

Tension attributes of the family caregiver of frail older adults*

ATRIBUTOS DA TENSÃO DO CUIDADOR FAMILIAR DE IDOSOS DEPENDENTES

ATRIBUTOS DE LA TENSIÓN DEL CUIDADOR FAMILIAR DE ANCIANOS DEPENDIENTES

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ABSTRACT

The objective of this study was to assess both theoretically and empirically the tension attributes of the family caregiver of frail older adults. The theoretical phase consisted of analyzing 52 studies addressing this issue. The analysis showed that the phenomenon is evidenced by the caregiver through physical and emotional changes, unbalance between activity and rest, and compromised individual coping. In the field phase, an assessment was made of 30 women who, during the nursing consultation, showed evidence of tension due to their role as caregiver. Data collection was performed through interviews at home, which were recorded and followed a script created based on the theoretical findings. Every time it was considered adequate, excerpts from the caregivers' discourses were added to improve understanding. The empirical assessment confirmed the tension attributes revealed in the theoretical analysis.

KEY WORDS

Caregivers.
Aged.
Family.
Frail elderly.

RESUMO

Este estudo objetivou averiguar teórica e empiricamente os atributos da tensão do cuidador familiar de idosos dependentes. Na fase teórica, analisamos 52 trabalhos que versavam sobre a temática. Essa análise demonstrou que o fenômeno é evidenciado pelo cuidador por meio de alterações físicas, alterações emocionais, desequilíbrio entre atividade e repouso, e enfrentamento individual comprometido. Na fase de campo, investigamos trinta mulheres que expressavam evidências de tensão proveniente do papel de cuidadora durante consultas de enfermagem. A coleta de dados ocorreu no domicílio mediante entrevista gravada, utilizando um roteiro estruturado fundamentado pelos achados teóricos. As informações objetivas foram analisadas quantitativamente. Sempre que adequado, acrescentamos trechos de discursos das cuidadoras para ampliar o entendimento das questões abordadas. Por fim, confirmamos empiricamente os atributos da tensão do cuidador apontados na análise teórica.

DESCRIPTORIOS

Cuidadores.
Idoso.
Família.
Idoso dependente.

RESUMEN

Este estudio objetivó averiguar teórica y empíricamente los atributos de la tensión del cuidador familiar de ancianos dependientes. En la fase teórica, analizamos 52 trabajos que versaban sobre la temática. Ese análisis demostró que el fenómeno es evidenciado por el cuidador por medio de alteraciones físicas, alteraciones emocionales, desequilibrio entre actividad y reposo, y enfrentamiento individual comprometido. En la fase de campo, investigamos treinta mujeres que expresaban evidencias de tensión proveniente del papel de cuidadora durante consultas de enfermería. La recolección de datos ocurrió en el domicilio mediante entrevista grabada, utilizando un guión estructurado con base en lo encontrado teóricamente. Las informaciones objetivas fueron analizadas cuantitativamente. Siempre que fue adecuado, agregamos trechos de discursos de las cuidadoras para ampliar el entendimiento de las cuestiones abordadas. Por último, confirmamos empíricamente los atributos de la tensión del cuidador apuntados en el análisis teórico.

DESCRIPTORIOS

Cuidadores.
Anciano.
Família.
Anciano frágil.

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INTRODUCTION

Family caregivers see the experience of assuming the responsibility for handicapped elderly patients as an exhaustive and stressful task, due to the emotional involvement and because there is a transformation from a previous reciprocity-based relationship to one of dependency, where the caregivers experience restrictions to their own lives when performing activities that focus on the physical and psychosocial well-being of the elderly patient.

The problems related to providing care to elderly patients turn the family caregiver into someone who needs careful observation. However, in Latin-American countries, reportedly, this activity is still not incorporated in the healthcare service, although it has been regarded as necessary in developed countries for some time already⁽¹⁾. In the Brazilian reality, the effects of the dependency of the elderly patient on the family has, as of late, determined certain professional or volunteer-based interventions, which did not stem from systemized, organized and methodologically-appropriate investigations⁽²⁾.

With such a necessity in mind, we note the importance of investigations that provide those assisting family caregivers with the acknowledgment of the clinical attributes of stress according to the care provided, since they represent important clues that can measure the phenomenon within the scope of clinical practice and research. The identification of the attributes of the phenomenon could contribute to elaborate a systematized, individualized plan of action for the caregiver. This would permit having the caregiving capacity at its maximum potential, regarding both the caregivers themselves and the elderly patients. We consider that the evidence or specific characteristics as attributes of

caregiver stress allow one to define and measure this phenomenon within the scope of clinical practice and research.

GOAL

According to the aforementioned aspects, the goal established for this study was to identify the specific attributes for the stress concept of family caregivers of handicapped elderly patients in healthcare literature, and to confirm them in an empirical study.

METHOD

This study was executed in 2001-2003, in two phases: a theoretical and an empirical or field stage. In the theoretical stage, a group of studies was analyzed, consisting of scientific articles covering the theme, identified in the MEDLINE, LILACS and SciELO databases, as well as books produced in Brazil. In this stage, the goal was to identify the attributes of the stress concept of handicapped elderly patients' family caregivers in order to elaborate the interview script that would be used in the field research. The literature review used the 1990s as a starting point, when relevant studies that nowadays are considered classics on the topic started to be published. The limit established for the literature review was the year 2002.

The theoretical analysis made it possible to identify specific evidence or characteristics of the concept which, when grouped according to the criteria of similarity and exclusivity, yielded four categories of attributes: changes in the physical state, changes in the emotional state, imbalances between activity/rest and impaired individual coping, as seen in Figure 1.

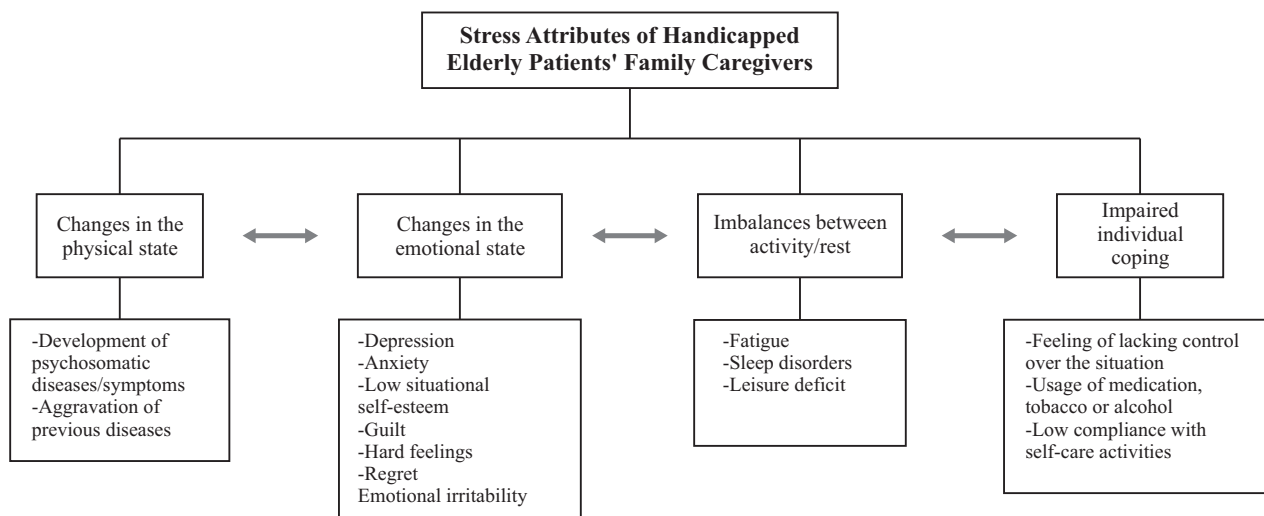


Figure 1 - Stress attributes of handicapped elderly patients' family caregivers - João Pessoa, PB - 2003

In the field research stage, we applied the analysis of the theoretical phase to the empirical observations made in the natural environment where the phenomenon was experienced, in order to verify the presence of the attributes of the stress concept of handicapped elderly patients' family caregivers registered in the Healthcare Program for Elderly Patients of Hospital Universitário Lauro Wanderley at Universidade Federal da Paraíba.

At the time, this Program provided care to nearly 50 handicapped elderly patients. The study subjects were those who met the criterion of being the main caregiver of an elderly patient, and who signed the term of consent after being explained about the goals of the study. As such, 30 women participated, who displayed biopsychosocial signs or evidence of harmful effects on their life/health due to the role of caregiver for elderly patients. The normative aspects for research involving human beings were observed, according to CNS Resolution #196/96⁽³⁾, after previous evaluation and approval of the project by the Review Board of the research institution (protocol #51/2001).

Data collection occurred during home visits, scheduled on dates and times the caregivers suggested, considering their availability. The interviews were recorded on cassettes, using an interview script with questions produced according to the theoretical analysis of the concept. Gerontology professionals (two nurses and one psychologist) validated the content of this interview. The attributes depression, anxiety and low situational self-esteem were measured, respectively, with scales developed by three authors⁽⁴⁻⁶⁾, chosen because of their proven reliability.

At the end of this research stage, objective information was analyzed quantitatively, using the Statistical Package for the Social Sciences software (SPSS). In this process, frequency analysis of the variables was performed and Pearson's correlation test was applied to the data. If necessary, we added excerpts from the caregivers' testimonies, collected during the interviews, for the sake of a better understanding about the studied issues.

RESULTS AND DISCUSSION

Changes in the physical state

Regarding the occurrence of psychosomatic signs and symptoms or chronic diseases, the caregivers manifested the following alterations: body aches (28 caregivers, 93.3%, predominantly backaches); body weight alterations (17 caregivers – 56.7%); changes in bowel habits (9 caregivers – 30%); cardiovascular problems (8 caregivers – 26.7%, predominantly hypertension); other changes, such as dyslipidemia, frequent flues, spinal disc herniations, osteoporosis, liver disorders, artrosis and asthma (8 caregivers – 26.7%). After taking over the care responsibilities, nine caregivers (30%) mentioned that their previous health problems had worsened.

As family caregivers are exposed to different stressors in the caregiving situation for a long period, they are at risk

of having health problems similar to those of the person he or she is taking care of, such as arthritis, hypertension, coronary diseases, pain, changes in body weight, immune system changes, dyspepsia, ulcers and others⁽⁷⁾.

Caregivers' greater susceptibility to physical changes modifies their quality of life and increases their risk of death⁽¹⁾. A prospective study with 392 caregiver spouses and 400 non-caregiver spouses analyzed care activities as a risk factor for mortality. Participants in both groups were aged 60 or older, with sociodemographic factors, prevalent diseases and sub-clinical cardiovascular diseases controlled. The results yielded 103 deaths in the total study population, 40 of which among non-caregivers and 63 among caregivers. Among the 329 surviving caregivers, 207 were at greater risk of mortality when compared to non-caregivers⁽⁸⁾.

Changes in the emotional state

Changes in the emotional state (depression, anxiety, low situational self-esteem, guilt, hard feelings, regrets and emotional irritability), as a group, were light/moderate in 26 (86.7%) and strong in four (13.3%) caregivers. Regarding depression, according to the Zung scale⁽⁴⁾, the score of the caregivers varied from 17 to 37 points, with a mean of 24.97 (RI 95% \pm 2.27; SD = 6.08) and median of 23.5 points. Regarding the individual intensity manifested by the study participants, seven (23.3%) expressed it lightly; 20 (66.7%) moderately and three (10%) strongly. The subjective expression of this state in the caregivers occurred especially due to changes in mood and sadness, as shown in excerpts from their testimonies:

I feel down, I feel sadness, an unending loneliness... I have no more hope... there's no more. It's really hard. Psychologically, I'm zeroed (E5).

Like depression, anxiety was also present in all caregivers. Their score on the Lipp scale⁽⁵⁾ varied from 17 to 57 points, with a mean of 30.87 (RI 95% \pm 3.3; SD = 8.83) and median of 31 points. Considering the intensity of the problem as reported by the caregivers, 15 (50%) expressed it lightly, 14 (46.7%) moderately and one (3.3%) strongly.

Psychiatric morbidity in family caregivers has been an object of considerable interest among researchers, with depression and anxiety as the clinical conditions most frequently studied. In any context, a significant share of these caregivers may be at risk of developing depressive disorders and anxiety – especially women, who respond more intensely to stress and spend more time involved in care activities for elderly patients and household chores⁽⁹⁻¹⁰⁾.

Caregivers' exposure to the different elements permeating the care situation also contributed to changes in their self-esteem. In the application of the self-esteem measurement scale⁽⁶⁾, the scores varied from 1 to 13 points, with a mean of 7.73 (RI 95% \pm 1.24; SD = 3.34) and median of 8 points. Regarding the intensity of expression of the phenomenon, eight (26.7%) expressed very low self-esteem, 13 (43.3%) moderately low and nine (3.3%) lightly changed.

This unfavorable appreciation of themselves contributed to the ever-increasing reduction of their psychological well-being, affecting their personal resources, such as sense of domain, emotional stability and physical health, and consequently reducing their internal degree of efficiency⁽¹¹⁾.

Regarding the feelings of guilt due to something involved in the care situation, eight (26.7%) caregivers reported having such a feeling casually, while five (16.7%) felt it regularly. Still, at a certain point, 19 (63.3%) felt guilty about their actions towards the elderly patient under their care, 15 (50%) reported that they should have acted differently sometimes, while four (13.3%) often felt guilty about their actions towards the elderly patient. Furthermore, the following statements show that the caregivers feel guilty both about the emotional imbalance when coping with care situations and because they somehow feel responsible for their relative's state of disability.

I feel guilty. Sometimes I think that I took her to the doctor too late, I don't know... She might not end up like that if we had found out about her disease early (E13).

Sometimes I scold her and I feel guilty, because she can't understand a thing (E2).

Performing the caregiving tasks alone and the lack of emotional support made 22 (73.3%) caregivers report hard feelings and resentment towards the other family members, which 15 (50%) felt frequently and seven (23.3%) casually.

I feel a little angry, discouraged, because there's nobody to help us... I feel discouraged (E7).

I'm resentful because there are four children, but all they say is: be patient! (E11).

The feeling of sorrow regarding the elderly patient was evident in the caregivers: 23 (76.7%) mentioned that they are aware that the health problems are taking the elderly patients to the brink of death, with 22 (73.3%) of them expressing this emotional suffering in advance.

I'm really afraid of that day (the death of the elderly patient). So much that I'd rather die first (E28).

Seeing her like this makes me really sad. She's all I got. I keep asking God to give me strength... (Death) is a reality that I know I'll have to face. I'll only know how when it happens. It's better to just let it be... (cries) (E9).

As the caregivers evidence, facing the progression of losses and the expectancy of the elderly patient's death becomes a strong cause for sorrow. In this context, they experience a gradual *farewell* from their relatives, consequently elaborating a new relationship with that person. The sorrow caregivers experiences during the loss of their relation with the elderly patient, determined by reduced cognitive functions, differs from sorrow due to the loss of interaction caused by death. Although death implies ending collective life by leading to the chronic loss of *openness* between handicapped persons and their caregivers, it results in the latter's prolonged

exposure to painful emotional sensations, which are significantly present in the stress they experience⁽¹²⁾.

Emotional irritability was a frequent stress indicator among the caregivers. Twenty nine (96.7%) of them mentioned such a state, which 13 (43.3%) felt frequently and 16 (53.3%) casually. This finding is compatible with the findings of a study with 1,303 caregivers, where 97% expressed emotional difficulties, with predominant complaints about irritability⁽¹³⁾.

Imbalances between activity and rest

Imbalances between activity and rest were identified in the caregivers by investigating fatigue, sleep disorders and leisure deficits. Regarding fatigue, 28 (93.3%) caregivers mentioned unwillingness to perform daily activities, 16 (53.3%) of them saying that such feelings were frequent and 12 (40%) that they were casual. Likewise, 28 (93.3%) caregivers reported physical and mental exhaustion as a result of providing care, 18 (60%) saying it was frequent and 10 (33.3%) saying it happened sometimes.

Regarding sleep disorders, 20 (66.7%) caregivers had difficulties to fall asleep, 23 (76.7%) woke up during the night and could not fall asleep again, and 17 (56.7%) did not feel rested or relaxed upon awakening in the morning.

Do you know what's wrong with me? Too much work, I feel too sleepy! I want to sleep, because it's stress, isn't it? At night, I don't sleep because he doesn't let me. I have to be up at five in the morning. I can't even sleep during the day! I have headaches and feel dizzy (E10).

My nights are awful. I have to wake up... I rise feeling dead tired, sleepy, red-eyed (E6).

Sleep disorders are a common phenomenon among caregivers, especially when they manifest depression and anxiety, resulting in poor perceptive and cognitive functions (memory, concentration, judgment), low emotional control, irritability and disorientation and reduction of the pain threshold, in addition to affecting the production of catecholamines, corticosteroids and hormones, substances that may increase the caregivers' levels of stress⁽⁷⁾.

Considering the leisure deficit, all caregivers stated that they felt as if they were denied the chance to enjoy leisure due to their intensive involvement in care for the elderly patient, which increased their levels of stress to cope with the daily activities.

Compromised individual coping

Compromised individual coping was made evident because of the low sense of control over the situation; use of medication, alcohol and tobacco; and low compliance with self-care activities. Regarding the low sense of control over the situation, 13 (43.3%) caregivers reported controlling the care situation occasionally, without problems for themselves, while seven (23.3%) reported not having any sort of control in this context. Furthermore, 14 (46.7%) mentioned being incapable

of implementing care without forfeiting other things that are important for themselves, and 13 (43.3%) often balanced the care demands with their own necessities.

Sometimes I get irritated, I feel angry, I despair... then people say: be patient! That's a God-given gift. You have to wait until the day comes. But I can't be patient all the time, I can't (E5).

A low sense of control over the care situation, as expressed by caregivers of handicapped elderly relatives, is evident in caregivers who cannot identify positive internal resources and are unable to recognize their need to ask for help, i.e. they have a low *locus* of internal control⁽¹⁴⁾, an aspect that was observed in this investigation. People with a good level of internal control believe that they can act in order to change an unfavorable situation using their personal resources; people with external control believe that the command of the situation lies in the hands of fate, luck, God, or in the power of other people⁽¹²⁾.

Coping has two functions. The first is to modify the relationship between the person and the environment, controlling or altering the distress (problem-centered coping, more realistic), which occurs more frequently when the stressors are considered easy to change. The second function is adapt the emotional response to the problem (emotion-centered coping), which usually occurs after considering that nothing can be done to change the reality under analysis⁽¹⁵⁾. The way of coping with a stressful situation is partially determined by the resources available to the person: physical and mental health, existential beliefs, social skills and social and material resources.

Within the scope of this study, in addition to few socio-economic resources for use in care, caregivers also presented a deterioration of personal resources, due to the chronic stress caused by the care process. As such, most of them manifested dysphoric behavior, resorting to divine strength to regain control and maintain the role.

I say... God, have mercy on me... God, give me strength to win in the end! I ask God to control me (E21).

Regarding the usage of medication before becoming involved with care, we verified that two (6.7%) of the caregivers used medication to sleep or tranquilizers, and six (20%) used therapeutic substances for other purposes. After taking over the responsibility of providing care to the elderly patient, 15 (50%) used sleeping pills or tranquilizers, with eight (26.7%) doing it constantly, seven (23.3%) under prescription and one (3.3%) by her own decision; seven (23.3%) used that medication occasionally, four of whom (57.1%) complied with medical prescription and three (10%) resorted to self-medication.

The use of medication for other purposes, after becoming involved with care, was identified in 20 (66.7%) caregivers: 16 (53.3%) used it frequently, 13 (81.3%) of whom used it according to medical prescription and three (10%) by their own decision; four (25%) used medication occasionally, two (12.5%) according to prescriptions and two (12.5%) with-

out a prescription. The aforementioned substances included anti-hypertensives, hormones, hypoglycemics, antidepressives, anti-inflammatories, analgesics, muscle relaxants and vitamins. Such findings were the consequence of the aggravation of diseases and the onset of new disorders or psychosomatic symptoms in the caregivers.

Regarding the use of other, non-medication substances, six (20%) smoked less than one pack of cigarettes a day and four (13.3%) used alcohol, albeit rarely, before becoming caregivers. After being inserted in this activity, seven (23.3%) started to smoke – two (6.7%) of them smoking less than one pack and five (16.7%) one or more packs of cigarettes a day. Regarding alcohol, six (20%) used it infrequently. As shown in these data, the use of tobacco and alcohol by the caregivers was of little significance. However, the use of medication was a relevant attribute of stress, an aspect corroborated by the following excerpts:

The doctor prescribed a tranquilizer because I smoke too much, with this life I have... I used to smoke less, but I smoke way too much nowadays because of my nervous system (E16).

I started using prescription drugs, I didn't accept it before... but I gave in. I was forced to (E30).

Considering compliance with self-care, we verified that 27 (90%) caregivers performed no physical activity. As for the others, three (10%) took walks three or four days a week. As for regular hours for eating, 15 (50%) had their meals at the usual times frequently and eight (26.7%), occasionally; seven (23.3%) reported not eating at regular hours. Eleven (36.7%) caregivers used healthcare services yearly to prevent diseases, eight (26.7%) occasionally, and 11 did not seek out this kind of service (36.7%). Among the 13 (43.3%) caregivers with chronic diseases, six (46.2%) had annual clinical evaluations, four (30.8%) did it occasionally and three (23.1%) did not follow this procedure. Regarding the overburdening of their role, the caregivers found no time to take care of their own health, despite dedicating their lives to promote the well-being of their family and their handicapped elderly relative in particular.

The feelings evoked by the caregivers in the scope of care, such as fear, pain, loss, perceived lack of control and guilt interfere in their well-being and self-care skills, such as following a balanced diet, avoiding or abandoning harmful habits, among others⁽¹⁶⁻¹⁷⁾. Caregivers' non-compliance with health-promoting behaviors deserves special attention from healthcare services and professionals, since their competence to provide care can be determined by their ability to take care of themselves.

Self-care deficiencies expressed by caregivers may cause a *cycle of negligence*. In this cycle, the lack of commitment to health promotion, associated to the adverse effects of the prolonged stress the role entails, deteriorates the health of the caregiver as she ages, making her become dependent at an advanced age. As such, she will need a caregiver for herself, perpetuating the cycle⁽¹⁸⁾.

Table 1 - Correlation between the attributes and the stress phenomenon of handicapped elderly patients' family caregivers – João Pessoa, PB - 2003

	Changes in the physical state	Changes in the emotional state	Imbalances between activity/rest	Compromised individual coping	Stress of the caregiver
Changes in the physical state	1.000				
Changes in the emotional state	0.033	1.000			
Imbalances between activity/rest	0.134	0.026	1.000		
Compromised individual coping	0.157	0.409*	0.234	1.000	
Stress of the caregiver	0.423*	0.367*	0.607**	0.575**	1.000

* significant correlation at 5% ** significant correlation at 1%

As seen in Table 1, there is a positive correlation between the attributes described in this study and the stress phenomenon of handicapped elderly patients' family caregivers. Two attributes presented a mild correlation with the phenomenon: imbalances between activity/rest ($r=0.607$) and compromised individual coping ($r=0.575$), significant at 1%; The two others, changes in the physical state ($r=0.423$) and changes in the emotional state ($r=0.367$) had a moderate correlation, significant at 5%. These results allow us to conclude that attributes and phenomenon covariate together, i.e. the more strongly the attributes become evident, the higher the stress of the handicapped elderly patients' family caregivers.

CONCLUSION

Considering the findings of this study, we empirically confirmed the stress attributes of handicapped elderly patients' family caregivers, as seen in the theoretical analysis. It is a multidimensional phenomenon, with the following attributes: changes in the physical state, changes in the

emotional state, imbalances between activity/rest and compromised individual coping.

As caregiver stress is a multidimensional phenomenon, attention to minimize/solve this problem needs to be supported on such a perspective. As such, it is dependent on the adoption of several strategies focused on solving specific daily care problems and improving the caregivers' social support. Caregiver's adjustment to the care situation strongly depends on the formal and informal resources health services and the community offer to help them meet the basic necessities of the elderly patient, as well as to provide opportunities for rest, leisure and personal care.

We believe that the healthcare mentioned herein demands systematic and contextualized planning for actions focused on improving the quality of life of handicapped elderly patients and their caregivers, so that their family life can be rewarding and enjoyable. This requires that people in charge of planning and executing such actions, particularly nurses, redirect their perspectives, in order to put in practice interventions that could minimize the impact of the elderly patient's dependency on the caregiver.

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