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Experiences of oldest-old caregivers whose partner is approaching end-of-life: a mixed-method systematic review and narrative synthesis

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ABSTRACT

Background and Objectives: Ageing populations have rapidly increased the number of people requiring end-of-life care across the globe. Governments have responded by promoting end-of-life in the community. Partly as a consequence, older spouses are frequently providing for their partner's end-of-life care at home, despite potentially facing their own health issues. While there is an emerging literature on young-old carers, less is known about spouse carers over 75 who are likely to face specific challenges associated with their advanced age and relationship status. The aim of this review, therefore, is to identify and synthesise the literature concerning the experiences of carers aged 75 and over whose partner is approaching end-of-life. We conducted a mixed-method systematic review and narrative synthesis of the empirical literature published between 1985 and May 2019, identified from six databases: Medline, PsychINFO, Cumulative Index to Nursing and Allied Health Literature, Embase, Sociological Abstracts and Social Service Abstracts. Gough's Weight of Evidence and Morgan's Feminist Quality Appraisal tool used to determine the quality of papers. From the initial 7760 titles, 10 qualitative studies and 9 quantitative studies were included. We identified three themes: 1) "Embodied impact of care" whereby caring was found to negatively impact carers physical and psychological health, with adverse effects continuing into bereavement; 2) "Caregiving spouse's conceptualisation of their role" in which carers' navigated their self and marriage identities in relation to their partner's condition and expectations about gender and place; 3) "Learning to care" which involved learning new skills and ways of coping to remain able to provide care. We have identified a recent up-surge in published papers about very old spousal carers, which comprise a small, medium-quality evidence base. This review outlines a range of potential lines of inquiry for future research including further clarification of the impact of caregiving on the likelihood of mortality, the incidence of men and women providing end-of-life care amongst this age group, and the role of anticipatory grief in shaping their perceptions of their relationship and their own longevity.

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