

# The Psychosocial Impact of Young Onset Dementia on Spouses

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Dementia in young adults is not very well studied in terms of clinical effects on the patient, and not much is known about the effects on spouses and caregivers. This study assessed the psychological impact of the diagnosis of young onset dementia on spouses. A questionnaire that used the Zarit Burden Interview and the Beck Depression Index was sent to 120 spouses of a cohort of patients with established diagnoses of young onset dementia (age of onset before 65 years), including frontotemporal lobar degeneration, Alzheimer's disease, and primary progressive

aphasia. A total of 100 usable responses were received. The mean age of respondents was 62.3 years (54% women, 46% men). A cross-sectional analysis showed that the diagnosis of young onset dementia has a significant impact on spouses, characterized by concerns of dependency, fear, and increased depression, especially in the spouses of patients with frontotemporal lobar degeneration.

**Keywords:** young onset dementia; depression; psychological impact

Dementia describes a group of illnesses that cause a progressive decline in mental abilities. Memory, intellect, rationality, social skills, and emotional reactions may all be affected.<sup>1</sup> Memory impairment is usually the first indication of dementia. It is mild at the onset of dementia and progressively becomes worse, so that patients may initially have difficulty remembering phone numbers and conversations, while later may retain only the earliest learned information, such as their name. Recent memory is lost before long-term memory in most cases of dementia, meaning that most patients experience high levels of distress about their obvious deterioration. Patient's identities begin to fade as they recall less of their past lives as the illness progresses. This can lead to emotional reactions, ranging from depression to severe anxiety.<sup>2</sup>

Patients with dementia frequently exhibit personality changes, which are especially disturbing for

their families.<sup>3,4</sup> They may become introverted, have paranoid delusions, or become irritable and hostile. In addition, an estimated 20% to 30% of patients with dementia experience hallucinations, and 40% to 50% experience symptoms of anxiety and depression, all contributing to caregiver stress.<sup>1</sup> In the end stages of dementia, patients are a shadow of their former selves—profoundly disorientated, incoherent, amnesic, and incontinent.

Young onset dementia is defined as dementia occurring in persons aged younger than 65 years. It is usually of relatively rapid onset and progression.<sup>5</sup> In younger adults with dementia, frontotemporal lobar degeneration (FTLD) is more common than Alzheimer's disease compared with the elderly.<sup>6,7</sup>

Spouses of patients with dementia have been identified as being at increased risk of psychological and physical morbidity, as well as social isolation and financial strain.<sup>8,9</sup> No direct correlation between dementia severity and caregiver burden has been demonstrated because spouses vary markedly in their response to the 3 manifestations of the disease: cognitive, functional, and behavioral decline.<sup>10</sup> Functional decline, however, has been linked to restriction in spouse activity,<sup>11</sup> and behavioral disturbances have been associated with spouse distress.<sup>12</sup>

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Spouses struggle with feelings of guilt, grief, anger, and exhaustion as they watch their husband or wife deteriorate.<sup>13</sup> Spouses of patients with young onset dementia have been identified as experiencing significantly greater caregiver burden than spouses of patients with late onset dementia, although no significant difference was found between the two groups studied in terms of patient behavioral disturbance or severity of dementia.<sup>10</sup>

Studies about caregiver burden in late onset dementia populations have identified the higher frequency of disturbing behavior of patients, cohabitation with the patient, and reduced social support as being related to higher levels of caregiver burden and depressive symptoms.<sup>3,4,8</sup> In particular, these studies have identified that younger age of the spouse is associated with depressive symptoms.<sup>9</sup>

Premorbid unsatisfactory relationships have been associated with greater spouse distress.<sup>14</sup> This may accompany the breakdown of communication between the couple, the decrease in intimacy and companionship, the loss of a confidante, and the increase in economic and household responsibilities.

It has been suggested that caring for a close relative, especially a spouse, who has become demented, is one of the most demanding situations that can be encountered.<sup>4</sup>

This study looked at the psychosocial burden of spouses of patients with young onset dementia in an attempt to provide information about their psychosocial well-being in Western Australia. It also addressed areas of current need by the Neurosciences Unit, Department of Health, Graylands, Selby Lemnos Health Care Complex, Perth, Western Australia. A clinic for young onset dementia was established in 1996 within the agency, and it is the main support service for patients with young onset dementia and their spouses in Western Australia.

## Methods

The study design was a cross-sectional cohort analysis. Participants in the study were the spouses of patients with young onset dementia registered with the Neuroscience Assessment and Care Clinic, with age of onset of dementia before 65 years. Ethics approval was obtained from the Institutional Ethics Committee, and the spouses signed informed consent to participate in the study.

Diagnoses in patients were established using the following criteria:

- probable Alzheimer's disease (National Institute of Neurological and Communication Disorders and Stroke-Alzheimer's Disease and Related Disorders Association criteria)<sup>15</sup>,
- frontotemporal lobar degeneration using consensus criteria<sup>16</sup>, and
- primary progressive aphasia<sup>17</sup>

Diagnoses included a patient with cerebral autosomal dominant arteriopathy and subcortical infarcts (CADASIL) who had a *Notch 3* mutation, and a patient with olivopontocerebellar degeneration who had progressive atrophy of the pons and cerebellum on magnetic resonance imaging (MRI). The patients with the clinical suspicion of Creutzfeldt-Jakob disease and corticobasal ganglionic degeneration (CBGD) were pathologically proven at postmortem. The patient with posterior cortical atrophy syndrome with a progressive visuospatial disorder with marked atrophy on MRI scanning of the parietal and occipital cortices was shown to have pathologically confirmed Alzheimer's disease (Consortium to Establish A Registry for Alzheimer's Disease criteria).

The spouses were sent questionnaires and a reply-paid envelope in June 2004, with responses collated during December 2005. The questionnaire had 2 sections. Section 1 consisted of the Zarit Burden Interview (ZBI),<sup>18</sup> a 22-item self-rated scale that examines burden associated with functional/behavioral impairments and the home care situation. The items are worded subjectively, focusing on the affective response of the spouse. A 4-point scale (ranging from never to nearly always) was used. Section 2 consisted of the 21-item Beck Depression Index (BDI).<sup>19</sup> The questionnaire also included items on the patient and caregiver's sociodemographic characteristics.

As determined from previous reports of psychological distress in spouses being linked with behaviors that are demanding of or disturbing to spouses, the spouse being a woman, and with the severity of dementia, the hypotheses to be tested were that (1) wives who are caregivers would have a higher BDI than husbands who are caregivers, (2) spouses with a patient living at home would have a higher BDI than those whose spouse had died or was in institutional care, and (3) spouses of patients with frontotemporal dementia would have a higher BDI.

**Table 1.** Diagnoses of Patients:  
Young Onset Dementia

Diagnoses	N	Frequency (%)
FTLD	42	2
Alzheimer's disease	36	36
PPA	6	6
Miscellaneous <sup>a</sup>	16	16
Total	100	

Note: FTLD = frontotemporal lobar degeneration; PPA = primary progressive aphasia.

a. Diagnoses included cerebral autosomal dominant arteriopathy and subcortical infarcts, olivopontocerebellar degeneration, Creutzfeldt-Jakob disease, corticobasal ganglionic degeneration, and posterior cortical atrophy syndrome.

The study also aimed to characterize the areas of burden of the population sampled through use of the ZBI for proposing areas of concern to the Neuroscience Assessment and Care Clinic.

Study variables were examined using analysis of variance and subject to regression analysis, using SPSS 11.5.0 (SPSS Inc, Chicago, Ill) for Windows (Microsoft Corp, Redmond, Wash). Spearman correlations ( $r_s$ ) were used to examine associations between BDI and continuous variables.

## Results

Of the 120 questionnaires that were sent, 100 responses were usable. The mean age of the respondents was 62.3 years (range, 49 to 73 years), and

54% were women. Thirty percent of spouses reported that their husband or wife was no longer living at home, 25% of spouses reported that they were currently employed, and 25% had completed tertiary education. Ten patients were institutionalized for their dementia, and 4 had died from dementia.

Most diagnoses were FTLD, Alzheimer's disease, and primary progressive aphasia (Table 1). The miscellaneous category included patients with dementia in the context of CADASIL, olivopontocerebellar degeneration, posterior cortical atrophy syndrome, Creutzfeldt-Jakob disease, and CBDG.

## The Burden of Caring

The ZBI reflects common areas of concern for spouses of patients with dementia, including the spheres of health, finance, social life, and interpersonal relations. It covers both objective and subjective burdens. The top 10 common concerns are given in Table 2. The least worrisome aspect for spouses, as elicited using the ZBI, was feeling uncomfortable about having friends over because of their spouse.

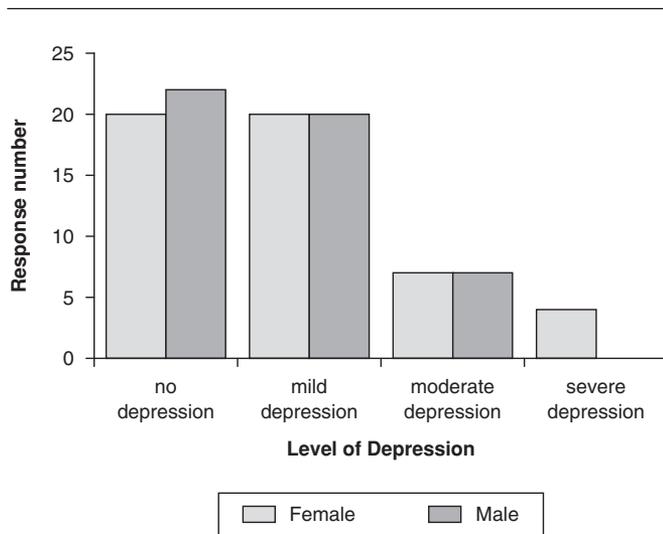
## Depression

Most of the spouses had no or mild-to-moderate depression (Figure 1). The highest reported response recorded using the BDI was reduced interest in sex. When the BDI score was analyzed against diagnosis, 50% of spouses caring for a patient with Alzheimer's

**Table 2.** Top 10 Concerns of Spouses of Patients With Young Onset Dementia Assessed by Using the Zarit Burden Interview Scores

Ranking	Concern	Score <sup>a</sup>
1	Feeling that their spouse is dependent on them.	342
2	Feeling afraid of what the future holds for their spouse.	306
3	Feeling stressed between caring for their spouse and trying to meet other responsibilities for their family or work.	239
4	Feeling that their spouse expects them to take care of them, as if they were the only one that their spouse could depend on.	227
5	Feeling burdened by caring for their spouse.	224
6	Feeling that their social life has suffered because of caring for their spouse.	209
7	Feeling that they don't have enough time for themselves due to the time they spend with their spouse.	206
8	Feeling strained when they are around their spouse.	200
9	Feeling that their health has suffered because of their involvement with their spouse.	194
10	Feeling that they don't have as much privacy as they would like because of their spouse.	170

a. Cumulative score for each question based on the response from all caregivers: rarely = 1, sometimes = 2, quite frequently = 3, nearly always = 4.



**Figure 1.** Level of depression in caregivers of spouses with young onset dementia as assessed by using the Beck Depression Index.

disease reported mild depression or greater, compared with 75% of spouses caring for a patient with FTLD. The highest BDI score reported was by the spouse of a patient with FTLD. Wives (53.4%) also reported slightly more depression than husbands (46.6%).

Results of statistical analysis indicated a significant correlation between the diagnosis of FTLD and BDI score ( $r_s = 0.4.15$ ,  $n = 36$ ,  $P < .05$ ). No correlation was found for age of patient or the caregiver's gender, education level, or employment status. No correlation was found for the diagnosis of Alzheimer's disease or other dementias and BDI scores. There was no statistical relationship with whether the spouse was at home with the patient or whether the patient was institutionalized or deceased.

## Discussion

Few studies have focused on the spouses of patients with young onset dementia. This study has implications for service provisions in Western Australia and may be generalized to other groups of caregivers of young onset dementia patients, with certain restrictions because of limitations of sample bias, lack of an older contrast group, and selective attrition due to early death from dementia.

In this sample, as found in previous studies, husbands caring for their wives report less emotional distress than wives caring for their husbands.<sup>12</sup> The BDI score was not correlated with whether the

patient was living at home. Evidence of higher levels of depression in spouses of patients with young onset FTLD was found, and this group requires special attention. Furthermore, spouses of patients with young onset dementia need to be monitored for depressive symptoms.

No correlation was found between younger age of spouse and level of depression, as reported by the BDI score, in contrast to the study by Freyne et al.<sup>10</sup> Our study confirmed that spouses of patients with young onset dementia are stressed, with numerous concerns such as financial and health worries, lack of effective support, and feelings of social isolation. This supports the findings of other studies on younger patients with dementia and their spouses and caregivers.<sup>10,12</sup>

Because social and leisure activities are closely linked to social support, the amount of support given needs to be assessed to address the concerns outlined by the spouses' responses to the ZBI. Interventions that allowed spouses more time for themselves and that helped to relieve some of the burden of caring for patients with young onset dementia are required. Interventions may be instrumental support, actual assistance in performing certain tasks, or emotional support. Examples might include a counseling service, a caregivers group, and home help with specific tasks as requested by spouses, such as laundry assistance when the patient is incontinent. Such services are now in place, and consideration must be made for their availability in clinics managing young patients with dementia. Many respondents highlighted concern about their financial status, and any intervention will need to take this into consideration. These interventions would help to lessen the frustration of spouses and provide some relief from their ongoing pressures.

## Conclusion

This study highlights the plight of spouses of young onset dementia patients, in particular with psychological, social, and financial effects, and has implications for service provision. Greater awareness of young onset dementia in the community and referral to the specialized young onset dementia clinics for specific support for both patient and spouse will help to relieve some of the burden experienced by caregivers of young onset dementia patients.

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