

Burden of caregivers of children and adolescents with Down Syndrome

Alina Lúcia Oliveira Barros ¹

Amanda Oliveira Barros ²

Geni Leda de Medeiros Barros ³

Maria Teresa Botti Rodrigues Santos ³

Abstract *The aim of this study was to evaluate the profile and burden of caregivers of children/adolescents with and without Down syndrome. The evaluations were performed through questionnaires about the profile and burden of the caregivers (Zarit Burden Interview) and the profile of the children/adolescents. These questionnaires were applied to 168 caregivers. The chi-square test, Fisher's exact test, and analysis of variance were used with a significance level set at $\alpha = 5\%$. Both groups were composed of 84 participants, and the caregivers of the disabled group had a significantly higher percentage of females ($p = 0.001$), those in the 41-60 age group ($p < 0.001$), those who had no occupation ($p < 0.001$), those with a low per capita income ($p < 0.001$), those with a low level of schooling ($p = 0.021$), those who were Catholic in religion ($p = 0.001$), those who had more health problems ($p < 0.001$), those who continued the use of medication ($p < 0.001$), and those with a moderate level of burden ($p < 0.001$). The children/adolescents with disabilities needed significantly more help for eating ($p = 0.051$), bathing ($p = 0.006$), dressing ($p = 0.042$), sphincter control ($p = 0.027$), and intimate hygiene ($p < 0.001$). The caregivers of children/adolescents with Down syndrome presented a moderate burden compared to the caregivers of normoreactive children/adolescents.*

Key words Caregiver burden, Down syndrome, Caregivers

¹ Unidade de Diagnóstico Oral e Odontológico para Pacientes Especiais, Universidade Federal de Sergipe. R. Cláudio Batista - lado par, Santo Antônio. 49060-102 Aracaju SE Brasil. alina.barros@terra.com.br

² Universidade Tiradentes. Aracaju SE Brasil.

³ Programa de Pós-Graduação em Odontologia, Universidade Cruzeiro do Sul. São Paulo SP Brasil.

Introduction

Down syndrome (DS) is the most frequent chromosomal disorder resulting from chromosome 21¹ trisomy, with an estimated incidence of 1/600 to 1/1000 live births worldwide², with a higher risk for advanced maternal age³. Recent Brazilian data indicate that on average, for every 600 to 800 births, a child with DS is born, regardless of ethnicity, gender, or social class⁴. The presence of intellectual disability occurs with varying degrees in these individuals⁵.

The demand of the family of children with DS is significantly higher because the family must actively participate in the care of the child due to the delay in development, the limitations in activities of daily living related to self-care such as dressing, personal hygiene, walking, and talking⁶, and aspects related to health, education, and leisure⁷.

The presence of chronic diseases such as congenital heart defects⁸, hypothyroidism, and immunological disorders⁹ can influence the multiple aspects of the life of caregivers of children with DS, leading to fatigue, isolation, burden, and stress¹⁰.

The burden results from a disturbance in addressing the individual's physical dependence and intellectual disability, the focus of attention and care. Objective aspects of caregiving burden include routine changes, decreased social and professional life, financial loss, overwork, and the supervision of problematic behaviours of the individual being cared for. The subjective aspects of this burden are related to the caregiver's perception, expectations, and positive and negative thoughts¹¹. Symptoms of anxiety and depression are reported by caregivers of individuals with intellectual disabilities¹².

The primary caregiver is the main person with total or greater responsibility in the care provided to the person being cared for, and no monetary compensation is given for the care provided¹³.

Within the family nucleus, mothers are particularly vulnerable because they take on the role of primary caregiver in most families. They present emotional, physical, and financial burden as well as restrictions on social and leisure activities¹⁴.

Based on the data collected, the need to assess the burden of primary caregivers of children/adolescents with DS is evident because they are mostly dependent and can generate significant changes in the life dynamics of their caregivers.

After a systematic search in the published literature, no study combining and permuting the terms Down syndrome and Zarit Burden Interview was found. In view of the above, the objective of this study was to evaluate the profile and the level of burden of primary caregivers of children and adolescents with DS.

Methodology

This study was submitted and approved by the ethics committee for research involving human beings at Cruzeiro do Sul University (Universidade Cruzeiro do Sul), following the norms of resolution 466/12 of the National Health Council and obtaining formal consent from the board of the University Hospital (Hospital Universitário - HU) of the Federal University of Sergipe (Universidade Federal de Sergipe - UFS).

This was a descriptive exploratory study, with a cross-sectional design and a quantitative approach.

The convenience sample consisted of 84 primary caregivers of children and adolescents with DS aged 0 to 21 years (study group), assisted in the Special-Needs Patient Dentistry Unit (Unidade de Odontologia para Pacientes Especiais) linked to the HU of the UFS, located in Aracaju and considered a reference in the state of Sergipe (SE) for outpatient and hospital dental care for people with disabilities in the Unified Health System (Sistema Único de Saúde - SUS).

To compare the results obtained from the study group, a control group was composed of 84 caregivers of children/adolescents without disabilities from 0 to 21 years old, matched by the sex and age of the children from the study group, followed up in the Department of Dentistry of UFS, located in the HU, who were of the same socioeconomic class.

The inclusion criteria were being a primary caregiver of children and adolescents with DS aged between 0 and 21 years old who provided care during most of the day for a period of at least six months, who were not paid to perform such activities, and who were at least 18 years old. Caregivers who refused to participate, complete, and sign the Informed Consent Form (Termo de Consentimento Livre e Esclarecido - TCLE) and who presented difficulties in understanding the research questionnaires were excluded from the study.

The data were individually collected from each caregiver in the form of an interview by the

researcher, conducted from January to July 2015, in which the objectives and ethical and legal procedures were explained and the voluntary signature of the TCLE was obtained. Questionnaires were used to characterize the profile of the caregivers (gender, age, marital status, employment, per capita income, kinship and schooling, religion, religious group, health problems, continuous use of medication) and of the children and adolescents (sex, age, whether attended school, medical diagnosis, social benefit, and care of caregivers for activities of daily living). The Zarit Burden Interview (ZBI) burden scale was also applied to the caregiver.

The ZBI burden scale has been translated and adapted into Portuguese. It is composed of 22 items that evaluate how care activities have an impact on the physical and emotional health, psychological wellbeing, social life, and financial situation of the caregiver. Each item is scored from 0 to 4 (Likert scale), where 0 = never, 1 = rarely, 2 = sometimes, 3 = often, and 4 = always. The exception is the last item, in which the respondent is asked if he or she is feeling overwhelmed by performing the caregiver role: 0 = not at all, 1 = slightly, 2 = moderately, 3 = very, and 4 = extremely¹⁵.

Finally, the items are summed, and the total scale score can vary from 0 to 88; the higher the score is, the greater the perception of the caregiver's burden. The scores are interpreted as follows: 0-20 points (absence or low burden), 21-40 points (moderate burden), 41-60 points (moderate to severe burden), and 61-88 (severe burden)¹⁵.

The data obtained were tabulated in a spreadsheet using the program Microsoft Office Excel, version 2010, for database construction. For statistical analysis, the data were transposed to the program R version 3.2.5¹⁶.

Descriptive statistics was used to analyse and describe the data on the profile of the caregivers and children/adolescents, using absolute and relative frequencies, and the ZBI burden scale, calculating position measurements (minimum, maximum, mean, and median) and dispersion (standard deviation).

The chi-square test and Fisher's exact association test were used for proportionality to verify significant differences between the distributions of the variable in question, according to the groups studied.

The parametric analysis of variance (ANOVA) statistical test was applied to test the equality of means of burden among the studied groups.

For all hypothesis tests, the level of significance adopted was 5% ($p < 0.05$).

Results

A total of 178 caregivers were interviewed. From this initial quantity, four caregivers who had difficulties understanding the questionnaires, two who refused to participate, and four who did not meet the eligibility criteria for inclusion in the study were excluded. Thus, the final sample consisted of 168 child/adolescent caregivers, 84 representing the study group (with disability) and 84 representing the control group (without disability).

The results on the profile of caregivers of children/adolescents with/without DS are shown in Tables 1 and 2.

The study group presented a significantly higher percentage ($p = 0.001$) of female caregivers, those in the age range of 41-60 years ($p < 0.001$), those who had no occupation ($p < 0.001$), and those with a low per capita income ($p < 0.001$).

The Fisher's exact association test showed a significantly larger association ($p < 0.001$) for mothers as the primary caregiver for both groups, although fathers, grandmothers, sisters, and aunts were cited.

Considering the level of schooling, the caregivers of children/adolescents with DS differed significantly ($p = 0.021$), with caregivers in the non-disabled group presenting a higher level of education for complete higher education (16.7%) than those in the DS group (2.4%).

Most of the caregivers of both groups had a religious belief, with Catholic being significant ($p = 0.001$) for the group of caregivers of individuals with DS (57.1%). In addition, the group of caregivers of individuals with DS had significantly higher percentages of health problems ($p < 0.001$) and medication use ($p < 0.001$).

Regarding the profile of the children and adolescents who participated in the study, homogeneity for the sex and age variables ($p = 1$) can be observed because they were paired. They were composed of 42 (50%) female children and adolescents. Regarding the age of the children and adolescents, 28 (33.3%) participants were included in each of the three age groups: early childhood (1-4 years old), childhood (5-10 years old), and adolescence (11-21 years old).

The non-disabled group had significantly higher percentages (98.8%) ($p < 0.001$) of par-

Table 1. Distribution of caregivers according to the variables of gender, age, marital status, labour occupation, and per capita income. Aracaju/SE, 2016.

Variables	Groups of caregivers		p value
	Down Syndrome N = 84	Without Disability N = 84	
Gender			
Female	84 (100%)	74 (88.1%)	0.001
Male	0 (0%)	10 (11.9%)	
Age			
15-20 years	0 (0%)	5 (6%)	< 0.001
21-40 years	26 (31%)	56 (66.7%)	
41-60 years	53 (63.1%)	22 (26.2%)	
Over 60 years	5 (6%)	1 (1.2%)	
Marital status			
Single	16 (19%)	12 (14.3%)	0.152
Married/Stable relationship	45 (53.6%)	59 (70.2%)	
Divorced	15 (17.9%)	9 (10.7%)	
Widower	8 (9.5%)	4 (4.8%)	
Labor occupation			
Does not work outside the home	67 (79.8%)	22 (26.2%)	< 0.001
Works part-time	15 (17.9%)	16 (19%)	
Works full-time	2 (2.4%)	46 (54.8%)	
Per capita income			
Less than 1 minimum wage	77 (91.7%)	44 (52.4%)	< 0.001*
1 minimum wage	2 (2.4%)	15 (17.9%)	
1 and a half minimum wages	5 (6%)	16 (19%)	
2 minimum wages	0 (0%)	2 (2.4%)	
2 and a half minimum wages	0 (0%)	7 (8.3%)	
Values of significance (p < 0.05)	Chi-square test	Fisher's exact test*	

Table 2. Distribution of caregivers according to the variables of religion, religious group, health problem, and use of continuous medication. Aracaju/SE, 2016.

Variables	Groups of caregivers		p value
	Down Syndrome N = 84	Without Disability N = 84	
Religion			
Yes	69 (82.1%)	64 (76.2%)	0.342
No	15 (17.9%)	20 (23.8%)	
Religious group			
Catholic	48 (57.1%)	24 (28.6%)	< 0.001*
Evangelical	19 (22.6%)	33 (39.3%)	
Spiritist	2 (2.4%)	7 (8.3%)	
Health problema			
Yes	53 (63.1%)	14 (17.9%)	< 0.001
No	31 (36.9%)	69 (82.1%)	
Continuous use medication			
Yes	48 (57.1%)	16 (19%)	< 0.001
No	36 (42.9%)	68 (81%)	
Values of significance (p < 0.05)	Chi-square test	Fisher's exact test*	

ticipants attending school, whereas the DS group had significantly higher percentages ($p < 0.001$) of the Continuous Care Benefit (Benefício de Prestação Continuada - BPC).

Considering the responses regarding the autonomy of children/adolescents with/without disabilities in activities of daily living, the groups differed significantly in their abilities with regard to feeding ($p = 0.051$), bathing ($p = 0.006$), getting dressed ($p = 0.042$), sphincter control ($p = 0.027$), and intimate hygiene ($p < 0.001$); the walking capacity variable was an exception, ($p = 0.254$), with the study group being more dependent on caregivers.

Regarding the assessment of the caregivers' burden by the ZBI scale, we present Table 3.

Regarding the classification of the burden, it was observed that all caregivers presented some level of burden, and the absence of or low burden was predominant in caregivers of children/adolescents without disabilities (89.2%), with a prevalence of moderate burden for the study group, with a percentage of 72.6% and with significance between groups (Table 3, $p < 0.001$).

After the comparison of the global burden responses between caregivers of children and adolescents, no significant association between them was observed ($p = 0.5986$), showing a similar level of burden between the groups of caregivers of children and adolescents.

In the present study, we also evaluated the frequency with which the values of higher and lower burden occurred. A single category was formed by adding the frequency of the responses of "Never", "Rarely", and "Sometimes" and by adding the responses of "Frequently" and "Always". Thus, the greater the frequency of "Frequently/Always" responses, the greater the burden presented for each of these questions.

Interpreting the frequency at which the highest burden values occurred, the highest prevalence of "Frequently" and "Always" answers for both groups was in questions 7, 8, 14, and 15. These questions are related to fears of what may occur in the future with the child/adolescent under their care, the dependence of the child/adolescent, and financial aspects (not having enough money for care), considering that the study group had the highest percentage of responses.

Analysing the responses with the lowest burden, i.e., "Never" and "Rarely", questions 4, 5, and 9, which were related to being ashamed of the child's/adolescent's behaviour, irritation when she/he was close by, and embarrassment, were similar in both groups.

The answers regarding questions 6, 10, 17, and 18 of the caregivers of the control group contributed to the lower burden of these aspects.

Table 4 shows the results of the descriptive analysis of the caregivers' burden according to the study groups, using summary measures with the presentation of the means, medians, standard deviations, and maximum and minimum values.

The ZBI burden scale score for the study group ranged from 9 to 61, with a mean of 34.58 ($SD = 9.11$) and a median of 33.50, whereas in the control group, there was a minimum score ranging from 0 to 33, with a mean of 15.13 ($SD = 7.28$) and a median of 17, which indicates that the caregivers of DS children/adolescents, on average, were more burdened than those of the non-disabled group.

The parametric ANOVA statistical test was applied to compare the means of burden of the caregivers, aiming to test the null hypothesis that the means of the ZBI burden scale would be equal between the groups. The results showed that the means are different ($p < 0.001$), indicating a significantly higher burden for the experimental group (Table 4).

Table 3. Classification of the levels of burden of the caregivers according to the Zarit scale. Aracaju/SE, 2016.

Score	Burden Level	Groups of caregivers		
		Down Syndrome N=84	Without Disability N=84	Total
0-20	Absence or low burden	5 (5.9%)	75 (89.2%)	80 (47.6%)
21-40	Moderate burden	61 (72.6%)	9 (10.7%)	70 (41.7%)
41-60	Moderate to severe burden	17 (20.2%)	0 (0%)	17 (10.1%)
61-88	Severe burden	1 (1.1%)	0 (0%)	1 (0.6%)
Total		84 (100%)	84 (100%)	168 (100%)

Fisher's exact test = 135.838 p 0.001

Table 4. Descriptive statistics and comparison of the means according to the groups studied. Aracaju/SE, 2016

Caregiver groups	Minimum	Average	Median	Maximum	Standard deviation
Down Syndrome	9	34.58	33.50	61	9.11
Without Disability	0	15.13	17	33	7.28
Total	0	24.86	22	61	12.76

ANOVA model for means of the Zarit scale according to groups with significance ($F = 233.8, p < 0.001$)

Discussion

Based on current knowledge, this is an unpublished study that evaluates how the activities of caring for children/adolescents with DS impact the physical, emotional, psychological, social, and financial condition of their caregivers, who were residents of the city of Aracaju-SE.

Only two studies have addressed the burden of caregivers in individuals with DS. Maenner et al.¹⁷ developed the Waisman Activities of Daily Living (W-ADL) Scale, which measures the limitations in the activities of daily living in adolescents and adults with developmental disabilities, completed by caregivers. The second study evaluated the possible predictors of psychological morbidity in parents of children with intellectual disability, in which depression and anxiety were the main symptoms¹⁸.

These results require proposals to support these caregivers because the health and wellbeing of children/adolescents with DS highly rely on their caregivers.

The female figure was predominant among the caregivers evaluated in this study, corroborating the literature¹⁹, emphasizing the historical and cultural tradition of the woman in taking the main responsibility for care, indicating that it does not depend on the condition of the person receiving care or the degree of caregiver kinship. This gender division among caregivers seems to be supported by the experience of motherhood, thus determining that women would be assigned to address the care activities taught to women within the family through generations²⁰. This fact contributes to women continuing to be viewed as care providers, and it can have consequences due to the accumulation of responsibilities²¹, particularly for those who are more fragile and dependent²².

Despite the changes that have occurred in the contemporary family, the difference in roles between men and women continues to be a reality, particularly in the case of families with lower

purchasing power²³. It is difficult for a man to take responsibility for direct care, and they generally participate in care in a secondary manner, through family support or in external tasks, such as transportation of the person in need of differentiated care²⁴.

Considering the age of the caregivers of the study group, it is worth noting a predominance of the 41-60 years old age group, which makes it possible to relate this study to studies in the literature that refer to the most advanced maternal age as a factor that favours the occurrence of chromosome 21 trisomy³.

Regarding marital status, it was observed that most caregivers had stable relationships, similar to the findings demonstrated in studies by Caicedo²⁵ and Zajicek-Farber et al.²⁶, who note the predominance of married caregivers, which seems to represent a potential for strengthen and support when care is divided between the spouses²⁷. The percentage of divorced couples in the families of individuals with DS (10%) is similar to that found in the Brazilian population²⁸, presented in the Brazilian Institute of Geography and Statistics (Instituto Brasileiro de Geografia Estatística - IBGE) 2010 census²⁹, corroborating the findings of this study.

Considering the data on the employment status of the caregivers of the study group, it is important to indicate that despite the productive age, it was noted that 79.8% did not work outside of the home, which is in agreement with the study by Giallo et al.³⁰, conducted in Australia. According to Vieira et al.³¹, the activity of caring for people with chronic diseases is related to intense daily work, often leading to the abdication of caregivers' professional activities, given that they dedicate themselves exclusively to the treatment of the person cared for and domestic activities.

When engaged in paid work, mothers prefer informal work activities because of the possibility of working from home and having greater flexibility in their working hours. The overin-

vestment of time and money in the care of the child, coupled with the low contribution to the household's finances, reduces the family's budgetary resources, which impairs social participation, leisure activities, and health³².

These results are consistent with the interpretation that caring for a child with a disability reduces the possibility that caregivers will dedicate themselves to paid work, mainly full-time work³³, which can lead to a decrease in family income and generate frustration and dissatisfaction³⁴.

The findings indicated that for most caregivers, the per capita income of the studied groups was low, which is similar to the result found by Raina et al.³⁵ in a study with parents of children with Cerebral Palsy (CP). These results are consistent with the interpretation that caring for a child with disabilities reduces the possibility of engaging in paid work, particularly full-time work, and constitutes a risk to economic stability³⁶.

Despite the socioeconomic improvements of recent years, Brazil remains a country where social inequality and income concentration are among the highest in the world. Being the seventh economy of the planet does not guarantee minimum conditions for enormous segments of the Brazilian population. According to the demographic census of the IBGE, although "the per capita household income was BRL 668.00 in 2010, 25% of the population received up to BRL 188.00, and half of Brazilians received BRL 375.00, which was less than the minimum wage in that year (BRL 510.00)", which reinforces the results found³⁷.

In the present study, a large portion of the caregivers stated that they only have the BPC for family support, suggesting that the sample belongs to a disadvantaged class with low financial resources, which is a user of the SUS. It is worth noting that the data were collected in a public hospital, thus justifying the low income among the participants of this research and that the benefit value tends to be incorporated into the family income³⁸.

According to Wijnberg-Williams et al.³⁹, although there has been a very positive evolution towards the sharing of tasks between father and mother, the care of children with chronic disabilities remains, in most cases, the responsibility of the mother. There are far more mothers than fathers who accompany their children to various consultations, who are responsible for their treatment, and who leave their jobs and their professional projects to stay close to the child.

Regarding the level of schooling, incomplete elementary/middle school corresponded to the highest percentage of answers for all studied groups, a result that corresponds to the findings of Trigueiro et al.⁴⁰, who studied the caregivers of people with physical disabilities, with a low level of education. There are studies that show lower schooling among mothers of disabled children compared to mothers of healthy children⁴¹. A low percentage of caregivers with higher education was demonstrated in the study by Mugno et al.⁴², a characteristic that the population of the present research also presented, suggesting a population with reduced cultural and economic resources.

Reflecting on the results concerning religious belief obtained in this study, it was observed that this factor has a fundamental effect and acts by modifying the world view of the individual, using it as a driving force for better coping with and better overcoming everyday difficulties, minimizing the burden, anguish, and stress of the caring process⁴³.

Among the most cited religions, Catholic and Evangelical prevailed, portraying the distribution of the Brazilian population according to religion, considering that based on data from the 2010 demographic census, published by IBGE, Brazil is still considered the country with the largest number of Catholics in the world and the Evangelical Church, which has been expanding considerably in recent years, is the second largest religious group in this country³³.

In the sample studied, it was observed that most of the caregivers of the study group reported being affected by some health problem. This result accords with a study by Chiarello et al.⁴⁴, who found worse health conditions in caregivers who were dedicated to people with disabilities compared to those caring for non-disabled individuals, generated by the burden process¹⁸. Complementing this positioning, Cardoso et al.⁴⁵ stated that the care-related burden directly favours that the caregiver, who neglects her own health in favour of the health of the person cared for, will become ill. This occurs for many reasons, among them the lack of time, the impossibility of leaving the person cared for alone, and exhaustion, all of them acting in a negative manner in the care provided⁴⁶.

Analysing the caregivers of the study group, it was observed that most used continuous medication, which, according to the literature, results from the emotional burden and is a means of controlling symptoms to be able to perform their care tasks⁴⁷.

The fundamental principle of the inclusive school is that all children learn together, regardless of the difficulties or differences that they may present⁴⁸. Naturally, this has resulted in a large number of children and adolescents with DS attending school.

Almost all participants in the study group benefited from the BPC, which was often the only family income, including individuals with CP in physical rehabilitation³⁸.

The children/adolescents with DS had less independence in activities of daily living, requiring greater assistance from their caregivers compared to the non-disabled group, which could favour burden, in agreement with the study by Caicedo²⁵. According to Queiroz *et al.*⁴⁹, those who assist in the tasks of bathing, dressing, feeding, and transporting have greater burden.

Considering that the higher the score in the dimensions of the ZBI burden questionnaire, the greater the burden experienced by the caregivers, the results of the present study showed that the burden indexes were in the moderate range. These data are similar to those found in the research by Cadman *et al.*⁵⁰, who evaluated caregivers of children with mental and neurological impairments.

The low percentage of caregivers with severe burden is justified because they present a process of psychosocial adaptation over the years and have a less negative perception of the situation⁵¹.

In view of the findings of this study, it was possible to observe that there is a need for the planning, development, and implementation of primary healthcare and support programmes for caregivers of children and adolescents with DS, essential in the area of public health. The absence of this primary care entails a potentialization of the factors that generate burden, requiring greater public investments for the treatment of these occurrences. Prevention by a support programme aimed at this population will contribute directly to the needs of the caregivers and indirectly to the improvement of the care provided to the person being cared for and to other relatives, minimizing the effects of the burden.

Conclusions

The profile of the caregivers of children/adolescents with DS is mothers, those who are at a more advanced age, those in a stable relationship, those without occupation, those with a low per capita income and low level of schooling, those with a Catholic affiliation, those with health problems, and those in continuous use of medication. The burden of these caregivers is predominantly moderate. DS children/adolescents attend school, receive social benefits, and rely on their caregivers for activities of daily living.

Collaborations

ALO Barros collaborated in the design, research, design, data collection, analysis, interpretation of data, writing of the article and approval of the version to be published; AO Barros in data collection, analysis, critical reading of the final version of the article; GLM Barros in the critical reading of the final version of the article; MTBR Santos in the design, design, interpretation of data, writing of the article and approval of the version to be published.

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