

Special Article – Family Caregivers

Wellbeing, Work and Life Balance, Working Family Carers of People with Dementia: A Review

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Abstract

In the United Kingdom, many people living with dementia are cared for by a member of their family. As the behavioural and psychological symptoms of dementia progress, caring roles can become burdensome and impact on the wellbeing of these family carers. For working family carers of a person with dementia, resources can become strained with the challenge of balancing both work and care roles. In line with the abolition of the retirement age, this review explores what is currently known about the wellbeing and work and life balance of working family carers of a person with dementia, and recommends where future research should expand on limited knowledge.

Keywords: Carers; Wellbeing; Work life balance; Dementia

Introduction

In the United Kingdom alone, there are around 800,000 people living with dementia [1]. Many of these are cared for by members of their family, with around 700,000 family carers of a person with dementia (PwD) in the UK [2]. The instrumental activities associated with caregiving include but are not limited to: managing household finances, housework, grocery shopping and preparing meals [3]. The emotional work of family carers of a PwD is an additional obligation alongside indirect caregiving duties, where the emotional management involved in care requires continual social interaction [4]. As the behavioural and psychological symptoms (BPSD) of dementia progress in severity, care becomes more demanding [5]. Impaired physical health among family carers of a PwD, has been correlated with BPSD, including: functional disabilities associated with cognitive impairment, the amount and duration of provided care and cohabitating with the PwD [6,7]. Sharing residence with the PwD can increase the risk of social isolation [8], particularly for family carers of individuals in the later stages of dementia [9]. In addition to witnessing changes in physical and cognitive status, the nature of care demands and the type of relationship between family carers and a PwD exacerbate psychosocial distress for family carers, increasing levels of depression and perceived burden [10]. Cognitive decline can also occur as a by-product of the chronic stress associated with caregiving [11]. In contrast, positive experiences of caring for a PwD have been conceptualised as enhanced relationships with others, feelings of self-confidence and positivity about life in general [12]. In 2009, The National Dementia Strategy [13] placed priority on the quality of support people with dementia and their family carers require living well with dementia. The Care Act [14] further stressed the need to support the wellbeing of individuals who are family carers. The elements of wellbeing covered under the Care Act include: economic wellbeing; personal dignity; control over daily life; participation in education, work and/or social activities; relationships with others; suitable accommodation and protection from abuse and neglect. In spite of the incentives to improve the needs and wellbeing of family carers, The National Dementia Strategy and the Care Act

have not accounted for how these strategies vary across family care groups. The policy on the abolition of the default retirement age of 65 in 2011 [15] is one factor which could have an impact on the profile of family carers. As the period of working life extends, the numbers of family carers who face the challenge of balancing care and work life is also likely to increase.

This paper will consider how far the existing literature has addressed the needs and wellbeing of working family carers (WfC) of people with dementia, reviewing the studies that provide guidance about what is currently understood, and identifying the gaps in knowledge.

Reviewed Literature Methodologies

A literature search was conducted between October 2015 and January 2016. Articles relevant to wellbeing of (non-working) family carers of a PwD were obtained from: ASSIA: Applied Social Sciences Index and Abstract (93); IBSS: International Bibliography of the Social Sciences (40); Scopus (2705); SCIE: Social Care Institute for Excellence (31) and Web of Science (481). Articles related to the work and life balance (WLB) of WfC of a PwD were obtained from: ASSIA (429); IBSS (68); Scopus (31) and Web of Science (334). Care was taken to include all variants of key words: search terms included: 'well-being', 'wellbeing' and 'well being', and phrases: 'work life balance'; 'work life conflict'; 'work family balance and 'work role conflict'; and bi-directionality of WLB: 'life work balance'. To cover all definitions of carers, we used the terms: carer OR family carer OR informal carer OR caregiver and care*. As this study is considering the wellbeing and WLB of family carers of a PwD, the terms 'dementia' OR 'Alzheimer's' were added to the search. Articles were selected on the basis that they included: a) family carers or WfC of a PwD; and b) measured wellbeing, quality of life outcomes, and health outcomes generally as these indices are frequently included in measures of overall wellbeing [16,17]. Non-working family carers of a PwD were included in studies which have measured wellbeing, owing to the paucity of WLB studies with WfC of a PwD. Articles were excluded on the basis that they were: a) over ten years old due

Table 1: Definition of wellbeing across studies of (non-working) family carers.

Author	Wellbeing/ Subjective Wellbeing	Psychological/ Mental Wellbeing	Emotional Wellbeing	Physical Wellbeing	Affective Wellbeing
Fauth et al. (2015)	X				
Papastavrou et al. (2011)		X			
Nicolaou et al. (2010).		X			
Ervin et al. (2015)			X		
Braun et al. (2009)		X			
Tommis et al. (2007)		X		X	
Raivio et al. (2015)		X			
Bristow et al. (2008)		X			
Davies et al. (2012)	X				
Stiadle et al. (2013)	X				X
Braun et al. (2010)		X			
O'Rourke et al. (2011)		X			
Chappell et al. (2015)	X				
Fauth et al. (2012)		X			

to recent developments in wellbeing assessments [18]; b) focused exclusively on outcomes of an intervention or randomised control trial; c) focused on carers providing end of life support; d) focused on family carers or WfC of a PwD in a long-term care institution. In total, sixteen studies explored the wellbeing and WLB of family carers and WfC of a PwD.

Across studies relating to family carers and WfC of a PwD (excluding one review [19]), the data was collected from a total of 2,705 family carers and 216 WfC, who comprised spouses, daughters/daughters-in-law, sons/sons-in-law, adult children/parents and others (nephew, niece, siblings and friends).

Appraisal of Included Studies

Family carers and WfC were recruited through a multiple range of agencies, including: specialist clinics; newspaper advertisements; health professionals; Alzheimer’s societies; support groups and programs; and registers. The most common limitations mentioned across studies related to: cross-sectional designs reducing investigations of causal factors; small sample sizes; insufficient control of socioeconomic; sampling strategies and samples biased towards Caucasian caregivers.

Only two studies conducted in Asia were related to family carers of a PwD who combined work and care [20] and explored work-related conflict [21]. This represents a considerable knowledge gap in the literature relating to WLB among WfC of a PwD. As studies relating to WfC of a PwD were scarce, alternative research with WfC of older people in the UK was sought to provide an insight into the experience of combining work and care in this country [22,23]. Questionnaires were the preferred mode of assessment across the literature, though two studies included open-ended questions relating to the use of social support. Six studies focused on caregiving stressors associated with BPSD and their effect on family carers [19,24-28]; six studies explored subjective stressors associated with the care dyad relationship and wellbeing outcomes from the perspective of family carers of a PwD [19,24,29-32]. Four studies explored the mediating effect of support [33-35] and coping mechanisms [4] on caregiving

stressors.

Wellbeing of (Non-working) Family Carers

Caring for a PwD has been claimed to be more strenuous than caring for patients with a chronic disease [36] or physical disability [37]. This makes family carers of a PwD a particularly unique and vulnerable group. As outlined in Table 1, four authors referred to the generic ‘subjective’ assessments of wellbeing (i.e. caregiver burden, stress, depression and self-esteem), whilst others included the physical, emotional and affective aspects of wellbeing (i.e. PwD’s ability to perform daily activities, caregiver education, and kin relationship). A total of nine studies alluded to the ‘psychological’ or ‘mental’ aspects of wellbeing, which included similar measures of depression, caregiver burden, anxiety and stress.

In contrast to the broad definition of wellbeing recommended by the Care Act, the psychological elements of wellbeing were dominant in the literature on overall health outcomes of WfC of a PwD. Of particular significance were studies which described a positive association between severe BPSD and poor wellbeing (i.e. greater anxiety and depression), particularly when caring for individuals with certain types of dementia (i.e. FTD: Frontotemporal dementia) [38]. Thus consideration of WfC perceptions of BPSD should also be included in future assessments of psychological wellbeing with WfC. Mediating factors for sustaining wellbeing among family carers (Bristow et al. [33], Raivio et al. [34] and Tommis et al. [35]) included emotional and instrumental support from individuals within and outside of the network. Papastavrou et al. [4] further found that positive coping mechanisms mediate the effects of caregiving stressors, particularly when caring for an individual with severe dementia. Among family carers of a PwD at least, support and coping mechanisms are key to promoting sustainable psychological wellbeing. However, aside from quantitative assessments of coping strategies, a clear description of what positive strategies carers adopt was noticeably absent from the literature. As positive coping strategies are influential in how family carers’ respond to stress, it is essential that this aspect of self-care is incorporated in future studies

into measures of psychological wellbeing for WfC of a PwD.

Work and Life Balance of Working Family Carers

As with research among non-working family carers of a PwD, family carers who are combining work and care are negatively affected by greater dependence needs and dementia in the severe stages. Nurfatihah et al. [20] and Wang et al. [21] (both studies conducted in Asia) found that greater support needs have an adverse effect on the psychological wellbeing of WfC, as well as their general health. Wang et al. found that greater caregiving demands were also associated with poorer psychological wellbeing for WfC who had high conflict between the work and caregiving role, and were less prepared for high caregiving demands. For WfC with low work-care conflict, higher preparedness was associated with decreased role strain, even when care demand was high. These findings indicated that the relationship between caregiving demands and psychological wellbeing depend on the unique function of work-care conflict and level of preparedness. An increase in preparedness, then, appears to operate in a similar manner to positive coping strategies, protecting WfC with low work and caregiving conflict from increasing care demands. For British WfC of older people, a good relationship with line managers is highly important [22,23], while little is known about the importance of supporting services and the actual use of emotional and instrumental support.

As the literature on working family carers of a PwD is in its infancy, there is a considerable amount that we do not know. Pearlin and colleagues' Stress Process Model [39] identifies the significance of job-caregiving conflict as a significant role strain which can lead to poor wellbeing outcomes for family carers of a PwD. Therefore, the impact of care on employment and vice versa warrants further investigation – as does the availability of support within and outside of the workplace, a potential mediating factor that reduces caregiving stress. As outlined at the beginning of this review, the withdrawal of the retirement age will increase the probability that family carers will remain in employment for a longer period. Therefore, it is important that these gaps in our knowledge are addressed sooner rather than later.

Conclusion

The aim of this mini review was to see how far the existing research has responded to the policy initiative on family carers and in particular those WfC of a PwD. The wellbeing literature highlights that the psychological factors of wellbeing strongly correspond to health outcomes of family carers and WfC. Studies also identify the impact of caregiving stressors relevant to BPSD, and mediators of caregiving stress (i.e. coping mechanisms and instrumental/emotional support). Though studies that have explored WLB among WfC of a PwD, however, are scarce, the effects of BPSD on the wellbeing of WfC remain the same as for non-working family carers. The effects of caregiving demands on work-care conflict also were alleviated when WfC are better prepared. The limitations of the literature include: emphasis on quantitative assessments of wellbeing and WLB;

- No clarity of how positive coping mechanisms are employed;
- No investigations of the bi-directional impact of WLB;

- No British studies of WLB among WfC of a PwD;
- Limited understanding of how mediating factors impact WLB.

The limitations of previous research studies in this field render further research on this subject area an absolute necessity. Moreover, as investigations into the experience of WLB among WfC of a PwD in the UK are forthcoming, much will be gained by including both subjective and objective evaluations of wellbeing and WLB. In the interests of stakeholders, (including policy makers, researchers and members of the publiclike), multiple sources of evidence are required to provide a more robust knowledge base necessary that can inform both theory and practice.

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