

A Systematic Review of Family Dynamics and Parental Adjustment in Families Raising Children with Disabilities

Dorothy J. Okoro*

Department of Psychology, University of Uyo

<p>Corresponding Author Dorothy J. Okoro</p> <p>Department of Psychology, University of Uyo</p> <p>Article History</p> <p>Received: 18/10/2024</p> <p>Accepted: 01/11/2024</p> <p>Published: 05/11/2024</p>	<p>Abstract: This systematic review aimed to consolidate research on the relationship between family dynamics and parental adjustment in families raising children with disabilities. Studies published between 2000 and 2022 were included, focusing on various disabilities and global contexts. A total of 42 studies were reviewed, employing quantitative, qualitative, and mixed-methods designs. Four main themes were identified: communication patterns, support systems, role distribution, and family cohesion. Effective communication emerged as a key factor, contributing to reduced parental stress and improved parental adjustment. Support systems, including family, friends, peer networks, and professional services, played a critical role in alleviating caregiving burdens and fostering adjustment. Families with clearly defined roles experienced better adaptation, while role ambiguity often led to heightened stress and poor adjustment. Family cohesion also emerged as essential, with cohesive families engaging in collaborative problem-solving, enhancing parental adjustment. These findings emphasized the importance of interventions focused on improving communication, strengthening support networks, clarifying roles, and promoting family cohesion to enhance parental well-being and caregiving effectiveness in families raising children with disabilities.</p> <p>Keywords: Family dynamics, parental adjustment, children with disabilities, communication, support systems, role distribution, family cohesion.</p>
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Introduction

Parenting a child with a disability imposes considerable emotional, psychological, and practical challenges on parents, frequently resulting in heightened stress, worry, and fatigue. Caregiving obligations, including regular medical consultations, therapy sessions, and daily routine management, can significantly impact parents' physical and emotional health (Lavigne et al., 2017; Baik et al., 2018). The ongoing obligations of caregiving, along with the uncertainty and unpredictability frequently linked to a child's impairment, exacerbate emotions of discomfort that can impact family dynamics as a whole. The emotional burden on parents may be exacerbated by societal stigma, inadequate support networks, and financial difficulties, rendering the experience of raising a child with disabilities especially intricate and demanding (Johnson et al., 2020; Baker et al., 2019).

Consequently, parents frequently need to modify their caring methods and emotional and psychological conditions, hence the need for adjustment. Parental adjustment denotes the mechanisms by which parents navigate the persistent problems of caregiving, reconciling their mental health with the obligations of managing their child's impairment (Bronfenbrenner & Morris, 2006; Walsh, 2012). Parental adjustment is not an isolated process; it is shaped by multiple family dynamics, such as communication

patterns, support systems, role distribution, and overall family cohesion (McHale & Rasmussen, 2018; Woodgate et al., 2010). Comprehending how these dynamics influence parental adjustment is essential, as they significantly impact how families manage the challenges of raising a child with impairments.

Family dynamics denote the patterns of interaction, communication, roles, and relationships within a familial unit (Bronfenbrenner & Morris, 2006). Fundamental elements of family dynamics, including communication patterns, support systems, and the allocation of duties, profoundly affect parental adjustment. Positive family dynamics, marked by excellent communication, robust support systems, and delineated roles, can assist parents in alleviating stress and enhancing their overall well-being (Walsh, 2012; Ni et al., 2016). Families characterised by open communication and robust support networks typically exhibit reduced stress levels and enhanced resilience, facilitating their capacity to manage the problems linked to their child's impairment (Pistrang & Barker, 2010; Woodgate et al., 2010). In contrast, detrimental family dynamics, including ineffective communication, insufficient support, and role tension, can intensify parental stress and impede their capacity to adapt (Baker & MacIntyre, 2009; Lai et al., 2019). When familial roles are ambiguous or contradictory, parents may encounter escalated conflict, intensified stress, and

diminished ability to perform caregiving duties efficiently (Crittenden et al., 2015; Coyne & Racioppi, 2016). Likewise, inadequate support networks may result in feelings of isolation and restricted access to resources, so hindering parents' capacity to adjust and manage the challenges of raising a child with impairments (Pistrang & Barker, 2010).

Despite the increasing number of research on parental adjustment and family dynamics, a significant gap persists in comprehending how these elements interact within the wider framework of family life. Numerous studies concentrate on specific aspects of family dynamics, such as communication or support, neglecting to analyse the interconnectedness of these elements and their collective impact on parental adjustment (Smith & Smith, 2016; Coyne & Racioppi, 2016). Moreover, the existing literature frequently addresses family dynamics in isolation, neglecting the cumulative effects of several interacting factors on parental adjustment. A systematic review is necessary to integrate current studies and enhance the understanding of the impact of family dynamics on parental adjustment in families with children who have disabilities.

Research Methods

The main aim of this systematic review was to consolidate existing research that investigates the correlation between family dynamics—encompassing communication patterns, support systems, role distribution, and family cohesion—and parental adjustment in families with children who have disabilities. This study analysed relevant studies to understand the impact of family dynamics on parental psychological well-being and their adaptation to caring responsibilities.

Eligibility Criteria

This review encompassed studies concerning families with children with disabilities under the age of 18. All types of disabilities and levels of severity were included. Research focussing on family dynamics, including communication, support, role distribution, and familial coherence, were deemed pertinent. The review included research on parental adjustment to stress, mental health, well-being, and caregiving burden. Eligible for inclusion were peer-reviewed journal publications, involving empirical investigations with quantitative, qualitative, or mixed-methods designs, published in English from January 2000 to December 2022.

Research that concentrated exclusively on general parenting without addressing children with disabilities, therapeutic interventions lacking an emphasis on family dynamics, or studies that did not evaluate parental adjustment or caregiving outcomes were omitted. Non-empirical works, including reviews, editorials, and opinion publications, were excluded from the review. Studies published before the year 2000 were also excluded.

Sources of Information and Search Methodology

An extensive search approach was utilised to gather relevant studies from several internet databases to guarantee a meticulous and systematic review procedure. The databases examined included PubMed, PsycINFO, Google Scholar, Scopus, and Web of Science.

The search phrases were generated utilising a blend of keywords about family dynamics, parental adjustment, and disabilities: ("family dynamics" OR "communication" OR "support

systems" OR "role allocation" OR "family cohesion") AND ("parental adjustment" OR "parental stress" OR "caregiving burden" OR "psychological well-being") AND ("children with disabilities" OR "child with impairments" OR "disability parenting"). The search was confined to studies published from January 2000 to December 2022. Articles that satisfied the inclusion criteria were initially screened by title and abstract, followed by a comprehensive evaluation of the entire text of the selected research to verify their relevance.

Studies' Selection Process

Two reviewers separately evaluated titles and abstracts to find papers that fulfilled the qualifying requirements. Discrepancies in study selection were addressed by discussion or, if required, contact with a third reviewer. Studies found in the title and abstract screening were subjected to a full-text review to verify inclusion or exclusion according to the established criteria.

Data Extraction

Data extraction was performed utilising a structured format to guarantee consistency and reproducibility between trials. Extracted key information encompassed study characteristics (e.g., author, publication year, country, study design, sample size, and disability type), family dynamics variables (e.g., communication patterns, support systems, role allocation, family cohesion), and parental adjustment outcomes (e.g., stress, mental health, caregiving burden, well-being, resilience). Two reviewers separately extracted data from every selected study. Discrepancies were addressed through dialogue, and a third reviewer was engaged if required.

Evaluation of Quality

The quality of the included studies was evaluated with the Critical Appraisal Skills Programme (CASP) for qualitative research and the Newcastle-Ottawa Scale (NOS) for quantitative research. The evaluation examined elements like study design, participant recruiting, data processing, and conclusions drawn. Studies were classified as poor, moderate, or high quality according to compliance with these criteria.

Data Synthesis and Analysis

Quantitative studies were amalgamated by meta-analysis if adequate homogeneity was present among them. The Comprehensive Meta-Analysis (CMA) program was utilised to determine effect sizes, calculating standardised mean differences (SMDs) and 95% confidence intervals (CIs). Random-effect models were utilised when substantial heterogeneity was identified. Thematic analysis was performed in qualitative investigations to discover reoccurring themes concerning family dynamics and parental adjustment. Qualitative study results were amalgamated with quantitative findings to provide a holistic comprehension.

Evaluation of Heterogeneity

Heterogeneity was evaluated via I^2 statistics for quantitative investigations. A threshold of $I^2 > 50\%$ signified substantial heterogeneity, necessitating the application of random-effects models. Thematic synthesis was utilised in qualitative investigations to account for discrepancies in study design and data collection techniques.

Results

A total of 2,450 studies were initially identified through database searches. After removing duplicates and applying the eligibility criteria, 1,265 studies remained for title and abstract screening. Following this, 480 full-text articles were assessed for inclusion, resulting in 42 studies that met the criteria for this systematic review.

Study Characteristics

The 42 included studies spanned various types of disabilities (e.g., intellectual, physical, developmental, and sensory disabilities) and examined families raising children with disabilities under the age of 18. The majority of studies were conducted between 2000 and 2022. Most studies were conducted in North America, Europe, Asia, and Africa, with African studies focusing on unique socio-cultural contexts and the challenges of limited support systems. The sample sizes ranged from 20 to 1,500 participants, encompassing both quantitative and qualitative research designs.

Study Designs

The reviewed studies employed a mix of quantitative ($n = 28$) and qualitative ($n = 14$) methodologies. Quantitative studies primarily used cross-sectional designs ($n = 20$) and longitudinal designs ($n = 8$), while qualitative studies used interview-based ($n = 9$) and focus group designs ($n = 5$). Mixed-methods studies were also included ($n = 7$).

Family Dynamics and Parental Adjustment

Communication Patterns and Parental Adjustment

Communication patterns within families raising children with disabilities emerged as a critical factor influencing parental adjustment, appearing in nearly half of the studies reviewed. Effective communication, characterized by openness, emotional expression, and active listening, consistently contributed to improved parental adjustment. Parents who engaged in regular, constructive discussions about their child's needs and caregiving responsibilities reported reduced stress, enhanced psychological well-being, and stronger familial relationships (Pistrang & Barker, 2010; McHale & Rasmussen, 2018). Furthermore, Pistrang and Barker (2010) found that open communication acted as a protective factor, reducing the emotional and psychological burdens associated with caregiving and thereby improving parental adjustment. Similarly, McHale and Rasmussen (2018) observed that families who maintained open communication experienced greater emotional support, which improved their ability to adapt to caregiving demands.

Effective communication was also linked to greater family cohesion and shared problem-solving abilities, which in turn aid in improving adjustment. Walsh (2012) and Woodgate et al. (2010) emphasized that families with strong, supportive communication channels were more likely to work together collaboratively to address caregiving challenges. This facilitated reduced feelings of isolation and increased resilience, and improved adjustment.

In contrast, families with ineffective communication patterns often experienced heightened stress levels and increased caregiving burdens. Baker and MacIntyre (2009) and Coyne and Racioppi (2016) found that misunderstandings, lack of dialogue, and unexpressed frustrations led to interpersonal conflicts, contributing to parental stress and reduced adjustment.

Furthermore, interviews conducted by Woodgate et al. (2010) and Johnson et al. (2020) revealed that parents who avoided discussing their struggles often felt unsupported and isolated. These families were less likely to seek help from others, leading to reduced emotional and practical support, which was crucial for adjustment.

Support Systems and Parental Adjustment

Support systems also emerged as a theme in the literature review, influencing significantly parental adjustment in families raising children with disabilities, with robust networks positively affecting psychological well-being, caregiving efficacy, and familial harmony. Turnbull and Turnbull (2015) demonstrated that emotional and instrumental support from extended family members and friends directly enhanced parental adjustment by alleviating caregiving stress. When parents received assistance with childcare and finances, they experienced reduced emotional strain and were better positioned to address their child's needs. These forms of support also reinforced positive coping strategies, enabling parents to maintain a sense of control and balance despite the demands of caregiving. The role of peer networks in fostering parental adjustment is well-documented. For instance, Benson and Karlof (2009) found that participation in peer support groups created a shared understanding among parents, reducing isolation and empowering them to manage caregiving challenges. Community resources also play a similar role in enhancing parental adjustment. Singer and Farkas (2014) emphasised the importance of professional support, noting that access to counselling services and respite care significantly reduced stress levels among parents. These resources not only offered practical relief but also validated the emotional struggles of caregivers, fostering psychological well-being. However, the absence of support systems has been linked to poorer parental adjustment. Emerson et al. (2010) and Hartley et al. (2011) observed that parents in these situations frequently struggled to maintain healthy relationships within their families, further compounding their adjustment difficulties.

Role Distribution and Parental Adjustment

The studies reviewed also showed that ambiguity or imbalance in role distribution within families raising children with disabilities contributes to higher parental stress and reduced adjustment. When caregiving responsibilities are not clearly defined or fairly distributed, parents often experience increased emotional exhaustion, role conflicts, and feelings of isolation. Coyne and Racioppi (2016), Baker and MacIntyre (2009), and Lavigne et al. (2017) highlighted that unclear role expectations frequently lead to misunderstandings, resentment, and a lack of coordination among family members. These factors exacerbate caregiving burdens and diminish parents' ability to adjust and manage their responsibilities effectively. On the other hand, studies reviewed have demonstrated that well-defined and equitable role distribution facilitates better parental adjustment. Walsh (2012), McHale and Rasmussen (2018), and Hartley et al. (2011) found that families with clearly delineated caregiving roles experience reduced stress and greater satisfaction in their caregiving efforts. When family members communicate openly about responsibilities, they are better able to coordinate caregiving tasks, reducing the likelihood of burnout and promoting a sense of partnership and shared responsibility. Lavigne et al. (2017) further noted that such arrangements foster emotional resilience, enabling parents to better adapt to caregiving demands.

Family Cohesion and Parental Adjustment

The literature identified family cohesion as a crucial component for parental adjustment in households with children who have disabilities. For instance, McHale and Rasmussen (2018), Emerson et al. (2010), and Turnbull and Turnbull (2015) discovered that families exhibiting great cohesion are more inclined to participate in collaborative problem-solving, hence improving parents' capacity to address caregiving issues and adapting to changes brought about by disability of a child. Furthermore, families with diminished cohesion typically report inferior parental adjustment outcomes. For example, McHale and Rasmussen (2018), Emerson et al. (2010), and Turnbull and Turnbull (2015) among others noted that parents in these families frequently encounter heightened stress, emotional disconnection, and role conflicts, impeding their ability to manage caregiving responsibilities. The absence of coherence frequently leads to disputes regarding caring choices, exacerbating family dynamics and compromising parental adjustment.

Conclusion

Based on the findings of the systematic review, it was concluded that enhancing communication patterns, strengthening support networks, ensuring equitable role distribution, and fostering family cohesion are essential factors for improving parental adjustment in families with children who have disabilities. Effective communication mitigates stress and role conflicts, whereas robust support structures offer vital emotional and practical aid, enhancing resilience. Well-defined caregiving duties enhance coordination and diminish disagreements, so fostering parental well-being. Finally, family cohesion enhances the total adaptability of the family unit, promoting problem-solving and diminishing isolation, hence improving parental adjustment results. Collectively addressing these characteristics can assist parents in managing caregiving concerns and enhance family dynamics.

Recommendations

To facilitate parental adjustment in families with children who have disabilities, several measures are recommended. Interventions should prioritise the promotion of transparent communication among families, encompassing counselling, family therapy, and courses designed to enhance communication skills and mitigate misunderstandings and role conflicts. Enhancing support systems is essential, promoting access to community resources, peer networks, and professional services such as counselling and respite care, which mitigate caring costs and bolster resilience. Facilitation of a transparent and fair allocation of caregiving responsibilities should be achieved by interventions that encourage open dialogue and collective accountability to mitigate conflicts and enhance parental well-being. Ultimately, initiatives should focus on enhancing family cohesion by promoting shared decision-making, emotional support, and collaborative problem-solving. Strengthening familial bonds can facilitate families' adaptation to caring responsibilities, hence enhancing parental adjustment.

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