

Correlation between fatigue and quality of life self-reported by adolescents with cerebral palsy

Correlação entre fadiga e qualidade de vida autorrelatadas por adolescentes com paralisia cerebral
Correlación entre fatiga y calidad de vida de autoinformes de adolescentes con parálisis cerebral

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ABSTRACT

Objectives: to investigate the correlation between fatigue and quality of life in adolescents with cerebral palsy who are susceptible to more significant fatigue and lower quality of life. **Methods:** cross-sectional study conducted with 101 adolescents with cerebral palsy. Instruments such as the Pediatric Quality of Life Inventory and Gross Motor Function Classification System were used, and Kolmogorov-Smirnov, Mann-Whitney, and Spearman tests were applied. **Results:** older adolescents self-reported higher fatigue levels, and female adolescents, quadriplegic, with worse motor function, older, and not attending school had lower quality of life scores. Higher fatigue levels correlated with lower quality of life in all domains ($p < 0.01$), especially in tiredness (general and mental) and functioning (social, academic, and psychosocial). **Conclusions:** fatigue correlated negatively with the quality of life of adolescents with cerebral palsy, showing that the higher the level of fatigue, the more compromised is the adolescents' life.

Descriptors: Quality of Life; Fatigue; Cerebral Palsy; Adolescent; Child.

RESUMO

Objetivos: investigar a correlação entre fadiga e qualidade de vida em adolescentes com paralisia cerebral e suscetíveis à maior fadiga e à menor qualidade de vida. **Métodos:** estudo transversal conduzido com 101 adolescentes com paralisia cerebral. Utilizaram-se os instrumentos *Pediatric Quality of Life Inventory* e *Gross Motor Function Classification System*. Aplicaram-se os testes de Kolmogorov-Smirnov, Mann-Whitney e de Spearman. **Resultados:** adolescentes mais velhos autorrelataram maior nível de fadiga; e adolescentes do sexo feminino, quadriplégicos, com pior função motora, mais velhos e que não frequentavam escola apresentaram menores escores de qualidade de vida. Maior nível de fadiga correlacionou-se com menor qualidade de vida em todos os domínios ($p < 0,01$), principalmente em cansaço (geral e mental) e em função (social, escolar e psicossocial). **Conclusões:** a fadiga correlacionou-se negativamente com a qualidade de vida de adolescentes com paralisia cerebral, mostrando que, quanto maior o nível de fadiga, mais comprometida é a vida dos adolescentes.

Descritores: Qualidade de Vida; Fadiga; Paralisia Cerebral; Adolescente; Criança.

RESUMEN

Objetivos: investigar correlación entre fatiga y calidad de vida en adolescentes con parálisis cerebral y susceptibles a mayor fatiga y a menor calidad de vida. **Métodos:** estudio transversal conducido con 101 adolescentes con parálisis cerebral. Utilizado los instrumentos *Pediatric Quality of Life Inventory* y *Gross Motor Function Classification System*. Aplicadas las pruebas de Kolmogorov-Smirnov, Mann-Whitney y de Spearman. **Resultados:** adolescentes mayores informaron mayor nivel de fatiga; y adolescentes del sexo femenino, cuádruplégicos, con peor función motora, mayores y que no frecuentaban escuela presentaron menores escores de calidad de vida. Mayor nivel de fatiga se correlacionó con menor calidad de vida en todos los dominios ($p < 0,01$), principalmente en agotamiento (general y mental) y en función (social, escolar y psicossocial). **Conclusiones:** la fatiga se correlacionó negativamente con la calidad de vida de adolescentes con parálisis cerebral, mostrando que, cuanto mayor el nivel de fatiga, más comprometida es la vida de los adolescentes.

Descriptorios: Calidad de Vida; Fatiga; Parálisis Cerebral; Adolescente; Niño.

INTRODUCTION

Cerebral palsy is the leading cause of physical disability in childhood, with a prevalence of 2 to 2.5 for every thousand live births⁽¹⁾. It is a chronic condition that accompanies the individual from early childhood to adulthood; and although the degree of impairment is highly variable, the motor disorder is the main characteristic. Thus, functional limitations, associated problems, and the risk of comorbidities mean that the affected person requires specialized treatment and long-term care⁽²⁾.

The International Classification of Functioning (ICF) describes body function and disability situations. It focuses on the individual's interaction with the environment and participation in activities of daily living⁽³⁾. As children develop, activities become more complex and require increasingly active participation. Adolescents undergo intense physical, emotional, and psychological transformations, confronting the social transition. Thus, adolescents with cerebral palsy suffers not only from the stress and emotional strain inherent in this phase of life but also from the numerous other challenges imposed on them⁽⁴⁻⁹⁾. The increase in body size intensifies physical problems⁽¹⁰⁾, functional limitations, and disabilities become more evident⁽¹¹⁾ so that severely affected people depend on their caregivers for most activities⁽⁶⁻⁷⁾. Studies^(4,6) show a 20% to 30% restriction in mobility, socialization, leisure activities, and daily life of people with cerebral palsy during adolescence. In addition, some adolescents also need to deal with problems associated with cerebral palsy, such as epilepsy, intellectual disability, and sensory deficits, and fatigue^(2,12-13).

A characteristic of cerebral palsy⁽¹³⁻¹⁶⁾, fatigue is a state of physical, mental and/or emotional exhaustion that occurs due to innumerable factors, resulting, for example, from the prolonged treatment of chronic diseases, long-lasting physical or mental effort, and depression. High levels of fatigue can cause manifestations such as increased social isolation, reduced habitual function, participation, and life satisfaction⁽¹⁷⁾. That way, dealing with the limitations resulting from cerebral palsy and developing strategies to cope with the disability may increase weariness, stress, and frustrations^(10-11,14,18) in adolescents, influence the level of fatigue⁽¹²⁻¹³⁾ and, consequently, decrease satisfaction with physical, emotional and social aspects, interfering with the quality of life^(8,15-16,19).

Previous studies suggest that high levels of fatigue^(12,20) and low quality of life^(15-16,19) should be cause for concern; in this sense, understanding the relationship between those variables is determinant to prevent poor quality of life^(12,21). However, the literature that studies fatigue in adolescents with cerebral palsy is scarce, and the relationship with quality of life is poorly known. Most papers prioritize the statement of parents or caregivers and mixture children and adolescents in the sample^(12,20). Nevertheless, listening to adolescents with cerebral palsy is important to understand their real needs and make them feel valued for participating in the process of knowledge construction^(8,13,16,22).

OBJECTIVES

To evaluate the relationship between fatigue and quality of life self-reported by adolescents with cerebral palsy and identify

groups of adolescents with cerebral palsy susceptible to higher levels of fatigue and lower quality of life.

METHODS

Ethical aspects

This study was developed according to the ethical standards for research with human beings and followed Resolution 466/12 of the National Health Council. The Research Ethics Committee of the Pontifical Catholic University of Goiás (*Comitê de Ética em Pesquisa da Pontifícia Universidade Católica de Goiás*) granted ethical approval.

Those responsible for the adolescents were duly informed about the study and authorized the adolescent's participation by signing the Informed Consent Form (ICF). The adolescents who had the authorization from the people responsible received clarification about the study and were invited to participate, with acceptance by signing the Free and Informed Assent Term.

Design, period, and place of study

It is a cross-sectional quantitative study, conducted from March to August 2017 in all public educational and/or rehabilitation institutions in the city of Goiânia, state of Goiás, Brazil. The STROBE tool guided the production and structuring of the work.

Population or sample; criteria of inclusion and exclusion

The study sample consisted of all adolescents with cerebral palsy who attended some public educational and/or rehabilitation institution in the city of Goiânia, Goiás, Brazil.

The study adopted the following inclusion criteria: attending some public educational and/or rehabilitation institution in the city of Goiânia; being between 10 and 19 years old and having a diagnosis of cerebral palsy confirmed by the medical chart. As exclusion criteria, we considered the existence of genetic syndromes associated with cerebral palsy and/or severe intellectual or communication impairment that would affect the participant's ability to understand the questionnaire questions and answer them verbally or gesturally. To confirm intellectual and communication impairment, the researchers asked a standardized test question, which corresponded to the first item of the Pediatric Quality of Life Inventory (PedsQL) instrument, module 4.0 ("Is it difficult to put on your shoes?"). Adolescents who did not understand the question nor answer it did not participate in the study.

Study protocol

Initially, the guardians answered a sociodemographic and clinical instrument designed by the authors to collect data from the adolescents, including gender, age, school attendance, comorbidities, and the amount of activities/therapy. The research team was trained to apply the questionnaire through a pilot test evaluated by judges.

Subsequently, the adolescents answered the PedsQL. It is an instrument based on a modular approach consisting of generic and specific modules. We used the PedsQL 4.0 Generic Core Scales (PedsQL Generic) and the PedsQL 2.0 Multidimensional Fatigue Scale (PedsQL Fatigue). The PedsQL Generic evaluates aspects of

quality of life and is composed of 23 items grouped into four subscales: 1) Physical functioning (8 items); 2) Emotional functioning (5 items); 3) Social functioning (5 items); and 4) Academic functioning (5 items)⁽²³⁾. The PedsQL Fatigue comprises 18 items divided into three subscales: 1) General tiredness (6 items); 2) Tiredness related to sleep/rest (6 items), 3) Mental tiredness (6 items)⁽²⁴⁾. Both PedsQL Generic and PedsQL Fatigue showed excellent reliability (Chronbach's alpha > 0.70) for the adolescents' self-report^(21,25). We used the self-report versions of 8-12 years old and 13-18 years old.

The questions in all PedsQL modules refer to the number of times each item was a problem in the previous month, so the answers are scored on a Likert scale from 0 to 4 (0 - never; 1 - almost never; 2 - sometimes; 3 - often; and 4 - almost always). Subsequently, the scores are converted (0 = 100; 1 = 75; 2 = 50; 3 = 25; and 4 = 0), and the average is taken for each subscale and the total. PedsQL Generic also calculates physical health (physical functioning) and psychosocial health (emotional, social, and academic functioning) scores. In both modules, the score ranges from 0 to 100, with higher scores indicating fewer problems: better quality of life and less fatigue⁽²³⁾. The PedsQL Generic and the PedsQL Fatigue were applied in person by the researcher, who read the items and marked the answers indicated by the participants.

In the end, the researchers performed a motor evaluation in the adolescents (tone, gross motor function, distribution of motor impairment, and deformities) based on their clinical expertise. Gross motor function was measured by the Gross Motor Function Classification System (GMFCS) in an observational analysis. This instrument classifies children and adolescents with cerebral palsy into five levels of motor skills. At Levels I and II, they can walk without restrictions in the indoor and outdoor environment, but in Level II, children require a mobility device. In Level III, they walk indoors with the aid of a locomotion device, and in the community, they use mobility on wheels; and in Levels IV and V, self-locomotion is limited⁽²⁾.

All research team members were trained to apply the research instruments and the motor evaluation of the participants.

Analysis of results and statistics

Categorical data were described by relative and absolute frequency. Quantitative data were described using mean, median, standard deviation, and interquartile range (IQR). Quantitative data were checked for normality using the Kolmogorov-Smirnov test.

The Mann-Whitney test was used to compare the sociodemographic and clinical data categories with the scores of the quality-of-life questionnaire (PedsQL). The correlation between fatigue and quality of life was investigated by Spearman's test, adopting significance of $p \leq 0.05$ and considering the strength of the correlation as weak (0.10 to 0.29), regular (0.30 to 0.59), moderate (0.60 to 0.79), and very strong (≥ 0.80)⁽²⁴⁾.

RESULTS

A total of 236 potentially eligible participants were identified through a previous consultation with public rehabilitation institutions in the city of Goiânia, Goiás. Out of those, 124 were ineligible for presenting genetic syndromes associated with cerebral palsy or presenting insufficient cognitive or communicative ability to

understand and answer the questionnaires. In addition, ten were ineligible because they did not have the consent of their guardians. Then, 102 adolescents were eligible, but due to a request to withdraw from the study, 101 were included in the analysis.

The mean age was 14.8 (SD: 2.8) years old. Most of them had gait (66.3%), and, out of those, only 11.3% used some locomotion aid. On average, each participant performed three therapies/activities (SD: 2), with a frequency of two days a week (SD: 1).

In the PedsQL Generic, the "Physical health" score was the lowest. On the PedsQL Fatigue, adolescents had the lowest score in the domain "Sleep-related tiredness" (Table 1).

Table 1 – Descriptive analysis of socio-demographic and clinical data and Pediatric Quality of Life Inventory scores, Goiânia, Goiás, Brazil, 2017 (n = 101)

Variables	Median (IQR)	n (%)
Gender		
Female	N/A	43 (42.6)
Male	N/A	58 (57.4)
Age range		
10-14 years old	N/A	50 (49.5)
15-19 years old	N/A	51 (50.5)
Tone/Movement Disorder		
Spastics	N/A	61 (60.4)
Dyskinetics	N/A	20 (19.8)
Hypotonia, ataxia and mixed	N/A	20 (19.8)
Diagnostic Groups		
Hemiplegia/Diplegia	N/A	32 (31.7)
Quadriplegia	N/A	69 (68.3)
GMFCS		
I, II and III	N/A	78 (77.2)
IV and V	N/A	23 (22.8)
Comorbidities		
Epilepsia	N/A	13 (30.2)
Orthopedic Deformities	N/A	31 (70.5)
Infections and respiratory diseases	N/A	20 (44.0)
School		
Yes	N/A	92 (91.1)
No	N/A	09 (8.9)
PedsQL Generic		
Emotional functioning	55.0 (45.0-65.0)	N/A
Social functioning	60.0 (45.0-65.0)	N/A
Academic functioning	60.0 (45.0-70.0)	N/A
Physical health	53.1 (37.5-62.5)	N/A
Psychosocial Health	55.0 (47.5-65.0)	N/A
Total score	53.2 (46.7-62.5)	N/A
PedsQL Fatigue		
General tiredness	62.5 (45.8-70.8)	N/A
Sleep-related tiredness	50.0 (39.5-66.6)	N/A
Mental tiredness	58.3 (41.6-70.8)	N/A
Complete fatigue	56.9 (44.4-66.6)	N/A

IQR – interquartile range; GMFCS – Gross Motor Function Classification System; N/A – not applicable.

In the PedsQL Generic, female participants scored lower in the "Emotional Functioning" subscale; participants older than 15 years scored lower in "Physical Health," "Psychosocial Health," and "Total Health"; and quadriplegic participants scored lower in the "Social Functioning" subscale and in the "Physical Health" and "Total Health" scores. Adolescents classified in GMFCS' Levels IV and V achieved a lower score in "Physical health," and participants who did not attend school scored lower in the "Emotional functioning" subscale and "Total health" score (Table 2). On the PedsQL Fatigue, older participants scored lower in the "Sleep-related tiredness" subscale and "Total fatigue" score. (Table 3).

Table 2 – Comparison of Pediatric Quality of Life Inventory 4.0 Generic Core Scales scores among groups, Goiânia, Goiás, Brazil, 2017 (n = 101)

Variables	Emotional Functioning Median (IQR)	Social Functioning Median (IQR)	Academic Functioning Median (IQR)	Physical Health Median (IQR)	Psychosocial Health Median (IQR)	Total score Median (IQR)
Gender						
Male	60.0(50.0-70.0)*	57.5(45.0-65.0)	52.5(40.0-66.2)	48.4(36.7-62.5)	55.8(47.9-65.4)	53.2(46.7-64.1)
Female	55.0(40.0-65.0)*	60.0(40.0-65.0)	60.0(50.0-70.0)	53.1(43.7-62.5)	53.3(45.0-65.0)	52.1(45.3-62.2)
Age range						
10-14 years old	60.0(48.7-70.0)	60.0(53.7-71.2)	60.0(45.0-70.0)	56.2(40.6-65.6)*	56.6(51.2-66.6)*	55.9(48.9-65.4)*
15-19 years old	55.0(45.0-65.0)	55.0(40.0-65.0)	55.0(40.0-70.0)	50.0(34.3-59.3)*	53.3(45.0-61.6)*	51.0(41.3-57.6)*
Diagnostic Groups						
Hemi/Diplegia	57.5(45.0-70.0)	65.0(55.0-75.0)*	65.0(45.0-70.0)	62.5(53.1-67.9)*	59.1(48.7-68.3)	59.7(50.2-67.9)*
Quadriplegia	55.0(47.5-65.0)	55.0(40.0-65.0)*	55.0(40.0-70.0)	46.8(34.3-59.3)*	53.3(45.0-62.5)	52.1(44.5-58.1)*
GMFCS						
I, II and III	55.0(48.7-65.0)	60.0(45.0-65.0)	55.0(45.0-70.0)	56.2(40.6-65.6)*	55.0(45.0-66.6)	54.3(46.7-64.1)
IV and V	60.0(45.0-70.0)	55.0(40.0-70.0)	60.0(35.0-70.0)	40.6(28.1-50.0)*	53.3(48.3-65.0)	51.0(40.2-55.4)
School						
Yes	60.0(50.0-65.0)*	60.0(45.0-65.0)	60.0(45.0-70.0)*	53.1(40.6-62.5)	56.6(48.3-66.6)*	54.3(48.0-64.1)*
No	45.0(30.0-52.5)*	50.0(25.0-57.5)	45.0(22.5-55.0)*	37.5(28.1-56.2)	48.3(35.8-52.5)*	41.3(35.3-53.8)*

IQR – interquartile range; GMFCS – Gross Motor Function Classification System; Mann-Whitney Test: *p ≤ 0,05.

Table 3 – Comparison of Pediatric Quality of Life Inventory 2.0 Multidimensional Fatigue Scale scores among groups, Goiânia, Goiás, Brazil, 2017 (n = 101)

Variables	General tiredness Median (IQR)	Sleep-related tiredness Median (IQR)	Mental tiredness Median (IQR)	Complete fatigue Median (IQR)
Gender				
Male	62.5(45.8-70.8)	50.0(41.6-63.5)	54.1(41.6-71.8)	55.5(46.8-66.6)
Female	62.5(45.8-75.0)	54.1(37.5-66.6)	58.3(41.6-70.8)	59.7(41.6-69.4)
Age range				
10-14 years old	64.5(58.3-71.8)	58.3(44.7-67.7)*	62.5(48.9-75.0)	59.7(51.0-69.4)*
15-19 years old	58.3(33.3-70.8)	50.0(33.3-62.5)*	54.1(33.3-70.8)	51.3(38.8-65.2)*
Diagnostic Groups				
Hemi/Diplegia	66.6(55.2-75.0)	58.3(45.8-70.8)	64.5(50.0-70.8)	61.1(50.3-70.4)
Quadriplegia	62.5(41.6-70.8)	50.0(37.5-62.5)	54.1(41.6-70.8)	55.5(40.9-64.5)
GMFCS				
I, II and III	62.5(45.8-71.8)	52.0(41.6-66.6)	58.3(41.6-70.8)	57.6(45.8-66.6)
IV and V	58.3(37.5-70.8)	50.0(29.1-62.5)	54.1(41.6-75.0)	55.5(36.1-69.4)
School				
Yes	62.5(45.8-73.9)	52.0(41.6-66.6)	58.3(41.6-70.8)	58.3(46.1-66.6)
No	50.0(27.0-66.6)	45.8(31.2-62.5)	54.1(22.9-64.5)	45.8(35.4-59.0)

IQR – interquartile range; GMFCS – Gross Motor Function Classification System; Mann-Whitney Test: *p ≤ 0,05.

Table 4 – Correlation between quality of life in adolescents with cerebral palsy and the level of fatigue, Goiânia, Goiás, Brazil, 2017 (n = 101)

PedsQL Generic Sub-scales	PedsQL Fatigue			
	General tiredness	Sleep-related tiredness	Mental tiredness	Complete fatigue
Emotional functioning	0.54	0.26	0.37	0.47
Social functioning	0.61	0.40	0.58	0.64
Academic functioning	0.55	0.40	0.63	0.62
Physical Health	0.44	0.43	0.38	0.50
Psychosocial Health	0.74	0.46	0.68	0.75
Total score	0.70	0.53	0.64	0.75

Spearman's correlation test (r) com p < 0,01.

Positive correlations were found between fatigue and quality of life in all domains (p < 0.01), with moderate strength in seven domains (Table 4).

DISCUSSION

Older adolescents self-reported more fatigue and worse quality of life; those with worse motor functioning and who did not

attend school had lower quality of life scores; female adolescents scored less on the emotional functioning domain in quality of life. There was a correlation between higher levels of fatigue and lower quality of life in all domains, which highlights a moderate connection between the tiredness (general and mental) and functioning (social, academic, and psychosocial) domains.

Other studies with children and adolescents found lower levels of fatigue and higher quality of life scores^(12,19-20), and this divergence may be justified by the exclusive participation of adolescents in this study. The adolescent phase differs from childhood because of its peculiarities, being a period of many physical and psychological changes and the search for independence and autonomy⁽¹⁰⁾ so that the needs and conditions are different in those two stages of life. Thus, it is recommended that quality of life studies do not combine different age groups in the sample⁽⁸⁾.

Previous studies^(18,26) reveal that socialization, participation in activities of personal interest, and the opportunity to choose are essential for a good quality of life. However, adolescents with cerebral palsy present functional limitations and disabilities⁽²⁾ that add to environmental barriers and hinder social interaction.

Consequently, people with cerebral palsy participate less frequently in pleasant tasks, often staying home alone^(5,7). Those factors impact the levels of fatigue^(12-13,27) and quality of life^(8,10,16), which shows the importance of studies aimed exclusively at adolescents with cerebral palsy⁽⁸⁾.

In this study, female participants showed the lower quality of life scores in the emotional domain. Some studies⁽²⁸⁻²⁹⁾ compared the quality of life of adolescent boys and girls and pointed out that girls, especially after 13 years old, show a marked decline in the physical and psychological domains. It is noteworthy that, for the emotional well-being, it is important to feel good about oneself; and, in a phase in which the concern with the body increases, dealing with differences in body structure, especially for women, can generate frustration, anger, stress, and depression⁽¹⁰⁻¹¹⁾. Moreover, that difference between boys and girls may originate in different social demands imposed on girls, triggering much more psychological overload. It should also be noted that puberty is physically more accentuated in women than in men and that the first menstruation (12-14 years old) is the cause of many complaints. All those peculiarities in women, added to hormonal fluctuations, can make them more sensitive and contribute to a poorer quality of emotional life⁽²⁹⁾.

Adolescents classified in GMFCS' Levels IV and V presented lower physical health scores, and older adolescents had lower physical health and total fatigue scores. In adolescence, it is common for physical changes in body shape and size to affect the balance of individuals with cerebral palsy, which intensifies with advancing age and reduced motor functioning. Thus, older adolescents with worse motor functions have more health problems and greater difficulty sustaining body size and weight. Consequently, they suffer a boost in energy expenditure in activities and locomotion and increased fatigue levels^(10,30-31). In addition, as age progresses, individuals with cerebral palsy improve their ability to perceive their condition compared to others and increase their concern for seeking independence and autonomy^(10,18), which may justify our findings that older adolescents had a lower psychosocial quality of life scores.

When comparing the quality of life scores between the motor impairment groups, people with quadriplegia had lower scores in physical health. Previous studies have pointed out that the way adolescents with cerebral palsy perceive themselves is altered by their level of socialization⁽³²⁾ and how they are perceived by others⁽¹⁸⁾. Furthermore, independence is considered a determinant for a better quality of life⁽¹⁰⁾. It is worth noting that people with quadriplegia have more limitations and comorbidities than diplegics and hemiplegics, which hinders the acquisition of independence and makes the disability more evident⁽¹¹⁾. Therefore, they may experience more social isolation and have a damaged perception of quality of life than others. Accessible environments can facilitate the socialization and participation of this group, suggesting that the enforcement of existing accessibility laws would help people with reduced mobility to have more participation and better quality of life.

In this study, adolescents who did not attend school scored less in the emotional domain and the total quality of life score. Living with adolescents without disabilities, being accepted, and feeling included promotes the development of high levels of emotional

regulation^(11,14), so that the success of this interaction is crucial for a better quality of life⁽¹⁸⁾. However, environmental barriers, stigma, prejudice, and lack of information hinder socialization⁽¹⁰⁻¹¹⁾. Thus, the school environment can facilitate adolescents with cerebral palsy in this process of interaction with peers without disabilities. Besides being a place that minimizes environmental barriers, the school environment allows them to face challenging situations and create self-defense strategies to overcome daily barriers and build friendships⁽¹⁸⁾. It is possible to participate in a range of self-interested activities at school and choose your company. In this sense, the opportunity to experience school impacts people's emotional and global quality of life with cerebral palsy^(11,18,29,32). However, the assistance of qualified teachers and professionals is crucial for the school to influence this population's quality of life positively⁽¹⁸⁾.

Our results found a correlation between fatigue and quality of life in all domains. It is noteworthy that the self-perception of quality of life suffers positive and negative influences. Although adolescents with cerebral palsy suffer from physical stress due to the clinical condition^(12,20,33), they also face socio-environmental barriers and are affected by emotional stress while dealing with disability, with differences in body structure and limitations^(10-11,13). Also, uncertainties about the future, the choice of academic career, and the anxiety in the search for independence and autonomy can cause frustration, stress, and depression^(10,18,32). That said, fatigue, either physical or mental, can decrease habitual functioning and motivation, further increasing the social isolation of those adolescents. Consequently, this will negatively interfere with the degree of satisfaction in living, compromising the quality of life^(17,33). It is noteworthy that fatigue, general and mental, showed a moderate correlation with psychosocial health, pointing out that high levels of fatigue can reduce the emotional, social, and academic functioning of adolescents with cerebral palsy.

It is important to emphasize the difficulty of accessing more adolescents. Today, the care model of rehabilitation centers is directed at children and young adolescents up to 12 years old. After this age, adolescents are no longer the focus of attention and start to be neglected. However, it is known that the number of adolescents with cerebral palsy who need multidisciplinary assistance and who should be receiving care in some institutions is much higher than that found in this study. Based on this, two questions arise: "Where are the adolescents with cerebral palsy?" and "Are there public assistance policies and health policies that cover this population?"

Study limitations

The limitations of this study are related to the epidemiological design employed, which makes it difficult to establish causality among the correlations found, preventing the identification of risk factors. Another limitation concerns the restriction of the sample to adolescents without severe communication impairment and assisted by some institution, school, or health care. That, however, does not diminish the relevance of the results since the investigation observed the relationship between two variables less studied in adolescents with cerebral palsy and covered all institutions in the municipality.

Contributions to the fields of Health or Public Policy

This study points out the specific needs of adolescents with cerebral palsy and highlights the need to develop assistance and health care public policies for the disabled focused on adolescence. Therefore, the research results facilitate the promotion of care actions for the vulnerable groups identified here, enabling the reduction of fatigue levels, and improving this population's quality of life.

CONCLUSIONS

The present study pointed out the connection between all domains of fatigue and quality of life in adolescents with cerebral palsy, as well as identified groups vulnerable to higher levels of fatigue (over 15 years old) and lower quality of life (females, over 15 years old, worse motor functioning, quadriplegic, and not attending school).

The results sustain that fatigue can serve as a warning sign for losses in the quality of life of adolescents with cerebral palsy, mainly females, older, quadriplegic, more compromised, and are not attending school. Given this, it is highlighted the importance that families and professionals involved with adolescents with cerebral palsy be informed that high levels of fatigue may predict problems in the quality of life. Thus, alerting parents, teachers, and therapists to the importance of being aware of the signs

of fatigue in the school, therapeutic, and home environments, and adjusting the effort and activities of those adolescents, may minimize losses in quality of life, especially in the psychosocial domain. Informative and socio-environmental measures are also necessary to reduce stigma and prejudice, facilitate independence, and increase the opportunities for those adolescents to participate in activities outside the therapeutic environment. Such actions can reduce fatigue and other factors that negatively influence the quality of life.

In conclusion, there is a need for longitudinal studies that examine temporality and causality in the correlation between fatigue and quality of life in cerebral palsy during adolescence.

SUPPLEMENTARY MATERIAL

Manuscript resulting from a dissertation published in the repository of the *Pontifícia Universidade Católica de Goiás* (PUC Goiás) <http://tede2.pucgoias.edu.br:8080/handle/tede/4451>

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