The Social Experiences of Spouses of Persons with Young-Onset Dementia (YOD): Social Change, Support and Resiliency

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The estimated global prevalence of dementia in 2010 was 35.6 million persons, and this number is expected to double in the next 20 years. In Canada, prevalence of dementia among the Canadian population (all types; all ages) is also projected to increase to 1.1 million persons by 2038. Although dementia is more common after age 65 (i.e. late-onset dementia [LOD]), it is not a natural part of ageing. Young-onset dementia (YOD; onset before 65) accounts not a natural part of normal ageing.

YOD spousal caregivers report greater burden than LOD spousal caregivers. Much like LOD, persons with YOD increasingly rely on caregiver support as the disease progresses, and the majority of caregiving is provided on an informal basis, often by the person’s spouse.

Participants (6 females, 4 males) had a mean age of 55 (sd=6.45), and all were currently employed. Persons with YOD had a mean age of 61 (sd=4.33; see Table 1). Qualitative analysis revealed four emergent themes (see Table 2).

**Sources of Social Support:**
- sources varied by type and description
  - e.g. Nancy contrasted disappointing experiences of friends acting as though her husband no longer existed, with unexpected sources of support such as her family’s church who had surprised Nancy and her 3 young sons by decorating the outside of their home with Christmas lights for the holidays. She stated that, “things like that encourage me about God”

**Giving up Social and Recreational Activities:**
- often due to fear of leaving their spouse home alone, and a lack of time
  - e.g. Pete described having “little windows of time,” to run or cycle between juggling his parental responsibilities, work responsibilities, and caregiving responsibilities. However, those windows disappeared when he “needed to be home at more regular hours,” in order to be home for his children and care for his wife, and he gradually gave up these activities.

**Adapting and Maintaining in Activities:**
- majority involved efforts to adapt and/or maintain activities in order to include their spouse, or to accommodate caregiving obligations
  - ‘one last trip’ fell thematically between adapting and maintaining because this involved something the couple had done previously, and recognition that travel was also no longer possible.
  - adaptation included changing an activity or way of participating in an activity so that the spouse or the person with dementia could continue to participate in it
  - e.g. William described taking up lawn bowling: “I’ll do that once or twice a week. It’s just around the corner from our house. We can walk over together… But those are the resources that are available. You don’t have resources… for middle age people because we’re all at work.”

**Social Spaces as Safe Spaces:**
- certain spaces considered safe if the caregiver could talk freely without feeling they were being judged, or worry about how others perceived their spouse with YOD
  - e.g. Pat developed a friendship with a woman she met at a support group and they began getting together on weekends with their spouses: “We would get together because we both understand – like social situations become very difficult when you are with people who don’t understand what that person is doing… so it seemed very comfortable to meet [together].”

**Conclusions**

New themes included giving up old activities in favour of new activities and social spaces as safe spaces. Results highlight the complex nature of these social experiences, and ultimately challenge and expand our theoretical understanding of the dementia caregiver experience.

Additionally, these findings carry practical significance. YOD spousal caregivers are more likely to be caregivers for longer periods of time, have less social support, and be the sole caregiver in comparison to LOD, demonstrating the need for targeted support interventions for this population.

**References**


**Background**

**Methods**

A descriptive, qualitative approach,7 was used to design the study. Semi-structured, face-to-face interviews were used to explore caregiver experiences, and a brief demographic questionnaire was used to collect contextual information.

Ethics approval was sought and approved by the McMaster Research Ethics Board (#2011-147). Participants were recruited through Alzheimer Society Chapters in Ontario. Ten YOD spousal caregivers (n=10) participated.

Interview transcripts were coded using NVivo 9 and analyzed using inductive content analysis8 to identify common themes.

**TABLE 1: Profile of Participants**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>M/F</th>
<th>Spouse Age</th>
<th>M/F</th>
<th>Marital Status</th>
<th>Caregiver Age</th>
<th>Children/Yr</th>
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