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

Authors: Cathal Blake

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 (\leq 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.

Objectives: Utilizing cultural transmission theory, the current research explored if the social and cultural perspective influences the narratives of children and younger adults of parental young onset dementia.

Methods: One-to-one interviews were held with children and younger adults (n = 17: 29·41% male) who currently live with (or have lived with) a parent with a formal diagnosis of young onset dementia (with various subtypes). The participants ranged in age from 14 to 33 years old (\bar{x} = 21·18 years) with n = 6 eighteen years of age or younger (\bar{x} = 16·17 years). Participant narratives were analyzed using inductive qualitative thematic analysis.

Results: Detailed thematic analysis of the participant narratives uncovered five main themes (with related subthemes); making sense; lack of representation; threat to the family system; life has completely changed; systemic psycho-social support and education.

Conclusion: It is clear from the current data that the social and cultural perspective can significantly influence the narratives of children and younger adults of parental young onset dementia. Children are faced with more responsibility, shifting roles, changing relationships, and may be forced to postpone educational or employment plans. Furthermore, the social perception of dementia as can act as a barrier to children and young adults accessing and using health and social care providers.

FC40: Social health and subsequent cognitive capability: examining the potential mediating roles of depression symptoms and inflammatory biomarker

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Objective: Social health (SH) markers, including marital status, contact frequency, network size, and social support, have been linked with increased cognitive capability. However, the underlying mechanisms remain poorly understood. We aim to investigate whether depression symptoms and inflammatory biomarkers mediate associations between SH and cognitive outcomes.

Methods: We used data from waves 1-9 of the English Longitudinal Study of Ageing, involving 7,136 participants aged 50 or older at baseline. First, we examined associations between SH (wave 1) and depression and inflammatory biomarkers (C-reactive protein (CRP) and fibrinogen) (wave 2) using linear regression models. Second, we tested associations between a) SH and b) depression and inflammation with subsequent standardised verbal fluency and memory in wave 3 and change between waves 3-9, indexed using slopes derived from multilevel models. We adjusted for age, sex, socio-economic position, cardiovascular disease, basic and instrumental activities of daily living, health behaviours, and baseline depression symptoms and cognition. We will also conduct causal mediation analysis.