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Carer experience of appetite changes in people living with dementia at home

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Statement of the Problem: The number of people providing unpaid care across the world is significant. 15.4million Americans and 670,000 UK adults provide US\$216billion and £8billion of unpaid care each year for people living with dementia. The term carer in this context relates to individuals who provide unpaid or informal care and usually comprise of family members. Being a carer often brings a sense of satisfaction but is also associated with greater risk of developing physical and psychological health problems. This 'cost' of caring is commonly described as carer burden. Appetite changes in people with dementia are a recognised cause of carer burden. This is significant as appetite change is one of the known behavioural and psychological symptoms of dementia and can cause malnutrition, hyperphagia and pica. These can significantly impact the health and function of the person with dementia and effect relationships and family dynamics. However appetite changes are also described as difficult to manage by both healthcare professionals and carers. The purposes of this study are to explore how carers of people with dementia living at home manage and respond to appetite changes and to understand their views on what resources or interventions they would consider useful to enable them and other carers to manage these changes.

Methodology: This study was developed with patient and public involvement and takes a narrative inquiry approach; a recognised method used to explore experience. Interviews using open-ended questions allow participants to tell the stories of their experience. The transcribed, anonymised data is analysed using logic and intuition with judgments made about meaning and relevance. This approach enables participant experiences to be described and interpreted providing insight into carer experience and how to best support carers in managing appetite changes in people living with dementia.

Biography

Emily R Walters has a passionate interest in the identification and management of disease related malnutrition in adults. As an experienced clinical dietitian she has spent many years working with patients and their family members in managing this and the associated appetite changes, which often occur. Much of the literature examines appetite changes in disease or illness from a quantitative perspective, focusing on mechanisms for appetite changes, interventions to improve or control appetite and dietary changes or nutritional treatment to support good nutrition. Her National Institute for Health Research doctoral fellowship has enabled her to take a novel approach to studying appetite changes in disease using qualitative methods. Her research explores the experience of family carers in the context of dementia. This innovative approach to a clinical challenge provides novel insight and understanding giving impetus to review how we support those affected by appetite changes and the advice provided.

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