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Family (Re)Organization in the Context of Alzheimer's Disease in the Elderly: An Exploratory and Descriptive Study

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ABSTRACT

Aims: To understand (re)organization of the family of elderly patients suffering from Alzheimer's disease from the perspective of complexity; to know the perceptions of teachers of health courses that relate to a project to support families/caregivers of Alzheimer patients about the need for family (re)organization; to identify/delineate care strategies that can contribute to the process of family (re)adjustment in coping with the disease. **Method:** This is an exploratory and descriptive study that uses a qualitative approach. **Results:** We identify some difficulties, such as unwillingness to accept the disease and the confrontation with the unknown. Among the possibilities, we highlight the discovery of new meanings. Teachers consider Alzheimers as a unique and multidimensional disease, and they suggest strategies such as the interconnection between support networks to assist in family (re)organization and care for the elderly. **Conclusion:** The disorientation experienced as a result of Alzheimer's disease is generated by, and is a generator of, continuous family (re) organization.

Descriptors: Family Relations; Alzheimer disease; Nonlinear Dynamics; Health Personne; Nursing.

INTRODUCTION

Alzheimer's disease (AD) is characterized as irreversible and degenerative and is considered the most common form of dementia among the elderly⁽¹⁾. Due to its symptoms, individuals experience a situation of dependence on care which, in most cases, is performed by family members at home. As part of the daily care process, close relatives experience physical and emotional suffering, causing sometimes a familiar feeling of uncertainty and disorder. In this context, the family plays a central role, as it needs to (re)organize itself in order to cope with the care process related to the diagnosis and treatment without disarticulating family and social ties.

AIM

General: to understand the (re)organization of the family of elderly individuals suffering from Alzheimers from the perspective of complexity.

Specifics:

- 1. To understand the perceptions of the teachers of health courses that relate to a project to support families/caregivers of people suffering from Alzheimers in terms of family (re)organization from the perspective of complexity;
- 2. To identify/delineate care strategies capable of contributing to the process of family (re)organization in coping with Alzheimers.

METHOD

This is an exploratory and descriptive research, which uses a qualitative approach using Complexity Theory as a theoretical framework⁽²⁾. The study subjects were five teachers in the area of health, five family caregivers, and a non-family caregiver for elderly people suffering from Alzheimer's disease. These care providers are participants in a support group for family/caregivers that has been developed in a city in the central region of Rio Grande do Sul. Data collection occurred between June and August of 2013 as a result of six meetings making use of the focus group technique⁽³⁾. Of these meetings, three involved family members, the caregiver and three teachers. The data were analyzed using the Focal Strategic Analysis⁽³⁾ technique and were supported by the Complexity Theory. Ethical procedures were followed according to resolution 466/2012 of the Health Ministry⁽⁴⁾. The project was approved by the Research Ethics Committee of the Health Area of the Federal University of Rio Grande under number 092/2013.

RESULTS

Some of the difficulties experienced by the families were identified. These included non-acceptance of the disease, confrontation with the unknown, lack of preparedness for dealing with the denial and the emotional instability of the family/caregiver. However we identified potentialities such as discovering new meanings in terms of patience, love and support for others, meeting people who were experiencing a similar reality, and sharing experiences. Teachers confirm AD as being unique and multidimensional, as it

has features that go beyond the core family, needing the help of professionals and society as a whole. Among the signaled strategies, we highlight the interconnection, interaction and feedback within the support networks that assist families who experience AD to assist in the family (re)organization and care for the elderly.

DISCUSSION

As a result of the symptoms of AD, family members experience conflict situations, and disarticulation of ties, feelings of certainty, uncertainty and instability⁽⁵⁾. The changes trigger actions that change the environment in a continuous circular motion of order, disorder and (re)organization. Teachers understand the disorder experienced both individually by each family/caregiver, and by families as complex units. However, the uncertainty in terms of how to act in order to meet the multidimensionality of the whole, remains. The complexity involves the recognition of a principle of incompleteness and uncertainty, from which arises the challenge of contemplating the completeness and the multidimensionality of human beings⁽²⁾. In this context, the relationship between health professionals and family members/caregivers of the elderly suffering from AD becomes necessary, so that these families members can (re)organize and live in the context of AD.

CONCLUSION

Family members are constantly exposed to the full disorder generated by AD, but open and flexible to the constant (re)organization. Such problems (initially triggered by the non-

acceptance of the disease by the family in a unique way or as a complex unit) are both generated and are generators of a constant family (re)setting. The teachers recognized that the family (re)organization is a complex process, and that the family will adapt as the disorders generated by the disease arise. Among the signaled strategies we highlight the interconnection between individuals within the support network, so that the procedures adopted may take into account the multi-dimensionality of the parts and of the whole.

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