ISRCTN15863801 https://doi.org/10.1186/ISRCTN15863801

Improving end of life in care homes using an implementation science approach

Submission date
16/12/2020

Recruitment status
No longer recruiting

Registration date
17/12/2020

Overall study status
Completed

Last Edited
25/07/2024

Condition category
Other

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
Up to 50% of care home residents in the UK die within 6 months of admission. Residents often don't get access to end of life care from hospice teams, and so may experience unnecessary and distressing symptoms at end of life.

Recent work conducted in Australia tested a new way to provide specialist palliative care to care home residents called 'Needs Rounds'. Needs Rounds are monthly staff meetings where up to 8 residents are prioritised for discussion, focusing on those most at risk of dying without an adequate plan in place. Needs Rounds include a review of the person's physical, psychological, and social wellbeing, education for staff on symptom management, and a plan of necessary actions such as medicine reviews or case conferences.

The study team want to understand whether Needs Rounds will work in the UK. This study will work with 6 specialist palliative care services, each of which will link with 4-6 local care homes. Individual/small group interviews will be conducted to learn how Needs Rounds should be adapted in each of the 6 case study sites. Workshops will then be run to co-design Needs Rounds with site clinicians. The newly designed UK-version will be used for 12 months in participating care homes, and the study team will seek feedback from local staff. The collaboration with local staff will allow for theidentification of strengths and weaknesses, with the flexibility to modify Needs Rounds throughout the study. The study team will monitor residents' health service use, quality of dying, and staff capacity to care for people using a palliative approach.

The study aims produce a UK-version of Needs Rounds, and have evidence on whether it helps UK care home residents to stay out of hospital, improves symptom control for better deaths, improves staff capability to look after older people in care homes at end of life, and reduces hospital costs.

Who can participate?
Stakeholders such as those working for specialist palliative care or a care home, residents in one of the collaborating care homes and their relatives, or those working in acute care impacted by hospitalised care home residents. The selected care homes will be: located near to the specialist palliative care team; provide care to residents who have high clinical nursing/medical needs; and

be a range of sizes (focusing primarily on larger care homes, following CQC data indicating lower quality in larger facilities), sole traders and large corporate provider, and with a range of funding models (NHS/social care and self-funded residents).

Up to six residents who can provide their own informed consent and live in one of the collaborating care homes will be invited to take part in an interview. All other care home residents with an anticipated life-expectancy of less than 6 months, or a deteriorating condition where they are at risk from dying without an adequate care plan in place, and experiencing sub-optimal bio-psycho-social symptoms will be discussed in Needs Rounds.

What does the study involve?
Initially, the study will involve interviews with 40 people (who will include staff in palliative care, staff in care homes, care home residents, and relatives of care home residents) to learn about current care for people approaching the last months and days of life. The information provided during these interviews will be analysed, and the study team will run two workshops to decide what a UK model of Needs Rounds should look like. The UK model will then be run for a year (July 2021-June 2022). We will measure During this time, how much NHS services residents use will be measured. The study team will also interview staff involved in running about how Needs Rounds is going. Staff will also be asked to fill out questionnaires about how capable they feel to look after people near the end of life. Families will be asked to fill out questionnaires about how they perceive the quality of care.

What are the possible benefits and risks of participating?
It is expected that the study will improve care, especially for residents approaching the end of life. The main part of Needs Rounds is providing staff support and education. There are no direct risks to participants anticipated.

Where is the study run from?
The University of Stirling (UK)

When is the study starting and how long is it expected to run for?
From October 2020 to October 2022

Who is funding the study?
The National Institute for Health Research (NIHR) (UK)

Who is the main contact?
Dr Liz Forbat
elizabeth.forbat1@Stir.ac.uk

Study website
https://needsrounds.stir.ac.uk/

Contact information

Type(s)
Scientific

Contact name
Dr Liz Forbat

ORCID ID
http://orcid.org/0000-0002-7218-5775

Contact details
Faculty of Social Sciences
University of Stirling
Stirling
United Kingdom
FK9 4LA
None provided
elizabeth.forbat1@Stir.ac.uk

Type(s)
Scientific

Contact name
Dr Aisha MacGregor

ORCID ID
http://orcid.org/0000-0001-5812-9323

Contact details
Faculty of Social Sciences
University of Stirling
Stirling
United Kingdom
FK9 4LA
No telephone contact available
aisha.macgregor@stir.ac.uk

Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
287447

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
CPMS 47310, IRAS 287447

Study information

Scientific Title
Improving end of life care: supporting the workforce and reducing hospitalisations through an implementation study in care homes

Acronym
Needs Rounds

Study objectives
Needs Rounds (triage meetings between specialist palliative care and care homes) reduce hospital use among care home residents

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 15/12/2020, South West - Frenchay Research Ethics Committee (Ground Floor, Temple Quay House, 2 The Square, Bristol, BS1 6PN, UK; +44 (0)207 104 8376; frenchay.rec@hra.nhs.uk), ref: 20/SW/0152

Study design
Interventional non-randomized implementation science study

Primary study design
Interventional

Secondary study design
Non randomised study

Study setting(s)
Care home

Study type(s)
Treatment

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

Health condition(s) or problem(s) studied
Health services research, care homes, end of life care

Interventions
This is an Implementation Science study which will take an approach to care with an established research evidence-base (called 'Needs Rounds') and identify what adaptations need to be made to integrate it into routine practice. The study is also prioritising co-design. Consequently, the adaptations to Needs Rounds will be made with patient/public involvement, involvement from specialist palliative care teams, and from care home staff.

Needs Rounds were developed in Australia. They are monthly 60 minute meetings, where 8-10 residents are discussed at care homes by the care home staff and someone from the local specialist palliative care team (hospice). The choice of residents to discuss is based on those who are at greatest risk of dying without a plan in place and who have a high symptom burden. Care home staff are asked to prioritise residents for discussion in Needs Rounds who, for example, have been transferred from hospital while actively dying, or where staff would not be surprised if the resident died within six months. Needs Rounds integrate case-based education, with a

discussion of each resident's medical, psychological, and social circumstances to promote symptom management and identify opportunities to reinforce and extend staff knowledge. Discussion of residents at Needs Rounds frequently leads to initiating case conferences (attended by the resident, GP, and care home staff), conducting advance care planning with resident input, management of current and anticipatory medicines, and, where needed, prompting the process of gaining a lasting power of attorney.

The intention of the study is to adapt and refine Needs Rounds to the UK context, therefore the study plans for flexibility and making changes to the protocol as the study progresses, for example meetings may happen bi-monthly, via video-conference and focus on only 4 residents each time.

Needs Rounds have been shown in a large randomised control trial (led by the Chief Investigator) to improve staff ability to look after people at end of life, improve deaths, and reduce resident hospitalisations.

This study will work with 6 specialist palliative care teams, from 4 hospices in England and 2 hospices in Scotland. Each specialist palliative care team will link with between 4-6 care homes, and provide 'Needs Rounds' to those care homes. A mix of care homes will be recruited including: urban/rural, service size, deprivation, cultural demographics, national charity /independent management, funding models, hospital transfer policies.

The study has two phases:
Phase 1: interviews will be conducted with 40 stakeholders to generate initial theories to explain how Needs Rounds could be used in the UK. Interviewees will include: residents/relatives /clinicians/managers in care homes, clinicians in specialist palliative care and related acute /primary care, and allied health practitioners. Key personnel (senior specialist palliative care nurses) will be trained in running Needs Rounds.
Phase 2: will test/evaluate the theories in Phase 1. A Phase 2 workshop with representatives from all 6 sites will be held to discuss Phase 1 data and continue to co-design. In a final workshop, some brief 'talking head' videos will be made for use in dissemination. Throughout Phase 2 the study team will continue to conduct interviews (at 4, 8, and 12 months of implementation) with key stakeholders to learn how implementation is going, and what adaptations sites are continuing to make. To measure the impact on hospital use, data will be collected at baseline for the 4 months prior to implementation, and during the final 4 months of implementation regarding all care home residents' hospitalizations. The study team will also record other demographic and health factors such as gender, age, and primary diagnosis. For residents discussed at Needs Rounds, information on activities that occurred as a result of the meetings will be collected - such as changes to medications, a case-conference, and whether investigations (e.g. urine tests or clinical assessments) are conducted.

All care home staff will be asked to complete two questionnaires before Needs Rounds is implemented, and at the end of implementation: "a quality of death" questionnaire for all residents who have died, and a "capability of adopting the palliative approach" questionnaire. During the 12 months of using Needs Rounds, the staff who attend Needs Rounds will also be asked each month to complete the "capability of adopting the palliative approach" questionnaire. The specialist palliative care team will be asked to audio-record the Needs Rounds.

The relatives of people discussed in Needs Rounds will be asked to complete a questionnaire about the 'family perceptions of care'.

Patient/public involvement (PPI) evaluation We will conduct interviews with the study's research team (co-investigators) and a sample of research site staff about the PPI involvement in the study. This will be conducted in the final few months of the project.

Intervention Type
Other

Primary outcome measure
1. Characteristics of effectiveness regarding 'What works for whom, under what circumstances, with the UK Model of Needs Rounds' assessed through qualitative interviews with key stakeholders (residents, relatives, care home staff, specialist palliative care staff, and acute care staff) during the 12 month intervention

Secondary outcome measures
1. Rate of hospitalization (in days) measured at baseline for 4 months and for the final 4 months of the intervention
2. Staff capability of all staff attending Needs Rounds measured using Staff capability of adopting a palliative approach (CAPA) gathered prospectively throughout the 12 months of implementation
3. Quality of Death and Dying measured using the quality of death and dying index (QODDI), gathered prospectively on all deceased residents throughout the 12 months of implementation
4. Family perceptions of care measured using the Canadian Health Care Evaluation Project (CANHELP) lite, gathered prospectively on families of residents discussed during the 12 month intervention

Overall study start date
01/10/2020

Completion date
31/10/2022

Eligibility

Key inclusion criteria
Stakeholders (for interviews in Phase 1 & 2):
1. Work for specialist palliative care or a care home in one of the six cases; or are a resident in one of the care homes; or are a relative of a care home resident in one of the six cases; or work in acute care impacted by hospitalised care home residents
2. Willing to provide informed consent
3. Have capacity to provide their own consent to participate
4. Not engaged in any current safeguarding investigations

Care homes:
1. Located near to the specialist palliative care team
2. Provide care to residents who have high clinical nursing/medical needs
3. Willing to sign a memorandum of understanding with the research team, outlining provision of hospitalisation data, facilitate access to staff for interviews, and engagement in Needs Rounds
4. A range of sizes (focusing primarily on larger care homes, following CQC data indicating lower quality in larger facilities), sole traders and large corporate provider, and with a range of funding models (NHS/social care and self-funded residents)

Residents:
1. Resident in a collaborating care home in one of the six case study locations
2. An anticipated life-expectancy <6 months, or a deteriorating condition where they are at risk from dying without an adequate care plan in place
3. Experiencing sub-optimal bio-psycho-social symptoms

Relatives completing 'family perceptions of care' questionnaire
1. Relative of a resident who was discussed in Needs Rounds
2. Able to provide their own informed consent

Interviewees (PPI evaluation)
1. Co-investigator or staff at one of the case study sites
2. Able to provide their own informed consent

Participant type(s)
Health professional, Resident

Age group
Adult

Sex
Both

Target number of participants
Planned Sample Size: 440; UK Sample Size: 440

Total final enrolment
349

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
18/01/2021

Date of final enrolment
30/06/2021

Locations

Countries of recruitment
England

Scotland

United Kingdom

Study participating centre

Arthur Rank Hospice
Cherry Hinton Road
Cambridge
United Kingdom
CB22 3FB

Study participating centre
Strathcarron Hospice
Research and Education
Fankerton
Denny
United Kingdom
FK6 5HJ

Study participating centre
Highland Hospice
7 Queensgate
Inverness
United Kingdom
IV1 1DE

Study participating centre
St Giles Hospice
Fisherwick Rd
Whittington
Lichfield
United Kingdom
WS14 9LH

Study participating centre
Princess Alice Hospice
West End Lane
Esher
United Kingdom
KT10 8NA

Study participating centre
St Helena Hospice
Myland Hall
Barncroft Close
Colchester

United Kingdom
CO4 9JU

Sponsor information

Organisation
University of Stirling

Sponsor details
-
Stirling
Scotland
United Kingdom
FK9 4LA
+44 (0)1786 466 196
rachel.beaton@stir.ac.uk

Sponsor type
University/education

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Publication and dissemination plan
Planned publication in a high-impact peer reviewed journal.

Intention to publish date
31/03/2024

Individual participant data (IPD) sharing plan
Anonymous data will be made available through the University of Stirling's online research data hub 'DataSTORRE'. Data can be applied for via DataSTORRE and by sending an ethics approved protocol to the study's Chief Investigator, Dr Liz Forbat (Elizabeth.forbat1@stir.ac.uk).

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article	protocol	22/02/2021	24/02/2021	Yes	No
HRA research summary			28/06/2023	No	No
Results article		24/07/2024	25/07/2024	Yes	No