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## Early Onset Dementia: A Narrative Review of the Literature

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### ABSTRACT

*Over the past forty years, significant research has been conducted on the epidemiology of late onset dementia. Less is known however, about the prevalence, incidence and burden of illness of early onset dementia (occurring prior to 65 years of age). The purpose of this narrative review is to examine existing literature regarding the experiences and implications of living with early onset dementia for patients, caregivers, and family members. The following questions were addressed: (1) What is the impact of early onset dementia on patients, families and carers? and (2) What are the needs of patients with early onset dementia and their family and carers? Key findings from this review are presented.*

**Key Words :** Onset dementia, Caregivers, Family members, Needs of patients.

Dementia is characterized by the development of deficits in multiple domains of cognition which may be due to a specific etiology such as Alzheimer's Disease (AD), Vascular Dementia (VaD), or front temporal dementia; from the effects of a general medical condition; or from the persisting effects of a toxic or intoxicating substance (Harvey, *et al.*, 1998a). Diagnosis is based on the application of validated clinical criteria such as the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV - TR) (American

Psychiatric Association, 2000), the World Health Organization 10th International Classification of Diseases (ICD-10) (World Health Organization, 1993), or the National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association (NINCDS/ADRDA) research diagnostic criteria for AD (McKhann *et al.*, 1984).

### Late Onset Dementia

The epidemiology of dementia in the elderly (over 65 years of age), termed late onset dementia (LOD) has been well-studied for over 40 years, with prevalence numbers of AD or VaD clearly showing an age-related increase. Three studies conducted in the late 1980's and early 1990's confirmed that the prevalence of dementia after the age of 65 years doubles with every 5 year increase in age (Kokmen, *et al.*, 1987; Jorm, *et al.*, 1987; Rocca *et al.*, 1991). In the World Alzheimer's Report 51.2 million people in south Asia were over the age of 60 years and 4.5 million people were diagnosed with dementia (Alzheimer's Disease International, 2009). Given that dementia prevalence increases with age, the number of people with dementia in south Asia is expected to increase to 9.31 million people by 2030 (a 108% increase) and to 18.12 million people by 2050 (a 304% increase). These LOD figures have driven service planning and research priorities for the elderly with dementia, with the burden of illness in terms of care provision and cost well-established.

### Early Onset Dementia

Less well known are the prevalence, incidence, and burden of illness of early onset dementia (EOD), described as dementia occurring in the under 65 years of age group. The most common dementia diagnosis among young adults is Alzheimer's disease, followed by VaD (Sampson, *et al.*, 2004). Diverse behavioural, cognitive, neurological and psychiatric symptoms characterize EOD; these include memory loss (particularly short-term memory loss), depression and anxiety, delusions and hallucination, and difficulties with word-finding and concentration (Harvey *et al.*, 1998b).

The prevalence of early-onset AD in the UK has been found to be 35 out of every 1,00,000 individuals age 45 to 64 (Harvey, *et al.*, 2003). Additionally, this prevalence was reported to approximately double

with each 5 year increase in age after the age of 35 (Ibid.). This extrapolates to approximately 18,319 (15,296 – 21,758) people under the age of 65 with dementia in the UK. According to the publication *Rising Tide – The Impact of Dementia on Canadian Society*, it is estimated that there are over 70,000 people under the age of 65 in Canada with a dementia; 50,000 of these people are estimated to be under the age of 60 (Smetanin *et al.*, 2010). In an epidemiological study conducted in an urban centre in India over a 3 year period (1998 – 2001), the projected crude prevalence rate of dementia was 0.43 per cent for persons over 40 years of age (Vas *et al.*, 2001). This is a somewhat lower prevalence than in developed countries but is consistent with other India-based studies of dementia.

## The Review

### Aim of the Review

The purpose of this narrative literature review was to examine existing literature and the current state of knowledge regarding the experiences and implications of living with EOD for patients, caregivers, and family members. The following questions were addressed:

1. What is the impact of early onset dementia on patients, families and carers?
2. What are the needs of patients with EOD and their family and carers?

### Design

The review is situated within our theoretical assumption that the impact of early onset dementia influences patient and family outcomes. We used a narrative overview design (Baumeister & Leary, 1997; Green, *et al.*, 2001; Oxman, *et al.*, 2002) to guide this comprehensive synthesis of the literature related to the experience of living with EOD. Preliminary criteria for inclusion in this review were papers: (a) in which the phenomena of early onset dementia was described, (b) showed relevance to the concept of living with dementia and/or included a focus on the experiences or implications living with EOD for carers and families, (c) pertained to adult populations (e.g. = 18 years to = 65 years of age) and (d) were written in English and published between January 1998 and November 2012.

Studies were excluded if they dealt specifically with causes, diagnostic or other medical aspects of EOD; evaluation of support strategies and/or service provision; or were primarily focused on prevalence and incidence of dementia. As well, studies were excluded if participants were > 65 years of age, were not written in English or were from the gray literature.

### Search Strategy

First, we searched the on-line databases Allied and Complementary Medicine (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, and PsychInfo (Figure 1). Dissertations or conference proceedings were not included in the initial search. Key terms for this phase of the search included early onset dementia OR young onset dementia OR young people with dementia OR Alzheimer's\* dementia combined with the terms "ethnicity", "care\*", "outcomes", "quality of life", "family", "experience" and "impact".

**Figure 1**

*Search Strategy for Preliminary Search*

<p>The following bibliographic databases were searched for the years 1998 – November 2012: ASP, CINAHL, Medline, and PsychInfo.</p> <p>MeSH ® Terms expl caregivers exp family exp quality of life</p> <p>AND Early Onset Dementia</p> <p>AND Dementia Alzheimer's Disease Frontal Lobe Dementia Vascular Dementia</p>
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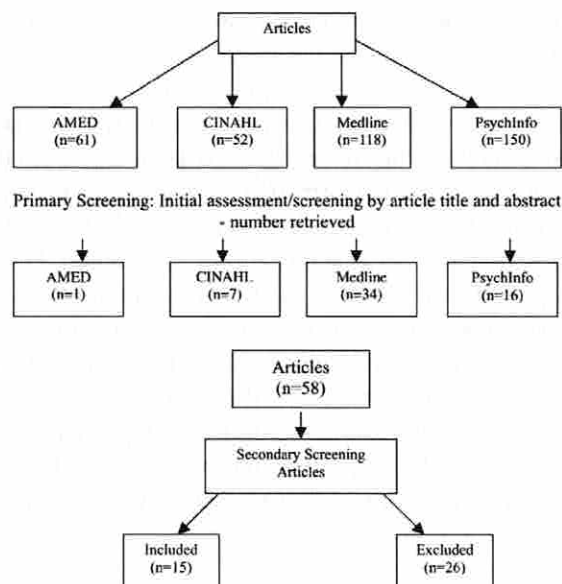
We reviewed papers published in English language journals that examined the experiences of patients with early onset dementia, including Alzheimer's disease, vascular dementia, and frontal lobe dementia; and those with a focus on caregivers and family outcomes.

This initial search strategy yielded 30 titles and abstracts. The first author assessed the titles and available abstracts electronically using these preliminary inclusion criteria. The non-applicable papers resulting from the broad search terms related primarily to year of publication (i.e. prior to 1998;  $n = 5$ ), and studies focused on prevalence and epidemiological issues related to dementia ( $n = 10$ ).

### Search Outcomes

Combining the search terms revealed a limited set of journal papers with a specific focus on quantitative and qualitative studies describing needs and impact of early onset dementia on patients, carers and families. Reference lists from original papers were scanned for additional relevant papers. The majority of papers included in this review were drawn from research conducted in North America and Europe. Using the preliminary inclusion criteria 15 articles were retained. The results of this process are illustrated in Figure 2. All papers were successfully retrieved.

**Figure 2**  
*Screening Process*



### Quality Appraisal

Inclusion in the final sample was guided by three criteria: (1) the report of original quantitative or qualitative research, discussion paper, or literature review; (2) a focus on patients with early onset dementia including Alzheimer's disease, vascular dementia, and frontal lobe dementia, and (3) a conceptualization of the impact of EOD that included a focus on quality of life, family and/or caregiver outcomes. Specifically, quality of life of the patient, family and/or caregiver, and family/carer outcomes including burden or strain must have been addressed. The final screening was also done by the first author, with consensus of the co-author on the final selection. Fifteen articles remained in the final data set. These papers and pertinent characteristics are described in Table 1

### Synthesis

The papers remaining in this systematic review of the literature reflect an increasing interest among researchers and clinicians about the experiences of patients and family living with early onset dementia. Not surprisingly however, there were no clinical trials found for this review; there were 6 systematic reviews (narrative), 1 retrospective review, 4 descriptive studies (cross-sectional survey and comparison studies), 3 qualitative reports, and 1 health report found. The results were therefore summarized in narrative format. Sample sizes of studies included in this review were generally small (i.e. < 40) and sampling methods were primarily convenience. Power analyses were not reported for the quantitative studies, thus it is difficult to determine the precision or generalizability of findings. The measures used in the quantitative studies to examine the outcomes of interest for either the person with EOD or the caregivers were also inconsistent. We therefore elected to critique each quantitative and qualitative article in the final selection for validity (Green *et al.*, 2001) and if rendered valid, synthesize the authors' interpretations of study findings (Oxman *et al.*, 2002). The mechanism used for coming to agreement regarding study validity and findings was consensus between authors.

**Table 1**  
*Characteristics of Included Studies*

<i>Retrieved</i>	<i>Authors</i>	<i>Title Year</i>	<i>Journal Citation</i>	<i>Population</i>	<i>Study Design</i>	<i>Outcomes</i>	<i>Primary Findings</i>
2012/11/07	Beattie A, Daker-White G, Gilliard J, & Means R.	'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services. (2004).	Health & Social Care in the Community, 12(4), 359-368.	14 interviews with younger people with dementia in the southwest of England	Qualitative study	<p>Comparative textual analysis of themes:</p> <ul style="list-style-type: none"> <li>● General experience of having dementia</li> <li>● Dementia diagnosis</li> <li>● Importance of age</li> <li>● Risk and danger issues</li> </ul>	<ul style="list-style-type: none"> <li>● Majority of participants articulate and insightful about their experiences and needs.</li> <li>● Challenge is to engage with and consult individuals with dementia directly about their experiences and what they want from dementia services</li> <li>■ Time to diagnosis</li> <li>■ Feeling invisible</li> <li>■ Age</li> <li>■ Risk and danger perceived differently</li> </ul>

*1. EOD-Patient*



## 1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/14	Harris PB, Keady J.	Selfhood in younger onset dementia: Testimonies	Aging and Mental Health (2009)	23 younger people with dementia 15 carers	Qualitative – Grounded Theory	<ul style="list-style-type: none"> <li>● Exploration of the meaning and construction of selfhood and identity; psychosocial impact of younger onset dementia</li> </ul>	<ul style="list-style-type: none"> <li>● Loss of identity as a 'worker'</li> <li>● Identity of abandoned individual – social isolation</li> <li>● Sexual identity</li> <li>● Family identity</li> <li>● Self-identity – engaged in living</li> </ul>
2012/11/15	Harris, PB	The Perspective of Younger People with Dementia: Still an Overlooked Population	Social Work in Mental Health (2003), 2(4):	23 younger people with dementia	Qualitative – interviews	<ul style="list-style-type: none"> <li>● Subjective experiences of younger people with dementia</li> </ul>	<ul style="list-style-type: none"> <li>● Trouble obtaining a diagnosis</li> <li>● Marginalization</li> <li>● Changing relationships within entire family structure</li> <li>● Work/force/retirement issues</li> <li>● Off time dependency</li> <li>● Lack of meaningful occupation</li> <li>● Issues of self-esteem</li> <li>● Awareness of changes in self</li> </ul>

<i>1. EOD-Patient</i>							
<i>Retrieved</i>	<i>Authors</i>	<i>Title Year</i>	<i>Journal Citation</i>	<i>Population</i>	<i>Study Design</i>	<i>Outcomes</i>	<i>Primary Findings</i>
2012/11/13	Roach P, Keady J, Bee P, & Hope K.	Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. (2008).	Reviews in Clinical Gerontology, 18(2), 165-172.	Younger people with dementia	Narrative literature review	Subjective experiences of younger people with dementia	<ul style="list-style-type: none"> <li>● Primary research involving those with young-onset dementia and their families is lacking.</li> <li>● Services and research need to consider the needs and experiences of the person with EOD's networks (family, friends and colleagues) when working with younger age groups</li> <li>● Include the younger person with EOD in the research</li> <li>● Themes for improvement include early diagnosis, information provision and support for families.</li> <li>● Consider age, employability, current family composition and presentation of dementia symptoms in assessing the experiences of those with EOD.</li> </ul>

## 1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Tolhurst E, Bhattacharyy a S, & Kingston P.	Young Onset Dementia: The impact of emergent age-based factors upon personhood. (2012).	Dementia 0(0) 1-14. 2012.	Young onset dementia	Literature review	<p>The concepts of 'personhood' and young onset dementia-approaches to outline and bring together.</p>	<ul style="list-style-type: none"> <li>• Competing views of dementia as medical/biological condition and the impact of psychosocial factors (biomedical perspective vs. experiential perspective).</li> <li>• Discussed awareness as related to disease being a threat to sense of self, and patients attempt to control responses and others views of themselves.</li> <li>• Discusses use of person-centred care approach, and social constructionist theory.</li> <li>• Lack of literature which examines personhood and young onset dementia, as opposed to self and identity.</li> <li>• Examined effect of social definitions of dementia, and association with aging. These contribute to a separated view within health care services and management.</li> <li>• Lack of age appropriate services and associated dissatisfaction with care.</li> </ul>

<i>Retrieved</i>	<i>Authors</i>	<i>Title Year</i>	<i>Journal Citation</i>	<i>Population</i>	<i>Study Design</i>	<i>Outcomes</i>	<i>Primary Findings</i>
<i>1. EOD-Patient</i>							
							<ul style="list-style-type: none"> <li>• Discussed unique age-related impact in finances and families.</li> <li>• Unique caregiving considerations for those patients who are younger and physically functioning.</li> <li>• Calls for integration of these concepts into future and further research to adequately support the early onset population.</li> </ul>
<i>2. EOD- Carer and Family</i>							
2012/11/07	Freyne A, Kidd N, & Coen R, & Lawlor B.A.	Burden in carers of dementia patients: higher levels in carers of younger sufferers. (1999).	International Journal of Geriatric Psychiatry, 14(9), 784-788.	22 EOD patients, and sample of community dwelling LOD patients.	Comparative study	Comparison of clinical characteristics of LOD and EOD patients as well as caregiver burden.	<ul style="list-style-type: none"> <li>• Increased burden found in carers of EOD group.</li> <li>• Those caregivers of EOD patients had been caring for up to 2 years longer than those with LOD patients.</li> <li>• EOD patient caregivers perceived less social support available and increased sense of isolation.</li> <li>• Did not extensively look at the effect on children; however majority agreed that they suffered psychological or emotional problems which lead to conflicts with parents and in school.</li> </ul>

## I. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
March 24, 2011.	Harvey R, Rossor M, Skelton-Robinson M & Garralda E.	Young Onset Dementia: Epidemiology, clinical symptoms, family burden, support, and outcome. (1998).	NHS RFG045. <a href="http://dementia.ion.ucl.ac.uk">http://dementia.ion.ucl.ac.uk</a>		Report		
2012/11/07	Luscombe G, Brodaty H, & Freeth S.	Younger people with dementia: Diagnostic issues, effects on carers and use of services. (1998).	International Journal of Geriatric Psychiatry, 13, 323-330.	102 EOD carers.	33 item questionnaire/survey	EOD patient caregivers including diagnosis, services, financial considerations and overall satisfaction.	<ul style="list-style-type: none"> <li>Discussed difficulties in obtaining diagnosis, health information and prognosis.</li> <li>75% of carers were female, and typically were spouses, relatives or had some relationship with the patient.</li> <li>Average number of professional consultations for AD was 2.8, and included GPs (89%), neurologists (64%), &amp; psychogeriatricians (9%).</li> <li>Average time to diagnosis for AD was 3.6 years.</li> <li>Emotional or psychological problems were stated by 57 per cent of caregivers (predominantly by females), and family conflict as a result of caregiving role was identified in 41 per cent.</li> </ul>

<i>1. EOD-Patient</i>							
<i>Retrieved</i>	<i>Authors</i>	<i>Title Year</i>	<i>Journal Citation</i>	<i>Population</i>	<i>Study Design</i>	<i>Outcomes</i>	<i>Primary Findings</i>
2012/11/07	Svanberg E, Spector A, & Stott, J.	The Impact of young onset dementia on the family: A literature review. (2011).	International Psychogeriatrics (2011), 23:3, 356-271.	Patients with early onset dementia	Narrative literature review - 26 studies	<ul style="list-style-type: none"> <li>Impact on individual family carer and children</li> </ul>	<ul style="list-style-type: none"> <li>Young onset dementia has wide ranging impacts on individuals and their family due to symptoms, lifestyle and role changes.</li> <li>Studies of younger people with dementia highlight their subjective experiences but emphasize the lack of research conducted.</li> <li>Future research should address frequency of diagnostic difficulties and stigma in dementia</li> <li>Amount of research on carers of younger patients with dementia indicative of the greater negative outcomes related to caring experience.</li> </ul>
2012/11/10	Van Kliet D, de Bugt ME, Bakker C, Koopman RT, & Verhay FR	Impact of early onset dementia on caregivers: a review (2010).	Geriatric Psychiatry, 25, 1091-1100	17 articles	Narrative literature review	<ul style="list-style-type: none"> <li>Impact of EOD on informal caregivers and children of EOD patients</li> </ul>	<ul style="list-style-type: none"> <li>Difference in impact between EOD and LOD caregivers unclear</li> <li>EOD caregivers do experience high levels of psychological suffering and specific problems related to phase of life.</li> </ul>

## 1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/10	Werner P, Stein-Shvachman I, & Korczyn AD.	Early onset dementia: clinical and social aspects	International Psychogeriatrics (2009), 21:4, 631-636.		Narrative literature review	<ul style="list-style-type: none"> <li>● Clinical aspects of EOD: prevalence, causes, symptoms, diagnosis, and management</li> <li>● Social aspects of EOD: Cost of care, challenges, services available</li> </ul>	<ul style="list-style-type: none"> <li>● Research needed that explores:               <ul style="list-style-type: none"> <li>■ Effective diagnosis and management</li> <li>■ Allocation of funds</li> <li>■ Development of services suitable to the unique needs of young people with dementia</li> </ul> </li> </ul>

3. EOD and Needs and Services.

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/07	Barber, R.	A Survey Of Services For Younger People With Dementia. (1997).	International Journal of Geriatric Psychiatry, 12(9), 951-954.	254 hospital and community trusts.	Postal survey	Assessment of services available for EOD people in England, and potential of specialization.	<ul style="list-style-type: none"> <li>• The most vulnerable carer was seen to be those who are younger females with competing caregiving demands (male patients, children and parents).</li> <li>• Of those carers working, only 42 per cent employment continued the same, and 5 per cent had reduced hours to part-time. This also was seen to be the cause of most financial problems for the majority of carers.</li> <li>• 3.4 years was the average time seen till diagnosis.</li> <li>• 101/254 agreed with the necessity of specialization, with some of those preparing to do so. However, more viewed specialization as unnecessary (314/254).</li> <li>• 52 of the trusts conducted an assessment of practice and the majority concluded there was a need development of a dedicated service.</li> <li>• Found that availability of community services, attitude, and competency of staff among the largest problems.</li> </ul>



## 1. EOD-Patient

Retrieved	Authors	Title Year	Journal Citation	Population	Study Design	Outcomes	Primary Findings
2012/11/13	Beattie AM, Dake-White G, Gilliard J, & Means R.	Younger people in dementia care: A review of service needs, service provision and models of good practice.	Aging and Mental Health, 6:3, 205-212	74 papers	Literature review	Review of the literature on younger people with dementia, in dementia care	<ul style="list-style-type: none"> <li>● Need for flexible, age-appropriate, and dedicated services was the central theme</li> <li>● A person-centered approach recommended with a tailor-made model of care</li> <li>● Recommendations for inter-agency collaboration, early assessment and an awareness of individual needs were based largely on the practical experience of professionals and paid carers, not through scientific evidence.</li> </ul>
2012/11/07	Harvey R, Roques P, Fox N, & Rossor M.	CANDID - Counselling and Diagnosis in Dementia: a national telemedicine service supporting the care of younger patients with dementia. (1998).	International Journal Of Geriatric Psychiatry, 13(6), 381-388.	Calls received at a telephone helpline over a 2 year period (n = 1121).	Retrospective review	Details of calls received to a London UK telephone helpline	<ul style="list-style-type: none"> <li>● service rapidly accepted and used by families of patients and general public: 547 registered calls related to 241 individual patient issues</li> <li>● healthcare professionals made less use of service; calls pertained to general information</li> <li>● caller and patient they were caring for; reason for call, advice given</li> </ul>

<i>EOD-Patient</i>							
<i>Retrieved</i>	<i>Authors</i>	<i>Title Year</i>	<i>Journal Citation</i>	<i>Population</i>	<i>Study Design</i>	<i>Outcomes</i>	<i>Primary Findings</i>
2012/11/13	Williams T, Dearden M, & Cameron IA.	From Pillar to Post - a study of younger people with dementia	Psychiatric Bulletin (2001). 25, 384-387	132 patients with EOD	Health needs assessment - postal survey	<ul style="list-style-type: none"> <li>• Gateways to specialist investigation and care</li> <li>• Access to information &amp; services</li> <li>• Coordinated services and daycare</li> </ul>	<ul style="list-style-type: none"> <li>• Needs of younger people with dementia very different from older people</li> <li>• Prevalence rate and experiences of carers and patients justifies the existence and further development of EOD services</li> <li>• Single gate-way to coordinated service provision and ensure continuity of care</li> <li>• Provide duffers and carers with information, advice, and expertise.</li> </ul>

Overview of selected papers

## Results

### *Patients*

Individuals with EOD face significant psychological and emotional challenges, including a loss of independence as their ability to perform everyday activities diminishes (Woods, 1999; Williams, *et al.*, 2001; Harris, 2004; Werner, *et al.*, 2009); these challenges are compounded by changing relationships with partners and other family members. Werner *et al.* (2009) describe three psychological and emotional implications of EOD for patients. There is a loss of independence resulting from difficulties accomplishing normal everyday tasks; this loss of independence leads to changes in the relationships within the family. For example, the parent with EOD becomes the 'cared for' and children often assume part of the caregiving role – a role reversal that contributes to feelings of diminished self-worth for the parent. Third, EOD often results in loss of employment for the patient with subsequent impacts on the family, the patient's self-esteem and sense of self-worth (Ibid.). Loss of employment benefits can also add to the strain felt by the patient and family and can lead to deterioration in marital quality as relationships change (Williams *et al.*, 2001; Beattie, *et al.*, 2004). These findings are supported by other researchers examining the impact of EOD on patients and families (Beattie, *et al.*, 2002; Svanberg, *et al.*, 2011). As younger patients are often more physically fit than those with LOD, the inability to engage in valued activities leads to a loss of independence and social isolation which in turn contributes to low self-esteem and depression for patients with EOD. Beattie *et al.* (2002) reported that as the ability to perform everyday tasks becomes impaired, further deterioration in self-esteem and mood is likely. Included in this are difficulties in maintaining an intimate relationship with a partner due to cognitive impairment, which further increases feelings of diminished self-esteem and self-worth.

Beattie *et al.* (2002) and nearly 10 years later, Svanberg *et al.* (2011), reported that the individual experience of the patient with EOD is still lacking in research and the need to speak with younger people about living with EOD is imperative. In a report by Alzheimer's Australia (2007), this sector of the dementia population was

characterized as a minority group with issues specific to this group – a need for a holistic approach to care and services, and recognition of the emotional impact of the diagnosis of EOD. This approach is supported by Tolhurst, *et al.*, (2012) in arguing that psychosocial (i.e. psychological, situational and social) as well as biological and medical factors impact on the nature of EOD and influence how the younger person will experience the condition.

Roach, *et al.*, (2008) also reiterated the need to further examine the phenomenon of EOD and in a review of the literature identified 3 key themes as resonating across the studies. These themes echo the findings of earlier researchers, with recognition of changes and associated stigma, isolation, guilt, helplessness and role and relationship changes surfacing as significant factors for those living with EOD. Harris and Keady (2009) also examined the psychosocial impact of EOD for patients, reinforcing the loss of identity and sense of isolation experienced by those living as a younger person with dementia.

### *Carers & Family*

Informal carers of younger adults with EOD are typically a family member and often a spousal partner (Harvey *et al.*, 1998; Luscombe, *et al.*, 1998; Svanberg *et al.*, 2011). The task of providing care can be associated with physical and emotional burdens, with levels of burden often rated higher for carers providing support for patients with EOD as compared to those providing care for those with LOD (Beattie *et al.*, 2004). Freyne, *et al.*, (1999) also conducted a comparative study examining the levels of carer burden between community-dwelling people with EOD and LOD and their carers. They discovered that while carer burden is significant for both groups, the perception of burden for those caring for the EOD group was significantly higher than the LOD group. In a more recent review of the literature, Van Vliet, *et al.*, (2010) explored the impact of EOD on caregivers and reported that while EOD caregivers reported high levels of burden, stress, and depression, the results were inconclusive when compared with LOD caregivers. These researchers reported caregivers of EOD patients experience psychosocial problems which seem to be age or stage of life related. These include relational issues,

family conflict, employment problems, financial difficulties, and problems obtaining a diagnosis. These difficulties are compounded by the lack of formal and informal support available to carers and family when assuming a caregiving role that may extend over a long period of time (Arai, *et al.*, 2007).

Anxiety and depression have been found to be common consequences of assuming the caregiver role for patients with EOD. Harvey *et al.* (1998) reported that anxiety was described by over 60 per cent of caregivers (higher in female carers) and for spouses as caregivers, depression was very prevalent; one cause might be related to feeling inadequately prepared for the caregiving role. (For caregivers, EOD often leads to financial insecurity, high stigmatization, and negative impacts on marital quality (Svanberg *et al.*, 2011). These reactions may be compounded by the lack of appropriate community services that 1) fit the needs of younger patients with EOD and 2) fit the needs of a carer who must work to support the family.

Luscombe *et al.* (1998) conducted a cross-sectional survey of 102 carers of people with EOD to assess psychological, physical, occupational and financial impacts of illness on carers and children. 81 per cent of carers reported frustration and other psychological effects, more so in female than male carers ( $p < 0.001$ ). The younger the carer, the more psychological and physical effects were experienced. 92 per cent of carers felt their children had experienced problems related to the dementia. These issues remain unresolved in reviews conducted on the impact of EOD on caregivers and family nearly 10 years later (Arai *et al.*, 2007; Van Vliet D *et al.*, 2010).

### Needs of Early Onset Dementia Patients, Carers and Family

#### *Patients*

Williams *et al.* (2001) reported that many patients (and carers) in Leeds, UK felt the diagnostic phase of their disease was stressful, as they were referred from their general practitioner to various specialists over the course of reaching a definitive diagnosis. Many patients were referred to at least two different consultants, including neurologists and psychiatrists. This process of seeking a diagnosis is not uncommon in other parts of the world (Vas *et al.*, 2001; Alzheimer's Australia,

2007); and patients continue to feel the path is too complex, uncoordinated and too lengthy (Roach *et al.*, 2008; Svanberg *et al.*, 2011). Luscombe *et al.* (1998) also reported that patients and carers encounter problems with the diagnostic process, often related to lack of knowledge on the part of the service provider.

Roach *et al.* (2008) reported that patients with EOD and their carers desired information about the meaning and nature of the diagnosis and contact with services. While health care/service providers may feel that patients and carers are not ready to receive the definitive EOD diagnosis, patients and carers feel that not having this information limits their ability to obtain timely follow-up for major areas of concern (Ibid.). Few were actually referred to an early onset dementia team and many felt they had not received enough information, practical help, support or counseling (Williams *et al.*, 2001).

Apparent in many of the articles reviewed was the need for age-appropriate services that take into account the social and psychological differences between younger people with dementia and older people (Arai *et al.*, 2007; Luscombe *et al.*, 2008; Freyne *et al.*, 2009; Van Vliet *et al.*, 2010; Svanberg, *et al.*, 2011). Beattie *et al.* (2004) reported that patients with EOD felt mixing with other younger people with memory difficulties were a positive experience, whereas care and services in older person's settings were viewed negatively. Age-appropriate settings and services gave patients with EOD a place to meet new people, socialize and engage in meaningful activities such as sporting events. Unfortunately for many patients with EOD, this type of service is not available in their community setting. Assessment of services within community settings has been recommended by several researchers, with a specific focus on applicability and support of younger patients with dementia (Harvey, *et al.*, 1998; Barber, 2007).

### *Carers & Family*

Caregivers and family members living with a person with EOD are often relatively young, with full and active lives outside of the home setting. Becoming a caregiver in the context of EOD thus entails a long duration of caregiving with little formal or informal support available.

Key issues identified in this literature review related to carers and families included:

1. The ability to have a break from caring – which necessitates access to appropriate respite care when needed. Respite care might include such things as day centres, hospital or nursing home care, or in-home services (Luscombe *et al.*, 2008), with options for hourly, daily or overnight or out-of-hours services/care available.
2. Access to age-appropriate day care services. Many carers are employed outside the home and leaving the patient with EOD at home alone is often the only option open to them in order to provide financial security for the family. As the disease progresses, safety of the person with EOD in the home becomes an issue and leaving the patient home alone is no longer an option. For many, this results in the carer taking time away from work, calling on extended family and friends for support, or asking children to provide supervision. Thus it is apparent that day care services need to be flexible to fit the needs of the family carer as well as the patient. Carer's advocate that this service should include flexible opening hours to accommodate the carer's working day, and the provision of transport (Ibid.).
3. Finding appropriate homes for permanent care – many carers in this review identified difficulties when searching for an alternate care facility when it becomes apparent the person with EOD can no longer be cared for at home. The carers felt they were not provided with information needed to streamline their search for a facility that offered age-appropriate care (Freyne *et al.*, 1999; Murray, *et al.*, 1999; Van Vliet *et al.*, 2010).

### Discussion

It is important to remember that most family and friends involved in providing informal care take pride in their role, and perceive many positives. In Canada, 80 per cent of a nationally representative sample of carers of people with dementia were able to identify positive aspects when asked to do so (Harris & Keady, 2009). These included companionship (23%), fulfillment (13%), enjoyment (13%), providing quality of life (6%) and meaningfulness (6%).

Nevertheless, carers of people with dementia also experience high levels of strain, psychological morbidity and, possibly, impaired physical health.

The negative consequences of caregiving have been widely studied. In LOD, high levels of burden (Vas *et al.*, 2001), stress, distress (Werner *et al.*, 2009), and depression (Williams *et al.*, 20012) have been identified in caregivers. While less research has been conducted with caregivers of individuals with EOD, this population has also been found to have high burden, stress (Baumeister & Leary, 1997; Williams, *et al.*, 2001; Werner *et al.*, 2009), and distress (Beattie *et al.*, 2002; Beattie *et al.*, 2004). Some of this may well relate to the unexpectedness of the diagnosis in a young person and the difficulty experienced in the process of reaching a diagnosis. In a qualitative study of caregivers of individuals with EOD, the most central theme in discussions was the burden of caring experienced (Svanberg *et al.*, 2011). Younger caregiver age is significantly related to negative psychological and physical impacts (Smetanin *et al.*, 2010) possibly related to the length of time one provides care to a person with dementia. This is likely to be longer in the EOD group given the younger age of both patient and carer, thus the burden of care may be perceived as being greater.

One element of living with EOD that did not appear in the literature in this review and may impact the burden of living with EOD relates to grief. Luscombe *et al.* (1998) did report that 73 per cent of the population included in a cross-sectional study of 102 carers of younger people with dementia, reported experiencing grief. However, there was no further discussion about the implications of grief in the context of EOD. It is likely that grieving the loss of self, partner, parent, or family member contributes to the psychological difficulties experienced by all people living with EOD.

Younger people with dementia are more likely to be employed outside the home at the time of diagnosis, have dependent children or family, have significant financial burdens, and may be more physically fit or active than those over age 65 with dementia. Caregivers of individuals with EOD are also likely to be working at the time of dementia diagnosis, and one study found that 59 per cent of these carers had to reduce their hours or stop working due to their



caregiving role (Luscombe *et al.*, 1998). Thus, to develop services for younger people with dementia and their caregivers, it is important to define the needs of service users according to age, activity and social relations. However, in most cities and countries, services for patients with dementia are based on the identified needs of the over 65 years of age group and their caregivers. It is important to actually talk to patients with EOD for perspective about these needs – they are still able to communicate their needs and wants and often feel they are being overlooked in the process.

The Alzheimer's Association (2011) in the United States (US) has emphasized that the occurrence of EOD is frequently unexpected, and therefore may result in different concerns. Due to more drastic changes in roles and activities of the individual with EOD, the impact of the diagnosis and the challenges faced by the patient and caregiver may be greater (Tolhurst *et al.*, 2012). Researchers from the UK, US, and Canada have found that EOD patients and caregivers experience difficulties in finding and accessing services appropriate to their needs (Murray *et al.*, 1999; Alzheimer's Australia, 2007; Smetanin *et al.*, 2010). In a survey of dementia services in England, only 12 out of 254 providers had specialized services for EOD (Arai *et al.*, 2007). Individuals with EOD and their caregivers have commonly expressed a desire to connect with others experiencing EOD and do not feel they "fit" into existing services targeted for older individuals (Luscombe *et al.*, 1998; Freyne *et al.*, 1999).

### Conclusion

While researchers have been exploring the needs and experiences of EOD from the perspective of patients, carers and families, changes in service provision for this population have been slow to follow. As identified by Werner *et al.* (2009), research is needed that will provide evidence to support patients and carers with services structured to meet the needs of those with EOD. This means conducting prospective studies to appreciate changes over time that will affect service needs, and clinical trials to assess strategies for meeting the needs of this special population.

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