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# 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia☆

Pamela Roach [a,*], Neil Drummond [b,1], John Keady [c,2]

[a] Department of Family Medicine, University of Alberta, Edmonton, AB, Canada
[b] Department of Family Medicine, University of Alberta, 1702 College Plaza, Edmonton, AB, Canada T6G 2C8
[c] University of Manchester, Jean McFarlane Building (Room 6.312), University Place Oxford Road, Manchester M13 9PL, UK

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ABSTRACT

*Objectives:* Family interaction and intergenerational dynamics have been known to influence the efficacy of therapeutic interventions and as such, the understanding of such dynamics in the experience of transitions can assist in strengthening the support provided to families living with such diagnoses. As such, the aims and objectives of this work were to develop a deeper understanding of family transition in early-onset dementia and to construct a representative model of this experience.

*Method:* This qualitative study used an 'initial-and-follow-up' interview design with semi-structured in-depth interviews in participants' homes. A framework approach to qualitative data analysis was used in order to identify important points of transition in the family experience of early-onset dementia and how families frame and respond to their own health expectations.

*Results:* Nine families provided written informed consent to participate in the study. The nine participating families were made up of 20 participants, including nine spousal pairs and two young adult children. Each family participated in two research interviews in their individual homes. Four major themes emerged from the data: Diagnosis; Finances; Relationships; and Meaningful Activity.

*Conclusion:* Transitions experienced by families in early-onset dementia can be significantly impacted by the opportunity and availability of meaningful activity and/or a purposeful role. Not only does this activity benefit both the person with dementia and their family, but also supports much needed home and community living for people with dementia, as demonstrated by predicted future bed shortages in Canadian hospitals and long term care facilities.



## Introduction

The global focus on dementia is increasing, as is the demand on health, social, legal and financial services (World Health Organisation, 2012), making it imperative to understand the experiences of those living with the diagnosis of dementia and their support networks in order to match demand to need and thereby improve quality of life for all concerned. Historically, there has been a paucity of research focused on people under the age of 65 living with dementia, and of the studies that do exist, only a handful that positions the younger person with dementia as an integral member of their family system and not separate from it (Roach, Keady, Bee, & Hope, 2008; Roach & Drummond, 2014; Williams, Dearden, & Cameron, 2001; Robinson, Ekman, Meleis, Winblad, & Wahlund, 1997). These studies suggest that for younger people with dementia critical factors such as age of onset, employability, current family composition and presentation of dementia symptoms can intensify experiences and increase stress for younger people

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* Corresponding author at: 58 Citadel Gardens NW, Calgary, AB, Canada T3G 3X5. Tel.: +1 403 805 2254.
*E-mail addresses:* pamelaroach@hotmail.com, pamelamarieroach@gmail.com (P. Roach), ndrummon@ualberta.ca (N. Drummond), John.Keady@manchester.ac.uk (J. Keady).
[1] Tel.: +1 780 492 4127.
[2] Tel.: +44 161 306 7854.

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and their families, especially at significant points of transition in the dementia journey; for example, at the time of diagnosis (Brown & Roach, 2010; Roach, 2010; Svanberg, Stott, & Spector, 2010, 2011). This may partly be due to the additional dynamics with the presence of young, or young adult children still living in the family home and the prospect that younger people with dementia may also still be caring for their own ageing parents. There are accompanying financial implications for this cessation of work, also, as the person with dementia may be the primary wage earner in the household, be paying mortgages, supporting dependent children and/or ageing parents and the sudden end to a working life can be a traumatic event and distressing transition for many families (Beaumont, 2009; Harris & Keady, 2009; McGowin, 1993; Ohman, Nygard, & Borell, 2001; Wain, Uhlmann, Heidebrink, & Roberts, 2009).

This dynamic suggests that interacting with the family over a prolonged period of time may be a more reliable way of obtaining this much needed understanding into relational and family functioning. As such, identifying areas of appropriate and meaningful support to early-onset families will be crucial objectives in managing the future economic, psychological and physical costs of dementia to society, particularly as there is an increasing emphasis on supporting persons with dementia to remain at home (Alzheimer Society of Canada, 2010). The literature also suggests that periods of transition place greater stress on families living with dementia (Harris & Keady, 2009; Roach et al., 2008). The present study was grounded in early-onset dementia and positioned from within a family perspective. Family interaction and intergenerational dynamics have been known to influence the efficacy of therapeutic interventions (Fisher & Lieberman, 1994; Luscombe, Brodaty, & Freeth, 1998; Schumacher, Stewart, & Archbold, 1998; Nolan, Brown, Davies, Nolan, & Keady, 2006) and as such, the understanding of such dynamics in the experience of transitions, and the construction of family health expectations, are crucial to undertaking collaborative research with this population and developing high-quality, individualized and needs-based care. These transitions take place across the whole trajectory of the dementia experience, from the first changes and diagnosis to long-term care and end of life decisions. Previous work in transitions in dementia and other lifelong conditions support the need for greater academic and clinical attention in these areas, and particularly in early-onset dementia as it remains an under-researched and often overlooked area of clinical need and patient experience in all areas of the literature (Roach et al., 2008). Many transitions in early-onset dementia come 'out of time' and lead to a disrupted social clock (Harris & Keady, 2009; Tindall & Manthorpe, 1997), not only for the younger person with dementia but also for the family members that make up the constructed family unit. This can impact coping ability and quality of life due to a lack of biographical continuity (Strauss & Glaser, 1975; Bury, 1982; Williams Simon, 2000). An increased need for clinical support, be that practical or relational, may often be experienced at such transition points that disrupt one's social clock (Roach, 2010) and the impact of such transitions can be exacerbated by the family structure and the ages of individuals within the family structure. A model of transition and health expectation in early-onset dementia can broaden this understanding and assist in strengthening the support provided to families living with such diagnoses. As such, the aims and objectives of this work were to develop a deeper understanding of the family experience of transition in early-onset dementia and to develop a representative model of this experience.

## Design and methods

This qualitative study received approval by the Health Ethics Research Board at the University of Alberta in Edmonton, Canada (study ID number: Pro00034855). It used an 'initial-and-follow-up' interview design with semi-structured in-depth interviews in participants' homes. Participants with early-onset dementia and their families were recruited through local branches of the Alzheimer Society in Calgary and Edmonton. Throughout this work, 'family' refers to the entire family unit, which includes the person with dementia in the familial role they have historically occupied and does not exclude them from the family unit that participated. Also, in this instance, family could include any individuals living within the same house, whether blood-related or not. Local Alzheimer Society offices throughout the province of Alberta were contacted and the first author then met with the individual offices' early-onset dementia support groups in order to present information regarding the study and distribute participant information sheets in recruitment packages. In every instance, these packages were given to the younger person with dementia and their spouse to take home and review. Included in the packages were pre-paid, self-addressed envelopes that facilitated the return of the reply slip to the lead author and indicated their interest in participation. Some respondents completed their reply slips immediately after receiving the information package, but the first author ensured that all respondents were not contacted until a minimum of 24 h after receipt of the reply slips had passed. All participating families were given a minimum of 24 h to consider whether or not to participate.

Among the families that responded to say they were interested, and the specific individual family members within them who elected to take part, informed, written consent was obtained at the beginning of the first interview with individual families in their own homes. Ongoing verbal process consent (Dewing, 2007) was used at all points of contact during the study. All interviews were audio-recorded, with permission. The first interview was completed with all consenting family members as a group and was semi-structured based on a priori themes developed from the literature of transition and early-onset dementia and from discussions on such themes with the external project advisory group made up of clinical and methodological experts. These a priori themes consisted of questions inviting the family to discuss their experiences around noticing changes in the person with dementia: the diagnosis, challenges, changes in their life as a family and how they plan to face future challenges as a family. These open-ended questions were general in nature and the only one that directly addressed a theme that emerged from the results was the question around the diagnosis. In every instance, however, respondents had already addressed the diagnostic process as part of the background to their family. The interviewer has prompts ready around themes from the literature (finances, relationships, driving, transitions in living situations) but provided room for the participants to direct the conversation