The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review and feasibility study for a cluster randomised controlled trial

https://neurodegenerationresearch.eu/survey/the-namaste-care-intervention-to-improve-the-quality-of-dying-for-people-with-advanced-dementia-living-in-care-homes-a-realist-review-and-feasibility-study-for-a-cluster-randomised-controlled-trial/

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Country

United Kingdom

Title of project or programme

The Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes: A realist review and feasibility study for a cluster randomised controlled trial

Source of funding information

NIHR

Total sum awarded (Euro)

€ 728,511

Start date of award

01/11/2016

Total duration of award in years

2.0

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Research Abstract

Background: Many people with advanced dementia live and die in nursing care homes (NCHs). The quality of life, care and dying experienced is variable. There is a need to identify appropriate, cost effective interventions that facilitate high quality end of life care provision appropriate for this population. Aim: To establish the feasibility of conducting a cluster controlled trial in nursing care homes to understand the impact on quality of dying of the Namaste Care intervention for people with advanced dementia, compared to usual end of life care. Design: a) Realist Evidence review: To determine which Namaste care intervention elements work best for people dying with advanced dementia in the NCH context. b) Intervention Refinement: Consultation workshop with care home staff (n=8-12 from 4 NCHs) and family members of people with advanced dementia, using findings from the Realist Review to refine the Namaste Care intervention. c) Feasibilty study in context of a cluster controlled trial: A feasibility study in 8 sites (6 intervention and 2 control) in the context of a cluster controlled trial (and embedded qualitative process and economic evaluation) to facilitate future design and measurement choices for a full trial. Setting: Nursing care homes (NCH) in England. Target population: Patient: People with advanced dementia (FAST=6-7) prognosis<3months. Informal carer: Main family or informal carer. NCH staff: Care staff paid to provide care in NCHs. Trial Inclusion criteria: NCHs providing palliative care for people with advanced dementia using an established palliative care intervention. Health technology: Namaste Care is a complex intervention delivering proactive structured care focused on enhancements to the physical environment, comfort assessment and management, and sensory engagement incorporating personalised activities to reflect an individual’s life story and preferences. Proposed primary/secondary outcomes and tools: A feasibility aim is to establish the appropriateness, acceptability, timing and administration of instruments for a full trial. We consider two contender primary outcomes for a full trial: (1) quality of dying (dementia) (CAD-EOLD) and (2) quality of life (QUALID). Secondary outcomes include sleep/activity (using actigraphy); neuropsychiatric symptoms (NPI-NH); pain (PAIN-AD). Informal carer outcomes: satisfaction with care at the end of life (EOLD-SWC). Staff outcomes: care giving experiences (ZARIT Burden Scale), satisfaction with care in end of life care (EOLD-SWC). Health Economic outcomes: EQ-5D-5L, ICECAP-O and ICECAP-SCM. Other data: medication/service use (medical records), work activity (staff diary). Sample size: People with advanced dementia (n=64) from 8 clusters; NCHs randomised to Namaste Care (n=6) or control (n=2) Analysis: Primary end point will be determined. Reporting will focus on recruitment, response and completion rates, and missing data. Proxy agreement will be determined. Estimates of standard deviation and intracluster correlation coefficent will be made for definitive trial design. No formal statistical tests of intervention effect will be performed. Process evaluation data will be analysed quantitatively (through descriptive statistics) and qualitatively (using Framework Analysis). Unit cost information will be applied to resource use data to provide initial estimates of cost-effectiveness, identifying drivers of efficiency.

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

United Kingdom

Diseases:
Alzheimer's disease & other dementias

Years:
2016

Database Categories:
N/A

Database Tags:
N/A