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Quality of life in children with cerebral palsy

THESIS

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BY

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TO OBTAIN HER DOCTORATE IN MEDICINE

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رَبِّ أَوْزِعْنِي أَنْ
أَشْكُرَ نِعْمَتَكَ الَّتِي
أَنْعَمْتَ عَلَيَّ وَعَلَىٰ
وَالِدَيَّ وَأَنْ أَعْمَلَ
صَالِحًا تَرْضَاهُ
وَأَدْخِلْنِي بِرَحْمَتِكَ
فِي عِبَادِكَ الصَّالِحِينَ

Hippocratic Oath

I swear by Apollo the physician, and Asclepius, and Hygieia and Panacea, and all the gods and goddesses, making them my witnesses, that I will carry out, according to my ability and judgment, this oath and this indenture.

To hold my teacher in this art equal to my own parents; to make him partner in my livelihood; when he is in need of money to share mine with him; to consider his family as my own brothers, and to teach them this art, if they want to learn it, without fee or indenture.

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.

I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect.

I will not give to a woman an abortive remedy.

In purity and holiness I will guard my life and my art.

I will not use the knife, not even on sufferers from stone, but will withdraw in favor of such men as are engaged in this work.

Into whatever houses I enter, I will go into them for the benefit of the sick, and will abstain from every voluntary act of mischief and corruption.

Whatever I see or hear in the lives of my patients, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private.

While I continue to keep this oath unviolated, may it be granted to me to enjoy life and the practice of the art, respected by all men, in all times. But should I trespass and violate this oath, may the reverse be my lot.

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321	GHARBI Khalid	MC	Gastro-entérologie
322	ATBIB Yassine	MC	Pharmacie clinique
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325	HENDY Iliass	MC	Cardiologie
326	HATTAB Mohamed Salah Koussay	MC	Stomatologie et chirurgie maxillo faciale
327	DEBBAGH Fayrouz	MC	Microbiologie-virologie
328	OUASSIL Sara	MC	Radiologie
329	KOUYED Aicha	MC	Pédopsychiatrie
330	DRIOUICH Aicha	MC	Anesthésie-réanimation
331	TOURAIF Mariem	MC	Chirurgie pédiatrique
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344	AJMANI Fatima	MC	Médecine légale
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386	EL OUARRADI Assia	MC	Microbiologie-virologie
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DEDICATIONS

"Gratitude is not only the greatest of virtues, but the parent of all the others."

— Cicero

I dedicate this thesis to...

اللّٰهُمَّ لَكَ الْحَمْدُ حَمْدًا كَثِيرًا طَيِّبًا مُبَارَكًا فِيهِ

اللّٰهُمَّ لَكَ الْحَمْدُ كَمَا يَنْبَغِي لِجَلَالِ وَجْهِكَ وَعَظِيمِ سُلْطَانِكَ

اللّٰهُمَّ لَكَ الْحَمْدُ عَدَدَ خَلْقِكَ، وَرِضَا نَفْسِكَ، وَزِنَةَ عَرْشِكَ، وَمِدَادَ كَلِمَاتِكَ

اللّٰهُمَّ لَكَ الْحَمْدُ حَتَّىٰ تَرْضَىٰ، وَلَكَ الْحَمْدُ بَعْدَ الرِّضَا

To my dear dad, Mohamed Karouach

À toi, mon papa,
mon pilier, mon refuge, ma force tranquille.

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Please accept, Dear Professor, the expression of my highest respect and sincere gratitude.

FIGURES AND TABLES

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ABBREVIATIONS

ABREVIATIONS LIST :

QoL	: Quality of life
CP	: Cerebral Palsy
CP QoL	: cerebral palsy quality of life
GMFCS	: Gross motor function classification system
SDQ	: Strenghts and difficulties questionnaire
VAS	: Visual analogue scale
HR-QOL	: health related quality of life

Table of Content

INTRODUCTION

Chronic neurological conditions in childhood have long-term effects on children's functioning and well-being, making the assessment of quality of life an essential outcome in pediatric care. Cerebral palsy (CP) is the most common cause of physical disability in childhood and represents a heterogeneous group of permanent but non-progressive disorders of movement and posture, frequently associated with disturbances of sensation, cognition, communication, behavior, and epilepsy (1,2). Beyond motor impairment, children with CP experience a wide range of functional limitations and comorbidities that substantially affect daily activities, social participation, and family functioning (3).

With improvements in survival and life expectancy, clinical attention has progressively shifted from motor outcomes alone toward broader indicators of health and well-being (4). In this context, quality of life (QoL) has emerged as a central outcome in chronic pediatric conditions, as it reflects the individual's subjective perception of physical, emotional, and social functioning (5). Assessing QoL in children with CP is therefore essential to better understand their lived experience, identify unmet needs, and guide patient-centered clinical care and public health interventions (6).

Several studies conducted in high-income countries have highlighted significant impairments in health-related quality of life among children with cerebral palsy, influenced by motor severity, associated impairments, and environmental factors (7,8). However, data from Morocco and comparable middle-income settings remain scarce. Moreover, few studies have simultaneously examined the combined effects of clinical severity, comorbidities, and sociodemographic and behavioral factors on quality of life using validated CP-specific assessment tools (9).

In this context, the present study aimed to assess the quality of life of children with cerebral palsy followed at the CHU of Marrakech using the CP-QOL questionnaire (10). The secondary objectives were to identify the sociodemographic, clinical, and functional factors associated with quality-of-life outcomes in this population, and to compare parent-proxy and child self-reported quality-of-life scores when available (11).

PATIENTS AND METHODOLOGY

I. Study design:

This study adopted a cross-sectional descriptive design to assess the quality of life (QoL) of children with cerebral palsy (CP) followed at the CHU of Marrakech, between September 2025 and December 2025.

II. Study setting and population:

1. Study setting:

This study was conducted primarily at the pediatric emergency department and the physical medicine and rehabilitation department at Mohammed VI university hospital in Marrakech.

2. Study Population:

The study included children aged 4 to 12 years with a confirmed clinical diagnosis of cerebral palsy (CP), residing in the Marrakech region and followed at the CHU of Marrakech.

❖ **Inclusion criteria :**

- Clinical diagnosis of cerebral palsy.
- Age between 4 and 12 years.
- Residence in the Marrakech region.
- Availability of a primary caregiver willing to provide informed consent, and child assent when feasible.

❖ **Exclusion criteria :**

- Acute medical condition preventing participation.
- Uncontrolled epilepsy.
- History of major surgery within the previous 6 months.
- Refusal of informed consent and/or child assent.

III. Recruitment and sampling:

Children with CP and their caregivers were invited to participate in the study during neuropediatric consultations at the pediatric emergency department as well as during outpatient visits at the physical medicine and rehabilitation department of Mohammed VI university hospital in

Marrakech. Only participants meeting the study's inclusion criteria were enrolled. The sample included children with different clinical types of cerebral palsy, providing a representative snapshot of this population at a given point in time.

IV. Data collection:

1. Data collection tool:

Quality of life was assessed using the validated Arabic version of the CP QOL-Child questionnaire, a disease-specific instrument designed to evaluate quality of life in children with CP (12,13). The questionnaire covers seven domains: social well-being and acceptance, feelings about functioning, participation and physical health, emotional well-being and self-esteem, access to services, pain and impact of disability, and family health (10). The validated Arabic version of the CP QOL Child questionnaire (self-report version) was obtained from the original authors with their permission.

The CP QOL-Child questionnaire includes two versions: a parent-proxy version consisting of 66 items and a child self-report version consisting of 52 items. The parent-proxy version includes the domains "access to services" and "family health," which are not assessed in the child self-report version (13). The child self-report questionnaire was administered to children aged 9 to 12 years who had sufficient communication abilities and cognitive capacity to complete the questionnaire, in accordance with the instrument's recommendations (14).

2. Data collection procedure:

At the beginning of each consultation, general sociodemographic information was collected for each child, including age, gender, place of residence, school enrollment, and academic level. Clinical data were also recorded, including age at diagnosis, type and severity of cerebral palsy, distribution of motor involvement, associated comorbidities, and current therapeutic management.

Subsequently, the child and their caregiver were invited to a private room to collect additional family and socioeconomic information, including parental marital status, parental consanguinity, household income level, number of siblings, health insurance coverage, caregiver's educational level, and distance traveled to the hospital. Emotional and behavioral difficulties were screened using

a standardized questionnaire (SDQ) (15), and pain and sleep problems were assessed using the visual analog scale (VAS) for pain (16) and the BEARS sleep screening scale (17), respectively.

The parent-proxy version of the Arabic CP QOL-Child questionnaire was then administered to caregivers (13). Parents were asked to rate how they perceived their child's feelings across different life domains, including family, friends, health, and school, using a 9-point Likert scale. To ensure comprehension, the meaning of each item and the response scale were explained when necessary. Parents were asked the standardized question: *"On a scale from 1 to 9, how do you think your child feels about…?"*

Children who had sufficient communication abilities and cognitive understanding were also invited to complete the child self-report version of the CP QOL-Child questionnaire using the same procedure (12). Completion of the questionnaires required approximately 20 to 30 minutes per participant. Domain scores were calculated according to the instrument guidelines, with higher scores indicating better quality of life.

V. Study variables:

1. Dependent variables:

Quality of life, assessed using the CP QOL-Child questionnaire, was considered the dependent variable.

2. Independent variables:

Independent variables included:

- Sociodemographic variables
- Medical and clinical variables
- Emotional and behavioral variables
- Pain and sleep variables

VI. Definitions of variables :

❖ **Monthly household income:**

Monthly household income was categorized into three levels based on national socioeconomic standards: low income (<2,800 Moroccan dirhams [MAD]), moderate income (2,800-

6,700 MAD), and high income (>6,700 MAD). These thresholds are derived from national data published by the Haut Commissariat au Plan (HCP) and related socioeconomic studies (18) .

- **Cognitive status:**

Cognitive status was classified as "documented intellectual disability" when a clinical diagnosis was recorded in the child's medical file at the CHU, and as "no known impairment" when no cognitive deficits were documented.

- **Emotional and behavioral difficulties:**

Emotional and behavioral difficulties were screened using the parent-report version of the Strengths and Difficulties Questionnaire (SDQ), a validated 25-item screening tool for children aged 4–17 years (18). In this study, only the Total Difficulties Score (TDS) was used for analysis. Standard cut-off values were applied: scores of 0–13 were classified as normal, 14–16 as borderline, and 17–40 as abnormal, indicating a higher likelihood of emotional or behavioral difficulties (19). The SDQ was used exclusively as a screening instrument and not for diagnostic purposes. Categorical classifications were included in the analysis.

- **Pain**:

Pain was assessed using the visual analog scale (VAS), a validated unidimensional measure of pain intensity, No pain (0), Mild (1–3), Moderate (4–6), Severe (7–8), Very severe (9), Unbearable (10) (16).

- **Sleep problems:**

Sleep problems were screened using the BEARS sleep screening tool, which evaluates bedtime issues, excessive daytime sleepiness, night awakenings, regularity and duration of sleep, and snoring (17).

- **Motor function impairment:**

Motor function impairment was classified according to the Gross Motor Function Classification System (GMFCS), a standardized five-level system describing functional mobility in children with cerebral palsy (20).

- **Quality of life scoring:**

Responses to the CP QOL-Child questionnaire were transformed into scores ranging from 0 to 100 according to the recommended scoring algorithm (10), with higher scores indicating better

quality of life. For each domain, mean percentage scores were calculated, resulting in seven domain scores ranging from 0 to 100 for each participant.

VII. Ethical considerations:

This study was approved by the Ethics Committee of the Faculty of Medicine, Cadi Ayyad University. Free and informed consent was obtained from caregivers, and assent was requested from children whenever possible. Confidentiality was maintained by using anonymous codes to identify participant files, which were securely stored. Participants were allowed to withdraw from the study at any time without any consequences for their care.

VIII. Data analysis:

The collected data were entered and analyzed using SPSS version 25 (Statistical Package for the Social Sciences), and these following tests were used: student t-test for independent samples, Mann-Whitney test and Kruskal-Wallis's test. A significance level of 5% ($p < 0.05$) was adopted for all tests.

RESULTS

I. Descriptive study:

1. Sample size:

A total of **104** children with cerebral palsy were included in the study.

2. Socio-demographic variables among children with cerebral palsy:

- **Gender**:

The study population showed a male predominance, with males representing 67.3% (n = 70). The sex ratio (male: female) was 2.06:1.

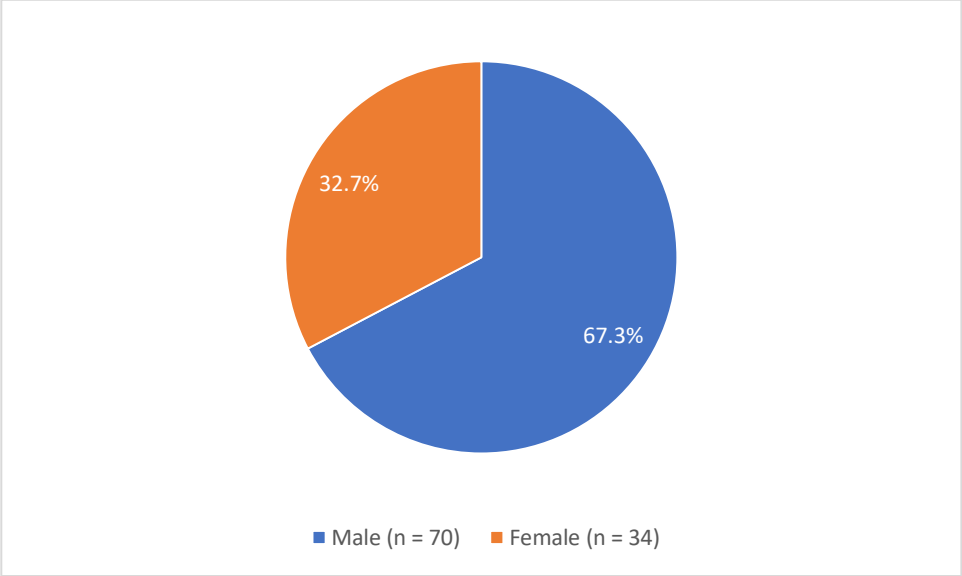


Figure 1: Gender distribution among children with cerebral palsy.

- **Age**:

Ages ranged from 4 to 12 years. Mean age was 8.25+/- 2.848.

The distribution showed variability across age groups, with the highest number of children aged 12 years (n = 20), followed by those aged 8 years (n = 15) and 4 years (n = 14).

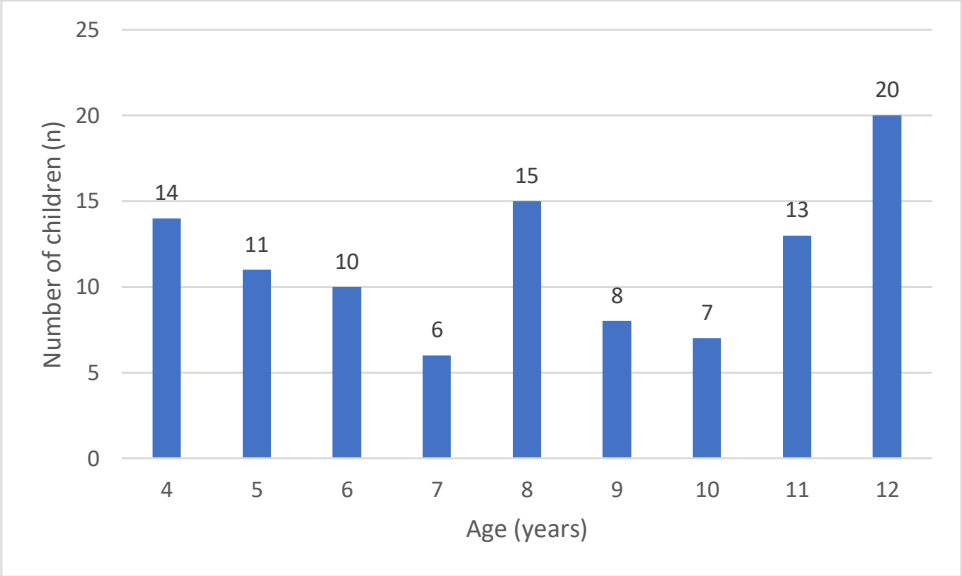


Figure 2: Age distribution of study participants.

❖ **Place of Residence:**

Most children in the study population were from rural areas (59.6%, n = 62).

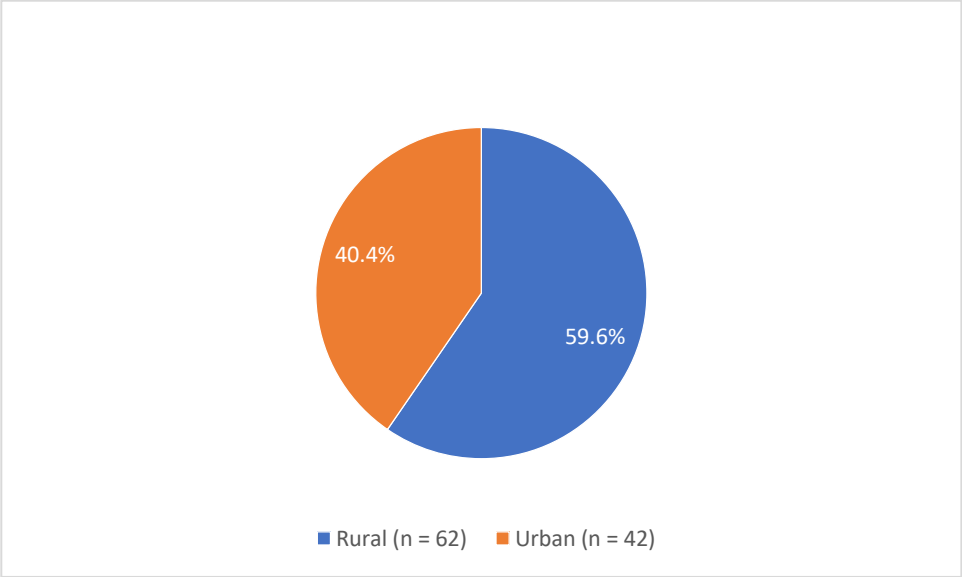


Figure 3: Distribution of place of residence among study participants.

❖ **School Enrollment:**

Among the children included in the study, 83.7% (n = 87) were not enrolled in school.

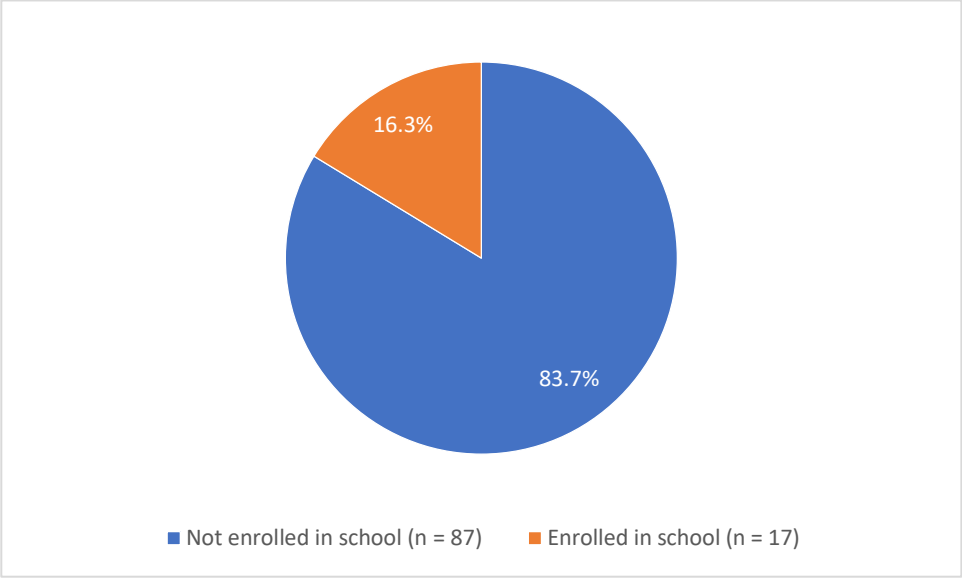


Figure 4: School enrollment status of the study population.

❖ **Parents' Marital Status:**

Most caregivers were married (74.0%, n = 77), followed by divorced caregivers (24.0%, n = 25), while widowed caregivers accounted for a small proportion of the sample (1.9%, n = 2).

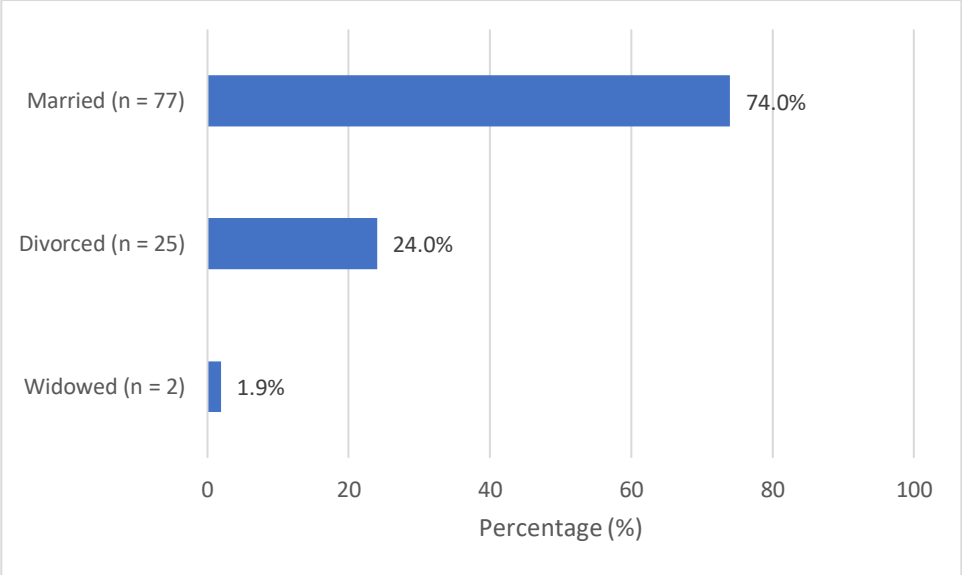


Figure 5: Distribution of parents' marital status in the study population.

❖ **Parental consanguinity:**

Parental consanguinity was absent in 61.5% (n = 64) of cases.

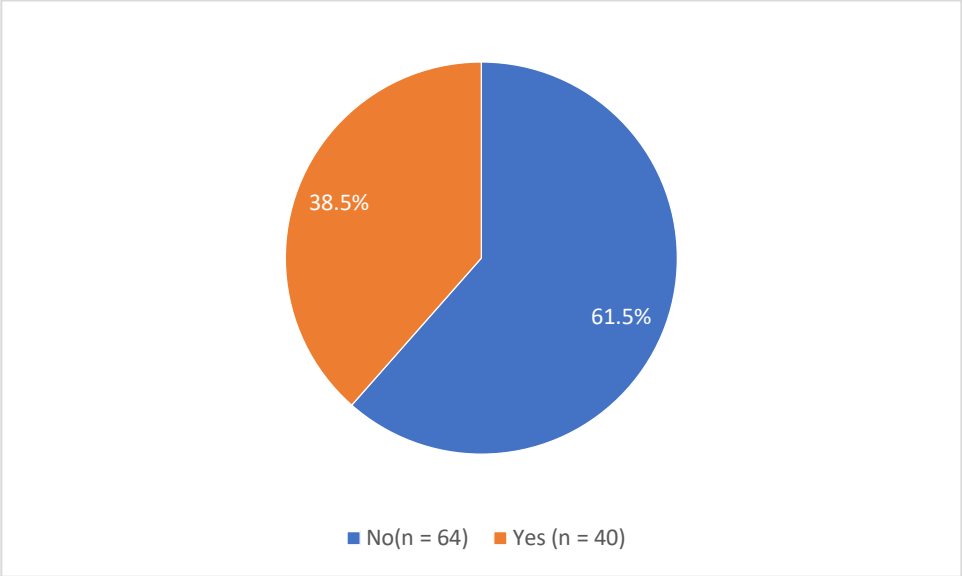


Figure 6: Parental consanguinity among families of the study population.

❖ **Monthly parental income level**:

Regarding parental income level, the majority of families were classified as low income, representing 76.9% (n = 80) of the study population, while 23.1% (n = 24) had a moderate income. No families were classified in the high-income category.

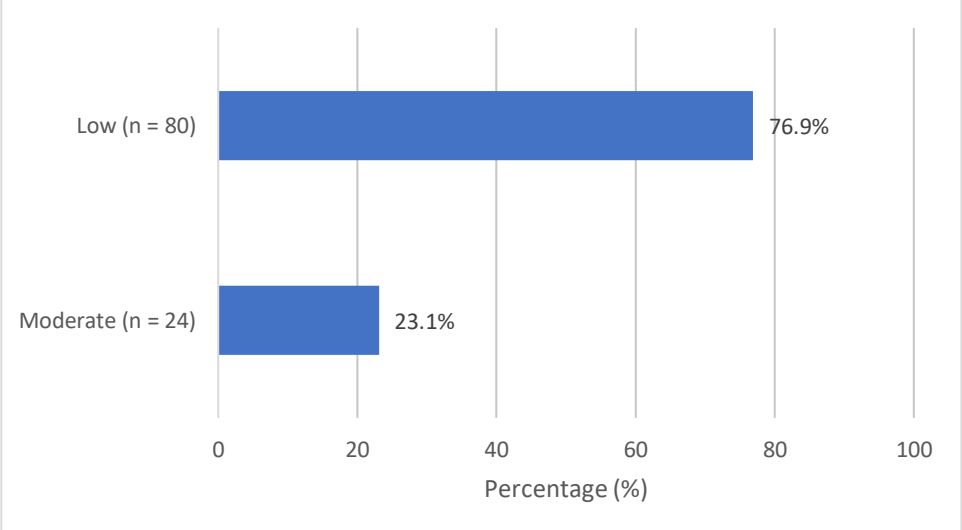


Figure 7: distribution of the parental income levels in the study population.

❖ **Presence of Siblings:**

The majority of children in the study had siblings, accounting for 89.4% (n = 93) of the sample.

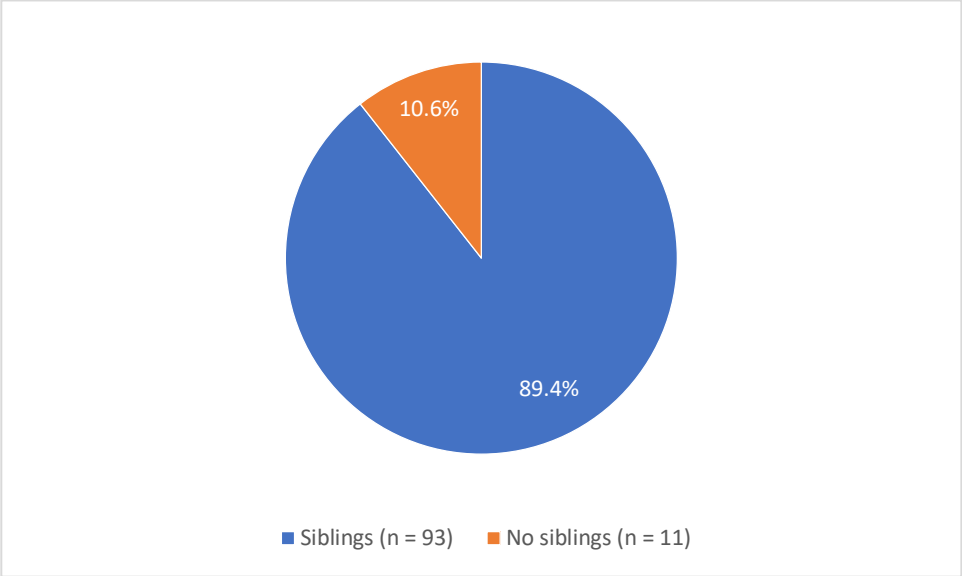


Figure 8: Presence of siblings among study participants.

❖ **Siblings with chronic disease:**

Among children who had siblings, 80.6% (n = 75) had no sibling with a chronic disease.

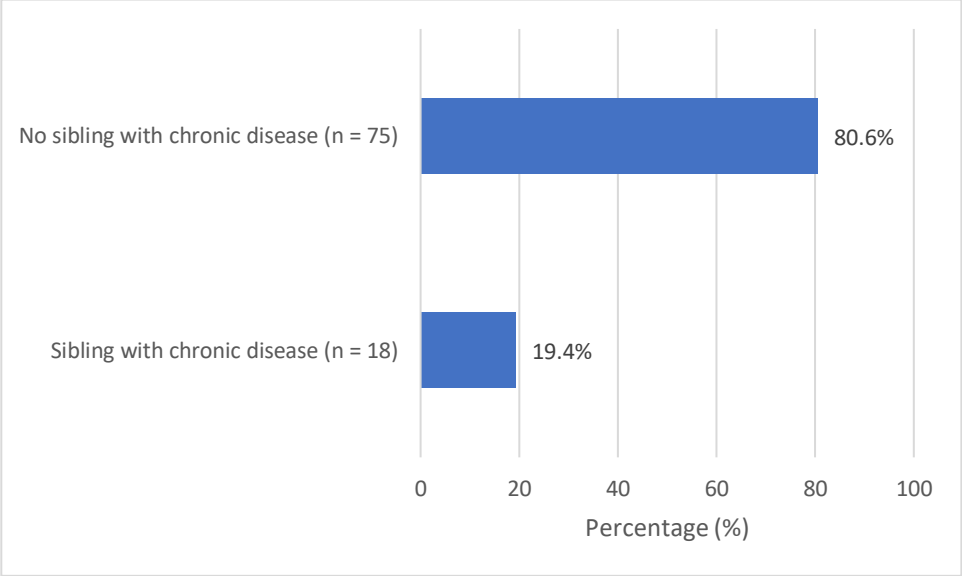


Figure 9: Presence of chronic disease among siblings of participating children.

❖ **Health insurance:**

The majority of children were covered by health insurance, representing 91.3% (n = 95) of the study population.

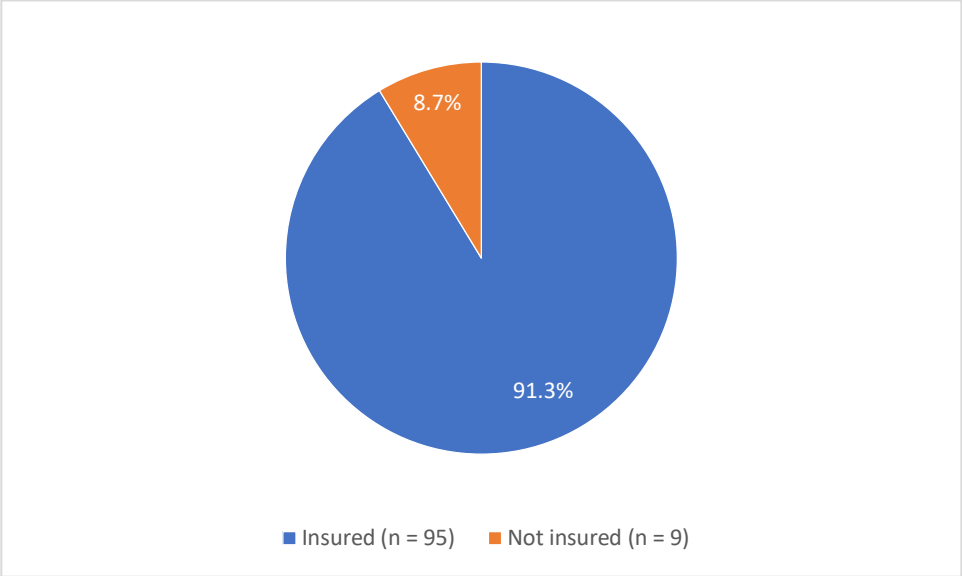


Figure 10: Health insurance coverage among the study population.

❖ **Caregiver relationship to the child:**

In most cases, the mother was the primary caregiver respondent (86.5%, n = 90).

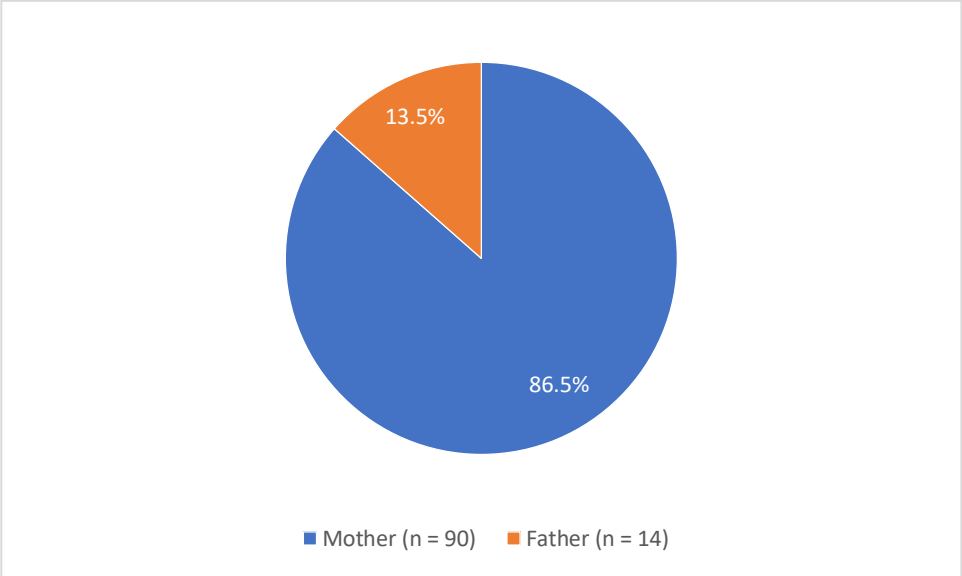


Figure 11: Distribution of the primary caregiver relationship to participating children.

❖ **Primary caregiver' s education level:**

Regarding caregivers' educational level, 51.9% (n = 54) were illiterate, 34.6% (n = 36) had primary or middle school education, 11.5% (n = 12) had completed high school, and only 1.9% (n = 2) had a university-level education.

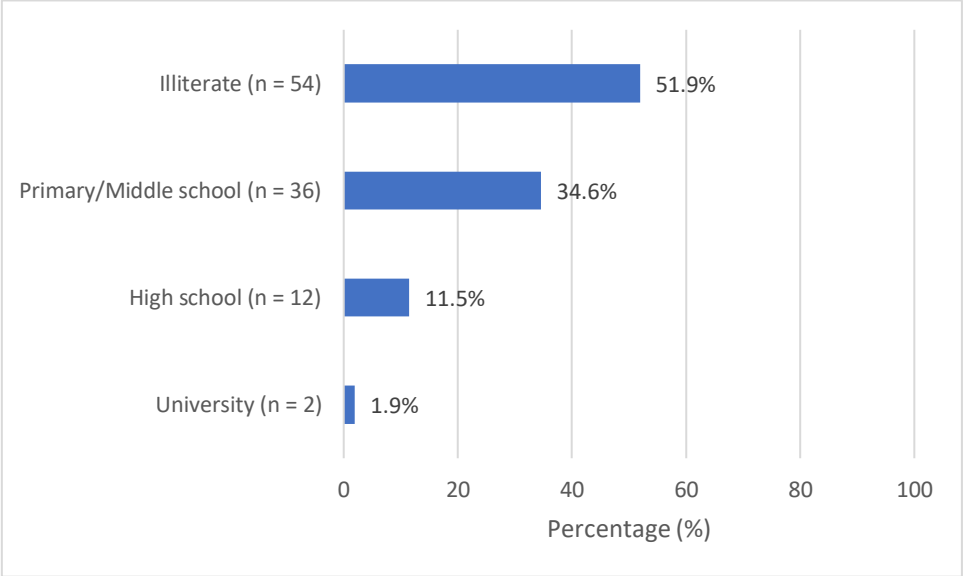


Figure 12: Distribution of primary caregiver education levels among participating children.

❖ **Distance to hospital:**

Most families traveled more than 30 km to reach the hospital (58.7%, n = 61), while 30.8% (n = 32) traveled 16–30 km, 8.7% (n = 9) traveled 5–15 km, and 1.9% (n = 2) lived within 5 km.

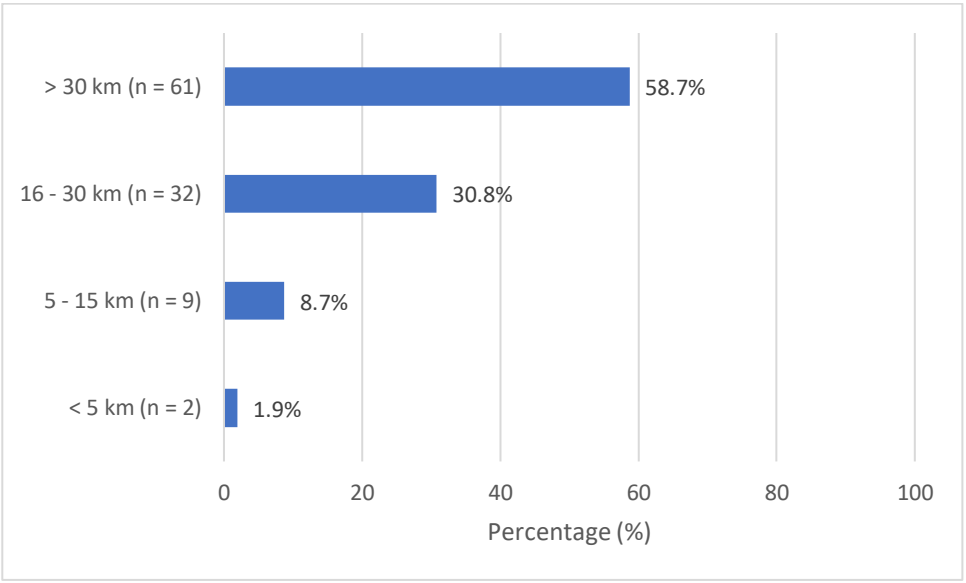


Figure 13: Distribution of distance from home to the hospital among study participants.

3. Medical and clinical variables among study group:

❖ **Age at diagnosis of cerebral palsy:**

Most children were diagnosed before 1 year of age (76.0%, n = 79), while 4.8% (n = 5) were diagnosed between 1–2 years and 19.2% (n = 20) after 2 years of age.

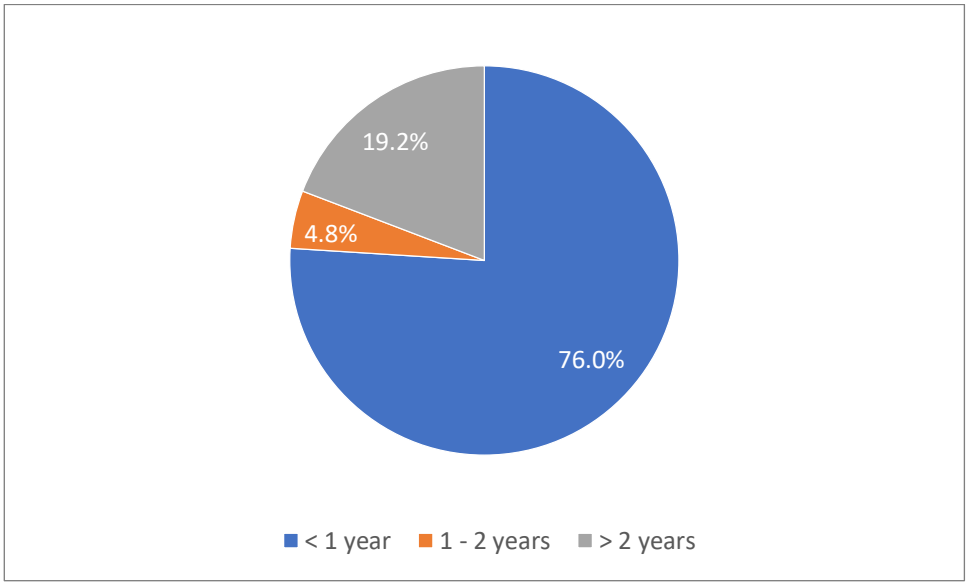


Figure 14: Age at diagnosis of cerebral palsy in the study population.

❖ **Type of Cerebral Palsy**:

Regarding the clinical type of cerebral palsy, the spastic form was the most frequent, accounting for 69% (n = 72) of cases. Ataxic cerebral palsy represented 15% (n = 16), followed by mixed forms in 9% (n = 9) of children, while the dyskinetic type was the least frequent, accounting for 7% (n = 7) of the study population.

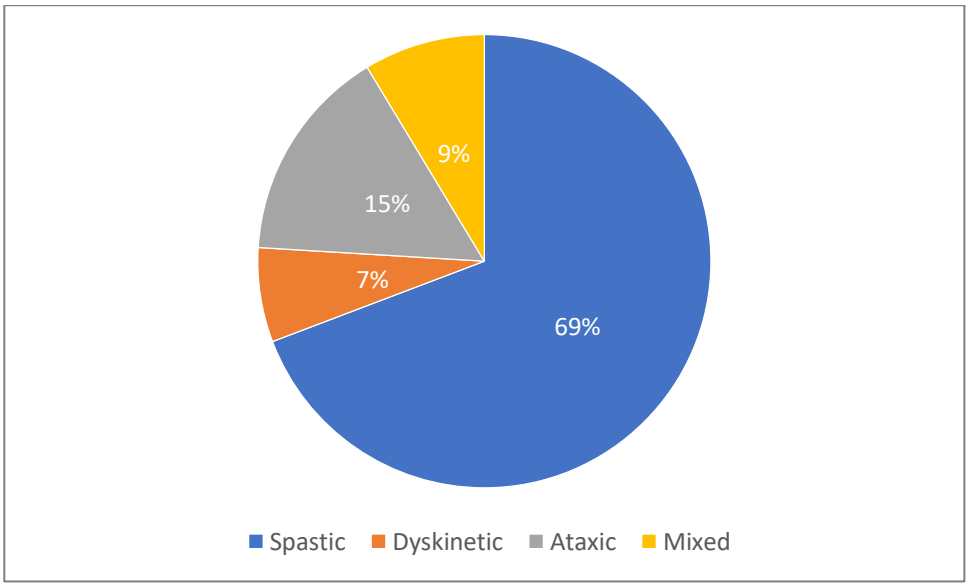


Figure 15: Distribution of cerebral palsy types in the study population.

❖ **Severity (GMFCS Level):**

Regarding motor function severity as assessed by the Gross Motor Function Classification System (GMFCS), nearly half of the children were classified as level V, accounting for 48.1% (n = 50) of the sample. GMFCS level I represented 18.3% (n = 19) of cases, followed by level II in 14.4% (n = 15), level IV in 11.5% (n = 12), and level III in 7.7% (n = 8) of children.

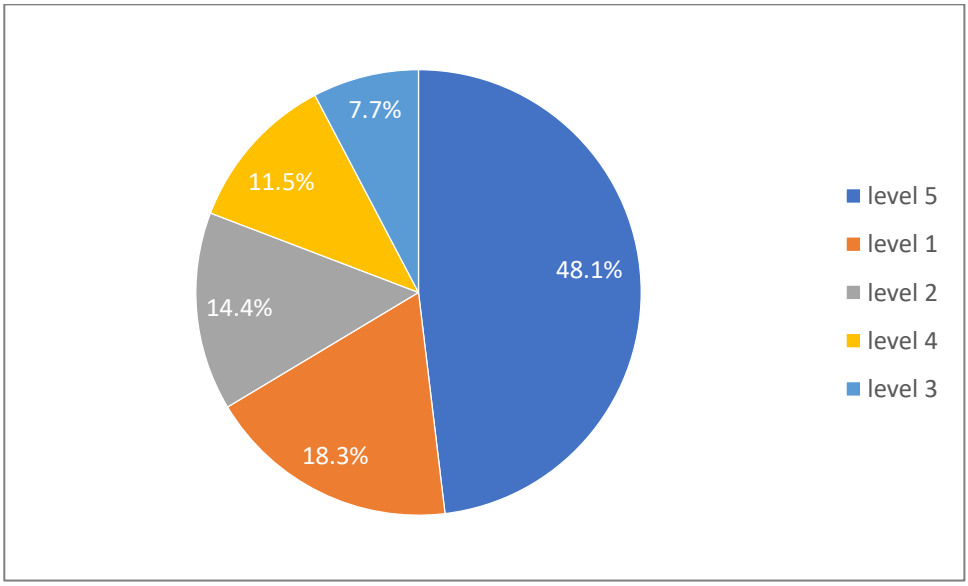


Figure 16: Distribution of motor severity according to Gross Motor Function Classification System levels in the study population.

❖ **Associated Conditions:**

Several associated conditions were observed among the children with cerebral palsy. Speech impairment was the most frequent, affecting 62.5% (n = 65) of the sample, followed by epilepsy in 55.8% (n = 58). Visual problems were reported in 32.7% (n = 34) of children, while swallowing disorders and hearing problems were present in 26.9% (n = 28) and 24.0% (n = 25) of cases, respectively.

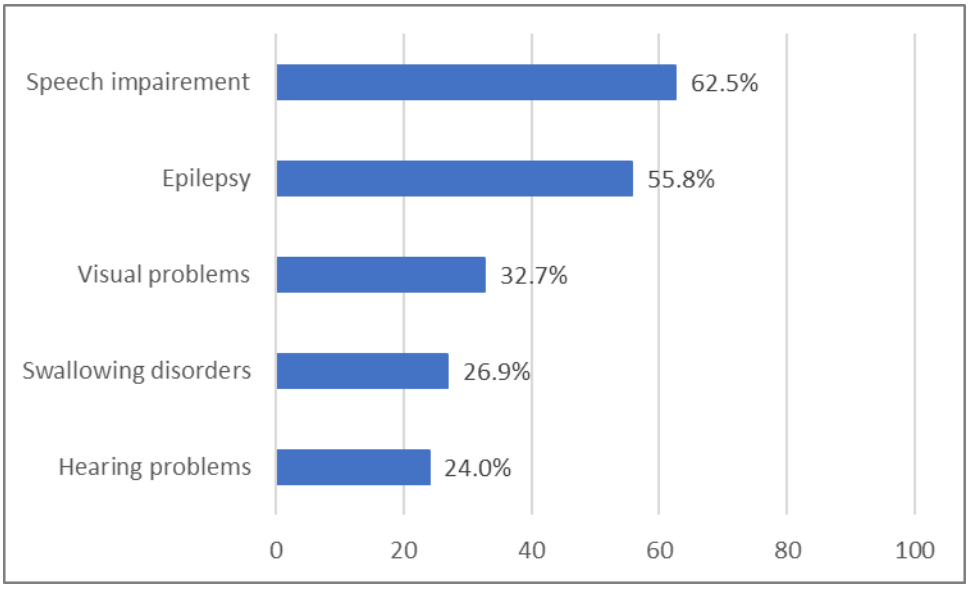


Figure 17: Distribution of associated conditions among children with cerebral palsy.

❖ **Cognitive status:**

More than half of the children had a documented intellectual disability (53.8%, n = 56).

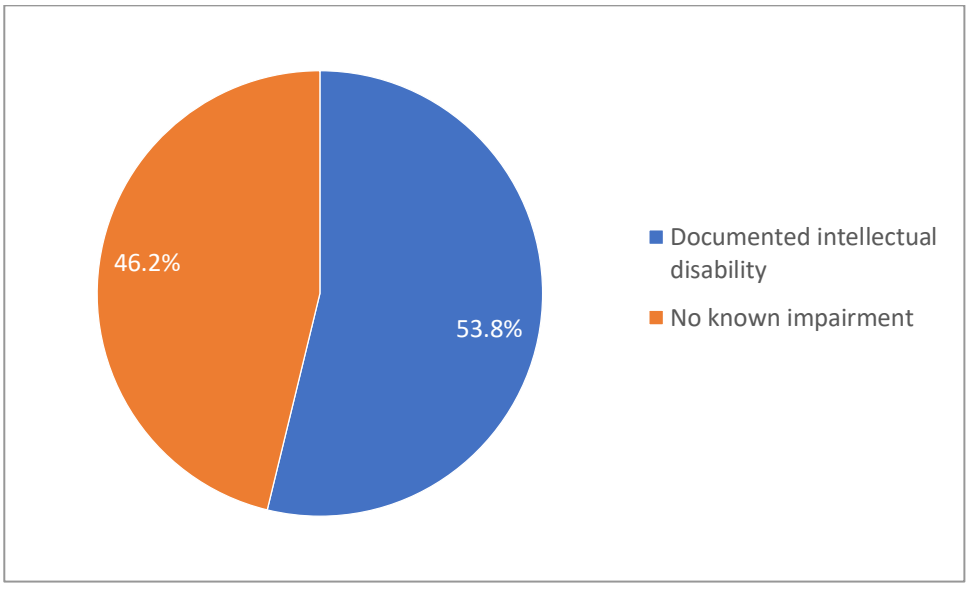


Figure 18: Distribution of cognitive status in the study population.

❖ **Motor topography:**

Regarding motor topography, quadriplegia was the most frequent presentation, accounting for 52.9% (n = 55) of cases. Hemiplegia was observed in 22.1% (n = 23) of children, followed by diplegia in 16.3% (n = 17). Monoplegia and triplegia were less frequent, representing 6.7% (n = 7) and 1.9% (n = 2) of the study population, respectively.

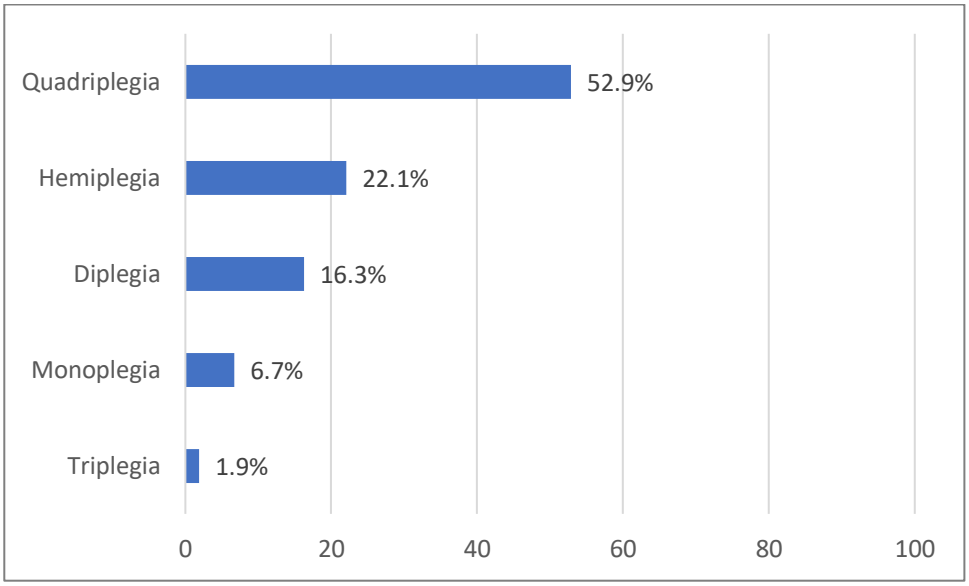


Figure 19: Distribution of motor topography among participating children.

❖ **Current therapies:**

Regarding current therapeutic management, physical therapy was the most commonly reported intervention, received by 80.8% (n = 84) of children. Pharmacological therapy was reported in 56.7% (n = 59), while speech therapy was received by 49.0% (n = 51) of the study population. Assistive devices were used by 19.2% (n = 20) of children. Orthopedic management and occupational therapy were each reported in 15.4% (n = 16) of cases. Botulinum toxin injections and aquatic therapy were less frequently used, each reported in 11.5% (n = 12) of children.

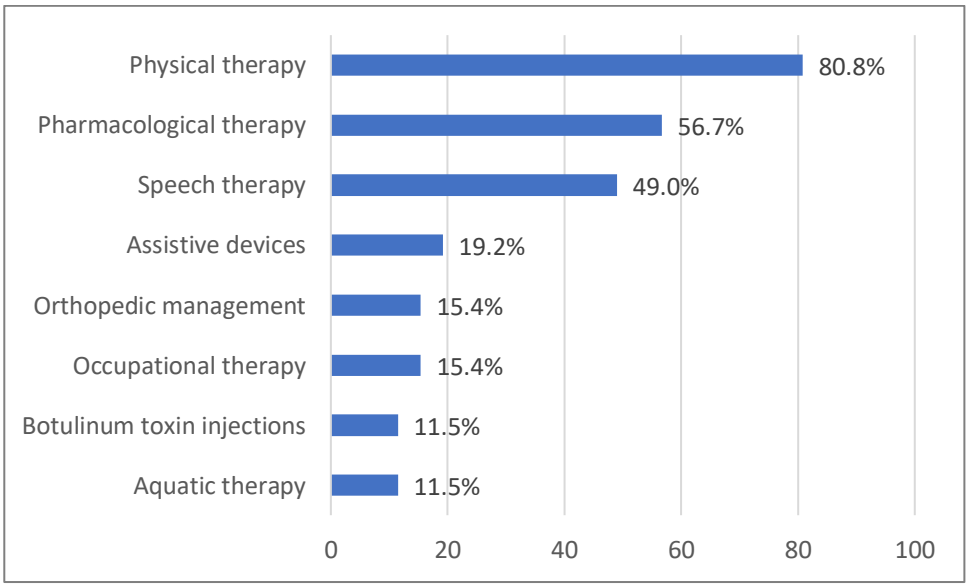


Figure 20: Distribution of current therapies used by study participants.

4. Mental health/behavioral difficulties screening in children with cerebral palsy:

Based on the Strengths and Difficulties Questionnaire (SDQ) total difficulties score, 39.4% (n = 41) of children were classified as having normal scores, 33.7% (n = 35) as borderline, and 26.9% (n = 28) as abnormal, indicating a high likelihood of emotional and behavioral difficulties.

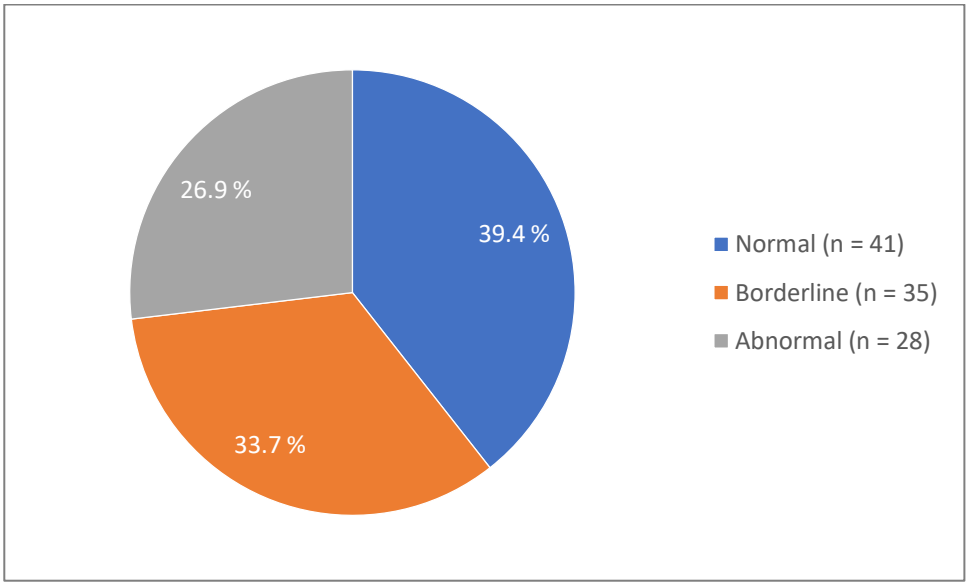


Figure 21: Distribution of emotional and behavioral assessment categories among participants.

5. Chronic pain and sleep problems variables among children with cerebral palsy:

- **Chronic Pain:**

Regarding pain intensity, 33.7% (n = 35) of children reported no pain. Among those experiencing pain, 29.8% (n = 31) reported unbearable pain, 13.5% (n = 14) reported moderate pain, 11.5% (n = 12) reported mild pain, 7.7% (n = 8) reported very severe pain, and 3.8% (n = 4) reported severe pain.

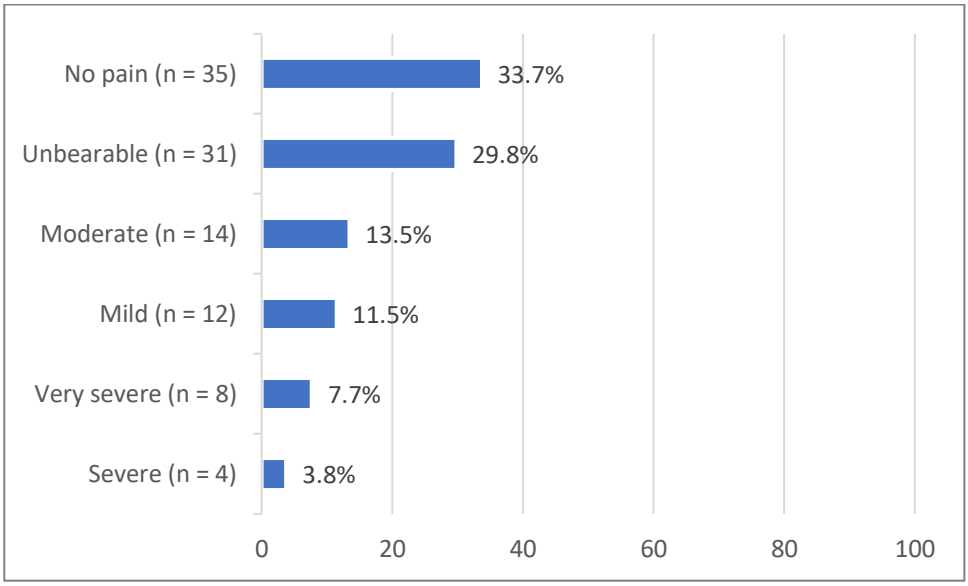


Figure 22: Distribution of pain intensity categories among participants.

❖ **Sleep problems:**

Sleep problems were common, with 63.5% (n = 66) of children having at least one reported sleep difficulty according to the BEARS screening tool.

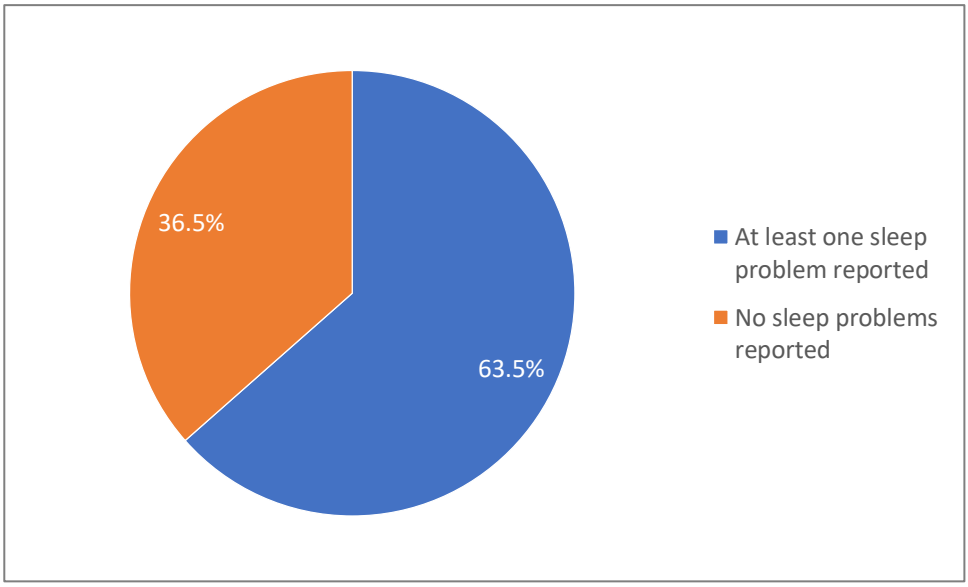


Figure 23: Distribution of sleep problem categories among participants.

6. Domains of the cerebral palsy quality of life questionnaire:

❖ **Parent proxy - Detailed Descriptive Statistics:**

Table 1: Parent-reported quality-of-life domain scores.

QoL Domain	Mean	Standard Deviation	25th percentile	50th percentile (Median)	75th percentile	Range
Family health	44.41	18.02	31.25	40.63	53.13	84.38
Access to services	22.91	19.05	8.33	18.15	33.78	70.83
Emotional wellbeing and self-esteem	61.24	22.53	47.92	61.46	79.17	89.58
Participation and physical health	42.71	30.08	19.06	32.50	72.44	94.32
Pain and impact of disability	40.63	24.23	21.43	37.50	62.95	87.50
Social wellbeing and acceptance	71.23	25.38	50.94	78.75	90.54	97.73
Feelings about functioning	46.38	23.19	29.17	45.31	67.71	86.46

Parent-reported QoL scores (N = 104) were highest for social wellbeing and acceptance (71.23 ± 25.38) and Emotional wellbeing and self-esteem (61.24 ± 22.53). Access to services (22.91 ± 19.05) and Participation and physical health (42.71 ± 30.08) were lower with marked dispersion.

❖ **Child report – detailed descriptive statistics:**

Table 2: Child self-reported quality-of-life domain scores.

QoL Domain	Mean	Standard Deviation	25th percentile	50th percentile (Median)	75th percentile	Range
Participation and physical health	69.70	26.20	61.56	77.27	85.80	69.66
Feelings about functioning	68.33	13.86	57.29	65.63	76.82	37.50
Pain and impact of disability	45.85	20.50	27.34	40.63	63.34	51.56
Social wellbeing and acceptance	90.75	3.04	88.28	90.63	92.40	8.33
Emotional wellbeing and self-esteem	69.58	12.00	60.42	62.50	78.65	29.17

Child self-reports (N = 10) showed very high, tightly clustered scores for social wellbeing and acceptance (90.75 ± 3.04; IQR 88.28–92.40), whereas Pain and impact of disability was lowest (45.85 ± 20.50; IQR 27.34–63.34). Participation and physical health (69.70 ± 26.20) and Feelings about functioning (68.33 ± 13.86) were moderately high, with notable variability for participation.

II. Analytical study:

1. Sociodemographic comparisons:

Table 3: Comparison of quality-of-life scores by gender.

QoL Domain	Male (n=70)	Female (n=34)	p-value
Social Wellbeing	80.1±22.1	74.9±24.5	0.288
Feelings about Functioning	48.3±21.9	42.4±25.5	0.224
Participation & Physical Health	49.9±28.1	27.8±28.9	0.001*
Emotional Wellbeing and self esteem	63.4±23.1	56.8±20.9	0.163
Access to Services	27.0±20.4	14.4±12.4	< 0.001*
Pain & Impact of Disability	36.8±23.0	48.6±25.0	0.019*
Family Health	45.8±18.6	41.6±16.7	0.276

It is observed that boys benefit from significantly higher scores in Access to Services (27.0±20.4) and Participation & Physical Health (49.9±28.1) compared to girls ($p<0.001$and $p=0.001$, respectively).

Furthermore, the Pain and Impact of Disability domain is perceived more positively by girls (48.6±25.0) vs (36.8±23.0) for boys; ($p=0.019$). In contrast, dimensions related to Emotional Wellbeing, Feelings about Functioning, and Family Health do not show statistically significant differences ($p>0.05$).

Table 4: Comparison of quality-of-life domain scores by age.

QoL Domain	Spearman ρ with Age	p-value
Family health	-0.308	0.001*
Access to services	0.077	0.436
Emotional wellbeing & self-esteem	-0.065	0.514
Participation & physical health	-0.132	0.181
Feelings about functioning	-0.105	0.289
Pain & impact of disability	-0.013	0.896

QoL Domain	Spearman ρ with Age	p-value
Social wellbeing & acceptance	-0.236	0.016*

Age was significantly and negatively correlated with Family health and social wellbeing & acceptance, indicating lower scores with increasing age in these domains.

Table 5: Comparison of quality-of-life domain scores by place of residence.

QoL Domain	Urban (n=42)	Rural (n=62)	p-value
Social Wellbeing	81.2±21.4	76.5±23.8	0.312
Feelings about Functioning	49.5±22.1	44.2±23.9	0.265
Participation & Physical Health	45.8±27.5	40.6±28.4	0.358
Emotional Wellbeing and self esteem	64.1±22.8	59.3±22.4	0.298
Access to Services	31.4±22.5	17.1±13.6	< 0.001*
Pain & Impact of Disability	38.2±22.4	42.3±25.1	0.395
Family Health	47.4±18.2	42.4±18.1	0.166

The most significant finding is in the domain of Access to Services ($p<0.001$), where children living in urban areas score significantly higher than those in rural areas (31.4vs. 17.1).

Despite the gap in physical resources, there are no statistically significant differences in Social Wellbeing, Emotional Wellbeing, or Participation between urban and rural settings ($p>0.05$). Furthermore, the Family Health score ($p=0.166$) and the perception of Pain and Disability ($p=0.395$) show no significant variation.

Table 6: Comparison of quality-of-life domain scores by school enrollment.

QoL Domain	Enrolled (n=17)	Not enrolled (n=87)	p-value
Social Wellbeing	83.5±21.2	77.4±23.2	0.315
Feelings about Functioning	62.1±18.4	43.3±22.8	0.001*
Participation & Physical Health	63.2±18.2	38.7±27.8	< 0.001*
Emotional Wellbeing and self esteem	72.5±15.8	59.0±23.1	0.021*

QoL Domain	Enrolled (n=17)	Not enrolled (n=87)	p-value
Access to Services	35.2±24.1	20.5±17.2	0.004*
Pain & Impact of Disability	29.4±17.6	42.8±24.9	0.035*
Family Health	47.1±14.8	43.9±18.8	0.510

Children who are enrolled in school (16.3%) show significantly higher scores in four out of the seven domains compared to those who are not. The most profound differences are seen in Participation and Physical Health ($p<0.001$) and Feelings about Functioning ($p=0.001$)

Furthermore, schooling is associated with better Emotional Wellbeing ($p=0.021$) and a better Access to Services ($p=0.004$). Interestingly, Pain and Impact of Disability domain is perceived significantly higher by unschooled children (0.035). However, Social Wellbeing and Family Health did not show significant differences.

Table 7: Comparison of quality-of-life domain scores according to parental consanguinity status.

QoL Domain	Consanguinity: Yes (n=40)	Consanguinity: No (n=64)	p-value
Family health	36.71 ± 15.26	29.66 ± 14.40	**0.019***
Emotional wellbeing	42.27 ± 26.51	35.68 ± 27.46	0.231
Feelings about functioning	47.46 ± 29.41	54.26 ± 27.04	0.231
Pain and impact of disability	18.05 ± 16.57	20.86 ± 18.56	0.435
Access to services	38.74 ± 17.88	40.85 ± 18.31	0.566
Social wellbeing and acceptance	71.25 ± 29.46	69.27 ± 22.80	0.702
Participation and physical health	51.73 ± 22.27	50.46 ± 26.05	0.799

Regarding parental consanguinity, a statistically significant difference was observed only in the Family health domain ($p=0.019$). Parents in the consanguineous group (n=40) reported significantly higher scores compared to non-consanguineous parents (36.71 ± 15.26 vs. 29.66 ± 14.40). No significant differences were found in the other domains: Social wellbeing ($p=0.702$),

Feelings about functioning (p=0.231), Participation and physical health (p=0.799), Emotional wellbeing (p=0.231), Access to services (p=0.566), and Pain and impact of disability (p=0.435).

Table 8: Comparison of quality-of-life domain scores by parental income level.

QoL Domain	Low Income (n=80)	Moderate Income (n=24)	*p*-value
Family Health	43.36±15.69	47.92±24.32	0.279
Access to Services	19.35±15.59	34.78±24.47	0.010*
Emotional Wellbeing	63.57±21.65	53.47±24.12	0.054
Participation & Physical Health	42.86±28.47	42.21±35.60	0.926
Feelings about Functioning	47.16±23.69	43.79±21.72	0.535
Pain & Impact of Disability	38.41±23.62	48.05±25.29	0.088
Social Wellbeing & Acceptance	72.71±23.74	66.31±30.27	0.281

The analysis of parental income level reveals that the most significant impact on the child's quality of life is found in the Access to Services domain (p = 0.010). Children from families with a "Moderate" income level reported a substantially higher mean score (M = 34.78) compared to those from "Low" income families (M = 19.35).

Table 9: Comparison of quality-of-life domain scores according to sibling presence.

CP QOL Domain	Only Child (n=11)	Has Siblings (n=93)	*p*-value
	Median [IQR]	Median [IQR]	
Feelings about functioning	28.41[28.4–35.2]	51.14[27.3–79.5]	0.034*
Participation and physical health	32.95[31.8–43.8]	52.27[27.3–75.0]	0.033*
Emotional wellbeing and self-esteem	16.67 [0.0–45.0]	45.83 [16.7–60.4]	0.072
Family health	36.12 [33.5–39.8]	29.38 [22.6–38.8]	0.128
Social wellbeing and acceptance	66.67 [66.7–75.0]	77.50 [51.2–91.2]	0.159
Pain and impact of disability	10.00 [7.5–27.5]	15.00 [5.0–32.5]	0.618
Access to services	44.44 [19.4–55.6]	36.25 [26.2–54.2]	0.638

IQR = Interquartile Range.

The analysis revealed statistically significant differences in two domains: Feelings about functioning (p=0.034) and Participation and physical health (p=0.033). In both cases, "children with siblings" reported higher median scores (Mdn=51.14 and Mdn=52.27, respectively) compared to "only children" (Mdn=28.41and Mdn=32.95). While the Emotional wellbeing domain showed a trend toward higher scores for children with siblings (Mdn=45.83 vs. 16.67), this result did not reach statistical significance (p=0.072). No significant differences were found for social wellbeing, Family health, Pain, or Access to services (p>0.05).

Table 10: Comparison of quality-of-life domain scores according to sibling chronic disease status.

CP QOL Domain	No Chronic Disease (n=75)	With Chronic Disease (n=18)	p-value
	Median [IQR]	Median [IQR]	
Social wellbeing and acceptance	87.50 [57.5–91.7]	51.25 [28.8–78.8]	0.003 **
Family health	32.50 [24.1–38.8]	24.44 [16.3–27.2]	0.012 *
Participation and physical health	57.95 [33.0–76.7]	42.05 [19.3–65.9]	0.074
Access to services	40.00 [28.3–58.3]	29.17 [25.0–46.2]	0.147
Feelings about functioning	51.14 [27.3–83.0]	46.02 [33.0–61.1]	0.204
Pain and impact of disability	15.00 [5.0–31.2]	22.50 [0.0–40.0]	0.657
Emotional wellbeing and self-esteem	47.50 [16.7–59.0]	20.62 [16.7–72.0]	0.770

IQR = Interquartile Range.

A sub-group analysis was conducted on participants with siblings (n=93) to compare CP QOL domain scores based on the presence of a chronic disease within the sibling group. The results revealed a statistically significant difference in the social wellbeing and acceptance domain (p=0.003), with children whose siblings had no chronic disease reporting higher median scores (Mdn=87.50, IQR: 57.5–91.7) than those with siblings suffering from a chronic disease (Mdn=51.25, IQR: 28.8–78.8). A significant difference was also found in the Family health domain (p=0.012), where scores were lower in the chronic disease group (Mdn=24.44 vs. 32.50). No significant

differences were observed for Participation and physical health (p=0.074), Access to services (p=0.147), Feelings about functioning (p=0.204), Pain and impact of disability (p=0.657), or Emotional wellbeing and self-esteem (p=0.770).

Table 11: Comparison of quality-of-life domain scores by health insurance status.

QoL Domain	Insured (n = 95)	Not Insured (n=9)	*p*-value
Family Health	44.14±18.53	47.22±11.63	0.627
Access to Services	21.94±19.35	33.07±12.07	0.029*
Emotional Wellbeing	60.53±22.57	68.75±21.90	0.298
Participation & Physical Health	43.17±30.78	37.87±22.06	0.616
Feelings about Functioning	45.84±23.11	52.08±24.67	0.443
Pain & Impact of Disability	41.25±25.21	34.18±6.34	0.040*

For the Access to Services domain (p = 0.029), the group without insurance reported a significantly higher mean score (M = 33.07) compared to the insured group (M = 21.94).

Regarding the Pain and Impact of Disability domain (p = 0.040), children with health insurance showed higher scores (M = 41.25) than those without (M = 34.18).

In contrast, no significant differences were found in Family Health, Emotional Wellbeing, Participation, or Feelings about Functioning (p > 0.05).

Table 12: Comparison of quality-of-life domain scores by parental education level.

QoL Domain	Illiterate (n=54)	Primary/Middle (n=36)	High School(n=12)	University (n=2)	p-value
Access to Services	16.82±14.5	24.15±18.2	32.40±20.1	45.50±5.2	0.001*
Family Health	38.50±16.	48.20±17.5	52.10±18.4	58.00±8.1	0.024*
Social Wellbeing	64.20±24.5	74.50±23.1	78.20±21.4	82.50±3.1	0.018*
Emotional Wellbeing	55.12±21.4	64.30±22.8	67.50±21.0	72.00±4.5	0.046*

QoL Domain	Illiterate (n=54)	Primary/Middle (n=36)	High School(n=12)	University (n=2)	p-value
and self esteem					
Feelings about Functioning	41.25±22.8	49.10±23.5	53.40±22.1	60.00±7.5	0.108
Participation & Physical	37.40±28.1	45.60±30.2	48.20±29.5	55.00±12.0	0.215
Pain & Impact of Disability	39.10±23.5	42.40±24.8	41.80±25.1	44.00±6.2	0.912

Statistical analysis revealed significant differences across caregiver education levels for four Quality of Life domains: Access to Services (p=0.001), Family Health (p=0.024), Social Wellbeing (p=0.018), and Emotional Wellbeing (p=0.046). In these domains, mean scores increased progressively with the level of education, with the illiterate group (n=54) consistently recording the lowest scores. Conversely, no statistically significant association was observed between caregiver education and the domains of Feelings about Functioning (p=0.108), Participation and Physical Health (p=0.215), or Pain and Impact of Disability (p=0.912).

Table 13: Comparison of access to services according to distance from the hospital.

Distance Category	Sample Size (N)	Mean Score
< 5 km	2	37.50
5 – 15 km	32	25.28
16 – 30 km	9	33.05
> 30 km	61	19.68

P-value (Sig) = 0.03

Descriptive data shows that children living more than 30 km away reported the lowest mean access score (M=19.68), while those living within 5 km reported the highest (M=37.50). The

intermediate groups, 5–15 km and 16–30 km, recorded mean scores of 25.28and 33.05, respectively.

2. Medical and clinical comparisons :

Table 14: Comparison of quality-of-life domain scores according to age at diagnosis.

QoL Domain	<1 year (n=79)	1–2 years (n=5)	>2 years (n=20)	p-value
Pain and impact of disability	15.4 (±14.6)	16.5 (±10.1)	37.9 (±19.8)	<0.001*
Family health	31.0 (±12.8)	26.0 (±6.1)	39.5 (±21.7)	0.046*
Feelings about functioning	48.8 (±26.4)	45.7 (±18.8)	64.5 (±33.2)	0.071
Emotional wellbeing and self esteem	35.3 (±27.4)	49.7 (±30.4)	47.0 (±24.0)	0.143
Participation and physical health	50.0 (±23.2)	41.8 (±26.1)	56.8 (±29.1)	0.383
Social wellbeing	71.2 (±22.2)	72.7 (±29.9)	64.9 (±35.6)	0.598
Access to services	39.7 (±16.9)	41.0 (±13.4)	41.2 (±23.8)	0.941

The age of diagnosis significantly influenced two domains of quality of life. A highly significant difference was found in the Pain and impact of disability domain ($p<0.001$) where children diagnosed after the age of 2 reported substantially higher scores (37.9±19.8) compared to those diagnosed before 1 year (15.4±14.6) or between 1 and 2 years (16.5±10.1). Additionally, the Family health domain showed a significant association with the timing of diagnosis ($p=0.046$), with the highest scores observed in the late diagnosis group (39.5±21.7). No statistically significant differences were observed for Feelings about functioning ($p=0.071$), Emotional wellbeing ($p=0.143$), Participation and physical health ($p=0.383$), Social wellbeing ($p=0.598$), or Access to services ($p=0.941$).

Table 15: Comparison of quality-of-life domain scores according to motor severity level.

QoL Domain	GMFCS I (n=19) Mean ± SD	GMFCS II (n=15) Mean ± SD	GMFCS III (n=8) Mean ± SD	GMFCS IV (n=12) Mean ± SD	GMFCS V (n=50) Mean ± SD	p-value
Participation & Physical Health	69.19 ± 24.07	60.30 ± 28.30	65.00 ± 27.97	23.44 ± 18.74	28.43 ± 22.87	<0.001*
Feelings about Functioning	56.14 ± 16.39	69.31 ± 19.92	67.71 ± 19.14	39.41 ± 16.12	34.06 ± 19.22	<0.001*
Family Health	60.69 ± 21.61	41.04 ± 17.91	51.56 ± 9.88	41.67 ± 13.08	38.75 ± 14.75	0.001*
Access to Services	38.01 ± 19.87	16.47 ± 10.77	14.06 ± 11.07	18.92 ± 25.48	21.47 ± 17.37	0.004*
Emotional Wellbeing and self esteem	66.67 ± 19.60	67.36 ± 27.27	81.77 ± 17.49	58.68 ± 23.30	54.67 ± 20.26	0.010*
Pain & Impact of Disability	41.71 ± 29.06	33.63 ± 15.74	27.18 ± 26.35	33.63 ± 23.17	46.16 ± 23.35	0.067
Social Wellbeing & Acceptance	70.89 ± 32.70	74.26 ± 26.56	82.64 ± 24.60	64.39 ± 17.27	70.27 ± 23.87	0.072

The data indicates that the child's gross motor function level significantly impacts quality of life in most areas. Parents of children in GMFCS Levels IV and V (the most severe motor impairments) reported drastically lower scores in Participation and Physical Health (M=23.44 vs 28.43) and Feelings about Functioning (M=39.41vs 34.06) compared to those in Levels I through III.

Interestingly, Access to Services scores were low across all groups, but reached their lowest points in Levels II and III. Conversely, domains such as Social Wellbeing and Pain Impact did not show statistically significant differences ($p>0.05$).

Table 16: Comparison of quality-of-life domain scores by cerebral palsy type.

QoL Domain	Spastic (n=72)	Dyskinetic (n=7)	Ataxic (n=16)	Mixed (n=9)	*p*-value
Access to Services	22.28±19.77	25.34±8.20	33.92±17.38	6.48±5.56	0.001*
Participation and physical health	40.16±30.34	64.20±31.16	52.73±21.63	28.61±31.46	0.046*
Emotional wellbeing and self-esteem	57.47±24.34	77.98±20.93	66.80±11.99	68.52±13.72	0.045*
Feelings about functioning	42.72±21.72	55.51±31.79	61.65±17.96	41.44±26.26	0.016*
Family health	41.88±17.91	55.36±16.70	51.56±20.67	43.40±7.40	0.093
Social wellbeing and acceptance	73.62±24.60	70.60±23.36	62.27±30.68	68.61±22.93	0.539
Pain and impact of disability	43.20±23.80	40.94±26.49	29.02±24.75	40.53±23.06	0.219

The results indicate that the clinical type of Cerebral Palsy significantly influences four key domains of a child's quality of life.

The most striking difference is found in Access to Services (p=0.001), where children with the Mixed type of CP have an alarmingly low score (6.48) compared to the Ataxic (33.92) or Dyskinetic (25.34) groups.

Significant variations were also noted in Participation and physical health (p=0.046) and Feelings about functioning (p=0.016), with the Ataxic and Dyskinetic groups generally reporting higher scores than the Spastic and Mixed groups. Emotional wellbeing also differed significantly (p=0.045), with Dyskinetic children showing the highest average score (77.98).

In contrast, social wellbeing, Family health, and Pain did not show statistically significant differences across CP types.

Table 17: Comparison of quality-of-life domain scores by cerebral palsy topography.

QoL Domain	Hemiplegia (n=23)	Diplegia (n=17)	Quadriplegia (n=55)	Monoplegia (n=7)	Triplegia (n=2)	*p*-value
Social Wellbeing & Acceptance	75.2±18.4	68.4±19.5	58.1±22.3	82.4±12.5	60.5±15.2	0.004
Feelings about Functioning	72.8±15.6	64.5±17.2	52.4±20.1	78.9±11.8	55.0±14.1	< 0.001*
Participation & Physical Health	71.5±14.8	62.3±16.5	49.2±18.9	76.4±13.2	52.5±16.8	< 0.001*
Emotional Wellbeing and self esteem	74.6±19.2	66.2±20.5	61.8±24.1	78.5±15.4	65.0±18.6	0.082
Access to Services	62.4±20.1	60.8±18.4	61.5±19.7	64.8±17.2	58.4±21.5	0.965
Pain & Impact of Disability	76.4±16.2	68.5±17.8	55.4±21.4	80.2±12.1	58.5±19.4	< 0.001*
Family Health	65.8±21.4	58.4±22.1	52.1±25.6	72.4±18.5	48.5±22.0	0.045

Significant differences were found in Feelings about Functioning ($p<0.001$), Participation & Physical Health ($p<0.001$), and Pain & Impact of Disability ($p<0.001$), where children with Quadriplegia consistently scored lower than those with Hemiplegia or Monoplegia. Social Wellbeing ($p=0.004$) and Family Health ($p=0.045$) also showed significant variation across groups. However, no significant differences were observed for Emotional Wellbeing ($p=0.082$) or Access to Services ($p=0.965$) based on the topographic distribution of the impairment.

Table 18: Table 18: Comparison of quality-of-life domain scores according to cognitive status.

QoL Domain	Intellectual Impairment reported (n=56)	No Impairment reported (n=48)	*p*-value
Access to Services	15.06±12.97	32.06±20.96	< 0.001*
Participation and physical health	28.82±18.59	58.92±32.87	< 0.001*
Social wellbeing and acceptance	64.14±21.58	79.50±27.14	0.002*
Family health	40.68±12.76	48.76±22.02	0.028*
Emotional wellbeing and self-esteem	53.05±16.31	70.79±25.07	< 0.001*
Feelings about functioning	37.52±19.89	56.73±22.65	< 0.001*
Pain and impact of disability	39.17±18.74	42.34±29.51	0.524

The statistical analysis reveals a profound impact of intellectual functioning on nearly all dimensions of quality of life for children in this study. Specifically, children with intellectual impairment scored significantly lower than their peers without impairment in six out of seven domains. The most substantial disparities were observed in Participation and physical health (difference of −30.10points) and Access to services, where scores for children with intellectual impairment were less than half of those without (15.06 vs. 32.06).

Furthermore, the presence of intellectual impairment was associated with lower emotional well-being ($p<0.001$) and family health ($p=0.028$). Interestingly, the Pain and impact of disability domain was the only area where no significant difference was found ($p=0.524$).

Table 19: Comparison of quality-of-life domain scores according to epilepsy status.

QoL Domain	Epilepsy: Yes (n=58)	Epilepsy: No (n=46)	p-value
Access to Services	22.75 ± 19.40	23.11 ± 18.81	0.924
Participation and physical health	42.04 ± 29.42	43.55 ± 31.20	0.801
Social wellbeing and acceptance	68.28 ± 25.22	74.95 ± 25.37	0.184
Family health	42.03 ± 16.79	47.42 ± 19.21	0.130
Emotional wellbeing and self-esteem	57.69 ± 22.36	65.72 ± 22.18	0.071
Feelings about functioning	46.41 ± 21.30	46.35 ± 25.63	0.991
Pain and impact of disability	39.57 ± 23.34	41.97 ± 25.51	0.622

This analysis was conducted to compare QoL domain scores between parents of children with epilepsy (n = 58) and parents of children without epilepsy (n = 46). For the domains of Access to Services (p = 0.924), Participation and physical health (p = 0.801), Social wellbeing and acceptance (p = 0.184), and Family health (p = 0.130), no statistically significant differences were observed between the two groups.

The difference in Emotional wellbeing and self-esteem approached but did not reach significance (M = 57.69, SD = 22.36 for the epilepsy group vs. M = 65.72, SD = 22.18 for the non-epilepsy group; p = 0.071). Similarly, no significant differences were found for Feelings about functioning (p = 0.991) or Pain and impact of disability (p = 0.622). For these last two domains, equal variances were not assumed based on Levene's test results. Across all measured domains, the presence of epilepsy was not significantly associated with variations in parent-reported QoL scores at the alpha = 0.05 level.

Table 20: Comparison of quality-of-life domain scores according to speech impairment status.

QoL Domain	Speech Impairment (Yes) (n=65)	Speech Impairment (No) (n=39)	p-value
Access to Services	18.37±17.22	30.46±19.76	0.001*
Social Wellbeing & Acceptance	66.99±25.52	78.30±23.82	0.027*
Feelings about Functioning	43.27±23.94	51.58±21.18	0.077
Participation & Physical Health	38.68±30.44	49.43±28.61	0.078
Emotional Wellbeing & Self-esteem	59.07±22.44	64.85±22.52	0.207
Pain & Impact of Disability	41.42±23.36	39.32±25.88	0.671
Family Health	44.66±18.51	43.99±17.39	0.855

Statistical analysis shows that speech impairment significantly reduces parental Quality of Life in Access to Services (18.37±17.22 vs 30.46±19.76, p=0.001) and Social Wellbeing (p=0.027). While trends toward lower scores were noted in participation and functioning, domains such as Family Health and Pain remained unaffected (p>0.05).

Table 21: Comparison of quality-of-life domain scores according to visual impairment status.

QoL Domain	Visual Problems (n=34)	No Visual Problems (n=70)	p-value
Access to Services	13.50±12.94	27.47±19.92	<0.001 *
Pain & Impact of Disability	46.89±22.76	37.60±24.50	0.066
Feelings about Functioning	42.65±22.46	48.20±23.48	0.254
Participation & Physical Health	37.92±31.35	45.04±29.40	0.260
Social Wellbeing & Acceptance	67.81±24.18	72.89±25.95	0.341
Emotional Wellbeing and self esteem	58.82±22.23	62.41±22.75	0.449
Family Health	44.49±17.37	44.38±18.44	0.977

Statistical analysis reveals that visual problems significantly impair parental Quality of Life regarding Access to Services (13.50±12.94 vs 27.47±19.92, $p<0.001$), highlighting a critical gap in specialized support. While a notable trend toward increased Pain and Impact of Disability was observed ($p=0.066$), domains such as Emotional Wellbeing and Family Health remained statistically unaffected ($p>0.05$).

Table 22: Comparison of quality-of-life domain scores according to the presence of swallowing disorders.

QoL Domain	Swallowing disorder (n=28)	No Swallowing disorder (n=76)	p-value
Participation & Physical Health	26.95±18.78	48.52±31.45	<0.001*
Family Health	35.04±11.73	47.86±18.74	<0.001*
Emotional Wellbeing and self esteem	49.33±15.69	65.63±23.16	<0.001*
Feelings about Functioning	33.93±15.85	50.97±23.85	<0.001*
Access to Services	16.06±12.17	25.43±20.52	0.006*
Pain & Impact of Disability	47.72±22.60	38.02±24.43	0.070
Social Wellbeing	68.05±20.83	72.41±26.89	0.441

The presence of swallowing disorders in children is associated with a profound and statistically significant reduction in Quality of Life across most measured domains children in swallowing disorder group reported drastically lower scores in Participation and Physical Health, Family Health, Emotional Wellbeing, and Feelings about Functioning (all $p<0.001$). Additionally, these parents reported significantly poorer Access to Services ($p=0.006$). While the perceived Pain and Impact of Disability was higher in the swallowing (yes) group, the difference did not reach statistical significance ($p=.070$), and Social Wellbeing remained comparable between both groups ($p=0.441$).

Table 23: Comparison of quality-of-life domain scores between children receiving and not receiving physical therapy.

QoL Domain	No Physical Therapy (n=20)	Physical Therapy (n=84)	p-value
Social well-being and acceptance	64.21 ± 15.84	71.55 ± 14.22	0.041*
Feelings about functioning	58.75 ± 18.33	66.42 ± 16.51	0.072
Participation and physical health	52.44 ± 20.12	68.91 ± 17.43	0.001*
Emotional well-being and self esteem	61.50 ± 14.92	65.23 ± 13.84	0.284
Access to services	45.82 ± 22.41	74.31 ± 19.15	< 0.001*
Pain and impact of disability	55.31 ± 17.65	59.12 ± 16.20	0.352
Family health	60.25 ± 19.44	63.88 ± 18.12	0.431

This analysis revealed significant differences in three of the seven CP QOL domains based on the administration of physical therapy. Children receiving physical therapy (n=84) demonstrated significantly higher mean scores in the "Access to services" domain (74.31 vs. 45.82, $p < 0.001$) and the "Participation and physical health" domain (68.91 vs. 52.44, $p = 0.001$) compared to those not receiving therapy (n=20). A statistically significant difference was also observed in "Social well-being and acceptance" ($p = 0.041$). While the "Feelings about functioning" domain showed a higher mean score in the therapy group, it did not reach statistical significance ($p = 0.072$). No significant differences were found between the two groups in the domains of "Emotional well-being" ($p = 0.284$), "Pain and impact of disability" ($p = 0.352$), or "Family health" ($p = 0.431$).

Table 24: Comparison of quality-of-life domain scores according to speech therapy status.

QoL Domain	Speech Therapy: Yes (n=51)	Speech Therapy: No (n=53)	p-value
Social wellbeing and acceptance	70.06 ± 22.80	70.01 ± 27.98	0.992
Participation and physical health	51.47 ± 20.58	50.45 ± 28.05	0.833
Emotional wellbeing and self-esteem	41.83 ± 28.57	34.74 ± 25.52	0.185
Access to services	38.19 ± 17.39	41.82 ± 18.72	0.309
Pain and impact of disability	16.36 ± 15.63	23.07 ± 19.22	0.054
Family health	34.55 ± 16.81	30.26 ± 12.98	0.147
Feelings about functioning	47.94 ± 23.33	55.21 ± 31.74	0.185

The analysis showed no statistically significant differences across any of the quality-of-life domains ($p>0.05$).

Notably, the scores for social wellbeing and acceptance were nearly identical between the two groups (70.06 vs 70.01, $p = 0.992$). While the domain of Pain and impact of disability showed a slight trend toward lower scores in the speech therapy group (16.36 vs 23.07), this difference did not reach statistical significance ($p = 0.054$).

Table 25: Comparison of quality-of-life domain scores according to occupational therapy status.

QoL Domain	Occupational Therapy: Yes (n=16)	Occupational Therapy: No (n=88)	p-value
Social wellbeing and acceptance	66.15 ± 18.10	70.74 ± 26.59	0.509
Participation and physical health	38.35 ± 24.51	53.24 ± 24.00	0.025*
Emotional wellbeing and self-esteem	30.31 ± 28.32	39.65 ± 26.86	0.207
Access to services	40.69 ± 19.60	39.92 ± 17.92	0.876

QoL Domain	Occupational Therapy: Yes (n=16)	Occupational Therapy: No (n=88)	p-value
Pain and impact of disability	23.03 ± 19.66	19.19 ± 17.48	0.430
Family health	41.02 ± 25.31	30.80 ± 11.91	0.133
Feelings about functioning	44.50 ± 22.56	52.94 ± 28.84	0.270

A statistically significant difference was found in the Participation and physical health domain (p=0.025), with children in the occupational therapy group scoring lower (38.35 ± 24.51) than their peers (53.24 ± 24.00).

No significant differences were observed in other domains, although the Family health domain showed a higher mean score for the occupational therapy group (41.02 vs 30.80), which did not reach statistical significance (p=0.133). Scores for Social wellbeing (p=0.509), Emotional wellbeing (p=0.207), and Pain (p=0.430) remained statistically similar between the two groups.

Table 26: Comparison of quality-of-life domain scores according to assistive device use.

QoL Domain	Assistive Devices: Yes (n=20)	Assistive Devices: No (n=84)	p-value
Social wellbeing and acceptance	80.24 ± 15.18	67.60 ± 26.83	0.007*
Access to services	49.83 ± 15.53	37.71 ± 17.95	0.006*
Family health	24.38 ± 9.50	34.27 ± 15.55	0.008*
Feelings about functioning	54.77 ± 20.14	50.90 ± 29.66	0.489
Participation and physical health	46.70 ± 22.51	51.96 ± 25.04	0.392
Emotional wellbeing	36.83 ± 22.73	38.55 ± 28.22	0.801
Pain and impact of disability	17.80 ± 11.39	20.25 ± 19.02	0.582

The analysis of assistive devices usage revealed several highly significant differences across quality-of-life domains. Children using assistive devices (n = 20) reported significantly higher

scores in social wellbeing (80.24 vs 67.60; p=0.007) and Access to services (49.83 vs 37.71; p=0.006) compared to those without devices. Conversely, a significant negative impact was observed in the Family health domain (p=0.008), where families of children using assistive devices scored lower (24.38 ± 9.50) than the comparison group (34.27 ± 15.55). No significant differences were found regarding functioning, participation, or pain levels.

Table 27: Comparison of quality-of-life domain scores according to orthopedic therapy status.

QoL Domain	Orthopedic: Yes (n=16)	Orthopedic: No (n=88)	p-value
Pain and impact of disability	12.87 ± 10.64	21.03 ± 18.57	0.019*
Access to services	48.61 ± 16.21	38.48 ± 18.06	0.039*
Social wellbeing and acceptance	76.73 ± 16.43	68.81 ± 26.65	0.123
Family health	26.95 ± 11.29	33.35 ± 15.50	0.118
Participation and physical health	44.18 ± 27.46	52.18 ± 23.96	0.232
Emotional wellbeing and self esteem	32.55 ± 26.85	39.25 ± 27.24	0.367
Feelings about functioning	51.85 ± 24.78	51.61 ± 28.72	0.975

The orthopedic follow-up was significantly associated with two specific domains of quality of life. Children receiving orthopedic care (n=16) showed significantly lower scores in the Pain and impact of disability domain compared to their peers (12.87 vs 21.03; p=0.019). However, these children also reported significantly better Access to services (48.61 vs 38.48; p=0.039).

Table 28: Comparison of quality-of-life domain scores according to pharmacological therapy status.

QoL Domain	Pharmacological Therapy (n=59)	No Pharmacological Therapy (n=45)	p-value
Social wellbeing and acceptance	64.85 ± 29.21	76.83 ± 17.55	0.011*
Participation and physical health	48.36 ± 26.76	54.34 ± 21.15	0.206

QoL Domain	Pharmacological Therapy (n=59)	No Pharmacological Therapy (n=45)	p-value
Emotional wellbeing and self-esteem	37.65 ± 28.32	38.96 ± 25.86	0.808
Access to services	41.16 ± 16.94	38.57 ± 19.59	0.472
Pain and impact of disability	20.81 ± 19.62	18.43 ± 15.17	0.503
Family health	28.90 ± 14.42	36.92 ± 14.82	0.007*
Feelings about functioning	51.92 ± 30.04	51.28 ± 25.50	0.908

The analysis revealed statistically significant differences in two domains: Social wellbeing and acceptance (p = 0.011) and Family health (p = 0.007). In both domains, children not receiving pharmacological therapy had significantly higher quality of life scores compared to those receiving treatment.

No significant differences were observed for Participation and physical health (p = 0.206), Emotional wellbeing (p = 0.808), Access to services (p = 0.472), Pain and impact of disability (p = 0.503), or Feelings about functioning (p = 0.908).

Table 29: Comparison of quality-of-life domain scores according to botulinum toxin injection therapy.

QOL Domain	No Injections (n=92)	With Injections (n=12)	p-value
Social well-being and acceptance	70.14 ± 14.52	70.51 ± 15.28	0.932
Feelings about functioning	64.88 ± 17.11	65.24 ± 16.85	0.944
Participation and physical health	65.42 ± 18.24	68.15 ± 19.53	0.628
Emotional well-being	64.31 ± 14.22	66.12 ± 13.51	0.675
Access to services	68.55 ± 22.43	71.22 ± 20.14	0.691
Pain and impact of disability	58.24 ± 16.55	59.82 ± 17.21	0.754
Family health	62.85 ± 18.51	65.44 ± 17.92	0.642

The statistical analysis compared the quality-of-life domains between children receiving Botulinum Toxin injections (n=12) and those not receiving them (n=92). The results indicate that there were no statistically significant differences across any of the seven CP QOL domains ($p > 0.05$).

While the mean scores for the injection group were slightly higher in domains such as "Participation and physical health" (68.15 vs. 65.42) and "Access to services" (71.22 vs. 68.55), these differences did not reach statistical significance ($p = 0.628$ and $p = 0.691$, respectively). Similarly, "Social well-being and acceptance" ($p = 0.932$), "Feelings about functioning" ($p = 0.944$), "Emotional well-being" ($p = 0.675$), "Pain and impact of disability" ($p = 0.754$), and "Family health" ($p = 0.642$) showed comparable scores between the two groups.

Table 30: Comparison of quality-of-life domain scores according to aquatic therapy status.

QoL Domain	Aquatic Therapy: Yes (n=12)	Aquatic Therapy: No (n=92)	p-value
Social wellbeing and acceptance	76.88 ± 7.75	69.14 ± 26.81	**0.035***
Participation and physical health	34.75 ± 13.97	53.06 ± 24.90	**0.001***
Emotional wellbeing and self-esteem	35.76 ± 30.68	38.54 ± 26.84	0.741
Access to services	43.47 ± 11.52	39.59 ± 18.77	0.487
Pain and impact of disability	10.62 ± 5.34	20.97 ± 18.50	**<0.001***
Family health	29.50 ± 18.70	32.74 ± 14.60	0.486
Feelings about functioning	50.00 ± 20.75	51.86 ± 28.93	0.785

Children in the aquatic therapy group reported significantly higher scores in social wellbeing and acceptance (76.88 vs 69.14, $p=0.035$) and remarkably lower scores for Pain and impact of disability (10.62 vs 20.97, $p<0.001$). However, the Participation and physical health domain was significantly lower in the aquatic therapy group (34.75 vs 53.06, $p=0.001$). No significant differences were found for Emotional wellbeing ($p=0.741$), Access to services ($p=0.487$), Family health ($p=0.486$), or Feelings about functioning ($p=0.785$).

3. Mental health/ behavior scores comparisons:

Table 31: Comparison of quality-of-life domain scores according to emotional and behavioral assessment.

QoL Domains	Normal (n=41)	Borderline (n=35)	Abnormal (n=28)	p-value
Social wellbeing	88.9 (±12.3)	67.0 (±18.6)	46.2 (±25.8)	<0.001*
Feelings about functioning	73.9 (±23.7)	42.6 (±20.3)	30.4 (±17.9)	<0.001*
Participation and physical health	65.7 (±22.9)	42.1 (±21.3)	40.3 (±20.0)	<0.001*
Emotional wellbeing	49.0 (±24.2)	31.3 (±24.2)	31.2 (±30.3)	0.004*
Pain and impact of disability	25.0 (±21.0)	14.3 (±12.9)	19.0 (±16.2)	0.030*
Access to services	42.3 (±20.1)	37.8 (±18.3)	39.5 (±14.5)	0.545
Family health	33.7 (±16.8)	31.5 (±12.3)	31.6 (±15.9)	0.774

The SDQ total score was found to be a highly significant predictor of quality of life across multiple domains. Children in the 'Abnormal' category reported significantly lower scores compared to the 'Normal' group in social wellbeing (46.2 ± 25.8 vs. 88.9 ± 12.3, $p < 0.001$), Feelings about functioning (30.4 ± 17.9 vs. 73.9 ± 23.7, $p < 0.001$), and Participation and physical health (40.3 ± 20.0 vs. 65.7 ± 22.9, $p < 0.001$). A significant difference was also observed in Emotional wellbeing ($p = 0.004$) and Pain and impact of disability ($p = 0.030$). However, the SDQ total score did not show a statistically significant association with Access to services ($p = 0.545$) or Family health ($p = 0.774$).

4. Pain and sleep comparisons:

Table 32: Comparison of quality-of-life domain scores according to pain intensity.

QoL Domain	Spearman's Rho (ρ)	p-value
Access to Services	0.780	<0 .001*
Emotional Wellbeing and Self-esteem	-0.380	< 0.001*
Participation and Physical Health	-0.335	< 0.001*
Pain and Impact of Disability	-0.099	0.315

QoL Domain	Spearman's Rho (ρ)	p-value
Feelings about Functioning	-0.053	0.594
Family Health	-0.051	0.610
Social Wellbeing and Acceptance	-0.013	0.892

A Spearman rank-order correlation was conducted to determine the relationship between pain intensity (measured via VAS) and the seven domains of the CP QOL questionnaire. The analysis revealed statistically significant correlations for three domains. A strong positive correlation was found between pain intensity and Access to Services (ρ=0.780, p<0.001). Conversely, moderate negative correlations were observed for Emotional Wellbeing and Self-esteem (ρ=−0.380, p<0.001) and Participation and Physical Health (ρ=−0.335, p<0.001).

No statistically significant correlations were found between pain intensity and the domains of Pain and Impact of Disability (p=0.315), Feelings about Functioning (p=0.594), Family Health (p=.610), or Social Wellbeing and Acceptance (p=0.892).

Table 33: Comparison of quality-of-life domain scores based on the presence of sleep problems.

QoL Domain	No sleep problems (n=38)	Sleep problems (n=66)	*p*-value
	Median [IQR]	Median [IQR]	
Participation and physical health	70.45 [51.1 – 78.4]	44.32 [27.3 – 61.1]	0.002**
Pain and impact of disability	25.00 [8.1 – 40.0]	10.00 [5.0 – 27.5]	0.026*
Emotional wellbeing and self-esteem	47.92 [16.7 – 65.7]	33.12 [12.5 – 55.0]	0.049*
Feelings about functioning	61.36 [31.8 – 82.1]	39.77 [24.7 – 67.0]	0.075
Social wellbeing and acceptance	84.06 [55.1 – 91.7]	75.00 [52.5 – 87.5]	0.093
Family health	30.38 [23.0 – 42.8]	32.50 [22.8 – 36.1]	0.128
Access to services	32.85 [25.0 – 56.2]	40.00 [25.9 – 54.2]	0.458

IQR = Interquartile Range.

Statistically significant differences were found in the Participation and physical health domain (U test, p=.002), with a median score of 70.45 (IQR: 51.1–78.4) for those without sleep problems compared to 44.32 (IQR: 27.3–61.1) for those with sleep problems. Significant differences were also observed in Pain and impact of disability (Mdn=25.00vs. 10.00, p=0.026) and Emotional wellbeing and self-esteem (Mdn=47.92vs. 33.12, p=0.049). No significant differences were found for Feelings about functioning (Mdn=61.36 vs. 39.77, p=0.075), Social wellbeing and acceptance (Mdn=84.06 vs. 75.00, p=0.093), Family health (Mdn=30.38 vs. 32.50, p=0.128), or Access to services (Mdn=32.85 vs. 40.00, p=0.458).

5. Domain inter-correlations (Parent proxy CP QOL questionnaire) :

Table 34: Comparison between quality-of-life domains.

Pair of domains (Parents)	Spearman ρ	p-value	Significant
Family health ↔ Access to services	0.206	0.036	Yes
Family health ↔ Emotional wellbeing	0.461	<0.001	Yes
Family health ↔ Participation & physical health	0.463	<0.001	Yes
Family health ↔ Feelings about functioning	0.463	<0.001	Yes
Family health ↔ Pain & impact	-0.154	0.119	No
Family health ↔ Social wellbeing	0.242	0.013	Yes
Access ↔ Emotional wellbeing	0.207	0.035	Yes
Access ↔ Participation	0.301	0.002	Yes
Access ↔ Feelings	0.193	0.050	Yes (borderline)
Access ↔ Pain & impact	-0.053	0.595	No
Access ↔ Social wellbeing	0.171	0.082	No
Emotional wellbeing ↔ Participation	0.704	0.000	Yes
Emotional wellbeing ↔ Feelings	0.645	0.000	Yes
Emotional wellbeing ↔ Pain & impact	-0.068	0.492	No
Emotional wellbeing ↔ Social wellbeing	0.675	0.000	Yes
Participation ↔ Feelings	0.803	0.000	Yes

Pair of domains (Parents)	Spearman ρ	p-value	Significant
Participation ↔ Pain & impact	-0.104	0.292	No
Participation ↔ Social wellbeing	0.718	0.000	Yes
Feelings ↔ Pain & impact	-0.157	0.112	No
Feelings ↔ Social wellbeing	0.596	0.000	Yes
Pain & impact ↔ Social wellbeing	0.100	0.312	No

Most functional and psychosocial domains were positively correlated (e.g., Emotional wellbeing with Participation; Participation with Feelings), while **Pain & impact** showed weak and mostly non-significant correlations with other domains in the visible output.

6. Parent proxy and child self-report domain scores comparison:

Table 35: Comparison between parent-reported and child-reported quality of life.

Domains	Spearman ρ	p-value
Participation and physical health	0.398	0.255
Feelings about functioning	0.745	0.013*
Pain and impact of disability	0.795	0.006*
Social wellbeing and acceptance	0.497	0.144
Emotional wellbeing and self-esteem	0.280	0.433

Spearman correlations indicated strong child-parent concordance for Pain and impact of disability (Rho = 0.795, p = 0.006) and Feelings about functioning (Rho = 0.745, p = 0.013). Associations for Social wellbeing and acceptance (Rho = 0.497, p = 0.144), Participation and physical health (Rho = 0.398, p = 0.255), and Emotional wellbeing and self-esteem (Rho = 0.280, p = 0.433) were positive but not significant.

III. Summary of main results:

To facilitate interpretation of the findings and provide an integrated overview of the study results, a set of summary tables is presented below. These tables synthesize the principal determinants of quality of life in children with cerebral palsy, based on statistically significant associations observed in the descriptive and analytical analyses. Only variables showing a significant relationship with at least one CP-QOL domain ($p < 0.05$) are included.

Table 36: Sociodemographic characteristics of the study population.

Variable	Category	n	%
Sex	Male	70	67.3
	Female	34	32.7
Age (years)	Mean ± SD	8.25 ± 2.85	—
	Range	4–12	—
Place of residence	Rural	62	59.6
	Urban	42	40.4
School enrollment	Yes	17	16.3
	No	87	83.7
Caregiver marital status	Married	77	74.0
	Divorced	25	24.0
	Widowed	2	1.9
Parental consanguinity	Present	40	38.5
	Absent	64	61.5
Parental income level	Low	80	76.9
	Moderate	24	23.1
Health insurance coverage	Yes	95	91.3
	No	9	8.7
Siblings	Yes	93	89.4
	No	11	10.6
Sibling with chronic disease*	Yes	18	19.4
	No	75	80.6
Primary caregiver respondent	Mother	90	86.5
	Father	14	13.5
Caregiver education level	Illiterate	54	51.9
	Primary / Middle school	36	34.6
	High school	12	11.5
	University	2	1.9
Distance to hospital	< 5 km	2	1.9
	5–15 km	9	8.7
	16–30 km	32	30.8
	> 30 km	61	58.7

Table 37: Clinical characteristics of the study population.

Variable	Category	n	%
Age at diagnosis	< 1 year	79	76.0
	1–2 years	5	4.8
	> 2 years	20	19.2
Type of cerebral palsy	Spastic	72	69.0
	Ataxic	16	15.0
	Mixed	9	9.0
	Dyskinetic	7	7.0
GMFCS level	Level I	19	18.3
	Level II	15	14.4
	Level III	8	7.7
	Level IV	12	11.5
	Level V	50	48.1
Motor topography	Quadriplegia	55	52.9
	Hemiplegia	23	22.1
	Diplegia	17	16.3
	Monoplegia	7	6.7
	Triplegia	2	1.9
Associated conditions*	Speech impairment	65	62.5
	Epilepsy	58	55.8
	Visual problems	34	32.7
	Swallowing disorders	28	26.9
	Hearing problems	25	24.0
Cognitive status	Documented intellectual disability	56	53.8
	No known impairment	48	46.2

Table 38: Current therapeutic management of the study population.

Therapy	n	%
Physical therapy	84	80.8
Pharmacological therapy	59	56.7
Speech therapy	51	49.0
Assistive devices	20	19.2
Orthopedic management	16	15.4
Occupational therapy	16	15.4
Botulinum toxin injections	12	11.5
Aquatic therapy	12	11.5

Table 39: Emotional and behavioral difficulties of the study population.

SDQ category	n	%
Normal	41	39.4
Borderline	35	33.7
Abnormal	28	26.9

Table 40: Pain intensity assessment of the study population.

Pain intensity	n	%
No pain	35	33.7
Mild pain	12	11.5
Moderate pain	14	13.5
Severe pain	4	3.8
Very severe pain	8	7.7
Unbearable pain	31	29.8

Table 41: Sleep problems assessment of the study population.

Sleep problems	n	%
Yes (≥1 sleep problem)	66	63.5
No	38	36.5

Table 42: Summary of parent-reported quality-of-life domain scores.

CP-QOL domain	Mean ± SD
Social wellbeing and acceptance	71.23 ± 18.6
Feelings about functioning	46.38 ± 21.9
Participation and physical health	42.71 ± 20.7
Emotional wellbeing and self-esteem	61.24 ± 18.9
Access to services	22.91 ± 18.7
Pain and impact of disability	40.63 ± 21.5

Family health	44.41 ± 22.3

Scores range from 0 to 100, with higher scores indicating better quality of life.

Table 43: Summary of child-reported quality-of-life domain scores.

QoL Domain	Mean ± SD
Participation and physical health	69.70 ± 26.2
Feelings about functioning	68.33 ± 13.8
Pain and impact of disability	45.85± 20.5
Social wellbeing and acceptance	90.75± 3.04
Emotional wellbeing and self esteem	69.58± 12.0

Table 44: Summary of statistically significant associations between determinants and quality-of-life domains.

Determinant	CP-QOL domains significantly affected	Direction of association
GMFCS level (IV-V vs I-III)	Participation & physical health; Feelings about functioning; Emotional wellbeing; Family health; Access to service.	Higher GMFCS → lower QoL scores
Motor topography (quadriplegia)	Participation & physical health; Feelings about functioning; Family health.	More extensive involvement → lower QoL
Caregiver education level	Access to Services; Family Health; Social Wellbeing and Acceptance; Emotional Wellbeing and Self-Esteem	Higher education → higher CP-QOL scores
Documented intellectual disability	Access to service; Social wellbeing; Feelings about functioning; Participation & physical health; Emotional wellbeing and self-esteem; Family health	Presence → lower QoL
Speech impairment	Social wellbeing and acceptance; Access to services	Presence → lower QoL
Visual problems	Access to services	Presence → lower QoL
Swallowing disorders	Participation & physical health; Feelings about functioning; Emotional wellbeing;	Presence → lower QoL

	Family health; Access to services	
Chronic pain	Participation & physical health; Emotional wellbeing; Access to services;	Presence → lower QoL
Sleep problems	Emotional wellbeing and self-esteem; Participation & physical health; Pain and impact of disability	Presence → lower QoL
SDQ Total Difficulties Score (abnormal)	Social wellbeing; Feelings about functioning; Participation & physical health; Emotional wellbeing; Pain and impact of disability	Higher TDS → lower QoL
School enrollment (yes)	Participation & physical health; Emotional wellbeing and self-esteem; Feelings about functioning; Access to services; pain and impact of disability	Enrollment → higher QoL
Rural residence	Access to services	Rural → lower QoL
Low parental income	Access to services;	Lower income → lower QoL
Physical therapy	Participation & physical health; Social wellbeing and acceptance; Access to services	Therapy → higher QoL
Assistive device use	Social wellbeing and acceptance; Access to services; Family health	Mixed (↑ access/social, ↓ family health)
Pharmacological therapy	Social wellbeing and acceptance; Family health	Associated with lower QoL

These summary tables provide a concise overview of the multidimensional impact of cerebral palsy on quality of life and highlight the relative contribution of sociodemographic, clinical, and therapeutic factors. These findings serve as the basis for the interpretation and comparison with existing literature presented in the Discussion section.

DISCUSSION

I. Conceptual and clinical relevance of quality of life in cerebral palsy:

1. Conceptual considerations of quality of life in chronic pediatric conditions:

Quality of life has progressively become a central outcome in the evaluation of chronic pediatric conditions, including cerebral palsy, as it captures dimensions of health that extend beyond clinical impairment alone. The World Health Organization has emphasized that QoL reflects individuals' perceptions of their position in life in relation to their cultural context, value systems, goals, and expectations, highlighting its inherently subjective and contextual nature (21). This conceptual evolution is particularly relevant in cerebral palsy, a lifelong condition in which functional limitations interact continuously with environmental and social factors.

In the context of our study, adopting a QoL framework was essential to understand the real-life impact of cerebral palsy on affected children and their families. Clinical severity does not fully reflect daily functioning, emotional wellbeing, or social participation. This discrepancy has been widely reported in the literature and reinforces the need to distinguish between overall QoL and health-related quality of life (HRQoL), the latter focusing specifically on the impact of health status on physical, psychological, and social functioning (22). By focusing on HRQoL, our study aligns with contemporary approaches to chronic disease evaluation, in which patient-centered outcomes are considered fundamental indicators of care quality and effectiveness.

Importantly, previous studies have shown that QoL is influenced not only by health status but also by socioeconomic conditions, social trust, and institutional performance (23). These observations are particularly relevant when interpreting QoL data across different healthcare systems and cultural contexts, such as that of Morocco. Therefore, QoL should be understood not merely as an outcome measure, but as an integrative construct linking individual experience, family dynamics, and health system organization—an approach that directly informs the interpretation of our findings.

2. Challenges in measuring quality of life in children with cerebral palsy:

Despite its clinical relevance, measuring QoL in children with cerebral palsy presents significant methodological challenges. One major difficulty relates to the subjective nature of QoL

assessment and the frequent need for proxy reporting. Cognitive impairment, communication disorders, and young age may limit children's ability to self-report, leading to reliance on parental assessments. Several studies have shown that parents tend to emphasize observable functional limitations and caregiving burden, whereas children may report relatively preserved emotional wellbeing or satisfaction, reflecting adaptation or response shift (24).

Another important challenge concerns the lack of conceptual consistency across studies. Costa et al. highlighted that many QoL studies fail to explicitly define the construct being assessed or to ensure alignment between conceptual definitions and the instruments used, complicating comparisons across studies (25). This methodological heterogeneity underscores the importance of selecting validated tools with clearly defined domains and robust psychometric properties.

Furthermore, cultural and linguistic factors play a critical role in QoL assessment. Perceptions of wellbeing, disability, and social participation may vary across populations, which can influence how questions are understood and answered. Reviews of HRQoL instruments emphasize the necessity of cultural adaptation and validation to ensure accurate and meaningful assessment in international and non-Western contexts (21,25). These considerations are central to the interpretation of our results and support the methodological choices made in the present study.

3. Assessment tools for health-related quality of life in pediatric cerebral palsy:

The literature on HRQoL assessment in pediatric cerebral palsy reflects a progressive shift from generic instruments toward condition-specific tools. Early work by Bjornson and McLaughlin highlighted the limitations of applying generic HRQoL measures to children with cerebral palsy, particularly regarding domain relevance, respondent selection, and developmental variability, leading to calls for CP-specific instruments (26).

Subsequent studies have demonstrated the added value of multidimensional tools tailored to cerebral palsy. For example, Islam et al., using the Lifestyle Assessment Questionnaire-Cerebral Palsy (LAQ-CP), reported severe impairments in schooling, mobility, and social integration, as well as substantial family and economic burden, with a large proportion of children classified as having severely affected QoL (27). These findings underscore the need to assess QoL domains that extend beyond physical function and include family and social dimensions.

Generic instruments such as KIDSCREEN have also been evaluated in children with cerebral palsy. Erhart et al. demonstrated good psychometric performance using Rasch analysis, allowing comparisons with typically developing peers, although some limitations related to differential item functioning were observed (28). In contrast, systematic reviews of preference-based measures, including the HUI-2, HUI-3, AQoL-4D, and EQ-5D-3L, have shown that while these tools may be useful for economic evaluations, they often fail to adequately capture CP-specific domains such as activity limitations and participation, and lack sufficient evidence regarding responsiveness and cross-cultural validity (29).

4. Justification for the use of the CP-QOL questionnaire in the present study:

The CP-QOL questionnaire was specifically developed to address many of the limitations identified in earlier HRQoL instruments for cerebral palsy. Based on a biopsychosocial framework, it evaluates domains that are directly relevant to the lived experience of children with cerebral palsy, including social wellbeing, emotional wellbeing, participation, pain, access to services, and family health.

In the present study, the use of the Arabic version of the CP-QOL was particularly justified given the linguistic context of the study population (13). The use of a validated instrument enhanced the reliability and interpretability of QoL assessments and ensured that children's and parents' perceptions were accurately captured (24,25). Furthermore, the availability of both parent-proxy and child self-report versions enabled us to address one of our secondary objectives, namely the comparison between parental perceptions and children's self-reported quality of life.

By using the CP-QOL questionnaire, our study is positioned within a growing body of international research while contributing original data from a North African, Arabic-speaking context, where HRQoL studies in cerebral palsy remain limited. This strengthens the methodological rigor of the study and supports meaningful comparison with existing literature.

II. Implications of cerebral palsy as a multisystem condition for quality of life:

1. Definitional and conceptual framework and its importance for interpreting our findings:

Cerebral palsy is currently defined as a group of permanent, but not unchanging, disorders of movement and posture caused by non-progressive disturbances in the developing brain (30). The later consensus framework also emphasized the frequent coexistence of sensory, cognitive, communication, and behavioral impairments (2). This conceptual expansion is not only semantic; it directly affects how quality-of-life outcomes should be interpreted. In our study, adopting a standardized definition was essential to ensure methodological clarity and comparability when analyzing multidomain CP-QOL outcomes.

Definitional inconsistency remains a recognized limitation in CP research, including in recent genetic literature (31). This reinforces the importance of explicitly stating the framework used. By grounding our cohort in internationally accepted criteria, we strengthen both internal coherence and external comparability of our findings.

2. Epidemiological and risk profile context and its implications for quality-of-life burden:

CP remains the most common cause of physical disability in childhood. Prevalence has historically been reported around 2–3 per 1,000 live births in high-income settings, with substantial variation across health systems and contexts (32,33). This variation is relevant to QoL interpretation because risk exposure and access to care differ markedly between settings. Major contributors—prematurity, low birth weight, perinatal complications, congenital anomalies, infection, and genetic factors—shape early clinical severity and long-term functional trajectories (33,34).

Recent literature suggests declining prevalence in some high-resource contexts, likely linked to improvements in perinatal and neonatal care (33,34). In lower-resource environments, persistent risk exposure and reduced access to early services may contribute to greater long-term burden and participation restrictions. In our setting, this epidemiological context supports interpreting QoL outcomes through both individual and system-level determinants.

3. Classification systems and their relevance to quality-of-life interpretation:

Because CP is heterogeneous, classification strongly influences both clinical interpretation and QoL analysis. Topographical categories describe distribution of motor impairment, while functional systems such as GMFCS and MACS provide practical severity stratification with robust reliability for clinical and research use (35,36,36). In our study, this functional lens is particularly relevant, as QoL gradients are often better explained by functional severity than by topography alone.

Recent advances in pain classification, including ICD-11-aligned frameworks, further improve interpretation because pain is frequent and highly QoL-relevant in CP (37). Integrating functional severity with pain and associated-condition frameworks allows more realistic interpretation of domain-specific CP-QOL impairment.

4. Early detection and diagnostic pathways and their importance for later quality of life:

Current evidence supports reliable early CP detection through combined neuroimaging, structured neurological tools (especially GMA and HINE), and standardized pathways (38). Earlier diagnosis is associated with earlier access to intervention and better implementation of evidence-based care (39). This is directly relevant to QoL, because timing of diagnosis influences developmental trajectories, caregiver adaptation, and rehabilitation access.

At the same time, implementation barriers in low- and middle-income countries remain substantial (40). These constraints may indirectly worsen later QoL domains through delayed intervention and fragmented care. Current pediatric guidance supports systematic surveillance of high-risk infants to use early neuroplastic windows (41,42). For our interpretation, QoL outcomes are therefore partly downstream consequences of detection systems and care timing.

5. Comorbidity burden as a central mechanism linking cerebral palsy to reduced quality of life:

A major shift in CP research is recognizing that non-motor comorbidities are central, not peripheral, determinants of outcomes. Studies in resource-constrained settings show that most children with CP have at least one comorbidity, with burden increasing at higher GMFCS levels

(43,44). Frequently reported conditions include communication disorders, intellectual disability, epilepsy, sensory deficits, feeding disorders, and behavioral difficulties (45).

Feeding and swallowing disorders are particularly important because of their association with malnutrition, aspiration risk, and recurrent respiratory morbidity (46). Across the lifespan, comorbidity burden remains high and contributes to severe complications and increased mortality (47). Collectively, this evidence supports interpreting CP as a multisystem condition requiring proactive screening and multidisciplinary care (48). In our framework, this justifies analyzing CP-QOL determinants beyond motor severity alone.

6. Prevention and neuroprotection as upstream determinants of future functional and quality-of-life trajectories:

Preventive and neuroprotective strategies are increasingly relevant to long-term QoL trajectories. Antenatal magnesium sulfate has strong evidence for reducing CP risk in preterm populations (49). Therapeutic hypothermia in neonatal hypoxic-ischemic encephalopathy reduces death or major disability, including CP-related outcomes (50). Infection prevention and management during pregnancy remain critical, given associations such as chorioamnionitis and later CP risk [30]. Evidence on corticosteroid-related long-term neurodevelopmental effects remains more nuanced and context-dependent (51).

Although our study is not interventional, this prevention literature provides essential context: the QoL profile observed in CP cohorts is partly shaped by upstream maternal-fetal and neonatal care pathways.

7. Advances in treatment and rehabilitation and their impact on current quality-of-life profiles:

Contemporary CP management emphasizes individualized, multidisciplinary, and function-oriented care. Pharmacological and orthopedic/surgical strategies remain important components in selected cases (52,53). Emerging modalities such as extracorporeal shock wave therapy and robotic-assisted rehabilitation show promising effects on spasticity and motor outcomes in specific populations (54,55). Evidence-based rehabilitation increasingly prioritizes task-specific, goal-directed, and family-centered interventions, while de-emphasizing low-value passive approaches (56,57).

Regenerative approaches, including cell-based therapies, remain investigational and face safety, ethical, and regulatory constraints (58). Complementary approaches such as aquatic therapy may offer functional and psychosocial benefits in selected children, although evidence remains heterogeneous (59) .

For interpretation of our findings, this treatment landscape suggests that QoL scores reflect not only disease severity but also variability in access, intensity, continuity, and appropriateness of care. QoL should therefore be interpreted as an outcome of both biology and health-system performance.

III. Methodological considerations in quality-of-life research in cerebral palsy:

1. Methodological approaches used in previous quality-of-life studies:

In previous studies on quality of life (QoL) in children with cerebral palsy (CP), the dominant methodology has been questionnaire-based assessment using standardized tools, most commonly CP QOL-Child, KIDSCREEN, CHQ, and PedsQL. Most studies are cross-sectional and use regression-based analyses to identify associations between QoL outcomes and clinical or sociodemographic variables (7,12,60–63). Systematic reviews have also emphasized ICF-informed approaches to integrate impairment, activity, participation, and contextual factors (7,62).

This methodological landscape is relevant to our study design. We similarly used a cross-sectional approach with multidomain assessment, while integrating a broad set of independent variables (clinical, social, behavioral, pain, and sleep factors) to support a biopsychosocial interpretation of QoL.

2. Quality-of-life domains commonly assessed and their limitations:

Across the literature, physical, emotional, and social domains are the most frequently assessed and most consistently affected in children with CP (62,64). Participation and pain are also recurrently identified as high-impact domains, especially in children with greater functional

limitation (60,61). These findings support multidomain instruments rather than purely functional scales.

However, domain coverage remains uneven. Cognitive functioning and autonomy are often handled as clinical correlates rather than directly measured QoL dimensions. In addition, participation is sometimes measured broadly, without sufficient detail regarding school inclusion and daily-life independence (7). These gaps may lead to partial representation of the child's lived experience.

3. Evaluation of therapeutic interventions through quality-of-life outcomes:

Although QoL is increasingly recognized as a clinically meaningful endpoint, intervention studies in CP still prioritize motor or functional outcomes, with QoL often treated as a secondary endpoint (7,62). Available evidence suggests that modifiable factors such as pain, communication support, swallowing care, and rehabilitation access can influence QoL trajectories (60,61). CP QOL-Child has also shown potential responsiveness in intervention-related contexts [61].

Nevertheless, the evidence base remains limited by the predominance of cross-sectional/observational designs and relatively few robust longitudinal pre-post evaluations focused primarily on QoL. As a result, the direct translation of therapeutic gains into broader emotional and social QoL improvements remains incompletely characterized.

4. Identified research gaps and positioning of the present study:

Major gaps persist in CP quality-of-life research, including heterogeneity of measurement tools, limited longitudinal evidence, underrepresentation of child self-report, and scarce data from North African settings (7,12,62,63). These limitations affect both comparability and interpretation across studies, since instrument choice and respondent type can alter domain-level estimates and apparent determinant patterns.

The present study contributes by providing context-specific data from a Moroccan tertiary-care cohort using a CP-specific QoL framework. It also integrates a broad set of determinants—sociodemographic, clinical, emotional-behavioral, pain, and sleep—to support multidimensional interpretation of QoL outcomes rather than motor-centered interpretation alone.

5. Justification of the Study Tool, Administration Strategy, and Determinant Framework:

The methodological coherence of this study rests on three linked choices: selecting a CP-specific QoL instrument, defining a clear respondent strategy, and applying a multidimensional determinant framework. We used the Arabic CP QOL-Child because it is condition-specific and captures domains that are central in cerebral palsy (participation, pain impact, emotional wellbeing, access to services, and family health), domains that are often less precisely captured by generic QoL tools (10). This made it appropriate for our primary objective of describing QoL patterns in children with CP.

For analytical consistency, the parent-proxy version was used as the principal source for the main objectives (global QoL profile and determinant analysis), while the child self-report version was used only for the dedicated parent-child comparison objective in eligible children. This separation was intentional: it avoids mixing heterogeneous respondent structures in core association analyses and preserves interpretive clarity.

To interpret QoL beyond motor severity alone, we structured independent variables into five groups: sociodemographic variables; clinical variables (GMFCS level, associated impairments, and therapies); emotional/behavioral screening; pain; and sleep. This framework reflects CP as a multisystem condition and strengthens ecological interpretation by integrating both clinical burden and contextual influences. Pain and sleep were deliberately included because they are often underemphasized in CP outcome models despite evidence linking pain to reduced participation and poorer QoL, and sleep disturbances to lower child wellbeing and greater family burden (65–69).

IV. Reminder of the study objectives:

In this study, our primary objective was to assess quality of life in children with cerebral palsy followed at CHU Marrakech using the Arabic CP QOL-Child questionnaire. The secondary objectives were to identify the main determinants associated with domain-specific QoL outcomes—across sociodemographic, clinical, emotional-behavioral, pain, and sleep dimensions—and to compare parent-proxy and child self-reported QoL in eligible children. Framing the discussion around these

objectives is essential to determine whether our results answer the initial research questions and to clarify the clinical relevance of the observed QoL profile.

V. Main findings and their implications:

1. Impact of sociodemographic factors on quality-of-life interpretation:

Our sociodemographic results show that the cohort is predominantly male, young (mean age 8.25 years), and largely rural, with marked social vulnerability (low income, low caregiver education, long travel distance). We consider this profile highly relevant to the interpretation of quality-of-life outcomes, because it confirms that our sample is not only clinically affected by cerebral palsy but also exposed to structural constraints that can worsen everyday functioning and healthcare access(2,70,71). In other words, these data support the secondary objective of identifying contextual factors likely to shape QoL beyond medical severity alone.

We observed a clear male predominance (sex ratio 2.06:1), which is broadly compatible with many CP cohorts and likely reflects both biological vulnerability and care-seeking patterns(72,73). We also note that all ages between 4 and 12 years were represented, which strengthens internal representativeness for this pediatric window. At the same time, the high concentration of children at the oldest ages of inclusion may suggest delayed referral pathways, delayed diagnosis follow-up continuity, or cumulative survival into specialized care, all of which may influence perceived QoL and family burden.

The strongest signal in our data is socioeconomic and geographic disadvantage: most families were low income, most caregivers had limited schooling or were illiterate, and most families traveled more than 30 km to reach CHU care. We interpret this triad (poverty–low health literacy–distance) as a major explanatory hypothesis for lower scores in structurally sensitive domains, especially Access to services(64,66,74,75), and potentially for downstream effects on Participation and physical health and Family health. This is a central contribution of our work: it shows that in our setting, QoL cannot be interpreted without integrating social and territorial barriers.

School exclusion is another major finding, with 83.7% of children not enrolled in school. We believe this is not a peripheral variable but a core determinant of social participation and developmental opportunity. This observation may help explain why even when some psychosocial

perceptions appear relatively preserved, functional and participation-related QoL domains remain heavily constrained. It also raises a practical issue for care models: without educational inclusion pathways, rehabilitation gains may not translate into real-life participation gains(76–78).

The caregiver structure also matters for interpretation. Mothers were the main respondents in most cases, which is expected in pediatric CP care, but this may also concentrate caregiving burden and shape proxy perceptions. High proportions of divorced caregivers and families with another chronically ill child further suggest cumulative household stress. These elements support our position that QoL in CP is family-embedded, and that child outcomes should be interpreted alongside caregiver context rather than in isolation(9,79,80).

From a methodological standpoint, a strength of these findings is the breadth of sociodemographic variables collected, allowing nuanced contextual interpretation. A limitation is that some variables are descriptive and may be interdependent (for example, rural residence, distance, and income), which can complicate attribution if not modeled jointly. Nevertheless, as a discussion point, the pattern is coherent and clinically meaningful: our cohort represents a high-constraint social context, which increases the relevance of our thesis for real-world service planning.

Based on these observations, we propose concrete changes: decentralization of follow-up pathways, reinforcement of social support navigation, caregiver-targeted education adapted to low literacy, and stronger school-inclusion coordination between health and education sectors. In our view, these are not optional add-ons; they are necessary if we want measurable improvement in QoL domains that are structurally disadvantaged in our population.

2. Impact of clinical severity on quality-of-life interpretation:

Our clinical results show a cohort with a high burden of severe and complex cerebral palsy, characterized by early diagnosis but substantial functional limitation and frequent associated impairments. We consider this profile central to interpreting our QoL outcomes, because it provides the clinical substrate that can explain low scores in Participation and physical health, Pain and impact of disability, Feelings about functioning, and Family health.

We found that most children were diagnosed before 1 year of age. This is an important positive signal in our setting, suggesting that early clinical recognition pathways are functioning for

a large proportion of children. However, early diagnosis in itself does not guarantee favorable long-term QoL when severity and comorbidity burden are high(38). In our cohort, this likely explains why early identification coexists with persistent multidomain burden: timing of diagnosis is necessary, but not sufficient, without sustained, multidisciplinary, and accessible follow-up.

The predominance of spastic CP is expected and aligns with most pediatric CP series, but the more decisive finding is severity distribution: nearly half of children were classified as GMFCS level V, and quadriplegia was the most frequent topography. We interpret this as evidence that our tertiary center receives a concentration of complex cases, which strengthens the clinical relevance of our findings for high-needs populations but may also shift the QoL profile downward compared with community-based cohorts. This referral effect is a strength for studying severe burden, but it is also a limit for broad generalization to milder CP populations(81).

Associated impairments were frequent and cumulative: speech impairment, epilepsy, intellectual disability, visual and hearing problems, and swallowing disorders were all highly represented. We believe this multisystem burden is one of the strongest explanatory hypotheses for reduced QoL across several domains. In practical terms, when communication, cognition, feeding, and neurological stability are simultaneously affected, the child's participation opportunities narrow and caregiver burden rises. This mechanism likely contributes not only to poorer Participation and physical health and Feelings about functioning, but also to lower Family health and higher impact in Pain and impact of disability(82).

The therapeutic profile further supports this interpretation. Physical therapy was widely used, and about half of children received pharmacological and speech interventions, but use of occupational therapy, assistive devices, orthopedic care, botulinum toxin, and aquatic therapy remained relatively limited. We interpret this pattern as partial multidisciplinarity: core rehabilitation is present, but complementary modalities that could improve participation, autonomy, and comfort may be underused or less accessible. This may partly explain why structural and functional QoL domains remain impaired despite active treatment in many children(83).

From a discussion perspective, the key message is that our cohort combines three interacting drivers of reduced QoL: high motor severity, high comorbidity load, and incomplete access to full-

spectrum multidisciplinary care. This triad supports a biopsychosocial interpretation of CP outcomes and reinforces the importance of integrated care pathways rather than isolated interventions.

Based on these findings, we propose prioritizing: (1) early comprehensive comorbidity screening (communication, cognition, swallowing, epilepsy, vision/hearing), (2) escalation from "rehabilitation presence" to "rehabilitation coordination" with clear functional goals, and (3) expansion of access to occupational therapy and assistive technologies, especially in severe GMFCS groups. In our view, these changes are necessary if early diagnosis is to translate into measurable QoL improvement.

3. Impact of emotional and behavioral difficulties on quality-of-life interpretation:

Our SDQ findings indicate a substantial emotional-behavioral burden in this cohort: only 39.4% were in the normal range, while 60.6% were borderline or abnormal. We interpret this as a clinically significant signal that psychological and behavioral difficulties are not peripheral in our population but part of the core burden of cerebral palsy in everyday life. This result supports the relevance of including emotional-behavioral screening among QoL determinants, because these difficulties can directly affect Emotional wellbeing and self-esteem, and indirectly influence Participation and physical health, Feelings about functioning, and Family health through reduced social engagement, increased dependence, and caregiver stress(84).

A plausible explanatory hypothesis is the cumulative effect of severe motor limitation, communication barriers, chronic symptoms (especially pain and sleep disturbance), and contextual constraints (school exclusion, socioeconomic vulnerability), which together increase the risk of emotional and behavioral dysregulation. This interpretation is also consistent with our broader cohort profile, where high clinical complexity and social burden coexist. Methodologically, using SDQ as a standardized screening tool is a strength because it provides structured psychosocial stratification(19); however, we acknowledge that SDQ remains a screening measure, not a diagnostic psychiatric assessment. Even with this limitation, the proportion of borderline/abnormal scores is too high to be considered incidental and argues for routine psychosocial assessment and referral pathways within CP follow-up.

From a practice perspective, we believe this finding justifies integrating mental-health informed care into routine CP management: periodic SDQ-based screening, parent guidance, targeted behavioral interventions, and closer collaboration between rehabilitation and child mental health teams(66). In our view, without this integration, improvements in motor care alone are unlikely to produce optimal gains in overall quality of life.

4. Impact of pain and sleep burden on quality-of-life interpretation:

Our results show that pain and sleep disturbances are major components of the clinical burden in this cohort and should be interpreted as central determinants of quality of life, not secondary symptoms. Two-thirds of children reported pain, and the distribution is particularly concerning because a large subgroup reported very high intensity, including "unbearable" pain. In parallel, sleep difficulties were present in 63.5% of children, confirming that disturbed sleep is common in daily life for this population.

We interpret this combination (high pain + frequent sleep problems) as a high-impact mechanism affecting several CP QOL domains simultaneously. Pain is likely to worsen Pain and impact of disability directly, but it can also reduce mobility and engagement, thereby influencing Participation and physical health and Feelings about functioning. Sleep problems may amplify daytime fatigue, irritability, and behavioral dysregulation, with likely downstream effects on Emotional wellbeing and self-esteem and Family health. In this context, the coexistence of pain and sleep disturbance probably contributes to cumulative burden on both child functioning and caregiver wellbeing(85,86).

A key implication is that symptom control must become systematic and proactive. We consider routine pain quantification and structured sleep screening essential components of CP follow-up, alongside motor rehabilitation. Clinically, this supports integrated care pathways combining rehabilitation, analgesic optimization, sleep-focused behavioral guidance, and caregiver education(83). In our view, without targeted management of pain and sleep, meaningful improvement in global QoL domains is unlikely, even when other therapies are in place.

5. Parent-reported quality-of-life patterns across domains:

Parent-reported CP QOL results show a clearly non-uniform domain profile. The highest scores were observed in social wellbeing and acceptance and emotional wellbeing and self-esteem, whereas Access to services and Participation and physical health were substantially lower, with wide variability between children. We interpret this pattern as a dissociation between relatively preserved psychosocial adaptation and major structural/functional constraints in daily life.

This dissociation is clinically meaningful. It suggests that children may retain perceived social-emotional resources despite limited participation opportunities and important barriers to services. At the same time, the marked dispersion in lower-scoring domains indicates strong heterogeneity of lived burden, likely reflecting unequal combinations of severity, comorbidity load, family resources, and geographic/service accessibility(75).

The major implication is that QoL in cerebral palsy must be interpreted by domain, not by overall average alone. In our view, Access to services and Participation and physical health should be considered priority action domains for care planning, because they capture modifiable barriers where targeted service organization, rehabilitation access, and participation-oriented interventions may produce the largest practical gains.

6. Patterns of child self-reported quality of life:

Child self-reports show a distinct profile: Social wellbeing and acceptance was very high and tightly clustered, while Pain and impact of disability remained the lowest domain. Participation and physical health and Feelings about functioning were moderately high, with wider variability—especially for participation. We interpret this as evidence that, among children able to self-report, perceived social acceptance can remain strong even when symptom burden and functional restrictions persist.

This pattern has two important implications. First, it reinforces that CP QOL domains do not move in parallel: a favorable psychosocial perception does not exclude substantial burden in Pain and impact of disability(10,66). Second, the wider spread in Participation and physical health

suggests unequal real-life opportunities across children, likely influenced by differences in functional severity, environmental accessibility, and family context.

Because this subgroup includes only children with sufficient communication/cognitive ability, these findings should be interpreted as a complementary perspective rather than a population estimate. Nevertheless, they are highly informative: they remind us that the child's lived experience can show resilience in some domains while still signaling unmet needs in pain control and participation support.

VI. Interpretation of results across domains:

1. Social wellbeing and acceptance :

In our cohort, social wellbeing and acceptance was the highest-scoring domain, indicating relatively preserved perceived social integration despite substantial disability burden. We interpret this as a sign of partial psychosocial resilience in children and families. However, this relative strength should not mask major limitations in other domains, especially those linked to participation and service access(75). Clinically, this supports maintaining and expanding inclusion-oriented actions that preserve peer connection and social belonging.

2. Emotional wellbeing and self-esteem:

Emotional wellbeing and self-esteem was the second highest domain, suggesting that emotional adaptation remains possible even in a context of important clinical and contextual constraints. This result is encouraging, but it remains fragile in children with higher emotional-behavioral burden and chronic symptom load. We therefore interpret this domain as a potential protective resource that requires active support rather than passive expectation. In practice, structured psychosocial follow-up and caregiver guidance remain essential to sustain this relative strength over time.

3. Feelings about functioning:

Feelings about functioning was clearly lower than the two psychosocially preserved domains, reflecting a more negative perceived experience of functional ability in daily life. This pattern is coherent with the high burden of severe motor limitation and associated impairments in our

sample. It also suggests that children's functional self-perception is influenced not only by impairment severity but by whether daily environments allow successful engagement and autonomy. Clinically, this supports goal-directed rehabilitation focused on meaningful real-life tasks, not only impairment reduction.

4. Family health:

Family health was in the lower-intermediate range, highlighting significant caregiver and household burden. We interpret this as a central component of QoL in CP, since family strain can both result from and contribute to poorer child outcomes(79). The domain likely captures accumulated effects of long-term care demands, symptom management, financial pressure, and logistical constraints. This finding supports family-centered models that include caregiver support, practical counseling, and sustained psychosocial accompaniment as routine elements of CP care.

5. Participation and physical health:

Participation and physical health was one of the most impaired domains, indicating major restrictions in activity, autonomy, and everyday functioning. The wide variability observed in this domain suggests unequal participation opportunities across children. We interpret this as a high-priority burden domain where clinical severity, associated impairments, school inclusion, and symptom control likely converge(76). In practical terms, improving this domain requires coordinated, participation-oriented rehabilitation linked to school and community contexts.

6. Pain and impact of disability:

Pain and impact of disability was also low, confirming that symptom burden remains a major contributor to reduced quality of life. This domain underscores that CP-related burden is not purely motor or functional: pain and discomfort shape daily experience directly and may worsen emotional regulation and participation. Even when social or emotional domains appear relatively preserved, untreated pain can maintain significant hidden burden(85). Clinically, this supports systematic and repeated pain assessment with proactive, multidisciplinary management strategies.

7. Access to services:

Access to services was the lowest domain in our cohort, making it the most prominent structural weakness in the CP-QOL profile. We interpret this as strong evidence that service organization and contextual barriers critically shape lived outcomes in our setting. This very low score is consistent with a context where socioeconomic vulnerability, geographic distance, and complex care needs may limit continuity and timeliness of care. From a health-system perspective, this domain should be treated as a priority target through decentralization, improved referral coordination, and active support for families facing the greatest access barriers.

VII. Determinants of quality of life in children with cerebral palsy:

1. Sociodemographic determinants:

Our analyses show that sociodemographic factors are not peripheral variables; they are major drivers of domain-specific quality-of-life differences in children with cerebral palsy(75). We found that gender was associated with significant contrasts in structurally sensitive and physical domains: boys had higher scores in Access to services and Participation and physical health, whereas girls had higher scores in Pain and impact of disability. This pattern suggests that gender effects in our cohort may reflect unequal pathways of care access and participation opportunities, while pain-related perception may be shaped by different symptom expression or reporting dynamics. By contrast, the absence of gender differences in Emotional wellbeing and self-esteem, Feelings about functioning, and Family health suggests that not all QoL dimensions are equally gender-sensitive.

Age showed a significant negative correlation with Family health and social wellbeing and acceptance, indicating declining scores with increasing age. We interpret this as a possible cumulative burden effect: as children grow older, caregiving strain and social-participation challenges may become more visible, especially in contexts with limited long-term support structures(79). This result reinforces the need for age-adapted follow-up strategies rather than static pediatric care models.

Place of residence revealed one of the clearest structural inequalities. Urban children scored substantially higher in Access to services, while psychosocial domains and pain-related perception

were not significantly different between urban and rural settings. This dissociation is important: it indicates that emotional/social adaptation can remain relatively stable despite territorial inequity in service availability. In our context, this finding strongly supports the hypothesis that geographic barriers primarily penalize access-dependent domains before they necessarily alter all psychosocial dimensions(74).

School enrollment emerged as a major protective factor. Schooled children had significantly better scores in Participation and physical health, Feelings about functioning, Emotional wellbeing and self-esteem, and Access to services. We consider this one of the most actionable findings in our thesis, because schooling likely reflects both inclusion and functional activation(76). The higher Pain and impact of disability score among unschooled children is counterintuitive and may indicate reporting/perception effects, reduced exposure to physically demanding environments, or subgroup differences in severity and daily routines. This result should therefore be interpreted cautiously, not as evidence that school worsens wellbeing.

Family-context variables also showed selective effects. Parental consanguinity was associated only with Family health, without differences in other domains, suggesting a family-level rather than child-function-level signal. Income significantly affected Access to services, with better scores in moderate-income families, which is coherent with financial facilitation of transport, consultations, and continuity of care. Sibling structure was also relevant: children with siblings had higher Feelings about functioning and Participation and physical health, and in the sibling subgroup, having a sibling with chronic disease was associated with worse social wellbeing and acceptance and Family health. These findings support the idea that household caregiving ecology influences both child participation and family-perceived wellbeing.

Health insurance showed a mixed pattern: uninsured children had higher Access to services scores, whereas insured children had better Pain and impact of disability scores. This apparently paradoxical result may reflect pathway effects (e.g., insured children being overrepresented among more severe chronic-care users, or uninsured families using alternative/local access routes). We therefore interpret insurance not as a simple binary advantage, but as a marker interacting with severity, care pathways, and service type.

Caregiver education was one of the most coherent social gradients in our data. Higher education level was associated with progressively better scores in Access to services, Family health, social wellbeing and acceptance, and Emotional wellbeing and self-esteem, while no significant association was seen for Participation and physical health, Feelings about functioning, or Pain and impact of disability. This pattern is clinically plausible: caregiver education may primarily improve navigation of systems, advocacy, communication, and psychosocial buffering, with less direct impact on core motor burden.

Distance to hospital confirmed a strong access gradient: the farther the family lived, the lower the Access to services score, with the worst values beyond 30 km. This finding is central for service planning in our setting and supports decentralization, outreach coordination, and transport-sensitive models of follow-up.

Overall, we conclude that sociodemographic determinants in our cohort operate through selective domain pathways, especially Access to services, Participation and physical health, and Family health. This strengthens our main thesis argument: QoL in CP is jointly shaped by clinical severity and social organization of care, and meaningful improvement requires interventions on both fronts.

2. Clinical determinants of quality of life in children with cerebral palsy:

Our analytical results show that clinical determinants influence CP QOL outcomes in a domain-specific manner rather than uniformly. Overall, the strongest and most consistent negative patterns were linked to severity markers (GMFCS, topography, intellectual impairment, swallowing disorder), while treatment-related associations were mixed and likely affected by indication bias (children with higher severity receiving more intensive care).

- **Timing of diagnosis:**

We found significant associations between age at diagnosis and two domains: Pain and impact of disability and Family health, with higher scores in children diagnosed after 2 years. We interpret this cautiously: this pattern may reflect phenotype heterogeneity (later-diagnosed children possibly having less severe early presentation), adaptation effects in families, or differences in

referral pathways. It should not be interpreted as "late diagnosis is better," but rather as a possible marker of clinical trajectory differences.

- **Motor severity and motor distribution:**

The GMFCS effect was clear in functional domains: children in higher severity levels had markedly lower Participation and physical health and Feelings about functioning. This supports the expected functional gradient between motor limitation and activity-restricted QoL(81).

Topographic analysis confirmed this gradient: children with quadriplegia had significantly lower scores in Feelings about functioning, Participation and physical health, and Pain and impact of disability, with additional differences in Social wellbeing and acceptance and Family health.

Together, these findings strongly support the interpretation that severe bilateral involvement drives multidomain burden, especially where autonomy and caregiver load are central(81).

- **CP clinical type:**

Clinical type also mattered for selected domains: differences were significant for **Access to** services, Participation and physical health, Feelings about functioning, and Emotional wellbeing and self-esteem. The very low Access to services score in the mixed group is clinically striking and may reflect greater complexity of needs with poorer pathway fit. By contrast, non-significant variation in other domains (e.g., Pain and impact of disability) suggests that symptom burden is not fully explained by CP type alone.

- **Associated impairments:**

Associated impairments were major determinant signals in this study:

- Intellectual impairment showed the broadest negative impact (significant in 6/7 domains), especially Participation and physical health and Access to services.

- Speech impairment and visual problems were significantly associated with lower Access to services, suggesting communication/sensory barriers to navigating care.

- Swallowing disorder had a profound multidomain effect (notably Participation and physical health, Feelings about functioning, Emotional wellbeing and self-esteem, Family health, and Access to services), consistent with high daily-care intensity and medical vulnerability.

- Epilepsy was not significantly associated with domain differences in your sample, despite a trend in Emotional wellbeing and self-esteem.

This pattern supports a key thesis argument: QoL burden in CP is strongly amplified by multisystem comorbidity, not only by motor status(82,87).

❖ **Therapy-related determinants:**

Therapy associations were heterogeneous and must be interpreted with attention to confounding by indication (children receiving certain therapies may already have greater baseline severity).

- Physical therapy was associated with better Access to services and Participation and physical health, with additional difference in social wellbeing and acceptance. This likely reflects both benefit and better care engagement.

- Occupational therapy was associated with lower Participation and physical health in users, likely because OT is preferentially prescribed in more functionally limited children.

- Assistive devices were associated with higher social wellbeing and acceptance and Access to services, but lower Family health — a plausible dual effect: improved child participation but increased family caregiving/logistical burden.

- Orthopedic follow-up showed better Access to services but lower Pain and impact of disability, again compatible with referral of more complex/painful cases.

- Pharmacological therapy was associated with lower social wellbeing and acceptance and Family health in treated children, likely reflecting higher underlying clinical complexity.

- Botulinum toxin showed no significant differences across domains.

- Aquatic therapy showed higher social wellbeing and acceptance, lower Participation and physical health, and lower Pain and impact of disability scores in users, suggesting mixed subgroup characteristics and possible selective referral.

❖ **Integrative interpretation**

Clinically, these findings support three conclusions.

First, the most robust negative determinants are severity/comorbidity markers (GMFCS, quadriplegia, intellectual impairment, swallowing disorder).

Second, **Access to services** appears highly sensitive to complexity and pathway navigation factors (sensory/communication deficits, clinical type, therapy linkage).

Third, treatment-outcome associations cannot be interpreted causally in this cross-sectional design without adjustment for baseline severity(83).

❖ **Practical implications**

Based on these determinant patterns, we propose:

1. systematic risk stratification using severity + comorbidity bundles (not motor status alone),
2. early integrated management of intellectual/communication/feeding impairments,
3. care-pathway redesign for children with complex phenotypes (especially mixed CP, severe GMFCS, multisystem deficits),
4. routine interpretation of therapy effects with severity-adjusted analyses in future studies.

3. Emotional and behavioral determinants of quality of life:

Our analysis shows that SDQ total difficulties is one of the strongest non-motor determinants of QoL in this cohort. Children in the abnormal SDQ category had markedly lower scores than the normal group in social wellbeing and acceptance, Feelings about functioning, and Participation and physical health, with additional significant reductions in Emotional wellbeing and self-esteem and Pain and impact of disability. We interpret this as strong evidence that emotional-behavioral burden

is not a secondary feature, but a core component shaping daily functioning and perceived wellbeing in children with CP(84).

The pattern is clinically coherent: emotional and behavioral dysregulation can reduce social engagement, worsen adaptation to functional limitations, and intensify pain-related distress, thereby affecting both psychosocial and activity-related domains. In contrast, the absence of significant association with Access to services and Family health suggests that these two domains may be driven more by structural/system factors (distance, income, care pathways) and household context than by child behavioral profile alone.

Methodologically, this is a strong finding because it is consistent across several CP QOL domains and shows large between-group contrasts. At the same time, SDQ remains a screening instrument, so interpretation should remain dimensional rather than diagnostic(15). Even with that caution, the signal is robust enough to support routine psychosocial screening in CP follow-up.

From a practical perspective, we believe these results justify integrating mental-health informed care into rehabilitation pathways: periodic SDQ-based screening, early behavioral intervention, parent coaching, and referral circuits linking rehabilitation teams with child mental health services. In our view, without addressing emotional-behavioral burden, improvements in motor care alone will not translate into optimal gains in overall QoL.

4. Pain and sleep disturbances as determinants of quality of life:

Our results confirm that pain and sleep are major symptom-level determinants of QoL, but with selective domain effects rather than global impact across all CP QOL domains. For pain intensity (VAS), we found significant associations with Participation and physical health and Emotional wellbeing and self-esteem (both negative), indicating that greater pain burden is linked to poorer functional participation and lower emotional wellbeing. This is clinically coherent and supports the interpretation of pain as a cross-domain burden amplifier rather than an isolated symptom(85).

A striking result was the strong positive correlation between pain intensity and Access to services. We interpret this cautiously: this likely reflects a care-contact effect (children with more severe pain may have more frequent interactions with services) rather than a beneficial effect of pain

itself. In other words, higher pain may trigger more care-seeking and therefore higher perceived access scores, without necessarily improving wellbeing outcomes. This interpretation is further supported by the simultaneous negative correlations with functional and emotional domains.

For sleep, children with reported sleep problems had significantly lower scores in Participation and physical health, Pain and impact of disability, and Emotional wellbeing and self-esteem. This pattern strongly suggests that sleep disturbance contributes to daytime functional limitation, pain-related burden, and emotional dysregulation(86). Non-significant differences in other domains (Social wellbeing and acceptance, Feelings about functioning, Family health, Access to services) may indicate either smaller effect sizes in those dimensions or mediation through other factors.

Taken together, pain and sleep show clinically meaningful and partly overlapping effects, especially on participation and emotional domains. We therefore consider them modifiable targets that should be systematically integrated into CP follow-up. Practically, this supports routine VAS/structured pain assessment, standardized sleep screening (e.g., BEARS), and coordinated symptom-management pathways embedded within rehabilitation care. In our view, ignoring pain and sleep would leave a major part of QoL burden untreated, even when motor therapy is optimized.

5. Inter-domain structure of parent-reported CP-QOL:

Our parent-reported inter-domain correlations show that CP QOL domains cluster into two main patterns. First, a strong psychosocial-functional cluster is evident: Participation and physical health, Feelings about functioning, Emotional wellbeing and self-esteem, and social wellbeing and acceptance are all strongly and positively correlated (ρ up to 0.803). This supports internal coherence of the questionnaire in our cohort and suggests that when functional participation improves, emotional and social perceptions tend to improve in parallel.

Second, Family health appears as a connected but intermediate domain: it correlates positively with Participation and physical health, Feelings about functioning, Emotional wellbeing and self-esteem, social wellbeing and acceptance, and modestly with Access to services. This pattern is clinically meaningful because it indicates that family wellbeing is linked both to child functioning

and to psychosocial adaptation, reinforcing the idea that child QoL and caregiver/family context are interdependent(75).

By contrast, Pain and impact of disability behaves relatively independently in the parent dataset. Its correlations with most other domains are weak and non-significant, including with Participation and physical health, Feelings about functioning, and Emotional wellbeing and self-esteem. This suggests that pain burden, as captured here, may follow partly distinct pathways (symptom episodes, reporting differences, treatment effects, or adaptation mechanisms) that are not fully represented by the broader psychosocial-functional network(75).

From an interpretation standpoint, these findings justify avoiding a single global-QoL reading(10). Instead, our results support interpreting CP QOL as a multidimensional system with:

1. a tightly linked participation-function-emotional-social core,
2. a family-linked contextual layer, and
3. a more independent pain-related dimension.

Clinically, this supports combined strategies: interventions targeting participation/function are likely to generate broad psychosocial gains, whereas pain requires specific and dedicated assessment/management pathways rather than being assumed to improve automatically with other domains.

VIII. Parent-proxy versus child self-report: a comparative discussion:

1. Agreement and discrepancies between parent- and child-reported quality of life:

Our comparative analysis shows a mixed parent-child pattern combining both concordance and divergence. Parent-proxy ratings (N=104) showed the highest scores in social wellbeing and acceptance and Emotional wellbeing and self-esteem, while Access to services and Participation and physical health were the lowest and most heterogeneous domains. In the child self-report subgroup (N=10), scores were very high and tightly clustered for social wellbeing and acceptance, whereas

Pain and impact of disability was the lowest domain; Participation and physical health and Feelings about functioning were moderately high with persistent variability in participation. Correlation analysis refined this picture: strong and statistically significant child–parent concordance was observed for Pain and impact of disability and Feelings about functioning, while correlations for social wellbeing and acceptance, Participation and physical health, and Emotional wellbeing and self-esteem were positive but non-significant. Overall, our data suggest that agreement is stronger for concrete symptom/functional experience and weaker for broader psychosocial perceptions(88,89).

2. Explanatory hypotheses for observed parent–child differences:

We consider several hypotheses to explain this profile. First, parent proxies may place greater weight on observable burden (care complexity, service barriers, dependency), whereas children may report their own adaptation and social experience more positively, especially in domains related to acceptance and self-perception. Second, the child-report subgroup included only children able to communicate and understand the questionnaire, which may select a relatively higher-functioning subgroup and shift child scores upward. Third, psychosocial domains are inherently more subjective and context-sensitive, which can increase parent–child divergence even when both perspectives are valid. Finally, significant concordance in Pain and impact of disability and Feelings about functioning suggests that when daily limitations are concrete and repeatedly observed, parent and child perceptions converge more easily.

3. Clinical implications of using dual perspectives:

Our results support using parent and child reports as complementary—not interchangeable—sources of information. In clinical practice, child self-report should be prioritized whenever feasible to capture lived subjective experience, while parent proxy remains essential when communication or cognitive limitations prevent direct reporting(88,89). Domains with stronger concordance (particularly Pain and impact of disability and Feelings about functioning) can be interpreted with greater confidence across informants, whereas psychosocial domains should be interpreted through a dual-perspective lens. We therefore recommend routine integration of both perspectives in follow-

up, with explicit documentation of discrepancies, because these differences may themselves identify unmet needs in communication, emotional support, or participation planning.

IX. Comparison of findings with previous studies:

To interpret our findings, we compared our results exclusively with studies that used the CP-QOL parent-proxy questionnaire, ensuring methodological comparability (Tables 44–49). This approach allows us not only to identify similarities and differences but also to critically examine how cohort characteristics, recruitment context, and reporting practices may influence quality-of-life outcomes in children with cerebral palsy.

1. Comparison of study cohorts:

As shown in Table 44, the age distribution and reliance on parent-proxy reporting in our cohort are comparable to those reported in Tunisian, Egyptian, Iranian, and Australian CP-QOL studies (13,60,90,91). This methodological consistency strengthens the validity of cross-study comparison. We also observed a male predominance similar to that described in international epidemiological literature(34,92).

Table 45: Comparison of cohort characteristics across studies.

Characteristic	Australia (Davis et al., 2010)(91)	Iran (Soleimani et al., 2015)(90)	Egypt (El-Weshahi et al., 2017)(13)	Tunisia (Marwa et al., 2022)(60)	Morocco (Our study)
Instrument	CP-QOL Parent-Proxy	CP-QOL Parent-Proxy	CP-QOL Parent-Proxy	CP-QOL Parent-Proxy	CP-QOL Parent-Proxy
Sample size (N)	204	200	200	68	104
Age range (years)	4–12	4–12	4–12	4–12	4–12
Male sex (%)	NR	NR	NR	~62	~67
Parent-proxy report	100%	100%	100%	100%	100%

2. Comparison of sociodemographic characteristics across studies:

We note important contextual differences between our cohort and those reported in the literature. Our population included a markedly higher proportion of children living in rural areas and a substantially lower rate of school enrollment than most comparator studies (Table 45), a pattern that has also been described as a major source of inequality in pediatric disability outcomes (78,93). We consider this both a limitation for strict comparability and a major strength of our work, as it captures a socially vulnerable population that is often underrepresented in CP-QOL research. In contrast, studies conducted in high-income countries, while methodologically robust, frequently include predominantly urban and ambulatory populations, which may partly explain their higher scores in participation and access-related domains (91).

Sociodemographic disparities were more pronounced in our cohort than in most comparator studies, with higher rates of rural residence, lower parental income, and lower caregiver educational levels. Rather than representing a methodological weakness, we believe these characteristics constitute critical contextual determinants of quality of life, particularly in settings where access to specialized care depends heavily on geographic proximity and socioeconomic resources (94). Tunisian and Egyptian studies report intermediate levels of socioeconomic vulnerability, whereas Iranian and Australian cohorts generally reflect more favorable social conditions and stronger healthcare infrastructure (13,60,90,91).

We hypothesize that these contextual differences contribute substantially to the marked impairment observed in the Access to services domain in our cohort. When rehabilitation services are geographically centralized, children living in rural and socioeconomically disadvantaged settings face structural barriers that directly limit access to care, regardless of clinical severity. Consequently, differences in access-related quality-of-life outcomes across studies appear to reflect healthcare organization and social context more than intrinsic differences in disease characteristics alone. This combination of rural residence, limited school inclusion, and socioeconomic disadvantage likely also contributes to lower participation opportunities, further amplifying quality-of-life disparities in our population.

Table 46: Comparison of sociodemographic characteristics across studies.

Sociodemographic Variable	Australia (Davis et al., 2010)(91)	Iran (Soleimani et al., 2015)(90)	Egypt (El-Weshahi et al., 2017)(13)	Tunisia (Marwa et al., 2022)(60)	Morocco (Our study)
Sample size (N)	204	200	200	68	104
Mean age (years)	NR	NR	NR	7.9 ± 3.1	8.25 ± 2.85
Male sex	NR	NR	NR	42/68 (61.8%)	70/104 (67.3%)
Rural residence	NR	NR	NR	26/68 (38.2%)	62/104 (59.6%)
Urban residence	NR	NR	NR	42/68 (61.8%)	42/104 (40.4%)
School enrollment (Yes)	>70%*	NR	75/200 (37.5%)	NR	17/104 (16.3%)
School enrollment (No)	<30%*	NR	125/200 (62.5%)	NR	87/104 (83.7%)
Low parental income	NR	63/200 (31.5%)	NR	38/68 (55.9%)	80/104 (76.9%)
Moderate parental income	NR	124/200 (62.0%)	NR	24/68 (35.3%)	24/104 (23.1%)
Good parental income	NR	13/200 (6.5%)	NR	6/68 (8.8%)	0
Low caregiver education	NR	NR	NR	32/68 (47.1%)	54/104 (51.9%)
Health insurance coverage	Universal	NR	NR	NR	95/104 (91.3%)

NR: *Not reported in original publication*

**Reported qualitatively in high-income cohorts without exact n/%*

3. Comparison of clinical severity and motor characteristics.

Our cohort was characterized by a high level of motor severity and medical complexity (Table 46), with nearly 60% of children classified in GMFCS levels IV–V. This severity profile closely resembles that reported in the Tunisian hospital-based cohort, supporting the comparability of tertiary-care populations in North Africa (60). In contrast, Egyptian, Australian, and Iranian studies included a higher proportion of ambulatory children, which we interpret as a strength of those

studies for community-based representation but a limitation when comparing results with hospital-based samples managing more severe clinical profiles (13,90,91).

Associated impairments were frequent across all studies, although their reporting and analytical integration varied considerably (Table 47). Intellectual disability and communication impairments were consistently associated with poorer quality-of-life outcomes, supporting the robustness and cross-contextual validity of these associations (8,60,91). Swallowing disorders, however, were explicitly quantified and analyzed only in our study and in the Tunisian cohort. We consider this discrepancy more reflective of methodological differences than of true clinical absence. Feeding and swallowing difficulties are known to be closely linked to nutritional status, respiratory morbidity, and caregiver burden, and we hypothesize that they may be under-recognized or underreported in several international CP-QOL datasets despite their substantial impact on medical complexity and family functioning (95,96).

Table 47: Comparison of clinical severity and motor characteristics across studies.

Clinical variable	Australia (Davis et al., 2010)(91)	Iran (Soleimani et al., 2015)(90)	Egypt (El-Weshahi et al., 2017)(13)	Tunisia (Marwa et al., 2022)(60)	Morocco (Our study)
Sample size (N)	201	200	200	67	104
GMFCS IV-V	~76 (38%)	98 (49.0%)	67 (33.5%)	**40 (59.7%)**	**62 (59.6%)**
GMFCS I-III	~125 (62%)	102 (51.0%)	133 (66.5%)	27 (40.3%)	42 (40.4%)
Quadriplegic/ extensive distribution	NR	NR	NR	30 (44.8%)	**55 (52.9%)**
Spastic CP	Majority	125 (62.5%)	Majority	Majority	**72 (69.2%)**
Mixed CP	NR	15 (7.5%)	NR	21 (31.3%)	**9 (8.7%)**

NR: *Not reported in the original publication.*

Table 48: Comparison of associated impairments across studies.

Associated impairment	Iran – Soleimani et al., 2015 (N=200)(90)	Egypt – El-Weshahi et al., 2017 (N=200)(13)	Tunisia – Marwa et al., 2022 (N=68)(60)	Morocco (Our study) (N=104)
Epilepsy	NR	NR	17 (32.1%)	58 (55.8%)
Intellectual disability	NR	NR	31 (45.5%)	56 (53.8%)
Speech impairment	NR	NR	36 (52.9%)	65 (62.5%)
Swallowing disorders	NR	NR	24 (45.3%)	28 (26.9%)
Visual problems	NR	NR	18 (26.5%)†	34 (32.7%)
Hearing problems	NR	NR	6 (8.8%)‡	25 (24.0%)

* ***NR****: not reported.*

† Tunisia "visual disturbances" total computed as: blindness (1) + strabismus (7) + amblyopia (7) + agnosia (2) + anophthalmos (1) = ***18/68****.*

‡ Tunisia "hearing impairment" total computed as: hypoacusis (5) + deafness (1) = ***6/68****.*

4. Comparison of emotional and behavioral aspects across studies:

In our study, emotional and behavioral dimensions emerged as major determinants of quality of life, confirming that cerebral palsy cannot be approached solely from the perspective of motor impairment. This observation is broadly consistent with findings from the international literature, although methodological approaches vary across countries. Studies conducted in Tunisia and Australia similarly highlight the substantial contribution of psychosocial factors to quality-of-life impairment, even when emotional domain scores appear relatively preserved compared with functional domains (60,91). However, unlike our work, these studies primarily rely

on overall quality-of-life profiles or global predictor analyses and do not incorporate a structured behavioral screening tool such as the Strengths and Difficulties Questionnaire (SDQ) (60,91).

Egyptian and Iranian studies, by contrast, are more focused on the psychometric validation and descriptive analysis of quality-of-life domains, which limits direct comparison of emotional and behavioral dimensions (13,90). Nevertheless, the variability observed in emotional domain scores across these contexts suggests that children's psychological experience is strongly shaped by social environment, family support, access to schooling, and healthcare organization. We believe that integrating a structured emotional and behavioral screening tool in our study provides a more nuanced understanding of the child's and family's daily experience, demonstrating that emotional difficulties extend beyond reduced self-esteem to directly affect participation, perceived functioning, and, indirectly, the experience of pain.

5. Comparison of pain and sleep assessment:

In our study, sleep disturbances and pain emerged as highly prevalent and clinically relevant dimensions, reinforcing their central role in shaping quality of life in children with cerebral palsy. This finding is consistent with the international literature, which increasingly recognizes sleep and pain as core non-motor contributors to reduced participation, emotional wellbeing, and family functioning. Studies from high-income settings have reported similarly high rates of sleep problems in children with cerebral palsy, often exceeding 50%, particularly among those with severe motor impairment or associated neurological comorbidities (86,97). These data support our interpretation that sleep disturbances are not incidental findings but reflect the cumulative burden of motor limitations, discomfort, and neurodevelopmental vulnerability.

Pain assessment across studies also shows substantial convergence. Previous work has consistently demonstrated that chronic pain is common in children with cerebral palsy and is associated with lower physical participation and poorer emotional wellbeing, even when psychosocial domains appear relatively preserved (85,98). This pattern mirrors our findings, where pain-related burden contributes to reduced participation and emotional quality-of-life domains rather than uniformly affecting all aspects of wellbeing. Importantly, several authors emphasize that pain is frequently under-recognized in routine clinical follow-up, particularly when

communication difficulties are present, which may partly explain the wide dispersion of pain-related quality-of-life scores reported across studies (98,99).

Methodological differences between studies must nevertheless be acknowledged. While many international studies rely on generic pain or sleep questionnaires, our use of the BEARS screening tool and a visual analog scale allows for pragmatic identification of clinically relevant sleep and pain problems within routine care settings. This approach strengthens ecological validity but may limit direct numerical comparison with studies using polysomnography-based or condition-specific sleep instruments. Despite these differences, the overall consistency of findings across contexts supports the interpretation that sleep disturbances and pain represent critical, yet often under-addressed, targets for improving quality of life in children with cerebral palsy.

6. Parent-proxy CP-QOL domain scores across studies.

Direct comparison of parent-proxy CP-QOL domain scores across studies (Table 48) reveals both shared patterns and marked disparities. In our cohort, social wellbeing and acceptance scores were comparable to those reported in Tunisian, Australian, and Iranian studies, suggesting a relative preservation of social integration and acceptance across diverse cultural and healthcare contexts (60,90,91). This consistency supports the robustness of this domain and indicates that social acceptance may be less sensitive to healthcare organization than other aspects of quality of life.

In contrast, Participation and physical health scores were substantially lower in our study than in Tunisian, Australian, and Iranian cohorts. Similar trends were observed for Feelings about functioning, indicating greater functional restriction in daily activities among children followed at the CHU of Marrakech. We hypothesize that these differences reflect not only a higher level of motor severity but also environmental barriers, including limited school inclusion, reduced accessibility of public spaces, and fewer opportunities for adapted physical and recreational activities (100).

The most striking disparity was observed in the Access to services domain. Our cohort demonstrated markedly lower scores compared with Tunisian, Egyptian, Australian, and Iranian studies (13,60,90,91). This finding strongly suggests that geographic distance to tertiary care, centralization of rehabilitation services, and socioeconomic vulnerability play a critical role in

shaping quality-of-life outcomes in our context. We believe that limitations in access to services amplify the impact of disability beyond motor impairment alone, transforming potentially manageable impairments into persistent participation restrictions.

Scores for Pain and impact of disability were relatively similar across studies, indicating that pain is a common and pervasive issue in children with cerebral palsy regardless of setting (85,98). However, in our cohort, pain appeared more closely intertwined with sleep disturbances, participation restriction, and family burden, suggesting possible gaps in pain recognition, assessment, and long-term management. This observation highlights the need for systematic pain screening and integrated management strategies within multidisciplinary cerebral palsy care.

Table 49: Parent-proxy CP-QOL domain scores across studies.

CP-QOL Domain	Australia (Davis 2010)(91)	Iran (Soleimani 2015)(90)	Egypt (El-Weshahi 2017)(13)	Tunisia (Marwa 2022)(60)	Morocco (Our study)
Social wellbeing & acceptance	73.0	74.1	53.7	73.9	71.23
Feelings about functioning	64.1	63.3	37.5	54.6	46.38
Participation & physical health	65.4	66.3	39.7	59.2	42.71
Emotional wellbeing & self-esteem	70.4	70.5	36.8	60.8	61.24
Access to services	55.6	56.1	38.3	57.2	**22.91**
Pain & impact of disability	44.6	46.5	40.1	39.1	40.63
Family health	50.7	48.5	41.1	48.2	44.41

5. Comparison of main determinants of quality of life across studies:

As summarized in Table 49, motor severity emerged as a consistent determinant of poorer quality of life across all studies, confirming its central role in cerebral palsy-related outcomes (60,90,91). Pain burden and communication limitations were also repeatedly identified as important

contributors, reinforcing their status as key non-motor determinants of quality of life (8,98). However, in our cohort, socioeconomic and geographic factors appeared to exert a stronger influence than in most comparator studies, suggesting that clinical severity alone does not fully explain quality-of-life impairment.

Table 50: Comparison of main determinants of quality of life across studies.

Determinant of QoL	Iran (Soleimani et al., 2015)(90)	Egypt (El-Weshahi et al., 2017)(13)	Tunisia (Marwa et al., 2022)(60)	Morocco (present study)
Motor severity (GMFCS)	Higher GMFCS associated with poorer QoL	Higher GMFCS associated with lower QoL	Significant predictor of lower QoL	Strong negative association across most CP-QoL domains
Pain severity	Pain associated with poorer QoL	Pain negatively correlated with QoL	Pain intensity predicts poorer QoL	Associated with poorer participation, emotional wellbeing, and family health
Cognitive status	Cognitive impairment linked to poorer QoL	Cognitive impairment linked to lower QoL	Absence of verbal communication linked to lower QoL	Major determinant across nearly all domains
Swallowing disorders	Not reported	Not reported	Identified as predictor of poor QoL	Associated with multidomain QoL impairment
Speech / communication impairment	Communication impairment linked to poorer QoL	Communication difficulties linked to lower QoL	Communication deficit predicts lower QoL	Associated with poorer social wellbeing and access
Epilepsy	Variable impact	Reported; limited impact	Not an independent predictor	High prevalence; no independent association after adjustment
Socioeconomic factors	Socioeconomic factors associated with QoL	Lower SES linked to poorer QoL	Socioeconomic vulnerability affects access	Low income and education associated with poorer access and participation

Geographic access to care	Not reported	Not reported	Less emphasized	Rural residence and distance strongly affect access
School enrollment / attendance	Educational participation linked to QoL	School attendance linked to better QoL	School participation beneficial	strongly associated with better QoL

We hypothesize that limited decentralization of services and reduced availability of community-based rehabilitation amplify the consequences of disability in our setting. While several international studies emphasize predominantly clinical determinants of quality of life, our findings highlight the interaction between motor severity and environmental constraints, underscoring the importance of contextualizing CP-QOL outcomes within the health system and social environment in which children and families live (78,101).

By restricting our comparison to studies using the CP-QOL parent-proxy questionnaire, we ensured methodological consistency and strengthened interpretability. Across studies, similar patterns of relatively preserved Social wellbeing and acceptance and impaired Participation and physical health were observed, suggesting shared lived experiences across cultures (60,90,91). However, the markedly lower Access to services and Participation scores in our cohort clearly distinguish it from most regional and international studies. We attribute these differences primarily to socioeconomic vulnerability, rural residence, and centralized healthcare delivery rather than to intrinsic differences in disease severity alone.

X. Clinical and public health implications:

The results of this study have already influenced clinical practice at the CHU of Marrakech by increasing attention to pain assessment and non-motor impairments during follow-up visits. Clinically, our findings support the integration of systematic pain screening, early identification of feeding difficulties, and routine assessment of cognitive and communication impairments.

Strengthening multidisciplinary coordination is essential. Decentralization of rehabilitation services, caregiver education programs, and promotion of school inclusion could substantially

improve participation and family wellbeing. These interventions align with WHO recommendations for community-based rehabilitation and inclusive care for children with disabilities (102).

XI. Strengths and limitations of the study:

This study is strengthened by the use of a validated, cerebral palsy-specific quality-of-life instrument, allowing assessment of domains that are directly relevant to the lived experience of children with cerebral palsy. In addition, the study integrates a comprehensive set of clinical, functional, emotional-behavioral, and sociodemographic determinants, enabling a multidimensional interpretation of quality-of-life outcomes beyond motor impairment alone. The inclusion of a real-world, hospital-based population further enhances the clinical relevance of our findings, as it reflects the complexity and severity typically encountered in tertiary-care practice.

However, several limitations must be acknowledged. First, the cross-sectional design precludes causal inference and limits interpretation to associations observed at a single point in time. Second, the single-center nature of the study may restrict generalizability to other settings, particularly community-based or less severe populations. Third, the proportion of child self-reports was limited, largely due to the high prevalence of cognitive and communication impairments in our cohort, necessitating reliance on parent-proxy reporting for most analyses. In addition, cognitive status—particularly the presence of intellectual disability—was determined based on information available in medical records rather than standardized neuropsychological assessment, which may have resulted in misclassification or underestimation of cognitive impairment in some children.

Finally, although we used a validated Arabic version of the CP QOL-Child questionnaire, linguistic validation does not necessarily guarantee full sociocultural equivalence with the Moroccan context. Cultural perceptions of disability, family roles, pain expression, and social participation may influence parental responses and the interpretation of certain domains. This limitation should be considered when interpreting absolute quality-of-life scores, particularly in domains related to family health, emotional wellbeing, and access to services.

CONCLUSION

This study was undertaken with the primary objective of assessing the quality of life of children with cerebral palsy followed at the CHU of Marrakech using a validated, condition-specific instrument, and with secondary objectives aimed at identifying the main determinants of quality-of-life outcomes and comparing parent-proxy and child self-reported perceptions when feasible. Implicitly, we hypothesized that quality of life in this population would be globally altered and influenced not only by motor severity, but also by associated impairments and contextual factors.

Our findings clearly confirm this hypothesis. Quality of life in children with cerebral palsy was globally compromised, with marked heterogeneity across CP-QOL domains. While social wellbeing and acceptance and emotional wellbeing and self-esteem appeared relatively preserved, domains related to participation and physical health, access to services, pain and impact of disability, and family health were substantially impaired. This dissociation highlights that psychosocial adaptation may coexist with significant functional, symptomatic, and structural constraints, and underscores the importance of domain-specific interpretation rather than reliance on a single global score.

Beyond motor impairment, multiple non-motor determinants emerged as major contributors to reduced quality of life. Emotional and behavioral difficulties, pain burden, and sleep disturbances were strongly associated with poorer outcomes across several domains, confirming that cerebral palsy must be approached as a multisystem condition. Furthermore, sociodemographic and contextual factors—particularly rural residence, low socioeconomic status, limited school inclusion, and distance from specialized care—exerted a pronounced influence on access-related and participation-related domains. These findings demonstrate that quality of life in cerebral palsy reflects not only clinical severity, but also the organization and accessibility of healthcare and social support systems.

Comparison with international studies using the CP-QOL parent-proxy questionnaire revealed both shared patterns and striking disparities. While social acceptance scores were broadly comparable across contexts, participation and access to services were markedly lower in our cohort. We interpret these differences primarily as the result of contextual vulnerability and centralized healthcare delivery rather than intrinsic differences in disease characteristics alone. By providing data from a Moroccan tertiary-care setting, this study contributes original evidence from an

underrepresented context and highlights the necessity of contextualizing quality-of-life outcomes within local social and health-system realities.

Several limitations must be acknowledged. The cross-sectional design precludes causal inference, and the single-center nature of the study may limit generalizability. Reliance on parent-proxy reporting for most children, due to cognitive and communication limitations, may have influenced domain-specific scores. In addition, although a validated Arabic version of the CP-QOL was used, cultural perceptions of disability, family roles, and symptom expression in the Moroccan context may have shaped responses and should be considered when interpreting absolute scores.

Despite these limitations, this work demonstrates the value of integrating quality-of-life assessment into routine cerebral palsy care. It emphasizes that improving quality of life requires more than motor-focused interventions and calls for comprehensive, multidisciplinary approaches that address emotional wellbeing, pain and sleep management, family support, school inclusion, and equitable access to services. Ultimately, placing quality of life at the center of clinical and public health strategies offers a more meaningful framework for improving the lived experience of children with cerebral palsy and their families.

RECOMMENDATIONS

I. Clinical recommendations:

Based on our findings, clinical care for children with cerebral palsy should move beyond a predominantly motor-centered approach toward a structured, multidimensional model of follow-up.

First, systematic screening of non-motor impairments should be integrated into routine clinical care. Emotional and behavioral difficulties, pain, sleep disturbances, communication disorders, intellectual impairment, and swallowing disorders were among the strongest determinants of reduced quality of life in our cohort. We therefore recommend routine use of standardized screening tools—such as the SDQ for emotional and behavioral difficulties, structured pain assessment scales, and sleep screening instruments (e.g. BEARS)—at regular follow-up visits, rather than relying solely on spontaneous reporting.

Second, pain and sleep should be treated as core clinical targets, not secondary symptoms. Given their strong association with participation restriction, emotional wellbeing, and family burden, proactive pain assessment and individualized pain-management strategies should be systematically implemented. Similarly, identification and management of sleep problems should become part of standard care, with caregiver education and behavioral sleep interventions where appropriate.

Third, early and comprehensive management of associated impairments is essential. Intellectual disability, speech impairment, visual problems, and swallowing disorders were associated with markedly poorer quality of life across multiple domains. Early referral to speech and language therapy, feeding and swallowing assessment, and vision/hearing evaluation should therefore be prioritized, particularly in children with severe motor impairment.

Fourth, rehabilitation goals should be participation-oriented, not limited to impairment reduction. Given the profound impairment observed in Participation and physical health, rehabilitation programs should explicitly target functional autonomy, daily-life activities, and school participation. Goal-directed, task-specific rehabilitation aligned with the child's real-life environment is likely to have greater impact on quality of life than isolated therapeutic interventions.

Finally, family-centered care must be reinforced. The Family health domain was substantially affected and closely linked to clinical and contextual burden. Supporting caregivers through counseling, education adapted to low literacy levels, and psychosocial support is necessary to improve both child and family quality of life.

II. Health system and organizational recommendations:

Our results highlight that quality of life in children with cerebral palsy is strongly shaped by healthcare organization and social context. Clinical interventions alone are therefore insufficient without system-level adaptation.

First, decentralization of rehabilitation and follow-up services should be a priority. The extremely low Access to services scores observed in our cohort are likely driven by geographic distance, centralized care pathways, and socioeconomic vulnerability. Developing regional or community-based rehabilitation units, mobile follow-up teams, or structured referral networks could substantially reduce access barriers for families living far from tertiary centers.

Second, coordination between health, education, and social sectors must be strengthened. School enrollment emerged as one of the strongest protective factors for quality of life. Closer collaboration between healthcare providers, educational authorities, and social services is needed to promote school inclusion, adapt learning environments, and ensure continuity between rehabilitation goals and educational participation.

Third, care-pathway navigation support should be implemented for families. Low caregiver education and socioeconomic disadvantage were strongly associated with poorer access-related quality-of-life outcomes. Assigning care coordinators or social workers to guide families through appointments, rehabilitation services, and administrative processes could improve continuity of care and reduce family burden.

Fourth, multidisciplinary CP care should be formalized and standardized. Access to occupational therapy, assistive devices, orthopedic care, and complementary therapies was uneven in our cohort. Establishing clear, severity-adapted care pathways—particularly for children with GMFCS IV–V and multisystem involvement—would help ensure equitable access to comprehensive care.

III. Research recommendations:

This study also highlights several priorities for future research in cerebral palsy and quality of life.

First, longitudinal studies are needed to better understand how quality of life evolves over time and how clinical and psychosocial determinants interact dynamically. Cross-sectional designs, including ours, cannot establish causal pathways or temporal relationships between interventions and quality-of-life outcomes.

Second, greater integration of child self-report is essential, even in populations with communication or cognitive limitations. Future studies should explore adapted communication methods, alternative response formats, or assisted self-report approaches to better capture the child's perspective, particularly for psychosocial domains.

Third, context-specific validation of quality-of-life instruments should be strengthened. Although validated Arabic versions exist, linguistic validation does not guarantee full sociocultural equivalence. Further work is needed to assess cultural relevance, response interpretation, and measurement invariance of CP-QOL domains in Moroccan and other North African contexts.

Fourth, intervention studies should incorporate quality of life as a primary outcome, not merely a secondary endpoint. Evaluating how pain management, sleep interventions, school inclusion programs, and multidisciplinary rehabilitation affect quality of life would provide clinically actionable evidence.

Finally, future research should explicitly model interactions between clinical severity and environmental determinants, including socioeconomic status, geographic accessibility, and health-system organization. Understanding these interactions is crucial for designing equitable care models that improve quality of life beyond motor outcomes alone.

SUMMARIES

SUMMARY:

Introduction:

Cerebral palsy (CP) is the leading cause of physical disability in childhood and is frequently associated with cognitive, sensory, behavioral, and social impairments that substantially affect quality of life (QoL). Beyond motor impairment, QoL reflects the combined influence of functional limitations, associated impairments, symptom burden, and contextual factors. This study aimed to assess the quality of life of children with CP followed at the CHU of Marrakech and to identify the main determinants influencing QoL outcomes.

Methods:

A cross-sectional study was conducted among 104 children with CP aged 4–12 years followed at the CHU of Marrakech. Quality of life was assessed using the CP-QOL parent-proxy questionnaire for all participants, with the child self-report version completed by 10 children with sufficient communication and cognitive abilities. Emotional and behavioral difficulties were evaluated using the Strengths and Difficulties Questionnaire (SDQ). Sociodemographic, clinical, functional level (GMFCS), associated impairments, pain intensity, sleep problems, and therapeutic data were collected. Comparative and correlational analyses were performed across CP-QOL domains.

Results:

Quality of life was globally altered, with marked inter-domain variability. The highest scores were observed in social wellbeing and acceptance and Emotional wellbeing and self-esteem, whereas Participation and physical health and Access to services were the most impaired domains. Severe motor impairment (GMFCS IV–V) and quadriplegia were significantly associated with lower functional and participation-related scores. Intellectual disability and swallowing disorders negatively affected multiple QoL domains. Chronic pain (66.3%) and sleep problems (63.5%) were common and were significantly associated with poorer physical, emotional, and participation outcomes. Emotional and behavioral difficulties were frequent (60.6%) and represented one of the strongest non-motor determinants of QoL. Sociodemographic vulnerability was strongly associated with reduced Access to services and Family health.

Conclusion:

Quality of life in children with CP is determined by a complex interaction between motor severity, comorbidities, symptom burden, psychosocial difficulties, and contextual factors. These findings support a multidimensional, family-centered approach to CP management.

RÉSUMÉ :

L'introduction :

La paralysie cérébrale (PC) est la principale cause de handicap physique chez l'enfant et est fréquemment associée à des troubles cognitifs, sensoriels, comportementaux et sociaux qui altèrent de manière significative la qualité de vie (QdV). Au-delà de lasévérité motrice, la qualité de vie reflète l'impact combiné des limitations fonctionnelles, des atteintes associées, de la charge symptomatique et des facteurs contextuels. Cette étude avait pour objectif d'évaluer la qualité de vie des enfants atteints de paralysie cérébrale suivis au CHU de Marrakech et d'identifier les principaux déterminants influençant les résultats de qualité de vie.

Méthodes :

Une étude transversale a été menée auprès de 104 enfants atteints de paralysie cérébrale, âgés de 4 à 12 ans, suivis au CHU de Marrakech. La qualité de vie a été évaluée à l'aide du questionnaire CP-QOL version parent-proxy pour l'ensemble des participants, et la version auto-évaluée par l'enfant a été complétée par 10 enfants disposant de capacités cognitives et communicationnelles suffisantes. Les difficultés émotionnelles et comportementales ont été évaluées à l'aide du Strengths and Difficulties Questionnaire (SDQ). Les données sociodémographiques, cliniques, fonctionnelles (GMFCS), les atteintes associées, l'intensité de la douleur, les troubles du sommeil et les données thérapeutiques ont été recueillies. Des analyses comparatives et corrélationnelles ont été réalisées pour explorer les déterminants de la qualité de vie à travers les différents domaines du CP-QOL.

Résultats :

La qualité de vie était globalement altérée, avec une variabilité inter-domaines marquée. Les scores les plus élevés ont été observés dans les domaines Bien-être social et acceptation et Bien-être émotionnel et estime de soi, tandis que les domaines Participation et santé physique et Accès aux services étaient les plus altérés. La sévérité motrice (GMFCS IV-V) et la tétraplégie étaient significativement associées à des scores plus faibles dans les domaines fonctionnels et de

participation. La déficience intellectuelle et les troubles de la déglutition affectaient négativement plusieurs domaines de la qualité de vie. La douleur chronique (66,3 %) et les troubles du sommeil (63,5 %) étaient fréquents et associés à une altération des dimensions physiques, émotionnelles et de participation. Les difficultés émotionnelles et comportementales étaient fréquentes (60,6 %) et constituaient l'un des déterminants non moteurs les plus importants de la qualité de vie. La vulnérabilité sociodémographique était fortement associée à une diminution des scores des domaines Accès aux services et Santé familiale.

Conclusion :

La qualité de vie des enfants atteints de paralysie cérébrale résulte d'une interaction complexe entre la sévérité motrice, les comorbidités, la charge symptomatique, les difficultés psychosociales et les facteurs contextuels. Ces résultats soutiennent la nécessité d'une prise en charge multidimensionnelle et centrée sur la famille.

الملخص:

:المقدمة

كبير بشكل تؤثر واجتماعية وسلوكية وحسية معرفية باضطرابات يرتبط ما وغالبًا ،الأطفال لدى الجسدية للإعاقة الرئيسي السبب الدماغي الشلل يُعدّ ،الأعراض وعبء ،المصاحبة والاضطرابات ،الوظيفية للقيود المشترك التأثير الحياة جودة تعكس ،الحركية الإعاقة شدة عن وبعيدًا .الحياة جودة على ،بمراكش الجامعي الاستشفائي بالمركز والمتابعين الدماغي بالشلل المصابين الأطفال لدى الحياة جودة تقييم إلى الدراسة هذه هدفت .السياقية والعوامل .الحياة جودة نتائج في المؤثرة والاجتماعية والنفسية والوظيفية السريرية العوامل وتحديد

:المنهجية

الجامعي الاستشفائي بالمركز ويتابعون ،سنة 12و 4 بين أعمارهم تتراوح ،الدماغي بالشلل مصابين أطفال 104 شملت مقطعية دراسة أُجريت ممن أطفال 10 لدى التقييم ذاتية النسخة استُخدمت كما ،المشاركين لجميع للرعاية المُقدِّم/الوالد بنسخة استبيان باستخدام الحياة جودة تقييم تم .بمراكش البيانات جُمعت كما . والصعوبات القوة نقاط استبيان باستخدام والسلوكية الانفعالية الاضطرابات تقييم تم .كافية وتواصلية معرفية قدرات لديهم تتوفر تحليلات وأُجريت .العلاجية والمعطيات ،النوم واضطرابات ،الألم وشدة ،المصاحبة والاضطرابات ، والوظيفية ،والسريرية ،والاجتماعية الديموغرافية .مجالات مختلف عبر الحياة جودة محددات لدراسة وارتباطية مقارنة

:النتائج

وتقدير العاطفي والرفاه والقبول الاجتماعي الرفاه مجالي في الدرجات أعلى سُجلت .المجالات بين واضح تباين مع عامًا تدهورًا الحياة جودة أظهرت الرباعي والشلل الحركية الإعاقة شدة ارتبطت .تضررًا الأكثر هي الخدمات إلى والوصول البدنية والصحة المشاركة مجالات كانت حين في ،الذات جودة من مجالات عدة على سلبي تأثير البلع واضطرابات الذهنية للإعاقة كان كما .المشاركة ومجالات الوظيفية المجالات درجات في ملحوظ بانخفاض .المشاركة ومستوى والعاطفية الجسدية الحياة جودة بانخفاض مرتبطة وكانت ،63.5% النوم واضطرابات ،66.3% المزمن الألم نسبة وبلغت .الحياة الاجتماعية الهشاشة وارتبطت .الحياة لجودة الحركية غير المحددات أهم أحد وشكّلت (60.6%) شائعة والسلوكية الانفعالية الاضطرابات كانت كما .الأسرة وصحة الخدمات إلى الوصول مجالي في ملحوظ بانخفاض والاقتصادية

:الخلاصة

،الأعراض وعبء ،المصاحبة والاضطرابات ،الحركية الإعاقة شدة بين معقّد تفاعل خلال من الدماغي بالشلل المصابين الأطفال لدى الحياة جودة تتحدد الشلل تدبير في الأسرة حول ومتمحورة الأبعاد متعددة مقاربة تبنّي أهمية النتائج هذه وتؤكد .السياقية والعوامل ،والاجتماعية النفسية والصعوبات .الدماغي

ANNEXES

OPERATION SHEET:

Section A: Child Information.

Variable	Response Options
Gender	1. ☐ Male 2. ☐ Female
Age	☐ 4 years ☐ 5 years ☐ 6 years ☐ 7 years ☐ 8 years ☐ 9 years ☐ 10 years ☐ 11 years ☐ 12 years
Place of Residence	1. ☐ Urban 2. ☐ Rural
Currently Enrolled in School	☐ Yes ☐ No
School Level	1. ☐ Preschool 2. ☐ Primary School 3. ☐ Middle School
School Attendance	1. ☐ 1 or more absences per year 2. ☐ 1 or more absences per month 3. ☐ 1 or more absences per week
School Grades	1. ☐ low (0-5/10) 2. ☐ average (5-6/10) 3. ☐ Good (6-8/10) 4. ☐ High (8-10/10)

Section B: Family and Socioeconomic Information.

Variable	Response Options
Parents' Marital Status	1. ☐ Married 2. ☐ Divorced 3. ☐ Single parent 4. ☐ Widowed
Consanguinity Between Parents	☐ Yes ☐ No
Monthly Parental Income Level	1. ☐ low (<2800 MAD) 2. ☐ Moderate (2800 MAD - 6700 MAD 3. ☐ Good (>6700 MAD)
Siblings	☐ Yes ☐ No

If yes, any siblings with chronic diseases?	☐ Yes ☐ No
Health insurance	☐ Yes ☐ No
Caregiver relationship to the child	☐Father ☐Mother ☐Grandparent ☐Other
Primary caregiver' s education level	☐ Illiterate ☐ Primary/Middle School ☐ High School ☐ University
Distance to hospital	☐ <5km 5-15km ☐16-30km ☐>30km

Section C: Medical and Clinical Information.

Variable	Response Options
Age at Diagnosis of Cerebral Palsy	1. ☐ <1 year 2. ☐ 1-2 years 3. ☐ >2 years
Type of Cerebral Palsy	1. ☐ Spastic 2. ☐ Dyskinetic 3. ☐ Ataxic 4. ☐ Mixed
Severity (GMFCS Level)	1. ☐ I 2. ☐ II 3. ☐ III 4. ☐ IV 5. ☐ V
Epilepsy	☐ Yes ☐ No
If yes	☐Controlled (no seizures in the past 12 months) ☐Uncontrolled (>= 1 seizure in the past month)
Cognitive status	☐ Intellectual disability (ID) reported ☐ ID not reported
Other Associated Conditions	☐ Speech impairment ☐ Visual problems ☐ Hearing problems ☐ Swallowing disorders

	☐ None
Body Parts involved in CP/ Topography	1. ☐ Hemiplegia 2. ☐ Diplegia 3. ☐ Quadriplegia 4. ☐ Monoplegia 5. ☐ Triplegia 6. ☐ Other
Current Therapies	☐ Physical therapy ☐ Occupational therapy ☐ Speech therapy ☐ Pharmacological treatment ☐ Botulinum toxin injections ☐ Assistive Devices ☐ Aquatic Therapy ☐ Orthopedic aids ☐ None

Section D: mental health/behavioral difficulties screening:

The Strengths and Difficulties Questionnaire (SDQ):

- SDQ subscales (scores) :

- Emotional symptoms: _____
- Conduct problems: _____
- Hyperactivity/inattention : _____
- Peer relationship problems: _____
- Prosocial behavior: _____

- Total Difficulties Score : _____

SDQ classification :

☐ Normal ☐ Borderline ☐ Abnormal

أستبيان مواطن القوة والصعوبة SDQ (4-17سنة)
للوالدين

يرجى الاجابة على كل بند ب : غير صحيح, صحيح نوعا ما , او صحيح بالتأكيد بوضع علامه ☑
تحت الأجابة المناسبة . حاول ان تكون دقيقا فى إجاباتك. سوف يساعدنا كثيرا اذا اجبت على كل بند حتى وان
كنت غير متأكد او ترى انه غير مناسب. يرجى ان تكون اجابتك حول سلوك الطفل خلال الستة الأشهر الأخيرة او هذه السنة الدراسية .

اسم الطفل: ..... ☐ ولد ☐ بنت

تاريخ الميلاد : .....

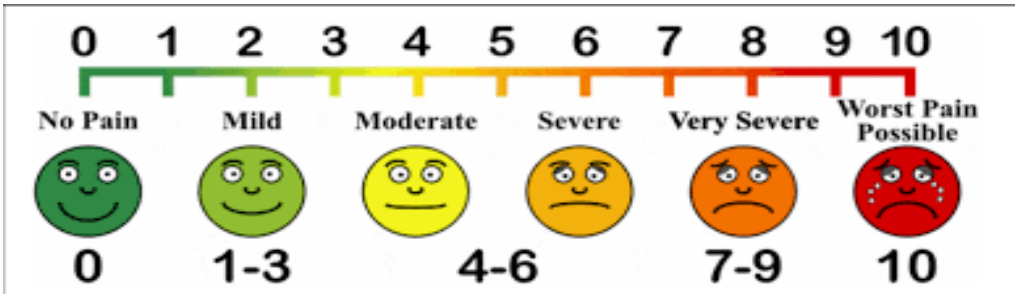
	غير صحيح	صحيح نوعا ما	صحيح بالتأكيد
يهتم بمشاعر الاخرين	☐	☐	☐
لا يستطيع البقاء او الاستقرار فى مكان واحد , كثير الحركة	☐	☐	☐
كثيرا ما يشكو من صداع او آلام فى البطن او الشعور بالغثيان	☐	☐	☐
يشرك الاخرين بسهولة فيما يخصه{ لعب, أقلام, ألعاب, حلويات .....الخ}	☐	☐	☐
كثيرا ما تنتابة نوبات من الغضب الشديد أ و سريع الغضب	☐	☐	☐
يحب العزلة, يميل الى اللعب لوحدة	☐	☐	☐
مطيع على وجه العموم, عادة يفعل ما يطلبه منه الكبار	☐	☐	☐
يقلق من اشياء كثيرة, كثيرا ما يبدو عليه القلق	☐	☐	☐
يساعد الاخرين اذا ما حدث لأحدهم مكروه	☐	☐	☐
يتململ او يتلوى باستمرار{جسمه فى حركه مستمره اثناء جلوسه}	☐	☐	☐
لديه على الاقل صديق واحد جيد	☐	☐	☐
كثيرا ما يتعارك مع الاخرين من نفس سنه او يستأسد عليهم	☐	☐	☐
كثيرا ما يكون غير سعيد, حزين او يبكى بسهوله	☐	☐	☐
فى الغالب محبوب ممن هم فى سنه	☐	☐	☐
يتشتت انتباهه بسرعه وقليل التركيز	☐	☐	☐
عصبى او متشبث{متعلق} بالاخرين فى المواقف الجديدة, من السهل ان يفقد ثقته بنفسه	☐	☐	☐
لطيف مع من هم أصغر منه	☐	☐	☐
كثيرا ما يكذب , يخدع او يغش	☐	☐	☐
يستهزأ منه او يستأسد عليه من هم فى سنه	☐	☐	☐
كثيرا ما يتطوع لمساعدة الاخرين{الوالدين, المدرسين, الاطفال الاخرين}	☐	☐	☐
يفكر قبل ان يتصرف	☐	☐	☐
يسرق من البيت او المدرسة او من أماكن اخرى	☐	☐	☐
ينسجم بشكل أفضل مع الكبار عنه مع الاطفال فى نفس سنه	☐	☐	☐
يخاف من اشياء كثيره , من السهل تخويفه	☐	☐	☐
يتابع اداء الواجبات حتى النهايه , لديه انتباه جيد	☐	☐	☐

Section E: Pain and sleep.

- Pain:

- Does your child have pain that occurs at least once a week?" ☐Yes ☐No

- "If yes: On most days with pain, how strong is the pain on a scale from 0 to 10? (0 = no pain, 10 = worst pain)." (parent circles one number) (VAS scale)



0. ☐ No pain
1. ☐ Mild
2. ☐ Moderate
3. ☐ severe
4. ☐ very severe
5. ☐ Unbearable

Sleep (BEARS sleep screening tool)

☐ Bedtime problems

☐ Excessive daytime sleepiness

☐ Awakenings during the night

☐ Regularity/duration problems

☐ Snoring

☐ No sleep problems reported

CP QOL QUESTIONNAIRE:

The validated Arabic version of the Cerebral Palsy Quality of Life Questionnaire (CP-QOL) was used to assess quality of life in children with cerebral palsy. Both the parent-proxy and child self-report versions were used when appropriate. The questionnaire assesses multiple domains including social well-being and acceptance, participation and physical health, emotional well-being, pain and impact of disability, and access to services.

The CP-QOL is a copyrighted instrument. In accordance with ethical and publication standards, it was used with authorization but not reproduced in full.

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أقْسِم بِالله العَظِيم

أن أراقبَ الله في مِهْنَتِي.

وأن أصُونَ حياة الإنسان في كآفّة أطوَارهَا في كل الظروف

والأحَوال باذلة وسْعِي في إنقاذها مِن الهَلاك ِوالمرَضِ

والألَم والقَلَق.

وأن أحفَظَ لِلنَاسِ كرَامَتهُم، وأسْتر عَوْرَتهُم، وأكتمَ

سِرَّهُمْ.

وأن أكونَ عَلى الدوَام من وسائِل رحمة الله، باذلة رعايتي الطبية للقريب والبعيد، للصالح والطالح، والصديق والعدو.

وأن أثابر على طلب العلم، وأسَخِّرَه لِنَفْعِ الإنْسَان لا لأذَاه.

وأن أُوَقّر َمَن عَلَّمَني، وأُعَلّمَ مَن يصغرني، وأكون أختا لِكُلّ زَميلٍ في المِهنَةِ الطِّبِيَة مُتعَاونِينَ عَلى البرّ والتقوى.

وأن تكون حياتي مِصْدَاق إيماني في سِرّي وَعَلانيَتي، نَقِيَّة مِمّا يشينها تجَاهَ

الله وَرَسُولِهِ وَالمؤمِنين.

والله على ما أقول شهيد

كليـــــــة الـطب
والصيدلة - مراكش
FACULTÉ DE MÉDECINE
ET DE PHARMACIE - MARRAKECH

MARRAKECH
جامعة القاضي عياض
UNIVERSITÉ CADI AYYAD

سنة 2026 الأطروحة رقم

70

يغامدلا للشلاب نيباصملا لافطلأا ىدل ةايحلا ةدوج

الأطروحة

قدمت ونوقشت علانية يوم2026/02/17

من طرف

الآنسة شاورق مير

المزدادة في22 رياير 2000 بمراكش

لنيل شهادة الدكتوراه في الطب

الكلمات الأساسية:

ةايحلا ةدوج– تلاالجملا– يغامدلا للشلا–داعبلأا ددعتم مييقت –لفطلا

اللجنة

السيد	يلع نب تيأ .س غامدلاو باصعلأا ةحارج يف ذاتسأ	الرئيس
السيد	سوروب.م لافطلأا بط يف ذاتسأ	المشرف
السيد	ىضار .ن لافطلأا بط يف ذاتسأ	الحكام
السيد	حاتفلا دبع .ي لهيأتلا ةداعإ و يئايزيفلا بط يف ذاتسأ	
السيدة	ينيمحل .و لافطلأا بط يف ةذاتسأ	