

206 - Suicide and euthanasia in young onset dementia

Background

Dementia affects people that have not reached the age of 65 years. Persons diagnosed with dementia before this age, are often referred to as people with “young onset dementia”. They are normally diagnosed in a later stage of the disorder compared to their older peers. This, probably due to a larger variety of brain disorders causing dementia among young persons compared to what is the case among elderly. People with young onset dementia experience a great transformation of existential life. Studies have shown that they are more aware of the disease and depressed than people with late onset dementia. The awareness of disease increases the risk of suicide ideation in this population. Health personnel should therefore be more trained to detect and diagnose young persons with dementia at an earlier stage, to meet their needs. Providing tailored services to them and their families may contribute to prevent suicide and adequately address thoughts about ending life.

Content of the Session

We will organize four lectures with speakers from Brazil, Norway, the Netherlands and Portugal. The first lecture will contain results focusing on awareness of the disease and suicide ideation and the different awareness between persons with young onset of dementia and late onset dementia. The second and third lecture will report results from two qualitative studies, in which young persons with dementia have been interviewed express ideas about suicide and end of life. The last one will build on a case report to discuss the role of family interventions in the clinical context of YOD, including scenarios involving including scenarios involving suicidality and challenges related with the legalization of euthanasia.

Scientific Purpose

To contribute to the development of knowledge and understanding of the situation of young persons with dementia and their life situation based on three scientific studies and a clinically based discussion of the topic.

1. Awareness of Disease and suicide ideation in young onset Alzheimer’s disease

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 Awareness of disease is the ability to acknowledge changes caused by deficits related to the disease process. The vast majority of studies on awareness of disease are focused on individuals with late-onset dementia (LOD), with relatively few focusing specifically on individuals with young-onset dementia (YOD). We aimed to investigate whether there are differences in awareness of disease between young-onset dementia (YOD) and late-onset dementia (LOD) and examined how awareness interacts with cognitive and clinical variables. We also report a case of a man with YOD who had preserved awareness of disease, depression and risk of suicide associated with the development of the dementia. Using a cross-sectional design, 49 people with YOD and 83 with LOD and their caregivers were included. We assessed awareness of disease, cognition, functionality, stage of dementia, mood, neuropsychiatric symptoms, and caregivers’ quality of life (QoL) and burden. The results showed that people with YOD were more aware of the disease than people with LOD. Multivariate linear regression revealed that higher impairment in functional level was associated with unawareness in both groups. In the YOD group, preserved awareness was related to worse self-reported QoL, whereas, in LOD, deficits in awareness were related to caregivers’ worst perceptions about people with dementia QoL. Regarding the case report, cognitive functioning, disease severity, depressive symptoms and awareness of disease were assessed using validated measures. The person with YOD showed a moderate level of disease severity and high degree of dependence for activities of daily living. There was recognition of memory problems and routine changes with presence of intense pessimism, low self-esteem and suicidal