

Mother's Perception of the Quality of Life of their Children with Cerebral Palsy

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Abstract

Background: Quality of life is defined as individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. Due to the motor impairment, the cerebral palsy population is believed to have a differentiated perception of quality of life. The present study aimed to verify the impact of cerebral palsy on children and adolescents according to their mothers' perception. The evaluation of these patients' quality of life may be an important health indicator.

Methods: For this purpose, a total of 43 mothers of children and adolescents diagnosed with cerebral palsy participated in this study. Following classification of their children's gross motor function according to the Gross Motor Function Classification System, the children were divided into the following groups: Mild; Moderate; and Severe. To evaluate the quality of life, the Pediatric Quality of Life inventory (PedsQLTM 4.0) was used, and, to evaluate the mother's social support, the Social Support Questionnaire.

Results: The main finding of this work was that significant difference was observed between physical domains, where the more severe the motor impairment of a patient was, the lower the physical domain score of the patient's quality of life was. The number of people giving social support was shown to be larger for the mothers who reported worse quality of life of the children and teenagers with cerebral palsy participating in the study. There was no difference in the scores of overall's quality of life among the groups of study.

Conclusion: Based on our findings we conclude that the mothers' perception of quality of life is independent of the motor impairment of their children in an overall analysis.

Keywords: Cerebral palsy; Mental health; Quality of life; Infant development

Introduction

Quality of life (QoL) is defined by the World Health Organization (WHO) as individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns [1]. In a general analysis, this definition is based on aspects that include: subjectivity (inherent to the perception of wellness), multidimensionality (which includes, at the very least, the physical, psychological, and social dimensions) and both positively and negatively expressed dimensions [2].

The measurement of QoL is directly linked to the daily care practices of health services, and have been used as an important indicator for assessing the effectiveness and impact of specific treatments for patients with several disabilities [3], including cerebral palsy (CP) [4], besides contributes to obtain empirical evidence for the effectiveness of a range of interventions in this population [5].

Although it is well established in literature that in children with CP, developmental outcome is more than the result of medical treatment, and includes several factors all shown by QoL [4]. The QoL measurements among individuals with CP are known to pose

important methodological challenges, such as communicative barriers and a variety of disorders associated with the CP population [6,7].

The main characteristic of CP is motor disability, which is closely related to the area and extension of the lesion in the central nervous system (CNS) [8,9]. According to their motor ability and impairment, the patients may be classified into levels I, II, III, IV, or V by the Gross Motor Function Classification System (GMFCS) [10,11]. The higher the level is, the greater the dependence for locomotion and motor function is, and due to the motor impairment of the CP patient, the CP population is believed to have a differentiated perception QoL [4].

Despite the evaluation of these patients' QoL has become an important health indicator [12,13]. Health has a number of other indicators, among which social support stands out. Social support is a multidimensional concept, which refers to material and psychological resources to which people have access through their social networks. The beneficial effects for one's physical and mental health may be influenced by social support, which is associated with wellness and QoL [14].

It is difficult to obtain reliable information from persons with intellectual and learning disabilities or even others commitments that impair the utilization of the QoL's questionnaires [15], as may occur in CP [16]. In this context, mothers of a child with CP can be crucial in informing the QoL of your son with information that goes beyond the functional individuals limitations [17]. However, there are few works

in the literature that study this topic. Therefore, the aim of this study was to determine the mother's perception of the QoL of their children with cerebral palsy among the different groups of motor disability, correlating the different QoL domains with the child's degree of motor disability. Moreover we correlated the QoL perceived by the mother with the social support she receives and the social support with the motor disability classified according to the GMFCS.

Materials and Methods

This is a descriptive and correlational research, characterized by a cross-sectional analysis. All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. This research was approved by the local institutional committee, no 64/2011.

Sample characterization, setting and group formation

43 mothers, averaged 32.02 ± 3.14 years of age, of children and adolescents with CP were randomly selected for this study. The children averaged 8.07 ± 2.36 years of age; 24 (55.8%) were boys and 19 (44.2%) were girls. The groups were formed according to the degree of motor disability as follows: mild (9 participants – GMFCS I and II); moderate (16 participants – GMFCS III); and severe (18 participants – GMFCS IV and V). The setting was a rehabilitation center specialized in the treatment of neurological commitments.

Inclusion criteria

Mothers who were the primary caregivers of patients diagnosed with spastic, dyskinetic, ataxic, or mixed cerebral palsy according to the GMFCS criteria were included in the study. The patients could be of both sexes.

Exclusion criteria

Caregivers of patients diagnosed with motor impairments other than CP, mothers of patients in a postoperative period shorter than six months, or caregivers of patients who were to undergo a previously scheduled orthopedic surgery were excluded from the study.

Procedure

To determine the mother's perception of her child's QL, the PedsQLTM 4.0 Generic Core Scales was used [18]. It is constituted by physical, emotional, social, and school dimensions and is applied by an interviewer. To evaluate the mother's social support, the Social Support Questionnaire (SSQ) was employed [19]. It provides the number of people who give support to the interviewee and the satisfaction with the support that is received.

Data analysis

Results were analyzed using the The Kruskal-Wallis test to determine nonparametric analyses of variance. To determine whether there was a linear relationship between pairs of variables, the coefficient of Pearson was used. When one of the variables was a continuous quantitative variable and the other an ordinal qualitative variable, the Spearman correlation coefficient test was used instead. The level of significance was set at $p < 0.05$

Results

Relationship between quality of life and classification by the GMFCS

The mothers' perception of the QL of their children with CP did not differ among the study groups. However, there was a difference in the physical domain scores between the severe and mild groups, as seen in Figure 1a ($p < 0.05$). A decreasing linear correlation was observed between the variables motor impairment and physical domain scores, that is, the more severe the motor impairment, the smaller the physical domain score, as seen in Figure 1b) (Figure 1, $p < 0.05$).

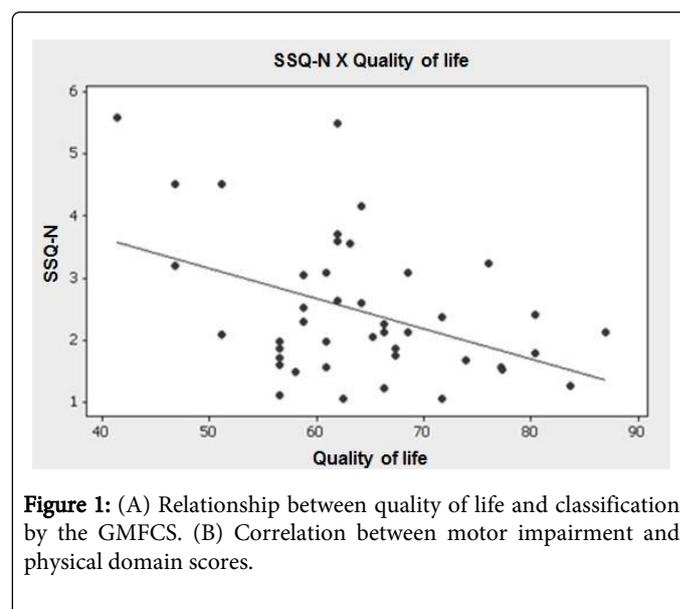


Figure 1: (A) Relationship between quality of life and classification by the GMFCS. (B) Correlation between motor impairment and physical domain scores.

Relationship between quality of life and social support

There was a decreasing linear correlation between the number of people giving the mothers social support (SSQ-N) and QL, that is, the lower the QL of the children and adolescents, the higher the SSQ-N score, as seen in Figure 2 ($p < 0.05$).

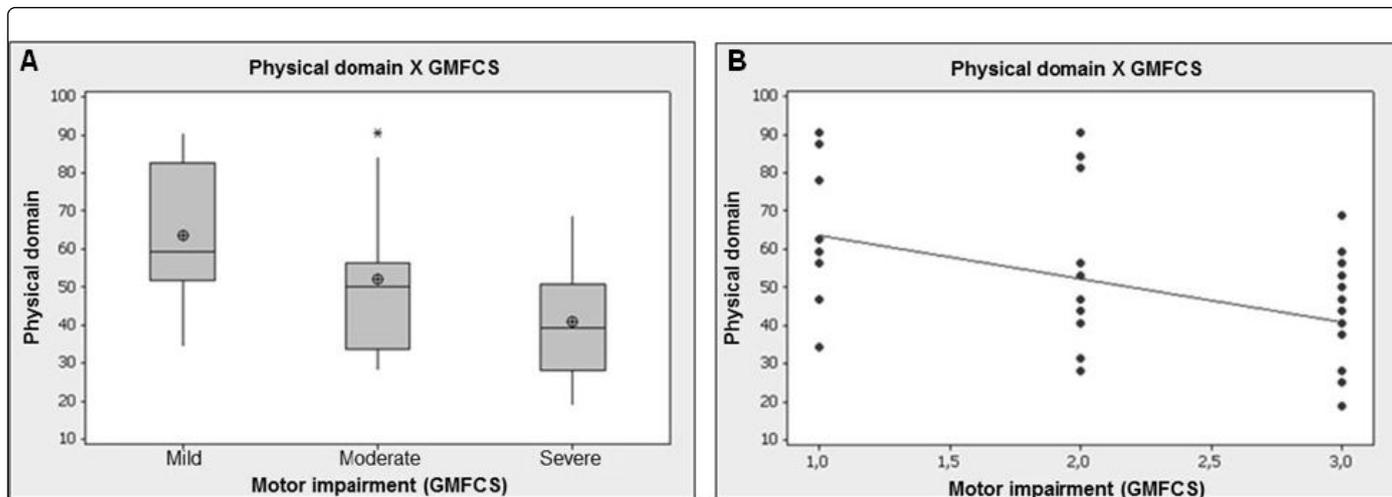


Figure 2: Relationship between quality of life and social support.

Relationship between social support and classification by the GMFCS

There was no significant difference in the number of people giving support to the mothers of children with CP among the mild, moderate, and severe groups.

Discussion

The main result of this study is that mothers' perception of QoL is not dependent on their children's degree of motor disability. Analysis of the physical domain of QoL also shows a correlation between the severity of the impairment and a decrease in the physical domain score. Furthermore, we observed a relationship between QoL and the number of supportive people indicating that the lower the QoL of the CP patient, the greater is the number of people who help the mother. Nevertheless, the mother's social support was not related to her child's degree of motor impairment.

The QoL in adolescents with CP varies with impairment and how it compares with the perceived QoL of peers in the general population [4]. In our work, the group with severe motor disability had a more impaired physical domain than the mildly motor disabled group. Also, the more severe the motor impairment of a patient was, the lower the physical domain score of the patient's QoL was. However the sample size in our study is representative just for the children with CP attended in our rehabilitation center. Further studies are needed, with larger samples.

Some findings showed that the most motor disabled children were the most prone to have their physical and autonomy domains impaired [20]. There is a strong correlation between motor disability in CP and QoL in the physical domain, where the more severe the disability, the lower the score given to the domain. For these authors, the psychosocial domain was better evaluated than the physical domain at all GMFCS levels [16].

Functional classification measures of systems such as the GMFCS were reliable indicators of physical function in QoL. However, they did not correlate consistently with psychosocial well-being; only physical well-being correlated with gross motor function [21]. In our study, no significant difference was observed between the patients' overall QoL

and mild, moderate, and severe motor impairment. This result is corroborated by other, who assessed the QoL of children with CP from their parents' standpoint with the Kidscreen generic questionnaire. These authors observed that children with severely impaired motor function were more likely to have poor QoL in the physical well-being and autonomy domains. However, greater severity of impairment was not always associated with poorer QoL. The risk of poor QoL in terms of social acceptance and school environment decreased with increasing severity of gross motor impairment [17].

The social support of the patients' caregivers was not associated with the children's motor disability. The degree of cognitive and motor impairment of adolescents with CP influenced neither the social support, assessed by the Multidimensional Scale of Perceived Social Support (MSPSS), given to the mothers nor the mothers' satisfaction with their life situation [21,22]. A study conducted in Canada, which compared the physical and psychological health of caregivers of children with CP with caregivers of the general population, found that social support received by caregivers of children with CP is greater than the support received by other parents [23]. Social support for patients with chronic diseases is help provided, for example, by family, friends, neighbours and others, and includes different domains, such as information, emotional comfort and practical help [24]. We observed that the lower the QoL of a patient, the greater the number of persons supporting the caregiver. It may be deduced that the decreased QoL of children and teenagers with greater motor impairment, from the standpoint of their mothers, required a larger number of supportive people due to the care geared towards helping the more dependent young in carrying out their tasks [25]. Thus, the greater the physical dependence, the greater the need for help [26,27].

In summary, the mothers' perception of QoL is independent of the motor impairment of their children in an overall analysis. However, more studies are needed to better understand the correlation between the multiple variables present in the CP and the measurement of the QoL. Assessing QoL of children with CP must be part of the main objectives in a rehabilitation program, contributing to promote well-being for this population.

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Declaration of Interest

The authors report no declarations of interest.

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