

Family (re)organization of elderly with Alzheimer: the professors perception based on its complexity

(Re)organização das famílias de idosos com Alzheimer: percepção de docentes à luz da complexidade
Reorganización de las familias con ancianos con Alzheimer: la percepción de los docentes a la luz de la complejidad

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ABSTRACT

Objective: To learn the perception of health professors who integrate a university project to support family/caregivers of elderly people with Alzheimer disease about the family (re)organization based on its complexity. **Methods:** Descriptive and exploratory study with qualitative approach made with health professionals who participate in a support group developed in a university institution in the central region of Rio Grande do Sul, Brazil. Data was collected between July and August of 2013, through focus group technique and submitted to strategic focus analysis. **Results:** Three categories were identified: Alzheimer - singular and multidimensional process; Factors that weaken the family (re)organization; Strategies that strengthen family (re)organization. **Conclusion:** The professionals recognize that the family (re)organization is a complex, gradual and singular process, understood as long as the alterations generated by the disease appear.

Keywords: Alzheimer's disease; Nonlinear dynamics; Health personnel; Nursing.

RESUMO

Objetivo: Conhecer a percepção de docentes dos cursos da área da saúde que integram um projeto universitário de apoio a familiares/cuidadores de idosos com a doença de Alzheimer acerca da (re)organização familiar à luz da complexidade. **Métodos:** Trata-se de uma pesquisa descritiva, exploratória de abordagem qualitativa, realizada com docentes que participavam do grupo de apoio desenvolvido em uma instituição universitária da região central do Rio Grande do Sul, Brasil. Os dados foram coletados entre julho e agosto de 2013, por meio da técnica de Grupo Focal, e submetidos à Análise Focal Estratégica. **Resultados:** Identificaram-se três categorias: Alzheimer: Processo singular e multidimensional; Fatores que fragilizam a (re) organização familiar; Estratégias que potencializam a (re)organização familiar. **Conclusão:** Os docentes reconhecem que a (re)organização familiar é um processo complexo, gradual e singular, compreendido à medida em que surgem as alterações geradas pela doença.

Palavras-chave: Doença de Alzheimer; Dinâmica não linear; Pessoal de saúde; Enfermagem.

RESUMEN

Objetivo: Conocer la percepción de los docentes del área de la salud que integran un proyecto universitario de apoyo a familiares/cuidadores de ancianos con la enfermedad de Alzheimer acerca de la (re)organización familiar a la luz de la complejidad. **Métodos:** Se trata de una investigación descriptiva, exploratoria, de abordaje cualitativo, realizada con docentes participantes de un grupo de apoyo desarrollado en una institución universitaria de la región central de Rio Grande do Sul, Brasil. Los datos fueron colectados entre julio y agosto de 2013, por medio de la técnica de Grupo Focal, y sometidos al Análisis Focal Estratégico. **Resultados:** Emergieron tres categorías: "Alzheimer: proceso singular y multidimensional"; "Factores que debilitan la (re)organización familiar"; "Estrategias que potencializan la (re)organización familiar". **Conclusión:** Los profesionales reconocen que la (re)organización de la familia es un proceso complejo, gradual y singular, comprendido a la medida que surgen las alteraciones generadas por la enfermedad.

Palabras-clave: Enfermedad de Alzheimer; Dinámicas no lineales; Personal de salud; Enfermería.

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Submitted on 05/28/2014.

Accepted on 03/05/2015.

DOI: 10.5935/1414-8145.20150045

INTRODUCTION

Due to the demographic changes and the consequent process of population aging, there is a significant increase in dementia, highlighting Alzheimer's disease (AD), being responsible by 70% of cases in elderly people¹. Considered as neurodegenerative, progressive and irreversible, AD has an insidious starting, resulting in the loss of functional capacity, spatial disorientation and gradual memory decline, especially from recent facts². The characteristics of insidious starting and gradual memory decline associated with other factors, hinder an early diagnosis.

Studies have been conducted in order to find an accurate diagnosis for AD^{3,4}. However, nowadays its diagnosis is accurate, since the only way to have an accuracy diagnostic is through histopathological analysis of the brain post-mortem tissue. In this way, the diagnosis has been carried out for assessing the patient's clinical history associated with additional tests such as CT scans, resonances and laboratory tests used to support the diagnosis⁵.

Initially reaching the cognitive area and then the motor are, AD does not only affect the elderly with the disease, but also the family as a whole, especially the family caregivers, that in the Brazilian context, they are the main source of care of their members⁶. By compromising the nuclear family in a unique way, AD promotes physical and emotional disorders in patients that produce reflections on all members, demanding constant (re)organization in the functional and relational family structure².

Health professionals must observe the family as a complex unit by their members interactions, so the professional behavior become natural and multidimensional. The term "complex" is a link between the unit and the multiplicity of something that was done together. In the case of the family, there are the different elements that come together at the same time and are inseparable and constitute the whole⁷. In this perspective, nursing care is considered complex, expanded, dynamic, inclusive and dialogic, enabling the co-participation of individuals. In the process of family (re)organization, Nursing has an important role in understanding of the human being as a whole and the possibility of mediating the relationships and systemic interactions⁸.

However, for the professional behavior contemplate the complexity of the care with the AD elderly and their families, it is essential the connection/reconnection of the different professional knowledge in a unique and multidimensional way. With a focus on complexity, it is necessary that nursing interact with other health professionals and family members/caregivers of the elderly with Alzheimer's, in order to establish relationships and interactions, so that the family can be (re) organized for living with AD. It is also considered important for health and nursing professionals in their training process, to be prepared for a performance that values family as a complex unit.

Issues related to AD, elderly health and family are of great importance in the current context of public policy, and highlighted

by the Ministry of Health as a research priority in Brazil⁹. Some of the studies have been held with the focus on family/caregiver health of elderly people with Alzheimer^{2,5}. However, there are not many investigations about the process of family (re)organization in order to face this disease with increasing rates, as it increases the expected population life. There is also a gap in knowledge about the perception of health professors who act as families/caregivers to AD elderly, justifying the need and relevance of this research.

By knowing the perception of the professors health who work as family members/caregivers about the family (re)organization based on its complexity, there is the opportunity to expand reflections about this theme and enhance discussions among health professionals. Such behavior may result in better care not only to the elderly and their caregivers, but to the family as a complex unit, in a constant process of (re)organization.

From these findings, the question is: What is the perception about family (re)organization in the context of Alzheimer's disease of professors in health courses of a higher education institution? Therefore, this study aimed to know the perception of health courses professor that integrate a university project to support the family/caregivers of patients with Alzheimer's disease about the family (re)organization based on its complexity.

METHOD

This is a descriptive and exploratory study with qualitative approach, having as reference the theory of complexity, guiding the researcher and the research participants to reflect on new ways of organizing the uncertainties and disorders to the new ways to (re) create the methods for understanding the phenomenon. The choice of reference was to understand that "a theory is not knowledge; it allows knowledge. One theory is not an arrival; it is the possibility of a match. One theory is not a solution; it is the ability to solve a problem"^{10:335}.

The study was conducted with professors of the health courses participating in the university support Project called "Integrated Multidisciplinary Care to caregivers of Alzheimer's disease patients (AMICA)", developed in a private institution of higher education in the central region of Rio Grande do Sul state, Brazil. This project is being developed systematically since 2007, by an interdisciplinary team, composed of eight professors of Health area courses: one nurse, one Pharmaceuticals, one physiotherapist, two nutritionists, one dentist, one psychologist and one occupational therapist, besides the participation of some students of these courses.

In one of the group meetings, the members were invited to participate. The inclusion criteria were: to be a professor of the health courses and be actively participating in the project for at least six months. Professor who, for some reason, were not participating in the group were excluded. Based on these criteria, there were five professors: one nurse, one Pharmaceutical, one physiotherapist and two nutritionists.

Data were collected through Focus Group technique (FG), which is characterized as a discussion group that dialogues about a particular topic, experienced and shared through common experiences, receiving appropriate stimulus for discussion. The choice of this data collection technique was due to the possibility to promote group interaction, since the collective expression was an element to explore and expand the understanding about the phenomenon under investigation¹¹.

The FG had the participation of a coordinator (principal researcher) and an observer, invited previously, who assisted in the collection process, the recording of collective speeches, the notes and the dynamics during the meetings. Three meetings were held between the months of June and August 2013, lasting about two hours each one.

Each meeting was guided by a specific theme. In the first one, it was sought to understand the perception of teachers about the family (re)organization in the coping process with Alzheimer's disease. Therefore, the moderator read a brief text from the book "The Head well-made: rethink the reform, reforming the thinking"⁷. Then, the subjects were asked to express/register on an A4 sheet of paper, the first idea that came to their minds when reflecting on Alzheimer's disease, and subsequently about the family. Next, participants presented their ideas, which allowed intense group discussions, gradually expanded based on the complex thinking. After the meeting, there was a synthesis, written by one of the participants willing to do it, with the help of others. The coordinator collected the synthesis and then the schedule and final combinations for the next meeting were discussed.

In the second meeting, some points from discussed at the previous meeting were discussed and also about the potential/strengths and weaknesses experienced in the care process to family/caregivers of elderly people with Alzheimer's. Initially, professors were asked to reflect on the questions: How was/is being for you to live with family members/caregivers of the elderly with Alzheimer and how do you perceive the family (re)organization in order to cope with the disease? After that, they were asked to record on paper, through drawings, illustrations, written or any other way, the main potential/strengths that assist the process of care/living with the family/caregivers and the weaknesses encountered in the care process for family members/caregivers. Then, there was a collective discussion from what they had recorded.

In the third meeting, the synthesis of the previous meetings were discussed again, and they continued to expand the discussions on opportunities, challenges and threats encountered by professors in the process of supporting the family (re)organization of elderly with Alzheimer's disease. While participants discussed these elements, the moderator noted some important issues from the speeches, preparing a scheme. Then, the moderator presented the registered topics to the professors, questioning them about their agreement and acceptance and if they would like to add something. After the analysis, a complex structure

was elaborated, involving elements discussed at the meeting, as strategies to help family caregivers, establishing some aspects of the AD that direct care from the perspective of complexity.

Data analysis began with the collective synthesis of each meeting. The researcher made a theoretical analysis of them based on the complexity theory and a methodological analysis based on the Focal Strategic Analysis (FSA)¹², proposing a dynamic and cooperative participation of the research subjects. The FSA is an analysis technique that aims to expand the phenomenon under investigation, in this case the family (re)organization, from the collective deepening based on strengths and weaknesses as well as challenges, threats, opportunities and strategies related to the personal and collective experiences. Thus, the subjects' speeches were recorded, transcribed and analyzed, giving rise to the analysis categories presented and discussed in the results.

The ethical and legal requirements involving research with human beings were considered according to Resolution number 466/2012, National Council of Health¹³. Participants signed the Informed Consent Term in two copies, one for the participant and the other for the researcher. The project was approved by the Ethics Committee in Research in Health Area of the Federal University of Rio Grande (CEPAS/FURG), Ordinance number 092/2013. To maintain the anonymity of the participants, they were identified by the letter P (professor) followed by a number (P1, P2... P5).

RESULTS

Dos dados organizados e analisados, emergiram três categorias, quais sejam: Alzheimer: processo singular e multi-dimensional; Fatores que fragilizam a (re)organização familiar; Estratégias que potencializam a (re)organização familiar.

From the organized and analyzed data three categories emerged: Alzheimer - singular and multidimensional process; Factors that weaken the family (re)organization; Strategies that strengthen family (re)organization.

Alzheimer: single and multidimensional process

AD is perceived by professors as a natural process because it is different from other diseases in which there is a single behavior. Due to its symptoms and procedural developments, it is unique for each individual, then the professional behavior is also unique and complex:

Alzheimer's disease is extremely singular. The care of each one is very individualized, that is why it is so complex to deal with because, unlike some other diseases, in Alzheimer there is not a single behavior, a management, a similar treatment. (P4).

The disease itself is uncertain. But, Alzheimer's disease for me is one of the most uncertain diseases, because in

other diseases you have a medicine that can extend that life or bring you healing [...] but in Alzheimer's disease we do not have any of that. (P2).

The professors' reports showed that, due to its uncertain and unpredictable characteristics, AD beyond the nuclear family, characterized as multidimensional, requiring health care professionals:

Alzheimer is as chronic problem, it is not only in the family, it needs health care from professionals, family itself and society to accept the patients and their limitations [...] (P1).

[...] I see that it is a disease interconnected within a system. It is a disease that covers not only the family but also society and health professionals and all these people form a large system [...]. (P3).

The speeches show the complexity involving AD and the uncertainty permeating each particular situation, since it is a disease without a single behavior for all cases. According to the study subjects, this fact requires an integrated behavior interconnecting the parties, understood in this study as the different elements composing the family and health professionals as a whole, that is, society forming a complex system through relationships and interactions and feedbacks between the whole and the parts and between the parts and the whole.

Factors that weaken the family (re)organization

During the professors' speeches, there were several factors weakening the process of family (re)organization of elderly patients with Alzheimer, of which ignorance, fear of the unknown and the denial of the disease by the family and society are highlighted:

It is a degenerative disease and not everyone has this perception, this view, until this happens within the family. At the same time it is the denial, I do not want to know, or I know, but pretend not to know, then they pretend that in a moment she or he will be all right, we see it a lot! (P3).

[...] we have a prejudice of the disease, and we do not understand as a society, as a group, how a person can lose many cognitive and autonomy, mostly. How difficult is this acceptance! (P1).

Due to the lack of acceptance or fear of the unknown, some family members may move apart and the family (re)organization occurs that the act of care is focused on a unique family member. This is may be due to ignorance or a way for families to protect themselves from the unknown:

I see this very separation of the family, in a family with more than one child, care usually focuses on one and the others move away [...] as a way of saying: "It's not that we do not want to take care, but the more far we are, the less we suffer, I do not see, do not feel!" Who is there in the fight is who sees every day, experiencing the physical and cognitive losses, it is a wear and has a whole breakdown. (P3).

[...] People have no idea what the disease is and what it means and this generates a moving apart. I do not want to know what I'll go further. Some people can deal best with it, but many people do not want to know. (P1).

The AD needs a constant family (re)organization due to changes caused by the disease. However, the (re)organization enables new experiences, which makes new orders generated are different from the existing ones. Following, there is a report:

[...] This restructuring is too long, it happens, you will be adjusting to the changes that are continuous until death. Then the family of restructuring as it was, this return to "normality", only happens after and perhaps not happening in the same way as before, because it has a big experience. (P2).

In this report, it can be seen that the (re)organization happens constantly in the lives of family members, being a long process that extends to the AD patients' deaths.

Strategies that strengthen family (re)organization

Professors recognize that the family (re)organization is difficult for the family due to the impact that the disease generates, in its different dimensions and realities. However, they realize that the support networks and the interconnection of different knowledge constitute important strategies to family (re)organization:

Patients who develop the disease come from different families, in different systems, so for me the family (re) organization, of the patient, has to be done through support networks, each professional in his area, but interconnected, trying to make this relationship because the initial impact of the diagnosis is already very painful for the family. (P2).

[...] it could have more interconnection of different systems and subsystems, services, let's call them like support services, support networks, units [...]. (P3).

Other professor has highlighted help groups as strategies for family (re)organization, but he said that the best would be to enter into their homes, strengthening the group's performance

as a support network. He also stressed the importance of coordination among the various support networks, such as support groups, basic units, hospitals and schools:

[...] The support group is very positive, but I think that coming into their homes also makes a difference as a support network, integrated visits and connecting our group with other systems that could be the subsystems, the basic units, the hospital and school. I think that way, only in this way that (re)organization may be better and less painful for the family. (P1).

In the following speech, it is possible to see that there are difficulties in working with the family as a unit, even though its importance:

I think it is really very difficult for us to work with the family, I think that's very important, that's where it starts, but it is very difficult to address it [...]. Only if we meet the family and go there (home) [...] and then that's what the Family Health Strategy would be. (P5).

Working with the family is something that still needs to be explored by health professionals, according to the professors' reports, by saying that the professionals' view is predominantly punctual, linear and focused on the disease. They also note the work that should exist by the Family Health Strategy:

Regarding the family (re)organization, I think we are still crawling a lot. For decades we have been focused on the disease, which is the biomedical model, we only see the disease and forget the person who is theoretically healthy, physically active, he is taking care of the other. We forget that behind all this, there is a lot of physical, mental pain, and this is not taken into account when we do not have this contact, we care about the patient. (P2).

In the professors' reports, this difficulty to work with the family can be attributed to the influence of the biomedical model, taking into consideration only the part understood here as the AD, often forgetting the healthy individual who is the caregiver.

DISCUSSION

To understand the family (re)organization of AD elderly people from the perspective of complexity, professors have more concerns than answers, since AD is perceived as unique since it affects each individual in a particular way, which leads to consider that the care offered is also unique, multidimensional and therefore complex. In addition, they stated that AD goes beyond the nuclear family, requiring a global vision by health professionals and the understanding of society as a whole.

Complex thinking is able to gather, contextualize, globalize and at the same time recognize the individual and the concrete. In this understanding, the whole, understood in this study as the family, is a complex unit that cannot be reduced the elements that constitute it¹⁴. Therefore, it is evident that professors of health courses have multidimensional knowledge of disease, comprising the disorder experienced both individually by each family/caregiver, as the families as complex units.

This view for the whole, but also to the parties, may be attributed to the active participation in the support group for family caregivers. To join the group, professionals have expanded knowledge, a fact that allows them to understand that the disorder is for everybody, allowing agreements and disagreements, co-organizing and disorganizing, alternately and at the same time because the disorder is always relative to the(re) organizers or dispersive interaction processes¹⁵.

Therefore, it is evident that the certainties and uncertainties are a constant in the performance of professors participating in this study to the support of family/caregivers of elderly with Alzheimer's disease in the process of family (re)organization. On the one hand, there is the certainty of the disease involving both the parties, that is, every member of that family, the family as a whole. On the other, it remains the uncertainty of how to act in order to meet the multidimensionality of the whole complex. The complexity precisely entails the recognition of a principle of incompleteness and uncertainty, with the challenge of care to contemplate the completeness and the multidimensionality of human beings¹⁵.

In this way, it is highlighted the need for multidimensional care, that is, directed not only to a part, but as a whole that, accordingly, there are the elderly with the disease, the family caregiver and the family¹⁶. It is important to consider the relations and systemic interactions of these people, since professionals actions directed to the whole can help the family to live with the inherent disorders to this process. Professors recognize that the family (re)organization is something that needs to occur for the the disease experience and between the part and the whole. However, they report that it is difficult for the family by the disorders generated by the lack of acceptance, ignorance, and fear of the unknown that the AD provides both the parties individually, as a whole.

With a focus on complexity, the relationship between health professionals, families and family/caregivers of the elderly with Alzheimer are needed, strengthening these relationships and interactions so that the family can be (re) organized for the coping with diagnosis and living with AD.

In this way, capacities for implementing strategies and multidimensional care behaviors are expanded and strengthened, contemplating, therefore, not only the welfare of the elderly person with AD, but also healthy living for their families/caregivers and the relationships and interactions. As possible strategies, there are support networks for families and elderly people with

chronic health conditions, which have drawn the attention of health professionals in general and psychology in particular, because they believe it is important for dealing with stress and suffering situations¹⁷. Through joint efforts, interventions to ensure that aging is seen as an achievement by reframing the negative values associated with dementia and the age are expanded¹⁸.

Professors of this study suggested as strategies the relationship and interconnection of knowledge of different professionals and the articulation of support networks, such as groups for family/caregivers, schools, hospitals and FHS. Strategies can assist in the process of (re)organization of these families, since they are characterized, according to Morin, as the art of integrating information and to form action schemes, in order to be able to gather as much certainty to face uncertainty⁷. The strategy brings with it the consciousness of uncertainty that will be addressed and, therefore, it contains a challenge. Professionals should be aware of the challenge, to not fall into false certainties⁷.

Such strategies can enhance the ability of families to organize themselves to live with AD. This self-organization develops continuous complexity, autonomy and (re)organization¹⁵. In this context, the family can be (re) organize internally to meet ever more complex levels of organization, which contributes to the strengthening of relations and associations between the whole and the parts and vice versa, contributing to further understanding of disorders. These forms of self (re)organization enable the construction of strategies for addressing the social and health problems through the emancipation of individuals and families as protagonists of their own history.

CONCLUSION

The study provided the perception of professors of health courses that were part of a university project to support family/caregivers of AD patients about the family (re)organization based on the complexity theory. AD is perceived as singular, so for the family (re)organization is necessary to think in multiple dimensions that is in the elderly with Alzheimer's disease, their family caregivers, in the family as a complex unit and society as a whole.

The professors recognized that the family (re)organization is a complex process and it happens all the time, that is, the family will be (re) organized as they have disorders generated by the disease. They cited several factors making difficult the family (re) organization, such as denial, ignorance of the disease and the fear of the unknown. These factors, according to the subjects of the study imply that the family who experiences the situation of AD needs to be assisted by support networks, which should be interconnected so that they can be met multi-dimensionality by the parties and also by the whole.

This study helped reflecting on the punctual perception, focused on the parts that sometimes guide the health professionals' behaviors, leading to the biomedical model still present

both in the training process of these professionals, and in their places of work. It was possible to understand that the perception of professors about the family (re)organization is more complex than we think because they realize the multidimensionality involved in this difficult and necessary process to families caring for an elderly person with Alzheimer's disease.

This study also enabled to understand some weaknesses found in the process of family (re)organization by professors as well as indicate possible strategies that can contribute to this process, as the coordination of existing support networks. It raised reflections on the process of family (re)organization of elderly people with AD, which may enable the interconnection of different knowledge to assist the family in this process.

Limitations of this study are because data collection was conducted at a single institution that has support group of family/caregivers to elderly with AD, which did not allow the comparison of results with those found in other realities at the time of the study. However, the data of this study were discussed and helped understand the perception of professors of health courses about family (re)organization from a complex perspective and then broaden perspectives on the phenomenon, allowing to view the order-disorder (re)organization as antagonistic and complementary processes, by the disorder understanding as a generator of a new order.

With this complexity involved in the process of family (re)organization of living with the elderly person with AD, it is stated that the problem does not end with this research. New studies focused on multidisciplinary and interdisciplinary perception about the family (re)organization of elderly with Alzheimer are suggested so that in the near future, this relationship of order-disorder (re)organization will be less troubled and disarticulated of family and social ties.

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