FAMILY BURDEN AND CHILDREN WITH AUTISM SPECTRUM DISORDERS: PERSPECTIVE OF CAREGIVERS

Sobrecarga familiar e crianças com transtornos do espectro do autismo: perspectiva dos cuidadores

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ABSTRACT

Purpose: to evaluate the burden of family caregivers of children with autism spectrum disorders, as perceived by themselves. **Methods:** 20 subjects participated, of both genders, aged between 22 and 60 years (mean = 32.6), ten families of children with autism spectrum disorders and, to compose the control group, ten family members of children with disorders language. The children were between three and ten years of age (Mean = 5.8). The control group was selected from the pairing of age, education and gender of children. In order to evaluate the caregiver burden Scale was used Burden Interview and sociodemographic data were collected from participants. The statistical analysis was performed from the Mann-Whitney and Spearman correlation analysis (p <.05). **Results:** mean overload index of family caregivers of both groups was 28, therefore, no difference was observed statistically significant and indicated that the G1 and G2 were moderately overloaded. Participant characteristics were not significant in overload index. **Conclusions:** caring for children with autism spectrum disorders can overwhelm their families similarly to the relatives of children with other disorders of development.

KEYWORDS: Autism; Child; Family; Quality of Life; Speech, Language and Hearing Sciences

INTRODUCTION

Burden on caregivers concerning people with chronic diseases is described as a disorder resulting from dealing with physical dependence and mental incapacity of the person, in need of attention and care[1]. By assuming the role of guardian or caregiver, responsible for the welfare and care of a dependent family member, the caregiver is subjected to stressor agents, as well as feeling satisfaction and wellness for helping the person[2].

Some authors consider that changes in family structure, such as the increased participation of women in the labor market and the increase in divorce rates, bring more difficulties concerning caring demands for people with severe chronic diseases [3]. In this context, the literature highlights the autism spectrum disorders (ASD) as childhood developmental disorders which can cause intense stress on caregivers, especially mothers, who may present as one of its consequences, the development of maternal depression , which can negatively affect both, the mother and the child[4].

ASD can be described as conditions with varying severity levels and symptomatologies, characterized by social interaction and communication disorders and the presence of restricted interests and stereotyped and repetitive behaviors[5]. Researchers reported that the development impairment, presented by children with autism spectrum disorders, may have several implications for the family dynamics[6-9,] from the physical and mental burden arising from daily life assignments[8,9], high

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levels of stress and low levels of quality of life for the family members[10], to the possibility of developing adaptability and resilience[7]. Changes are reported in daily activities and psychological functioning of its members, heavy workloads and specific demands[11]. These aspects may interfere in aspects referring to family, work, social and personal life and may predispose the caregiver to conflicts[12,13].

In order to provide health care for the child, more interaction with the family and life story of the child is necessary [14]. Assessment of the caregiver burden, according to his/her own perception, contributes to the analysis about the real impact, which this condition determines in their lives, and constitutes an important factor in promoting health and wellness[15], therefore, health and education professionals should give special attention.

Tasks assigned to the caregiver, often without proper guidance and support from the institutions which attend the family member under care, impact on their quality of life[16]. Thus, understanding the interactions of family members with the disease, allows the professionals to realize that family caregivers also need care and help, guidelines and strategies for stress relief. Thus, they may have better living conditions and hence may provide better care to the sick family member[17]. The performance along with such issues, constitutes a challenge for health and education professionals, which demands intersectorial attention[18] for promoting overall health of families and communities[14]. According to this perspective, this study aimed to assess the burden of family caregivers of children with autism spectrum disorders, according to the report of caregivers.

■ METHODS

This is a cross-sectional study, approved by the Ethics Committee of the Faculty of Philosophy and Sciences, São Paulo State University, Campus of Marília, Protocol n ° 2048/2009. All participants were asked about their agreement to participate in the study and signed an informed consent.

A total of 20 families were evaluated; ten family members of children with autism spectrum disorders (G1), aged between 22 and 65 years (mean = 32.6). To compose the control group, ten family members of children with language disorders (G2) participated. Inclusion criteria for family members were: to be literate; have a degree of kinship; live and be responsible for the child with autism spectrum disorders or language disorders, playing the role of main caregiver. The description of the characteristics of the participants are shown in Table 1.

The ages of children and pre-adolescents ranged from three to ten years (mean = 5.8) and should be attending speech therapy twice a week for at least three months and maximum two years, in therapeutic process of the same clinic-school, in a midsize city of São Paulo state. The diagnoses of children with autism spectrum disorders were established by a psychiatrist, according to specific criteria[4,19]. Children with language disorders underwent speech evaluation in the clinic-school and their families were selected matching age, sex and education of children.

To collect data about the subjects in this study, a questionnaire was elaborated specifically for this research. Data relating to children comprised age, gender, education, medical diagnosis and length of speech therapy. Regarding the caregivers, data comprised age, gender, relationship, number of children, marital status, education, occupation and family income, calculated on minimum wages.

For assessing the burden of family caregivers, the Brazilian version of the Scale Burden Interview[20], which verifies the burden on caregivers who take care of people with mental and physical disabilities, was employed. The scale includes 22 questions that cover the areas of health, social and individual life, financial status, emotional stability and interpersonal relationships.

For the application of the scale of caregiver burden, interviews were conducted in groups with caregivers in the clinic-school, during hours of speech therapy for children. The examiner first explained the purpose of the questionnaire and caregivers who wished to participate signed a consent form. Afterwards, instructions were given, concerning completion of burden questionnaires and characterization of participants. The instruction states that the questionnaire is a list of statements that reflected how people felt when they took care of another person. After each statement, the participant should indicate how often he/she felt that way: never, rarely, sometimes, often, or always in questions 1-21 and: even a little, a little, moderately, very or extremely, in question 22, and there are no right or wrong answers.

Table 1 – Characteristics of family caregivers and children.

Data of the family members					Data of the children			
Participants	**Parentship**	**Education**	**Profession**	**Income minimum salary**	**Age (years)**	**Gender**	**Diagnoses**	**Length of therapy**
1	Mother	High school	Maid	4	3	Male	LD	3 months
2	Father	High school	Metal worker	4	3	Male	LD	3 months
3	Mother	High school	Housewife	3	8	Male	LD	5 years
4	Mother	College	Industry worker	1	6	Female	LD	2 years
5	Mother	Elementary. School incomplete	Maid	2	6	Male	LD	2 years
6	Mother	High school	Housewife	1	7	Female	LD	5 months
7	Mother	Elementary. School incomplete	Maid	2	6	Female	LD	3 years
8	Mother	College degree	Teacher	6	6	Female	LD	2 years and 5 months
9	Mother	High school	Housewife	2	4	Male	LD	1 year
10	Mother	High school	Housewife	Up to 1	6	Male	LD	4 months
11	Mother	High school incomplete	Self-employed	above 6	8	Male	ASD	1 month
12	Sister	High school	Does not work	3	10	Male	ASD	7 years
13	Mother	High school	Kitchen assistant	6	6	Male	ASD	1 year
14	Mother	Elementary. School	Housewife	2	6	Male	ASD	3 years
15	Mother	College degree	Housewife	3	9	Male	ASD	2 years and 3 months
16	Mother	High school	Housewife	above 6	5	Male	ASD	3 months
17	Grandfather	College degree	Retired	3	3	Female	ASD	1 month
18	Mother	College degree	Teacher	4	6	Male	ASD	2 years
19	Father	High school	Metal worker	6	6	Male	ASD	1 year
20	Mother	High school	Housewife	2	7	Male	ASD	1 year and 6 months

Abbreviations: LD = Language disorders; ASD = Autism spectrum disorder

In analyzing the data, each individual was scored at first. For this, the responses of each subject were scored on a scale ranging from 0 to 4, according to the presence or intensity response. Issues relating to items 1-22 were scored as: 0 – never; 1 – rarely; 2 – sometimes; 3 – often; 4 – always; and item 22 as: 0 – not a bit; 1, a little; 2 – moderately; 3 – and 4 very – extremely, this last question assesses the intensity of the caregiver burden. All questions were scored and the final score, which can range from 0 (lowest overhead) to 88 (more overhead), was obtained from the total sum of all responses, ranging from 0-88. The higher the final score, the greater the caregiver burden, as follows: <than 21 – no burden; 21-40 – moderate burden; 41-60 – ranging from moderate to severe and> or equal to 61 – severe burden.

INSTRUCTIONS: The following questionnaire is a list of statements which demonstrate how people sometimes feel when taking care of other people. After each statement, indicate how often he/she feels that way: never = 0; rarely = 1; sometimes = 2; frequently = 3; always = 4. There are no right or wrong answers.

1. Do you. feel that S asks for more help than he / she needs?
2. Do you feel that the amount of time spent with S. does not leave enough time for yourself?
3. Do you feel stressed for taking care of S and other responsibilities with family and work?
4. Do you feel embarrassed with the behavior of S?
5. Do you. feel irritated when S is close by?
6. Do you feel that S negatively affects the relationships with other family members or friends?
7. Do you feel afraid about the future of S ?
8. Do you feel that S depends on you?
9. Do you feel some tension when S is close by?
10. Do you feel that your health was affected due to your involvement with S?
11. Do you feel that do not have as much privacy as you would like, because of S?
12. Do you feel that your social life has been undermined because you are caring for S?
13. Do you feel uneasy when having visitors at home, because of S?
14. Do you feel that S expects you to take care of her / him, like the only person he / she can depend?
15. Do you feel that do not have enough money to take care of S, in addition to other expenses?
16. Do you feel that you will be unable to take care of S for much longer?
17. Do you feel you've lost control of your life, since the disease of S?
18. Would you allow someone else take care of S?
19. Do you feel unsure about what to do for S?
20. Do you feel you should be doing more for S?
21. Do you feel you could take better care of S?
22. In general, do you feel overwhelmed for taking care of S?

*In the text, S refers to the caregiver

Figure 1 – Brazilian version of the Scale of Caregiver Overload –. (Burden Interview-BI) [20]

Statistical analyses of the data, employing Mann Whitney Test was realized in order to check if there was a significant difference between both groups surveyed. In order to check the degrees of relationship between variables: education, minimum wage, age of children and length of therapy with the burden value, the Spearman Correlation Test was employed. The adopted significance level was 5% ($p < 0.05$) for the statistical tests.

RESULTS

Table 2 shows the mean and the standard deviation of the scores obtained from the Burden Interview Scale of caregiver. In addition, Table 1 shows the results for the comparative analysis of G1 and G2.

G1 and G2 had score 28, indicating moderate burden. The comparison between the individuals in the different groups (G1 and G2) was performed using the Mann-Whitney test. It was found that there was no significant difference when comparing the burden rates of G1 with G2 (Table 2).

Table 3 presents the results for the degree of relationship between the burden of G1 and G2 and the variables: education, minimum wage, age of children and length of therapy .

As it can be observed in Table 3, the analysis of correlations between the burden of family and schooling variables: minimum wages, age of children and length of therapy showed statistically significant results.

Table 2 – Individual scores, means, standard deviations and comparison of the burden scores, presented by the two groups.

Questions	Participants																			
	G1										G2									
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1	4	2	2	1	3	2	2	2	3	2	3	3	2	0	2	3	1	2	3	2
2	2	0	2	2	2	1	2	2	0	2	0	0	2	2	0	2	2	2	1	2
3	2	3	2	2	3	2	2	2	0	2	1	0	2	3	3	2	0	2	1	2
4	3	4	0	0	2	2	1	2	0	0	0	0	1	2	2	1	0	2	0	0
5	0	0	0	0	0	0	0	0	0	0	0	0	0	2	2	0	0	0	0	0
6	2	0	0	0	0	0	0	0	0	0	0	0	0	2	0	1	0	0	0	0
7	2	2	4	4	4	4	3	4	0	3	2	0	4	4	3	3	2	4	4	0
8	4	2	4	4	2	4	3	4	2	3	3	3	4	4	2	4	3	4	4	3
9	2	0	0	2	0	0	0	1	0	2	0	0	0	2	0	0	0	0	0	0
10	2	0	0	0	1	0	0	0	0	2	0	0	0	2	0	2	0	1	0	0
11	1	0	4	2	1	1	2	2	0	0	0	0	2	2	0	1	0	1	0	0
12	0	2	0	0	0	0	2	2	0	2	0	0	0	2	0	0	0	1	1	1
13	2	1	0	0	0	0	0	0	0	0	0	0	0	2	2	0	0	1	0	0
14	2	2	4	4	0	4	1	1	0	4	1	1	4	1	2	2	0	0	1	1
15	0	3	0	2	0	2	0	0	0	2	0	0	0	4	2	3	0	0	2	2
16	0	2	0	0	0	0	0	0	0	0	0	0	0	3	0	1	0	0	0	0
17	0	2	0	2	1	0	0	1	0	2	0	0	0	4	0	3	0	0	1	1
18	0	4	0	0	2	0	0	0	0	0	0	0	2	0	2	0	0	0	0	0
19	2	4	0	1	0	2	2	2	0	2	1	1	0	4	2	1	2	1	2	2
20	0	2	0	4	1	4	2	4	1	2	4	4	4	4	2	4	0	2	2	2
21	0	2	0	4	0	4	2	4	2	2	4	4	4	3	2	3	0	4	1	1
22	1	1	0	0	2	0	0	1	0	1	0	1	2	3	1	2	0	2	0	0
Total Score	31	38	22	34	24	32	24	34	8	33	19	12	33	55	29	38	10	29	36	19
Mean	28										28									
Standard deviation	8,76										13,59									
Sig. (p)	0,820																			

Significante (p<0,05) – Mann-Whitney Test

Table 3 – Results of the analysis between the independent variables and the scores of G1 and G2 obtained on Burden Interview Scale

Variable	Statistics	Burden
Education	Correlation coefficient (r)	+0,184
	Significance (p)	0,437
	n	20
Salários Mínimos	Correlation coefficient (r)	-0,352
	Significance (p)	0,128
	n	20
Idade Crianças	Correlation coefficient (r)	+0,357
	Significance (p)	0,123
	n	20
Tempo Terapia	Correlation coefficient (r)	+0,309
	Significance (p)	0,185
	n	20

Significance value (p<0,05) – Spearman Correlation Test

DISCUSSION

The results observed in this study made it possible to analyze aspects of the burden for families of children with autism spectrum disorders and children with language disorders who received speech therapy in a clinic-school. These data illustrate how the family members of this study reported their feelings, when caring for kids with autism spectrum disorders, and constitute an important element for planning interventions targeting children with autism spectrum disorders and their families.

Regarding the participants, it was observed that the majority (85%) of caregivers responsible to take care of children were females[12] and 80% were mothers; only two of them were fathers and one grandfather, corroborating data from other studies[21,22]. Concerning the occupation of mothers, 40% worked out and the remaining (40%) worked as teachers maids and industry workers. In another study, the authors found that mothers of autistic children had difficulty in pursuing their professional careers, due to excessive time demand for caring the child [23].

The aspects investigated relate to implications for the personal life of family members, satisfaction with caring demands and financial burden, related to the child. From these findings it was found that the average rate of caregiver burden in both groups was the same, score 28, therefore, they were moderately overloaded. These findings corroborate descriptions of the literature on impairments in quality of life of families of children with disorders of the autism spectrum disorders[10,24]. The consequences and limitations on personal life of the caregiver comprises many situations, which may cause changes and impact on personal life, such as reduced time available, affected health, and also the necessity of changing many habits, in order to support the needs of the children[12].

When comparison G1 and G2, data show that the burden for families caring for children with autism spectrum disorders is similar to the burden for families of children with other chronic developmental disorders, such as occurs in some cases of language alterations. Furthermore, in this study, correlations between the burden of family and schooling variables, minimum wages, age of children and length of therapy were not statistically significant. These results are consistent with the statements of other authors who observed significant difference in family burden, due to the type of diagnosis of chronic patients with other psychiatric and behavioral disorders[25] On the other hand, some authors have described significant differences concerning the burden upon families of people with different chronic diagnoses and correlations between sociodemographic variables of the family members[26]. In this research, the sample size may have influenced the non-significant difference, in relation to sociodemographic variables. Moreover, specifically in cases investigated, the support offered by the speech therapy could have mitigated such differences, so, additional studies are necessary.

In the present study, the fact that both groups had a moderate burden index, may be related to social support which helps coping strategies and can positively influence the perception of burden[27], since caregivers studied here attend an orientation group every week, for parents of the clinic-school where children receive care.

As observed by other authors[28], it is important to consider the possibility that this study may have been influenced by the fact that the interviewed respondents felt some kind of apprehension or were even embarrassed to answer honestly about their relationship in reference to the task of caring for children with language and autism spectrum disorders. In addition, other variables may be related to the quality of life of participants in this study, as the intensity of behavioral problems presented by the child [8,29], the support of other family members[29] and professionals, offered to the children and their families[6-8,10,29,30.]

Another aspect shows that the instrument used in this study proved to be effective in raising important data on the burden of children caregivers with autism spectrum disorders and language disorders. However, it should be considered the relevance of other studies with a higher amount of participants, in order to confirm whether or not there statistically significant differences between the populations studied. It is suggest the development of longitudinal studies and analyzes which compare data from families of children with autism spectrum disorders and data from families of children without any development complaints.

■ CONCLUSION

The observed results showed no difference in mean index of burden for family caregivers of children with ASD and children with language disorders. Also, the data showed that both groups were moderately overloaded. Thus, the findings of this study suggest that caring for children with autism spectrum disorders can overwhelm their family members, similarly to families of children with other developmental disorders.

Finally, it is emphasized that acknowledging the factors which influence the burden of caregivers, constitutes another factor to be added into the care planning and intervention and can assist in developing strategies for guidance and assistance to patients and their caregivers.

RESUMO

Objetivo: avaliar a sobrecarga de familiares cuidadores de crianças com transtornos do espectro do autismo, segundo a percepção dos próprios cuidadores. **Métodos:** participaram 20 sujeitos, de ambos os gêneros, com idades entre 22 e 60 anos (Média= 32,6), sendo dez familiares de crianças com transtornos do espectro do autismo e para compor o grupo controle dez familiares de crianças com transtornos de linguagem. As crianças apresentavam entre três e dez anos de idade (Média= 5,8). O grupo controle foi selecionado a partir do pareamento de idade, escolaridade e gênero das crianças. Todas as crianças encontravam-se em atendimento fonoaudiológico. Para avaliar a sobrecarga dos cuidadores foi utilizada a Escala Burden Interview e foram coletados dados sociodemográficos dos participantes. A análise estatística dos dados foi realizada a partir do teste de Mann-Whitney e da análise da Correlação Spearman (p< 0,05). **Resultados:** a média do índice de sobrecarga do familiar cuidador de ambos os grupos foi 28, portanto, não foi observada diferença estaticamente significante e indicou que os G1 e G2 estavam moderadamente sobrecarregados. As características dos participantes também não foram significantes no índice de sobrecarga. **Conclusão:** cuidar de crianças com transtornos do espectro do autismo pode sobrecarregar seus familiares de modo semelhante ao de familiares de crianças com outros transtornos do desenvolvimento.

DESCRITORES: Autismo; Criança; Família; Qualidade de vida; Fonoaudiologia

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