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## RESEARCH

## O impacto da atuação dos enfermeiros na perspectiva dos cuidadores de idosos com demência

The impact of nurses' performance in the view of the caregivers of elderly with dementia

El impacto de la ejecución de las enfermeras en vista de los cuidadores de personas mayores con demencia

Mirian Da Costa Lindolpho<sup>1</sup>, Jaqueline Burlandi De Oliveira<sup>2</sup>, Selma Petra Chaves Sá<sup>3</sup>, Ana Karine Brum<sup>4</sup>, Geilsa Soraia Cavalcanti Valente<sup>5</sup>, Thiara Joanna Peçanha Da Cruz<sup>6</sup>

## ABSTRACT

**Objective:** describing the opinion of the people who are taking care of seniors with dementia about the actuation of the nursing in their benefit and identifying the results of the nursing aid in the opinion of the people who are taking care of seniors with dementia. **Method:** it is an exploratory and descriptive research with a qualitative approach. The subjects are the people who are taking care of senior with dementia enrolled in the "Nursing Outreach Program in Health Care of the Elderly and Their Caregivers", Niterói-Rio de Janeiro/Brazil. In this study was used a semi-structured interview. **Results:** it was submitted to a content analysis and there were constructed eight categories: the quality of the nursing service in the opinion of the people who are taking care of senior with dementia; they teach to taking care; they inform about the disease; the importance of the relationship between the professional and people who are taking care; change of feelings; change of experiences; the patience as essential element in taking care and acceptance of the disease. **Conclusion:** it was concluded that through the relationship between nurses and the people who are taking care of those seniors, the life perspective of those people and the seniors with dementia can change positively, improving their quality of life. **Descriptors:** dementia, people who are taking care, senior, nursing care.

## RESUMO

**Objetivo:** descrever a visão dos cuidadores de idosos com demência sobre a atuação da enfermeira em seu benefício e identificar os resultados desta assistência. **Método:** consiste numa pesquisa exploratória, descritiva, de campo com abordagem qualitativa. Os sujeitos foram os cuidadores de idosos com demência, inscritos no Programa de Extensão "A Enfermagem na Atenção à Saúde do Idoso e Seu Cuidador". A pesquisa foi realizada em Niterói-Rio de Janeiro/Brasil. Utilizamos a entrevista semiestruturada, submetida à análise de conteúdo. **Resultados:** foram construídas oito categorias: A qualidade do atendimento da enfermeira na visão dos cuidadores; Ensinam a cuidar; Informam sobre a doença; A importância da relação profissional-cuidador; Mudança de sentimentos; Troca de experiências; Paciência como elemento essencial no cuidar e Aceitação da doença. **Conclusão:** através da relação enfermeira-cuidador a perspectiva de vida do cuidador e do cuidado do idoso com demência pode mudar positivamente, melhorando a qualidade de vida do mesmo. **Descritores:** demência, cuidador, idoso, cuidado de enfermagem.

## RESUMEN

**Objetivo:** describir la visión de los cuidadores de ancianos con demencia en el labor de las enfermeras en su beneficio y para identificar los resultados de esta ayuda. **Método:** consiste en una investigación exploratoria, descriptiva, de campo con un enfoque cualitativo. Los sujetos fueron los cuidadores de ancianos con demencia matriculados en programas de extensión "La Enfermería en la atención a la salud de las personas mayores y sus cuidadores". La investigación se realizó en la ciudad de Niterói-Rio de Janeiro/Brasil. Hemos utilizado la entrevista semiestructurada, objeto de análisis de contenido. **Resultados:** fueron construidos ocho categorías: la calidad de la atención de la enfermera en la visión de los cuidadores; enseñan el cuidado; Informar acerca de la enfermedad; la importancia de relación profesional/tutor; cambio de sentimientos; el intercambio de experiencia, paciencia como un elemento clave en el cuidado y la aceptación de la enfermedad. **Conclusiones:** a través de la relación enfermera y cuidador, la perspectiva de la vida del cuidador y el cuidado de los ancianos con demencia pueden cambiar positivamente, mejorando la calidad de vida de los mismos. **Descriptor:** demencia, anciano, atención de enfermería.

<sup>1</sup>Nurse. Associate Professor of the Fundamentals of Nursing I and of the Department of Fundamentals of Nursing. Responsible for the Administration of the Nursing School Aurora Afonso Costa - Universidade Federal Fluminense - UFF. End: Rua: Dr. Celestino, nº 74, 4º andar, sala nº 41 - Centro - Niterói/RJ. E-mail: profmirianlindolpho@yahoo.com.br. <sup>2</sup>Nurse. Graduate nurse at the Nursing School Aurora Afonso Costa (EEAAC) Universidade Federal Fluminense-UFF. Attending Multidisciplinary Residency at Clementino Fraga Filho University Hospital (HUCFF), Federal University of Rio de Janeiro - UFRJ. E-mail: jburlandi@hotmail.com. <sup>3</sup>Professor of the Fundamentals of Nursing II Nursing School Aurora Afonso Costa - Universidade Federal Fluminense - UFF. Program Coordinator of the Extension Nursing in Care of the Elderly and their Caregivers. E-mail: spetra@ig.com.br. <sup>4</sup>Nurse. Doctor in Nursing. Management Professor in the department of Nursing Fundamentals and Administration, School of Nursing Afonso Costa - Universidade Federal Fluminense - UFF. E-mail: karinebrum@yahoo.com.br. <sup>5</sup>Nurse. Doctor in Nursing. Associate Professor, Department of Nursing Fundamentals and Administration EEAAC / UFF. E-mail: geilsavalente@yahoo.com.br. <sup>6</sup>Nurse. Master of Nursing. Substitute Professor of Nursing Fundamentals II School of Nursing Aurora Afonso Costa, Universidade Federal Fluminense - UFF. Participant Outreach Program Nursing in Care of the Elderly and their Caregivers Health. E-mail: thiaracruz08@gmail.com.

## INTRODUCTION

**T**he demographic profile of the Brazilian has changed, especially in recent decades, with a demographic transition influenced by the fall in mortality in the 1940s, and the decline in fertility since 1960, and this is the really decisive factor for the expansion of the population most elderly.<sup>1</sup> Thus, we can say that there was a progressive narrowing of the base of the population pyramid, and a peak broadening of the same.

This global aging population creates greater likelihood of chronic diseases and, thus, the development of disabilities associated with aging.<sup>2</sup> And one of them is dementia.

Dementia is a syndrome manifested by the global decline of cognitive functions, though not necessarily uniformly associated with a preserved state of consciousness.<sup>3</sup>

The central pattern of dementia is memory impairment. Furthermore, dementia includes at least one of the following cognitive impairments: aphasia; agnosia; disturbance and apraxia in execution functions, such as planning, organization, and abstraction sequence<sup>4</sup>, which leads to a progressive dependence on someone in their daily activities, directly interfering in the quality of life of the families involved.

Disease manifestations generate multiple demands for the elderly, requiring special care, therefore, becomes dependent. Right now arises of the caretaker, who is most often a family member or close friend who helps this old, partially or totally in difficulties or disabilities to perform activities of daily living form. This person is called informal caregiver.<sup>1</sup>

This informal care is usually reserved for women. However, the family structure in the Brazilian reality is changing and the women no longer working exclusively at home, instead, engage increasingly in the labor market.

The daily and ongoing care to dependent elderly produces perturbations, however small that may be, affect family life. As a result, some seeking other care alternatives like hiring an individual to assist the elderly. These individuals formal caregivers not alone take care to the elderly are called.<sup>1</sup>

This is where the role of the nurse is needed in the life of a caregiver for elderly patients with dementia.

Besides serving the elderly, the nurse must seek alternatives and ways to enhance the quality of life of the caregiver, since from the time of diagnosis, this shall be the necessity of peculiar care, in the same way that the elderly person.<sup>5</sup> This requires a good relationship between nurse and caregiver is precisely the object of the study.

As a result, we use and we base our research on the theory of Peplau; a nursing theory that deals with the interpersonal process. Peplau is centered on a specific nurse-patient relationship.<sup>6</sup>

Throughout his work, Peplau identified four sequential phases in interpersonal relationships: orientation, identification, exploitation and resolution.

This interpersonal relationship possibly culminates in more appropriate and positive results contributing to the quality of life of the caregiver treatments.

Thus, it is interesting to recognizing what is the opinion of caregivers of elders with dementia in relation to the treatment they are receiving nurse. Know recognize the importance of shared guidelines and validate the practice of the same in their lives, but mostly, if there really positive results.

The objective of the study is to describe the vision of caregivers of elderly with dementia on the role of nurses to their benefit and to identify the outcomes of care in view of nurse caregivers for the elderly with dementia.

## METHOD

Exploratory, descriptive study with a qualitative approach as it deepens the meaning of actions and human relations, which is not noticeable and procurable in equations, averages and statistics.<sup>7</sup>

The subjects are the caregivers of the elderly with dementia inscribed in the Extension Program "The Nursing in Care of the Elderly and Their Caregivers Health" (EASIC / UFF), which participate in the workshops for caregivers and / or of PROCUIDEM (Guidance Program to caregivers for Seniors With Dementia - a group of guidance to the caregiver).

The data were collected from twenty (20) caregivers from May 2009, through semi-structured interviews recorded and later transcribed, with the guiding questions: How long have you participated in the workshops for caregivers of patients with dementia and / or the PRÓCUIDEM? How is your relationship with the nurses who participate in therapeutic and / or workshops PRÓCUIDEM? There results the performance of the nurses outside his problem in the care of the elderly with dementia? What are these results?

After approval by the Research Ethics Committee of the Faculty of Medicine of the University Hospital Antonio Pedro, Federal Fluminense University, Case No. 044/09. Caregivers were asked to participate in the study. After all the information, it was requested that the caregiver of elderly patients with dementia to sign the Term of Free and Informed Compliance.

For analysis of the findings we used the referential of Bardin about content analysis. After the construction of the categories we used to subsidize them and interpret them, Peplau's theory and other authors that deal with the subject.

## RESULTS

From the data analysis coming from interviews with caregivers emerged eight (8) categories: 1) The quality of care in view of nurse caregivers of elderly with dementia; 2)

Teach to care; 3) inform about the disease; 4) The importance of the professional-caregiver; 5) Change of feelings; 6) exchange of experience; 7) Patience as an essential element in the care; and 8) Acceptance of the disease.

### 1 - The quality of care of nurse caregivers of seniors with dementia

We observed that 100% of the caregivers interviewed reported having a good and / or excellent relationship with the nurses who relate to them in workshops.

The nurse is the most sought professional in the 10 to 15 year of disease progression,<sup>9</sup> directing the adaptation of the progressive care dependency of the elderly; the instrumentalization of the family for the care; and encouraging self-care and preservation of self-esteem in old-binomial family.<sup>10</sup>

Today, the nurse performs work that presents a different interpersonal relationship.<sup>2</sup>

*I think out of serious! Contact with nurses is much better than with the geriatrics. The geriatrician doesn't make any examination, or measure the pressure. Already the nurses do the full exam from head to toe. They ask me more; want to know more about me and my family to help me. (C6)*

*They even link here home to encourage my mother doing certain activities and go to the program. (C4)*

We can identify that an acceptance and closeness nurse and caregiver with professionalism, which extends from the individual to the collective occurs, as is expressed in the understanding of Peplau, the nurse assesses today many concepts such as intrafamily dynamics, socio-economic forces, and considerations of social space for each patient.<sup>6</sup>

*They are charismatic and given to the situation. (C10)*

*They're all very polite, helpful, always looking for help and guiding. (C13)*

These statements identify the importance given by the research subjects the way they are received and processed. According to them the education and charisma are positives in a health professional.

The type of person who is a nurse, and comes to be, has a direct influence on its ability interpersonal therapeutic relationship.<sup>6</sup> This statement is confirmed in the statements cited above show that caregivers like them because of certain features that are sure directly or indirectly influence in obtaining quality care and that appeal to users.

*They are very good, very friendly, are people who care about us, with the sick, with caregivers. The nurses are very nice, girls, interns as well. The girls are great. We will miss them when they come out because they're going to graduate. (C7)*

*Here they receive the family, not just the elderly. Welcome everybody. (C1)*

It is established a link between the nurse and the patient, who continues to be strengthened while the concerns are being identified.<sup>6</sup> And this bond is perceived when citing "miss".

The lines indicate the quality of the relationship between nurse and patient. A good interaction between them indicates that the pipes are suitable professional and efficient therefore value the good interpersonal relationship.

The first phase of interpersonal relationship Peplau (orientation) reports that it is of utmost importance that the nurse works in collaboration with the patient and family in the situation analysis, so that together we can recognize, clarify and define the existing problem.<sup>6</sup> In this sense the nurses were capable to accommodate all the family caregiver and the elderly providing the necessary support and helping to find relevant solutions.

Being thus put into practice a theoretical concept, providing breaking a paradigm where talk that theories cannot be applied in practice by the dichotomy between theory and practice. Thus we see that the application of a theory in nursing practice is possible and can provide the achievement of positive results.

## 2 - Teach caring

*Teach on how to deal with the patient if we don't fight with him all day. (C2)*

*For me the nurses give us much explanation, agent knows best deal, knows what to do at certain times, I love coming here, it's very good. Back home everybody noticed. Even his doctor, who is geriatrician, noticed (C5)*

This category can be analyzed through the second phase of the Theory Peplau where the initiative comes after the patient specific care guidelines. The patient's sense of belonging and reacts selectively to those who can fulfill their needs. Still occurs interdependent setting goals.<sup>6</sup>

We note that after receiving the guidelines on care, these subjects began to deal with the situation better.

Most lay people are unaware of basic practices that visibly facilitate the caregiver's life and consequently improve the quality of life of the same. Note-if the point in the speech:

*The guidance I get is technique and is fundamental. Without it we didn't get anywhere and we caregivers of seniors, even less. (C15)*

*I was watching, but I wasn't sure of anything. Put more practical in the way they treat you. (C19)*

The data offered by the speeches are suggestive of the need to provide programs for caregivers, addressing the issue of care to reduce their wear, as is done in the therapeutic workshops. Just that they only absorb what it is appropriate and possible, and implement in their homes as reported:

*Everything I learn when I'm greatly improves back home and in my personal life. (C14)*

*I've become more aware of how to treat it. (C4)*

We realized that, through the words of those, the practice of the nurse promotes changes in the personal life of the caregiver and care for her demented elderly.

Peplau talks about it in the last phase of interpersonal relationships - Resolution - the problem definition phase, the selection of appropriate professional assistance and use of professional assistance to the alternatives of problem solution.<sup>6</sup> He discovers his problem, selects the guidelines that are necessary, takes him home, practices and adopts new goals.

### **3 - Inform about the illness**

In the exploration phase the patient actively seeks and obtains knowledge and expertise who can help.<sup>6</sup> We saw that provide knowledge about the disease is of paramount importance for one who deals with it daily.

The nurse has the necessary information to convey adequately instruments. Peplau also says that the nurse can clarify misconceptions the patient, <sup>6</sup> and this was exactly the point made by the subjects.

*I feel safer understanding the reality of the disease. (C7)*

*I thought she was doing certain things because I wanted to, but here it is because she wants to, is the disease. Everything just got easier. (C12)*

We notice that from the guidelines on the disease they felt safer knew how to do better and understand certain attitudes of the elderly.

One of the most important ways to help people is by giving them information. People who have information are better prepared to handle the situation in which they find.<sup>9</sup>

### **4 - The contact Professional-caregiver**

*Here are questions for me. Of Course! Who cares it's me! (C9)*

*They give us the freedom to speak. (C18)*

In this category we can return to the first phase of nursing Peplau - Guidance. Because according to the theory, during the conversation between the patient, family and nurse, joint decisions should be taken. They work together to recognize, clarify and define the existing problem.<sup>6</sup> This in turn reduces tension and anxiety associated with perceived need and fear of the unknown.

When there are conversations and discussions, the bonds of trust will intertwining, confirming, making every day, every conversation, confidence increases and the results are better. Together, nurse and patient can find the best solutions to their problems.

The statements indicate that there is a search for acceptance, protection and exploitation by caregivers. They need to talk, be heard and have the freedom to say what they wish. This space exists in workshops with caregivers rounds of conversation and the nurse plays the role of welcoming.

## 5 - Change of feelings

*I learned to take it easy, he was agitated and nervous. (C16)*

*Here we are happy and have peace of mind. We feel well. It is a distraction. (C14)*

*I'm less stressed. My mind is lighter. (C10)*

According to Peplau, when clarifying and defining the problem, the patient can direct the energy stored in their anxiety to unmet needs, starting to work with the presented problem.<sup>6</sup>

The role of the nurse in the workshops helps the caregiver to discuss their feelings and emotions, allowing often he abandons certain anxieties and acquire new strengths and mitigate negative feelings.

*They teach us many things to become more capable. (C3)*

*I'm stronger and driver. (C3)*

*I've been adjusting better; have been getting more steady, understanding and analyzing. (C20)*

Peplau states that through self-determination, the patient gradually develops responsibility for himself, belief in their potential and adaptation directed the Self-Competence and independence.<sup>6</sup> As a result developing sources of inner strength that allows them to face new challenges.

These patients begin to establish their own goals for a better state of health.<sup>6</sup> The nurse promotes this reflection and the pursuit of well-being by caregivers themselves.

Gradually the mental work will make getting the caregiver trace their goals independently and get better with their feelings and emotions to deal with.

*I see the things with other eyes. (C7)*

*Today, I have another vision. (C16)*

The interpretation of the manifest content revealed that caregivers come to see and analyze your entire life after the diagnosis of dementia in the elderly differently. Nurses help in the analysis of what is happening to them and so many times, his vision regarding the disease and its consequences in your life and change in the elderly. This change will facilitate the care for the elderly and have a positive effect on the health of the caregiver.

*They help us to have a social life, not bury ourselves. (C8)*

Through this speech we can understand that the treatment they receive enables them to see the need to maintain an active social life and not devote himself exclusively to the care of demented elderly forgetting themselves.

Caregivers need support from the public health system because they generally give themselves to caring for others and do not realize the need to take care, away from society, as well as abandoning leisure activities.<sup>10</sup>

Anyway, the nurse has a key role in the recovery and maintenance of emotional health of caregivers of elderly with dementia, because according to the theoretical Peplau it should encourage the patient to recognize and explore their feelings, thoughts, emotions and behaviors, providing an atmosphere uncritically and a therapeutic emotional climate.<sup>6</sup>

## 6 - Experiences exchanges

*Here a wrong experience to another. (C1)*

*I see people who spend a good piece of their relatives too. It comforts me a little. I see I'm not alone in this. (C6)*

The reports reflect the loneliness and identification with the situation of abandonment that caregivers experience. However, the fact of being in contact with other caregivers of elderly with dementia reveals that there is someone with the same problems or even larger than yours and it often comforts the caregiver.

The nurse should provide an atmosphere of acceptance and support, in which a person can become more self-conscious, beginning to use their strengths to minimize the weaknesses.<sup>6</sup> Therefore, it plays an essential role in providing the meeting of these people with similar problems direct the issue and allow there among all participants exchange experiences, mutual exchange of comfort and strength.

Thus, "therapeutic workshops arise as a support mechanism, an environment that provides advice, information, besides being a space that provides quality of life and experience exchange between subjects".<sup>11</sup>

Study by Silva<sup>12</sup> showed similar results when talking about the waiting room that contributes shares of education and health promotion, generating conscious and intentional attitudes of the people involved, strengthening thus the importance of group work.

#### **7 - Patience as an essential element in care**

*Nurses teach the whole family to have patience. (C18)*

*We learn how patience is important. (C3)*

It is noticed in the speech of the caregivers that they value the concern of nurses in teaching to have tolerance and patience, respecting their elders at his existentialism.

And for being a quality most often cited by respondents (almost 100% placed patience as a characteristic to be learned by attending the workshops), was built a category all to itself.

Peplau's theory identifies the needs, frustrations, conflicts, anxiety of those who are under their care as important situations that may interfere with their health-disease and thus the caregiver experiencing all these feelings.<sup>6</sup> He needs to deal with the behavior changes of your elderly, balance your everyday and still have patience to care without harming, or he needs to control himself, be more tolerant.

From the moment that the nurse is part of this process and identifies the lack of caregiver knowledge about the disease, its treatment and explains the abnormal behavior of the elderly with dementia, the nurse provides the allowance for understanding caregivers about the disease process that your family experiences, thus enabling the development of patience.

#### **8 - Disease acceptance**

*They helped me to accept my husband's illness. (C5)*

*It was formed with the stuff, after living that took more. (C9)*

Through these speeches you realize that the process of denial is very common, and refusal to get in touch with the feelings often manifests itself through psychological distress. According to Peplau in the orientation phase is when the nurse and the patient are the identification of needs and the patient is occurring and why he seeks professional.<sup>6</sup>

But he does not always identify this need, a fact that we can relate to the difficulty of accepting the disease, so important that the nurse assists the caregiver and the family understand what is happening with the demented elderly. The nurse collaborates with the process of acceptance of the disease by allowing the caregiver to take care becomes easier.

## CONCLUSION

What was proved is that the nurse is a key element to providing a comprehensive care to individuals' caregiver of an elderly with dementia. And that his performance positively influences the life thereof.

We note that it is through good nurse - caregiver relationship that the prospect of life of the caregiver and care for the elderly with dementia can change. And that depends only on the caregiver's own decision to value it receives from the nurses.

Despite the good results guided by carers themselves, still see the need for development of new intervention strategies that favor their daily practices. Fortunately, this study has revealed issues related to caregivers to whom the nurse may be based to make these new strategies aiming to ensure a comprehensive and quality treatment for these patients. This shows the great contribution of research in the area of geriatric practice, especially in nursing.

At last, still is needed a good training of health professionals specializing in this area, implementation of counseling and caregiver support programs that involve the family, the community and the state is still required in addition to the development of more research on caregivers in Brazil, because the more we know our customer, the better we can treat it. Remember that those who care cannot be without care!

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Contact of the corresponding author:  
Mirian Da Costa Lindolpho  
Dr. Celestino, nº 74, 4º andar, sala nº 41 - Centro - Niterói/RJ.  
profmirianlindolpho@yahoo.com.br