

Congenital Zika virus syndrome: the role of primary health care and healthcare network

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Abstract: The article aims to understand the care network and the challenges that children with congenital Zika virus syndrome (CZS) and their caregivers face to ensure comprehensive care. This is a qualitative study, part of research carried out at the Hospital das Clínicas of the Federal University of Pernambuco, which followed 151 children suspected of having CZS. Two focus groups were carried out, one with health workers and the other with caregivers. Children with CZS travel long distances, attending various network services. Difficulty in conducting and recognizing the role of the PHC reference team was observed, resulting in fractional care, with obstacles to communication between services and lack of attention to caregivers. A fragile network was perceived, with fragmented meetings and a reduced look. It is fundamental that the efforts prioritize the strengthening of the bond between the nodes of the care and support network. The essential and derivative attributes of PHC are crucial for the network of services and the provision of care for children with CZS and their families.

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Introduction

In 2016, the World Health Organization (WHO) declared an international emergency due to the increase in cases of microcephaly in endemic areas with the proliferation of the Zika virus (ZIKV) (Gulland, 2016). In Brazil there was the largest ZIKV epidemic of the Americas and were recorded the first reports of an increase in the prevalence of microcephaly associated with virus infection. The Northeast region accounted for more than 30% of reported cases and most microcephaly records (Barreto *et al.*, 2016; Brasil, 2016).

The association between congenital Zika virus infection and microcephaly emerges as a surprising hypothesis, as there were no previous records of malformations associated with congenital flavivirus infection (Albuquerque *et al.*, 2018; Castanha *et al.*, 2018). Unusual characteristics were found in newborn children with microcephaly caused by other congenital infections, generally severe and characterized by diffuse, punctate calcifications, predominant at the cortico-subcortical junction (Costa *et al.*, 2017).

Since the beginning of the epidemic, the state of Pernambuco has had the highest number of registered children with congenital Zika virus syndrome (CZS) reported in Brazil. Between August 2015 and October 2016, 2,159 cases of newborns with head circumference malformation were reported. In January 2017, 409 cases were confirmed, with most records in the Metropolitan Region of Recife (Brasil, 2016; Souza *et al.*, 2018).

In the Brazilian reality, for Lesser and Kitron (2016), diseases transmitted by mosquitoes affect portions of the population with more precarious living conditions. ZIKV, like the yellow fever, malaria and dengue epidemics, is yet another indicator of the social inequality that exists in contemporary Brazil, even decades after the process of redemocratization and health reform. Health policies, therefore, must be oriented to consider people and their ways of living and coexisting, considering families, networks and territories in vulnerable situations.

In this context, Primary Health Care (PHC) is essential for recognizing the subjectivities and needs of people and territories (Fertonani *et al.*, 2015). Articulated in a network, in accordance with its guidelines and ways of operating, it provides access, reception, vulnerability assessment, therapeutic bond, with singular attention, care coordination, matrix support, among others. It is the means to

achieve longitudinality and integrality, principles and guidelines essential to the SUS. Primary care is essential to care for the complex demands and subjectivities of children with CZS and their caregivers, since both require comprehensive care with specificities and new prognoses throughout their lives (Santos *et al.*, 2019). At the beginning of the Zika epidemic, PHC was also responsible for monitoring and identifying the circulation of the Zika virus and also identifying the first cases of microcephaly during prenatal care (Diniz, 2016).

The health problems that arose with the discovery of CZS caused the need to reorganize health actions and services to meet new demands, especially through the organization of care networks for the affected population. For this reason, considering PHC as the main gateway for all users, access and the concept of territory as a guarantee of providing care to the studied population, this article aims to investigate the composition of the care network and what challenges children with CZS and her caregivers work on a daily basis to ensure essential care for their health and development.

Methodological path

Descriptive study, with a qualitative approach, which sought to analyze in depth the relationship between PHC, the health network and care for children with CZS based on the meanings and subjectivity of the subjects involved in the studied context. It is part of the results of a study that followed, for four years, 151 children born at the Hospital das Clínicas of the Federal University of Pernambuco (HC/UFPE) between October 2015 and February 2016, including children whose mothers reported febrile illness and/or rash during pregnancy. Of the total number of children, 21 were confirmed to have CZS.

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At the end of the follow-up, two focus groups were held, respectively in August and September 2019 in the city of Recife: the first with workers (W) from PHC and specialized care (child development outpatient clinic at HC/UFPE) and the second

with family caregivers (C) of accompanied children confirmed with CZS. Each group consisted of six to ten participants. The discussions were recorded in audio and video.

Content analysis of the focus groups' speeches was carried out using the meaning condensation technique (Kvale, 1996), considering: reading the transcriptions, identifying natural units, defining central themes and, finally, organizing the descriptions of themes, considering the role of primary care attributes in the care of children with CZS, the organization of the health network and its challenges. The attributes of primary care included the concept established by Bárbara Starfield (2001).

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PHC and care for children with CZS

PHC is the basis of several universal health systems around the world, being considered the main gateway and responsible for the integration and coordination of care. When organized from its essential and derived attributes (Starfield, 2001) it can generate positive results in the health of the population (Sellera *et al.*, 2020).

With complex demands that will last throughout their lives, children with CZS need health care in different specialties, even if the clinical manifestations are not yet apparent. Monitoring must be family-centered (cultural competence, family and community guidance) and cross-sectional (Santos-Pinto *et al.*, 2020), finding in PHC, especially in the Family Health Team (FHT), the possibility of building and strengthening of a link that will enable articulation and access to actions and services in the care network. This health network needs to be organized and articulated, so that the provision of actions occurs preferably from PHC (Almeida; Santos, 2016).

When asked about the role of the primary care team in caring for children, the professionals pointed to the role of preferential access door and the role of reference team that has responsibility for care as it is in the territory where the children live.

Primary care is the first contact we have with the child. [...] We in primary care, who are the link, the user's gateway... they often have the first contact with us. (T1 – PHC Doctor)

I don't think it's possible not to be the reference team, primary care. Because we are there, close to them. (T2 – PHC Doctor)

The coordination of care carried out by primary care depends on the gateway with timely and resolute access and its ability to welcome, offer actions for promotion, prevention and treatment that are comprehensive (Fausto *et al.*, 2014). It is PHC that must guide the health network, ensuring that the needs of children with CZS and their families, known and those yet to come, are met.

The bond between staff and users is a consequence, among other factors, of access. The relationship between worker and user must be built in order to develop comprehensive care. While for some family members there is no difficulty in accessing the basic service, for others, not all actions are available, and this is a commitment to comprehensive care. Evidence of weaknesses in achieving access and connection relate to the difficulty of diagnostic and therapeutic support, unique projects built from children's needs and instruments to guarantee access to the specialized and hospital network.

In my case, the professionals who work there even have good will. However, what they offer them... terrible. Right where I live, the nurse is excellent. When I get there, they treat me... they're there, they take care of me... However, they don't have many resources to pass on to us, due to the administration being not good. (C1)

An established bond is essential for the health unit to be recognized as a reference team. It means expanding clinical and health work and taking responsibility for managing the case and monitoring users; thus, PHC would monitor the route taken by children with CZS, affirming its responsibility and strengthening the bond with families. This was not perceived or felt in the experiences lived by workers and caregivers, nor in the evidence of therapeutic itineraries activated by a territorial reference team.

A primary care team that presents itself as a reference in the territory assumes the management of therapeutic projects and the coordination of care, ensuring the attributes of longitudinality and comprehensive care. For this to become operational, health network services must establish bridges between themselves, using matrix support and the Singular Therapeutic Project (STP) as tools for care to be primarily developed in the territory, in addition to contributing to the definition of paths between services that children with CZS need to access.

In turn, when caregivers were asked about the role of the primary care team, the family members' speech leads to the hypothesis that in the case of children with CZS, specialized services took the lead in care, even if in a fragmented way and without reference team for accountability, triggering a sense of integrality in the articulation between different services and interprofessional collaboration.

Neurologist! (C1)

[...] my [reference team] is neuro... (C2)

[...] my [reference service] is neuro too [...] I think it's the most important. (C4)

Not being considered a reference team for caregivers of children with CZS demonstrates fragility in the role of primary care in comprehensive care and care coordination. It means the commitment of their responsibility, which according to Cunha and Campos (2011, p. 963), is “non-transferable by the user (non-transferable, but shareable)”.

According to Porto (2020, p. 188), the inefficiency in assisting children from the first generation of children with CZS reveals the fragility and according to the author, “the existence of a conflicting dynamic between professionals and patients that intersects, in fact, in these issues of gender, class and racism – when not generational”.

It is the responsibility of PHC to coordinate care, expand the clinic and health practices, increase people's autonomy and capacity for action over their lives, reorganizing the work process to promote a unique and shared clinic (Campos; Amaral, 2007). Professionals point to a reality with little financial, budgetary and technical investment in supporting arrangements and devices that articulate the clinic and health surveillance. The agendas worked to produce serial consultations, without case discussion in complex situations with the CZS and without management support. The understanding of the role of PHC articulated in the network and the difference in the praxis of subjects in the epicenter of zika/CZS is clear.

[...] it is clear that there must be investment in large centers, but part of this investment, including financial, for the clinical management of these people [in PHC]. We have the ability to manage children and their entire families in the community context. That's why we wanted to have it on our agenda, to make time for these people, to have a specific time to discuss... [...] then, we don't have it. It is the main example of all that I have seen in my life where shared case management is fundamental. (T4)

Recognizing the role of primary care is a challenge in the current political and health situation. In the daily life of the health service, faced with so many threats

faced by PHC, but also in the care of children and families affected by ZIKV and all the complexity produced by the syndrome, which demands different types of attention. Care that needs to be orchestrated in a network, with dialogue and sharing of the case between the actors involved.

The actual functioning of the networks and their implementation point to greater resolution in the health production of children with CZS, improvement in the efficiency of health system management in the regional space, and contributes to the advancement of the SUS implementation process. The paradox brought as evidence in this research is between the ideas of an integrated health system made up of networks and its implementation based on the link and access to reference teams in PHC.

This means that for children with CZS and their families, or expanding, for people with disabilities, it is essential to organize a health care network with a set of decentralized and regionalized care and services, with accessibility strategies for children and families to guarantee comprehensive care, under PHC coordination.

The organization of the health network

PHC is defined as coordinating care and organizing actions for the Health Care Network (HCN). When a fragmented network predominates, structured based on “overlapping” levels, the referral of cases considered more serious to specialized services means that the link with PHC is threatened, resulting in a fragile care clinic incapable of ensuring longitudinality. This network is assumed comprehensively, being recognized as a health production network that considers the relationship between the care network and the territory. In this relationship, there is no hierarchy between the services that make up the network (Righi, 2010).

According to professionals, when asked about the health network, despite the need to organize an HCN that makes it possible to meet the needs of children with multiple disabilities and their families, a path with well-defined lines of care is still not clear. There are still steps to be taken and agreements to be established between services that ensure the organization of the health network based on PHC.

[...] we even learned how to work in primary care, but we haven't learned how to work in a network yet. (T4 – PHC Doctor)

[...] another (child) who has microcephaly, who has been in referral for a while, awaiting diagnosis. I didn't receive anything from her, and she's “skating” on the internet, I'm ashamed of this case and I'm embarrassed [...] (T2 – PHC Doctor)

The National Health Policy for People with Disabilities ensures that assistance to this population must be provided within a health network. The Health Care Network for People with Disabilities (NHPPD), implemented in 2012, was founded on the organization of network care and services in lines of care, considering the needs of the population and territorial arrangements (Brasil, 2002; Campos; Souza; Mendes, 2015; Machado *et al.*, 2018). Caregivers reflect on this health network, pointing out that its organization involves an extensive therapeutic itinerary that includes consultations, therapies and exams in different network services, often distant from each other and from the children's homes, with a bureaucratized pattern and fragile communication teamwork, little collaboration between different services and different professions. A unique health work, but fragmented due to the lack of integrated planning with financing, regionalization and guidance based on the needs of the subjects involved.

There's a neurologist. She has a gastroenterologist, because she has reflux, she has a pediatrician, she has an ophthalmologist because she has strabismus... This is in addition to the therapies I take... (C1)

A complex and broad spectrum of needs that demands a lot from these women and their support network, which is also primarily female. Pinheiro and Longhi (2017) recognize that it is really children and their bodies that guide families on the battlefield. For the authors, mothers feel moved to fight for the rights and care of their children. According to Fleischer (2020, p. 331), in a scenario characterized by the need to care for a child with a new disease, hope is what moves day-to-day life and "becomes a vocabulary of survival". Three years later, the author reveals that mothers still travel throughout the city of Recife to ensure assistance and all necessary care for their children. A frenetic pace of life, as stated by Williamson (2018).

Professionals also analyze that from the perspective of the care network, this division represents an extensive schedule of care across different services and specialists. It is up to all points in the network to ensure that PHC receives information regarding the types of specialties or therapies attended by the child, test results and the prognoses achieved.

In other words, I'm going to go back to get the referral, it's going to be all that ordeal again to get another referral. They try to find another professional from within... (T6 – Specialized Care Physiotherapist)

[...] with this professional who is treating them, they already try to refer them to another specialty. (T3 – Specialized Care Physiotherapist)

Two possible problems can be seen: the specialized service and/or regulatory flows do not guarantee that the user returns to PHC; or, when accessing the specialized service and needing a new referral to another specialty, families choose not to return to the basic unit. Both interfere with the longitudinality and coordination of care provided by the territorial service. In the opposite direction, when the referral originates from PHC to other points in the network, workers are faced with slowness and resistance, precisely in the regulation system, creating an obstacle to coordinating care.

Workers also highlight the importance of reference and recognition of actors and their roles to streamline the communication flow necessary for the user's movement on the network, without losing reference to the more territorial service.

Sometimes we send it, the service picks it up, and we wait for the service to return, even if there is no vacancy. But they don't actually return. And then we don't know if the mother is "lost". (T3 – Specialized Care Physiotherapist)

It is necessary to change the work process by composing an organization of services that promotes new relationships between “those who accompany over time and those who intervene” (Righi, 2010). A PHC responsible for children, families and territory, recreating communication between teams, points in the network and with other sectors of public policies.

An elementary concept for the implementation of networks, Milton Santos (1997) defines horizontality as the sharing of territory in daily life. It is necessary to prioritize and understand the place where subjects live and value their strengths, because, in the opposite case, where there is verticality there is isolation or rupture between points in the network.

The network that seeks to expand democracy and qualify the SUS needs to value the territory. The territory cannot be seen only as an agent of demands, but rather as a living space that, in the exchanges established with the network, produces new experiences and modifies its own organization (Righi, 2010). Primary care needs to rethink its role in the care model for children with CZS and their families, so that it can accumulate skills necessary for networking.

The challenges of comprehensive healthcare

In primary care, subjects, subjectivities, vulnerabilities, landscapes, actions and intentions coexist. Public policies must consider this plurality and in the case of children and families affected by ZIKV - this is an urgent need.

The issue about the challenges in organizing the network led workers to state that family caregivers of children with CZS do not receive attention or are not cared for by network services, especially in relation to mental health.

How are we going to deal with the mental health of these mothers? What do the services that support these children with Zika have to offer us in relation to mother care? How many percent become depressed, how many percent start using antidepressants, how many take sleeping pills? (T4 – PHC Doctor)

According to Scott *et al.* (2018), caregivers dedicate a large part of their daily hours to caring for and managing children, which compromises many of their occupations, including work and family income.

For Kathryn Williamson (2018, p. 693), “the Zika virus casts a long shadow over the lives of those affected, whether directly or indirectly”. These are effects that occur on children and their families, especially their mothers, who experience care on a daily basis and who do not receive the necessary care.

An unexpected diagnosis during pregnancy, complications during childbirth or after birth, the need to quickly adapt to a new reality, can lead to feelings of grief, conflicts, stress, sadness, depression, reaching the point of compromising care and relationship with the child (Scott *et al.*, 2018; Barbosa; Silva, 2003). The challenges become more complex given the identified vulnerabilities. These are families that bring in their stories abandonment, loneliness and financial precariousness, as the workers highlight.

They have difficulty accessing it. One of the things that is fundamental, in general they are families who have difficulty getting a job, they also have other children... sometimes the mother left her job to be able to take care of the child. The father has to pay for everything and other expenses. So, this issue of transportation to physiotherapy, speech therapy, various therapies... is missing. (T2 – PHC Doctor)

Camargo, Lima and Fleischer (2019, p. 1) reveal that even after the CZS epidemic began, families’ routines remain intense. In addition to care, there are still great challenges in seeking children’s rights. For the authors, “amid a daily routine of care, mothers and children with the syndrome also struggle to avoid falling into oblivion.” Williamson (2018) reflects on the issue of time in caring for people with disabilities, revealing that it is determined by appointment times, exams and medications. A difficult time that is felt not only by the child, but also by those who care for them. Most mothers have their time shaped by care and guided by their children’s progress, which is repeated and sometimes appears to be paralyzed.

The difficulty in establishing dialogue is another challenge highlighted by workers and which needs to be overcome so that PHC can coordinate care effectively, fulfilling its role as organizer and ensuring longitudinality. Liane Righi (2010) states that the network is strengthened when it is capable of producing better meetings, meetings between different people “that produces a commonality while maintaining singularity” resulting in the strengthening of matrix support, the effect of multidisciplinary in sharing knowledge and ways of doing things.

She was diagnosed with Zika at the very end of her pregnancy, and... in fact, I had my first contact with the child, but the child... we still haven't received it from the hospital that the mother gave birth, we haven't received it for follow-up in specialized care and at the health center. (T1 – PHC Doctor)

[...] a few professionals make counter-referrals and this makes a big difference in the care, in the care provided to us. (T2 – PHC Doctor)

An essential tool for comprehensive care, matrix support ensures training for the management of more complex cases for the territorial team. Offered by a supporter or specialist, it allows interaction between professionals and expands the possibilities of care (Campos; Domitti, 2007). This meeting reveals the face and address of the actors and puts them in a position to establish contracts for comprehensive network care.

There were many challenges highlighted by health professionals and validated by families, who expressed in their speeches the fragmentation of the network, the bureaucratized pattern of communication between services and the difficulty in access. At other times, they point to a lack of care or a lack of supply that does not absorb the full complexity of cases and health needs.

Final considerations

The discovery of CZS brought about complex and unexpected needs that transformed the course of life and the previously planned future of several families. It filled the lives of individuals with multiple disabilities with uncertainty and required the State to organize comprehensive care, capable of achieving the subjectivity and complexity of these families' new ways of existing and living.

Although the evidence points to the pressing need for strengthened primary care with access management capacity, integrating the care and support network, it is clear that it is difficult to conduct and recognize the role of reference team,

which compromises the doing and acting in an expanded sense, in an individual and collective sense.

This means expanding clinical and collective health into an integrated praxis, strengthening horizontal networks, subjects and territory, teams and services, arrangements and devices that enable the construction of unique projects, promotion and prevention actions, organization of the care network, interprofessional action, co-management, expansion of autonomy and recognition and assessment of vulnerabilities.

A weakened network was perceived, with fragmented meetings and reduced views. There is also a lack of support for mothers, most of whom are abandoned and vulnerable. Lonely women who follow different therapeutic paths, seeking care in different spaces. The birth of their children accompanied by the diagnosis of CZS produces a feeling of insecurity in the face of the unknown. It was in the most vulnerable places that CZS claimed its greatest victims. A vulnerability that increases in the face of a State that remains distant and inert.

The meeting to be promoted by the network should prioritize comprehensiveness, the expansion of care, the articulation between the clinic and surveillance, the production of intersectoral networks and shared practice. However, isolated meetings are observed, which are not interconnected, and which reduce the action and being of children and their families.

It is essential that efforts prioritize strengthening the link between the nodes of the care and support network, enabling longitudinal monitoring and coordination of care, giving power to the role of primary care in comprehensive care. This means recognizing PHC in the territory where these children live and its clinical and health responsibility, as well as the ability to transform and defend people's lives.

The essential and derived attributes for primary health care must be considered determinants for the service network and the provision of care for children with CZS and their families. It is clear that there is a need to invest even more in its concrete implementation in the daily lives of the network points, as only when such concepts are on the horizon of health policies and care practices will it be possible to guarantee full care for this population.¹

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Note

¹ K. M. da N. Cabral, B. P. Coêlho and G. M. D. de Miranda: conception and design of the article, analysis and interpretation, final writing and critical analysis.

Resumo

Síndrome congênita do Zika vírus: o papel da atenção primária e da rede de saúde

O artigo objetiva compreender a rede de atenção e os desafios que as crianças com Síndrome Congênita do Zika Vírus (CZS) e seus cuidadores enfrentam para garantir o cuidado integral. Trata-se de estudo qualitativo, parte de pesquisa desenvolvida no Hospital das Clínicas da Universidade Federal de Pernambuco, que acompanhou 151 crianças com suspeita para CZS. Foram realizados dois grupos focais, um com trabalhadores de saúde e outro com cuidadores. As crianças com CZS percorrem longas distâncias, frequentando diversos serviços da rede. Observou-se a dificuldade de condução e de reconhecimento do papel de equipe de referência da APS, resultando em um cuidado fracionado, com obstáculos à comunicação entre serviços e ausência de atenção às cuidadoras. Percebeu-se uma rede fragilizada, com encontros fragmentados e olhar reduzido. É fundamental que os esforços priorizem o fortalecimento do vínculo entre os nós da rede de atenção e apoio. Os atributos essenciais e derivados da APS são determinantes para a rede de serviços e a oferta de cuidados às crianças com a CZS e seus familiares.

► **Palavras-chave:** Assistência à Saúde. Atenção Primária à Saúde. Infecção por Zika vírus.

