

RESILIENCE OF FAMILY CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH CANCER AND ASSOCIATED FACTORS: MIXED METHOD STUDY

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ABSTRACT

Objective: to analyze the relationship between resilience and associated factors (stress, minor psychiatric disorders and quality of life) of family caregivers with children and adolescents undergoing cancer treatment.

Method: mixed methods research, with sequential explanatory strategy, carried out with family caregivers of children and adolescents undergoing cancer treatment in a public hospital in the Rio Grande do Sul State, Brazil. Data collection took place from February to September 2018. The quantitative study was cross-sectional in nature, and the qualitative research was descriptive-exploratory. Participants included 62 family caregivers in the quantitative stage and 16 responded to semi-structured interviews. An instrument containing sociodemographic, economic, labor, health and resilience scales (CD-RISC-10-Br), minor psychiatric disorders (MPDs) (SRQ-20), quality of life (QOL) (WHOQO-Bref) and stress and semi-structured interview were applied. Descriptive and inferential statistics were used for quantitative data and content analysis for qualitative data.

Results: family caregivers had a moderate level of resilience (48.4%); high level of perceived stress (41%); suspicion for MPDs (45%). They presented satisfaction in the physical QoL domains (67.7%); psychological (62.9%); personal relationships (61.3%), and dissatisfaction in the environment domain (75.8%). The interviews reported for health changes that could trigger MPD, stress and changes in quality of life.

Conclusion: high level of stress; suspicion for MPD and low QoL, with the environment, were evidenced as associated factors for a lower level of resilience of family caregivers. The need to develop actions that strengthen resilience was perceived, as caregivers were essential for the effectiveness of the care plan for children and adolescents undergoing cancer treatment.

DESCRIPTORS: Psychological resilience. Nursing. Cancer. Caregivers. Caregiver burden.

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RESILIÊNCIA DE CUIDADORES FAMILIARES DE CRIANÇAS E ADOLESCENTES COM CÂNCER E FATORES ASSOCIADOS: ESTUDO DE MÉTODOS MISTOS

RESUMO

Objetivo: analisar a relação entre resiliência e fatores associados (estresse, distúrbios psíquicos menores e qualidade de vida) de cuidadores familiares de crianças e adolescentes em tratamento oncológico.

Método: pesquisa de métodos mistos, com estratégia explanatória sequencial, realizado com cuidadores familiares de crianças e adolescentes em tratamento oncológico em um hospital público do interior do Rio Grande do Sul, Brasil. A coleta de dados ocorreu de fevereiro a setembro de 2018. O estudo quantitativo foi de natureza transversal e a pesquisa qualitativa teve caráter descritivo-exploratório. Participaram 62 cuidadores familiares na etapa quantitativa e 16 responderam as entrevistas semiestruturadas. Aplicaram-se instrumento contendo questões sociodemográficas, econômicas, laborais, de saúde e escalas de resiliência (CD-RISC-10-Br), distúrbios psíquicos menores (DPMs) (SRQ-20), qualidade de vida (QV) (WHOQO-Bref) e estresse e entrevista semiestruturada. Utilizou-se estatística descritiva e inferencial para os dados quantitativos e análise de conteúdo para os qualitativos.

Resultados: os cuidadores familiares possuíam nível moderado de resiliência (48,4%); alto nível de estresse percebido (41%); suspeição para distúrbios psíquicos menores (45%). Apresentaram satisfação nos domínios de qualidade de vida físico (67,7%); psicológico (62,9%); relações pessoais (61,3%), e insatisfação no domínio meio ambiente (75,8%). As entrevistas reportaram para alterações de saúde que poderiam desencadear distúrbios psíquicos menores, estresse e alterações na qualidade de vida.

Conclusão: alto nível de estresse; suspeição para distúrbios psíquicos menores e baixa qualidade de vida, com o meio ambiente, evidenciaram-se como fatores associados para um menor nível de resiliência dos cuidadores familiares. Percebeu-se a necessidade de desenvolver ações que fortalecessem a resiliência, pois os cuidadores foram essenciais para a efetividade do plano de cuidado de crianças e adolescentes em tratamento oncológico.

DESCRITORES: Resiliência psicológica. Enfermagem. Neoplasias. Cuidadores. Fardo do cuidador.

RESILIENCIA DE CUIDADORES FAMILIARES DE NIÑOS Y ADOLESCENTES CON CÁNCER Y FACTORES ASOCIADOS: ESTUDIO MÉTODO MIXTO

RESUMEN

Objetivo: analizar la relación entre la resiliencia y los factores y el tratamiento del cáncer asociados (estrés, trastornos menores de la calidad de vida) de los cuidadores de niños y adolescentes familiares.

Método: investigación de investigación, con estrategia secuencial, realizada por niños y adolescentes ex plan con tratamiento oncológico familiar mixto en un hospital público del interior de Rio Grande do Sul, Brasil. La recolección de dato se llevó a cabo de febrero a septiembre 2018. El estudio cuantitativo fue de carácter transversal, y la investigación cualitativa fue descriptiva-exploratoria. Participaron 62 cuidadores familiares en etapa cuantitativa y 16 respondedores a entrevista semiestruturada. Un instrumento que contiene escalas sociodemográficas, económicas, laborales, de salud y resiliencia (CD-RISC-10-Br), trastornos psíquicos menores (ODM) (SRQ-20), calidad de vida (CV) (WHOQO-Bref) y estrés y -Se aplicó entrevista estructurada. Se utilizaron estadísticas descriptivas e inferenciales para datos cuantitativos y análisis de contenido para datos cualitativos.

Resultados: los cuidadores familiares presentaron un nivel moderado de resiliencia (48,4%); alto nivel de estrés percibido (41%); sospecha de MDD (45%). Presentaron satisfacción en los dominios de la CV física (67,7%); psicológico (62,9%); relaciones personales (61,3%) e insatisfacción en el dominio medio ambiente (75,8%). Las entrevistas informaron sobre cambios en la salud que podrían desencadenar PMD, estrés y cambios en la calidad de vida.

Conclusión: alto nivel de estrés; la sospecha de SMD y la baja CV, con el medio ambiente, se evidenciaron como factores asociados para un menor nivel de resiliencia de los cuidadores familiares. Se percibió la necesidad de desarrollar acciones que fortalezcan, los cuidadores fueron fundamentales para la efectividad del plan de atención a niños y adolescentes con tratamiento oncológico.

DESCRITORES: Resiliencia psicológica. Enfermería. Neoplasias. cuidadores La carga del cuidador.



INTRODUCTION

Despite its low incidence (2 to 3%), childhood cancer is the second leading cause of death in children under 19 years of age in Brazil, second only to external causes. However, the number of cases has been growing significantly, presenting itself as a public health problem¹. The treatment of these comorbidities is performed in specialized centers that are often far away from the patients' places of residence. As a result, children/adolescents need to move away from family life, school and friends in order to receive treatment.

During this trajectory, which begins with the diagnosis, the active presence of the family is considered fundamental, because its actions and decisions interfere in the care of patients². Despite this, the family needs to deal, both with demands that involve the treatment and care of the child or adolescent and with those arising from their own uncertainties and anxieties³. Coping with childhood cancer implies a period of great tension and suffering; obstacles and difficulties to be overcome, and changes in the daily life and life of family caregivers. This can change the way the family lives their day to day lives, requiring reorientation in their personal expectations and future projections⁴. A family caregiver is understood to be the person in the family unit responsible for monitoring the illness and treatment process; for assisting in the various tasks of direct or indirect care, in facing challenges and making decisions²⁻³. In the case of children and adolescents, it is understood that, in addition to parents, other family members, such as grandparents, uncles aunts, can assume this role.

Painful procedures and treatments, which are often necessary, cause feelings of helplessness, fear of death, insecurity and difficulty in adapting to the different routine of life. In some cases, they give up their lives to dedicate themselves to the care of the child/adolescent, which can lead to physical and emotional overload. The constant and exhausting demands can lead them to feel stress and experience signs and symptoms of minor psychiatric disorders (MPDs), with negative repercussions on their quality of life (QoL)²⁻⁵.

The MPDs refer to anxious, depressive or psychosomatic symptoms, which do not meet all the criteria for diagnosing mental disorders, such as sadness, anxiety, fatigue, irritability, forgetfulness, difficulty concentrating, insomnia and somatic complaints. These symptoms can cause changes in sleep quality, diet and other aspects that impact the quality of life of family caregivers^{3-4,6}.

However, in the midst of the stressful circumstances, family caregivers tend to be resilient, with the capacity to reorganize and overcome adversities. Resilience refers to the human being's ability to overcome stressful events that occur throughout life. It is the ability that the person has to face the changes, to overcome obstacles and to recover after diseases, injuries or other difficulties⁷⁻⁹. It is a set of dynamic, psychological and social processes that help in coping with stressful situations, such as cancer, whether for patients or family members, i.e, it results in a positive adaptation in contexts of adversity and significant risks⁹.

Based on a literature review on the subject, a gap in knowledge was evidenced regarding the development of mixed methods research, which could indicate the existence of a relationship between resilience, stress, psychological disorders and quality of life of family caregivers of children and adolescents with cancer. Only a few studies were found with caregivers/family members of children and adolescents undergoing cancer treatment and the relationship between resilience and associated factors such as stress, overload, quality of life and psychological disorders^{7-8,10}. In this context, the present study aimed to analyze the relationship between resilience and associated factors (stress, minor psychiatric disorders and quality of life) of family caregivers of children and adolescents undergoing cancer treatment.

METHOD

This was a mixed methods research, with a sequential explanatory strategy (QUANT → QUAL), which took place in two distinct phases, in which the second phase was intended to monitor the results of the first¹¹. Thus, in relation to the attribution of weight, priority was given to quantitative research¹¹. The Mixed Methods Appraisal Tool was used to assess and strengthen the methodological rigor of the research¹². The quantitative study was cross-sectional and the qualitative research had a descriptive-exploratory character.

The study site was the pediatric oncology hospitalization unit of a public teaching hospital in the inner city of Rio Grande do Sul State, Brazil. This oncology service is a reference in the state, as it is one of the few specialized, public centers for the diagnosis and treatment of childhood cancer.

Quantitative data were collected by means of an instrument containing sociodemographic, economic, labor, health and resilience scales (CD-RISC-10-Br), minor psychiatric disorders (MPD) (SRQ-20), quality of life (QoL) (WHOQOL-Bref) and stress. Qualitative data were produced through semi-structured interviews. They explored themes related to the discovery of the disease, fears and desires; to the routine of care after the discovery of the disease; changes in the health of family caregivers; the positive and negative aspects of the care process; difficulties; social support received; to the coping process, and what helped them at that moment.

Data collection occurred from February to September 2018, according to the date of hospitalization (convenience and non-probabilistic sample). In the period, 58 hospitalizations were recorded.

The quantitative stage was performed with 62 family caregivers who agreed to participate in the research. In case more than one person exercised the role of caregiver, both were invited to participate in the research and the interview was conducted individually. The research instrument contained questions about: sociodemographic data (gender, age, education, number of children, housing, religion); economic and labor (if employment, income, origin of income were possessed and maintained); (previous disease, use of medication, physical activity); the Connor Davidson Resilience Scale (CD-RISC-10-Br);¹³ the Self-Reporting Questionnaire-20 (SRQ-20);¹⁴ the WHOQOL-bref¹⁵ and the Perceived Stress Scale (PSS-14)¹⁶.

The CD-RISC-10-Br presented 10 items, which investigated factors, such as: adaptation to changes; deal with any situation; seeing the funny side of the problems; dealing with stressful situations; land on one's feet; achieve objectives, concentration and clear thinking; not be discouraged by failure; be a strong person and deal with unpleasant feelings. The answer options were on a Likert scale, from 0 (never true) to 4 (always true). The score ranged from 0 to 40 points. The higher the score, the higher the level of resilience of the individual. The score from 0 to 24 referred to the low level of resilience, from 25 to 74, at a moderate level, and from 75 to 100 considered a high level of resilience¹³.

The SRQ-20¹⁴ was used to identify MPDs related to non-psychotic symptoms. Twenty dichotomous questions (0 and 1) were presented, in which score one (1) indicated that the symptoms were present in the last month, and zero (0) when they were absent. The score of seven or more positive responses was considered as suspicion for MPDs.¹⁷

QoL was measured by the Brazilian version of the WHOQOL-bref¹⁵. It referred to the individual's perception of their position in life, in the context in which they lived, and in relation to their goals, expectations, standards and interests¹⁸. The instrument was composed of 26 questions, two of which referred to perception about QoL and health, and 24 were related to four domains (physical, psychological, social relations and environment). The answers were given on a Likert scale, from 1 to 5 points. The higher the result, the better the quality of life^{15,19}.

The perceived stress was evaluated through the Brazilian version of the PSS-14¹⁶. There were 14 questions, with answer options, ranging from 0 (never) to 4 (always). The score ranged from zero (no stress) to 56 (extreme stress). Scores between 22 and 27 were considered with low perceived stress; 28 to 29, and high perceived stress, from 30 to 43 points.

The population consisted of all family caregivers of children and adolescents who were hospitalized for cancer treatment, and who met the criteria of being a family caregiver during the hospitalization period, and aged ≥ 18 years. As instructed by the team, caregivers who presented some form of cognitive deficit were excluded.

Independent double typing was performed by typists previously trained by the responsible researcher. Typing errors and inconsistencies were checked and corrected in the review process, using the Epi-Info® “validate” software (version 6.4). The SPSS software (Statistical Package for the Social Sciences, SPSS Inc, Chicago) version 18.0 for Windows was used for analysis.

The reliability of responses to the instruments was tested using Cronbach’s Alpha Coefficient. Values >0.70 were considered indicative of internal consistency. Categorical variables were evaluated using absolute (n) and relative (%) frequencies. Bivariate analyzes were performed using Pearson’s chi-square and chi-square tests with correction, with a significance level of 5% ($p < 0.05$).

Qualitative data were collected through 16 semi-structured interviews with family caregivers who participated in the quantitative study and who agreed to voluntarily participate in the second stage of the research. The criterion to end the interviews was the achievement of theoretical saturation, i.e., when the collected data allowed the study objectives to be answered and began to be repeated²⁰. The interviews lasted from 20 minutes to 1 hour and 23 minutes and were conducted by a single interviewer. They were recorded and fully transcribed, and included hesitations, laughter and silence²¹, using the Microsoft Office Word® program.

Data were submitted to Bardin’s content analysis, following the steps of pre-analysis, material exploration, treatment of results, inference and interpretation²¹. From the floating reading of the transcribed material, we sought, through immersion in the data, to elaborate possible codes that were grouped by convergence of meaning into categories, which in comparison with the set of information led to the organization phase in the content analysis²¹.

The qualitative data analysis was performed in the light of quantitative results, i.e., more understanding of the significant findings of the first stage of the research was sought through interviews¹¹. Afterwards, it was interpreted to what extent and in what way the qualitative results explained and added insights to the quantitative results¹¹. The relevant literature on the subject was also considered.

To carry out this research, ethical precepts were preserved, according to Resolution 466/2012, of the National Health Council, which establishes parameters for research involving human beings. After receiving information regarding the research, all participants proceeded with reading and signing the Free and Informed Consent Term (FICT). The family members’ statements were coded with the letter “F” and an assigned number, according to the order in which the quantitative data were collected.

RESULTS

The sociodemographic profile of family caregivers showed that 80.6% (n=50) were female and predominantly composed of mothers (67.7%; n=42). The others were parents, grandparents, an aunts and girlfriends. Ages ranged from 37 to 66 years (54.8%; n=34), with complete high school (35.5%; n=22); married or in civil union (69.4%, n=43); had one child (32.3%, n=20), and practiced some

religion (77.4%, n=48). Regarding health status, 79% (n=49) reported not having a previous disease, and 77.4% (n=48) did not use medications. Among those who used medication: antidepressants, antihypertensives and hormonal repositors, were mentioned. 32.3% (n=20) of the family caregivers who practiced physical activity before the discovery of the diagnosis, no longer practiced. Regarding leisure activity, 67.7% (n=42) reported having some activity, such as drinking chimarrão, walking, reading and crocheting or knitting, for example.

Table 1 describes the levels of resilience and perceived stress of family caregivers.

Table 1 – Distribution of family caregivers of children and adolescents undergoing cancer treatment, according to the level of resilience and perceived stress. Santa Maria, RS, Brazil, 2018. (n= 62)

Health variables	Low level n (%)	Moderate level n (%)	High level n (%)
Resilience	16 (25.8)	30 (48.4)	16 (25.8)
Perceived stress	18 (29.5)	18 (29.5)	25 (41)

It was possible to verify that, despite the difficulties experienced by family caregivers in caring for a child or adolescent undergoing cancer treatment, there was a predominance of a moderate level of resilience (48.4%; n=30). This finding may be associated with the positive view they had of the situation they were experiencing. In this way, positivity and learning seemed to be factors that promoted resilience, as the testimonies illustrate: [...] *I think that what will remain is the appreciation of life, appreciation of the family, appreciation of the silent hug [...] family* (F13). [...] *It would take me a long time to talk about everything I learned in each hospitalization. This disease has a lot to teach: what seems to be bad can turn into good [...]* (F2).

Another factor that could explain the strengthening of the resilience of family caregivers was the support they received during the treatment of children or adolescents. The reports showed that this support was essential in the process of coping with childhood cancer: [...] *God forbid, if it wasn't for my mother! And the other mothers, we talk, sometimes we cry. One consoles the other [...]. Thank God my family is always fighting. I feel like I'm not alone* (F4).

The support received at this time seemed to be fundamental during the experience. However, although family caregivers could see a positive side, such as union, support, teachings and appreciation of life, the context was still stressful. Thus, it was possible to verify that family caregivers had a high level of perceived stress level (41%), according to Table 1.

Among the manifestations of perceived stress, nervousness and irritation stood out. This result was convergent with the qualitative findings of the study, in which family caregivers reported an increase in the level of stress and concern during the care process, as pointed out in the statements: [...] *much more stressed and more nervous* (F3). *I'm much more angry, everything annoys me* (F16).

Table 2 presented the percentage of suspicion regarding MPDs in family caregivers, as well as satisfaction/dissatisfaction with QoL in the physical, psychological, social relations and environment domains.

Table 2 – Distribution of family caregivers of children and adolescents undergoing cancer treatment, according to the level of suspicion for Minor Psychiatric Disorders (MPDs) and quality of life. Santa Maria, RS, Brazil, 2018. (n= 62)

SRQ-20	Yes n (%)	No n (%)
Suspicion for MPDs	27 (45)	33 (55)
Whoqol-Bref (QV)	Unsatisfied n (%)	Satisfied (%) n (%)
Physical domain	20 (32.3)	42 (67.7)
Psychological domain	23 (37.1)	39 (62.9)
Domain social relations	24 (38.7)	38 (61.3)
Environment domain	47 (75.8)	15 (24.2)

Note: MPD – minor psychiatric disorders; QoL – Quality of life.

Suspicion for MPD was present in 45% (n=27) of family caregivers. Some questions of the SRQ-20 instrument referred to sleep quality and eating habits. These were common alterations present in the reports: [...] *and I do not sleep, sleep is not the same* (F2). [...] *I couldn't get my sleep in order anymore. In addition to the pounds I have gained, the anxiety makes me eat* (F6).

Other symptoms characteristic of MPD corresponded to the presence of anxious, depressive and psychosomatic symptoms. These were explicit in the participants' statements during the care process: [...] *much more anxious, more nervous, more everything, all together* (F8). [...] *Anxiety, chest pain* (F16).

Despite presenting high levels of stress and propensity for MPD, they were satisfied in the physical domain (67.7%) and in the psychological domain (62.9%) of QoL. Possibly because, when asked about changes in health status at first, they reported not having them, however, when asked about the occurrence of psychological changes, they reported experiencing several problems during the treatment. This finding could be clarified in the analysis of interviews in which family caregivers interpreted that changes in health status were restricted to physical ones: *I have no health changes [...]. Ah, the emotional changes a lot* (F4). *I am healthy [...]. Ah, the psychological, yes [...]. very worried [...]. I feel more nervous* (F3).

In an attempt to appear strong and courageous, family caregivers often cried and suffered alone, in order not to externalize feelings of fear or anguish, in front of the child or adolescent, and other family members. It was also evident that there was an initial attempt by the participants to demonstrate that the situation was under control, being observed, when answering the questionnaire, that "everything was fine." However, the qualitative data diverged when signaling to moments of suffering: [...] *I cry in the bathroom, not in front of him [the son], nor in front of the husband* (F10). [...] *I got tired of going to the hospital bathroom to cry, so as not to cry in front of him [the son]* (F6).

In addition, family caregivers showed surprise when asked about their health, and first, they wanted to confirm whether the questionnaire was actually directed to them. Also, initially, they could not tell if what they felt was any health change or not. At some moments, they demonstrated that they did not even stop to think about themselves, because they directed care to the patient and, thus, many ended up forgetting self-care, as illustrated by the statements: [...] *stress is a disease? [...]. yes, that's very complicated* (F8). [...] *I didn't even have time to think, but I feel tired, I'm much more irritable* (F16).

Another result, which could be found in Table 2, referred to satisfaction in the domain of social relations in QoL (61.3%). This evidence was strengthened by the support received from the family, the health team and other family caregivers who were in a similar situation, and who were essential in coping with the situation experienced: [...] *my greatest therapy is my sister's house [...] I have support from my family [...] we, mothers, we support each other* (F13). [...] *If it wasn't for the help we had here at the beginning: the psychologist, the nurses, the doctor, I don't even want to imagine* (F 11).

In the environment domain, dissatisfaction predominated (75.8%). This domain was related to physical security and protection, financial resources, among others. In this sense, family caregivers reported on the full dedication to care and the consequent abdication of life, work and other work projects, as observed: [...] *I gave up everything [...] I had no choice [...] it is my child* (F7). [...] *It's cruel to quit work, because we have a whole routine, I've always worked, I had several projects and this year I was going to study [a lot of crying]* (F12).

Table 3 presented an analysis of the relationship between resilience levels and study variables.

Table 3 – Analysis of resilience levels, according to sociodemographic variables, religion, MPD, perceived stress and quality of life of caregivers of children and adolescents undergoing cancer treatment. Santa Maria, RS, Brazil, 2018. (n= 62)

Sociodemographic variables	Resilience						p
	Low		Moderate		Loud		
	n	%	n	%	n	%	
Sex							0.183**
Female	14	28.0	25	50.0	11	22.0	
Male	2	16.7	5	41.7	5	41.7	
Age group							0.713*
20 to 36 years	7	25.0	15	53.6	6	21.4	
37 to 66 years old	9	26.5	15	44.1	10	29.4	
Schooling							0.255**
E. Incomplete primary	6	33.3	6	33.3	6	33.3	
E. Complete primary	2	45.5	6	54.5	-	-	
E. Incomplete secondary	-	-	2	66.7	1	33.3	
E. Full secondary	4	18.2	11	50	7	318	
Incomplete Undergraduate	1	33.3	1	33.3	1	33..3	
Complete Undergraduate	-	-	3	75.0	1	25.0	
Post-grad Complete	-	-	1	100	-	-	
Marital status							0.057**
Single/no partner	6	31.6	12	63.2	1	5.3	
Married/stable union	10	23.3	18	41.9	15	34.9	
Number of children							0.532**
0 a 1	7	31.8	11	50.0	4	18.2	
2 or more	9	22.5	19	47.5	12	30.0	
Practice some religion							0.208**
No	4	28.6	9	64.3	1	7.1	
Yes	12	25.0	21	43.8	15	31.3	

Table 3 – Cont.

Sociodemographic variables	Resilience						p
	Low		Moderate		Loud		
	n	%	n	%	n	%	
MPD							0.012**
No	4	12.1	17	51.5	12	36.4	
Yes	12	44.4	11	40.7	4	14.8	
Perceived stress							0.020**
Low level	1	5.6	10	55.6	7	38.9	
Moderate level	4	22.2	11	61.1	3	16.7	
High level	11	44.0	8	32.0	6	24.0	
Quality of Life (QoL) Domain							
Physical domain							0.491**
Unsatisfied	7	35.0	9	45.0	4	20.0	
Satisfied	9	21.4	21	50.0	12	28.6	
Psychological domain							0.211**
Unsatisfied	7	30.4	13	56.5	3	13.0	
Satisfied	9	23.1	17	43.6	13	33.3	
Domain social relations							0.342**
Unsatisfied	8	33.3	12	50.0	4	16.7	
Satisfied	8	21.1	18	47.4	12	31.6	
Environment domain							0.004**
Unsatisfied	14	29.8	26	55.3	7	14.9	
Satisfied	2	13.3	4	26.7	9	60.0	

Note: * Pearson Chi-Square Test; ** Pearson Chi-Square with correction.

Although the results did not show statistical significance of the relationship between religiosity and resilience ($p > 0.05$), this strategy was reported by many family caregivers as a strengthening factor in the care process: [...] *My faith has been strengthened a lot in here. I have faith. It is faith that strengthens us, it is not a question of religion, but it is a matter of faith (F1).* [...] *If it were not for faith, I confess to you, with certainty, that I would have lost this battle [...] if it wasn't for the faith I have, I would have already gone into depression (F2).* [...] *God! He gives me strength every day to get out of bed (F10).*

When analyzing the relationship of resilience with other variables, statistical significance was obtained with MPDs ($p = 0.012$), perceived stress ($p = 0.020$) and QoL related to the environment domain ($p = 0.004$), i.e, in low levels of resilience, there was greater suspicion for MPD, stress and dissatisfaction with QoL in the environment domain.

The statements of family caregivers reinforced changes to health, which triggered MPDs, stress and qoL alterations. It was evidenced that even living with other family members could cause MPDs: [...] *people do not know what this is, it is not a headache, it takes medicine and passes, it is a fight, a war (F2).* [...] *What kills us mothers the most is the coexistence with those who have relapsed [...] look at that child there and know that the mother and father will be with him only a few more days, is to think that in a few days it might be me [...] it's horrible [...] taking medication to have self-control, to be able to live, to be able to continue living (F13).* *From time to time I began to feel more distressed, it makes me want to be alone [...] wanting to disappear (F9).* In view of the above, these situations influenced the QoL of family caregivers mental health, leading to stress and MPDs.

DISCUSSION

Having a child with cancer is a disorganizing factor for family balance, such a diagnosis has an impact on the entire dynamics of life for the people involved. Although it is a painful and desperate experience, the family, which experiences this situation, looks for ways to adapt to this new reality²⁻⁵.

This adaptation requires the most varied forms of coping. These are ways that modify the day to day, and that are useful for its reorganization in front of the treatment. In this sense, resilience is composed of a strengthening dimension of the family caregiver, as it improves the ability to overcome the challenges that arise. In this study, resilience levels were moderate, unlike a study that showed high levels of resilience in family caregivers of children with cancer²¹. In another study, family members of patients undergoing chemotherapy also showed a high level of resilience (55.38%)⁹.

Some factors favor resilience, such as positivity, in which, even when faced with the situation, they can see a positive side. Similar results were found in a study that showed that family caregivers learned to value the small things in life, given the treatment and circumstances that involved illness⁹.

Another factor, which also strengthened the resilience of family caregivers was social support, which is fundamental for coping with the context experienced. This support, provided by the family, or by people outside the family circle helped them to endure the adversities caused by cancer and could be seen as strengthening when faced with the situation of illness⁵. Studies also reinforced the importance of the support received as a strategy for health promotion^{6,22}. The support of family and friends, as well as family caregivers, who went through a similar situation and the health level itself, fortified them in those moments³. Another study showed that the help of third parties in the care of patients in cancer treatment, presented a positive association with the burden of these caregivers²³. These were factors that promoted resilience, and showed that, even in the face of the situation of having a family member undergoing cancer treatment, resilience was strengthened, and this contributed to being better at facing difficulties and reducing health changes.

Although positive aspects have been recognized in this experience and the appreciation of social support, the dedication to the care of the child or adolescent caused psychological and physiological implications for the whole family, with several repercussions in their lives, which included changes in daily life and conditions²⁴. Thus, when reporting feelings of fear and anguish, family caregivers became susceptible to the development of stress and psychological consequences, such as MPDs.

This study identified that family caregivers of children and adolescents undergoing cancer treatment had a high level of stress and were suspected of having MPDs. These findings corroborate the results of other studies, in which the caregivers presented disturbances in the psychological structure². They declared themselves as being tired, stressed, frightened, sad, anxious and nervous and, often, tearful, experiencing great emotional oscillation²⁻³. There were also reports of physical changes, such as weight changes, reduced vitality and changes in sleep patterns and eating habits⁵. In addition, caregiver anxiety and depression symptoms were associated with poor specific and generic child quality of life over time⁴.

From this perspective, the study that sought to identify sociodemographic and psychosocial factors that predicted resilience in family caregivers of children with cancer identified that this situation was associated with mild (37.6%) and moderate (34.2%) symptoms of depression²². In addition, mild symptoms of anxiety (37%)²² were also reported.

In this study, most family caregivers indicated dissatisfaction in the environment domain of QoL. A study that evaluated this variable, caregiver burden and resilience, among family caregivers of cancer survivors, also showed low QoL scores in this population⁸.

In the present study, faith and religiosity did not have statistical significance with resilience. However, this strategy was reported as strengthening in the life of the family caregiver and in the

constant search for a positive confrontation. Similar results were found in studies that pointed out the great attachment to religiosity at this time, being effective for health promotion, providing support to balance emotions and to cope better with the child's illness. Family caregivers found strength to deal with adversities and promote resilience in faith and religiosity^{2,24}.

In this perspective, a previous study showed that higher levels of resilience were associated with lower levels of depression, anxiety and overload in family caregivers of children with cancer;²⁴ they are also less likely to present mental disorders and behavioral disorders²⁵.

The situation experienced in the care of children and adolescents with cancer was a factor that had repercussions on the physical and mental health of family caregivers, but through a positive reassessment, family caregivers were able to discover aspects that softened the situation, reducing the burden and stress in the care process²². In this sense, resilience was a form of greater preparation of the family caregiver, greater readiness for substitute decision-making, in addition to being associated with a lower rate of anxiety and depressive symptoms. Thus, showing the importance of this concept and greater expansion of studies in the area²⁶.

Further research, especially with interventions, will be fundamental to help improve QoL, health and strengthen resilience in this population. The reduced number of participants in this study may be a limitation, which suggests caution in the generalization of the findings.

CONCLUSION

There was a significant association between low level of resilience and high level of stress, propensity for the occurrence of MPDs and change in quality of life (environment domain) among family caregivers of children and adolescents hospitalized for cancer treatment. It was also identified that, even in the face of health-related changes, family caregivers had a moderate level of resilience. From the adoption of the mixed method, which enriched the understanding of the phenomenon investigated, it was found that this evidence was related to the social support received from both family, friends, other mothers and fathers and the team involved in the care of children and adolescents. Other important factors were positive outlook and being strengthened by faith and religiosity.

In view of the health alterations found, the potential of the study to assist health professionals and managers in planning and expanding the perspective and attention to family caregivers is emphasized, with the intention to strengthen resilience. This is fundamental, and by strengthening it, it focuses on the positive aspects of the care process. Therefore, family caregivers are essential in the care plan for children and adolescents undergoing cancer treatment.

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NOTES

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