



Mothers of children that need continuous and complex care: Factors associated with social support

*Mães de crianças que necessitam de cuidados contínuos e complexos:
fatores associados ao apoio social*

*Madres de niños con necesidades de cuidados continuos y complejos:
factores asociados al apoyo social*

Paula Rossi Baldini¹

Bruna Josiane de Lima²

Juliana Coelho Pina³

Aline Cristiane Cavicchioli Okido¹

1. Universidade Federal de São Carlos,
Programa de Pós-Graduação em Enfermagem.
São Carlos, SP, Brasil.

2. Universidade Federal de São Carlos, Curso
de Graduação em Enfermagem. São Carlos,
SP, Brasil.

3. Universidade Federal de Santa Catarina,
Departamento de Enfermagem. Santa
Catarina, SC, Brasil.

ABSTRACT

Objective: to analyze the factors associated with social support for mothers of children who need continuous and complex care.

Method: an observational, analytical and cross-sectional study, with a quantitative approach. Data collection took place in the outpatient clinics of a pediatric hospital located in the inland of the state of São Paulo. A total of 36 mothers participated in the study, who answered a characterization instrument and the Medical Outcomes Study - Social Support Survey. For statistical analysis, the Mann-Whitney, Kruskal-Wallis and Spearman correlation tests were used. The ethical precepts of research involving human beings were followed. **Results:** affective, material and social interaction social support had satisfactory scores (above 80 points). The scores for the information and emotional dimensions were 78.06 and 78.33, respectively. The maternal age variable showed a negative correlation with emotional (0.040) and information (0.009) social support. **Conclusion and implications for the practice:** the mothers, especially older ones, receive less support from people who can guide and give advice, as well as someone they can trust to talk about their problems. This result can support the planning of intervention strategies with families in order to strengthen social support.

Keywords: Nursing; Child; Social Support; Mothers; Family.

RESUMO

Objetivo: analisar os fatores associados ao apoio social às mães de crianças que necessitam de cuidados contínuos e complexos.

Método: estudo observacional, analítico e transversal, de abordagem quantitativa. A coleta de dados ocorreu nos ambulatórios de um hospital pediátrico localizado no interior do estado de São Paulo. Participaram do estudo 36 mães, que responderam a um instrumento de caracterização e ao *Medical Outcomes Study- Social Support Survey*. Para análise estatística foram utilizados os testes Mann-Whitney, Kruskal-Wallis e Correlação de Spearman. Seguiram-se os preceitos éticos de pesquisas que envolvem seres humanos. **Resultados:** o apoio social afetivo, material e de interação social apresentaram escores satisfatórios (acima de 80 pontos). Os escores das dimensões informação e emocional foram 78,06 e 78,33, respectivamente. A variável idade materna apresentou correlação negativa com o apoio social emocional (0,040) e de informação (0,009). **Conclusão e implicações para a prática:** as mães, em especial as mais velhas, recebem menos apoio de pessoas que possam lhe orientar e dar conselhos, bem como de alguém de confiança para falar sobre seus problemas. Tal resultado pode subsidiar o planejamento de estratégias de intervenção com famílias, a fim de fortalecer o apoio social.

Palavras-chave: Enfermagem; Criança; Apoio Social; Mães; Família.

RESUMEN

Objetivo: analizar los factores asociados al apoyo social a las madres de niños que necesitan cuidados continuos y complejos.

Método: estudio observacional, analítico y transversal, con enfoque cuantitativo. La recolección de datos tuvo lugar en las clínicas ambulatorias de un hospital pediátrico ubicado en el interior del estado de São Paulo. 36 madres participaron del estudio, quienes respondieron a un instrumento de caracterización y al Estudio de Resultados Médicos - Encuesta de Apoyo Social. Para el análisis estadístico, se utilizaron las pruebas de correlación de Mann-Whitney, Kruskal-Wallis y Spearman. Se siguieron los preceptos éticos de la investigación en seres humanos. **Resultados:** participaron 36 madres. El apoyo social afectivo, material y de interacción social tuvo puntajes satisfactorios (más de 80 puntos). Los puntajes para las dimensiones de información y emocional fueron 78,06 y 78,33, respectivamente. La variable edad materna mostró una correlación negativa con el apoyo social emocional (0.040) e información (0.009). **Conclusión e implicaciones para la práctica:** las madres, especialmente las mayores, reciben menos apoyo de personas que pueden guiar y dar consejos, así como alguien en quien pueden confiar para hablar sobre sus problemas. Este resultado puede apoyar la planificación de estrategias de intervención con las familias para fortalecer el apoyo social.

Palabras clave: Enfermería; Niño; Apoyo Social; Madres; Familia.

Corresponding author:

Aline Cristiane Cavicchioli Okido.
E-mail: alineokido@ufscar.br.

Submitted on 07/02/2020.

Accepted on 11/03/2020.

DOI:<https://doi.org/10.1590/2177-9465-EAN-2020-0254>

INTRODUCTION

Children who require continuous and complex care have severe chronic conditions as well as severe functional limitations.¹ Generally, they use some technological device for maintaining life, such as gastrostomy for enteral feeding, for example.² They are considered as a subgroup of children with special health needs (CRIANES).²⁻⁴

Caring for a child who requires continuous and complex care implies the need for family rearrangements to meet the intense care routine,⁵ leading to family breakdown^{3,6} and overload of the main caregiver, usually mothers.⁷ To this end, the importance of the social network and social support in coping with this reality is reinforced.^{6,8}

The concepts of social network and social support are mutually complementary, but are distinguished from each other. Social network refers to a structural dimension, such as religious organizations, the neighborhood and the health system. Social support, the study object the present research, concerns a personal dimension, that is, individuals who make up the social network and are effectively relevant to a particular family.⁹ The social support construct involves five dimensions: material support related to financial assistance and the availability of material resources; emotional support that represents the availability to have someone to talk to, to vent and trust; affective support that corresponds to the physical demonstrations of love and affection; positive social interaction regarding the availability of people with whom to have fun or relax; and information, that is, the existence of people to support with guidelines, advice, opinions.⁹

According to a Scoping Review that sought to identify and describe the tools used to measure social support for caregivers of children with congenital disabilities, a subgroup of CRIANES, social support acts as a protective factor, to the extent that it provides mental and physical well-being to the caregivers, favors adaptation to the care demanded by the child and, consequently, positively impacts on the quality of life of the whole family.¹⁰ Despite the benefits of social support, most caregivers dedicate themselves to the care of CRIANES and abstain from other activities and roles in order to restrict their social relationships.¹¹

Measuring social support for the mothers of children in need of continuous and complex care adds new knowledge to the national literature, as the existing studies to date are of a qualitative approach.^{6,8,11,12} In addition, it is opportune to recognize the elements of the social and family context that may be associated with greater or lesser availability of social support, in order to subsidize health professionals in the management of cases.

Considering the above, the present research started from the following research questions: How is social support given to the mothers of children in need of continuous and complex care? Are the variables related to the social and family context associated with social support? To this end, this study aimed to analyze the factors associated with social support for the mothers of children in need of continuous and complex care.

METHOD

This is a study with an observational, analytical and cross-sectional design, with a quantitative approach.¹³ The data were collected in a large tertiary hospital located in the inland of the state of São Paulo, responsible for more than 79,000 pediatric visits in 2019.

Regarding the study participants, the inclusion criteria were the following: being mother of a child in need of continuous and complex care between zero to 12 years of age, and being over 18 years old. Mothers with experience of home care of less than three months were excluded for understanding that the availability of social support could be compromised in such a short period of experience. To define whether or not the child needed continuous and complex care, the following criterion was used: the child should require at least three care demands (developmental care, medication care, technological care and modified usual care).⁴

In this study, no sample calculation was performed and the non-probabilistic sampling method for convenience was adopted. Thus, all mothers of children in need of continuous care and eligible complexes who were present at the hospital on the dates and times for data collection and who agreed to participate in the study were included.

After authorization from the referred hospital and approval by the Research Ethics Committee, the data collection procedure began, which took place between the months of January and April 2019. The eligible mothers were approached and invited to participate when they were waiting for medical care at the clinic. For fear of not being called and missing the medical appointment, all chose to answer the questionnaire in the waiting room, although there was a private place reserved for the research. It is important to highlight that the Nursing team helped in the indication of children known to need continuous and complex care. No approached mother refused to participate in the study. To make it possible to recruit a greater number of mothers, the collection previously planned to occur in two months was extended to four months; in addition, it occurred at different dates and times, in order to cover all the medical specialties offered by the hospital.

After reading and discussing the Free and Informed Consent Form (FICF), the application of the characterization instrument and of the Medical Outcomes Study- Social Support Survey (MOS-SSS) scale was started, with an approximate duration of 20 minutes. The characterization instrument consisted of questions related to the mothers' social and family context, such as age, race, schooling, marital status, family income, occupation, religious belief and number of residents in the house. This instrument also explored information about the children, such as age, number of medications used, use of technological devices and hospitalizations in the last year.

With regard to the Medical Outcomes Study- Social Support Survey (MOS-SSS), it is an instrument consisting of 19 items related to the five dimensions of social support, namely: material (4 items), affective (3 items), emotional (4 items), informational (4 items) and positive social interaction (4 items). The items do not specify

the source of support (friends, family, community or others); they only measure the availability of social support. The answer options are according to a *Likert* scale, namely: 1 (never); 2 (rarely); 3 (sometimes); 4 (almost always), and 5 (always). The instrument makes it possible to obtain the general score and dimensions by relation between the sum of the values obtained in the set of items and their maximum possible score, multiplied by 100. The scores can vary between 20 and 100 and those above 80 are considered satisfactory, since they indicate that social support is almost always or always available.^{9,14}

Outcome variables were considered the scores obtained in the five dimensions of social support (numerical variable) and, as independent variables, those obtained from the application of the characterization instrument, which were as follows: maternal age, family income, number of residents in the house, schooling, occupation, religious belief and race.

At the end of the empirical material production, data was coded and transferred to The SAS System for Windows (*Statistical Analysis System*), version 9.2. Subsequently, from the Shapiro-Wilk and Kolmogorov-Smirnov normality tests, the absence of normal distribution of variables was verified. In the descriptive analysis, for the categorical variables, tables of absolute (n) and percentage (%) frequency were made and, for the numerical variables, the values of mean, standard deviation, minimum and maximum, median and quartiles were used. For comparative analysis between the scores for each dimension of social support and the categorical variables, the Mann-Whitney and Kruskal-Wallis tests were applied. To analyze the relationship between the numerical variables and the social support scores, the Spearman's correlation coefficient was calculated. For the tests, an alpha significance level of 5% was adopted.¹⁵

The study followed the ethical assumptions of research involving human beings, was submitted to the appreciation of the Research Ethics Committee (CAEE 91091318.9.3001.5440) and approved under opinion number 2,748,531.

RESULTS

The sample consisted of 36 mothers of children with continuous and complex care needs, with a mean age of 32.17 years old. The mean number of residents in the house (child not counted) was three, with a minimum of one and a maximum of six. The mean family income was 1,894 reais. As for schooling and occupation, the majority (72.2%) had secondary education and a small portion (11.1%) had some paid activity. Religious belief was confirmed by 29 mothers (80.6%). Table 1 presents the description of the numerical variables that characterize the mothers:

As for the children with continuous and complex care needs, the following stand out: mean of 3.8 years old, 100% made continuous use of medications (mean 3.69, minimum one, and maximum 13 medications). All were dependent on some technological device for maintaining life, with enteral feeding through gastrostomy and oxygen therapy through tracheostomy being more frequent. Regarding elective hospitalizations or not, in the last 12 months, 12 (33.3%) children needed to be hospitalized once, seven (19.5%) were hospitalized twice and five (13.8%), more than three times. It is worth mentioning that 12 (33.3%) did not need to be hospitalized in the last year.

Regarding social support, the scores for the five dimensions ranged between 78.06 (information) and 90.93 (affective). Scores below 80 points were observed for the information and emotional dimensions, indicating that the mothers perceive less often the availability of a person who can guide and give advice, as well as the availability of a trusted person to talk about their problems. The description of the scores for the five dimensions of social support is shown in Table 2.

Next, in Table 3, the result of the comparison of the means of the social support scores between the schooling, race, religious belief and occupation categorical variables is presented. No association was statistically significant.

Table 1. Description of the mothers' characteristics (n=36) according to age, family income and number of residents in the house. Ribeirão Preto/SP, 2019.

Variables	Mean	Standard deviation	Minimum	Q1	Median	Q3	Maximum
Age	32.17	8.14	18.00	26.50	31.00	35.00	56.00
Family income (reais)	1,894	1,464	200	1,000	1,400	2,400	8,400
Residents in the house	3.19	1.04	1.00	3.00	3.00	4.00	6.00

Table 2. Description of the scores for the five dimensions of social support, Ribeirão Preto, SP, Brazil, 2019.

Social support	Mean	Standard Deviation	Minimum	Q1	Median	Q3	Maximum
Material	84.44	20.17	35.00	75.00	97.50	100	100
Affective	90.93	20.36	33.33	100	100	100	100
Emotional	78.33	26.78	20.00	55.00	90.00	100	100
Information	78.06	27.73	20.00	57.50	97.50	100	100
Social interaction	87.64	21.92	20.00	80.00	100	100	100

Table 3. Comparison of the mean scores of each dimension of social support between the categorical variables of interest. Ribeirão Preto/SP, 2019.

Variables	n	Material Support				Affective Support				Emotional Support				Informational Support				Social Interaction Support			
		Mean (SD)	95% CI	p		Mean (SD)	95% CI	p		Mean (SD)	95% CI	p		Mean (SD)	95% CI	p		Mean (SD)	95% CI	p	
Schooling*				0.963				0.731													0.120
Elementary	04	78.75 (30.65)	29.97-100.00		90.00 (20.00)	58.18-100.00		71.25 (34.73)	15.99-100.00		61.25 (37.50)	1.58-100.00		91.25-17.50	63.40-100.00						
High School	26	85.77 (17.87)	78.55-92.99		92.05 (19.60)	84.14-99.97		82.69 (22.24)	73.71-91.67		84.62 (22.22)	75.64-93.59		87.88-2.05	78.98-96.79						
Higher Education	06	82.50 (25.45)	55.80-100.00		86.67 (26.67)	58.68-100.00		64.17 (38.00)	24.29-100.00		60.83 (35.56)	23.52-98.15		84.17-26.91	55.93-100.00						
Race*				0.586				0.726													0.882
White	16	84.38 (22.65)	72.31-96.44		90.42 (21.63)	78.89-100.00		76.56 (29.71)	60.73-92.39		78.13 (28.63)	62.87-93.38		87.81 (20.00)	77.16-98.47						
Brown	20	84.50 (18.56)	75.81-93.19		91.33 (19.84)	82.05-100.00		79.75 (24.89)	68.10-91.40		78.00 (27.74)	65.02-90.98		87.50 (23.87)	76.33-98.67						
Religious belief*				0.593				0.641													0.638
No	07	75.00 (31.49)	45.88-100.00		91.43 (22.68)	70.46-100.00		83.57 (28.97)	56.78-100.00		82.14 (26.12)	57.99-100.00		94.29 (13.05)	82.11-100.00						
Yes	29	86.72 (16.38)	80.49-92.96		90.80 (20.19)	83.12-98.48		77.07 (26.61)	66.95-87.19		77.07 (28.46)	66.24-87.89		86.03 (23.47)	77.11-94.96						
Occupation†				0.435				0.189													0.914
Paid work	04	80.00 (22.73)	43.83-100.00		81.67 (28.48)	36.35-100.00		81.25 (34.25)	26.75-100.00		81.25 (23.94)	43.16-100.00		91.25 (14.36)	68.40-100.00						
Housework	32	85.00 (20.16)	77.73-92.27		92.08 (19.41)	85.08-99.08		77.97 (26.36)	68.46-87.47		77.66 (28.48)	67.39-87.93		87.19 (22.82)	78.96-95.42						

SD = Standard Deviation; CI = Confidence Interval; * Kruskal-Wallis test; † Mann-Whitney test

The correlation matrix, involving the scores for each dimension of social support and the numerical variables, is shown in Table 4. This table shows statistically significant negative correlations between maternal age and the dimensions of information and emotional social support.

DISCUSSION

According to the results presented, social support proved to be satisfactory for the material, affective and positive social interaction dimensions. Satisfaction with material and affective support corroborates a qualitative study conducted in the inland of the state of Rio Grande do Sul. In this study, the mothers of children with cerebral palsy mentioned the strengthening of family emotional support as well as friends and neighbors due to the child's condition. They also stressed that family members and friends help care for younger siblings and, in some cases, help financially.¹⁶

Also with regard to material support, according to an international study conducted in China with caregivers of children with physical disabilities, material support is beneficial and is associated with a lower level of psychological distress among the caregivers.¹⁷ For the authors, when family members are available to help with household chores, caregivers can dedicate themselves specifically to the responsibilities related to child care.¹⁷

In the present study, the positive social interaction dimension had satisfactory scores, a result that differs from the literature. According to a "scoping review" that analyzed studies on the social support of primary caregivers of children with some congenital disability, social isolation is common due to the care demands as well as the social stigma around the disability.¹⁰ In the same direction, a recent study that described the family dynamics and

social support network of families of children with special needs for multiple, complex and continuous care in the inland of the state of Paraná, emphasized in its results that the physical condition of the children limits social interaction, especially due to the lack of accessibility and the need to take with them appliances and many objects necessary to provide care to the child.⁶

The dimensions of emotional and information support showed unsatisfactory scores, a result similar to that found in a research study carried out with 100 caregivers of children with cerebral palsy who also adopted the MOS-SSS instrument. According to this study, the information and emotional dimensions had the lowest scores (76 in both).¹⁸

The issue of social support related to information is commonly addressed in the literature, especially with regard to the role of Nursing in providing information, clarifying doubts and offering permanent support to the families of CRIANES.^{4,5,11,12} In this sense, nurses are seen as educators both in the hospital and in primary care⁴ and have the potential to become sources of social support, as they promote comprehensive and resolute care through informative, instrumental and emotional assistance.¹² However, the discontent of family members of children who need continuous and complex care is still common, complaining that they have not been adequately prepared to perform care after discharge.¹⁹

Regarding emotional support, it can be made available by people who experience similar situations, as they exchange experiences and share information.⁶ A Chinese study already contextualized reinforces the importance of emotional support that emerges from the relationships between people who have similar experiences. According to the authors, this feeling of connection generally minimizes the loneliness associated with care.¹⁷

In the present study, the mean family income was 1,894 reais and most of the mothers did not perform any paid work. Furthermore, the statistical tests did not identify a significant relationship between the dimensions of social support and the family income and occupation variables. However, financial difficulties can negatively impact on the social participation and leisure activities of the families.²⁰ In the same direction, according to a research study that described the extent of financial and social difficulties experienced by families of children with medical complexities, most of them indicated that they have or have had financial difficulties; in addition, they were more likely to report an expectation of little or no help from family members and friends.²¹

According to the results of the present study, maternal age showed a statistically significant negative correlation with the dimensions of information and emotional social support, that is, young mothers (younger age) perceived greater availability of people to talk to, vent and trust (emotional support) as well as greater availability of people to support with guidelines, advice and opinions (information support). This result is in line with the study carried out in New Zealand with 585 parents of children with autism spectrum disorders, a subgroup of CRIANES.²² In this study, the age of the parents was also negatively correlated with the social support perceived, and the hypothesis elaborated by

Table 4. Spearman's correlation between the scores of each dimension of social support and the numerical variables of characterization of the mothers (n=36). Ribeirão Preto- SP, Brazil, 2019.

Variables		Age	Family income	Residents in the house
Material	r=	0.10349	-0.01408	-0.09307
	p=	0.5481	0.9350	0.5893
Affective	r=	-0.29323	-0.13114	-0.19198
	p=	0.0826	0.4458	0.2620
Emotional	r=	-0.34319	0.13965	-0.13538
	p=	0.0404	0.4458	0.4311
Information	r=	-0.42883	0.17117	-0.11842
	p=	0.0091	0.3182	0.4915
Social interaction	r=	-0.03064	0.16215	-0.27018
	p=	0.8592	0.3447	0.1110

r = Spearman's correlation coefficient; p = p value.

the authors to explain such correlation was as follows: the parents' adaptive coping skills tend to increase over time, which can justify the lower availability of people because they understand that the parents do not need so much support as in the beginning.²²

In the same perspective, a study that applied the MOS-SSS instrument to 75 mothers of children born prematurely, suggests that greater availability of social support can be due to the age and marital status of the mothers participating in their study, who were mostly young and with a partner. According to the researchers, modifications and losses of network components are common and, therefore, of the social support available over time.²³

CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

It is concluded that the results presented met the proposed objectives and answered the research questions. Social support was satisfactory in three of the five dimensions, namely: affective, material and social interaction support. The emotional and information dimensions obtained unsatisfactory scores, below 80. Among the variables referring to the social and family context, only the mothers' age showed a significant correlation with social support.

Regarding the implications for the practice, the findings of the present research have the potential to direct specific intervention strategies with families of children who need continuous and complex care in order to strengthen social support, especially the emotional and information dimensions. In addition, it is recommended that Nursing acts assertively in monitoring these children and their families, seeking to support them emotionally, as well as providing them with precise and relevant guidelines for each situation.

With regard to the limitations of the study, the small number of participating mothers is pointed out, which hinders the generalization of the results, as well as the cross-sectional design. It is important to develop new research studies with an increase in the number of participating mothers as well as with a longitudinal design.

FINANCIAL SUPPORT

This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES) – Finance Code 001.

AUTHORS' CONTRIBUTIONS

Study design. Aline Cristiane Cavicchioli Okido. Paula Rossi Baldini

Data collection or production. Paula Rossi Baldini. Bruna Josiane de Lima

Data analysis. Aline Cristiane Cavicchioli Okido. Paula Rossi Baldini. Bruna Josiane de Lima. Juliana Coelho Pina

Interpretation of the results. Aline Cristiane Cavicchioli Okido. Juliana Coelho Pina

Writing and critical review of the manuscript. Paula Rossi Baldini. Bruna Josiane de Lima. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido

Approval of the final version of the article. Paula Rossi Baldini. Bruna Josiane de Lima. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido

Responsibility for all aspects of the content and integrity of the published article. Paula Rossi Baldini. Bruna Josiane de Lima. Juliana Coelho Pina. Aline Cristiane Cavicchioli Okido

ASSOCIATE EDITOR

Aline Aparecida Monroe

REFERENCES

1. Leyenaar JK, O'Brien ER, Leslie LK, Lindenauer PK, Mangione-Smith RM. Families' priorities regarding hospital-to-home transitions for children with medical complexity. *Pediatrics*. 2017;139(1):e20161581. <http://dx.doi.org/10.1542/peds.2016-1581>. PMID:27940509.
2. Berry JG, Hall M, Cohen E, O'Neill M, Feudtner C. Ways to identify children with medical complexity and the importance of why. *J Pediatr*. 2015;167(2):229-37. PMID:26028285.
3. Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child Care Health Dev*. 2017;43(3):323-33. <http://dx.doi.org/10.1111/cch.12430>. PMID:27896838.
4. Góes FGB, Cabral IE. Discursos sobre cuidados na alta de crianças com necessidades especiais de saúde. *Rev Bras Enferm*. 2017;70(1):163-71. PMID:28226056.
5. Dias BC, Arruda GO, Marcon SS. Vulnerabilidade familiar de crianças com necessidades especiais de cuidados múltiplos, complexos e contínuos. *REME*. 2017;21:e1027. <http://dx.doi.org/10.5935/1415-2762.20170037>.
6. Dias BC, Marcon SS, Reis PD, Lino IGT, Okido ACC, Ichisato SMT et al. Family dynamics and social network of families of children with special needs for complex/continuous cares. *Rev Gaúcha Enferm*. 2020;41:e20190178. <http://dx.doi.org/10.1590/1983-1447.2020.20190178>. PMID:32491146.
7. Rodrigues DZ, Ferreira FY, Okido ACC. Sobrecarga do cuidador familiar de crianças com necessidades especiais de saúde. *Rev. Eletr. Enf*. 2018;20:v20a48. <https://doi.org/10.5216/ree.v20.53190>.
8. Cabral IE, de Moraes JR. Familiares cuidadores articulando rede social de criança com necessidades especiais de saúde. *Rev Bras Enferm*. 2015 dez;68(6):1078-85. <http://dx.doi.org/10.1590/0034-7167.20156806121>. PMID:26676430.
9. Griep RH, Chor D, Faerstein E, Werneck GL, Lopes CS. Validade de constructo de escala de apoio social do *Medical Outcomes Study* adaptada para o português no Estudo Pró-Saúde. *Cad Saude Publica*. 2005 jun;21(3):703-14. <http://dx.doi.org/10.1590/S0102-311X2005000300004>. PMID:15868028.
10. Mantri-Langeveldt A, Dada S, Boshoff K. Measures for social support in raising a child with a disability: a scoping review. *Child Care Health Dev*. 2019;45(2):159-74. <http://dx.doi.org/10.1111/cch.12646>. PMID:30690765.
11. Neves ET, Cabral IE, da Silveira A. Family network of children with special health needs: implications for nursing. *Rev Lat Am Enfermagem*. 2013 mar/abr;21(2):562-70. <http://dx.doi.org/10.1590/S0104-11692013000200013>. PMID:23797550.
12. Okido ACC, Cunha ST, Neves ET, Dupas G, Lima RAG. Criança dependente de tecnologia e a demanda de cuidado medicamentoso. *Rev Bras Enferm*. 2016 ago;69(4):718-24. <http://dx.doi.org/10.1590/0034-7167.2016690415i>. PMID:27508478.
13. Hulley SB, Cummings SR, Browner WS, Grady DG, Newman TB. *Delineando a pesquisa clínica*. 4. ed. Porto Alegre: Artmed; 2015.

14. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32(6):705-14. [http://dx.doi.org/10.1016/0277-9536\(91\)90150-B](http://dx.doi.org/10.1016/0277-9536(91)90150-B). PMID:2035047.
15. Pituch KA, Stevens JP. *Applied multivariate statistics for the social sciences*. 6th ed. London: Routledge; 2016.
16. Gomes GC, de Jung BC, Nobre CMG, de Oliveira Norberg PK, Hirsch CD, Dresch FD. Social support network of the family for the care of children with cerebral palsy. *Rev Enferm*. 2019;27:40274.
17. Ma GY, Mak WW. Caregiving-specific worry, affiliate stigma, and perceived social support on psychological distress of caregivers of children with physical disability in Hong Kong. *Am J Orthopsychiatry*. 2016;86(4):436-46. <http://dx.doi.org/10.1037/ort0000171>. PMID:26950080.
18. Lima MBS, Cardoso VDS, Silva SSDC. Parental stress and social support of caregivers of children with cerebral palsy. *Paidéia (Ribeirão Preto)*. 2016;26(64):207-14. <http://dx.doi.org/10.1590/1982-43272664201608>.
19. Dias BC, Ichisato SM, Marchetti MA, Neves ET, Higarashi IH, Marcon SS. Challenges of family caregivers of children with special needs of multiple, complex and continuing care at home. *Esc Anna Nery*. 2019;23(1):e20180127. <http://dx.doi.org/10.1590/2177-9465-ean-2018-0127>.
20. Ribeiro MFM, Sousa ALL, Vandenberghe L, Porto CC. Parental stress in mothers of children and adolescents with cerebral palsy. *Rev Lat Am Enfermagem*. 2014;22(3):440-7. <http://dx.doi.org/10.1590/0104-1169.3409.2435>. PMID:25029055.
21. Thomson J, Shah SS, Simmons JM, Sauers-Ford HS, Brunswick S, Hall D et al. Financial and social hardships in families of children with medical complexity. *J Pediatr*. 2016;172:187-93.e1. <http://dx.doi.org/10.1016/j.jpeds.2016.01.049>. PMID:26897040.
22. Goedeke S, Shepherd D, Landon J, Taylor S. How perceived support relates to child autism symptoms and care-related stress in parents caring for a child with autism. *Res Autism Spectr Disord*. 2019;60:36-47. <http://dx.doi.org/10.1016/j.rasd.2019.01.005>.
23. Almeida LI, Ramos SB, Figueiredo GL. Support and social network in the urban context: perceptions of mothers of premature children. *Aletheia [Internet]*. 2019; [citado 2020 maio 13];52(1):22-36. Disponível em: <http://www.periodicos.ulbra.br/index.php/aletheia/article/view/5279/3458>