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REVIEW

Health needs of mothers of children with Congenital Zika Syndrome: an integrative review

Necessidades de saúde de mães de crianças com Síndrome Congênita pelo vírus Zika: revisão integrativa

Necesidades de salud de las madres de niños con Síndrome Congénito por el virus del Zika: una revisión integradora

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ABSTRACT

Objectives: to evidence and analyze the health needs of mothers of children with Congenital Zika Syndrome. **Methods:** a total of 44 articles published between October/2015 and March/2021 on PubMed, LILACS, Scopus, Web of Science and Science Direct were included. The RTI bank and CASP score were applied to classify the methodological quality of the studies. Reflective content analysis and Cecílio and Matsumoto's taxonomy were used for analysis. Visual map was used as a technique for presenting the results. **Results:** mothers need access to social protection, family-centered, multi-professional empathetic monitoring, cultivating bonds and affection by professionals, sharing of care between health network services, strengthening the social support network and fostering coexistence groups between them. **Final Considerations:** intersectoral initiatives must be implemented for better housing conditions, fighting stigma, holding parents accountable and resuming life project.

Descriptors: Maternal and Child Health; Congenital Abnormalities; Caregivers; Zika Virus Infection; Health Service Needs and Demand.

RESUMO

Objetivos: evidenciar e analisar as necessidades de saúde de mães de crianças com Síndrome Congênita pelo vírus Zika. **Métodos:** foram incluídos 44 artigos publicados, entre outubro/2015 e março/2021, na PubMed, LILACS, *Scopus*, *Web of Science* e *Science Direct*. Foram aplicados o RTI *bank* e escore CASP, para classificar a qualidade metodológica dos estudos. A análise de conteúdo reflexiva e a taxonomia de Cecílio e Matsumoto foram utilizadas para análise, e o mapa visual, enquanto técnica de apresentação dos resultados. **Resultados:** as mães necessitam de acesso à proteção social, acompanhamento multiprofissional empático centrado na família, cultivo de vínculo e afeto por parte dos profissionais, compartilhamento de cuidados entre serviços da rede de saúde, fortalecimento da rede de apoio social e fomento de grupos de convivência entre elas. **Considerações Finais:** devem ser implementadas iniciativas intersetoriais para melhores condições de moradia, enfrentamento do estigma, responsabilização do genitor e retomada do projeto de vida.

Descritores: Saúde Materno-Infantil; Anormalidades Congênitas; Cuidadores; Infecção por Zika Vírus; Necessidades e Demandas de Serviços de Saúde.

RESUMEN

Objetivos: demostrar y analizar las necesidades de salud de las madres de niños con Síndrome Congénito causado por el virus del Zika. **Métodos:** se incluyeron 44 artículos publicados entre octubre/2015 y marzo/2021 en PubMed, LILACS, *Scopus*, *Web of Science* y *Science Direct*. Se aplicó el puntaje RTI bank y CASP para clasificar la calidad metodológica de los estudios. Para el análisis se utilizó el análisis de contenido reflexivo y la taxonomía de Cecílio y Matsumoto, y se utilizó el mapa visual como técnica para presentar los resultados. **Resultados:** las madres necesitan acceso a protección social, centrado en la familia, multidisciplinar, seguimiento empático, cultivar vínculos y afectos por parte de los profesionales, compartir la atención entre los servicios de la red de salud, fortalecer la red de apoyo social y fomentar grupos de convivencia entre ellas. **Consideraciones Finales:** se deben implementar iniciativas intersectoriales para mejorar las condiciones de vivienda, combatir el estigma, responsabilizar al padre y retomar el proyecto de vida.

Descriptores: Salud Materno-Infantil; Anomalías Congénitas; Cuidadores; Infección por el Virus Zika; Necesidades y Demandas de Servicios de Salud.

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INTRODUCTION

The record of Congenital Zika Syndrome (CSZ) in more than 20 countries in the Americas, such as Brazil, in addition to a higher prevalence in the course of the epidemic, reported recent cases, indicating the phenomenon's continuity as a threat to mothers' and children's health(1). Between 2015 and 2020 the country had 3,577 children with confirmed CZS, of which 35 were recently notified in 2020(2), indicating the need to ensure the continuity of health surveillance actions and monitoring of new cases. There is no knowledge that adequately responds to the needs of mothers and children and the impact of this syndrome on the daily lives of Brazilian families, as well as the existence of health communication actions and professional qualification programs to assist these specific groups(3).

CZS is understood as the set of neurological alterations caused by the Zika virus through congenital transmission(4). Children's illness due to CZS sets up a rupture or transformation in mothers' life projects, which directs her daily life towards child care and places personal desires, leisure and self-care in the background(5).

The routine of mothers of children with CZS is predominantly constituted by complex therapeutic itineraries with children(6), almost always accessing rehabilitation spaces or other health facilities, in addition to caring for children at home, other children without CZS and the home environment itself(7). Cleaning the house, cooking, washing clothes and dishes are actions performed by most mothers of children with CZS to cultivate good relationships between family members(8). Children with CZS are nursed, sanitized, played, fed and stimulated, managing moments of muscle stiffness, agitation, intense crying, drooling, airway obstruction, regurgitation and seizure(8), which are situations likely to happen in the daily life of a child with CZS.

Based on the repercussions experienced by mothers of children with CZS, this study adopts the concept of social determination of the health-disease process based on historicity and social organization. Therefore, we consider the historically imposed socioeconomic, cultural, environmental, labor, social and community relations conditions as determinants of the health-disease process(9) that justify mothers' health needs.

In this context, health needs are understood as human needs that need to be met to continue existing as a being, such as food, which maintains and dignifies people as a socio-historical being. Therefore, the intervention to remedy the need must also be considered a health need(9). Health needs are constituted from the social and historical interaction performed by people, characterizing them as specific to an individual or a certain group of people(10). The needs, desires and expectations of each individual make up the needs.

Thus, it is possible to point out some studies(7,11-12) that investigated the experience of mothers with children with CZS; however, there is no evidence about the health needs of these women from a theoretical analysis that systematizes their problems, desires, wishes and expectations. In consultation with the PROSPERO systematic reviews registry repository, carried out in September 2021, using the terms "mothers of children with congenital Zika virus syndrome" and "congenital zika virus syndrome", only two ongoing reviews were identified, one on depressive symptoms and the other on mothers' emotional aspects, thus characterizing a gap in scientific knowledge about mothers' health needs.

OBJECTIVES

To evidence and analyze the health needs of mothers of children with Congenital Zika Syndrome.

METHODS

This is an integrative review, carried out in five steps: problem identification, literature search, data quality and risk of bias analysis, data extraction and synthesis presentation(13). This type of study seeks to broaden the research question in order to deepen knowledge on a particular topic(13). The final writing of this review met the recommendations of the PRISMA 2020 checklist (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) and the PRISMA 2020 for Abstracts checklist(14).

The acronym PICo (Population, Interest, Context)(15) was used to elaborate the following research question: what are the health needs of mothers of children with CZS? Thus, this review included studies that dealt with the population of mothers of children with CZS, whose phenomenon of interest is health needs in the context of CZS.

The descriptors were crossed with Boolean operators and generated the search strategies that, adapted for each database, are described in Chart 1. In all databases, filters were used by year and type of publication, selecting the years 2016 to 2021 and primary articles, respectively.

The PubMed (NLM/NCBI), Latin American and Caribbean Health Science Literature (LILACS), Scopus, Web of Science Core Collection and Science Direct databases were accessed through the federated academic community on the Portal of Journals of the Coordination for the Improvement of Higher Education Personnel (CAPES - *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*).

The search strategy was carried out on March 22, 2021 by three independent examiners, finding the same number of publications in each database. The publications found were stored and organized in the Endnote Web bibliography manager (https://access.clarivate.com/login?app=endnote) for identification and exclusion of duplicates. The articles found were then imported into Rayyan Web (http://rayyan.qcri.org), where the second stage of exclusion of duplicates and decision to keep the publications by the blind authors took place. The organization of citations and reference lists for this review were managed by the Mendeley reference manager software (https://www.mendeley.com/).

Primary articles published between 2016 and March 21, 2021, period between the beginning of the epidemic and the performance of the search strategy, were included. Publications available in any language, with a qualitative, quantitative or mixed approach were considered. Due to the emerging and little studied nature of the CZS phenomenon, which tended to restrict the sampling of publications, the research team chose not to apply exclusion criteria, avoiding increasing selectivity and reducing the corpus of analysis(16).

To analyze publication adequacy to the inclusion criteria, articles were submitted to the following sequential steps: title reading -> abstract reading -> full reading. The screening of articles included in the review was performed independently and blindly by first and second author, and differences were sorted out by a sixth author.

Chart 1 - Search strategies inserted in each database and number of publications found

Database	Search strategy	Number
PubMed	((((((((mother[All Fields]) OR (mother[MeSH Terms])) OR (family[All Fields])) OR (family[MeSH Terms])) OR (parents[MeSH Terms])) OR (parents[All Fields])) OR (caregiver family[All Fields])) OR (caregiver, family[MeSH Terms])) AND ((((needs assessment[MeSH Terms]) OR (Determination of Health Care Needs[All Fields])) OR (Assessment of Healthcare Needs[All Fields])) OR (health needs[All Fields])) AND (((((((microcephaly[MeSH Terms]) OR (Microcephaly [All Fields])) OR (Severe Congenital Microcephaly[All Fields])) OR (Microcephaly, Severe Congenital[All Fields])) OR (congenital zika syndrome[All Fields])) OR (Zika virus infection [MeSH Terms])) OR (Zika [All Fields]))	17
LILACS	mother OR family OR parents OR caregiver AND “needs assessment” OR “determination of health care needs” OR “assessment of healthcare needs” OR “health needs” AND microcephaly OR “severe congenital microcephaly” OR “congenital zika syndrome” OR “zika virus infection” OR zika	13
Scopus	mother OR family OR parents OR caregiver AND “needs assessment” OR “determination of health care needs” OR “assessment of healthcare needs” OR “health needs” AND microcephaly OR “severe congenital microcephaly” OR “congenital zika syndrome” OR “zika virus infection” OR zika	62
Web of Science	((TS=(mother) AND TS=(“needs assessment”) OR TS=(“health needs”) AND TS=(microcephaly) OR TS=(“congenital zika syndrome”)))	380
Science Direct	mother AND “health needs” AND microcephaly OR “congenital zika syndrome”	32
Total	-	504

Once eligible studies were included, the reference list was read independently and blindly by the first and second authors. At this time, new studies that were not in the initial selection in the databases and that addressed the population, interest and context were identified, accessed and read their titles and abstracts, followed by full reading by the same authors. Thus, those publications that met the inclusion criteria were added to the articles included in the previous phase.

The included studies were organized in an Excel spreadsheet, version 2016, to carry out the data extraction phase, which was performed by the first and second author by filling in the following data: first author; publication date; DOI link; title; aim; study design; data collection location; technique and data analysis used; number of participants; and main results.

After data extraction, the methodological quality and risk of bias were assessed. Publications with a quantitative approach were assessed for risk of bias according to the Research Triangle Institute Item Bank (RTI-Item Bank) scale(17), while the Critical Appraisal Skills Programme (CASP)(18) was the instrument used to assess the methodological quality of studies with a qualitative approach.

The RTI-Item Bank consists of 29 items that may be eligible for better suitability to the nature of the analyzed studies(17). Therefore, considering the methodological diversity(17) of the studies included in this review, items that were not applicable to all of these were excluded, such as issues related to control group selection or recall bias in retrospective/prospective designs. Therefore, the following items were eligible and applied: clearly defined inclusion/exclusion criteria; inclusion/exclusion criteria: valid and reliable measures; inclusion/exclusion criteria: applied uniformly; precision: enough sample size; pre-specified main results; exposures assessed using valid and reliable measurement; results evaluated using valid and reliable measures; if there is high loss to follow-up: the assessed impact; any pre-specified results are missing from the results; results are reliable.

The CASP seeks to analyze the rigor, validity and impact of results for science, with ten questions organized into three sections: “validity of results”, “reliable description of results” and “impact of results for society”. For each question, the researcher chooses one of the options “yes”, “does not reveal”, “no”(18). Studies with low methodological rigor were those that received between zero and four positive answers, moderate rigor between five and eight, and high with nine or ten items.

This step was performed independently and blindly by first and second author, and the divergent cases were decided by the sixth author.

Data analysis, of the deductive type, was based on the theoretical construct considered by Cecílio and Matsumoto(19) and organized into four dimensions of health needs: needs for good living conditions, which contain external factors that determine the way of life, such as access to clean water, housing conditions and personal habits; access to health technology capable of improving and prolonging life, consisting of technology consumption needs, whether hard, soft-hard or soft; creation of (a)effective bonds between each user and a team and/or a professional, while meeting subjectivities, building relationships of trust and reference, establishing continuous, personal and non-transferable relationships over time; and autonomy in their way of life as a possibility to rebuild and give new meaning to life, seeking to satisfy their needs, for this, information and health education is essential.

Once the dimensions were defined, the authors followed six stages of reflective thematic content analysis, in order to identify the main themes and relate them to the four predefined theoretical categories. The steps were as follows: 1) data reading and rereading; 2) creation of initial codes for important topics, resulting in 26 codes; 3) code grouping, totaling 11 final codes; 4) construction of a mental map identifying the relationships between themes; 5) designation of four categories that best represents the relationship between themes; 6) and analysis synthesis production(20).

Synthesis of results was carried out in consensus by first, second and sixth author and developed according to a visual map of the literature organized in a hierarchical structure(21), resulting in Figure 2, presented in the following section.

RESULTS

A total of 44 articles from primary studies were included in this study. Figure 1 shows the steps of identification, eligibility and inclusion, according to the recommendations of the PRISMA 2020 flowchart (Figure 1).

As for the main results, 28.8% (n=13) addressed the need for mothers to participate in social groups among themselves; 24.4% (n=11) deal with the importance of social support networks; the same number of 24.4% (n=11) of articles deals with maternal self-care and the need to build happiness projects for mothers. There is also an emphasis on studies that discuss parent accountability (20%) (n=9) and a decrease in family income (17.7%) (n=8).

Other characteristics and analysis of the methodological quality and risk of bias of each study are detailed in Table 1 (additional file).

The summary of results of this review is presented in a visual map of the literature(21) (Figure 2), organized into the four categories of needs of mothers of children with CZS highlighted in this study, namely: *Access to social protection rights, goods and services*; *Qualified services and empathic multidisciplinary care*; *Reception, strengthening of bonds and acceptance*; and *Sharing daily responsibilities and self-care*.

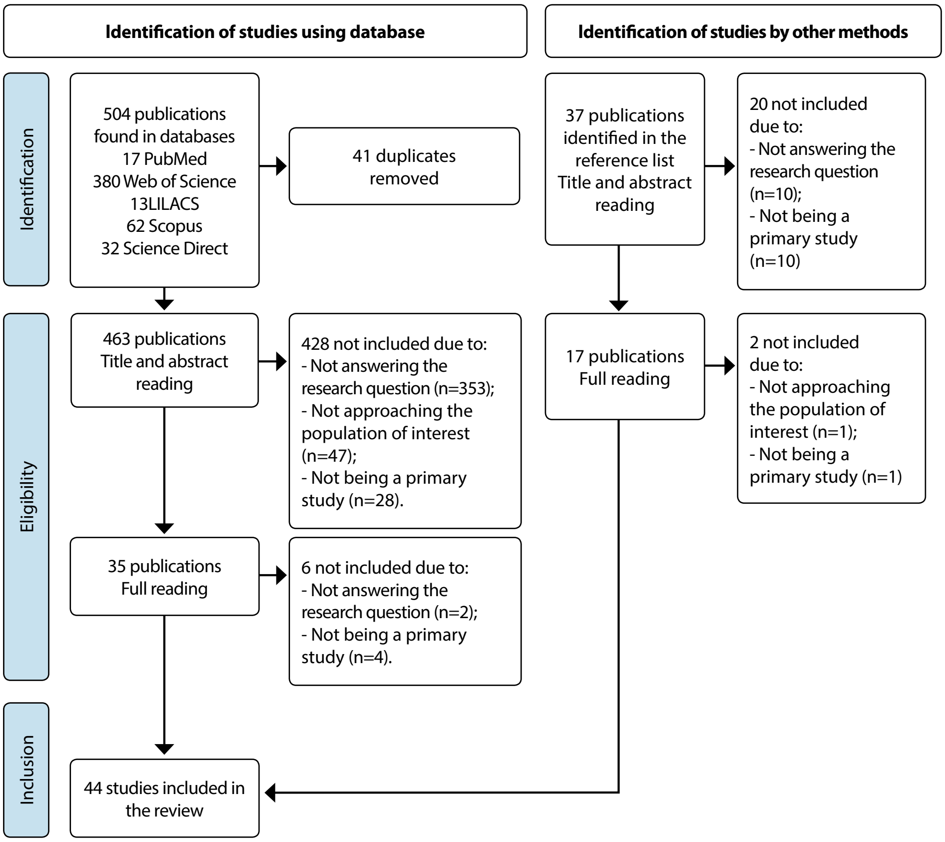

Figure 1 - Flowchart of the selection process of studies included in the integrative review

DISCUSSION

Access to social protection rights, goods and services

Mothers live in extreme socioeconomic vulnerability(31), low education(22) with worse living conditions indices when they are black(23). More than half of them live in peripheral areas under precarious conditions, such as wooden houses located in hillside regions with risk of collapse, absence of garbage collection and sanitation, with constant presence of mosquitoes(24-25).

A study showed that most mothers used public buses (82.93%) and lived on a rental basis (68%). Prior to CZS diagnosis, most of them worked in the area of service provision, such as housewives (36%) and other occupations (64%)(25).

Other evidence indicates that the occupational roles of mothers changed after the arrival of a child with CZS: the majority dropped out of regular education (77.8%); lost paid employment (76.5%); and started to seek help from non-governmental organizations(32).

The arrival of a child with CZS increases families' financial expenses(22,45), who live with difficulties to pay the expenses(24,27,38), since about 72.1% are unable to meet families' basic needs(28). To aggravate the situation, 75% of mothers who had an employment relationship were fired(25) or coerced to resign after the diagnosis of a child with CZS(10,24,38,45). Such unemployment situation is associated with the emergence of common mental disorders in mothers(32).

A study involving 25 participants showed that only 48% of them accessed the Continuous Cash Benefit Programme (BPC - *Benefício de Prestação Continuada*), aimed at their children(25). However, the amount received was insufficient to cover children's expenses, which required mothers to access help mainly to obtain food and medicine(40). Retired grandparents or pensioners contribute financially to purchase medicines and diapers, pay for the rent for the house, in addition to the studies of other grandchildren(8).

For mothers living in countryside cities, one of the greatest difficulties is the transfer between their residence and the rehabilitation service often located in metropolitan regions(24,30). For the transport to take place successfully, it is necessary to wait for an agreement from the municipality of residence with the one who offers the service, reserve a vehicle with the health department, schedule a time and wake up around four in the morning to make the trip, which, consequently, reduces the number of hours of sleep of mothers and children(5,24,26,30-31).

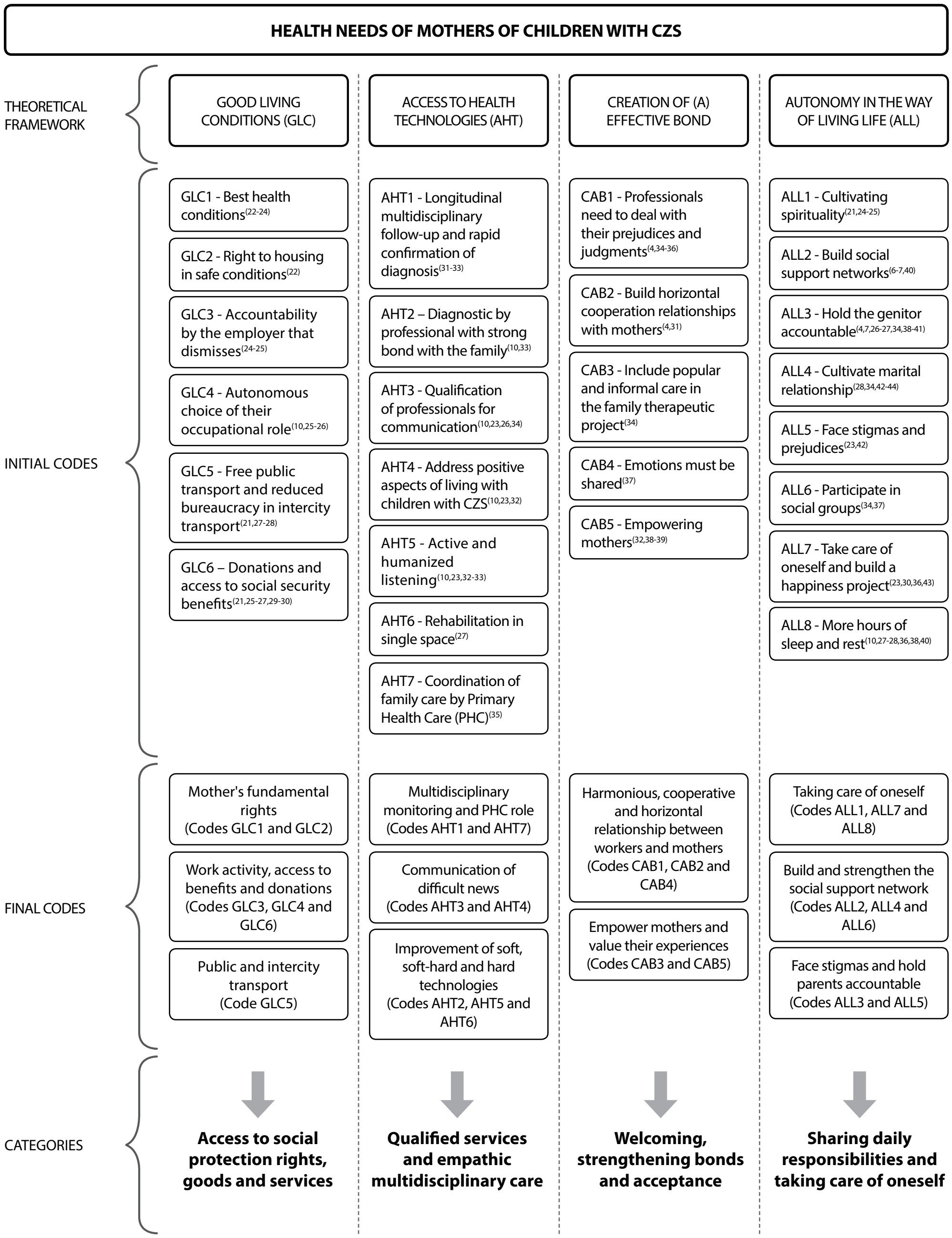

Figure 2 – Visual map of the health needs of mothers of children with Congenital Zika Syndrome

Of the various challenges faced by mothers to access services, using public transport is one of the most exhausting moments(6), due to long daily journey and child presentation in a public space, which generates discriminatory comments and looks of curiosity and revulsion(7).

In addition to the pension that part of the children are entitled to(46), the State must encourage policies of inclusion in employment or offer conditions for self-employment, respecting women's decisions. Regardless of their employment status, mothers require financial compensation for the State's inefficiency in combating the vector of the Zika virus. It should be noted that the previously granted BPC and the lifelong pension in the amount of one minimum wage, regulated by Federal Law 13.985/2020(46), benefit less than half of the children with CZS (48%)(25) and does not supply all the needs of children with CZS(46).

The child benefiting from the BPC is entitled to a lifetime pension prior to the regulation of Federal Law 13,985/2020, and for that, they must meet the criterion of family income less than ¼ of the minimum wage. Therefore, there is a relativization of disability due to the poverty condition(34), which does not reach all children. As an aggravating factor, the pension is not transferable to the family in the event of a child's death, and women are not guaranteed any specific incentive to encourage the resumption of their personal or professional projects.

Ensuring employment and decent working conditions promote an increase in family income, can awaken or make more evident the feeling of social value(34), enhance self-care(5) and encourage the development of unique life projects(7).

Qualified services and empathic multidisciplinary care

Access to health services endowed with qualified multidisciplinary teams and health technologies is necessary since the suspicion of the existence of microcephaly is raised. The experience of mothers shows that, to confirm diagnosis, whether during prenatal care or immediate and late postpartum, they live with exhaustive comings and goings to health services(24), receiving negative prognoses(38), omissions, controversial, incomplete, wrong and/or late news(12,42).

The period between the suspicion of CZS raised in the prenatal period and the diagnostic confirmation is permeated by anxiety(24). CZS diagnosis generates anguish(45), despair(11), fear, worry(35), feeling of loss of the idealized child(11,45), denial, sadness, pain, and shock(11,35,38,45).

Studies(12,24,42,47) indicate that health professionals are poorly prepared to communicate difficult news, demonstrate insecurity(24), communicate in a unidirectional hegemonic way, without spaces for dialogue, in addition to demonstrating a lack of knowledge about what they are communicating(47). Furthermore, they omit information, are evasive in the statements(42) and do not offer support or emotional support before, during or after diagnosis(12,47-48). Some professionals emphasize the negative prognosis, do not point out ways, nor do they present alternatives and positive points of living with a child with a disability(12).

The maternal perception of the quality of professional care points to it as outdated, performed by tired and unmotivated professionals who develop little innovative care(34) and with limitations for active and humanized listening. Mothers report difficulty in clarifying doubts about children's clinical condition, prognosis, motor and intellectual evolution(45). They also indicate obstacles to obtaining the medical report necessary to claim social benefits: about 45% of the participants in a study were unable to access this document(48).

Mothers want professionals to express attentive looks, develop strategies for guidance and health education(45) and parental training on how to deal with a child's crying, exacerbated irritation and muscle stiffness during daily activities of life(6). Some parents suggest the formation of social groups only with the parents, so that they have moments to freely express themselves, socialize experiences and that professionals share performances, images and videos demonstrating the ideal care(39).

When examining mothers' perceptions about the care received in health units, the study showed that family care for children with CZS is predominantly directed towards orienting them to procedures for the child, carried out at the secondary level of the health care network(41). It is understood that Primary Health Care (PHC) professionals can collaborate with the matrix support and other needs of families of children with CZS, thus requiring PHC to take over the coordination of care for these families through sharing and execution of a single family therapeutic project together with other levels of health care.

To overcome the difficulties in accessing services, it is recommended: incorporation of physiotherapists and occupational therapists in Family Health Strategy teams(40); creation of referral centers by health microregions, offering multidisciplinary follow-up(37) centered on family care(43), adjusted according to the viable time for child and family; and formation of municipal and state consortia for the concession of assistive technology equipment(37).

Therefore, integrating the various professionals for monitoring children with CZS and their mothers in a single environment can ensure more hours of stimulation/rehabilitation for children, development of activities aimed at mothers' needs and reduce the feeling of tiredness caused by extensive therapeutic itineraries(30,34). It is known that the home environment is a comforting, safe and welcoming place to establish the health-disease process balance, so we assume that stimulation/rehabilitation care for children performed at home can favor mothers' well-being(36), even meaning more hours of sleep and rest for them.

Mothers are in constant physical, psychological and social burdens(27), high emotional stress, mental distress(22,24) and have symptoms of anxiety and depression(44). In addition to this, they experience situations that require multidisciplinary longitudinal care, with emphasis on follow-up in the field of nursing, psychology(22) and social assistance(48). It is considered that the lack of psychosocial support may have a more negative impact on mothers' lives than the lack of medical support for children with CZS(48).

Welcoming, strengthening bonds and acceptance

Different perceptions about the relationship between family/mother/child and health workers are published in the studies, from unsympathetic attitudes during diagnosis communication, misinformation about itineraries to the lack of emotional support, words of consolation, and demonstration of affection(12,24,35,47).

Professional attitudes such as judgment and responsibility of mother for CZS, insensitivity(24,35,47), attitudes of distancing, indifference and impersonality cause despair and fear in mothers and that can be aggravated if they are not offered reception throughout treatment(35,47).

Professionals' attitudes and behaviors can weaken or strengthen the bond with mothers and determine the access, support and success of therapies. In order to build significant (a)effective bonds, it is important for professionals to avoid discriminatory judgments and expressions, to value the principles and customs of mothers respecting their decisions(5), to treat them with love and empathy, deconstructing positions that make their position inferior in society, labeling them "poor things"(8).

The relationship with workers stands out negatively when some mothers express the desire to abort or have a second child after the birth of children with CZS. Even if they cultivate these desires, mothers need to overcome the oppression of professionals who do not have the opportunity to address these themes in consultations. They feel to live under the reproductive surveillance of society, with emphasis on professionals, restricting autonomous decision-making(30,47).

Professional attitudes imposed as an overlap of scientific care for family care and that undervalue maternal knowledge and practices(5), delegitimize professional care and build barriers in the creation of effective bonds. The bond is also weakened when workers' expressions and behaviors naturalize the maternal role as the primary caregiver or try to abort hope about the children's better development in the future(42).

Mothers require behaviors that provoke maternal empowerment and self-care; however, workers' actions are focused on child health, and few are willing to understand the maternal experience(45), recognize the needs of mothers and their attitudes of coping, militancy or isolation and limit the construction of (a) effective bonds(4,34).

Some mothers see as relevant the relationship with Community Health Workers and home visits of the PHC team, although scarce(27). For them, affective and effective bonds are built mainly during prenatal care in PHC(7) and in rehabilitation services, when professionals are available to remove doubts and teach stimulation at home, considering these relationships as family members.

Sharing daily responsibilities and self-care

With the arrival of a child with CZS, mothers need to restructure their daily life(11,38), justified by burden of care(5,30,34), fatigue, difficulty in maintaining an available social support network(5,34,38,40), decreased family income and treatment costs(11,24-25,31-32,40,42).

Mothers do not enjoy extra time for sleep and rest(7,30), leisure, self-care, manifest dissatisfaction with body image and low level of satisfaction with life(30,45).

They fear leaving children with third parties because they believe they do not take good care of(27), so they take over children's full zeal(8,24). However, it is known that the provision of a social support network reduces burden of care(42), can mitigate vulnerability to mental problems(44), and contrasts with stigmatization, loneliness and abandonment.

Mothers take care of the home environment, other children and partner(7,45) living with exhausting, tiring journeys(26-27,38,45) and with exaggerated exposure of children's and families' lives in the media during the epidemic(5,12,45).

Due to neglected care during pregnancy, some mothers feel responsible for their child being born with CZS(24,42). Another group of mothers repudiates maternal self-blame, justifying that the State's ineffectiveness in combating the *Aedes aegypti* vector is the main cause of CZS; however, they identify manifestations of society that attribute this guilt to them, expressed mainly by health authorities and health professionals(5).

Beliefs, spirituality and religiosity are protective factors for mothers' health, attenuating feelings arising from diagnosis discovery, giving new meaning to daily challenges and justifying the divine project of caring for children with CZS(26). However, there are families who believe in CZS as a punishment or punishment, and thus religious experience means faith redemption and strengthening(38).

With the full dedication to child care, it is inevitable to overlap mothers' and fathers' role to those of wife and husband, respectively(38), in addition to the removal of the condition of being a woman and abdication of one's own life(26-27). In this context, from the deficit in family income and with unequal burden of care sustained by mothers(24), some parents blame them, engage in extramarital relationships, abandon them, direct physical and verbal aggressions to them, reproducing the toxicity of heteronormative masculinity(24). Thus, studies indicate that family support is restricted and many families are single-parent maternal, in which mother is the only caregiver and provider(45,47).

The participation of fathers in child care forms with mothers and grandmothers the child care tripod(8). When parents take care of children directly, they understand that this is not an exclusively maternal function(39), which tends to strengthen the marital relationship. Some mothers also have the support of children's cousins, uncles, friends and neighbors(8,11).

The reconstruction of families' daily life also deals with the social stigma of children and families in front of a society that values individuals considered healthy and is surrounded by prejudices and negative opinions(5,11,24,38,41,47). Discrimination can arouse fear, clashes, oppression and directly affect the care provided by family members(11).

The main network of mutual assistance and exchange of knowledge is built and maintained by mothers in associations or virtual and face-to-face groups facilitated by them(43) and are spaces that enable building knowledge and practices, mutual cooperation(30,33) and trust relations between them(30,33). The social support network also nourishes families' hope and helps in coping with difficulties(8,33,36,38) such as stigma and prejudices.

Mothers consider social networks and the Internet as the main channels for learning through the exchange of information and experiences(12,38,47), an action that promotes well-being, can reduce the emotional impact and improve self-care among them. However, it is necessary the collaborative support of health professionals, in order to validate the information shared among them, avoiding adherence to harmful care practices.

The need for professional care for autonomy in the way mothers' lives walk is essential in the experience that emerges from CZS, in order to prevent family conflicts and the loss of marital function, manage jealousy among children, encourage self-care(49) as well as share burden of care and life project construction.

It is believed that the novelty of the CZS epidemic, the feelings aroused in the face of diagnosis(35), the uncertainties of prognosis(40) and the exhaustive routine of mothers(7) can hinder the construction of new social roles for them, leading them to naturalize the maternal role. The leading role of care exercised by mothers has little social value compared to the provider role of fathers(34); therefore, by understanding such social judgment they can aim for their reintegration into the labor market, sharing child care with other family members, including their parent. It is up to health professionals to establish interventions(43) that embody mothers to take on conducts rationally accepted by them, such as the search for taking care of themselves and valuing their life project.

Study limitations

The results of this integrative review should be interpreted according to their limitations. The initial prevalence of the CZS epidemic in Brazil justifies the inclusion of 91.1% of studies in this review to be developed in the country, so there seems to be a gap in scientific knowledge about the health needs of mothers living in other countries. Similarly, the absence of a national study with global data on a representative sample of mothers from each region of the country limited the authors' inferences and made it impossible to analyze equity, safeguarding regional inequalities. It is worth noting that health needs have stages of singular priorities for mothers, because aspects such as children's age and development can modify mothers' and children's needs.

Of the 44 articles that constituted the corpus of this review, only 5 were assessed with low methodological quality or high risk of bias, allowing us to infer that the high quality of studies that compose this review allowed analysis of the health needs of mothers of children with CZS. The protocol of this review was planned and previously generated according to the five stages of the integrative review(13), although it has no record in an open access database.

Contributions to nursing, health, and public policies

The results of this review motivate nurses to develop specific innovative care that seeks to meet mothers' health needs. Mothers of children with CZS need intersectoral initiatives of public managers, in order to ensure good living conditions related to the best conditions of basic sanitation and housing, as well as assist them in the process of empowerment on their social role and resumption of their life projects.

There is a need for family-centered longitudinal multidisciplinary follow-up, integration of health care and social assistance network services, as well as possibilities for quaternary prevention interventions when considering mother-child dyad care in a single physical space. It is necessary that health professionals promote coexistence groups and assist in the construction of social narratives that require the fulfillment of the moral duty of parents to care for children with CZS, in addition to their legal obligations before justice.

It is recommended the development of almost experimental or experimental scientific studies, in order to validate professional care attitudes, popular and unusual knowledge that favor mothers' quality of life and well-being.

FINAL CONSIDERATIONS

The analysis of health needs indicates that mothers of children with CZS live in precarious housing conditions. They lose their jobs and have high costs and expenses since the confirmation of CZS diagnosis. Donations and access to social security benefit are essential, while the role of primary caregivers of children is imposed on them. They demand for health services that take care of children and them in the same physical space, in a multidisciplinary and longitudinal way, valuing the bond, active and humanized listening, as well as qualification of professionals.

Mothers need health professionals to understand and respect their emotions, avoid stigmatizing comments, act with cooperation and value their knowledge. It is clear that mothers are overwhelmed, need more hours of sleep and rest, a social support network with strong relationships and responsibility of fathers in child care. They require support to plan their life project with goals that go beyond child care, such as self-care, advancement or resumption of studies and work activity.

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