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RESEARCH

Cuidar do cuidador: vivências relacionadas à doença de alzheimer

Caring for the caregiver: experiences related to alzheimer's disease

Cuidado del cuidador: experiencias relacionadas con la enfermedad de alzheimer

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ABSTRACT

Objective: To understand the feelings and difficulties faced by the family caregiver to the person affected by Alzheimer's disease (AD). **Method:** This is thought to understanding the phenomenon under study, using oral history of life in the light of Bom Meihy. **Results:** The discussion of the phenomenon was based on the analysis of five categories: incorporation of the role of family caregiver, life before and after assuming the role of caregiver, caregiver feelings after taking care, difficulties in care, group participation as a foundation for caregivers, allowing the construction of new ways to approach and care to people who play the role of family caregiver. **Conclusion:** It was observed in this research that the situation experienced by family caregivers of a person affected by AD is a public health issue highlighting the urgency of government measures of political-social character, and care programs and health promotion to that audience. **Descriptors:** Nursing, family caregiver, Alzheimer's disease, Oral history.

RESUMO

Objetivo: Compreender os sentimentos e dificuldades enfrentadas pelo cuidador familiar à pessoa acometida pela Doença de Alzheimer (DA). **Método:** Trata-se de reflexão para compreensão do fenômeno estudado, utilizando a história oral de vida à luz de Bom Meihy. **Resultados:** A discussão do fenômeno pautou-se na análise de cinco categorias: incorporação do papel de cuidador familiar, a vida antes e após assumir o papel de cuidador, sentimentos do cuidador após assumir o cuidado, dificuldades no cuidado, participação do grupo como alicerce para os cuidadores, possibilitando a construção de novas formas de abordagem e cuidado às pessoas que desempenham o papel de cuidador familiar. **Conclusão:** Percebeu-se com essa pesquisa que a situação vivenciada pelo cuidador familiar de uma pessoa acometida pela DA é uma questão de saúde pública evidenciando a premência de medidas governamentais de caráter político-social, além de programas de atenção e promoção da saúde ao referido público alvo. **Descritores:** Enfermagem, Cuidador familiar, Doença de alzheimer, História oral.

RESUMEN

Objetivo: Comprender los sentimientos y las dificultades que enfrenta el cuidador familiar de la persona afectada por la enfermedad de Alzheimer (EA). **Método:** se cree que la comprensión del fenómeno en estudio, utilizando la historia oral de vida en la luz de la Bom Meihy. **Resultados:** Discusión del fenómeno fue basada en el análisis de las cinco categorías siguientes: incorporación de la función de la vida del cuidador familiar antes y después de asumir el papel de cuidador, los sentimientos del cuidador después de cuidar, dificultades en la atención, la participación del grupo como una fundación a los cuidadores, lo que permite la construcción de nuevas maneras de acercarse y cuidar a las personas que desempeñan el papel de cuidadora de la familia. **Conclusión:** Se observó en esta investigación que la situación vivida por los cuidadores familiares de una persona afectada por la EA es un problema de salud pública que destaca la urgencia de las medidas oficiales de carácter político - social, así como los programas de atención y promoción de la salud a esa audiencia. **Descriptor:** Enfermería, Cuidador de la familia, La enfermedad de alzheimer, Historia oral.

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INTRODUCTION

The population aging, the present situation on the world stage, has been observed to form more substantial since the last century, due to the accelerated growth of the elderly. Long ago, this process was observed only in developed countries, over the years, there have been changes in the demographic and economic profile of the population.^{1,2}

In the current scenario, the growth of the elderly is also present in the developing countries, including Brazil. Accordingly^{3,4,5}, in 2025, Brazil will occupy the sixth place in number of elderly, with 32 million people 60 years or older.

According to WHO³, several factors contribute to the increased life expectancy of the world's population; among them, the cure of diseases that presented high mortality, the improvement of quality of life and the advancement of technology.

Due to the longer life of the general population, has seen a significant increase in the onset of chronic degenerative diseases, among which stands out the dementia, which is a syndrome characterized by a gradual decline in cognitive functions, behavior and personality changes and deterioration in the daily activities of the person involved.⁶

Most seniors who have access to better quality of life keeps biopsychosocial wellbeing, living more independently, without needing assistance to accomplish activities of daily living. However, some seniors need help to carry out their activities, whether for a simple shift from one environment to another within your own home, to something more complex, such as assistance in personal hygiene.⁷

Situation of dependency and loss of autonomy are reflected in dementias because they are considered progressive and degenerative emerging need for assistance and care.⁸

One of the dementias, the AD is the most common in the elderly, representing between 50% and 70% of the total of their incidence⁹, being characterized by gradual loss of short-term memory. There are estimates that, by 2025, there will be 34 million cases of the disease in the world.^{8,10}

According to published data, recently¹², in the United States of America, there are about 5,4 million people with the AD, with 5,2 million present ages greater than or equal to 65 years old. It is estimated that, in Brazil, there are 500 million people with the disease.¹⁰

The AD is directly associated with age, so the chance of contracting it increases with age. This disease affects 5 to 8% of people aged between 65 and 70 years, while individuals with more than 80 years, this percentage may reach 40%.¹¹

This, however, does not mean that the person aged less than 60 years cannot acquire this disease, including the first case was diagnosed in a woman with 51 years of age. It is clear that the probability of that happening is smaller, but it exists.

This can be due to a variety of situations and conditions present in the everyday life of the aged, interfering in their health, such as in cases where it is acquired to dementia.

According to the national policy for the Elderly (PNI), the family is responsible for taking care of and meet the needs of the elderly in their homes.¹¹ However, in spite of the PNI consider family as responsible for the care of elderly, does not yet exist an efficient support system of government programs to families, which, in most cases, consider themselves unassisted.^{12,13}

With the emergence of the, in one of its members, the family faced with the need to take care, understand each other the way he is and as shown, your lines and gestures, their pain and limitations. Thus, caring for a person with limitations has its peculiarities, being required by the family caregiver, the understanding and acceptance of individual and collective form of the aging process as something inherent in the human being's existential process.¹⁴

From the diagnosis of the patient's family, often a family member becomes the primary caregiver. It is usually a close relative, closely linked to the person affected, sometimes chooses to exercise this function, other times are chosen. It is understood, in the context of the family, who is the main caregiver familiar that performs most of the care to the person affected by the disease, and is responsible for overseeing, monitoring and guidance of others who assist in this role.¹⁵

Family caregivers often seek guidance on the care and AD. Most often, they come to health facilities, stunned, shaken by the first changes caused by disease in his family. Thus, the dynamics of the family suffers modifications, making care a challenge.

This research has the purpose of analyzing the experiences of family caregiver of a person affected by Alzheimer's disease (AD), based on the story of some people who have experienced providing reflections on this theme.

It is expected, therefore, that this reflection provides subsidy for a better understanding of the effects originating in the drastic change in the dynamics of life of the caregiver. In this sense, the caregiver needs support and guidance and the nurse has the possibility to intervene, leaving the identification of the needs of who cares.

METHOD

It is a reflection to comprehension of the studied phenomenon, using oral history of life in the light of Bom Meihy.¹⁶

In this study, it is considered that oral history of life will allow understanding of the feelings and difficulties experienced by family caregivers of people afflicted by the based on their life experiences as a caregiver; Therefore, the choice of oral history as the methodological referential to guide this study, allows capturing life experiences of a person who is willing to talk about herself.

However to study Oral history of Life it is necessary to understand the universe of memory, since it is constructed through personal experiences, of events in the life of the individual, presenting as main attributes, selection, construction, subjectivity, individual, collective, social, national and affective.¹⁷

Memory is a subjective and personal memory is inserted in a collective context to make sense.¹⁸

In this same context, we observe the oral history as the living history of the present, but that has roots in the past, in which social, cultural values and individual memory are in constant construction, allowing employees and readers an understanding of the historical sequence, and possibly his identification as a participant.¹⁶

Among the methods of oral history is oral history of life which is the set of experiences of a person's life, narrated by her, which seeks primarily to subjectivity of the details and the version on the developer's existential morality.¹⁶

For that, we proceeded to a division in the oral history of life of employees from the moment they took on the role of family caregivers of a person affected by AD.

In this study, the oral history was regarded as the centerpiece and the narrations of employees, conducted through interviews, the main focus of the analysis.

The interview is subdivided in three steps; at first, the pre-interview referred to the Organization and scheduling of the meeting for the day of recording.

The next step is the actual interview, conducted in a calm and cozy environment.

The third step, known as debriefing, when sought to maintain the link between interviewer and interviewee, in order to maintain the continuity of the process.¹⁶

After the interviews, the data had been treated, whose oral report was transformed into written text to thus make it available for reading and subjected the steps of transcription, textualization and transcreation.

The survey was developed with five family caregivers of people affected by AD, Group participants "Caring for the carers" located in the Basic Health Unit of Candelaria (UBS).

The choice of UBS Candelaria as a place for research is justified by the fact that the unit be characterized as a reference in Natal, to develop eleven years working with family caregivers of people with AD and other dementias.

Inclusion criteria for participation in this study were: caregiver or family caregiver of a person with AD; reside with relatives affected by the disease; submit attendance to the meetings of the group and have experience in caring for at least one year.

Because it is a research involving humans, this study was fulfilled by assent CEP University Hospital Onofre Lopes (HUOL), the no. 215.229/2013, given the precepts of Resolution n°. 466/12 of the National Health Council (CNS/MS), which provides guidelines and standards for the regulation of research involving human subjects.¹⁹

In the days of meeting of the Group "Caring for the carers", the family caregivers were invited by the researcher to participate in the study, and the opportunity, were informed their goals, as well as the likely benefits that the work would lead to the health of families experiencing the process of being a family caregiver of a person with AD.

Caregivers who have demonstrated interest in participating in the study were selected according to the criteria for inclusion. Of these, were chosen by the researcher, research collaborators, the five caretakers who have, in the course of the meetings, the higher qualification, seeking to contribute to the study in question.

To ensuring the anonymity of contributors throughout the research, were used codenames, specifically names, chosen to replace the names of the interviewees.

Thus, the analysis has been carried out according to the contextual levels. The results of this process were organized into themes which together reflect the understanding gained of the phenomenon.

RESULTS AND DISCUSSION

Being a caregiver and your experiences

After perusal of all the stories narrated, noted some points in common that could be grouped and fleshed out. It attempted to perform the interpretation of these points evidenced by employees in order to understand the life stories narrated by family caregivers of people with AD.

In interpretative approach chosen for this study, we tried to describe each experiment respecting the way she was experienced, on the perspective of the developer that experienced.

Characterization of carers participating in the study

The group chosen to participate in this study consisted of five family caregivers of people with AD, all participants in the group "Caring for Who Cares". This choice was made in order to understand in greater depth the reality of being a family caregiver of a person affected by AD considering the different perspectives of each coping in relation to life's adversities.

There were interviewed three women and two men, some studies claim that most caregivers are female. This could be associated with gender issues, because the woman, in the course of the story, is who performs the role of caregiver, mainly due to the maternal instinct. The role of women caregiver is still an assignment expected by the Brazilian society.^{20,21}

As regards the marital status of participants, three are married, a widow and a single.

Married people assume, with greater frequency, the careful, this causes them to have greater overhead, since you have marital, family, domestic commitments and also at work.²²

As for the age of carers, it ranged from sixty to seventy years.

Of these, one's spouse; a's son-in-law; two daughters and a niece of the person is affected by Alzheimer's and all reside with the person affected, providing all necessary assistance twenty-four hours a day.

To the person affected, living with the family caregiver is beneficial, since it can be assisted immediately.

In contrast, exposure to the negative effects of care on the part of the caregiver increases causing high levels of stress.²³

Of the caregivers, all have defined religion, two practicing Catholics, a spiritualist and two non-practicing Catholics.

Religion acts as a form of support and reassurance to carers and religiosity functions as a positive mediator in the task of caring.²⁴

As for education, three graduated from high school and two had incomplete higher education.

Two of these three are working and retired, one of which had to reduce their work hours weekly, for he is the only caregiver, and began working more at home. The other divides the tasks of caring for his wife, so he continues performing their professional activities without problems.

The time that family caregivers play this role varies from one to thirteen. The period in which caregivers attend the group "Caring for Who Cares" at UBS Candelaria, ranging from one to eleven, where the majority is between one to three years.

VITAL TONES OF EACH EMPLOYEE

Each narrative revealed a different vital tone and enabled the understanding of concrete phenomena from the interconnection of the inner world with the outer world of each employee.

The vital tone matches the phrase that serves as the epigraph for the reading of the interviews, this criterion aims to organize the perception of readers, serving as a beacon to direct the receipt of work.¹³

Tom vital/Chrysanthemum: [...] if it was the other way around, she would do it for me with the same dedication.

For chrysanthemum, his thirty-eight years of conjugal union were filled with love, affection, patience, complicity, comradeship, dedication and overcome many difficulties. Would not be the DA that would change this long and beautiful history.

Tom vital/Lily: "[...] Alzheimer's disease is full of surprises."

AD is characterized lily as set volatile due to variations in mood, behavior, personality, memory and others that occur in the development of the disease. Learned, with his experience, that does not preclude the affected person, as this process becomes more exhausting and stressful for the caregiver.

Tom vital Violet: "[...] He forgets my name is very painful. Shocking! "

Violet has trouble accepting the failure of his father's memory as a result of the disease. She associates that oblivion to the degree of importance that it has in his life, which intensifies their suffering.

Tom vital/Orchid: "[...] it is challenging, stressful and very difficult, especially at the beginning."

Orchid clearly demonstrates the burden of being a family caregiver of a person with AD, the challenges are constant and visible changes in your life in any perspective. The adaptation of the whole family to the new routine imposed by the disease, the major difficulties arise in the beginning is needed.

Tom vital/Azalea: "[...] If you do not have calm and patience, you despairs and falls ill."

Azalea considers an essential virtue of patience so that the caregiver can play their role successfully. Emphasizes that its absence may lead to physical and/or psychological caregiver illness affecting the entire care process.

The speeches of employees gathered around five topics presented below.

THE ROLE OF FAMILY CAREGIVER

Practice care demands commitment, patience and time and family caregivers are subject to change in your lifestyle and wellbeing; this happens due to the activities performed by them in the care.²⁶

This reality can generate great impact on their quality of life, especially in the psychological and social context. This appears in the speeches:

[...] I have to travel in her world, some people may think I'm crazy, but I do it to have quality of life [...] (LILY)

[...] Being a caregiver for me is taking over [...] Is to have patience and a lot of love [...] and seek to do what is best for the person affected [...] But it is also necessary to take care of ourselves. (CHRYSANTHEMUM)

The quality of life can be defined as the individual's perception that includes several derived meanings of values, experiences and individual and collective knowledge and such a concept is considered too complex by treat-relationships between the environment and social, physical and emotional aspects, beyond the beliefs espoused by the individual.²⁶

Another study showed significant changes in the quality of life of caregivers, the physical, emotional and social aspects, especially when the person affected by the AD filed its functional capacity more committed.²⁷

Changes in quality of life of caregivers occur due to heavy and stressful daily care burden faced by caregivers, leading to decreased self-care, social life, love life and leisure time for family caregivers.²⁸

[...] We need to take care of you also to take care of each other, but that's really pruned. (VIOLET)

[...] I always say that if you do not have calm and patience, you despairs and falls ill [...] (AZALEA)

In addition to causing changes in the life of the affected person, the AD also destabilizes the family context in which it is inserted, bringing, as a consequence, physical and emotional distress for those involved.²¹

[...] The AD arrived and disrupted my life, live recluse ... I concluded that this disease disrupts the family emotionally, financially, without relying on family issues [...] (LILY)

[...] I have to find the way less stressful for me, it's too difficult, but not impossible [...]. (CHRYSANTHEMUM)

To be responsible for the care of their loved one with AD, the family caregiver becomes an essential element in the care process and it is important to note that this person usually does not have the training and expertise to assist your practice; has only the experience acquired during the course of their lives.

So for the family caregiver successfully performs the daily activities of care, support and guidance are health professionals required.

Thus, it is essential that professionals know and understand the reality of the routine of each caregiver with your family affected by the disease, as this experience is very particular for each; it depends on the dynamics and history of each family.

Follow the progressive involution of a loved family imposes on the caregiver a state of great weakness, anxiety, and other feelings.²⁹

The lines, then, portray this whirlwind of emotions:

[...] be caregiver is a mission that is not easy, we have to prepare ourselves spiritually and physically, because of illness, of momentary memories [...] my father didn't recognize me more [...] this is very painful for me. Shocking! (VIOLET)

[...] When I search on the AD, was a hit knowing that my wife was affected by this disease [...] I was very sad and worried about [...]. (CHRYSANTHEMUM)

The experience of being a family caregiver of a person affected by AD is referred to by the caretakers as a stressful and difficult activity; it happens due to emotional involvement between caregiver and who is being careful, and also by modifying the relationship between them for a reciprocal dependence.

The role of the caregiver becomes increasingly difficult as the disease progresses, because the affected person becomes more dependent, which requires an even longer time, dedication and care by the family caregiver. In this construct, this tends to give up your life priorities take better care of their loved one, which can negatively impact their quality of life.

Because AD is a chronic, progressive, degenerative disease, inevitably in the process home care of the affected person can generate overhead for all families, especially for caregivers, affecting their mental and physical health:

[...] My wife, who is also a carer, recently had a heart attack; it was certainly caused by excessive concern and care for his mother, affected by AD. (LILY)

The AD also undertakes the dynamics and functioning of family life, with physical and emotional burden, besides affecting the lives of people affected by the disease .³⁰

So there is a satisfactory interaction between the affected person and their family, is required great ability to adapt to the new scenario, mainly by the caregiver, because the DA causes gradual loss cognitive, behavioral and emotional changes. In this circumstance, it is essential to be caregiver lot of love, patience, time, dedication, affection, energy, effort and goodwill.²⁹

In this sense, are emblematic lines of the participants:

[...] Everything we do within the Watch has to have a lot of love and care [...] lots of patience, too, because the disease is evolving very fast, you have to walk next to her, in their procedures, day-to-day care, you need to adapt your life the disease. (AZALEA)

The difficult experience of the day to day of being a family caregiver of a person with AD is softened when the caregiver himself breaks the barrier of its simple occupation and begin to understand the scale of the disease.

[...] Be caregiver is to me challenging, stressful and very difficult, especially at the beginning [...] you don't know what is the disease [...] I was in a situation he couldn't even talk to anybody, I just cried, I didn't understand, had no knowledge about the subject. (ORCHID)

Care is a way of expressing interest and affection with each other and with the world. Unfortunately, many caregivers do not realize the care with love and affection.³⁰ One of the employees emphasizes this aspect:

[...] the worst is that nobody cares how we families, as much as we pay well, people don't treat you as they should, no love [...]. (LILY)

LIFE BEFORE AND AFTER TAKING ON THE ROLE OF CAREGIVER

With regards to being a family caregiver, there is the issue of fatigue and stress resulting from caring as demand requires 24 hours of daily care, causing the rupture of some activities that previously performed and such evidence can be found when care is played by one person.²⁹

It is noticed that the daily caregiver is completely transformed with the disease, as he becomes part of a world that is unfamiliar to you.

This process marked by hardship and responsibilities in caring causes employees to reflect on the events of their lives before and after they become family caregivers.

This is visible in the speech:

[...] Before my life was like a dream, walking a lot [...] were too many visitors, get together with family [...] today is no longer so [...]. (VIOLET)

With advancing disease, the affected person becomes increasingly dependent on family caregivers who suffer a growing physical and emotional wear to provide the necessary care.³¹

For this reason, most of the time, the family caregiver begins to live according to the person affected by the disease:

Before the disease [...] had many activities, worked a lot. After I became a caregiver that has changed a lot, now the care requires of me forever [...]. (CHRYSANTHEMUM)

[...] With my mother it was exclusive dedication, I took care of her all the time. (AZALEA)

Regarding the life of caregivers before and after taking care to relatives with AD, all caregivers consider increasing social isolation as a determinant of change in their lives after taking such a role:

[...] After taking on the role of caregiver, my life was restricted only to my father and my mother; I didn't go out more, not traveling [...]. (AZALEA)

[...] Before I had a quiet life, active, walking a lot. Until they arrived and has disrupted my life, and all of this is over [...] alive recluse, you can't walk with my wife [...]. (LILY)

The reports show the social isolation that caregiver's experience.

Man is a social being in need of coexistence with others to continue his story.³²

At that time, nursing plays a key role and must articulate related to promoting and protecting the health of the individual and their family activities to provide a quality life for these people.³⁰

The quality of life of employees showed mainly influenced by the restriction of social life, the difficulty of leaving home, traveling and meeting friends and family.

The restriction of social life for all employees is a major obstacle to be faced daily. The care becomes a prison that limits the life of the caregiver, since freedom and jeopardizes its daily routine.

The repercussions of the effects of the restriction of social life appear related primarily to factor that guides the actions of these people in care, the way they perceive

themselves in the role of caregiver, the value it attaches to it in the course of his own life and his family affected by the disease.

Caregiver's feelings after taking care

The experience of being a caregiver for a family member with AD, the individual can express his love by caring, dedication, respect, patience, concern and consideration towards his family with AD. This aspect appears in the following statements:

[...] I have pleasure in looking after, I feel like I have so much more love her than I imagined [...]. (CHRYSANTHEMUM)

[...] I've always been pleased to take care, because she was taking care of who took care of me [...]. (AZALEA)

[...] all I know is that I have to take care [...] I am grateful to her for taking such good care of my children [...]. (ORCHID)

Some revealed other feelings:

[...] some things bother me as, for example, no longer have that social life before, [...] now this became narrower [...]. (CHRYSANTHEMUM)

[...] What bothers me the most is my wife hide from his family the real situation of his mother [...] I want to talk, but she asked me not to say anything about the problems [...] I'm against it. (LILY)

[...] almost don't care [...] but when that happens, ask for it, I say it is well cared for, these words I learned from a friend of the Group of caregivers [...]. (ORCHID)

It is observed, in the narratives, the externalization of mixed feelings and conflicting; on the one hand, being a family caregiver is returning love, affection, care and contribute to a person affected by the AD have a quality life even after the onset of disease. Furthermore, caregiver entails many hardships and sacrifices in the daily routine of those who exercise care, your daily life will undergo many changes and adjustments according to the development of AD in their family affected.

Speech, then, is a clear reversal of roles between parents and Azalea, very common occurrence in the context of disease. The AD causes loss of family identity and role reversal, in which the affected by the disease becomes increasingly dependent day care, requiring constant help and dedication of their families.³⁰

[...] of course I was sad because of role reversal, before they took good care of me, after the disease spent taking care of them [...]. (AZALEA)

The context in which it appears the AD causes changes in family dynamics, loss, leading often to the feeling of anticipatory grief.³⁰

This feeling appears in the statements below:

[...] We know it's hard and it goes up when God wants.

[...] (LILY)

[...] There are times I ask God to take me, if I get to have this disease. Is it worth to survive like that? (LILY)

Through faith in God, these employees were able strength, hope and patience to face the difficulties and also to comply with the development of AD in their loved one.

In AD, behavioral changes such as insomnia, aggressiveness, among others, and also psychological symptoms such as depression, anxiety, delusions, hallucinations are very common.³³

The speeches then highlight this statement:

[...] at first she was seeing things [...] had hallucinations [...] this ended when he started taking the medications [...]. (ORCHID)

[...] He snaps at times [...] it is sometimes aggressive [...] had that loving father and all of a sudden he's out there attacking me verbally or physically [...]. (VIOLET)

Difficulties in care

Among the many difficulties that the family caregiver faces on a daily basis to provide care to people affected by AD, predominant in all the speeches of the employees, is the lack of interest, support and help from family members:

[...] the great difficulty I feel is that for now I don't have a lot of support and help the family in care [...] my children live here on Christmas, but I feel like they're missing a lot, just help me financially [...]. (CHRYSANTHEMUM)

[...] the family assumes the disease, doesn't want to help take care, never can, I usually say it's the Hummingbird family, come and kiss back home [...] this is my greatest difficulty [...]. (LILY)

[...] It's even harder when you don't have help family members [...] rarely connect [...] does not give any financial aid or ask [...] (ORCHID)

[...] the greatest difficulty was in relationship with the family, not to unjoin the family [...] swallow cats, frogs and lizards [...]. (AZALEA)

The lack of support from family in the care process can cause a crisis in the performance of caregivers.³⁴

It is extremely important that the caregiver receives help from other family members and / or persons hired, because the overhead generated by the execution of tasks in the care, the lack of financial resources, the difficulties involved in caring for the mental and physical stress can lead stress.³¹

Other difficulties appeared in the narratives of employees:

[...] the great difficulty is not knowing the disease [...] at the beginning I discussed a lot with my aunt, was going forward even [...]. (ORCHID)

[...] the difficulties are the limits imposed by illness, especially of social life [...] (VIOLET)

[...] the difficulty in dealing with the disease, learn about and she [...] learned to travel with the person affected, came to the conclusion that one should not antagonize it [...] the more you do, the more you will suffer [...]. (LIRIO)

At the onset of AD, ignorance of how the disease develops, what it entails and how to deal constitute impediments that hinder the performance of much of the care for some caregivers. The participation of employees in the "Group Caring for the carers" contributed to assuage these doubts and anxieties.

The group as a foundation for caregivers

Studies show that AD can lead to breakdown of interpersonal relationships, especially between the caregiver and their families; Furthermore, it has a considerable financial burden on the family.^{35,36}

For these reasons, among many others existing in the context of AD, it is extremely important the existence of "Caring Group Who Cares", which offers support and mutual aid to family caregivers of these people.

By telling their stories, all caregivers recognized the importance of their participation in the "Group Caring for the carers" in existing UBS Candelaria. At meetings, they share experiences, receive guidance on DA and learn to deal with it.

[...] It is this group that is supporting me, giving me allowance for who can do the best [...] the group gives full support for Exchange of experiences, one helps the other. This group really hold me, it helps me a lot. (CHRYSANTHEMUM)

[...] for me the Group was everything, the door of hope for knowledge, exchange of ideas, experiences of other people who care for their loved ones [...] the group only makes me stronger, every day, every meeting that participate get lit, stronger, more full of knowledge to continue taking care of my father. (VIOLET)

[...] with this group of caregivers was I found support and quiet, the name is quiet, so much to take care of me as it is to take care of her. (ORCHID)
[...] the group for me fell from the sky. There I felt supported by caregivers and also gave support to them. It's a constant learning [...] is a comfort, there's a lot of exchange of experience between caregivers [...] with the help of the US realizes that there's a light at the end of the tunnel. (AZALEA)

As evidenced in the reports, the participation of family caregivers in "Caring Group who Cares" is extremely important and necessary to continue to play its role properly, contributing to improving the quality of life and well-being of the person affected by AD and himself. The group empowers caregivers, provides the emotional support they need, and assist them in making decisions in the context of AD.

The group directs the discussions, proposes experience exchanges, transmission of knowledge about the ways of caring for a person with AD, as well as the expectations and seeks to alleviate the anxiety that arose during the process of care.

Factors such as family support, faith, resignation, resignation before the disease, support of a support group, among others, are used as ways of strengthening so that they can continue on their journeys. It is noteworthy that these factors vary from one caregiver to another, since they are influenced by beliefs and values existing in each individual in his own life story.

CONCLUSION

In this study, we used the life stories told by five family caregivers of people with AD about their trajectory after assuming the role of caregivers.

It is believed that the qualitative approach gave carers the opportunity to talk about their difficulties, perceptions and anxieties after taking such a mission.

Oral history, if allowed to capture the feelings of employees willing to talk about their experiences as caregivers, this phase of life. The seizure of these experiences has enabled better understand the difficulties faced by family caregivers in caring for people affected by AD.

Through the narratives of employees sought to describe each experience respecting the way it was experienced from the perspective of each caregiver who experienced it.

This study allowed us a better understanding of the experience of being a family caregiver of a person affected by AD, which is a painful, exhausting and stressful condition with implications and sacrifices of life of social actors.

The situation experienced by family caregivers as well as the very people affected by AD a public health issue, given it is considered, the trend of increasing elderly increase, and therefore the number of people with dementia.

Thus, measures necessary investment in social policies and health promotion and care of people affected by AD and also their family programs are.

Despite the physical, social and emotional impact suffered by employees, all seek to improve their quality of life and also of their relatives with AD.

However, that these improvements are made, other issues should be considered as a guarantee of constitutional rights, the provision of greater support from health professionals, family and society to face the difficulties caused by the AD.

The life stories show many difficulties in the daily routine of caregivers, and also that their participation in "Group Caring for the carers" help in maintaining the quality of their lives.

This result opens possibilities to build new approaches and care to people who play the role of family caregivers contributing to the strengthening of subsidies that help them better cope with the daily difficulties.

Health professionals, especially nurses, need to understand the difficulties caregivers' face of numerous situations experienced in his career in the care of his family with AD.

In each situation is critical as the role of professional support in guiding care. For this, you must know the real difficulties of daily life of each caregiver to then articulate related to promoting and protecting the health of the individual with AD, their caregivers and other family members in order to create conditions that provide a life activities quality for these people.

It defends the need for all Schools, Colleges and Universities training of nurses and nursing technicians awaken the future professionals of the importance of caregiver support.

As a cross-cutting issue in the speeches of caregivers, it was shown in this study, the feeling of loneliness, translated in the absence of solidarity and support from family and friends. This reinforces the importance of "Taking Care Group who Cares" trying to assuage this feeling through the wheels of conversation.

Accordingly, we propose the creation of support groups for family caregivers in all health institutions in the country for primary care, where professionals can work with caregivers using interdisciplinary strategies with a focus on caring for yourself and the person affected by AD, thus providing welfare, more autonomy and quality of life for caregivers and their affected relatives.

Such policies may help to minimize the impact of disease and provide more security for caregivers with lower burden of suffering and anxiety to face life.

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