

Personhood in dementia: A participatory-action research investigation of the value of agency in community

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Personhood in dementia: A participatory-action research investigation of the value of agency in community

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Research Abstract

Dementia Friendly Communities (DFC) aim to ensure that people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. Although DFC are now the dominant intervention in the lives of people with dementia (PWD) living at home, there is little direct evidence relating to outcomes and personal experiences of the use of DFC.

However, previous research has highlighted the various barriers preventing active participation in the community for PWD, which include; communication difficulties, stigma, shame, lack of organised activities and information. PWD also report the loss of responsibility as a particularly difficult aspect of living with dementia. Although agency can be seen as pivotal to understanding the barriers and increasing positive experiences, research has yet to examine the role of agency and how it effects the quality of life of PWD. This indicates the need to systematically explore how PWD understand community, agency, and meaningfulness of activity, and how they can be supported to increase their sense of agency within DFC.

Understanding how PWD experience a sense of agency within their current environment is a crucial step in improving quality of life and models of care.

Using participatory action research, this study aims to understand how PWD can be supported within DFC to increase their sense of agency. This will involve: (i) completing ongoing focus groups (FGs); (ii) carrying out a longitudinal ethnography of PWDs' experience of agency and meaningfulness in two different settings- a care home and PWD's own homes; and (iii) design and evaluation of a community based intervention for PWD to test how they might be supported to have meaningful agentive experiences in DFC. Sampling will be opportunistic and field notes will be analysed using narrative inquiry.

Further information available at:

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