

Elderly persons in a situation of dependence: informal caregiver stress and coping

Idoso em situação de dependência: estresse e *coping* do cuidador informal

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Keywords

Nursing; Geriatric nursing; Community health nursing; Caregivers; Aged

Descritores

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Abstract

Objective: Study the relationship between psychological (stress) and psychological (coping) of the informal caregiver of the elderly in a situation of dependence.

Methods: Cross-sectional study involving a sample selected by convenience, of 110 informal caregivers of “Conselho de Faro”, Portugal. Data was collected in the homes by application of four instruments to these caregivers (sociodemographic data, assessment of stress intensity; abbreviated scale of coping and Barthel's dependence assessment).

Results: The coping strategies centered on the problem (Chi-square = 10.243, $p \leq 0.037$) and on the medium (Chi-square = 9.574, $p \leq 0.048$) were used by the informal caregivers of the more dependent elderly. However, strategies centered on the caregiver were those that generated less stress ($\beta = -0.378$, $p \leq 0.000$).

Conclusion: The “coping strategies centered on the caregiver” are those that generate less perception of stress in the informal caregivers.

Resumo

Objetivo: Estudar a relação entre o estresse psicológico (estresse) e a adaptação psicológica (*coping*) do cuidador informal do idoso em situação de dependência.

Métodos: Estudo transversal envolvendo uma amostra selecionada por conveniência de 110 cuidadores informais do Conselho de Faro, Portugal. A coleta de dados, realizada nos domicílios, ocorreu por meio da aplicação de quatro instrumentos junto a esses cuidadores (dados sociodemográficos, avaliação da intensidade do estresse, escala de avaliação de *coping* abreviada e avaliação de dependência de Barthel). Resultados: As estratégias de *coping* centradas no problema (Qui-quadrado = 10,243, $p \leq 0,037$) e no meio (Qui-quadrado = 9,574, $p \leq 0,048$) foram utilizadas pelos cuidadores informais de idosos mais dependentes. Contudo, as estratégias centradas no cuidador foram as que geraram menos estresse ($\beta = -0,378$, $p \leq 0,000$).

Conclusão: As “estratégias de *coping* centradas no cuidador” são aquelas que geram menor percepção de estresse nos cuidadores informais.

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Introduction

The elderly population is increasing, particularly those over the age of 80 years. Associated with the increase in the average life-expectancy there is the prevalence of chronic diseases and increase in the number of persons in a situation of dependence.^(1,2)

Based on the impressive increase in the number of dependent elderly persons, and in view of the institutional incapability of meet these needs, the informal caregiver has emerged as a key figure in the promotion of quality of life in a situation of dependence. Playing this role is not an easy task and it is accompanied by sociocultural difficulties that go beyond the psychological and physical demands already existent in the activity of informal caregiving.

With respect to the definitions of caregiver and informal caregiver presented by the literature, there are many and not all are unanimous as regards reference to the concepts. In general, when the types of caregivers are specified, the main (or primary) caregiver is defined as the person who has the greatest responsibility in the daily care of the dependent elderly person, performing the majority of day to day tasks; and the secondary caregiver, as the one who performs tasks without much regularity, and without having much responsibility or power of decision, helping the main caregiver only with complementary activities.^(3,4) Secondary caregivers may constitute a relevant source of help to the caregiver.⁽⁵⁾ Moreover, the informal caregiver is distinguished from the formal caregiver, because the former is not remunerated.⁽³⁾

To satisfy all the different concepts of an informal caregiver in order to conduct this study, the main informal caregiver was defined as the person who most closely provides care during most of the time, and who cooperates within his/her possibilities with the activities of life in which the elderly person is dependent, in a non remunerated manner, irrespective of his/her basic educational background or experience of life.

From the perspective of a family caregiver, the situation of having to deal with a dependent elderly person constitutes a situation of crisis, since a significant change occurs in the course of the caregiver's life.⁽⁶⁾ Therefore, being an informal caregiver

constitutes a situation for the assiduous application of the model of stress in which the "care" arises as a stressor agent, something object and that perturbs or threatens the habitual activity of the individual caregiver, which will oblige him /her to seek an adjustment in his/her conditions in the sense of dealing with the situation.⁽⁷⁾

With respect to the informal caregivers of dependent elderly persons, the success in dealing with situations of stress will depend on coping; that is, they are the strategies each individuals define, which will enable him/her to deal with the situation in a healthy manner, adjusting himself/herself to the adversities and guaranteeing better adaptation to the circumstances.⁽⁸⁾

Thus there are a high number of coping strategies, and it is considered important that health professionals should be the ones to help caregivers potentiate them, making it possible to use them in an efficient manner. Health professionals must be alert to the symptoms of anguish in caregivers,⁽⁹⁾ as preventing the decline in their mental health is a tool for their greater involvement in care, improving the quality of life of elderly dependent persons.⁽¹⁰⁾

The approach to stress and coping of the informal caregiver of elderly persons in a situation of dependence arises, as the overload to which the individual who cares for a dependent person is subjected, is implicated to a large extent in his/her physical and mental health. The changes in the life of caregivers of dependent persons occurs at the level of physical weariness, emotional exhaustion and depression, as well as in the alterations in social, work and economic life.⁽⁴⁻¹³⁾

In spite of this, it is also acceptable to eliminate the premise that caring for a dependent elderly person is mandatorily/necessarily a situation that generates difficulties at the emotional, physical, economic and social levels. Various authors have demonstrated precisely the contrary, and have stated that the activity of caring for a dear one may also be accompanied by rewards of satisfaction⁽¹¹⁾ and that beliefs, feelings and positive values are fundamental for one's quality of life.⁽¹⁴⁾

The aim of this study was to study the relationship between the stress of informal caregivers of

elderly persons in a situation of dependence, and their coping strategies.

Methods

This was a cross-sectional study with 110 informal caregivers of the “Conselho de Faro” - Portugal. A convenience sample was used drawn from data of informal caregivers of users of a home support service. The number of participants of the sample was calculated to meet the minimum number of five participants for each item formulated ($n = 5k$) to effectuate a factorial analysis of a scale with 22 items, specifically constructed to evaluate the intensity of stress in the informal caregiver.^(16,17)

For data collection, the four instruments mentioned as follows were used: the one for the purpose of collecting the sociodemographic data; that for evaluating the intensity of the informal caregiver's stress, created and validated for the present study;⁽¹⁷⁾ the scale of “abbreviate assessment of the informal caregiver's coping”, validated for the Portuguese population⁽²⁾ and the Barthel instrument for assessing dependence, also validated for the Portuguese population.⁽²⁾

The instrument for assessment of stress intensity, developed for conducting the study described, sought to measure the intensity of stress in the degree of frequency from various aspects, on a Likert type scale with six degrees of response.⁽¹⁷⁾ The intensity of stress was obtained based on the product between degree and frequency.⁽¹⁶⁾

To prepare the instrument of psychological evaluation, aspects of methodological strictness, also used by Cardoso and Baptista,⁽¹⁵⁾ were taken into consideration.⁽¹⁵⁾

The first question asked “Indicate your level of stress”, divided into two lines, one in terms of “degree” and the other in terms of “frequency”. The second, asked “to which degree does each of the factors cause you stress?”, presenting ten options for reply, in which the following were evaluated: relationships with the family, with the health technicians, social life, physical and/or emotional effort of taking care of the dependent family member, the

time spent on taking care of the dependent family member, planning the future, your economic situation, your privacy, lack of knowledge about care and the attitudes of your family member”. Lastly, a third question evaluated exactly the same factors of stress as the second, but only in terms of frequency.

In the analysis of the item-total correlation, it was verified that there is positive and significant correlation for all the items. The conditions for performing the exploratory factorial analysis were satisfied, as the coefficients of KMO obtained were 0.813 and the Bartlett test of sphericity ($\chi^2(45) = 396,722$; $p < 0.000$). In the exploratory factorial analysis and applying Kaiser's rule, two factors were obtained.

Factor 1, which was denominated “Stress related to the caregiver's social and economic life”, comprises the items: “relationships with the health technicians”, “his/her social life”, “planning his/her future”, “his/her economic situation”, “his/her privacy” and “the lack of knowledge about the care of his/her family member”. Factor 2, which was denominated “Stress related to the caregiver's family life and providing care”, comprising the items: “relationships with his/her family”; “the physical / emotional effort of taking care of his/her family member”; “the time spent taking care of his/her family member”; and “the attitudes of his/her family member”. The Cronbach's Alpha of this instrument was $\alpha = 0.85$ (subscale of “stress related to the caregiver's social and economic life” $\alpha = 0.777$; subscale of “stress related to the caregiver's family life and providing care” $\alpha = 0.775$).⁽¹⁷⁾

The scale for the “abbreviated assessment of the caregiver's coping”, adapted and validated for the Portuguese population,⁽²⁾ is an instrument developed to find out the way caregivers deal with the difficulties perceived in a perspective of coping strategies, by means of a Likert type scale with four options of response and 26 items ($\alpha = 0.94$) composed of six subscales (subscale of “strategies centered on providing care” $\alpha = 0.81$; subscale of “perceptions of alternatives about the situation” $\alpha = 0.76$; subscale of “strategies centered on the problem” $\alpha = 0.62$; subscale of “strategies centered on the caregiver” $\alpha = 0.63$; subscale of “strategies centered in the medi-

um" $\alpha = 0.72$; and subscale of "strategies centered on sharing of the problem" $\alpha = 0.55$).

The goal of the Barthel instrument for assessing dependence is to evaluate the basic activities of daily life, ranging between "0" (totally dependent) and "100" (independent), presented a value of $\alpha = 0.89$.⁽²⁾

The caregivers were approached in their homes, where the object of the study and the predicted duration of data collection were explained to them, they were asked to authenticate their informed consent to participate on the front page of the form. Data collection, constituted of the above-mentioned four instruments, was applied by the investigator only to the main informal caregiver, out of the hearing and sight of third parties.

Data analysis was performed in the computer software application *Statistical Package for Social Sciences*, version 15.

The study was developed in compliance with national and international rules of ethics in research involving human beings.

Results

The majority of caregivers of elderly persons (89.1%) were over 50 years of age, with a mean (M) age of 64.29 years being verified, with a standard deviation (SD) of 11.18 years, ranging between 26 and 85 years. Of the 110 caregivers under study, 12.7% were men with a mean age = 68.57 (SD = 13.91) years, ranging between 48 and 85 years, and 87.3% women with a mean age = 63.67 (SD = 10.67) years, ranging between 26 and 85 years.

The participants' educational level varied, however, it is pointed out that 67.3% had 4th grade elementary schooling, or less. The mean value of the number of years of schooling was 5.85 (Median = four) years, ranging between zero and 17 years of schooling.

With reference to the variables of formal and informal help of the informal caregivers, it was found that 58.2% received help from secondary caregivers.

In the sample, there was 14.5% of formal help provided by private persons; 16.4% by Private Institutions of Social Solidarity, and in over 90%

there was home nursing support from the National Health System. Of the 110 caregivers, 35.5% admitted having had past experience of caring for someone.

As regards the age of the dependent persons, it was verified that 72.7% were of an age equal to or greater than 80 years, $M = 82.72$ (SD = 6.56) years, ranging between 65 and 97 years, with a varying degree of dependence, and mean score of 25.27 (Median = ten), ranging between score zero and score 95 on the Barthel scale, thus 71% of the elderly in the study were completely or severely dependent.

Of the sample, the percentage of elderly persons who presented bodily lesions was 31.8%.

Having characterized the participants, the description will now be given of the manner in which stress and coping are related with the remaining variables under study.

Attending to the causes of stress, it was verified that the variable stress related to family life and providing care ($M = 14.75$; SD = 6.55 points) was that which caused the greatest intensity of stress in the caregivers (MP) = 18.5 points). The variable stress related to social and economic life ($M = 9.22$; SD = 8.38 points) was that which generated the least intensity of stress (MP = 18.5 points) (Chart 1).

The statistical analysis of stress about the existence of bodily lesions demonstrated a positive relationship both for stress related to the caregiver's social and economic life (Chi-square = 13.766, $p \leq 0.000$) and for stress related to the caregiver's family life and providing care (Chi-square = 6.060, $p \leq 0.014$).

Whereas, the analysis between the intensity of stress and the existence of informal help demonstrated that these are positively related to stress with reference to the caregiver's social and economic life (Chi-square = 4.373, $p \leq 0.037$).

With respect to the coping strategies, the "strategies centered on providing care" ($M = 3.25$; SD = 0.58 points) and the "strategies centered on the problem" ($M = 3.25$; SD = 0.64 points) were those most used by the caregivers (MP = 2.5 points). Those least used were the "strategies centered on sharing the problem" ($M = 2.75$; SD = 0.87 points) (Chart 1).

Chart 1. Causes of stress in the informal caregivers of elderly persons in a situation of dependence and coping strategies used (n=110)

| | Variables | M | SD |
|---|---|-------|------|
| Stress intensity in informal caregivers | Stress related to the caregiver's family life and providing care | 14.75 | 8.38 |
| | Stress related to the informal caregiver's social and economic life | 9.22 | 6.55 |
| Coping strategies | Strategies centered on providing care | 3.25 | 0.58 |
| | Strategies centered on the Problem | 3.25 | 0.64 |
| | Strategies centered on the Caregiver | 3.23 | 0.76 |
| | Alternative perceptions of the situation | 3.12 | 0.69 |
| | Strategies centered on the environment | 2.88 | 0.66 |
| | Strategies centered on sharing the problem | 2.75 | 0.87 |

M – Mean; SD – Standard Deviation

With regard to the coping strategies, the existence of a relationship between these and the caregivers' educational level was verified, by which the "alternative perceptions about the situation" ($\beta = -0.321, p \leq 0.001$) and the "strategies centered on sharing the problem" ($\beta = -0.223, p \leq 0.015$) are those that are related with a low level of schooling. Whereas the "strategies centered on the medium" were those most used when the educational level was higher ($\beta = 0.274, p \leq 0.004$).

When coping was related to the family group income, it was only statistically significant for the "strategies centered on the medium" (Chi-square = 10.972, $p \leq 0.027$), by which intervening in the medium is more related to those who have higher incomes.

When analyzing the strategies of those who had past experience in the caregiving activity, it was verified that these persons tended to use the "alternative perceptions about the situation" (Chi-square = 4.840, $p \leq 0.028$) and the "strategies centered on the caregiver" (Chi-square = 3.961, $p \leq 0.047$), as the strategies of choice.

When the level of dependence of the elderly persons was higher, the caregivers tended to use

"strategies centered on the problem" (Chi-square = 10.243, $p \leq 0.037$) and "strategies centered on the medium" (Chi-square = 9.574, $p \leq 0.048$).

As regards the informal caregivers' coping strategies in relation to the perception of the intensity of their stress, it was verified that the "strategies centered on the caregiver" were those that were related to less perception of the total intensity of stress by the informal caregiver ($\beta = -0.378, p \leq 0.000$).

When the relationship is made with the two factors of stress, the "strategies centered on the caregiver" were those that were related to less perception of the intensity of stress in relation to the informal caregiver's social and economic life ($\beta = -0.387, p \leq 0.000$), and with total stress and that related to the caregiver's family life and providing care ($\beta = -0.205, p \leq 0.040$). Also efficient with respect to this latter variable, were the "alternative perceptions about the situation" ($\beta = -0.257, p \leq 0.012$). On the contrary, the "strategies centered on sharing the problem" are related to an increase in the perception of this type of stress ($\beta = 0.235, p \leq 0.011$) (Figure 1).

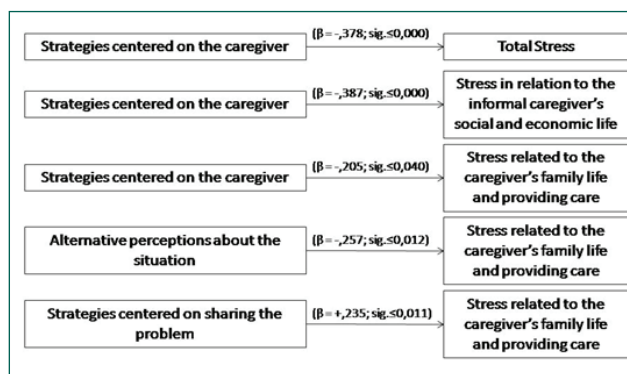


Figure 1. Relationship between coping strategies used and the intensity of stress in informal caregivers of elderly persons in a situation of dependence

Discussion

The limit on the results was the sample size (n=110) and by the method of selection by convenience, motivated by the difficulty of getting to know the caregivers.

It was verified that a large proportion of the caregivers were women, which is in agreement with related studies.^(2,3,6,12)

With regard to help received from others, almost half of the caregivers did not have informal support provided by family members, friends or neighbors, and around one third of the sample had past experience in the activity of caring for someone dependent, which tends to be a task of long duration that may last for years. Figueiredo⁽³⁾ affirms that anyone who has previously cared for someone, tends to care for another person, with this phenomenon being designated “serial caregiver”.

It was found that the existence of bodily lesions in the elderly person has a negative impact on the informal caregiver’s social life. Imaginario⁽¹¹⁾ mentions that one of the priority needs felt by informal caregivers is the issue of technical situations, namely wounds. Although there are few direct studies that relate wounds to caregivers’ stress, pressure ulcers tend to diminish the quality of life of dependent persons and caregivers,⁽¹³⁾ future studies must be conducted and may be important to clarify the subject.

Another finding was the fact that secondary informal caregivers also constitute a relevant source of stress to primary informal caregivers. Essentially, the literature demonstrates the opposite, that the socioemotional support of the family constitutes an important resource for the feelings of personal appreciation of caregivers⁽⁵⁾ and that the lack of a secondary caregiver favors their overload.⁽¹¹⁾ However, when a caregiver assumes the role of caregiver, the other potential caregivers may exempt themselves from the responsibilities, thereby increasing the feeling of inequality among them.⁽⁶⁾ These divergences in consensus justify future investments in study about this question in particular.

It was verified that a high educational level and income are related to strategies oriented towards problem solving. A higher educational level allows the development of practical capacities, namely more knowledge and social resources.⁽¹²⁾

A low educational level is related to “strategies centered on sharing the problem” and “alternative perceptions about the situation”. Whoever has

greater experience in the activity of providing care adopts the “strategies centered on the caregiver” and “alternative perceptions about the situation” as being the most effective. Sequeira⁽²⁾ added that in view of the complexity of the problem and the difficulty of finding a complete solution, the strategies of avoidance are more successful because they reduce expectations and consequently, the eventual frustrations, protecting caregivers from high levels of anxiety.

When the elderly person’s dependence increase, the strategies oriented towards the problem and medium also tend to increase, among which seeking help is included, in the sense of suiting the informal caregiver’s life to the situation of providing care on the way to adaptation.

The “strategies of coping centered on the caregiver” are more efficient in the management of the intensity of total stress; stress related to the informal caregiver’s social and economic life. Whereas stress related to family life and providing care is minimized when “strategies centered on the caregiver” and “alternative perceptions about the situation” are used, and intensified with the “strategies oriented towards sharing the problem”. Therefore, the caregiver must be instructed to accept the situation as it is, perform activities other than providing care, remember the good times, live one day at a time, look for the positive side of situations, and not blame persons or situations. It is questionable to think about whether this conformist thinking could have negative implications for the mental health of caregivers in the medium or long term, and here lies the fundamental role of the nurse in guiding the caregiver, so that he/she will be in a condition to face up to his/her problem with confidence.

The literature also reinforces the importance of the caregiver adopting a protective philosophy about his/her meaning of life, reinforcing positive values⁽¹⁴⁾ and that strategies of avoidance are more effective in situations that are difficult to resolve, and that the caregiver must reserve some time for himself/herself to prevent caregiver from becoming overloaded.⁽¹⁰⁾

Thus it was verified that there is a potential in nursing care that may have implications for the qual-

ity of care for the elderly. It is recommended that the informal caregiver should initially be instructed to seek strategies centered on the medium and problem, making available the necessary support and resources, in the sense of preparing the entire environment around the objective of providing care (physical environment and products of support, formal and informal human resources of support, training of caregivers). When this initial stage of disorganization and reorganization has passed, it would be important to instruct the caregiver to maintain his/her activity from the perspective of a chronic activity, adjusting his/her expectations to achievable goals and adapting him/herself to the situation, and for this purpose, using strategies oriented towards the caregiver and alternative perceptions about the situation.

As regards the difficulties in conducting this study, the need for performing data collection in the homes of users/caregivers is pointed out, as this visit could have been felt to be an invasion of privacy, in addition to an approach to a subject to about which the informal caregiver may feel sensitive. Part of the difficulty was initially related to establishing confidence, because not all the caregivers knew the investigator, although they knew that they would be contacted. In addition the low educational level and the sensorial limitations of the older caregivers were factors that obliged one to make a careful approach, so that one could be sure that the response would effectively be the answer to the question.

Conclusion

It was concluded that the “strategies of coping centered on the caregiver” are those that generated the least perception of stress in the informal caregivers.

Collaboration

Rocha BMP and Pacheco JEP declare that they contributed to the conception and Project, analysis and interpretation of data; writing the article, critical review of the intellectual content and final approval of the version to be published.

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