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Quality of Life among Caregivers of Children with Disabilities in the Kingdom of Saudi Arabia: A Systematic Review

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ABSTRACT

Caregivers provide different types of care, such as physical care, transfers, and follow-ups with doctors and rehabilitation professionals. All these types of care impact the caregivers' quality of life (QOL). Due to a lack of collective evidence on the QOL of caregivers having children with disabilities in the Kingdom of Saudi Arabia, we conducted this review to find the QOL of caregivers of children with disabilities. A thorough literature search was performed using an electronic database and a gray literature search to obtain relevant articles. These two distinct literature searches found a total of 233 studies. Out of these, 12 studies were on the QOL of caregivers with children with disabilities in Saudi Arabia. The methodological quality assessment of all 12 studies was done by using the quality assessment tool for observational cohort and cross-sectional studies. We established that caregivers of children with disabilities had a reduced QOL in the physical, psychological, and social relation domains. Factors such as gender, age, and low income impact the QOL among caregivers of children with disabilities.

KEYWORDS

caregiver, disability, QOL, cerebral palsy, autism, Saudi Arabia, Down syndrome, physical health, psychological health

INTRODUCTION

In the last few decades, there has been increasing concern about the concept of quality of life (QOL) (Barcaccia et al., 2013). According to the World Health Organization, QOL is defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (Majumdar and Jain, 2020). It is a broad-ranging concept affected complexly by the person's physical health, mental state, level of independence, social relationships, personal beliefs, and relationship to salient features of their environment (Cai et al., 2021).

Children have long-term physical, mental, intellectual, and sensory abnormalities, either congenitally or caused due to injury or disease (Almosawi et al., 2020). Physical or mental incapacity leads to impairments, activity limitation, and participation restriction in these children, and they are termed as children with disability. These children require health and other related services beyond the requirements of normal children (Isa et al., 2016). Research indicates that, in recent decades, there is a positive acceptance of disabled children in families compared to when there was a negative attitude toward children with illness (Kandel and Merrick, 2007). A child's disability has a three-way connection between the child who suffers the dysfunction, the family, and the environment where the disability is exhibited (Heiman, 2002).

A caregiver is a parent (mother or father) or others (grandmother, grandfather, aunt, uncle, sibling, and adopted parent) responsible for caring for a disabled child (Isa et al., 2016). A (family) caregiver, also called an informal caregiver, is an unpaid individual assisting others with daily living activities and medical tasks (Zablotsky et al., 2019) and plays an essential role in the life of children with disabilities. Parenting of typically developing children is not stressful and burdensome, but it is a rewarding process (Raj, 2022). On the contrary, parenting children with disabilities is strenuous as they

have to adjust to many fluctuating demands related to the specific needs of their disabled children. Due to variations in the healthcare system and social services, children with disabilities are under the care of families at home rather than institutional care (Isa et al., 2016).

Caregivers' burdens and ill health will impact their QOL. They experience this impact on many aspects of life's physical, emotional, social, and spiritual domains (Pop et al., 2022). The stressors include obtaining regular pediatric assessments, diagnosis, and seeking rehabilitation services. Adapting the caregiver role has an impact on employment, facing disability stigma, and physical burden in terms of assisting or helping the child with self-care activities, aiding in transfers, and performing home exercise programs advised by rehabilitation professionals (Masefield et al., 2020).

In Saudi Arabia, disability is a significant social and economic problem. According to the demographic survey by Bindawas and Vennu in 2016, the prevalence rate per 100,000 is around 2670 of any disability in the age group of 0-19 years (Bindawas and Vennu, 2018). The most common types of disabilities reported were physical (37%), vision (36%), hearing and communication (21%), mental (4%), and others (1%) (Milaat et al., 2001). Saudi Arabian culture is based on Islamic instructions. A traditional Saudi family is based on the extended family unit that resides in one home consisting of a husband, wife, children, spouses of their children, and grandchildren. Family members in Saud Arabia accept familial commitments and live in harmony, which gives them a personal identity in the society. Therefore, families care for a disabled person rather than an institution (Alwhaibi et al., 2020). In the literature, studies have reported on the QOL of caregivers of disabled children in Saudi Arabia. A collective evidence on the QOL of caregivers of children with disabilities in Saudi Arabia is lacking. Hence, this study aims to review and report on the caregivers' QOL among children with disabilities in Saudi Arabia.

METHODOLOGY

The protocol of this review was registered in an international platform of registered systematic reviews and meta-analysis protocols (INPLASY). The registered protocol number is INPLASY 202330052; doi: 10.37766/inplasy2023.3.0052.

Search strategy

A literature search was undertaken in bibliographic databases about the items related to QOL in caregivers of children with disabilities in the Kingdom of Saudi Arabia (KSA). Electronic databases such as Campbell Library, Data Base of Promoting Health Effectiveness, EMBASE, NHS EED, PROSPERO, PubMed, PsycINFO, MEDLINE (Ovid), SCOPUS, DOAJ, CINHAHL, Web of Science, and Saudi Digital Library were searched for obtaining the articles. We used the medical subject headings such as quality of life, caregiver, disabled children, cerebral palsy (CP), Down syndrome, autism, and Saudi Arabia as keywords in the databases mentioned above to find the relevant studies. In addition, we have searched gray literature in Google Scholar also. Furthermore, we searched gray literature by manually checking the reference list of the obtained articles.

Study selection criteria

Two researchers from the review team who were blinded to publishers, journals, and authors made their judgment by evaluating the title, year, and abstract of each appropriate paper. Abstracts that lacked differences after discussion were confirmed and included. Two authors of our review team again revised the full-text articles of the included abstracts. In addition, we followed the selection criteria of the studies to include in the review, which is mentioned below.

Eligible studies were cross-sectional designs of original articles and also longitudinal studies that were published in the English language. Research studies that measured the QOL among caregivers of children with disabilities or pediatric disorders with or without having a comparison group conducted in the KSA were included in this systematic review. The studies that fulfilled the criteria mentioned above were considered for the review.

Data extraction and quality assessment

Two authors from our review team were involved in data extraction: author and year, study design, province where the study was conducted, the total number of participants, demographic and other factors, such as educational level of the caregiver, employment status, and economic status of the caregiver, the QOL questionnaire used in each study, results, and conclusion. Another two authors performed a methodological assessment of all the included studies using the quality assessment tool (QAT) for observational cohort and cross-sectional studies proposed by the National Institutes of Health. The discrepancies were resolved with the opinion of a third reviewer.

RESULTS

Search results

Our search revealed 233 studies; consequently, we removed 165 studies, as they were duplicates. Out of the remaining 68 studies, we further excluded 24 studies as they were irrelevant to the review. A total of 44 records were assessed for eligibility. In total, 32 articles were excluded from these 44 as they focused on the following: studies focused on depression as an outcome measure (5), studies focused on mental health (3), studies with QOL in disabled children (5), studies outside of Saudi Arabia (14), and studies focused on QOL in oral health (5). After rejecting these 32 studies, we finally included 12 full-text articles in this review. We present the details of the included studies in Figure 1.

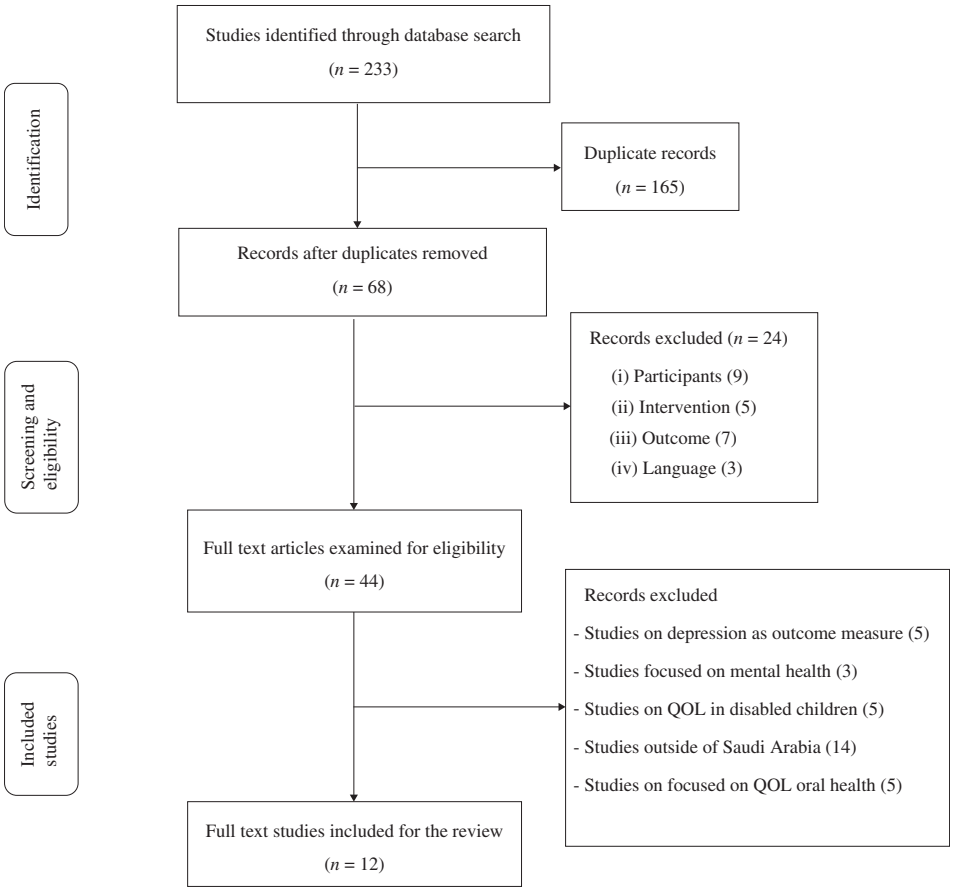

Figure 1: Flow diagram of search strategy, screening and included studies.

Methodological quality assessment of included cross-sectional study

In our search, we found 12 studies on the caregivers' QOL among children with special needs in different provinces of Saudi Arabia. All the included studies underwent methodological assessment using the QAT for observational cohort and cross-sectional studies. Among the 14 questions, studies scoring 0-4 were considered poor, studies that fell within the range of 5-10 were fair, and studies that scored within the range of 11-14 were of good quality (Bagias et al., 2021). In our review, all 12 cross-sectional studies fell within the category of fair quality after methodological quality assessment by QAT for observational cohort and cross-sectional studies (https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools). All reviewed studies specified the research questions, objectives, and rationale. All correlational studies provided multiple regression analyses to see which factors correlated to parental QOL in each domain. Moreover, all the studies except one (Aman et al., 2022) used outcome measures with good psychometric properties. The details of the methodological quality assessment are provided in Table 1.

Participants

Out of the 12 studies, exclusively studies conducted for caregivers of autism were four (Alenazi et al., 2020; Allah Fardan Alamri et al., 2020; Al-Jabri et al., 2022; Lone et al., 2022). However, two studies mixed the caregivers of autism with the caregivers of other types of children with disabilities such as caregivers of physical disability and caregivers of mental retardation (MR) children (Haimour and Abuhwaash, 2012; Awaji et al., 2021). There was one study (Aman et al., 2022) exclusively on caregivers having children with CP, but in one study they mixed the caregivers of CP with the caregivers of Down syndrome (Alwhaibi et al., 2020). One study had participants who had children with Down syndrome only (Allah Fardan Alamri et al., 2020), but Alwhaibi included caregivers of Down syndrome with the caregivers of CP children. Three studies (Haimour and Abuhawaash, 2012; Alwhaibi et al., 2020; Awaji et al., 2021) included caregivers having children with different types of disabilities, which are represented in Table 2. One study on parents of sickle cell disease children (Madani et al., 2018), one study on caregivers of children with epilepsy (Asiri et al., 2022), and one study included participants having children with congenital heart disease (Khoshhal et al., 2019).

Data collection process in the included studies

Two studies collected the data online by sending the Google forms through snowball sampling. The rest of the 10 studies took the data by giving questionnaires to the participants

Table 1: Methodological quality assessment of included studies by using the NIH quality assessment tool for observational cohort and cross-sectional studies.

Author, year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Overall quality
Alwhaibi, 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Lone et al., 2022	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Al-Jabri et al., 2022	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Allah Fardan Alamri et al., 2020	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Aman et al., 2022	Y	Y	Y	Y	NR	N	N	Y	Y	NA	N	N	NA	Y	Fair
AlAhmari et al., 2022	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	N	NA	Y	Fair
Haimour and Abuhawaash, 2012	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	N	NA	N	Fair
Asiri et al., 2022	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	NR	NA	Y	Fair
Madani et al., 2018	Y	Y	Y	Y	NR	N	N	Y	NA	NA	Y	NR	NA	Y	Fair
Alenazi et al., 2020	Y	Y	Y	Y	Y	N	N	NA	NA	NA	Y	N	NA	Y	Fair
Khoshhal et al., 2019	Y	Y	Y	Y	NR	N	N	NA	NA	NA	Y	Y	NA	Y	Fair
Awaji et al., 2021	Y	Y	Y	Y	Y	N	N	N	NR	NA	Y	Y	NA	Y	Fair
Alaqeel et al., 2022	Y	Y	N	Y	Y	N	N	NA	NA	NA	Y	N	NA	Y	Fair

Note: Quality was rated as 0 for poor (0-4 out of 14 questions), i for fair (5-10 out of 14 questions), or ii for good (11-14 out of 14 questions).
1. Was the research question or objective in this paper clearly stated?
2. Was the study population clearly specified and defined?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
5. Was sample size justification, power description, or variance and effect estimates provided?
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as a continuous variable)?
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
10. Was the exposure(s) assessed more than once over time?
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?
12. Were the outcome assessors blinded to the exposure status of participants?
13. Was loss to follow-up after baseline 20% or less?
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?
Abbreviations: NA, not applicable; NR, not reported; Y, yes; N, No.

directly. Most studies were conducted in government rehabilitation centers, the Ministry of Health, and university hospitals. However, one study collected data from participants visiting private and government rehabilitation centers (Alwhaibi et al., 2020).

All the 12 studies were cross-sectional, with participants with children with disabilities only. However, three studies (Alwhaibi et al., 2020; Awaji et al., 2021; Al-Jabri et al., 2022) had a comparison group consisting of a control group who were parents of children without disabilities; one study had a comparison group of parents of children with minor illness (Khoshhal et al., 2019). One study recruited the participants equally in both groups (Al-Jabri et al., 2022); the rest of the three studies (Khoshhal et al., 2019; Alwhaibi et al., 2020; Awaji et al., 2021) had unequal participants in both groups. The total number of study participants ranged from 63 to 406; among them, female participants were more than male participants.

Demographic characteristics of participants

Participants' age ranged from below 16 years to above 70 years; all the studies classified the age groups within the 10-year range, but one study classified age groups within the 7-year range (Awaji et al., 2021). All the studies included participants with education levels from elementary school to college level, university level, and participants with Ph.D. degrees also. Three studies included most participants with a higher secondary education level (Allah Fardan Alamri et al., 2020; Aman et al., 2022; Lone et al., 2022). In the three studies, the majority of participants had college-level education (Alwhaibi et al., 2020; Awaji et al., 2021; Al-Jabri et al., 2022); in two studies, most of the participants completed primary school (Khoshhal et al., 2019; AlAhmari et al., 2022), and one study did not mention about the education level of the participants (Haimour and Abuhawaash, 2012). All the studies included working and non-working caregivers. Most participants were homemakers in five studies (Madani et al., 2018; Khoshhal et al., 2019; Awaji et al., 2021; Al-Jabri et al., 2022; Aman et al., 2022). In two studies, more participants were employed (Allah Fardan Alamri et al., 2020; Alwhaibi et al., 2020). The other factors, such as monthly income ranging from <1300 to 15,000 SR and type of accommodation, were also mentioned in some studies.

Three studies mentioned demographic characteristics of disabled children like age, gender, duration of the disease, severity of disease, number of children with the same

Table 2: Characteristics of the included studies in this systematic review.

Author, year	Province (or) city where the study was conducted	Diagnosis and age of children	Total number of caregivers	Total no of comparison group	Outcome measure	Conclusion
Alwhaibi, 2020	Riyadh	CP Down syndrome (2-10 years)	299 mothers	99 mothers of typically developing children	QOL-I, generic version-II	1. No significant difference in the total QOL between mothers having children with disabilities and mothers of children without disabilities 2. Mothers of children with disabilities show dissatisfaction in the economic and social domain of part-1 (Satisfaction) of the QLI 3. Mothers of children with disabilities gave more weight to the health and functioning domain of part-2 (Importance) of the QLI, less importance to psychological and spiritual aspects
Lone et al., 2022	Hofaf city	Autism (NM)	Parents (62 females, 43 males)	NA	Arabic version of validated SF-36	1. Male, younger age caregivers, married participants demonstrated higher scores in bodily pain domain of QOL 2. Females were poor in role limitation due to physical health and social functioning domain of QOL but demonstrated good QOL in vitality domain of SF-36. 3. Higher-income group showed good mental health QOL, mental health and vitality than lower-income group
Al-Jabri, 2021	Riyadh, Makkah, Madinah, Eastern, Asir, Baha, Northern Border, Al Jouf, Qassim, Hail, Jazan, Najran, and Tabuk.	Autism spectrum disorder (2-18 years)	Parents—406 (140 males, 266 females)	Parents—406 (93 males, 313 females)	Arabic version of RAND SF-36	1. There was a significant difference in all domains when comparing the QOL of caregivers of children with and without ASDs except for the domain of health change. 2. Caregivers of children with ASDs tended to have lower scores across most domains. 3. The relation of the caregivers to the children with ASDs and QOL demonstrated significant negative association in several domains. 4. Parents of children with ASDs had the lowest scores in physical functioning, mainly mothers scoring the lowest: role limitations due to physical health, emotional problems, energy/fatigue, and pain. Fathers of children with ASDs had the lowest scores for general health, whereas brothers reported the lowest scores for emotional well-being and social functioning. 5. Older age group demonstrated lowest QOL in different domains like physical functioning, role limitation due to emotional problem, social functioning, general health. Pain also has an negative impact on QOL.
Allah Fardan Alamri et al., 2020	Tabuk	Autism (1-3 years)	100 (58 females, 42 males)	NA	WHO QOL-BREF	1. Overall QOL of parents/caregivers of children with autism in Tabuk was good. Least percentage of participants reported poor QOL. 2. Most affected domains were psychological and environmental domains, physical health. 3. Majority of them have self-perceived their QOL as neutral or satisfied with their general health. 4. Parents/caregivers aged between 31 and 40 years, unmarried, with low income, who had autistic children aged 3 years and had autistic children with the duration of the diseases of 3 years were more likely to have a poor overall QOL than others

Table 2: Continued.

Author, year	Province (or) city where the study was conducted	Diagnosis and age of children	Total number of caregivers	Total no of comparison group	Outcome measure	Conclusion
Aman et al., 2021	Jeddah	CP (NM)	129 mothers (93 completed, 36 deceased)	NA	Caregiver QOL Self-structured (not standard)	1. More than half of the caregivers reported low QOL. 2. Physical and social health, family and social support, and financial problem domains are significantly associated with reduced QOL. 3. Most of the participants reported a decline in physical health, a lot of psychological and mental stress, a decline in participating social activities visiting family and friends, heavy financial burdens, and employed caregivers had problems in working places.
AlAhmari et al., 2022	Riyadh	Downs syndrome (NM)	261 (137 females, 124 males)	NA	WHOQOL-BREF	1. QOL of caregivers with Down syndrome children was significantly affected in different domains; social domain was affected more than other domains. 2. Significant association between social relationships and physical, psychological, and environmental domains (P <0.001), the physical and psychological domains (P = 0.021), the physical and environmental, and the psychological and environmental domains. 3. Environmental domain was having the highest score; social domain was having the lowest score. 4. Educational level and number of children significantly affect the physical and psychological domains, whereas the number of children significantly affected the domain of social relations not with other factors
Asiri et al., 2022	Abha	Epilepsy (<1 to 15 years)	133 (69 females, 64 males)	NA	WHOQOL-BREF MARS (medication adherent rating scale)	1. QOL of the caregivers decreased when parents forgot to give their children the medication and the QOL of the caregivers increased when they continued to take the medication. 2. QOL increases as adherence to treatment increases. 3. Strategies for improving adherence to medications need to be implemented.
Haimour and Abuhawaash, 2012	Jeddah Al-Baha Damam	1. Autism 2. Children with physical disability 3. Children with MR 4. Children with learning disability (NM)	306 (NM)	NA	WHOQOL-100	1. Caregivers scored the highest score in the environmental domain and the lowest score in the spiritual domain. 2. The overall QOL and general health component of WHO-QOL-100 were higher in the caregivers, whereas on the social support component, they scored low scores. 3. All six domains influenced the total facet score, but the independence domain followed by the psychological domain showed a significant positive higher contribution to the total score, but the spiritual domain showed a significant negative lower contribution to the total score. 4. Parents having children with learning disability had the highest QOL, followed by parents having children with a physical disability, parents having children with MR, and parents having children with autism scored the lowest QOL.

Table 2: Continued.

Author, year	Province (or) city where the study was conducted	Diagnosis and age of children	Total number of caregivers	Total no of comparison group	Outcome measure	Conclusion
Madani et al., 2018	Jeddah	Sickle cell disease (NM)	63—mostly female parents and even siblings	NA	TAA-QOL questionnaire TNO-AZL Questionnaire for Adult's Health-Related Quality of Life	1. Emotions, sleep quality, and sexual life were the most affected dimensions in caregivers. 2. Older-age factor showed a significant negative association with gross motor aptitudes. 3. Mothers are represented with more negative emotions than fathers. 4. There was a more financial and emotional burden on the caregivers.
Alenazi et al., 2020	Arar	Autism (<7 to >10 years)	84 (16 males, 68 females)	NA	Arabic version of SF-36	1. Two-thirds of caregivers had impaired QOL. 2. Main domains affected were role limitation due to emotional problems and energy and fatigue. 3. Females, joblessness, and low income of caregivers were significant factors associated with poor QOL. 4. Autistic children of the first birth order and with a long duration of the disease were more likely to be associated with poor parental QOL. 5. Gender, income, occupation, and duration of illness were associated with poor QOL which were statistically nonsignificant.
Khoshhal et al., 2019	Madinah	Congenital heart disease (7.8 ± 6.4)	120	80 parents of children with general disease	WHOQOL-BREF	1. The control group had significantly higher mean scores in all domains of the questionnaire than the group of parents of CHD children 2. There was a significant difference in the scores of all domains according to the severity of the disease. 3. Class-4 subgroup of parents of CHD children showed the most significantly lower total score of domains between all classes
Awaji et al., 2021	Saudi Arabia	Autism, physical impairment, Down syndrome, growth retardation, thyroid, cancer, kidney problems, brain hypoxia, hearing impairment, ADHD language delay (NM)	93 mothers	247 mothers	WHOQOL-BREF	1. Overall QOL was significantly higher in mothers of children without disabilities compared to the mothers of children with disabilities, during the COVID-19 lockdown 2. Social well-being and environmental well-being were lower in mothers of children with disabilities compared to mothers of children without disabilities. 3. Age and children with disabilities demonstrated a significantly small amount of variance on QOL.
Alaqeel et al., 2022	Riyadh	Pediatric cancer (NM)	73 (66 females, 7 males)	NA	WHOQOL	1. Gender was significantly associated with all four domains of QOL. 2. Age was significantly affecting the physical health and environmental domains, and the duration of illness was significantly associated with the physical health domain. 3. Education level did not show a significant association with any of the domains.

Abbreviations: ADHD, attention deficit hyperactivity disorder; ASD, autistic spectrum disorder; CHD, congenital heart disorder; CP, cerebral palsy; F, female; M, male; MR, mental retardation; NA, not applicable; NM, not mentioned; QOL, quality of life; QOL-I, Quality of Life Index; SF-36, 36-item short-form survey; WHOQOL, World Health Organization Quality of Life Questionnaire; WHOQOL-BREF, World Health Organization Quality of Life Questionnaire; WHOQOL-100, World Health Organization Quality of Life Assessment Instrument.

disability, and birth order of the diseased children (Khoshhal et al., 2019; Alenazi et al., 2020; Allah Fardan Alamri et al., 2020; Asiri et al., 2022). The duration, hours of caregiving, and place of caregiving were also considered in data collection (Madani et al., 2018; Aman et al., 2022). Some studies mentioned the total number of children and other children with the same type of disorder; in one study (Al-Jabri et al., 2022), two or more children had the same disorder.

Outcome measures

The authors have implemented various questionnaires across the studies to measure the QOL of caregivers. Three studies implemented the abbreviated version of the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF) (Allah Fardan Alamri et al., 2020; AlAhmari et al., 2022; Asiri et al., 2022); three studies used an Arabic version of 36-item short-form survey (SF-36) as an outcome measure (Alenazi et al., 2020; Al-Jabri et al., 2022; Lone et al., 2022). Other questionnaires that are used were the Quality of Life Index (Alwhaibi et al., 2020), WHOQOL-100 (Haimour and Abuhawaash, 2012), TNO-AZL Questionnaire for Adult's Health-Related Quality of Life (Madani et al., 2018), and caregiver QOL (Aman et al., 2022).

DISCUSSION

In the literature, the caregivers' QOL was affected by one's disability. Disability is prevalent among children in the KSA. There were many studies on the QOL of caregivers of children with disabilities in Saudi Arabia, but a collective evidence pertaining to this issue is lacking. Hence, this review augments the literature by comprehensively evaluating the QOL of caregivers of children with different disabilities.

QOL of caregivers having children with autism

Out of four studies, one cross-sectional study was without a control group (Alenazi et al., 2020) and the remaining three studies had a control/comparison group. Overall, QOL is reduced in the caregiver of children with autism. One more comparative study (Al-Jabri et al., 2022) stated that the QOL of caregivers of children with autism was poorer than caregivers of children without autism. This could be due to parents of children with autism demonstrating lower scores in most dimensions. These findings are similar to the review conducted by Vasilopoulou on the QOL of parents of children with autism (Vasilopoulou and Nisbet, 2016). Only one study stated that most caregivers reported good QOL (Allah Fardan Alamri et al., 2020). One study focused only on factors affecting the QOL of caregivers (Lone et al., 2022).

However, various domains were affected in all three studies. In two studies, the Arabic version of SF-36 was the outcome measure tool (Alenazi et al., 2020; Al-Jabri et al., 2022). The common domains affected in both studies were role limitation due to emotional problems and energy/fatigue. The other domains, such as physical functioning, role limitation due to physical health, emotional well-being, social functioning, and general health, were also affected in one study (Al-Jabri et al., 2022). Nevertheless, in another study (Allah Fardan Alamri et al., 2020), physical health, psychological domain, and environmental domain were affected, using the WHOQOL-BREF. In this review, autism had an impact on both physical health dimension and mental health dimensions. This can be because autistic children negatively affect the QOL of caregivers. Dealing with the abnormal behaviors and tantrums of autistic children is more strenuous; other people's attitudes toward these children make parents experience psychological stress, and parents restrict participating in social events to avoid embarrassment. Nevertheless, in a recent review (Vasilopoulou and Nisbet, 2016), physical health domain was affected more than the mental health dimension. The findings of our review and the findings of a review by Vasilopoulou and Nisbet (2016) are different regarding the component of which dimension was affected most. Vasilopoulou and Nisbet (2016) reviewed the studies with outcome measures that might have allowed for a positive evaluation of caregiving.

Females, mainly the mothers, scored lower scores on physical aspects, role limitation due to physical health and general health, emotional well-being, energy/fatigue, and bodily pain domains. These results were the same as the findings of a comparative review (Vasilopoulou and Nisbet, 2016), where they reported poorer mental health, more bodily pain, more fatigue, and less energy in mothers than in fathers. According to a cultural context, mothers are the primary caregivers for the children.

The older-age group demonstrated poorer QOL than the younger group in the physical domain. The low-income group had lower scores on mental health and social functioning. Other factors, such as the severity of the disease, duration of the disease, and age of the autistic children, had a greater negative impact on the QOL of caregivers.

QOL of caregivers having children with Down syndrome and CP

The overall QOL is significantly affected by the caregivers of CP children. Physical, psychological, and social relationships; family and social support; and financial problem domains also affected caregivers of children with CP; a review conducted by Pousada et al. (2013) stated that parents of children with CP demonstrated low levels of QOL and high levels of depression and stress.

The QOL in Down syndrome was also poor. The affected domains in parents with Down syndrome were physical, psychological, social, and environmental domains on WHOQOL-BREF. The social domain is the one most affected and influences the other domains. Education level and number of children significantly affected the physical and psychological domains. Several children significantly affected the social relationship among the parents of children with Down syndrome.

QOL of caregivers having children with mixed disabilities

In one study (Haimour and Abuhawaash, 2012), the overall QOL and general health were good for caregivers having children with learning disabilities, MR, physical disability, and autism. However, the spiritual domain and social support components were lower. The type of disability shows an impact on the QOL of caregivers. Parents of children with learning disabilities had the highest QOL, followed by parents having a child with a physical disability. Parents having a child with MR and parents having a child with autism scored the lowest QOL.

In another study (Awaji et al., 2021), the QOL of mothers with different disabilities and diseases was poor compared to mothers of children without disabilities. Age and children with disabilities demonstrated a significantly small variance in the QOL of mothers of children with disabilities. The most affected domains were social and environmental well-being, using WHOQOL-BREF. This study was conducted during the pandemic; due to the lockdown, caregivers might not have to participate in social events, and there was no opportunity for leisure activities during COVID-19.

QOL of caregivers having children with different types of disorders

QOL was affected in the parents of children with epilepsy, congenital heart disease, and sickle cell disease. A recent study (Khoshhal et al., 2019) compared the QOL of the parents of children with the parents of children with congenital heart disease, such as upper respiratory infections, sore throat, diarrhea, abscess, and rest of the studies (Madani et al., 2018; Alaqeel et al., 2022; Asiri et al., 2022) did not have a comparison group. Females and older-age groups were shown to affect the QOL of the parents of children with sickle cell disease; adherence to medication has an impact on the QOL of parents of children with epilepsy, and the severity of the disease had a greater impact on the QOL of parents having children with congenital heart disease. Emotions, sleep quality, and sexual life dimensions were affected by the parents of children with sickle cell disease. Parents of children with congenital heart disease experienced impact in the psychological domain and perception of the QOL domain. The psychological domain was most affected by the parents of children with pediatric cancer. This could be because caregivers of all these disorders have to face financial issues for the medical treatment of their children. However, they are receiving potential financial and psychological support from the government.

Most of the studies were cross-sectional and single-centered; most recruited participants through convenience sampling, and the comparative studies recruited participants in both groups unequally. Very few studies were with blinding for the outcome measurement, which might have affected the internal and external validity of the studies and would have influenced the review findings. The study on caregivers of CP did not use the validated questionnaire and did not evaluate the factors affecting caregivers' QOL. Studies on congenital disorders only reported the QOL according to the severity of the disease. Most studies did not have a control group, such as studies on CP and Down syndrome. Most of the studies represented small sample sizes, and very few studies reported on sample size determination. We have reviewed the studies that include different QOL measures. Due to heterogeneity in the disabilities of included studies, we could not perform the meta-analysis.

Future recommendations are that studies focus on longitudinal research and independent cohort studies with larger sample sizes to attain reliable results on the QOL of caregivers of children with disabilities. Further, multicentered studies should be conducted for generalizing the results. Future studies on parental QOL with CP should focus on using the validated questionnaire and factors affecting parental QOL. Further studies should emphasize factors such as the severity of the disability and duration of the disease affecting the parental QOL. A further review should focus on reviewing similar outcome measure questionnaires and single disabilities rather than combining many diseases. Future studies should focus on the meta-analysis by including similar studies with similar disabilities.

CONCLUSION

We conclude that caregivers of children with disabilities have a poor QOL. Physical, psychological, and social relation domains were affected by caregivers of children with CP, autism, and Down syndrome. The psychological domain was affected by caregivers of children with different disorders. Mothers of most children with disabilities have been affected in most domains and have poor QOL. Older-age groups were affected in physical health and physical functioning. The low-income group reduced their QOL in mental health and social functioning. Healthcare providers should be aware of caregivers' physical and psychological burdens and implement interventions to improve their physical abilities and coping strategies to reduce mental stress and improve QOL caregivers and children with disabilities. Healthcare professionals must be aware and should share information about how social health-related networks provide emotional support for empowering these populations. The creation of organizations and community self-help groups should be emphasized.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest in association with the present study.

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