IES Platform – development of an awareness-based intervention to enhance quality of life in severe dementia

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Title of project or programme

IES Platform – development of an awareness-based intervention to enhance quality of life in severe dementia

Principal Investigators of project/programme grant

Title	Forname	Surname	Institution	Country
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- United Kingdom

Source of funding information

Medical Research Council

Total sum awarded (Euro)

484922.32

Start date of award

01-03-2009

Total duration of award in months

20

The project/programme is most relevant to

- Alzheimer’s disease and other dementias

Keywords

Research abstract in English

Quality of residential care for people with severe dementia is poor and in urgent need of improvement. One reason for this may be the assumption that people with severe dementia are unaware of their surroundings and of what is happening to them. However, there is converging evidence to suggest that global assumptions of unawareness are inappropriate. This trial platform study builds on this evidence, aiming to assist care staff in perceiving and responding to subtle signs of awareness and thus enhance their practice. The study will be conducted in three stages. Initially, a measure of awareness in severe dementia will be developed. In Stage One, two focus groups and an expert panel will contribute to item and scale development, modifying the content and format of a measure designed to identify signs of awareness in people with very severe brain injury (the WHIM). In Stage Two observational data will be used to further develop the measure. Working in four care homes, we will recruit 40 individuals with severe dementia who have no, or very limited, verbal communication. Data on inter-rater reliability and frequency of all items and exploratory factor analysis will be used to identify items to be retained. Test-retest and inter-rater reliability for the new measure will be calculated. Correlations with scores for well-being and behaviour and with proxy ratings of quality of life will provide an indication of concurrent validity. In Stage Three the new measure will be used in a pilot single blind cluster randomised trial. Eight care homes will participate, with 10 residents recruited in each giving a total sample of 80 people with severe dementia. Homes will be randomised to intervention or usual care conditions. In the intervention condition, staff will receive training in using the new measure and will undertake observations of designated residents. For residents with dementia, outcomes will be assessed in terms of change from baseline in scores for behaviour, well-being and quality of life. For care staff, outcomes will be assessed in terms of change from baseline in scores for attitudes, care practice, and well-being. The results will inform the design of the definitive trial. A major output will be a reliable and valid measure of awareness in people with severe dementia. Findings will be incorporated into training provision for care staff.

Lay Summary