

Sleep quality of primary caregivers of children with microcephaly from a public health facility in Alagoas, Brazil

ABSTRACT

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OBJECTIVE: To evaluate the sleep quality of primary caregivers of children with microcephaly that receive treatment in a public health facility.

METHODS: This is a transversal, descriptive and quali-quantitative study. Ten informal primary caregivers of children with microcephaly from a public health facility in Alagoas were interviewed one-on-one for 20 minutes using the mini-sleep questionnaire (MSQ). MSQ scores were statistically analyzed to describe sleep disturbances (mean, median and standard deviation), and the relationship between the level of microcephaly and sleep quality was tested by Kruskal-Wallis non-parametric test.

RESULTS: Results found herein shows the predominance of women as caregivers of children with microcephaly. Overall, the studied population showed a high prevalence of alteration in sleep quality, with 70% of sampled caregivers showing severe sleep disturbances (scores greater than 30). No relationship between the level of microcephaly and sleep disturbances were found ($p>0.05$).

CONCLUSIONS: There is a high prevalence of sleep disturbances among primary caregivers of children with microcephaly in the studied facility. This pattern is of great concern as such disorders may negatively affect not only the caregivers' life quality, but also the quality of provided care.

KEYWORDS: Life quality. Sleep disturbances. MSQ.

INTRODUCTION

Starting in October 2015, an unexpected raise in the number of microcephaly cases was observed in the whole Brazilian territory, with the majority of cases reported in the Northeastern region (MARINHO *et al.*, 2016). In Maceió, for example, 31 cases of children with microcephaly were reported by the end of 2017 (MERCADO, 2017), all linked to Zika virus infection during pregnancy. Such matter led the Brazilian government to declare a national public health emergency in the end of 2015 (JAENISCH *et al.*, 2017).

Children born with microcephaly may develop different disorders throughout their growth process, such as hearing loss, vision problems and learning disabilities (PEREIRA-JÚNIOR *et al.*, 2018), making the presence of a full-time caregiver extremely necessary (BARBOSA *et al.*, 2017). In general, one or more family members arise as the caregivers and assume the caring task, facing the different problems caused by the children's condition and giving their total physical and emotional support (VEGA ANGARITA; GONZÁLEZ ESCOBAR, 2009). These caregivers are usually females, housewives, and first-degree relatives who provide all necessary support during normal daily activities, such as feeding and bathing (VELÁSQUEZ; LÓPEZ; BARRETO, 2014).

Although satisfactory, the caregiver role has been consistently linked to many disorders undergone by caregivers, especially those related to the physical, psychic and emotional burden (PERES; BUCHALLA; SILVA, 2018). Burden can make caregivers vulnerable to frustrations and tensions, causing stress and social exclusion (BUTCHER; HOLKUP; BUCKWALTER, 2001; SÁ *et al.*, 2017). These issues can directly affect the life quality of caregivers, triggering several problems associated with physical and mental health, like fatigue, weight loss, anxiety, depression and physiological changes in sleep (LEE *et al.*, 2015; SOUZA; COUTINHO, 2006).

In this context, sleep disturbances deserve a considerable attention due to its concerning potential in causing health problems (ALIHOSSEINI; NAJAR; HAGHIGHIZADEH, 2017). The human sleep is characterized as necessary recovery process for the body (CARSKADON; DEMENT, 2011; ORENGO *et al.*, 2012), being physiological regulated by the circadian rhythms and adjusting the biological clock (DAAN; BEERSMA; BORBELY, 1984). Any alteration in sleep quality may result in disturbances that affect the well-being of individuals, such as systemic arterial hypertension and cardiovascular diseases with short, medium and long-term consequences (BIANCHI *et al.*, 2013; GONÇALVES *et al.*, 2015; LIU *et al.*, 2016).

Furthermore, sleep disturbances may also have an impact on the quality of provided care (ABAY *et al.*, 2016), being harmful for the children's treatment. In this respect, it is extremely necessary to identify possible alterations in sleep quality of caregivers of children with microcephaly to not only promote strategies of public attention for these individuals, but also to guarantee that the children are not affected by the caregivers' state. Therefore, the present study aimed to characterize the primary caregivers of children with microcephaly in a public health facility in Alagoas, Brazil, and evaluate their sleep quality.

MATERIALS AND METHODS

This is a quali-quantitative, descriptive and transversal study. The study was carried out in a public health facility located in Maceió, Alagoas, Brazil. The Specialized Center of Rehabilitation (CER III) offers assistance in the diagnosis and treatment of children with special needs, including those with microcephaly (BRASIL, 2018). Currently, the CER III provides treatment for 15 children with microcephaly that live in the city of Maceió and nearby areas.

SAMPLE SIZE, INCLUSION CRITERIA AND DATA COLLECTION

The participants of this study were the primary caregivers of children with microcephaly that receive treatment in the CER III in Maceió. Only one caregiver at legal age (+18 years old) per child was included in this study. Caregivers responsible for other children with special needs and those which were considered formal caregivers (paid to give care) were excluded. Sample size and the completeness of our sample were evaluated following recommendations of Miot (2011). Although, the sample size test showed that seven interviews would accurately express sleep alterations in caregivers, all 15 caregivers that currently seek treatment in the CER III were invited to participate.

Out of these, five subjects decided not to participate, and interviews were carried out with the remaining 10 caregivers. Participants were approached by researchers in the clinic while children were receiving physiotherapy treatment. First, the purpose of study was explained to participants and the Informed Consent Form (TCLE) was read and clarified by researchers. After acceptance of subjects to participate in the present study, the TCLE was signed by caregivers and data collection started. Caregivers were interviewed one-on-one for 20 minutes in a closed room using a small semi-structured socio-demographic questionnaire (to characterize sample) and the mini-sleep questionnaire (MSQ).

MINI-SLEEP QUESTIONNAIRE (MSQ)

Sleep quality of caregivers of children with microcephaly was evaluated by the mini-sleep questionnaire (MSQ) of Zomer *et al.* (1985), which was adapted and translated into Portuguese by Gorenstein, Tavares and Alóe (2000). This questionnaire is comprised of 10 evaluative items that quantify the frequency of occurrence of events that could negatively impact the sleep of interviewed subjects. The maximum score is 70, and a score greater than 30 indicates severe alteration in sleep quality (GORENTEIN; TAVARES; ALÓE, 2000).

Caregivers were classified into four sleep quality categories following Ghezzi *et al.* (2005): scores between 10 and 24 represent a good sleep quality; scores of 25 to 27 show weak alterations in sleep; scores of 28 to 30 denote moderate alteration in sleep and scores greater than 30 indicate extreme alterations in sleep.

DATA ANALYSIS

Sleep quality of caregivers was analyzed by descriptive statistics (mean, median and standard deviation), and alterations in sleep of all caregivers were evaluated by the one-tailed student's t-test. For the t-test the mean score of 24 was used for comparison as this value is a well-established threshold that represents a good sleep quality (GHEZZI *et al.*, 2005).

In order to identify whether the level of microcephaly is a crucial factor in altering caregivers' sleep quality, a Kruskal-Wallis test was performed to compare the MSQ scores acquired from caregivers of child with mild (-2 standard deviation) and severe microcephaly (-3 standard deviation) (ALANIZ, 2018). Kruskal-Wallis test was chosen as data did not meet the assumptions of parametric tests (normality and homoscedasticity) even after several transformations. Statistical analyses were carried out in the software PAST Statistic version 3.21 (HAMMER; HARPER; RYAN, 2001) at a significance level of 5% ($p < 0.05$).

The research project was approved by the Committee on Research Ethics of the State University of Health Sciences of Alagoas (UNCISAL) under the number #86632718.2.0000.5011/2018.

RESULTS

All 10 interviewed caregivers were family-related women with age ranging from 18 to 48 years (mean age of 33 ± 10 years). Seven caregivers were the child's mother ($n=7$), two were the grandmother and only one was the aunt. All caregivers reported to be unemployed, dedicating their full-time to the caring task. In regard to the education level, four caregivers had primary education (40%), two had finished their secondary studies (20%), three had ended high school (30%) and only one had completed a university degree (10%). A family income of one minimum wage per month or less was reported for all caregivers.

Scores retrieved from the mini-sleep questionnaire (MSQ) ranged from 16 to 56 with an average score of 37.5 ± 12 (Table 1). Overall, the caregivers of children with microcephaly were found to present severe alterations in sleep (t-test, t-value = 3.53, $p < 0.05$) with only one caregiver (10%) showing a good sleep quality, two (20%) presenting moderate alterations in sleep, and seven caregivers (70%) displaying extreme alterations in sleep (Figure 1).

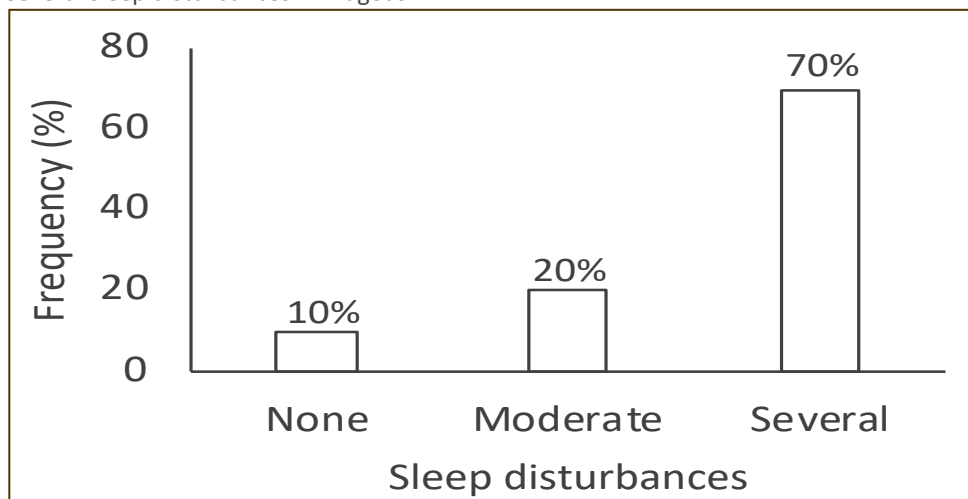
Table 1 – Description of sleep quality of primary caregivers of children with microcephaly in Alagoas through the mini-sleep questionnaire (MSQ) scores

Level of Microcephaly	Sleep Quality (MSQ scores)				
	N	Range (min-max)	Median	Mean	Standard deviation
Mild	6	28-56	41	41.33	12.1
Severe	4	16-41	35	31.75	10.9
Total	10	16-56	35	37.50	12.0

Source: Authors (2019).

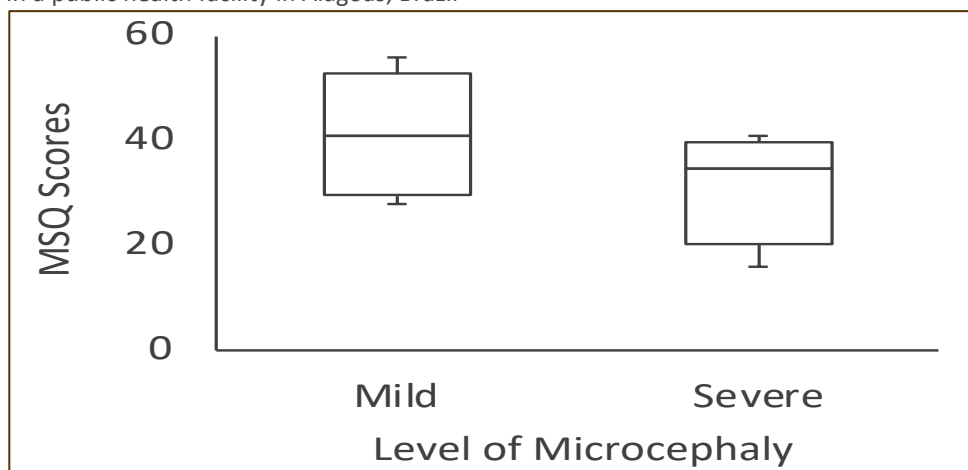
Although the lowest values for the MSQ score were found for caregivers of children with severe microcephaly (Figure 2), no significant differences were identified between both studied groups – caregivers of children with mild microcephaly and children with severe microcephaly (Kruskal-Wallis, $p>0.05$). This result indicates that sleep quality of caregivers may be negatively affected by the act of caring regardless the child’s level of microcephaly.

Figure 1 – Frequency in percentage of primary caregivers presenting none, moderate and several sleep disturbances in Alagoas.



Source: Authors (2019).

Figure 2 – Variability in sleep quality of primary caregivers of children with microcephaly in a public health facility in Alagoas, Brazil



Source: Authors (2019).

DISCUSSION

In this study, women were the only support of children with microcephaly, comprising 100% of our sample size. This pattern of females as primary caregivers of children with special needs has been reported in many other studies and it is usually associated to traditional beliefs rooted in a cultural context (MONTEIRO *et al.*, 2016; SANTOS *et al.*, 2010).

For instance, women have been, culturally and historically, characterized as the main source of support for disabled children (PEREIRA-JÚNIOR *et al.*, 2018), as they are typically romanticized as responsible for the caring task (KURZ; LUZ, 2014).

This pattern may be problematic for two main reasons. First, many studies have shown that female caregivers present a poorer quality of life than male (BYRNE *et al.*, 2010), as women tend to put the child's needs and safety before their own (LITORP *et al.*, 2015).

This leads women to assume intense and complex tasks, not worrying about their physical and mental health (CASADO-MEJÍA; RUIZ-ARIAS, 2016). Second, the rooted belief that women are natural caregivers is only an idea and norm regarding gender-role behavior that reinforces the feeling of duty and obligation (GUBERMAN; MAHEU; MAILLÉ, 1992), which creates distress that can be aggravated when the caregiver is family-related to the child (FAVERO-NUNES; SANTOS, 2010).

In this respect, it is important to notice that all interviewed caregivers were family-related to the children, with 70% of them being the child's mother. This is also a common pattern found in other studies and typically results from social and economic factors. For example, more than half of our sample size had little schooling and all of them had a monthly income of one salary or less per family, which is a typically setting of caregivers that use public health services (BARROS *et al.*, 2017).

The mean age of 33 years found for the caregivers is considered a highly productive age for paid employment, however, all subjects reported being unemployed and having no paid work at the time they were interviewed. Although concerning, this pattern is very common among primary caregivers since the caring task may require their full-time (GONÇALVES; TENÓRIO; FERRAZ, 2018).

For example, children with microcephaly are totally dependent on caregivers for daily activities, demanding their total attention and devotion, which causes a negative impact on work activities or any other activities outside their homes (PIMENTEL; FURTADO; SALDANHA, 2018). This affects mainly women – especially when they are the child's mother – that tend to quit their jobs to take care of the child, adding to the financial burden (DHANDAPANI *et al.*, 2015).

The total dedication combined with the intensity of performing multiple tasks and the financial burden of low income affect the functional capacity, health and well-being of caregivers (NOZOE *et al.*, 2017). For instance, 70% of studied caregivers presented severe alterations in sleep, which is contrasting to what was observed by Carvalho, Gomes and Trindade-Filho (2010) that showed that more than 50% of the adult population in Maceió have a good sleep quality. This high prevalence of alteration in sleep among caregivers shows the impact that the caring task may have on the health of primary caregivers of children with microcephaly.

Nozoe *et al.* (2017) highlight the importance of sleeping for caregivers, as sleep disturbances when untreated may cause other severe injuries such as depression and neuropsychiatric disorders (PEREIRA; SOARES, 2015), having a negative impact in the caregivers' life quality.

Even though the relationship between the caregiver role and sleep disturbances has been widely described in literature (MARX *et al.*, 2011), the factors that drive such correlation are often difficult to be identified. For example, in the present study, the level of microcephaly was tested as a main factor causing alterations in sleep quality of caregivers, however, no significant differences were found between sleep quality of caregiver in both studied groups – caregiver of children with mild and severe microcephaly (Figure 1). The absence of a relationship between the level of microcephaly and sleep quality of caregivers may be due to the factor that regardless the level of microcephaly, the children born with microcephaly is totally dependent on caregivers (PIMENTEL; FURTADO; SALDANHA, 2018). Indeed, many studies have shown that dependency is a crucial factor in altering sleep (CHRISTOFOLETTI *et al.*, 2013).

Furthermore, it is important to be noticed that there are many daily challenges faced by informal caregivers, which can have negative impacts on sleep, especially when they are family-related to the patient. For example, housework, taking care of other children, comments from society and even the exacerbated exposure of the subject in the media (COSTA *et al.*, 2018). In fact, the study of Diniz *et al.* (2018) showed that there are many aggravating factors of sleep disturbances for informal caregivers in comparison to those who are formal, since the emotional burden plays an important role in affecting the life quality of caregivers, causing a constant feeling of sadness and guilty.

Anyhow, this prevalence of sleep disturbances in informal caregivers of children with microcephaly is of extreme concern as disorders in sleep can be associated to many health problems, especially to arterial hypertension and cardiovascular diseases with short, medium and long-term consequences (BIANCHI *et al.*, 2013; GONÇALVES *et al.*, 2015; LIU *et al.*, 2016). Moreover, many studies have shown a close relationship between poor sleep quality and depression in caregivers (CUPIDI *et al.*, 2012), which is problematic as depressive symptoms are not always recognized, leading caregivers to fail in seeking treatment.

Although the present work has only been carried out in one public health facility, the results showed herein give ground to initiate the discussion about how important is to promote health actions for caregivers of children with microcephaly. Sleep quality is a determinant factor of good physical and mental health of caregivers and has great potential to influence the quality of provided care. Therefore, future researches about caregivers' sleep and health are extremely necessary. In conclusion, our study shows that there is a high prevalence of sleep disturbances among primary caregivers of children with microcephaly in the studied facility. This pattern is of great concern as such disorders may negatively affect not only the caregivers' life quality, but also the quality of provided care.

Qualidade do sono de cuidadores primários de crianças com microcefalia em uma unidade de saúde pública de Alagoas, Brasil

RESUMO

OBJETIVO: Avaliar a qualidade do sono de cuidadores primários de crianças com microcefalia que recebem tratamento uma unidade de saúde pública.

MÉTODOS: Este é um estudo transversal, descritivo e quali-quantitativo. Dez cuidadores primários informais de crianças com microcefalia de uma unidade de saúde pública em Alagoas foram entrevistados por 20 minutos utilizando o mini-questionário do sono (MQS). Os escores do MQS foram analisados estatisticamente para descrever alterações no sono (média, mediana e desvio padrão), e a relação entre o grau de microcefalia e qualidade do sono foi testada pelo teste não paramétrico de Kruskal-Wallis.

RESULTADOS: Os resultados encontrados mostram a predominância de mulheres como cuidadoras de crianças com microcefalia. No geral, a população estudada mostrou uma alta prevalência de alterações na qualidade do sono, com 70% dos cuidadores entrevistados apresentando distúrbios severos no sono (escores maiores que 30). Não foram encontradas relações entre o grau de microcefalia e os distúrbios do sono ($p > 0,05$).






CONCLUSÕES: Existe uma alta prevalência de distúrbios do sono entre os cuidadores primários de crianças com microcefalia na unidade estudada. Este padrão é de grande preocupação uma vez que distúrbios no sono podem afetar negativamente a qualidade de vida dos cuidadores, e a qualidade do cuidado.

PALAVRAS-CHAVE: Qualidade de vida. Distúrbios do sono. MQS.


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