

Improving everyday function: Translating evidence into a cognitive intervention for dementia through public engagement

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BRIEF OUTLINE

Background: Ageing is one of the greatest risk factors for dementia. With old age, people may start to experience some difficulties in performing everyday activities. This becomes particularly exacerbated in the pre-clinical and clinical stages of dementia, where people with dementia (PwD) experience increasing levels of dependency in instrumental activities of daily living (IADLs), such as preparing a hot meal or dressing. This can cause heightened levels of burden in their family carers, which are mostly spouses, and who thus might experience their own age-related health difficulties such as frailty.

The purpose of the proposed study is to involve those affected by everyday activity deficits (older PwD and their carers), and those involved in the management of the dementia and in the potential implementation of interventions (staff groups such as occupational therapists), in the design and development of a psychosocial and cognitive intervention to maintain or improve everyday functioning. Guidelines from INVOLVE strongly recommend involving the public, and in particular patient and carer groups, in the design process of research studies. This is to ensure that the intervention truly reflects the wishes, needs, and experiences of those involved in the final intervention. The proposed study is multi-disciplinary as it spans the areas of neuropsychology (CG), social care (DC), and cell biology (NH), with the addition of practical experience in the field of carer support (SF).

Method: The development of the intervention would be conducted in a five-step process. Previous evidence collated from one of the researcher's (CG) PhD thesis on the level of impairment of individual IADLs and their relationship to cognition and the well-being of PwD and their carers would firstly be reviewed and translated into aspects linked to potentially effective interventions. These aspects would be the focus of the first set of focus groups (one with PwD and carers, and one with staff), to receive feedback and information on whether these aspects reflect the experiences and needs of these groups. In the third step, information gathered from the first set of focus groups would be integrated into the development process. Following on from the general design aspect of the intervention, the researcher would produce a more detailed account of the intervention and its specific components. In the fourth step, the researcher would feed back to the groups how their ideas have shaped the further development of the intervention. Additionally, participants would be asked for their opinions on the emerging intervention components. Finally, all information gathered from the second set of focus groups would result in the final intervention.

LIKELY OUTCOMES AND OUTPUTS

There are two intended outcomes of this study. First, findings of this study are intended to be disseminated in an international journal in the field of old age psychiatry and ageing. On a non-academic level, it is intended to publicise the findings directly to carers, PwD, and older adults through a local support group, such as those provided by Age UK, as well as through social media outlets such as twitter and the School of Nursing, Midwifery and Social Work blog. It is furthermore planned to share the findings of this study at the annual Dementia Research Network meeting from The University taking place in June 2016.