ORIGINAL ARTICLE

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Quality of life in adult patients with cerebral palsy

Qualidade de vida em pacientes adultos com paralisia cerebral

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ABSTRACT

Cerebral palsy (CP) is a group of permanent motor and postural developmental disorders that are attributed to nonprogressive disorders that have occurred in the developing brain. Several factors can interfere with the quality of life of these patients and with the increase of longevity it is important to prevent and intervene early in the aspects that compromise the quality of life. **Objective:** To verify how the adult patients with CP treated at the AACD outpatient clinic self assess their current health condition and correlate with some factors that affect the quality of life of this population. **Method:** A screening questionnaire was applied to assess patients' quality of life via telephone (CDC HRQOL-4) and an evaluation protocol was completed using the medical record. Data collection was performed from March 13 to June 30, 2016. Statistical analysis of the data was performed. **Results:** 349 patients were treated and 66 patients who met the inclusion criteria answered the questionnaire via telephone. The overall average age was 26.5 years. The division by gender was equal (50%); the maximum age was 52 years old. There was a predominance of patients with spastic diparesis for both sexes (57.5% for women and 54.5% for men). Among women, 77.5% were not practicing any activity. Overall, 19.7% reported some chronic pain and 31.8% complained of mood swings in the last 30 days. In the self-rated general health, 25.8% reported being excellent and only 10.6% fair. Most were single, had no children and lived with their family (parents and siblings). **Conclusion:** Adult CP patients seen at the AACD Ibirapuera outpatient clinic are predominantly young, single adults living with their families. In general, they report very good or excellent health and less than 20% live with some chronic pain, but it does not interfere with daily activities. Regarding mood changes, more than one third reported having stress, sadness or anxiety, but that they have no strong influence on their quality of life.

Keywords: Cerebral Palsy, Quality of Life, Adult

RESUMO

Paralisia cerebral (PC) é um grupo de desordens permanentes do desenvolvimento motor e postural que são atribuídas a distúrbios não progressivos que ocorreram no encéfalo em desenvolvimento. Diversos fatores podem interferir na qualidade de vida desses pacientes e com o aumento da longevidade é importante prevenir e intervir precocemente nos aspectos que comprometem a qualidade de vida. **Objetivo:** Verificar como os pacientes adultos com PC atendidos no ambulatório da AACD auto avaliam sua atual condição de saúde e correlacionar com alguns fatores que interferem na qualidade de vida dessa população. **Método:** Foi aplicado um questionário de triagem para avaliação de qualidade de vida dos pacientes via telefone (CDC HRQOL-4) e foi preenchido um protocolo de avaliação utilizando o prontuário. A coleta de dados foi realizada do dia 13 de março até 30 de junho de 2016. Realizada a análise estatística dos dados. **Resultados:** Foram atendidos 349 pacientes e 66 pacientes que obedeciam aos critérios de inclusão responderam ao questionário via telefone. A idade média geral foi de 26,5 anos. A divisão por sexo foi igual (50%); a idade máxima foi de 52 anos. Houve predomínio de pacientes com diparesia espástica para ambos os sexos (57,5% para mulheres e 54,5% para os homens). Entre as mulheres, 77,5% não estava praticando nenhuma atividade. No geral, 19,7% referiram alguma dor crônica e 31,8% tiveram queixa de alteração de humor nos últimos 30 dias. Na auto avaliação sobre a saúde em geral, 25,8% referiu estar excelente e apenas 10,6% regular. A maioria era solteiro(a), não tinha filhos e morava com a família (pais e irmãos). **Conclusão:** Os pacientes adultos com PC atendidos no ambulatório da AACD Ibirapuera são predominantemente adultos jovens, solteiros e que estão vivendo com seus familiares. Em geral, eles referem ter uma saúde muito boa ou excelente e menos de 20% convive com alguma dor crônica, mas esta não interfere nas atividades do cotidiano. Já em relação às alterações de humor, mais de um terço referiu ter estresse, tristeza ou ansiedade, mas também não tem forte influência na sua qualidade de vida.

Palavras-chave: Paralisia Cerebral, Qualidade de Vida, Adulto

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INTRODUCTION

Individuals with cerebral palsy (CP), by definition, have their motor and postural development permanently altered by a non-progressive brain lesion that is still immature. These motor disorders may be accompanied by changes in sensitivity, perception, cognition, communication, and behavior, convulsive syndromes, and secondary musculoskeletal problems.[1]

These are therefore important factors that can compromise the quality of life of the adult individual with CP and should be addressed when possible. The term quality of life was first used in the 1960s and has since been applied in various studies in health, social science and philosophy. Technological development has brought great concern about the new standard of living adopted mainly in the urban area and the subjective assessment of quality of life has become an interesting tool to study the impact on health status. Measurement of quality of life also serves as an indicator of the quality of services offered and interventions performed in this population.[2]

Studies that investigated the satisfaction of adults with cerebral palsy with their own health found that it is satisfactory or excellent compared to the general population, and that those who reported a worsening quality of life were related to the presence of pain and functional loss, but not with the severity of the disability.[3] However, the life expectancy of CP patients is increasing and it is evident that mobility, functionality and existing musculoskeletal problems will change inherently with aging, making it even more difficult for these individuals.

OBJECTIVE

To verify how adult CP patients evaluate their current health condition through a simple four-question questionnaire and correlate with some factors that affect the quality of life of this population.

METHOD

This is a cross-sectional and observational study. First, a literature review of quality of life assessment methods for the general population was conducted and an assessment protocol was drawn up that gathers relevant information about each patient based on information contained in the medical record. The questionnaire chosen for this study was the Healthy Days Questionnaire (CDC HRQOL-4), which consists of four simple and comprehensive questions. It is a questionnaire validated in English and Spanish, and allows to measure quickly and simply how the patient evaluates their own physical and mental health, with the objective of screening these patients. This short questionnaire (CDC HRQOL-4) is being widely used in demographic information systems, prevention surveys and population health profile.[4]

Thus, the questionnaire could serve as an additional tool to identify individuals with higher demands for health care and, consequently, a higher risk of compromising quality of life. The four questions were then translated into Portuguese. The score of "unhealthy" days is generated by summing the second and third question with a maximum score of 30. The first and last question are analyzed independently.

Data collection was performed from March 13 to June 30, 2016. To participate in the study, patients had to meet the following criteria: be older than 18 years; be able to understand and answer telephone survey questions without help from others; accept and sign the free and informed consent form. Patients treated at the adult CP clinic were informed about the study and invited to participate by signing the informed consent form on the day of consultation. A single examiner applied the questionnaire via telephone call and the other protocol data were obtained directly from the electronic medical record. After this period, data analysis was performed using the ANOVA test and the Chi-square test. The study was approved by the AACD Research Ethics Committee.

RESULTS

349 patients were attended, 66 patients met the inclusion criteria and answered the questionnaire via telephone; 283 were excluded because they did not meet the inclusion criteria, did not answer the telephone number registered in the attendance form or because it was difficult to understand the questions asked by the examiner (Figure 1). Of the 66 patients evaluated there were 33 men and 33 women aged 18 to 52 years and an average of 26.5 years. Regarding the type of CP, there was a predominance of patients with spastic diparesis (n = 37) and hemiparesis (n = 17).

In the self-rated general health, 25.8% reported being excellent and only 10.6% fair. Figure 2 shows the self-rated health for each type of CP, and in the three groups most consider themselves to be very good or excellent, and the group with hemiparesis had the most dissatisfaction, i.e. classified their health as regular.

Assessment Protocol

Name:	Age:
ID:	D.O.B.:
Diagnosis:	
From:	GMFCS:
Gender:	Marital Status:
Education:	Profession:
Social: • Family, Alone, Spouse & Children, Institution	
Pain: • Yes • Where: • No	Mood or emotional condition alteration: • Yes • No
Unhealthy Days Questionnaire (CDC HRQOL-4)	
1. How do you think your overall health is? • Excellent, very good, good, fair or bad? 2. In the last 30 days, how many days has your physical health been regular or poor? For example: Pain, tiredness, malaise 3. In the past 30 days, how many days has your mental or emotional health been regular or poor? For example: Stress, Anxiety, Sadness 4. In the last 30 days, how many days did you stop doing your day to day tasks for health reasons?	

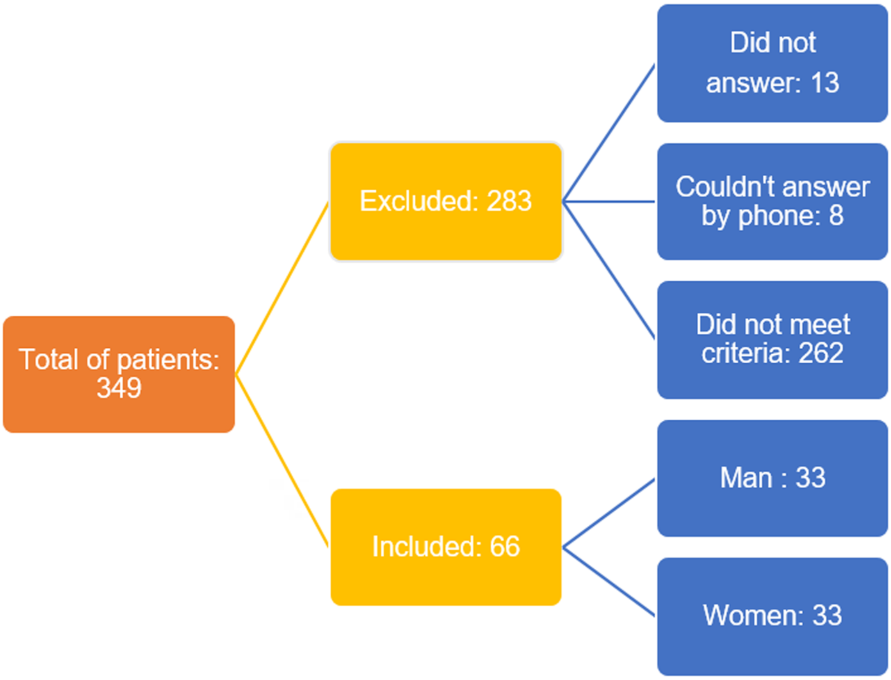

Figure 1. Included patients

We also evaluated patients for their level of weekly physical or therapeutic activity: 62% do not perform any activity, 18% do it 1-2 times a week and 20% do it 3-5 times a week. Figure 3 shows that patients who rated their health as excellent are those who engage in physical activity 3-5 times a week. There was no statistically significant difference between the number of days of weekly physical activity and the self-rated health (p = 0.8) and dissatisfaction, that is, classified their health as regular.

At the last medical appointment, 19.7% reported some chronic pain and 31.8% complained of mood swings. The same patients who reported chronic pain also had a mean number of days of weekly physical activity three times less than that of the non-pain group. According to Figure 4, patients with GMFCS II were those who least practiced physical or therapeutic activity (16.7%) and those with GMFCS III (53.3%).

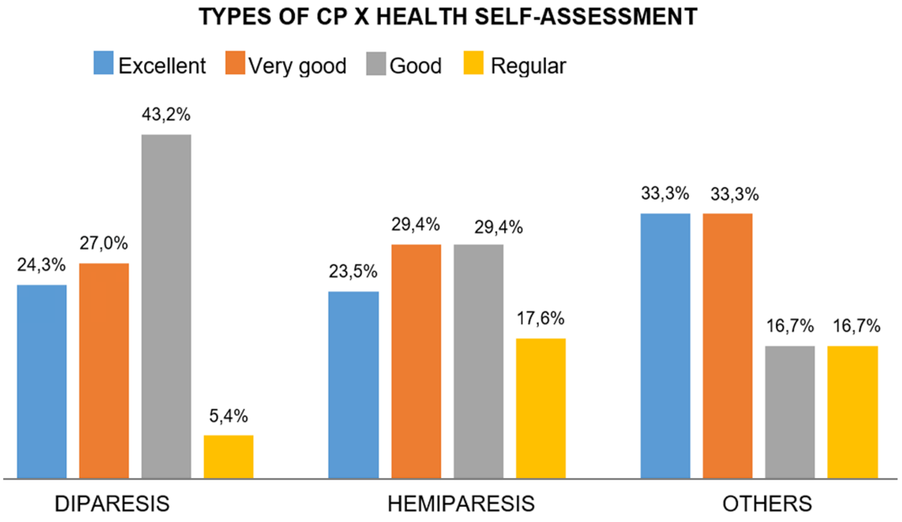

Figure 2. Self-rated general health according to type of cerebral palsy: diparesis, hemiparesis or others (nontoxic, dystonic, tetraparesis).

Figure 5 shows the difference between the group with pain and without pain: the first had more days with some physical problem, emotional problem and more disabling days, which are the last 3 questions of the questionnaire. The pain group score was 16.31 while the pain-free score was 3.63. There was no statistically significant difference between pain, mood change and GMFCS level in relation to self-rated health, with p values> 0.05.

The sites that the patients reported having chronic pain were: low back, knee, hip, foot, cervical and two reported having chronic headache (Chart 1).

DISCUSSION

This is an observational cross-sectional study that aims to know how adult CP patients treated at the AACD outpatient clinic in the city of São Paulo evaluate their general health condition and correlate with some factors that interfere with their quality of life. Regarding the sample characteristics of the 66 patients who completed the questionnaire, they are young adults with a mean age of 26.6 years, single, living with their families and no difference in gender distribution. This sample of patients closely resembles other adult PC studies.[5,6]

Most were from the city of São Paulo and were not performing any paid work activity. Factors evaluated in this study include weekly frequency of physical activity or regular therapy, such as physical therapy or hydrotherapy. Previous studies that addressed the quality of life theme considered regular physical activity important.[7,11]

In our study, patients with GMFCS II are those who least practice physical activity or therapy (16.7%) and those who do most are those with GMFCS III (53.3%). Nooijen et al.7 found that young walking patients with CP are physically less active and have a more sedentary behavior, especially those with spastic diparesis, than the general age-matched population.

Shkedy Rabani et al.8 further demonstrate that young adult adolescents with CP are sedentary between 82% and 96% of the day. Another factor well studied in the literature is the chronic pain reported by these patients, ranging from 14% to 73% of prevalence.[12]

Patients in our study reported having more musculoskeletal-related pain, with

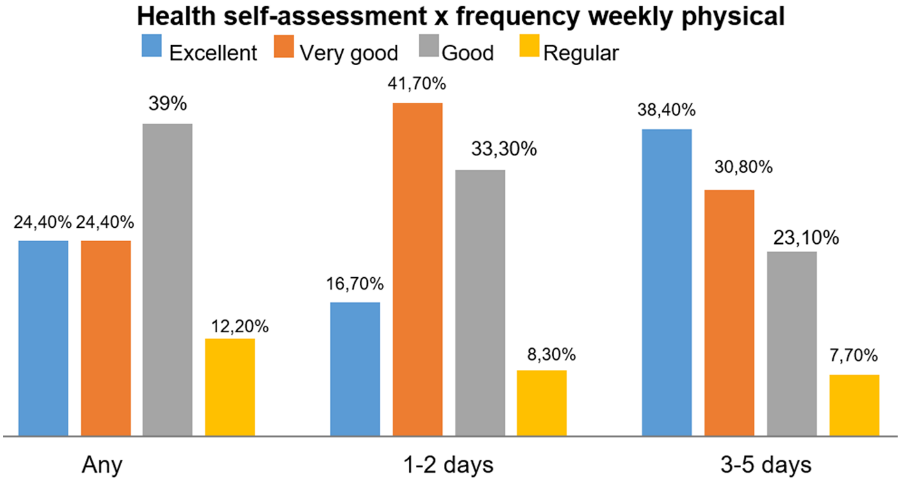

Figure 3. Health self-assessment according to the frequency of weekly physical or therapeutic activity.

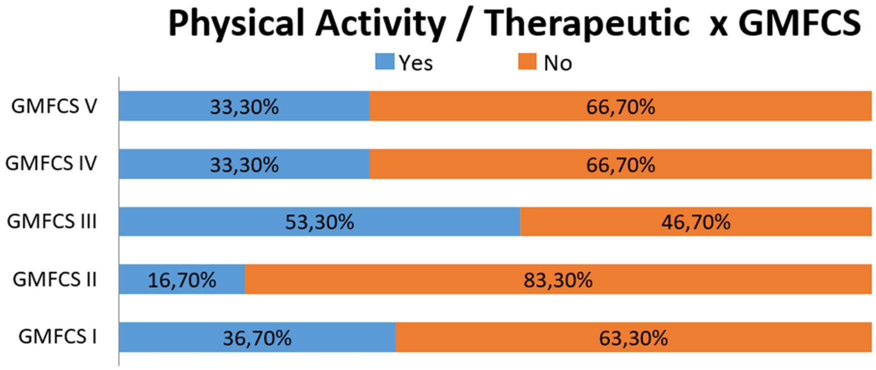

Figure 4. Practice of weekly physical activity or therapy according to the GMFCS.

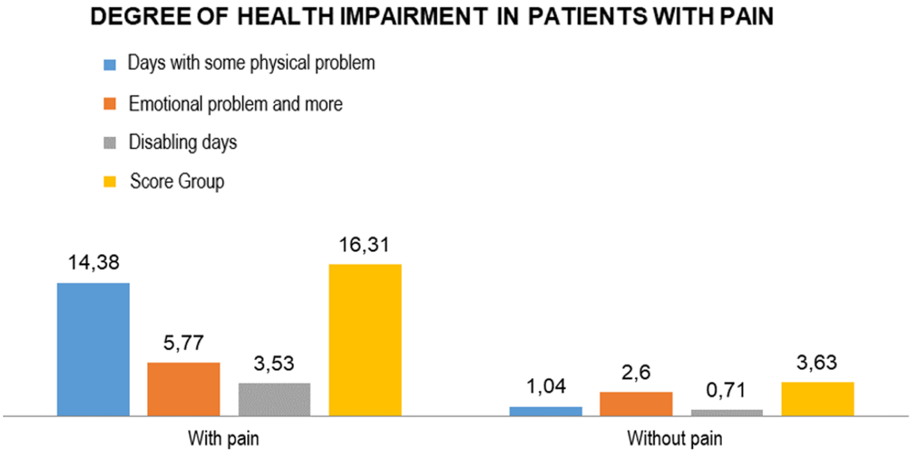

Figure 5. Degree of impairment of physical and mental health in patients with chronic pain.

lower back pain being the most prevalent, followed by lower limbs, being similar to that found by Badia et al. [13] Chronic pain has a negative impact on quality of life in the population. general. In patients with physical disabilities, recognizing and treating pain appropriately can be challenging but needs to be seen as a priority by the doctors who accompany these patients.[12-14]

In our study we found that patients with pain had more disabling days to perform activities of daily living and were also those who had more emotional complaints, mainly related to stress and anxiety. Other studies with children with CP have also found that pain intensity is still related to changes in behavior and emotional problems.[14] Further studies need to be done to see if early childhood pain management has interference with psychological and behavioral factors in age. Adult

Finally, the aging of the CP population is already a reality and the multidisciplinary team now has the challenge of giving these patients a better quality of life. Using screening tools to identify which patients need more staff attention may be of interest to referral institutions in cerebral palsy. We should not forget, however, that these patients are also subject to the most prevalent chronic diseases in the general population, such as hypertension, diabetes mellitus and other long-term comorbidities that can cause functional deterioration[15] and should therefore be referred to trained specialists. investigation and treatment when necessary.

Among the limitations of the study we can say that the sample number was small, which may perhaps explain the non-statistical significance of the factors studied with self-rated health. The mode of application of the questionnaire via telephone is also limiting since these patients may have difficulties in speech and hearing, making it difficult to understand the questions asked.

CONCLUSION

The studied population is characterized by young adults, single, living with their family and without children, independent community walkers, with spastic diparesis. Most reported very good or excellent health and did not report chronic pain or mood changes.

Chart 1. Pain location in patients with CP

Pain Location	*N*
Low Back	8
Knees	5
Hip	2
Foot	2
Cervical	1
Headache	2

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