

FC38: Young Onset Dementia: Examining the experience through Family Systems Theory

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Objective: Research tends to focus on the issues couples face – i.e., the dyadic relationship between carers and the affected person. This study examined young onset dementia from the broader family systems approach, focusing on the impact on the entire family following a diagnosis.

Methods: Public patient involvement was utilised to explore the specific issues of relevance to people with young onset dementia. Participatory workshops with members of the Alzheimer Society of Irelands Dementia Research Advisory Team were held to develop questions for the focus group interviews. Focus group interviews involved people with young onset dementia and their family members. The sample (n = 44) included people with a formal diagnosis of young onset dementia (with various subtypes) living in the community, and their family members including children.

Results: Analysis of the qualitative data uncovered five main themes with related sub-themes including: initial onset of dementia; personal and social impact; behavioural and psychological symptoms of dementia; age-appropriate support and the shifting family roles.

Conclusion: It is clear from the current data that a diagnosis of young onset dementia results in significant challenges for the entire family system. The traditional model of care, which tends to narrow the focus to the person with dementia and primary caregiver, needs to be expanded to include the entire family/caregiving system.

FC39: The influence of social constructivism on children and young adults perspectives of parental young onset dementia: A thematic analysis of the narratives

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Background: Western countries have a significant cohort of children (≤ 18) and young adults who live with a parent with a life limiting condition. Children and young adults' perspectives of certain parental illnesses have been well documented. However, the perspectives of children and younger adults of parental young onset dementia tend to be absent from the academic literature. Older adult children have reported on the impact parental young onset dementia, however, there is a necessity for research with younger adult children and children under the age of eighteen in relation to their perspectives of the condition.