

Caregiver's Quality of Life Among Children with Cerebral Palsy in the Kingdom of Saudi Arabia, and Various Influencing Factors: A Single Cohort Study

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Purpose: Quality of life (QOL) among disabled children and their caregivers is an important concern in healthcare. We aim to evaluate the quality of life among caregivers of children with cerebral palsy and to observe the effects of various demographic factors and affected child-related factors on caregivers' quality of life.

Patients and Methods: After ethical approval and written consent was obtained from the participants. One hundred six caregivers of children with cerebral palsy from the Asir region were recruited for the study. Caregivers provided details, including their demographic characteristics, social factors, and information regarding their affected children regarding age, gender, mobility levels, etc. They also completed the Arabic version of the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire for assessing their QOL.

Results: All the caregivers were women; their mean age was 40.38 years and SD7.09, and the overall QOL mean and standard deviations were 66.38 ± 12.88 . There was a moderately significant correlation between total QOL in comparison with caregivers' educational level and mobility capacity, with R values of 0.54 ($p < 0.001$) and 0.62 ($p < 0.001$), respectively.

Conclusion: All the subdomains of WHOQOL-BREF were found to be very closely related to the total scores for QOL. The caregivers of children with cerebral palsy had better QOL scores than the cutoff scores proposed in the WHOQOL-BREF scale. Factors such as increased mobility and education of the affected child contributed to better total QOL scores.

Keywords: caretakers, life participation, disability, pediatric, cerebral paralysis

Introduction

Caregivers of disabled children are essential for maintaining and improving the health status of the affected child.¹ As the disability of the affected individuals increases, the physical and psychological burden on their caregivers increases.^{2,3} Caregivers help the affected person in many activities, including bed mobility, transition to sitting, standing, mobility, toileting, bathing, dressing, eating, etc.⁴ Most of the time, the caregivers are parents of the affected children or family members in the case of affected adults. However, in some cases, relatives or friends become caregivers, and, in some situations, the role is taken by paid healthcare workers.⁵⁻⁷

Cerebral palsy is the name given to a group of disorders that affect a child's movements and posture due to non-progressive damage that happens to the immature brain. Children affected with cerebral palsy (CP), Down syndrome, muscular dystrophies, congenital disorders, chromosomal conditions, or other disabilities require special care by their caregivers.^{8,9} There are many types of CP, including hypotonic, spastic, ataxic, athetoid, and mixed varieties.^{10,11} Irrespective of the type of CP, all affected children require special attention and care. The care needed by the child depends on many factors such as disease severity, general health status, functional capacity, financial level of the family, etc.¹²

Most relevant scientific literature commonly focuses on the affected people's quality of life (QOL). However, the caregiver's QOL is also critical for enhancing the health status of the affected individual. Since caregivers have taken on the extra burden of another individual, the resultant lack of time and energy for socializing and entertainment can affect their physical and mental health. Furthermore, they cannot leave that person and attend gatherings, trips, or holidays to improve their socialization. Wellbeing and understanding the caregiver's QOL are also essential for positive development.

There is a need for more studies pertaining to QOL information relating to the caregivers of children with CP in this region. The various factors influencing QOL also need to be understood to improve the QOL among caregivers of children with CP. Hence, we aim to identify the levels of QOL among caregivers of children with CP in the Asir region of Saudi Arabia. Moreover, we evaluate the effects of various demographic characteristics and socioeconomic factors on QOL among caregivers of children with CP.

Materials and Methods

This single cohort study complies with the Declaration of Helsinki and obtained certificated ethical clearance with approval number ECM#2023-612 from the ethical research committee of King Khalid University (HAPO-06-B-001). The sample size was assessed using the <https://clincalc.com/Stats/SampleSize.aspx> website. While calculating the sample size, the selected design for the study group was one study group versus the population, and the primary endpoint chosen was continuous means. The general population means, and standard deviation were obtained from a previous study conducted by Khoshhal et al,¹³ and the anticipated study group mean was chosen based on the known mean. The probability of type I error, ie, alpha, was selected at the level of 0.05, and the power of the study was maintained at 80%. We calculated a suitable sample size of 96, including a 10% dropout rate; the sample size was 106. The study was conducted at King Khalid University, Abha, and the duration of the study was one year.

The investigators obtained permission letters and ethical approval and approached various hospitals and disability centers to collect the data. Convenience sampling was utilized to select the participants. The caregivers of children with cerebral palsy were approached specifically for the recruitment process, and the age of the child with cerebral palsy should be between two and 12 years. Caregivers with any other psychological disorders, difficulty reading and understanding Arabic, and who were not willing to participate were excluded from the study. Their written informed consent was obtained after the study procedure was explained to the caregivers. After receiving demographic characteristics, including age, gender, height, weight, and BMI, further specific questions were asked about their socioeconomic status, number of siblings for the affected child, their accommodation type, financial and social support received, etc. More information related to the affected children was also obtained, which includes the child's age, gender, level of mobility, schooling capacity, etc.

Additionally, the participating caregivers filled out the Arabic version of the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire. The full assessment was conducted either in paper-based format or online Google form. A therapist was available to address the participants' queries during the completion of the examination, and the caregivers were informed that the collected data would be stored confidentially. Participants were not obliged to participate in the study and were free to withdraw their details at any time without affecting the care of their children. The collected data were analyzed to obtain the results.

Details of the Outcome Measure

The WHOQOL-BREF instrument contains 26 questions in total. The Arabic version of this questionnaire is freely available on the WHO website under the tools section, and it can be accessed from this URL, which is available here: <https://www.who.int/tools/whoqol/whoqol-bref/docs/default-source/publishing-policies/whoqol-bref/arabic-whoqol-bref>. Each question is rated on a 5-point Likert scale: 1 indicates poor QOL, and 5 means good quality of life. Among the 26 questions, questions 1 and 2 measure the subject's overall perception of QOL and satisfaction with their health, respectively. The remaining questions are divided into four domains: physical health, psychological health, social relationships, and environment. Physical fitness was assessed by seven questions: 3, 4, 10, 15, 16, 17, and 18; this domain sets pain, discomfort, energy, fatigue, sleep, rest, dependence on medication, mobility, activities of daily living, and working capacity. Psychological health was evaluated by six questions: 5, 6, 7, 11, 19, and 26; this domain evaluates positive feelings, negative feelings, self-esteem, thinking, learning, memory,

concentration, body image, spirituality, religion, and personal beliefs. Three questions examine the domain of social relationships: questions 20, 21, and 22 evaluating personal relationships, sexual life, and practical social support. The environment was analyzed by eight questions: 8, 9, 12, 13, 14, 23, 24, and 25, assessing financial resources, information and skills, recreation and leisure, home environment, access to health and social care, physical safety and security, physical environment, and transport. The mean score of each domain ranged from 1 to 5; hence, the total raw scores of the four domains ranged from 4 to 20. These raw scores were later converted to the full linear scores for the scale, ranging from 0–100, where 100 indicates the highest quality of life, and 0 indicates the lowest.^{13–15} Out of the 100 scores, at least 60 and above show normal QOL. The reliability and validity of the WHOQOL-Bref Arabic version were evaluated by Dalky et al in their study on the Jordan population. They obtained excellent internal consistency with Cronbach's alpha values of 0.92 and very good general construct validity of 0.88.¹⁶

Data Analysis

The study variables underwent univariate analysis using descriptive statistics to obtain the mean, standard deviation, minimum, maximum, range, percentage, and ratio details. The software used for the analysis was Statistical Package for the Social Sciences version 24. The normal distribution of the study parameters was analyzed using the Shapiro–Wilk test. Pearson and Spearman's rank correlation coefficient was applied to analyze the correlations between the parameters. Furthermore, regression analysis was conducted to identify the influence of factors on the total QOL.

Results

In this cross-sectional study, we measured the quality of life among 106 caregivers of children with CP. The demographic characteristics, including age, weight, height, body mass index, age of the child with a disability, and QOL of the caregivers, were analyzed using descriptive statistics in terms of mean, standard deviation, minimum, and maximum. The mean age of the sample was 40.38 years, and the overall QOL measured by WHOQOL-BREF was 66.38 out of a maximum score of 100. The most affected domain was the caregivers' physical health, and the parameter details are presented in Table 1. The mobility level of the children was classified into six grades, distributed as follows: Grade one indicates that the child is completely bedridden; grade two suggests that they move in a wheelchair only; grade three demonstrates that they are mobile with a wheelchair and sometimes walk with support; grade four that the child walks

Table 1 Demonstrating the Mean, Standard Deviation, Minimum, and Maximum Values for Demographic Variables and Quality of Life Measurements for the Caregivers

Variables (106 Subjects)	Mean	Standard Deviation	Minimum	Maximum
Age (Years)	40.38	7.09	22.00	54.00
Weight (Kilograms)	74.06	16.07	49.00	110.00
Height (Meters)	1.64	0.09	1.37	1.88
Body Mass Index (Kilograms/ Meter ²)	27.51	5.19	19.20	44.22
Number of siblings for the child who has a disability	4.07	2.64	0.00	10.00
Overall rating of QOL (Q1)	70.75	18.96	40.00	100.00
Overall Satisfaction with Health (Q2)	75.47	20.15	40.00	100.00
Physical Health (Q - 3, 4, 10, 15, 16, 17, and 18)	62.45	12.17	42.86	94.29
Psychological Health (Q - 5, 6, 7, 11, 19, and 26)	65.44	15.04	36.67	93.33
Social Relationship (Q - 20, 21 and 22)	72.83	17.47	40.00	100.00
Environment (Q - 8, 9, 12, 13, 14, 23, 24, and 25)	64.69	15.24	37.50	97.50
Total Quality of Life (All questions)	66.35	12.88	50.30	92.95

with support; grade five indicates that the child walks independently but not like other children; and the final grade six that they walk normally like other children. These mobility levels of affected children of these caregivers were further demonstrated in Figure 1. The physical characteristics of the children of these caregivers, the numbers of children in each group and the corresponding percentages are shown in Table 2.

Out of the 106 caregivers, 91 (85.84%) were mothers, and the other 15 (14.16%) were female maids; 61 (57.5%) had their own house, and 45 (42.5%) of them did not own a home. The largest group in the sample, ie, 56 (52.8%) caregivers, each have a monthly income of less than SAR 5000; 40 (37.7%) other caregivers in the sample each have a monthly income between SAR 5000–10,000; only a few, ie, 10 (9.4%) caregivers, have a monthly income of greater than SAR 10,000.

Concerning financial support, more than half of the sample, ie, 59 (55.7%) caregivers, received financial support from the government, and the remaining 47 (44.3%) did not receive any financial support. Within the sample, 56 (52.8%) caregivers had male children with CP, and 50 (47.2%) had female children with CP. Of the children of many caregivers, 68 (64.2%) did not attend school; only a few of them, ie, 38 (35.8%), were in school attendance. Fifty-nine (55.7%) caregivers thought that they were receiving very good support that they needed from others, whereas 47 (44.3%) people reported that they were receiving excellent support from others. These caregiver details are also further described in Table 3.

The correlations between the demographic parameters of age, weight, height, age of the child with a disability, and number of siblings, compared with total QOL measured by WHOQOL-BREF, were analyzed by Pearson correlation. There was a slight significant correlation between total QOL and the age and height of the caregivers, with R values 0.28 ($p<0.001$) and 0.27 ($p<0.001$), respectively. More details of these correlations are provided in Figure 2.

The correlations between total QOL along with various parameters, including owning a house, monthly income, financial support, gender of the child, educational level of the child, and mobility of the child, were calculated using the Spearman correlations. There were moderate correlations between total QOL and children's academic status and mobility capacity, with R values of 0.54 ($p<0.001$) and 0.62 ($p<0.001$), respectively. More details of these correlations can be seen in Figure 3.

The correlations between the total QOL scores, the four subdomains, and two overall questions were calculated to determine their relationships. All four domains showed a very good correlation. Still, the environmental domain was found to have an excellent correlation, with an R-value of 0.91 ($p<0.01$), whereas Q1 and Q2, representing overall perceptions of QOL and satisfaction with health, respectively, showed a moderately significant correlation. The details of these correlations are presented in Table 4.

Regression analysis was performed to identify the factors that can influence total QOL, showing that the child's mobility, the child's educational level, and the subjects' height significantly affected the full QOL scores. Their details are described in Table 5.

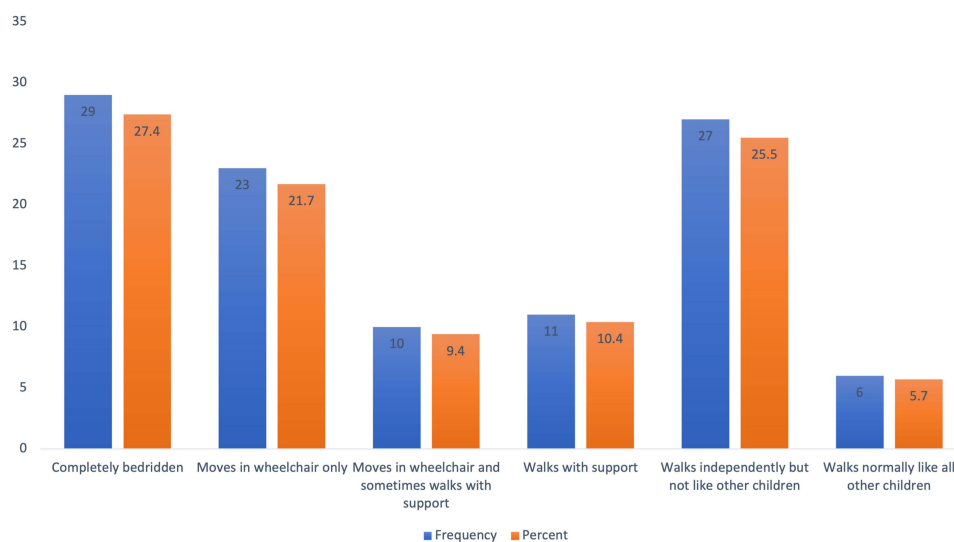


Figure 1 Demonstrating the distribution of the children according to six grades based on their mobility capacity.

Table 2 Characteristics of the Participating Caregiver's Children

S. No	Characteristics	Values
1	Number of subjects in each mobility category and their percentage	
	Grade – I: Child is completely bedridden	29(27.3)
	Grade – II: The child moves in a wheelchair only	23(21.7)
	Grade – III: The child is mobile with a wheelchair and sometimes walks with support	10(9.4)
	Grade – IV: Child walks with support	11(10.4)
	Grade – V: The child walks independently but not like other children	27(25.5)
	Grade – VI: The child walks normally like other children	06(05.7)
2	The average age of the subjects with a disability (Years) (Mean ± SD)	7.55 ± 3.04
3	Gender of the subjects (number and percentage)	
	Boys	56(52.8%)
	Girls	50(47.2%)
4	Distribution of subjects according to schooling	
	Number of subjects attending school	38(35.8%)
	Number of children not attending school	68(64.2%)

Table 3 Characteristics of the Participating Caregivers

S. No	Characteristics	Subdivision	Number (Percentage)
1	Type of the caregivers	Mothers	91(85.84%)
		Female maids	15(14.16%)
2	Caregivers' accommodation type	Living in their own house	61(57.5%)
		Living in a rented house	45(42.5%)
3	Monthly income of the caregivers	Less than 5000 SR	56(52.8%)
		5000–10,000 SR	40(37.7%)
		More than 10,000 SR	10(9.4%)
4	Financial support to the caregivers	By government	59(55.7%)
		No financial support from anyone	47(44.3%)
5	Other support from people around caregivers	Receiving very good support	59(55.7%)
		Receiving excellent support	47(44.3%)

Discussion

The current study is unique among studies conducted in the Asir region. Until now, limited research has been available to provide knowledge of QOL among caregivers of children with CP in the region. This study fills that gap and provides specific evidence of caregivers' QOL and associated factors.

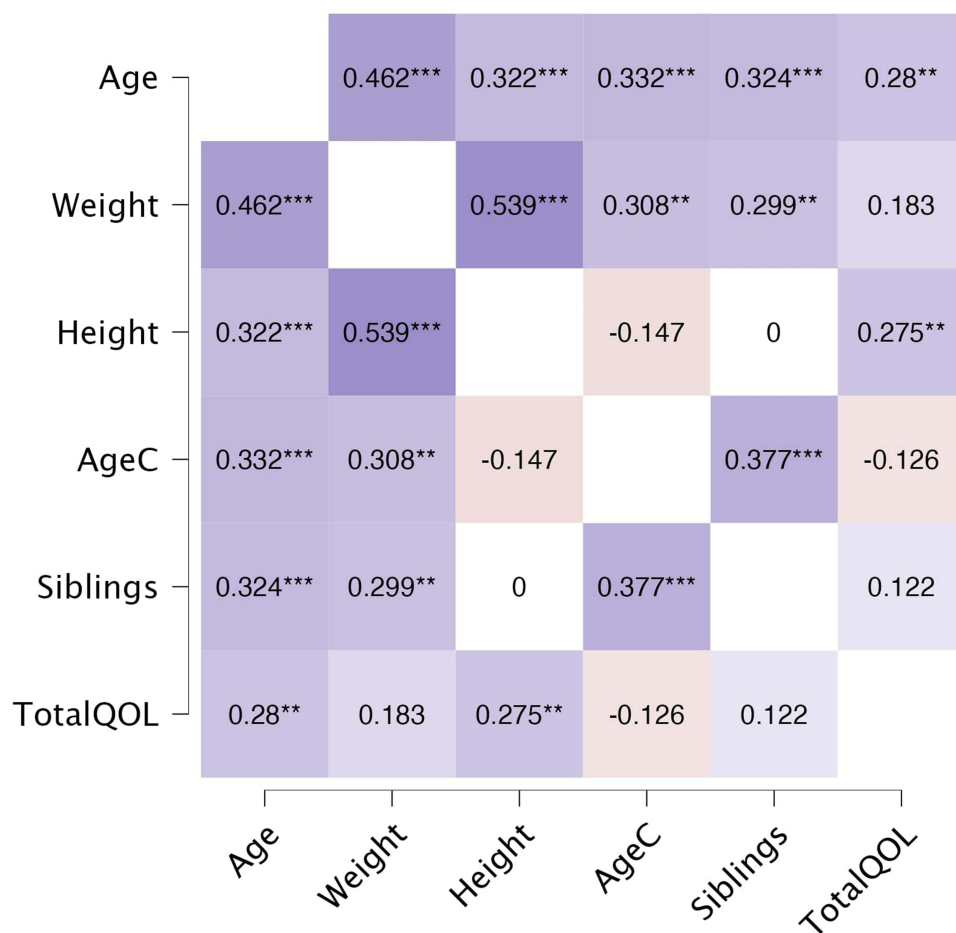


Figure 2 The correlation between the total QOL scores and demographic characteristics of the caregivers of children with CP. **Notes:** **Correlation is significant at the 0.01 level, ***Correlation is significant at the 0.001 level. Negative correlations are depicted by orange accent 2 colour and as the correlation is increasing the colour becomes darker, whereas positive correlations are depicted by purple colour and as the correlation is increasing the colour becomes darker. **Abbreviations:** AgeC, Age of the child; QOL, Quality of life.

Silva et al determined the cutoff points for WHOQOL-BREF among older adults that can be used to detect better QOL. WHOQOL-BREF scores of less than 60 can determine poor QOL, and more than 60 may indicate better QOL among older adults treated in primary health care.¹⁷ Similarly, Barbosa et al also performed a study to identify the cutoff points for WHOQOL-BREF to determine QOL among older adults. They also concluded that the same cutoff score of less than 60 on WHOQOL-BREF could be used to determine poor quality of life.¹⁸ AlBusaidi et al also used WHOQOL-BREF scores of less than 60 as the cutoff point to determine the poor quality of life among the caregivers of children with autism spectrum disorders in Oman.¹⁹ The total QOL score obtained in our study according to WHOQOL-BREF was 66.38; hence, compared with previous literature, we can conclude that the QOL was better for caregivers of children with CP in the Asir region.

Aman et al²⁰ conducted a cross-sectional study to examine QOL among caregivers of children with CP in Jeddah, Saudi Arabia. They assessed the QOL of 93 caregivers of children with CP aged between 4–18 years; the majority of caregivers were females, and they were evaluated using a self-structured QOL questionnaire with a maximum score of 16 points. The median QOL score they obtained was 8.98 out of 16, near the 56% total score reported in our study. Most subjects in that sample were also females; the children’s ages ranged between 3 and 13 years. However, the QOL scores were slightly better in the current study than in the previous, with a mean ± SD score of 66.35 ± 12.88. We believe that in the Aman et al study, the children were severely affected, which is why the QOL was more involved in caregivers than in ours.

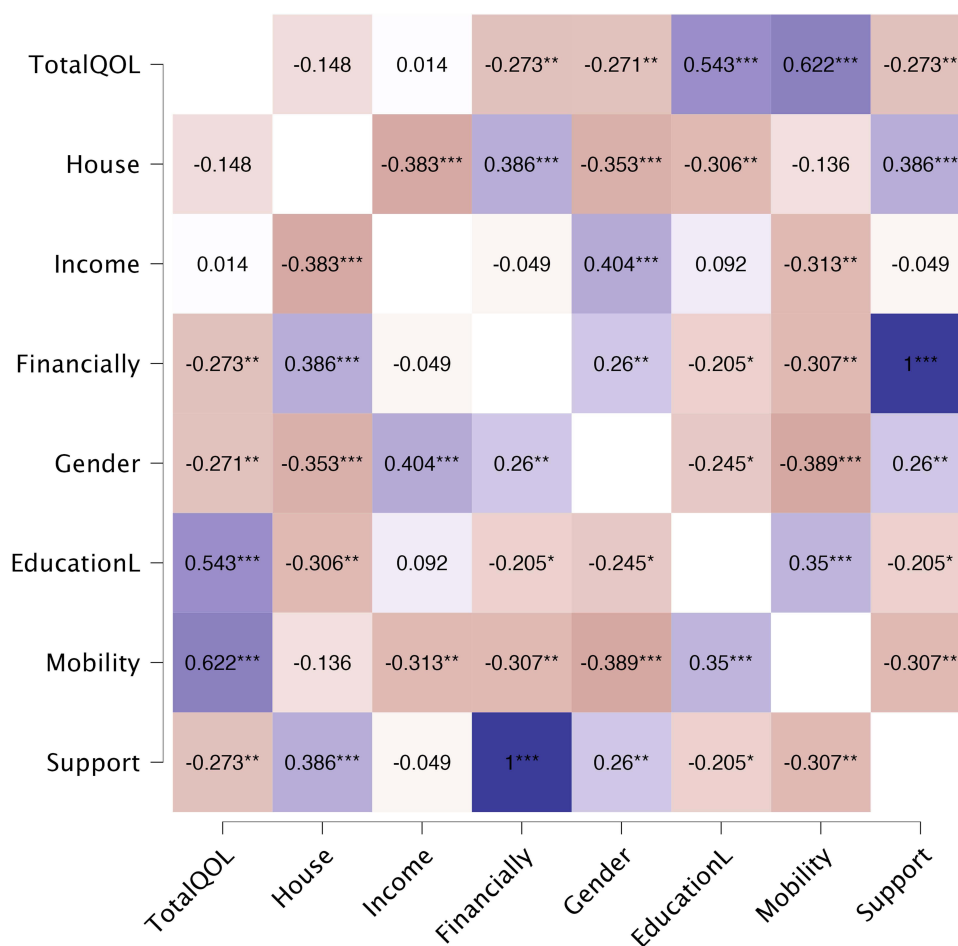


Figure 3 The correlation between the total QOL scores and owning a house, monthly income, financial help, gender of the child, educational level of the child, mobility of the child, and family support.

Notes: *Correlation is significant at the 0.05 level, **Correlation is significant at the 0.01 level, ***Correlation is significant at the 0.001 level. Negative correlations are depicted by orange accent 2 colour and as the correlation is increasing the colour becomes darker, whereas positive correlations are depicted by purple colour and as the correlation is increasing the colour becomes darker.

Abbreviations: QOL, Quality of life; Financially, Financial help from family and government; EducationL, educational level of the child.

Alwhaibi et al,²¹ conducted a comparative study to identify the differences in QOL among mothers of children with and without disabilities. They used a sample of 399 caregivers, of whom 300 cared for children with disabilities, comprising 155 caregivers of children with CP and 145 caregivers of children with Down syndrome. The remaining 99 were caregivers of children without disabilities, typically attending normal school. Their QOL was assessed using the Quality-of-Life Index Generic Version III. The total QOL scores did not differ greatly between caregivers of children with and without disabilities. However, the social and economic domains showed significant differences. The total quality of life score was 22.35 ± 3.59 out of 30, which is around 74.5%, whereas the results in our study were lower but comparable, at about 67%. These differences can be due to a mixture of disorders in the affected group in the study by Alwhaibi et al. Down syndrome children usually have normal lives like other children in physical activities; hence, their influence on the results might be the reason for better QOL.

When we compared the mean \pm SD of total QOL scores of caregivers of individuals with other health issues such as congenital heart disease (60.55 ± 10.5),¹³ autism spectrum disorders (64.8 ± 13.8),²² and cancer (49 ± 16.7)²³ the QOL of caregivers for children with CP in the Kingdom of Saudi Arabia (66.35 ± 12.88) had better scores. Among all these disorders, physical health was one of the most affected subdomains for caregivers, similar to the current study.

Saudi Arabia was built on a family-centered system. Here, women are the most important people in the family and take care of the children; hence, most of the caregivers in our study were mothers.^{24,25} The children's physical capacities are significantly

Table 4 Correlation Between Various Domains of the Questionnaire with Total QOL Scores

Correlation Variables	Total QOL	Physical Health Domain 1	Psychological Health Domain 2	Social Relationship Domain 3	Environment Domain 4	Q1: Overall Perception of QOL	Q2: Overall Satisfaction with Health
Total QOL	1						
Physical Health Domain 1	0.875**	1					
Psychological Health Domain 2	0.821**	0.723**	1				
Social Relationship Domain 3	0.835**	0.578**	0.495**	1			
Environment Domain 4	0.916**	0.783**	0.646**	0.728**	1		
Q1: Overall perception of QOL	0.655**	0.328**	0.568**	0.634**	0.666**	1	
Q2: Overall Satisfaction with health	0.671**	0.523**	0.545**	0.589**	0.638**	0.757**	1

Notes: **Correlation is significant at the 0.01 level (2-tailed).

Table 5 Regression Analysis Showing the Relationship Between Parameters

Parameters ($R^2 = 0.55$)	Coefficient	Importance
School	13.84	0.62
Mobility	2.3	0.211
Height	35.28	0.16

affected, and their mobility is restricted. Hence, most of the children's tasks were taken care of by the caregivers, and the caregiver's physical health was affected more than the other subdomains.²⁶ However, due to the strong systems of governmental and family support, the QOL of caregivers was better, and they were more able to manage their health and that of their affected children.²⁷⁻³¹ The authors feel that providing focused education to caregivers about their health and improving the services to children with cerebral palsy can drastically improve the QOL of the caregivers effectively. Another important correlation is a positive relationship between height and improved QOL. Many previous researchers also indicated a positive relationship between height and improved health-related quality of life. As per their understanding, increasing height increases confidence levels and thus enhances an individual's physical capacity. Even in the current situation, improving the height of caregivers increases their capacity to take care of the children due to their good stature and physical ability.³² Hence, we hypothesize that height can be one of the important factors in determining the QOL of a caregiver.

Limitations and Future Recommendations of the Study

The study was restricted to only one region of Saudi Arabia and considered the QOL of caregivers of individuals with a single childhood disability, ie, cerebral palsy; moreover, the QOL of the affected children was not assessed in this study. As the participants were recruited from a single region of Saudi Arabia, there could be a probability of a source of bias that could have influenced our results. Hence, future researchers can focus on various disabilities to better understand the QOL of caregivers of individuals with multiple disorders. We recommend future studies focusing on QOL caregivers in different regions of the Kingdom of Saudi Arabia. Furthermore, analysis of the QOL of affected individuals is another crucial component to understanding their circumstances more clearly. It will allow us to identify correlations between the QOL of caregivers and the involved subjects.

Conclusion

Caregivers of children with cerebral palsy in the Asir region reported higher QOL ratings than the recommended WHOQOL-BREF cutoff values. This study's QOL ratings were similar to previous research conducted in the Kingdom

of Saudi Arabia. The subdomains and overall scores of the QOL scale were consistent, indicating a strong relationship between the subsections and total QOL scores. The physical health domain scores were lower than other WHOQOL BREF domains. Rehabilitation professionals should address strategies for improving the physical health of caregivers and educate them about their health aspects. The study found that total QOL ratings improved with increased children's mobility and school attendance. However, there were only slight correlations between the caregivers' height and age on their overall QOL ratings.

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Disclosure

The authors report no conflicts of interest in this work.

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