

Cross-sectional study

Help seeking increases stress among caregivers of partners with young-onset dementia

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Commentary on: Kobiske KR, Bekhet AK, Garnier-Villarreal M, *et al.* Pre-death grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. *West J Nurs Res* 2018;193945918806689.

Implications for practice and research

- ▶ Carers of partners with young-onset dementia have strong perceptions of stress associated with predeath grief which are worsened by help seeking behaviours.
- ▶ Carers of partners with young-onset dementia have different support needs from those with older onset dementia. Provision of services need to reflect these differences.

Context

Young-onset dementia (YOD) is the development of dementia before the age of 65.¹ The carers of partners with YOD face a dynamic situation of continual, multiple and diverse loss. The loss of loved ones, as dementia progressively affects their partners and loss of identity and personal freedom are threats to working life and companionship. Many are of working age and lack social support networks available to older carers and have other caring roles, parenting children or supporting older relatives. Kobiske *et al*² equated such loss to predeath grief (PDG), which is widely recognised among caregivers of people with dementia.³ PDG is associated with increased stress and contributes to mental and physical health problems. Resourcefulness takes two forms, personal resourcefulness 'self-help' and social resourcefulness 'help seeking' and protects well-being in carers of older onset dementia.² This study tests whether resourcefulness also offers protection to carers of partners with YOD.

Methods

A cross-sectional study tested correlations between PDG and perceived stress and whether, personal or social resourcefulness has a moderating effect on this relationship. All variables were measured using tools that were reliability and validity tested. A convenience sample of 104 carers were recruited from support organisations. As the survey was in English and online, participants had to be literate and capable of using the Internet. Linear correlation established the relationship between PDG and perceived stress while regression models evaluated whether personal or social resourcefulness moderated this.

Findings

Participants were mainly white, female, in reasonable health and well educated. A strong positive association was identified between PDG and caregiver perceived stress. However, there was no evidence that personal resourcefulness had a moderating effect on the relationship between PDG and perceived stress. Among those participants with higher social resourcefulness, there was a reported positive moderation of the association between PDG and perceived stress.

Commentary

The finding that there was a positive correlation between PDG and high levels of perceived stress was expected, replicates findings in other groups of caregivers and demonstrates the burden of caring.

No moderating effect of personal resourcefulness was demonstrated; this differs from that seen among carers of older onset dementia. Possible explanations offered for this difference were that some of the scale items used to test personal resourcefulness, such as visualisation or time management, would require prior knowledge. An alternative explanation was that the continual losses characteristic of YOD would prevent carers from adjusting and develop resourcefulness. In carers of older adults, a negative moderating effect between personal resourcefulness and stress supports the teaching of self-help strategies to carers as a means of reducing stress.⁴ If this finding was true then using strategies to promote self-help among carers of partners with YOD would not be appropriate.

A confounding finding was that social resourcefulness and help seeking led to an increase in perceived stress. This is contrary to that found among carers of partners with older onset dementia. The authors suggested that this reflected the lack of age appropriate support for this group of carers. Consequently, frustration at being unable to access resources tailored to their particular needs exacerbate stress.

While this study is limited by its sampling approach and method of data collection, it is an interesting design and should be repeated with a more robust approach. It suggests that carers of partners with YOD require different services to other carers of people with dementia and that currently available support strategies may be ineffective or harmful.

Competing interests Lead applicant for a research grant to Marie Curie on the preparedness of people with Down syndrome to deal with the end-of-life care implications of a diagnosis with dementia.

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