental health support and counselling services.
- **Financial:** Government schemes and policies to alleviate therapy and care costs.
- **Social:** Community awareness programs to reduce stigma and promote inclusion.
- **Educational:** Mandatory inclusive education and teacher training.
- **Systemic:** Improved healthcare communication and access to early intervention.

Nurses are at the forefront of this support system. The implications for nursing are vast:

- **Practice:** Nurses must act as counsellors, coordinators, and patient advocates.
- **Education:** Nursing curricula must include robust training on developmental disabilities and family-cantered care.
- **Administration:** Nurse leaders must advocate for and help establish parent support groups and specialized clinics.
- **Research:** Further research is needed to develop and test nurse-led intervention models for these families.

By addressing these multi-faceted needs, healthcare professionals and policymakers can significantly enhance the quality of life for both children with Down syndrome and their families.

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