

“Living Together with Dementia”: Construction and Conceptual Validation of Training Programme for Family Caregivers of People with Dementia Living at Home.

LIA SOUSA

MSc, PhD student, Centro Hospitalar de São João, EPE, Porto, Portugal |

CARLOS SEQUEIRA

PhD, Escola Superior de Enfermagem do Porto

CARMÉ FERRE-GRAU

PhD, Universidade Rovira i Virgili. Tarragona

PEDRO NEVES

MSc, PhD student, ULS Matosinhos, Porto

MAR LLEIXÀ-FORTUÑO

PhD, Universidade Rovira i Virgili. Tarragona

INTRODUCTION:

Considering the rising incidence of dementia, more and more families need to exercise the role of caregiver. The complexity of the symptoms associated with this syndrome carries a set of needs and consequently difficulties for the family caregiver, who often need to care without the knowledge and skills desirable for the exercise of the role. It is therefore important to develop interventions to support family caregivers of people with dementia, enabling train them for this role.

Objective: to construct and to validate the concept of the programme “Living Together with Dementia”.

Methods: 1st) integrative literature review about the main characteristics of training programmes for family caregivers of people with dementia living at home; 2nd) Focus group with 18 Portuguese and Spanish experts about the characteristics to be included in such programs; 3rd) Delphi study with 26 Portuguese and Spanish experts to validate to validate the concept of the programme “Living Together with Dementia”.

Results: Of the methodological steps followed resulted in the psychoeducational program “Living together with dementia”, structured in seven weeks and composed of 7 individual and weekly sessions of 60 minutes/each and 2 group sessions of 90 minutes/each. The participants are assessed before and after the intervention with a set of instruments. Throughout the sessions the following subjects will be addressed: dementia, communication and behaviour; emotions, demands and expectations of the caregiver role; basic and instrumental activities of the daily living; general cognitive stimulation and environment management; coping and problem solving strategies; physical and mental health of the caregiver; management of relationships and community support. The methodologies to be applied are stating and discussion issues, practical 4 examples/simulations, skill training, practical exercises, video showing and group sharing.

Abstract of the research project presented at International Meeting of Doctoral Students in Nursing of Universidade de Lisboa, May 2016.

Conclusion: The psychoeducational program “Living together with Dementia” aims to empower family caregivers of people with dementia, providing them with knowledge and skills to perform their daily functions. Their content was carried out by experts in the field and their implementation may be an advantage for these caregivers. However, it is important to develop the experimental validation of this program to test its practical effectiveness, which is the next step in this research.

Keywords: caregivers, training, dementia, elderly

“Living Together with Dementia”: Construction and Conceptual Validation of Training Programme for Family Caregivers of People with Dementia Living at Home.

REFERENCES

- Cohen-Mansfield, J. (2005). Nonpharmacologic interventions for persons with dementia. *Alzheimer's Care Quarterly* April/June, 129-145. Acedido em http://journals.lww.com/actjournalonline/Abstract/2005/04000/Nonpharmacological_Interventions_for_Persons_With.7.aspx
- Gallagher-Thompson, D.; Tzuang, Y.; Au, A.; Brodaty, H.; Charlesworth, G.; Gupta, R.; Lee, S.; Losada, A. and Shyu, Y. (2012). International perspectives on nonpharmacological best practices for dementia caregivers: a review. *Clinical Gerontologist*, 35, 316-355. DOI: 10.1080/07317115.2012.678190.
- Nelis, S.; Quinn, C. e Clare, L. (2007). Information and support interventions for informal caregivers of people with dementia (Protocol). The Cochrane collaboration. Acedido em <http://www.cochranelibrary.com/>
- Silva, A. (2009). Efetividade de um programa de intervenção na percepção de sobrecarga dos cuidadores familiares de pessoas idosas com demência [dissertação de mestrado]. Lisboa: Faculdade de Medicina de Lisboa da Universidade de Lisboa, 180p.
- World Health Organization (2012). *Dementia: a public health priority*. Accessed: <http://www.humana-mente.com/resources/relatorio-OMS-demencia.pdf>

Contact: liasousa_27@hotmail.com