

THESIS ABSTRACT

GARCÍA-TORO, MARITZA (2019). "TAKING CARE OF HER IS NOT THE DIFFICULT PART": CONFIGURATIONS OF FAMILY CAREGIVING IN EARLY-ONSET ALZHEIMER'S DISEASE BY E280A MUTATION. (PHD THESIS). UNIVERSITY OF SALAMANCA (SPAIN)

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The defense of Maritza Garcia-Toro doctoral thesis took place on June 17th 2019, obtaining the grade of Outstanding Cum Laude unanimously. This thesis exposes the experience of a group of family caregivers who take care of people carrying the E280A mutation for Early-onset Alzheimer's Disease.

Family caregivers of people with Early-onset Alzheimer's Disease face several challenges, including the lack of adequate support services because professionals and the community in general, are unaware of their specific needs. The challenges become greater when the disease is genetically inherited, there are multiple affected members in several generations, and the caregiver himself can eventually become a recipient of care when he or she develops the disease.

In this mixed method study, semi-structured interviews were conducted and questionnaires were applied to 50 participants to examine anxiety, depression, burden, self-efficacy, social support, resilience, and coping strategies. In the qualitative component, two categories emerged: Other life experiences that interfere with care and representations about the disease.

It was found that the use of escape-avoidance coping strategies, as well as low self-efficacy to

controlling upsetting thoughts associated to caregiving, and insufficient income are the main risk factors for adverse psychological outcomes such as anxiety, depression and burden. On the other hand, active coping strategies like focusing on the solution of problems and positive evaluation of the situation, high self-efficacy, and social support are associated with resilience and, therefore, operate as psychological protective factors.

The results show that caring for a loved one while simultaneously running the risk of developing the same disease, permeates the caregivers' experience both in a negative and a positive way, because the deterioration of the person with dementia is a constant reminder of one's genetic vulnerability, but it also helps to have greater empathy and devotion in the care.

In previous research, anxiety and depression have shown to be preclinical symptoms of Alzheimer's Disease, this aspect should be seriously considered in caregivers who belong to families carrying a genetic mutation associated with this condition. In the first place, these caregivers could be at risk of accelerating the onset of symptoms, by being exposed to continued emotional stress; second, the early symptoms of Alzheimer's Disease, such as memory loss, attention problems or mood changes, could be confused with the emotional consequences of care, which would interfere with an early diagnosis.

The findings also confirm that caring for a young loved one with dementia exposes family caregivers to specific emotional demands such as the concern to inherit the mutation, changes in future expectations, the interruption of the course of life, and the changes and investment of family roles (especially in spouses and children). That is

why, the professionals who provide support to these caregivers must support the construction of new interpretations focused on the gains, so that they find meaning and enrichment in their care experience, since it has been demonstrated that the caregivers provide a better attention when they interpret the experience as satisfying and rewarding.

For their part, the support programs should be aimed to the entire family group, not only to the caregiver, from a systemic approach, with the purpose of helping assume the changes and stress experienced by the family as understandable and expected, allowing them to overcome the frustration, guilt, and confusion. Specifically,

the programs should be aimed at: 1) create networks of solidarity, promoting cohesion and the balance of the family group and, even, restoring its functioning; 2) develop strategies aimed at family adaptation, including acceptance and construction of new roles and relationships; 3) the maintenance of intergenerational bonds between younger members of the family. This would allow the caregiver to perceive and receive more support from their relatives, because sometimes the other members of their family do not take care of the person with dementia, because they cannot assimilate the emotions associated with the diagnosis, the deterioration of their loved one, and to instrumental care.