

Congenital zika syndrome and family impacts: an integrative review

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Abstract *In 2015, a range of congenital anomalies resulting from mother-to-child transmission of the zika virus emerged. Later called congenital zika syndrome (CZS), the condition includes microcephaly. Since then, around 4,000 children have been affected in 27 countries, with Brazil accounting for the largest proportion of cases. Family caregivers have also been affected. This study analyzes the literature on caregivers of children with CZS and how the disease has affected their everyday lives. We conducted an integrative review using the PubMed, Virtual Health Library, and Embase databases. Thirty-one articles were identified for analysis after screening. The findings were grouped into four categories: a) social impacts – changes in family relationships, life projects, and social life; b) subjective impacts – feelings of resilience, loneliness, grief, overburdening, fear, uncertainty, and spirituality and religion; c) economic and material impacts – loss of income, increased household expenses, change of residence, and unemployment; and d) health impacts – service unpreparedness, selflessness, self-care, changes in nutritional and sleep patterns, and mental health problems, including stress, anxiety and depression.*

Key words *Congenital zika syndrome, Family caregivers, Zika virus, Family, Review*

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Introduction

In 2015, various parts of Brazil witnessed a microcephaly epidemic in newborns, leading the World Health Organization (WHO) to declare a Public Health Emergency of International Concern (PHEIC)¹.

Studies reported an association between these cases and Zika virus infection during pregnancy²⁻⁴ and named the condition congenital Zika syndrome (CZS). CZS is a complex disease that affects the neuropsychomotor development of children, resulting a variety of conditions ranging from asymptomatic infection to severe defects and disabilities, such as microcephaly, arthrogryposis, contractures, hearing and ophthalmic disorders, dysphagia, and learning difficulties^{5,6}.

According to data from the Pan American Health Organization, there were 3,720 confirmed cases of CZS across 27 countries in the Americas up to 2018. The main concentration of cases was in Brazil (80%), followed by Colombia (6.7%)⁷. The WHO declared the end of the PHEIC and the disease is no longer considered an epidemic, meaning that the problem has moved away from the media spotlight. However, the old challenges remain and new ones are emerging as the affected children grow and new problems arise in various areas, including education, accessibility, and social inclusion.

Studies undertaken since the first cases arose have underlined the need to restructure the health system to tackle the complexity of the disease. In this regard, a number of advances have been made in the description of signs and symptoms, diagnostic testing, development of medications and vaccines, and childhood stimulation. However, a range of publications addressing the etiopathology of the disease and children with microcephaly have blurred the direct and indirect effects of the syndrome on the lives of their families.

Studies with family caregivers of people with disabilities have shown that caregiving has various impacts that encompass various contexts of everyday life, including physical, psychological, and financial burden, uncertainty over the future, and difficulties accessing services. Aspects related to resilience capacity and feelings associated with the benefits of the role of caring were also highlighted⁸⁻¹⁰.

Bringing up, caring for, and accompanying the development of children with chronic diseases requires mobilization and changes in

family dynamics, increasing care demands. Six years after the identification of the first cases of CZS, what impacts on the lives of these families have been identified, considering that the arrival of these children occurred within the context of an epidemic permeated by uncertainties and unknowing? How does the news of the diagnosis and the daily care routine affect the dynamics of the lives of the families of children with CZS? How have these issues been addressed in scientific publications? This integrative review aims to describe and analyze the main evidence regarding these questions in the relevant literature on this topic.

Methods

We conducted a descriptive analytical study taking a quantitative and qualitative approach in the form of an integrative literature review. This type of review enables the researcher to analyze a phenomenon drawing on studies using different research designs, providing a more comprehensive understanding of the topic of interest¹¹. We used the Problem, phenomenon of Interest, Context framework, suggested for reviews of non-clinical or qualitative literature^{12,13}, to define the research question: How has congenital Zika syndrome affected different aspects of the lives of family caregivers of affected children?

A search was performed in June 2021 of PubMed, Embase, and the Virtual Health Library (VHL) using the following inclusion criteria: full-text original articles published after 2014 in peer-reviewed journals describing studies involving family caregivers of children affected by CZS and focusing on everyday contexts of life and life changes after diagnosis. There were no language restrictions. The search strategy (Chart 1) used combined descriptors from the Medical Subject Headings (MeSH) and Health Sciences Descriptors (DeCS).

After excluding duplicates, the records identified by the search were screened by reading the titles, followed by a reading of the abstracts and full-text versions of the articles to identify the studies that met the inclusion criteria. The selected articles were inputted into the Mendeley Reference Manager.

The information extracted from the articles was organized into three tables as follows: a) title, journal details, year of publication, languages, author(s) and affiliation; b) research design, instruments, study period, study location, and

Chart 1. Search strategy showing combined descriptors and Boolean operators.

PUBMED – 99 publications found
<p>#1 “Zika Virus”[Mesh] OR “Zika Virus Infection”[Mesh] OR (ZikV) OR (Virus, Zika) OR (Infection, Zika Virus) OR (Virus Infection, Zika) OR (ZikV Infection) OR (Infection, ZikV) OR (Fever, Zika) OR (Zika Virus Disease) OR (Disease, Zika Virus) OR (Virus Disease, Zika) OR (Zika Fever) OR (Congenital Zika Syndrome) OR (Congenital Zika Virus Infection)</p> <p>AND</p> <p>#2 “Infant, Newborn”[Mesh] OR “Infant”[Mesh] OR “Child”[Mesh] OR (Children) OR (Infants, Newborn) OR (Newborn Infant) OR (Newborn Infants) OR (Newborns) OR (Newborn) OR (Neonate) OR (Neonates) OR (Infants)</p> <p>AND</p> <p>#3 “Caregivers”[Mesh] OR “Parents”[Mesh] OR “Fathers”[Mesh] OR “Mothers”[Mesh] OR (Caregiver) OR (Carers) OR (Carer) OR (Care Givers) OR (Care Giver) OR (Spouse Caregivers) OR (Caregiver, Spouse) OR (Caregivers, Spouse) OR (Spouse Caregiver) OR (Family Caregivers) OR (Caregiver, Family) OR (Caregivers, Family) OR (Family Caregiver) OR (Parent) OR (Parenthood Status) OR (Status, Parenthood) OR (Step-Parents) OR (Step Parents) OR (Step-Parent) OR (Stepparent) OR (Stepparents) OR (Parental Age) OR (Age, Parental) OR (Ages, Parental) OR (Parental Ages) OR (Father) OR (Mother) OR (Mothers’ Clubs) OR (Club, Mothers’) OR (Clubs, Mothers’) OR (Mother Clubs) OR (Mother’s Clubs) OR (Mothers Clubs) OR (Mothers’ Club)</p>
Embase Elsevier – 240 publications found
<p>#1 ‘Zika fever’/exp OR (infection with Zika virus) OR (Zika virus infection) OR (ZIKV infection)</p> <p>AND</p> <p>#2 ‘newborn’/exp OR ‘infant’/exp OR ‘child’/exp OR (children) OR (animals) OR (newborn) OR (child) OR (newborn) OR (full term infant) OR (human neonate) OR (human newborn) OR (infant, newborn) OR (neonatal animal) OR (neonate) OR (neonate animal) OR (neonates) OR (newborn animal) OR (newborn baby) OR (newborn child) OR (newborn infant) OR (newly born baby) OR (newly born child) OR (newly born infant)</p> <p>AND</p> <p>#3 ‘caregiver’/exp OR ‘parent’/exp OR ‘father’/exp OR ‘mother’/exp OR (care giver) OR (caregivers) OR (carer) OR (carers) OR (family caregiver) OR (family caregivers) OR (biological parente) OR (parentes) OR (fatherhood) OR (fathers) OR (motherhood) OR (mothering) OR (mothers)</p>
VHL – 327 publications found
<p>#1 Mh:”Zika virus” OR Mh:”Infecção por Zika virus” OR (Zika virus) OR (Zika Virus) OR (Virus Zika) OR (Virus Zika) OR (Virus Zika) OR (Virus da Febre Zika) OR (Virus da Zika) OR (Virus de Zika) OR (ZIKV) OR (ZikV) OR (Zikavirus) OR MH:B04.820.250.350.995\$ OR (Infecção por Zika virus) OR (Zika Virus Infection) OR (Infección por el Virus Zika) OR (Infection par le virus Zika) OR (Doença pelo Virus Zika) OR (Doença pelo Zika virus) OR (Doença pelo Zikavirus) OR (Doença por Virus Zika) OR (Doença por Zika virus) OR (Febre Zika) OR (Febre pelo Virus Zika) OR (Febre por Virus Zika) OR (Febre por Zika) OR (Febre por Zika virus) OR (Infecção Congênita por Zika) OR (Infecção pelo Zika virus) OR (Infecção pelo Zikavirus) OR (Infecção por Virus Zika) OR (Infecção por ZIKV) OR (Infecção por Zika) OR (Infecção por Zikavirus) OR (Síndrome Congênita de Zika) OR MH:C01.920.500.990\$ OR MH:C01.925.081.990\$ OR MH:C01.925.782.350.250.990\$ OR MH:SP4.012.183.312\$ AND</p> <p>#2 Mh:”Criança” OR Mh:”Recém-Nascido” OR Mh:”Lactente” OR (Criança) OR (Child) OR (Niño) OR (Enfant) OR (Crianças) OR MH:M01.060.406\$ OR (Recém-Nascido) OR (Infant, Newborn) OR (Recien Nacido) OR (Nouveau-né) OR (Criança Recém-Nascida) OR (Crianças Recém-Nascidas) OR (Lactente Recém-Nascido) OR (Lactentes Recém-Nascidos) OR (Neonato) OR (Neonatos) OR (Recém-Nascido (RN)) OR (Recém-Nascidos) OR MH:M01.060.703.520\$ OR (Infant) OR (Lactante) OR (Nourrisson) OR (Lactentes) OR MH:M01.060.703\$</p> <p>AND</p> <p>#3 Mh:”Cuidadores” OR Mh:”Pais” OR Mh:”Pai” OR Mh:”Mães” OR (Cuidadores) OR (Caregivers) OR (Cuidadores) OR (Aidants) OR (Cuidador) OR (Cuidador Familiar) OR (Cuidador de Família) OR (Cuidadores Cônjuges) OR (Cuidadores Familiares) OR (Cuidadores de Família) OR (Cônjuges Cuidadores) OR (Familiar Cuidador) OR (Familiares Cuidadores) OR (Outro Apoiador) OR MH:M01.085\$ OR MH:M01.526.485.200\$ OR MH:N02.360.200\$ OR (Pais) OR (Parents) OR (Padres) OR (Parents) OR (Madrasta) OR (Padrasto) OR (Padrastos) OR MH:F01.829.263.500.320\$ OR MH:I01.880.853.150.500.340\$ OR MH:M01.620\$ OR (Pai) OR (Fathers) OR (Padre) OR (Pères) OR MH:F01.829.263.500.320.100\$ OR MH:I01.880.853.150.500.340.210\$ OR MH:M01.620.390\$ OR (Mães) OR (Mothers) OR (Madres) OR (Mères) OR MH:F01.829.263.500.320.200\$ OR MH:I01.880.853.150.500.340.270\$ OR MH:M01.620.630\$</p>

Source: Authors.

study participants; and c) study objectives and main findings. The latter were grouped into four impact categories: social, economic and material, subjective, and health.

The study did not require ethical approval as it was conducted using original published studies available in electronic databases.

Results

The research strategy yielded 666 records: 99 from PubMed, 240 from Embase, and 327 from the VHL. Five were removed because they did not have sufficient information for screening, two because they were published in 2014, and 52 because they were duplicates. The screening of the titles and abstracts resulted in 41 articles, 10 of which were excluded after reading the full-text versions, resulting in 31 eligible articles (Figure 1).

General characteristics of the articles

Chart 2 shows the main characteristics of the selected articles. Only one study was conducted outside Brazil, in the Caribbean region of Colombia¹⁴. The remaining studies were conducted in the following regions: the Northeast – 23 studies, mainly in the states of Pernambuco¹⁵⁻²¹ and Bahia²²⁻²⁷; the Southeast – four studies in the states of Rio de Janeiro^{28,29}, Minas Gerais³⁰, and Espírito Santo³¹; and the Midwest – one study in the state of Goiás³². One study used data collected in the Nordeste and Southeast³³ and another used YouTube videos as the data source, without specifying where they were produced³⁴. Most of the studies collected the data between 2017 and 2018 (22 articles).

Twenty-two studies (71%) were qualitative, seven (23%) were quantitative, and two (6%) were mixed-method^{14,35}. The most common data collection method used in the qualitative studies was semi-structured interviews, with one study using a psychoanalytic approach²³ and two studies using ethnographic methods^{20,34}. The quantitative studies employed different collection instruments, with the majority using standardized scales.

The primary data were provided by family caregivers of children affected by CZS. Study participants were predominantly mothers, referred to by 21 articles. Only two articles focused on aspects related to fathering, with fathers being the only participants of these studies^{25,36}.

Most of the articles (22) were published in Brazilian journals and 18 were published in both Portuguese and English. The articles published in international journals were written in English, except for one article by Brazilian researchers published in Portuguese in a Colombian journal³⁰. Nursing journals accounted for most articles (14 or 45%), followed by public health journals (7 or 22%).

Most of the articles involved various authors (average of six authors per article) and national and/or international institutions. Some Brazilian studies involved researchers from outside Brazil (the United States and United Kingdom). Only one article¹⁴ was written exclusively by researchers from outside Brazil (Colombia and Spain).

Impacts of congenital Zika syndrome on families

The objectives of the selected studies focused on understanding experiences and perceptions related to family dynamics and the impact of the diagnosis of CZS, including aspects such as mental health, quality of life, adaptive challenges, parent needs, coping strategies, and therapy.

The study findings were grouped into the following categories: social, subjective, economic and material, and health. Although these aspects are interrelated, we chose to synthesize the findings into categories to illustrate the most common impacts.

Social impacts

The findings show that having a child with CZS directly impacts the lives of families, especially that of mothers, leading to changes in routines and family dynamics. Overburdening, exhaustion, lack of time, and an overlap between domestic tasks and caregiving were some of the impacts highlighted by the articles^{16,17,21,22,25,27-32,35,37,38}.

Scott *et al.*²⁰ highlighted that women were practically obliged to take on the role of caregiver, resulting in home isolation and the interruption of personal projects. Melo *et al.*¹⁵ analyzed the caregiving process using the concept of biographical disruption, which is commonly used in medical anthropology to interpret the consequences of chronic illnesses. The authors point out that although women are not themselves ill, their lives are fundamentally affected by their children's disabilities.

The women also mentioned the interruption of personal projects, such as work and career,

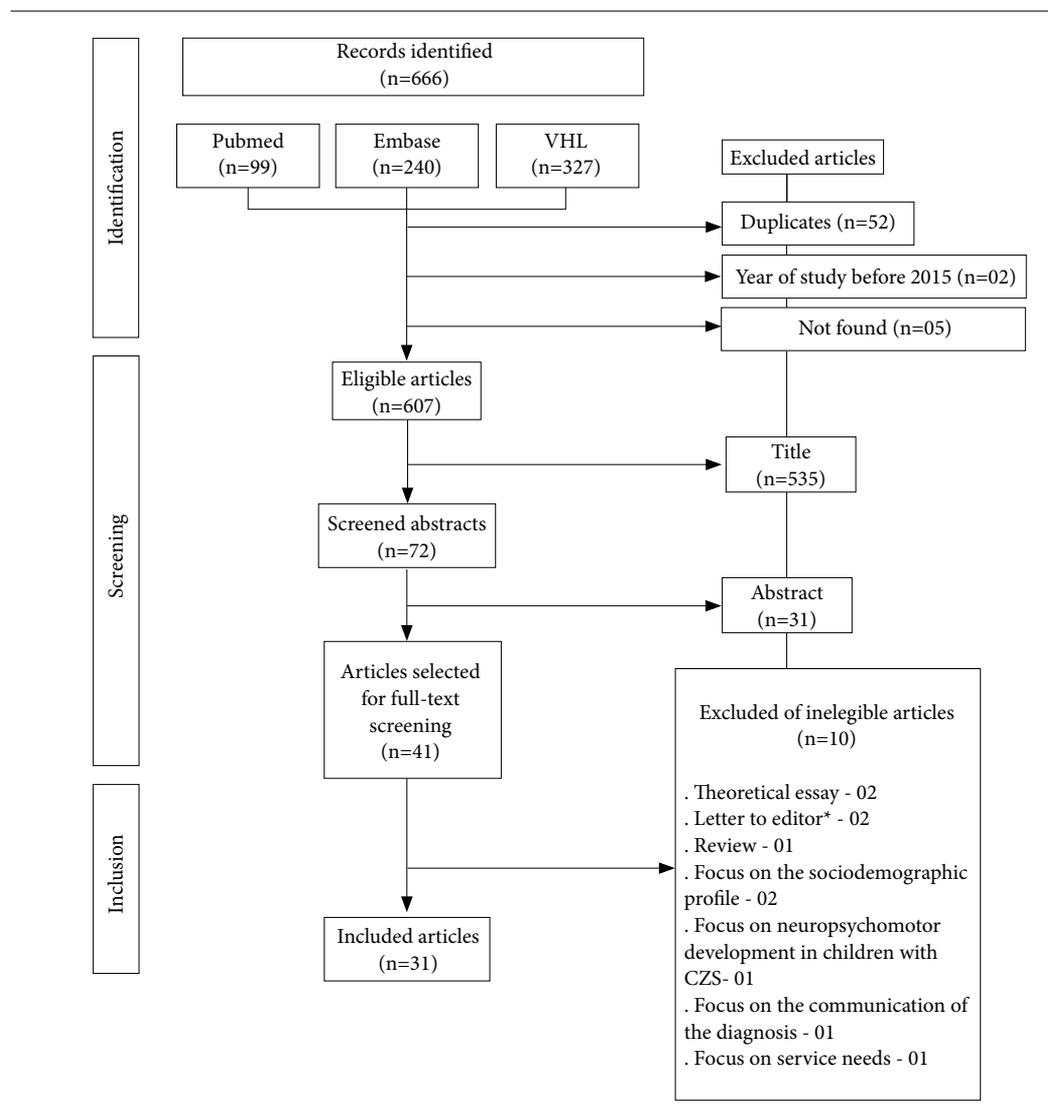


Figure 1. Article selection flowchart.

* Although the letters to the editor included health impacts, they were excluded because they did not meet the inclusion criteria.

Source: Authors.

and changes in routine activities and habits. The findings also highlight that caregivers frequently fail to care for themselves, sacrificing rest and sleep and social activities with friends and family^{16,21,22,25,26,31,35,39,40}. Social support is provided by women across different generations, with grandmothers, aunts, and sisters being the main family caregivers. Although often limited, this support network is essential to allow mothers engage in personal projects¹⁵.

With regard to solidarity among women, Scott et al.²⁰ emphasize the complementary support role of mothers' groups, widening the scope of possible responses and helping women to cope better with the lack of or ineffectiveness of state actions¹⁵. Mendes et al.²⁹ highlight that this articulation between women and consequent political mobilization strengthens both individuals and groups. Sá et al.¹⁶, Kuper et al.³³, and Lima et al.¹⁹ emphasize that support networks can act

Chart 2. General characteristics of the selected articles.

Reference	Journal and language	Objective	Type of study and instruments used	Study location, data collection period, and participants	Types of impacts identified
Bulhões <i>et al.</i> (2020) ³⁶	Esc Anna Nery Portuguese and English	Investigate emotional effects in mothers of children with complications resulting from CZS	Mixed-methods Sociodemographic questionnaire, Self-Reporting Questionnaire (SRQ-20), and semi-structured interview	State in the Northeast of Brazil 2017 and 2018 15 mothers	. Social . Economic and material . Subjective . Health
Bulhões <i>et al.</i> (2020) ²¹	Texto Context - Enferm Portuguese and English	Understand the stories and experiences of mothers of children with	Qualitative Individual semi-structured interviews - thematic oral history	Goiana, PE, Brazil 2017 e 2018 13 mothers	. Social . Subjective . Health
Cajuhi <i>et al.</i> (2020) ²⁶	Rev Enferm UFPE Portuguese and English	Describe caregivers' experiences of caring for children with microcephaly associated with the Zika virus	Qualitative Semi-structured interviews	Bahia, BA, Brazil 2019 2 mothers	. Social . Economic and material . Subjective
Calazans <i>et al.</i> (2020) ¹⁷	Rev Bras Enferm Portuguese and English	Explore the adaptive challenges faced by mothers of children with CZS abandoned by the child's father using the Roy Adaptation Model	Qualitative Interviews	Recife, PE, Brazil 2017 6 mothers abandoned by the father	. Social . Subjective . Health
Campos <i>et al.</i> (2018) ³⁸	Rev Da Rede Enferm Do Nord Portuguese and English	Understand the challenges and perceptions of mothers of children with microcephaly caused by the Zika virus	Understand the challenges and perceptions of mothers of children with microcephaly caused by the Zika virus	Fortaleza, CE, Brazil 2017 and 2018 12 mothers	. Social . Subjective
Costa <i>et al.</i> (2021) ⁴¹	Rev Paul Pediatr Portuguese and English	Investigate the perceptions of quality of life of mothers of children with microcephaly associated with the Zika virus	Qualitative Sociodemographic questionnaire Semi-structured interviews	MA, Brazil 2015 to 2018 10 mothers	. Social . Economic and material
Dias <i>et al.</i> (2019) ²⁵	Rev Enferm UFPE Portuguese	Describe the feelings and perceptions of the fathers of children with microcephaly cause by the Zika virus	Qualitative Semi-structured interviews	Inland Bahia, BA, Brazil 2017 4 fathers	. Social . Subjective
Félix e Farias (2019) ³⁷	Cad Saúde Publica Portuguese and English	Analyze the impact of the diagnosis of microcephaly on paternal function	Qualitative Questionnaire Semi-structured interview	Inland Paraíba, PB, Brazil 2016 5 fathers	. Social . Economic and material . Subjective . Health
Freire <i>et al.</i> (2018) ²⁸	Cad Saúde Publica Portuguese and English	Discuss the impacts of the promotion of families' mental health following the diagnosis of Zika virus infection in the pregnant woman and/or congenital Zika virus syndrome (CZVS) in the infant. Foster reflection on mother-infant bonding in this context.	Qualitative Participant observation during visits to the health center	RJ, Brazil 2016 9 mothers with fathers, 10 mothers with other family members or friends, 1 single mother	. Social . Economic and material . Subjective
Freitas <i>et al.</i> (2019) ³²	Rev Enferm Atual Derme Portuguese and English	Assess the family impact on parents of children diagnosed with microcephaly caused by the Zika virus	Quantitative Sociodemographic questionnaire Occupational psychosocial questionnaire and health questionnaire Questionnaire regarding family context Family impact scale	Goiania, GO, Brazil 2017 68 mothers, 8 fathers	. Social . Subjective

it continues

Chart 2. General characteristics of the selected articles.

Reference	Journal and language	Objective	Type of study and instruments used	Study location, data collection period, and participants	Types of impacts identified
Freitas <i>et al.</i> (2020) ³¹	Int J Gynecol Obstet English	Describe impacts from the perspective of mother caregivers of children with CZS	Qualitative Semi-structured interviews	ES, Brazil 2017 25 mothers	. Social . Subjective . Health
Hamad and Souza (2019) ³⁹	Esc Anna Nery Portuguese and English	Understand what it means to have a child with CZS from the experience of women and, based on this understanding, what they would say to other women in the same situation	Qualitative Semi-structured interviews	Different cities in Paraíba, PB, Brazil 2017 40 mothers	. Social . Subjective
Kotzky <i>et al.</i> (2019) ⁴³	J Dev Behav Pediatr English	Examine depressive symptom severity and care demands among primary caregivers of children aged 15 to 26 months with evidence of congenital Zika virus infection (ZVI)	Quantitative Ages and Stages Questionnaires-3 PHQ-9 (Patient Health Questionnaire-9) - Depression Risk Assessment NSCH - Support and Care Demands (National Survey of Child Health)	PB and CE, Brazil 2017 143 mothers, 7 other family members	. Economic and material . Health
Kuper <i>et al.</i> (2019) ³³	PLoS Negl Trop Dis English	Explore the association between having and child with CZS and depression, anxiety, and stress and assess whether these relationships are buffered by social support and socio-economic status	Quantitative Depression, Anxiety and Stress Scale - DASS-21, Social Support Scale (MOS-SSS) Sociodemographic data	Recife, PE and Rio de Janeiro, RJ, Brazil 2017 and 2018 163 CZS caregivers, 324 non-CZS caregivers (mainly mothers)	. Social . Health
Lima and Souza (2021) ³⁵	Cienc e Saude Coletiva Portuguese	Assess the role parenting self-efficacy plays in mediating socioenvironmental factors and the mental health of mothers of children with CZS	Quantitative Sociodemographic questionnaire Positive and Negative Affect Schedule Satisfaction with Life Scale Fatigue Severity Scale General Health Questionnaire Parental Self-Efficacy Scale	CE, Brazil Study period not informed 69 mothers	. Health
Lima <i>et al.</i> (2018) ²⁷	Rev Baiana Enferm Portuguese and English	Understand the experiences of mothers of children with microcephaly	Qualitative Semi-structured interviews	Feira de Santana, BA, Brazil 2017 8 mothers	. Social . Economic and material . Subjective
Lima <i>et al.</i> (2020) ¹⁹	Rev Bras Enferm Portuguese and English	Identify elements that contribute towards strengthening the family system of a child with CZS in the light of Betty Neuman's nursing theory	Qualitative Semi-structured interviews	Recife, PE, Brazil 2017 13 mothers	. Social . Economic and material . Subjective . Health
Melo <i>et al.</i> (2020) ¹⁵	Viruses English	Analyze some of the social impacts experiences by women involved in caring for children with CZS	Qualitative Semi-structured interviews	Metropolitan Region of Recife, PE, Brazil 2017 16 mothers, 4 grandmothers, 2 aunts, 1 great-grandmother	. Social . Economic and material . Subjective

it continues

Chart 2. General characteristics of the selected articles.

Reference	Journal and language	Objective	Type of study and instruments used	Study location, data collection period, and participants	Types of impacts identified
Mendes <i>et al.</i> (2020) ²⁹	Cienc e Saude Coletiva Portuguese and English	Analyze the impacts of the diagnosis of CZS on the lives of families visiting a referral center	Qualitative Semi-structured interviews	RJ, Brazil 2017 and 2018 15 mothers	. Social . Economic and material . Subjective
Menezes <i>et al.</i> (2019) ³⁰	Av En Enfermería Portuguese	Understand how the families of children diagnosed with microcephaly caused by the Zika virus react emotionally to the diagnosis and the impact of this event on family dynamics	Qualitative Semi-structured interviews	Montes Claros, MG, Brazil 2017 5 mothers	. Social . Economic and material . Subjective
Pereira <i>et al.</i> (2021) ⁴⁴	Matern Child Health J Inglês	Examine levels of parental stress among primary caregivers of children with evidence of CZS and the association with developmental delays	Quantitative Questionnaire Hammersmith Infant Neurological Examination (HINE) - neurological assessment Ages and Stages (ASQ) - child development assessment Parenting Stress Index (PSI-SF) - assessment of parental depression and stress	João Pessoa and Campina Grande, PB and Fortaleza, CE, Brazil 2017 146 primary caregivers	. Economic and material . Health
Queiroz (2019) ²³	Matern Child Health J English	Reflect on the clinical treatment received by families of children with CZS	Qualitative Psychoanalytic therapy	BA, Brazil Not informed Families	. Subjective . Health
Reis <i>et al.</i> (2020) ⁴²	Am J Occup Ther English	Investigate changes in occupational roles and effects on the mental health of mothers of children with CZS	Quantitative Questionnaire to assess demographic and socioeconomic characteristics, mental health status and occupational role before the birth of the child and at time of data collection SRQ-20 (screens for common mental disorders) Occupational Role Checklist	AL, Brazil 2017 and 2018 40 mothers	. Economic and material . Health

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as a protective factor for families and caregiving. Teaching other family members how to care for the child is essential to ensure that children receive care when the mother is absent²². Some authors^{24,29,32,39} highlighted that the responsibility for caregiving falls mainly on the parents, who find it difficult to find people they can trust to care for their children. The studies also report that a lack of understanding of the burden of caregiving can result in the absence of family support networks and consequent lack of support for caregivers.

Impacts on the dynamics of the family and couple were also highlighted by some studies, including the interruption of plans to have more children³², differentiated treatment in relation to siblings^{21,36}, and drifting apart or coming closer together, resulting either in conflict and break ups or support^{20,21,26,27,30,31,36,39}.

Fathers/husbands/partners were less inclined to contribute to domestic tasks and care^{20,30,36}. When they do contribute, their participation is seen to be an attitude that should be valued and

Chart 2. General characteristics of the selected articles.

Reference	Journal and language	Objective	Type of study and instruments used	Study location, data collection period, and participants	Types of impacts identified
Romero-Acosta <i>et al.</i> (2020) ¹⁴	Behav Sci (Basel) English	Explore perceptions of ZIKV and mental health in women exposed to ZIKV during pregnancy in Colombia	Mixed-methods Structured interviews The State-Trait Anxiety Inventory (STAI)A Self-Rating Depression Scale General health questionnaire Sociodemographic questionnaire using the Hollingshead index to assess parental education, occupation, etc.	Rural are of the Caribbean region in Colombia 2016 to 2018 17 women exposed to Zika virus, including 9 mothers of children with CZS	. Social . Subjective . Health
Sá <i>et al.</i> (2017) ⁴⁰	Rev Bras Em Promoção Da Health Portuguese and English	Analyze the dynamics of families of children with CZS in Petrolina, Pernambuco	Qualitative Focus groups	Fortaleza, CE, Brazil 2016 23 parents/guardians	. Social . Economic and material . Subjective . Health
Sá <i>et al.</i> (2020) ¹⁶	Cad Saude Publica Portuguese	Analisar a dinâmica familiar de criança com a síndrome congênita associada ao zika vírus (SCZV) no município de Petrolina, Pernambuco.	Qualitative Semi-structured interviews	Petrolina, PE, Brazil 2017 9 mothers, 5 other family members	. Social . Economic and material . Subjective
Scott <i>et al.</i> (2018) ²⁰	Interface Commun Heal Educ Portuguese and English	Understand the way different contexts (discovery, household, health units, social work, associations) contribute to creating notions about maternity and childhood	Qualitative Ethnography, field diaries, in-depth interviews, online document search	PE, Brazil Since 2016 People from family networks and state services	. Social . Economic and material . Subjective . Health
Souza <i>et al.</i> (2019) ²⁴	Rev Baiana Enfermagem Portuguese and English	Analyze the therapeutic itinerary of families of children with microcephaly in inland Bahia	Qualitative Semi-structured interview e dados sociodemographic	Feira de Santana, BA, Brazil 2017 6 mothers, 3 fathers	. Social . Economic and material . Subjective
Vale <i>et al.</i> (2019) ³⁴	Nurs Inq English	Understand the experiences and perceptions of families of babies diagnosed with microcephaly associated with the Zika	Qualitative Netnography (ethnography using the internet)	Internet 2015 and 2016 18 videos of family members posted on YouTube	. Social . Subjective . Health
Vale <i>et al.</i> (2020) ²²	Rev Gaúcha Enferm Portuguese and English	Understand the caregiving experiences and practices of mothers of children with CZS	Qualitative In-depth interviews	Feira de Santana, BA, Brazil 2017 10 mothers, 1 sister	. Social . Economic and material . Subjective
Williams <i>et al.</i> (2019) ¹⁸	Disabil Rehabil English	Examine the psychological well-being of primary caregivers of infants and toddlers with CZS, and the roles of family resources, parenting stress, and coping strategies in caregivers' adaptation	Quantitative Beck Anxiety Questionnaire Beck Depression Inventory II Child dependence/health status questionnaire Parenting Stress Index Family Crisis Oriented Personal Scale Family resources scale	Recife, PE, Brazil 2018 46 mothers, 3 grandmothers, 1 father	. Health

Source: Authors, based on selected articles.

praised, unlike women, whose care role is taken for granted²⁰. In some cases, the paternal care role is sacrificed, with the argument that the man should play the role of provider and conciliate family and work^{30,36}.

Subjective impacts

The majority of studies identified that family members (especially mothers) experience a diverse range of feelings from the moment that the news of the diagnosis is received and throughout the process of development of the syndrome. The feelings identified by the articles were grouped into the word cloud in Figure 2, highlighting emotions such as guilt, fear, loneliness, uncertainty, stress, anxiety, adaptation, and prejudice. These feelings arise from the experience of living an epidemic that affected newborns and causes disability and slows down neuropsychomotor development. This is compounded by the lack of information on the prognosis, strategies to deal with the situation, and government support. Hamad et al.³⁸ highlight positive feelings such as patience, love, coping, and adaptation to an unexpected situation, while Lima et al.²⁷ and Melo et al.¹⁵ reported will power and determination and solidarity and resilience, respectively.

Fourteen articles mentioned the impacts of the diagnosis on families^{14,15,20-23,25,27,29-31,34,36,37}. Melo et al.¹⁵, Vale et al.³⁴, Scott et al.²⁰, and Félix et al.³⁶ suggest that having a child with CZS shatters the usual expectations of a pleasant motherhood. The image of a child with a disability contrasts with the ideal of the expected child, triggering feelings of grief and loss. Vale et al.³⁴ point out that families who learnt of the diagnosis from an ultrasound during pregnancy feared for the future with an anticipatory sense of failure, loss, and pain. However, these feelings were replaced with a sense of triumph upon unexpectedly hearing the baby's cry at birth. Félix et al.³⁶ discuss the paternal function and invisibility of fathers, who can also be badly affected by the news of the diagnosis, emphasizing that fathers of CZS children are prone to depression.

Adaptation involves all areas of family life²⁹ and everyday experiences bring uncertainties, surprises, and shared learning^{15,22} ("learning to live with the problem", "learning by experience"). Knowledge gained from the everyday practice of caring frequently contradicts the advice received from health professionals, who often lack the necessary skills and knowledge and give wrong prognoses^{14,15,31}.

Spirituality and religion were highlighted both as a source of family support and strength for

coping with difficult moments^{15-17,19,21,24,25,27,29,36,38} and as a basis for interpreting the situation, relating it to punishment, divine providence, and/or the sacralization of children and motherhood^{15,28,34,38}.

Economic and material impacts

The articles show that job loss was one of the main consequences of having a child with CZS in Brazil^{15,16,20,24,26-28,35,39-42}. Care demands combined with constant visits to health services interfere with work activities, meaning that family caregivers are often forced to leave or are dismissed from their job.

Increased household expenses were also reported by some studies^{16,20,27-30,36,39,40}, which, combined with unemployment, led to a decrease in family income and impoverishment¹⁵, negatively affecting maternal mental health⁴¹. A study by Kotzky et al.⁴² found that roughly 72% of caregivers of children with developmental delays had difficulty covering basic needs, compared to 31% of parents of children without delays. Lima et al.¹⁹ highlighted that job security was a protective factor promoting well-being and the strengthening of families.

Increased expenses were related to a series of adaptations, including moving home or reorganizing the residence to reduce costs and improve access to social services, purchase of medicines and medical supplies, travelling to health services, special diets, and purchase of toys for children with special needs^{15,16,20}. In response to difficulties accessing resources, some families improvised alternatives to the instruments and equipment recommended by doctors and therapists²⁰.

The new reality led families to seek ways to increase their income and mobilize financial, material, and relational resources¹⁵, including social services, income, housing, and employment benefits. With regard to housing, Sá et al.¹⁶ highlighted the existence of housing programs for low-income families and non-homeowners. The mobilization of support and partnerships by mothers' groups also resulted in material gains and alternative sources of income through training and capacity building²⁰.

The cash benefit program *Benefício de Prestação Continuada*, introduced by the National Social Assistance Policy, was the main government benefit received by the families. However, some articles highlighted difficulties accessing this benefit^{35,44} and Scott et al.²⁰ mention that the eligibility criteria can affect other benefits/income, such as pensions and work, given that

depression, anxiety, and stress were very common among mothers of young children in Brazil. The authors also observed that mothers of children with CZS are particularly vulnerable to mental health problems and that social support acts as a protective factor. In the study conducted in Colombia, Romero-Acosta¹⁴ reported lower levels of general health and worse mental health in women whose children had microcephaly. Maternal self-perception of health and anxiety were worse in the assessment conducted in the second year of life of their children.

The qualitative studies also reported health impacts, including mental health problems, such as stress^{16,30}, loss of control¹⁶, reactive depression²³, and distress³¹, and physical problems, including overburdening, physical exhaustion, nutritional problems, inadequate patterns of activity and rest¹⁷, and fatigue³⁶.

The studies also mentioned aspects related to the structure and provision of health services. Scott *et al.*²⁰ highlighted failings in state services, resulting in difficulties accessing care. Felix and Farias³⁶ reported that psychosocial care services and policies directed at families of children with CZS often fail to include fathers, while Freitas *et al.*³¹ highlighted difficulties in accessing health services among families living far from large urban centers and feelings of guilt among caregivers reinforced by the stance of health professionals.

In contrast, Vale *et al.*³⁴ reported that the support and advice provided by health professionals helped reduce feelings of guilt. Bulhões *et al.*²¹ highlighted that therapeutic groups were important spaces for welcoming and supporting families, while Lima *et al.*¹⁹ underlined that frequent appointments with health professionals can help strengthen families.

Discussion

Despite the large body of literature on Zika⁴⁵, studies on the contexts of life of families of children with CZS remain relatively scarce. The majority of the studies analyzed by this review were qualitative, focusing on the narratives, experiences, and perceptions of reality of the study participants. These methods appear to gain special significance when the object of study is part of a diverse and interconnected field.

Although the present study focused on health journals, the analyses and methodologies drew on theoretical frameworks from the social sciences and humanities. In addition to disease

and health-related aspects, the articles explored the interface between these elements and social, political, ethical, and economic issues. This area constitutes an important niche within the literature, given that a large proportion of studies on Zika are from the field of biomedical sciences^{46,47}.

The findings of this review corroborate the results of studies focusing on caregivers of other dependents, which highlight physical, psychological, and financial burdens, as well as uncertainty, social withdrawal, and difficulties related to health services⁸⁻¹⁰. In the case of other types of disabilities, the caregiving process frequently tends to be a lonely experience, with caregivers often taking some time to meet fellow caregivers dealing with the same problem during the process of seeking diagnosis, care, and information.

Caring for children with CZS has several distinctive characteristics. The media coverage of the epidemic brought visibility to this generation of affected children, also increasing the attention paid to families of children with other disabilities and rare diseases, who have long battled for spaces of care for themselves and their children²⁰.

The CZS epidemic in Brazil disproportionately affected poor families, complexifying lives already marked by various forms of exclusion, bringing to light underlying intersectionalities. The hardships faced by these families demonstrate the neglect that pervades social and economic structures and health, social, and basic sanitation services, while at the same time underlining the urgent need for action to tackle inequalities⁴⁸⁻⁵⁰.

The central role played by mothers in family caregiving identified by practically all the articles analyzed by this study evidences an alliance between women manifested in support networks, especially family and community networks. The exhausting routines endured by women illustrate the maintenance and reinforcement of gender inequalities, where motherhood and care are defined as a condition of female existence. This configuration limits their choices, resulting in biographical disruption¹⁵ and the interruption and readjustment of life projects, unlike the men in the families of children with CZS^{25,36}.

The agency of these women has challenged the tone of tragedy broadcast by the media and the scientific race to combat the “global threat”⁵¹. They are women who have resigned their lives, their trajectories, and their projects, coming together in associations, constructing and sharing knowledge, and “going where they need to go”¹⁵ to claim their rights. They develop remarkable

resilience in the face of an exhausting routine that affects not only their children's but their own health. However, these women are able to see beyond the burdens to the benefits and positive feelings associated with the caring role in a process of renunciation of self-care in favor of caring for the other⁹.

Theoretical feminist literature and the political discussion surrounding gender equality and sexual division of labor have highlighted the role women play in caregiving. For a long time, the biological functions of gestating, giving birth, and breastfeeding were linked to caring, strengthening the understanding that the activity is intrinsically feminine⁵².

While being an essential part of human development, both in terms of learning and socialization, the act of caring has commonly been distanced from the notion of work. Like other domestic tasks, caring is understood to have less value and often looked down on and rendered invisible, both within the family and from a relations of production and social reproduction perspective⁵².

In her analysis of the work of caring for dependents, Kittay⁵³ emphasizes that this type of work, whether imposed or not, has traditionally been assigned to the women in the family. It is generally unpaid or underpaid and has a greater toll on people who suffer racism, poverty, and other forms of inequality. Despite the gendered nature of dependence, motherhood, and care, there is nothing that justifies assigning the caregiving role intrinsically, inevitably, or exclusively to women.

The social media commotion around the CZS epidemic put the affected children and the women involved in their care under the spotlight; however, they share their citizenship with many other women and people with disabilities. It is therefore important to consider that, as highlighted by both Kittay⁵³ and Tronto⁵⁴, the act of caring encompasses moral, psychological, social, cultural, economic, political, technical, and normative aspects. Caregiving should be understood as a democratic value that affects the whole of society rather than an exclusively dual or private relationship defined within the families and personal networks that include dependent persons. This dimension of life should be treated as something to be defined at the heart of political decision-making and tackled from the perspective of social justice.

Conclusions

Responses to public health emergencies employing exclusively biomedical strategies focused on *infectious agents* and disease treatment have been insufficient. It is necessary to broaden the perspective to include life contexts and understand that public policies are more effective when they take into account the reality of the people affected.

The results of this review provide an initial broad overview of this issue, helping understand the burdens faced by family caregivers of children with CZS, in particular women. This review has some limitations. First, it is possible that the search missed some studies. Furthermore, the knowledge on this disease and associated problems is under construction and new challenges and impacts are likely to be identified as the children grow up.

It is noteworthy that few studies referred to the siblings of the children with CZS and those that did so only mentioned them indirectly. Part of the literature on childhood chronic diseases or disabilities address impacts on the lives of siblings^{55,56}. It is suggested that future studies address this issue, considering siblings born both before and after the birth of the child with CZS.

It is essential to learn from the existing literature. The studies analyzed by this review point to certain resources and coping strategies that appear to act as protective mechanisms, minimizing the impact of CZS on the various dimensions of life of the people directly involved in caregiving, including: keeping jobs and maintaining family income; social support networks, including creches and family support service; and psychosocial support and strategies that strengthen parenting self-efficacy.

Although CZS is no longer considered an epidemic, new cases continue to be reported^{57,58}. However, Costa et al.⁵⁹ estimate that the fatality rate is approximately 10%. It is important to understand family dynamics have been affected by the arrival and loss of these children when "the issue is no longer talked about".

The challenges are many. The realities presented here are compounded by a previously unimaginable context of an overlapping COVID-19 pandemic, resulting in restrictions and impacts felt by the whole of society, especially by the families of children with CZS. This raises other important issues, including the importance of integrating traditional health surveillance and the surveillance and care of chronic diseases such as CZS.

Collaborations

All authors contributed significantly to the construction of the text. APL Melo worked on the design, methodology construction, data selection and analysis, and writing. TM Lyra and TVB Araújo supervised all stages. JMV Barbosa contributed to the design and methodological review. All authors contributed equally to the revision and approval of this manuscript version.

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