ELDERLY PEOPLE, FAMILY, AND CULTURE: A STUDY ON THE CONSTRUCTION OF THE CAREGIVER’S ROLE

ANCIANOS, FAMILIA Y CULTURA: UN ESTUDIO ACERCA DE LA CONSTRUCCIÓN DEL PAPEL DEL CUIDADOR

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The book “Elderly people, family, and culture: a study on the construction of the caregiver’s role”1, by Silvia Maria Azevedo dos Santos, was published having the author’s PhD thesis as the basis, whose study object was living along and caring for adults and elderly people with dementia. It consists of four chapters:

1) The care for frail elderly people in the family domain: issues proposed to theory and research in Gerontology and to the public policies with regard to old age;

2) A study in families of Japanese-Brazilian and Brazilian origin: objective, assumption, subjects, and procedures for collecting and analyzing data;

3) The process of living (along) and caring for adults and elderly people with dementia; and

4) Reflections on the condition of the family caregiver of elderly people with dementia.

In Chapter 1, intrafamily care is addressed, showing the diversity of caregivers a family may have. The author approaches theoretical issues of Gerontology with regard to the family caregiver’s typologies, the Brazilian data from researches involving caregivers, the issue of the public and the private to meet the demands of elderly people, the main current public policies in Brazil, and how research has been developed within the area.

In Chapter 2, the author presents the study objective, which was to understand the construction of the role of family caregiver of elderly people with dementia and the resignification given by the family member to the new situation experienced. It was grounded on the framework of Anthropology to better understand the study object and it chose the ethnographic method. The study unit consisted of twelve families. The procedures for data collection involved the Blessed, Tomlisson, and Roth scales, the Clinical Dementia Rating (CDR), to evaluate the demential condition and the impairment level to undertake daily life activities, semi-structured interview, and observation. For data organization and analysis, statistical softwares and content analysis were used.

In Chapter 3, through the study of the living along and caring process in Brazilian and Japanese-Brazilian families with an elderly person with dementia, the author identified five important kinds of evidence for discussion:

a) “Dementia is regarded as a resignified disease by the family caregiver”. The dementia diagnosis of a relative significantly changes the routine of families, although, at first, the families face dementia, in old age, as something usual and natural, making diagnosis more difficult. However, the family, by realizing that the elderly person with dementia will need a caregiver, seeks someone to take on this role, usually among close relatives; they, by caring for the elderly person, have to resignify, in many respects, their daily life routine;
b) “The plurality of the caregiver”. The caregiver is a person who needs to live, have leisure, care for her/himself, actions which become compromised when she/he is caring for her/his elderly relative with dementia. Thus, the caregiver needs not only technical, but emotional, physical, and personal support;

c) “The complexity of caring for”. The act of caring for is multidimensional; caring for a human being with compromised needs requires commitment and hard work on the part of the one who cares for, because the actions undertaken cause physical and emotional distress;

d) “Family dynamics must be evaluated in context”. It’s important to create a network of support, involving not only the primary caregiver (usually spouse, children), but also grandchildren, sons-in-law, daughters-in-law, and friends. The family and social relationships become crucial to the fullness of a more harmonious and collaborative care; and

e) “The caregiver’s dilemmas and tensions”. People who underwent the role of care provider need to be cared for in a holistic perspective. These tensions are now between the caregiver and the elderly person with dementia, and then between the caregiver and the family members. In the first case, they’re due to the caregiver’s difficulty to understand the disease and the patient, causing tensions which, if not mitigated, can fully compromise the caregiver-elderly person relationship. In turn, in the second case, the caregiver faces tensions with the other family members, who don’t understand the caregiver’s role, causing distress to her/his.

In Chapter 4, the author highlights that, currently, government policies are leading to the privatization of home care for the elderly people, with or without dementia. It’s a trend occurring not only in Brazil and it depends on the culture that this family shares, in the case of the author’s study, Brazilian or Japanese-Brazilian; the embracement to the elderly relative occurs differently. Among the Brazilian families, “any” family member care for, while in the Japanese-Brazilian ones, the older son is usually the one who assumes such a role. The author claims, thus, that the health care institutions need to collaborate in a more effective way with regard to the support for social and family networks for the home care for elderly people, in order to provide this population with specific care.

One concludes that the book is important because it shows evidence which can support the nurse’s action, both for the care for the elderly person with dementia and for her/his family. The intrafamily care needs a special attention, since the family members aren’t always ready to care for an elderly person with dementia. The elderly population with some kind of dementia has increased in recent decades, making it necessary that the family is prepared to provide this patient with care. There’s a need that the caregiver’s role is regarded as a priority in the family’s daily life, and it has to care for its patient and beloved one. The nurse shall help this family to care for and better understand the sickening process of its elderly individual.

REFERENCE