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Publication date:
2018

Document Version
Accepted author manuscript, peer reviewed version

Link to publication from Aalborg University

Citation for published version (APA):
Living with a partner with dementia: A qualitative study of female spouses’ lived experiences of changes in everyday life

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Introduction: The prevalence of Persons with Dementia is, according to World Health Organization, expected to increase rapidly over the next years. Living with dementia leads to changes in everyday life of families, relatives and spouses. Loss, grief, and a feeling of uncertainties occurs in relation to the changes in everyday life due to dementia, and spouses seems to manage these changes, by accepting and trying to adjust and adapt to the new living situation. Mentally and practical restrictions are reported as a result of an increasing responsibility, obligation and worries among spouses. Studies report that due to the progression of dementia, spouses experience shifts in roles from sharing a mutual relationship to focusing on practicalities in their shared everyday life, which leads to major changes in their relationship. Powerlessness and a lack of control over the course of the disease and the changes in the relationship occur as a major challenge to the spouses. Former reviews have found an association between perceived caregiver burden and informal care, due to the hours involved in care, leading to stress, depression, anxiety and social isolation among spouses. In order to understand the individual needs of spouses living with a partner with dementia, this study explores the spouses lived perspective of everyday life challenges. Insight into the spouses’ lived experiences could inform future interventions, targeting not only people living with dementia, but also the needs of the spouses. The aim of this study is to explore and gain a deeper understanding of female spouses’ lived experiences of changes in everyday life, while living with a partner with dementia.

Methods: A phenomenological study design including semi-structured interviews, with a particular focus on spouses’ lived experiences of changes in everyday life, were employed. Nine female spouses, living with a partner with mild-to-moderate dementia, in their mutual homes participated in the individual interviews. A theoretical frame of reference inspired by everyday life theory helped structuring the themes for the interview guide. Phenomenological descriptive analyses inspired by Amedeo Giorgi’s five analytic steps were performed and themes of importance were identified.

Results and conclusion: The results of the study will be presented at the conference, as the analysis is in process.