

and use the implementation plan more effectively (demonstrating collective action). Teams were less likely to engage in the collective action or reflexive monitoring required to improve care integration if they did not feel engaged with their learning collaborative.

Discussion: Learning collaboratives hold promise as a strategy to improve cross-sector service collaboration for people with YOD and their families but must maximise group cohesion and shared commitment to change.

Impairment in Awareness and its Domains Vary According to the Age at Onset of Dementia

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Introduction: Awareness is the recognition of changes caused by deficits related to the dementia process. Awareness is related to a given object, like memory functioning or functional status. Objects of awareness can be grouped into a range of domains, including cognition, functional ability, emotional and social functioning, and behavioral difficulties. Preserved awareness in people with young onset dementia (YOD) has been reported; however, there is a lack of research investigating whether there are differences in the domains of awareness impairment according to the age at onset of dementia. This study compared the differences in awareness and its domains and examined associations with cognition, functionality, neuropsychiatric symptoms, social and emotional functioning, and quality of life (QoL) among people with YOD and late onset dementia (LOD).

Methods: A group of 136 people with dementia and their caregivers (YOD= 50 and LOD= 86) were consecutively selected. We assessed awareness of disease, dementia severity, cognition, functionality, neuropsychiatric symptoms, social and emotional functioning, and QoL.

Results: People with YOD presented more neuropsychiatric symptoms and worse cognition and functional ability than those with LOD. Compared to people with LOD, there were higher levels of awareness total score, awareness of cognitive functioning and health condition, and awareness of functional activity impairments domains in people with YOD, even in the moderate stage of the disease. There were no significant differences between groups in the emotional state, and social functioning and relationships domains of awareness. Multivariate linear regressions showed that functionality had a broad relationship with awareness in people with YOD. In contrast, neuropsychiatric symptoms and QoL were more significant to the awareness of people with LOD.

Conclusion: Different clinical variables are associated with different domains in YOD and LOD groups, reinforcing the heterogeneity of awareness in dementia. Differences in awareness and its domains in YOD and LOD may be particularly relevant to enabling interventions focused on meeting their specific needs and those of their families.

Developing dementia: The existential experience of the quality of life with young-onset dementia – A longitudinal case study

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Introduction: Cognition and the ability to take care of daily activities and oneself gradually declines among people with dementia. Studies are scarce, especially regarding how people with young-onset dementia (YOD) (<65 years) experience

the quality of their lives with the progression of dementia. People with dementia living alone face special challenges. The aim was to examine the experience of the quality of life with YOD as a single person.

Methods: The study presents a longitudinal case study with in-depth interviews exploring the experiences of a person with YOD. Individual interviews were conducted seven times over a period of three years from 2014 to 2017.

Results: We examined if and how seven themes concerning the quality of life and well-being were fruitful for understanding the experiences of dementia in the everyday life of a single individual. The study explored needs and challenges during the development of dementia, and how the person reacted over time, set in context. The themes significant for well-being are: identity, connectedness, security, autonomy, meaning, growth and joy.

Conclusion: The study shows how treatment, support, and services must be individualized when dementia develops in order to support identity, resources and mastering capacity, and promote well-being.

Dementia Experts for Involvement Network-Young Dementia [DEFIN-YD]: Developing a national network of younger people with dementia prepared to get involved in research.

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In September 2020, a University of Northampton (UK) team, led by Professor Parkes and Dr Mary O'Malley (now at the University of Worcester) were successful in securing funding from the Wellcome Trust Public Engagement Fund. The central aims of the DEFIN-YD project were to share knowledge about young onset dementia (YOD) research; create a younger onset dementia public and patient involvement (PPI) network; develop ideas for future YOD research; and provide a reference group to support researchers developing YOD projects. Currently, 21 people have been recruited into one of three regional groups. Prof Parkes leads the Midlands group, Dr Cole from University of West London hosts the Southern group, and Bradford University supports the Northern group. The members were recruited via the Young Dementia Network (YDN), Dementia UK, Alzheimer's Society, the DEEP network, and local NHS Services. They come from urban and rural settings across the UK. Some attend the meetings alone and others are supported by advocates (usually carers). They have a variety of diagnoses and are at different stages of their dementia journey. The groups include members from different cultural backgrounds. They are able to share their personal experiences and are keen to do so in order to improve the care experiences of others. Due to COVID, members effectively completed all 5 regional workshop sessions from August 2021-March 2022 via Microsoft Teams. They are now fully prepared to engage in designing and developing YOD research projects. The top priority they identified for future research was for professionals to be more specifically trained in YOD. Once the workshops were designed and delivered, the first phase of the project was complete. Phase 2 (from April-October 2022) has sort to capture the experiences of participating in the workshops from the group members, facilitators, and project team; as well as developing a sustainable model for the future of the regional groups. The project comes to an end on the 31st March 2023.

In this presentation we would like to explore the following objectives:

1. Why we need specific YOD PPI research groups.
2. How we run the workshops and meetings.
3. How we hope to sustain the groups.