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ASSESSMENT OF THE RESILIENCE OF PEOPLE WITH CHRONIC CONDITIONS AND THEIR CAREGIVERS

AVALIAÇÃO DA RESILIÊNCIA DE PESSOAS COM CONDIÇÕES CRÔNICAS E CUIDADORES EVALUACIÓN DE LA RESISTENCIA DE LAS PERSONAS CON ENFERMEDADES CRÓNICAS Y SUS **CUIDADORES**

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ABSTRACT

Objective: to evaluate the resilience of people with chronic diseases and their caregivers. Method: this is a quantitative, descriptive and cross-sectional study, conducted with 98 patients and family members, in the participant's residence. Data collection occurred through semi-structured interviews and the Young resilience scale. Descriptive statistics were performed, as well as the chi-square and Fisher's exact test adopting pvalue <0.05 as significant. The results are presented in tables. Results: of the 98 participants, 26.53% are caregivers and 73.47%, patients. The average resilience scale score were 143.90 points (± 15.98) and median of 145.00 points, with a minimum score of 53 and a maximum of 171, considering the maximum possible scale score of 175 points. *Conclusion*: prevalence of caregivers aged less than 60 years, females and with incomplete elementary education. The patients presented higher minimum resilience scale scores, proving to be more resilient than their caregivers. *Descritores*: Chronic Disease; Psychological Resilience; Nursing; Caregivers; Family Relations; Health Promotion.

Objetivo: avaliar a resiliência de pessoas com doencas crônicas e seus cuidadores. Método: trata-se de um estudo quantitativo, descritivo e transversal, realizou-se com 98 pacientes e familiares, na residência do participante. Coletaram-se os dados por entrevistas semiestruturadas e a escala de resiliência de Young. Realizaram-se estatísticas descritivas e o teste qui-quadrado e exato de Fischer adotando-se p- valor <0,05 como significativo. Apresentam-se os resultados em tabelas. Resultados: revela-se que, dos 98 participantes, 26,53% cuidadores e 73,47% pacientes. Observou-se a pontuação média da escala de resiliência de 143,90 pontos (±15,98) e mediana de 145,00 pontos, com pontuação mínima de 53 e máxima 171, considera-se que o score máximo possível da escala é de 175 pontos. Conclusão: predominou-se cuidadores com menos de 60 anos de idade, do sexo feminino e com ensino fundamental incompleto. Apresentaram-se os pacientes maiores scores mínimos para escala de resiliência, mostrando-se mais resilientes que seus cuidadores. Descritores: Doença Crônica; Resiliência Psicológica; Enfermagem; Cuidadores; Relações Familiares; Promoção da Saúde.

RESUMEN

Objetivo: evaluar la capacidad de resistencia de las personas con enfermedades crónicas y sus cuidadores. Método: se trata de un estudio cuantitativo, descriptivo y de corte transversal, realizado con 98 pacientes y familiares, en la residencia del participante. Los datos fueron recogidos mediante entrevistas semiestructuradas y la escala de la resistencia de Young. Se realizó estadística descriptiva y la prueba de chicuadrado y la prueba exacta de Fisher, adoptándose p- valor <0,05 como significativo. Se presentan los resultados en tablas. Resultados: de los 98 participantes, 26,53% son cuidadores y 73.47%, pacientes. La puntuación promedio de la escala de resiliencia fue de 143,90 puntos (±15,98) y mediana de 145.00 puntos, con un puntaje mínimo de 53 y un máximo de 171, considerándose la puntuación máxima posible en la escala de 175 puntos. Conclusiones: predominaron los cuidadores con menos de 60 años de edad, mujeres y con educación primaria incompleta. Los pacientes presentan puntuaciones mínimas superiores en la escala de resiliencia, demostrando más resistencia que sus cuidadores. Descritores: Enfermedad Crónica; Resiliencia Psicológica; Enfermería; Cuidadores; Relaciones Familiares; Promoción de la Salud.

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health

to

INTRODUCTION

continuing treatment and care throughout life.1 Among these conditions are chronic noncommunicable diseases (CNCD), such as: cardiovascular and respiratory diseases, mellitus, hypertension, among others.² In 2012, the CNCD were the of main causes death in the world,

conditions

deaths.

require

of corresponding approximately 75% of deaths from CNCD occur in low- and middle-income countries, and 40% of them are premature, i.e., occur in individuals aged less than 70 years. In Brazil, the control of CNCD became one of the priorities of public health policies.2

68%

The house represents a privileged space for the treatment of these individuals: caring for a person with a chronic condition at home is becoming an experience more and more frequent.³ The balance of the chronic condition can be favored when the family participates in the care, providing the necessary support, assisting in the routine, accompanying in leisure activities, examinations, consultations and even in the preparation of meals.

The changes in routine triggered by the disease are not always addressed adequately, which may lead to difficulties in its care and control, as well as stress and suffering, not only for the patient, but also for the closest relatives. Some people manage to overcome the difficulties, adhere to treatment and face the adversities, in this way, being resilient.4

Resiliency refers to humans' ability to respond to processes of evervdav disregarding problems positively, the experienced. This process results from the combination between the individual's attributes, his/her family, social and cultural environment.⁵ It is defined as a set of social intrapsychic processes that developing a healthy life, even if in an unhealthy environment.6

Few studies address resilience in the Nursing area, but in the health area, studies addressing individuals in traumatic situations have been developed and, more recently, people with chronic health conditions.4

In this way, it is important to know better the resilient factors of people as a way of overcoming or reframing everyday problems.6 The resilience process is generated from the ability to deal positively with the adversity, seeking to overcome it, using adaptive resources in the positive building for coping with the reality. This process can make the individual more or less vulnerable to the risk Assessment of the resilience of people...

and, furthermore, define how some individuals can be resilient to adversity, which may or may not relate to their survival.7

Since this is a recent theme with few studies investigating the resilience related to the conditions of chronic disease, enlarging the knowledge about it can be a significant concept for dimensioning nursing researches, collaborating to reflections in the education and care practices areas.

OBJECTIVE

• To assess the resilience of people with chronic diseases and their caregivers.

METHOD

This is a quantitative, descriptive and cross-sectional study, conducted with patients and family members participating in the extension project "Assistance and support to the family of chronic patients at home" of the State University of Maringá and patients and caregivers treated in the University Hospital of Maringá, in the city of Maringá, Paraná, Brazil, in the period from June to December 2017.

The project aims to support and assist families of chronic patients performance of routine care to their sick member after hospital discharge, occurring biweekly through weekly, monthly homecare.

The population consisted of patients and their caregivers, selected by convenience, resulting in a sample composed by 98 individuals. The inclusion criterion of the study were individuals with any chronic disease for at least one year and exclusion criterion were those who were not able to understand and respond to the questionnaire.

semistructured questionnaire with questions sociodemographic regarding characteristics was used: gender (male/female), age, education (illiterate, complete primary education, primary education, complete high school, incomplete complete high school, undergraduation and incomplete undergraduation), religion (catholic, evangelical, spiritism and another), marital status (single, married, widowed, divorced and stable union) and family income (up to one minimum wage, up to two minimum wages, up to three minimum wages, up to four minimum wages, more than four minimum wages).

Information on the resielience assessment scale was collected. translated and validated8, which contains 25 items on a

Likert scale of seven points, being 1 (totally disagree) and 7 (totally agree), the total of scores varies from 25 to 175 points, with higher values indicating high resiliency.

Data were collected between June and December 2017, by means of an individual interview with the patient and the family main caregiver. Then, data were inserted and organized in a spreadsheet using Microsoft Excel®, and later, analyzed with the aid of statistical analysis. In order to characterize the population, descriptive statistics (mean and standard deviation) was used. The association between patients and caregivers and sociodemographic variables was analyzed using the chi-square test or Fisher's exact test. The Spearman correlation was used to correlate the degree of resilience with the sociodemographic variables, and the degree of resilience with the time of chronic disease, considering significance levels of 95%. The SPSS version 20 was used for statistical analyses.

The study was developed according to the National Health Council Resolution 466/2012, after approving the project by the Permanent Human Research Ethics Committee of the State University of Maringá (COPEP/EMU)

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under the opinion 2,251,831 and C.A.A.E 71053617.9.0000.0104.

RESULTS

The study participants were 98 individuals, 26.53% were caregivers and 73.47% were patients, followed by the extension project. The age varied from 22 to 86 years (mean 54.48±14.58), with younger caregivers (Table 1).

The majority were women (72.4%), aged less than 60 years (58.2%) and catholic religion (62.2%). Regarding marital status, 59.2% were married, with a mean of 3.18 children (±1.25). Most participants had incomplete elementary education (51.0%), and income from two to three minimum wages, R\$1,874.00 - R\$ 2,811.00 (55.1%) (Table 2).

The number of female caregivers was signicantly higher (p=0.025), as well as those aged less than 60 years (p=0.006), with lower level of education (p=0.024), and patients with lower wage income (p=0.001) (Table 2).

Table 1. Age and resilience scale scores of caregivers and patients of the extension project. Maringá (PR), Brazil, 2017.

Individuals	Mean Score	Deviation (SD)	Minimum Score	Maximum Score							
Age											
All	54.48	14.58	22	86							
Caregiver	44.85	11.88	22	65							
Patient	57.96	13.95	23	86							
Resilience Scale											
All	143.90	15.98	53	171							
Caregiver	145.15	21.83	53	163							
Patient	143.44	13.43	108	171							

The results obtained from the application of the resilience scale showed an average score of 143.90 points (± 15.98) and median of 145.00 points, with a minimum score of 53 and maximum of 171, considering that the maximum possible score in the scale is 175 points.

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Table 2. Association between caregivers, patients and sociodemographic variables. Maringá (PR), Brazil, 2017.

Variable	Care	giver	Pati	ent	Tota	ıl	p- value
Gender	n	%	n	%	n	%	
Female	23	88.5	47	65.3	70	71.4	0.025*
Male	3	11.5	25	35.7	28	28.6	
Age							
< 60 years	21	80.8	36	50.0	57	58.2	0.006
> 60 years	5	19.2	36	50.0	41	41.8	
Education							
Illiterate	-	-	6	8.3	6	6.1	0.024
Complete Elem.	-	-	8	11.1	8	8.2	
Incomplete Elem.	11	42.3	39	54.2	50	51.0	
Complete High Sc.	8	30.8	14	19.4	22	22.4	
Incomplete High Sc.	7	26.9	5	6.9	12	12.2	
Religion							
Catholic	16	61.5	45	62.5	61	62.2	0.931
Evangelic	10	38.5	27	37.5	37	37.8	
Marital Status							
With partner	17	65.4	41	56.9	58	59.2	0.453
Without partner	9	34.6	31	43.1	40	40.8	
N. of Children							
None	5	19.2	6	8.3	11	11.2	0.320
One	4	15.4	13	18.1	17	17.3	
More than one	17	65.4	53	73.6	70	71.4	
Income							
1 wage	1	3.8	26	36.1	27	27.6	0.001
2-3 wages	16	61.5	38	52.8	54	55.1	
4 or more wages	9	34.6	8	11.1	17	17.3	

Note: *Fischer exact test

DISCUSSION

There was a predominance of female caregivers (88.5%) in the present study, and in others⁹⁻¹¹, which emphasize women's role as a representative of the family care¹⁰. This responsibility conferred to woman historically demarcated by western culture and by important political implications, because of the male irresponsible healthcare behavior, thus attributing to men the task of working out and financially managing the house, and women are responsible for the activities of the household environment, considered a conservation of female oppression¹¹. Despite the insertion of women into the labor market and social changes in the family composition, routinely women are expected to play the role of caregiver. 11

Regarding the caregivers, 42.3% had incomplete primary education, and there was an association between caregiver and low schooling, a datum that corroborates the study carried out in Fortaleza, in which 35% of the respondents had from one to four years of study and 23% were illiterate. The society requires higher levels of schooling to integrate the formal labor market, thus, family members with fewer years of schooling often have no fixed work, thus, they are expected to perform household chores and care for their relatives that need their assistance.

A high number of caregivers are less than 60 years, as also evidenced in studies

conducted in Santa Catarina and Pernambuco, which showed, respectively, mean age of 51.7 and 52.62 years and standard deviation of 11.0 and 14.14 years. 11-2 Another study conducted in João Pessoa showed that caregivers' age may be related to the fact that female spouses and sons/daughters perform most of the care, who tend to be younger than the partners. 12

There were significant differences between the minimum scores; however, the average score for caregivers and patients was very close. Patients had higher minimum resilience scale scores, thus, are more resilient than their caregivers (Table 1). A study conducted Canada identified the barriers caregivers' resilience: higher demand, the time required for the care; challenges to learn about the appropriate care; change of roles and responsibilities; emotional responses; personal health; change in family dynamics and financial tensions. Caregivers detected as facilitators for resiliency: spirituality, coping emotional experiences, strategies, motivations for the care, sense of purpose and validation. 13

A study performed with 48 individuals showed that resilience scores vary according to the sense of control over the spiritual and personal life, because, in addition to positive correlations between total resilience scores and positive affect scores (r = 0.62, p = 0.001), and the higher resilience scores was associated to increased morphological

individual, can bring the feeling of deprivation of personal life, frustration, lack of time for activities, impatience pleasurable

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differences observed in the right subpericional furrow of the brain (sub-region of the PPC) (SA: B (4.43) = 4.17, B = 0.29 se = 1.93, n = 48, q = 0.04). ¹⁴ The highest levels of resiliency are correlated to different morphological changes in brain regions involved in networks of cognitive and emotional control, thus developing, in individuals, a better ability to from recover adverse events, cognitive and emotional control and more persistence. People with low resilience may have compromised limbic-cyclical inhibition, making them more susceptible to morbidities related to stress.14

difficulty to bond with other people of the caregiver's social life, exalting even more the burdens experienced this moment. 17

The diagnosis of a chronic disease results in a change in the whole family structure, because the literature has presented family as the main provider of care and support¹², since each family member receives and faces this period in a peculiar way, influenced by several factors: culture, financial condition, family structure, and the old and new family habits.15

CONCLUSION

Within the family nucleus, the caregiver needs to meet his/her individual demands; however, he/she can feel overwhelmed, because of the time necessary to dedicate to this family member¹⁶. In most cases, the caregiver abdicates from his/her personal life, suddenly affecting his/her routine feelings, by assuming a routine geared to the requirements and demands from development of the disease of his/her family member. 17

The need to find options that help enable better control of chronic diseases and a more harmonious coexistence with them brought the concept of resiliency as a possibility to overcome or reframe everyday problems. This study identified a predominance of caregivers aged less than 60 years, females and with incomplete elementary education, patients presenting had higher minimum resilience scale scores, proving to be more resilient than their caregivers.

The burden presented by caregivers has physical and emotional nature, and such injuries can lead to psychosomatic diseases to the caregiver, because the excessive care practiced daily often requires great physical or emotional commitment of the caregiver. This burden can generate feelings (fears, anxieties and depressions) that directly influence the quality of care provided. 16

results should provide health professionals a wide view of the patient and his/her family, in order to know all the feelings that emerge from the experience, since only the knowledge of the mishaps of this journey can allow nurses to mobilize in favor of these individuals' health needs.

A cohort study performed in Canada identified that the prevalence of burden in caregivers is not specific according to the disease stage, being stable over time. Therefore, health professionals should assess caregivers' burden and refer them to the necessary services¹⁸, since each individual develops the process of being a caregiver and resilience in a singular way.

A limitation of the study is the sample composed only by patients from an extension project. Thus, it is important to develop new studies exploring the association with other variables, as well as the evaluation of strategies to promote resilience, as well as the need for reflection on new public policies and actions aimed at this population.

Caring for an individual goes beyond its expression, requiring a unique dedication, which often requires the abdication of one's own plans and desires in favor of others. Therefore, two lives become one once the patient and his/her caregiver experience similar mishaps that, when imposed on the

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