

Quality of life and level of anxiety and depression in caregivers of children with cerebral palsy

Qualidade de vida e grau de ansiedade e depressão em cuidadores de crianças com paralisia cerebral

Calidad de vida y grado de ansiedad y depresión en cuidadores de niños con parálisis cerebral

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ABSTRACT

Objective: To evaluate the level of anxiety and depression and the quality of life of caregivers of children with cerebral palsy.

Methods: A cross-sectional and descriptive study with caregivers of children followed by two institutions: the Association of Parents and Friends of Exceptional Children (Apae) and the Association of Physically Disabled of Children of Alagoas (Adefal), in Maceió, Alagoas (Northeast Brazil). A total of 82 caregivers were enrolled and answered the following questionnaires: Hospital Scale of Anxiety and Depression and the SF-36 (Medical Outcomes Study 36 – Item Short-Form Health Survey). Data were analyzed using mean, standard deviation, median, and 95% confidence intervals (95%CI).

Results: The mean age of the caregivers was 32.4±10.3 years-old, ranging from 18 to 77. Anxiety was detected in 49% of the caregivers (95%CI 38–60), and depression in 31% (95%CI 22–42). In the SF-36, the most affected areas were: limitation by emotional aspects (score=56; 95%CI 46–65) and vitality (score=57; 95%CI 52–62).

Conclusions: Caregivers presented high anxiety and depression values; they did not have a good quality of life, with special limitations in the “emotional aspects” and the “vitality” domains.

Key-words: caregivers; cerebral palsy; anxiety; depression; quality of life.

RESUMO

Objetivo: Avaliar o grau de ansiedade e depressão e a qualidade de vida dos cuidadores de crianças com paralisia cerebral.

Métodos: Estudo transversal descritivo com cuidadores de crianças acompanhadas na Associação de Pais e Amigos dos Excepcionais (Apae) e na Associação dos Deficientes Físicos de Alagoas (Adefal), em Maceió, Alagoas. Para a coleta de dados, realizada com uma amostra de 82 cuidadores, utilizou-se a Escala Hospitalar de Ansiedade e Depressão (HAD) e um instrumento genérico de avaliação de qualidade de vida, o SF-36 (*Medical Outcomes Study 36 – Item Short-Form Health Survey*). Os dados foram analisados utilizando-se média, desvio padrão, mediana e intervalo de confiança de 95% (IC95%).

Resultados: A média de idade dos cuidadores foi de 32,4±10,3 anos, variando de 18 a 77. Constatou-se ansiedade em 49% dos cuidadores (IC95% 38–60) e depressão em 31% (IC95% 22–42). No questionário SF-36, os domínios mais afetados foram: limitação por aspectos emocionais, com 56 pontos (IC95% 46–65), e vitalidade, com 57 (IC95% 52–62).

Conclusões: Os cuidadores apresentaram alta ansiedade e depressão; não possuíam boa qualidade de vida, especialmente nos domínios “limitação por aspectos emocionais” e “vitalidade”.

Palavras-chave: cuidadores; paralisia cerebral; ansiedade; depressão; qualidade de vida.

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RESUMEN

Objetivo: Evaluar el grado de ansiedad y depresión y la calidad de vida de los cuidadores de niños con parálisis cerebral.

Métodos: Estudio transversal descriptivo, con cuidadores de niños acompañados en la *Associação de Pais e Amigos dos Excepcionais* (Apae) y en la *Associação dos Deficientes Físicos de Alagoas* (Adefal), en Maceió, Alagoas (Brasil). Para la recolección de los datos, realizada con una muestra de 82 cuidadores, se utilizó la escala hospitalaria de ansiedad y depresión y un instrumento genérico de evaluación de calidad de vida, el SF-36 (*Medical Outcomes Study 36 – Item Short-Form Health Survey*). Los datos fueron analizados utilizando promedio, desviación estándar, mediana e intervalo de confianza de 95% (IC95%).

Resultados: El promedio de edad de los cuidadores fue de $32,4 \pm 10,3$ años, variando de 18 a 77. Se constató ansiedad en el 49% de los cuidadores (IC95% 38–60%) y depresión en el 31% (IC95% 22–42%). En el cuestionario SF-36, los dominios más afectados fueron: limitaciones por aspectos emocionales, con 56 puntos (IC95% 46–65), y vitalidad, con 57 (IC95% 52–62).

Conclusiones: Los cuidadores presentaron alta ansiedad y valor elevado de depresión; no poseen buena calidad de vida, especialmente en los dominios limitación por aspectos emocionales y vitalidad.

Palabras clave: cuidadores; parálisis cerebral; ansiedad; depresión; calidad de vida.

Introduction

Cerebral palsy is still a stigma in Brazilian culture. Families are usually not prepared for the arrival of a child with some kind of deficiency or to face the sequelae caused by problems occurring after birth⁽¹⁾. Besides the emotional damage due to the loss of the idealized child, other psychological risks are certainly associated with this situation⁽²⁾.

In this context, the caregiver of a child with cerebral palsy takes on a major role: he or she is the one who provides and coordinates the basic care required by the child, and is also responsible for him/her, whether as his/her legal guardian or not. Considering that cerebral palsy results in chronic non-progressive neurological disorders, affecting particularly movement control and/or posture, these children need

constant and qualified attention from caregivers, aiming at a more effective treatment.

The need of constant assistance for children with cerebral palsy can make their caregivers become stressed, due to both the expectation regarding the result of the treatments and the future that these children might have. Such distress state can lead to changes in anxiety and depression levels. These factors directly influence quality of life, which comprises some characteristics such as satisfaction of individual need and desires, participation in activities enabling personal development, self-accomplishment, and satisfactory comparison between oneself and the others^(3,4).

Due to the importance of measuring the extent of changes in these emotional aspects, the use of instruments and questionnaires on quality of life has been acknowledged as an important contribution in the health field. In the clinical practice, these instruments can identify patient's needs and evaluate the effectiveness of interventions⁽⁵⁾. After studying the impact that different diseases have on quality of life, productivity, and social disability, the World Health Organization (WHO) stated that depression will be, by the year of 2020, the second leading cause of disability, after cardiovascular diseases⁽⁶⁾. In a study conducted by Westphal *et al*⁽⁷⁾ comparing quality of life and burden of caregivers of patients with epilepsy due to mesial temporal sclerosis and juvenile myoclonic epilepsy using the instrument Medical Outcomes Study 36 – Item Short-Form Health Survey (SF-36), a significant interference in their quality of life was observed in most domains.

Although many surveys on cerebral palsy have been conducted to evaluate its physiopathology, epidemiology, and treatment techniques, among other aspects, works on the caregivers and relatives of these children are still scarce⁽⁵⁾. Given the importance of better knowing the caregiver of children with cerebral palsy, this study aimed to evaluate the quality of life and the degree of anxiety and depression among these people.

Method

A cross-sectional and descriptive study was conducted in two public institutions that provide assistance to children with different deficiencies in the city of Maceió, state of Alagoas, Northeast Brazil: Association of Parents and Friends of Exceptional Children (Apae) and Association of Handicapped of Alagoas (Adefal). The size of the sample of caregivers of children with cerebral palsy was calculated by

convenience sampling, including 82 caregivers who attended the described institutions.

The study primary variables were: degree of anxiety and depression of caregivers of children with cerebral palsy, assessed by the Hospital of Anxiety and Depression Scale (HADS), and caregivers' quality of life, assessed by the SF-36.

The HADS is a short scale used to assess disorders in non-psychiatric settings; it has 14 items, seven for anxiety and seven for depression, and can also assess subjective symptoms more specific for depression. The scale was developed by Zigmond and Snaith, with a Portuguese version validated by Botega *et al*⁽⁸⁾.

The SF-36 is a Portuguese version of the Medical Outcomes Study 36 – Item short form health survey, which was translated and validated by Ciconelli⁽⁹⁾. It is a generic questionnaire, with concepts non-specific for a given age, disease, or treatment group, and allows comparisons between different diseases and treatments. Moreover, it considers the perception of individuals regarding their own health status and contemplates the most representative health aspects⁽¹⁰⁾. It is a multidimensional questionnaire comprising 36 items, grouped into eight scales or components: functional capacity (ten items), physical aspects (four items), pain (two items), general health status (five items), vitality (four items), social aspects (two items), emotional aspects (three items), mental health (five items), and also one question asking to compare the current health conditions with those from one year ago. The SF-36 evaluates both negative (disease or illness) and positive (well-being) health aspects.

After the application of the questionnaires, a semi-structured interview was conducted with caregivers, which explored the following guideline subjects: representations, repercussions, and demands arising from taking care of a child with cerebral palsy. The interviews were analyzed with the content analysis method.

HADS data were presented as mean, standard deviation, and 95% confidence interval (95%CI). SF-36 data were assessed based on the transformation of the answers into scores ranging from 0 to 100 for each component, which means that there was no unique value summarizing the entire evaluation, resulting in a better or worse general health status⁽¹⁰⁾.

The research was performed according to the ethical criteria established by resolutions 196/96 and 251/97, after approval by the Research Ethics Committees of Universidade Federal de São Paulo (Unifesp) and Universidade Estadual de Ciências da Saúde de Alagoas (Uncisal). Caregivers signed a free informed consent, after being informed on the purpose of the research.

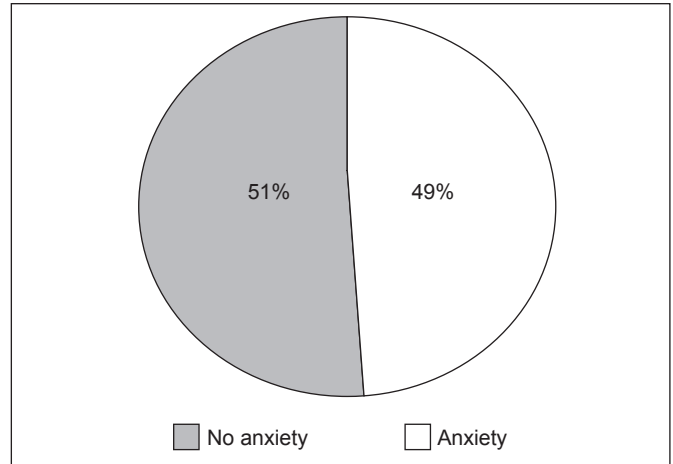


Figure 1 - Distribution of anxiety as assessed by the Hospital of Anxiety and Depression Scale

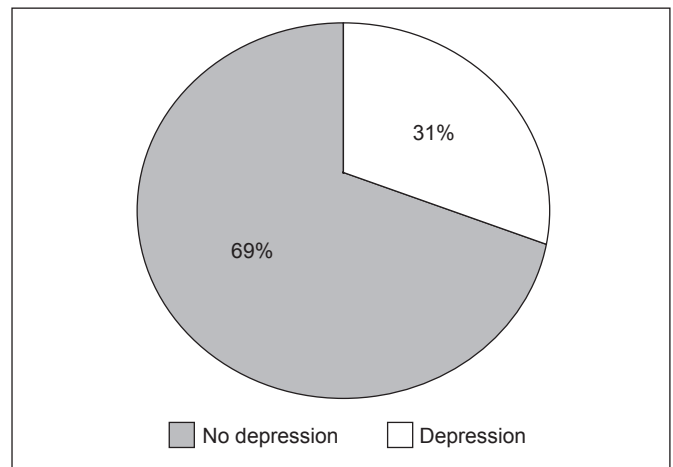


Figure 2 - Distribution of depression as assessed by the Hospital of Anxiety and Depression Scale

Table 1 - SF-36 score in the study sample

Domain	SF-36 score		
	Minimum	Mean (95%CI)	Maximum
Functional capacity	15	70 (65–75)	100
Limitation by physical aspects	0	67 (58–65)	100
Pain	0	60 (55–65)	100
General health status	5	60 (56–64)	100
Vitality	15	57 (52–62)	100
Social aspects	0	69 (63–75)	100
Limitation by emotional aspects	0	56 (46–65)	100
Mental health	8	63 (58–68)	100

Results

A total of 82 caregivers were interviewed, with a mean age of 32.4 ± 10.3 years, ranging from 18 to 77 (median of 31 years). Regarding educational level, the group showed the following rates: 5% were illiterate or had not completed elementary school; 67% completed elementary school; 23% completed high school; and 5% completed undergraduate school. The mean duration of care was 3.8 ± 1.3 years (median of four; range of two to five years).

The result obtained by the HADS (Figure 1), with a cutoff point of eight, showed a high rate of anxiety among the caregivers: 49% (95%CI 38–60%). Using a cutoff point of nine to assess depression (Figure 2), it was found a 31% rate for this condition (95%CI 22–42%).

As for the evaluation of caregivers' quality of life (Table 1), the domain 'functional capacity' showed a mean of 70 (95%CI 65–75); 'social aspects', 69 (95%CI 63–75); 'limitation by physical aspects', 67 (95%CI 58–65); 'mental health', 63 (95%CI 58–68); 'pain', 60 (95%CI 55–65); 'general health status', 60 (95%CI 56–64); 'vitality', 57 (95%CI 52–62); and 'limitation by emotional aspects', 56 (95%CI 46–65).

Discussion

The high levels of anxiety and depression observed among the caregivers studied (49 and 31% respectively), as well as their low quality of life, demonstrate the need for a greater attention to the health of these people. The caregiving routine is exhausting for the caregiver, causing different levels of stress, depression, anxiety, insomnia, physical symptoms like muscular pain, and hypertension⁽¹¹⁾.

During the performance of this research, it was also possible to notice a high degree of resignation among caregivers. This leads us to believe that the anxiety values observed may have been reduced due to this resignation. Many resigned caregivers reported that observing the deficiency of other children makes them resign to their own situation: "my child is so nice and is not as demanding as the others". Religious beliefs have also shown to be an important factor for this resignation, because many caregivers think that: "if it was God's will, it was meant to be". The allowance (pension) received by the child were also seen as an aspect that reduced anxiety, pointing out that this allowance is usually the main source of income of the family.

Among the factors that contribute to the establishment of anxiety and depression in caregivers, the stressful routine

to which they are submitted should be highlighted, usually facing transportation problems (lack of adequate means of transportation). In addition, this routine becomes even harder when one observes the poor knowledge that caregivers have about their children's disease and the treatment they require, especially considering the variability of cerebral palsy, which presents uniquely in each patient.

Rayna *et al*⁽¹²⁾, in a cohort study with mothers of children with cerebral palsy in Ontario, Canada, observed that the adoption of caregiving techniques with less energy expenditure in handling and positioning children contributes to the reduction in anxiety and depression levels. In Canada, 62% of caregivers were satisfied with the information regarding their children's diagnosis. This satisfaction was related to the amount and content of information⁽¹³⁾. The most important predictors of well-being in caregivers were child's level of impairment, caregiving demand, and family structure: the higher child's impairment is, the higher caregiver's physical and psychological impairment is; the lower child's impairment is, the higher caregiver's self-perception and stress management is; the lower caregiving demand by the children with cerebral palsy is, the better caregiver's physical and psychological well-being is. Stress levels showed to be directly related to cerebral palsy severity and to parent's satisfaction with diagnosis management and the information provided⁽¹³⁾.

Still with regard to determining factors of stress levels among caregivers, the difficulties in accessibility with wheelchairs, even in adapted buses, should be highlighted, which frequently obliges caregivers to carry their children on their back. Therefore, although these caregivers have knowledge on the correct positioning of their children, the fact of carrying them incorrectly hinders their treatment, due to the loss of the correct way of carrying.

Caregiver's self-perception and stress management are directly related to psychological well-being but not to physical well-being. The higher self-esteem and sense of mastery over care is, the higher psychological well-being is⁽¹²⁾.

Another important aspect for the increase in anxiety is the fact that caregivers usually compare the treatment response shown by their children with that of other children. This comparison can be a triggering factor for resignation or depression, if the caregiver concludes that the progress of his/her child was not the same as that shown by the other children who they met during the routine of treatment.

Caregivers of children with cerebral palsy also have higher likelihood of reduced physical well-being, with backache, migraine, intestinal and stomach ulcers, asthma, or arthritis/rheumatism,

as well as a higher number of chronic physical diseases⁽¹⁴⁾. Zarit⁽¹⁵⁾ reports that caregivers show higher rates of depression, anxiety, and other psychiatric symptoms, as well as other health problems, compared with the general population. Overall, these caregivers participate less in social activities, have more problems at work, and showed higher frequency of family conflicts⁽¹⁶⁾.

The evaluation of the quality of life of caregivers of children with cerebral palsy showed similar results to those found in caregivers of individuals with other diseases, such as childhood cancer, chronic obstructive pulmonary disease, multiple sclerosis, and juvenile idiopathic arthritis⁽¹⁴⁻¹⁷⁾, but differ in regard to the most affected domain. In a survey that assessed the quality of life of caregivers of children with juvenile idiopathic arthritis using the SF-36, the domains with worse score were: pain, with 65.4 points, and mental health, with 68.5⁽¹⁷⁾. It bears stressing that the score obtained by the caregivers of cerebral palsy patients in these domains was even lower, with 60 and 63 points respectively. On the other hand, in a survey by Forbes *et al.*⁽¹⁸⁾ that assessed the quality of life of caregivers of multiple sclerosis patients, the most affected domains were vitality, with 52 points, and general status, with 64. In the present survey, the domain limitation by emotional aspects was the most affected, with 56 points, followed by the domain vitality, with 57. The similarity of these results with those for multiple sclerosis is probably due to the fact that both conditions require constant care

from caregivers, leading them to a cumulative daily burden that often makes them lose their own self-care perception.

Klassen *et al.*⁽¹⁹⁾, in an investigation on the quality of life of caregivers of children with cancer, pointed out that the domains with worst performance were vitality (39 points) and mental health (54 points). Although the domains mental health, vitality, and limitation by emotional aspects were among the most impaired domains in the caregiver of cerebral palsy patients, it was possible to observe better raw scores than those found in caregivers of children with cancer, to whom the onset of the disease of their children happens abruptly and is not a gradual experience.

Therefore, the results of this research reveal that caregivers of children with cerebral palsy present high anxiety rate and a considerable depression value; additionally, they do not have a good quality of life, with special limitations in emotional aspects and vitality. It should be emphasized that caregiver's well-being is directly related to child's well-being. Professionals usually guide their actions to the patients that directly demand their health services. It is frequently forgotten that caregivers are also susceptible to disease. In this sense, it is important for health professionals to consider that the need of care to the child with cerebral palsy should be extended to the caregiver. This emphasizes the need of new studies that contribute to the search of an integral care of the child with cerebral palsy.

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