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Congenital zika syndrome: analysis of parent support networks

Síndrome congênita pelo vírus zika: análise das redes de apoio de pais

Síndrome congénito por el virus del zika: análisis de las redes de apoyo de padres

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Abstract

Objective: To understand the role of support networks in the care of children affected by Congenital Zika Syndrome.

Methods: This is a qualitative study, conducted at a State Reference Center on Neurodevelopment, in northeastern Brazil, between April 2017 and February 2018. Parents of children with microcephaly treated at the site participated. 18 semi-structured interviews were conducted, three with father and mother and 15 only with mothers, totaling 21 participants. The sample was defined by the saturation criterion and content analysis was used in the thematic modality.

Results: The results are presented from the categories of analysis “informal network” and “formal network”. The informal support network, especially grandparents, exercised important emotional and financial support to parents. Virtual social networks stood out as a space for sharing information and experiences. Regarding the formal support network, the families established stronger bonds with specialized care professionals who offered technical support and care to parents and children. Primary care, on the other, played the role of referral to specialized care. Different degrees of resolution were reported by the municipalities, in terms of programs, the performance of managers and professionals.

Conclusion: Formal and formal networks acted in a complementary way in the treatment and support of children with Congenital Zika Syndrome. The insertion in different indirect networks allowed social support to face the impact caused by the disease. Despite the ministry of health’s investment in primary care, fragility was identified in this level of care.

Resumo

Objetivo: Compreender o papel das redes de apoio no cuidado de crianças acometidas pela Síndrome Congênita pelo Vírus Zika.

Métodos: Estudo qualitativo, realizado em Centro de Referência Estadual em Neurodesenvolvimento, no nordeste brasileiro, entre abril de 2017 e fevereiro de 2018. Participaram pais de crianças com microcefalia atendidos no local. Foram realizadas 18 entrevistas semiestruturadas, sendo três com pai e mãe e 15 somente com mães, totalizando 21 participantes. A amostra foi definida pelo critério de saturação e foi utilizada análise de conteúdo na modalidade temática.

Resultados: Os resultados são apresentados a partir das categorias de análise “rede informal” e “rede formal”. A rede de apoio informal, especialmente os avós, exerceu importante suporte emocional e financeiro aos pais. As redes sociais virtuais se destacaram como espaço de compartilhamento de informações e experiências. Quanto à rede de apoio formal, as famílias estabeleceram vínculos mais fortes com profissionais da atenção

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especializada que ofertaram suporte técnico e acolhimento aos pais e às crianças. Já a atenção primária desempenhou mais o papel de encaminhamento para a atenção especializada. Foram relatados diferentes graus de resolutividade por parte dos municípios, em termos de programas, de atuação de gestores e de profissionais.

Conclusão: As redes informais e formais atuaram de modo complementar no tratamento e apoio às crianças com Síndrome Congênita pelo Vírus Zika. A inserção em diferentes redes informais possibilitou apoio social para enfrentar o impacto provocado pela doença. Apesar do investimento do Ministério da Saúde na atenção primária foi identificada fragilidade neste nível de atenção.

Resumen

Objetivo: Comprender el papel de las redes de apoyo en el cuidado de niños afectados por el síndrome congénito por el virus del zika.

Métodos: Estudio cualitativo, realizado en un Centro de Referencia Regional en Neurodesarrollo, en el nordeste brasileño, entre abril de 2017 y febrero de 2018. Participaron padres de niños con microcefalia atendidos en el lugar. Se realizaron 18 entrevistas semiestructuradas, de las cuales tres fueron con el padre y la madre y 15 solo con madres, un total de 21 participantes. La muestra fue definida por el criterio de saturación y se utilizó análisis de contenido en la modalidad temática.

Resultados: Los resultados se presentan a partir de las categorías de análisis “red informal” y “red formal”. La red de apoyo informal, especialmente los abuelos, ejerció un importante soporte emocional y financiero para los padres. Las redes sociales virtuales se destacaron como un espacio para compartir información y experiencias. Respecto a la red de apoyo formal, las familias establecieron vínculos más fuertes con profesionales de la atención especializada, que ofrecieron soporte técnico y acogida a los padres y a los niños. Por otro lado, la atención primaria cumplió más el papel de derivar a la atención especializada. Se relataron diferentes niveles de resolución de problemas por parte de los municipios, en términos de programas, de actuación de gestores y de profesionales.

Conclusión: Las redes informales y formales actuaron de modo complementario en el tratamiento y apoyo a niños con síndrome congénito por el virus del zika. La inserción en diferentes redes informales permitió un apoyo social para enfrentar el impacto provocado por la enfermedad. A pesar de las inversiones en atención primaria del Ministerio de Salud, se identificó fragilidad en este nivel de atención.

Introduction

In 2015, the circulation of Zika Virus in Brazil(1) associated with the epidemic of children diagnosed with microcephaly was confirmed. The following year, a health emergency was declared by the Ministry of Health (MoH) and the World Health Organization.(2)

Microcephaly alters the structure and function of the neurological system, being characterized by head circumference less than two standard deviations below the mean for sex and gestational age.(3) Delays in neuropsychomotor development may be associated with microcephaly in varying degrees of impairment. When caused by Zika Virus, it may be isolated or part of Congenital Zika Syndrome (CZS), resulting in poor quality and life expectancy.(4,5)

Faced with the birth of a child with a disease at risk for their life and development, parents face difficulties, fears and uncertainties. An aggravating factor of CZS was that it was a disease still unknown, highlighted by the media. There was intense dissemination of information, often unenlightening, including images of children with microcephaly. The reality faced by parents and the mismatch of information generated a need for support. The families then sought health services in search of care and explanations and also from other parents in the same situation.(1,6)

The epidemic brought challenges to the health system, especially considering gaps in care already in the network, which was not prepared to meet this new demand.(7) The high prevalence of the disease, the severity and chronicity of the cases, caused the need for an agile response of the State with actions mainly related to social assistance and health, such as benefits, exemption from taxes, examinations and medications.(8)

Caring for children with little-known disease triggers changes in family routine, requiring the reorganization of life.(9) CZS affected many families already living in a vulnerable situation, which was aggravated by the disease.(10–12)

The knowledge of organization and interaction between members of these families, their forms of cooperation and problem solving, as well as their approximation with health services and professionals are fundamental to understand the needs and potentialities of healthcare, in general and, particularly, of nursing.

Knowing the experience of the disease and the challenges caused by the severity and uncertainty in the future of these children can contribute to the understanding of the bonds constituted, reinforced or even broken.(13)

This work was carried out considering the support networks, consisting of networks of formal and formal relationships. The formal ones are those established with health and social care professionals, while the informal ones comprise family or friendship bonds, with emphasis on affection.(14,15) Such networks sometimes also provide material and cognitive support.

Thus, the aim of this study was to understand the role of support networks in the care of children affected by CZS.

Methods

This is a qualitative research based on comprehensive theory, that seeks to understand and interpret social action, i.e., the behavior and meanings attributed by the investigated subjects.(16)

This study was conducted between April 2017 and February 2018 at a State Reference Center on Neurodevelopment that offers specialized treatment to children, including microcephaly due to CZS. The institution assists children by monitoring neuropsychomotor development and supports family members. It has a multidisciplinary team composed of physicians, physiotherapists, occupational therapists, psychologists, social workers and speech therapists.

Participants were mothers and/or fathers, whose children received care at the research site, and 146 children with microcephaly were identified. To define the sample, a picture containing children's clinical conditions and parents' sociodemographic characteristics was constructed, based on data from 146 medical records.

The parameters used to contemplate the diversity of families were: disease severity; place of residence (capital or countryside), mothers' age, marital status, number of children, religion, occupation, income and education, seeking to contemplate the diversity of situations encountered.

The final number of the sample was 18 families and was defined by the saturation criterion, at which time the data obtained in the field allow the researcher to understand the object of study, under the logic of the interviewees.(16)

The initial approach with parents, made on the day of the consultation or by telephone contact, was previously authorized and mediated by the institution, considering that there was no previous relationship with the researcher. This contact sought to inform about the research, make the invitation to participate and schedule a meeting in the children's next consultation to conduct the interviews. There were no refusals.

The data collection technique was a semi-structured interview, conducted based on the following guide question: what is the role of support networks in the care of children affected by CZS? A script was used with open-ended questions related to support received in child care: from whom it received support, as was this support and related feelings. The interviews were conducted by the main researcher, in private rooms, with an average duration of 37 minutes, audio-recorded and later transcribed.

Content analysis was performed in the thematic modality.(16) Pre-analysis consisted of text skimming and exhaustive reading in the search for central ideas - thematic units Material systematization took place from two central analytical categories: informal support network and formal support network. The codes and thematic units identified in the process of categorization of the informal network were: absence of network, companion, family, friends and virtual social networks; and the formal network: absence of network, municipal, state and federal managers, healthcare professionals and social assistance.

The research was approved by the Institutional Review Board, under Opinion 2,111,125, following Resolution 466/12 of the Brazilian National Health Council (CNS – *Conselho Nacional de Saúde*). The signing of the Informed Consent Form was performed prior to the interview. To safeguard participants' identity, fictitious names were assigned.

Results

Eight interviews were conducted, three with father and mother and 15 with mothers only. Mothers were the main caregivers in all situations.

Chart 1. Sociodemographic characteristics of respondents

Son of*	Interview with	Mothers' age	Father age	Income (MW)	Father's education	Mother's education	Father occupation	Mother occupation	Marital status	Residence	Religion **	Planned pregnancy	Number of children
Moana	Mother	30	-	1.5	-	EDU	-	Housewife	Married	COU	-	No	4
Marina	Mother	18	31	1	IES	IES	Unemployed	Self-employed	Consensual union	CAP	Evangelical	Yes	2
Mônica	Mother	21	28	1	CHS	CHS	Unemployed	Housewife	Married	CAP	Evangelical	No	3
Melissa	Mother	18	21	2	IHS	IHS	Salesperson	Housewife	Married	COU	Catholic	No	1
Marcela	Couple	35	29	2	CHS	CES	Salesperson	Housewife	Married	COU	Evangelical	No	5
Maria	Couple	21	26	2	CHS	CES	Guard	Housewife	Married	COU	Evangelical	Yes	3
Márcia	Couple	22	28	1	CES	IHE	Unemployed	Student	Consensual union	COU		Yes	1
Mary	Mother	20	22	1.5	CES	CHS	Painter	Housewife	Consensual union	COU	Catholic	No	2
Milena	Mother	31	37	3	CHS	CHE	Merchant	Housewife	Married	COU	No religion	Yes	2
Mariana	Mother	22	24	1.5	CHS	CES	Unemployed	Housewife	Consensual union	CAP	-	No	3
Maísa	Mother	42	37	1	IES	IES	Self-employed	Housewife	Separate	CAP	-	No	9
Michele	Mother	19	24	1.5	IES	CHS	Unemployed	Housewife	Married	COU	Catholic	No	1
Marisa	Mother	32	37	1.5	CHS	CHS	Unemployed	Housewife	Married	CAP	Evangelical	No	2
Mel	Mother	20	22	1	CHS	CHE	Salesperson	Housewife	Consensual union	COU	Evangelical	Yes	3
Matilde	Mother	26	16	2	IHE	CHS	Receptionist	Housewife	Lovers	CAP	Catholic	No	1
Mirian	Mother	39	42	1	IES	CES	Self-employed	Housewife	Widowed	COU	-	Yes	2
Melani	Mother	15	26	3.5	CHS	CHS	Self-employed	Housewife	Consensual union	CAP	Catholic	No	1
Mila	Mother	20	35	1	CHS	CHS	Self-employed	Sealesperson	Consensual union	COU	-	No	1

MW - Minimum wage; EDU - Education; IES - Incomplete Elementary School; CES - Complete Elementary School; IHS - Incomplete High School; CHS - Complete High School; CHE - Complete Higher Education; IHE - Incomplete Higher Education; COU - Countryside; CAP - Capital; *Fictitious name; **Religion of respondents

Most women lived with their partner; had two or more children and did not plan the pregnancy. Two reported a new pregnancy at the beginning of the study, so children with CZS were the youngest children in 16 cases.

The mothers were between 15 and 42 years old and their partners were between 26 and 42 years old. Education ranged from incomplete elementary school to complete higher education. Most families had an income of less than two minimum wages and, in five, the main income was the Continuous Cash Benefit Program (BPC - *Benefício Assistencial de Prestação Continuada*). The majority of respondents lived in the state countryside (Chart 1).

Of the children, eleven were female. They were between 11 and 23 months old (Chart 2). All had the phenotype characteristic of CZS. The most present comorbidities were epilepsy and subnormal vision (Chart 3).

Report analysis was based on the categories "informal support network" and "formal support network". In each category, the presence or absence of support networks and their consequences for family dynamics and child care were identified.

Informal support networks

With the exception of one mother, respondents reported having some informal support network. The partner, family, friends and contacts made through virtual networks were mentioned. In this research, nine women demonstrated the couple's partnership in coping with the situation, highlighting its importance in caring for children.

> *"So, we were comforting each other" (Melissa)*

> *"Me and him all the time" (Marina)*

Chart 2. Characteristics of children with Congenital Zika Syndrome

Son of*	Sex	Age	Place of birth	Diagnosis time	PC (cm)
Moana	F	1y5m	Countryside municipality	At birth	27
Marina	F	1y4m	State capital	Pregnancy	24
Mônica	F	1y5m	State capital	Labor	29
Melissa	F	1y3m	Countryside municipality	At birth	28
Marcela	F	1y7m	Countryside municipality	After birth - 2m	28
Maria	M	1y7m	Countryside municipality	After birth - 15d	27
Márcia	F	1y4m	Countryside municipality	At birth	28
Mary	F	1y4m	State capital	Pregnancy	26
Milena	M	1y4m	Countryside municipality	After birth - 11d	28
Mariana	M	1y6m	State capital	At birth	28
Maísa	F	1y1m	State capital	After birth - 2m	33
Michele	M	11m	Countryside municipality	After birth - 8m	30
Marisa	M	1y9m	State capital	After birth - 7m	29
Mel	F	1y9m	Countryside municipality	Pregnancy	31,5
Matilde	F	1y10m	State capital	After birth - 8m	31
Mirian	M	1y11m	Countryside municipality	After birth	30,5
Melani	F	1y8m	State capital	Pregnancy	26,5
Mila	M	1y11m	State capital	Pregnancy	32

M - Male; F - Female; d - days; m - months; y - years; PC - Head Circumference; *Fictitious name

Chart 3. Comorbidities of children with Congenital Zika Syndrome

Son of*	Comorbidities	Skull-face disproportion	Biparietal depression	Prominent occipital	Excessive nuchal skin	Congenital clubfoot	Cleft palate/ cleft lip
Moana	Microcephaly, epilepsy, hydrocephalus, adenoid hypertrophy	Yes	Yes	Yes	Yes	Yes	No
Marina	Microcephaly, low vision	Yes	Yes	Yes	Yes	No	No
Mônica	Microcephaly, epilepsy	Yes	Yes	Yes	Yes	Yes	No
Melissa	Microcephaly, epilepsy, low vision	Yes	Yes	Yes	Yes	Yes	No
Marcela	Microcephaly, epilepsy	Yes	Yes	Yes	Yes	No	No
Maria	Microcephaly, epilepsy, protein-calorie malnutrition	Yes	Yes	Yes	Yes	No	No
Márcia	Microcephaly, seizures	Yes	Yes	Yes	No	Yes	No
Mary	Microcephaly, bifid uvula, seizures	Yes	Yes	Yes	Yes	No	No
Milena	Microcephaly, epilepsy	Yes	Yes	Yes	Yes	No	No
Mariana	Microcephaly, pityriasis versicolor, epilepsy	Yes	Yes	Yes	Yes	Yes	No
Maísa	No information	Yes	Yes	Yes	Yes	No	No
Michele	Microcephaly, pityriasis versicolor	Yes	Yes	Yes	No	No	No
Marisa	Microcephaly, cerebral palsy	Yes	No	No	No	No	No
Mel	Microcephaly, seizures, low vision	Yes	Yes	No	No	No	No
Matilde	Microcephaly	Yes	No	No	No	No	No
mirian	Microcephaly, epilepsy, pericardial effusion	Yes	No	No	No	No	No
Melani	Microcephaly, epilepsy, hydrocephalus	Yes	Yes	Yes	Yes	Yes	No
Mila	Microcephaly, epilepsy, low vision	Yes	Yes	Yes	Yes	Yes	No

*Fictitious name

In couples who had planned the pregnancy and who had a more stable marital relationship, men participated more in the division of activities related to child care, providing support to the mother, the main caregiver.

For some women, a father who "knows how to take care" was somehow different.

> *"He is a different father... He knows how to take care" (Moana)*

Another important support reported was the material and emotional support received by their parents, the child's grandparents, especially the maternal grandmother.

> *"And my mother [maternal grandmother] always by my side" (Mary)*

> *"And he [paternal grandfather] had it deposited in our account" (Márcia)*

> *"With everyone around, I didn't even have time to think about bad things" (Mônica)*

> *Mothers also reported the support received by their other children.*

> *"He plays with his brother while I need to do something" (Manuela)*

Another result found was the support received in a chat group by application. A group of parents was created at the beginning of the epidemic, still active at the time of the research, with the objective of exchanging information and experiences.

> *"I embraced this group" (Maria)*

Parents sought two types of information: scientific, provided by healthcare professionals and information based on experiences shared by family members and virtual groups.

One mother declared that she had no support. Maísa lived with her partner at her mother-in-law's house, but she moved with her daughter, who cried a lot and bothered everyone. The partner did not accompany her, remaining in the other house. In addition to being alone, Maísa reported that the other children, adults with established families, only looked for her to ask for financial help and to request care for their own children.

> *"I don't have anyone's support" (Maísa)*

Despite the fatigue and a narrative full of dissatisfaction, Maísa spoke with hope about future plans for improvements in the house to provide well-being for her daughter.

Formal support networks

Formal support networks included municipal, state and federal managers, social and healthcare professionals.

Regarding the network organization in the state countryside, different degrees of municipal resolution were described in the interviews, in terms of programs and performance of managers and professionals. In eight interviews, a positive view regarding the network organization was reported:

> *"She [Municipal Health Department employee] gets everything for me" (Maria)*

Network (dis)organization within the State, according to the reports of eleven respondents, refers to the lack of guidance on assistance programs for people with special needs, little resoluteness in assistance and the need for judicial mediation to guarantee care and treatment.

> *"In my city there is no treatment" (Moana)*

> *"In my city there's everything: speech therapist, physiotherapist, doctor, nurse, but they never went to follow up" (Marcela)*

> *"Almost every month I have to go after the prosecution" (Mary)*

Primary Health Care (PHC) was mentioned in only one interview. The mother reported a home visit made by the nurse who provided information about child care.

> *"The nurse came to the house and explained things to me very well" (Melissa)*

In 13 cases with prenatal care in PHC, the parents knew the diagnosis of microcephaly only after birth.

The performance of these professionals was presented by the interviewees as a step towards referral to treatment with specialized professionals. These represented the therapeutic support they needed so much for parents.

> *"She [specialized care physician] was all the professionals we needed" (Maria)*

Specialized assistance was mentioned in all interviews, with emphasis on infrastructure and, above all, the reception and competence of professionals.

Discussion

Informal support networks are made up of people who are part of individuals' social relationships. These networks are essential for coping with difficult situations and make an important contribution to managing the changes required by the disease. They have multiple dimensions, such as bonds of friendship and family support, and sometimes include, in addition to emotional and cognitive support, material support as well.(14,15)

Historically, caring for children was the mothers' responsibility, with fathers' role being linked only to material support. The lack of support from the child's father, referred to in the results, may be a reflection of this historical, systemic and ingrained construction that still shapes expectations. Overcoming it is a challenge.(17,18) Although changes are currently observed, such as the participation of women in the labor market and advances in the concept of fatherhood, domestic work and childcare are still mostly performed by women.(18,19)

In this sense, the concepts of fatherhood (which goes beyond the role of family supporter) and fatherhood (linked to fathers' affection and willingness to care)(20) help to understand different forms of conjugality. This understanding is important because the experiences of maternity and paternity, in front of a child with microcephaly due to CZS, are marked by the overload of care required by the severity of CZS.(4,21) Research on maternity and care during Zika's time has highlighted the place of mothers as the main caregivers.(9,22–24) The division of tasks with the child's father provided women with a reduction in their workload and perception of care.

As described in the results, grandparents were mentioned several times. In a study with families of children with cerebral palsy, grandparents were recognized as the main sources of support, as they help in various ways, including organizing the tiring routine of regularly taking the child to consultations, which can result in deprivation of social life.(25) Children with CZS require daily care(4,21), and closeness to the family in these cases was highly valued, especially the maternal grandmother.

The birth of a child with a disability is surrounded by impacts on the family routine.(9,26) The changes caused can restrict the time parents spend with other children and the attention given to them. Like other children, they can also take on some activities in caring for their sibling.(27)

The use of virtual social networks was another form of support reported by respondents. These have been an important space for exchanging experiences, both in care and in the search for treatment.(13) Faced with the emotional challenge of raising a child with a disability, the support of other parents allows the family to better apprehend the shared information, enabling the resignification of painful experiences.(28)

In fact, socializing in virtual groups has been reported as a protector for the quality of family life, as it allows the sharing of everyday themes and, above all, the appreciation of children's developmental milestones, not just focusing on illness. (5,29) Moreover, the sharing of experiences and information received by professionals and even that collected on the internet contributed to making them feel better prepared to face the situation.(13,29)

The situation of chronic illness can contribute to strengthening or, on the contrary, to breaking family ties.(15) Denial to care for a child or of their illness condition, by family members, causes sadness and a feeling of isolation in the main caregiver.(30) Despite this suffering, a research participant, who reported a lack of support, mentioned that the expectation of providing well-being to her daughter encouraged her to go ahead and deal with this serious situation.

The role of the formal network was essential in the Zika virus epidemic. Bill 3,974 of 2015 made the retirement of these children possible, providing financial support.(31) However, for children and their family to receive these benefits, the work of the formal network is essential, including with regard to access to information.(32)

The Tripartite Inter-Management Commission approved the Interministerial Ordinance 405/MoH/MSDA in 2016, which established, within the Unified Health System (SUS – *Sistema Único de Saúde*), the rapid action strategy for strengthening healthcare and social protection for children with microcephaly, including the right to care in primary care.(33) Other proposals for care and professional training were created by the Ministry of Health, aiming at greater speed in diagnosis and early intervention.(2)

In an attempt to minimize their fears and anxieties, parents sought instructions on how to meet the demands of children with disabilities, including how to stimulate development, choose the best education, contribute to their child's autonomy, deal with child safety and rights.(34)

However, the right to information was not always guaranteed. A survey of mothers of children with microcephaly reported a lack of sensitivity on the part of healthcare professionals, who favored guidelines and interventions without considering family demands, producing discredit in child care.(13)

Public policies aimed at families of children with special needs, even when adequate to the guidelines of integrality, universality and equity of SUS, do not always create strategies that make it possible to guarantee this assistance.(35)

In the national plan to fight the Zika virus, it was up to PHC to manage care through childcare, early stimulation, referral to specialized care and identification of families at social risk. PHC comprises actions that promote disease prevention, healthcare promotion and protection, diagnosis, treatment, rehabilitation, harm reduction and health maintenance.(1) Therefore, it has the potential to be an important support network for parents due to the proximity and knowledge of the reality faced and its immediate demands; however, in this research it played mainly the role of referring children to specialized care.

The needs caused by the Zika virus epidemic led the State Government in question to create a specialized service, which has become a reference in the care for children with microcephaly and their families.

The work shared between PHC and the specialized service can contribute to reducing the damage caused by microcephaly. However, the PHC team, which was supposed to coordinate care in a network, did not seem to play this essential role with children with CZS. It was the specialized multidisciplinary team that played a role as a reference for parents.

Most interviews were carried out while the mothers were waiting for care at the referral center. This may have been a limitation of the study, considering the need to reconcile the interview time with the waiting time for the appointment. Furthermore, the child's presence and needs were also determinants of caregivers' availability for the interview.

Conclusion

Informal and formal support networks acted in a complementary way in the treatment and support to the care of children with CZS. The informal network significantly contributed to the way of dealing with the disease. Virtual social networks stood out as a new means of communication that allowed for the exchange of experiences and sharing of information between parents who were experiencing similar situations. As for the formal network, state countryside municipalities showed different degrees of resoluteness, showing gaps in the network organization so that users depended on professionals' individual work to have access to services and benefits. In relation to healthcare professionals, the links established were mainly with specialized care. With PHC professionals, the sharing and guidance of care for family members was more intermittent and fragile.

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Collaborations

Costa RPUV, Lamy ZC, Soares P, Carvalho RHSBF, Pereira MUL, Guimarães CNM, Batista RFL, Nascimento MDSB contributed to the study design, data analysis and interpretation, article writing and approval of the final version to be published.

References

1. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Virus Zika no Brasil: a resposta do SUS. Brasília (DF): Ministério da Saúde; 2017 [citado 2020 Jul 28]. Disponível em: https://bvsms.saude.gov.br/bvs/publicacoes/virus_zika_brasil_resposta_sus.pdf
2. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Monitoramento dos casos de dengue, febre de Chikungunya e febre pelo vírus Zika até a Semana Epidemiológica 42 de 2018. Bol Epidemiol. 2018;40(44):1-14.
3. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Protocolo de atenção à saúde e resposta à ocorrência de microcefalia relacionada à infecção pelo vírus Zika. Brasília (DF): Ministério da Saúde; 2016 [citado 2020 Jul 28]. Disponível em https://bvsms.saude.gov.br/bvs/publicacoes/protocolo_resposta_microcefalia_relacionada_infeccao_virus_zika.pdf
4. Oliveira PS, Lamy ZC, Guimarães CN, Rodrigues CB, Silva AA, Simões VM, et al. Experiências de pais de crianças nascidas com microcefalia, no contexto da epidemia de Zika, a partir da comunicação do diagnóstico. Cad Saude Publica. 2019;35(12):e00226618.
5. Oliveira MC, SÁ SM. A experiência parental após o diagnóstico da microcefalia por zika vírus: um estudo de caso. Rev Pesqui Fisioter. 2017;7(4):64–70.
6. Bosaipo DS, Lamy ZC, Oliveira PS, Gomes CM, Assis MR, Ribeiro MR, et al. Itinerário terapêutico de crianças com microcefalia pelo vírus zika. Cien Saude Colet. 2019 Ago 30. [Ahead of print].
7. Santos DB, Silva EF, Lima SO, Reis FP, Oliveira CC. Health Care Network: Maternal perception regarding the quality of care to children with microcephaly. Esc Anna Nery. 2019;23(4):e20180335.
8. Barbosa LA, Bem IP. Microcefalia pelo Zika Vírus: as ações dos Poderes Legislativo e Executivo brasileiros no combate à epidemia. Cad Ibero-Amer Dir Sanit. 2018;7(1):127–46.

9. Sá SA, Galindo CC, Dantas RS, Moura JC. Dinâmica familiar de criança com a síndrome congênita do Zika vírus no Município de Petrolina, Pernambuco, Brasil. Cad Saude Publica. 2020;36(2):e00246518.
10. Abreu TT, Novais MC, Guimarães IC. Crianças com microcefalia associada a infecção congênita pelo vírus Zika: características clínicas e epidemiológicas num hospital terciário. Rev Ciênc Méd Biol. 2016;15(3):426–33.
11. Almeida LS, Araújo LA, Cota AL, Rodrigues DF. Processos sociais e vulnerabilidades na saúde: comportamento da infecção por zika vírus. Social Questão. 2020;23(48):339–61.
12. Dotta AG, Tomazoni LR. The impact of the ZIKA Virus on the reproductive health of Brazilian women, environmental racism and the action for Direct Control of Unconstitutionality (ADI) No. 5581. Braz J Law Res. 2020;1(2):109–32.
13. Fleischer S. Segurar, caminhar e falar: notas etnográficas sobre a experiência de uma “mãe de micro” no Recife/PE. Cad Gênero Divers. 2017;3(2):93-112.
14. Rosa TE, Benício MH. As redes sociais de apoio: o conviver e a sua influência sobre a saúde. Bol Inst Saúde. 2009;(47):80-83.
15. Herzlich C, Adam P. Sociologia da doença e da medicina. Bauru: EDUSC; 2001.
16. Minayo MC. O desafio do conhecimento: pesquisa qualitativa em saúde. 14a ed. São Paulo: Hucitec; 2014.
17. Botton A, Cúnico SD, Barcinski M, Strey MN. Os papéis parentais nas famílias: analisando aspectos transgeracionais e de gênero. Pensando Famílias. 2015;19(2):43–56.
18. Lins ZM, Salomão NM, Lins SL, Carneiro TF, Eberhardt AC. O papel dos pais e as influências externas na educação dos filhos. Rev SPAGESP. 2015;16(1):43–59.
19. Bernardi D. Paternidade e cuidado: “novos conceitos”, velhos discursos. Psicol Rev. 2017;26(1):59–80.
20. Zornig SA. Construção da parentalidade: da infância dos pais ao nascimento do filho. In: Piccinini CA, Alvarenga P. Maternidade e paternidade: a parentalidade em diferentes contextos. São Paulo: Casa do Psicólogo; 2012. p. 17–31.
21. Pedrosa RK, Guedes AT, Soares AR, Vaz EM, Collet N, Reichert AP. Itinerário da criança com microcefalia na rede de atenção à saúde. Esc Anna Nery. 2020;24(3):e20190263.
22. Scott RP, Lira LC, Matos SS, Souza FM, Silva AC, Quadros MT. Itinerários terapêuticos, cuidados e atendimento na construção de ideias sobre maternidade e infância no contexto da Zika. Interface. 2018;22(66):673–84.
23. Moreira MC, Mendes CH, Nascimento M. Zika, protagonismo feminino e cuidado: ensaiando zonas de contato. Interface. 2018;22(66):697-708.
24. Vale PR, Alves DV, Carvalho ES. “Very busy”: daily reorganization of mothers to care of children with Congenital Zika Syndrome. Rev Gaúcha Enferm. 2020;41:e20190301.
25. Milbrath VM, Soares DC, Amestoy SC, Cecagno D, Siqueira HC. Mães vivenciando o diagnóstico da paralisia cerebral em seus filhos. Rev Gaúcha Enferm. 2009;30(3):437–44.
26. Castro BS, Moreira MC. (Re) conhecendo suas casas: narrativas sobre a desospitalização de crianças com doenças de longa duração. Physis Rev Saúde Coletiva. 2019;28(3):e280322.
27. Woodgate RL, Edwards M, Ripat JD, Rempel G, Johnson SF. Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life. Child Care Health Dev. 2016;42(4):504–12.
28. DeHoff BA, Staten LK, Rodgers RC, Denne SC. The role of online social support in supporting and educating parents of young children with special health care needs in the United States: a scoping review. J Med Internet Res. 2016;18(12):e333. Review.
29. Vuorenmaa M, Halme N, Perälä ML, Kaunonen M, Åstedt-Kurki P. Perceived influence, decision-making and access to information in family services as factors of parental empowerment: a cross-sectional study of parents with young children. Scand J Caring Sci. 2016;30(2):290-302.
30. Bolla BA, Fulconi SN, Baltor MR, Dupas G. Cuidado da Criança com anomalia congênita: a experiência da família. Esc Anna Nery. 2013;17(2):284-90.
31. Brasil. Câmara dos Deputados. Projeto de lei n.º 3.974, de 2015. Dispõe sobre direito a dano moral e concessão de pensão especial à pessoa com Microcefalia ou com Síndrome de Guillain-Barré, decorrentes do Zika Vírus. Brasília (DF): Câmara dos Deputados; 2015 [citado 2020 Jul 28]. Disponível em: https://www.camara.leg.br/proposicoesWeb/prop_mostrarintegra;jsessionid=1E4761D5ACA3A532108D609F570795BD.proposicoesWeb2?codteor=1431118&filename=Avulso+-PL+3974/2015
32. Brunoni D, Blascovi-Assis SM, Osório AA, Seabra AG, Amato CA, Teixeira MC, et al. Microcephaly and other Zika virus related events: the impact on children, families and health teams. Cien Saude Colet. 2016;21(10):3297-302.
33. Brasil. Ministério da Saúde. Portaria nº 405, de 15 de março de 2016. Institui, no âmbito do Sistema Único de Saúde (SUS) e do Sistema Único de Assistência Social (SUAS), a Estratégia de Ação Rápida para o Fortalecimento da Atenção à Saúde e da Proteção Social de Crianças com Microcefalia. Brasília (DF): Ministério da Saúde; 2016 [citado 2020 Jul 28]. Disponível em: https://www.in.gov.br/materia/-/asset_publisher/Kujrw0TZC2Mb/content/id/22541437/do1-2016-03-16-portaria-interministerial-n-405-de-15-de-marco-de-2016-22541371
34. Piškur B, Beurskens AJ, Ketelaar M, Jongmans MJ, Casparie BM, Smeets RJ. Daily actions, challenges, and needs among Dutch parents while supporting the participation of their child with a physical disability at home, at school, and in the community: a qualitative diary study. BMC Pediatr. 2017;17(1):12.
35. Baltor MR, Matos AP, Wernet M, Ferreira NM, Dupas G. The perceptions of families with children having chronic diseases and their relationships with healthcare professionals. Rev Esc Enferm USP. 2013;47(4):808–14.