THE REDEFINITION OF THE EXPERIENCE OF THE FAMILY CAREGIVER OF ELDERLY WITH ALZHEIMER FROM CARE ACTIONS

A RESSIGNIFICAÇÃO DA VIVÊNCIA DO CUIDADOR FAMILIAR DO IDOSO COM ALZHEIMER A PARTIR DO CUIDAR

LA REDEFINICIÓN DE LA EXPERIENCIA DEL CUIDADOR FAMILIAR DE PERSONAS MAYORES CON ALZHEIMER DE ACCIONES DE ATENCIÓN

ABSTRACT
Objective: understanding the feelings experienced by family caregivers in care of people affected by Alzheimer’s disease. Method: a study of qualitative nature based on the oral history of life proposed by Bom Meihy, conducted from an interview with five family caregivers of the elderly with Alzheimer’s. After Thematic Analysis three categories emerged. The study had authorization of the project by the Research Ethics Committee, CAAE nº 09886412.2.0000.5292, Protocol nº 215.229/2013. Results: the difficulties are experienced in the daily routine of life of the caregivers and on the maintenance of the quality of their lives. In addition, it is possible to observe the exteriorization of ambiguous and conflicting feelings. Conclusion: being a family caregiver is a matter of public health and thus highlights the urgency of government measures of political and social character, as the formation of groups of family caregivers, in addition to care and health promotion programs. Descriptors: Alzheimer’s disease; Emotions; Elderly.

RESUMO

RESUMEN
Objetivo: comprender los sentimientos experimentados por los cuidadores familiares en el cuidado de las personas afectadas por la enfermedad de Alzheimer. Método: este es un estudio cualitativo basado en la historia oral de vida propuesta por Bom Meihy, realizado a partir de una entrevista con cinco cuidadores familiares de personas mayores afectadas por la enfermedad de Alzheimer. Después del Análisis Temático emergieron tres categorías. El estudio tuvo la aprobación del proyecto de por el Comité de Ética en la Investigación, CAAE nº 09886412.2.0000.5292 y Protocolo nº 215.229/2013. Resultados: las dificultades que se experimentan en la rutina diaria de la vida de los cuidadores y en el mantenimiento de la calidad de sus vidas. Además, se puede ver la manifestación de sentimientos ambiguos y conflictivos. Conclusión: ser cuidador familiar es un asunto de salud pública y por lo tanto pone de relieve la urgencia de las medidas gubernamentales de carácter político y social, como la formación de grupos de cuidadores familiares, además de programas de la atención y los de promoción de la salud. Descriptores: Enfermedad de Alzheimer; Emociones; Idoso.
INTRODUCTION

Aging is considered a major challenge to public health because the Brazilian who lived in the last century on average of 33 years old, went to live 74, six years in 2012. Thus, both the government and society had little time to understand this process and its demands.

Given the long life of the general population, due to changing of lifestyles and progress in health care, it has been observed a significant increase in the occurrence of chronic degenerative diseases, among which stand out dementias. Among them, Alzheimer’s disease (AD) is more common in the elderly, because there is a new case of dementia every seven seconds in the world. AD is characterized by gradual loss of recent memory. It is estimated that by 2030 there will be 65.7 million cases of the disease in the world. It is estimated that in Brazil there are 500,000 people with this disease, this number continues to increase each year, following the worldwide reality, and most of them feature age over than or equal to 65 years old.

With the onset of AD in one of its members, the family is faced with the need to care for, this described as perceiving the other in the way it is and as it turns out, its speech and gestures, pain and limitations. Therefore, caring for a person with limitations has its peculiarities, being necessary to the understanding and acceptance of individual and collective form of the aging process as something inherent in the existential process of the human being.

From the AD diagnosis in the family, often a family member becomes the primary caregiver. This is usually a close relative, closely linked to the affected person sometimes chooses to exercise this function, other times it is chosen. It is understood within the family, primary caregiver is the family that performs most of the care to the person affected by the disease and is responsible for supervision, monitoring and mentoring of others who assist in this function when it is dedicated entirely to the care may show signs of workload, which are aggravated by care alone, without the aid of other individuals.

Family caregivers often look for guidance on the care and AD. Most of the time, they come to health facilities, shaken by the first changes resulting from the disease in their family. In addition, the family dynamics suffers modifications, making care a challenge.

The redefinition of the experience of the family…

The experience of being a caregiver involves compromise, time and patience that require skills and fundamental for the achievement of the Activities of Daily Living (ADL) with the family. However, these undergo changes in their own physical, psychological, social and spiritual well-being, due to drastic change in their life dynamics. In this context, the following question arises: What are the feelings experienced by family caregivers to take daily care of a person with Alzheimer’s disease? To answer this question we need to reflect on the family caregiver and his experience in care.

This theme is pertinent to the own family caregiver, as well as nursing and other health professionals. Therefore, this study aimed to understand the feelings experienced by family caregivers in the care of people affected by Alzheimer’s disease.

Thus, studying the strong feelings and emotions to the family caregiver of a person affected by AD based on the story of some people who lived them provided reflections on this theme.

OBJECTIVE

- Understanding the feelings experienced by the family caregiver in the care of people affected by Alzheimer’s.

METHOD

This is a study of a qualitative nature, which used as a methodological reference the Oral History of Life. It was carried out with 05 family caregivers, the Group participants “Taking care of who takes care” of the Basic Health Unit (BHU) of Candelaria, located in the city of Natal-RN, from March 2013.

The study had as inclusion criteria for participation: (1) being a caregiver (a) relative of a person with Alzheimer’s disease; (2) living with the relative affected by the disease; (3) provide attendance to group meetings; and (3) have experience in caring for at least one year.

The Oral History of Life is characterized as an official picture of the employee and is considered true the version told by the narrator who is free to reveal or hide situations and experiences lived by it. So the witness is considered subject of its history and this part of the process being called employee. Thus, it was made a cut in the oral history of life of employees from the moment they assumed the role of family caregivers.

In today’s meeting of the Group “Taking care of who takes care”, which occurs weekly,
family caregivers were asked by the researcher to participate in the study through interviews, which were preceded by formal acceptance of respondents, by signing the Informed Consent (IC) and authorization to write the speech, which is essential for the oral history exists. And, in order to guarantee the anonymity of employees throughout the survey, codenames have been used, more precisely named after flowers.

As caregiver’s instrument approach, a script with open questions related to the emotions of being a family caregiver of a person with AD and the repercussions of this in his life was used. At the end of each interview notes were made in order to best record the moment and the feelings that it arose. After the interview, the processing passes through the transcript, textualization and transcreation. In the transcription, the oral account is converted into written text so as to make it available for reading. For this there are required the stages of the process of changing the content of the interviews of the oral recording stage for written.

During textualization, the questions asked by the interviewer are suppressed and merged in the responses of employees, this text reorganization of the employee happens to be unique in history, and it is suggested that the authors choose the vital tone. The last step is to transcreation, there is the author’s interference in it in the text that recreates in its fullness, which seeks to highlight the sensations perceived during the interviews. After examination of all the stories narrated it was found some common ground that could be grouped and depth, where the points highlighted by the employees in order to understand the life stories told by family caregivers of people with AD have been interpreted. Based on that, three themes were revealed: recognizing the family caregivers of seniors with Alzheimer’s; between reason and emotion: the developing of care; and basing the care: sharing experiences and feelings.

Because it is a research involving human subjects, this study was performed in accordance with aspects of Resolution no 466/2012 of the National Health Council (CNS/MS), which provides guidelines and standards for the regulation of research involving human subjects; by the assent of the Research Ethics Committee (CEP) of the University Hospital Onofre Lopes (HUOL) under CAAE n° 09886412.2.0000.5292 and Protocol n° 215.229/2013.

RESULTS AND DISCUSSION

♦ Recognizing the family caregivers of the elderly with Alzheimer’s

The group selected to participate in this study was composed of five family caregivers of people with Alzheimer’s, all participants of the Group “Taking care of who takes care”. We interviewed three women and two men, studies state that most caregivers are women. It may be associated with gender issues, for the woman, throughout history, being her who performs the role of caregiver, mainly due to maternal instinct. The role of women caregiver is still an expected honor by Brazilian society.

Regarding the age of the caregivers, the study participants were in the age group between sixty and seventy years old. Of these, one is husband; one is son in law; both are daughters and a niece of the person affected by AD and all reside with the affected person, giving all essential assistance 24 hours a day.

Of respondents caregivers all have defined religion: two practicing Catholics, a Spiritist and two non-practicing Catholics. Religion acts as a form of support and reassurance to caregivers.

Concerning education, three graduated from high school and two had incomplete higher education. Of these, two of them work and three are retired, one of which works had to reduce their weekly working hours, as it is the only caregiver, and went to work more at home. The other divides care tasks with his wife, so he continues to play his professional activities easily.

The time that family caregivers play this role varies from one to thirteen years; the period in which the interviewed caregivers attend the group “Taking care of who takes care” at BHU Candelaria, ranging from 1 to 11 years, where the majority is between 1 and 3 years.

♦ Between reason and emotion: the developing of the handle

Caring is intrinsic to human existence from the beginning, where it is emphasized that the subject needs to receive and give this care, which promotes the link between the meanings of each individual, not being totaled and finished, but the building process and constant redefinition, allowing shared mixed feelings resulting from this function.
The vital care is built in its essence through the experience of reality, in which there is the will and desires, being considered as a fundamental attitude that comes out from the human being and focuses on the other, by caring and concern. The experience of being the caregiver of a family member with AD, the subject can perceive positive feelings through the manifestation of his love through care, dedication, respect, patience, concern and gratitude to his relative with AD. This aspect appears the following statements: [...] I have pleasure in looking after, I feel like I have more love to her than I thought [...] (Chrysantheme) [...] I was always happy to look after, because I was taking care of who took care of me [...] (Azalea) [...] I’m grateful to her for taking such good care of my children [...] (Orchid) [...] my life today is dedicated to my family: husband, kids and he, my father. (Violet) Mister of feelings experienced in everyday family caregiver is a result of surprises present in the prognosis of the disease, leading to the care the negative features such as an obligation, insecurity and the burden. Thus, some employees revealed different feelings to the above: [...] I only know that I have to care. (Orchid) [...] what bothers me the most is my wife hiding from her family the real situation of her mother [...] I want to talk, but she asked me not to say anything about the problems [...] I’m against it. (Lily) It is observed in the narratives the manifestation of ambiguous and conflicting feelings on the one hand, be familiar caregiver is giving back the love, affection, care and help the person affected by the AD to have a life with quality even after the appearance of the disease. On the other hand, it involves many adversities and sacrifices in the routine of life of those who exercise care, our daily routine will go through several changes and adjustments according to the development of AD in their family affected by times. Their social and emotional life, self-care and leisure time are set aside in favor of care as described in the speech below: [...] some things bother me as, for example, no longer have that social life before [...] now it became more restricted [...] (Chrysantheme) The characteristics of care emerge and therefore change in appearance of behavioral changes such as insomnia, aggressiveness, among others, and also psychological symptoms such as depression, anxiety, delusions, and hallucinations are very common. The statements below show the perception of caregivers about the disease in the elderly: [...] at first she was seeing things [...] had hallucinations [...] (Orchid) [...] she needs to take medicine to calm down and go to sleep [...] otherwise turns twenty-four hours in the awake. (Lily) [...] He comes apart at times [...] is sometimes aggressive [...] had that loving father and all of a sudden he’s out there attacking me verbally or physically [...] (Violet) It is still evident, due to the progress of AD is noticeable engines and neurological signs characteristic common to this health-disease process, which are damaging the performance of the Activities of Daily Living. [...] she is very dependent on me, very much, for their motor function is greatly impaired [...] can no longer cook, undress, go to the bathroom alone [...] (Chrysanthemum) [...] my mother is very dependent, needs help even to move from room to room in the house [...] (Lily) In addition, the role reversal between Azalea and parents is a common fact in the context of disease. The AD causes the loss of family identity and role reversal in which the affected by the disease becomes increasingly dependent care, and requires constant support and dedication of their families. [...] of course I was sad because of the role reversal, before they took good care of me, after the illness, I started to take care of them [...] (Azalea) Thus, the context in which it appears the AD causes changes in family dynamics, losses, leading often to the feeling of anticipatory grief. This feeling appears in the following lines: [...] we know it’s difficult and it will as long as God wants. [...] (Lily) [...] There are times I ask God to take me, is if I get to have this disease. Is it worth survive like that? (Lily) [...] always I question myself: God, how old age is? She used to do everything [...] I’m thinking about it [...] just know I have to take care of [...] (Orchid) By faith in God, these employees managed to strengthen, hope and patience to face the difficulties and also conform to the development of AD in their loved one. Together with the spiritual support groups for family caregivers emerge as a form of support and assistance to these subjects, mediators...
and facilitators of re-framing linked to caring for the elderly with Alzheimer’s.

Building on the handle: the sharing of experiences and feelings

The breakdown of interpersonal relationships, especially between the caregiver and his family members may be the result of AD. Moreover, it has a considerable financial burden on the family. For these reasons, among many others existing in the context of AD, it is extremely important that there are support groups for family caregivers, offering common support and help for these. In addition to instigate collective search of problems coping strategies experienced by them, in order to foster the biopsychosocial well-being of family caregivers and elderly with Alzheimer: being careful.

From the sharing of their stories in the meetings is made possible the exchange of experiences, the construction of the meaning of caring, and its constant redefinition. This time it is enriched by the Guidelines on the AD.

 […] it is this group that is supporting me, giving me allowance so you can make the best […] the group fully supports, there is exchange of experiences, one helps the other. This group really holds me, it helps me a lot. (Chrysanthemum)

 […] for me the group was all, the door of hope for knowledge, exchange of ideas, experiences of other people who care for their loved ones […] the group only strengthens me, every day, every meeting I participate I leave lit, stronger, fuller knowledge to continue taking care of my father. (Violet)

 […] today this group for me is everything, without him I do not know how I would be. There are days when the group get emotional and still cry, depending on the topic discussed. Some days you get lower, a little sad, but I go out very good of the group […] (Orchid)

 […] with this group of caregivers was that I found support and quiet, the name is that, quiet, both to look after me and to take care of her. (Orchid)

 […] the group to me fell from the sky. There felt supported by carers and also gave support to them. It’s a constant learning […] is a comfort, has a lot of exchange of experience among caregivers […] with the group helps people realize you have a light at the end of the tunnel. (Azalea)

As evidenced in the reports participation in supporting carers groups is of utmost importance for them to play their role properly, contributing to effecting the quality of life and well-being of the person affected by AD and themselves.

It should be noted that care allows the subject to rescue the human essence through this practice, and get envision the paths of healing, which is not restricted to the physical aspects, but is related to the whole biopsychosocial context experienced by caregivers and seniors with Alzheimer’s.

The search for guidance on the AD, the care provided, and self-care, enable the family caregiver be prepared to face new situations that are likely to appear in his daily life due to progressive and long disease. So the caregivers group provides the exchange of experiences in which the participants benefit from finding answers to their questions, anxieties and concerns, so that their quality of life is encouraged.

It is observed that each employee has a unique way of dealing with AD and its role, as well as by the impact on his life in the process. Factors as support of family, faith, resignation before the disease, supporting a support group, among others, are used as ways of strengthening so that they can continue on their journey. It is noteworthy that these factors vary from one caregiver to another, since they are influenced by beliefs and values existing in each subject in his own life story.

CONCLUSION

The life stories show the (re) significance in the daily context of family caregivers of the elderly affected by AD, and also that their participation in support groups to assist caregivers in maintaining the quality of their lives.

Promoting the possibility of exchanging experiences through speech and the expression of their feelings and perceptions, after assuming such a role, describing each lived experience, makes possible the construction of new approaches and care to people who play this role contributing to the strengthening of grants to assist them in better coping with daily difficulties.

Thus, through the realization of this paper suffered, exhausting and stressful that is caring, involvement with many sacrifices in their life makes this issue be considered a public health problem that requires urgent investment in social policies and care programs and promoting the health of people affected by AD and also their families.

Health professionals, especially nurses, need to understand the feelings of caregivers across the numerous situations experienced in
his performance in the care of his relative with AD. In every situation it is very important the role of professional and support in guiding care.

Called for the need for all schools, colleges and universities forming by nurses and nursing technicians awaken future professionals to the importance of support to the caregiver. Moreover, it is necessary to create support groups for family caregivers, providing welfare, autonomy and quality of life for caregivers and their families affected by AD.

Therefore, such policies could help minimizing the impact of the disease and provide more security to caregivers. Also, encourage the reduced burden of suffering and anxiety to face life, enhancing the positive characteristics related to caring for the elderly with Alzheimer’s.

REFERENCES


