Burden in caregivers of children with congenital Zika syndrome in Pernambuco, Brazil: Analysis and application of the Zarit burden interview scale

jeronimo faustino rego filho [Corresp., 1] , **Claudia Alves de Sena** [2] , **Rubens Wajnsztejn** [3]

1 CENTRO UNIVERSITÁRIO DA FACULDADE DE MEDICINA DO ABC PAULISTA, SÃO PAULO, BRAZIL

2 Universidade de Pernambuco, RECIFE, Brazil

3 CENTRO UNIVERSITARIO DA FACULDADE DE MEDICINA DO ABC PAULISTA, SÃO PAULO, BRAZIL

Corresponding Author: jeronimo faustino rego filho
Email address: jeronimofausto@yahoo.com.br

ABSTRACT With the increase in cases of microcephaly caused by the Zika virus, the demand for special care and a better quality of life for the child and caregiver increased proportionally.

Objective. This study aimed to analyze the burden on caregivers of children with congenital Zika syndrome associated with viral infections in the state of Pernambuco, Brazil using the Zarit burden interview scale.

Method. A quantitative study was conducted at the Oswaldo Cruz University Hospital, Recife City, State of Pernambuco, Brazil. By convenience sampling, 56 mothers, two grandmothers, and two caregivers were enrolled, all are female. Data were collected from July 2019 to January 2020. In the analysis, the percentage frequencies were calculated. The normality was identified using the Kolmogorov–Smirnov test, and participant profiles were compared using Student's t-test and analysis of variance. In descriptive statistics, quantitative variables are described by the median and interquartile range and categorical variables by proportions using the Chi-square test.

Results. In the comparative analysis, all factors evaluated were significant, except for the "gestational period in which the disease occurred" ($p < 0.111$). The significance of differences in all activities was evaluated. In the mean comparison test, only the factor "has a job" was significant ($p < 0.043$). When comparing the average of caregivers' responses to the categories of the Zarit burden interview scale, the highest level of burden was regarding the feeling that the child is dependent on the caregiver (3.62 points). Caregiver burden was classified as absence, light, moderate, and high.

Conclusion. The consequences of contracting the Zika virus in the first trimester of pregnancy, lack of paid work, financial scarcity, full-time dedication to the child, and lack of time for themselves increase the burden on caregivers. Thus, caregivers have mild-to-moderate burden.

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5   ***interview scale***

6   Jerônimo Faustino do Rego Filho[1], Claudia Alves de Sena[2], Rubens Wajnsztejn[3]

7   [1]Centro Universitário FMABC, Postgraduate Course in Health Sciences. Santo André, Sao

8   Paulo, Brazil.

9   [2]University of Pernambuco. Recife, PE, Brazil.

10   [3]Centro Universitário FMABC, Postgraduate Course in Health Sciences. Santo André, Sao

11   Paulo, Brazil.

12   **Responsible author**: Jeronimo Rego Filho. E-mail: jeronimofausto@yahoo.com.br

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56 lack of paid work, financial scarcity, full-time dedication to the child, and lack of time for

57 themselves increase the burden on caregivers. Thus, caregivers have mild-to-moderate burden.

58 **KEYWORDS**: Child; Microcephaly; Zika virus infection; Caregivers; Caregiver's burden.

59 **INTRODUCTION**

60 The Zika virus is a neurotropic stranded ribonucleic acid arbovirus of the genus

61 *Flavivirus*. It is found in rhesus macaques in the Zika Forest, Uganda, in 1947. *Flavivirus*

62 infection results in a rash infection of epidemiological importance because of its binding to

63 several types of neuronal cells, which may be associated with neurological changes in

64 newborns.[1,2] In 2016, the World Health Organization confirmed the causal association between

65 congenital microcephaly and the Zika virus, observing the development of congenital

66 neurological malformations associated with viral infection in pregnant women, highlighting the

67 congenital Zika syndrome. Since then, a public health emergency of international importance has

68 emerged.[2,3,4]

69 In March 2016, the Ministry of Health in Brazil created a surveillance protocol in

70 response to the increase in microcephaly cases in the country. From week 45 of 2015 to week 45

71 of 2020, 3,563 cases of the congenital Zika syndrome were confirmed in Brazil. Most cases were

72 concentrated in the Northeast region (61.9%). In Pernambuco, 13.1% were recorded in this

73 period, of which 78% affected infants, and 74 fetal deaths were confirmed, of which 45 occurred

74 in 2016. In 2021, Brazil recorded 5,710 probable cases of congenital Zika syndrome. The

75 Northeast region accounted for 4,252 cases, and Pernambuco added 610 cases to this total.[5,6]

76 Microcephaly is defined by the deformation of the skull size, inappropriate for age and

77 sex at birth. It is a complex and multifactorial etiological anomaly and was diagnosed by

78 measuring the head circumference 24 h after birth. In the first week of life, microcephaly is noted

79 when the head circumference is less than two or more standard deviations in relation to age, sex,

80 or gestational age. The World Health Organization adopted a head circumference of ≤31.5 cm

81 for girls and 31.9 cm for boys.[7,8]

82 Alterations in the circulatory, digestive, auditory, musculoskeletal, ocular systems and,

83 mainly, nervous systems are associated with the Zika virus, resulting in some motor and

84 cognitive alterations. The most common are intellectual deficit, brain paralysis, epileptic

85 seizures, autism, and attention-deficit hyperactivity disorder.[9,10]

86 With the increase in cases of microcephaly associated with the Zika virus, the demand for

87 special care and a better quality of life for the child–caregiver binomial increased proportionally.

88 Family members of children with microcephaly face considerable challenges such as reduced

89 income, marital and family breakdown, uncertainties about the child's progression, and the

90 opportunities they will have in the future.[4] Among the various concerns and difficulties faced by

91 caregivers, a relevant factor is that it is the child's accessibility, which, depending on the degree

92 of need, causes mental and physical burden to caregivers.[11]

93 In this sense, some scales and instruments measure the general burden of caregivers, such

94 as interviews and competency questionnaires. One of the most used in the assessment of

95   caregiver burden is the Zarit burden interview scale, which is a revision of the original version.

96   Consisted of 29 items covering aspects of psychological and physical health, economic

97   resources, work, social relationships and the relationship with the care receiver.

98   It is self-administered and allows assessing the objective and subjective burden of

99   informal caregivers, collecting information related to their health, social life, personal situation,

100   pecuniary, emotion, and relationship consisting of 22 items on a Likert scale. Each item is

101   scored quantitative/qualitative as follows: never = (0); rarely = (1); sometimes = (2); many times

102   = (3); always = (4). In the version used (0 to 4), an overall score ranging from 0 to 88 is

103   obtained. The higher the score, the greater the perceived overload. [12,13]

104   Society has changed in terms of the demographic, epidemiologic, and nutritional aspects

105   of the population. Consequently, there were demographic advances, urbanization processes, and

106   agglomerations, causing the emergence of several epidemics. Despite this, technological

107   advances in health have led to a reduction in infant mortality and survival of newborns with

108   congenital alterations. Thus, there is an increasing need for attention and care, reinforcing the

109   reorganization of health parameters to maintain the quality of life of children and their

110   caregivers.

111   Therefore, this study aimed to analyze the burden on the caregivers of children with

112   congenital Zika syndrome in the state of Pernambuco, Brazil, by analyzing the results of the

113   Zarit burden interview scale. Therefore, understanding the process from the emergence of the

114   virus to the care burden is important.

115   **MATERIALS AND METHODS**

116   This cross-sectional, exploratory-descriptive study with a quantitative approach was

117   conducted at the Oswaldo Cruz University Hospital, University of Pernambuco (HUOC/UPE),

118   located in Recife City, State of Pernambuco, Brazil. It is a reference institution in the care of

119   children with microcephaly caused by the Zika virus. The study population consisted of 60

120   caregivers of children with microcephaly caused by the Zika virus, including 56 mothers, two

121   grandmothers, and two caregivers.

122   As a selection criterion, caregivers of children diagnosed with microcephaly caused by

123   the Zika virus and treated at the aforementioned health center were included. Caregivers who

124   refused to participate in the study, even after signing the free and informed consent term,

125   caregivers who had been admitted to the unit for <6 months, and visually impaired caregivers

126 were excluded. Convenience sampling was used because only a small number of eligible patients

127 were identified. The study variables were sex, kinship with the child, age, marital status,

128 gestational period in which the signs and symptoms of the Zika virus disease occurred, family

129 income, profession, time spent caring for the child, time dedicated to the child, and activities

130 performed as a caregiver.

131 The instruments for data collection were a self-administered sociodemographic

132 questionnaire and the Zarit burden interview scale to analyze the burden of caregivers of children

133 with microcephaly. This care questionnaire was developed by a group of researchers headed by

134 Steven Zarit, a professor at the University of Pennsylvania, and it was translated and validated

135 for Brazil by Scazufa (2002).[13]

136 Data collection took place in the pre-appointment (waiting room). All caregivers who met

137 the inclusion criteria were invited to participate in the study. They received information about the

138 research content, in which all doubts were clarified, and they were assured of the confidentiality

139 of both their identities and data. Data were collected from July 2019 to January 2020.

140 For data analysis, a database was built in the electronic spreadsheet using Microsoft

141 Excel (which was exported to the SPSS Statistics version 18, SPSS Inc., Chicago, NY, USA).

142 To characterize the personal profile of caregivers and the practice of caring for children

143 with microcephaly, the percentage frequencies were calculated, and the respective frequency

144 distributions were constructed. The Chi-square test was used to compare the proportions of

145 categorical variables.

146 For the evaluation of the Zarit score items, the prevalence of caregivers' responses to the

147 questionnaire items was obtained. In addition, the total Zarit score was obtained for the burden of

148 caregivers of children with microcephaly. Score normality was assessed using the Kolmogorov–

149 Smirnov test. If the score showed a normal distribution, the caregivers' profile was compared

150 using the two-tailed Student's t-test for variables with two categories, and a one-way analysis of

151 variance test was used to analyze variables with three or more categories. Descriptive statistics

152 was also used, in which quantitative variables were described as median and interquartile range

153 and categorical variables as proportions using the Chi-square test to verify whether a relationship

154 exist between the care burden of caregivers.

155 Finally, care burden was classified; each item was scored 0 to 4 on the Likert scale: 0,

156 never; 1, rarely; 2, sometimes; 3, often; and 4, always. The sum of the scores was considered

157   absence (<21 points), light (21–40 points), moderate (41–60 points), and high (61–88 points)

158   burden. A significance level of 5% was considered.

159   The study was approved by the Ethics Committee for Research on Human Beings (CEP)

160   of the University Center of the Faculty of Medicine of ABC Paulista under Opinion No.

161   3,373,788 under CAAE: 13840419.6.0000.0082. All ethical and legal aspects were respected as

162   recommended by Resolutions 466/12 and 510/2016 of the National Health Council.

163   **RESULTS**

164   Table 1 shows the distribution of the sociodemographic profile of the caregivers of

165   children with microcephaly caused by the Zika virus. Of the total of 60 female caregivers

166   (100.0%), 93.4% were the mothers of the affected children. Of these mothers, 47% were between

167   31 and 40 years old, 65.0% were single, and 31.7% were in the first trimester of pregnancy when

168   they showed signs and symptoms of Zika disease. As regards income, 96.7% received 1

169   minimum wage (1 MW), and 98.3% do not have paid work. As shown in Table 1, the proportion

170   of all factors compared was significant ($p < 0.05$), indicating that the profile described is

171   common among the evaluated caregivers, except for the factor "gestational period that the

172   disease occurred" ($p < 0.111$), which indicates that the disease appears with similar prevalence in

173   the three gestational trimesters.

174   Table 2 shows the comparison of the mean and standard deviation of the Zarit score for

175   caregiver burden according to the sociodemographic profile. The mean burden score was higher

176   in caregivers who were related to the child (mean = 40.0), aged <20 years (mean = 49.0),

177   divorced (average = 40.5), diagnosed with the disease in the first trimester of pregnancy (mean =

178   37.1), eared 1 MW (average = 32.8), did not receive treatment (average = 33.6), and had paid

179   work (average = 59.0). In the mean comparison test, only the factor "has a job" was significant

180   ($p < 0.043$), indicating that having paid work outside the home, in addition to caring for the

181   child, significantly increases the burden score.

182   As shown in Table 3, all activities evaluated were significant ($p < 0.05$), indicating that

183   the number of caregivers who practice such activities to care for children with microcephaly is

184   statistically relevant.

185   Table 4 shows the distribution of responses in relation to the items of the Zarit burden

186   interview scale. The categories most denied by caregivers were as follows: feel stressed in taking

187   care of the child and their other responsibilities with the family and work (41.7%), feel ashamed

188   of the child's behavior (98.3%), feel irritated when the child is around (88.4%), feel that the child

189   negatively affects their relationships with other family members or friends (75.0%), feel tense

190   when the child is around (85.0%), feel that their health was affected because of their involvement

191   with the child (51.7%), feel that they do not have as much privacy as they would like because of

192   the child (48.3%), feel that their social life has been harmed due to having to take care of the

193   child (65.0%), does not feel comfortable having visitors at home because of the child (85.0%),

194   feel that they will be unable to take care of the child for much longer (76.6%), feel that he/she

195   has lost control of his/her life since the child's illness (68.4%), would simply like to let someone

196   else take care of the child (58.4%), feel in doubt about what to do for the child (53.4%), and feel

197   overwhelmed by caring for the child (46.7%).

198   Still, as shown in Table 5, most caregivers stated the following categories that occur

199   frequently: feel that the child asks for more help than he/she needs (41.7%); feel that because of

200   the time they spend with the child, they do not have enough time for themselves (43.4%); fear

201   for the child's future (38.3%); feel that the child depends on you (90.0%); feel that the child

202   expects you to take care of them as if you were the only person they can depend on (53.3%); feel

203   that they do not have enough money to take care of the child, in addition to their other expenses

204   (68.4%); feel that they should be doing more for the child (48.3%); and feel that they could take

205   better care of the child (36.7%).

206   Table 6 shows normality and data values using the Kolmogorov-Smirnov non parametric

207   test. Normal parameters: mean (32.8167), standard deviation (13.12197). More extreme

208   differences: absolute (.089), positive (.089), negative (-.086). Statistical test (.089) and bilateral

209   significance (.200).

210   The findings show that 71.7% of the caregivers have a mild level of burden, followed by

211   26.7% with a moderate burden and 1.6% with a severe burden, and the absence of burden was

212   0%.

213   **DISCUSSION AND CONCLUSION**

214   Of the 60 female caregivers, mothers (mean age, 31–40 years), single, were in the first

215   trimester of pregnancy when they showed signs and symptoms of congenital Zika syndrome.

216   Almost all the factors evaluated in the proportion comparison test were significant. However,

217   when comparing the mean and standard deviation of the Zarit score for caregiver burden,

218   according to the sociodemographic profile, only the factor "has a job" was significant (p <

219 0.043), indicating that having paid work outside the home, in addition to caring for the child,

220 significantly increases the burden score. The study showed that most caregivers have a mild level

221 of burden (71.7%), followed by those with a moderate level (26.7%).

222 In this study, all caregivers of children with microcephaly caused by the Zika virus were

223 women, with the predominance of mothers as caregivers. In this sense, mothers who care for a

224 child with a congenital malformation tended to be responsible for the integral care of the child.

225 In addition, she tends to adapt to the new reality and redirect her concepts and prejudices about

226 children with disability; a similar pattern was found in the studies by Delfino *et al.* and Nam *et*

227 *al.*[14,15] Arguably, full dedication can result in work burden, compromise their quality of life, and

228 cause or worsen health problems for caregivers.

229 Regarding sociodemographic data, most caregivers are single, which shows the constant

230 maternal presence in the care of the child. Dedication to the child with special needs, often

231 without the help of the child's father, can cause excessive tiredness, exhaustion, and frustration

232 for caregiver-mothers. The absence of a partner in doing care activities and concerns about the

233 health of the child with microcephaly reverberate in mothers through the lack of time for their

234 personal care. Corroborating the results of Pinto *et al.*,[16] the data show that divorced caregivers

235 had a higher level of burden.

236 As caregivers were not employed, possibly due to the need to provide comprehensive

237 care to the child, the family income is low. By compromising relationships between family

238 members, low family income can demonstrate the urgency of creating measures, strategies, and

239 public policies that can support such families in a state of physical and emotional vulnerability.

240 Therefore, the results of the present study strengthen the findings of Feliz *et al. a*nd Padilha *et*

241 *al.*[17,18] who discussed the importance of the social security law and public access to the health

242 system for children. The recognition of the child with microcephaly as a disability, according to

243 Ordinance No. 58 of June 3, 2016, presents the need to assist these families. Caregivers receive

244 regular benefit that helps them with the expenses of the children.[19]

245 Children with microcephaly demand time and full attention from caregivers, increasing

246 the workload. These children have high-risk levels because of alterations in the

247 neuropsychomotor development, such as prematurity and abnormal growth of the head

248 circumference. If there is abnormal neurogenesis, synaptogenesis, or neuronal migration in the

249 first and second trimesters of pregnancy, brain growth and development are hindered, and

250   congenital infections, neurological changes, cerebral palsy, attention-deficit hyperactivity

251   disorder, behavioral disorders, and vision, hearing, motor coordination, and learning problems

252   occur. These conditions can even interfere with the actual care delivery. The finding corroborates

253   those of Pires *et al.*, Ferreira *et al.*, and Sa *et al.*[20,21,22,23]

254   The light burden (71.7%) identified in caregivers appears to be related to marital status,

255   age, and degree of kinship with the child. As regards the degree of limitations, motor, cognitive,

256   visual, and auditory alterations make it difficult for caregivers to provide care, as children

257   progressively become more dependent. This finding is similar to that found by Ribeiro *et al.*[24] on

258   microcephaly caused by the Zika virus, as it causes serious damage and changes in neurological

259   development, with a high potential for overloading caregivers. Torquato and Moore *et al*.

260   reported similar results.[7,25]

261   As for the division of tasks, in which spouses or other family members share concerns

262   and tasks, there are fewer risks to the physical and mental health of those who play the role of the

263   primary caregiver. These data were verified by Reis *et al*.[26] The vast majority of caregivers

264   directly perform all the daily tasks of the child, such as bathing, feeding, transporting, etc. This

265   reinforces children's dependence and caregivers' burden.

266   As the study limitations, this is a descriptive study; thus, more in-depth conclusions

267   regarding the burden of caregivers of children with microcephaly caused by the Zika virus as

268   well as other issues such as the correlation of some variables cannot be inferred. The use of

269   convenience sampling and closed questions of the instrument did not allow considerations from

270   the caregivers' point of view in relation to the care burden of the Zarit burden interview scale. A

271   qualitative study could provide better answers to these questions.

272   Therefore, a multicenter study is recommended to obtain a greater number of participants

273   and deepen the data. Since the research was carried out in a single care service for patients with

274   congenital microcephaly syndrome caused by the zika virus. Therefore, the generalized results of

275   caregivers being all female participants, mostly single, unemployed, do not represent the entire

276   population of caregivers in Pernambuco, Brazil. Thus, institutional support, an adequate place for

277   consultations and procedures, proper disclosure, and promotion of scientific research on the

278   subject are essential. Government investments in public policies and the psychosocial well-being

279   of caregivers are also important, allowing for development in caring not only for the child but

280   also for the caregiver.

281   Microcephaly is a disabling chronic condition; therefore, health professionals and
282   managers should understand the real care requirement of a family member with this condition
283   and the consequences in the life of the caregiver. This can improve caregivers' quality of life,
284   reflecting better care for children with microcephaly.

285   The absence of primary care programs for caregivers promotes factors that generate
286   burden. Investing in prevention support can promote the quality of life of caregivers and
287   children, minimizing the burden of care.

288   This study presents relevant points because it used a standardized and validated
289   instrument in Brazil and has already been applied in studies that portray the importance of
290   caregiver satisfaction and quality. Furthermore, these findings could be a good indicator of the
291   health of caregivers of children with microcephaly caused by the Zika virus and may contribute
292   to the planning of public actions aimed at this population.

293   The proportion comparison test showed that microcephaly appears with similar
294   prevalence in the three gestational trimesters. When genetic deformations occur more frequently
295   during pregnancy, caring for a child with a neurological disability can generate weariness, as it
296   makes tasks increasingly difficult to perform because of time constraints. The mean comparison
297   test was significant only for the factor "has a job," indicating that having paid work outside the
298   home significantly increases the burden level, in addition to the exhaustive care for the child,
299   lack of family support, other house chores, lack of infrastructures, and poor financial condition.

300   When comparing the average of caregivers' answers to the items on the Zarit burden
301   interview scale, caregivers reported a higher burden level on these items: feel that the child is
302   dependent on you, feel that he/she does not have enough money to take care of the child in
303   addition to other expenses, and feel that spending time with the child reduces the time for
304   oneself.

305   Microcephaly is a disabling chronic condition; thus, health professionals and managers
306   should understand the real care requirement of a family member with this condition, considering
307   its consequences on the life of the caregiver. This can improve caregivers' quality of life,
308   reflecting better care for children with microcephaly.

309   Contracting the Zika virus in the first trimester of pregnancy, resulting in the
310   impossibility of having paid work outside the home, not having enough money for expenses,
311   total dependence on child care, and lack of time for personal care are factors that increase the

312 care burden on caregivers. Overall, the survey score of the participants was classified as light

313 burden.

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Table 1. Distribution of the sociodemographic profile of caregivers of children with microcephaly. Recife, PE, Brazil, 2021 (n = 60)

Note: [1]p-value of the Chi-square test for the proportion comparison. * Current minimum wage

= BRL 1,212.00, Brazil, 2022

1 **Table 1. Distribution of the sociodemographic profile of caregivers of children with**

2 **microcephaly. Recife, PE, Brazil, 2021 (n = 60)**

Evaluated factor	n	%	p-value[1]
Sex			
Female	60	100.00	0
Kinship			
Mother	56	93.4	
Grandmother	2	3.3	< 0.001
Caregiver	2	3.3	
Age			
< 20 years	1	1.0	
21–30 years	25	42.0	< 0.001
31–40 years	28	47.0	
>41 years	6	10.0	
Marital status			
Married	19	31.7	
Single	39	65.0	< 0.001
Divorced	2	3.3	
Gestational period in which the disease occurred			
1st trimester	19	31.7	
2nd trimester	15	25.0	< 0.111
3rd trimester	7	11.6	
No information	19	31.7	
Family Income			
1 Minimum wage*	58	96.7	
2 Minimum wage*	2	3.3	< 0.001
Paid employment			
Yes	1	1.7	
No	59	98.3	< 0.001

3 Note: [1]p-value of the Chi-square test for the proportion comparison. * Current minimum wage =

4 BRL 1,212.00, Brazil, 2022

Table 2. Mean and standard deviation of the Zarit score for caregiver burden according to the personal profile. Recife, PE, Brazil, 2021 (n = 60)

Note: ¥ standard deviation. ¹p-value of the ANOVA test. ²p-value of Student's t-test. * Current minimum wage = BRL 1,212.00, Brazil, 2022.

1   **Table 2. Mean and standard deviation of the Zarit score for caregiver burden according to**

2   **the personal profile. Recife, PE, Brazil, 2021 (n = 60)**

Evaluated factor	Overload level		p-value
	Average	DP[¥]	
Kinship			
Mother	33.2	13.0	
Grandmother	15.5	2.1	0.127[1]
Caregiver	40.0	11.3	
Age			
<20 years	49.0	0	0.332[1]
21–30 years	29.8	12.4	
31–40 years	34.2	12.4	0.332[1]
>41 years	35.8	18.6	
Marital status			
Married	31.9	15.2	
Single	32.9	12.4	0.684[1]
Divorced	40.5	7.8	
Gestational period in which the disease occurred			
1st trimester	37.1	15.3	
2nd trimester	36.5	12.3	0.085[1]
3rd trimester	27.0	8.2	
No information	28.5	11.0	
Family income			
1 Minimum Wage*	32.8	13.2	0.930[2]
2 Minimum Wage*	32.0	17.0	
Health treatment			
Yes	30.0	11.3	0.386[2]
No	33.6	13.6	
Paid employment			
Yes	59.0	0	0.043[2]
No	32.4	12.8	

3   Note: ¥ standard deviation. ¹p-value of the ANOVA test. ²p-value of Student's t-test. * Current

4   minimum wage = BRL 1,212.00, Brazil, 2022.

Table 3. Distribution of Activities Performed by Caregivers of Children with Microcephaly. Recife, PE, Brazil, 2021. (n=60)

[1]p-value of the Chi-square test for proportion comparison

1   **Table 3. Distribution of activities performed by caregivers of children with microcephaly.**

2   **Recife, PE, Brazil, 2021 (n = 60)**

Analyzed activities	Perform the activity		*p-value[1]
	Yes	No	
Alimentation	56 (93.3%)	4 (6.7%)	<0.001
Medication	55 (91.7%)	5 (8.3%)	<0.001
Shower	56 (93.3%)	4 (6.7%)	<0.001
Clothing	56 (93.3%)	4 (6.7%)	<0.001
Transportation	56 (93.3%)	4 (6.7%)	<0.001

[1]p-value of the Chi-square test for the proportion comparison

Table 4. Distribution of the responses to the items of the Zarit burden interview scale, category that never occurs. Recife, PE, Brazil, 2021 (n = 60)

1 **Table 4. Distribution of the responses to the items of the Zarit burden interview scale,**
2 **category that never occurs. Recife, PE, Brazil, 2021 (n = 60)**

Zarit scale	Never	Rarely	A few times	Often	Always	Average
1. Stressed about taking care of the child?	25 41.7%	7 11.7%	14 23.3	3 5.0%	11 18.3%	1.47
2. Embarrassed by the child's behavior?	59 98.3%	0 0.0%	1 1.7%	0 0.0%	0 0.0%	0.03
3. Angry when the child is around?	53 88.4%	1 1.7%	2 3.3%	2 3.3%	2 3.3%	0.32
4. Does the child negatively affect your relationships?	45 75.0%	4 6.7%	5 8.3%	0 0.0%	6 10.0%	0.63
5. Are you tense when the child is around?	51 85.0%	1 1,7%	6 10.0%	0 0.0%	2 3.3%	0.35
6. Has your health been affected because of the child?	31 51.7%	7 11.7%	10 16.6%	1 1.7%	11 18.3%	1.23
7. Don't have as much privacy as you would like?	29 48.3%	7 11.7%	11 18.3%	3 5.0%	10 16.7%	1.30
8. Has your social life been affected?	39 65.0%	4 6.6%	7 11.7%	3 5.0%	7 11.7%	0.92
9. Don't feel comfortable having visitors?	51 85.0%	1 1.7%	2 3.3%	2 3.3%	4 6.7%	0.45
10. Will you be unable to care for the much longer?	46 76.8%	4 6.6%	4 6.6%	5 8.3%	1 1.7%	0.52
11. Have you lost control of your life?	41 68.4%	3 5.0%	8 13.3%	3 5.0%	5 8.3%	0.80
12. Would you like to simply let someone else take care?	35 58.4%	2 3.3%	9 15.0%	5 8.3%	9 15.0%	1.18
13. Do you feel in doubt about what to do?	32 53.4%	3 5%	17 28.3%	3 5.0%	5 8.3%	1.10
14. Do you feel like you should be doing more?	16 26.7%	4 6.7%	8 13.3%	3 5.0%	29 48.3%	2.42

15. You feel overwhelmed?	28	3	6		7	16	
	46.7%	5.0%	10.0%		11.0%	26.6%	1.67

Table 5. Distribution of responses to the items of the Zarit burden interview scale, a category that always occurs frequently. Recife, PE, Brazil, 2021 (n = 60)

1   **Table 5. Distribution of responses to the items of the Zarit burden interview scale, a**

2   **category that always occurs frequently. Recife, PE, Brazil, 2021 (n = 60)**

Zarit scale	Never	Rarely	A few times	Often	Often	Average
1. Does the child ask for more help than he or she needs?	19 31.7%	3 5.0%	8 13.3%	5 8.3%	25 41.7%	2.23
2. Because of the time you spend with the child, don't you have enough time for yourself?	9 15.0%	3 5.0%	14 23.3%	8 13.3%	26 43.4%	2.65
3. Fear for the child's future?	16 26.7%	3 5.0%	16 26.7%	2 3.3%	23 38.4%	2.22
4. Does the child depend on you?	5 8.3%	1 1.7%	0 0.0%	0 0.0%	54 90.0%	3.62
5. Does the child expect you to take care of him/her as if you were the only person he/she can depend on?	13 21.7%	6 10.0%	6 10.0%	3 5.0%	32 53.3%	2.58
6. Don't have enough money to take care of the child in addition to your other expenses?	8 13.3%	3 5.0%	5 8.3%	3 5.0%	41 68.4%	3.10
7. Do you feel that you could take better care of the child?	21 35.5%	5 8.3%	7 11.7%	5 8.3%	22 36.7%	2.03

Table 6. Normality of the Zarit scale score results using the Kolmogov-Smirnov test. Recife, PE, Brazil, 2021. (n=60)

a. The test distribution is normal. b. Calculated from the data. c. Liliefors meaning correction.

d. This is a lower bound of true significance.

1 **Table 6. Normality of the Zarit scale score results using the Kolmogov-Smirnov test. Recife, PE, Brazil,**

2 **2021. (n=60)**

3 **NPAR TESTS**

4 **/K-S(NORMAL)=SUM_ZARIT**

5 **/MISSING ANALAYSIS.**

6 **TEST OF A SAMPLE OF Kolmogorov-Smirnov**

		SUM DE ZARIT
N		60
Normal parameters [a,b]	Mean	32,8167
	Standard deviation	13,12197
More extreme differences	Absolute	,089
	Positive	,089
	Negative	-,086
Test statistic		,089
significance sig. bilateral		,200 [c,d]

7 **a.**   The test distribution is normal.

8 b.   Calculated from the data.

9 c.   Correction of significance of Liliiefors.

10 d.   This is a lower bound of true significance.