

ORIGINAL ARTICLE

FEMALE CAREGIVER'S EXPERIENCES REGARDING THE CARE OF CHILDREN WITH MICROCEPHALY*

VIVÊNCIAS DE CUIDADORAS SOBRE O CUIDADO DE CRIANÇAS COM MICROCEFALIA

EXPERIENCIAS DE CUIDADORES CON RESPETO AL CUIDADO DE NIÑOS CON MICROCEFALIA

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ABSTRACT

Objective: to describe experiences related to female caregivers' experience regarding the care of children with microcephaly associated with the Zika virus. **Method:** this is a qualitative, descriptive, exploratory study, conducted with the support of two female participants/caregivers of children with microcephaly, through semi-structured interviews and analyzed by the IRAMUTEQ software, which generated the word cloud and the similarity tree. **Results:** the term "child" was evidenced in the reports as of paramount importance in the female caregivers' lives. It was noticed that the father figure and/or family members were not linked to the care process and the governmental assistance directed to the female caregivers was flawed due to the lack of specific health promotion activities. It is pointed out that mothers faced drastic changes in their life trajectories and felt alone. **Conclusion:** it can be seen that the experiences revealed the overload, the responsibilities and the resignification of the female identity with self-perception, primarily focused on the social role of mother/female caregiver of the child with microcephaly. **Descriptors:** Microcephaly; Zika Virus; Female Caregivers; Child; Nurse; Qualitative Research.

RESUMO

Objetivo: descrever experiências relacionadas à vivência de cuidadoras sobre o cuidado de crianças com microcefalia associada ao Zika vírus. **Método:** trata-se de um estudo qualitativo, descritivo, exploratório, realizado com o apoio de duas participantes/cuidadoras de crianças com microcefalia, por meio de entrevistas semiestruturadas e analisadas pelo software IRAMUTEQ, que gerou a nuvem de palavras e a árvore de similitude. **Resultados:** evidenciou-se o termo "filho" nos relatos como de suma importância na vida das cuidadoras. Percebeu-se que a figura paterna e/ou os familiares não estavam vinculados ao processo de cuidado e a assistência governamental direcionada às cuidadoras era falha devido à carência de atividades específicas de promoção de saúde. Aponta-se que as mães enfrentaram mudanças drásticas em suas trajetórias de vida e se sentiram sozinhas. **Conclusão:** constata-se que as experiências revelaram a sobrecarga, as responsabilidades e a resignificação da identidade feminina com a autopercepção, prioritariamente, voltada para o papel social de mãe/cuidadora da criança com microcefalia. **Descritores:** Microcefalia; Zika Vírus; Cuidadores; Criança; Enfermagem; Pesquisa Qualitativa.

RESUMEN

Objetivo: describir las experiencias relacionadas con la experiencia de los cuidadores con respecto al cuidado de niños con microcefalia asociada al virus del Zika. **Método:** este es un estudio cualitativo, descriptivo, exploratorio, realizado con el apoyo de dos participantes/cuidadores de niños con microcefalia, a través de entrevistas semiestructuradas y analizadas por el software IRAMUTEQ, que generó la nube de palabras y el árbol de similitud. **Resultados:** el término "hijo" se evidenció en los informes como de suma importancia en la vida de los cuidadores. Se observó que la figura paterna y/o los miembros de la familia no estaban vinculados al proceso de atención y que la asistencia gubernamental dirigida a los cuidadores era defectuosa debido a la falta de actividades específicas de promoción de la salud. Se señala que las madres enfrentaron cambios drásticos en sus trayectorias de vida y se sintieron solas. **Conclusión:** se encontró que las experiencias revelaron la sobrecarga, las responsabilidades y la resignificación de la identidad femenina con la autopercepción, principalmente enfocada en el papel social de la madre/cuidadora del niño con microcefalia. **Descriptores:** Microcefalia; Virus Zika; Cuidadores; Niño; Enfermería; Investigación Cualitativa.

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INTRODUCTION

It is known that microcephaly became the protagonist of studies in Brazil and worldwide when, between 2015 and 2016, the number of reported cases in Pernambuco was alarming, besides being highlighted for being associated with gestational infection by Zika virus, a correlation that, *a priori*, was unprecedented on the world stage. After the change and strengthening of several ordinances and norms for the notification, investigation and diagnosis of microcephaly, the relationship between the cause and consequence of Zika virus infection and microcephaly was indeed proven.¹

In this sense, it is pointed out with the confirmation of the diagnosis of microcephaly in proportions never experienced in the country, that challenges arose, such as understanding which host and care network should be formed. Thus, it was established the creation of new services and the improvement of existing ones for the care of children with special needs in order to ensure that, immediately after delivery, multidisciplinary care was offered, in order to carry out a complete assessment of the needs and demands that these children should receive, both to promote early stimulation and to perform management. Therefore, physical development is envisaged to try to minimize the limitations of microcephaly, and social development, which includes the family and society.²

Recommendations regarding the care with difficult eating, the need for daily exercises for early stimulation, the change of periodic position and other demands are difficult to apply in practice, since families, in most cases, are unaware how to proceed, a fact aggravated by the unpreparedness of professionals regarding quality care and guidance that meets the reality of affected families.³

It is necessary for caregivers to understand that caring for a child with special needs involves individual, social and labor renunciation, due to the great demand for exclusive dedication. In the case of a developing country such as Brazil, the renunciation of labor activity directly compromises family income and, consequently, the necessary financial resources for child care and family maintenance makes reality versus necessity contradictory and permeated by sacrifices and actions involving the female caregivers of children in this condition.³⁻⁴

The approach of this theme is anchored in the progressively high rates of confirmed cases of microcephaly in the country, as well as the compromised quality of life of those who experience this occurrence in their families.⁵ In this context, it is sought to deepen the understanding of the social and political aspects

that permeate family involvement and public institutions, by understanding and interpreting the epidemiological situation of microcephaly in municipalities of the Northeast, especially the state of Bahia. Thus, in order to unveil family involvement in the face of the problem, the research question was: “What do the experiences of female caregivers reveal about the care of children with microcephaly associated with the Zika virus disease?”.

OBJECTIVE

- To describe experiences related to female caregivers' experience regarding the care of children with microcephaly associated with the Zika virus.

METHOD

This is a qualitative, descriptive, exploratory study that had as its locus the Rehabilitation Center located in the city of Senhor do Bonfim, in the state of Bahia. It is found that the three cases registered in the municipality, related to the occurrence of Zika virus during pregnancy and occurred between 2015 and 2018, had the support of two female participants/caregivers of children with microcephaly. As inclusion criteria, female caregivers of children with microcephaly who were over 18 years old and residing in the municipality of Senhor do Bonfim were adopted. Female caregivers of children with microcephaly with confirmed diagnosis of syphilis, toxoplasmosis, rubella, cytomegalovirus or herpes (STORCH).

Data was collected through interviews, conducted in January 2019, following a semi-structured script containing sociodemographic data and questions about the trajectory of the Zika virus infection from the moment of diagnosis to the present moment, highlighting if the caregiver's experience. Responses to the interviews were recorded after consent on an MP3 player and transcribed to Microsoft Word. They were then processed in the Software interface of R pourles Multidimensional Analysis of Textes and Questionnaires (IRAMUTEQ).

The following word classes were removed for software processing: indefinite and supplementary adjectives; definite and indefinite articles; prepositions and the word “no” in order to eliminate from analysis terms that are often repeated in the statements and which would not add analytical meanings. One chose to select the words that presented frequency of five or more. Following, two figures were obtained: the tree of similarity and the word cloud, which allowed the analysis of co-occurrence and frequencies.

Similitude analysis by researchers of social representations is often used, as it makes it possible to identify the co-occurrences between

words and their results indicate the existence of connectedness; However, its use also presents consistency for other theoretical contributions.⁶ After the analysis, based on the generated figures, the results and findings of the scientific literature on the theme were compared to the discussion and conclusion of this paper.

This research was conducted according to Resolution 466 of 2012 of the National Health Council, with emphasis on the principles of bioethics: beneficence; nonmaleficence; autonomy and justice.⁷ Participants were clarified regarding the benefits of research and its contribution to the production of scientific knowledge in public health, as well as the collaboration to strengthen research in the area of nursing.

The risks of participants 'emotional compromise and exposure of personal factors were minimized by conducting a private interview and ensuring the confidentiality of the participants' information and identity. In addition, the interview served as a listening moment and enabled female caregivers to answer questions about microcephaly caused by the Zika virus.

It is indicated that the signing of the Free and Informed Consent Term (FICT) made clear the right of participants to refuse or withdraw the research at any time. The study was submitted and approved in 2018 by the Ethics Committee on Research with Human Beings of the State University of Bahia under the Certificate of

Presentation for Ethical Appreciation (CAAE) 02359118.7.0000.0057.

RESULTS

Three confirmed cases of microcephaly caused by the Zika Virus occurred in the municipality of Senhor do Bonfim, according to records from the Rehabilitation Center. The three female caregivers were invited to participate in the study, but only two accepted. It is noteworthy, as both assumed to be the only female caregivers of the children, that the corpus of this study consisted of the interviews of the two participants.

Many similarities were found regarding the characteristics of the participants: ages 25-30 (young adults); mothers were the main female caregivers of children with microcephaly; neither worked at the time of data collection due to the child's need for care; both had financial difficulties and received about one minimum wage and neither attended higher education. They refer to the differences found in previous occupations, since one of them worked outside the home, but left the service to dedicate herself exclusively to the care of her child. Only one of the pregnancies was planned, but both were accepted by the interviewed mothers and their families.

It is noted that the interviews were initially lemmatized and grouped by similar meanings in meaning nuclei. They were then processed in the IRAMUTEQ software, which generated figure 1.

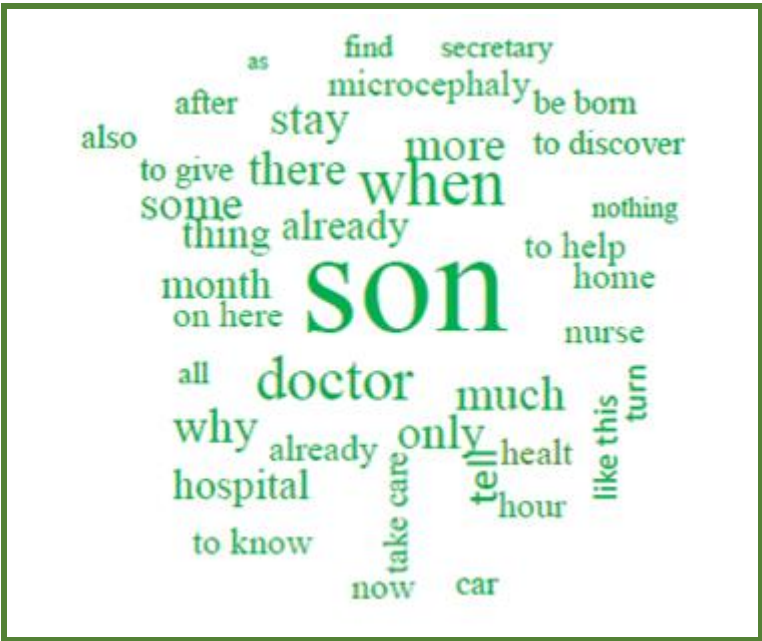


Figure 1. Word cloud about experiences related to female caregivers' experiences regarding caring for children with microcephaly. Senhor do Bonfim (BA), Brazil, 2019.

The word cloud is known to relate the most frequently occurring terms and to highlight the most relevant ones in a larger size. From this parameter, it can be seen that the term “child” has importance in the lives of these women, being the element that stands out the most by the frequency criterion. There are also occurrences of terms related to health care provided to both the

female caregiver and child, evidenced by the word “doctor”, with high frequency. Other terms in the cloud are also related to health care delivery, but they are less frequent: “nurse”; “hospital”; “Health” and “caring”.

It is understood that the textual corpus, formed from the interviews, also made possible

the analysis of similarity, resulting in the production of the similarity tree (Figure 2).

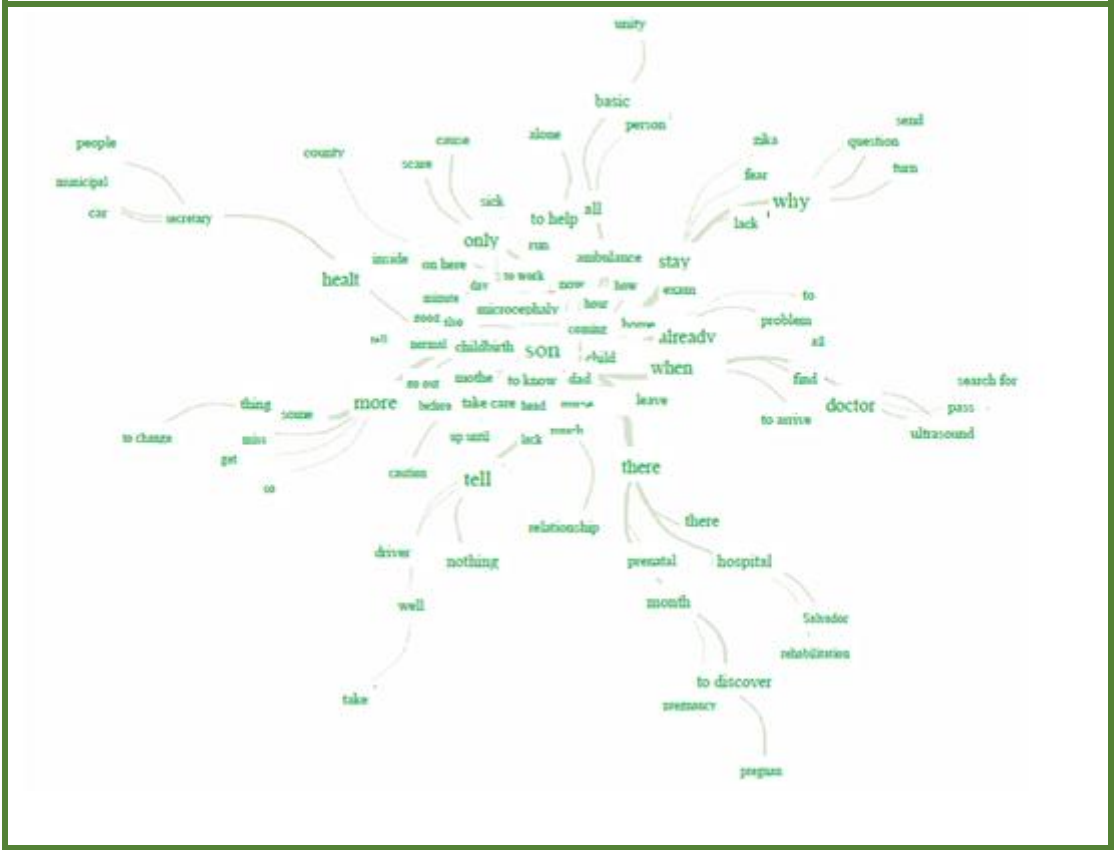


Figure 2. Tree of similarity about the experiences related to the experience of female caregivers about caring for children with microcephaly. Senhor do Bonfim (BA), Brazil, 2019.

In the structure of the tree a single core of meaning is identified and, as in the cloud of words, the term "son" is the center that aggregates all branches. The branches reveal the existence of subgroups related to the points that can be linked to Zika virus and microcephaly aggravation. In addition, aspects related to the assistance of health professionals, such as "prenatal care", "diagnosis of microcephaly", "experience of childbirth" and "postpartum care" are visualized. Finally, issues related to changes in female caregivers' lives are located through the terms "everything", "alone" and "caring".

DISCUSSION

It is considered that the term "child", in the word cloud, when occupying the centrality of the image, forms the nucleus of agglutinating sense facing the main issues experienced by the female caregivers when faced with the microcephaly situation. From the other words associated with the problem and involving health professionals, it is demonstrated the role that doctors have/had in the lives of these participants, mainly because they are the professionals responsible for the remarkable moment of the diagnosis of Zika virus infection in pregnancy.⁵ In addition to the impact caused from the moment of infection diagnosis until the confirmation of microcephaly, the branches reveal feelings and anxieties that mark the time between diagnosis and delivery, according to the proximity between the words "doctor" and "to know". It is evident, however, as

well as the doctor, the nurse, in the speeches of the participants, as a recognized professional and active in the path of care and experience of microcephaly associated with the virus.

It is suggested that the remarkable moment between the experience and the experience arises in the home environment of the mother and female caregiver woman. Through the analysis of figure 1, elements that show their importance in the words "home", "help" and "nothing", which occupy the same core of meaning, are presented. Attention is drawn to the detachment of the father figure in the care process, since the expression "father" is linked to another core, although related to the term "care", but far from "help", which characterizes the mother as the child's primary female caregiver.

Regarding the assistance provided by the Unified Health System (UHS), it is observed that the service provided to children is presented in the axis composed by the words "microcephaly", "born" and "secretary", proving the relationship and, in a first analysis, the development of actions by public health services. However, it is warned that there is no evidence of assistance to mothers or health promotion activities of female caregivers.

In this scenario, it is understood that the first branch analyzed portrays the Zika virus and microcephaly as something feared, demonstrated by the proximity of the term "fear", as well as the perception of misunderstanding of the situation, evidenced by the word "why". This is a recent

injury at the time the participants were affected. Also noteworthy is the recent discovery about the association of microcephaly with Zika virus infection, which, in the female caregivers' imagination, represents something incapacitating and difficult to overcome.^{4,8}

In the second subgroup under analysis, it is pointed out that the term "prenatal", being close to the words "discover", "pregnancy" and "nurse", demonstrates that, for these women, prenatal is related to apprehension, as it is critical for Zika virus infection. It is understood that the term "nurse" reveals the consultations performed by this professional and its importance in monitoring and guidance on diagnostic tests to confirm contamination and the occurrence of microcephaly in their children. It is emphasized that, for female caregivers, ultrasound imaging was inaccessible due to poor financial conditions.

It is also considered, in this axis of appreciation, that prenatal care is the crucial moment of the "revelation" of the diagnosis of microcephaly and, therefore, the association between the terms "doctor", "find" and "ultrasound" demonstrated that the diagnosis was made through prenatal consultations, performed by the doctor and/or nurse, after the ultrasound examination. However, it is noteworthy that the expression "microcephaly" is only located in another subgroup, associated with the terms "born" and "childbirth", which reveals the realization of the diagnosis only at the time of the child's birth.

There are multiple nuclei of meaning related to the experiences of childbirth, such as the terms "mother", "care", "more", "missing", "change" and "achieve", associated with the expression "microcephaly". Therefore, it is understood that the moment of childbirth marks, in the lives of these women, a new universe of real ideas and demands, as, when looking at their children, they visualize the modification of physical characteristics, which consolidates the diagnosis.

It is known that microcephaly presents new challenges that add to those already experienced.² It can be seen in figure 2, by the proximity of the words, that there is a lack in the provision of care services, as well as the mother's responsibility for the need to overcome the difficulties caused by the new situation in which there is a family member affected by microcephaly that demands special care.

One can understand by analyzing the terms "working", "alone", "running" and "helping" the level of impact that caring mothers of children with special needs face. In this scenario, it is observed that the mother puts her individuality, desires and needs aside, in order to provide the best care. It is pointed out that, feeling alone, on a few occasions, it has punctual help. Thus, it is

believed that the life trajectory of caregiving mothers conforms to the changes that impacted their routines and, consequently, overloaded them.

The literature discusses the centrality of the figure of the child because it sometimes overlaps with the woman's own age, which, by dedicating herself exclusively to the care of her children with special needs, causes the psychosocial exhaustion of the mother figure, who usually, by social convention of machismo and social imposition, be considered solely responsible for taking care of the child. It is argued that this phenomenon generates a social stigma according to which the female caregiver should believe that only she is capable and responsible for the integral attention to the child, especially in the conditions of chronic illness, as happens in microcephaly.^{3,8}

Health professionals are defined as indispensable for breaking negative social constructs, which place on women, mothers and female caregivers the unique burden of family care. It is suggested that the nurse, in providing care to families affected by microcephaly, should promote a detailed dialogue on this condition, individually, in order to explain its complications, clinical condition, consequences, necessary care and involvement of the woman's social network.⁹ It is specified that this is where family and social media should be made available.

It is pointed out that the role of the multiprofessional team is important for effective care for children with microcephaly, since neurological impairment leads to delays and deficits that can be resolved or mitigated with Speech Therapy, Nutrition, Physical Therapy, Occupational Therapy, Psychology services and nursing.¹⁰ In this sense, Nursing is inserted as the profession of greatest continuity in care, since it accompanies family health in all life cycles.

Through childcare consultations, we evaluate the expected parameters for age and health condition in children with microcephaly, orientations to the family on the development of home care and direct attention to the child. Nursing acts effectively in the care of children with microcephaly and one of its actions is the installation of the nasogastric tube, to facilitate the process of infant feeding in the early periods of children with microcephaly, since many of them have difficulties in swallowing.¹¹⁻²

The importance of communication between the nurse and the family members of children with microcephaly, who need information about the disease and the reception of professionals in view of the feelings generated by the diagnosis of the disease, is emphasized. It is verified that parents and other family members experience feelings of surprise, sadness, despair, pain, shock,

disorientation and fear, demanding attention and care from the entire team, especially Nursing.¹³

Regarding home care and primary care, it is known that there are care networks for pregnant women and children with microcephaly. However, it is clear that setting up an effective comprehensive care network is a major challenge for most municipalities. Since, besides the countless needs demanded by this grievance, which requires investments and political commitment, there is the problem of family relations, in which members do not want to compromise or take responsibility for the care. In addition, there are cases in which family income is not compatible with the expenses that the disease demands.¹⁴

In the home environment, the lack of preparation and lack of structure to deal with something new that changes the family routine is recognized. The financial issue is seen as the main argument for the removal of family members, of the child's father, but it is emphasized that the attention given by public agencies and institutions is still deficient, as the demand for costs and public policy-making is disproportionate to the impact that Zika virus-related microcephaly can have on families and in society.¹⁵

It is observed that the changes caused in the child's life, associated with the caregiver's burden, involve structural issues of the social system, the historical predominance of machismo and, perhaps, the inefficient care networks, which make the mother responsible for the integral care delivery. In addition, the caregiver often has to leave the job to take care of the child, which causes the impairment of social and psychological life, especially regarding the aspects of self-care, empowerment and self-perception as a woman.^{3,8}

Another relevant aspect associated with care overload is that mental health may be impaired due to suffering resulting from the diagnosis of microcephaly. It is noted that mothers experience less positive and more negative effects, have a lower level of life satisfaction and a higher level of fatigue, and therefore may have worse mental health. Parents are found to be less involved in childcare, and women assume primary responsibility for childcare and other housework.¹⁶

CONCLUSION

It was concluded that the research developed was sufficient to unveil the experiences of female caregivers about caring for children with microcephaly. The findings revealed the child's role as a central axis in the participants' lives. Thus, it is pointed out that the other aspects of the existence of these women always pass by the figure of the child, evidencing, also, the resignification of the individual self-perception for the priority function of mother/female caregiver.

In relation to family support, the distance from both the father figure and other family members and friends was evidenced. It is believed that this causes feelings of abandonment that generate defining changes in the female caregivers' lives, such as the loss of autonomy, the withdrawal of their identity as a woman and the overload of responsibilities. This study aims to contribute to the discussion of important aspects for the development of programs and public policies aimed at holistic care of female caregivers and children with microcephaly.

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