What does social participation mean to family carers of older people living with dementia?

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Background

Social participation is a key element of wellbeing across the lifespan. Family carers of older adults living with dementia can become socially isolated because they are reluctant to leave the person with dementia at home alone, but also reluctant to take them out, often due to changes in behaviour and/or personality that can accompany the onset of dementia (Drentea et al., 2006). Despite these challenges, support from social networks and social participation are highly valued by this population (Dow et al., 2011). The aim of this study was to report the descriptions and experiences of social participation as related by family carers of older people living with dementia.

Method

Drawing on grounded theory methods to guide sampling and data analysis, semi-structured face-to-face or telephone interviews were conducted with family carers of older people with dementia. Data collection and analysis occurred in parallel and continued until no new themes emerged. Thirty three family carers participated. Carers were mostly female (82%) and lived in metropolitan areas (74%). Approximately equal numbers of spouses (52%) and child/child-in-law (48%) carers participated in the study.
Method continued...

There was a shared view that social participation had changed for the carer (and care recipient) following the diagnosis of dementia. The core category of Adaptation encompassed four themes:

1) Autonomy to choose when
2) The impact of dementia care-giving
3) Employing strategies
4) Establishing new meaningful connections.

Results

The core category arising from the data was adaptation, which encompassed the four main themes below:

**Autonomy to choose when, in what ways, and for what reasons to socially participate**

Well, basically, in the past I was travelling more, I was able to go away, I was able to study, I was an actively published writer and I haven’t been doing a lot of published written stuff lately or in the last 10 years or so. I would go and take lessons in ballroom dancing, I would go swimming and snorkelling and fishing and lots of things like that. (Female adult child carer, aged 63 years)

**The impact of dementia caregiving on social participation**

‘I’ve got a male friend but I can’t think of the future. Like I can’t think of . . . we can’t progress a relationship any further, or I can’t’. (Female adult child carer, non-English speaking background, aged 51 years)

**Employing strategies to maximise desired social participation**

‘Carers . . . they are my anchor. They help with lectures and offer advice on where to go for respite. I do have other friends and I receive a bit of support from the congregation. . . .’ (Male spouse carer, aged 79 years)
‘But when you’re at the Memory Lane Café, everybody’s in the same boat so people can sort of bounce off one another, what’s happening to you? How’s things been over the past month? I think that’s really helpful...because sometimes you can say your life has really been a bit shitty lately.’ (Female spouse and adult child carer, aged 66 years).

**Discussion**

The experience of social participation for carers of people living with dementia can be understood as a process of adaptation from the pre-carer situation of relatively unimpeded choice, through the diverse but uniformly significant losses that come with the adoption of the carer role, to accessing available resources and creating new meaning. Individual carers vary in the level of support needed to enable them to access the resources required to progress through this process of adaptation. Similarly, how carers wish to socially participate will be different from one carer to the next; for many, this will take the form of face-to-face carer support meetings, while for others the internet or other forms of technology may hold more appeal. Social participation is essential to carer well-being, and there is a societal responsibility to ensure the active engagement of carers is supported by social inclusion policies that acknowledge difference and serve individual need and agency.

**References**

