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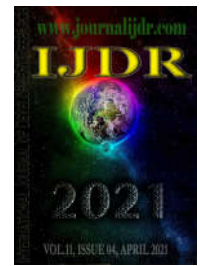
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RESEARCH ARTICLE

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IMPACTS OF MICROCEPHALY ON MATERNAL AND CHILD LIVES: SYSTEMATIC REVIEW AND META-ANALYSIS

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ABSTRACT

The aim of the study is to identify the psychosocial and financial impacts of microcephaly on maternal and child lives. This study is a systematic review followed by meta-analysis covering the databases from the Virtual Health Library: SCIELO and LILACS. Articles in English, Portuguese and Spanish within a publication period of the last 5 years were taken as references, using the descriptors in DeCS: Microcephaly, mother and quality of life, in addition to the use of the Boolean operator AND. The analysis has a final effect of 0.39 considering a CI from 0.36 to 0.41, which represents a large effect on the impacts of microcephaly on quality of life. Therefore, it is crucial to understand the impacts that the pathology generates, so that more public policies are implemented aimed at improving not only the quality of life of the patients, but also of the family and society. Thus, ensuring a better health care guideline.

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INTRODUCTION

Characterized by reduced head circumference, microcephaly is a neurological condition defined by the Live Birth Information System (SINASC) as a head circumference (HC) ≥ 3 standard deviations below the average established for sex and age. In boys, the measurement is equal to or less than 31.9 centimeters, while for girls it is equal to or less than 31.5 centimeters (Bertuoli, 2016). Microcephaly has a complex and multifactorial etiology, and can be caused by genetic and environmental factors.

Children with microcephaly have their health conditions impaired due to numerous complications resulting from the disease, such as developmental delay, intellectual deficit, seizures, physical, auditory and visual limitations, difficulty in coordination and balance as well as learning disabilities (Félix, 2018; Costa et al., 2018). The aforementioned factors make those children totally dependent on their mother's daily care, which can lead to physical and mental complications due to the overload of activities that are relied on their caregiver, the mother, in order to care for the child (Félix, 2018; Costa et al., 2018). The diagnosis of microcephaly can mean, for

some families, a moment of distancing from what they have wanted and imagined as perfect. After being aware of microcephaly, the family faces not only the mourning process for an “ideal baby”, but also judgment and prejudice due to the perception of a defective body, resulting in stigma. Thus, the family's living system is completely changed. It is common for the family to be unable to talk about the subject and deny the situation. Many mothers after receiving the diagnosis go through moments of shock, anger, fear, anxiety, somatization, sadness, among others (Vale, 2018; Santos, 2018). Some of the changes in daily routine experienced by most families that receive the diagnosis of microcephaly include: having all the attention directed to the sick child, needing more time and greater dedication in caring for the sick child; and leaving aside other activities that were previously performed, such as household chores, other children's and husband care, study and leisure (Freitas, 2018; Garcia et al., 2019).

Given the context, the following guiding question arises from the research: What are the impacts of microcephaly for the binomial mother and child? This study was based on the acronym PVO, in which "P" refers to mother and child, "V" to psychosocial and economic impacts and "O" to microcephaly. It is fundamentally important to understand the psychosocial and financial impacts, both on the affected child and on the family, so that a full and early diagnostic evaluation and treatment can be carried out, with the support of a multi-professional health team. Therefore, this study aims to identify the psychosocial and financial impacts of microcephaly on maternal and child lives.

METHODS

This study is a systematic, exploratory review, followed by meta-analysis. Moreover, the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) (Downs, 1998) ([hHYPERLINK "http://www.prisma-statement.org/"](http://www.prisma-statement.org/) HYPERLINK "<http://www.prisma-statement.org/>" [ttp://www.prisma-statement.org/](http://www.prisma-statement.org/)) were followed. The search period was carried out in 2020, during June, and it covered the articles from the databases: LILACS and SCIELO via the Virtual Health Library. Articles in English, Portuguese and Spanish within a publication period of the last 5 years were taken as references (2015-2020). Regarding descriptors, this study followed the Health Sciences Descriptors (DeCS): Microcephaly, mother and quality of life (QOL), in addition to the use of the Boolean operator AND. Studies in Portuguese, English and Spanish, that had been published between the years 2015 and 2020, and that were available in full and free of charge, were included. Inconclusive and/ or replicated articles, studies that were unavailable in full or that were paid, and papers that did not focus on impacts, as well as reports and reviews, were excluded. The selection of articles was carried out based on the evaluation of the titles and abstracts selected from the research, followed by the evaluation of the eligibility of potential full papers. All studies that met the eligibility criteria were included. When more than one study was sampled, the one with the largest sample size was included. The risks of bias in the selected studies were analyzed according to Downs and Black (1998) scale⁸, which consists of the analysis of the quality of the study (10 items); ability to generalize study results (3 items); study bias (7 items); determination of bias by the sample (6 items) and determination of random findings (1 item). From the data collected, a meta-analysis was done based on the samples and populations described in order to better assess the impact that the clinical situation can cause.

RESULTS

Using the aforementioned descriptors, 150 studies were found. Considering both inclusion and exclusion criteria, 5 studies were selected and included in the systematic review and meta-analysis. Figure 1 is a summary of the methodological steps for searching and selecting studies in order to come to a final sample. In the following

table there is a summary of information extracted from the selected articles in order to analyse the risk of bias, containing the name of the author and the year when it was published; aim of the study; its outcome and score on the Downs and Black scale. Based on the selected articles, a meta-analysis was developed in order to evaluate the impacts of microcephaly in the analyzed context, that is, maternal quality of life.

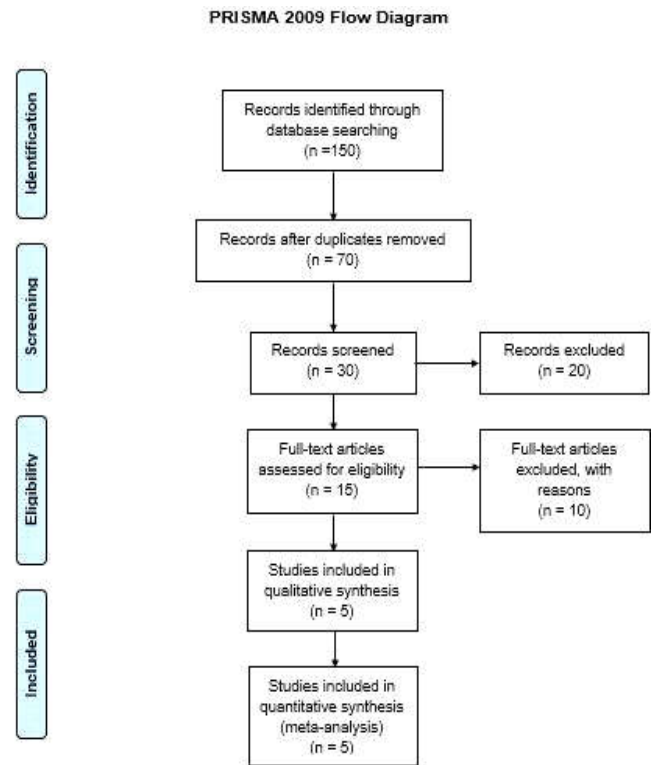


Figure 1. Searching and selection method.

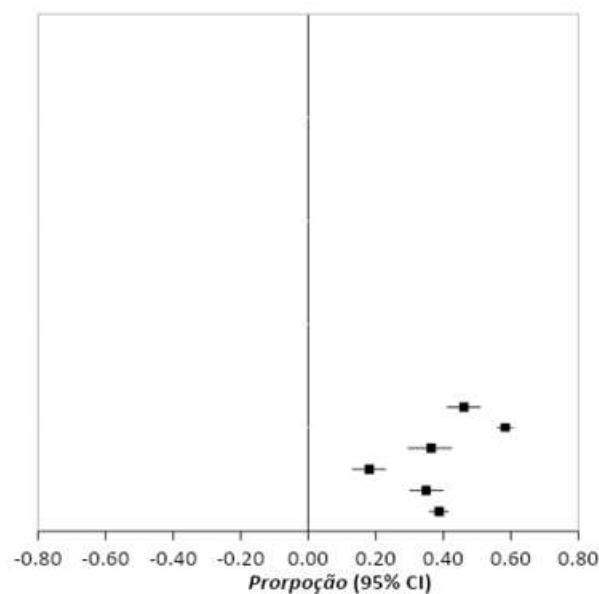
DISCUSSION

The analysis shows a final effect of 0.39 with a CI of 0.36 to 0.41, which represents a large effect on the impacts of microcephaly on quality of life. Microcephaly is characterized by a congenital malformation, has a very complex etiology and can occur due to multiple factors. Moreover, it impacts not only the child with the disease, but also the family environment, since there is a greater vulnerability in psychological, cultural and socioeconomic aspects, as well as in the society they experience (Lowe, 2020; Barata Ana Luiza Santos Ramalho Beirão, 2019). The profile of most women infected with Zika Virus was of low educational level, low income, brown or black skin, young and who had difficulty in inclusion in the work environment. This shows a profile related to part of the population that is in a state of social vulnerability (Diniz, 2016; Butler, 2016). Corroborating with studies that concluded that most cases of Congenital Zika Syndrome (CZS) occurred in families that live in disadvantaged and marginalized areas (United Nations Development Program, 2017; Souza, 2018). The microcephalic child demands special care, because of this the caregiver ends up renouncing important moments in life, since they tend to leave aside their needs to maintain the child's well-being by dedicating their full time to activities such as bathing, feeding, managing medications and helping to maintain the child's skills. Another study (2018) reports that most mothers of children with microcephaly had a professional occupation before the child's birth, but gave up their job because they became unable to fulfill their tasks, as a result these changes end up promoting social and financial changes in the lives of these women (Garcia, 2019; Fernandes, 2018). Mothers of children with microcephaly are entitled to the Continuous Cash Benefit (BPC) which is guaranteed by the Organic Law on Social Assistance

Table 1. Risk of bias based on the selected studies

SANTOS DBC, 2018.	To analyze the quality of life and burden of primary caregivers of children with microcephaly associated with congenital infection.	All care for the child was performed by the mothers; 39% presented severe burden and 30.5% strong burden. Mothers were classified as having moderate to severe burden. Environmental and physical domains showed greater losses in QOL; as well as an inversely proportional correlation between QOL and burden of care.	23
COSTA ES, et al., 2018.	To analyze the consequences of integral care of children with microcephaly in the life of their caregiver.	99.1% of caregivers are female. Most mothers reported that their child's health is regular; 34.9% reported not enjoying life very much and 22.6% declared not enjoying anything at all. The vast majority (62.3%) said they had impaired sleep and 39.6% said they were dissatisfied with themselves; 43.4% stated that they do not have enough time to perform their tasks due to or care for the child.	23
FREITAS AAF, 2018.	To assess the family impact in parents of children with microcephaly affected by Zika Virus.	The mother is the main caregiver and the majority belongs to a low social class status. Moreover, higher scores in relation to family impact were found in young mothers and in divorced people; many of the investigated mothers left aside their role as a wife, professional, mother of other children and student to dedicate themselves exclusively to the child with microcephaly.	24
GARCIA ER, et al., 2019.	To analyze the quality of life of caregivers of children with microcephaly.	The mother was identified as the main caregiver (91.76%), being the majority of them also responsible for housework (58.82%). Health satisfaction, perception of QOL and the environment domains had the lowest percentages related to QOL. Moreover, the physical domain had the highest percentage. Aspects of healthcare and financial resources were listed as the most difficult by caregivers.	24
FERNANDES CCF, 2018.	To evaluate mothers of children with microcephaly's quality of life and compare it with the mothers of children without neuropsychomotor impairment.	Mothers of children with microcephaly obtained low scores not only with regard to QOL but also considering the sum of scores from all other domains. However, the statistical difference with the mothers of children without neuropsychomotor impairment were not very significant. Thus, QOL transcends the absence of disease, being also influenced by living conditions, absence of transport, among others.	25

Source: Developed by authors, 2020.



Source: Developed by authors, 2020.

Figure 2. Meta-analysis of the impacts of microcephaly on maternal quality of life

Corroborating with studies that concluded that most cases of Congenital Zika Syndrome (CZS) occurred in families that live in disadvantaged and marginalized areas (United Nations Development Program, 2017; Souza, 2018). The microcephalic child demands special care, because of this the caregiver ends up renouncing important moments in life, since they tend to leave aside their needs to maintain the child's well-being by dedicating their full time to activities such as bathing, feeding, managing medications and helping to maintain the child's skills. Another study (2018) reports that most mothers of children with microcephaly had a professional occupation before the child's birth, but gave up their job because they became unable to fulfill their tasks, as a result these changes end up promoting social and financial changes in the lives of these women (Garcia, 2019; Fernandes, 2018). Mothers of children with microcephaly are entitled to the Continuous Cash Benefit (BPC) which is guaranteed by the Organic Law on Social Assistance (LOAS). This assistance aims to defray the expenses that involve child care. Nonetheless, given the lack of financial alternatives due to full-time dedication to the child, this aid ends up being the main source of income used to supply the family's needs (Santos, 2018). Another study carried out with 85 mothers who cared for children with microcephaly identified that most of these women did not work due to the need for full-time care for the child and had BPC as their main source of income (Garcia et al., 2019). A study carried out with mothers of children with cerebral palsy, a condition similar to microcephaly, compared fatigue among mothers of children with and without cerebral palsy, showing that fatigue had higher rates in mothers of children with paralysis and, these mothers also had higher chances of developing depression (Garip, 2016). Quality of life of mothers of microcephalic children is not only influenced by the chronicity of the child's condition and the care demanded by them, it is also influenced by housing conditions, absence of transportation, basic sanitation and other factors, being evidenced by the low scores in the environmental domain (Fernandes, 2018). Microcephaly can usually promote changes in the family's routine, generating psychological, physical, social and professional changes of their caregivers, who, in most cases, are their mothers. It is important that the caregiver also receives care, social assistance, recognition and guidance, since the full-time dedication to the care of their microcephalic child can promote an overload of work that results in processes of physical and emotional stress (Silva, 2019; Santos, 2017).

FINAL CONSIDERATIONS

The impacts caused by microcephaly permeate the family environment, generating difficulties in addition to psychosocial and economic changes, as well as the need for new implementations of family routines. Therefore, it is essential to understand the impacts generated by the pathology, so that more public policies can be implemented and carried out with a view to improving the quality of life of the patients and families involved.

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