



Who cares for the carer?

A qualitative exploration into the wellbeing and support needs of younger carers of people with dementia

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Background

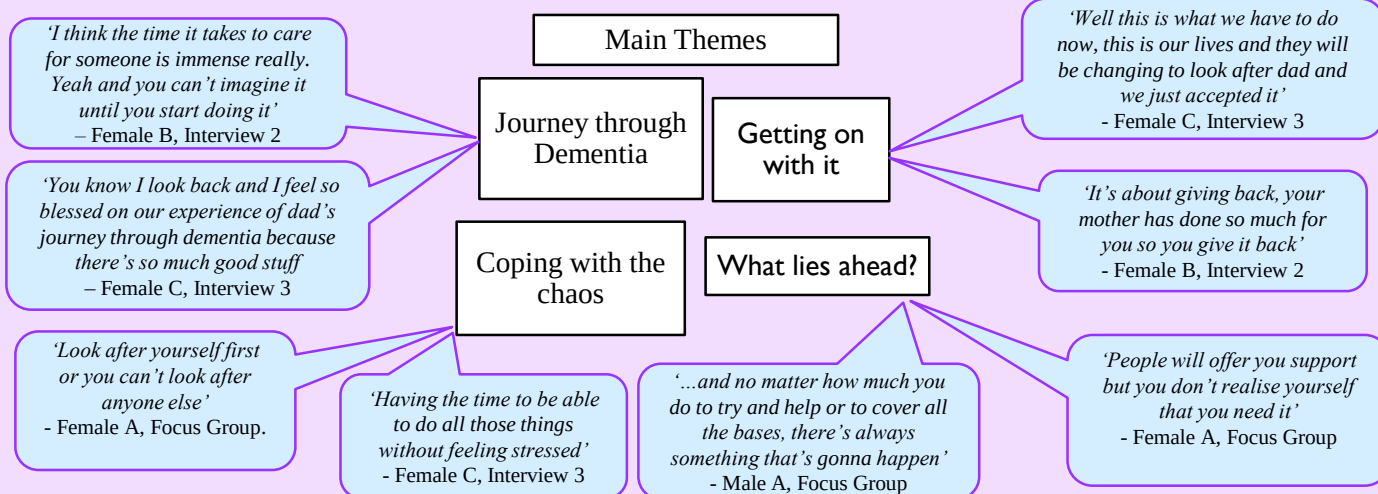
- There are around 850,000 people living with a dementia diagnosis in the UK, a number that is expected to rise to over 2 million by 2020 (Alzheimer's Disease International, 2013)
- Dementia care costs the UK economy around £26m and a proportion of this care is provided informally by family members (Dementia UK Report, Alzheimer's Society 2017).
- Providing care for someone with dementia can lead to negative effects on a person's physical and mental health (Markut & Crane, 2005; Koyama et al., 2016).
- The present study formed part of a Masters Dissertation exploring the wellbeing and support needs of carers under 65 providing informal care for a family member with dementia.

Method

Four females and three males were recruited to take part in one focus group discussion and four in-depth telephone interviews. To be eligible to take part, individuals had to be aged 65 or under and provide informal care for someone with dementia. The questions asked encouraged participants to think about themselves and their role as a carer for someone with Dementia, covering broad issues such as; individual wellbeing, the impact of the caring role, daily challenges, coping strategies, access to information and support and advice for others.

Results

- Interpretive Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) of one focus group and four in-depth telephone interviews resulted in four superordinate themes and 13 subthemes.
- 'Journey through Dementia' was the strongest theme for all participants, as it was clear that although their experiences of caring for someone with Dementia are very different, it was seen as a long and ever changing journey.
- Each individual discussed experiencing an impact on their physical and mental health and the coping strategies they have learned to put in place in order for them to look after their own wellbeing and manage daily challenges.
- Participants were able to reflect on their experiences and discussed how they now know the importance of looking after themselves and that this is crucial to be able to continue caring effectively for the person with Dementia.
- Participants were all at different stages of their caring role with varying levels of concerns and stressors. However collectively they all discussed the value of sharing experiences and information with others during informal support groups.



Conclusions

- Participants felt that they had gained the most valuable support during their journey from their engagement with informal support groups as they could gain access to these quicker than professional support (Toot et al., 2013).
- Engaging in social activities and having time to spend on themselves would be useful in allowing them to manage stress and engage in more self-care activities (Flynn & Mulcahy, 2013).
- At some point carers experienced the same critical time points throughout their journey although they did not occur in a linear pattern.

Recommendations

The British Psychological Society (2016) policy document 'Psychological dimensions of dementia: putting the person at the centre of care' outlines the requirement for a more tailored approach to dementia care and treatment. Future research should explore whether adopting some of these principles of person-centred care would be an appropriate way of supporting carers as well as those with dementia.

Special Thanks

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