

REPRESENTATIONAL STRUCTURE OF MICROCEPHALY AND SELF-IMAGE FROM MOTHERS OF CHILDREN WITH THE NEUROLOGICAL AFFLICTION

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ABSTRACT: This study aimed to analyze the representational structure of microcephaly, as well as the self-image that mothers of children with the illness possess. There were 105 Brazilian women, aged between 20 and 50 ($M=31$; $SD=7.32$), who live, mostly, in the south-eastern region of Brazil (39.0%). For data acquisition, in 2018, it was used the Free Word Association Technique. Prototypical analyses of the collected material demonstrated that the participants build their representations upon microcephaly based on scientific knowledge, also describing it using signs that refer to spirituality and love. When it comes to the participants' self-image, it was possible to notice elements that support the feature resilience and other factors that are associated with self-transcending characteristics. The identified representations reveal adaptive processes, based on the allocation of resilient resources that allow the participants from this study to give a different meaning of being a mother of a child with microcephaly.

KEY WORDS: Behavioral medicine; Microcephaly; Psychology, social; Self concept.

ESTRUTURA REPRESENTACIONAL DA MICROCEFALIA E AUTOIMAGEM DE MÃES DE CRIANÇAS COM TAL CONDIÇÃO NEUROLÓGICA

RESUMO: Objetivou-se no presente estudo analisar a estrutura representacional da microcefalia, bem como da autoimagem que mães de crianças com tal condição neurológica possuem. Participaram da pesquisa 105 brasileiras com idades entre 20 e 50 anos ($M=31$; $DP=7,32$), que moram, maioritariamente, na região Sudeste do Brasil (39,0%). Para recolha de dados, em 2018, foi utilizado a Técnica de Associação Livre de Palavras. Análises prototípicas do material coletado demonstraram que as participantes constroem suas representações sobre a microcefalia com base no conhecimento científico, a descrevendo, ainda, através de signos que se referem à espiritualidade e ao amor. No que diz respeito à autoimagem dos participantes, foi possível perceber elementos que remetem-se a resiliência, além de outros fatores associados a características auto-transcendentes. As representações identificadas revelam processos adaptativos, a partir da alocação de recursos resilientes que permitem com que as participantes deste estudo ressignifiquem sua condição de mães de crianças com microcefalia.

PALAVRAS-CHAVE: Autoimagem; Microcefalia; Psicologia da saúde; Psicologia social.

INTRODUCTION

Microcephaly is characterized as a congenital malformation on the development of the brain; which affects the size of the cerebral perimeter and leads to the modification of its functions and structure. Among the most common factors for its occurrence, chromosomal anomalies, multifactorial disorders, teratogenic factors, as well as malnutrition and the exposition of women to harmful substances during pregnancy stand out. In the last five years, besides these causes, the infection caused by the Zika virus during pregnancy has also been associated with the etiology of microcephaly^{1,2}.

Classified by the World Health Organization as a public health emergency problem, microcephaly may be classified as primary, when it has its development in the child before their birth; or secondary, when it is brought about after their birth. This neurological disorder is considered rare, as studies estimate that 2 to 12 in every 100 thousand liveborn children (LC) in the world might display it during their development³.

Furthermore, it was observed in Brazil, in the year of 2015, an exponential incidence of this neurological disorder in LC, as 55 cases were registered for every 100 thousand children. This growth occurred, mainly, due to the aforementioned etiological association between Zika and cases of microcephaly^{1,2}. Amongst the most affected regions in the country, the Northeast stands out (139 cases in 100 thousand LC); which showed during that same year an occurrence average 28 times superior to the period between 2000 and 2014 (5 cases for every 100 thousand births). Following this, the Mid-West region, having a coefficient that was five times lower than the one found in the Northeast, still had 31 cases for every 100 thousand LC^{4,5}.

Socio-demographic data from some studies developed with the population that composes these numbers from the year 2015 show that the majority of mothers that bore children who had microcephaly were of ages that varied between 24 and 40, with a level of instruction mainly of elementary and high school, family income up to one minimum wage and who self-declared to be black or brown^{4,5}.

This socio-demographic profile indicates that the social class which is affected the most by the microcephaly outbreak is mainly from a low socioeconomic level. Brazil, bearing such aspects, encompasses a high level of social imbalance, especially when it comes to the per capita income of the families. Thus, it is understood that social determinants, such as people's socioeconomic conditions are linked to the higher incidence of microcephaly^{6,7}.

Beyond the cognitive and psychomotor changes, focusing on the mental impairment which describes individuals who have microcephaly^{8,9}, psychosocial implications are highlighted as they not only exist in these people's daily lives, as well as in their family members' and/or caretakers'. Such implications refer to the stigma and discrimination, pointed out by Goffman¹⁰ and Costa Filho¹¹ as a result of relationships between people who have and those who do not have "physical deformities". To the authors, when the "deformities" are easily perceived, the attention of the population is directed to characteristics that deviate from the norm, i.e., from what is considered "normal", causing some differentiation that targets the aforementioned groups, hence the exclusion/segregation of the group that possesses the deviant characteristics. Therefore, microcephaly leads to subjective experiences to the ones immersed in this environment; which refers to social exclusion, and these experiences are enhanced by the self-representation of handicap and the lack of capacity^{12,13}.

Furthermore, it is noteworthy that during pregnancy the idealization of a typical child occurs with its potential. Thus, with the malformation diagnosis advent, a frustration process occurs due to what was initially conceived about the child. That is, the family and, especially the mother, live a time of mourning the idea previously created. This reality can affect the baby's conception in several ways, from its acceptance in the present, even in the awe construction towards the premature that is developing. Hence, the need for psychosocial support to these mothers and families is reinforced, either from important people for these mothers, as well as from the health teams that assists families of children with microcephaly¹².

Another aspect that must be considered in this context refers to mothers' self-concept, which can

be understood as a set of self-perceptions, feelings, images and traits that they have about themselves and that is projected in the relationship with other people. Thus, concerning the pregnancy process, with the child idealization rupture that occurs with the disability diagnosis, the mother goes through a stressful moment that causes an explosion of feelings related to the loss of the ideal child. As a result, the mothers' perceptions, beliefs and values end up undergoing situational changes, which, depending on resilient factors, may be directed to adaptation or not given their context¹³.

In this direction, understanding these women self-perception and their self-image construction helps in the interventional development to maintain their psychological state, as well as the mother-baby bond; which can be affected within contextual changes caused by the diagnosis condition. This is stated, therefore, the way individuals perceive themselves modify their behaviour and their way of relating to people and their context¹⁵.

The outlined landscape demonstrates, generally speaking, the imperative nature of a proximal proposal between health sciences and humane and social sciences to fully grasp microcephaly beyond the pathophysiology, going over the limits of pragmatism that hinders the biomedical model. Understanding people's representations that live with it on a daily basis and facilitate care for individuals who have microcephaly (for instance, mothers who care for their children) presents itself as a strategy to reach the social meaning of such neurological disorder, as well as presenting the possibility to point to directions for the development of interventions that promote quality of life for the population that possesses and lives with the affliction.

Also, considering how important subjectivity is when thinking about the idea connected to topics that relate to health¹⁴, this article's theoretical framework takes as reference a psychosocial perspective, namely the Social Representation Theory^{15,16}, to reflect upon the following issues: what are the social representations that mothers of children who have microcephaly possess on this neurological condition? Specifically, what is the representational structure/configuration of this social object for the specified group? Beyond that, considering

the social expectancy imposed on the role of motherhood in the society, it was also one of the goals to describe and analyze the representational structure for self-image considering mothers of people who have microcephaly. The starting point was the assumption that this group's microcephaly comprehension would be associated with the way they are self-represented. So, utilizing this theoretical input not only allows the comprehension of elements that encompass microcephaly, but also enables the perception of psychosocial implications and adaptive strategies to face the daily life of this neurological affliction developed by mothers.

METHODOLOGY

It is a mixed study, i.e., quantitative and qualitative, which has a descriptive-exploratory nature, based on a theoretical input and a structural approach of the Social Representation Theory^{15,16}. This theory is used in this research as it is assumed that social representations guide people's behavior who face the social object here studied¹⁵. It is also highlighted that to fully comprehend the figurative elements of the microcephaly's SR, as well as the self-image of mothers of people who have the disorder, it was used in this study, a specific approach of the theory; which consists of an SR structural approach. The latter is characterized as a methodological proposition aiming to identify and analyze the processes that determine the SR from two systems: the central system, considered structural, responsible for giving meaning to social representation; and the peripheral systems, responsible for the protection and defense of the meanings given to the former¹⁶.

The sample was put together in a non-probabilistic way, as a matter of convenience, with the participation of 105 Brazilian women who are mothers of children who have microcephaly. It is worth noting that these women were part, by the time the data was collected, of groups linked to the subject of microcephaly in social networks, such as *Facebook*, *Instagram* and *WhatsApp*. The criteria to include them in the current study were: to be over the age of 18, to be Brazilian, to be the mother of one or more children who have microcephaly (diagnosed by a doctor), as well as to be available to participate in the

research voluntarily. Participants that started but did not conclude answering the online form from the research were excluded.

For data collection, it was utilized an online form divided in two sections: the first one, titled "Socio-demographic Questionnaire", encompassing matters like age, sex, education and concentration of participants according to region; the second one, had the "Free Word Association Technique" (FWAT).

It is important to point out that the FWAT; which is a projective technique that aims to identify the latent dimensions of the SR, is structured according to any response evocation from the participants (opinion variables) that are given from inductive stimuli previously defined by researchers according to the study's subject, thus allowing the access to semantic universes that are shared in face of a given object¹⁷. Moreover, for the current work, evocations from the participants were sought in face of the inductive stimuli: *microcephaly* and *myself*, the latter is related to the perception that mothers of children who have microcephaly possess about themselves.

To data collection, first, a form was generated through one of the tools offered by the virtual platform *Google Forms*, with the aforementioned instruments. Subsequently, this form was posted on groups connected to the subject of microcephaly on *Facebook*, *Instagram* and *WhatsApp*. During the period of three months in the year of 2018, the completion of the questionnaire was requested, informing the participants the criteria for inclusion, the average time to fill out the questionnaire (four minutes), as well as ensuring the anonymity of their identities.

Data from the FWAT was processed with the help of the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ). This tool enabled the development of prototypical lexicographical analyses of the collected material. Such analyses, with the creation of four quadrants, highlight words evoked by the FWAT and their respective frequency (F) and average evocation order (AEO)¹⁸.

According to Sá¹⁹, the combination of these two criteria (frequency and average order of evocation for each

word) bundle together the evocations; considering their projection from the central core and peripheral systems of representation. For that matter, the prototypical analysis describes, in the first quadrant (upper left), words that had a high frequency (above the average) and a low average evocation order (the ones that were evoked first); this being an indicator of the representation's central core. The second quadrant (upper right) and the third quadrant (lower left) compose the representations' proximal peripheral system, it features expressions that possessed high frequency, but that were not promptly evoked. The fourth and last quadrant (lower right) indicates the far peripheral system. In it, expressions that were less frequent and that were not promptly evoked are present¹⁸.

It is worth mentioning that the word groups that came from this analysis were also interpreted in a qualitative manner, in such a way to evince the SR aims that are created and shared by the participants of the study in face of microcephaly and their self-image¹⁷.

Data were only collected upon authorization from the Committee for Ethics in Research on Human Beings, located at the University Center for Higher Education in Paraíba, number of registry 3.952.695; and due authorization from each participant, according to Resolution n. 510 by the Health National Council²⁰.

RESULTS

The 105 Brazilian women that participated in this study were aged between 20 and 50 years old ($M=31.68$; $SD=7.32$), were predominantly of brown skin color (61%), have finished high school (60%) and were, mostly, residents in the Southeast region of Brazil (39.0%). The detailed socio-demographic characteristics from the participants of this research are displayed in table 1.

Table 1. Socio-demographic characteristics of the participants

| VARIABLE | | (%) |
|---|-------------------|------|
| Skin colour | Brown | 61,0 |
| | White | 25,7 |
| | Black | 11,4 |
| | Yellow | 1,9 |
| Education | High School | 60,0 |
| | Higher Education | 18,1 |
| | Elementary School | 14,3 |
| | Post-Graduation | 7,6 |
| Age group | From 18 to 28 | 43,8 |
| | From 29 to 39 | 43,8 |
| | From 40 to 50 | 12,4 |
| Concentration of participants according to region | Southeast | 39,0 |
| | Northeast | 34,3 |
| | Mid-West | 15,3 |
| | North | 5,7 |
| | South | 5,7 |

Footnote. (N = 105; % = percentage).

ANALYSIS OF THE MICROCEPHALY STIMULUS

The prototypical analysis of the inductive stimulus, microcephaly, considered a number of 525 words evoked by the participants of the study. From those, 135 are different from each other. Chart 1 presents the results on this stimulus, it was created with a minimum frequency of 9.75 and average evocation order of 2.95 as the analytic criteria.

Chart 1. Representational structure in face of the *microcephaly* stimulus

| Central Core | | | Proximal Peripheral System | | |
|----------------------------|---------------|-----------------|----------------------------|---------------|--------------|
| Word | F $\geq 9,75$ | AEO $\leq 2,95$ | Word | F $\geq 9,75$ | AEO $> 2,95$ |
| Love | 64 | 2.8 | Overcoming | 28 | 3.2 |
| god | 14 | 2.9 | Struggle | 19 | 3.3 |
| Micro brain | 11 | 1.5 | Hope | 19 | 3.2 |
| Son | 11 | 1.8 | Faith | 16 | 3.0 |
| Disability | 11 | 1.8 | Difficulty | 13 | 3.0 |
| | | | Care | 12 | 3.3 |
| | | | Treatment | 11 | 3.9 |
| | | | Inclusion | 11 | 3.1 |
| | | | Learning | 10 | 3.0 |
| Proximal Peripheral System | | | Far Peripheral System | | |
| Word | F $\geq 9,75$ | AEO $> 2,95$ | Word | F $\geq 9,75$ | AEO $> 2,95$ |
| Limitation | 7 | 2.1 | Achievement | 7 | 4.1 |
| Mother | 7 | 2.6 | Challenge | 7 | 3.0 |
| Respect | 6 | 2.8 | Strength | 6 | 3.7 |
| Prejudice | 5 | 2.4 | Happiness | 6 | 4.7 |
| Necessity | 5 | 2.0 | Care | 6 | 3.0 |
| Deley Develop | 4 | 2.2 | Stimulus | 6 | 3.5 |
| Head | 4 | 1.0 | Dedication | 5 | 3.2 |
| Uncertainty | 4 | 2.5 | Frustration | 5 | 3.8 |
| Doubt | 4 | 1.5 | Development | 4 | 4.2 |
| Daughter | 4 | 2.5 | Disease | 4 | 4.0 |
| | | | Perseverance | 4 | 3.5 |
| | | | Family | 4 | 3.2 |

In the upper left quadrant, the representational object microcephaly was elicited along with the words *love, God, micro_brain, son* and *disability*. According to its prominence, this quadrant features the SR core content on microcephaly, i.e., it indicates what is central on representing this neurological condition. According to Abric¹⁵, the central core has as primordial attributes, historical, sociological and ideological conditions; as it is imprinted in the collective memory of a group. This core's content enables the comprehension of the reality that is experienced by the participants of this research in face of the current situation in which they are, presenting meaningful internal aspects that support and organize the way microcephaly is comprehended.

For that matter, the word *love* is noteworthy as the most likely feeling to sort the way the mothers, from this research, comprehend and have a stand in face of their children's *disability (micro brain)*. Moreover, it is interesting to note that the word *God* may demonstrate a way for the participants to minimize their cognitive dissonance in face of the representational object that looms over their lives, citing "God's will" as the factor for having a child who suffers from microcephaly. Such term may still play as a much needed anchor for the (re) signification and adaptation in face of the daily difficulties exacerbated by the object in question.

In the proximal peripheral systems, featured in the upper right quadrant and lower left one, the group's heterogeneous aspects are presented. Thus, from these quadrants, individual history and experiences of the participants may be accessed, as they give sense for the comprehension of microcephaly. In these systems, microcephaly is objectified based on the words *overcoming, struggle, hope, faith, difficulty, care, treatment, inclusion, learning, limitation, mother, respect, prejudice, necessity, delay, development, head, uncertain, doubt, and daughter*.

These signs show that maintaining the contact between the mothers of this study and microcephaly is somewhat challenging, due to the limitations and special learning needs of their children, that, overall, come from the delay in their bio-psychosocial development. Uncertainty and doubts that permeate this group's daily life do not seem to be impeding factors to overcome what

is imposed by microcephaly, as they struggle with the offers for care and treatment, inclusion and minimizing prejudiced attitudes towards their children. It is worth mentioning, hence, these results make comprehensible one of the most prominent cognitions of microcephaly's SR, *God*, once that this one receives support and signification by the daily experiences of faith and hope lived by the mothers of the research.

However, in the far peripheral system, located in the lower right quadrant, the subjects objectified microcephaly with the signs *achievement, challenge, strength, happiness, care, tiredness, stimulus, dedication, frustration, development, disease, perseverance, family and life*. In consonance with Abric¹⁵, the peripheral elements of the microcephaly's SR are identified as possessing the function to ratify their central sense, guiding how the practices for care are offered, as well as positives conducts and feelings from the mother (happiness, care, perseverance, dedication, achievement, stimulus and strength) to deal with the daily frustrations and tiredness that their children's condition imposes on the family.

ANALYSIS OF THE MYSELF STIMULUS

When it comes to the analysis of the participants' SR structure for self-image, accessed from the evocations in face of the inductive stimulus *myself*, a total of 525 evoked words were identified, from which 69 were distinct.

In Chart 2, constructed in face of the stimulus *myself*, with frequency higher or equal to 13.76 and average evocation order of 2.95, it is presented the SR central core on how the participants of this study see themselves. In the upper left quadrant, the participants evoked the terms *strong, warrior, tired, privileged* and *responsible* to talk about themselves. Reinforcing and giving meaning to the central core, the proximal peripheral systems, located in the upper right and lower left quadrants, are there associated with the words *lovely, determined, happy, confident, preoccupied, fighter, chosen, patient, insecure, mother, fearful, persistent, frightened, blessed, weak* and *perseverant*.

Chart 2. Representational structure in face of the stimulus *myself*.

| Central Core | | | Proximal Peripheral System | | |
|----------------------------|-----------------|-----|----------------------------|--------------|-----|
| F \geq 13,7 | OME \leq 2,95 | | F \geq 13,76 | OME $>$ 2,95 | |
| Palavra | F | OME | Palavra | F | OME |
| Strong | 39 | 2.6 | Lovely | 47 | 3.5 |
| Warrior | 28 | 2.8 | Determined | 29 | 3.0 |
| Tired | 25 | 2.8 | Happy | 29 | 3.5 |
| Privilegiada | 21 | 2.0 | Confident | 26 | 3.2 |
| Responsável | 15 | 2.8 | Preoccupied | 21 | 3.2 |
| | | | Fighter | 17 | 3.2 |
| | | | Sad | 15 | 3.0 |
| Proximal Peripheral System | | | Far Peripheral System | | |
| F $<$ 13,76 | OME \leq 2,95 | | F $<$ 13,76 | OME $>$ 2,95 | |
| Palavra | F | OME | Palavra | F | OME |
| Chosen | 11 | 2.3 | Caring | 13 | 3.4 |
| Patient | 11 | 2.5 | Protective | 10 | 3.4 |
| Insecure | 9 | 2.9 | Resilient | 9 | 3.0 |
| Mother | 7 | 2.0 | Background | 7 | 3.1 |
| Fearful | 7 | 1.6 | Anxious | 7 | 3.3 |
| Persistent | 7 | 2.7 | Courageous | 7 | 3.1 |
| Frightened | 6 | 2.0 | Accepted | 7 | 3.0 |
| Blessed | 5 | 2.6 | Dedicated | 7 | 3.9 |
| Weak | 4 | 1.5 | Empowered | 5 | 3.8 |
| Perseverant | 4 | 2.8 | Frustrated | 5 | 3.0 |
| | | | Sensitive | 4 | 3.0 |
| | | | Accomplished | 4 | 3.0 |

It is worth mentioning that the signs evoked in the central core suggest a relationship of the mothers' images being crossed by resilience aspects, stating that even in the presence of difficulties that are found amidst limiting conditions that are brought by microcephaly, as well as social contexts of struggle, exclusion and prejudice; these women can face reality in such a way to project contents that allow the possibility for transcendence and signification in their social environment.

Moreover, it is highlighted, as a way of maintaining and supporting the sense of the SR self-image of this study's participants; the semantic fields that emerged in the proximal peripheral systems of these representations which evince characteristics that concern self-esteem aspects, as well as those linked to the participants' resilience. However, in an ambivalent way, in the systems that were presented, aspects were identified that relate to insecurity, weakness and the fear that mothers of people who suffer from microcephaly have. So, it is understood that such elements may suggest the emotional dimension

that is singular to mourning the ideal child when faced with the diagnosis of microcephaly.

Contrasting with the central core, in the far peripheral system, located in the lower right quadrant, there are the words *caring*, *protective*, *resilient*, *background*, *anxious*, *courageous*, *accepted*, *dedicated*, *empowered*, *frustrated*, *sensitive* and *accomplished*. Due to its function to support the SR structure, it is noticeable, based on this quadrant, that mothers associate their self-image to self-transcendence factors, postulated in words such as care, protection and background. This might suggest that the trajectory of purpose that the women from this study face to represent themselves, is deeply rooted in forgetting their own selves to focus on their children's needs.

Not only that, there are still elements that strengthen the realization of their purpose of life, outlined by values that indicate, through the knowledge and empowerment of those that face microcephaly; as they may characterize a new strategic point of acceptance,

commitment and confrontation of the reality that was imposed by their children's neurological condition.

DISCUSSION

The set of analyses that were carried out aiming to identify the representational structure of microcephaly by mothers of children who suffer with this affliction, as well as capture the representational structure of self-image of this same group; offered intelligibility to social representations in face of the object.

Concerning the participants' sociodemographic statistics, the data identified in this study are related to those already disclosed in the literature on the profile of mothers of people with microcephaly^{4,5}. This profile also noticed here reinforces the conception that social determinants such as socioeconomic conditions are linked to the higher incidence of microcephaly in the Brazilian context^{6,7}. In this sense, the need to create and develop public policies, as well as interventional practices that consider these social group characteristics, is emphasized.

Regarding the representational structure analyses, it stands out that in the central system of the microcephaly stimulus, elements, that denote erudite knowledge, were identified, i.e., there is some kind of apprehension of what the scientific literature says about characterizing this neurological condition. Besides, still concerning the central core, some signs emerged that support such scientific knowledge in everyday life, associated with faith, described by the belief in a higher power (God); which are linked to these women's resilient aspects.

In face of the elements that were found in this study; which relate to spirituality and faith, Kochla²¹ describes during her research that mothers who experienced the process of having children afflicted by cancer, also had to deal with hard decision-making. Specially, according to the author, this made them self-transcend allowing them to find some sort of guidance; which is a positive side in order to give them a reason to live, a goal in life. Not only that, but it is important to mention the spiritual experience and the bond with God as the main mean of support, this allows the possibility to

overcome the situation and its potential confrontation. Another topic that is worth mentioning is the support given by the family, by the healthcare team and, even, by strangers, which comes to assuage their suffering, contributing for the process to generate resilience.

Therefore, the spirituality seems to constitute a regulatory process of the caretakers and of the families, allowing the production of new purposes in face of the challenging reality that comes with the microcephaly diagnosis. Faith becomes, in this perspective, a protective factor for fighting that was developed by the mothers, hence its relevance when constructing their speech, as they aim to find a god, and in spirituality, some kind of point of support for acceptance and repurposing²².

On the same topic, maternal love constitutes another meaningful element for guidance in face of the children's disability; which allows the confirmation of support and comprehension of their own reality when dealing with the affliction. Such understanding of love may be associated with a historical construction of motherhood; which imprints the ideas of unconditional love, happiness, the gift of being a mother and the blessing that the child is, as approached by Mata²³.

Consequently, the unconditional love that is evoked also connects to God's divine expression as it describes some spiritual love; which is constituted, according to Kierkegaard²⁴, by means of duty. Therefore, it becomes free from any distinction and is unchanging before difficulties or any adversity that may befall their kin; acknowledging them as fellows, as people and alter egos²⁵.

In spite of the great amount of signs positively characterized in this quadrant, there were also signs that had a negative connotation, associated with uncertainty, tiredness and frustration. Such elements are comprehended in a figurative context of the reality the caretaker has in face of the future the child who suffers from microcephaly will have.

In the peripheral systems, the social group's individual experiences are described; which encompass topics associated with limitations and the conditions that come with the disability, as well as the social weight that is linked to stigmatization and prejudice because of the potential delays in development. Bearing that in mind,

Campos and collaborators²⁶ write that when faced with a diagnosis of microcephaly, there is a possibility of being stricken by a feeling of frustration, fear, anxiety, as well as denial of one's own afflictions. Consequently, this might affect mothers in such a way that they develop signs of psychological weariness, depression and lack of much needed care to develop a mature child.

So, the birth of a child who has some kind of malformation might be considered a traumatic event for the family, mainly for the mother, given that during pregnancy, there was the construction of the concept of an ideal child and the moment of realization is permeated by much uncertainty and insecurity. In that regard, all family members go through an adaptation process in their routine to learn the limitations that come along the disability brought by the affliction, as stated by Andrade²⁷. Another aspect that highly denotes such reality is the abdication with which the mother has to live, putting herself in the background to attend the needs of the child²⁸.

However, when it comes to the evocation of negative contents, such signs, in the group accessed by this study, do not possess any defining characters of their behaviors, as even with the feeling of insecurity, there are characteristics of resilience that overlap the other elements. But when dealing with the results presented on the mother's self-image, it is also noticeable a great prevalence of signs that denote positivity in face of the negative ones that were evoked. For this purpose, it is important to note that these women understand themselves from characteristics of resilience, permeated by aspects of self-transcendence and accomplishment. It should be noted that the duality or even coexistence of positive and negative feelings in mothers, especially those of children with disabilities, has already been observed in other studies²⁹. Hence, at the same time that they consider motherhood to be a good thing, linked to personal fulfilment, they do not fail to recognize the difficulties faced in the mothering process.

So, in the central core, elements that allude to aspects that denote resilience are present. In this scenario, Hamad and Souza²⁹ illustrate in their study that mothers, during the process of adaptation and emotional adjustment, because of the neurological condition,

acquire repurposing capacities that are helpful when facing this new environment. Therefore, resilience becomes one factor to promote the construction of the bond with the child, to break the cycle of prejudice, given the awakening of hope when faced with themselves and the world in which the child lives.

According to the analysis, frustration, tiredness, prejudice and struggle all point to the mothers' self-image in this study. Thus, the findings from this study corroborate with Barros, Monteiro, Neves and Maciel¹² who noticed that mothers feel greater issues when dealing with difficulties that are linked to communication in a familiar and social context, due to the possible incomprehension, the lack of support and the prejudice that comes from the family itself or from the spouse, as well as the lack of access to public services.

Therefore, the lack of support from people that have a meaningful relationship with the mothers brings about socio-emotional harm during this new phase. Moreover, results found here corroborate the findings of Nascimento³⁰; who mentions the social support as a positive enabling aspect in the process to develop resilience. The author covers what a meaningful approach to their families and a relationship with their spouses bring; as such relationships describe how easy the communication and the initial struggle when faced with the affliction can be. Another aspect in the social environment is the relationship with other parents; which enables the establishment of trust, comfort and confrontation, due to shared experiences, evincing the idea that these mothers are not the only ones to go through such event.

It is evident that the mothers from this study and their caretakers' experiences are permeated by implications that come from the disability; which encompasses a process of intense adaptation that is constructed by their aspects of resilience. Considering microcephaly in its bio-psychosocial dimension, the need to come up with interventional measures is noteworthy; which should aim, initially, to build and strengthen the bond between mother and baby, because, as determined, when faced with the mourning period caused by the diagnosis, such relationship may be affected by the

elaboration and construction of negative beliefs and feelings towards the future of the child.

Besides, it is noticeable that there is a need to create a social support network aimed at the caretaker, as they deal with a heavy stress load. Thus, such strengthening could serve as an establishing point for social and psychological bonds. Consequently, the importance for group techniques and therapies must be reinforced, in order to promote bio-psychosocial development, social abilities and emotional regulation, as well as to widen the knowledge on the affliction from shared experiences between the parents and/or caretakers. It is also highlighted the importance to develop public policies that reach the social needs of this public.

Still, in order to amplify the spectrum that was proposed in this research, it is suggested that future studies aim to expand, equalize and homogenize the participants' samples, be it according to age group, or education, or accessed income, or religion, or region in Brazil where they reside, as it is believed that with a great number of people, different representations of the social object at hand could be verified from the suggested variables. Furthermore, the utilization of multifaceted methodological inputs to assimilate the phenomenon is necessary for future studies, as that is a complex matter. Thus, the suggestion for future researches, for instance, is to have focal groups, as well as to carry out more in-depth interviews.

CONCLUSION

Understanding the representational structure of microcephaly through the knowledge shared by the mothers of children with such a neurological condition, allowed to identify the crossings and ways of experiencing this phenomenon, revealing it as multifaceted. Besides, considering that SRs function as guides for social practices, it is possible to observe, from this study's results, a behavioural direction produced through feelings and thoughts that start from adaptive and situational processes (e.g. resilience, maternal love and spirituality) of mothers of children with microcephaly.

This could also be confirmed through the analysis concerning the construction of the participants' self-image (mothers), in which the results indicated the apprehension of an active and adaptive posture towards the context they are. In this scenario, such women perceive themselves to be crossed by the strength they find in their faith and mission to face the maternity that they assumed, adopting, besides a warrior stance, a kindness for themselves, characterizing a positive elaboration of their self-concept.

Consequently, from an adaptive point of view, both analyzes carried out highlight cognitions that may facilitate the process of reframing the condition of a mother of a person with microcephaly and the respective steps involved in this process. However, there are some signs on the possibility that these cognitions are also anchored in the crystallized social roles of what becomes the ideal mother. These roles, sometimes, may contribute to the exclusive dedication of these mothers to their children, promoting neglect of their own needs as a woman and as a human being who is not an extension of their children.

In general terms, the present study contributes to the literature advancement that deals with the bond understanding between mother and child with microcephaly, showing that the self-concept of the mothers of these children seems to be closely related to their understanding of the neurological condition. Furthermore, the representational structures identified here guide to characteristics that should be considered in practical actions and the creation of public support policies to caregivers of people with microcephaly. These actions and public policies should seek to build a psychosocial support network for the group in question, through, for example, the implementation of therapeutic groups, since these can enable the development of feelings and existential conditions that seem to contribute to the care offered to people with microcephaly, as well as a reception for those responsible.

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