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Knowledge and overload of the family care before the patient with dementia

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Abstract

Objective: To verify the knowledge of the family caregiver before the patient with dementia, in addition to assessing the burden resulting from care. *Method:* This is a qualitative research, developed at the outpatient clinic of a reference hospital in neurology in the city of Recife, PE, Brasil. The data were collected through a semi-structured interview, a sociodemographic questionnaire and the application of the Zarit Scale and discussed through the content analysis proposed by Bardin and according to the constructs of Paulo Freire's problematization and autonomy. The participants signed the informed consent form attesting the consent for the research. *Results:* From the analysis of the interviews with 17 family caregivers, three thematic categories emerged: lack of knowledge about the disease, perception of the family caregiver regarding the patient's needs and family burden. With the progression of the disease, the presence of the caregiver becomes essential, however most do not have the necessary support to assist their family members. *Conclusion:* The study verified the unpreparedness and difficulty of the caregiver in managing his family members who have some dementia syndrome. Thus, it is necessary to continue more productions on this theme and its repercussions on the lives of family caregivers, in order to assist in health promotion strategies for this population.

Keywords: Dementia. Caregivers. Family. Health Education.

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INTRODUCTION

The increase in life expectancy of the world population is one of the great achievements of modern society. Consequently, there is a growing population aging and the presence of pathologies resulting from this process, with the possibility of a natural decline in organic functions and the appearance of chronic-degenerative, disabling and involutive diseases, as in the case of dementias[1,2].

Regarding dementia syndromes, Alzheimer's disease (AD) can be highlighted, corresponding between 60% to 70% of cases, followed by vascular dementia (VD), dementia by Lewy bodies and frontotemporal dementia[3]. There are also studies indicating, especially in older age groups, brain abnormalities associated with another type of dementia, called mixed dementia[3].

According to the Alzheimer's Disease International report in 2015, it is estimated that 46.8 million people worldwide currently have dementia, which is expected to reach 74.7 million in 2030 and 131.5 million in 2050. In addition, the total number of new cases of dementia each year worldwide is almost 9.9 million, which means a diagnosis every 3 seconds[4,5.]

In Brazil, population aging has been occurring at an accelerated rate. The proportion of old people in the Brazilian population is close to 12.5%, increasing the probability of being affected by the dementia syndrome[6]. A study carried out in 195 countries between 1990 and 2016, found that dementia was the fifth leading cause of death, with a doubled prevalence among people over 60 years of age. Therefore, with population growth, demographic trends in aging tend to increase, as well as the burden on caregivers and areas of health systems dedicated to the care of this population[7].

In this scenario, the responsibility of the family as a participant in this course of change stands out, both in the patient's life and in the family environment, as it requires time, attention and effort. The family caregiver is in need of information and preparation to exercise his new assignment, needing support from health professionals in this process, so that he feels safe and confident[8].

Faced with this new circumstance experienced by the family caregiver, Paulo Freire's view is always up-to-date, due to the understanding that human beings cannot be understood outside their context. He is considered a social and historical subject, protagonist of his own formation, and develops through continuous reflection on his reality[9,10]. In this perspective, health education becomes possible when autonomy is provided to the components involved. Thus, the present study aims to verify the knowledge of the family caregiver before the patient with dementia and to evaluate the burden arising from care.

METHODS

It is a descriptive, exploratory and analytical research, with a qualitative approach. The research was carried out in a referral hospital for neurology located in the city of Recife, Pernambuco, Brazil.

Seventeen family caregivers who had any degree of relationship with the patient participated in the study. Family caregivers present at the time of the consultation were invited to participate in the study, and family members who were not directly involved with the care of patients were excluded, as well as family members of patients at the first consultation, since they had no diagnosis.

Data were collected using a semi-structured instrument, built by the researchers, which was previously tested with 05 family caregivers before conducting the study, to verify their suitability and the possibility of adaptations to respond to the objective of the study. In this instrument, sociodemographic data were included to characterize the participants as to age, education, profession and data of kinship with the patient, in addition to open questions, answered in a descriptive manner: What do you know about dementia? What needs do you perceive in your relative with dementia? How do you feel taking care of your relative with this disease? Have you received any instructions on how to care for your relative with the disease? If so, from whom did you receive this instruction?

The reduced Zarit Burden Inventory, translated by Scazufca and validated in research already carried out in Brazil, was applied concurrently in order to assess the burden of the family caregiver. Burden is the name given to "a set of physical, psychological, emotional, social and financial problems experienced by family members and caregivers for old people with disabilities", that is, when adaptation to the health-disease process does not occur in a healthy way[11,12]. The Zarit scale is used to assess the burden, exploring the caregiver's perception of how care impacts his life.

This scale consists of seven closed questions in which the caregiver must indicate how often he feels in relation to what was asked (never, rarely, sometimes, often or always). The burden categories assessed in this instrument include the impact of care provision, interpersonal relationships, expectations with care and perception of self-efficacy[12].

Data were collected between the months of August and October of the year 2017, during the day. The interviews were conducted after consultation with a neurologist, in a private environment in the outpatient offices. Family members were invited to participate in the study, attesting to their willingness to sign the Free and Informed Consent Form. The speeches were recorded with the aid of a digital recorder and, later, transcribed in full in analysis grids. The participants were coded with the letter F of a family member with a numerical sequence between 1 and 17. The average time of each interview varied between 25 to 30 minutes.

The speeches were treated through the content analysis of thematic modality proposed by Bardin[13]. There was a complete transcription of the interviews to identify the nuclei of meaning, using the criteria of exhaustiveness and representativeness. The data were discussed according to the theoretical constructs of Paulo Freire's problematization and autonomy. This study is in line with Resolution 466/12 CNS/MS, under the opinion number: 2,146,218.

RESULTS

Among the 17 study participants, the majority 16 (94.11%) were female, 9 married (52.94%), aged between 18 and 68 years, with an average age of 47 years. More than half 11 (64.70%) had no source of income and are the daughters of the patients. Eight (47.05%) have completed high school and 5 (29.41%) have completed higher education.

Regarding the responses of participants related to the care of their family members, most respondents said they counted on the help of another member/other people, 13 (76.47%) of the respondents said they counted on the help of another member/person and 12 (70.58%) reported having received instruction for care. Among these, 10 (83.33%) said that they were guided only by doctors, and 2 (16.66%) said that they were guided by other professionals who were not nurses.

Regarding the diagnosis of the disease of the family members, 12 (70.58%) patients had mixed dementia, 3 (17.64%) vascular dementia, 1 (05.88%) frontotemporal dementia and 1 (05.88%) Alzheimer's dementia. Regarding the duration of the disease, only 5 (29.41%) patients had been diagnosed for more than five years, the others varied in decreasing order between five years and less than one year. Finally, when the Zarit questionnaire was applied, 7 (41.17%) family caregivers had moderate care burden, 6 (35.29%) mild burden and 4 (23.52%) severe burden. From what emerged from the participants' speeches, it was possible to construct three thematic categories: a) Ignorance about the disease; b) The family caregiver's perception of the patient's needs; c) Family burden.

Theme I: Ignorance about the disease

The family caregivers demonstrated insufficient knowledge about the pathology, having difficulties and many doubts to answer when asked about the theme, as can be seen in the following statements:

> "So (sigh), it is difficult for me to speak, because when the diagnosis was made, we had no support to know what it is. I have no knowledge!" (F2).
>
> "Very little. Yeah... I actually have a lot of doubts about the disease, because I don't know that... my concern is the question of phases, there are phases... yeah... how long will it stay like this, when it can get worse, when.... but it is.... I have a lot of doubts, actually" (F5).

Some family members point out that the disease affects the brain, recognize the neuron as the affected morphophysiological unit and even try to conceptualize the disease using terms from the literature, however, a still limited understanding is seen, and sometimes confused when explaining.

> "It is a disease that affects the brain, that the person practically does not stay in himself, he keeps remembering something from the past or things that happened, which may have affected" (F10).

> "I know that dementia is going to be... it's a type of disease, right?! [...] There will be a moment... I think the nerves, something, right?! The neurons, something. That dementia is a part, I think, that comes from the head... it affects the limb, it affects everything, it is, it... it affects the whole neuron, with ... with all the organs" [...] (F11).

In the following speech, in addition to reinforcing the lack of knowledge that the interviewee has about the topic, it is evident that he delimits dementia only to Alzheimer's disease.

> [...] "I only knew the name "Alzheimer, Alzheimer..." now, now that I see it like this... because we keep noticing her difference. Forgetting things, getting lost like that [...] I know that there is a much more rigorous process, even for films I've already watched, but I don't have knowledge!" (F1).

A fact observed during the interviews is that the family members express their understanding of the disease referring to the clinical manifestations during their care routine, of which the patients' forgetfulness predominates. This situation highlights the superficiality of knowledge about dementia and its varieties: the phases, the characteristic signs and the form of treatment in each case, as explained in the statements below:

> "What I know now is because of this problem that as I see it, right?! His reaction, that he changes, from... from... he is wonderful for an hour, suddenly he totally changes and gets aggressive" (F7).

> "About dementia is that (pause) so (pause). Now it's blank (pause). It is (pause). That as soon as... you can't do things, right?! You have... you have trouble going to the bathroom, not speaking properly, expressing yourself, right?! [...] there are times when he doesn't, no, he doesn't even ask for food, we have to offer him things, because if we give him food, he eats itbut if we don't... that's it!" (F13).

Theme II: Perception of the family caregiver regarding the patient's needs

The family member understands changes in the life of the person with the disease through gradual changes in activities of daily living (ADLs), and in instrumental activities of daily living (IADL's). In the statements below, some changes in the ADL's are reported, such as the ability to bathe, feed, dress and move from place to place.

> [...] **"**In the past she did everything. And now, she doesn't do anything anymore [...] She doesn't walk. She has no way of moving. You have to move her, you have to bathe her, you have to feed her, she can't raise her hand to her mouth" (F11).

> "Shower and eat. She doesn't, and she doesn't remember that she does. We have to bathe her and feed her, too. We have to put food for her and keep insisting [...] She does it like this: "Did I eat?" She keeps asking, you see?!" (F12).

In the reports below, in addition to highlighting the issue of hygiene, nutrition and apraxia, attention is also paid to sphincter modifications.

> "If she walks alone, she falls. She needs you to bathe her. She needs you to be changing her, because she is peeing in her pants. Sometimes he goes to the bathroom to defecate, she soils everything. So she always needs someone close to her" (F8).

> "She can't do anything, not even eat alone, we have to give her food. It's because her hand isn't helping, no! [...] You have to get her to pee, which she doesn't do anymore. It has to be in the diaper. Sometimes she forgets, doesn't even remember. She does and says she didn't. Then I'll look, she has already done" (F9).

In the following statements, the family caregiver demonstrates a state of alertness and fear of the environment in which the person with dementia resides, as a danger scenario is identified by objects that may cause an accident.

> "We are very concerned, it is... the materials that she... that she uses, so as not to have a problem, be careful with gas, not to leave it on, with matches, stove, pliers, knife..." (F3).

> "It's more like this... like: now I have to be more careful about fire, for example, stove, to let... be careful to observe, not to stay... not to let her use it alone, without anyone observing" (F5).

Family members also realize that the disease has affected some tasks related to IADL's, such as the act of managing, having to participate or assume this responsibility completely.

> [...] "She was always very dynamic, right?! Taking and picking her grandson up from school, she did everything. We noticed her getting more dependent, and we thought it was because of her age. So we already had no confidence in letting her go out alone [...] but like this... she sets the boys' dinner when they arrive from work, she warms up the food, she does everything like this" (F1).

> [...] "The disease, she... hindered, because she can't do some... she can't do anything at home. The food, tidying the house, washing clothes, those things" (F10).

Another aspect highlighted in the research was about dependence on medication administration.

> [...] "Sometimes she says: "I didn't take it, no! And did I take it?" So we started taking away her medication. Because there are times when she really forgets. So now we're giving the medication" (F1).

> "There are some medications he was taking too much. Two of the same, and the other not! He confuses, you know?! Understood?! That's right, I separated because of that" (F17).

Theme III: Family burden

The appearance of a relative with dementia creates a conflictive environment, which can affect family dynamics. The impairment of ADLs/IADLs, especially in the most severe stages of the disease, is capable of causing physical and emotional burden in the caregiver's life. Respondents expose about their feelings when performing the care exercise.

> "Me in 1 year... I really limited, you know?! [...] Even though I have the girls, they can help, but then my head was very much on her. But then I go out, I travel, I go out on the weekend, I have my boyfriend [...] I take my time, but I keep calling" (F1).

> "Then I feel like this... I'm worried, right?! [...] I worry too much because I am alone with her. Sometimes no one gets there. Sometimes my kids go there. Sometimes not. This sister of mine is also difficult to go there" (F9).

In the aforementioned statements, social restriction and stress generated by the assistance provided are noted. Another point that draws attention is the impact that dementia has on the family/patient's daily life. The family caregiver F2 brings the feeling of loss of identity and the lack of interaction between their loved one and the family, causing a feeling of frustration in the face of their limitations. The F3 family member also mentions how difficult it is to accept and live with a person still young with the pathology. In addition, he reveals his depression with care for his mother, who also has a degenerative disease. Such situations reinforce the caregiver's emotional disruption.

> [...] "The biggest problem is... it's also seeing, right?! The person that way, because he was normal [...] You feel like you're losing the person, right ?! And.... yeah, besides the tiredness, that's it! You feel it so much... that the person is no longer there" (F2).

> "It is difficult (crying)... very difficult (crying). Because we see such a young person, right?! In this

> situation... we want to solve it and not... (crying) [...] I already have depression, then I have my mother's situation [...] She has Parkinson's disease, she's already on top of a bed and there is... the concern also with her 14 year old daughter [...] It is a triple care for us" (F3).

The following reports mention that at the beginning of the diagnosis it was a very difficult moment, because it generated a situation not yet faced by the family, marked by fear of the unknown. However, the feeling of pleasure and satisfaction in caring is visible, even if in some circumstances, this work is hard and tiring.

> "At first it is a shock to the family, because it limits you with your daily and private activities, of course. But, everything with treating with affection and love, especially a loved one [...] So, I do everything with great pleasure [...] Of course there is this burden, but basically it seems that we feel pleasure, the need to be together, to do, get it?! (laughs)" (F6).

> "Look... in my... in... in my heart I feel good, do you understand?! Because only the pleasure that I have to take care of him, my father and my mother [...] In the beginning, when as I didn't have the, the... that notion, then it really was difficult [...] But now I'm managing to deal with this problem very well, do you understand?!" (F7).

Despite all the negative repercussions that the disease causes in the life of the caregiver and the patient, there is an emotional component that reveals personal satisfaction and solidarity in the care provided. The examples below show the motivation that each family member has to continue taking care, with the caregiver's affective bond and gratitude for care being the strongest links in the commitment.

> [...] "I can't live a life like other young people. Sometimes I walk away from friends, they walk away from me. But I know what I'm doing is not bad. It's for the good of a person, a relative, a person I like, who didn't turn their back on me when I needed, even being sick" (F10).

> [...] "I feel that I need to take care of him, because we... 38 years of marriage, we have always been very close [...] so, how would I ever leave him alone. I had to take care, and I take care with love. I want to take care of him with love, until the last days of life" (F17).

DISCUSSION

The female gender was predominant in the family caregivers of patients in the outpatient clinic, corroborating findings similar to other studies found in the literature in which the female gender commonly performs the role of caregivers in the family environment[14-16].

Sociodemographic data shows that most of the interviewed participants have no work and no other source of income, counting only on the patient's pension/retirement plan. This reality shows two aspects: the abdication of their profession to care for their loved one, as well as showing the insufficient value for the demand for the care required by the person with dementia. All these circumstances can favor the appearance of stress in caregivers[17,18.]

A study carried out in the outpatient clinic of a referral hospital, with 31 caregivers of old people with dementia, identified that one of the stressors was the lack of financial resources to provide the necessary measures to perform the care. Caregivers reported difficulties in adapting the home environment, acquiring assistive technologies and material resources for consumption[19,20].

Although degenerative dementias constitute 80% of all dementias, with a higher incidence/prevalence for AD[21], this research identified that in the diagnosis of patients, mixed dementia prevailed. This distinct result can be justified by the past history of patients with diseases such as hypertension, diabetes, metabolic syndromes, among others, which predispose to the appearance of other dementia, increasing the number of diagnoses of associated dementias[22].

For the assistance to be effective, it is necessary that the caregiver knows the pathology, the stages of evolution, the characteristics of each one of them, and the actions that can be performed according to the need. Thus, you will know how to deal with the person who has dementia[23]. Freire's thought encourages reflection on the reality of life and the condition in which the caregiver is involved. The construction of critical thinking permeates the condition that the family member must sharpen their questions about the theme addressed.

For Paulo Freire, knowledge of reality makes it possible to identify the elements necessary for effective interventions. Therefore, the action of problematizing is necessary to emphasize the praxis, as the subject seeks solutions to reality, transforming it with his own action, at the same time that he transforms and starts to detect new problems, and to seek transformations. In this sense, knowledge about the reality experienced provides autonomy, critical awareness and decision-making capacity[9,10].

By understanding the clinical signs of dementia, the family member has the opportunity to reflect on the day-to-day situations, and thereby pay attention to changes in functional capacity, being able to decide their actions autonomously and independently. The decline in cognition would be related to functional losses, involving ADLs and IADLs. When these are impaired, they can request greater interventions for those who care[24,25].

With the progression of the disease, a greater degree of dependence is expected, where the family caregiver starts to assist the old person in carrying out daily activities. This will require integrated care, since cognitive changes generate important impacts on the patient's autonomy from self-care. It is important to note that the degree of dependence will be linked to the stage of the disease in which the person is[26,27].

Mainly, for the old person with dementia, the presence of the caregiver is essential to assist in these activities, since in the progress of the disease, the tasks will become increasingly complex. The changes most frequently mentioned by family members in this study were the issue of bathing, feeding, sphincter control and drug administration. All of these functions require attention, especially when offering the medication, so that there are no errors and delays[28,29].

In addition, one of the most common conditions in the dementia syndrome is the appearance of agnosias, characterized by the difficulty in recognizing objects, images, people, despite keeping the sensory function intact. By causing distortion, this symptom may bring risks in some rooms of the house, such as in the kitchen, causing fear and insecurity for those who care[30].

In addition to the issues addressed, the care of the old person with dementia causes numerous and distinct repercussions on the lives of caregivers, highlighting exhaustion and physical and emotional exhaustion. The caregiver suffers from the stress generated by the care and may have a related burden, implicatiing in his physical and mental health[31,32.] Faced with this context, there is a need to envision spaces for guidance, support and assistance for family caregivers, with a dialogical approach, which understands the reality of the family nucleus in which the person with dementia is inserted.

When assessing the burden of the interviewed family members, it is noted that caregivers have moderate levels of burden. The burden of negative or positive emotions associated with care can be related to factors such as the patient's clinical characteristics, the reasons that lead the family member to assume the care, the characteristics of the division of care work, etc. In this sense, it has been shown that the positive aspect associated with the caregiver's well-being is inversely related to the burden involved in the care relationship[33.]

The research had important limitations, as the interviews were carried out after the neurological consultations, and often the family members were not available to participate, mainly due to having transportation waiting to return home. There were also difficulties in relation to the place where the interview was applied, due to the high demands for care in the hospital outpatient clinic, which culminated in the difficulty in obtaining a more significant sample.

CONCLUSION

The data analyzed and the results found showed that the topic addressed is still quite incipient for the family caregiver, generating many doubts and difficulties in exposing their ideas when asked. Most caregivers are unprepared to cope with the disease, and knowledge is limited by the perceptions of care they perform on a daily basis.

Thus, it becomes necessary to establish spaces for the development of training and qualifications with caregivers, as it is through these actions that planning and elaboration of strategies to face the daily difficulties experienced by the family caregiver arise.

In the research it was also possible to observe the moderate level of burden of family caregivers, revealing that several factors contributed to the physical, emotional and social strain of this public, but that despite all the stress, the feeling of pleasure and gratitude prevailed, justifying that the affective bond established is the most solid connection for continuity of assistance.

Finally, this study concluded that, despite existing research, it is necessary to continue producing more on dementias and their repercussions on the lives of family caregivers, in order to assist in health promotion strategies for this population.

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