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Development of a postal questionnaire to measure satisfaction with services received in the year before death.

Submission date 23/01/2004	**Recruitment status** No longer recruiting	☐ Prospectively registered
		☐ Protocol
Registration date 23/01/2004	**Overall study status** Completed	☐ Statistical analysis plan
		☒ Results
Last Edited 15/12/2008	**Condition category** Signs and Symptoms	☐ Individual participant data

Plain English summary of protocol
Not provided at time of registration

Contact information

Type(s)
Scientific

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers
PSI12-30

Study information

Scientific Title

Study objectives

A major obstacle to research in palliative care is the lack of reliable and valid methods of collecting information on patient and family outcomes. The views of patients can be very difficult to obtain as many are too ill to be interviewed or to complete a questionnaire by the time they are referred to palliative care. In addition, only half of terminally ill cancer patients and fewer than a tenth of patients with non-malignant diseases who die receive specialist palliative care. Using patients as sources of data on the quality of care is therefore likely to lead to an incomplete picture of these services. An alternative method is to collect information from bereaved relatives and friends in the months after the patient's death. This retrospective approach has been used in a number of influential palliative care studies. Although there is uncertainty about the extent to which the views of bereaved relatives reflect those of the patients themselves, the great advantage is that by drawing random samples from death registrations it is possible to get information on a complete population of people who die - not just those referred to specialist services or, indeed, those known to be dying.
To date, retrospective surveys of care for the dying have been interview-based. However, interview surveys are costly to execute. For many purchasers and providers the cost of an interview survey of bereaved relatives is likely to be prohibitive. Alternatively, self-completed postal questionnaires are cheaper than interviews and need fewer trained staff to administer and analyse. A postal questionnaire which assesses use of and satisfaction with services for the dying could, therefore, be a useful addition to the limited measures available to health districts and service providers seeking to evaluate services for the dying.
However, before recommending that a questionnaire be used to collect this information it is necessary to establish that this method of data collection is acceptable to bereaved respondents, and to understand whether and how responses and information collected in this way differs from that obtained in an interview survey. We therefore developed a short form of the interview schedule used successfully in previous nationally representative samples, and which covered both primary and secondary care. In the study we have investigated the effect of administering it by post on response rate, response bias and on the nature of responses to questions on service used, unmet needs for and satisfaction with services. Following consultation with health purchasers and providers a shortened version of the Regional Study of Care for the Dying (RSCD) interview schedule was developed. This is called VOICES (Views Of Informal Carers - Evaluation of Services) and contains 42 questions about care received in the last year of life.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Not provided at time of registration

Study design

Randomised controlled trial

Primary study design

Interventional

Secondary study design
Randomised controlled trial

Study setting(s)
Not specified

Study type(s)
Not Specified

Participant information sheet

Health condition(s) or problem(s) studied
Symptoms and general pathology: Pain

Interventions
1. Postal questionnaire
2. Interview questionnaire

Intervention Type
Other

Phase
Not Specified

Primary outcome measure
Questionnaire responses. Of the 431 informants who were sampled for this study, 230 agreed to take part giving a response rate of 53%. This corresponded to 56% of those approached to become postal respondents and 52% of the informants approached to become interviewees. These results demonstrate that the postal questionnaire is a viable alternative to interviews for use in collecting information on outcomes in palliative care, at least in terms of response rate. Overall the results of this study show that the postal questionnaires are a viable alternative to a face-to-face interview in retrospective bereavement surveys of care for the dying. However, particular care needs to be paid to ensuring that the wording of the questionnaire is ambivalent and are understood by members of the target population, and, in particular that respondents are helped to identify whether the deceased did in fact receive care from target services. The VOICES questionnaire is currently being revised in the light of these findings.

Secondary outcome measures
Not provided at time of registration

Overall study start date
23/06/1995

Completion date
20/11/1997

Eligibility

Key inclusion criteria

A random sample of death was drawn from death certificates of residents in an inner London health district who died from cancer and whose death were registered by someone resident in, or near, the district.

Participant type(s)
Patient

Age group
Not Specified

Sex
Not Specified

Target number of participants
230

Key exclusion criteria
Not provided at time of registration

Date of first enrolment
23/06/1995

Date of final enrolment
20/11/1997

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
Department of Palliative Care and Policy
London
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Sponsor information

Organisation
Record Provided by the NHS R&D 'Time-Limited' National Programme Register - Department of Health (UK)

Sponsor details

The Department of Health
Richmond House
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Sponsor type

Government

Website

http://www.doh.gov.uk

Funder(s)

Funder type

Government

Funder Name

NHS Primary and Secondary Care Interface National Research and Development Programme (UK)

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	01/12/1998		Yes	No