

Factors that Influence Parental Stress When Caring for Children with Intellectual Disabilities: A Systematic Literature Review

Faktor-faktor yang Mempengaruhi Tekanan Ibu Bapa Apabila Menjaga Kanak-Kanak Kurang Upaya Intelek: Kajian Literatur Bersistemik

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ABSTRACT

Parents of children with intellectual disabilities (ID) frequently experience role-related stress and difficulties in the caregiving process. To systematically identify the key factors influencing parental stress, this study, following the PRISMA framework, searched the Scopus and Web of Science databases for relevant literature published between 2015 and 2024 and identified 269 articles. After quality screening using the Mixed Methods Assessment Tool (MMAT), 19 studies were ultimately included for a systematic review and thematic analysis. The results show that parental stress is mainly influenced by three categories of factors: children, parents, and the social environment. Among them, children's behavioural problems and skills and educational needs, parents' emotional distress, caregiving challenges, concerns about the child's future, and demographic characteristics, as well as economic pressure, social discrimination, the level of social support, and the impact of COVID-19, are all closely related to parental stress. This review, based on integrating existing empirical evidence, systematically clarifies the key factors influencing parental stress among children with ID, providing not only a theoretical perspective for future research but also practical evidence to inform the development of targeted support and intervention strategies, thereby promoting family well-being and alleviating parental stress.

Keywords: intellectual disability, parents, stress, Influencing factors, systematic review

ABSTRAK

Ibu bapa kanak-kanak kurang upaya intelektual (ID) kerap mengalami tekanan dan kesukaran berkaitan peranan dalam proses penjagaan. Untuk mengenal pasti faktor utama yang mempengaruhi tekanan ibu bapa secara sistematik, kajian ini, mengikut rangka kerja PRISMA, mencari pangkalan data Scopus dan Web of Science untuk literatur berkaitan yang diterbitkan antara tahun 2015 dan 2024 dan mengenal pasti 269 artikel. Selepas pemeriksaan kualiti menggunakan Alat Penilaian Kaedah Campuran (MMAT), 19 kajian akhirnya dimasukkan untuk semakan sistematik dan analisis tematik. Keputusan menunjukkan bahawa tekanan ibu bapa terutamanya dipengaruhi oleh tiga kategori faktor: kanak-kanak, ibu bapa dan persekitaran sosial. Antaranya, masalah tingkah laku dan kemahiran kanak-kanak serta keperluan pendidikan, tekanan emosi ibu bapa, cabaran penjagaan, kebimbangan tentang masa depan kanak-kanak dan ciri demografi, serta tekanan ekonomi, diskriminasi sosial, tahap sokongan sosial dan kesan COVID-19, semuanya berkait rapat dengan tekanan ibu bapa. Kajian ini, berdasarkan penyepaduan bukti empirikal sedia ada, menjelaskan secara sistematik faktor utama yang mempengaruhi tekanan ibu bapa dalam kalangan kanak-kanak kurang ID, bukan sahaja memberikan perspektif teori untuk penyelidikan masa depan tetapi juga bukti praktikal untuk memaklumkan pembangunan strategi sokongan dan intervensi yang disasarkan, sekali gus menggalakkan kesejahteraan keluarga dan mengurangkan tekanan ibu bapa.

Kata kunci: ketidakupayaan intelek, ibu bapa, tekanan, Faktor yang mempengaruhi, kajian sistematik

INTRODUCTION

The global prevalence of intellectual disability (ID) is 1%. When a person's intelligence quotient (IQ) test score is less than 70 points, the individual may be diagnosed with intellectual disability (ID). The prevalence of ID is highest in children and adolescents (Maulik et al 2011). Intellectual disability (ID) can exist alone or co-occur with congenital malformations or other neurological characteristics (such as epilepsy, sensory impairment, and autism spectrum disorder (ASD)). The degree of intellectual disability can be divided into mild, moderate, severe, and highly severe (Vissers et al 2016). ID is characterized by severe limitations in intellectual functioning and adaptive behaviour. Without continuous support, adaptive deficits will limit one or more daily life functions of children with ID, such as communication, social participation, and independent living in multiple environments such as home, school, work, and community (Bélanger & Caron 2018). This characteristic accompanies people with ID throughout their lives. People with ID need different levels of lifelong support, including access to education, living independently, health care, employment, and community participation and integration (Patel et al 2018).

Informal caregivers provide unpaid care to relatives, friends, or partners with disabilities, long-term illnesses, or conditions (Totsika et al 2017). They are usually family members, friends, or neighbours (Boluarte-Carbajal et al 2022). As intellectual disability makes it impossible for people who have it to live independently, family members (especially parents) become the prominent ones caring for such people (Emerson & Hatton 2008; Bunga et al 2020).

Parents must assist children with ID with living skills, such as helping them use the toilet, eat, bathe, and dress (Badu 2016; Oti-Boadi 2017; Ntshingila et al 2021; Raliphaswa et al 2022) and menstrual management issues for adolescent girls with ID (Nurkhairulnisa et al 2018). In addition, they need to take care of their children's emotional needs, visit and communicate, and provide educational materials (Enoch et al 2017). Long-term care has caused significant stress for caregivers of children with ID (Patton et al 2018; Syed et al 2020; Purpura et al 2021; Rogers et al 2021). This caregiving stress can cause parents of children with ID to experience higher levels of depression and anxiety (Woodman et al 2013; Gogoi et al 2017; Scherer et al 2019; Willner et al 2020; Islam et al 2022) and lower quality of life (Rodrigues et al 2019; Williams et al 2021; Dizdarevic et al 2022; Staunton et al 2023).

Unlike traditional narrative reviews, a systematic literature review (SLR) systematically integrates scientific evidence to answer specific research questions. This method is transparent and reproducible and aims to comprehensively cover all relevant published literature in the field and conduct a rigorous assessment of the quality of the included evidence (Lame 2019). For example, Kamil et al (2023) explored the impact of the COVID-19 pandemic on the physical environment of people with ID through a systematic literature review, demonstrating the advantages of SLR in identifying key topics, synthesizing cross-research findings, and providing practical recommendations (Kamil et al 2023). Narrative reviews usually comprehensively review existing literature based on expert insights and the author's subjective judgment. Due to the lack of objectivity of this method, the conclusions may vary due to the author's subjectivity (Cipriani & Geddes 2003).

Although studies on stress in caring for children with ID have increased over the past decade, a comprehensive review of the factors affecting parental stress still needs to be completed. It is crucial to study the factors influencing parental stress to effectively support parents of children with ID and explore effective stress-coping strategies to reduce parental stress. Therefore, this research aims to review the existing literature systematically and comprehensively analyse stress factors in parents caring for children with ID.

LITERATURE REVIEW ON STRESS IN PARENTS OF CHILDREN WITH ID

Since the adaptive behaviour of children with ID affects the practical, social, and conceptual skills required by individuals (Ishak et al 2025), it is often difficult for children with ID to achieve independent living. Their independence is influenced by a range of personal and environmental factors, including cognitive ability, self-attitude, community, policy, and education (Zambri et al 2023). Limited independent living skills increase children's dependence on family members, particularly parents, for daily care.

In this caregiving structure, parents are typically defined as "informal caregivers," that is, family members who provide long-term, unpaid support based on a close relationship (Levine & Murray 2004; Lopez-Hartmann et al 2012). However, compared with role definition, an increasing number of studies focus on the impact of this ongoing caregiving responsibility on parental stress. Empirical research shows that parents of children with ID experience significant physical, psychological, social, and economic stress (Perkins & Hewitt 2016). For example, the study by Tlale (2019) indicates that mothers, as primary caregivers, not only bear multiple caregiving tasks in the daily lives of children with ID but also face multiple challenges such as physical fatigue, psychological stress, and social isolation (Tlale 2019). The study by Hoyle et al (2021) also shows that parents of children with ID have a significantly higher risk of experiencing anxiety and depressive symptoms than the general parent group (Hoyle et al 2021). Furthermore, insufficient medical, educational, and social service resources further exacerbate the burden on families (Rodrigues et al 2019). Although the studies consistently reveal the pervasiveness of parental stress, most studies analyse it from a single dimension (such as mental health or economic burden), lacking an integrated exploration of multi-layered influencing factors.

From a theoretical perspective, family stress models provide an important framework for understanding parental stress. Hill (1949) initially proposed the ABCX model, pointing out that family crises (X) are the result of the combined effects of stressful events (A), family resources (B), and cognitive appraisal of the situation (C) (Hill 1949). Building on this, McCubbin and Patterson (1983) proposed the Double ABCX Model, emphasizing the cumulative nature of stress (aA), the expansion of resources (bB), cognitive restructuring (cC), and the dynamic process of long-term family adaptation (xX), and stressing that this theory is particularly suitable for explaining the adaptation mechanisms of families in chronic stress situations (McCubbin & Patterson 2014). Compared with the single crisis model, the Double ABCX Model is better able to explain the persistent and cumulative caregiving stress characteristics in situations of intellectual disability, and this model has also been widely used in research on parental stress of children with ID.

For example, Molero et al (2024) used the Double ABCX Model of family adaptation as a reference to analyse the association between kinship stigma (the internalization of stigma by parents regarding their children) as a stressor and parental marital satisfaction as an adaptation

outcome variable (Molero et al 2024). Kerr et al. (2023) used the Double ABCX Model to explore parental stress in children with ID. Their research found that parental stress in children with ID originates from various levels of society, service provision, family, and individual, and each type of stress interacts with others, creating a vicious cycle (Kerr et al 2023). Therefore, the Double ABCX Model has high theoretical fit in exploring the influencing factors of parental stress in children with ID.

Social support is considered a protective factor in alleviating parental stress. A study by Halstead et al (2018) found that establishing social support, especially in families for children with ID who have behavioural and emotional problems, may improve the well-being of mothers of children with ID and reduce their parental stress (Halstead et al 2018). Zhao et al (2021) further showed that there is a significant correlation between parenting stress, social support, and resilience, and increasing social support can effectively reduce the parental parenting stress of children with disabilities (Zhao et al 2021). The research results of Staunton et al (2023) also showed that the perception of support by parents of children with ID was negatively correlated with stress (Staunton et al 2023). Therefore, social support is an effective way to reduce the stress on parents of children with ID. In summary, existing research mainly focuses on the “buffering” or “protective function” of social support, emphasizing the relationship between support levels and parental stress outcomes, while paying insufficient attention to the risk perception of inadequate social support during the stress formation process.

Therefore, it is necessary to integrate existing research through a systematic literature review to gain a more comprehensive understanding of the multilayered factors influencing parental stress.

METHODOLOGY

This SLR was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standards. The PRISMA 2020 version was used, which contains updated reporting guidelines to reflect recent advances in methods for identification, screening, eligibility, and synthesizing studies (Page et al 2021). The PRISMA 2020 version is beneficial for planning and implementing SLR, ensuring that all relevant information is covered.

RESEARCH QUESTIONS

The question formulation for this study was based on PICO. This tool helps authors formulate appropriate research questions for a review, including population, interest, and context (Shaffril et al 2020). Based on this concept, this SLR consists of three aspects: parents of children with ID (population), influencing factors (interest), and stress (context). Therefore, the main research question of this SLR is: What influencing factors are associated with stress levels in parents of children with ID?

IDENTIFICATION

This SLR used the National University of Malaysia (UKM) electronic library website (https://www.ukm.my/ptsl/?page_id=757&lang=ms (accessed on July 2, 2024)) to search for

articles related to stress in parents of children with ID and the search years were 2015-2024. This study mainly focused on:

- Web of Science (<https://www-webofscience-com.eresourcesptsl.ukm.remotexs.co/wos/woscc/basic-search>) accessed on July 2, 2024 and
- Scopus (<https://www-scopus-com.eresourcesptsl.ukm.remotexs.co/search/form.uri?display=basic#basic>) accessed on August 10, 2024.

The Web of Science and Scopus databases cover many high-quality academic journals and research literature in social sciences. This literature is peer-reviewed in high-quality academic journals, ensuring that the review's literature is scientific and reliable. In addition, Scopus and Web of Science are updated regularly, allowing researchers to obtain the latest research results and progress, providing a comprehensive and timely source of information for SLR. Therefore, they are suitable databases to achieve the research objectives of this article and provide high-quality SLR.

Based on the July to August 2024 search, 84 articles were retrieved from the Web of Science and 185 from Scopus, totalling 269. The search keywords of this SLR include "intellectual disability," "children," "parents," and "stress." To ensure the breadth of the search, multiple search terms were used for each key concept; for example, intellectual disability includes "Intellectual disability" and "Learning disability." Stress includes "burden" and "strain." This SLR also uses Boolean operators (OR/AND) to combine the search terms for each concept to generate an overall search strategy for the database.

Specific keyword search: (("intellectual disability" OR "learning disability" OR "Intellectual disabilities" OR "learning disabilities") AND ("child" OR "children") AND ("mother" OR "father" OR "parent") AND ("burden" OR "strain")).

SCREENING

Since it is almost impossible for the authors to review all the articles that have been published, according to Higgins and Green (2008), only when relevant research can be reported within a specific period should a limit on publication time be set (Higgins & Green 2008). According to the research question and search strategy, it was found that there were many research articles related to parental stress of children with ID since 2015. At the same time, the reason for stopping the search strategy in 2024 is that articles related to the research question have been published in 2024. Therefore, this review will select the timeline between 2015 and August 2024 as one of the inclusion criteria. In addition, the review only includes articles published in English to ensure clarity in understanding. This process excluded 136 articles, leaving 133, and removed 23 duplicate articles, leaving 110 for qualification review. Specific inclusion and exclusion criteria (See, table 1)

TABLE 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Articles related to stress in parents of children with intellectual/learning disabilities (based on title, abstract, keywords).	Articles about other children with disabilities who were not cared for by their parents, for example, if the caregiver was a grandparent, were also excluded.
Full-text access to original journal articles.	Access restricted articles, review articles, books, book chapters, and conference proceedings.
English publications and articles included from 2015 to 2024.	Non-English publications.

ELIGIBILITY CRITERIA

During the eligibility review process, the authors read the titles and abstracts of the retrieved articles to ensure that all articles remaining after screening met the review criteria. This process excluded 91 articles because those articles did not focus on stress in parents of children with ID, some articles focused on studying strategies for coping with stress in parents of children with other types of disabilities, and some articles were review articles rather than empirical data. Overall, only 19 articles were obtained for analysis (See, Figure 1).

QUALITY ASSESSMENT

To ensure the research quality of this study, the authors used the Mixed Methods Assessment Tool (MMAT) to assess each article involved, which involves three aspects: "qualitative" research, appropriate "quantitative" research, and "mixed methods" research (Pace et al 2012). The quality assessment is based on six questions: 1. Is the research question straightforward? 2. Do the subjects fit the theme of this SLR? 3. Are the data analysis methods explained? 4. Is the data collection process described? 5. Do the results reflect the research question of this SLR? 6. Do the conclusions reflect the participants' views based on the data? The authors must answer each question with "yes" or "no" to judge the overall quality. Four "yes" and above are considered "high quality," three "yes" are considered "medium quality," and two "yes" and below are considered "low quality." Through further discussion by the authors, all articles were supposed to meet the reviewing criteria.

After the quality assessment, the identified articles were then critically reviewed. The authors read the abstracts, methods, and results of the 19 identified articles, abstracted the data according to the research questions, and identified the factors related to the parents' stress of children with ID. This study focused on using qualitative techniques to identify themes and sub-themes by conducting a thematic analysis of the content of the abstracted data. Braun and Clarke (2006) pointed out that thematic analysis identifies, analyses, and reports patterns (themes) in data. It not only organizes and describes the data in a rich and detailed manner at a basic level, and usually further interprets various aspects of the research topic (Braun & Clarke 2006).

Through thematic analysis, the authors identified three themes, and eleven sub-themes related to the factors affecting stress in parents of children with ID. Subsequently, the three authors and the corresponding author reviewed these themes and subthemes to ensure the accuracy of the data.

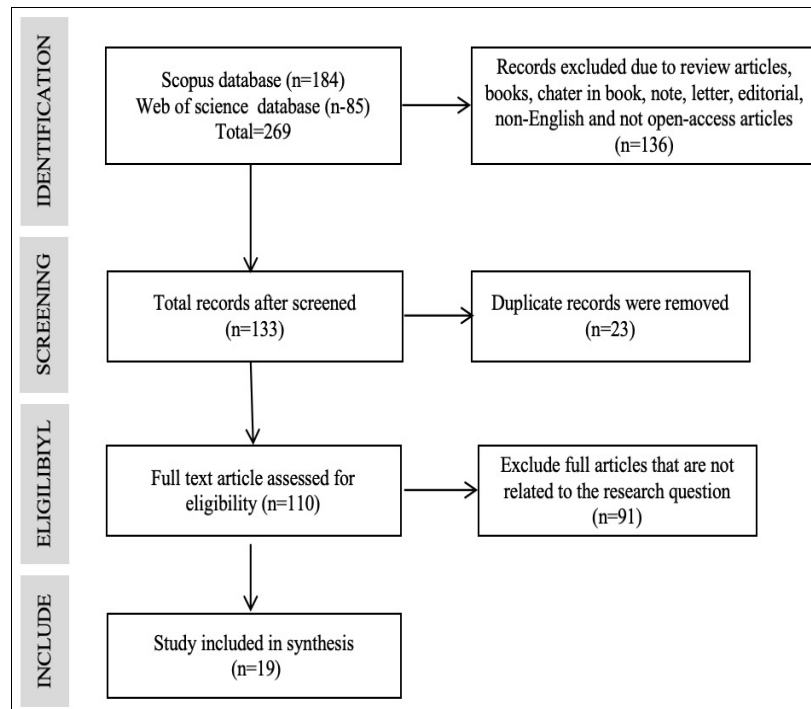


FIGURE 1. PRISMA Flow Diagram of the study

RESULT

BACKGROUND OF THE STUDIES

According to the inclusion and exclusion criteria, 269 articles were removed for duplicates and abstract screening, and 110 studies were selected for full-text review. These 110 studies were open-access, full-text readable, written in English, and had no duplicated journal articles related to caregiver stress. After the analysis, 19 selected articles were obtained, and all authors agreed that thirteen articles were high quality, three were medium quality, and three were low quality (See, table 2).

Four studies were conducted in South Africa, two in China, two in the United States, and two in Ghana. One study was conducted in Bangladesh, Nigeria, Pakistan, Australia, Spain, the United Kingdom, Italy, South Korea, and Malawi. Among these 19 articles, twelve articles directly focused on parents of children with ID (Cohen 2016; Badu 2016; Oti-Boadi 2017; Masulani-Mwale et al 2018; Adeleke et al 2020; Arzeen & Irshad 2021; Ntshingila et al 2021; Islam et al 2022; Raliphaswa et al 2022; Van der Mescht et al 2023; Buthelezi et al 2024; Biggs et al 2024). Two articles studied parents of children with autism and ID (Tsermentseli & Kouklari 2021; Wan et al 2022). In addition, two articles analyzed the stress of parents of children with developmental disabilities (including ID) and typically developing children (Patton et al 2018; Jung et al 2023). One article studied parents of children with ID, autism, and hearing impairment (Chen et al 2020), another research focused on the family members (mainly parents) of people with ID (including children with ID) (Jenaro et al 2020), and there was one study involving mothers of children with Down Syndrome (all have ID) (Fucà et al 2022).

Regarding the year of publication, two articles were published in 2016 (Badu 2016; Cohen 2016), one article was published in 2017 (Oti-Boadi 2017), two articles were published in 2018 (Masulani-Mwale et al 2018; Patton et al 2018), and three articles were published in 2020 (Chen et al 2020; Adeleke et al 2020; Jenaro et al 2020). Next, three articles were published in 2021 (Ntshingila et al 2021; Tsermentseli & Kouklari 2021; Arzeen & Irshad 2021), and three articles were published in 2022 (Raliphaswa et al 2022; Islam et al 2022; Fucà et al 2022). Subsequently, three articles were published in 2023 (Van der Mescht et al 2023; Jung et al 2023; Wan et al 2023), and two were published in 2024 (Buthelezi et al 2024; Biggs et al 2024).

TABLE 2. Background of the studies

No	Author	Year	Methodology	Sample	Quality			Region	
					High	Medium	Low		
1	Ntshingila et al	2021	Qualitative, exploratory, descriptive, and contextual design	8 parents of children with ID	█			South Africa	Africa
2	Raliphaswa et al	2022	Qualitative, exploratory, descriptive, and contextual	13 mothers of children with ID	█			South Africa	
3	Van der Mescht et al	2023	Quantitative	218 caregivers of children with severe ID	█			South Africa	
4	Buthelezi et al	2024	Qualitative	6 caregivers of children with ID	█			South Africa	
5	Badu	2016	Qualitative	20 parents of children with ID	█			Ghana	
6	Oti-Boadi	2017	Qualitative	11 mothers of children with ID	█			Ghana	
7	Adeleke et al	2020	Quantitative simple survey research design	150 parents of children with ID	█			Nigeria	
8	Masulani-Mwale et al	2018	Cross-sectional study	170 parents of children with ID	█			Malawi	
9	Chen et al	2020	Quantitative	1450 parents of children with autism, ID, or visual impairment and hearing impairment			█	China	Asia
10	Wan et al	2023	Quantitative	941 parents of children with ID and ASD	█			China	
11	Arzeen & Irshad	2021	Cross-sectional study	150 parents of children with ID	█			Pakistan	
12	Islam et al	2022	Cross-sectional study	60 parents of children with ID	█			Bangladesh	
13	Jung et al	2023	Qualitative	79 parents of children with DD (59 with ASD, 61 with ID, 12 with language disorder) and 117 with TD			█	Korea	
14	Jenaro et al	2020	Qualitative	515 relatives of individuals with ID	█			Spanish	Europe
15	Tsermentseli & Kouklari	2021	Quantitative	133 mothers of children with ASD-ID		█		England	
16	Fucà et al	2022	Cross-sectional, observational study	78 mothers of children with ID and DS		█		Italy (Rome)	
17	Cohen et al	2016	Quantitative	66 fathers of children with ID and 116 fathers of children with TD		█		America	North America
18	Biggs et al	2024	Mixed methods	37 parents of children with IDD	█			America	
19	Patton et al	2018	Cross-sectional study	1152 carers from the Household Income and Labour Dynamic in Australia study and 284 carers of adolescents with ID			█	Australia	Oceania

MAIN FINDINGS

Through thematic analysis, the factors affecting the parents' stress of children with ID can be summarized into three main themes and eleven sub-themes. The main themes are child factors, parent factors, and environmental factors. After further analysis of these central themes, children factors include three sub-themes: behavioural problems, skills, and educational needs. Parental factors include four sub-themes: emotional distress, care challenges, concerns about the child's future, and parents' demographic characteristics. Environmental factors include four sub-themes: economy, social discrimination, social support, and the impact of COVID-19 (See, Table 3).

Children's factors included three sub-themes: behavioural problems, skills, and educational needs.

BEHAVIOURAL PROBLEMS

Behavioural problems of children with ID affect parental stress (Cohen et al 2016; Badu 2016; Jenaro et al 2020; Fucà et al 2022; Wen et al 2023; Biggs et al 2024). According to Chen et al (2020), behavioural problems of children with ID (e.g., unwillingness to wear masks, unwillingness to wash hands, requests to go out, sleep problems, eating problems, and mood swings) predict parents' mental health and increase parents' psychological stress (Chen et al 2020). Ntshingila et al (2021) pointed out that when bathing children with ID, children will have behavioural problems such as hitting their parents or biting themselves; when feeding food, children will hit their heads on the floor, these types of challenging behaviour increase parental stress (Ntshingila et al 2021). Similarly, Jung et al (2023) also showed that behavioural problems of children with ID are the main factors causing parenting stress, including aggressive behaviour, hyperactivity, inattention, high demands, and stubbornness (Jung et al 2023).

SKILLS

The skills mastered by children with ID are also significantly impact parental stress. Parental stress is closely related to the social impairment of children with ID. In addition, children's difficulties in executive function, especially in starting tasks and working memory, are also related to mothers' parenting stress (Tsermentseli & Kouklari 2021; Fucà et al 2022). Jung et al (2023) pointed out that the social communication difficulties and weak social motivation of children with ID strongly correlate with parental stress. The study also found poor adaptive function increases parental parenting stress (Jung et al 2023). The more evident social impairment of children with ID, the higher level of parental parenting stress. Therefore, interacting with dysfunctional children with ID increases parental stress (Jenaro et al 2020).

TABLE 3. Themes and sub-themes

No	Themes Sub-themes	Children factors			Parental factors			Environmental factors				
		Behavioural problems	Skills	Educational Demands	Emotional Disturbance	Care Challenges	Worries about the Child's Future	Demographic Characteristics of Parents	Economy	Social Discrimination	Social Support	Impact of the COVID-19
Author (Year)												
1	Cohen et al 2016	■						■				
2	Badu 2016	■			■	■	■	■	■	■		
3	Oti-Boadi 2017				■	■	■	■	■	■		
4	Masulani-Mwale et al 2018				■			■	■		■	
5	Patton et al 2018				■	■		■	■		■	
6	Adeleke et al 2020			■	■			■	■	■		
7	Chen et al 2020					■		■				■
8	Jenaro et al 2020	■	■					■				■
9	Ntshingila et al 2021				■	■	■		■	■		
10	Tsermentseli & Kouklari 2021		■	■							■	
11	Arzeen & Irshad 2021							■			■	
12	Raliphaswa et al 2022				■				■	■	■	
13	Fucà et al 2022	■	■			■			■			
14	Islam et al 2022							■			■	
15	Wan et al 2023	■						■				■
16	Van der Mescht et al 2023								■		■	
17	Jung et al 2023		■						■			
18	Buthelezi et al,2024			■	■				■	■	■	■
19	Biggs et al 2024	■			■						■	■

CHILDREN FACTORS

EDUCATIONAL NEEDS

Due to the unique needs of children with ID, education is also a factor that affects parental stress because it directly reflects the unique requirements and difficulties of children with ID for educational resources. Adeleke et al (2020) pointed out that due to the impact of the unique needs of children with ID on the allocation of family resources, it is difficult for children with ID in Nigeria to obtain a quality education, and this indirectly leads to negative impacts on the education of their brothers and sisters. Therefore, having children with ID damages the family's education and causes increased psychological stress on parents (Adeleke et al 2020). Due to the special educational needs of children with severe ID, in South Africa, even if a child with ID is admitted to a public school, parents are usually told that the child with ID is very disruptive in class and cannot learn anything (Buthelezi & Mawila 2024). Tsermentseli et al (2021) pointed out that the mother's stress level varies according to the educational stage of the child with ID. As academic requirements increase, children with ID need more support, especially mothers in the upper grades of elementary school who are under more significant stress (Tsermentseli et al 2021).

PARENTAL FACTORS

Parental factors included four sub-themes: emotional distress, caregiving challenges, concerns about the child's future, and parents' demographic characteristics.

EMOTIONAL DISTRESS

The emotional distress of parents in the process of caring for children with ID is one of the critical factors affecting parental stress. According to Masulani-Mwale et al (2018), some parents lack the confidence to manage children with ID (Masulani-Mwale et al 2018). Subsequently, studies have pointed out that mothers with ID will feel frustrated because they have a child with ID and show fear, anger, self-blame, and helplessness (Badu 2016; Raliphaswa et al 2022; Buthelezi & Mawila 2024). This low emotional health will cause psychological distress to parents (Jenaro et al 2020).

In addition, according to the research of Ntshingila et al (2021), the emotional reactions of parents caring for adolescents with ID manifest as feelings of sadness, pain, worry, fear of death and the future, along with a sense of having neglected other family members (Ntshingila et al 2021). Parents and siblings of children also face emotional problems such as anger and guilt when caring for children with ID (Adeleke et al 2020). During the COVID-19 pandemic, as the mood of children with ID worsened, parents experienced increased unhappiness and became more irritable during the caregiving process (Biggs et al 2024). These negative emotions will increase the psychological stress level of parents.

CAREGIVING CHALLENGES

Caring for children with ID presents numerous challenges, including managing their aggressive behaviours and difficult-to-handle physical issues. As parents age and become physically frail, coping with these challenges becomes increasingly tricky. Additionally, poverty and a lack of resources, such as the absence of assistive devices like wheelchairs, further exacerbate the burden of caregiving (Ntshingila et al 2021). Dysfunctional parent-child interactions and difficult-to-discipline children with ID increase the challenges of parenting, which are significantly correlated with parenting stress (Fucà et al 2022). Children with ID require much care in daily living skills (such as toileting, eating, bathing, brushing teeth, and dressing), and the considerable care challenges increase parental stress (Badu, 2016; Oti-Boadi 2017).

In addition, according to the study by Chen (2020), parents must provide continuous, long-term, and repeated training to children with ID to gradually improve their daily behaviours. This caregiving difficulty is a predictor of the mental health status of parents of children with ID, posing a direct challenge they face during the caregiving process (Chen et al 2020).

CONCERNS ABOUT THE CHILD'S FUTURE

Many parents of children with ID expressed feeling uncertain and worried about their children's future (Badu 2016; Oti-Boadi 2017). They also worry about who will take care of their intellectually disabled child if they become ill (Biggs et al 2024). Furthermore, Ntshingila et al (2021) also emphasized how parents of children with ID are worried about their children's future. They are concerned about how their children will live if they die before their children and who will take care of their children after they die (Ntshingila et al 2021).

PARENTAL DEMOGRAPHIC CHARACTERISTICS

Parental demographic characteristics, including personality, gender, education level, and relationship status, are essential factors that influence stress in parents of children with ID.

First, the personality of the parents. Parents' neuroticism level is an essential individual factor affecting their mental health. Higher neuroticism is often associated with higher stress and a higher risk of psychological problems (Chen et al 2020). Another study also showed that parents with high agreeableness and low neuroticism felt less stress when caring for children with ID (Wen et al 2023).

The second demographic characteristic is gender. Parental gender is significantly correlated with stress, and female caregivers experience more significant parent-related stress than male caregivers (Patton et al 2018). Subsequently, according to the study by Arzeen and Irshad (2021), the challenges experienced by parents of children with ID vary by gender, and fathers receive more support than mothers, so mothers have more psychological distress (Arzeen & Irshad 2021). In addition, the study by Islam et al (2022) also pointed out that mothers of children with ID have lower marital satisfaction in their families than fathers (Islam et al 2022).

Next is the education level of the parents. Parents of children with ID who have higher education levels and less psychological distress (Masulani-Mwale et al 2018). The study of Cohen et al (2016) found that the annual family income was highly correlated with the father's education level of a child with ID. Fathers with higher education levels had higher socioeconomic status and lower psychological stress (Cohen et al 2016). Another study suggested that parents with higher education levels could participate in seminars and workshops to obtain knowledge about (the causes, effects, and remedies of children with ID) and reduce psychological stress by increasing their knowledge (Arzeen & Irshad 2021).

Finally, the relationship status of the parents. Parents of children with ID who are married or in a relationship report lower stress levels, while single parents or parents without a partner tend to experience more significant stress (Badu 2016; Patton et al 2018; Masulani-Mwale et al 2018).

SOCIAL ENVIRONMENTAL FACTORS

Environmental factors included four sub-themes: economy, social discrimination, social support, and the impact of COVID-19.

ECONOMY

Economic burden is a critical environmental factor affecting parental stress. Mothers who take care of children with ID and are not well-off are more likely to feel stressed (Patton et al 2018). Parents of children with ID said that medical and nursing costs are expensive, most medicines are not covered by medical insurance, and some specialists' fees far exceed the scope of medical assistance, which puts parents under a financial burden (Buthelezi & Mawila 2024). Due to the lack of material resources, parents have to pay for medicines and accessories such as wheelchairs out of their own pockets (Ntshingila et al 2021; Raliphaswa et al 2022). Another study also stated that caring for children with ID without social or disability benefits may exacerbate economic challenges, which puts parents of children with ID under tremendous financial stress (Van der Mescht et al 2023).

In addition, parents said that their children's intellectual disability would affect their employment, thus affecting the family's financial situation (Badu 2016; Oti-Boadi 2017; Raliphaswa et al 2022). According to Adeleke et al (2020), because children with ID require multidisciplinary approaches and various services to develop independent living skills, some

parents have to give up their jobs to take care of their children with ID, which hurts the family's overall economy (Adeleke et al 2020). Another study also showed that unemployed mothers of children with ID suffer more significant parenting stress than working mothers (Fucà et al 2022). Therefore, low socioeconomic status directly affects parents' mental health and leads to high parenting stress (Masulani-Mwale et al 2018; Jung et al 2023).

SOCIAL DISCRIMINATION

Parents of children with ID said that they rarely receive social invitations, and even if they are invited, they often feel unwelcome, so they gradually withdraw from social activities. In addition, they also need to deal with the discomfort caused by their children attracting too much attention and being watched by others (Buthelezi & Mawila 2024). According to Oti-Boadi (2017), parents of children with ID feel discriminated against and isolated (Oti-Boadi 2017). In addition, some studies have also pointed out that parents who take care of children with ID say that their children are dehumanized, some people in the community do not treat their children as human beings, and they often suffer discrimination and insults from some people at home and in the community (Badu 2016; Ntshingila et al 2021; Raliphaswa et al 2022).

In addition to the discrimination, they face at home and in the community, teachers at school also refuse to accept children with ID, especially those with severe disabilities. Teachers believe that even if only having even one child with ID in the classroom may trigger unhealthy behaviours and hurt teaching activities (Adeleke et al 2020).

SOCIAL SUPPORT

Social support is essential in alleviating parental stress. Parents with higher social support have significantly lower stress levels than those with lower social support, and lack of adequate support in families of children with ID predicts higher levels of parental stress (Patton et al 2018; Jenaro et al 2020). Support from family members affects the parents' stress of children with ID (Cohen et al 2016; Chen et al 2020; Ntshingila et al 2021; Islam et al 2022; Biggs et al 2024). In the study by Oti-Boadi (2017), about 70% of mothers reported receiving support from their husbands, family, friends, churches, and healthcare professionals, this support is essential for maintaining their mental health (Oti-Boadi 2017). However, some mothers with ID also report less perceived social support (Arzeen & Irshad 2021). They lack support from their partners, community, and relatives. They expect support from close family members, such as their husbands and parents-in-law, but never get it, which makes mothers feel stressed (Raliphaswa et al 2022).

Lack of educational support for children with ID is also related to parental stress. Some parents of children with ID need more support from schools and professional service providers. Schools and teachers' stress increases significantly when they feel unsupported by schools and teachers, their stress increases significantly (Adeleke et al 2020; Biggs et al 2024). Buthelezi and Mawila (2024) state that children with ID need more educational support. The South African government needs to provide more educational options for special children. Only a few preschools specialize are provided for children with ID. There is no government assistance, which makes parents feel stressed (Buthelezi & Mawila 2024).

In addition, psychological support is also related to parental stress for children with ID. The results of Masulani-Mwalen et al (2018) found that parents of children with ID who received more psychological support had less psychological distress, and parents who did not receive

support had higher psychological stress (Masulani-Mwalen et al 2018). At the same time, another study also showed that parents' lack of social and emotional support would increase their psychological burden (Van der Mescht et al 2023).

IMPACT OF COVID-19

Parents of children with ID need to continue to seek unique treatments, medical equipment, and related services to deal with their children's behavioural problems, and COVID-19 may hinder their access to these solutions (Chen et al 2020). In addition, according to the research of Wen et al (2023), COVID-19 has changed the environment, further highlighting the moderating role of parental personality traits in parenting stress. Parental agreeableness plays a protective role in coping with the relationship between problematic behaviours of children with ID and parenting stress. At the same time, in the unique environment of the epidemic, neuroticism becomes a risk factor for increased stress (Wen et al 2023). Some parents expressed that during the COVID-19 lockdown and isolation, the continuous transformation of teaching services for children with ID further exacerbated parents' anxiety and uncertainty, leading to increased parental stress (Biggs et al 2024).

DISCUSSION AND CONCLUSION

This study, based on the theoretical perspective of the Double ABCX Model, systematically reviews the main factors influencing parental stress in children with ID. This systematic literature review explores the main factors affecting parental stress in children with ID, including three main categories: children, parents, and the social environment. Within the framework of the Double ABCX Model, these factors can be understood as significant stressors faced by parents in caring for children with ID, increasing the parental stress through different pathways. These factors not only reveal the multiple challenges parents face in caring for children with ID but also provide valuable perspectives for future research and practice.

Child factors, children's behavioural problems, insufficient social skills, and educational needs are the primary sources of parental stress. From the perspective of the Double ABCX Model, these child-related issues constitute the most direct source of stress for families in the daily care process (Shahrier et al 2016). Children's behavioural issues (Cohen et al 2016) and educational barriers (Buthelezi & Mawila 2024) often increase parents' anxiety and parenting burden. In addition, according to Jung et al (2023) children's social communication difficulties are closely related to parents' stress levels (Jung et al 2023). Solving these problems is crucial to alleviating parents' caregiving stress. These results indicate that difficulties children face in behaviour, social interaction, and learning not only affect their own development but also significantly increase parental stress levels by increasing caregiving needs.

In terms of parental factors, emotional distress and caregiving challenges significantly affect parents' mental health. Furthermore, in the Double ABCX Model, parental gender differences influence their perceived stress to some extent (Boettcher et al., 2025). Arzeen and Irshad's (2021) research also showed that factors such as parents' gender, education level, and marital status also show significant differences in stress tolerance levels. Female caregivers bear greater emotional and psychological burdens (Arzeen & Irshad 2021), while parents with higher education levels are less stressed (Masulani-Mwale et al 2018).

In terms of social environmental factors, lack of social support, economic burden, social discrimination, and the impact of COVID-19 are also widely considered to be significant sources of stress for parents. According to the Double ABCX Model, family stress and adaptation result from the combined effects of stressors, resources, and cognitive appraisal. In this process, parental social support, mental health, and long-term care experience can be considered important components of the family stress system, which further exacerbate parents perceived stress (Boettcher et al 2025). Financial difficulties are particularly prominent. Many families cannot afford the high medical expenses related to ID (Buthelezi & Mawila 2024). Social discrimination against children with ID further exacerbates the isolation and psychological burden of parents (Raliphaswa et al 2022). Insufficient social support is also a common problem. The lack of help from family members, schools, and professional institutions makes parents feel helpless in the care process (Biggs et al 2024). In addition, during COVID-19, the challenging behaviours of children with ID will increase, and parents need to invest more support and patience, which makes them feel overwhelmed (Buthelezi et al 2024). These social environmental factors not only increase the caregiving burden on families but also limit parents' access to social support resources.

The interweaving of multiple factors has aggravated the psychological stress of parents of children with ID. By systematically reviewing the existing literature through the lens of the Double ABCX Model, this study clarifies the multidimensional stressors—related to children, parents, and the social environment—that parents experience. This theoretical contribution enhances the applicability of the Double ABCX Model to the stress of parents of children with ID. It provides a conceptual foundation for future research and interventions targeting these stressors. This theoretical clarification provides a structured framework for future research to examine stress pathways and intervention points systematically. Therefore, providing multi-level social support, economic assistance, and policy guarantees will be an essential approach to reducing stress on these families in the future. At the same time, intervention measures for the education and behaviour management of children with ID, as well as psychological services for parents, should also be included in policy formulation.

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