ANALYSIS OF SOCIODEMOGRAPHIC FACTORS OF THE PAIR CAREGIVER-CHILD/ADOLESCENT WITH DISABILITY: A CASE-CONTROL STUDY[1]

ANÁLISE DE FATORES SOCIODEMOGRÁFICOS DE DUPLAS CUIDADOR-CRIANÇA/ADOLESCENTE COM DEFICIÊNCIA: UM ESTUDO CASO-CONTROLE

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ABSTRACT: Sociodemographic factors of the pair caregiver-child/adolescent with disability are important issues, but they are still little explored in national studies. The aim of this study was to analyze the association of sociodemographic factors and disability between pairs of caregiver - child/adolescent with and without disability. A case-control study design was used. The study included 112 caregiver-child pairs, of which 56 were children with disabilities (cases) and 56 children without disabilities (controls). For data collection, the following instruments were used: Self-Reporting Questionnaire (SRQ-20) and Sociodemographic Questionnaire. Most of the pairs caregiver-child with disability presented more unfavorable sociodemographic conditions when compared to the pair caregiver-child with no disability. The final logistic regression model indicated that caregivers of children with disabilities perceive their health more negatively, and children with disabilities present more food restrictions, make more use of controlled medications and rely more heavily on Government benefits. The associated variables are fundamental to understand the issue of disability more clearly and the influence of the caregiver in this context.

KEYWORDS: Person with disability. Family influence. Emotional Health.

RESUMO: Fatores sociodemográficos de duplas cuidador-criança/adolescente com deficiência são questões importantes, mas que ainda são pouco exploradas em estudos nacionais. O objetivo deste estudo foi analisar a associação de fatores sociodemográficos e deficiência entre pares de cuidador – criança/adolescente com e sem deficiência. Um estudo com desenho caso-controle foi conduzido. O estudo incluiu 112 pares de cuidador-criança, dos quais 56 foram crianças com deficiência (casos) e 56 crianças sem deficiência (controles). Para coleta de dados, os seguintes instrumentos foram usados: *Self-Reporting Questionnaire* (SRQ-20) e questionário sociodemográfico. A maioria dos pares cuidador-criança com deficiência apresentou condições sociodemográficas desfavoráveis quando comparados aos pares cuidador-criança sem deficiência. O modelo final de regressão logística indicou que cuidadores de crianças com deficiência percebem sua saúde mais negativamente, e crianças com deficiência apresentam mais restrição alimentar, fazem mais uso de medicamentos controlados e dependem mais de benefícios do governo. As variáveis associadas são fundamentais para entender mais claramente a questão da deficiência e a influência do cuidador nesse contexto.

PALAVRAS-CHAVE: Pessoa com deficiência. Influência da família. Saúde Emocional.

1 INTRODUCTION

The birth of a child with disability is a situation of extreme discomfort, with important repercussions on the family routine, since it represents a chronic and complex condition. Such reality may imply different feelings and reactions in family members, which changes the family structure established before the child is born. Incapacity, visibility of disability, emotional

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problems, behavioral difficulties, and fragility of the child's health overwhelm parents. This leads parents/caregivers to be at greater risk of developing diseases that compromise their biopsychosocial integrity, such as depression, panic syndrome, anxiety, among others (Cramm & Nieboer, 2010).

The discussion about the conditions of parents and caregivers of people with disabilities has been growing in recent years and this fact can be perceived by the increased number of published papers on the subject in the academic field (Sarkar, Sanders, Kelleher, & Chisolm, 2015; Yotani et al, 2014).

There are several contexts experienced daily by families who care for children with disabilities, and in many circumstances, caregivers live their daily lives in a suffocated and stressed way, with constant physical and mental fatigue. In the family context, the person who plays the role of caregiver is subject to the production of care demands that affect his/her physical, mental and social dimension (Pazin & Martins, 2007).

The caregiver has a greater involvement because he or she is permanently responsible for taking care of the children and managing household activities. In many circumstances, the caregiver is the mother. If the child has a disability, this involvement increases even more, due to the care taken with the individual's particularities with the disability, as well as the abandonment of his/her partners. It can be assumed that these caregivers are likely to be potential targets of different stressors such as: daily annoyance, excessive responsibilities, noises, violent or sudden changes in the behavior of the child/adolescent, among others.

Maternal and domestic obligations can become particularly burdensome for low-income families, who already face an accumulation of stressors. Thus, the need for investigations in this area seems evident in order to contribute to the understanding of the complex process of caring for children or adolescents with disabilities or other complications in their health within the family context (Matsukura, Marturano, Oishi, & Borasche, 2007).

In Brazil, studies on the care of people with functional losses and dependence on their caregivers has aroused interest. In this perspective, there is also a need for effective public policies that support families of people with functional losses and dependence, since prejudice is prevalent in society. Faced with this problem, fundamental actions are necessary to reduce the burden on caregiver's and to provide protection from the effects of stressful situations that predispose the physical and mental exhaustion of individuals inspired to care for those with the disability (Kluthcovsky & Kluthcovsky, 2009).

It should be noted that, generally, the primary caregiver is female. According to Neves and Cabral (2008), the intense demand for care has led the female caregiver to the limit of physical and mental exhaustion. In addition, it is known that historically, there is a social construct that in a particular way assigns the domestic tasks exclusively to the woman.

Sociodemographic factors can contribute positively or negatively when the issue is about caring for others. People who have a financially less fortunate reality tend to suffer more, since the social and economic conditions are factors that can explain the possible association of mental disorders, fatigue, negative perception of health and dependence on other people. This is especially true for mothers or caregivers of people with disabilities, because if she cannot put up with all of this, she will not be able to care for her child, thus becoming more and more exposed to stressful situations, with her mental health compromised and presenting mood changes (Cramm & Nieboer, 2011).

Regarding the caring process and its implications arising from risk factors for the health of the primary caregiver, the study of Herring et al (2006) pointed out that poor mothers of children with autism have poorer physical and mental health and well-being, with a greater tendency of developing stress, when compared to mothers of typically developing children and children with other disabilities.

Based on the above, studies aimed at identifying sociodemographic factors that interfere with the relationship of the caregiver-child/adolescent with disability are fundamental to understand if this reality, which is often not so favorable to the caregiver, may negatively impact the family routine and the physical and mental health of those involved in this process.

Based on the hypothesis that the caregiver of a child/adolescent with disability presents higher sociodemographic risk factors when compared to the caregiver of a child/adolescent without disability, the aim of this study was to analyze the association of sociodemographic factors and disability among caregivers of child/adolescent with or without disabilities.

2 Methods

2.1 Study characterization

This is a case-control study of a quantitative nature. The research was approved by the Ethics Research Committee of the local University and it is in compliance with principles of the Declaration of Helsinki. The Free and Informed Consent Form (TCLE) was applied to all volunteer participants of this study.

2.2 Study locations

This study was carried out in four small cities in Brazil, located in the region of Piemonte da Diamantina, in the State of Bahia. The total population of the first city is 12,344 people, the second city has a population of 79,247 inhabitants. The third city has 10.376 inhabitants, and the fourth city has a population of 11,847 inhabitants (Instituto Brasileiro de Geografia e Estatística [IBGE], 2010). The main economic source of this region is agriculture and trade of livestock. In agriculture, subsistence activities are predominant. In addition, mining is also one of the main sources of economic activity in the region (IBGE, 2010).

The choice for such regions was due to the fact that it is a context still little explored in researches with outcomes such as those of this study. Moreover, the four cities have units of Specialized Educational Care (SEC) and health units in effective working, being a reference in this region, which facilitated the access of researchers to the target public. Due to the specific cultural and economic characteristics of the region, these municipalities add peculiarities that are not very explored in field studies. Specifically with populations of children and adolescents with disabilities and their caregivers, there are no epidemiological survey data that can describe sociodemographic factors as potential risk or protection factors in these subjects.

Data collection took place in the Specialized Educational Care Unit (SEC), in the regular educational network or directly in the medical/physiotherapeutic centers in health units of these municipalities between July 2016 and September 2016.

2.3 SAMPLING

The selection of cases in this study was based on the location of mothers or primary caregivers of children and adolescents with disabilities who attended the SEC rooms, or who attended health units to perform medication or rehabilitation follow-up, and all of which are residents in the municipalities described above. Control subjects were recruited by observing data such as kinship, age, gender and socioeconomic status that could have the greatest possible similarity in the matching of pairs. Children and adolescents with typical development should be properly enrolled in the regular education network of their municipalities.

The sample calculation was performed considering 95% confidence interval, an unknown prevalence, power of 80% and alpha of 5%. Thus, 100 caregivers, 50 cases and 50 controls would be needed as the minimum sample size of this study. The number of participants in this study was 112 pairs of caregiver-children with and without disabilities, 56 (cases) and 56 (controls), who fulfilled the study inclusion criteria.

2.4 INCLUSION/EXCLUSION CRITERIA

Primary caregivers of children and adolescents with disabilities attending the SEC Unit regular educational institution, or those at follow-up health units of their municipalities and residents in the respective municipalities participated in the study. The caregivers should be 18 years of age or older. Caregivers who were not able to understand the issues present in the data collection instruments were excluded from the study; however, caregivers were not excluded by this criterion.

2.5 VARIABLES AND INSTRUMENTS

In this study, the following variables were investigated: Screening of Common Mental Disorder (CMD) of caregivers and sociodemographic variables of pairs of caregiver - child/adolescent with disabilities.

The Self-Reporting Questionnaire (SRQ-20) was used to identify characteristic signs of CMD, which is a standardized questionnaire for the screening of non-psychotic mental disorders in adults (≥ 18 years). This questionnaire has 20 questions with dichotomic responses (YES or NO) about anxious, depressive, and somatoform symptoms in the last 30 days, and classifies the subject into positive CMD when there are ≥ 8 YES responses and negative CMD when there are < 8 YES responses.

A standardized sociodemographic questionnaire elaborated specifically for the study, based on the main risk and/or protection factors pointed out in epidemiological studies, was used to evaluate sociodemographic factors. This questionnaire contains 55 items that aimed to investigate information about income, schooling, health profile and physical activity.

2.6 Procedures

Participants of the research were initially oriented on the aim of the project and its evaluation instruments. Subsequently, caregivers signed the informed consent form, formally making their participation in this investigation possible. Mothers or primary caregivers of typical children/adolescents and those with disabilities received the information about the day, time and place to respond to the scientific work instruments by means of a letter previously delivered by the researchers to the coordination of the Multifunctional Resource Rooms (MRR), in schools and in the basic health units of the municipalities, in case those included in the research were carrying out procedures in these places. Finally, Self-Reporting Questionnaire (SRQ-20) and the Sociodemographic Questionnaire were answered in the form of an interview, being performed individually with each caregiver.

It is important to emphasize that, due to the case-control design of this study, pairs of caregiver-child/adolescent with disabilities were recruited first and then pairs of caregiver-child/adolescent without disabilities were recruited for adequate matching. Thus, for each child with a disability another child without a disability of the same age and sex was recruited for the study.

2.7 Statistical analysis

Subjects were characterized by means of absolute frequencies, means and standard deviations. The t-test was applied for independent measurements in order to compare the average age between cases and controls. Bivariate analysis was performed for caregiver's characteristics between cases and controls, and child's characteristics between cases and controls using the Chi-square test at significance level of 5% and, where possible, the Odds Ratio analysis to calculate the Odds Ratio (OR) with 95% confidence interval, considering the group factor as independent variable and sociodemographic issues as dependent variables of the study.

Variables with significance level ≤20.0 were included in the Logistic Regression Analysis of the study. The Binary Logistic Regression model was used to verify the effect of the remaining sociodemographic variables between cases and controls. In order to facilitate the understanding of variables remaining in the Logistic Regression model, the discussion was carried out by topics for each of the variables.

3 Results

The study sample was composed of 112 pairs of caregiver-children/adolescents, 56 caregiver-children/adolescents with disability (cases) and 56 caregiver-children/adolescents without disability (controls). Most caregivers were mothers (88.4%), followed by grandparents (5.4%), father (4.5%), aunt (0.9%) and foster mother (0.9%). The mean age of case caregivers was 39.21 years (11.71 SD) and the mean age of control caregivers was 37.33 years (7.56 SD). The mean age of children/adolescents with disabilities was 11.55 years (4.53 SD) and the children/adolescents without disabilities was 11.33 years (4.53 SD). There was no significant difference in the mean ages of caregivers (t = 1.006, p = 0.31) and children/adolescents (t = 0.25, p = 0.80) between cases and controls, which shows adequate matching by age of caregiver-children/adolescents.

Table 1 emphasizes the analysis of the association between sociodemographic variables of caregivers between cases and controls. Association between variables 'Work' (OR = 5.73, CI 2.54-12.92, p <0.01) and 'Caregiver's health perception' (p = 0.02) was observed.

Variables	**Children with Disabilities (Cases)** n (%)	**Children without Disabilities (Controls)** n (%)	**Total** n (%)	**p-value***	**OR (CI: 95%)**
Marital status					
With marital relationship	22 (44.0)	28 (56.0)	50 (100)	0.25	1.54 (0.73 – 3.27)
No marital relationship	34 (54.8)	28 (45.2)	62 (100)		
Schooling					
Up to incomplete high school	28 (60.9)	18 (39.1)	46 (100)	0.05	2.11 (0.98 – 4.54)
Up to complete higher education	28 (42.4)	38 (57.6)	66 (100)		
Employed					
Yes	16 (29.1)	39 (70.9)	55 (100)	<0.01	5.73 (2.54 – 12.92)
No	40 (70.2)	17 (29.8)	57 (100)		
Monthly income					
≤2 MW	26 (53.1)	23 (46.9)	49 (100)	0.56	1.24 (0.58 – 2.62)
>2 MW	30 (47.6)	33 (52.4)	63 (100)		
Receives benefit					
Yes	23 (48.9)	24 (51.1)	47 (100)	0.84	0.92 (0.43 – 1.96)
No	33 (50.8)	32 (49.2)	65 (100)		
Disease					
Yes	16 (59.3)	11 (40.7)	27 (100)	0.24	1.67 (0.69 – 4.04)
No	39 (46.4)	45 (53.6)	84 (100)		
Treatment for disease					
Yes	16 (66.7)	08 (33.3)	24 (100)	0.05	2.69 (1.002- 7.23)
No	26 (42.6)	35 (57.4)	61 (100)		
Food restriction					
Yes	04 (36.4)	07 (63.6)	11 (100)	0.34	0.53 (0.14 – 1.95)
No	52 (51.5)	49 (48.5)	101 (100)		
Use of controlled medication					
Yes	14 (73.7)	05 (26.3)	19 (100)	0.10	2.61 (0.83 – 8.20)
No	30 (51.7)	28 (48.3)	58 (100)		
Use of alcohol					
Yes	13 (52.0)	12 (48.0)	25 (100)	0.82	1.10 (0.45 – 2.70)
No	43 (49.4)	44 (50.6)	87 (100)		
Smoking					
Yes	04 (100)	00 (00)	04 (100)	0.11	_____
No	52 (48.1)	56 (51.9)	108 (100)		
Use of other drugs					
No	56 (50.0)	56 (50.0)	112 (100)	______	_____

Health perception					
Excellent	01 (11.1)	08 (88.9)	09 (100)	0.02	_____
Good	35 (55.6)	28 (44.4)	63 (100)		
Regular	17 (45.9)	20 (54.1)	37 (100)		
Poor	03 (100)	00 (00)	03 (100)		
Physical exercise					
Yes	18 (41.9)	25 (58.1)	43 (100)	0.17	1.70 (0.78 – 3.67)
No	38 (55.1)	31 (44.9)	69 (100)		
Religion					
Catholic	33 (47.8)	36 (52.2)	69 (100)	0.79	______
Protestant	15 (53.6)	13 (46.4)	28 (100)		
Spiritualist	02 (66.7)	01 (33.3)	03 (100)		
Candomblé	01 (100)	00 (00)	01 (100)		
Others	05 (45.5)	06 (54.5)	11 (100)		
CMD					
Yes	17 (58.6)	12 (41.4)	29 (100)	0.28	1.59 (0.67 – 3.76)
No	39 (47.0)	44 (53.0)	83 (100)		

Table 1. Bivariate analysis of the association of caregiver/informant variables between cases and controls

Source: Elaborated by the authors.

* Significance level p <0.05 with the use of chi-square

CI – Confidence Interval

MW – Minimum Wage in Brazil corresponding to R$880,00 in 2016.

CMD - Common Mental Disorder

Table 2 shows an analysis of the association between sociodemographic variables of children between cases and controls. It was observed an association between the following variables: 'Disease' (OR = 3.33, CI: 1.31 - 8.42, p = 0.01), 'Treatment for disease' (OR=4.63; IC: 1.22 – 17.49; p=0.02), 'Use of controlled medication' (OR = 38.73, CI: 8.57 - 175.08, p <0.01), 'Child health perceived by the caregiver' (p<0.01), 'Physical exercise' (OR = 4.00, CI: 1.79 - 8.93, p <0.01) and 'Child receiving government benefit' (OR = 14.27, CI: 5.65-36.05, p <0.01).

Variables	**Children with Disabilities (Cases) n (%)**	**Children without Disabilities (Controls) n (%)**	**Total n (%)**	**p-value***	**OR (CI: 95%)**
Sex					
Female	19 (47.5)	21 (52.5)	40 (100)	0.69	0.85 (0.39 – 1.85)
Male	37 (51.4)	35 (48.6)	72 (100)		
Food restriction					
Yes	11 (73.3)	04 (26.7)	15 (100)	0.06	3.17 (0.94 – 10.67)
No	45 (46.4)	52 (53.6)	97 (100)		
Disease					
Yes	20 (71.4)	08 (28.6)	28 (100)	<0.01	3.33 (1.31 – 8.42)
No	36 (42.9)	48 (57.1)	84 (100)		

Treatment for disease					
Yes	12 (80.0)	03 (20.0)	15 (100)	0.02	4.63 (1.22 – 17.49)
No	44 (46.3)	51 (53.7)	95 (100)		
Use of controlled medication					
Yes	33 (94.3)	02 (5.7)	35 (100)	<0.01	38.73 (8.57 – 175.08)
No	23 (29.9)	54 (70.1)	77 (100)		
Lives with biological father					
Yes	27 (49.1)	28 (50.9)	55 (100)	0.85	0.93 (0.44 – 1.95)
No	29 (50.9)	28 (49.1)	57 (100)		
Type of dwelling					
Own	42 (47.2)	47 (52.8)	89 (100)	0.27	———
Leased	11 (68.8)	05 (31.2)	16 (100)		
Borrowed	01 (25.0)	03 (75.0)	04 (100)		
Donation	02 (66.7)	01 (33.3)	03 (100)		
Number of rooms					
≤5 rooms	22 (51.2)	21 (48.8)	43 (100)	0.84	1.07 (0.50 – 2.31)
>5 rooms	34 (49.3)	35 (50.7)	69 (100)		
Number of residents					
≤4 people	17 (48.6)	18 (51.4)	35 (100)	0.83	0.92 (0.41 – 2.04)
>4 people	39 (50.6)	38 (49.4)	77 (100)		
Child health perceived by mother					
Excellent	01 (5.6)	17 (94.4)	18 (100)	<0.01	———
Good	37 (53.6)	32 (46.4)	69 (100)		
Regular	17 (70.8)	07 (29.2)	24 (100)		
Poor	01 (100)	00 (00)	01 (100)		
Physical exercise					
Yes	14 (30.4)	32 (69.6)	46 (100)	<0.01	4.00 (1.79 – 8.93)
No	42 (63.6)	24 (36.4)	66 (100)		
Receives benefit					
Yes	41 (82.0)	09 (18.0)	50 (100)	<0.01	14.27 (5.65 – 36.05)
No	15 (24.2)	47 (75.8)	62 (100)		

Table 2. Bivariate analysis of the association of child/adolescent variables between cases and controls

Source: Elaborated by the authors.

* Significance level p <0.05 with the use of chi-square

CI – Confidence Interval

Table 3 presents the final binary logistic regression model of the association of sociodemographic variables between cases and controls. Among variables included in the initial model, the ‘caregiver’s health perception’, ‘child’s food restriction’, ‘use of controlled medications by the child’ and ‘child receiving government benefit’ remained associated in the comparison between cases and controls.

R-Square of 0.801 was found in the final Logistic Regression model, which makes this logistic regression model a good model to explain the associations required here. In other words, this model accounts for 80.1% of the fact that pairs of caregiver-child with disability presents more unfavorable sociodemographic conditions when compared to pairs of caregiver-child without disability, since caregivers of children with disability perceive their health more negatively, and children with disabilities have more food restriction, make more use of controlled medication, and rely more heavily on government benefits.

Likelihood of associated factors	B	Exp(B)	p-value	Constant	-2 log
Final model				-25.075	23.690
Caregiver's health perception	-2.780	0.062	0.03		
Child's food restriction	4.633	102.870	0.03		
Use of controlled medications by the child	6.726	834.152	<0.01		
Government benefit	6.270	528.606	<0.01		

Table 3. Final Binary Logistics Regression Model on associated factors between cases and controls
Source: Elaborated by the authors.

4 DISCUSSION

The aim of this study was to analyze the association of sociodemographic factors and disability between pairs of caregiver-children/adolescents with and without disability'. In brief, it is important to highlight that family support is essential in anyone's life because the family relationships will determine the human behaviors and this would not be different in those individuals with disabilities. Comfortable homes for children and adolescents tend to positively subsidize behavior outside the home, extending into adult life (Baptista, Baptista, & Dias, 2011). The final logistic regression model revealed that the variables: Caregiver's health perception, child's food restriction, use of controlled medications by the child and child receiving government benefit remained associated in the comparison between cases and controls, revealing that, in general, these factors could explain the sociodemographic condition of the people with disabilities, that is, they would be the main risk factors for children and adolescents with disabilities and their caregivers of the reality investigated and that represent the greatest negative impact on the life of these subjects.

4.1 INFORMANT'S HEALTH PERCEPTION

In the social perception, sometimes the person with a disability is perceived as weak and fragile, sometimes as someone with a lot of courage and willpower. Even when socially, culturally and temporally contextualized, disability brings with it a strong emotional burden to people involved in the process - parents, children and other relatives (Sá & Rabinovich, 2006).

When analyzing the results of the caregiver's health perception, it was evidenced that caregivers of children with disabilities perceive their health in a negative way. Behind this observation, there are some important implications for a better understanding of the reality exposed by informants. The unfavorable sociodemographic conditions of pairs of caregiver-children with disabilities when compared to pairs of caregiver-children without disabilities end up predisposing the main caregivers to have a negative view of their health.

This negative predisposition that caregivers feel about their health is intrinsically related to the lack of support that they receive in the task of caring. This is due to little involvement of family members, overburdening those who directly take care of the child with the disability, not only for having some disease, food restriction or use of controlled medications by the child/adolescent and/or the caregiver, but also because the family is often exposed to complicated financial conditions, which is certainly due to the lack of information to family members about rights guaranteed by law. Given this context, it should be pointed out that the use of the terminology 'person with disability' is full of precipitated meanings, since this subject is often loaded with prejudices, stigmas and stereotypes, in a way that negatively instigates relatives own perceptions about their health (Sassaki, 2005).

Garip et al (2017), in a study on the fatigue of mothers of children with cerebral palsy, showed that care delivery is a natural role for mothers. However, the care for a child with functional limitations and long-term dependence is totally different and negatively influences mothers or primary caregivers in their quality of life in terms of physical and emotional functioning. In this perspective, when fatigue is constant with a continuous overload in the task of caring, the consequence to the caregiver is to visualize or perceive his or her health in a negative way.

Brehaut et al. (2011) reported that caregivers of children with complex medical conditions were more likely to report poorer physical health than caregivers of healthy children. Parents reported feeling emotionally frustrated, anxious, angry, helpless, and hopeless. Socially, they felt isolated, as people did not make them understand their family situation, and that it was difficult to talk to other people, including doctors and nurses about the child.

These results are consistent with those of other studies, such as that of Hatzmann, Heymans, Ferrer-i-Carbonell, Van Praag and Grootenhuis (2008), in which parents of children with chronic diseases reported significant problems with daily living, vitality, sleep, difficulties in making family decisions compared to parents with healthy children of school age, evidencing the disparity in relation to quality of life and vision about their physical and mental health.

In addition to an unfavorable sociodemographic picture, the fact that the caregiver is frequently witnessing the conditions of suffering of whatever the deficiencies of their children, may lead to a process of physical and mental exhaustion, and these individuals internalize a thought and self-perception of complete impotence in relation to the reality that they experience. In many cases, the dedication is so intense that these caregivers abdicate their social life, family, school, leisure programs, church etc., thus restricting their lives exclusively to care, which, by the way, is usually a painful and lonely task.

Keller and Honig (2004) reported that parents play an important role in the task of caring for children with special needs, and this requires increased attention. However, in many cases, they fail to notice their own existence, possibilities and potential. Some authors (Vieira, Mendes, Frota, & Frota, 2008; Castro & Piccinini, 2002) have observed that social isolation is a frequent occurrence in the lives of caregivers of people with disabilities. Perhaps, this is also a preponderant factor for the caregivers of children with disabilities and so they perceive their health negatively.

Even for these caregivers of children or adolescents with disabilities who dedicate their time to care, believing that they are strong enough to overcome the difficulties faced in their daily lives, there is an arduous pilgrimage of family members potentially exposed to constant fatigue and stress, who cannot perceive their health in a positive way and end up incorporating for themselves the reality lived by the individual with disability. In this perspective, it is not uncommon to find high levels of tension in caregivers of children with special needs that result in depression, fatigue, lack of physical health and social isolation (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Cousino & Hazen, 2013).

The lack of social support, as a possible agent that can prevent the onset of diseases, and social isolation, can also reinforce the negative health perception of the main caregivers of children or adolescents with disabilities, given the great dependence on family members, friends, school, and the health system for the treatment or follow-up medication of children with disabilities. Ribeiro (1999) describe social support as a set of functions performed by people who may be members of the nuclear family and friends who offer instrumental, informational or emotional assistance.

For these and other reasons, Lima (2006) described some difficulties faced by mothers of people with disabilities: intense emotional overload of mothers due to their own difficulties, discrimination, exclusion and social reaction to the person with disability and often to the lack of or little support received; exhaustion and abandonment of other family members, difficulties in moving their children with disabilities and other issues. This could explain the more negative health perceptions of caregivers of children and adolescents with disabilities in this study.

4.2 CHILD'S FOOD RESTRICTION

The child/adolescent food restriction was the risk factor associated to the presence of disability among the investigated subjects. Probably the major risk of food restriction in child/adolescent with disabilities is due to the diseases that they have. This finding may confirm to the theory that children with disabilities present, in addition to their deficiency, other health complications that consequently restrict their feeding.

That association indicates a worrisome situation in the life of subjects with disability as well as in the routine of their caregivers. It is necessary to take into account that children with disability are more susceptible to the diseases that might cause any food restriction. This generates an extra demand for family members at the time of purchase, preparation and provision of adequate food for children/adolescents with disabilities. The financial hardship experienced for many families can be a major obstacle in this process, given the high costs of maintaining a varied diet. Consequently, these children/adolescents tend to be more exposed to the appearance of other diseases acquired by malnutrition and by the inherent immunological fragility in relation to the condition of disability.

It should also be noted that the low socioeconomic status of families makes access and maintenance of a healthy diet difficult. Rose-Jacobs et al (2016) reported that, in 2014, 3.4 million (19.9%) of North American families with children under six years of age presented family food insecurity, and 1.6 million (9.1%) reported that children have food insecurity. Food insecurity refers to the inability to pay enough to have quality food for an active and healthy life for all members. Thus, it could be concluded that food restriction of children with disabilities does not come from financial difficulties, but it can negatively impact something that comes from the condition imposed by the disability itself.

Since disabilities involve specific conditions in relation to health care, food restriction has a major impact on their lives and also on the lives of family members, especially caregivers, who need to control the feeding of these children/adolescents. Food restrictions require controlling the labeling of foods and/or beverages, often necessitating the manipulation of certain products to meet the quantity and quality of nutrients needed for these children and adolescents. Often, products that are free of substances such as gluten, lactose or sugar are more expensive, and as such their access is much more restricted, such as those living in counties far away from large urban centers as are the cities eligible for this study.

In this sense, caring for children with special needs in the long term may entail direct and indirect financial consequences, since all the family resources may be managed in favor of the care of the child with disability. This significantly affects low-income families, with direct consequences to the subjects' health. Yet, it also prevents the ability of the family to meet the needs of having quality basic food items in their household (Rose-Jacobs et al, 2016).

Costs associated with access to complex health and/or educational services can challenge the financial capacity of low-income families to meet basic needs. In addition, caregivers in their routine still live with the possibility of observing the dietary restrictions of children and adolescents with disabilities and receive guidance through a differentiated food schedule, but not being able to maintain this food schedule. Thus, these caregivers often need to change working hours, work more flexible hours (even with a lower salary), or give up work to devote exclusively to maintaining the medical, educational and food needs of the child/adolescent with disability.

4.3 USE OF CONTROLLED MEDICATION

This study found that most case children use controlled medications, whose data refer to the very fragile condition of the child with disabilities, since they need continuous and long-term specialized care to maintain their state of health. The drug therapy of these children is frequent. Elias, Murphy and Council on children with disabilities (2012) point out that children with special needs usually receive five times more medication than children in general. In view of this finding, the use of controlled drugs would lead to more diseases, greater search for health services and greater exposure to intoxication. In addition, the susceptibility of pediatric patients to adverse drug reactions may change during the various stages of their development and growth, especially in cases of chronic treatments (Caicedo, 2015).

Santos, Barreto and Coelho (2009) point out that continued use of medications, besides being an important indicator of health problems, also reflects social inequalities, deficiencies, among other factors. In this context, Silva and Tuleski's (2015) study indicates that complaints related to mental suffering at different levels of severity have been increasingly perceived, and this reality being treated in a biological and pharmacological way. Mental disorders are responsible for five of the ten major causes of disability in the labor market, manifested through depression, bipolar disorder, schizophrenia, alcoholism and obsessive-compulsive disorder, diseases that cause drug dependence to reduce the effects of these risk factors.

Another important aspect, in addition to the intake of drugs by children with disabilities, is the regularity of medication administration, which is a challenge that increases maternal overload, since the mother usually becomes the main person responsible for the care and management of the therapy. Due to predominantly cultural and certainly sexist reasons, the role of the woman caregiver is still an attribution expected by society in the face of the problem of maternal care and even so more when the child has a disability (Karsch, 2003).

Okido, Cunha, Neves, Dupas, & Lima (2016) point out that these mothers present emotional, social and physical problems, such as difficulty sleeping at night, because they need to wake up to check the child's condition or to administer medication. Thus, it is important to strengthen the link with the health system's social network with the aim of promoting the effective and integral follow-up of these mothers who are vulnerable to psychic diseases. This denotes how caregivers and the one being cared for are immersed in the use of drugs to solve problems in the physical and/or mental health of both. Although this study found no association between positive CMD among caregivers and the children/adolescent deficiency condition, it is worth mentioning that the prevalence of CMD was higher among these caregivers (58.6%), when compared to caregivers of children/adolescents without disability (41.4%). These results should not be disregarded in the context of sociodemographic risk factors presented by pairs of caregiver-children/adolescents with disabilities.

It is worth mentioning that the low socioeconomic status hinders access to specialized medicines and services. According to Gaiva, Neves and Siqueira (2009), the financial difficulty is present in the lives of the study sample, mainly because the majority of them have low socioeconomic status and part of the family income is used for curative activities and rehabilitation of children.

4.4 CHILD RECEIVING GOVERNMENT BENEFIT

The fact that most children with disabilities receive a Continuous Care Benefit (CCB), provided for by specific Brazilian legislation (Lei nº 8.742, 1993) allows us to identify an improvement in the welfare conditions of people with disabilities after receiving the CCB, in addition to the increase and security of family income. According to the Organic Law of Social Assistance (called LOAS) (Lei nº 8.742, 1993), people with disabilities who carry out follow-ups with rehabilitation services promoted by specialized institutions have the right to this benefit, which is equivalent to the value of the national minimum wage, and must be used for the cost of treatment, for items such as food, transportation and medications.

According to Santos (2011), CCB is one of the most important public policies of combating inequalities in the country. CCB is an unconditional income transfer equivalent to a minimum wage, for poor people with disabilities and also for older adults over 65 years of age, which is a benefit of social assistance guaranteed in the Federal Constitution of 1988, regulated by Law No. 8,742, of December 7, 1993 Organic Law of Social Assistance (LOAS).

Across the country, children and adolescents are the age group with the highest incidence of people with disabilities receiving CCB: one in five CCBs granted in the country is for children and adolescents up to eighteen years of age. Thus, CCB was created as a social policy aimed at addressing the citizenship rights of poor people with disabilities who need social assistance (Santos, 2011).

In addition to the fact that the benefit is mainly focused on providing minimum survival needs, the importance of the benefit as a social protection is also revealed when the role of CCB in the composition of the family income of persons with disabilities is established.

Significant changes in the notions of well-being have been observed because of access to the benefit, since the CCB target public is composed of very poor and very socially vulnerable people, and allows the monthly guarantee of a minimum wage to change the standards of consumption of families of people with disabilities even if this consumption is of basic goods such as food, health care and household expenses (Santos, 2011).

Contrary to this, the lack of knowledge about these rights characterizes the non-exercise of the citizenship of these children and, in this case, it is the moral duty and obligation of health professionals to provide the necessary information. We point out that in many families, the total income they have comes from this resource which, in turn, should be to care for the person with disability. In fact, this benefit turns out to be the only financial source of family members who do not have the time to dedicate themselves to another work activity because they are involved in the care of child/adolescent with disability.

Another issue to be mentioned is the eligibility criteria for access to CCB, which relates to incapacity for work. This criterion is one of the great controversies for the granting of the benefit, since determining incapacity for work is not a simple task, and ends up restricting people with disabilities access to this social right. In addition, certain disabilities are not totally disabling for work; however, the experience of disability and the restriction of skills resulting from it disadvantages these people in the labor market because it is not well adapted to the characteristics of people with disabilities, preventing the promotion of autonomy and financial and social independence.

5 Conclusion

Considering the results presented in this study, it could be inferred that pairs of caregiver-children with disabilities presented the greatest risk factors, when compared to pairs of caregiver-children without disabilities. These variables were: negative perception of the informant's health, child's food restrictions, use of controlled medication by the child and child receiving government benefit.

In fact, these findings indicate that families that care for people with disabilities are immersed in unfavorable economic and social conditions when compared to families of caregivers of children without disabilities. The results also showed the dependence on the use of controlled medications to try to heal the disorders presented by infants. In addition, the use of controlled medications and the food restriction of children/adolescents reinforce the need for state support through benefits such as the Continuous Care Benefit (CCB) to support families regarding the difficulties they face in their daily lives. Moreover, the evaluation of the health of these caregivers is worrisome, since it denotes an extreme perception of fragility and weakness, which may be related to the task of caring.

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