ISRCTN32119670 https://doi.org/10.1186/ISRCTN32119670

Evaluation of Pilgrims Hospices rapid response community end of life service in East Kent

Submission date
22/06/2012

Recruitment status
No longer recruiting

Registration date
22/06/2012

Overall study status
Completed

Last Edited
24/06/2016

Condition category
Other

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

Plain English summary of protocol

Background and study aims
In England over half a million people die each year and while most people would prefer to die at home, many are not able to do so and more than half die in hospitals. This study will investigate a new rapid response hospice at home service which aims to support patients under hospice care to die in their preferred place. The aim of the study is to provide evidence on the outcomes and costs of rapid response hospice at home teams. The objectives are to assess the impact of the service on:
1. Patients' preference - whether the service enables more patients to die in their preferred place.
2. Carers' quality of life during and after death.
3. The relative costs and consequences of a rapid response hospice at home team compared with usual services.
4. A 'good death'.

Who can participate?
The study will monitor the actual and preferred place of death for 441 newly referred patients to the hospice. We will recruit 504 carers to complete postal questionnaires on quality of life, well-being and caring activities. We will also carry out up to 60 interviews with bereaved carers about the patients end of life experience.

What does the study involve?
The intervention to be tested is a rapid response hospice at home service. The main features of the service are that it:
1. Is available to patients in their own home (including care homes).
2. Has a robust hospice standard assessment which takes account of: patient preferences, carer /family preferences, patient needs and patient prognosis.
3. Provides hands-on care.
4. Responds rapidly to crises using human and material resources available 24/7 with access to health care assistants, a service coordinator, palliative care nursing, medical advice, and small pieces of equipment which can be carried by car.
5. Works in coordination with other community services.
The hospice operates from three sites covering separate catchment areas. Each site will be

randomly allocated to the order in which it will receive the service, with the first site starting with the service and the others offering it after 6 and 12 months, respectively. All patients will be eligible to access the service when it is offered in their area. Sites which do not yet have the service will continue to offer usual services.

What are the possible benefits and risks of participating?
There are no specific benefits or risks to participants as patients and carers will still be able to access the full range of hospice services, including hospice at home if they do not participate.

Where is the study run from?
The study is run from Pilgrims Hospices in East Kent, in collaboration with the Universities of Kent and Surrey and sponsored by East Kent Hospitals University NHS Foundation Trust.

When is the study starting and how long is it expected to run for?
The study started in December 2009 and will run until October 2012. Participants will be recruited for 2 years.

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

Who is the main contact?
Dr Claire Butler, Pilgrims Hospices, claire.butler@pilgrimshospices.org
Laura Holdsworth, University of Kent, l.m.holdsworth@kent.ac.uk

Contact information

Type(s)
Scientific

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers

9051

Study information

Scientific Title
Evaluation of Pilgrims Hospices rapid response community end of life service in East Kent: A Quasi-experimental multi-centre controlled trial

Study objectives
The quantitative evaluation is a pragmatic quasi-experimental multi-centre controlled trial, with an embedded cost evaluation. The study also includes a qualitative evaluation using in-depth interviews to explore carers' perceptions.

The aim of the study is to contribute to the development of the evidence base on the outcomes and costs of rapid response hospice at home teams.

The main hypothesis to be tested is that the rapid response service will significantly increase the number of patients who die in their initial preferred place of death compared to the control group of patients who receive usual services. Related hypotheses to be tested are that:
1) The rapid response service improves the quality of life of carers of patients in the intervention compared to carers in the control group
2. The overall cost of providing care for patients in the intervention group is not significantly different to the cost of providing care for patients in the control group. In addition the study will contribute to generating a hypothesis on the ways in which carers perceive the quality of care and judge a 'good death.

Ethics approval required
Old ethics approval format

Ethics approval(s)
NRES Committee South East Coast Kent, 09-H1101-75; First MREC approval date 22/12/2009

Study design
Quasi-experimental multi-centre controlled trial

Primary study design
Interventional

Secondary study design
Randomised controlled trial

Study setting(s)
Hospital

Study type(s)
Quality of life

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

Health condition(s) or problem(s) studied
Topic: National Cancer Research Network, Generic Health Relevance and Cross Cutting Themes; Subtopic: All Cancers/Misc Sites, Generic Health Relevance (all Subtopics); Disease: All, Health Services Research

Interventions
Hospice at home, The main features of the intervention are that it:
1. Is available to patients in their own home
2. Has a robust hospice standard assessment
3. Provides hands on care
4. Responds rapidly to crises using human and material resources available 24/7 and
5. Works in coordination with other community services

Intervention Type
Other

Phase
Not Applicable

Primary outcome measure
Patient preferred place of death

Secondary outcome measures
1. Carer quality of life and well-being - Carer outcomes will be measured at baseline on patient intake and 8 months later using self completion postal questionnaires. The outcome measures included in the questionnaire are the short-form SF12, measure of anxiety and depression (HADS), a measure of health utility (EQ-5D), and caregiving demand measured at baseline only.
2. Cost evaluation

Overall study start date
01/01/2010

Completion date
31/01/2012

Eligibility

Key inclusion criteria
1. All patients referred to the Pilgrims Hospices during the study and who die during the data collection period will be entered into the study.
2. All carers and bereaved carers who are able to consent will be eligible to participate.
3. Target Gender: Male & Female ; Lower Age Limit 18 years

Participant type(s)
Patient

Age group
Adult

Lower age limit

18 Years

Sex
Both

Target number of participants
Planned Sample Size: 1005; UK Sample Size: 1005; Description: 441 patients, 504 carers for questionnaires, 60 bereaved carers for interviews

Key exclusion criteria
Carers and bereaved carers not capable of giving consent

Date of first enrolment
01/01/2010

Date of final enrolment
31/01/2012

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
East Kent Hospitals EKHUFT
Canterbury
United Kingdom
CT2 8JA

Sponsor information

Organisation
East Kent Hospitals NHS Trust (UK)

Sponsor details
Ethelbert Road
Canterbury
England
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CT1 3NG

Sponsor type
Hospital/treatment centre

ROR
https://ror.org/02dqqj223

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research (NIHR (UK) - Research for Patient Benefit Programme, Grant: PB-PG-0808-16126

Results and Publications

Publication and dissemination plan
Not provided at time of registration

Intention to publish date

Individual participant data (IPD) sharing plan

IPD sharing plan summary
Not provided at time of registration

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/10/2015		Yes	No
Results article	results	01/10/2015		Yes	No
Results article	results	23/12/2015		Yes	No