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Feasibility of the NIDUS-Professional home carer training intervention

Submission date
24/02/2020

Recruitment status
No longer recruiting

Registration date
01/06/2020

Overall study status
Completed

Last Edited
04/07/2024

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[X] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims
The most effective support programmes for people living with dementia at home involve making active choices, individualising care, training carers in communication and coping skills and making changes to the environment. Researchers have developed and tested two support programmes which aim to increase the time people with dementia are able to live at home. The NIDUS-family intervention will be delivered to people with dementia and family carers in their homes. NIDUS-professional will be a training and support programme for the paid home care workforce. The researchers have developed the support programmes together with people living with dementia, family carers, home care workers and managers, health practitioners and researchers using their personal experiences and evidence on best current practice in training and support for family carers and home care workers for people living with dementia.

Who can participate?
Home carers from four home care agencies who provide support to people living with dementia, people living with a diagnosis of dementia or probable dementia who the home carer supports, and their family carers (if they have one).

What does the study involve?
At the beginning of the study the researchers will collect information from each home carer on things like their age, gender, marital status, ethnicity, employment, work-related stress and training. Home carers in two agencies will receive six training and support sessions (NIDUS-professional) on how to support people living with dementia to be independent at home, and one home care agency will receive their usual training and support from their home care agency. The NIDUS professional training will take place over 3 months. The sessions will be for groups of 6-8 home care workers, and will be facilitated by two researchers. The researchers will ask the home carers if they can audio record the sessions so that they can offer training and supervision to the researchers working with them. At the end of the training programme, the home carers will be asked to complete the same questionnaires that they completed at the start of the study and they can also take part in a focus group or interview about their experiences of it if they wish. People living with dementia and family carers who are supported by the home carers taking part in the study will also be approached to take part. If they wish to take part the researchers will collect information on things like their age, gender, marital status, ethnicity,

quality of life, service use and satisfaction with home care services at the start and end of the study. People living with dementia and their family carers who are working with home carers receiving the NIDUS-professional training and support programme will also be offered an eight-session support programme over 6 months aimed at helping family carers and people living with dementia achieve goals around living independently at home (NIDUS-family). The researchers will ask family carers and people living with dementia if they can audio record the sessions so that they can offer training and supervision to the researchers working with them.

What are the possible benefits and risks of participating?
There may be no direct benefit to people from taking part in the study. By taking part, people will be contributing to the understanding of whether support programmes can help home care workers and family carers to support people living with dementia be independent at home for longer.

Where is the study run from?
University College London (UK)

When is the study starting and how long is it expected to run for?
May 2020 to May 2023

Who is funding the study?
Alzheimer's Society (UK)

Who is the main contact?
Jessica Budgett
j.budgett@ucl.ac.uk

Contact information

Type(s)
Public

Contact name
Ms Jessica Budgett

Contact details
UCL Division of Psychiatry,
A Wing, 6th Floor, Maple House,
149 Tottenham Court Road
London
United Kingdom
W1T 7NF
+44 (0)7899858684
j.budgett@ucl.ac.uk

Type(s)
Scientific

Contact name
Prof Claudia Cooper

Contact details
UCL Division of Psychiatry,
A Wing, 6th Floor, Maple House,
149 Tottenham Court Road
London
United Kingdom
W1T 7NF
+44 (0)2035495875
claudia.cooper@ucl.ac.uk

Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
129313

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
IRAS 129313

Study information

Scientific Title
Assessing the feasibility and acceptability of a home care workers' training and support intervention, from the perspectives of home care workers, clients living with dementia and family carers: stream three of the NIDUS (New interventions for Independence in Dementia) programme

Acronym
NIDUS-Professional

Study objectives
To determine the feasibility and acceptability of a home care training and support intervention (NIDUS-professional) with linked delivery of NIDUS-family, through:
Phase 1: Assessing whether the NIDUS-professional intervention is acceptable and feasible to deliver in practice.
Phase 2: Confirming if a priori criteria for progression to a full trial are met; these are adherence of home care staff to the NIDUS-professional intervention and completion of follow-up measures by service clients and staff.

Ethics approval required
Old ethics approval format

Ethics approval(s)

Approved 22/05/2020, Camden & Kings Cross Research Ethics Committee (NHSBT Newcastle Blood Donor Centre, Holland Drive, Newcastle upon Tyne, NE2 4NQ, UK; +44 (0)207 104 8222; camdenandkingscross.rec@hra.nhs.uk), ref: 20/LO/056

Study design
Pilot study and randomized cluster feasibility trial

Primary study design
Interventional

Secondary study design
Cluster randomised trial

Study setting(s)
Home

Study type(s)
Other

Participant information sheet
Not available in web format, please use the contact details to request a participant information sheet

Health condition(s) or problem(s) studied
Dementia

Interventions
Two home care agencies will be randomised to receive the NIDUS-professional intervention and one agency will be randomised to the control (they will not receive the training). The NIDUS-professional intervention is a six-session training programme for home carers working with people living with dementia. After it has been piloted it will be delivered to small groups of around 6-8 staff. These groups will receive six training sessions each lasting around 1.5 hours over a three month period. This will be followed by a three month period of implementation, where the facilitators and research team clinical psychologists keep in contact with agencies and support them to implement action plans they have developed (individual and for the agency). Training topics include:
1. The importance of peer support and home care staff wellbeing
2. Building positive relationships and managing reluctance to engage with support
3. Supporting people to stay involved in meaningful activities
4. Supporting each other and working as a team
5. Managing behaviours that challenge and other care challenges
6. Putting it all together (developing action plans)

Within the intervention arm, the researchers will offer the NIDUS-family intervention to all participating clients with a formal dementia diagnosis and a family carer who is in regular contact. NIDUS-family is a 6-8 session intervention that the researchers are currently testing in an RCT (https://www.isrctn.com/ISRCTN11425138). The main premise of the intervention is for family carers and/or people with dementia to select personal goals and modules to help them achieve their goals. The intervention consists of 6-8 face-to-face sessions, with fortnightly to monthly contact over 6 months. It is delivered to people with dementia and their family carers in

their own homes by NIDUS researchers, trained, supervised and clinically overseen by a clinical psychologist.

Intervention Type
Behavioural

Primary outcome measure
1. Intervention adherence by home care workers as measured by the number of training sessions attended/number of planned training sessions at 3 months (end of training period)
2. Follow-up outcome completion by home care workers and clients with dementia (self-rated and proxy outcomes) as measured by the proportion of recruited home care workers, family carers and clients with dementia with follow-up data for each measure at 6 months after baseline

Secondary outcome measures
1. Recruitment rate recorded as the number of eligible participants who consent to participate at baseline
2. Fidelity of delivery of the structured, manualised intervention measured by the number of training components delivered as intended at 3 months (at the end of the training)

Home care workers will be asked to complete at baseline and 6 months after baseline:
3. Work-related strain inventory to measure the impact of work on everyday life
4. Sense of Competence in Dementia Care Scale to assess how able staff feel to deliver person-centred care

The paid carer working most closely with each client with dementia will be asked to complete the following measures at baseline and 6 months after baseline:
5. The Dementia Quality of Life (DEMQOL) proxy that measures quality of life in people with dementia in the last week
6. Disability Assessment for Dementia scale, a standard measure of functional independence (basic and instrumental activities of daily living)
7. The brief Neuropsychiatric Inventory Scale (NPI-Q): a 12-domain survey assessing neuropsychiatric symptomatology. The NPI-Q provides symptom Severity and Distress ratings and total Severity and Distress scores

Family carers will be asked to proxy-complete at baseline and 6 months after baseline:
8. Adapted version of the Client Services Receipt Inventory to measure health and social care resource utilisation including home care, hospitalisations, respite and all-cause time to transition from home to an institution
9. Home care satisfaction measure which measures how satisfied the client is with their receipt of home care
10. The Dementia Quality of Life (DEMQOL) proxy that measures quality of life in people with dementia in the last week
11. The brief Neuropsychiatric Inventory Scale (NPI-Q): a 12-domain survey assessing neuropsychiatric symptomatology. The NPI-Q provides symptom Severity and Distress ratings and total Severity and Distress scores

Clients with dementia will be asked to complete, at baseline and 6 months after baseline if they are able to:
12. The DEMQOL, to measure their own quality of life in the last week
13. Home care satisfaction measure which measures how satisfied the client is with their receipt of home care

The researchers will also assess team-level and individual-level goals and action plans to determine the types of goals that were formulated and progress with achieving goals 6 months after baseline

Overall study start date
01/05/2020

Completion date
31/05/2023

Eligibility

Key inclusion criteria
People with dementia:
1. 18 years or older
2. Any gender
3. Clients of a participating home care agency, with a documented diagnosis of dementia of any severity who are living in their own homes: alone and with others and with or without a family carer willing to participate in the study
4. Clients of a participating home care agency who screen positive for probable dementia (a score of 5 or 6) on the Noticeable Problems Checklist

Family carers:
1. 18 years or older
2. Any gender
3. Family carers who are in at least monthly face-to-face, email or telephone contact with the person with dementia
4. Family carers who can speak English (for participation in NIDUS-family). Family carers do not need to speak English to take part in NIDUS-professional
5. Willing and able to provide written informed consent

Home care staff:
1. All employees of participating home care agencies providing direct care to dementia clients or involved in managing/training home care workers
2. 18 years or older
3. Males or females
4. Be able to understand spoken English
5. Willing and able to provide written informed consent

Participant type(s)
Mixed

Age group
Mixed

Lower age limit
18 Years

Sex
Both

Target number of participants
Phase I: 6-8 home care workers and 2-3 clients with dementia and family carer dyads working for 1 participating agency (max n=14). Phase 2: 60-90 home care staff (20-30 per agency) working for 3 participating agencies; 60-90 home care agency clients (20-30 per agency) living with dementia or probable dementia with or without family carers; 30-50 family carers (10-20 per agency) supporting clients with dementia; Total sample size: 244

Key exclusion criteria
1. People living with dementia who are receiving palliative care support and considered to be in the last 6 months of their life
2. People living with dementia who, because they are temporary clients or have given notice, are not expected to be clients of the agency in 6 months' time
3. Home care staff who do not plan to remain working in the agency for 6 months or more
4. Family carers or home care workers who lack capacity to consent

Date of first enrolment
01/06/2020

Date of final enrolment
30/09/2022

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
University College London
Division of Psychiatry
A Wing, 6th Floor, Maple House
149 Tottenham Court Road
London
United Kingdom
W1T 7NF

Study participating centre
University of Bradford
The Centre for Applied Dementia Studies
Faculty of Health Studies
Richmond Road
Bradford
United Kingdom
BD7 1DP

Sponsor information

Organisation
University College London

Sponsor details
Joint Research Office, UCL, 1st Floor Maple House
149 Tottenham Court Road
London
England
United Kingdom
W1T 7NF
+44 (0)20 3447 5557
uclh.randd@nhs.net

Sponsor type
University/education

Website
https://www.ucl.ac.uk/joint-research-office/

ROR
https://ror.org/02jx3x895

Funder(s)

Funder type
Charity

Funder Name
Alzheimer's Society

Alternative Name(s)
alzheimerssoc

Funding Body Type
Private sector organisation

Funding Body Subtype
Associations and societies (private and public)

Location
United Kingdom

Results and Publications

Publication and dissemination plan
The researchers will disseminate their findings in a peer-reviewed journal and present findings in appropriate local forums for health and social care professionals. Participants who have indicated they are interested in reading the final paper will be sent it.

Intention to publish date
31/07/2023

Individual participant data (IPD) sharing plan
The data sharing plans for the current study are unknown and will be made available at a later date.

IPD sharing plan summary
Data sharing statement to be made available at a later date

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		26/12/2022	28/12/2022	Yes	No
Other publications	Nested qualitative study	24/04/2021	04/07/2024	Yes	No
Other publications	Process evaluation	01/05/2024	04/07/2024	Yes	No
Other publications	Qualitative results	06/02/2022	04/07/2024	Yes	No