

Healthcare for children with congenital Zika syndrome: analysis of access to social rights

Atendimento das crianças com síndrome da Zika congênita: análise do acesso aos direitos sociais

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Abstract *The objective of this study was to describe if the victims of the Zika have access to essential public policies to guarantee social rights. Methods: We used a cross-sectional study of a historical cohort of children with congenital Zika syndrome (CZS) in a reference hospital. CZS diagnosis was based on the Ministry of Health protocol. The variables analyzed were sociodemographic and social rights of children. Results: Of the 161 children seen from April 2016 to July 2018, 42 were diagnosed with CZS. Of these, 37 children participated in the study and 75.7% of them had severe neurological disorders. Anticonvulsants were used by 73% of the children, with 81% paid by families. The families were also responsible for purchasing nutritional formulas and diapers in, respectively, 79% and 100% of cases, and 89% of the children had access to rehabilitation therapy, although 70% of them faced several barriers to do it. Of the 24 working mothers, 83% did not return to the labor market after the birth of their children. Conclusions: The results showed that the families were at an intersection between the integral activity of caring for a child with severe disabilities and inefficient and omissive public authorities, a disincentive and discouraging context that made them give up in seeking their rights.*

Key words *Public policies, Human rights, Congenital Zika syndrome*

Resumo *Este estudo teve como objetivo analisar se as vítimas da epidemia da Zika têm acesso às políticas públicas essenciais à garantia dos direitos sociais. Métodos: Estudo transversal de uma coorte histórica de crianças com síndrome da Zika congênita (SZC) em um hospital de referência. Utilizou-se o protocolo do Ministério da Saúde para o diagnóstico de SZC. As variáveis analisadas foram características sociodemográficas e direitos sociais das crianças. Resultados: Das 161 crianças avaliadas de abril/2016 a julho/2018, 42 apresentavam SZC. Destas, 37 participaram do estudo, 75,7% com grave comprometimento neurológico. Anticonvulsivantes eram utilizados em 73% dos casos, 81% custeados pelas famílias. As famílias ainda custeavam fórmulas nutricionais (79%) e fraldas (100%). A terapia de reabilitação era realizada por 89% das crianças, embora 70% enfrentassem diversas barreiras para tal. Das 24 mães que trabalhavam, 83% não retornaram ao mercado de trabalho após o nascimento dos filhos. Conclusões: As famílias estavam situadas na interseção entre a atividade integral de cuidado de um filho com deficiências graves e a ineficiência e omissão do poder público, um contexto de desincentivo e desalento que, vencendo-as pelo cansaço, fazia com que muitas acabassem desistindo de tentar buscar seus direitos.*

Palavras-chave *Políticas públicas, Direitos sociais, Síndrome da Zika congênita*

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Introduction

An unprecedented epidemic with dire social consequences spread throughout Brazil from 2015 to 2017. Having the northeast as its epicenter, the medical community was surprised by the significant increase in cases of microcephaly and other congenital malformations in newborns, which were later associated with the Zika virus (ZIKV) infection during the intrauterine period. It is a severe congenital disease in which the virus is transmitted to the mother by the bite of the *Aedes aegypti* mosquitoes that could reach vertical conceptus, leading to congenital Zika syndrome (CZS)¹. The ZIKV can be transmitted through sexual intercourse², characterizing the infection also as a sexually transmitted infection.

Between 2015 and 2020, 19,622 suspected cases of SZC were notified to the Ministry of Health (MH) in Brazil, of which 3,577 (18.2%) were confirmed. In 2020 alone, there were 1,007 notifications, of which 35 (3.5%) were confirmed and 597 (59.3%) remain under investigation¹. In May 2017 there was a 95% reduction in the number of CZS notifications compared to the same period in 2016. The epidemic was weakening and the contentment resulting from the strengthening of the national and local response capacity to the advance of a hitherto unknown epidemic was clear³. However, prudence was recommended, as although health needs are prioritized during health crises, the impacts resulting from the lack of attention to those who are living with the consequences the epidemic can persist for many years after the end of an emergency⁴.

The ZIKV epidemic also had a severe socioeconomic impact on the healthcare and social welfare systems in the countries affected. Zika was placed on the list of “diseases of poverty”, as it tends to become endemic in underprivileged places without public health, lacking prevention information, and with ineffective resources to contain the spread of diseases⁴.

The State is responsible for providing basic material conditions for each and every citizen, as each of the social rights has a minimum content that must be protected called “existential minimum”⁵, which includes the minimum qualitative standards that ensure each person a healthy life with dignity⁶.

There are few articles on the impact of the ZIKV epidemic on the population, most consisting of studies discussing inequalities and their effects on reproductive health, and on access to the list of existing social rights⁷⁻¹⁰. More than five

years after the beginning of the epidemic, these children, who are at the end of early childhood, still lack a structured network of public policies to ensure their health, well-being, and enough social support for a minimally dignified existence⁹. In this context, the objective of this study was to describe whether the victims of the Zika epidemic actually have access to essential public policies to ensure their constitutionally guaranteed social rights.

Methods

This is a cross-sectional study of a historical cohort of children with CZS, which is part of a broader survey entitled “Clinical and epidemiological study of children exposed to ZIKV during the gestational period: A prospective cohort study”.

The Hospital Universitário Antônio Pedro of the Universidade Federal Fluminense (HUAP-UFF) is a highly complex healthcare unit for tertiary and quaternary care to the Metropolitan Region II of the State of Rio de Janeiro, which encompasses the cities of Niterói, Itaboraí, Maricá, Rio Bonito, São Gonçalo, Silva Jardim, and Tanguá. In April 2016, the “Zika Project” began in this hospital, with specialized care for pregnant women with exanthem and for their children, as well as for children with suspected CZS regardless of reports of maternal exanthem during pregnancy.

Children were referred by spontaneous demand or from health units and maternity hospitals in Niterói and cities in Metropolitan Region II, in addition to those from the HUAP-UFF maternity hospital. In its elaboration and execution phase, the project was propagated among the health professionals of the aforementioned institutions.

The study population consisted of children with CZS diagnosed according to the MH protocol¹¹ seen at the HUAP-UFF from April 2016 to July 2018.

The data were collected in the period of November 2019 to December 2020 at the HUAP-UFF. Interviews with parents/legal guardians and searches in the original project database were concomitantly and complementarily used as data sources. Sociodemographic, clinical, and laboratory variables were extracted from the original project database. Variables related to access to social rights were obtained in the interviews through a specific questionnaire for the study.

The interview took place before or after the medical appointment, according to the availability of the multidisciplinary team in charge, in an appropriate place to ensure the privacy of the data obtained. Participant observation was conducted during the application of the research protocol by the author, who used a notebook to write down observations on healthcare and the mothers' narratives.

The information obtained formed a database that was stored in the PASW Statistics 18 software for Windows (IBM). The results were described as medians and interquartile ranges (IQR) for continuous variables. Categorical variables were described as frequencies and compared using the chi-square test with $p < 0.05$ considered significant. The association between categorical variables was calculated with the Epi Info 2015 software version 7.1.5.2 (Centers for Disease Control and Prevention, Atlanta, Georgia, USA).

After agreeing to participate in the study, the children's legal guardians signed an informed consent form. The research project was approved by the Research Ethics Committee of the UFF School of Medicine (CAAE number 62992016.9.0000.5243) on January 31, 2017.

Results

From April 2016 to July 2018, 161 children with suspected CZS or whose mothers had exanthem during pregnancy were referred to the HUAP-UFF. Of these, 42 children were confirmed with CZS¹¹⁻¹³. Five children were lost to follow-up, two to project abandonment, two to change of address, and one to death. The remaining 37 children comprised the study population (Figure 1).

According to the clinical-neurological examination conducted by the study team^{12,13} during the research period, the 37 participating children were classified into severe neurological impairment (28 cases, 75.7%) and moderate neurological impairment (9 cases, 24.3%).

Sixteen (43%) children lived in Niterói, ten (27%) in São Gonçalo, and 11 (30%) in other Metropolitan Region II cities. Of the total number of respondents, 19 (51%) reported living in urban slums. The median maternal age at the time of childbirth was 23 years (IQR=20-32.5) and 73% were younger than 30 years (Table 1).

As for the monthly family income, 29 (79%) interviewees reported receiving less than two national minimum salaries, with the income of 11 (30%) families being exclusively composed of

assistance benefits from the federal government. In 34 (92%) families, the mothers were the main child caregivers. Of the 24 mothers who worked, 20 (83%) did not return to the labor market after childbirth. There was no emotional and financial abandonment of the child by the father in 78% of the families (Table 1).

Twenty-seven children (73%) were using anticonvulsant medication, of which 22 (81%) had their medication paid by the families. Of the 14 (38%) children who needed nutritional formula supplementation, 11 (79%) families paid for it. Thirty-one (84%) children needed diapers and medical supplies, with the family being responsible for purchasing all of it in all cases (Table 2).

Of the 33 children whose mothers reported they were undergoing rehabilitation at the time of the interview, 28 (85%) were assisted by a free public rehabilitation service and five (15%) by a private service. In 27 cases, it was possible to obtain the age at which rehabilitation began, with a median of five months (IQR=3-6) and a range from one to 36 months. Only ten (30%) mothers reported no problems in conducting rehabilitation. For the others (23 cases, 70%), the main difficulties alleged were unadapted transport (eight cases), distant location from the household (seven cases), need for more than one ride (five cases), or not included in the public transport fee exemption policy (one case), and few weekly sessions (two cases). There was need for the use of strollers and wheelchairs for 26 (70%) children, of which 19 (73%) obtained it free of charge from the public system. At the time of the interview, two children were still waiting to receive strollers and wheelchairs (Table 2).

The data related to assistance benefits for families and access to justice to meet the basic needs of children with CZS were obtained from the child's legal guardian in 34 (92%) of the 37 cases in the study population. The median age in months of the children at the time of the interview was 41.5 (IQR=39.2-48), ranging from 36 to 55 months.

Of the 34 families interviewed, 22 (65%) received the Continuous Cash Benefit (*Benefício de Prestação Continuada* - BPC) and 12 (55%) of these families took from one to six months to obtain the benefit; the other ten families (45%) took more than six months to obtain the BPC. Twelve families did not receive the BPC at the time of the interview, and the alleged reasons for not receiving it were: six interviewees did not administratively apply for the benefit with the National Institute of Social Security (*Instituto*

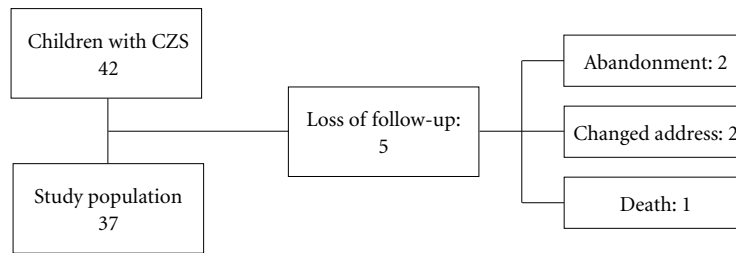


Figure 1. Study population selection flowchart.

Source: Authors.

Table 1. Sociodemographic characteristics of the families of children with congenital Zika syndrome.

Characteristics	N=37 (%)
Maternal age	
Median in years (IQR)	23 (20-32,5)
Urban slums	
Yes	19 (51)
No	17 (46)
Ignored	1 (3)
Family income (in minimum salaries)	
Up to 1	15 (41)
>1-2	14 (38)
≥3	5 (13)
Ignored	3 (8)
Main financial provider	
Paternal income	7 (19)
Maternal income	5 (13)
BPC and family income	11 (30)
BPC only	11 (30)
Ignored	3 (8)
Stopped working after childbirth	
Yes	20 (54)
No	4 (11)
Did not work before childbirth	10 (27)
Ignored	3 (8)
Main caregiver	
Mother	34 (92)
Father	2 (5)
Grandmother	1 (3)
Did the father abandon the family after the child was born?	
No	29 (78)
Yes	7 (19)
Ignored	1 (3)

Ignored: data not obtained because the mother no longer remembered or could not inform; IQR: interquartile range; BPC: Continuous Cash Benefit.

Source: Authors.

Table 2. Basic needs of children with congenital Zika syndrome.

Characteristics	N=37 (%)
Use of anticonvulsants	27 (73)
Acquisition of anticonvulsants (n=27)	
Family	22 (81)
Public system	1 (4)
Ignored	4 (15)
Use of special nutritional formulas	14 (38)
Acquisition of nutritional formulas (n=14)	
Family	11 (79)
Donation	3 (21)
Diapers and supplies	31 (84)
Acquisition of diapers and supplies (n=31)	
Family	31 (100)
Rehabilitation (physiotherapy, speech therapy and/or OT)	
Yes	33 (89)
No	1 (3)
Ignored	3 (8)
Rehabilitation start age in months ^a	
Median (IQR)	5 (3-6)
Range	1-36
Type of rehabilitation service (n= 33)	
Free	28 (85)
Private	5 (15)
Use of strollers and wheelchairs for locomotion	26 (70)
Form of acquisition of strollers and wheelchairs (n=26)	
Family	1 (4)
Public system	19 (73)
Donation	1 (4)
Still do not have it	2 (8)
Ignored	3 (11)

^aIn six cases, the age at which rehabilitation began was ignored. Ignored: data not obtained or not remembered or unable to be informed; OT: Occupational Therapy.

Source: Authors.

Nacional de Seguro Social - INSS), of which five considered that their children did not qualify as a person with a disability and one family had a higher income limit than the one established by law for the benefit. The other six families not receiving the BPC had applied for it and considered themselves within the legal requirements for the benefit, but they attributed not receiving it until the time of the interview to the slow granting process at the INSS and formalities such as administrative policies, pending issues related to medico-legal reports, and presentation of documents (Table 3).

Of the 34 interviewed families, eight (24%) received the assistance benefit of the *Bolsa Família* Program, four (12%) were exempted from drawing lots for families in Range 1 of the *Minha Casa Minha Vida* Program, and five (15%) had access to the social tariff for electricity. Twenty children (59%) had free public transport and four (12%) received free special municipal transport to go to the rehabilitation service (Table 3).

As for inclusive education, 15 (44%) children were enrolled in day care centers or schools, 12 (80%) of which in the public school system, with the median entry age in months being 30 months (IQR=14-36) (Table 3). Only three mothers reported being part of family support associations for children with CZS.

The BPC was the main reason that led families to file a lawsuit. Of the 34 interviewees, nine (27%) said they went to court to claim some rights. The median age of the child when the lawsuit was filed for the first time was 24 months (IQR=12-27), ranging from four to 36 months (Table 4). Of all characteristics of the study population evaluated regarding the variable access to justice, the only significant factor ($p=0.0165$) for filing a lawsuit was “whether the mother had stopped working after childbirth”. All nine mothers who went to court to obtain the basic needs of children with CZS belonged to the group of 20 mothers who had to leave their jobs to take care of their children.

Discussion

This study reports concentrated effects of the epidemic in precarious regions inhabited by groups marked by numerous persistent factors of inequality, such as inadequate access to basic sanitation and socioeconomic disparities in accessing social assistance, education, and health. This context situates the ZIKV epidemic as the

Table 3. Benefits received by families of children with congenital Zika syndrome.

Characteristics	N=34 (%)
Child's age at the time of the interview (in months)	
Median (IQR)	41,5 (39,2-48)
Range	36 - 55
BPC ^a	
Yes	22 (65)
No ^b	12 (35)
Time to obtain the BPC (n=22)	
1-6 months	12 (55)
7-12 months	7 (32)
>12 months	3 (13)
<i>Bolsa Família</i> Program	
Yes	8 (24)
No	26 (76)
<i>Minha Casa Minha Vida</i> Program	
Yes	4 (12)
No	30 (88)
Free public transport	
Yes	20 (59)
No	14 (41)
Special municipal transport for rehabilitation	
Yes	4 (12)
No	30 (88)
Social electricity tariff	
Yes	5 (15)
No	29 (85)
Inclusive education	
Yes	15 (44)
No	19 (56)
Age in months at the start of inclusive education (n=15)	
Median (IQR)	30 (14-36)
Range	6-41
Type of Inclusive Education (n=15)	
Public	12 (80)
Private	3 (20)

BPC: Continuous Cash Benefit; IQR: Interquartile range; ^aBPC and *Bolsa Família* Program: 25 families received both benefits.

^bSix asked, but had the benefit denied by the INSS; six never asked.

Source: Authors.

consequence of a historical process of the violation of fundamental rights, being another indicator of the social inequalities that persist in Brazil.

The association between poverty and CZS was also reported by Souza *et al.*¹⁴ in Recife-PE, with no microcephaly cases being reported in the

Table 4. Lawsuit filed for fulfilling basic needs of children with congenital Zika syndrome.

Characteristics ^a	N=34 (%)
Did you go to court to receive any rights?	
Yes	9 (27)
No	25 (73)
Child's age when the family went to court for the first time (n=9)	
Median in months (IQR)	24 (12-27)
Range	4-36
Main reason to go to court (n=9)	
BPC	6 (67)
Others ^b	3 (33)
Did you have access to any rights through a court decision? (n = 9)	
No	7 (78)
Yes	2 (22)

IQR: Interquartile range; ^aThree ignored; ^bOthers: diaper, nutritional supplement, medication, and surgery.

Source: Authors.

wealthier region of the city during the six months of the study. In contrast, 91.1% of the 347 notifications came from regions characterized as low-middle and low-income. In this study, the income of the affected families did not exceed two minimum salaries in 79% of the cases, and 51% of the interviewees reported living in urban slums characterized by the lack of basic sanitation and low supply of essential public services.

Working-age women left the labor market to devote themselves fully to caring for their severely handicapped children. Studies by the United Nations Development Program (UNDP)⁴ on the impact of the ZIKV epidemic on gender led to the assumption that the mother/caregiver will abandon (or never join) the formal workforce and will renounce an average of 35 years of salaries to care for their child.

Ten (27%) of respondents in this study were not working before pregnancy and continued not to work after pregnancy. Of the 24 working mothers, 83% did not return to the labor market after the birth of their children diagnosed with CZS, a percentage higher than that found in Alagoas by Ambrogi *et al.*¹⁰, who reported that 76% of women did not return to the paid work they performed before pregnancy.

These families that previously had the possibility of income from maternal work were sub-

jected to an unexpected expense called by scholars of the impact of diseases on the quality of life as “catastrophic expenditure on health”¹⁵. From this perspective, and considering the results of this research, the statement that “where there is disability, there is a potential increase in poverty” makes sense. A cruel dichotomy was created in which families already subjected to situations of social vulnerability saw, when affected by the ZIKV, that their income earning potential had drastically reduced due to the removal of one of their members from the labor market, and to the simultaneous and significant increase in expenses related to the health and well-being of children with disabilities.

In the analysis of the access to social rights of children with CZS, the lack of infrastructure and adapted transport planning were identified as serious obstacles, not only to social interaction and social integration, but also to the continuity of their medical treatment. Free public transport alone was not enough, constituting a group of individuals detached from a greater right: the right to urban mobility as a “right to the city,” health, and citizenship. Of the studied group, 59% of the children had free public transport; however, only 12% of the children managed to join municipal inclusive transport programs for the disabled, which represented, according to these assisted mothers, a “watershed” in the quality of life of the family group.

Data collected by the MH in 2016 indicated that of 2,865 newborns confirmed with CZS in Brazil, only 1,000 (34%) were assisted in early stimulation activities¹⁶. This percentage reflects a low rate of access to the Early Stimulation Guidelines established by the MH for children from zero to three years of age affected by CZS, a crucial period for child neuro-psychomotor development¹⁷. In the population studied, the panorama of access to rehabilitation therapy was more comprehensive, as 89% of the children were enrolled in adequate institutions, of which most in the public health system. However, despite the high percentage of children enrolled, 70% of respondents reported several barriers in conducting their children's rehabilitation. Considering that 75.7% of the children studied had severe neurological disorders, these barriers negatively influenced the effectiveness of the necessary actions to decrease neuro-psychomotor development sequelae.

Children assisted in this research were prescribed continuous-use medications that are essential for their treatment, especially anticon-

vulsants and special nutritional formulas, all included in the National List of Essential Medicines (*Relação Nacional de Medicamentos Essenciais* - RENAME)¹⁸ or in the Specific Component of Pharmaceutical Assistance (*Componente Específico de Assistência Farmacêutica* - CEAF)¹⁹. However, 81% of the children who used anticonvulsants had these medications paid by the family. Ambrogi *et al.*¹⁰ reported equally frustrating results, as only six of the 23 children with CZS in Alagoas received medication from the public health system.

According to Mendes *et al.*²⁰, enrolling children in day care centers and preschools brings benefits beyond encouraging development and social inclusion, by also generating a potential contribution to the reorganization of the life of these families. In this study, reports referring to inclusive education, in general, indicated that mothers had no major obstacles to enroll their children, since 44% were enrolled in educational institutions, of which 80% were public.

The BPC is a right guaranteed by the Brazilian Federal Constitution of 1988, regulated by the Social Welfare Organic Law (LOAS) (Federal Law No. 8,742/1993)²¹, in the amount of one minimum salary, intended for the elderly over 65 years of age and people with disabilities, provided that the family income, in both cases, is less than $\frac{1}{4}$ (one quarter) of the minimum wage (salary). In this study the BPC in the monthly amount of the current minimum salary was of significant importance for the survival of the family unit, given that 65% of the families received this benefit, which in 30% of the cases was their only source of income. The time between filing the request and receiving the BPC in 55% of the cases ranged from one to six months and in 45% of the cases was longer than six months. The longer these families were without this benefit, the more difficult it became to reorganize the family routine, since the costs to enable the development and social inclusion of children with CZS are high.

By way of comparison, in a public hearing held in the National Congress²², it was reported that in the state of Pernambuco, of the 425 children confirmed with CZS, 110 belonged to families not supported by the BPC. A study by Ambrogi *et al.*¹⁰ inland Alagoas also reported an adverse scenario, as 63% of families did not receive the BPC. This gap was justified by the authors by the excessive requirement of documents for medical and social service reports, or even by the lack of transport, seen in this research as an

insurmountable barrier to complying with the bureaucratic steps of procedural analysis for BPC access.

A study by Pereira *et al.*²³ about the incidence of microcephaly related to the ZIKV in Brazil and data of the BCP grants to children diagnosed with microcephaly showed that BPC grants increased eight times in 2016. However, this amount was less than 65% of the demand for incident cases. Considering the severe incapacitating injuries related to ZIKV infection during pregnancy, the authors highlight the importance of BPC for the reorganization of the routine of families in this condition.

The inability of the public health system to provide the necessary care and services at the right time and in the right place for those who need them has led to a multiplication of individual lawsuits seeking fundamental rights to health, calling on the Public Administration to operate in a field where it has been apathetically resting in passivity for years. Despite the phenomenon of legal intervention in public policies being assimilated as an attempt to equalize distorted access to comprehensive health²⁴, in this study, the approach followed another direction. More than identifying “how legal intervention took place”, it was necessary to understand “why” the population under analysis sought so little to bring to judicial scrutiny the repeated violations of their social rights.

During the interviews, only 27% of the interviewees claimed to have sought legal intervention to require some social right. None of these families were able to legally obtain access to medicines, treatments, diapers, nutritional formulas, and adapted transport. Only two interviewees managed to obtain a favorable decision in lawsuits, in two cases proposed by private lawyers, with the objective of receiving the BPC, which was administratively denied by the INSS.

In this study, the only significant factor for legal intervention as a means of enforcing social rights was “whether the mother had stopped working after the birth of the child in need of permanent care”, which allowed the following association to be established: all women who resorted to lawsuits to protect their rights did so as a result of the decreased family income for abandoning the labor market, since they lacked enough resources to support themselves and their children.

Barriers imposed by the level of education, income, difficulties arising from the full-time care of a disabled child, high level of stress and

anxiety for the caregiver, ommissive and inefficient social policies, and disbelief in the Judiciary system favor those who have the financial means and the knowledge necessary to instruct and file a lawsuit, excluding the less wealthy classes from the phenomenon of legal intervention, which are exactly the portion of the Brazilian population most affected by the ZIKV epidemic²⁴.

This study has some limitations, including the difficult data collection during the SARS-CoV-2 pandemic. During this period, circulation was restricted at the HUAP-UFF, thus, it was not possible to administer the research protocol to all mothers of the children assisted in the Zika Project. Another limitation is related to the sample

size and its geographic location. Thus, these findings cannot be generalized since the study does not intend to be nationally representative.

In this study, the families were at the intersection between the integral activity of caring for a child with severe disabilities and inefficient and ommissive public authorities, a context of disincensive and discouragement that made them give up seeking their rights.

Children exposed to an epidemic within their mothers' womb had to face a new and fiery health crisis early in their lives. For their families, the search for social protection with the government during the SARS-CoV-2 pandemic was a struggle not to be forgotten.

Collaborations

FA Oliveira: conceived the original idea, collected the data, analyzed the data and interpreted the results, wrote the paper. AM Silva: collected the data, analyzed the data and interpreted the results, wrote the paper. SS Hora: collected the data, analyzed the data and interpreted the results, wrote the paper. SA Oliveira: conceived the original idea, analyzed the data and interpreted the results, wrote the paper. AG Silva Junior: conceived the original idea, analyzed the data and interpreted the results, wrote the paper. CAA Cardoso: conceived the original idea, collected the data, analyzed the data and interpreted the results, wrote the paper, acquired resources.

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