

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.

Authors: Professor Jacqueline Parkes¹, Dr Mary O'Malley², Dr Laura Cole³, Dr Natasha Bayes¹, Anna Crawford⁴

1. The University of Northampton, United Kingdom (Main author)
2. Worcester University
3. University of West London, United Kingdom
4. University of West London, United Kingdom

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.