

## REVIEW ARTICLE

# Determinants of the quality of life of mother with children with disability: A systematic review

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## Abstract

Mothers who care for children with disabilities experience various problems that affect their quality of life. The objective of this study was to identify the factors that influence the quality of life of mothers with disabilities children. A systematic review was conducted using data from six prominent electronic databases. Studies were observational, cross-sectional designs, and original research conducted from 2019 to 2023. Mothers who have children with Autism Spectrum Disorder (ASD) have the lowest scores for quality of life compared to mothers who have children with other types of disabilities. Parents have lower quality of life scores as primary caregivers compared to other caregivers. WHOQOL-Bref is the most widely used method as an instrument for evaluating quality of life. Parents who have children with disabilities experience problems, especially psychological health. The main factor related to the quality of life of parents who have children with disabilities is lifestyle. Parents who experience a decrease in quality of life are worried that their ability to provide care will not be optimal. It is recommended for health workers to socialize healthy lifestyle behaviors so that they can help improve the quality of life of parents who have children with disabilities. (*Afr J Reprod Health* 2024; 28[10s]: 332-347).

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**Keywords:** Quality of life; mother; disability children

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## Résumé

Les mères qui s'occupent d'enfants handicapés rencontrent divers problèmes qui affectent leur qualité de vie. L'objectif de cette étude était d'identifier les facteurs qui influencent la qualité de vie des mères d'enfants handicapés. Une revue systématique a été menée à l'aide de données provenant de six bases de données électroniques de premier plan. Les études étaient des études observationnelles, transversales et des recherches originales menées de 2019 à 2023. Les mères qui ont des enfants atteints de troubles du spectre autistique (TSA) ont les scores les plus bas en matière de qualité de vie par rapport aux mères qui ont des enfants atteints d'autres types de handicaps. Les parents ont des scores de qualité de vie inférieurs en tant que principaux soignants par rapport aux autres soignants. WHOQOL-Bref est la méthode la plus utilisée comme instrument d'évaluation de la qualité de vie. Les parents qui ont des enfants handicapés rencontrent des problèmes, notamment de santé psychologique. Le principal facteur lié à la qualité de vie des parents qui ont des enfants handicapés est le mode de vie. Les parents qui subissent une diminution de leur qualité de vie craignent que leur capacité à fournir des soins ne soit pas optimale. Il est recommandé aux agents de santé de socialiser des comportements de vie sains afin qu'ils puissent contribuer à améliorer la qualité de vie des parents qui ont des enfants handicapés. (*Afr J Reprod Health* 2024; 28 [10s]: 332-347).

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**Mots-clés:** Qualité de vie; mère; enfants handicapés

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## Introduction

Children with disabilities are typically defined as those encountering limitations in their activities and participation due to various impairments. Globally, over 100 million children grapple with disabilities,

and the nature of these disabilities can significantly affect their daily lives. The presence of a child with a disability invariably impacts their family, presenting both physical and emotional challenges. The family, and particularly the mother, plays a central and indispensable role in raising children

with disabilities, emphasizing the crucial significance of their care and support network within the familial and social spheres<sup>1</sup>.

The responsibilities carried out by primary caregivers, particularly those tending to children with disabilities, are commonly referred to as caregiver burden. This caregiver burden encompasses a range of emotions and challenges, such as feelings of overwhelming responsibility, constant apprehension, uncertainty in meeting the unique needs of children with disabilities, and difficulties in maintaining social connections. As this burden escalates, it often leads to physical and mental health issues for the caregivers, financial strains, and disruptions in family life. These factors, in turn, contribute to a decline in the overall quality of life, especially when the duration and severity of the illness increase. Additionally, the emotional toll of caregiving, including self-blame, guilt, and shame, can further compound the challenges faced by caregivers<sup>2</sup>.

According to Whmeyer & Schalock, key dimensions of quality of life encompass emotional well-being, interpersonal relationships, material well-being, physical health, social engagement, and environmental harmony<sup>3</sup>. The term "quality of family life" refers to the degree to which the family, particularly one with a member with a disability, can satisfy their fundamental needs, relish shared moments, pursue leisure activities, and cultivate interests. Indeed, the upbringing of children with disabilities within a family setting can have a profound impact, often entailing stress, limitations on parental free time, sleep disruptions, heightened emotional strains, feelings of rejection, shame, anxiety, and an increased risk of various psychological disorders, all of which can influence their overall quality of life<sup>4</sup>.

Extensive research on the quality of life of mothers caring for children with disabilities underscores the multitude of factors that influence maternal well-being. These factors encompass the nature of the disability, challenges associated with child behaviour, parenting dynamics, employment status, social engagement, parental stress levels, and the strategies employed in coping with these unique circumstances<sup>5</sup>. This study aims to identify

the factors that influence mothers' quality of life when their children have special needs.

## Methods

The review convention for this precise survey has been registered with Prospero (Prospero registration number CRD42023462008).

### Search Strategy

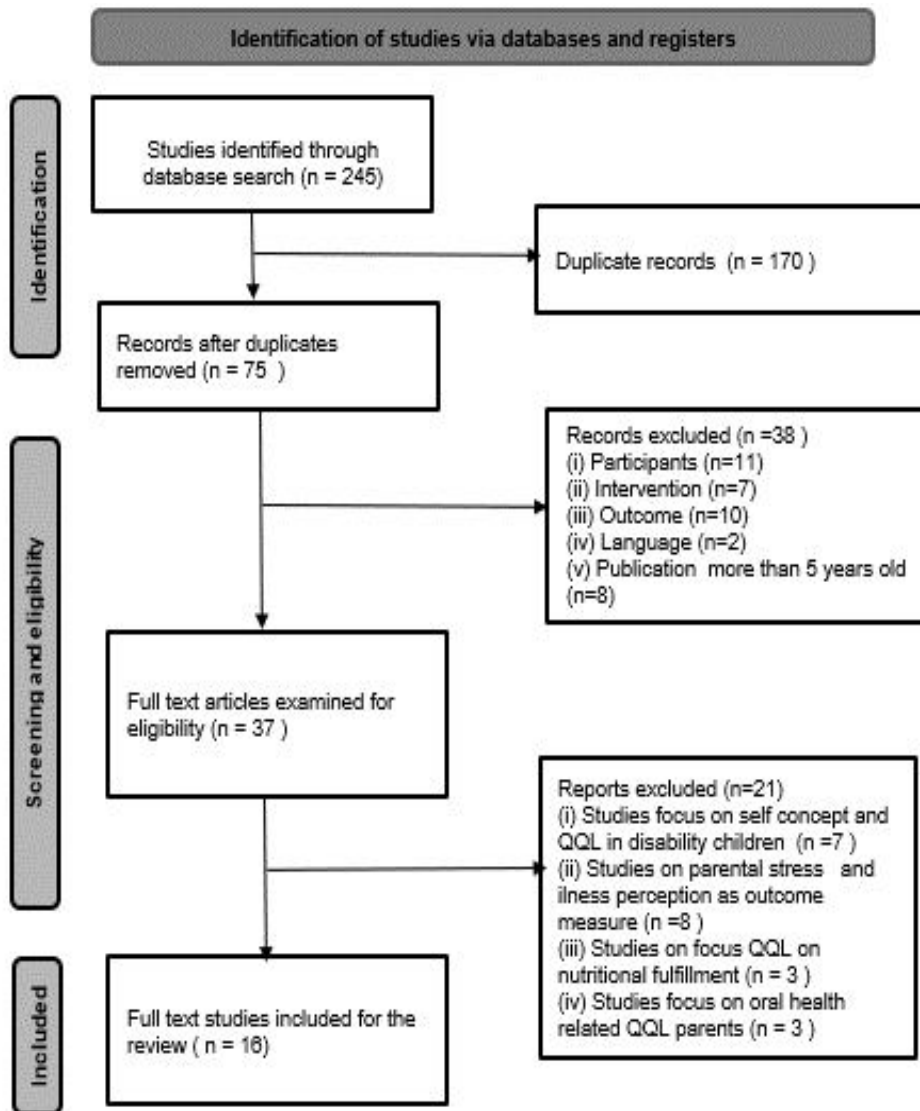
A comprehensive literature sourced from six prominent electronic databases: Scopus, Web of Science, Science Direct, EBSCO host, ProQuest, and PubMed. The search was meticulously conducted employing a set of targeted keywords, including terms such as "factors" or "determinants," "quality of life," "mother" or "caregiver," and "child disabilities" or "children with disabilities."

### Study selection criteria

To be eligible for inclusion, studies had to follow observational cross-sectional designs, articles published in English language, research studies that measured quality of life of mothers or caregivers of children with disabilities without having comparison group and qualify as original research from 2019 to 2023. The screening process, encompassing title screening, abstract screening, full-text screening, and data abstraction, was conducted to ensure an unbiased selection. The selected studies underwent a risk of predisposition appraisal utilizing the JBI basic examination instrument.

### Data extraction and quality assessment

Two authors and a team of reviewers were involved in data extraction, including author, year, cut where the study was conducted, type of disability of children, type of caregivers, total of caregivers, outcome measure, conclusion (including factors that influence the low quality of life of participants who have children with disabilities) and quality assessment. Next, a methodological assessment was carried out on 16 articles using the quality evaluation instrument (QAT) for observational



**Figure 1:** Flow diagram of search strategy, screening, and included studies

cross-sectional studies proposed by the National Institutes of Health.

**Methodological quality assessment of study**

Methodological assessment was carried out using QAT for observational research, namely a cross-sectional study on 16 relevant studies. The results obtained were that the entire article had a fairly good score after assessing methodological quality using QAT. Details of the methodological quality assessment are presented in Table 1.

**Participants**

In research conducted 10 studies participants were parents of children with developmental disabilities. There are 3 studies the respondents are family caregivers (mother, father, brother and sister). Participants in 2 studies were mothers of children and persons with disabilities and the participants in 1 research were spouse (child's father), parent (child's grandparent), friends/acquaintances/relatives.

**Table 1:** Methodological quality assessment of study

<b>Author, year</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b>	<b>14</b>	<b>Overall quality</b>
Chakraborty, et all, 2019	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Eljiri K & Matsuzawa A, 2019	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Jeoung Bogja, 2019	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Borilli, et al., 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Ghazawy, et al., 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Mahmutovic, et al., 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Pineio, et al, 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Xia, et al., 2020	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Ali Usman, et al., 2021	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Colak B & Kahrman I, 2021	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Fereidouni, et al., 2021	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Dizdarevic, et all, 2022	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Jeoung Bogja, 2022	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Letovancova K. M & Slana M, 2022	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Widyawati, et all, 2022	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Sulaimani, et all, 2023	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	Y	NA	Y	Fair

**Table 2:** Characteristics of the included studies

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
Chakraborty, et al, 2019	India	Developmentally disabled children	Primary caretaker (mother, father)/parents of developmentally disabled children.	69 parents with developmental disabilities children and 137 parents with healthy children.	The Parental Stress Scale survey and the Brief Form-12 adaptation 2, Physical Health Component Score (PCS) and the Mental Health Component Score (MCS).	<ol style="list-style-type: none"> <li>1. There are significant differences between the intervention group and the treatment group regarding employment variables, conditions of siblings of children with disabilities, smoking and physical activity. Parents of children with developmental disorders have significantly higher levels of stress and worse quality of life, especially in the mental health domain, compared to the control group.</li> <li>2. There is no difference in quality of life in the physical health domain between the two groups.</li> <li>3. Stress has a negative correlation with parental quality of life in the mental and physical health domains.</li> </ol>	Stress caused by caring for a disabled child can harm the parents' quality of life. It's important to have strategies to manage and reduce this stress, as it can greatly improve the well-being of caregivers <sup>6</sup> .
Eljiri K & Matsuzawa A, 2019	Japan	Intellectual disability, autism spectrum disorder, down syndrome (DS), epilepsy, genetic disorders (except DS), attention deficit hyperactivity disorder.	child's father, child's grandparent, friends/acquaintances/relatives	243 Japanese mothers with special needs children.	Questionnaires employment, financial, and health issues.	<ol style="list-style-type: none"> <li>1. The majority of respondents have a lower employment rate (49%) among Japanese mothers with children aged 6 to 18 living in the same area.</li> <li>2. More than half (57%) of unemployed mothers expressed a desire to work.</li> <li>3. About 62% of mothers are in the low-income group.</li> <li>4. Mothers' status as single parents, good health, high education, and use of child care services are positively related to employment. In particular, good maternal</li> </ol>	Mothers with disabilities had lower job participation and income compared to other Japanese mothers. Most jobless mothers expressed a desire for paid employment <sup>7</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
Jeoung Bogja, 2019	Incheon, South Korea	Intellectual disability, autism, Down syndrome, and developmental delay.	Parents of children with developmental disability (father and mother).	243 mothers of children with developmental disabilities.	Quality of life; the health practice behaviour questionnaire comprised details of health condition, caring behaviour, and diet.	health is strongly related to employment that generates income for them. 1. The mother's quality of life score increased by 0.173 (P<0.01) when the child's quality of life score increased by 1. The increase in the mother's quality of life score can be seen from the coefficient of determination that explains the change R2=0.086. 2. The standard of living score increased by 0.132 (P<0.05) when the child's health condition score increased by 1, this can be seen from the coefficient of determination R2=0.014. 3. The physical condition score increased by 0.209 (P<0.001) when the child's condition score increased by 1. The coefficient of determination that explains this change is R2=0.04.	Significant differences emerged in exercise habits, quality of life, family and neighbour relationships, living standards, physical well-being, emotions, and self-esteem among various sub-factors. It was observed that diet habits correlated with quality of life, physical well-being, and emotional state within the quality of life sub-factor <sup>8</sup> .
Borilli, et al., 2020	Brazil	Intellectual disability (ID) and Autism spectrum disorder (ASD).	Parents (mother and father)	69 families who have children with mild ID and ASD	The Barthel index for activities of daily living and the Beach Centre FQoL scale.	1. The factors that most influence quality of life are "family interaction" (3.91±0.42; p<0.001), "caregiving" (3.79±0.35; p<0.001) and "disability-related support" (3.98±0.16; p<0.001); and higher than the scores for the domains "physical/material well-being" (3.19±0.64; p<0.001) and "emotional well-being" (2.75±0.62; p<0.001). 2. Marital status, monthly family income, family spirituality and effective	The well-being of the families studied was maintained through elements like family interactions. However, it was negatively affected by emotional well-being and physical and material circumstances <sup>9</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
						communication skills are predictors of Family Quality of Life (FqoL).	
Ghazawy, et al., 2020	Egypt	Visual/hearing, physical, mental and mixed.	Family caregivers.	260 family caregivers of disabled patients	Caregiver Burden Inventory (CBI) developed by Novak and Guest	Factor analysis yielded a five-factor solution using 20 items (four for each dimension) that accounted for 72.7% of the total variance. The Caregiver Burden Inventory (CBI) and its dimensions demonstrated high internal consistency (Cronbach's alpha values > 0.70). Caregiver education, family income, mental illness, and mixed disability were significant predictors of total Caregiver Burden Inventory (CBI)	Caregiver Burden Inventory (CBI) is an effective multidimensional measure of the caregiver burden of disabled subjects. Caregiver education, family income, mental impairments, and mixed disabilities were the significant predictors of Caregiver Burden Inventory (CBI) <sup>2</sup> .
Mahmutovic, et al., 2020	Sarajevo, Canton	Intellectual and developmental disabilities.	Mothers of children and persons with disabilities	100 mother of children and persons with disabilities	World Health Organization QOL-BREF	<ol style="list-style-type: none"> <li>1. There is a significant relationship between the number of family members with the social interaction domain (<math>r_s = 0.219</math>; <math>p &lt; 0.05</math>), the environmental domain (<math>r_s = 0.220</math>; <math>p &lt; 0.05</math>) and general QOL (<math>r_s = 0.227</math>; <math>p &lt; 0.05</math>).</li> <li>2. There is a significant relationship between the age of the respondents with the environmental domain (<math>r_s = 0.205</math>; <math>p &lt; 0.05</math>).</li> <li>3. Respondents who drive cars show significantly higher levels of QOL in the</li> </ol>	Individuals with larger households, family support, good health, and independent transportation using their own car tend to perceive a higher quality of life <sup>10</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
Pineio, et al, 2020	Epirus, Erop.	Down syndrome, and Autism.	Parent (Father and Mother) of children with disabilities	59 parents of children with disabilities	WHOQOL-BRIEF	<p>areas of mental health (<math>p = 0.042</math>) and environment (<math>p = 0.005</math>).</p> <p>4. Mothers with higher income levels, their Quality of Life is better in the following domains: Physical health (<math>p = 0.030</math>), mental health (<math>p = 0.002</math>), environment (<math>p = 0.000001</math>), and general Quality of Life (<math>p = 0.0002</math>).</p> <p>The results of the study showed a statistically significant relationship between the gender of parents and the WHOQOL-BRIEF variables. The results also showed that the type of child's disability and the family's socioeconomic level influenced several parameters of the quality of life of parents of children with disabilities.</p>	The type of disability of the child and the socio-economic level of the family had an impact of the quality of life of parents <sup>4</sup> .
Xia, et al., 2020	Shanghai, China	Vision, hearing, speech, physical, cerebral palsy, intellectual, mental and multiple disabilities.	Caregivers (mother, father and grandparents).	170 caregivers (mother, father and grandparents).	WHOQOL-BREF, 12-item Short Form Health Survey (SF-12)	<p>Caregivers of children with CWD had slightly higher scores on the physical health domain variables (PCS, <math>52.57 \pm 8.41</math>), but very low scores on the mental health domain (MCS, <math>31.58 \pm 7.72</math>).</p> <p>Caregivers with illness and caregivers living in large families were associated with higher mental HRQOL. These findings indicate poor mental HRQOL among caregivers of children with CWD in Shanghai.</p>	Key factors include the caregiver's health, family size, and household income, highlighting their importance in understanding quality of life <sup>5</sup> .
Ali Usman, et al., 2021	Pakistan	Autism spectrum disorder, attention deficit	Parents of children with developmental	301 participants, with 151	WHO Quality of Life	1. Parents of children with disabilities had lower scores as measured by WHOQoL-BREF.	This study showed statistically significant differences in WHOQoL-

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
		hyperactivity disorder, cerebral palsy, global developmental delay, learning disability and speech delay.	disabilities and parents of children without disabilities.	parents of children without disabilities and 150 parents of children with developmental disabilities.	Measure Abbreviated version (WHOQOL-BREF).	2. Statistically noteworthy contrasts were found within the physical and natural spaces of parental quality of life.	BREF scores in the physical and environmental health domains of parents of children with disabilities. There were no significant differences found in the psychological and social health domains between the intervention and control groups <sup>11</sup> .
Colak B & Kahriman I, 2021	Turkey	Mental disability, physical disability, multiple disabilities.	Mother and father of children with disabilities.	518 parents with disabilities	Family Burden Assessment Scale" and "WHOQOL-BREF-TR Scale	There was no significant relationship between the physical health domain and the Family Burden Assessment Scale (FBAS) score in the research subjects, while a strong and significant negative relationship was detected in the spiritual, social, and environmental domains.	The quality of life has diminished as the family burden of the parents increased. In expansion, family burden had a negative impact on their quality of life <sup>1</sup> .
Fereidouni, et al., 2021	Iran	Visual, auditory, kinetic, intellectual and physical, intellectual and neural, audiovisual.	Mother with neurotypically developing children and mother with disable children	240 mothers, with 120 having disabled children and 120 having typically developed children.	WHOQOL-BREF and CD-RISC.	1. The average quality of life score of mothers who have children with physical disabilities is lower than mothers with neurotypically developing children in the psychological, social and environmental domains. 2. Mothers who have children with disabilities (P<0.001), education level (P<0.001) and resilience (P<0.001) affect their quality of life, meaning that the lower the level of education, the lower	Mothers of disabled children had a lower quality of life than mothers of typically developing children. There was no difference in the level of resilience between these two groups of mothers <sup>12</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
Dizdarevic, et al, 2022	Bosnia and Herzegovina	Autism spectrum disorder, Mild intellectual disability, moderate intellectual disability.	Parents of children with disabilities.	270 parents of children with disabilities.	FQOL and DASS.	<p>the mother's quality of life and high resilience can improve her quality of life.</p> <p>1. Parents of children with autism spectrum disorders and parents of children with moderate intellectual disabilities have statistically significant lower family quality of life (FQOL) than parents of children with mild intellectual disabilities and parents of typically developing children.</p> <p>2. The child's gender had a significant impact on FQOL. Additionally, FQOL was significantly influenced by levels of depression, anxiety, and stress, whereas the parents' gender, age, and employment status did not have a crucial impact</p>	Parents of children with disabilities have a lower quality of family life than parents of typically developing children. It is important to create parent support groups to improve the overall quality of family life <sup>13</sup> .
Jeoung Bogja, 2022	Incheon, South Korea	Intellectual and developmental disabilities.	Children with IDD.	254 parents (both fathers and mothers) of children with IDD.	Health-Promoting Lifestyle Profile-II (HPLP-II)	<p>1. There is a correlation between parental quality of life and lifestyle in parents of children diagnosed with IDD (<math>r=0.562</math>, <math>P&lt;0.001</math>): spiritual growth (<math>r=0.238</math>, <math>P&lt;0.001</math>), health responsibility (<math>r=0.146</math>, <math>P&lt;0.005</math>), exercise (<math>r=0.317</math>, <math>P&lt;0.001</math>), nutrition (<math>r=0.486</math>, <math>P&lt;0.001</math>), interpersonal relationships (<math>r=0.434</math>, <math>P&lt;0.001</math>) and stress management (<math>r=0.404</math>, <math>P&lt;0.001</math>).</p> <p>2. There was high correlation shown between the subfactor of family</p>	Exercise, nutrition, and stress management improve QoL. Implementation and reinforcement of health-promoting behaviours and lifestyles are important in increasing the QoL of parents of children with IDD <sup>14</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
Letovancova K. M & Slana M, 2022	Republic of Slovakia	Physical, Intellectual and combined.	Parents raising a child with a disability.	550 parents raising a child with a disability	Family Quality of Life Scale (FQOL)	relationships with quality of life and lifestyle ( $r=0.308$ , $P<0.001$ ). 1. The results of the study showed that the level of respondents' quality of life was higher than the initial prediction, however, the respondents' quality of life was in the dimensions of the "Parenting" scale, "Family interaction" and "emotional well-being". 2. Significant differences in respondents' quality of life were observed based on marital status, self-governing region, and educational background	Social support is one of the factors that is directly correlated with the quality of family life so it is considered very important. The findings of this study, namely the factors that influence the quality of life of parents of children with disabilities, can help professionals in developing appropriate strategies to help parents cope with their life situations due to their child's condition <sup>15</sup> .
Widyawati, et al, 2022	Indonesia	Autism, intellectual disability, ADHD, Down syndrome, learning disability, speech or hearing disorder, and physical or visual impairment are various conditions	Many parents have at least one child diagnosed with a developmental disability.	497 families Parents have at least one child diagnosed with a developmental disability.	The Parenting Resilience Elements Questionnaire (PREQ) was employed to assess parental resilience.	1. Communication and influence were lower in families with children with autism spectrum disorders ( $M=2.69$ , $SD=0.516$ ) compared to families with children with intellectual disabilities ( $M=2.88$ , $SD=0.322$ ), ADHD ( $M=2.91$ , $SD=0.516$ ), or learning disabilities ( $M=3.01$ , $SD=0.374$ ) also showed lower levels of socio-emotional well-being compared to children with intellectual disabilities ( $M=2.97$ , $SD=0.424$ ) and ADHD ( $M=3.01$ , $SD=0.525$ ).	Certain results could be unique to a collectivist culture, highlighting the complex relationships between diverse perspectives on parental adaptability and the well-being of children with developmental disabilities <sup>16</sup> .

Author, year	City	Type disability of children	Type of caregivers	Total caregivers	Outcome measure	Result	Conclusion
		that can affect individuals.				2. Knowledge of child characteristics was significantly related to dimensions of quality of life, namely the communication domain (P<0.01), physical activity (P<0.001), and social emotional well-being (P<0.01).	
Sulaimani, et al, 2023	Arab Saudi	Physical, speech, growth failure, learning, autism, ADHD, down syndrome, cerebral palsy, epilepsy.	Family caregivers (father, mother, brother, sister).	95 family caregivers	QoL assessed using the RAND 36-Item Short Form Health Survey (SF-36).	1. The average of quality of life score among caregivers was 57, ranging from 12 to 94. There was no significant difference in quality of life scores based on caregiver age, gender, employment status or income. 2. There was a significant relationship between caregiver education and emotional well-being.	The quality of life (QoL) included their education level, the relationship with the child, the disability's severity, and whether multiple children in the family had disabilities <sup>17</sup> .

### ***Data collection process in the included studies***

Data collection across all research studies involved the administration of questionnaires to participants directly, a method that ensured hands-on interaction and facilitation for collecting responses.

### **Discussion**

The well-being of mothers and their families is profoundly influenced by the circumstances surrounding children with disabilities. A crucial aspect is the quality of the relationship between a mother and her child, which significantly impacts the child's healthy growth and development. The mental health of the mother and her ability to assume the caregiving role play key roles in shaping this relationship. Children who spend most of their time with their mothers are strongly influenced by their early childhood environment, with parental teachings and values playing a pivotal role in their development.<sup>18</sup>.

### ***Quality of life based on child disability type***

Mothers who have children with developmental disabilities have a lower quality of life compared to mothers who have children who grow neurotypically in physical, social and mental aspects. The interaction between mothers and children with special needs (especially behavioral problems) will cause a decline in overall performance in the mother so that her quality of life decreases. Parents who have children with disabilities often experience higher levels of stress compared to parents of children with normal conditions (without disabilities). This can happen because most of the parents' time is spent caring for children with special needs so that their social interactions are limited and anxiety increases in line with the decline in the parents' quality of life<sup>6</sup>. Parents of children with autism spectrum disorders had lower quality of life scores compared to parents of children with intellectual disabilities (ID)<sup>9</sup>. Four studies covered visual/hearing, physical, mental and mixed conditions. When compared with the general population, caregivers of children with mixed disabilities showed slightly higher scores on the physical health domain compared with those with one type of disability<sup>5</sup>.

Mothers who have children with Autism Spectrum Disorder (ASD) have the lowest scores for quality of life compared to mothers who have children with other types of disabilities such as intellectual disabilities, communication disorders, attention deficit/hyperactivity disorder, specific learning disorders and motor disorders. This happened because children with autism spectrum disorder (ASD) experience a series of complex developmental disorders characterized by delays or problems in cognitive, social, emotional, language, sensory and motor skills. Symptoms of autism spectrum disorder (ASD) usually begin at twelve until eighteen months of age and the prevalence of autism spectrum disorder (ASD) in boys is almost five times higher than in girls<sup>19</sup>.

### ***Quality of life of primary caregivers of children with disabilities***

The main caregivers of children with disabilities based on sixteen articles reviewed are 10 articles of the main caregivers who experience low quality of life are parents (father and mother) of children with disabilities, four articles entrust workers as the main caregivers of children and two articles of the main caregivers are mothers of children with disabilities. Most caregivers of children with disabilities experience their own levels of stress, mental and physical burdens are parents. Parents of children with disabilities show lower physical and mental health as well as poorer social relationship functioning and lower satisfaction with their environment. Deficits in the quality of life of parents can be understood in the context of the challenges faced by parents. Increased levels of stress, lack of sleep and fatigue are associated with challenges experienced by parents who. In addition to stigmatization, increased caregiving responsibilities and high financial demands for caring for children with disabilities can reduce the opportunity for parents to socialize with others which can hinder the capacity of parents to make positive changes in their environment<sup>20</sup>. The capacity and ability to provide care to children with disabilities is influenced by the physical and emotional health conditions of the parents. When parents experience a decline in quality of life, it is

feared that their ability to provide care will not be optimal<sup>21</sup>.

### ***Measuring tools used to measure quality of Life***

The measuring instruments used by researchers to measure the quality of life of parents who have children with disabilities are very important for attention too. The majority of articles use WHOQOL-Bref as an instrument (eight articles). Other articles use The Parental Stress Scale survey and the Brief Form-12 adaptation 2, the health practice behavior questionnaire encompassing details of health condition, The Barthel index for activities of daily living and the Beach Center FQoL scale, Caregiver Burden Inventory (CBI), FQOL and DASS, Health-Promoting Lifestyle Profile-II (HPLP-II), The Parenting Resilience Elements Questionnaire (PREQ), Health Survey (SF-36). WHOQOL-Bref is the most widely used method as an instrument for evaluating quality of life. WHOQOL-Bref was used in quality of life measurement studies from several different countries that showed differences in the quality of life of family members. The differences in quality of life are influenced by welfare, individual factors, family support, individual support and systemic factors. Treatment or therapy also has a big impact on psychological health, such as experiencing depression and health problems experienced by the family<sup>22</sup>.

### ***The main domains that most affect quality of life***

Quality of life refers to the level, standard and level of excellence where there are 4 domains included in the quality of life, namely the physical health domain, the mental health domain, the environmental domain and the social life domain. Based on the findings of the reviewed research studies, the majority stated that the psychological health domain is the domain that has the lowest score among other domains related to quality of life. Followed by the physical, environmental and social health domains. Disability is an integral part of a person's health condition or disorder. Disability is a physical, intellectual, mental, and/or sensory

limitation over a long period of time. Parents who have children with disabilities experience problems, especially psychological health, due to increased fatigue, physical inadequacy, high levels of stress in mothers, which are defined as mental or emotional tension or pressure<sup>19</sup>.

### ***Key factors affecting the quality of life of Mother or Caregivers of Children with disabilities***

The findings from the research results obtained that the majority of the main factors that are most significantly related to the quality of life of parents who have children with disabilities are lifestyle, followed by income, education, employment, marital status, knowledge, marital status and family burden. There is a relationship between lifestyle and quality of life that has a positive impact on the health of parents of children with disabilities. The factors that influence the low quality of life of parents are spiritual, health behavior, exercise, nutritional fulfillment, interpersonal relationships and stress management. Health workers must be able to help parents who have children with disabilities in improving their quality of life by facilitating lifestyle behaviors that can improve health through interventions designed to increase physical activity, nutrition, stress management, interpersonal relationships, health behavior and spiritual growth<sup>23</sup>.

### **Limitations and strengths**

The reviewed research is about factors that influence the quality of life of parents and caregivers who have children with disabilities. The weakness of this review is that the type of disability studied is parents or caregivers with different types of disabilities where the needs of each disability are definitely different so that it is necessary to review the quality of life of parents who have children with disabilities with the same type. This study only reviews observational research, other reviews are needed regarding problem solving in the form of interventions to overcome the problem of the quality of life of parents. The strength of this study is that the results of the reviewed research were conducted in fifteen countries that vary so that the

results of the review are quite representative of the results with the same variables in developing and developed countries. Reviews on the quality of life of parents who have children with disabilities are still rarely carried out, so far they have focused on the quality of life of children with disabilities even though children with disabilities have a high dependence on their parents as the main caregivers to carry out daily activities.

## Recommendation

This study is an observational study that overall suggests conducting intervention research to solve the research problem. The main factor that affects the quality of life of parents who have children with disabilities is lifestyle so that health workers are highly recommended to socialize healthy lifestyle behaviors so that they can help improve the quality of life of parents who have children with disabilities, socialization can be done through social media or directly through counseling.

## Conclusion

Mothers who have children with Autism Spectrum Disorder (ASD) have the lowest scores for quality of life compared to mothers who have children with other types of disabilities. Most caregivers of children with disabilities experience their own levels of stress, mental and physical burdens as parents. Parents of children with disabilities show lower physical and mental health as well as poorer social relationship functioning and lower satisfaction with their environment. WHOQOL-Bref is the most widely used method as an instrument for evaluating quality of life. WHOQOL-Bref was used in quality of life measurement studies from several different countries that showed differences in the quality of life of family members. The psychological health domain is the domain that has the lowest score among other domains related to quality of life. Parents who have children with disabilities experience problems, especially psychological health, due to increased fatigue, physical insecurity, high levels of stress in mothers, which are defined as mental or emotional tension or pressure. The main factors related to the quality of life of parents

who have children with disabilities are lifestyle, then income, education, employment, marital status, knowledge, marital status and family burden. Parents who experience a decline in quality of life are worried that their ability to provide care will not be optimal.

## Contribution of authors

Eka Falentina Tarigan: conceptualized the study

Trias Mahmudiono: designed the study.

Nunik Puspitasari: wrote the introduction, discussion and edited the paper.

Pramesti Pradna Paramita: designed the methodology

Ira Dwijayanti: collected and analysed the data.

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