Children with Intellectual Disabilities: Impact on the Well-Being of Primary Caregivers

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Abstract

Caregivers of children with intellectual disabilities experience mental, psychological, and social challenges, yet relatively limited research has examined these effects on their health and well-being. This paper adopts a literature review approach to gather information from peer-reviewed journals, online books, and reports from the last ten years. A total of 32 literature sources met the inclusion criteria. Research evidence shows the impact of early childhood intervention on the mental, psychological, and social well-being of primary caregivers of children with intellectual disabilities. The successful strategies to enhance caregiver well-being include early intervention programs that incorporate stress management, counselling, mental health support services, workplace flexibility, and financial support initiatives for caregivers. The findings indicate that caregiver well-being is a critical factor in the effectiveness of interventions for children with intellectual disabilities. It is recommended that policies and programs that support family-centered early interventions be designed.

Keywords: Children, Early intervention, Intellectual disability, Well-being

Introduction

Intellectual disability, formally called as a neurodevelopmental condition that impacts the cognitive ability, intellectual functioning, and adaptive behaviour of an affected person (Hooda & Gupta, 2017). It is a general term denoting the difficulties in the use of knowledge in practice and can include Down syndrome, Fragile X Syndrome, fetal alcohol syndrome, birth defects, and infections (Abdul Hameed & Kotian, 2022). Children with intellectual and developmental disabilities (IDD) usually experience challenges in key aspects of daily life, such as thinking and learning, paying attention and communicating, socialising and interacting with others, and managing daily living (Llobet et al., 2024; Schlebusch et al., 2022; Abdul Hameed & Kotian, 2022; Gopalan, 2016). Children with severe intellectual disability are likely to have other health conditions, such as seizures, mood disorders (including anxiety and autism spectrum disorder), poor coordination, and vision or hearing impairments (Abdul Hameed & Kotian, 2022). Caregivers' mental health is one of the most important factors influencing children's development (Bai et al., 2022). Thus, well-being is broadly understood as a multidimensional construct that encompasses both subjective and psychological dimensions. Subjective

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well-being relates to an individual's evaluation of life satisfaction and overall emotional experiences, while psychological well-being pertains to personal growth, self-acceptance, and the ability to find meaning through life's challenges (Linley, Maltby, Wood, Osbourne, & Hurling, 2009; Keyes, Shmotkin, & Ryff, 2002, cited in Palamaro Munsell et al., 2012). In the context of this study, well-being is defined as a combination of caregivers' subjective life satisfaction and the absence of mental or physical symptoms commonly associated with anxiety and depression (Palamaro Munsell, Kilmer, Cook, & Reeve, 2012, cited in Palamaro Munsell et al., 2012). In addition, good mental health is a significant asset to parents and caregivers of children with intellectual disabilities, given the important role that mental health plays in allowing responsive caregiving (Marguerite et al., 2022).

However, the global prevalence of intellectual disabilities among children continues to increase his, therefore, calls for attention, especially to the family caregivers who provide long-term support such as medication administration, monitoring their physical condition, and behaviour management, to enable them to attain their potential despite their disorder (Leonard et al., 2024). Hence, a child with an Intellectual Disability (ID) can present multiple stressors for parents and families. The difficulties are spread across multiple areas of family life, including housework, finance, lack of leisure and relaxing time, stress on all family members, family members' poor physical health, neglected needs of other children, and tense family relationships (Abdul Hameed & Kotian, 2022).

Early childhood intervention (ECI) refers to a range of evidence-based services and support provided to children from birth to eight years of age and their families to promote optimal development, learning, and well-being (McCabe & Klein, 2025). Within this review, ECI encompasses multidisciplinary programs such as: (1) family-centred developmental programs, including parent coaching, skills training, and home-based therapy; (2) health and allied-health services such as speech, occupational, and behavioural therapy; (3) psychosocial support programs, including parental counselling, stress-management, and mental-health interventions; and (4) educational or community-based supports, including inclusive early-education and social-participation initiatives. These interventions collectively aim to enhance children's developmental outcomes and caregiver well-being by recognising the uniqueness of each family unit and are grounded in evidence-based principles that support both children and their families (McCabe & Klein, 2025).

However, one of the factors is that parents' effectiveness at being the best caregivers that they can be depends on their experiences and well-being. Hence, the focus should not only be on children with disabilities and their intervention, but attention should be given to caregivers, as there is much more to be researched on how best to support and improve the well-being of the primary caregivers of children with intellectual disabilities (Friedland & Perks, 2022). As parents or caregivers interact daily with their children with disabilities, these continuous caregiving experiences influence their well-being in varying ways, sometimes enhancing emotional resilience and satisfaction, but at other times contributing to stress, fatigue, or psychological strain (Tan, 2017; Schlebusch et al., 2022; Abdul Hameed & Kotian, 2022). This, in turn, affects their efficiency in discharging their care duties. Therefore, this paper aims to explore how caregiving impacts the well-being of caregivers of children with intellectual disabilities and then to suggest ways for improvement.

Theoretical Framework

This paper is grounded on the Stress Process Model (SPM), as described by Pearlin et al. (1981). The model offers a strong theoretical base for explaining how caregiving stressors affect caregivers' well-being and how coping resources and support systems act as mediators of these effects (Atkins, 2021). Grounded 'in' the stress process model which includes: 1. Caregiving context, such as caregivers' socio-economic background, work-life balance, nature and demands of their child's disability, and the duration and intensity of caregiving responsibilities. These contextual elements determine how caregivers perceive and react to stress, which leads to the experience of primary and secondary stressors (Johnson, 2020). 2. Primary stressors, such as behavioural challenges, cognitive limitations, and the need for assistance with activities of daily living. These stressors often lead to role overload and role captivity, In which caregivers may feel overwhelmed or trapped in their caregiving roles (Pearlin et al., 1990, as cited in Johnson, 2020).

3. Secondary Stressors, for example, role strain, such as balancing caregiving with employment and other family responsibilities, and intrapsychic strain, which refers to the erosion of self-concept, self-esteem, and identity. It has been revealed hat caregivers may feel their career identity, social roles, or personal goals are diminished or inaccessible, which can lead to psychological distress, anxiety, or depression (Johnson, 2020), although resources such as coping strategies and social support from family and friends can help mitigate these adverse effects (Johnson, 2020). This paper uses the SPM to systematically capture the caregiving experience, identify critical stress points, and evaluate how intervention and support systems can mitigate negative outcomes.

Materials and Methods

A systematic search was conducted in the following electronic databases to identify and synthesise relevant studies: ProQuest, PsycINFO, PubMed, and Google Scholar for peer-reviewed journal articles, and other credible research publications that focus on the well-being of parents or caregivers of children with intellectual disabilities. To achieve this, the search was focused on keywords such as ‘well-being,’ ‘caregivers,’ ‘parents,’ ‘intellectual disability,’ ‘intellectually disabled children,’ ‘mental health support for caregivers,’ and ‘effect of early intervention on the caregivers/parents.’ This review discusses the welfare of the caregivers of children with disabilities and then narrows down to the caregivers of children with intellectual disabilities. Furthermore, literature on early interventions concerning children with intellectual disabilities was reviewed.

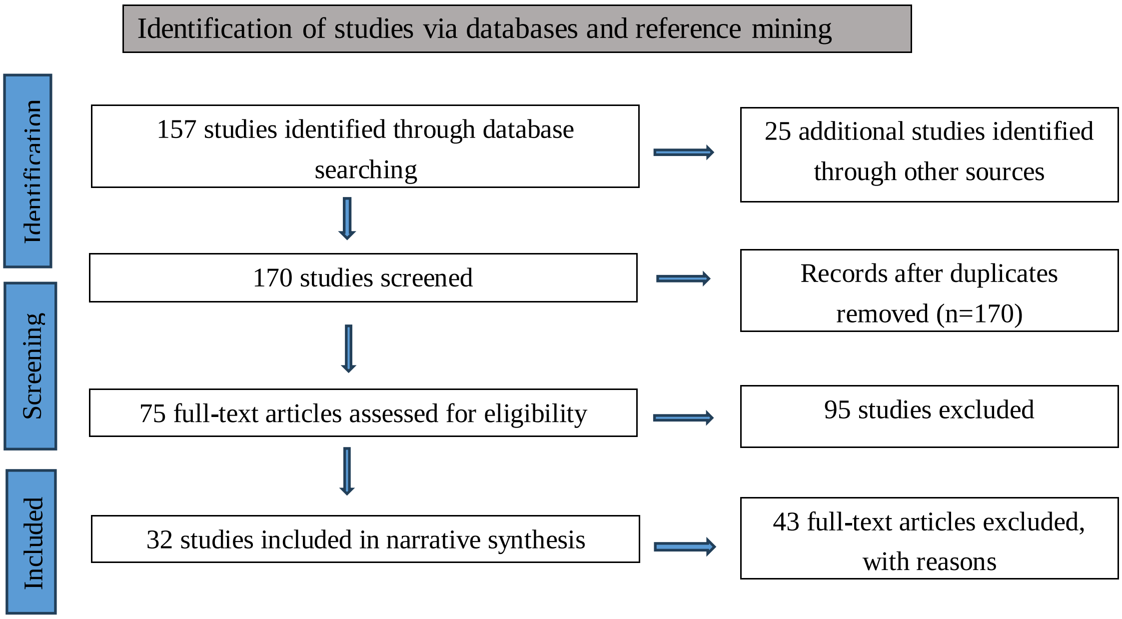
The inclusion criteria for this literature review were determined based on the central research objective of understanding how early childhood intervention affects the well-being of primary caregivers of children with intellectual disabilities. A systematic and comprehensive search strategy was developed to identify studies that directly addressed the mental, psychological, and social health outcomes of caregivers. The search was also influenced by the need to include recent, relevant, and high-quality sources of evidence on caregiving experiences and early intervention practices. The eligibility criteria included the following: 1. Publication type: The study included peer-reviewed journal articles, together with government and non-governmental organization reports, and credible online books. 2. Language: Publications available in English. 3. Date range: The study included publications from 2013 to 2025 to ensure current findings and relevance, although a few studies from up to 12 years prior were retained due to their relevance to the research topic. 4. Topical Relevance: Studies had to focus on the mental health, psychological well-being, or social well-being of caregivers or parents. Moreover, the information sources had to be about children (aged 0–8 years) with intellectual disabilities, developmental disabilities, or autism spectrum disorder. However, studies involving caregivers of adults with disabilities were also included to provide additional insights into caregiver well-being and coping, as these experiences share relevant similarities with those of caregivers of children with intellectual disabilities. Additionally, studies had to focus on the impact of early childhood intervention strategies or programs on caregiver outcomes.

The target population for the study was primary caregivers (including parents and legal guardians) of children with intellectual and developmental disabilities. The study's global geographical scope was adopted. The emphasis was on including a combination of low-, middle-, and high-income countries to reflect a wide range of caregiving contexts. The research included studies conducted using quantitative, qualitative, and mixed-method designs. The review also incorporated secondary data from scientific repositories such as PsycINFO, Google Scholar, Web of Science, and the Scientific Information Database.

A total of 32 pieces of literature, including peer-reviewed journals, online books, and reports from the last ten years that are related to the topic (inclusion criteria) were used, except in a few cases where publications from 12 years ago that were relevant were cited. Out of 32 literature sources included in the study, 14 centred on caregivers of children with intellectual/ or developmental disabilities, 4 discussed caregivers of children with autism, 2 focused on caregivers of adults with disabilities, 1 on both developmental disabilities and autism, and 11 were about caregivers' well-being with no specific child disability. The selection strategy included both inclusivity and focus to ensure that the literature review contained rigorous findings that captured the diverse experiences of primary caregivers in early childhood intervention settings. Sources were excluded if they did not meet the following criteria: 1. Studies published before 2013 that did not have enduring relevance. Enduring relevance was defined as studies with findings, frameworks, or evidence that remain applicable to contemporary caregiving contexts (McKenzie et al., 2019); studies focusing on outdated interventions or populations no longer relevant were excluded. 2. Studies in which the authors did not directly examine caregiver well-being. 3. Studies that focused exclusively on adult caregiving or institutional care without any connection to family caregiving. 4. Studies for which the full text was unavailable for download or review. 5. Studies not published in English.

A search strategy conducted through databases such as ProQuest, PsycINFO, PubMed, and Google Scholar identified 157 literature sources. 25 additional records were identified through other sources such as grey literature and hand-searching. In total, 182 records were identified. After removing the 12 duplicate records, 170 studies remained and were screened by title and abstract. Of these, 95 were excluded for not meeting the inclusion criteria. The remaining 75 records were assessed for eligibility. This process of using full text led to the exclusion of a further 43 records, which were excluded due to reasons of having the wrong population and for not describing the intervention. Finally, 32 records met the inclusion criteria and were reviewed for this study. The PRISMA flowchart is presented in Figure 1 below.

Figure 1 Prisma Flowchart



Results

The first section of the findings is reflected in Table 1, which discusses the characteristics of the selected papers. A narrative presentation of the emerging themes regarding the impact on the well-being of primary caregivers of children with intellectual disabilities follows this. The impacts discussed thereafter pertain to mental health as well as psychological and social well-being.

Table 1 Findings from selected papers.

Author(s)	Year	Country of origin	Type of article	Type of method	Summary findings on the impact of informal caregiving
Abdul Hameed, P.V., & Kotian, S.	2022	India	Peer Reviewed	Systematic review	Parents who provide informal care to children with intellectual disabilities experience substantial physical and psychological challenges, which negatively impact their mental health and raise their chances of developing mental health problems.
Bai, Y., Abulitifu, R., & Wang, D	2022	China	Peer reviewed	Randomised controlled trial	The high rates of depression, anxiety, and stress among female caregivers in rural areas are largely due to informal caregiving, which is shaped by caregiving roles and socioeconomic factors, but interventions can help reduce anxiety and enhance social interactions.
Bongelli, A., Busilacchi, G., Pacifico, A., Fabiani, M., Guarascio, C., Sofritti, F., Lamura, G., & Santini, S.	2020	India	Peer reviewed	Cross-sectional study	Parents who provide informal care to children with intellectual disabilities experience substantial physical and psychological strain, which negatively impacts their mental health and elevates their chances of developing mental health problems.
Bunga, D., Giriprasad, H., Nikhil, M., & Shankar, R. U.	2020	India	Peer reviewed	Cross-sectional study	Parents who provide informal care to children with intellectual disabilities experience substantial physical and psychological strain, which negatively impacts their mental health and elevates their chances of developing mental health problems.
Capri, C., Abrahams, L., Mckenzie, J., Coetzee, O., Mkabile, S., Saptouw, M.,Hooper, A.,	2018	South Africa	Peer reviewed (scoping review)	Document analysis	Informal caregivers experience challenges advocating for the rights of people with intellectual disabilities due to systemic barriers in a discriminatory and under-resourced environment, which requires more

Author(s)	Year	Country of origin	Type of article	Type of method	Summary findings on the impact of informal caregiving
Smith, P., Adnams, C., & Swartz, L.					rights-based support and inclusive services.
Duxbury, L., Ding, R., Stevenson, M., & Sadavoy, J	2024	Canada	Peer reviewed	Validation study	Informal caregivers face multiple condition-related demands when providing care for the recipients, because they must handle daily activities and manage various health issues, including mental health problems, cardiovascular conditions, and immune system disorders.
Falk, N. H., Norsk, K. & Quin, M. G.	2014	USA	Peer reviewed	Quantitative study	The level of stress, anxiety, and depression experienced by informal caregivers of children with autism is more closely related to their own beliefs, perceived support, and socio-economic conditions than to the severity of the child's symptoms or behaviours.
Friedlander, S. & Perks, B.	2022	Global (UNICEF)	Grey literature	Narrative report	Children's development strongly relies on the informal caregiving they receive. The research shows that early childhood development programs that support both children and caregivers result in better caregiver mental health, improved parenting practices, and sustained positive effects for the entire family in crises.
Garcia-Grau, P., Martinez-Rico, G., Gonzalez-Garcia, R., Escorcia-Mora, C. T., & Canadas-Perez, M.	2024	Spain	Peer reviewed	Empirical study-Quantitative survey	The burden of informal caregiving creates negative effects on family quality of life, but family confidence at higher levels helps reduce these effects, which demonstrates why caregivers need empowerment to enhance family well-being.
Singh, G. & Dubey, A.	2016	India	Peer reviewed	Literature review	The psychological impact of informal caregiving for chronically ill family members results in depression and reduced quality of

Author(s)	**Year**	**Country of origin**	**Type of article**	**Type of method**	**Summary findings on the impact of informal caregiving**
					life, but research about positive caregiving experiences remains scarce.
Githera M., Obondo, A., Tele, A., Thornicroft, G., & Kumar, M	2020	Kenya	Peer reviewed	Cross-sectional study survey	Providing care for children with intellectual disabilities in informal settings creates a high risk of depression among parents, especially women, younger caregivers, and those who experience stigma, thus requiring specific mental health interventions and stigma reduction programs.
Gopalan, R. T.	2016	Global Handbook	Grey literature	Theoretical	Parenting children with intellectual disabilities is challenging, as many of these children are misunderstood, while their parents are often blamed for their difficulties.
Harris, E. C., D’Angelo, S., Syddall, H. E., Linaker, C., Cooper, C. & Walker-Bone.	2022	UK	Peer reviewed	Longitudinal study survey	High-intensity informal caregiving results in worse physical and mental health outcomes, particularly for socio-economically disadvantaged individuals. It also affects their employment status, thus requiring immediate supportive policies and resources for caregivers.
Hooda, S. & Gupta, A.	2017	India	Peer reviewed	Empirical study	Fostering a child with intellectual disabilities results in increased risk of mental agony, frustration, stress, anxiety, depressive symptoms, and other psychological problems among the primary caregivers.
Irfan, B.; Irfan, O.; Ansari, A., & Qidwai, W.	2017	Pakistan	Peer reviewed	Cross-sectional study survey	Young caregivers experience substantial physical, psychological, and professional challenges because of high caregiving demands and insufficient support, which demonstrates the requirement for healthcare provider-directed targeted assistance.
Leonard, R., Hughes, N., Forbes, T., Brown, M., Marsh, L.,	2024	UK/Ireland	Peer reviewed	Systematic literature review	The results indicate that online intervention programs may be useful in reducing stress and enhancing the psychological well-being of caregivers of people with intellectual

Author(s)	Year	Country of origin	Type of article	Type of method	Summary findings on the impact of informal caregiving
Truesdale, M., Todd, S., & Linden, M.					disabilities, but more research is required to confirm the effectiveness of the programs.
Llobet, M. P., Roger, M. R., Silva, T. N., Gimenez, G. P., Agüera, Z., Canut, M. L., Merino, J. F.R., Arroyo, C.M., Arimon, M. P., Ortega, M.A.S., Mascaró, X. D., Blanco, M. A, H., & Poyato, A. M.	2024	Spain	Peer reviewed	Qualitative study	The COVID-19 lockdown period caused increased stress for informal caregivers of people with intellectual and developmental disabilities in residential care because of disrupted routines, social isolation, and communication challenges, thus demonstrating the necessity of crisis support.
Mahak, A.	2023	India	Grey literature	Expert validation	The development of a child depends on ten factors, including heredity, environment, sex, exercise and health, hormones, nutrition, familial influence, geographical influences, socio-economic status, and learning and reinforcement.
Marguerite, M., Skeen, S., Hunt, X., Sundin, P., Robert, E. W., Soeshoe, M. Makhetha, M., Cluever, L., Sherr, L. & Tomlinson, M.	2022	Lesotho	Peer reviewed	Cross-sectional study survey	Most informal caregivers experience severe psychological distress, together with depression, anxiety, and suicidal thoughts, because of food insecurity and parenting stress. The situation demonstrates the necessity to tackle public health and socioeconomic issues that intersect with each other.
McConnell, D., & Savage, A.	2015	Canada	Peer reviewed	Literature review	Providing care for children with intellectual disabilities by their parents leads to increased psychological distress and family dysfunction, because of the child's behaviour problems; thus, interventions that focus on child behaviour and parental coping skills can lead to better caregiver well-being.

Author(s)	**Year**	**Country of origin**	**Type of article**	**Type of method**	**Summary findings on the impact of informal caregiving**
Moosa-Tayob, S. & Risenga, P. R.	2022	South Africa	Peer reviewed	Exploratory, descriptive, and contextual research design.	Multiple challenges affect informal caregivers because they experience stress, lack of support, and their work remains unrecognised by the community, thus requiring institutional support and skill-building programs for effective caregiving.
Mundakir, M., Choliq, I., Sukadiono, S., Fitriyani, V. R., & Firman, F.	2024	Indonesia	Peer reviewed	Qualitative systematic review	The caregiving responsibilities for children with physical and intellectual disabilities create emotional strain, physical demands, and social challenges on families because of discrimination, insufficient support, and unclear situations. This requires family-focused, well-informed, and inclusive interventions.
Muthukaruppan, S. S., Cameron, C., Campbell, Z., Krishna, D., Moineddin, R., Bharathwaj, A., Poomariappan, B. M., Mariappan, S., Boychuk, N., Ponnusamy, R., MacLachlan, J., Brien, M., Nixon, S., & Srinivasan, S. R.	2022	India	Peer reviewed	Intervention Study	Family empowerment and reduction of informal caregiving strain can be achieved through Family-centered early intervention programs that provide caregivers of children with developmental delays with targeted training and education.
Palamaro Munsell, E., Kilmer, R. P., Cook, J. R., & Reeve, C. L.	2012	USA	Peer reviewed	Empirical Study	The care of children with severe emotional disturbances by informal caregivers leads to caregiver strain, but caregivers who maintain strong social connections experience better well-being, which leads to positive outcomes for their children.
Razaei, H., Niksima, S. H. & Gheshlagh, R. G..	2020	Iran	Peer reviewed	Systematic review and Meta-analysis	The informal caregivers of chronically ill patients in Iran experience substantial physical, mental, social, and financial

Author(s)	Year	Country of origin	Type of article	Type of method	Summary findings on the impact of informal caregiving
					challenges because of insufficient healthcare resources, insufficient training, and the heavy burden of caring for patients, which frequently results in neglect of their health.
Roberson, M., Hayes, K., Shekouh, K. R., Alhich, E., & Zlomke, K..	2024	USA	Peer reviewed	Empirical study	The negative effects of informal caregiving stress on the quality of life for caregivers of children with autism can be buffered by positive mood and strong social support. This suggests that interventions could be targeted at enhancing caregiver well-being.
Scheibner, M., Scheibner, C., Hornemann, F., Arélin, M., Hennig, Y.D., Kiep, H., Wurst, U., Merkenschlager, A., & Gburek-Augustat, J.	2024	Germany	Peer reviewed	Cross-sectional Study	The high stress levels experienced by informal caregivers primarily affect mothers, single parents, and part-time workers, which negatively impacts both their mental health and child development, thus requiring systematic stress assessment and targeted support.
Schlebusch, L., Chambers, N., Rosenstein, D., Erasmus, P., & De Vries, P. J.	2022	South Africa	Peer reviewed	Quantitative Study-Program evaluation	A well-being program improved caregiver resilience but did not eliminate caregiving challenges
Schulz, R., & Elden, J.	2016	USA	Grey literature	Policy analysis/Report	The responsibilities of informal caregiving result in substantial effects on caregivers' physical and mental health while changing family relationships and affecting their ability to work.
Shepherd, D., Landon. J., Goedeke, S., & Meads, J.	2021	New Zealand	Peer reviewed	Quantitative survey	The research shows that informal caregiving for children with autism leads to psychiatric distress in parents at clinical levels, while parenting stress stands as the main predictor and mediator of poor mental health outcomes, rather than parent or child characteristics.

Author(s)	Year	Country of origin	Type of article	Type of method	Summary findings on the impact of informal caregiving
Soytac, E., Kahraman, T., & Genc, A.	2022	Turkey	Peer reviewed	Case-control study	Primary caregivers who provide care for children with autism experience high caregiver burden together, including increased anxiety, reduced sleep quality, and health-related quality of life, but their pain, fatigue, and depression levels remain similar to those caring for typically developing children.
Tan, S. H.	2017	Malaysia	Grey literature	Qualitative study	The informal caregivers of children with learning and multiple disabilities experience substantial unmet needs regarding information, coping support, childcare, and financial assistance, especially among those with lower education levels and medical issues.

Discussion

Impact on the well-being of primary caregivers of children with intellectual disabilities

The analysis of the above literature sources reveals three themes regarding the impact on the well-being of primary caregivers of children with intellectual disabilities. These emerging themes are: 1. Mental health impacts. 2. Psychological well-being and implications. 3. Social well-being and implications. Caregivers, according to Capri et al. (2018), are individuals who support care recipients in carrying out their essential daily activities, which can be formal or informal. They face more burdens in caring for children with disabilities. These burdens, however, may be dependent on the age of the caregiver, the intensity of caregiving responsibilities, and the nature of the disability of the child. An understanding of the burden of caregivers, according to Moosa-Tayob and Risenga (2022), is vital in developing empowerment programs for caregivers to optimally fulfil their caregiving role.

This literature review enhances understanding of the challenges faced by caregivers of children with intellectual disabilities. It also highlights opportunities to improve parental well-being by reducing caregiver stress and burden. (Abdul Hameed and Kotian, 2022). Thus, the impact of caregiving on the caregivers is presented in themes to address the research question: “How does early childhood intervention impact the mental health, psychological, and social well-being of primary caregivers of children with intellectual disabilities?"

The impact on the mental health of primary caregivers

Among the factors that affect child development, the caregiver and their mental health, which is a part of the environment, are most important. Previous studies have indicated that parents’ mental health is a key determinant of their effectiveness in caring for their children with disabilities (Mahak, 2023; Friedlander and Perks, 2020). Hence, it is crucial to know the health of the caregiver to offer the right treatment to the children with disabilities (Falk et al., 2014). In the study of the effect of caregiver social connections on caregivers, children, and family well-being, Palamaro Munsell et al. (2012) pointed out that caregivers in most families have the responsibility of meeting the basic needs of family members and making sure that everyone is protected and in good health. In their view, therefore, the health of the caregivers is important for the adjustment of the child as well as for the family cohesion and harmony.

In their study, Muthukaruppan et al. (2022) explained that caregiving stressors of children with disabilities may negatively impact the physical and mental health of the caregivers to the extent of seeking medical attention, which may, in turn, affect the quality of care provided to the child. Thus, new knowledge on health-related needs of the caregivers is important for improving the current services and developing new strategies to address the vital role they play. In the same vein, Marguerite et al (2022) examined the rates of depression, anxiety, and psychological distress among the caregivers of young children in rural Lesotho and examined the relationship between the caregiver, child, and household factors and depression symptoms, anxiety symptoms, psychological distress, suicidal ideation and help-seeking for mental health. The result shows that the rate of symptoms of psychological distress was 42%, depression 25%, anxiety 17.1% and suicidal ideation 27.5% among caregivers.

In another study, McConnell and Savage (2015) reported that stress levels were higher among families of children with intellectual disabilities than the national average. This is in line with the findings of Bai et al. (2022), who investigated the rates of depression, anxiety, and stress symptoms in rural family caregivers. Similarly, Garcia-Grau et al. (2024) conducted a study on caregiver burden and family quality of life in early intervention. They found that the child's support needs were positively related to caregivers' burden experienced through depression, anxiety, and stress. Therefore, the more demands are made on the caregiver in the context of caring for someone with a disability, mental illness, cancer/immune issues, and cardiovascular disease in a typical month, the more likely it is that an employee will report subjective caregiver burden (SCB) (Duxbury et al., 2024). In the meantime, the overall evidence from the works of various authors and researchers suggests that caregiving responsibilities, particularly for parents of children with disabilities, negatively impact the mental health of caregivers.

To help caregivers who are anxious, depressed, and psychologically distressed, mental health services should be made more accessible and cost-effective (Marguerite et al., 2022; McConnell & Savage, 2015). Some measures like stress management programs, counselling, and peer support groups designed for caregivers may enhance mental resilience (Muthukaruppan et al., 2022). Furthermore, integrating mental health support into early childhood intervention services can also assist in identifying caregivers' distress, thus providing timely and appropriate support (Garcia-Grau et al. 2024).

The impact on the psychological well-being of primary caregivers

Caring for children with intellectual disabilities presents several challenges, including psychological issues. Bunga et al. (2020) in their study established that intellectual disabilities, also known as 'intellectual disability, are associated with low socioeconomic status (SES). So, the parents of these children feel guilty, sad, resentful, and shocked, along with new roles and responsibilities. In addition, studies have pointed out high levels of psychological distress, like anxiety and depression, in parents and other family members of children with intellectual disabilities, including siblings (Bunga et al., 2020).

In addition, Bongelli et al. (2024) in their study of caregiving burden, social support, and psychological well-being of families, reported that caregiving burdens affect caregivers' psychological well-being. Furthermore, Sheferd et al. (2021) also provided a summary of it when they established that 65% of the parents they studied have reached clinical levels of psychiatric distress, including anxiety. In essence, the burden of caregiving can indeed affect parents/ caregivers of children with disabilities. In supporting this, Duxbury et al. (2024) reported that the caregiver's burden and psychological well-being are influenced by the care recipient's health condition. This could be due to the extra energy that is required in caring for children with disabilities.

Moreover, Razaei et al. (2020) concluded in their study on psychological distress as a predictor of caregiving burden in Iranian families that caregivers experience significant care-related burdens, largely due to psychological distress such as depression and anxiety. This suggests that caregiving negatively impacts caregivers' psychological well-being. Similarly, studies on the psychological well-being of children with intellectual disability, specifically about stress, depression, and anxiety, reveal that the stress and frustration levels of these parents are higher than the national average (McConnell & Savage, 2015).

These findings are concerning. Furthermore, a systematic review of the mental well-being of caregivers of children with intellectual disabilities found that the demands of caregiving usually led to psychological and physical distress of the caregivers, which, according to the researchers, negatively affects their overall well-being in daily life. Roberson et al. (2024) examined the daily impact of mood and the quality of social support on caregivers of children with autism spectrum disorder and observed a positive correlation between caregiving and stress and depression. This suggests that caregivers of children with intellectual disabilities experience a high level of stress and depression. Similarly, Soytac et al. (2022) examined the experiences of mothers of children with Autism Spectrum Disorder (ASD), focusing on pain, anxiety, depression, fatigue, sleep, and health-related quality of life. Based on their findings, these caregivers had a greater caregiving burden, more anxiety, worse sleep quality, and an overall worse health-related quality of life than mothers of typically developing children. However, the results of Bunga et al. (2020) contrast with other studies, in that their study showed that most parents of selected children with intellectual disabilities experienced a positive rather than a negative impact of it. To them, this indicates that these parents became more patient, tolerant, sensitive, and had stronger and more enduring relationships with their children. Despite this contrast in parental well-being, most studies indicate that the psychological well-being of primary caregivers of children with developmental disabilities is negatively affected.

To prevent the psychological impact and strain, caregivers should be provided with structured respite care and opportunities for relaxation (Bongelli et al., 2024). Workshops on coping mechanisms, positive parenting, and time management to empower caregivers to handle stress effectively should be organised (Duxbury et al., 2024). Additionally, family-based intervention approaches that strengthen family dynamics and promote patience, tolerance, and emotional bonding can be encouraged to improve caregivers' psychological well-being (Bunga et al., 2020).

Impact on the social well-being of family caregivers

It is important for a caregiver to sustain positive relationships within society for them to maintain a healthy lifestyle. Thus, caregiving can either foster social isolation or enhance connections. Schulz and Eden (2016) in their literature review pointed out that caregiving is associated with negative consequences for caregivers, and that they do not work in isolation; they also have other roles and responsibilities in their lives. Singh and Dubey (2016), in their study, observed that the impact of caregiving is both broad and unique to each individual. They opined that caregivers may be vulnerable to potential risk in virtually every aspect of their lives, including social aspects, and may be impacted negatively. Supporting these findings, Irfan et al. (2017) investigated the experiences of primary caregivers of children with disabilities and discovered that most of them were negatively affected. Their study established the impact of caregiving on different areas of life, with 40.8% having physical effects, 47.8% having psychological distress, and 51.8% having professional challenges. The researchers opined that these adverse effects were mainly due to the extensive demands of caregiving combined with the limited available resources.

Caring for a child with an intellectual disability can be not only challenging and stressful but also stigmatising (Scheibner et al., 2024). In line with this, Githara and Obondo (2020) conducted a cross-sectional study to examine depressive symptoms and stigmatisation among parents in Nairobi, Kenya, and the results showed that 24% of participants were at risk of developing depressive symptoms and, therefore, needed screening for these tendencies. Moreover, according to Mundakir et al. (2024), parents who are the primary caregivers of their children with ID are likely to feel socially isolated because of the specific demands of caregiving. The need for specialised care and constant attention may limit their capacity to engage in social activities, which in turn may lead to feelings of loneliness and exclusion (Mundakir et al., 2024).

In their study on the relationship between informal caregiving, health, and work within the Health and Employment After Fifty study, Harris et al. (2020) established that most respondents were socio-economically disadvantaged. They were also unlikely to be employed, especially if they were trying to juggle caregiving with part-time or shift work. This suggests that caregiving responsibilities can negatively impact employment opportunities for this group. These findings show that caregivers' burdens are not only on behavioural issues but also on other aspects of their health. Moreover, characteristics such as caregivers' age, level of training, and the intensity of caregiving tasks may also influence their overall health and stability. Likewise, parents and caregivers of children with intellectual disabilities make numerous lifestyle changes that include restricted access to social activities and loss of personal time. Their leisure and recreational activities are often sacrificed (Bunga et al., 2020). To cope, they seek support from relatives, neighbours, and friends; however, such help is often limited. Therefore, improving both formal and informal support systems may be crucial for their quality of life (Bunga et al., 2020).

To reduce social isolation and stigma, public awareness campaigns aimed at changing societal perceptions of intellectual disabilities are essential (Githara & Obondo, 2020). Developing community-based programs and inclusive recreational activities will help caregivers engage socially and rebuild connections (Mundakir et al., 2024). Furthermore, workplace flexibility policies, caregiving leave, and financial support initiatives can ease the socio-economic pressures on caregivers, enabling better work-life balance and social participation (Harris et al., 2020).

Conclusions

This literature review has established the profound impact on the mental, psychological, and social well-being of primary caregivers of children with intellectual disabilities. The findings of the studies reviewed indicate that caregivers, especially mothers, experience high levels of stress, anxiety, depression, and social isolation because of the demanding duties of caregiving. These burdens often lead to negative consequences in the family, little or no personal time, and reduced employment opportunities. However, some positive outcomes included enhanced family cohesion, resilience, and resourcefulness in some instances; although the overall impact was mainly negative.

To this end, the literature advocates for easily accessible mental health services, structured respite care, Family-centered support programs, and community integration strategies that aim at eliminating prejudice against the affected individuals. Moreover, public awareness campaigns and flexible workplace policies are crucial in improving the caregivers' quality of life. Further research and policymaking should be directed towards enhancing both formal and informal support systems to help caregivers support their children and themselves.

Limitations

The analysis of the included literature shows multiple important limitations that impact the reliability and usefulness of the research results. Firstly, most studies reviewed stem from low-and middle-income countries, including India, South Africa, Kenya, and Lesotho. The findings lack generalizability to high-income countries such as Australia because their service structures, social expectations, and support systems differ substantially. Secondly, there is an underrepresentation of diverse caregivers, as most of the studies reviewed are based on mothers, with little attention paid to fathers, grandparents, siblings, or other informal caregivers. This gives a limited view of caregiving experiences and ignores different family structures. Most of the studies reviewed focus on primary caregivers of children with various disabilities, including autism spectrum disorder, developmental delay, and intellectual disabilities, which can mask the specific effects and challenges associated with intellectual disability.

Thirdly, there is a lack of longitudinal evidence, as most of the studies reviewed employed cross-sectional designs, which present only a momentary view of caregiver experiences without showing how caregiving changes throughout time. Fourthly, inconsistent measurement tools: The measurement tools used to assess caregiver well-being and psychological distress, and social impacts, show limited consistency between studies, which creates challenges for comparison and synthesis. Lastly, limited intervention-based evidence: The reviewed studies lack direct assessment of how Early Childhood Intervention or ECI programs affect caregivers' well-being. Most of the studies document stress and burdens, but they do not assess intervention effectiveness.

Recommendations

The following recommendations are proposed for further research and program development, practice, and policy based on the identified limitations:

Recommendations

Future research should be conducted in high-income and multicultural settings like Australia to mirror the actual caregiving situations found in these regions. The research should increase participant selection criteria to include fathers and grandparents, and extended family members, to achieve a more complete understanding of caregiving experiences. Moreover, research should concentrate on caregivers who care for children with intellectual disabilities to identify the distinctive difficulties that this condition presents. Future research on caregiving impact needs to employ longitudinal and mixed methods studies to understand how caregiving impacts evolve and how interventions influence well-being. Using consistent and validated tools to measure caregiver stress, well-being, and burden will allow for better comparison across studies and improve the reliability of findings. Further research is needed to evaluate the direct effects of ECI programs on caregivers' mental, psychological, and social well-being.

Practice implications

The research findings from the literature review produce multiple essential implications that affect social work and healthcare practice. Early childhood programs must provide caregivers with regular mental health screenings, together with counselling and support services. Services should focus on supporting both the child's developmental requirements and the emotional, practical, and psychological needs of their caregiver. Social workers, together with health professionals and educators, need training in trauma-informed and caregiver-sensitive methods to improve their support delivery. Community-based caregiver support groups should be established to reduce isolation and enable knowledge sharing among members.

Policy implications

The following policy directions are proposed as informed by the literature: 1. The disability and healthcare systems need official policy recognition of informal caregivers because they serve as vital contributors who deserve support and representation. 2. The government should allocate funding to support caregivers through financial assistance and respite care services, and subsidised mental health programs. 3. Legislative frameworks need to establish caregiver leave provisions and flexible work arrangements, and job protection for parents who have children with disabilities. 4. The government should allocate funding to launch national awareness campaigns that aim to reduce stigma about intellectual disability while promoting the acceptance of caregiver support seeking.

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