

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

Submission date 22/06/2012	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 22/06/2012	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
Last Edited 24/06/2016	Condition category Other	<input type="checkbox"/> 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

Protocol serial number

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

Study type(s)

Quality of life

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(s)

Patient preferred place of death

Key secondary outcome(s)

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

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

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Sex

All

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

United Kingdom

England

Study participating centre

East Kent Hospitals EKHUFT

Canterbury

United Kingdom

CT2 8JA

Sponsor information

Organisation

East Kent Hospitals NHS Trust (UK)

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

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?
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Results article	results	01/10/2015	Yes	No
Results article	results	01/10/2015	Yes	No
Results article	results	23/12/2015	Yes	No