

Quality of life of family caregivers of children with microcephaly

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ABSTRACT. Assess the quality of life of family caregivers of children with microcephaly. This is an analytical cross-sectional study developed in Teresina-PI, carried out in a rehabilitation center. For data collection a form was used to investigate the sociodemographic profile and the Medical Outcomes Study 36 - Item Short-Form Health Survey instrument to assess quality of life. For data analysis, we used the statistical tests Student's t, ANOVA, U- Mann Whitney and Kruskal-Wallis. The descriptive analysis of the results showed that the functional capacity domain presented the most impairment by obtaining the highest score. The dimensions vitality and pain showed the lowest averages, representing the less affected domains. The associations between the sociodemographic characteristics and the domains of quality of life were significant between the variables marital status and pain, education and the domains vitality and emotional aspect, and between employment status and general health status. The quality of life of family caregivers presented losses related to the change of routine and the difficulties faced on a daily basis, highlighting the importance of covering the health of caregivers within the assistance offered to children with special needs, contributing to the well-being of those who care and consequently of those who are cared for.

Keywords: microcephaly; caregivers; quality of life; family.

Received on June 7, 2020.
 Accepted on March 15, 2021

Introduction

Microcephaly is a congenital malformation characterized by a significant reduction in the head circumference expected for age and sex, leading to cognitive and motor alterations that vary according to the degree of brain impairment. In addition to intellectual deficit, the commonly found alterations are associated with delayed motor and/or language development, ophthalmologic, cardiac, and renal impairments, contributing to a higher degree of dependence on care (Brasil, 2016; Brunoni et al., 2016).

The estimates made by the Ministry of Health for the year 2015 confirmed the increase in incidence indicators in the Brazilian northeast, relating its occurrence to the outbreak of infection by Zika virus, a flavivirus transmitted by the *Aedes aegypti* mosquito that occurred in the beginning of the same year in this region (Faccini et al., 2015).

From then on, strategies were strengthened for monitoring the epidemiological situation and the impacts on pregnant women and newborns. According to the 2018 epidemiological bulletin, 15,298 suspected cases were reported, in which 18.8% remain under investigation, 44.4% were discarded, 20.1% confirmed, 2.2% classified as probable for relation to congenital infection during pregnancy, and 1.5% as inconclusive (Brasil, 2018). In Piauí, since 2015 there have been 233 notified cases, with 115 confirmed through clinical and laboratory analysis (Piauí, 2018).

Although microcephaly is associated with Zika virus infection, this malformation can also be triggered by exposure or combination of different factors involving biological, chemical, physical or genetic dimensions. It is also a condition that has no specific treatment; however, there are supports to help children in their development (Brasil, 2015).

In this context, early stimulation stands out as an essential element for child development, being considered the main support measure capable of preventing and minimizing motor and posture alterations during the first years of life, a period considered being of greater brain plasticity. Thus, professionals and family members who participate in this early stimulation interfere in a positive way to improve neurological, behavioral, cognitive, social, and affective development (Brasil, 2016).

Children with neurological diseases need care that requires continuous knowledge, effort, and dedication, especially from caregivers. In the case of family caregivers, the need to prepare themselves to recognize new tasks and responsibilities makes the situation complex, stressful, and distressing, which can lead to other negative emotional reactions (Batista et al., 2016; Marques, Verza, Rossatti, Carbonero, & Campos, 2016).

In this context, it is emphasized that a caregiver is the person who is dedicated to the care of another person, taking care of his/her feeding, hygiene, leisure, and well-being. Caregivers can be differentiated into two categories: formal - who have specialized training for this function, and informal - family member, friend, or neighbor who performs the care without a professional relationship or specific training (Toledo & Ballarin, 2013).

The family caregiver plays a relevant role in the development and treatment of microcephaly, because they are people who stay most of the time with the child, taking care of his/her basic needs in an integral way, overlapping many times their own needs. Therefore, the evaluation of quality of life requires both the analysis of issues related to the disease and the biopsychosocial factors (Souza et al., 2014).

Because it is a complex task, the caregiver who does not receive support to meet his/her needs runs the risk of becoming a patient as well. The successful developmental evolution of these children is influenced by the health of their caregivers, which justifies the importance of assessing the quality of life of the primary caregiver of children with microcephaly (Ferreira et al., 2015; Santos et al., 2017).

For the World Health Organization (WHO), quality of life is the individual's perception of his own life, taking into account the cultural environment and the value system in which he lives and according to his goals, expectations, and concerns. This subjective concept covers psychological, social and physical aspects and their levels of independence, and this is the concept of quality of life adopted in this study (World Health Organization [WHO], 1995).

The objective of this study was to evaluate the quality of life of family caregivers of children with microcephaly.

Methods

Analytical cross-sectional study developed in Teresina, Piauí, between March and April 2018, in a rehabilitation center that offers specialized care for people with physical-motor, hearing, and intellectual disabilities, developing various therapies, sports rehabilitation, cognitive rehabilitation, and hearing.

This is a census survey, involving all family caregivers of children with microcephaly registered and actively participating in the said center during the collection period. The total population enrolled in the center was composed of 72 people, and 65 participants were selected. The inclusion criteria were: age 18 years old or older, to effectively participate of the child's care routine and to be attending the rehabilitation center during the research period; formal caregivers were excluded from the research.

Data collection was guided by two forms that investigated the sociodemographic profile and the demand for care. Thus, the following variables of interest were considered: sex, age, degree of kinship, marital status, education, employment status, family income, origin, religion, and amount of time as a caregiver.

To measure quality of life we used the generic instrument Medical Outcomes Study 36 - Item Short-Form Health Survey (SF-36) (Ciconelli, 1999). It is a multidimensional questionnaire, translated and validated for Brazil, composed of 36 items, distributed in eight domains: functional capacity, physical aspects, pain, general health status, vitality, social, emotional and mental health aspects. Its final score ranges from 0 to 100, where 0 corresponds to the worst general health status and 100 to the best health status.

Data was analyzed in the Statistical Package for the Social Sciences (SPSS) program. The descriptive analysis was expressed as mean, standard deviation, absolute and relative frequencies. The association between the sociodemographic characteristics, the demand for care and the domains of quality of life were evaluated by parametric Student's t test and ANOVA, and non-parametric tests U- Mann Whitney and Kruskal-Wallis. For all statistical tests a significance level of $p < 0.05$ was considered.

Data was collected after obtaining informed consent from the participants. The procedures were conducted in accordance with the ethical precepts contained in Resolution 466/12 of the National Health Council and with the Helsinki Declaration of 1964, revised in 1975, 1983, 1989, 1996 and 2000. This study was approved by the Research Ethics Committee of the Universidade Federal do Piauí under opinion number 2,527,878.

Results

The descriptive analysis of the sample studied showed a predominance of women ($n = 62$, 95.38%), with maternal relatedness ($n = 56$, 86.2%). The mean age of the participants was 30.2 years (± 8.5 years), 31 were 25 to 34 years old (47.69), and 39 (60.00%) were married. Regarding the level of education, 32 (49.2%) had completed high school, 54 (83.1%) were unemployed at the moment, 50 had income between 1 and 2 minimum wages (76.9%), 41 caregivers (63.1%) lived in the state capital, 42 (64.6%) were catholic, and the prevalent time as caregiver was 25 to 36 months (32; 49.23%) (Table 1).

Table 2 presents the quality of life scores, revealing greater impairments in the Functional Capacity domain (76.08 ± 18.65), while the lowest scores are verified in the Vitality dimensions (54.00 ± 23.77), followed by pain (55.98 ± 24.43).

Table 1. Characterization of caregivers according to demographic aspects. Teresina (PI), 2018.

Variables	N	%
Sex		
Male	3	4.62
Female	62	95.38
Age group		
18 to 24 years	18	27.69
25 to 34 years	31	47.69
35 to 44 years	10	15.39
45 or more	6	9.23
Degree of kinship		
Father	3	4.62
Mother	56	86.15
Grandparents	4	6.15
Uncles/Aunts	2	3.08
Marital status		
Married/Stable Union	39	60.00
Single	26	40.00
Esducation		
Incomplete elementary school	9	13.85
Complete elementary school	7	10.77
Incomplete High school	6	9.23
Complete High school	32	49.23
Incomplete Higher education	2	3.07
Complete High school	9	13.85
Work situation		
Formal work	8	12.31
Informal work	3	4.61
Unemployed	54	83.08
Family income		
Without income	1	1.54
Less than 1 MW	8	12.31
1 to 2 MW	50	76.92
3 to 5 MW	6	9.23
Origin		
Teresina	41	63.08
Interior of Piauí	23	35.38
Timon, Maranhão	1	1.54
Religion		
Catholic	42	64.61
Protestant or Evangelical	14	21.54
Jehovah's Witness	1	1.54
No religion	8	12.31
Time you have been a caregiver		
0 to 12 months	6	9.23
13 to 24 months	26	40.00
25 to 36 months	32	49.23
37 months or older	1	1.54

Table 2. Description of the score obtained in the domains of the SF-36 questionnaire in the family caregivers' assessments. Teresina (PI), 2018.

Domains	Min – Max*	Mean ± SD
Functional Capacity	20.00 - 100.00	76.08 ± 18.65
Physical Aspect	0 - 100.00	64.61 ± 31.53
Pain	0 - 100.00	55.98 ± 24.43
General Health Status	10.00 - 92.00	57.01 ± 18.72
Vitality	0 - 100.00	54.00 ± 23.77
Social Aspect	0 - 100.00	66.92 ± 26.74
Emotional Aspect	0 - 100.00	57.95 ± 37.40
Mental Health	12.00 - 100.00	66.89 ± 22.11

Key: Min: minimum; Max: maximum; SD: standard deviation; *The variation of minimum and maximum scores results from the individual evaluation of the participants in each domain.

The associations between the sociodemographic characteristics of family caregivers, the demand for care and the SF-36 domains showed statistical significance between the variables marital status and the Pain domain ($p = 0.018$), education and the Vitality ($p = 0.029$) and Emotional Aspect ($p = 0.046$) domains, and between Work Status and General Health Status ($p = 0.031$) (Table 3).

Table 3. Association between caregivers' demographic aspects and the domains of the SF-36 questionnaire. Teresina (PI), 2018.

Variables	Functional Capacity	Physical aspect	Pain	General health status	Vitality	Social aspect	Emotional aspect	Mental Health
	p-value	p-value	p-value	p-value	p-value	p-value	p-value	p-value
Sex	0.541 ^k	0.625 ^u	0.941 ^u	0.115 ^t	0.288 ^t	0.734 ^u	0.521 ^u	0.965 ^u
Age Group	0.552 ^a	0.857 ^k	0.235 ^k	0.446 ^k	0.409 ^a	0.797 ^k	0.860 ^k	0.927 ^k
Relationship	0.859 ^k	0.789 ^k	0.192 ^k	0.362 ^a	0.221 ^a	0.284 ^k	0.802 ^k	0.556 ^k
Marital Status	0.493 ^u	0.338 ^u	0.018 ^u	0.795 ^t	0.908 ^t	0.249 ^t	0.080 ^u	0.506 ^u
Education	0.554 ^k	0.566 ^k	0.679 ^k	0.282 ^k	0.029 ^k	0.114 ^k	0.046 ^k	0.062 ^k
Employment status	0.640 ^k	0.118 ^k	0.241 ^a	0.031 ^a	0.658 ^a	0.931 ^k	0.640 ^k	0.931 ^k
Family income	0.172 ^k	0.860 ^k	0.356 ^k	0.355 ^k	0.863 ^a	0.254 ^k	0.536 ^k	0.238 ^k
Origin	0.435 ^k	0.133 ^k	0.690 ^k	0.965 ^a	0.320 ^a	0.476 ^k	0.406 ^k	0.424 ^k
Religion	0.185 ^k	0.215 ^k	0.564 ^k	0.820 ^a	0.782 ^a	0.709 ^a	0.406 ^k	0.147 ^k
Time as a caregiver	0.053 ^k	0.452 ^k	0.422 ^k	0.724 ^a	0.415 ^a	0.895 ^k	0.199 ^k	0.940 ^k

Key: k: teste Kruskal-Wallis; u: teste U Mann-Whitney; a: Anova; t: teste t de Student;

Discussion

The family caregiver spends a lot of time attending to the child's needs, most of the time relegating their own needs. The personal separation from family, work, and social life are the main factors in the decrease of quality of life. In this study, it was observed that in the quality of life instrument, the vitality domain was the most affected, followed by the pain domain.

Similar to the results of this study, research conducted with caregivers of people with special needs evidenced the impairment of vitality and also pain (Pellosiet al., 2017). The vitality domain involves factors related to the presence of vigor and/or physical and mental exhaustion, directly involved with the adaptation process when assuming the role of caregiver, which brings responsibilities and tasks to the daily life that did not exist before, besides the other activities that already existed, which leads the person to have to adjust his/her entire daily routine and meet this excessive and continuous demand, which can become exhausting (Santos et al., 2017).

The pain domain also presented a low score in the caregivers' quality of life. A cross-sectional study carried out with mothers of children with cerebral palsy in Turkey presented similar results, showing musculoskeletal pain as the most frequent, especially in the lumbar and neck regions (Albayrak, Biber, Çalışkan, & Levendoğlu, 2019).

It is worth noting that caring for children with neurological problems involves support in terms of feeding, bathing, dressing, walking, and assisting in transferring, exposing these caregivers to problems in the musculoskeletal system (Terzi & Tan, 2016).

When relating the eight domains of the SF-36 questionnaire and the sociodemographic questionnaire, it was observed that the marital status variable associated with the Pain domain presented significant statistics. In some situations, the caregiver presents health problems that, added to the responsibility of care, can

intensify the already existing comorbidities, such as the presence of pain, interfering in his/her physical well-being (Barros, Barros, Barros, & Santos, 2017).

When the amount of burden and the difficulties of care increase, mothers feel desperate and, as a result, their QoL decreases significantly (Garip et al., 2017; Farajzadeh, Amini, Maroufizadeh, & Wijesinghe, 2018). Thus, it is fundamental to reduce the care load of the caregiver by other family members to help reduce further functional impairments and improve the emotional and psychosocial aspect (Albayrak et al., 2019).

Education was statistically significant in the Vitality and Emotional Aspect domains. The level of education has influence on the care provided, because the little education can hinder the process of knowledge about the pathology, the adherence to proper care to be offered, making the care process more distressing and consequently generating a greater emotional burden to the caregiver (Araújo et al., 2013). As these emotional aspects can interfere significantly in caregiving, the multi-professional support helps in the development of strategies to overcome the daily difficulties in the lives of family members (Brunoni et al., 2016).

Another significant association was the variable Work Status and the domain General Health Status. This finding can be justified by the predominant age group in the study. Younger caregivers tend to suffer more with the new responsibility, because they are in an active age group in society and in the labor market, thus they end up having difficulties or withdrawing from social and professional life, which can generate frustration in the personal, emotional, and social areas (Costa, Costa, Fernandes, Martins, & Brito, 2015; Barros et al., 2017).

In addition, the caregiver's work activity directly influences the family's income. In cases of absence from work, financial problems may occur, making this process more difficult for the caregiver (Costa et al., 2015).

Quality of life is a current highlight in the health scenario, since the process of caring is very complex, since the family caregiver is vulnerable to so many negative feelings such as anxiety, anguish, depression, frustration, among others (Fernandes, Ferreira, Marodin, Val, & Fréz, 2013). Studying the impacts of the act of caring on the caregiver's quality of life enables new dimensions to be adopted by health services, guiding more specific conducts and treatments (Santos et al., 2017).

Conclusion

This study identified that most of the family caregivers of children with microcephaly are the mothers themselves, most of them married, with complete high school education, unemployed and with family income of 1 to 2 minimum wages. The quality of life presented losses related to the change of routine and the difficulties faced on a daily basis, thus, one can highlight the importance of covering the health of caregivers within the assistance offered to children with special needs, contributing to the welfare of those who care and consequently of those who are cared for.

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