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Family Medicine Strategies in Enhancing Paternal and Sibling Participation in the Rehabilitation of Children with Neurodevelopmental Disorders: Review

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Abstract

Background: Neurodevelopmental disorders (NDD) in children, including conditions such as autism spectrum disorder and cerebral palsy, represent a significant global health challenge, particularly in low- and middle-income countries (LMICs). The family unit is crucial in managing the healthcare needs of affected children, yet the engagement levels of fathers and siblings remain inadequately documented.

Methods: This scoping review employed the Joanna Briggs Institute's 9-step process to systematically assess existing literature regarding the involvement of fathers and siblings in home rehabilitation programs for children with NDD. A comprehensive search was conducted across multiple databases to identify relevant peer-reviewed articles and grey literature, focusing on the extent of familial participation and the barriers and facilitators influencing engagement.

Results: The review revealed a notable disparity in the involvement of fathers compared to mothers, with participation rates ranging from 12% to 91% across various studies. While paternal engagement positively impacted maternal stress levels and child developmental outcomes, the involvement of siblings was less quantitatively documented, despite anecdotal evidence suggesting their supportive roles. Key enablers for participation included familial harmony and stigma reduction, while barriers were predominantly cultural beliefs, economic constraints, and limited educational attainment among fathers.

Conclusion: The findings highlight a crucial gap in the literature regarding father and sibling participation in the rehabilitation of children with NDD, emphasizing the need for targeted interventions to enhance familial support systems. Addressing the identified barriers and promoting inclusive practices could significantly improve outcomes for children and alleviate caregiver stress.

Keywords: Neurodevelopmental disorders, Family involvement, Rehabilitation, Low-income countries, Paternal engagement

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1. Introduction

Neuro-developmental delay (NDD) refers to the delayed or unmet attainment of predicted developmental milestones in one or more of the five domains: motor, cognition, communication, adaptive abilities, and social-emotional, relative to the normative developmental benchmarks for a child's age group [1-4]. NDD entails a compromised development of the central nervous system, impacting several domains of a child's functioning, including language, behavior, sleep, physical capabilities, and mental health. Conditions related with neurodevelopmental disorders (NDD) include autism spectrum disorder, intellectual disabilities, and cerebral palsy [5]. Developmental disorders in children represent a significant worldwide illness burden, constituting 34% of the total burden in 2019 [6,7]. Approximately 95% of children with impairments reside

in low- and middle-income countries (LMICs), with the Sub-Saharan Africa (SSA) area being disproportionately impacted. For instance, SSA constitutes 73% of all global developmental delay cases [8]. The predominant cause of neurodevelopmental disorders, particularly frequent in low-income environments, is cerebral palsy [9].

The family serves as a crucial core for addressing and supporting the healthcare requirements of children diagnosed with neurodevelopmental disorders (NDD) [10,11]. For some parents, actively participating in the rehabilitation of a child with neurodevelopmental disorders (NDD) may be uplifting, while others may see it as a burden or stressful. However, without sufficient assistance for family members, particularly mothers, their health and welfare are jeopardized [12]. The significance of fathers is crucial, as research indicates a robust correlation between their involvement and child behavior and developmental outcomes [13, 14]. The prevalence of developmental delay was found to be elevated in a subset of dads who were uninvolved in their child's caregiving, with rates of 59%, 50%, 47%, and 27% for cognitive, language, social-emotional, and motor abilities, respectively [15]. Notably, the involvement of male caregivers correlated with enhanced academic achievement, as well as social and cognitive development in children [16, 17]. Fathers and siblings need to play a crucial position in assisting and supporting moms of children with neurodevelopmental disorders by practical aid and emotional support, including empathy, emotional reassurance, and enhancement of self-esteem [18]. Significant prior research indicates that heightened paternal involvement in the upbringing of children with neurodevelopmental disorders correlates with a reduction in maternal parenting stress [19, 20].

Regrettably, there exists a deficiency in the collective familial contribution to home-based healthcare, with fathers and siblings demonstrating significantly less involvement and participation than mothers or maternal guardians in early childhood development (ECD) [2, 9, 21-24]. Research by Dambi et al. [25] shown that women in low-income nations experienced considerable stress, physical strain, and pain while solely responsible for child caring tasks. The presence of a "partner or father figure" is crucial for women who bear the obligation of caring for their children afflicted with a chronic neurodevelopmental disorder.

Kauchali and Davidson [26], Bakare et al. [27], and Dambi et al. [25] emphasized the need of emphasizing public health interventions and research aimed at the rehabilitation of children with neurodevelopmental disorders at the familial and home-based level. The little focus on this area may suggest underlying issues or obstacles impeding the active participation of dads and siblings in the rehabilitation of children diagnosed with NDD. Towers [28] and Ogourtsova et al. [29] also documented that dad of children with neurodevelopmental disorders (NDD) reported being marginalized and excluded by healthcare professionals (HCPs) during treatment sessions [28, 29]. The persistence of this scenario remains ambiguous; however, it constitutes a research gap that warrants investigation, since current studies mostly emphasize women as the major caregivers in domestic environments, in contrast to their male counterparts [30]. This occurs despite the changing dynamics of gender roles inside families, where an increasing number of women are pursuing external economic possibilities, and more dads are assuming the role of stay-at-home parents.

Fjermestad et al. [5] suggest that in low- to middle-income nations, siblings may assume more informal caregiving responsibilities, perhaps resulting in heightened stress levels. This may become an obstacle to their involvement in caring for their siblings diagnosed with neurodevelopmental disorders [31,32]. Clinical facilities and healthcare experts are more accessible, and community support systems are better organized to address the needs of siblings of children with neurodevelopmental disorders (NDD) [33]. Regrettably, in low-income nations, clinical facilities and healthcare professionals are either inaccessible or too costly for the majority of families [27, 34]. In low-income nations with under-resourced public health facilities, families of children diagnosed with neurodevelopmental disorders would undoubtedly encounter substantial obstacles in their lifetime rehabilitation.

The objectives of the scoping review are to assess the extent of involvement of fathers and siblings in the rehabilitation of children with neurodevelopmental delays (NDD) and to identify the facilitators and barriers influencing their participation in this process.

2. Methods

This scoping study used the Joanna Briggs Institute (JBI) 9-step process as delineated by Peters et al., providing a thorough and methodical framework for executing scoping reviews [35]. This strategy was used to guarantee a comprehensive identification, mapping, and analysis of the current literature about the involvement of dads and siblings in home rehabilitation programs for children with neurodevelopmental disorders (NDD). The need for doing a scoping study was reinforced by the necessity to swiftly delineate important ideas, ascertain primary sources, and investigate the breadth and characteristics of research on this inadequately examined subject, especially in low- and middle-income nations. This methodology corresponds with the aims of assessing the scope, synthesizing results, and pinpointing deficiencies in the literature, as delineated by Arksey and O'Malley [36].

3. Extent of involvement of parents and siblings in the rehabilitation of children with neurodevelopmental delays

Participation levels were classified as paternal involvement and sibling involvement. Six research documented paternal involvement, with three of these studies quantifying this involvement in percentages [37-41]. Song et al. [20] indicated that the engagement percentage of dads in South Korea (HIC) was 70% (n = 82), correlating with reduced stress levels in mothers; father involvement exceeded 50% in three areas and fell below 50% in the other eleven items [20]. The minimum participation rate was 12% in male-exclusive support groups [42]. da Cruz et al. [43] found a higher involvement rate of dads in Brazil (MIC) at 91% (n = 23) [43]. Conversely, Olawale et al. [44] indicated from Ghana (LIC) that about 50% of parents (n = 52), including 32.7% dads, favored alternative forms of care for their children over medical rehabilitation methods [44]. Five research revealed the adverse consequences of caring for parents. Three studies have shown that the absence of paternal involvement in the caring of children with neurological diseases correlates with elevated stress levels in mothers and decreased developmental outcomes in children with neurodevelopmental disorders. Vadivelan et al. [45], qualitative research conducted in India (a MIC nation), especially identifies significant interpersonal stresses as the absence of support and assistance from the spouses and siblings of children with disabilities [45]. Ten female caregivers engaged in semi-structured in-depth interviews. Two studies [46, 47] documented the involvement of siblings in qualitative descriptions; however, none defined their degree of engagement in particular percentages.

Eight papers found in the scoping study explicitly highlighted enablers for paternal engagement. Nonetheless, no research identified obstacles to sibling involvement in caregiving or the implementation of home rehabilitation programs, whereas one study highlighted factors that facilitate sibling engagement.

4. Discussion

This study aimed to examine the participation of dads and siblings in the home rehabilitation programs for children with neurodevelopmental disorders (NDD). This scoping review's principal results indicated a significantly lower degree of engagement by dads compared to mothers of children with neurodevelopmental disorders (NDD) [48-53]. Six studies investigated paternal involvement, with three measuring it in percentage terms. Song et al. [20] reported a 70% engagement rate among dads in South Korea (HIC), correlated with reduced mother stress [20]. This supported Laxman et al. [54], who found that paternal involvement in the caregiving of children with neurodevelopmental disorders correlates with reduced maternal stress levels [54]. Participation levels fluctuated across activities, surpassing 50% in some instances while plummeting to 12% in male-exclusive support groups [42]. In contrast, da Cruz et al. documented a father involvement rate of 91% in Brazil (MIC) [43]. Nevertheless, siblings were noted to be enthusiastic and supportive playmates for children with developmental difficulties [51], but their involvement was not measured in percentages. The scoping review also validated that in low-income countries, families with children diagnosed with neurodevelopmental disorders encounter stigma,

superstitions, and social ostracism within deeply religious communities that uphold strong cultural beliefs, which serve as contextual barriers to paternal involvement in the care of these children in certain African contexts [51, 55]. This research provide valuable insights on the involvement of dads compared to mothers in the caring of children diagnosed with neurodevelopmental disorders (NDD) and the potential engagement of siblings, as well as the variables influencing this participation.

The involvement of dads and siblings is hardly documented. The quantified engagement percentages of dads vary between 45.5% and 91%, demonstrating discrepancies across different settings. A study incorporated in the scoping review by Vadivelan et al. (2020) corroborated the antiquated behavior of fathers from previous decades, characterized by minimal interest, the use of physically punitive disciplinary methods, and diminished involvement in assisting their partners with caregiving for their child with neurodevelopmental disorders (NDD) [45]. Abusive and drunken husbands were unsupportive and a cause of stress for moms owing to dads' lack of involvement.

This contrasts with the 70-point score given by Song et al. [20], which evaluated dads' involvement in parenting activities. In their research, a score of 70 on the parental participation scale showed that, on average, dads exhibited a degree of involvement that was above moderate but not at the maximum level of engagement. The measure, spanning from 0 to 100, quantified the degree of dads' engagement in everyday parenting activities, with increased scores indicating more involvement [20]. This research investigated moms of impaired kindergarteners in Gwangju, South Korea, a high-income nation, by distributing 100 questionnaires randomly, of which 82 were totally completed and included in the analysis. Fathers' involvement in parenting was evaluated using a modified questionnaire including 30 Likert-scale items. The assessment of parenting stress in moms was conducted using 35 questions. Results demonstrated that dads' substantial involvement in parenting is associated with reduced mother stress levels. The research emphasizes the possible effect of paternal engagement in alleviating mother stress in households with handicapped children. Bagner observed that single moms were more likely to discontinue rehabilitation programs compared to two-parent households [53]. This highlights the father's position within a household that has a kid with neurodevelopmental disorders. In high-income nations, a minimum of seven studies from the USA (n = 4), Canada (n = 1), and Australia (n = 2) indicated that dads exhibited increased involvement in caring and support for their partners. Research conducted in Brazil revealed that, among middle-income nations, 65% of dads participated in holding newborns on their laps and assisting with mobility, while 74% engaged in play with their children [43]. Joint engagement of mothers and fathers was recorded at 45.5% in the multicounty survey [56]. This signifies a considerable disparity in paternal involvement across different countries, suggesting that father engagement in childcare cannot be generalized.

Two studies [46, 47] documented the involvement of siblings in qualitative descriptions; however, none defined their degree of engagement in particular percentages. Both studies advocated for the involvement of siblings in the caregiving of children with neurological conditions, as increased sibling warmth and reduced sibling conflict serve as protective factors for children with Down syndrome, a cause of neurodevelopmental disorders; additionally, siblings can serve as role models for those diagnosed with cerebral palsy and can contribute to their intervention programs. Although prior research have not assessed sibling engagement, it is crucial to acknowledge their possible significance in the caregiving process for children with cerebral palsy [57]. Dambi et al., [25] recognize the existence of 3 (6.5%) caregivers who were siblings of children with cerebral palsy [25]. This discovery highlights the importance of siblings in offering care and support to their impacted brothers or sisters. The inclusion of sibling caregivers underscores the complex patterns of caring among families impacted by neurodevelopmental disorders, despite the absence of quantification. Comprehending the degree of sibling engagement in caregiving is essential for thoroughly evaluating the family support system and recognizing possible facilitators and obstacles to their involvement. Consequently, further research should focus on quantifying and examining the distinct roles and contributions of siblings in the rehabilitation process, with the goal of finding facilitators and obstacles to sibling involvement in the care of children with neurodevelopmental disorders in particular circumstances.

5. Factors that promote and hinder the involvement of dads and siblings in the rehabilitation of children with neurodevelopmental delays

Two papers highlighted in our scoping analysis made significant references to facilitators for paternal engagement [29, 48], while one addressed facilitator for sibling participation [46], indicating areas for additional investigation. A study highlighted the significance of sibling involvement in the care of children with neurodevelopmental disorders (NDD), as it enhances motor skill development and promotes engagement during play. The inclusion of siblings in the care of children with NDD is strongly advocated [58]. Turbiville and Marquis is an early research that identified family activities and group planning as essential enablers of paternal involvement [42]. Fisman et al. highlighted that familial harmony, characterized by increased sibling friendliness and less sibling conflict, serves as a crucial facilitator for their engagement [46]. The child's condition may enhance paternal involvement, as dads of children with Congenital Zika Syndrome (CZS) engage more effectively than fathers of children with comparable disorders, such as Cerebral Palsy. This indicates that CZS is less stigmatized in comparison to other illnesses such as CP. Consequently, reducing stigma enhances fathers' involvement in home rehabilitation programs for impacted children [48].

Home-based treatment for children with neurodevelopmental disorders poses considerable obstacles in low-income nations. Factors include insufficient family support, restricted finances, inadequate understanding, and unfavorable attitudes adversely affect participation and adherence to home-based treatment [50]. Research from Africa and middle-income nations (Brazil, India) has shown the detrimental impact of poverty on families pursuing rehabilitation programs for children with neurodevelopmental disorders (NDD) [44, 48]. Financial difficulties, as described by health care providers in Uganda, impede access to sufficient manpower and resources. Conversely, dads in Brazil have been shown to actively participate in childcare, exhibiting the greatest levels of involvement in providing practical and resource assistance to their offspring [48]. Correspondingly, research from China indicates that dads exhibit resilience among financial difficulties, with up to 88.5% of participants refusing to cease employment for the sake of their children [52].

Other environmental impediments, including culture, superstition, and religious views, significantly impacted involvement for families in Africa compared to other continents. Research conducted by Kyerematen et al. indicated that in Ghana, children with neurodevelopmental disorders (NDD) with a medical diagnosis of hydrocephalus are referred to as 'nsuoba', translating to 'water children' [51]. Furthermore, research from Africa indicates the prevalence of superstitions and social stigma encountered by families with children diagnosed with neurodevelopmental disorders, which affects their access to rehabilitation programs [51, 55]. Olawale et al. [42] emphasize that in African civilization, illnesses like cerebral palsy are often linked to witchcraft and sorcery. Many families see it as a divine retribution for a transgression committed by a family member, often the mother. These results highlight the need of addressing socioeconomic circumstances and cultural attitudes to improve the involvement of fathers and siblings in the rehabilitation of children with neurodevelopmental disorders in low-income nations, particularly in African settings. Tsomondo [55] emphasizes the need of disability awareness programs to alleviate the stigma linked to disability in low-income settings [55].

Additional obstacles to involvement highlighted by the scoping study were the father's limited educational attainment and lack of interest in acquiring understanding about his child's neurodevelopmental disorder [42, 49]. These align with other study findings on paternal involvement in early childhood development programs. Fathers with inadequate education may struggle to understand and manage the complexity of their child's illness, thereby hindering their active participation in rehabilitation programs. Furthermore, dads who exhibited disinterest or ignorance about their child's health were likely to have restricted involvement. These results underscore the need for focused treatments designed to educate and engage dads in the rehabilitation process, therefore enhancing outcomes for children with neurodevelopmental disorders. Future research and clinical practice must emphasize overcoming these obstacles to enhance father and sibling engagement and support in the treatment and rehabilitation of children with neurodevelopmental disorders (NDD).

6. Consequences for future research and clinical application

The lack of quantitative data about the participation of fathers and siblings in rehabilitation programs for children with neurodevelopmental disorders, especially in low-income countries, underscores the need for more quantitative research in these settings. Our evaluation revealed considerable obstacles and enablers to paternal engagement, although there is a scarcity of studies about sibling involvement. Additional research concentrating on siblings is necessary to improve our comprehension of their function in rehabilitation programs. The noted differences in father and sibling involvement, along with the obstacles and enablers to their engagement, may arise from economic and cultural variances across various nations. Future study needs to investigate regional contextual variations to identify certain obstacles and facilitators that may be more prominent in distinct places. Through the analysis of these data, we might suggest specific treatments, policy modifications, or program improvements that tackle identified difficulties and foster more effective family involvement in the recovery process. We advocate for an innovative strategy by rehabilitation specialists that actively involve dads and siblings in home rehabilitation programs. This method may alleviate stress and physical strain on moms while enhancing developmental results for children with neurodevelopmental disorders.

7. Advantages and drawbacks

This study used research from peer-reviewed publications across several internet databases and grey literature. Although it produced few publications, the grey literature enhanced our results by offering distinctive and context-specific insights absent from the peer-reviewed sources. The scoping review included qualitative, quantitative, and mixed-method research from both high- and low-income nations across six continents. The authors possess expertise in pediatric rehabilitation for neurodevelopmental delay deficits across a lower-middle-income nation (PM and JM), an upper-middle-income country (SM), and a high-income country (LC). This may have improved the writers' comprehension of the objective of this scoping review. An adept librarian assisted the writers, facilitating a comprehensive literature search across several electronic databases. Although our study on the inclusion of global literature is robust, this scoping review was constrained to publicly accessible articles solely in English due to limited financial resources for translating studies published in other languages, potentially resulting in the omission of pertinent articles in other languages; furthermore, the quality of the included studies was not evaluated in accordance with scoping review protocols, in contrast to systematic reviews where article quality is assessed [39]. Nevertheless, the authors endeavored to provide the included research designs and sample sizes to provide the reader with a basic understanding of the studies' rigor.

8. Summary

This review identified a lack of research on the involvement of dads and siblings in home rehabilitation programs for children with neurodevelopmental disorders (NDD). It underscored the gap in parenting responsibilities across genders, with dads exhibiting lesser involvement than women. Economic difficulties in low-income nations and cultural beliefs intensify stigma and social marginalization of families with children with neurodevelopmental disorders, hence further restricting paternal involvement. In contrast, siblings demonstrate prompt acceptance and readiness to participate in activities that assist their siblings with neurodevelopmental disorders (NDD). Comprehending the degree of engagement, obstacles, and enablers in low-income settings is essential for policy and practice. Future study needs to investigate participation dynamics across many contexts, especially in Africa, to rectify the knowledge deficit highlighted in studies mostly conducted in high-income nations. This study enhances global comprehension of rehabilitation program participation, directing future research and influencing actions internationally. Rehabilitation specialists should use an innovative strategy that incorporates dads and siblings into home rehabilitation programs. This method may alleviate stress and physical exertion for moms while improving developmental results for children with neurodevelopmental disorders.

References

1. Brown KA, Parikh S, Patel DR. Understanding basic concepts of developmental diagnosis in children. Transl Pediatr. 2020;9(Suppl 1)–S22.
2. Choo YY, Agarwal P, How CH, Yeleswarapu SP. Developmental delay: identification and management at primary care level. Singap Med J. 2019;60(3):119–23.
3. Madzimbe P. The prevalence of, and risk factors for developmental delay among children under the at-Risk Surveillance System at United Bulawayo Hospitals, Zimbabwe. Johannesburg: University of Witwatersrand; 2022.
4. Madzimbe P, Potterton J. Prevalence of developmental delay and associated risk factors among at risk Surveillance System (ARSS) children at United Bulawayo Hospitals, Zimbabwe. Ann Clin Biomed Res. 2023;4(2).
5. Fjermestad K, Pat P, Dearozet S, Vatne T, Hafting M, Jegannathan B. Manual-Based Group Intervention for Siblings and Parents of Children with neurodevelopmental disorders in Cambodia. J Dev Phys Disabil. 2021;33(5):839–56.
6. Institute for Health Metrics and Evaluation. The Lancet: Latest global disease estimates reveal perfect storm of rising chronic diseases and public health failures fuelling COVID-19 pandemic. 2020.
7. Kamiya Y. Current situation of children with disabilities in low- and middle-income countries. Pediatr Int. 2021;63(11):1277–81.
8. Olusanya BO, Storbeck C, Cheung VG, Hadders-Algra M, on behalf of the Global Research on Developmental Disabilities Collaborators (GRDDC). Disabilities in early childhood: A Global Health Perspective. Children. 2023;10(1):155.
9. Bitta M, Kariuki SM, Abubakar A, Newton CRJC. Burden of neurodevelopmental disorders in low and middle-income countries: a systematic review and meta-analysis. Wellcome Open Res. 2017;2:121.
10. Gmmash AS, Wynarczuk KD, Effgen SK. Parents' perspectives on the application of Home activities in early intervention. Phys Occup Ther Pediatr. 2022;42(4):416–33.
11. Hurd CL, Pritchard L, Yang JF. Perspectives of parents partnering with physical therapists to deliver intensive rehabilitation for their young children with perinatal stroke: a qualitative study. Child Care Health Dev. 2024;50(1).
12. Kokorelias KM, Gignac MAM, Naglie G, Camron JI. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res. 2019;19(1):564.
13. Pancsofar N, Vernon-Feagans L, The Family Life Project Investigators. Fathers' early contributions to children's Language Development in families from low-income Rural communities. Early Child Res Q. 2010;25(4):450–63.
14. Yogman MW, Eppel AM. The Role of Fathers in Child and Family Health. In: Grau M, las Heras Maestro M, Riley Bowles H, editors. Engaged Fatherhood for Men, Families and Gender Equality. Contributions to Management Science. Cham: Springer; 2022. pp. 155–172.
15. Wang L, Hui L, Dill S, Zhang S, Rozelle S. Does paternal involvement matter for early childhood development in rural China? Appl Dev Sci. 2022;26(4):741–65.
16. Engle PL, Breaux C. Fathers' involvement with children: perspectives from developing countries. Soc Policy Rep. 1998;12(1):1–24.
17. Garcia M, Pence A, Evans JL. Africa's future, Africa's Challenge Early Childhood Care and Development in Sub-saharan Africa Human Development. Washington: World Bank; 2008.
18. Nguyen L, Bootsma J, Ketelaar M, Di Rezze B, Jack SM, Gorter JW. Programs to prepare siblings for future roles to support their brother or sister with a neurodevelopmental disability: a scoping review. Curr Dev Disord Rep. 2023;10(1):47–79.
19. Fagan J, Barnett M. The relationship between maternal gatekeeping, paternal competence, mothers' attitudes about the father role, and father involvement. J Fam Issues. 2003;24(8):1020–43.
20. Song CS, Chun BY, Choi YI. The influence of fathers' parenting participation with disabled children on parenting stress in mothers. J Phys Ther Sci. 2015;27(12):3825–8.
21. Altenburger LE. Resident and Non-resident Father Involvement, Coparenting, and the Development of Children's Self-Regulation Among Families Facing Economic Hardship. Front Psychol. 2022;13.

22. Crnic K, Arbona AP, Baker B, Blacher J. Mothers and fathers together: contrasts in parenting across Preschool to Early School Age in Children with Developmental Delays. Int Rev Res Ment Retard. 2009;37:3–30.
23. Vasudevan P, Suri M. A clinical approach to developmental delay and intellectual disability. Clin Med (Lond). 2017;17(6):558–61.
24. Vilaseca R, Rivero M, Ferrer F, Bersabé RM. Parenting behaviors of mothers and fathers of young children with intellectual disability evaluated in a natural context. PLoS ONE. 2020;15(10).
25. Dambi JM, Jelsma J, Mlambo T. Caring for a child with cerebral palsy: the experience of Zimbabwean mothers. Afr J Disabil. 2015;4(1):168.
26. Kauchali S, Davidson LL, Commentary. The epidemiology of neurodevelopmental disorders in Sub-saharan Africa – moving forward to understand the health and psychosocial needs of children, families, and communities. Int J Epidemiol. 2006;35(3):689–90.
27. Bakare MO, Munir KM, Bello-Mojeed MA. Public health and research funding for childhood neurodevelopmental disorders in Sub-saharan Africa: a time to balance priorities. Healthc Low Resour Settings. 2014;2(1).
28. Towers C. Let's not forget about fathers. Learn Disabil Today. 2007;7:15–21.
29. Ogourtsova T, O'Donnell ME, Chung D, Gavin F, Bogossian A, Majnemer A. Fathers matter: enhancing healthcare experiences among fathers of children with developmental disabilities. Front Rehabil Sci. 2021;2.
30. Blacher J, Baker BL, Kaladjian A. Syndrome specificity and mother-child interactions: examining positive and negative parenting across contexts and time. J Autism Dev Disord. 2013;43(4):761–74.
31. Chesley N. Stay-at-home fathers and breadwinning mothers. Gend Soc. 2011;25(5):642–64.
32. Donald KA, Samia P, Kakooza-Mwasige A, Bearden D. Pediatric cerebral palsy in Africa: a systematic review. Semin Pediatr Neurol. 2014;21(1):30–5.
33. Zeng W, Lannes L, Mutasa R. Utilization of Health Care and Burden of Out-of-Pocket Health expenditure in Zimbabwe: results from a National Household Survey. Health Syst Reform. 2018;4(4):300–12.
34. Peters MD, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth. 2020;18(10):2119–26.
35. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol. 2005;8(1):19–32.
36. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. Ann Intern Med. 2018;169(7):467–73.
37. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci. 2010;5(1):69.
38. Vaismoradi M, Jones J, Turunen H, Snelgrove S. Theme development in qualitative content analysis and thematic analysis. J Nurs Educ Pract. 2016;6(5):100–10.
39. Bengtsson M. How to plan and perform a qualitative study using content analysis. Nurs Plus Open. 2016;2:8–14.
40. Turbiville VP, Marquis JG. Father participation in early education programs. Top Early Child Spec Educ. 2001;21(4):223–31.
41. da Cruz TA, de Souza Santos EM, da Silva FC, da Silva Reis MC, da Silva ÂC. Sociodemographic profile and participation in the daily care of children with microcephaly. Cad Bras Ter Ocup. 2019;27(3):602–14. https://doi.org/10.4322/2526-8910.ctoao1830.
42. Olawale OA, Deih AN, Yaadar RK. Psychological impact of cerebral palsy on families: the African perspective. J Neurosci Rural Pract. 2013;4(2):159–63.
43. Vadivelan K, Sekar P, Sruthi SS, Gobichandran V. Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. BMC Public Health. 2020;20:645.
44. Fisman S, Wolf L, Ellison D, Freeman T. A longitudinal study of siblings of children with chronic disabilities. Can J Psychiatry. 2000;45(4):369–75.

45. Mophosho M, Widdows J, Taylor-Gomez M. Relationships between adolescent children and their siblings with cerebral palsy: A pilot study. J Dev Disabil. 2010;15(3):81–87.
46. Smythe T, Duttine A, Vieira AC, Castro B, Kuper H. Engagement of fathers in parent group interventions for children with congenital Zika Syndrome: a qualitative study. Int J Environ Res Public Health. 2019;16(20):3862.
47. Navalkar P. Fathers' perception of their role in parenting a child with cerebral palsy: implications for Counselling. Int J Adv Couns. 2004;26:375–82.
48. Demeke ZD, Assefa YA, Abich Y, Chala MB. Home-based therapy and its determinants for children with cerebral palsy, exploration of parents' and physiotherapists' perspective, a qualitative study, Ethiopia. PLoS ONE. 2023;18(2).
49. Kyeremateng JDA, Edusei A, Dogbe JA, Opoku MP, Nketsia W, Hammond C, et al. Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. Afr J Disabil. 2019;8.
50. Huang YP, Chen SL, Tsai SW. Father's experiences of involvement in the daily care of their child with developmental disability in a Chinese context. J Clin Nurs. 2012;21(21–22):3287–96.
51. Bagner D. Father's role in parent training for children with developmental delay. J Fam Psychol. 2013;27(4):650–7.
52. Laxman DJ, McBride BA, Jeans LM, Dyer WJ, Santos RM, Kern JL, et al. Father involvement and maternal depressive symptoms in families of children with disabilities or delays. Matern Child Health J. 2015;19(5):1078–86.
53. Tsomondo EDI. Lived experiences of parents of children with neuro-developmental disorders in Harare city. Harare: University of Zimbabwe; 2018.
54. Law J, Levickis P, Rodríguez-Ortiz IR, Matić A, Lyons R, Messarra C, et al. Working with the parents and families of children with developmental language disorders: an international perspective. J Commun Disord. 2019;82:105922.
55. Pfeifer LI, Silva DB, Lopes PB, Matsukura TS, Santos JL, Pinto MP. Social support provided to caregivers of children with cerebral palsy. Child Care Health Dev. 2014;40(3):363–9.
56. Law J, Levickis P, Rodríguez-Ortiz IR, Matić A, Lyons R, Messarra C, et al. Working with the parents and families of children with developmental language disorders: an international perspective. J Commun Disord. 2019;82:105922.
57. Pfeifer LI, Silva DB, Lopes PB, Matsukura TS, Santos JL, Pinto MP. Social support provided to caregivers of children with cerebral palsy. Child Care Health Dev. 2014;40(3):363–9.
58. Barnett AL, Dawes H, Wilmut K. Constraints and facilitators to participation in physical activity in teenagers with Developmental co-ordination disorder: an exploratory interview study. Child Care Health Dev. 2013;39(3):393–403.

استراتيجيات طب الأسرة لتعزيز مشاركة الآباء والأشقاء في إعادة تأهيل الأطفال المصابين بالاضطرابات العصبية النمائية: مراجعة

الملخص

الخلفية :تمثل الاضطرابات العصبية النمائية(NDD) ، بما في ذلك اضطراب طيف التوحد والشلل الدماغي، تحدياً صحياً عالمياً كبيراً، لا سيما في البلدان منخفضة ومتوسطة الدخل. تعد الأسرة وحدة أساسية في تلبية احتياجات الرعاية الصحية للأطفال المصابين، ومع ذلك تظل مستويات مشاركة الآباء والأشقاء غير موثقة بشكل كافٍ.

الطرق :استخدمت هذه المراجعة الإرشادات المكونة من 9 خطوات لمعهد جوانا بريجز لتقييم الأدبيات الموجودة بشكل منهجي فيما يتعلق بمشاركة الآباء والأشقاء في برامج إعادة التأهيل المنزلي للأطفال المصابين بالاضطرابات العصبية النمائية. تم إجراء بحث شامل عبر قواعد بيانات متعددة لتحديد المقالات العلمية المنشورة والأدبيات الرمادية ذات الصلة، مع التركيز على مدى المشاركة الأسرية والمعوقات والعوامل الميسرة التي تؤثر على هذه المشاركة.

النتائج :كشفت المراجعة عن تفاوت ملحوظ في مشاركة الآباء مقارنة بالأمهات، حيث تراوحت معدلات المشاركة بين 12% و91% في الدراسات المختلفة. أثرت مشاركة الآباء بشكل إيجابي على مستويات التوتر لدى الأمهات وعلى نتائج تطور الأطفال، بينما تم توثيق دور الأشقاء بشكل أقل من الناحية الكمية، على الرغم من وجود أدلة قصصية تشير إلى أدوارهم الداعمة. وشملت العوامل الميسرة الرئيسية للمشاركة الانسجام الأسري وتقليل الوصمة الاجتماعية، في حين تضمنت المعوقات المعتقدات الثقافية والقيود الاقتصادية وانخفاض المستوى التعليمي لدى الآباء.

الخلاصة :تسلط النتائج الضوء على فجوة كبيرة في الأدبيات المتعلقة بمشاركة الآباء والأشقاء في إعادة تأهيل الأطفال المصابين بالاضطرابات العصبية النمائية، مما يبرز الحاجة إلى تدخلات مستهدفة لتعزيز نظم الدعم الأسري. يمكن أن يؤدي التغلب على المعوقات المحددة وتعزيز الممارسات الشاملة إلى تحسين النتائج للأطفال وتخفيف الضغوط على مقدمي الرعاية.

الكلمات المفتاحية :الاضطرابات العصبية النمائية، المشاركة الأسرية، إعادة التأهيل، البلدان منخفضة الدخل، مشاركة الآباء.