

The Experiences of Apathy in People with Dementia and Mild Cognitive Impairment and their Carers: A Qualitative Interview Study



Clare Burgon¹, Sarah Goldberg¹, Veronika van der Wardt^{1,2} and Rowan H Harwood^{1,3}

1 University of Nottingham, Nottingham, United Kingdom, 2 Philipps-Universität Marburg, Marburg, Germany, 3 Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom

POSTER #53464



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Promoting Activity, Independence
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Rather than a simple and direct product of neurodegeneration in dementia, apathy is a complex phenomenon, and may be developed in response to experiencing struggle, loss of support, and challenges to identity.

Apathy, defined as reduced goal-directed activity, social engagement and emotion, is highly prevalent in dementia and Mild Cognitive Impairment (MCI), and has important consequences for the individuals that experience it and those who care for them. However, the lived experiences of this population is not well understood.

This study aimed to explore how people with dementia and MCI and their carers experience apathy

People with early dementia and MCI living in four geographical areas of England were invited to take part in a qualitative interview. All participants had capacity to give informed consent.

In-depth semi-structured interviews were conducted with 14 people with dementia or MCI and carer dyads, and 2 participants without a carer present. Patient's mean age was 76 years, Montreal Cognitive Assessment score was 20, and five were female. Interviews, conducted in the participant's homes, lasted between 38 and 115 minutes, were audio-recorded and transcribed verbatim.

Reflexive thematic analysis was used to analyse the data.

Findings were organised into two connected themes: 'The struggle of everyday life is not worth it' and 'Threatened identity: changing sense of self and place in the world'. Participants' everyday lives required more effort and were a "struggle" due to cognitive and physical impairments. This could make the effort to engage, act, and maintain interest not worth it, resulting in apparent apathy. Motivation to stay engaged despite difficulty was influenced by the accessibility of opportunities, and support from others. Participants views of their (past) autonomous and competent self were challenged by the changes they experienced. Participants sometimes focused on their present capabilities, and did what they were still able, whilst others found changes difficult to accept and withdrew from situations which challenged their sense of self.

Apathy is experienced as a response to the everyday difficulties participants faced, which could be exacerbated by lack of support and opportunities. This is in contrast to the popular view of apathy as a symptom of neurodegenerative changes that occur in dementia.

Our findings echo those of qualitative research in people with Parkinson's Disease (Simpson et al., 2014), and recently published qualitative interviews with people with dementia (Baber et al. 2021) and their carers (Chang et al., 2021).

Baber, W., Chang, C. Y. M., Yates, J., & Dening, T. (2021). The Experience of Apathy in Dementia: A Qualitative Study. *International Journal of Environmental Research and Public Health*, 18(6), 3325.

Chang, C. Y. M., Baber, W., Dening, T., & Yates, J. (2021). "He Just Doesn't Want to Get Out of the Chair and Do It": The Impact of Apathy in People with Dementia on Their Carers. *International Journal of Environmental Research and Public Health*, 18(12), 6317.

Simpson, J., McMillan, H., Leroi, I., & Murray, C. D. (2015). Experiences of apathy in people with Parkinson's disease: a qualitative exploration. *Disability and Rehabilitation*, 37(7), 611-619.



clare.burgon@nottingham.ac.uk

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