

Sociodemographic profile and participation in the daily care of children with microcephaly¹

Tainá Alves Rocha da Cruz^a , Emanuele Mariano de Souza Santos^b ,
Flávia Calheiros da Silva^c , Monique Carla da Silva Reis^b ,
Ângela Cristina Dornelas da Silva^d 

^aUniversidade Estadual de Ciências da Saúde de Alagoas – UNCISAL, Maceió, AL, Brasil.

^bNúcleo de Propedêutica e Terapêutica, Universidade Estadual de Ciências da Saúde de Alagoas – UNCISAL, Maceió, AL, Brasil.

^cNúcleo de Saúde Materno-infantil e do Adolescente, Universidade Estadual de Ciências da Saúde de Alagoas – UNCISAL, Maceió, AL, Brasil.

^dDepartamento de Terapia Ocupacional, Universidade Federal da Paraíba – UFPB, João Pessoa, PB, Brasil.

Abstract: Introduction: The family lives sociocultural transformations requesting more of the man in the children's daily cares with deficiency because commonly the mothers wrap up in the tasks causing an overload in the daily tasks. Objective: To verify the paternal participation in the daily care to the child with microcephaly, to trace the paternal socio-demographic profile, to know the main activities performed by the fathers and to analyze their perception in the participation of the children daily cares. Method: This is a quantitative and qualitative study, held in 3 Specialized Centers in Rehabilitation in the city of Maceio, AL, Brazil, with 23 fathers of children with microcephaly, in the period of September of 2017 to February of 2018. For the quantitative component, a specific questionnaire and analysis through descriptive statistics, arithmetic average and percentage were used. In the qualitative component, a semi-structured interview was used that was analyzed through the Analysis of Content. Results: Most of the fathers live with the child, 70% make available 2 hours of time for the son's daily care, and there was a larger paternal engagement in the activities of playing on 74% and social participation on 91%. In the qualitative component, 4 parents participated in the interview, and three thematic categories emerged: Paternal perception and self-assessment regarding the participation in the daily care of the child with microcephaly; Factors associated with paternal engagement in the daily care; and Identification of the activities performed by the fathers in the care to the child with microcephaly. Conclusion: The fathers engaged in daily care to assist the mothers and not as the protagonist. It stands out the need for strategies that favor such participation in the dimensions of the care to the child with a disability.

Keywords: *Social Participation, Paternity, Child Care, Disabled Children.*

Perfil sociodemográfico e participação paterna nos cuidados diários de crianças com microcefalia

Resumo: Introdução: A família vivencia transformações socioculturais, solicitando mais do homem nos cuidados diários dos filhos com deficiência, pois comumente são as mães que se envolvem nesta tarefa, ocasionando assim uma sobrecarga da mulher nos cuidados com o filho. Objetivo: Verificar a participação paterna no cuidado diário da criança com microcefalia, traçar o perfil sociodemográfico paterno, conhecer as principais atividades desempenhadas pelos pais e analisar a percepção destes na sua participação nos cuidados diários do filho. Método: Estudo quantitativo

Corresponding author: Emanuele Mariano de Souza Santos, Universidade Estadual de Ciências da Saúde de Alagoas – UNCISAL, Rua Dr. Jorge de Lima, 113, Térreo, Coordenação do Curso de Terapia Ocupacional, Trapiche da Barra, CEP 57010-382, Maceió, AL, Brasil, e-mail: manumsouza@yahoo.com.br

Received on Nov. 23, 2018; 1st Revision on Feb. 20, 2019; 2nd Revision on Apr. 16, 2019; Accepted on May 22, 2019.



e qualitativo, ocorrido em três Centros Especializados em Reabilitação na cidade de Maceió, AL, Brasil, com 23 pais de crianças com microcefalia, no período de setembro de 2017 a fevereiro de 2018. Para o componente quantitativo utilizou-se questionário específico e a análise por meio de estatística descritiva. No componente qualitativo utilizou-se entrevista semiestruturada, que foi analisada por meio da Análise de Conteúdo. Resultados: A maioria dos pais reside com a criança, 70% disponibilizam duas horas de seu tempo para cuidado diário do filho, sendo verificado maior engajamento paterno nas atividades de brincar (74%) e participação social (91%). No componente qualitativo, quatro pais participaram da entrevista e três categorias temáticas emergiram: percepção e auto avaliação dos pais em relação à participação nos cuidados diários da criança com microcefalia; fatores associados ao engajamento no cuidado diário; e identificação das atividades desempenhadas pelos pais no cuidado à criança com microcefalia. Conclusão: Os pais se envolvem nos cuidados diários de maneira auxiliar às mães e não como protagonistas. Ressalta-se a necessidade de estratégias que favoreçam a participação dos pais nas dimensões do cuidado à criança com deficiência.

Palavras-chave: *Participação Social, Paternidade, Cuidado da Criança, Crianças com Deficiência.*

1 Introduction

The family structure has undergone several socio-cultural and economic transformations in the role of men, requiring greater paternal involvement in the family routine, especially in caring for children. These changes have emerged since women's entry into the labor market, culminating in a series of modifications about the gender hierarchy between men and women by dividing responsibilities in family life (ARIÈS, 1981; BRAGA; AMAZONAS, 2005; LANGARO; PRETTO, 2015). Thus, a co-genitor father is expected, sharing responsibilities, engaging with children and assisting the mother in the daily care and education of children, without gender stereotypes and with participation in the development of the child from birth to adulthood (VIEIRA et al., 2014).

This new concept of established paternity seeks to acquire new responsibilities, which are not only limited to fulfilling the obligation to ensure basic survival conditions for the family but continuous participation of fathers in the performance of tasks related to the basic care of children (SOUZA; SANGUINET, 2012).

The basic care of children in daily life is identified in the occupations that the parents perform for their children and according to Krammer, Hinojosa and Royeen (2003), the occupation is composed of purposeful daily tasks and activities, in which people engage and have a personal and subjective meaning or value. Participation in occupations is inherent in subjective experience, in which personal, cultural and social values are attributed. Occupations are symbolically constituted in culture and interpreted from the context and life history of people (LARSON; WOOD; CLARCK, 2005).

According to the official document of the American Occupational Therapy Association (AMERICAN..., 2015) called "Occupational Therapy Practice Structure: Domain and Process - 3rd Edition", some occupations are categorized such as the Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), rest and sleep, work, education, play, leisure, and social participation.

Occupations involve a range of tasks that require attention, time and care, and the experience of performing duties in maternity and paternity can have difficulties with the presence of a disabled child in the family, especially in daily care (LUCCA; PETEAN, 2016), requiring parents to be more involved in unexpected tasks, requiring the roles of men and women to be flexible and to be rethought, favoring the reorganization of tasks in daily basic care and sharing responsibilities (BRASIL, 2015; HENN; SIFUENTES, 2012).

However, the mothers are commonly who engage in the daily care of their children, which leads to overload, physical and psychological damage and changes in their occupational roles, requiring paternal support in sharing the tasks that involve childcare. Although there is an increase in the participation of the fathers in the care of their children, the idea that "taking care of the child" is the mother's responsibility still prevails (MARTINS; COUTO, 2014).

Corroborating these aspects, the male involvement, and participation as a parent in childcare is of paramount importance for the development of family relationships and child development conditions. The father cannot be seen only as an adjunct in the care and support of the mother, so it must be considered as a participant because he influences and is influenced in its direct interaction with

the child (CREPALDI et al., 2006; OLIVEIRA; SILVA, 2011).

In 2015 and 2016, the increased number of children with microcephaly due to possible infection with Congenital Zika Virus Syndrome (SCVZ) in some regions of Brazil resulted in a clinical situation that led to a series of impairments in the neuropsychomotor development of many children and they need to be referred to early stimulation programs for therapeutic support and family support. However, 60% of the caregivers who accompanied the children with microcephaly in the therapies were maternal mothers or grandmothers, implying the need to understand the issues related to the fathers and the daily care they have with their children in the family context (SCHULER- FACCINI et al., 2016; CRUZ; SILVA; SANTOS, 2017).

Given the importance of the father for the development and daily care of the child, the difficulty of his participation in monitoring a child with microcephaly in therapies, and aiming at building actions that can bring fathers closer to the daily care of a child with disabilities, and sharing the responsibilities, this study aims to verify the paternal participation in the daily care of the child with microcephaly, to trace the socio-demographic profile of these fathers, to know the main activities performed by them in childcare and to analyze their perception about the participation in the care of their sons on a daily basis.

2 Method

This is a quantitative and qualitative descriptive cross-sectional study. The study was conducted in three Specialized Rehabilitation Centers (SRCs), located in the municipality of Maceió, Alagoas state, which provides care to children with Congenital Zika Virus Syndrome (SCZV).

Fathers of children attended in SRCs who agreed to participate in the study answered the survey, held from September 2017 to February 2018. Fathers of children with microcephaly older than three years old and those who did not have daily coexistence with the child were excluded. Those who accepted to participate in the research signed the Informed Consent Form (ICF). Initially, 48 fathers were identified in the services and, after applying the exclusion criteria, 23 fathers remained eligible for this study.

Data were collected from a questionnaire developed by the researchers. These data were

analyzed by two external evaluators and adjusted according to their suggestions. The instrument was self-applicable, easy to understand and it was read and explained by the researcher. Fathers' education level was verified before answering the questionnaire.

The questionnaire included information regarding paternal personal and socio-demographic data, data from children with microcephaly and the main occupations and activities performed by the caregivers in the daily lives of the young children. Fathers should report the frequency of these activities as follows: Always (100%), Frequently (75%), Occasionally (50%), Rarely (25%), and Never (0.1% to 0%).

The questionnaire was administered during the child's treatment hours while the fathers were waiting for the therapy to end. In the case of fathers who worked full time, the questionnaires were delivered, with their authorization, to the caregivers or mothers who accompanied the children in the treatment to be answered at home.

The data collected from the questionnaire were tabulated and stored in a Microsoft Excel 2013 spreadsheet. A descriptive analysis was performed using percentage and arithmetic mean. It was sought to preserve the anonymity of the participants, identifying the questionnaires by a number starting with the number 1 (one) until completing the final list of fathers of children with microcephaly who were contacted.

After analyzing the questionnaires, the fathers were invited to participate in a semi-structured interview, conducted from a script with guiding questions prepared by the researchers: "What do you think about the father's participation in daily care with the child?"; "Who participates in the daily care of your child/children?"; "What is it like to take care of a child with microcephaly?"; "How do you participate in your child's daily care?"; and "How do you evaluate or consider your participation in your child's daily care?".

The interview was conducted individually, in a place reserved at SRC, with each father of the child with microcephaly who previously answered the questionnaire. The interview was recorded in audio, with permission of the participant, to later be transcribed, ensuring the confidentiality of the participants and the veracity of the information. At this stage, only four fathers agreed to participate in the interview.

All interviews were analyzed using the Thematic Content Analysis technique proposed by Bardin

(2011), organized in exhaustive reading of the material to identify the central ideas; interpretation of the data; grouping of data into categories; comparison between the different nuclei of meaning found; and writing of the interpretative synthesis of each of the defined categories.

From the analysis of the interviews, three thematic categories emerged: *Paternal perception and self-assessment regarding the participation in the daily care of the child with microcephaly; Factors associated with paternal engagement in the daily care; and Identification of the activities performed by the fathers in the care to the child with microcephaly.* Their presentation of the fathers' speeches will be identified by the name "Interviewee" and a cardinal number following the order of the interviews.

The research was approved by the Research Ethics Committee of the State University of Health Sciences of Alagoas (UNCISAL), under CAAE 68355917.2.0000.5011 on June 13, 2017, and with amendment approval on October 3, 2017.

3 Results

The results include information regarding the quantitative and qualitative data produced in this study.

From the quantitative data, Table 1 shows the profile of the 23 fathers in the personal and socio-demographic characteristics, time available for the care of the child with microcephaly and information on paternal participation in daily childcare.

Table 1. Paternal personal and socio-demographic characteristics and time available for the care of the child with microcephaly (N = 23).

Variable	n (%)	
Age	18 to 29 years old	15 (65%)
	30 to 39 years old	5 (22%)
	40 to 49 years old	2 (9%)
	More than 50 years old	1 (4%)
Origin	Region Valleys of Paraíba and Mundaú	2 (9%)
	Metropolitan region	15 (65%)
	South region	1 (4%)
	Agreste Region	1 (4%)
	North region	4 (18%)
Marital Status	Married	8 (35%)
	Single	5 (22%)
	Stable Union	10 (43%)
Years of study	≤ 4	4 (17%)
	05 to 09	6 (26%)
	10 to 12	10 (44%)
	≥ 13	3 (13%)
Living with the child	Yes	20 (87%)
	No	3 (13%)
Family Income	No fixed income	6 (26%)
	Less than 1 minimum wage	2 (9%)
	1 minimum wage	13 (56%)
	2 or more minimum wages	2 (9%)
Practicing his profession and/or occupation	Yes	19 (83%)
	No	4 (17%)
Time available for daily childcare	No time available	1 (4%)
	Less than 1 hour	1 (4%)
	1 hour	5 (22%)
	2 hours or more	16 (77%)
The child participates in social programs	Yes	20 (87%)
	No	3 (13%)

Source: Own Elaboration/Research data (2018).

It was observed that 65% of fathers were between 18 and 29 years old. Regarding their origin, the data were grouped by demographic regions², 65% of fathers of children with microcephaly lived in the metropolitan region of the state of Alagoas. Regarding their marital status, 43% had a stable union; and 70% of fathers said they provide two hours or more of time daily.

Regarding the education, 44% of fathers had between 10 and 12 years of study; 83% of the fathers exercised some profession and/or occupation, and 26% had no fixed income. Among children, 87% participated in social programs such as *Bolsa Familia* and/or Continuous Benefit (BPC).

The professions and/or occupations reported by the fathers were: rural service, production assistant, bricklayer assistant, metallurgist, student, gardener, service representative, concierge agent, realtor, concierge, telephone technician assistant, bricklayer, motoboy, computer technician, warehouse assistant, and driver.

For a better understanding and analysis of the occupations performed, Table 2 shows the description and frequency of activities by occupation category. Regarding Activities of Daily Living (ADLs), there was a significant number of fathers who never performed them and the most involved activity (65%) was to carry on the lap or assist

Table 2. Frequency Levels of Paternal Participation in the Daily Care of Children with Microcephaly (N = 23).

Variable	A		F		O		R		N	
	n	(%)	n	(%)	n	(%)	N	(%)	n	(%)
Activities of Daily Living (ADLs)										
I bathe my child	4	17	4	17	4	17	4	17	7	30
I dry my child	8	35	3	13	3	13	1	4	8	35
I brush my child's teeth	4	17	3	13	1	4	3	13	12	52
I change my child's diapers	6	26	4	17	2	9	6	26	5	22
I put on/take off my child's clothes	7	30	8	35	4	17	3	13	1	4
I choose my child's clothes	4	17	4	17	5	22	5	22	5	22
I give food or help with food	5	22	7	30	2	9	4	17	5	22
I carry him on lap or aid in locomotion	15	65	4	17	2	9	2	9	0	0
I comb my child's hair	5	22	7	30	4	17	1	4	6	26
I perfume my child	6	26	6	26	4	17	3	13	4	17
Instrumental Activities of Daily Living (IADLs)										
I prepare my child's food	1	4	4	17	3	13	3	13	12	52
I take my child to the doctor/treatment	7	30	3	13	3	13	8	35	2	9
I shop or prepare the shopping list	12	52	4	17	2	9	2	9	3	13
I administer my child's medicine	4	17	6	26	5	22	4	17	4	17
I clean food and tools after meals	4	17	6	26	2	9	5	22	6	26
I take care of the goods and repairs of the house	10	43	7	30	5	22	1	4	0	0
I manage the finances of the house	14	61	6	26	2	9	0	0	1	4
I participate in my child's education	23	100	0	0	0	0	0	0	0	0
Rest and Sleep										
I prepare my child to sleep	10	43	9	39	1	4	0	0	3	13
I organize the moment of rest	6	26	9	39	1	4	3	13	4	17
I do night care if necessary	6	26	6	26	2	9	4	17	5	22
Playing										
I play with my child	17	74	4	17	0	0	1	4	1	4
I offer toys to my child	12	52	6	26	3	13	0	0	2	9
Leisure										
I go out with my child	9	39	5	22	7	30	1	4	1	4
Social Participation										
I engage my child with the family	21	91	1	4	0	0	1	4	0	0
I encourage my child to interact with other children	17	74	5	22	0	0	0	0	1	4

A – Always / F – Frequently / O – Occasionally / R – Rarely / N – Never. Source: Own Elaboration / Research data (2018).

in locomotion of their child. Among the least involved, 30% of fathers never engaged in bathing activities, 26% rarely changed diapers and 52% never brushed their children's teeth.

As for Instrumental Activities of Daily Living (IADLs), the highest performance of fathers (61%) in managing household finances prevailed and 100% said they participated in the education of their children. Among the least involved activities, there were: 52% never prepared food for their children and 35% rarely took their child to the doctor or treatment. In rest and sleep, 43% of fathers always prepared their children to sleep and 22% never performed night care of children. Occupations with more paternal involvement include playing with their children (74%), going out with their children for a walk and going elsewhere (39%) and always involving their children with their families (91%).

To analyze the perception and participation of fathers in caring for the child with microcephaly, the results of the interviews with the four fathers allowed identifying the following categories: *Paternal perception and self-assessment regarding the participation in the daily care of the child with microcephaly; Factors associated with paternal engagement in the daily care; and Identification of the activities performed by the fathers in the care to the child with microcephaly.*

3.1 Paternal perception and self-assessment regarding the participation in the daily care of the child with microcephaly

This category was created by the perceptions that fathers had about their role as a participant in caring for their child, that is, perceptions of an active or auxiliary father in daily life; as well as their self-assessments of getting involved in the child's daily care.

In the active paternal participation, the fathers understood the importance of fully participating in their child's routine, especially as a child with a disability, that is, the exhaustive routine of care and treatment cannot be attributed to just one person. Also, this essential participation for the full development of the child was highlighted in the following statements:

The father must participate more intensely, because since the children are special they have this need and, the work, he is 10 times in everything [...], the doctor's routine, when not, it is the examination, treatment, it's a consultation [...] so it's a very big routine and one person just can't handle it (Interviewee 1).

It is important because it helps in the child's development and better stimulates the child's development [...]. (Interviewee 2).

In the perception of auxiliary paternal participation, fathers understood that they should contribute by assisting the mother in the basic tasks, when necessary:

Changing clothes, bath the child, helping the mother in whatever is necessary to always be on the child's side, right (Interviewee 2).

Then you have to see that he also has to do something too, so do his part because it is very difficult just for the mom to change diapers, to make porridge, to take care of the house... it's always good to have your participation too (Interviewee 3).

It's important, right, because the people who accompany us daily see that it is difficult for mothers to take care of everything because they have the house [...] (Interviewee 4).

When assessing their participation in the daily care of their children, most participants consider having good participation, supporting the mother in what is necessary and better for the child, and cannot perform more functions due to the short time they stay with the child.

I think my participation is very active, you know? And so ... I think that what I do in participating in her development is of paramount importance, we participate in everything that is necessary for her (Interviewee 1).

My participation, I see that from 100% is 80%, what I can do for him, so when I am with him, I do [...] then I consider my participation good, because I could do more if I had more time to do it, I would consider it a good help for her (Interviewee 4).

I evaluate that as much as I can do for him I try, because I have my own tasks, too (Interviewee 3).

Despite highlighting his participation in the financial aid and affirming that he had contact with the child, Participant 2 considered his participation ineffective because he did not live with them daily.

Man, I don't think it's so effective, because we're separate, but what I can do, when I get her to stay with me, I do everything to see her well. My biggest participation is financial, when she needs me I do everything to help, well not help, because it is our obligation (Interviewee 2).

3.2 Factors associated with paternal engagement in daily care

In this category, some factors that may be associated with greater or less paternal engagement in daily care for children with microcephaly are pointed out.

One factor that enables the father's greater engagement in care is associated with his perception of the child's difficulties in daily life and that this can lead to maternal overload when there is no division of tasks between parents.

Yes, I consider the father's participation important, because the daily needs are so great so the mother has to take care of the house, the husband, so this division of tasks she is fair and deserved them (Interviewee 1).

On the other hand, the fact that they have other attributions, added to the limited availability of work-related time, does not allow more active paternal participation in daily life, adding participation in the daily care of children with disabilities only to the financial management function of the home and family work routine, reducing engagement in other activities.

[...] It's always the mother because I work, but it's not because I work that it's an excuse, right?! It's because I leave home early, I go to the catwalk (rural activity), then I arrive at 11 a.m. or 11:30 a.m., that's when I get him more, and she will finish the rest of the house, I stay with him and in the afternoon too (Interviewee 3).

Another factor showing less involvement of the father in daily care is related to the expressive presence of cultural values, the belief that the father considers that he already has his commitments/work,

delegating the care of the child only as a duty of the mother.

So, the woman nowadays wants more work, something more external, and forgets a little about the house, so I really let her do it because otherwise she won't do anything and I work too, I have my commitments. There are things I let her do because I think I really have to (Interviewee 1).

The inability and/or insecurity to perform some activities related to bathing, eating and personal hygiene due to the limitations presented by the child can also interfere with the fathers' daily involvement.

[...] she eats little by little, she has the right positioning because otherwise, she chokes (Interviewee 1).

I participate with him like that, I just don't bathe [...] so, I don't bathe because he's soft, so I'm afraid of letting him fall (Interviewee 4).

I don't do much, at first I was afraid when she was younger, then I was afraid to take her so I wouldn't hurt her (Interviewee 2).

The participation of other caregivers besides the mother, especially grandmothers and uncles who help and support the care of the child is a predictor that may contribute to the less paternal engagement in childcare.

In the morning, my daughter stays with her maternal grandmother, and her aunt also helps every morning. The whole family participates, especially in the grandparents' house (Interviewee 1).

Other people participate, whenever I take her home, my sister, my father, and my mother (Interviewee 2).

[...] The paternal grandmother also participates a lot in the care [...] at home everyone participates, they help! (Interviewee 3).

[...] her family, sister, mother, my mother, when she has time goes inside and is always visiting her and him, in this way she is never alone, you know? There is always someone to assist her (Interviewee 4).

3.3 Identification of the activities performed by the fathers in the care to the child with microcephaly

In this category, activities that were not considered in the questionnaire were included, but they were significant in the statements of fathers.

According to the statements of participants 1, 3 and 4, it appears that some fathers, in their free time, often perform the activity of holding the child to help the mother to perform the domestic services, they hold the child so the mother rest and talk with the child.

[...] stand with her on my lap, smell her, talk to her (Interviewee 1).

[...] I'm not that much of playing children either, but I talk like that (Interviewee 3).

The most I do is pick him up for her (wife) to do things, whenever I get home from work, there is lunch to do, house to sweep, still she'll do laundry, that's when I get him to finish the rest of things [...] (Interviewee 3).

What I do most often is stay with him while she's making food for him, you know? Or sometimes, when she's too tired, I stay with him all day [...] (Interviewee 4).

4 Discussion

It was observed that 43% (n = 10) of the fathers of children with microcephaly were in a stable marital status and lived with their children in the same household. Studies have shown that a stable marital relationship and frequent cohabitation with children also seem to favor the father's engagement in daily childcare (RESENDE et al., 2014; VIEIRA et al., 2014).

There was a larger number of fathers in our study between 10 and 12 years of study. According to this aspect, Resende et al. (2014) states that the higher the fathers' level of education, the greater their chances of understanding and changing the reality they are part. However, the total family income did not much exceed a minimum wage, considering them as a family with low socioeconomic level, since many fathers are in labor activities whose remuneration does not meet the family's needs,

even with the complementation of income from the participation of children in social programs, mainly because the arrival of a child with microcephaly requires care that culminates in increased expenses for the family (FELIX; FARIAS, 2017).

According to the results presented, many of the fathers lived in the metropolitan region of the state of Alagoas. Such aspect could positively influence their participation in child health care since treatment sites are located in the state capital. However, some parents rarely participated in this activity, which may be associated with the work factor. Felix and Farias (2017) found that the attempts of a man to reconcile the life of father and worker, in view of the perspective that deals with setting up as a home provider, is difficult to follow the child in treatments.

Regarding the type of work activity of the fathers, they perform functions that require a lot of time away from home due to longer working hours, implying less involvement in the daily care of the child. For Parke (1996), men who are highly committed to work and who spend long hours in employment tend to be less involved in parenting. Work can be considered a factor that decreases the father's involvement in the daily care of the child with microcephaly, due to the extensive daily work hours that lead to absence in family daily life.

Fox and Bruce (2001) stated that fathers' beliefs about their "father/husband" versus "worker" roles drive their behaviors and, in particular, their involvement in the child's daily life. Believing that their sense of identity is determined by how well they play their role as a father, their father's involvement with his children is expected to be greater. However, if their sense is strengthened by increased time and effort in the workplace, the father's involvement with his children is expected to be reduced. However, a parent's beliefs about his own role may relate to changes in involvement during the child's childhood.

Despite the work activities performed by them, most claimed to provide more than two hours in childcare. However, paternal involvement in daily activities is conditional on both the amount and quality of time that parents devote to their children and the types of tasks they perform during this period (LAMB et al., 1985).

In general, fathers are more engaged in tasks related to playing, leisure and social participation.

However, as in ADLs, IADLs and rest and sleep, this engagement ends up decreasing in some activities, implying that tasks related to direct childcare, in most cases, are delegated to the mother, and the man develops activities that involve less expenditure of time and energy (SUTTER; BUCHER-MALUSCHKE, 2008).

Activities such as talking and lapping are performed by fathers mainly on the night shift and/or when time is available due to work, staying with the child so the mother can complete the housework. Concomitantly with these data, some research revealed that parents participate little in household chores and basic childcare, with only the play activities being mentioned (ARAÚJO; SCALON, 2006; CREPALDI et al., 2006).

A study by Planalp and Braungart-Rieker (2016), when examining the patterns and determinants of father's care for children and playing behaviors over time, found that levels of care and play changed over time as the child got older. And regarding care, fathers who were less involved in changing diapers helped with toilet use and dressed their children's clothes more often.

The Instrumental Activities of Daily Living (IADLs) are considered activities to support daily life at home and in the community (AMERICAN..., 2015). Thus, the results of this research indicated greater parental participation only in the performance of activities aimed at the establishment and management of the home and the finances and education of the children, referring to the idea that men are mainly responsible for family support and due to their work routine, there would not be much time left to help with domestic activities.

However, this role attributed to the father refers to probable cultural and moral remnants of the maintenance of roles of the father and mother between the eighteenth and nineteenth centuries, with the mother is the main caregiver and responsible for the child's development, while the father is the family's financial provider (BORSA; NUNES, 2011; SEABRA; SEIDL-DE-MOURA, 2012; GOMES; ALVARENGA, 2016).

In the perception of parents about participation in daily care, it was well known for the understanding of their responsibilities when recognizing the importance of involvement in the child's daily life, and such participation was still based on a perspective of helping the mother more related

to physical presence, implying non-involvement required for the basic care of children.

Among the factors associated with parents' involvement in childcare, there was their recognition of the child's daily difficulties and the need to support caregivers. As much as the father does not perform all activities on par with the mother, recognition of the child's care demands contributed to greater parental involvement in the division of tasks, reducing maternal burden. Silva and Piccinini (2007) concluded that parents participated in basic care and, although often irregular, they shared with the mother the responsibility for raising the children, proposing that the father can have broad participation in the children's lives, not restricting their involvement of financial support, walks and games.

Another study found that when mothers of children with disabilities experience psychological problems, they can benefit from a social support network, particularly support from an immediate family member. In this sense, an immediate family member who can play a particularly important role in supporting mothers and helping to reduce stress, anxiety and depressive symptoms is the father (OLSSON; HWANG, 2001; BOYD, 2002; FELDMAN et al., 2007; RAINA et al., 2005; LAXMAN et al., 2015).

The results of this study showed that the care and play of the father with his children are under the influence of several determinants intrinsically linked to involvement in daily tasks (PLANALP; BRAUNGART-RIEKER, 2016). Corroborating the statement, the study by Bronte-Tinkew et al. (2006) found that the role that the father assumes in the family affects the way he engages with the child.

On the other hand, fathers' insecurity in performing some activities is related to lower engagement. Often insecurity is also associated with lack of knowledge. In this case, performing hygiene, clothing, and drug administration activities require knowledge of the proper way to perform it. In general, this information is transmitted to caregivers who accompany children in treatment by therapists during care in an educative manner, through verbal or demonstration or written guidance. Monteiro, Rios, and Shimo (2014) realized that even aware of the importance of their presence, fathers are still afraid to participate because they do

not know how far they are helping or disrupting, being afraid of harming the child.

Also, sociocultural values also imply less engagement, either by the division of care with other family members or by gender division. Depending on this aspect, there are beliefs linked to the sexual division of domestic work, which would prevent men from investing time and effort in this type of activity, delegating to the mother the responsibility for basic childcare, while men would perform activities more related to the social life and leisure of the child (GOMES; ALVARENGA, 2016).

Moreover, fatherhood carries conceptions about heterosexual virility related to the ability to support and educate children, so these attributions place paid work as men's fundamental reference in the conceptions of paternity and masculinity, especially hegemonic. Such conceptions prove the physical attribute of paternity, in which to be able to support and educate them to prove their moral attribute (VIEIRA et al., 2014; RIBEIRO et al., 2015).

These values and beliefs are also part of the perceptions of many mothers, contributing to the reality experienced, because the fear of men in developing activities aimed at childcare is attributed, in some cases, to the mothers that do not allow their partners to effectively take care of their children, giving them a substitute or supporting role, perpetuating a more traditional parental role in the daily care of their children (DESSEN; OLIVEIRA, 2013). Since men have difficulty taking initiative to engage in their child's life, it is important that women and other family members facilitate the development of care skills (CARDELLI; TANAKA, 2012).

However, the presence of other family members involved in childcare may imply non-co-responsibility of the father. According to Marion et al. (2015), the way parents participate in child-rearing can be influenced by socioeconomic and cultural factors, especially regarding the performance of basic care activity. Families tend to organize childcare from the extended family network, uncles and grandparents, and this includes holding women in the family responsible for direct childcare, contributing the father to be less required to perform such care of activity with the children.

Vieira et al. (2014) evidenced the coexistence of family models in which there is the sharing of

tasks by the father and the mother, others indicated that mothers are directly responsible for the care of their children. Although more paternal involvement is reported with children, there is no equivalent participation in household chores, which men still perceive as belonging to the female universe, and even men sharing care and household chores with their wives, the father's role as the provider continues to stand out.

The exercise of fatherhood encompasses a series of historical, socio-cultural and gender transformations, resulting from the new family arrangements, which take more direct care of parents with young children. Changes in the family environment led to redefinitions that the male role goes beyond the role of provider and requires the appreciation of affective, interactive and companion activities with children, including dialogue and participation in daily leisure. However, despite these changes, women are still considered primarily responsible for childcare in most Brazilian families, expressing a gender hierarchy in daily practices (MARTINS, 2009).

5 Final Considerations

The study provided knowledge about the socio-demographic profile of fathers of children with microcephaly, outlining the frequency of participation in occupations, and analyzing the perception they have about their participation in day-to-day childcare. Such information is relevant to the scientific community, families, professionals, and managers of health services, favoring a broader perspective on the topic.

The perception of fathers regarding their participation in the daily care of their children has been supported by a cultural bias, fostering the fact that women are only delegated to the home caregiver's assignment and men to the financial management function, in such a way that the father understands that he can participate in the performance of daily tasks when he has time available. However, men believe they contribute sufficiently, assisting mothers in daily childcare. However, the presence of a child with disabilities requires greater involvement in activities that require more time and energy expenditure and, most of the time, the mother do not exercise their occupational roles in society to devote to their child.

The need for health professionals to contribute to fathers' commitment to childcare is emphasized,

developing strategies in specialized rehabilitation services or Primary Health Care, through guidance during care and activities directed to fathers, either in meetings, commemorative and educational groups or events. Nevertheless, the importance of strategies and public policies that enable parents to engage in the treatment of their children and help promote parental participation in all dimensions of care for children with disabilities is emphasized.

Acknowledgements

To the Fundação de Amparo à Pesquisa do Estado de Alagoas (FAPEAL) for funding the research throughout the period, the parents of the children with microcephaly who contributed directly to the results and the Specialized Rehabilitation Centers (SRCs) of the city of Maceió/AL who supported the development of this study.

References

- ALAGOAS (Estado). *Municípios Alagoanos*. Maceió: Secretaria de Estado da Cultura, 2018. Disponível em: <<http://www.cultura.al.gov.br/municipios/municipios-alagoanos-1>>. Acesso em : 15 set. 2018.
- AMERICAN OCCUPATIONAL THERAPY ASSOCIATION – AOTA. Estrutura da prática da Terapia Ocupacional: domínio & processo. *Revista de Terapia Ocupacional da Universidade de São Paulo*, São Paulo, v. 26, p. 1-49, 2015.
- ARAÚJO, C.; SCALON, C. Gênero e a distância entre a intenção e o gesto. *Revista Brasileira de Ciências Sociais*, São Paulo, v. 21, n. 62, p. 45-68, 2006. <http://dx.doi.org/10.1590/S0102-69092006000300003>.
- ARIÈS, P. *História social da criança e da família*. Rio de Janeiro: Zahar, 1981.
- BARDIN, L. *Análise de conteúdo*. São Paulo: Edições 70, 2011.
- BORSA, J. C.; NUNES, M. L. T. Aspectos psicossociais da parentalidade: o papel de homens e mulheres na família nuclear. *Psicologia Argumento*, Curitiba, v. 29, n. 64, p. 31-39, 2011.
- BOYD, B. A. Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, Georgia, v. 17, n. 4, p. 208-215, 2002. <http://dx.doi.org/10.1177/10883576020170040301>.
- BRAGA, M. G. R.; AMAZONAS, M. C. L. A. Família: maternidade e procriação assistida. *Psicologia em Estudo*, Maringá, v. 10, n. 1, p. 11-18, 2005. <http://dx.doi.org/10.1590/S1413-73722005000100003>.
- BRASIL. *Protocolo de vigilância e resposta à ocorrência de microcefalia relacionada à infecção pelo vírus Zika*. Brasília, 2015. Disponível em: <http://combateaesd.saude.gov.br/images/sala-de_situacao/Protocolo_SAS_versao_3_atualizado.pdf>. Acesso em: 29 dez. 2017.
- BRONTE-TINKEW, J.; CARRANO, J.; GUZMAN, L. Resident fathers perceptions of their roles and links to involvement with infants. *Fathering*, Estados Unidos, v. 4, n. 3, p. 254-285, 2006. <http://dx.doi.org/10.3149/fth.0403.254>.
- CARDELLI, A. A. M.; TANAKA, A. C. D. Ser/estar pai: uma figura de Identidade. *Revista Ciência, Cuidado e Saúde*, Maringá, v. 11, n. 1, p. 251-258, 2012.
- CREPALDI, M. A. et al. A participação do pai nos cuidados da criança, segundo a concepção de mães. *Psicologia em Estudo*, Maringá, v. 11, n. 3, p. 579-587, 2006. <http://dx.doi.org/10.1590/S1413-73722006000300014>.
- CRUZ, T. A. R.; SILVA, F. C.; SANTOS, E. M. S. Perfil clínico, sociodemográfico e funcional dos lactentes com microcefalia atendidos no setor de terapia ocupacional de um Centro Especializado em Reabilitação. In: REUNIÃO ANUAL DA SBPC, 69., 2017, São Paulo. *Anais...* São Paulo: SBPC, 2017. p. 1-4.
- DESSEN, M. A.; OLIVEIRA, M. R. Envolvimento paterno durante o nascimento dos filhos: pai “real” e “ideal” na perspectiva materna. *Psicologia: Reflexão e Crítica*, Porto Alegre, v. 26, n. 1, p. 184-192, 2013. <http://dx.doi.org/10.1590/S0102-79722013000100020>.
- FELDMAN, M. et al. Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay. *Journal of Intellectual Disability Research*, Oxford, v. 51, n. 8, p. 606-619, 2007. <http://dx.doi.org/10.1111/j.1365-2788.2006.00941.x>.
- FELIX, V. P. S. R.; FARIAS, A. M. Microcefalia: o filho real e as mudanças na dinâmica familiar sob a perspectiva do pai. In: CONGRESSO BRASILEIRO DE CIÊNCIAS DA SAÚDE, 2., 2017, Campina Grande. *Anais...* Campina Grande, 2017. p. 1-12. Disponível em: <https://editorarealize.com.br/revistas/conbracis/trabalhos/TRABALHO_EV071_MD1_SA13_ID1726_09052017103029.pdf>. Acesso em: 19 mar. 2018.
- FOX, G. L.; BRUCE, C. Conditional fatherhood: identity theory and parental investment theory as alternative sources of explanation of fathering. *Journal of Marriage and the Family*, United States, v. 63, n. 2, p. 394-403, 2001. <http://dx.doi.org/10.1111/j.1741-3737.2001.00394.x>.
- GOMES, Q. S.; ALVARENGA, P. O envolvimento paterno em famílias de diferentes níveis socioeconômicos. *Psicologia: Teoria e Pesquisa*, Brasília, v. 32, n. 3, p. 1-9, 2016. <http://dx.doi.org/10.1590/0102-3772e323216>.
- HENN, C. G.; SIFUENTES, M. Paternidade no contexto das necessidades especiais: revisão sistemática

- da literatura. *Paidéia*, Porto Alegre, v. 22, n. 51, p. 131-139, 2012.
- KRAMMER, P.; HINOJOSA, J.; ROYEEN, C. B. *Perspectives in human occupation: participation in life*. Baltimore: Lippincott Williams & Wilkins, 2003.
- LAMB, M. E. et al. Paternal behavior in humans. *American Zoologist*, United Kingdom, v. 25, n. 3, p. 883-894, 1985. <http://dx.doi.org/10.1093/icb/25.3.883>.
- LANGARO, F.; PRETTO, Z. Experiências de parentalidade como fatores geradores de sofrimento em mulheres. *Fractal Revista de Psicologia*, Niterói, v. 27, n. 2, p. 130-138, 2015. <http://dx.doi.org/10.1590/1984-0292/453>.
- LARSON, E.; WOOD, W.; CLARCK, F. Ciência Ocupacional: Desarrollo de la ocupación através de uma disciplina acadêmica. In: CREPEAU, E. B.; COHN, E. S.; SCHELL, B. A. B. *Willard & Spackman: Terapia Ocupacional*. Buenos Aires: Medica Pan Americana, 2005. p. 16-26.
- LAXMAN, D. J. et al. Father involvement and maternal depressive symptoms in families of children with disabilities or delays. *Maternal and Child Health Journal*, New York, v. 19, n. 5, p. 1078-1086, 2015. <http://dx.doi.org/10.1007/s10995-014-1608-7>.
- LUCCA, S. A.; PETEAN, E. B. L. Paternidade: vivências de pais de meninos diagnosticados com distrofia muscular de Duchenne. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 21, n. 10, p. 3081-3089, 2016. <http://dx.doi.org/10.1590/1413-812320152110.20302016>.
- MARION, J. et al. Desafios de ser pai em uma sociedade em transformação. In: GOETZ, E. R.; VIEIRA, M. L. *Novo pai: recursos, desafios e possibilidades*. Curitiba: Juruá, 2015. p. 171-180.
- MARTINS, A. C. Paternidade: repercussões e desafios para a área de saúde. *Revista Pós Ciências Sociais*, Maranhão, v. 1, n. 11, p. 1-28, 2009.
- MARTINS, M.; COUTO, A. P. Vivências do dia-a-dia de pais com filhos deficientes. *Revista de Enfermagem Referência*, Portugal, v. 4, n. 1, p. 117-124, 2014. <http://dx.doi.org/10.12707/RIII1266>.
- MONTEIRO, F. P.; RIOS, M. I. M.; SHIMO, A. K. K. A participação paterna em Unidades de Terapia Intensiva Neonatal. *Revista Ciencia Médica*, Campinas, v. 23, n. 3, p. 145-151, 2014.
- OLIVEIRA, A. G.; SILVA, R. R. Pai contemporâneo: diálogos entre pesquisadores brasileiros entre o período de 1998 a 2008. *Psicologia Argumento*, Curitiba, v. 29, n. 66, p. 353-360, 2011.
- OLSSON, M. B.; HWANG, C. P. Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, Oxford, v. 45, n. 6, p. 535-543, 2001. <http://dx.doi.org/10.1046/j.1365-2788.2001.00372.x>.
- PARKE, R. D. *Fatherhood*. Cambridge: Harvard University Press, 1996.
- PLANALP, E. M.; BRAUNGART-RIEKER, J. M. Determinants of father involvement with young children: evidence from the ECLS-B. *Journal of Family Psychology*, United States, v. 30, n. 1, p. 135-146, 2016. <http://dx.doi.org/10.1037/fam0000156>.
- RAINA, P. et al. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, Springfield, v. 115, n. 6, p. 626-636, 2005. <http://dx.doi.org/10.1542/peds.2004-1689>.
- RESENDE, T. C. et al. Participação paterna no período da amamentação: importância e contribuição. *Bioscience Journal*, Uberlândia, v. 30, n. 3, p. 925-932, 2014.
- RIBEIRO, C. R.; GOMES, R.; MOREIRA, M. C. N. A paternidade e a parentalidade como questões de saúde frente aos rearranjos de gênero. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 20, n. 11, p. 3589-3598, 2015. <http://dx.doi.org/10.1590/1413-812320152011.19252014>.
- SCHULER-FACCINI, L. et al. Possible association between zika virus infection and microcephaly Brazil 2015. *Morbidity and Mortality Weekly Report*, Atlanta, v. 65, n. 3, p. 59-62, 2016. <http://dx.doi.org/10.15585/mmwr.mm6503e2>.
- SEABRA, K. S.; SEIDL-DE-MOURA, M. L. Cuidados paternos nos primeiros três anos de vida de seus filhos: um estudo longitudinal. *Interação em Psicologia*, Curitiba, v. 15, n. 2, p. 135-147, 2012. <http://dx.doi.org/10.5380/psi.v15i2.17330>.
- SILVA, M. R.; PICCININI, C. A. Sentimentos sobre a paternidade e o envolvimento paterno: um estudo qualitativo. *Estudos de Psicologia*, Campinas, v. 24, n. 4, p. 561-573, 2007. <http://dx.doi.org/10.1590/S0103-166X2007000400015>.
- SOUZA, M. B.; SANGUINET, E. T. *Pais que assumiram sozinhos os cuidados parentais de seus filhos*. Psicologia Pt, 2012. Disponível em: <<http://www.psicologia.pt/artigos/textos/TL0285.pdf>>. Acesso em: 05 fev. 2018.
- SUTTER, C.; BUCHER-MALUSCHKE, J. S. N. F. Pais que cuidam dos filhos: a vivência masculina na paternidade participativa. *PSICO*, Porto Alegre, v. 39, n. 1, p. 74-82, 2008.
- VIEIRA, M. L. et al. Paternidade no Brasil: revisão sistemática de artigos empíricos. *Arquivos Brasileiros de Psicologia*, Rio de Janeiro, v. 66, n. 2, p. 36-52, 2014.

Author's Contributions

Tainá Alves Rocha da Cruz worked on the text writing, data collection, systematization, and analysis. Emanuele Mariano de Souza Santos performed the conception, systematization, and analysis of data, the text revision and orientation. Flávia Calheiros da Silva performed data systematization and analysis, the text revision and co-orientation; Monique Carla da Silva Reis worked on the review of the text, and Ângela Cristina Dornelas da Silva revised the text. All authors approved the final version of the text.

Funding Source

Fundação de Amparo à Pesquisa do Estado de Alagoas (FAPEAL).

Notes

- ¹ The work followed all ethical parameters for research in human beings according to Resolution 466/2012, approved by the Research Ethics Committee, under CAAE 68355917.2.0000.5011 on June 13, 2017, and with amendment approval on October 3, 2017. The study shows the results of research carried out with the Scientific Initiation Scholarship Program (PROBIC) of the State University of Health Sciences of Alagoas (UNCISAL), linked to the Alagoas Research Support Foundation (FAPEAL).
- ² The extraction of demographic regions was based on the website of the State Secretariat of Culture of Alagoas (ALAGOAS, 2018). The Metropolitan Region covered the municipalities of Maceió and Murici; the Agreste region encompassed Estrela de Alagoas; the northern region covered the municipality of São Luís do Quitunde, Novo Lino and Maragogi; the Paraíba and Mundaú Valleys regions included the municipalities of Atalaia and Viçosa; In the southern region, the municipality of Penedo was included.