

2nd International Conference on

Int J Ment Health Psychiatry 2019, Volume: 5 DOI: 10.4172/2471-4372-C1-030

DEMENTIA AND DEMENTIA CARE

April 15 -16, 2019 | Toronto, Canada

Awareness of dementia from the perspective of informal caregivers

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he present study is part of the participatory action research which aims to organize support groups which empower the informal caregivers of people with dementia (PwD). From February to May in 2017 narratives were carried out with 16 caregivers from different Estonian counties. The research is based on phenomenological approach and narrative inquiry. One of the study subthemes was to explore the experiences of the informal caregivers about the awareness of dementia in the caring process and find out their expectations of supporting them. The results are divided into four thematic headings and one of them is awareness of dementia. The current study revealed that the caregivers noticed the deteriorating of cognitive functioning already years ago but they did not seek help, because they taught that these are normal signs of aging. The caregivers pointed out the lack of knowledge among professionals in the process of diagnosing, or them uncompassionate attitude and they experienced lack of collaboration with health and social care services. In addition, the caregivers felt the lack of advice and suggestions on how to get support and how to care for the relatives. They emphasized that they had to search the internet for additional information. In order to empower the informal caregivers, it is necessary to raise awareness among the health and social care professionals. It is also important to raise the public awareness about dementia and encourage citizens to support PwD and their family members and develop the national dementia strategy.

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