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Vechia, Akeisa Dieli Ribeiro Dalla; Mamani, Abigail Roxana Nina; Azevedo, Rosemeiry Capriata de Souza; Reiners, Annelita Almeida Oliveira; Pauletto, Thalita Tonial; Segri, Neuber José
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CAREGIVER ROLE STRAIN IN INFORMAL CAREGIVERS FOR THE ELDERLY

Akeisa Dieli Ribeiro Dalla Vechia[1]
Abigail Roxana Nina Mamani[1]
Rosemeiry Capriata de Souza Azevedo[1]
Annelita Almeida Oliveira Reiners[1]
Thalita Tonial Pauletto[1]
Neuber José Segri[2]

[1]Universidade Federal de Mato Grosso, Faculdade de Enfermagem. Cuiabá, Mato Grosso, Brasil.
[2]Universidade Federal de Mato Grosso, Faculdade de Estatística. Cuiabá, Mato Grosso, Brasil.

ABSTRACT

Objective: to analyze the frequency of the "caregiver role strain" nursing diagnosis in informal caregivers for the elderly, the defining characteristics and the related factors.
Method: a cross-sectional, descriptive study carried out with 99 informal caregivers for elderly residents living in the areas covered by five units of the Family Health Strategy of Cuiabá, Mato Grasso, Brazil. Data collect took place between July and September 2017, through home interviews. A questionnaire elaborated from the literature on the diagnosis caregiver role strain established by NANDA-International taxonomy II was used. A descriptive analysis with relative and absolute frequency was accomplished.
Results: the frequency of the "caregiver role strain" nursing diagnosis found in caregivers was 98.0%. The most common defining characteristics were: difficulty in seeing the care receiver with the disease (69.1%); apprehension about the future health of the care recipient (66.0%); apprehension about the welfare of the care recipient, if the caregiver is unable to offer it (61.9%); apprehension about the future ability to provide care (60.8%); apprehension about the possible institutionalization of the care recipient (55.7%); concern with the routine care (55.7%) and social isolation (51.5%). The related factors most frequently found were: duration of care (92.8%); 24-hour a day care responsibilities (75.3%); dependence (77.3%) and alteration in the cognitive function was (73.2%) in the elderly; physical conditions (73.2%) and codependency of the caregiver (61.9%).
Conclusion: the frequency of the "caregiver role strain" nursing diagnosis found in this study is high, its defining characteristics concerning mainly the caregiver's apprehension with the elderly and the related factors refer to the demands of the care provided. The nurse and other team's professionals must pay attention to the caregivers as well as to the elderly being cared of in the health units, helping them to overcome the difficulties involved in performing their role.

DESCRIPTORS: Nursing diagnosis. Caregivers. Family caregivers. Dependent elderly. Geriatric Nursing.

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TENSÃO DO PAPEL DE CUIDADOR EM CUIDADORES INFORMAIS DE IDOSOS

RESUMO

Objetivo: analisar a frequência do diagnóstico de enfermagem "tensão do papel de cuidador" em cuidadores informais de idosos, as características definidoras e os fatores relacionados.
Método: estudo transversal, descritivo, realizado com 99 cuidadores informais de idosos residentes nas áreas de abrangência de cinco unidades de Estratégia Saúde da Família de Cuiabá, Mato Grasso, Brasil. A coleta de dados ocorreu entre julho e setembro de 2017, por meio de entrevista em domicílio. Foi utilizado questionário elaborado a partir da literatura sobre diagnostico "tensão do papel de cuidador" estabelecido pela taxonomia II da NANDA-Internacional. Realizou análise descritiva com frequência relativa e absoluta.
Resultados: a frequência do diagnóstico de enfermagem "tensão do papel de cuidador" encontrada nos cuidadores foi de 98,0%. As características definidoras mais frequentes foram: dificuldade em ver o receptor de cuidados com a enfermidade (69,1%); apreensão quanto à saúde futura do receptor de cuidados (66,0%); apreensão quanto ao bem-estar do receptor de cuidados, caso seja incapaz de oferecê-los (61,9%); apreensão quanto à capacidade futura para fornecer cuidados (60,8%); apreensão quanto à possível institucionalização do receptor de cuidados (55,7%); preocupação com a rotina de cuidados (55,7%) e isolamento social (51,5%). Os fatores relacionados mais frequentes encontrados foram: duração dos cuidados (92,8%); responsabilidades de cuidado 24 horas por dia (75,3%); dependência (77,3%) e alteração na função cognitiva (73,2%) do idoso; condições físicas (73,2%) e codependência do cuidador (61,9%).
Conclusão: a frequência do diagnóstico de enfermagem "tensão do papel de cuidador" encontrada neste estudo é alta, suas características definidoras dizem respeito principalmente à apreensão que o cuidador tem com o idoso e os fatores relacionados se referem às demandas de cuidado prestado. O enfermeiro e demais profissionais da equipe devem estar atentos aos cuidadores tanto quanto aos idosos assistidos nas unidades de saúde, ajudando-os a superar as dificuldades envolvidas no desempenho do seu papel.

DESCRITORES: Diagnóstico de enfermagem. Cuidadores. Cuidadores familiares. Idoso dependente. Enfermagem geriátrica.

TENSIÓN DEL ROL DEL CUIDADOR EN CUIDADORES INFORMALES DE ANCIANOS

RESUMEN

Objetivo: analizar la frecuencia del diagnóstico de enfermería "tensión del rol del cuidador" en cuidadores informales de ancianos, las características que lo definen y los factores relacionados.
Método: estudio transversal y descriptivo, realizado con 99 cuidadores informales de ancianos residentes en las áreas de cobertura de cinco unidades de la Estrategia de Salud Familiar de Cuiabá, Mato Grasso, Brasil. Se realizó la recolección de datos entre julio y septiembre de 2017, por medio de entrevistas en los domicilios. Se utilizó una encuesta elaborada a partir de la literatura sobre el diagnóstico "tensión del rol del cuidador" establecido por la taxonomía II de NANDA Internacional. Se realizó un análisis descriptivo con frecuencia relativa y absoluta.
Resultados: la frecuencia del diagnóstico de enfermería "tensión del rol del cuidador" que se encontró en los entrevistados fue del 98%. Las características definitorias más frecuentes fueron: dificultad para ver al receptor de los cuidados con la enfermedad (69,1%); preocupación por el futuro estado de salud del receptor de los cuidados (66%); preocupación por el bienestar del receptor de los cuidados, en caso de no poder ofrecerlos (61,9%); preocupación por la capacidad futura para proporcionar los cuidados (60,8%); preocupación por el posible ingreso del receptor de cuidados a una institución (55,7%); preocupación por la rutina de los cuidados (55,7%) y por el aislamiento social (51,5%). Los factores relacionados que se encontraron con más frecuencia fueron: duración de los cuidados (92,8%); responsabilidades por el cuidado las 24 horas del día (75,3%); dependencia (77,3%) y alteración de la función cognitiva (73,2%) del anciano; condiciones físicas (73,2%) y codependencia del cuidador (61,9%).
Conclusión: la frecuencia del diagnóstico de enfermería "tensión del rol del cuidador", encontrada en este estudio, es elevada y sus características definitorias apuntan, principalmente, a la preocupación que tiene el cuidador hacia el anciano, y los factores relacionados se refieren a las demandas del cuidado proporcionado. El enfermero y los demás profesionales del equipo deben brindar atención tanto a los cuidadores como a los ancianos asistidos en las unidades de salud, ayudándolos a superar las dificultades que implica el desempeño de su función.

DESCRIPTORES: Diagnóstico de enfermería. Cuidadores. Cuidadores familiares. Anciano dependiente. Enfermería geriátrica.

INTRODUCTION

With the increase in the worldwide elderly population, so does the number of individuals with physical and emotional weaknesses and predisposition to pathologies, especially chronic degenerative diseases, that, if not properly treated or controlled, can lead to functional disability and loss of autonomy.[1] In this situation, the need for caregivers also increases.

The caregiver's role includes assisting the elderly in their daily activities such as eating, personal hygiene, routine medication, follow-up in health services, banks, pharmacies, supermarkets, among others.[2]

Caregiving by the caregivers can bring about many changes in your life, as they take on tasks for which they are generally unprepared, and neglect personal care, leading to physical and emotional illness.[3–4] They still live with isolation, illnesses, loneliness, responsibilities and difficulties. Some have yet to face the challenge of their own aging, as more and more older people take care of the elderly.[5–6]

These factors, to a greater or lesser extent, may interfere with the caregiver's quality of life and health, contributing to the difficulty to fulfill their role over time. When this happens, a situation called caregiver role strain (CRS) arises.

CRS has been studied for some years in various types of caregivers and in those who experience different situations, such as caring for children with cancer, hospitalized chronic patients and stroke patients.[7–10]

In nursing, NANDA-International identified CRS as a problem that nurses have to deal with in their practice and defined it as "difficulty in playing the role of caregiver for the family or other signifiers."[11:275] It is a multidimensional phenomenon that is characterized in the caregiver through changes in physical and emotional state, imbalance between activity and rest and compromised individual coping.[12]

CRS prevalence in caregivers found in scientific production is generally high. In a study carried out with caregivers of children with cancer, 78.0% had this diagnosis.[7] In a survey held in Fortaleza, in 2013, with caregivers of stroke patients, CRS prevalence in this population was 73.8%.[9] Moreover, in another study conducted in the city of Recife, with primary caregivers of children with cancer, CRS prevalence diagnosis was 95,6%.[10]

However, there are few studies on CRS diagnosis in caregivers for the elderly. In an integrative review, 66 national and international studies, produced in the period from 2005 to 2011, related to CRS were found.[13] Of these, only three were performed with caregivers for the elderly. One study aimed to identify nursing diagnoses found in general in caregivers for the elderly with dementia;[14] the other investigated the determinants of family caregiver strain in dependent elderly;[15] and the latter theoretically and empirically investigated the attributes of family caregiver strain in dependent elderly.[16]

Investigations are still needed to measure the CRS phenomenon within clinical practice and research.[12–13] Therefore, this study aimed to analyze the frequency of nursing diagnosis, the "caregiver role strain" in informal caregivers for the elderly, the defining characteristics and the related factors.

METHOD

A cross-sectional and descriptive study conducted in five Family Health Strategy (FHS) units in the northern region of Cuiabá, Mato Grosso, Brazil. These units have the largest registered elderly population in the region.

The population consisted of all informal caregivers for the elderly cared by the respective FHS, where the selection of participants was defined by non-probability convenience type sampling. Caregivers who met the following criteria were included in the study: being 18 years old or older, being the primary caregiver for the elderly and living in the same residence as the elderly.

From a list of elderly individuals registered in the e-SUS System's Individual Register, and with the help of the Community Health Agents responsible for the micro areas, 158 seniors who had caregivers were identified. Of these, 28 were excluded for not meeting the inclusion criteria, 24 were not found in their respective homes after two attempts and seven did not accept to take part in the research. At the end, the sample consisted of 99 primary informal caregivers for the elderly.

Data were collected between July and September 2017 through interviews conducted at home, after each caregiver to be interviewed signed the Free Informed Consent Form. A questionnaire based on the literature on CRS diagnosis established by Taxonomy II of NANDA-International version 2015-2017 was used.[11] In addition, conceptual definitions were also used from a study that validated the diagnosis in caregivers for the elderly.[17]

The applied questionnaire had questions divided into four parts: (1) caregiver identification and socio-demographic characteristics; (2) data from the elderly receiving the care; (3) defining CRS diagnosis characteristics; and (4) factors related to CRS diagnosis. The questionnaire was evaluated and validated by nine judges elected from their qualification and experience, according to pre-established criteria after consulting *Currículo Lattes* on the *Lattes* Platform of the National Council for Scientific and Technological Development. To validate the content and reliability of the instrument, the Content Validity Index (CVI) was calculated.[18] The final CVI was 0.99, showing judges' agreement regarding the adequacy of the questionnaire content.

To support CRS diagnosis determination, some instruments were also used, such as the Major Depression Inventory (MDI), for depression screening in the caregivers; the Functional Independence Measure (FIM), to assess the degree of help demanded by the elderly in performing a series of motor and cognitive tasks; and the Mini Mental State Examination (MMSE), with caregivers over 60 years old and elderly, in order to assess their cognitive abilities.

CRS diagnosis has 36 defining characteristics and 54 related factors.[11] In this study, all defining characteristics were investigated and we chose to investigate only three categories of related factors - caregiver health state, caregiver health state and care activities - as they are the most frequent in caregiver research.[7–8,13] In the caregiver's health state category, the factor related to unrealistic expectations about oneself was not investigated because it is a subjective data that is difficult to measure.

In this study, diagnosis was determined by the presence of at least one defining characteristic and a related factor.

Data were coded and double entered into Epi Info, version 7.2, spreadsheets (*Centers for Disease Control and Prevention*, CDC), to check for disagreements, and analyzed using the *Stata* program, version 7.0.

The analysis was descriptive in the form of tables and graphs, with absolute and relative frequencies following all ethical precepts for research involving human beings.

RESULTS

99 informal caregivers for the elderly took part in the study. Most (83.8%) are female, aged between 18 and 59 years old (67.7%), have more than nine years of schooling (69.7%), live in houses that have 3 to 5 people (68.7%) and are mainly sons or daughters of the elderly (61.6%). 47.5% of the caregivers are married or in stable union. Among the 70.7% of caregivers with income, most receive up to one minimum wage (34.3%) mainly from retirement (25.7%) and pension (11.4%).

Regarding the caregiver role, 44.5% are in this role for a period between <1 and 4 years. Most (72.7%) have no previous experience as a caregiver, 74.8% take care of the elderly and only 24 hours a day, 56.6% report receiving help, mainly from family, especially to perform the care (60.7%).

Regarding the health conditions of caregivers, most (95.9%) have a preserved cognitive capacity, have health problems (71.7%), especially cardiovascular (33.3%), osteoarticular (29.3 %) and endocrine (14.1%).

Regarding the characteristics of the elderly, the majority (57.5%) is in the age group of 80 years old or older, having cognitive impairment (73.7%) and modified dependence requiring assistance of up to 25% in tasks (40.4%). The main health problems in the elderly are cardiovascular (74.7%), sensory (30.3%), endocrine (29.3%) and osteoarticular (29.3%).

In this study, out of the 99 interviewed caregivers, 97 had CRS diagnosis, making a frequency of 98.0%. Regarding the defining characteristics, higher frequencies were found in the following categories: (1) relationship between caregiver and care recipient - difficulty in seeing the care provider with the disease (69.1%); (2) care activities - apprehension about the future health of the care recipient (66.0%), apprehension about the welfare of the care recipient, if the caregiver is unable to offer it (61.9%); apprehension about the future ability to provide care (60.8%); apprehension about the possible institutionalization of the care recipient and concern about the care routine (both 55.7%); and (3) caregiver's health state: socioeconomic state - social isolation (51.5%) (Table 1).

Table 1 – Defining characteristics of the "Caregiver role strain" nursing diagnosis in the informal caregivers for the elderly. Cuiabá, MT, Brazil, 2017. (n=97)

Defining characteristic	**n†**	**%**
Care activities		
Apprehension about the future health of the care recipient	64	66.0
Apprehension about the welfare of the care recipient if unable to offer it	60	61.9
Apprehension about the future ability to provide cares	59	60.8
Apprehension about the possible institutionalization of the care recipient	54	55.7
Concern with the routine of cares	54	55.7
Dysfunctional changes in care activities	33	34.0
Difficulty to carry through the necessary activities	41	42.3
Defining characteristic		
Difficulty to conclude the necessary tasks	10	10.3
Caregiver's health state: Emotional		
Stressors (self-reported)	45	46.4
Impatience	39	40.2
Nervousness	38	39.2
Change in sleep pattern	33	34.0
Emotional hesitation	27	27.8

Table 1 – Cont.

Defining characteristic	n†	%
Somatization	26	26.8
Rage	15	15.5
Depression (MDI)*	13	13.4
Frustration	12	12.4
Lack of time to satisfy personal needs	08	08.2
Ineffective Coping Strategies	05	05.2
Care receiver health state: Physiological		
Fatigue	38	39.2
Hypertension (self-reported)	29	29.9
Chronic headache	04	04.1
Gastrointestinal disorders	04	04.1
Cardiovascular disease	02	02.1
Caregiver's health state: Socio-economic		
Social isolation	50	51.5
Changes in leisure activities	44	45.4
Low productivity at work	29	29.9
Family processes		
Concerns about family members	37	38.1
Familiar conflict	32	33.0
Relationship between caregiver and care recipient		
Difficulty to see care recipient with a disease	67	69.1
Uncertainty about changes in the relationship with the care receiver	05	05.2
Grief about changes in the relationship with the care receiver	03	03.1

*Major Depression Inventory; † Multiple choice variable, the caregiver may have reported more than one related factor, which changed the frequency of the responses.

Regarding factors related to CRS nursing diagnosis, the highest frequencies found in the care activities category were: care duration (92.8%) and 24-hour care responsibilities (75.3%); in the category care recipient health state - dependence (77.3%) and alteration in cognitive function (73.2%); and in the caregiver's health state category - physical conditions (73.2%) and codependency (61.9%) (Table 2).

Table 2 – Factors related to the "Caregiver role strain" nursing diagnosis in the informal caregivers for the elderly. Cuiabá, MT, Brazil, 2017. (n=97)

Related factor	n‡	%
Care activities		
Duration of cares	90	92.8
24-hour care responsibilities	73	75.3
Unpredictability of the care situation	38	39.2
Changes in the nature of activities	34	35.1
Recent hospital discharge for the home of a relative that needs cares	16	16.5
Complexity of care activities	12	12.4
Excessive care activities	08	08.2
Caregiver's health state:		
Physical conditions	71	73.2
Codependency	60	61.9
Inability to meet the expectations of others	23	23.7
Inability to take care of to the proper expectations	11	11.3
Ineffective Coping Strategies	05	05.2
Change in cognitive function (MMSE)*	04	04.1
Substance abuse	02	02.1
Care receiver health state:		
Dependence (FIM)†	75	77.3
Change in cognitive function (MMSE)*	71	73.2
Codependency	57	58.8
Unpredictability of disease course	47	48.5
Increased need for care	35	36.1
Chronic illness	32	33.0
Problematic behaviors	21	21.6
Disease severity	19	19.6
Condition of unstable health	19	19.6
Psychiatric disorders	10	10.3
Substance Abuse	02	02.1

*MMSE= Mini Mental State Examination; †FIM: Functional Independence Measure ‡Multiple choice variable, the caregiver may have reported more than one related factor, which changed the frequency of the responses.

DISCUSSION

The relevance of this study lies in the fact that researches on CRS nursing diagnosis in caregivers for the elderly are still incipient. It is well known that CRS diagnosis frequency in this population was investigated in just one study.[9]

The socio-demographic and health characteristics of the participants in this study are similar to those found in the caregivers for the elderly from other studies. These are usually middle-aged, married, caregiving daughters with higher education and health problems.[19–20] Similarly, regarding the caregiver function, other studies show that they have little experience and are in charge for the care most of the day.[19,21]

CRS frequency found in this study is higher than that identified in another survey.[9] The difference between these values may be due to using different methods intending to evaluate the CRS in the

studies. When using different methods, the results may be equally different.[22] While in the previous study, the frequency was verified using the *Caregiver Burden Scale* (CBS) and validated by *expert* nurses.[9] In this study, frequency was measured with a questionnaire validated by judges based on pre-established criteria.

CRS's high frequency found in this study was also observed in researches with other caregiver populations.[9–10,23] This is understandable since they are mostly family caregivers who are continually and daily exposed to various stressors from caring for people. The continued conviviality and different care situations imply exhaustion, gradual and widespread changes in the caregiver's personal resources and well-being.[24–25]

The defining characteristics that are most frequently found in CRS nursing diagnosis of the caregivers in this study show the weight that concern exerts on the caregiver's role. They, in addition to having difficulty observing the health situation of the elderly, are concerned in advance with future problems that may come to fall on them.

Living with the elderly in the same environment can lead to constant apprehension and exposure to the negative effects of the care process.[19] For many caregivers, care does not mean giving attention, being willing with the elderly, but living in a constant state of concern about them, which brings disharmony and difficulty in maintaining the balance in the care, contributing, on the long-term, that CRS may be settled.[26]

This is probably due to the responsibility of caring for the elderly that the caregiver attributes to themselves. This accountability is often tied to a moral duty conditioned in part on the family bond.[26] In this emotional connection, the caregiver tends to see the care for the elderly as a mission, considering himself the only person able to do it, which can generate a state of constant concern and being hard on themselves.[27] Thus, the closer the relationship between caregiver and care recipient is, the greater the impact on the caregiver's mental health.[24]

Caregivers may also feel the responsibility of caring for the elderly becuase of a moral issue stemming from their role in society. This is particularly true for women, whose job in caring for dependent people lies on wives, daughters and daughters-in-law. This responsibility is often determined by emotional and consanguineous proximity to the elderly.[24] In addition, most of the time, women are responsible for other family functions, which leads to accumulating social roles, thus contributing to CRS.[20]

Changes in the caregiver's life lead to social isolation, one of CRS evidences, which may cause feelings of loneliness in these individuals.[25] For many caregivers, this makes their routine even more arduous.

In this study, the results show that the duration and continuity of activities that caregivers develop with the elderly have an important contribution to the CRS related factors.

In fact, the length of care influences the caregiver's workload.[3,6] Studies have shown that over time, the functional capacity of older people tends to become more compromised, bringing progressively higher and more complex demands.[3,28–29] Especially in the case of degenerative diseases, care may lead to distress due to increasingly distressing situations.[3] Similarly, a number of researches indicate that taking care of the elderly 24 hours a day also causes physical and mental fatigue due to continued exposure to stressors.[5,30]

Studies also show that the health state of the care recipient, in this case the cognitive problems of the elderly, contributes to CRS.[5–6,31] In fact, changes in the mental processes of the elderly with the possibility of behavioral changes, especially those related to their safety, usually lead to physical and emotional overload on the caregiver.[31] Caregivers for older people with behavioral problems and dementia are more prone to depression because they are usually unprepared to deal with these changes in the elderly.[25]

Research results show that care brings harm to the caregiver's health.[32–33] In this regard, studies with caregivers for the elderly show that those with compromised health have more CRS.[15–16] This may explain why, in this study, both the caregiver's physical problems and their codependency in relation to the elderly, which are factors related to the caregiver's health state, were found to contribute to CRS presence.

The health condition of the already impaired caregiver often adds to the lack of care that they have with themselves. The constant dedication and complexity of the care task makes caregivers forget about themselves and their needs, devoting little time to care for their lives and health, which increases CRS likelihood.[16,19,34]

The lack of time for self-care may be due to the caregiver's codependency in relation to the elderly, who, in their work routine, believe that their family member needs more care than themselves. Emotional overload often becomes superior to physical overload, which in the short or long term causes harm to your health.[34–35]

In this codependency relationship, caregivers tend to consider themselves as irreplaceable and, when someone offers help, they do not accept it.[8] Sometimes, their life is directed towards meeting the needs of the care recipient. This attitude can be explained by the caregiver's fear of abandoning the elderly, leaving them unaided, for some more severe complications to occur.[35] These numerous and complex demands lead to multidimensional burdens that make it difficult for the caregiver to perform their role.[16,36]

It is noteworthy that this study has some limitations. Using a convenience sample may restrict the generalization of the results. Only three categories of related factors were explored, which may limit the range of factors contributing to CRS occurrence. Even so, the results show how the most frequent related factors can contribute to this occurrence. Thus, it is considered that these findings are relevant to broaden the knowledge about CRS diagnosis in caregivers for the elderly.

CONCLUSION

CRS diagnosis frequency found in this study was 98.0%. The most prevalent CRS defining characteristics were: difficulty in seeing the care recipient with the disease; apprehension about the future health of the care recipient; apprehension about the welfare of the care recipient, if the caregiver is unable to offer it; apprehension about the future ability to provide cares; apprehension about the possible institutionalization of the care recipient; concern with routine care and social isolation.

The factors related to CRS were: duration of care; 24-hour a day care responsibilities; dependence and alteration in the cognitive function in the elderly; physical conditions and codependency of the caregiver.

The study found that most caregivers for the elderly have difficulty performing their role. This calls our attention because it directly impacts on the elderly, on the caregivers and on the entire complex support network involved, such as services, family and society. In the family context, care shared with other family members can minimize the occurrence of this diagnosis.

Knowledge of the defining characteristics and related factors to the CRS diagnosis gives visibility to the deleterious effects caused to the health and well-being of the caregiver and the elderly. It also enables us to plan and implement nursing interventions to prevent and minimize this problem individually.

In this sense, the actions should be carried out especially in the home environment, including practical guidance activities regarding the care procedures; information about the patient's disease/dependence; necessary adaptations in the physical care environment; space for the reception of feelings; encouragement to report difficulties and coping experiences.

Considering the future projections and the rise of the Brazilian elderly population, the work of CRS teams in the FHS units should be aware of the health needs for the elderly under dependency condition, as well as be closer to the caregivers for meeting their demands. Therefore, nurses should be able to set up the CRS diagnosis, helping caregivers to find better strategies to provide care for the elderly and helping them to overcome difficulties in performing their role.

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NOTES

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CONTRIBUTION OF AUTHORITY

study desing: Dalla Vechia ADR, Mamani ARN, Azevedo RCS, Reiners AAO, Pauletto TT.
Data collection: Dalla Vechia ADR, Mamani ARN.
Analysis and interpretation of data: Dalla Vechia ADR, Mamani ARN, Azevedo RCS, Reiners AAO, Segri NJ.
Discussion of the results: Dalla Vechia ADR, Azevedo RCS, Reiners AAO.
Writing and/or critical review of content: Dalla Vechia ADR, Azevedo RCS, Reiners AAO
Review and final approval of the final version: Dalla Vechia ADR, Mamani ARN, Azevedo RCS, Reiners AAO, Pauletto TT, Segri NJ.

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CONFLICT OF INTERESTS

There is no conflict of interest.

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CORRESPONDENCE AUTHOR

Akeisa Dieli Ribeiro Dalla Vechia
akeisa_drdv@hotmail.com