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Understanding the pastoral, spiritual and religious care and support needs of children and young people with life-threatening or life-shortening conditions, and their families

Submission date
19/08/2020

Recruitment status
No longer recruiting

Registration date
10/09/2020

Overall study status
Completed

Last Edited
05/06/2025

Condition category
Other

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

Plain English summary of protocol
Background and study aims
Having a life-threatening or life-shortening condition is an extremely challenging experience and raises troubling questions in people's minds. Having the chance to explore these thoughts and feelings, and to feel valued and supported, are core elements of what is known as pastoral and spiritual care. For some, support to practice religious beliefs is important to coping. Not meeting these needs causes additional suffering. In the NHS, chaplaincy is defined as the main provider of pastoral, spiritual, and religious (PSR) care. Anyone, religious or not, may have spiritual and pastoral needs. We know very little about how to best meet the PSR needs of children diagnosed with a life-threatening or life-shortening condition, and their parents.

The aim of this study is to gather evidence that the NHS and children's hospices can use to guide how they meet the PSR needs of children and their families, including how chaplaincy services can best care for and support them.

The study is made up of four work packages (WP):
1. Work package 1: A survey of NHS and children's hospice chaplaincy services in England will describe their characteristics, ways of working, and compare provision for adult patients, parents, and children.
2. Work package 2: Focus groups with chaplaincy staff will explore their views on the differences between caring for children, parents, and adult patients, the unique needs of families, and barriers to meeting the PSR needs of families
3. Work package 3: Interviews with children and parents will explore their PSR needs, sources of support, understanding of chaplaincy services, and experiences of using them
4. Work package 4: Focus groups with clinical/care teams will investigate their views on the PSR needs of families, how they respond to them, and their views about how chaplaincy services can support families and the team

Who can participate?
1. Work package 1: Chaplaincy service leads at acute NHS Trusts or chaplains/heads of care at children's hospices in England
2. Work package 2: Salaried chaplains and chaplaincy volunteers based in acute NHS Trusts in England, and chaplains based in children's hospices across England
3. Work package 3: Children and young people with life-threatening or life-shortening conditions, and their parents. Clinical or hospice care teams will identify children and young people on their caseloads suitable for the study, and for whom they have no concerns about passing on information about the study. Around 12 clinical teams and 5 hospices will be supporting the recruitment of children/young people and parents to the study.
4. Work package 4: Staff in clinical or care teams from the clinics and hospices supporting the recruitment of children and young people, and their parents, to work package 3

What does the study involve?
The study will last 26 months, and is made up of four work packages:
1. Work package 1: Chaplaincy service leads will complete an electronic survey which will take about 20 minutes to complete.
2. Work package 2: Chaplaincy staff will attend a single focus group discussion, lasting 60-90 minutes and taking place in their usual place of work or via a virtual conferencing facility.
3. Work package 3: Children, young people and parents will take part in a single interview – conducted face-to-face or via telephone or video call. Interviews with children/young people will around 40-70 minutes; interviews with parents will last around 60-90 minutes.
4. Work package 4: Clinical team members will attend a single focus group discussion, lasting 60-90 minutes and taking place in their usual place of work or via video conference. Focus groups for hospice chaplains will either be via video conference or take place at three children's hospices, with chaplains working in other hospices travelling to these venues.

What are the possible benefits and risks of participating?
Professionals taking part in this study will be doing so in their professional capacity and the study concerns their professional role. There are no risks to them taking part in the study.

There are no direct benefits to the children, young people, and parents who take part in this study. However, we know from other studies that people typically value the opportunity to 'tell their story'. There is a risk that children, young people, and parents may find talking about their situation, concerns and experiences cause them to become upset or feel uncomfortable. The study has put in place a number of strategies to minimise that risk and to ensure distress is well-managed, there is access to appropriate support, and there are no longer-term negative impacts.

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

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

Who is funding the study?
The National Institute for Health Research (UK) Health Services and Delivery Research Programme

Who is the main contact?
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Contact information

Type(s)
Scientific

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Integrated Research Application System (IRAS)
288298

Study information

Scientific Title
Supporting the complete care of children and young people with life-threatening or life-shortening conditions, and their families: a mixed-method study of pastoral, spiritual and religious needs and support, and the role of chaplaincy services

Study objectives
To support evidence-informed change and practice in the provision of pastoral, spiritual and religious care, through chaplaincy services and other health/care professionals, to children and young people facing end of life and their parents

Ethics approval required
Old ethics approval format

Ethics approval(s)
1. Work package 1, not required
2. Work packages 2, 3, and 4, Pending 01/09/2020, NHS REC via UK Health Research Authority approvals process

Primary study design
Observational

Study design

A mixed-method observational study, comprising four work packages:
1. Work package 1, a survey of chaplaincy services in acute NHS trusts and children's hospices
2. Work package 2, focus groups with chaplaincy staff based in acute NHS trusts and children's hospices
3. Work package 3, interviews with children and young people, and parents
4. Work package 4, focus groups with clinical and hospice care teams

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Children and young people, and their parents, diagnosed with a life-shortening or life-threatening condition

Interventions
The study will last 26 months, and is made up of four work packages:
1. Work package 1: A survey of heads of chaplaincy services in all acute NHS Trusts and children's hospices in England will describe the organisation and delivery of NHS and hospice chaplaincy services, and identify differences in the nature of provision for children, parents, and adult patients
2. Work package 2: Focus groups with chaplaincy staff and chaplaincy volunteers will explore views and experiences of the pastoral, spiritual and religious (PSR) needs of children and young people facing end of life, their parents and the staff involved in their care, and the ways chaplaincy meets those needs
3. Work package 3: Interviews with children and young people, and parents, will explore pastoral, spiritual, and religious (PSR) needs, sources of support, and experiences of accessing and using PSR care within NHS or children's hospice settings, including chaplaincy services
4. Work package 4: Focus groups with clinical teams will explore understanding, awareness and use of chaplaincy services, and their perceived impacts; their observations of the pastoral, spiritual and religious needs of patients, and their parents; and their roles (perceived or actual) in identifying and responding to these needs

Intervention Type
Other

Primary outcome(s)
1. Pastoral, spiritual, and religious needs of children and young people facing end of life, and their parents, will be collected between 7 and 19 months:
1.1 Via interviews with children and young people (facing or who have faced end of life), parents of such children, and bereaved parents
1.2. Via focus groups with chaplaincy staff (salaried and volunteer) working in acute hospitals and children's hospices
1.3. Via focus groups with members of clinical and care teams in acute hospitals and children's hospices

Key secondary outcome(s)
1. Identification and description of the organisation and delivery of pastoral, spiritual and religious care in the NHS and children's hospice by chaplaincy services, and differences in that care for children and young people, parents and adult patients, using the following:
1.1. A cross-sectional survey of NHS chaplaincy services in England and all children's hospices in England between 3 and 6 months

1.2. Via focus groups with chaplaincy staff (salaried and volunteer) working in acute hospitals and children's hospices between 7 and 19 months

Completion date
30/09/2022

Eligibility

Key inclusion criteria
1. Work package 1:
1.1. Head/service lead of chaplaincy services of an acute NHS Trust or children's hospices in England, or, in case of children's hospice where no in-house chaplaincy service, the head of care
2. Work package 2:
2.1. Salaried chaplains and chaplaincy volunteers based in chaplaincy services participating in the study. Services will be purposefully selected to represent both different organisational settings (such as children's NHS Trusts, children's hospitals, general acute services, and hospices) and faiths/religions represented in the local population.
3. Work package 3. Comprises three sub-samples:
3.1. Sub-sample A:
3.1.1. Aged 10 to 18 years
3.1.2. Diagnosed with: relapsed cancer or cancer with ≤75% survival rate; a degenerative neuromuscular condition with evidence of significant deterioration in the past 12 months; or kidney failure
3.1.3. Aware of (potentially) life-limiting nature of condition
3.1.4. Not at end-stage/dying
3.1.5. No significant cognitive impairment
3.1.6. Parents of children aged 0 to 18 years and with the characteristics listed in 3.1.2. to 3.1.4.
3.2. Sub-sample B:
3.2.1. Aged 12 to 24 years
3.2.2. Diagnosed with cancer when aged between 5 and 17 years
3.2.3. Transferred to long-term follow-up within the past 1 year
3.2.4. Within 10 years of the end of treatment
3.2.5. No significant cognitive impairment
3.3. Sub-sample C:
3.3.1. Bereaved parents
3.3.2. Child's cause of death was a life-threatening or life-shortening condition or associated complications
3.3.3. Child died aged 0 to 18 years
3.3.4. Child died ≥3 months ago and ≤2 years ago
4. Work package 4:
4.1. Member of specialist paediatric clinical teams (oncology, renal, neurology, and paediatric and neonatal intensive care) or children's hospice care/bereavement team. Purposive sampling ensures representation of relevant professions (medical, nursing, and allied health), as well as post/role (inpatient, community/outreach, and clinic/outpatient), duration of experience, and faith/beliefs within the recruited sample.

Participant type(s)
Mixed

Healthy volunteers allowed
No

Age group
Mixed

Sex
All

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
01/10/2020

Date of final enrolment
28/02/2022

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of York, Social Policy Research Unit
Alcuin B Block
York
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YO10 5DD

Sponsor information

Organisation
University of York

ROR
https://ror.org/04m01e293

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

Individual participant data (IPD) sharing plan
The data sharing plans for the current study are unknown and will be made available at a later date

IPD sharing plan summary
Data sharing statement to be made available at a later date

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		01/05/2025	05/06/2025	Yes	No