

Quality of life and mental disorders in caregivers of children with special needs

Qualidade de vida e transtornos mentais em cuidadores de crianças com necessidades especiais

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ABSTRACT

Objective: to analyze the relationship between quality of life and presence of common mental disorder in caregivers of children who need special health care. **Methods:** cross-sectional study with 87 caregivers of children with special health care needs. A sociodemographic questionnaire, the World Health Organization Quality of Life-bref and the Self-Reporting Questionnaire were used. Descriptive statistical analyses were performed based on frequencies and inferential with Mann-Whitney, Kruskal-Wallis and Spearman's Correlation Coefficient tests. **Results:** mean rank differences were found in the relationship between responsible caregiver and common mental disorder; caregiver has some grievance, undergoes psychopharmacological treatment and psychological monitoring and the physical and general domains of quality of life and common mental disorder. Moreover, there was an inverse correlation between the domains of quality of life and common mental disorder. **Conclusion:** the lower the scores in the quality of life domains, the higher the development of common mental disorder in caregivers.

Descriptors: Quality of Life; Mental Disorders; Caregivers; Disabled Children.

RESUMO

Objetivo: analisar a relação entre qualidade de vida e presença de transtorno mental comum em cuidadores de crianças que necessitam de atenção especial à saúde. **Métodos:** estudo transversal com 87 cuidadores de crianças com necessidades especiais de saúde. Utilizaram-se um questionário sociodemográfico, o *World Health Organization Quality of Life-bref* e o *Self-Reporting Questionnaire*. Realizaram-se análises estatísticas descritivas com base em frequências e inferenciais com testes de Mann-Whitney, Kruskal-Wallis e Coeficiente de Correlação de Spearman. **Resultados:** encontraram-se diferenças nos postos médios na relação entre: cuidador responsável e transtorno mental comum; cuidador apresenta algum agravo, realiza tratamento psicofarmacológico e realiza acompanhamento psicológico e os domínios físico e geral da qualidade de vida e o transtorno mental comum. Verificou-se correlação inversa entre os domínios da qualidade de vida e transtorno mental comum. **Conclusão:** quanto menores forem os escores dos domínios da qualidade de vida, maior será o desenvolvimento de transtorno mental comum em cuidadores.

Descritores: Qualidade de Vida; Transtornos Mentais; Cuidadores; Crianças com Deficiência.

Introduction

Children with special health care needs (CSHCN) present or have a higher risk to present dysfunctions and/or physical, developmental, behavioral, intellectual or emotional limitations that compromise their social performance and activities of daily living⁽¹⁾. The demands of daily care required for these children depend on the nature of the injury or disability and are classified as developmental care, related to neuromotor and muscular dysfunctions, functional and disabling limitations that require functional and developmental stimulation; technological care related to ostomies and invasive devices (gastrostomy, tracheostomy, colostomy, implantable catheters for dialysis, chemotherapy; medication care related to continuous drug management); modified usual care requiring the application of adaptive technologies in the activities of daily living; mixed care, which combines one or more specific care technologies described above, excluding technological care; and, finally, clinically complex care that combines the care technologies described above, including technological care⁽²⁻³⁾.

The care demands from children with special health care needs are inherent to the complexity of their clinical and developmental condition and affect the family dynamics, requiring the structuring of a comprehensive and coordinated formal and informal support network, vital for the socioemotional development and well-being of the whole family⁽⁴⁾, with special repercussions for the scope of nursing work at all levels of health care, especially with regard to the management of extended care for this audience.

The level of dependence on CSHCN impacts on the caregivers' routine, psychosocial needs, and health, causing changes in sleep patterns, loss of appetite, feelings of helplessness, social isolation, and depressive and anxious symptoms, in addition to impacting the family's financial organization with exhaustive routines of caregiving activities and increased demand for health services⁽³⁾.

In this context, the aspects involving the care of these children may have as an aggravating factor the

development of common mental disorders in caregivers. The common mental disorder is conceptualized as a condition of psychological suffering manageable, a priori, at the level of primary health care, characterized by non-psychotic symptoms such as insomnia, fatigue, irritability, forgetfulness, difficulty in concentration and somatic complaints, associated with living conditions and work situation and that impairs the family, social, personal and occupational life⁽⁵⁾. Being a pathological condition, the common mental disorder encompasses anxious and depressive manifestations that, despite not fulfilling sufficient criteria for the classical diagnosis of depressive or anxious disorder, have an impact on mood, feelings and psychosocial functioning, and may vary according to the severity and duration of symptoms⁽⁶⁾.

Besides the manifestation of common mental disorder, the quality of life of caregivers of children with special health care needs can be impaired⁽⁷⁻⁸⁾ and negatively influence their perception of their own life condition, interfere with their cultural standards and moral values, making them rethink their purposes, expectations, and maximize concerns⁽⁹⁾.

In view of the above, the questions of this research are outlined: do the challenges of daily care of CSHCN impact the quality of life and the occurrence of common mental disorders in caregivers? Is there a relationship between quality of life and the probability of presenting common mental disorder in caregivers of CSHCN? Far from explaining all the nuances involved in the life and health condition of caregivers of CSHCN and facing the intrinsic complexity that involves this phenomenon, the aim of the present study was to analyze the relationship between quality of life and presence of common mental disorder in caregivers of children who need special health care.

Methods

This was a cross-sectional study conducted in a Parent and Friends of Exceptional Children Association and in a psychomotor rehabilitation service of a city in the west of Santa Catarina, Brazil. Included in

the study were people over 18 years of age who develop direct care of children with special health needs in the daily life at home, regardless of consanguinity, being defined as caregivers.

The study sample was composed of 87 caregivers of children with special health care needs, selected by convenience based on a population of 250 caregivers. For the sample calculation, an estimated percentage of 0.5%, confidence interval of 95%, and a sampling error of 0.085% were considered. Participants were invited to participate in the survey when dropping off or picking up children at their respective services. Data collection was performed between August and October 2017 by applying the following instruments: sociodemographic characterization questionnaire developed by the authors of the study, World Health Organization Quality of Life (WHOQOL-bref)⁽¹⁰⁾ and Self-Reporting Questionnaire (SRQ-20)⁽⁵⁾.

The characterization questionnaire presented sociodemographic and economic data of the caregivers (gender, caregiver responsible, age, ethnicity, marital status, level of education, work status, and level of economic classification established by the Brazilian Economic Standard Criteria Classification created by the Brazilian Association of Business and Research and based on the Family Budget Survey of the Brazilian Institute of Geography and Statistics which stratifies the average family income in levels between A - highest family economic level and E - lowest level), as well as data on CSHCN (sex and age), the characteristics of care required by the children and information on the caregivers' health (time of daily care, health problems, psychopharmacological treatment and psychological follow-up).

The WHOQOL-bref proposes to measure the perception of satisfaction that people have regarding their quality of life, considering their position in life in their cultural context and value system. The answers to the items of the instrument are organized in Likert type scales of five points/levels with five gradual possibilities of answer for each item and has two general items, one of which is related to the perception of quality of life itself and the other, to the satisfaction with

one's own health, and other 24 items related to the four domains assessed (physical, psychological, social relations and environment). Each domain is assessed individually, and the scores are arranged in a positive way, so the higher the response scores of each domain, the better the quality of life. The raw scores were adjusted and vary between four and 20 points, representing the worst and the best quality of life in each domain, respectively⁽¹⁰⁾. Regarding the evaluation of psychometric properties of the domains of WHOQOL-bref, it was possible to identify the internal consistency through Cronbach's alpha in the domains: physical (0.773); psychological (0.688); social relations (0.688); environment (0.689); and general quality of life (0.696).

The SRQ-20 is a sensitive instrument to screen for psych emotional disorders, applied to screen for common mental disorder. The SRQ-20 presents 20 items with "yes" or "no" responses, with scores ranging from zero to 20. The cut-off score for the probability of common mental disorder in males corresponds to a score equal to or higher than six, and in females, to a score equal to or higher than eight⁽⁵⁾. The internal consistency of the SRQ-20, evaluated by Cronbach's alpha was 0.845.

Data were double and independently entered in the Epi Info® software and analyzed using the PASW Statistics (Statistical Package for the Social Sciences) version 18.0 for Windows. Descriptive statistics, inference analyses between quality of life and common mental disorder and other study variables were performed. The Shapiro-Wilk test was used to verify the normality of the quantitative variables (quality of life domains and common mental disorder). Then, non-parametric tests were performed: Mann-Whitney test (two categories) and Kruskal-Wallis test (three categories or more) to compare the mean ranks of the variables and Spearman's correlation coefficient for the relationship between the domains of quality of life and the common mental disorder. In the hypothesis tests, a significance level ≤ 0.05 was considered.

This research was conducted according to the required ethical standards and approved by the

Research Ethics Committee of the Federal University of the Southern Border under opinion number 2,194,442/2017 and Certificate of Ethical Appreciation Submission: 68764017.1.0000.5564.

Results

We evaluated 87 caregivers of children with special health needs, who presented a general median of 16.0 quality of life and the other domains: physical (14.9); psychological (14.4); personal relations (14.7); and environment (13.5). Regarding the common mental disorder, the median score was 6.0, and 44.8% of the caregivers were more likely.

Among the caregivers, 81.6% were the children's mothers, 92% were female with a mean age of 35.2 ± 9.77 years, ranging from 18 to 68 years old, 69.0% were married or in a stable union, 52.9% had attended or finished high school, 41.4% were unemployed and 60.9% presented economic classification level C. Regarding the profile of the children, 62.1% were male, with mean age of 5.3 ± 3.03 , ranging from 1 to 11 years old. The responsible caregiver presented mean rank difference in relation to common mental disorder ($p=0.007$) (Table 1). For Dunn's test, it was possible to identify significant difference between mother caregivers and father caregivers of children with special health care needs ($p=0.027$).

Table 1 – Sociodemographic and economic profile and comparison of mean ranks of the domains of quality of life and common mental disorder. Chapecó, SC, Brazil, 2017. (n=87)

Variables	n (%)	Domains					Common mental disorder
		Physical	Psychological	Social Relationships	Environment	General	
Gender							
Female	80(92.0)	14.86	14.40	14.67	13.00	16.00	6.00
Male	7(8.0)	14.86	14.40	14.67	14.00	16.00	6.00
P-value		0.936	0.470	0.817	0.082	0.694	0.861
Responsible caregiver [†]							
Mother	71(81.6)	14.86	14.40	14.67	13.00	16.00	7.00
Father	7(8.0)	16.57	15.20	16.00	13.50	16.00	2.00
Other relative	9(9.2)	15.43	15.20	13.33	14.00	14.00	3.00
P-value		0.110	0.377	0.991	0.225	0.362	0.007
Caregiver age (years) [†]							
18 to 30	25(28.7)	14.86	14.40	14.67	13.50	16.00	8.00
31 to 40	42(48.3)	14.86	14.40	14.67	13.00	16.00	6.00
≥ 41	20(23.0)	15.43	14.40	15.33	13.75	15.00	5.00
P-value		0,623	0.891	0,855	0.629	0.517	0.106
Age of CSHCN (years) [†]							
1 to 4	39(44.8)	15.43	14.40	14.67	13.50	16.00	5.00
5 to 8	33(37.9)	14.29	14.40	14.67	13.00	16.00	6.00
≥ 9	15(17.2)	14.86	14.00	14.67	14.00	16.00	7.00
P-value		0.194	0.721	0.469	0.892	0.447	0.436
Marital status*							
Lives alone	27(31.0)	15.43	14.40	13.33	14.00	14.00	6.00
Married/stable union	60(69.0)	14.86	14.40	14.67	13.00	16.00	6.00
P-value		0.793	0.743	0.202	0.861	0.471	0.195
Level of education [†]							
Illiterate	3(3.4)	14.86	13.60	13.33	11.50	16.00	7.00
Elementary school	12(13.8)	14.14	14.40	14.00	13.25	14.00	9.00
High school	46(52.9)	14.86	14.40	14,67	1350	16.00	6.00
Higher education	26(29.9)	15.43	14.40	14.67	13.25	16.00	5.00
P-value		0.689	0.850	0.960	0.310	0.536	0.812
Employment status [†]							
Unemployed	36(41.4)	15.43	14.40	14.67	13.50	16.00	5.00
Employed	31(35.6)	14.29	13.60	14.67	13.00	16.00	7.00
Retired	20(23.0)	15.43	14.40	14.00	13.75	15.00	5.00
P-value		0.088	0.474	0.601	0.363	0.663	0.451
Economic classification [†]							
B	30(34.5)	14.57	14.80	14.67	14.25	16.00	6.50
C	53(60.9)	14.86	13.60	14.67	13.00	16.00	6.00
D	4(4.6)	15.43	15.60	14.00	12.50	17.00	6.50
P-value		0.875	0.186	0.742	0.116	0.119	0.909

*Mann-Whitney test; [†]Kruskal-Wallis test; CSHCN: children with special health care needs

Regarding the daily care time, 72.4% of the caregivers spent between 17 and 24 hours, and 48.3% of the children with special health needs required developmental care. Regarding the caregiver's health,

24.1% had some health problem, 13.8% underwent psychopharmacological treatment and 14.9% were under psychological follow-up (Table 2).

Table 2 – Caregiving characteristics of children with special health needs and caregivers' health and comparison of mean ranks of the domains of quality of life and mental disorder. Chapecó, SC, Brazil, 2017. (n= 87)

Variables	n (%)	Domains					Common mental disorder	
		Physical	Psychological	Social Relationships	Environment	General		
Daily Care Duration† (hours per day)								
1 to 8	6(6.9)	15.43	15.20	13.60	14.67	13.50	16.00	5.00
9 to 16	18(20.7)	14.57	14.40		14.00	12.50	14.00	7.50
17 to 24	63(72.4)	15.43	15.20	13.60	14.67	13.50	16.00	6.00
P-value		0.334	0.457		0.914	0.511	0.639	0.228
Demand for the care of CSHCN†								
Development	42(48.3)	15.43	14.40		14.67	13.00	13.00	5.50
Medications	1(1.1)	13.14	14.40		13.33	14.50	14.50	5.00
Mixed	39(44.8)	14.86	14.40		14.67	13.50	13.50	6.00
Complex	5(5.7)	10.29	15.20		16.00	12.00	12.00	14.00
p-value		0.311	1.000		0.594	0.418	0.501	0.840
Caregiver has any grievances*								
No	66(75.9)	15.43	14.40		14.67	13.00	16.00	5.00
Yes	21(24.1)	13.71	14.40		13.33	14.50	12.00	8.00
P- value		0.010	0.288		0.510	0.557	0.001	0.146
Performs psychopharmacological treatment*								
No	75(86.2)	15.43	14.40		14.67	13.50	16.00	5.00
Yes	12(13.8)	12.86	13.60		14.00	13.50	11.00	10.00
P value		0.003	0.184		0.639	0.706	0.028	0.011
Performs psychological follow-up*								
No	74(85.1)	15.43	14.40		14.67	13.50	16.00	5.00
Yes	13(14.9)	13.71	13.60		13.33	13.50	12.00	10.00
P- value		0.004	0.090		0.188	0.783	0.049	0.001

*Mann-Whitney test; †Kruskal-Wallis test; CSHCN: children with special health care needs

The caregiver who did not manifest any health problem, who did not undergo psychopharmacological treatment and who did not undergo psychological follow-up presented better mean scores in the physical domain and in the general domain of quality of life. In addition, the caregiver who needed to undergo psychopharmacological treatment and psychological follow-up presented higher scores of common mental disorders in relation to the one who did not undergo psychopharmacological treatment and psychological follow-up (Table 2).

Table 3 – Comparison of mean ranks and correlation of quality-of-life domains and common mental disorder of caregivers of children with special health care needs. Chapecó, SC, Brazil, 2017. (n=87)

Quality of life domains	Common mental disorder			
	Yes	No	p*	r†
Physical	13.14	16.00	0.000	-0.705‡
Psychological	12.80	15.20	0.000	-0.623‡
Social relations	13.33	16.00	0.004	-0.319‡
Environment	12.50	14.00	0.002	-0.448‡
General quality of life	14.00	16.00	0.000	-0.552‡

*Mann-Whitney test; †Spearman's correlation coefficient; ‡Significant correlation at $p \leq 0.01$

When comparing the mean scores of the common mental disorder in relation to the domains of quality of life, it was possible to observe that the caregivers who were likely to have the presence of common mental disorder exposed significantly lower means in all domains of quality of life (Table 3). There were significant and inverse correlations between the domains of quality of life and the probability of presence of common mental disorder: high correlation between common mental disorder and physical ($p=0.000$) and psychological ($p=0.000$) domains; moderate correlation between common mental disorder and the domains of environment ($p=0.000$) and general quality of life ($p=0.000$); and low correlation between common mental disorder and social relations domain ($p=0.000$) (Table 3).

Discussion

The limitation of this study is its cross-sectional nature, considering that the scales used are intended for a punctual evaluation at the time of their application. Thus, considering the relevant position of nurses to ensure the quality of care for children with special health needs and the qualification of caregivers for the management of home care that enhances the autonomy of these children and adolescents in everyday life, this study contributes to an expanded understanding in nursing about the context of life and family arrangements in this group and intends to subsidize intersectoral and psychosocial interventions in the territory that strengthen the support network of these people.

The participants evaluated their quality of life as good/average and presented borderline results in the common mental disorder, indicating a higher probability of not presenting a common mental disorder. The relationship between the scales was inversely correlated, evidencing a relationship between all domains of quality of life and the presence of common mental disorder in caregivers of children with special health needs. Another aspect identified was that the

mother as the main caregiver presented better mean scores of common mental disorders in relation to the responsible caregiver father. Thus, the mean scores of common mental disorders in the mother may be associated with the greater insertion and commitment of women in health care practices⁽¹¹⁾.

The impairment of quality of life and mental health in this public has been related to the demands of care and health care presented by children with special health needs⁽¹¹⁻¹³⁾. Thus, it is perceived those caregivers, depending on the demand and overload of care, may present feelings of vulnerability and emotional readjustment, increasing the risk of disease, need for psychosocial and medication monitoring⁽¹⁴⁾. These aspects are directly related to the physical and general domains of quality of life, as in the common mental disorder. In addition, these caregivers, who are mostly mothers, often need to give up their jobs to directly assist their children⁽¹²⁾, which was verified by the present study, considering the time from 17 to 24 hours of care practices with these children.

Besides the care, which includes hygiene, feeding, locomotion and management of equipment and adaptive technological and health resources, which require full dedication⁽¹³⁾ and tend to be financially burdensome, the literature indicates that caregivers have negative feelings, frustration and guilt for having given birth to a child with some chronic health condition⁽¹⁵⁻¹⁶⁾. The demands generated by this context potentiate anxiety, depressive symptoms, stress and tension reactions, feelings of impotence and helplessness in caregivers, which may culminate in social isolation⁽¹⁷⁾ and worsen the family situation.

It is noteworthy that, besides the typical care related to growth and development, the caregiver needs to meet the other specific demands of each pathology associated with the child's condition, which may require permanent monitoring in health and psychomotor rehabilitation services and hospitalizations⁽¹⁸⁾.

The multidimensional indicators of quality of life of parent caregivers of children with special health care needs point out that in this construct, qua-

lity of life is associated mainly with three aspects: children's characteristics (age, disease severity, behavior, disabilities and associated diseases); caregiver's characteristics (marital status, family coping patterns and socioeconomic status) and environmental factors (school environment, consumption of medications by the child, access to support services, age of the caregiver's spouse and presence of a domestic worker in the household)⁽¹⁹⁾. The caregiver's perception of his routine with the children tends to be influenced by stressful experiences, adherence to health-promoting behaviors, and by social support⁽²⁰⁾.

Conclusion

When analyzing the domains of quality of life and the common mental disorder, it was identified that the domains (physical, psychological, social relations, environment and general quality of life) present an inverse correlation with the common mental disorder in caregivers of children with special health needs. In this context, the higher the mean ranks of the quality-of-life domains of a caregiver of children with special health care needs, the lower the mean ranks of common mental disorder. Thus, the findings of this study reinforce those caregivers of children with special health needs are vulnerable to decreased levels of quality of life, regardless of domain, which is associated with the likelihood of developing common mental disorder.

Collaborations

Pegorin TC, Rosa L and Conceição VM contributed to the conception and design process, data analysis and interpretation, and article writing. Leo MMF, Zuge SS, and Brum CN contributed to the conception and design, analysis and interpretation of data, writing of the article, relevant critical review of the intellectual content, and approval of the version to be published.

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