Study Protocol

Full Title:

What does 'good' palliative care look like for children and young people? A qualitative study of parent experiences and perspectives.

Short title: Learning from parents' experiences of palliative care for their child.

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1 Protocol Version Number and Amendment History

Version	**Author**	**Date**		**Approved**
1.0	Jo Taylor	16/04/2021		
Amendments				
Version	**Author**	**Date**	**Changes made**	**Approved**
1.1	Jo Taylor	14/07/2021	Clarified eligibility criteria for child age (0-17 in line with NICE guideline) and parent status (i.e. including parents or legal guardians). Reduced information to be collected at consent to contact, added marking of prepaid envelopes for recruitment as confidential, clarified details about transcription and storage of interview recordings, and clarified timing of data withdrawal from study.	

Contents

2 Plain English summary

Around 4,500 infants and children die in England and Wales every year, and the number of children and young people with conditions that will shorten their life (life-limiting conditions) is rising. In children, more than 300 conditions are life-limiting, including Duchenne muscular dystrophy and cancer.

Palliative care is an important element of the care that these children need, and focuses on improving quality of life for children and their families throughout a child's life and death. In England, palliative care is mainly provided by NHS and children's hospice services, but this varies across the country. This means that children, even with similar healthcare needs, may have quite different experiences of palliative care.

In 2016, guidelines for children's palliative care in England were published to ensure all children receive the care they need, including care provided by doctors with training in children's palliative care, nursing care that enables children to stay at home at the end of their life and better planning for what happens when they die.

However, there is little evidence about what good experiences of palliative care for children are and how the guideline recommendations may feature in these. This study aims to explore this, by listening to parents' accounts of the palliative care their child and family receive and examining these accounts to understand what good palliative care is. We hope to include the parents or legal guardians of around 30 children and young people (age 0-17) who are either receiving palliative care or who have died.

The study is being carried out by an experienced research team at the University of York, who are working closely with a parent advisory group who will provide input throughout the study.

The study will provide important evidence to inform future policy and service developments in children's palliative care.

3 Background

Around 4,500 infants and children (age 0-19 years) die in England and Wales every year (1, 2), and the number of children with life-limiting or life-threatening conditions has been rising with latest figures estimating there are more than 86,000 children and young people with a life-limiting condition in England (3).These include conditions for which there is no reasonable hope of cure and from which children or young people will die, as well as conditions for which curative treatment may be feasible but can fail, such as cancer or heart failure. In children and young people, more than 300 diagnoses are life-limiting or life-threatening (4), including Duchenne muscular dystrophy, severe cerebral palsy, neurodegenerative conditions, and severe congenital anomalies. Prognosis varies significantly, with some children living only a few weeks or months and others living into adulthood despite families receiving a diagnosis in infanthood (5). Although many of the individual diagnoses are rare, as a group children and young people with a life-limiting condition are a larger patient population than many other long-term conditions in children and young people, such as diabetes mellitus (6).

Palliative care, which for children is defined as "an active and total approach to care, which begins from diagnosis or recognition and continues throughout the child's life and death" (7), is an important component of the care that children and young people with a life-limiting condition as well as children who die from other causes will require, and includes symptom and pain management, provision of short breaks for the child and their family, psychosocial and spiritual care, and end of life and bereavement care. Palliative care is provided by a range of services, including the hospital or community healthcare team that provides ongoing care for a child, for example for children with cancer by a paediatric oncology team, or for infants born with a life-threatening condition by a neonatal team. For other children, palliative care may be provided by a children's community nursing team, a specialist paediatric palliative team or a children's hospice, some of which also provide specialist palliative care, defined as palliative care that is provided by a team or service led by a palliative care trained clinician or nurse (8).

In England, palliative care provision for infants, children and young people varies significantly by service, region and specialty, and there are also known barriers to accessing palliative care (9), meaning that families of children even with similar healthcare needs may receive a very different experience of palliative care (10, 11). The age range covered by the services that provide palliative care for children also varies, with some services caring for young adults in their 20s yet others stopping when young people turn 18 (12). To help standardise and improve children's palliative care in England, the National Institute for Health and Care Excellence (NICE) developed a new clinical guideline in 2016 (13) and associated quality standard in 2017 (14), although it is worth noting here that the guideline only applies to infants, children and young people aged 0-17 years. The quality standard sets out six quality statements about the care that children with a life-limiting condition should receive, which include access to specialist palliative care and psychological support, being involved in advance care planning, and having access to appropriate support and care when approaching the end of life (see Table 1 for a summary of the NICE quality standards).

Table 1 – NICE quality standards for end of life care for infants, children and young people (13)

Statement 1	Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.
Statement 2	Infants, children and young people with a life-limiting condition have a named medical specialist who leads and coordinates their care.
Statement 3	Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.
Statement 4	Infants, children and young people with a life-limiting condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.
Statement 5	Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.
Statement 6	Infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

Little is known about how the elements of care set out in the NICE quality standard feature in families' experiences of palliative care, and what, for families, good palliative care is about. There are numerous qualitative studies that explore parents' experiences about being a parent of a child with a life-limiting condition, and about the care provision and needs for these children in their everyday lives (15-17). While these studies provide important insights about families' care needs and highlight points in the care pathway that could be improved such as around diagnosis and when to introduce palliative care, they tend to provide fewer insights about palliative care provision and how this is experienced. There are other studies that focus on palliative care, which while usefully highlighting aspects of care that can be improved when a child dies, tend to be limited in focus. For example, exploring only the very end of life care period or a specific aspect of that care such as decision-making (18), advance care planning or communication (19), or focusing on a particular population such as children with cancer (9), or a particular setting such as a neonatal unit, paediatric intensive care unit or children's hospice (20, 21).

To our knowledge, there is no robust or recent UK study that has explored parental experiences of palliative care for children or sought to understand what good palliative care looks like from an experiential perspective and how the NICE quality standards feature in these experiences. The study proposed here aims to address this evidence gap and hopes to inform future service developments and clinical guidelines for children's palliative care.

4 Study aim and research questions

This study will explore parents' experiences and perspectives of palliative care and palliative care planning for their child with an aim to understand what 'good' palliative care experiences are for parents. The study will also seek to understand the role of key aspects of care covered in the NICE Quality Statements (see Table 1).

The study will answer the following questions:

1. What are parents' experiences of palliative care for their child and the wider family?
2. What do parents perceive are the factors that influence access to and experiences of palliative care?
3. How do the NICE Quality Statements feature in parents' accounts of palliative care?
4. What do parents perceive are the factors that influence access to and experiences of the care elements set out in the NICE Quality Statements?
5. What does 'good' palliative care look like for children with life-limiting conditions from parents' experiences and perspectives?

5 Study design

This is an exploratory qualitative study involving thematic analysis of semi-structured individual interviews with parents of children with a life-limiting condition who are receiving palliative care or have discussed palliative care with their child's healthcare team, and parents whose child has died. The aim of the study is to explore experiences and perceptions of palliative care.

The study will be informed by Appreciate Inquiry (22), which while most commonly used as a service improvement methodology, can usefully focus qualitative research on drawing out what works well (the Discovery phase) and what could be (the Dream phase), and is aligned well with qualitative methods because it uses story telling as a means to explore this. Appreciative Inquiry has been successfully used in a UK study looking at the needs of children with a life-limiting condition in one region of England (23), and has also underpinned qualitative research exploring other areas of health (24-27).

Appreciative Inquiry has its origins in participatory action research, but rather than being problem-oriented (i.e. what is wrong that needs to change?), Appreciative Inquiry is underpinned by five foundational principles (see Table 2) which encourage from the outset a focus on what works and on drawing out positive experiences and imaginings from participants and the research process itself (22). This approach can be particularly valuable for research about populations, like children with life-limiting conditions, who are viewed as disadvantaged or vulnerable, which can lead to research that is either problem-oriented or research findings that are problem-focused (28).

Table 2 – The foundational principles of Appreciative Inquiry (22)

Principle	*Definition*
The Constructionist Principle	Reality is socially constructed through language
The Simultaneity Principle	Change begins from the moment a question is asked
The Poetic Principle	Our choice of what we study determines what we discover
The Anticipatory Principle	Our image of the future shapes the present
The Positive Principle	Positive questioning leads to positive change

The underpinning philosophy and principles of Appreciative Inquiry will inform the design and conduct of this study, in particular the data collection and analytical processes, shaping first the questions we will ask participants (to ensure a focus on positive experiences and imaginings as well as experiences that parents may wish to share that may be negative), and then our process of developing analytical themes and the interpretations we draw from the study, which we will co-construct with our parent advisors (see Section 5).

6 Patient and public involvement

We will work closely with the MHRC Family Advisory Board (FAB), which is an advisory board of parents and other adult family members of children with a life-limiting condition including parents of a child who has died.

The FAB (referred to as 'our parent advisors' herein) have already advised us on our plans, for example highlighting the importance of including parents of children who are living with a life-limiting condition as well as parents of children who have died; the importance of including diverse end of life and care experiences and developing a sampling strategy that will achieve this; and the need to advertise the study outside of NHS and hospice organisations, e.g. through social media.

We have identified key points during the study that our parent advisors will be asked to provide input:

- Helping to develop the recruitment approach and topics to be covered in interviews
- Helping to prepare participant information sheets and study adverts and letters
- Helping to refine and test the interview topic guide
- Providing feedback on the quality and content of initial interviews to inform any refinements to the topic guide
- Developing and sense-checking analytical themes during the analysis
- Interpreting study findings and developing recommendations for policy and practice
- Reviewing public facing outputs (e.g. website content, Plain English summaries).

Our parent advisors will either input through discussion at the FAB monthly meetings or by email, post or telephone when needed between meetings or when reviewing documents, depending on individual parent preferences regarding mode of communication.

7 Study methods

7.1 Sample and sampling strategy

The study sample will include parents or legal guardians of a child who meet the following criteria:

- Parent or legal guardian is 18 years old or greater
- Their child has a life-limiting diagnosis (see Table 3) or has died (at least 3 months ago and less than 3 years ago)
- Their child is <18 years old (or died when <18 years old) (i.e. age range of children included is 0-17)
- There is evidence that palliative care has been discussed (i.e. their child is supported by a palliative care service or has an advance care plan) or the child has died.

We will not include those:

- Parents/legal guardians aged less than 18 years
- Those whose child has died in the last 3 months or longer than 3 years ago
- Those who lack capacity to participate in the study, guided by the 2005 Mental Capacity Act

Table 3 – Categories of life-limiting conditions (29)

Life-threatening conditions for which curative treatment may be feasible but can fail	Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.	Examples: cancer, irreversible organ failures of heart, liver, kidney.
Conditions where premature death is inevitable	There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.	Examples: cystic fibrosis, Duchenne muscular dystrophy.
Progressive conditions without curative treatment options	Treatment is exclusively palliative and may commonly extend over many years.	Examples: Batten disease, mucopolysaccharidoses.
Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health	Children can have complex health care needs, a high risk of an unpredictable life-threatening event or episode, health complications and an increased likelihood of premature death.	Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury.

All adults who provide regular parenting for a child with a life-limiting condition or a child who has died will be invited to take part (e.g. mothers, fathers, step-parents, adoptive parents, legal guardians). This will be made clear in the invitation letter and participant information sheet that parents receive by referring to the term parent / guardian throughout these documents. Parents who are separated or divorced will both receive an invitation pack for the study. For all families, parents will be offered the choice of being interviewed together or separately if more than one parent of a child wishes to take part.

Exclusion criteria for bereaved parents have been informed by recent literature (30-32), our own experiences of carrying out research with this population (33), through discussion with our parent advisors, and due to our focus on NICE quality standards which were introduced in 2017 (14).

A stratified maximum variation purposive sampling strategy (34) will be undertaken in order that the sample includes similar size sub-groups of parents who are currently receiving elements of palliative care for their child with a life-limiting condition and parents whose child has died, and reflects the diversity within this population of parents both in terms of their own characteristics but also in terms of their child's condition. These purposive sampling criteria include type of diagnoses in the child (with similar numbers of parents recruited for each category in Table 3), and including at least 5-6 parents of children with cancer as the existing research suggests they experience distinct barriers to accessing palliative care that are important to explore (9), duration of illness and prognosis, age and capacity of child, and ethnic origin, all of which have been identified as potentially affecting access to palliative care (9). Variations in provision of palliative care will also be sought (e.g. access to children's hospice, and for bereaved parents the setting in which end of life care took place, the organisations providing palliative care and where their child died, and if any follow-up bereavement care has been offered). This will enable diverse perspectives to be captured, but also comparative analyses where appropriate (35). To capture the diversity of perspectives, we anticipate that a sample of approximately 30-40 parents of around 20-30 children or young people will be required. We will monitor recruitment to ensure that we are seeing a spread across these key characteristics.

7.2 Recruitment

Participants will be recruited from children's hospices, third sector organisations (e.g. Together for Short Lives, CLIC Sargent, Muscular Dystrophy UK, Child Bereavement UK), NHS trusts (e.g. through relevant acute and community paediatric services, e.g. palliative care teams, community nursing teams, neuromuscular and oncology services), parent facing organisations and via social media. We are recruiting from a range of settings because not all children with a life-limiting condition are supported by their local children's hospice.

We will recruit from organisations in several regions of England to ensure that regional variations in care provision can be explored, and to include areas that are diverse in terms of their geography, ethnicity and economy. We will initially recruit via 3-6 NHS palliative care teams and 3-6 children's hospices, and expand to other NHS services and organisations to achieve the required sample size and diversity during the allocated data collection period. The palliative care teams and children's hospices will be selected to reflect a mix of urban/rural, wealthy/deprived and areas in which minority ethnic groups are well represented, and also their involvement in other children's palliative care research to minimise burden on sites and families.

Our parent advisors are keen for us to recruit parents via parent facing organisations e.g. Together for Short Lives, and via social media sources e.g. Twitter and Facebook, so we will advertise the study throughout the data collection period via appropriate websites and social media pages. Parents are keen that we use these sources to avoid healthcare practitioner gate-keeping (36). We will work closely with our parent advisors in developing a strategy for recruitment via social media to ensure that parents are explicitly aware that the study is focused on palliative care, including planning for end of life, and that the study is looking for parents who have either received palliative care for their child or have been involved in discussions and/or planning for end of life. This strategy of using social media has been used successfully in other research carried out by the study team.

Taking advice from our parent advisers, we will use separate study documents to recruit bereaved parents and non-bereaved parents (this will include separate invitation letters, participant information sheets, consent forms, and social media adverts).

The following methods of recruitment will be used across the sites, to be negotiated with each site depending on their infrastructure and service provision and also to accommodate the different ways in which organisations stay in contact with families:

7.2.1 Face-to-face, telephone, email or postal invitation from participating organisations (NHS trusts, children's hospices and parent bereavement services)

Clinical staff or other staff who are known to families will discuss the study with all potentially eligible parents who they see or speak to in consultations, meetings and visits, or provide eligible parents with a study information pack by post or email (for example if they are not expected to have direct contact with them during the data collection period). This information pack will contain an invitation letter, participant information sheet, the contact details of the study team at the University of York, a consent-to-contact (CTC) form (electronic or paper), and where relevant a pre-paid return envelope addressed to the study team and marked confidential.

The CTC form will include the parent's name, address, contact details, and statements of consent for the study team to contact them. For parents who are introduced to the study verbally, the CTC form can either be completed with the parent at the time of introducing the study (and securely uploaded by the member of staff to the study team at the University of York) or be taken away by the parent to complete and return by post (parents will be provided with a pre-paid envelope), email or via a telephone call with the study team. Parents who receive information about the study by email or post will be asked to complete and return the CTC form or contact the study team directly.

The study team will contact all participants who complete a CTC form or express an interest in taking part to discuss the study, check eligibility, and provide the participant with a consent form if they meet the eligibility criteria and would like to take part in the study. After the consent form is completed and returned to the research team, the study researcher will contact the participant to book an interview.

7.2.2 Study promotion with parents self-referring (NHS trusts, hospices and other relevant organisations)

An advert (developed in collaboration with our parent advisors) will be placed in outpatient clinics, third sector organisation and hospices; and/or on trust / organisation websites, Facebook pages, Twitter feeds

and in newsletters. Participants who, having seen the study advert, are interested in taking part in the study will be directed to contact the study team at the University of York. As above, they will be provided with an information pack about the study by post or email, and will be asked to complete the consent form via post, email or a telephone call before taking part in an interview.

7.3 Data collection

We will conduct video call or telephone in-depth semi-structured interviews, depending on the preference of individual participants. Although face to face interviews are most commonly used in qualitative research, there are a growing number of studies that successfully use telephone interviews (37-39), including our own with parents of children with a life-limiting condition (40), and parents of children with a gastrostomy (41). We will draw on learning from these studies, which show some differences between data collected by telephone compared to face to face, about techniques to employ during interviews to ensure the data we obtain is rich and detailed. If Covid-19 restrictions lessen during the study to safely allow face to face contact, we will also offer face to face interviews as an option; however, we anticipate that this is unlikely to occur (data collection period is May to September 2021). If participants are interviewed face to face, these will take place in a setting of their choice (e.g. home, hospice or university building).

The interviews will explore the parents' accounts of any palliative care their child and the wider family have received, the introduction and timing of palliative care services, any palliative care discussions or planning that have happened, and perceptions on what aspects of care enhance quality of life for their child and the family, which is the primary aim of palliative care services. Unmet needs for palliative care will also be explored, and for parents of children who have died, their experiences of care provided during the end of life period of care will be explored (including access to but not provision of bereavement services which is beyond the scope of the study). Prompts for each of the NICE quality standards will be used to ensure these are covered across the topics. Appreciative Inquiry informed topic guides (see Appendix A and B), initially developed from the literature and then revised and piloted in collaboration with our parent advisors, will be used to ensure that interviews are consistent in the issues covered. The semi-structured nature of the interviews will allow collection of rich data on parents' own views and experiences but will also allow for consistent exploration of prioritised topics and therefore comparison between individuals and exploration of similarities and differences based on sampling characteristics (42). As bereaved parents will be asked different questions, a separate topic guide will be developed for this group of participants.

We will aim for the interviews to last between 60-90 minutes to allow for exploration of all key topics but taking into account the potential burden for parents (see section 8). Before the interview starts, written informed consent will be obtained (see section 8). With the participant's consent, the interview will be recorded digitally and later transcribed intelligent verbatim. Interviews will be conducted by experienced qualitative researchers who will meet regularly with the study team to reflect on the interviews conducted and debrief as required. Researchers conducting the interviews will make field notes during the data collection period to record key points, observations and thoughts they have during and after individual interviews. This will be used during the analysis to aid interpretation and encourage researcher reflexivity throughout the study (43).

Interviews will continue until we reach either 1) data saturation, in that no new topics are being raised (44), or 2) a sample size of 40 families if data saturation is not reached by this point (which the study resources

and timeline will allow for). We will begin to monitor data saturation after we have conducted 20 interviews, and check after each additional interview.

7.4 Data analysis

The interview data will be analysed using thematic analysis (45). NVivo version 12 will be used for managing, coding and exploring data. The analysis will be an iterative process, informed by the principles of Appreciative Inquiry, with some steps repeated if necessary (45):

7.4.1 Familiarisation

The interview transcripts will be read and re-read to familiarise with these data, with notes taken on key concepts and emerging ideas, issues and experiences.

7.4.2 Generating initial codes

Interesting features of the data will be systematically coded across all the transcripts, identifying all data in relation to each code. A priori codes pertaining to the NICE Quality Standards will be used to ensure these aspects of care are explored explicitly. Codes will be grouped into descriptive categories to explore the meaning of codes and potential relationships between codes.

7.4.3 Theme development

Analytical themes that seek to explain what good palliative care looks like and why, and that represent participants' experiences and perspectives on palliative care will be developed by summarising and seeking to understand the coded data and descriptive categories and further exploring relationships between these. Comparison between the different accounts will be undertaken to clarify the recurring themes and ensure that the themes represent the individual cases (including unusual accounts of palliative care and key differences between children in the different diagnostic groups (see Table 2) that make up the data.

7.4.4 Reviewing themes

In this phase the themes will be reviewed and refined in relation to the coded data and through discussion with the study team, and our parent and clinical advisors. A thematic map of the themes will be developed.

7.4.5 Defining and naming themes

During this phase the key features of each theme will be specified and clearly defining and naming each theme. Quotations that illustrate the meaning of each theme and the relationship between themes and any sub-themes will be selected for reporting.

7.4.6 Assuring quality

We will use several methods to enhance the quality of data analysis (46). An experienced qualitative researcher will analyse the data with regular input from the study team during the coding process and development of themes. As we develop the analytical themes, we will also seek regular input from our parent advisors. Preliminary findings will then be discussed and interpreted with our academic, clinical and parent advisors to help assure credibility (truth value) and authenticity (that findings represent a range of different realities), and to inform any policy and practice recommendations arising from the study.

8 Study management and oversight

8.1 Study team

Dr Johanna Taylor (study lead)

Professor Lorna Fraser

Professor Karl Atkin

Dr Jackie Martin-Kerry

8.2 Sponsorship

University of York

8.3 Study management and oversight

Jo Taylor (JT), an experienced qualitative researcher with significant experience of conducting research in paediatric palliative care, will lead the study, supported by Lorna Fraser (LF), Director of the Martin House Research Centre (MHRC) (www.york.ac.uk/mhrc) and Karl Atkin (KA), a medical sociologist and experienced qualitative researcher. Dr Jackie Martin-Kerry (JMK), an experienced qualitative research fellow, has been appointed to work on the study under the supervision of JT, to conduct the qualitative interviewing and undertake the analysis. JT will be responsible for the study's timely completion, the quality of the work, adherence to ethical standards, and effective dissemination and impact. JT will meet with JMK weekly throughout the study, and LF will join these meetings monthly.

The MHRC Management Team (who together contribute qualitative, topic and clinical expertise) will review study progress and provide expert input when needed. The MHRC Advisory Board, which brings clinical, service, academic and family expertise from outside MHRC, will also offer guidance to the study team, particularly around interpretation of study findings and development of recommendations for policy and practice. The study will also receive input as required from the funder's (Together for Short Lives, a UK charity for children with life-threatening and life-limiting conditions) own independent Advisory Council.

9 Governance and ethics approval

The study will be conducted to protect the human rights and dignity of the participant as reflected in the 1996 version of the Helsinki Declaration. The explicit wishes of the participant will be respected including the right to withdraw from the study at any time, the interest of the participant will prevail over those of science and society, provision will be made for indemnity by the investigator and sponsor and a contact name for further information will be provided.

We will seek ethical approval from the NHS Health Research Authority, addressing issues concerning informed consent, participant burden and distress, participant confidentiality, data management and researcher safety and distress, as summarised below.

9.1 Informed consent

The study will use a 3-stage consent process.

1. Participants will be provided with brief information about the study from a recruiting organization and can express an interest in taking part by completing a "consent to be contacted form" to return to the research team, or by emailing or phoning the study team directly. Parents who see information about the study on social media or via recruiting organization websites or newsletters will be directed to contact the study team, who will then send them the information pack.

2. A researcher from the team will arrange a call with potential participants who are interested in taking part to explain and discuss the study, to provide an opportunity for them to ask questions, and to check that the parent understands what the study is about, what will happen to them if they take part and how we will use their information.

3. If the participant is happy to continue, the formal process of documenting consent will be started and an interview will be arranged. Both the researcher and the participant will sign and date a hard copy or electronic Consent Form to confirm that consent has been obtained prior to the start of an interview. The participant will receive a copy of this document and a copy will be securely filed by the study team at the University of York.

Consent will be monitored throughout the interviews of parents, e.g. looking for disengagement or withdrawal, checking that they are happy to continue; and participants will be reminded that they can choose not to answer questions that are too distressing or that they would prefer not to answer, and that they can stop the interview at any time.

Participants will be informed of their right to withdraw at any time and without giving a reason. This is covered in the participant information sheet and will be reiterated prior to starting the interview.

If a participant chooses to withdraw they will be able to withdraw their information as long as it has not already been used in the study (i.e. for analysis). To ensure fairness and to allow for concurrent data collection and analysis we have specified that participants can withdraw any data they have provided up to 30 days after their interview. No further data will be collected from participants who withdraw and all data able to be withdrawn (from their contribution) will be destroyed unless consent is provided to include data collected up to the point of withdrawal in the study.

9.2 Participant burden and distress

It is possible that parents may feel pressurised to participate, or feel distressed by interview questions. They will be informed that the decision about whether to participate is voluntary and will not affect any services or benefits they or their children receive. If a participant becomes distressed during the interview, the interviewer will ask the participant if they want to continue or to take a break, and be guided by the participant, who may wish to continue despite experiencing some distress. In cases where distress is significant or sustained, the interviewer may suggest that the interview is stopped, although the decision will be made with the participant. In these cases, a second interview may be arranged to enable parents to participate fully if they wish. Where needed, assistance will be given to help the participant identify appropriate sources of support, or a recommendation made that they contact their GP or mental health professional.

After the interview the participants will be offered a follow-up call 24-48 hours after to check that they do not have any additional questions.

So that parents can weigh up the risk of becoming distressed during an interview, an outline of areas that the interviews will cover will be provided in the participant information sheet. This will also help to make sure that participants are prepared for the interview.

Participants will be reimbursed any personal expenses incurred as a result of taking part in the study (e.g. travel, childcare).

9.3 Participant confidentiality

Participants will be informed of their right to confidentiality, and what this means if they disclose information that suggests that they or others are at serious risk of harm. Participants will also be informed that they have the right to withdraw from the study at any time, and to exclude their data from the study if not already analysed as part of the research.

All personal data will be stored in password-protected files, using a participant identifier to link participants' details to their data (i.e. interview transcript). On entering the study all participants will be given a study identifier code. Codes and the corresponding names will be kept in a separate file location to the study data, in a password-protected file. This information and all data will be stored on the University of York servers and will not be accessed by anyone outside of the research team.

Data will comprise interview transcripts and researcher fieldnotes. The interview transcripts, which will have all potentially identifiable data removed, will be the primary data source for the study. Audio-recordings, which will be password-protected and stored securely on the University of York server following participants' interviews, will be kept until the transcripts have been checked and anonymised. They will then be destroyed.

Quotations from participants may be used in research reports and other publications and presentations; however, care will be taken to protect the anonymity of participants so that others are not able to identify them. Any quotations that are used in the final report or any other publications will be anonymised through giving the participant a pseudonym. Additionally, the characteristics of participants and their children will be presented in a way that will ensure anonymity, e.g. condition categories rather than individual diagnoses will be reported.

9.4 Data management/Data protection

In line with the 2018 General Data Protection Act and the Research Governance Framework for Health and Social Care Research, data (anonymized interview transcripts and field notes) will be securely archived by the University of York for a minimum of 10 years. Personal data of participants and consent forms will be stored for up to 3 years after the study has ended for the purpose of disseminating study findings. It is unlikely that this will take longer than 12 months, however to ensure that participants receive adequate and full information about the study after it has finished, additional time has been allocated.

All information collected during the study will be kept strictly confidential. Information will be held securely in paper and/or electronic formats at the University of York. The University of York complies with all

aspects of the 2018 General Data Protection Act and operationally this will include obtaining consent from patients and carers to record personal details including name, postal and email address, and contact telephone numbers; and appropriate storage, restricted access and disposal arrangements for patient and carer personal details. All participants will be anonymised at the point of consent, by assignment of a study identifier code. Personal data and pseudonymised data will be stored separately in a restricted access folder on a secure university server and access will be password protected.

- All data will be stored in accordance with data protection requirements and will be kept either in a locked filing cabinet in a secure office or in the case of electronic data on a secure sever with a password-protected computer and files.
- Participants' names and contact details will be stored in a secure place (a locked office) and only accessed by the research team. Electronic data will be stored on password-protected secure computers in the research team members' locked offices.
- Audio recordings of the interviews will be downloaded onto a password-protected area of the University of York server and deleted from Zoom or the recording device. These will be destroyed when the transcripts have been checked and anonymised.
- No data will be stored on a home computer or laptop.
- All anonymised interview data will be stored for a minimum of 10 years, which will allow time for any academic challenge to be made. All data will be deleted after this time.
- Personal data and consent forms will be stored for up to 3 years after the end of the study. It will then be destroyed.

9.5 Researcher safety and distress

To ensure researcher safety, we will adhere to the University of York policy and procedure on lone working and employ a buddy system to monitor researchers' whereabouts and safety if visiting participants or conducting virtual interviews from University premises outside of normal office hours. We will also develop risk management protocols that are consistent with those used by the Trusts and hospices we will be working with. All research staff will be GCP (Good Clinical Practice) trained.

We will only use experienced qualitative researchers who have previously worked on sensitive topics to interview participants and analyse data. However, it is possible that the researchers may experience some emotional distress as a result of interviewing parents about their experiences of end of life care for their child or during the process of data analysis. To monitor and manage this, the researchers will meet weekly throughout the study to reflect on data collection and analysis. In preparing for data collection, the researchers will also have an opportunity to conduct one or two pilot interviews with our parent advisors. Additionally, debrief meetings will take place 1-3 days after the first few interviews (between the interviewer and the study's Chief Investigator), and then organised as and when needed after this and throughout the data collection process. These strategies have been used successfully in similar studies.

10 Dissemination

The main outputs from this study are:

1. A final report for the funder with an Executive (Plain English) Summary

2. A slide set for the funder
3. An academic paper which will be submitted for publication in an open access peer review journal such as Palliative Medicine or the Archives of Disease in Childhood
4. A short (Plain English) leaflet containing a link to the published academic paper

These outputs will be available in downloadable format from the study website which will be hosted by the MHRC website. Email and/or social media alerts to highlight key outputs from the study will be coordinated through Together for Short Lives and MHRC networks, children's palliative care regional networks, and other professional networks (BACCH, RCPCH and the RCGP) and third sector organisations which the applicants are linked in to.

Copies of the Executive Summary will be sent to all Children's Palliative Care Regional Network Chairs, recruiting organisations and study participants (who consent to receive this at the time of participating in the study).

A launch event will be hosted by Together for Short Lives at the end of the study, either as a webinar or face-to-face event, to be attended by children's hospice and palliative care professionals. Together for Short Lives will also include a feature about the study in their Care Exchange newsletter which is disseminated to children's palliative care professionals across the UK.

The wider clinical and academic audience will be reached via presentations at relevant UK and international palliative care conferences (e.g. the Association for Palliative Medicine Palliative Care Congress; the Hospice UK national annual conference; the European Association for Palliative Care Research Congress; Maruzza International Congress on Paediatric Palliative Care).

11 Timeline

The timeline for key phases of the study is provided below and a more detailed Gantt chart is provided in Appendix C.

Jan-Apr 2021	Protocol and topic guide development, HRA and ethics approvals
May-Nov 2021	Site set up, recruitment and interviews with parents
June-Dec 2021	Data analysis and interpretation
Nov-Dec 2021	Produce funder report and slide set
Jan-Mar 2022	Prepare and submit academic paper
Jan-June 2022	Dissemination activities (e.g. conference presentations)

12 References

1. Petrou S, Fraser J and Sidebotham P. Child death in high-income countries. *Lancet* 2014;384:831-3. DOI: 10.1016/s0140-6736(14)61372-6.

2. Office for National Statistics. Mortality statistics - underlying cause, sex and age. https://www.nomisweb.co.uk/query/construct/summary.asp?mode=construct&version=0&dataset=161[2019].

3. Fraser LK, Gibson-Smith D, Jarvis S, Norman P and Parslow RC. Estimating the current and future prevalence of life-limiting conditions in children in England. *Palliative Medicine* 20200269216320975308. DOI: 10.1177/0269216320975308.

4. Hain R, Devins M, Hastings R and Noyes J. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. *BMC Palliat Care* 2013;12:43. DOI: 10.1186/1472-684x-12-43.

5. Liben S, Papadatou D and Wolfe J. Paediatric palliative care: challenges and emerging ideas. *Lancet* 2008;371:852-64. DOI: 10.1016/s0140-6736(07)61203-3.

6. National Paediatric Diabetes Audit RCoPaCH, *National Paediatric Diabetes Audit*. May 2016,.

7. Chambers L, *A Guide to Children's Palliative Care Supporting babies, children and young people with life-limiting and life-threatening conditions and their families*, DA Goldman, Editor. 2018, Together for Short Lives: Bristol,.

8. Alliance WPC, *Global Atlas of Palliative Care at the End of Life*, Connor S and Bermedo M, Editors. 2014: London.

9. Taylor J, Booth A, Beresford B, Phillips B, Wright K and Fraser L. Specialist paediatric palliative care for children and young people with cancer: A mixed-methods systematic review. *Palliat Med* 2020;34:731-775. DOI: 10.1177/0269216320908490.

10. Constantinou G, Garcia R, Cook E and Randhawa G. Children's unmet palliative care needs: a scoping review of parents' perspectives. *BMJ Support Palliat Care* 2019;9:439-450. DOI: 10.1136/bmjspcare-2018-001705.

11. Noyes J, Edwards RT, Hastings RP, Hain R, Totsika V, Bennett V, et al. Evidence-based planning and costing palliative care services for children: novel multi-method epidemiological and economic exemplar. *BMC Palliat Care* 2013;12:18. DOI: 10.1186/1472-684x-12-18.

12. Kerr H, Widger K, Cullen-Dean G, Price J and O'Halloran P. "Transition from children's to adult services for adolescents/young adults with life-limiting conditions: developing realist programme theory through an international comparison". *BMC Palliative Care* 2020;19:115. DOI: 10.1186/s12904-020-00620-2.

13. National Institute for Health and Care Excellence (NICE), *End of life care for infants, children and young people with life-limiting conditions: planning and management*. 2016.

14. National Institute for Health and Care Excellence (NICE). End of life care for infants, children and young people Quality standard [QS160]. https://www.nice.org.uk/guidance/qs160/chapter/Quality-statements[2017].

15. Grinyer A, Payne S and Barbarachild Z. Issues of power, control and choice in children's hospice respite care services: a qualitative study. *Int J Palliat Nurs* 2010;16:505-10. DOI: 10.12968/ijpn.2010.16.10.79216.

16. Bailey-Pearce O, Stedmon J, Dallos R and Davis G. Fathers' experiences of their child's life-limiting condition: An attachment narrative perspective. *Clin Child Psychol Psychiatry* 2018;23:381-397. DOI: 10.1177/1359104517730115.

17. Rodriguez A and King N. The lived experience of parenting a child with a life-limiting condition: a focus on the mental health realm. *Palliat Support Care* 2009;7:7-12. DOI: 10.1017/s1478951509000030.

18. Popejoy E. Parents' experiences of care decisions about children with life-limiting illnesses. *Nurs Child Young People* 2015;27:20-4. DOI: 10.7748/ncyp.27.8.20.s23.

19. Brouwer MA, Maeckelberghe ELM, van der Heide A, Hein IM and Verhagen EAAE. Breaking bad news: what parents would like you to know. *Archives of Disease in Childhood* 2021;106:276. DOI: 10.1136/archdischild-2019-318398.

20. Mitchell S, Spry JL, Hill E, Coad J, Dale J and Plunkett A. Parental experiences of end of life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: a qualitative interview study. *BMJ Open* 2019;9:e028548. DOI: 10.1136/bmjopen-2018-028548.

21. M JT. Approaches to community-based palliative care provision by children's hospices in the UK. *Nurs Child Young People* 2019;31:42-48. DOI: 10.7748/ncyp.2019.e1199.

22. Cram F. Appreciative Inquiry. *MAI Review* 2010;3.

23. Hunt A, Coad, J., West, E., Hex, N., Staniszewska, S., Hacking,, S. F, M., Brown, E., Owens, C., Ashley, N., Kaur, J., May, K.,, Chandler V, Barron, D., Wik, A., Magee, H., Lowson, K., Wright, D., and Gunn K, *The Big Study: Meeting the Needs of Life-Limited Children in the West Midlands*, SW Katrina Kelly, Editor. 2013, Together for Short Lives,.

24. McSherry R, Timmins F, de Vries JMA and McSherry W. A reflective qualitative appreciative inquiry approach to restoring compassionate care deficits at one United Kingdom health care site. *J Nurs Manag* 2018;26:1108-1123. DOI: 10.1111/jonm.12630.

25. Trajkovski S, Schmied V, Vickers M and Jackson D. Implementing the 4D cycle of appreciative inquiry in health care: a methodological review. *J Adv Nurs* 2013;69:1224-34. DOI: 10.1111/jan.12086.

26. Shrivastava R, Couturier Y, Girard F, Bedos C, Macdonald ME, Torrie J, et al. Appreciative inquiry in evaluating integrated primary oral health services in Quebec Cree communities: a qualitative multiple case study. *BMJ Open* 2020;10:e038164. DOI: 10.1136/bmjopen-2020-038164.

27. Scerri A, Innes A and Scerri C. Using appreciative inquiry to implement person-centred dementia care in hospital wards. *Dementia (London)* 2019;18:190-209. DOI: 10.1177/1471301216663953.

28. Ludema JD and Fry RE, *The practice of appreciative inquiry.* , in *The Sage handbook of action research participative inquiry and practice*, P Reason, Bradbury, H. , Editor. 2011, SAGE: Thousand Oaks, CA. p. 280-296.

29. Lives TfS. Categories of life-limiting conditions. https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/categories-of-life-limiting-conditions/.

30. Butler AE, Hall H and Copnell B. Bereaved parents' experiences of research participation. *BMC Palliat Care* 2018;17:122. DOI: 10.1186/s12904-018-0375-4.

31. Hynson JL, Aroni R, Bauld C and Sawyer SM. Research with bereaved parents: a question of how not why. *Palliat Med* 2006;20:805-11. DOI: 10.1177/0269216306072349.

32. Sque M, Walker W and Long-Sutehall T. Research with bereaved families: A framework for ethical decision-making. *Nursing Ethics* 2014;21:946-955. DOI: 10.1177/0969733014521097.

33. Martin House Research Centre. Martin House Research Centre - Our Research. https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/research/.

34. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N and Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health* 2015;42:533-544. DOI: 10.1007/s10488-013-0528-y.

35. Barbour R, Introducing Qualitative Research. 2008, London,: Sage Publications Ltd.

36. Peake JN, Beecham E, Oostendorp LJM, Hudson BF, Stone P, Jones L, et al. Research barriers in children and young people with life-limiting conditions: a survey. *BMJ Support Palliat Care* 2018. DOI: 10.1136/bmjspcare-2018-001521.

37. Irvine A, Drew P and Sainsbury R. 'Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qualitative Research* 2012;13:87-106. DOI: 10.1177/1468794112439086.

38. Johnson DR, Scheitle CP and Ecklund EH. Beyond the In-Person Interview? How Interview Quality Varies Across In-person, Telephone, and Skype Interviews. *Social Science Computer Review* 20190894439319893612. DOI: 10.1177/0894439319893612.

39. Heath J, Williamson H, Williams L and Harcourt D. "It's just more personal": Using multiple methods of qualitative data collection to facilitate participation in research focusing on sensitive subjects. *Appl Nurs Res* 2018;43:30-35. DOI: 10.1016/j.apnr.2018.06.015.

40. Martin House Research Centre. Crisis prevention rather than crisis management: the health of mothers of children with a life-limiting condition. https://www.york.ac.uk/healthsciences/research/public-health/projects/crisis-prevention-health-mothers-children-llc/[2021].

41. Maddison J, Taylor J, O'Neill M, Cade J, Hewitt C, Horridge K, et al. Outcomes for gastrostomy-fed children and their parents: qualitative findings from the 'Your Tube' study. *Developmental Medicine & Child Neurology* 2021. DOI: https://doi.org/10.1111/dmcn.14868.

42. Fielding N, *Interviewing*, in *Researching Social Life*, Gilbert N, Editor. 1993, Saga,: London,.

43. Barrett A, Kajamaa A and Johnston J. How to … be reflexive when conducting qualitative research. *Clin Teach* 2020;17:9-12. DOI: 10.1111/tct.13133.

44. Francis JJ, Johnston M, Robertson C, Glidewell L, Entwistle V, Eccles MP, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010;25:1229-45. DOI: 10.1080/08870440903194015.

45. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3:77-101. DOI: 10.1191/1478088706qp063oa.

46. Mays N and Pope C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ* 2000;320:50-2. DOI: 10.1136/bmj.320.7226.50.

Appendix A: Outline topic guide - parents

Research study: Learning from parents' experiences of palliative care for their child

Outline Topic Guide - parents

Background

Can you start by telling us a bit about your child?

Prompts: health conditions and when diagnosed, schooling, family, likes, dislikes, understanding & communication

How is your child doing at the moment?

Researcher to introduce study aim and scope

This study aims to increase understanding about what good palliative care is for children and we are going to ask you about the palliative care your child receives.

When we ask you about palliative care, this includes care you may have received from a palliative care professional or service, or a children's hospice, but also care that your child receives from other services (e.g. their healthcare team, a community nursing team, a GP) that helps to make your child comfortable, provides support for you at home, and addresses any other needs, such as emotional or social needs. We would also like to know about any palliative care planning that has happened, both for the care your child has now but also in relation to their future care needs, including any planning for end of life care.

Palliative care introduction

Can you tell me about when palliative care or end of life care was first talked about for your child?

Prompts: Who was involved? How did it happen? What was offered and from who? What did you think and feel at the time? What happened next?

<u>If appropriate to ask:</u> How was your child involved in these discussions?

Palliative care provision

Can you tell us about any palliative care your child and family receives?

Prompts: What is provided? Who provides it? How long has this been in place for? How has this changed over time?

What sort of involvement did you have in what happened and the decisions about what care is provided?

<u>If appropriate to ask:</u> How is [child] involved in these decisions?

Does your child have an advance care plan?

If yes, tell us about how this happened?

Prompts: Who was involved? How did it happen? What did you think and feel at the time? Is it used, updated, discussed etc.? <u>If appropriate:</u> how was your child involved?

If no, is this something that has been discussed with you?

If yes, tell us about these and why your child doesn't have an advance care plan?

If no, can you tell us what you know about advance care plans? Is this something you would like to be offered?

Can you tell us about any other plans you have made for the care your child might want or need in the future, including any end of life care planning?

Learning from what works well

How do you think your child benefits from the palliative care s/he receives? And what about the benefits for you and other family members?

What have been the most valued experiences of the palliative care and palliative care planning you have received and why?

What do you think made these experiences possible? Can you remember in detail what specific factors made them that way?

If those experiences were to become the norm, how would things need to change?

What are the things that you most value from the individuals who provide care to [child]?

Learning from what works less well

For this study, we really want to learn from what works well, but we understand that learning from what doesn't work so well is also important.

Can you tell us about any experiences that could have been better?

How do you think these experiences have affected your child and family?

What would have made these experiences more valued for [child] and your family?

Are there things that the individuals who provide palliative care for [child] could do better?

Can you tell us about any unmet care needs your child and family have?

Suggested improvements and final thoughts

Do you have any other thoughts about how palliative care can be improved for children and young people?

If there was only one thing you could change about how palliative care is introduced and provided, what would it be?

Is there anything else you would like to share?

Appendix B: Outline topic guide – bereaved parents

Research study: Learning from parents' experiences of palliative care for their child

Outline Topic Guide – bereaved parents

Background

Can you start by telling us a bit about your child?

Prompts: health conditions and when diagnosed, schooling, family, likes, dislikes, understanding & communication, where and when they died

Palliative care understanding

This study aims to increase understanding about what good palliative care is for children, and we are going to ask you about the care your child received before s/he died.

When we ask you about palliative care, this includes care you may have received from a palliative care professional or service, or a children's hospice, but also care that your child received from other services (e.g. their healthcare team, a community nursing team, a GP) that helped to make your child comfortable before they died, provided support for you at home, and addressed any other needs, such as emotional or social needs. We would also like to know about any palliative care planning that happened and how that affected the care your child received in the weeks and months before they died.

Palliative care introduction

Can you tell me about when palliative care or end of life care was first talked about for your child?

Prompts: Who was involved? How did it happen? What was offered and from who? What did you think and feel at the time? What happened next?

<u>If appropriate to ask:</u> How was your child involved in these discussions?

Palliative care provision

Can you tell us about the care your child received in the last weeks and months of their life?

Prompts: What was provided? Who provided it? How did it change during those last few weeks or months? Where did your child spend time during this time (e.g. hospice, home, hospital)?

Can you tell us about any palliative care your child or family received before then?

Prompts: children's hospice care, symptom management, palliative care team input etc.

What sort of involvement did you have in what happened and the decisions about what care was provided?

<u>If appropriate to ask:</u> How was [child] involved in these decisions?

Did your child have an advance care plan?

If yes, tell us about how this happened and how it was used before your child died?

Prompts: Who was involved? How did it happen? What did you think and feel at the time? Was it used, updated, discussed etc.? <u>If appropriate:</u> how was your child involved?

If no, is this something that was discussed with you?

If yes, tell us about the discussions? Why didn't your child have an advance care plan?

If no, can you tell us what you know about advance care plans? Is this something you think may have made a difference to the care your child received?

Have you and your family been offered bereavement support? Can you tell us about what was offered, who offered it and when this happened?

Learning from what works well

How do you think your child benefited from the palliative care s/he received? And what about the benefits for you and other family members?

What aspects of care or care planning made a positive difference to the weeks and months leading up to your child's death? What else helped during this time?

Are there any other experiences of the palliative care you received that you particularly valued and why?

What do you think made these experiences possible? Can you remember in detail what specific factors made them that way?

If those experiences were to become the norm, how would things need to change?

What are the things that you most valued from the individuals who provided care to [child]?

Learning from what works less well

For this study, we really want to learn from what works well, but we understand that learning from what doesn't work so well is also important.

Can you tell us about any experiences that could have been better?

How do you think these experiences affected your child and family?

What would have made these experiences more valued for [child] and your family?

Are there things that the individuals who provided palliative care for [child] could do better?

Can you tell us about any unmet care needs your child and family had during the weeks and months before they died?

Suggested improvements and final thoughts

Do you have any other thoughts about how palliative care can be improved for children and young people?

If there was only one thing you could change about how palliative care is introduced and provided, what would it be?

Is there anything else you would like to share?

Appendix C – Study Gantt chart

	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13	M14	M15	M16	M17	M18
	Jan-21	Feb-21	Mar-21	Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22	Apr-22	May-22	Jun-22
Study timeline																		
Protocol																		
PPI input - protocol																		
Clinical / academic input - protocol																		
Study materials and ethics application																		
Topic guide development																		
PPI input - topic guide																		
Site set-up																		
Recruit families																		
Interviews																		
PPI input on interviews																		
Data analysis																		
PPI input - analysis / interpretation																		
Clinical / academic input - interpretation																		
Funder report, summary and slide set																		
PPI input - summary																		
Academic paper																		
Dissemination activities																		
Study milestones																		
HRA submission																		
HRA approval																		
Start recruitment																		
Finish data collection																		
Finalise analytical themes																		
Submit funder report																		
Submit academic paper																		