ADAPTIVE PROCESS OF CAREGIVERS OF A PERSON ELDERLY WITH ALZHEIMER: CONTRIBUTIONS OF NURSING

PROCESSO ADAPTATIVO DOS CUIDADORES DE UMA PESSOA IDOSA COM ALZHEIMER: CONTRIBUIÇÕES DA ENFERMAGEM

RESUMO


ABSTRACT

Objective: to understand the adaptation process experienced by caregivers of a person elderly with Alzheimer’s disease. Method: exploratory-descriptive study, qualitative, conducted between December 2009 and April 2013, through interviews with five caregivers of an Alzheimer’s person. Data were analyzed using content analysis. The research project was approved by the Research Ethics Committee, Opinion No 233/2009. Results: two categories were identified << Conflicts and family instability: from the acceptance of the diagnosis to the reversal of social roles >>; << Certainties and uncertainties lived in the adaptive process >>. Conclusions: the diagnosis of Alzheimer’s transcends the individual disease. Involves relational and associative processes, which involve daily family adaptations, overcoming gradual losses, roles reversal, i.e., a new order of relationships, routines and care environments. Descriptors: Alzheimer’s Disease; Elderly; Family; Caregivers; Geriatric Nursing.

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INTRODUCTION

The society is faced with a progressive population aging. Aging, according to the Pan American Health Organization (PAHO), is a dynamic process, progressive, individual, cumulative, irreversible, non-pathological, of deterioration of a mature organism, of all members of a species. The process does not reduce only to organic and psychological evidence, but is related also, to the socio-cultural and scientific characteristics.

The last census of the Brazilian Institute of Geography and Statistics (IBGE), conducted in 2010, counted 14.5 million Brazilians aged 60 or more. It is clear that this population is increasing significantly, causing global demographic changes. The changing in the demographic profile of the Brazilian population directly affects rates of chronic diseases. It is estimated, for the year 2020, about 80% of the developed diseases tend to be chronic morbidities. Among chronic diseases, there is dementia, especially Alzheimer’s disease (AD), accounting for over 50% of cases.

AD is considered degenerative and is characterized by cognitive impairment that brings as a consequence the loss of functional capacity, spatial disorientation and gradual decline of memory, especially of recent events. It is divided into three stages: in the first, considered mild, the individual expresses confusion and memory loss, spatial disorientation, progressive difficulty in daily life, changes in personality and judgment.

In the second, considered moderate, the disease progresses to disability in performing acts of daily living, anxiety, delusions, hallucinations, nocturnal restlessness, sleep disturbances, difficulty recognizing friends and family. Finally, the third and most serious stage, is characterized by a marked reduction in the vocabulary, decreased appetite and weight, sphincter decontrol and fetal positioning.

Data published in 2012, in the United States of America (USA), indicate that there are approximately 5.4 million Americans affected by Alzheimer’s disease, with the majority aged over 65 years. Another statistic states that every 68 seconds some American individual develops the disease.

In the Brazilian context, the majority of patients with AD are cared by family members at home, often, deprived of specific training as well as human, material, structural, and social resources, thus causing physical and emotional burden. As the disease progresses, treatment becomes gradual and increasingly complex, requiring an adaptive process by either the carrier as by family caregivers.

The development of this study is relevant, since its data may assist in understanding about the adaptation process experienced by family caregivers of a patient suffering from Alzheimer’s disease. Corroborates with a body of proper knowledge about the care for patients of the disease and family caregivers, enabling interactive tools which can assist in the systematic care and understanding of the importance of a social support network.

Based on the above, the question is: How do the adaptive process of caregivers of a patient with Alzheimer given the complexity of the disease occur? In attempting to answer the question and in anticipation of possible interactive views and engaged with human being inserted in its context, the objective is:

- to understand the adaptation process experienced by caregivers of a person elderly with Alzheimer’s disease.

METHODOLOGY

Exploratory-descriptive study of qualitative character. This type of study aims to provide an overview of a situation that can be considered as the first step in a broader research, since, due to its results, can be organized strategic action plans, contributing to the changing of the investigated reality.

The study was conducted between December 2009 and April 2013 with five caregivers of an elderly carrier of Alzheimer’s disease, of which four family and a non-family caregiver, from periodic home visits to the carrier and their caregivers, living in the northwest region of the state of Rio Grande do Sul As inclusion criteria, was established: being a caregiver with or without blood bond carrier of Alzheimer's disease carrier and be watching daily adaptive process imposed by the disease.

Data were collected by interview technique through the following guiding questions: Which feelings the disease aroused in you and the family? Which were the changes in family life? How did/is the adaptive process of the carrier in relation to family and vice versa?

Data were analyzed based on the analysis technique of thematic content proposed by Bardin. The same consist to discover the meaning nucleus that compose a communication whose presence or frequency add significant perspectives to the study object in question. The notion of the subject is associated with an affirmation that relates to a particular subject, and may be presented for a word, phrase or idea.
Thus, the operationalization of the analysis process followed the three steps of the method. In the first stage, called pre-analysis, it was attempt to make a comprehensive reading of the data, followed by the organization of the material and the formulation of hypotheses. Following, the exploration of the material was performed, i.e., encode the brute data. In the third and final phase, the data were interpreted and defined in themes according to the assigned meanings.\(^{10}\)

The ethical and legal issues involving research with human subjects were considered, according to Resolution 196/96 of the Ministry of Health\(^{10}\). Clarified the objectives and methodology of the survey, participants signed a Informed Consent Form, in two via, getting one with the participant and one in the power of the researcher. In the document was guaranteed free access to the collected data. Participants were also informed that their names would not be disclosed and that they could pick from the study at any time without restrictions.

The anonymity of participants was maintained, and they were identified by the letter P (Participating) followed by a numerical digit, as research order (P1, P2 ... P5). The project was approved by the Ethics Committee in Research of Franciscan University Centre under the number 233/2009.

RESULTS

Organized and analyzed data resulted in two categories << Conflicts and family instability: from the acceptance of the diagnosis to the reversal of social roles >>; <<Certainties and uncertainties lived in the adaptive process. >>

- Conflicts and family instability: from the acceptance of the diagnosis to the reversal of social roles

Conflicts and instabilities begin with a confirmed or suspected diagnosis of Alzheimer’s disease. The initial feeling of family caregivers is discomfort, conflict, by designing the disease as irreversible and, crucially, the fear of the unknown, as the speech:

> A degenerative disease, neurons are dying, and losing memories (crying), making difficult the skills and to the point of not knowing who we are neither where we are; And for this disease “still” does not have a cure. (P1)
>
> How to be sure that this is the best treatment for this stage? Am I doing something wrong? (P2)

The difficulty comes for some uncertainty and the desire to make the best of the best possible way. (P5)

In the speeches, it is observed that caregivers feel insecure because of the disease develop without healing prognosis. It was clear that, with the evolution of the disease, the degree of dependence also evolves, i.e., care becomes more complex and differentiated. Given the growing and complex process, new conflicts and uncertainties are generated. While for some the process is designed for constant losses, for others it is understood in a healthy way, i.e., by the recognition of gains. Both understandings are visible in the statements below:

> How to look at your mother, to see a big size dependence level on her, and she was your support, your advisor, your counselor, your friend. (P1)
>
> Feeling of loss and gain at the same time: Loss of the present “mother”, always worried about taking care of myself, and gain: a daughter, a child who must care for and enjoy to the fullest I can. (P2)

It can be observed that the AD triggers on family caregivers feeling of role reversal, in which the “child becomes a father (mother) and vice versa”. There are also feelings of loss and gain, associated with emotions such as sadness, helplessness and even escape from reality.

> The feeling that this causes you “has no name”. Is a sadness mingled with pity, I feel powerless to change this situation. “Given all this, to get the job, I do not stop to analyze, I pretend everything is alright and I say to myself - I’ll think about this tomorrow”. (P4)

Is displayed that the challenge of caring and experience the process of Alzheimer’s disease goes beyond punctual and linear assignments. Involves emotional, ambivalent feelings towards the process of illness in the elderly.

- Certainties and uncertainties experienced in the adaptive process

To make this process acceptable, bet on strategies, which for several moments can both succeed as result in failure, as in the adaptive process there are no ready recipes, especially when the need is aligned to ensure staff safety, family life and socialization. In addition to facilitating the care, decision making together is essential in the process of taking responsibility and avoid family conflict, as speech:

> When it was no longer safe, the family came to the conclusion that in order to better serve the needs of “our mother”, it would...
be better she to live with us. So we agreed that she would live a season with one of us (daughter) and that each one would adapt their home as best they could, so that she (mother) feel at home, even retain her furniture so she could feel familiar with the environment. (P1)

In the speech, the made adaptation is clear, both in physical structure with the maintenance of furniture, as the division of responsibilities and the care that is characterized by human adaptation in favor of care for patients of AD. Changes and modifications in the course of the disease demand that family caregivers adapt to the new routine, which is essential for patience, sacrifices and sometimes even the restriction of freedom, as expressed in the following lines:

We need to change habits of noise, the music, environments, spaces, food. (P2)

[...] As a couple, we had the freedom to get out of the house any time for as long as was necessary, at the time that the mother stays with us, this “freedom of movement”, is very restricted. (P4)

Certainties and uncertainties are also related to the adequacy of the physical environment, such as reducing the amount of furniture, removing carpets, put iron bars in bathrooms and other.

[...] We put safety bars in the bathroom, we removed the doors carpets, bathrooms, bedrooms and living rooms. We removed some furniture of the house to open more space avoiding some domestic accidents. (P5)

[...] we avoid her presence in the kitchen while a meal was being prepared, because at the beginning she was always willing to help and we considered dangerous due to the stove, hot pot or flame. (P3)

The adjustment is necessary to prevent possible accidents. Accordingly, in addition to the physical structure adaption to the needs of the carrier AD, some families, in order to protect them, seek to separate her from places and situations that offer health risks.

**DISCUSSION**

From a broader view, it fits to value, recognize and analyze human and all parties involved. The isolated information or data are insufficient, being essential to place them in their real context. In addition to this perception, it is noteworthy that the context of care carrier of AD, changes or explains by the interactions and systemic retroactions, i.e., by the complexity that the care for patients of Alzheimer’s disease presents.

Considering the uniqueness and multidimensionality of every human being and their families, emerges the need to make the elderly with Alzheimer integrated, recognized and valued by all around him. Such integration must be able to recognize and adapt the certainties and uncertainties related to the adaptive process. Therefore, it is necessary to overcome paradigms, seek and recognize values that pervade the individual, the family and society as a whole.

To understand the complexity of being family/caregiver of a person with Alzheimer’s, we must broaden the focus beyond the disease and enter new paradigms in order to apprehend the significance of the disease process in a multidimensional way.12 Research shows that the caregiver to take care of the carrier alone, at home, often manifest discomfort and feelings of loneliness and depression.13

It denotes the need to share with other people wear caused by situations of negative coping, being a strategy to soften the impact caused by overloading.13 The results show that the conflicts generated by Alzheimer’s disease, in the family environment, are inherent to the process, however, need to be rethought and integrated with the ability to design new adaptive strategies.

Aiming to recognize the carrier of Alzheimer’s disease as a human being and therefore, multidimensional and keep it integrated in the family, family caregivers (re)organized physical structure aiming to make the environment best suited to the conditions of the carrier AD. With this initiative, the family tried/promoted a better quality of life, almost to meet the requirements, decrease the limitations and to ensure security, and become the environment as facilitator to autonomy maintain.14

In this respect, it became clear that the family recognize the need to adapt the physical structure of the residence. Changes were made, such as reducing furniture, and removed or stopped up mirrors.

As the disease progresses and limitations are established, the performance declines gradually and slowly. Although Alzheimer’s disease alter the intellectual, the instinct will be preserved and should be valued. It is recognized that patients with pathology, reject the new and does not adapt easily to new conditions. Thus, is denoted that to force unknown activities are irritability situations easily to be generated. Because of this, it stresses the need to work with the uniqueness of each individual valuing and recognizing their culture and their history.

Due to the physical and mental wearing brought about by the continuous care for
patients of AD, evidences the need of rotation/division of responsibility and care among family caregivers. Thus, decreased the physical and mental overload, leading to collective reflection of this process that becomes every day more important to recognize and value the uniqueness of the individual within the specifics of Alzheimer’s disease.12

In this design, one realizes the need for health professionals, particularly nurses for being responsible for the systematic care, to reflect about the importance of ensuring the necessary support, both carrier as to family members who experience a continuous adaptive process.15 In that context, we reaffirm the importance of health professionals being prepared to live/cope with new experiences, thereby expanding the vision of care.

Caring, in this perspective, includes recognizing and valuing interpersonal relationships, to respect the individuality, autonomy and freedom of others. Implies in the useful human actions for the person to become recognized in the family environment. In this design, the adaptive process of Alzheimer’s disease, which involves both the individual and the family context, requires strategies to ensure autonomy, rehabilitation and family and social ties. Entails in the developing of process differentiated and adapted to live/live with this condition which generates sometimes, feelings of disorder, fear, insecurity and gradual loss.16

CONCLUSION

The results demonstrate that both the elderly person with Alzheimer’s as the family / carers experience a gradual and natural process of adaptation. This process becomes easier in that it is shared with other family members allowing the division of activities and care, as well as the inclusion of alternative activities that promote the autonomy of the carrier on the different everyday movements.

The challenge of caring and experience this process goes beyond taking care the pathology. Entails recognizing the family groups and to value emotional, ambivalent feelings towards the process of illness in the elderly, in addition to recognizing the uniqueness of each family member.

Professional education, today, must be grounded in experiences that they can develop, in every healthcare professional, the sensitivity required to know when to intervene, when silence, when understanding and when taking certain attitudes and/or intervention strategies. Dealing with family members/caregivers goes far beyond any recipe carefully. It is important that interactive and associative skills able to integrate the different elements and movements that make up the whole are developed.

We conclude, in short, that the diagnosis of Alzheimer’s goes beyond the pathological process. The same transcends the individual disease and involves relational and associative processes, which involve daily family adaptations, overcoming gradual losses, roles reversal, i.e., a new order of relationships, routines and care environments. It realizes the need for health care professionals, especially nurses, to reflect about the importance of ensuring the necessary support both for carrier as to family members who experience the adaptive process. Thus emerges the need for further studies aimed to monitor/evaluate/guide adaptive processes through which they pass the carrier of Alzheimer’s disease and their family caregivers.


