Original Article

Nutritional status as predictors for quality of life among caregivers of children with severe cerebral palsy

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Background: Individuals with severe cerebral palsy (CP) often experience various health issues, including feeding difficulties, which can adversely affect their nutritional status and caregivers' quality of life, e.g., more time spent for feeding rather than own selfcare. This study aimed to determine the prevalence of poor nutritional status among individuals with severe CP and explore its role as predictors for caregivers' quality of life.

Methods: This cross-sectional study was conducted in a government hospital (Cheras Rehabilitation Hospital), Community-Based Rehabilitation (CBR) Program, and Spastic Centre [non-profit organization (NGO)] in Klang Valley, Malaysia. Seventy-one participants with Gross Motor Function Classification System (GMFCS) level IV and V were recruited. Sociodemographic data, health-associated data, and anthropometric data were collected. Caregivers' quality of life was assessed using the Pediatric Quality of Life Inventory (PedsQL) CP module version 3.0 which included domains such as Movement and Balance, Eating Activities, and School Activities.

Results: Most participants were males (60.6%), with 61 classified as level IV in the GMFCS classification. According to the Eating and Drinking Ability Classification System (EDACS), 59 children were at level IV. In total, 40.8% were underweight according to CP growth chart and 49.3% had mid-upper arm circumference (MUAC) readings below the 5th percentile. The lowest scores in the PedsQL CP module version 3.0 were observed in the Daily Activities (5.34±10.87), and School Activities domains (8.15±18.65). Sociodemographic and anthropometric data, including body mass index (BMI)-for-age, MUAC, body fat, triceps, and subscapular skinfold measurement, were predictors for the School Activities domain [$F(11, 44)=3.981$, $P<0.005$, $R^2=0.499$].

Conclusions: Poor nutritional status in individuals with severe CP has been shown to negatively impact

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caregivers' quality of life. Therefore, a multidisciplinary approach involving nutritional intervention is essential to improve dietary provision and the nutritional status of children with CP.

Keywords: Neurological disorder; poor nutritional status; quality of life; feeding difficulties; nutritional intervention

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Introduction

Background

Cerebral palsy (CP) is a term that refers to a physical disability characterized by a non-progressive brain injury. The prevalence worldwide was 17 million, which accounts for about 1 in 500 neonates. At this time, CP cannot be cured, and treatment focuses on rehabilitation to help address issues with physical limitations and other clinical issues such as epilepsy and feeding difficulties (1). A study by Abd Elmagid and Magdy pointed out several risk factors contributing to CP occurrence. Findings indicated that 30.7% of cases occurred during the natal period, 30.5% during postnatal periods, 21% during the antenatal period, and 17.1% during the post-neonatal period (2). In a study conducted in Moldova, a low-income country, among 351 individuals with CP, several significant risk factors were identified. These included maternal alcohol consumption during pregnancy [odds ratio (OR) 1.7, P=0.002], maternal hypertension (OR 2.0, P<0.001), living in rural areas (OR 1.6, P<0.001), maternal age of more than 35 years old (OR 0.6, P=0.001), maternal epilepsy (OR 4.3, P<0.001), breech delivery (OR 3.1, P=0.001), home births (OR 6.3, P=0.001), umbilical cord around neck (OR 2.2, P<0.001), assisted vaginal delivery (OR 3.1, P<0.001), male gender (OR 1.3, P<0.001), small gestational age (SGA) (OR 1.3, P=0.027), multiple gestations (OR 1.7, P<0.001) and hyperbilirubinemia (OR 4.5, P<0.001) (3). CP classification, proposed by Ingram and Hagberg, encompasses types of neurological syndromes, affected sites, and severity of symptoms. The classifications include Diplegia, Hemiplegia, Tetraplegia, Spastic, Ataxia, Dyskinesia and Mixed types (4). In 1997, Palisano introduced Gross Motor Function Classification System (GMFCS) as a way of communication between health professionals' regarding the physical ability of individuals with CP. The classification consist of level I–V, with higher levels, indicating greater physical disability and dependance on others (5).

Children with CP has often been associated with nutrition problems resulting in malnutrition and being underweight. A study by Melunovic *et al.* conducted in Bosnia and Herzegovina among 80 patients with CP aged between 2 to 18 years old revealed that 38 of them were underweight, 26.5% had a minor motor impairment, and 63.0% from severe motor impairment (6). This findings aligns with Caramico-Favero *et al.* which showed that those with CP and feeding problems had a low average daily intake leading to underweight conditions (n=33, 82.5%) (7). In Saudi Arabia, 119 subjects with CP who had a problem with delayed growth and feeding problems indicated that 84.9% were underweight (8). Another study conducted in Malaysia found that more than half of the subjects (60.8%)

Highlight box

Key findings
- 40.8% of the individuals with severe cerebral palsy (CP) were underweight.
- 49.3% had below 5th percentile of Mid-upper arm circumference (MUAC) reading.
- The lowest score of caregivers' quality of life was the Daily Activities domain, the School Activities domain and the Eating Activities domain.
- Sociodemographic and anthropometric data predicted the total score of School Activities domain.

What is known and what is new?
- Our findings correspond to the prevalence of poor nutritional status, which is predominantly observed among children with severe CP.
- This study further identified that among the severe category, poor nutritional status is also a predictor of the quality of life of the caregivers.

What is the implication, and what should change now?
- Individuals with severe CP rely on caregivers. A multidisciplinary nutritional intervention is crucial to improve caregivers' quality of life by addressing their child's nutritional status.

were underweight in a more severe GMFCS classification category (n=153) (9).

Individuals with CP may take their nutrition orally, via tube, or through mixed feeding. Maggioni and Araújo, in their finding, presented that the type of feeding practice that were taken by the subject was 10.2% with mixed feeding (oral and tube feeding) and 89.8% taken food orally among level IV and V of GMFCS classification, and most food modification reported taken were liquid (84.7%) (10). In a study conducted by Mahmoud *et al.*, a positive correlation (P<0.05) was found between the complexity of GMFCS classification and different types of food texture among individuals with CP (11). This finding was supported by a study by Weir *et al.*, which included 170 individuals with CP in Australia. The study reported that individuals at GMFCS level I could consume "all textures" compared to those GMFCS level II to IV who experienced a decrease in their ability to handle rough food textures (12). The texture of the food reduces in consistency and size as the severity of GMFCS classification is higher. Benfer *et al.* stated that severe GMFCS classification took puree and liquid texture types among 99 children with CP in community and tertiary care centers in Australia (39%) (13).

A study conducted by Bhanuprakash and Reddy in India, involving 100 children with CP, revealed a direct correlation between the severity of CP and the level of parental stress related to nutritional problems (14). This research also carried out by Polack *et al.* among 76 caregivers in Ghana, showed that feeding problems were closely related to the quality-of-life scores of caregivers (15). Among the main factors causing higher stress levels were emotional disturbances during the eating process when children faced the problem of physical limitations, uncontrollable drooling, and choking problems when eating (16). In addition, the process of eating becomes longer due to increased food preparation requirements, resulting in a lack of time for caregivers to generate additional income and improve their socioeconomic status. This study shows that parents were more concerned with emotions experienced during the feeding process rather than focusing on lack of nutrition and child weight. Yousafzai *et al.* suggested a deeper study through qualitative methods to understand the issue of nutritional problems with the quality of life of caregivers (17).

Rationale and knowledge gap

To our knowledge, there are a few studies exploring the association of nutritional status among individuals with severe CP with caregivers' quality of life. Other studies focused on these two parameters separately. A study by Polack *et al.* discussed the relationship between feeding problem and nutritional status with quality of life of the caregivers which showed higher feeding problem associated with lower quality of life. The highest feeding problems score was associated with being underweight [OR 10.7, 95% confidence interval (CI), 2.3–49.6, P=0.002] and was higher among the severe category of CP (71%) compared to mild (43%) CP (15). Our study was conducted to determine any association between nutritional status of individuals with severe CP with caregivers' quality of life.

Objective

The objectives of the current study were to see the prevalence of nutritional status of individuals with severe CP and to determine any predictor factors affecting the quality of life among their caregivers. We present this article in accordance with the STROBE reporting checklist (available at https://tp.amegroups.com/article/view/10.21037/tp-23-195/rc).

Methods

This is a cross-sectional study design with convenience sampling techniques. The study was conducted between August to September 2022. The study population was selected from the Klang Valley, which includes a government hospital [Cheras Rehabilitation Hospital (HRC)], Community-Based Rehabilitation (CBR) Program, and Spastic Centre [non-profit organization (NGO)], in Selangor and Kuala Lumpur, Malaysia. There are 60 CBRs in Selangor and 10 CBRs in the Federal Territory of Kuala Lumpur that are registered under the Disabled Development Department (JPPWD), Department of Social Welfare (JKM), Malaysia. A total of 17 CBRs have been selected randomly and proportionally, which were 15 CBRs in Selangor and 2 CBRs in the Federal Territory of Kuala Lumpur.

For data collection in HRC, subjects were recruited from pediatric outpatients' clinics, approached, and identified before, during or after patient waiting time seeking consultation from medical officers. Medical information obtained from medical records, anthropometric measurements and completion of the questionnaires were in the empty treatment room after permission was obtained. For inpatients in the pediatric ward, the researcher contacted the head nurse of the pediatric ward for subject identification. For data collection at CBRs and Spastic Centre, a letter of authorization was obtained from the JKM before data collection started. The researcher contacted the CBRs manager, who has been listed to explain the study procedure, and an appointment was set with the caregiver. For caregivers who are unable to attend CBR due to time constraints and some other reasons, anthropometric measurements were done by the researcher at CBR with the help of the teachers, provided consent obtained prior to the measurements.

In Malaysia, so far there is no specific data for the number of individuals with CP. But in 2019, a total of 548,195 people with disabilities (OKU) registered with the JKM. A total of 197,414 people was under the category of physically disabled, and CP is under this category (18). Therefore, the sample size is calculated using the single proportion formula by Cochran, which yielded required sample size of 72 subjects. Considering 10% of the dropout rate, a total of 79 subjects were required for this study (19,20).

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study obtained ethical approval from UKM Research Ethics Committee, with reference number UKM PPI/111/8/JEP-2022-387. Permission to conduct data collection in a government hospital obtained from the Medical Research and Ethics Committee Malaysia (MREC) with reference number 22-01018-IN3(2) and approval granted by the JKM for research conducted in a CBRs with a reference number of JKMM 100/12/5/2: 2022/569. Informed consent was obtained from all participants and their parents/family members.

Study participants

Participants were from 2 to 20 years old individuals with severe CP (GMFCS Level IV and V) classification, experienced feeding difficulties, however still consume food orally. Individuals with severe CP were chosen between 2 to 20 years old as the data of anthropometric measurement are plotted to the specific growth chart for CP (2 to 20 years old).

Sociodemographic data

Caregivers were asked to fill in sociodemographic data such as the birth date and age of their child, child's gender, race, household income, email address, contact number and type of education received by their children.

Health information

For this section, information on the clinical diagnosis of their child, CP classification based on the site of the body affected (topography) and GMFCS classification was needed. Besides that, any past medical history, medication, and other health issues also need to be filled.

Anthropometric data

Body weight was obtained using a calibrated digital scale, Seca 674, EMR-ready electronic platform base, with an accuracy of 0.05 kg. For subjects who did not use wheelchairs, weight was obtained by subtracting the weight of the caregiver when they were together. For wheelchair-bound subjects, the weight of the subject together with wheelchair was measured and then the weight of the wheelchair was deducted to obtain actual weight. Body weight measurement was taken to the nearest 0.1 kg, and this process was repeated three times to find the average. Subjects were encouraged to wear thin clothing and if they used a support device such as an orthosis, subjects were asked to remove them prior to measurement to ensure accurate weight recording.

For height measurements, knee height measurement was used to estimate height using a measuring tape. Knee height refers to the distance from the heel to the upper surface of the knee femoral condyle. The subject needs to sit and bend their legs up to 90 degrees. The reading is taken on the less affected part of the leg. Readings were taken three times, with the closest reading to 0.1 cm and put into the formula. The Stevenson formula was used for subjects aged 2–12 years old and Gauld *et al.* formula was used for subjects aged 7 years and older (21,22).

Stevenson equation:

$$\text{Height}(\text{cm}) = 2.68\ \text{KH} + 24.2 \quad [1]$$

Gauld *et al.* equation:

$$\begin{aligned}&\text{Males: Height}(\text{cm}) = 2.423\ \text{KH} + 1.327\ \text{A} + 21.818\\&\text{Females: Height}(\text{cm}) = 2.473\ \text{KH} + 1.187\ \text{A} + 21.151\end{aligned} \quad [2]$$

where $\text{KH} = \text{knee height}(\text{cm})$, $\text{A} = \text{age}$.

Body mass index (BMI) was calculated using the formula

Table 1 Original Slaughter equations

Sum (TST, SST)	Gender	Tanner stage	Equation
35 mm and below	Male	Stage 1 & 2	1.21 (TST + SST) – 0.008 (TST + SST)^2 – 1.7
		Stage 3	1.21 (TST + SST) – 0.008 (TST + SST)^2 – 3.4
		Stage 4 & 5	1.21 (TST + SST) – 0.008 (TST + SST)^2 – 5.5
	Female	Stage 1–5	1.33 (TST + SST) – 0.013 (TST + SST)^2 – 2.5
More than 35 mm	Male	Stage 1–5	0.783 (TST + SST) + 1.6
	Female	Stage 1–5	0.546 (TST + SST) + 9.7

Tanner stage 1 or 2 = prepubescent; Tanner stage 3 = pubescent; Tanner stage 4 or 5 = post-pubescent. TST, triceps skinfold thickness; SST, subscapular skinfold thickness.

Table 2 Original Slaughter equation with modification of Gurka equation (for children with cerebral palsy)

Correction factors	Value
Overall correction	+12.2
Males	−5.0
More severe GMFCS	+5.1
Pubescent	+2.0
Postpubescent	−4.6
Sum (TST, SST) >35 mm	−3.2

GMFCS, Gross Motor Function Classification System; TST, triceps skinfold thickness; SST, subscapular skinfold thickness.

weight (kg)/[height (m) × height (m)]. Measurements of weight, height, and BMI were plotted on a specific graph for CP children according to GMFCS classification and gender. This graph consisted of five classifications based on the GMFCS, which reflects the individuals' physical ability. The subjects were categorized as underweight, normal weight, and overweight according to their plotted body weight on the graph. Individuals with CP had different physical abilities compared to typical individuals. Thus, it is necessary to refer to the growth chart specifically for this group. Brook *et al.* aimed to create a growth chart that can represent the Centers for Disease Control and Prevention (CDC) growth chart (used in typical children) for the CP group (23). The growth chart was validated with a sample of 25,545 participants with CP, aged 2–20 years from California and 56% were males. The growth chart was differentiated based on GMFCS classification, gender and for level V GMFCS, further divided based on oral or tube feed as a feeding method. The interested reader can find growth chart individuals with CP in website: https://cdn.amegroups.cn/static/public/tp-23-195-1.pdf (23).

Mid-upper arm circumference (MUAC) was taken close to 0.1 cm using measuring tape. Skinfold thickness on two parts of the body i.e., triceps (back of arm) and subscapular (back of the body) with measurements taken three times close to 0.1 millimeter (mm) using Harpenden Skinfold Caliper to determine the nutritional status of the subject by pulling a skin and fat on the part desired using calipers. The measurement was transformed to the body fat percentages using an equation from Slaughter (*Table 1*) with modification of Gurka equation (*Table 2*) (24,25). The body fat percentages were labeled as very low, low, optimal, moderately high, high, and very high according to the range and based on gender (26). All measurements were performed by the researcher experienced in taking anthropometric measurements.

EDACS classification

The subject's eating and drinking ability classification was classified according to the Eating and Drinking Ability Classification System (EDACS) which assesses safety and efficiency rate. There are five classifications for safety, labeled as level I to V. A higher level indicates the need for greater attention to food texture modification, and some children may need tube feeding. Level I individuals can eat a variety of textures of appropriate for their age, eat at a similar pace to peers, and may have gag reflex for higher level food texture, Level II individuals can eat a wide range of food textures but may face challenges with new textures or when fatigued, Level III individuals eat softer textures like puree and mashed foods and may depend on caregivers' assistance, positioning, or specialized utensils. Level IV individuals eat well-mashed food or smooth purees, have difficulty to differentiating between fluids and foods, take longer time to finish food. Level V individuals are at risk of aspiration, may tolerate very small of food but require proper positioning to avoid choking and may use tube feeding as an alternative feeding (27).

For the efficiency rate, there are three categories, whether children can eat by themselves, eat with assistance and are totally dependent on the caregivers. The EDACS was developed through several processes including literature searched, clinical experience, nominal group process and an online Delphi survey to gather expert knowledge and thoughts before proceeding to the reliability testing (27).

Pediatric Quality of Life Inventory (PedsQL) for CP

For the questionnaire regarding the quality of life, the questionnaire used the PedsQL CP Module version 3.0 questionnaire. There are two types of questionnaires, which are either completed by the caregivers or by the individual with CP themself. For this study, the questionnaire for the caregiver's category was used and filled based on the child's behavior for a period of the past month. The questionnaire had undergone reliability and validity testing compared with the healthy group quality of life questionnaire. The internal consistency reliability of more than alpha coefficient standard (>0.70) was detected and it was assessed among caregivers with 2 to 20 years old of children with CP (28). This questionnaire is divided according to the age category of individuals with CP i.e., age categories 2–4, 5–7, 8–12, and 13–18 years. The questionnaire contains 35 items with 7 domains related to (I) Daily Activities, (II) School Activities, (III) Movement and Balance, (IV) Pain and Hurt, (V) Fatigue, (VI) Eating Activities, and (VII) Speech and Communication. Each item has a 5 Likert scale consisting of (0= never a problem; 1= almost never a problem; 2= sometimes a problem; 3= often a problem; 4= almost always a problem). Total marks were calculated in reverse and changed linearly on a scale of 0–100 (0=100, 1=75, 2=50, 3=25, 4=0) and divided by the number of questions answered. A high total score indicates a better quality of life. PedsQL CP was developed through joint research and clinical experience of individual with CP through focus groups, cognitive interviews, pretest, and field test protocol (29,30). The original questionnaire used the medium of English. This form went through the process of translation two times from English to Malay language and from Malay to English language again (back-to-back translation) by two groups that vary according to expertise to see the difference with the original questions (31).

Statistical analysis

Statistical analyses were performed using SPSS version 20.0 (IBM, Armonk, NY, USA). Sociodemographic data such as gender, age range, ethnicity, household income and education level were analyzed descriptively. Health-related information, anthropometric data, GMFCS and EDACS classification were also analyzed descriptively to find the prevalence with percentage. An independent t test was performed to see any significant difference between dependent and independent variables among genders. Normality was checked by using the Shapiro-Wilk test and skewness. A value of the Shapiro-Wilk test more than 0.05 and skewness lies outside between the z value of −3.29 and +3.29 will proceed with a non-parametric test. P value less than 0.05 was significant with 95% confidence interval. Pearson correlation test was used to see the correlation of anthropometric data with the domain of PedsQL CP. Multiple linear regressions were performed to determine predictor factors affecting each domain of PedsQL CP questionnaire.

Results

A total of 71 subjects were recruited, most of them were male with n=43 (60.6%). The mean age of the subject was 9.00 with standard deviation of 5.02. Most of them were from the 5 to 7 years age category (n=27). The highest ethnicity that participated in this study was Malay (78.9%) followed by Chinese (12.7%) and the least was Indian (8.5%). Various educational backgrounds were discovered in individuals with CP with most of them did not go to school (n=32), followed by went to a CBR (n=21), and 13 of them going to a Spastic Centre. The highest contribution of the household income group was between RM2,501–4,850 (USD551–1,068) (29.6%). Based on the health-related information, most of them were classified as quadriplegia, also known as tetraplegia (73.2%), which affected their upper and lower limbs. According to GMFCS classification, most of them were in GMFCS Level IV (n=61) and 59 of them were in Level IV EDACS classification. Due to this, most of them were totally dependent on the caregivers when preparing and giving food to their children (*Table 3*).

Based on *Table 4*, anthropometric data of weight, height, BMI, MUAC, arm MUAC, and body fat classification was determined descriptively. The reading was plotted in the CP

Table 3 Characteristics of participants (n=71)

Characteristics	Value
Gender	
Male	43 (60.6)
Female	28 (39.4)
Age, years	9.00 [5.02]
2–4	15 (21.1)
5–7	27 (38.0)
8–12	13 (18.3)
13–20	16 (22.5)
Ethnicity	
Malay	56 (78.9)
Chinese	9 (12.7)
Indian	6 (8.5)
Anthropometric data	
Height (m)	1.10 [0.23]
Weight (kg)	20.27 [10.85]
BMI (kg/m²)	15.95 [5.23]
MUAC (cm)	17.33 [3.72]
Triceps (mm)	7.92 [3.87]
Subscapular (mm)	6.08 [2.94]
Body fat percentage	26.13 [6.53]
Education level	
Early Intervention Program	3 (4.2)
Spastic Centre (NGO)	13 (18.3)
Integrated Special Education Program (PPKI)	1 (1.4)
Community-Based Rehabilitation Program	21 (29.6)
Not going to school	32 (45.1)
Others	1 (1.4)
Household income	
≤RM2,500 (≤USD550)	19 (26.8)
RM2,501–4,850 (USD551–1,068)	21 (29.6)
RM4,851–10,970 (USD1,068–2,417)	19 (26.8)
RM10,971–15,040 (USD2,417–3,313)	8 (11.3)
>RM15,040 (>USD3,313)	4 (5.6)
Classification of cerebral palsy	
Hemiplegia	2 (2.8)
Paraplegia	7 (9.9)
Diplegia	6 (8.5)
Quadriplegia	52 (73.2)
Others	4 (5.6)
GMFCS classification	
Level IV	61 (85.9)
Level V	10 (14.1)
EDACS classification	
Level III	3 (4.2)
Level IV	59 (83.1)
Level V	9 (12.7)
Level of assistance required	
Requires assistance	24 (33.8)
Totally dependent	47 (66.2)

Table 3 (*continued*)

Table 3 (*continued*)

Data are presented as n (%) or mean [standard deviation]. BMI, body mass index; MUAC, mid-upper arm circumference; NGO, non-profit organization; RM, Ringgit Malaysia (1 RM ≈ 0.22 USD); GMFCS, Gross Motor Function Classification System; EDACS, Eating and Drinking Ability Classification System.

Table 4 Anthropometric measurement of study participants (n=71)

Indicators	N (%)
Classification weight-for-age percentiles	
Underweight (<5th)	29 (40.8)
Normal (5th–95th)	39 (54.9)
Overweight (>95th)	3 (4.2)
Classification stature-for-age percentiles	
Stunted (<5th)	1 (1.4)
Normal (5th–95th)	68 (95.8)
Above normal (>95th)	2 (2.8)
Classification BMI-for-age percentiles	
Wasted (<5th)	11 (15.5)
Normal (5th–95th)	58 (81.7)
Overweight (>95th)	2 (2.8)
Classification MUAC	
Low (<5th)	35 (49.3)

Table 4 (*continued*)

Table 4 (*continued*)

Indicators	N (%)
Normal (5^{th}–95^{th})	35 (49.3)
High (>95^{th})	1 (1.4)
Classification arm MUAC	
Low (<5^{th})	25 (35.2)
Normal (5^{th}–95^{th})	45 (63.4)
High (>95^{th})	1 (1.4)
Body fat classification	
Optimal range	11 (15.5)
Moderately high	34 (47.9)
High	17 (23.9)
Very high	9 (12.7)

BMI, body mass index; MUAC, mid-upper arm circumference.

graph accordingly. There were 40.8% of subjects that were classified as underweight and only 4.2% were overweight (>95^{th} percentile). For MUAC, the reading was compared with the Frisancho table, and it was found that the number of subjects that were below the 5^{th} percentile range (low) was similar to the 5^{th} to 95^{th} percentile range (normal) (n=35) (32). Based on body fat classification, the reading value of skinfold measurements was calculated using Slaughter and modified Gurka equation and most of the subjects were high in body fat (84.5%). *Table 5* showed, there was no significant difference in anthropometric parameters between male and female was found (P>0.05).

A higher score indicates better quality of life based on the PedsQL CP questionnaire. Based on *Figure 1*, Pain and Hurt, Fatigue, and Movement and Balance domains were observed among the highest average scores. The lowest score was the Daily Activities domain (5.34±10.87), followed by the second lowest School Activities domain (8.15±18.65), and the third lowest was the Eating Activities domain (17.25±21.51) (*Figure 1*).

Table 6 demonstrated Pearson correlation to assess the linear relationship between anthropometric data with each domain of PedsQL CP. A weak positive correlation between body weight and the Daily Activities domain was found, r (69)=0.300, P=0.011. A moderate positive correlation showed between height and School Activities domain, r (69)=0.470, P≤0.01. For variable triceps measurement with Movement and Balance domain, a weak positive correlation was found, r (69)=0.242, P=0.042. There was no significant correlation between the anthropometric data with Pain and Hurt, Fatigue, and Eating Activities domains of PedsQL CP.

Multiple regressions were run to predict associated factors toward the total score for each domain in the quality-of-life questionnaire (*Table 7*). The analysis showed that sociodemographic data and anthropometric data were not statistically significant in predicting the value of the total score in the Daily Activities domain, Movement and Balance domain, Pain and Hurt domain, Fatigue domain, Eating Activities Domain, and Speech and Communication domain. However, it was found the overall regression was statistically significant between the sociodemographic data and anthropometric data with the total score of the School Activities domain, [F (11, 44)=3.981, P<0.005, R^2=0.499].

It was found that EDACS classification significantly predicted the total score in the School Activities domain (β=0.51, P≤0.001). Furthermore, other variables did not significantly predict the total score in the School Activities domain. The general form of the equation to predict the total score for the School Activities domain from sociodemographic and anthropometric data is:

$$\begin{aligned}\text{Predicted total score for the School Activities domain} = {} & -22.47 + (1.16\times\text{age}) + (3.15\times\text{gender}) - (0.67\times\text{household income}) \\ & -(1.30\times\text{education}) + (41.89\times\text{EDACS}) - (2.86\times\text{GMFCS}) \\ & +(0.17\times\text{BMI}) - (0.93\times\text{MUAC}) - (0.09\times\text{Triceps}) \\ & -(1.73\times\text{Subscapular}) + (5.53\times\text{Body Fat})\end{aligned} \quad [3]$$

Table 5 Independent *t*-test of the anthropometric parameters between gender

Factor	Male		Female		*t*-test	P value
	Mean	SD	Mean	SD		
Height (m)	1.09	0.24	1.12	0.21	–5.5	0.585
Weight (kg)	21.06	12.22	19.07	8.40	0.75	0.454
BMI (kg/m^2)	16.84	6.24	14.59	2.70	1.80	0.076
MUAC (cm)	17.50	4.04	17.08	3.20	0.47	0.641
Triceps (mm)	7.53	3.86	8.53	3.88	–1.07	0.289
Subscapular (mm)	6.04	3.26	6.14	2.43	–0.14	0.890

BMI, body mass index; MUAC, mid-upper arm circumference.

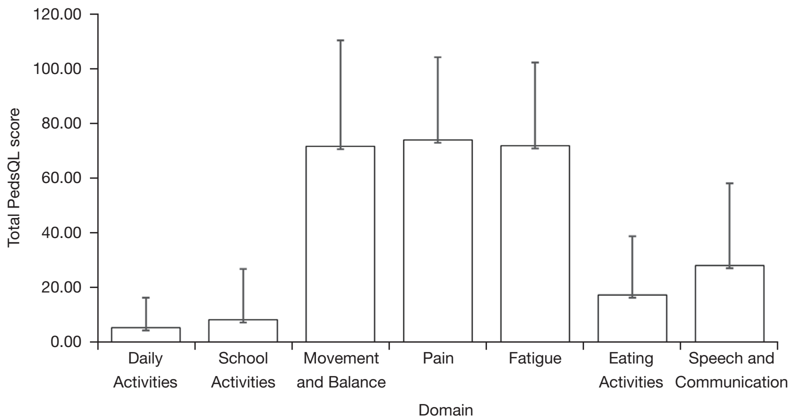

Figure 1 Total mean score and standard deviation of domain PedsQL CP. PedsQL, Pediatric Quality of Life Inventory; CP, cerebral palsy.

Discussion

Key findings

The study aimed to see the prevalence of poor nutritional status among individuals with severe CP and its predictors with caregivers' quality of life. Results showed the prevalence of CP is higher among male (n=43, 60.6%) compared to female. Research done in a university hospital in Brazil among children with spastic quadriplegic CP, also indicated, that the male participants were higher (63%) compared to women and all the subjects had adequate height according to CP growth chart (33). Our study revealed 95.8% of the participants had stature within 5th to 95th percentile. Alternatively, study in Indonesia had a prevalence of 61.1% females with CP attended a rehabilitation program in the local hospitals with 67.7% of them were classified as undernutrition (34). The finding was similar by a study conducted by Mohana in India, found underweight children with CP was significantly higher among females (n=120) (P<0.05) and prevalence of underweight was found in the more severe category of GMFCS (35). CP affects both male and female, but research suggests that male is slightly more likely to develop CP than female. However, the difference in incidence rates between male and female is relatively small that may not be significant to represent the populations as CP occurrence might happen through different phases of life cycle. A systematic review conducted by Mushta *et al.* revealed that the occurrence of moderate to severe underweight was most reported with up to 84.9% among children with CP (36). Undernutrition might lead to health consequences including stunted growth and development, impaired cognitive function and weakened immune systems (37). Individuals with severe CP which is known to have limited physical ability may have higher energy requirements due to increased muscle tone and spasticity (38).

Table 6 Pearson correlation of anthropometric data with total score for each domain of PedsQL CP

Variables	Statistic	Domain						
		Daily Activities	School Activities	Movement and Balance	Pain and Hurt	Fatigue	Eating Activities	Speech and Communication
Weight-for-age	r value	0.300*	0.397*	0.161	0.100	0.037	0.131	0.283*
	P value	0.011	0.002	0.181	0.408	0.762	0.278	0.035
Height-for-age	r value	0.298*	0.470*	0.035	0.105	0.102	0.146	0.299*
	P value	0.012	0.000	0.773	0.382	0.395	0.225	0.025
BMI-for-age	r value	0.013	–0.006	0.119	0.096	–0.102	–0.025	–0.034
	P value	0.912	0.967	0.321	0.424	0.399	0.838	0.804
MUAC	r value	0.284*	0.346**	0.176	0.136	0.085	0.217	0.287*
	P value	0.017	0.009	0.141	0.260	0.480	0.069	0.032
Triceps	r value	0.073	0.067	0.242*	0.195	0.014	0.102	0.006
	P value	0.544	0.626	0.042	0.103	0.907	0.395	0.964
Subscapular	r value	0.156	0.119	0.197	0.225	0.130	0.078	0.006
	P value	0.194	0.381	0.099	0.060	0.279	0.517	0.966
Body fat percentage	r value	–0.032	0.005	0.165	0.138	–0.004	0.082	0.015
	P value	0.792	0.972	0.169	0.252	0.972	0.495	0.910

*, correlation is significant at the 0.005 level (2-tailed); **, correlation is significant at the 0.001 level (2-tailed). PedsQL CP, Pediatric Quality of Life Inventory Cerebral Palsy; BMI, body mass index; MUAC, mid-upper arm circumference.

In a study conducted in Malaysia among 93 children with CP attending CBR, 55.9% of the subjects were found to have a normal reading of MUAC (39). This was consistent with our study that found nearly half of the participants (49.3%) had normal MUAC. However, a previous study conducted among 101 children with CP matched with control group aged 2 to 12 years old in CBR and Spastic Center in Malaysia found that 80% of children with CP had smaller MUAC compared to control group (40). Possible reason with nearly half of them had normal MUAC might be due to limited immobility that eventually reduced muscle mass (33). MUAC is a useful tool to determine nutritional status but using the tool as a single predictor might not be accurate (41). Thus, it is necessary to perform other types of anthropometric measurements such as measurement of weight, height, and BMI. An in-depth method using bioelectrical impedance analysis (BIA) has been showed able to determine the body composition and body fat percentage among individuals with CP that is known to have different level of muscle tone (42).

For skinfold measurement, current study agreed with a study conducted by Caselli *et al.* that revealed fat mass was higher in spastic quadriplegic CP category due to lack of mobility and physical activity that led to decreased muscle mass as compared to a healthy individuals (33). Most of them had a normal range (5^{th}–95^{th} percentile) of triceps skinfold measurement (66.7%) from 54 individuals with spastic quadriplegic CP. A study by Martínez de Zabarte Fernández *et al.* compared anthropometry measurements with BIA. It was reported that based on the BIA finding, GMFCS V had lower fat mass, lean mass, and cell mass percentage than GMFCS III and IV (43). This was in contrast with our study that found all the subjects were not having low body fat percentages. Our study found that 84.5% had a high body fat percentage. Higher body fat percentage among individuals with severe CP can be due to combination of decreased physical activity (25). However, a previous cohort study among 161 children with CP aged 18–60 months demonstrated that the fat free mass was higher among GMFCS I compared to GMFCS II–V category which showed the body fat percentages higher in the severe category of GMFCS level using assessment of BIA (44).

Among the factors associated with being underweight

Table 7 Multiple linear regression of sociodemographic and anthropometric data with each domain of PedsQL CP

Domains	Variables	B	95% CI		β	*t*	P
			LL	UL			
Daily Activities	Constant	–4.42	–35.36	26.53	–	–0.29	0.776
	Age	–0.19	–1.06	0.67	–0.09	–0.44	0.659
	Gender	1.81	–3.94	7.56	0.08	0.63	0.532
	Household income	–1.38	–4.95	2.20	–0.10	–0.77	0.444
	Education	–2.56	–8.58	3.47	–0.12	–0.85	0.399
	EDACS classification	15.37	2.09	28.65	0.29	2.32	0.024*
	GMFCS classification	–2.86	–10.51	4.79	–0.09	–0.75	0.457
	BMI	–0.04	–0.64	0.55	–0.02	–0.14	0.889
	MUAC	1.04	–0.45	2.53	0.36	1.40	0.168
	Triceps	–0.69	–1.91	0.52	–0.25	–1.14	0.259
	Subscapular	–0.24	–1.87	1.40	–0.06	–0.29	0.772
	Body fat categories	3.87	–4.87	12.61	0.13	0.89	0.379
School Activities	Constant	–22.47	–70.97	26.02	–	–0.93	0.355
	Age	1.16	–0.25	2.57	0.30	1.67	0.104
	Gender	3.15	–6.42	12.71	0.08	0.66	0.51
	Household income	–0.67	–6.68	5.34	–0.03	–0.23	0.823
	Education	–1.30	–11.04	8.44	–0.03	–0.27	0.79
	EDACS classification	41.89	22.70	61.08	0.51	4.40	<0.001*
	GMFCS classification	–2.86	–16.41	10.70	–0.48	–0.43	0.676
	BMI	0.17	–0.72	1.05	0.05	0.38	0.708
	MUAC	0.93	–1.28	3.15	0.19	0.85	0.4
	Triceps	–0.09	–1.90	1.72	–0.02	–0.10	0.919
	Subscapular	–1.73	–4.17	0.71	–0.29	–1.43	0.161
	Body fat categories	5.53	–9.20	20.26	0.11	0.76	0.453
Movement and Balance	Constant	57.81	–57.25	172.86	–	1.01	0.319
	Age	–1.08	–4.29	2.14	–0.14	–0.67	0.506
	Gender	–5.74	–27.12	15.65	–0.07	–0.54	0.593
	Household income	–7.69	–20.98	5.60	–0.15	–1.16	0.252
	Education	6.04	–16.35	28.42	0.08	0.54	0.592
	EDACS classification	24.22	–25.15	73.59	0.13	0.98	0.33
	GMFCS classification	–18.18	–46.61	10.26	–0.17	–1.28	0.206
	BMI	0.69	–1.53	2.90	0.09	0.62	0.538
	MUAC	0.59	–4.94	6.12	0.06	0.23	0.831
	Triceps	1.61	–2.90	6.12	0.16	0.72	0.477

Table 7 (*continued*)

Table 7 (*continued*)

Domains	Variables	B	95% CI		β	*t*	P
			LL	UL			
	Subscapular	–0.71	–6.78	5.36	–0.05	–0.23	0.816
	Body fat categories	13.54	–18.97	46.04	0.13	0.83	0.408
Pain and Hurt	Constant	81.02	–6.46	168.5	–	1.85	0.069
	Age	0.94	–1.50	3.38	0.16	0.77	0.443
	Gender	–18.74	–35.00	–2.48	–0.31	–2.31	0.025*
	Household income	4.79	–5.32	14.89	0.12	0.95	0.347
	Education	4.34	–12.69	21.36	0.07	0.51	0.612
	EDACS classification	8.61	–28.93	46.15	0.06	0.46	0.648
	GMFCS classification	–16.50	–38.12	5.13	–0.19	–1.53	0.132
	BMI	0.17	–1.51	1.86	0.03	0.21	0.839
	MUAC	–2.70	–6.9	1.51	–0.33	–1.29	0.204
	Triceps	1.13	–2.3	4.56	0.15	0.66	0.512
	Subscapular	2.40	–2.21	7.02	0.23	1.04	0.302
	Body fat categories	19.22	–5.50	43.93	0.23	1.56	0.125
Fatigue	Constant	93.74	2.03	185.46	–	2.05	0.045*
	Age	0.44	–2.13	2.30	0.07	0.34	0.735
	Gender	–7.84	–24.89	9.21	–0.13	–0.92	0.361
	Household income	1.05	–9.55	11.65	0.03	0.20	0.844
	Education	7.48	–10.37	25.33	0.12	0.84	0.405
	EDACS classification	21.42	–17.94	60.78	0.14	1.09	0.281
	GMFCS classification	–18.31	–40.98	4.36	–0.21	–1.62	0.111
	BMI	–0.76	–2.52	1.01	–0.13	–0.86	0.395
	MUAC	–0.90	–5.31	3.51	–0.11	–0.41	0.685
	Triceps	–1.17	–4.77	2.43	–0.15	–0.65	0.518
	Subscapular	2.96	–1.87	7.80	0.29	1.23	0.225
	Body fat categories	6.13	–19.78	32.04	0.07	0.47	0.638
Eating Activities	Constant	2.51	–58.26	63.27	–	0.08	0.934
	Age	–0.75	–2.45	0.95	–0.18	–0.89	0.38
	Gender	1.73	–9.56	13.03	0.04	0.31	0.76
	Household income	–4.06	–11.08	2.96	–0.14	–1.16	0.252
	Education	1.72	–10.10	13.55	0.04	0.29	0.772
	EDACS classification	31.96	5.88	58.03	0.30	2.45	0.017*
	GMFCS classification	–12.12	–27.14	2.90	–0.20	–1.62	0.112
	BMI	–0.18	–1.35	0.99	–0.05	–0.32	0.754

Table 7 (*continued*)

Table 7 (*continued*)

Domains	Variables	B	95% CI		β	*t*	P
			LL	UL			
	MUAC	2.34	−0.58	5.26	0.41	1.61	0.114
	Triceps	−0.05	−2.44	2.33	−0.01	−0.04	0.966
	Subscapular	−2.27	−5.48	0.93	−0.31	−1.42	0.161
	Body fat categories	6.57	−10.60	23.73	0.11	0.77	0.447
Speech and Communication	Constant	−19.49	−113.21	74.23	–	−0.42	0.677
	Age	−0.98	−3.71	1.74	−0.16	−0.73	0.471
	Gender	12.43	−6.06	30.91	0.20	1.34	0.182
	Household income	−5.73	−17.34	5.88	−0.14	−0.99	0.326
	Education	−6.78	−25.60	12.04	−0.11	−0.73	0.472
	EDACS classification	19.43	−17.66	56.52	0.15	1.60	0.297
	GMFCS classification	−7.68	−33.88	18.53	−0.08	−0.59	0.558
	BMI	−0.23	−1.93	1.48	−0.04	−0.27	0.79
	MUAC	5.87	1.59	10.15	0.73	2.77	0.008*
	Triceps	−1.28	−4.78	2.22	−0.18	−0.73	0.467
	Subscapular	−4.41	−9.13	0.31	−0.46	−1.89	0.066
	Body fat categories	1.59	−26.88	30.05	0.02	0.11	0.911

Daily Activities: R^2 adj=0.09 (N=71, P=0.117), School Activities: R^2 adj=0.37 (N=71, P=0.000*), Movement and Balance: R^2 adj=0.01 (N=71, P=0.426), Pain and Hurt: R^2 adj=0.06 (N=71, P=0.203), Fatigue: R^2 adj=−0.03 (N=71, P=0.605), Eating Activities: R^2 adj=0.10 (N=71, P=0.090), Speech and Communication: R^2 adj=0.10 (N=71, P=0.143). *, P<0.05. PedsQL CP, Pediatric Quality of Life Inventory Cerebral Palsy; CI, confidence interval; LL, lower limit; UL, upper limit; EDACS, Eating and Drinking Ability Classification System; GMFCS, Gross Motor Function Classification System; BMI, body mass index; MUAC, mid-upper arm circumference.

were due to oral-motor dysfunction/feeding difficulties which the frequency was higher among the severe category of GMFCS classification. Our study found that 33.8% needed assistance while feeding, which was consistent with a finding among 70 individuals with CP attending dental school for special needs children in Brazil, which demonstrated 35.6% need help when feeding (45). This finding was supported by a study from Brazil among 100 patients with CP who identified malnutrition had been linked with GMFCS classification, 35.1% malnutrition happen in ambulatory and the remaining occurred in the non-ambulatory category (10). According to a study by García Ron *et al.*, it was found that there was a correlation between EDACS and GMFCS classification (46). All subjects in the level V GMFCS are classified as EDACS level III to IV. Another study conducted in Egypt among moderate to severe CP with feeding difficulties used EDACS to classify the feeding ability. It was found that half of the 20 subjects who participated were in level III, followed by levels IV, 40% and level V, 10% (47). Feeding in individual with severe CP can be challenging as they often had difficulties with their motor skills to chew, swallow and control mouth while eating. Higher GMFCS are generally associated with higher levels of EDACS classification, indication greater feeding difficulties and need for assistance while feeding (48). However, individual with CP should be treated individually and GMFCS and EDACS classification may not always correspond precisely.

A study conducted in 128 persons with CP in children's hospital in Poland was in agreement with our study which found out that the highest score of quality of life using PedsQL CP questionnaire was in the Pain and Hurt domain (68.02) and in the Fatigue domain (58.40).

Tetraplegia CP shows the lower score in all domains compared to hemiplegia and diplegia group (49). Another study conducted by Yang *et al.*, also found that the Pain and Hurt domain scored the most (83.63±18.82) followed by the Movement and Balance domain (67.02±28.36), based on parent-reported among 126 children with CP in China (50). The finding is also in agreement with a study by Varni *et al.* which found the highest score was in the domain of Pain and Hurt (65.28±25.89), in 243 parents of children with CP (28). For the domain of Eating Activities reported by parents, it is shown that the score was inversely proportional to GMFCS classification, which indicated that the more severe the GMFCS classification, the lower the score of the Eating Activities domain (GMFCS I =89.82±15.44, GMFCS II =83.28±21.40, GMFCS III =72.40±24.70, GMFCS IV =49.95±31.33 and GMFCS V =17.59±29.87) (32). This was in accordance with our study, which demonstrated the Eating Activities domain was among the lowest average scores as the subject of our study was from severe GMFCS classification and supported by a study conducted by Michalska *et al.* which found that the lowest score was in the domain of Daily Activities, followed by the second lowest found in the domain of School Activities, and the third lowest was in the Eating Activities domain (16.9±20.0) (51).

Monem Fouad *et al.* conducted a study in Egypt aimed to assess the burden and self-efficacy level among 50 caregivers of children with CP revealed that there was a negative significant relation between caregivers' burden and self-efficacy due to children dependency. The study showed 54% of children with CP were severely dependent, whereas 24% were totally dependent which limit their children to performed activity daily living such as bathing, dressing and toilet (52). Tseng *et al.* identified several factors that affect the quality of life of caregivers of children with CP. Three main categories were child characteristics, caregiver characteristics, and environment factors. Child characteristics included age of the severity of CP, other health related issues, behavior and emotions, visual and hearing impairment. For caregivers' categories, components such as mental health, parenting stress, marital status and socio-economic status plays a role in quality of life whereas environmental factors such as school setting, current rehabilitation service and family life impacts might contribute to the level of quality of life (53).

Additionally, a review from Lui *et al.* revealed factors that contribute to caregiver's burden include the severity of the child's health condition and the caregiver's own anxiety and depression (54). The severity of CP has been shown to be associated with caregivers' quality of life. The Physical Component Summary (PCS) questionnaire was used to assess quality of life, and the results indicated that hemiplegia CP had a higher overall score than quadriplegia CP (43.79±8.11), which indicated better quality of life (55). In a study by Lee *et al.*, a longer period of disability may indicate greater physical health-related quality of life (56). The quality of life of caregivers of CP can also be affected due to economic and social factors (57,58). It is important to note that in severe CP, individuals may have limited ability to participate in certain activities, which may impact scores on the PedsQL.

Our study found that the School Activities domain was a significant predictor of the quality of life of caregivers. It was defined as children that participate in social activities and can perform well in school, resulting in a better score of caregiver's quality of life. The current study was supported by Kolman *et al.* who demonstrated that lower overall quality of life was significantly predicted by feelings of unhappiness or sadness (OR 59.9, 95% CI, 1.6–2,209.8), difficulty understanding the parent or guardian (OR 29.8, 95% CI, 1.6–543.7), and not attending school (OR 57.2, 95% CI, 2.6–1,274.4) (59). A review by van der Kemp *et al.* demonstrated that environmental factors influenced the participation of individuals with CP to school. The family ecology, type of school, and parental stress were the most frequent environmental factors linked to participation (i.e., attendance and involvement). The physical environment and parental stress were the most frequent determinants in relation to participation-related categories (activity competence, sense of self, and preferences) (60). Pedersen *et al.* conducted a population-based cohort study in Denmark among 463,126 children born from 1997 to 2003. The study found that poor school performance among individuals with CP was due to motor impairment, as well as comorbidities such as visual impairments [OR =12.21 (5.28–28.22)] and epilepsy [OR =10.90 (5.63–21.08)], and maternal education. The severity of the condition emerged as a significant predictor of academic success, with decreased learning achievements closely linked to intellectual deficiencies, motor impairments, and comorbidities (61). It is crucial that caregivers and healthcare professionals to work together and develop an educational plan to ensure the child's needs are met and facilitate their socialization within the community, considering their physical ability.

Strength and limitations

Several limitations have been acknowledged within the study conducted. The study only focused on the severe GMFCS classification, as lower nutritional status is more prominent in this group. For the nutritional status assessment, diet recall is a method that can be used as an additional predictor to see the association between nutrient intake with anthropometric measurement. The sample size was small and focused on a location with a high population density. However, the researcher conducted the study in a different location including government institutions and private centers in which the environment varied. The study also included both outpatient and inpatient subjects in a hospital setting. The study can be expanded to other regions of the country and include individuals with mild and moderate levels of GMFCS classification in future research.

Conclusions

Improving caregiver quality of life by addressing nutritional status is crucial among individuals with severe CP. This study provides data and knowledge on the current nutritional status of individuals with CP and predicts associated factors that can affect the quality of life of caregivers. A nutrition intervention such as providing a nutrition module to assist caregivers in daily life is necessary with the help of a multidisciplinary approach to improve nutritional status of individuals with CP and involvement of the caregivers and their children with social activities together might improve caregivers' quality of life.

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Footnote

Reporting Checklist: The authors have completed the STROBE reporting checklist. Available at https://tp.amegroups.com/article/view/10.21037/tp-23-195/rc

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). This study was approved by the Institutional Review Board from UKM Research Ethics Committee, National University of Malaysia (UKM) with reference number UKM PPI/111/8/JEP-2022-387. Permission to conduct data collection in a government hospital attained from Medical Research and Ethics Committee Malaysia (MREC) with reference number 22-01018-IN3(2), approval granted by the Department of Social Welfare Malaysia for research conducted in a Community-Based Rehabilitation Program (CBR) with a reference number of JKMM 100/12/5/2: 2022/569 and informed consent was obtained from all participants and their parents/family members.

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