OptCare: Optimising palliative care for older people in the community

Submission date	Recruitment status	[X] Prospectively registered
10/10/2012	No longer recruiting	Protocol
Registration date	Overall study status	Statistical analysis plan
05/06/2013	Completed	Results
Last Edited	Condition category	Individual participant data
07/07/2016	Other	[] Record updated in last year

Plain English summary of protocol

Not provided at time of registration

Study website

http://www.csi.kcl.ac.uk/optcare.html

Contact information

Type(s)

Scientific

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers

13275

Study information

Scientific Title

Optimising palliative care for older people in community settings: development and evaluation of a new short term intergrated service

Acronym

OptCare

Study objectives

The aim of this study is to develop and evaluate the feasibility of the new STIPC service for frail older people in community settings (including care homes) delivered through integrated working between specialist palliative care services and community nursing teams, and close with GPs and geriatricians.

Ethics approval required

Old ethics approval format

Ethics approval(s)

NRES Committee South East Coast - Brighton and Sussex, 24/09/2012, ref: 12/LO/1367

Study design

Non-randomised observational cross-sectional study

Primary study design

Observational

Secondary study design

Non randomised controlled trial

Study setting(s)

Hospital

Study type(s)

Quality of life

Participant information sheet

Patient information can be found at http://www.csi.kcl.ac.uk/files/Link%20to%20patient% 20information%20sheet.pdf

Health condition(s) or problem(s) studied

Primary Care Research Network / Palliative care

Interventions

The research methods follow the Medical Research Council guidance for the development and evaluation of complex interventions.

Phase 1:

Intervention development involves a post-bereavement survey to determine preferences for care and palliative care outcomes by place of death for older people (n=900); and a stakeholder consultation with recipients of care and service providers/commissioners, on the survey findings to develop the intervention and then, an on-line/postal survey on the proposed components and outcomes.

Followed up at 2 months

Phase 2:

Participants were randomly allocated to intervention or control group following consent. The intervention arm involved a service delivered by two palliative care teams working with four community nursing teams in a single Community NHS Trust. The new service involved up to three visits in the community by the specialist palliative care teams to provide an extra layer of support over a 12 week period.

The control arm received their usual care provided by their GP or community nursing team. After 12 weeks, this group were offered the intervention however there was no research follow-up for this group beyond the 12 weeks from consent.

Both groups were given questionnaires to complete at baseline, 6 weeks and 12 weeks and the GP records were followed up for 6 months. The intervention group were also invited to take part in a qualitative interview after the 12 week study period.

Intervention Type

Other

Phase

Not Applicable

Primary outcome measure

Primary outcome as of 05/07/2016:

Five key symptoms are measured using the integrated Palliative care Outcome Scale at baseline, 6 weeks and 12 weeks (primary end point).

Original primary outcome:

Palliative care Outcome Scale

Secondary outcome measures

Secondary outcomes as of 05/07/2016:

- 1. Assistance with activities of daily living is measured using the Barthel Index at baseline and 12 weeks questionnaires
- 2. Performance status is measured using the Australia Karnofsky Index at baseline and 12 weeks questionnaires
- 3. Carer burden is measured using the Zarit carer burden at baseline and 12 weeks questionnaires

- 4. Service use and cost is measured/calculated using the Client Service Receipt Inventory at baseline and 12 weeks questionnaires
- 5. Survival is measured by reviewing GP medical records for mortality

Original secondary outcomes:

- 1. Client Service Receipt Inventory
- 2. EQ5D
- 3. QUALYCare survey
- 4. Texas Revised Inventory of Grief

Overall study start date

24/09/2012

Completion date

06/05/2016

Eligibility

Key inclusion criteria

Inclusion criteria as of 07/07/2016:

Phase one:

- 1. Older adults living with frailty using one of the participating community groups or residing in the participating care home; or
- 2. Carers of older adults (either informal carers e.g. family members or a carer working as a volunteer for one of the participating charitable organisation supporting older people in community settings)
- 3. Adults with capacity to give informed consent and communicate in English

Phase two:

- 1. The service providers are health or social care practitioners providing community based services including: specialist palliative care, general practice, community nursing, end of life care facilitators, dementia services and social care, providing services in the locality of Sussex Community NHS Trust
- 2. The commissioners are leads for end of life care services and are identified from the Care Commissioning Groups in the study site
- 3. Voluntary sector representatives are local individuals representing local/national organisations supporting/advocating for older people, e.g. Age UK, Alzheimer Society, Brighton and Hove Older People's Council, Carers Centre Brighton and Hove

Original inclusion criteria:

Individuals who registered the death of a person who died:

- 1. In the study site
- 2. In the 4-10 months prior to survey administration
- 3. Aged 75 years and over
- 4. From cancer or selected non-malignant illness common in advanced age
- 5. Died in a community setting (e.g. at home, care home or hospice) or hospital
- 6. Male or female participants

Participant type(s)

Patient

Age group

Senior

Sex

Both

Target number of participants

UK Sample Size: 900

Key exclusion criteria

- 1. Individual included in the National VOICES survey administered by Office for National Statistics (ONS) in 2012
- 2. Deaths where an informants address is missing
- 3. Deaths where an informant was an official (e.g. solicitor) or other identified person who would not be able to provide the required information

Date of first enrolment

06/01/2014

Date of final enrolment

18/03/2016

Locations

Countries of recruitment

England

United Kingdom

Study participating centre Sussex Community NHS Foundation Trust

Brighton General Hospital Elm Grove Brighton United Kingdom BN2 3EW

Sponsor information

Organisation

King's College London

Sponsor details

School of Social Sciences & Public Policy London

England United Kingdom WC2R 2LS

Sponsor type

University/education

Website

http://www.kcl.ac.uk/

ROR

https://ror.org/0220mzb33

Funder(s)

Funder type

Government

Funder Name

NIHR Trainees Coordinating Centre (UK)

Results and Publications

Publication and dissemination plan

1. The development work has been accepted for publication in Journal of the American Geriatrics Society (JAGS) and Age and Ageing (see below). Findings from the stakeholder and focus groups have also been presented orally and as a poster at the 9th World Research Congress of the European Association of Palliative Care, 9-11th June 2016, Dublin, Ireland and at the Palliative Care Congress, 9th-11th March 2016, Glasgow.

Bone AE, Morgan M, Maddocks M, Sleeman KE, Wright J, Taherzadeh S, Ellis-Smith C, Higginson IJ, and Evans CJ 'Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: perspectives of older people, carers and other key stakeholders' Age and Ageing 2016 (in-press)

2. Findings from the post-bereavement survey have also been presented at the Expo and Awards, Kent, Surrey and Sussex Academic Health Science Network, Lancaster Hotel, London 19th January 2016 and the International Research Conference EAPC, Copenhagen 2015 (Oral presentation):

Bone AE, Gao W, Gomes B, Sleeman KE, Maddocks M, Wright J, et al. Factors Associated with Transition from Community Settings to Hospital as Place of Death for Adults Aged 75 Years or Older: A Population-Based Mortality Follow-back Survey. Journal of the American Geriatrics Society. 2016 (in press).

3. Submission of the main paper to BMC Medicine

Intention to publish date

01/08/2017

Individual participant data (IPD) sharing plan

IPD sharing plan summary Available on request