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https://doi.org/10.3310/ZMLF1648

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Health and Social Care Delivery Research

*Volume 13 • Issue 16 • May 2025*

*ISSN 2755-0079*

# The spiritual needs and care of children and young people with life-threatening or life-shortening conditions, and parents (SPARK): a mixed-method investigation

*Bryony Beresford, Natalie Richardson, Suzanne Mukherjee, Rebecca Nye, Jan Aldridge, Karl Atkin, Mark Clayton, Faith Gibson, Julia Hackett, Richard Hain, Mohammed Arshad, Paul Nash and Bob Phillips*

*DOI 10.3310/ZMLF1648*

Health and Social Care Delivery Research

Extended Research Article

# The spiritual needs and care of children and young people with life-threatening or life-shortening conditions, and parents (SPARK): a mixed-method investigation

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Published May 2025
DOI: 10.3310/ZMLF1648

This report should be referenced as follows:

Beresford B, Richardson N, Mukherjee S, Nye R, Aldridge J, Atkin K, *et al*. The spiritual needs and care of children and young people with life-threatening or life-shortening conditions, and parents (SPARK): a mixed-method investigation. *Health Soc Care Deliv Res* 2025;**13**(16). https://doi.org/10.3310/ZMLF1648

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ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

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This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

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## This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number NIHR128468. The contractual start date was in August 2020. The draft manuscript began editorial review in August 2023 and was accepted for publication in October 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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# Abstract

**Background:** The human experience comprises four interconnected dimensions: physical, psychological, social and spiritual. Our spirituality is evidenced in the need to make sense of and find meaning, to feel our lives have purpose, to feel we matter and to feel connected to ourselves, others, the natural world and the sacred or divine. Having a life-shortening or life-threatening condition threatens spiritual well-being and causes spiritual suffering. While health care aspires to be holistic, the evidence on meeting spiritual needs and spiritual care in healthcare settings is limited, particularly for neonatal and paediatric populations.

**Objective(s):** To generate evidence to support evidence-informed approaches for the spiritual care of children/young people and their parents, including the role of chaplaincy.

**Design and research participants:** A mixed-method, multicomponent design was used with the quantitative and qualitative data collected. There were four work packages.

- Work package 1: survey of chaplaincy services in the National Health Service acute trusts in England (*n* = 98/136).
- Work package 2: focus groups with National Health Service chaplains across 13 acute trusts (*n* = 77).
- Work package 3: interviews with young people (12–25 years) (*n* = 19) and parents (*n* = 62).
- Work package 4: focus groups with National Health Service clinical staff and allied health professionals based in services caring for children with life-threatening or life-shortening conditions (*n* = 48).

**Results:** Multiple threats to children's/young people's and parents' spiritual well-being were identified. These included struggling to make sense and find meaning in their situation; existing belief systems (or personal philosophies) found wanting, existential worries and concerns; a sense of disconnectedness from others and 'normal life'; and a lack of pleasure and joy, moral distress and feelings of insignificance and invisibility. Almost all described hiding their spiritual distress from themselves and others. At the same time, parents and young people also spoke of wishing for people on whom they could unburden themselves: either at critical moments, or to 'journey' with them. For some, chaplains had provided this care and support. Many, including those identifying themselves as not religious, described drawing comfort from religious rituals and practices (e.g. prayer and blessings). For some, a religious faith protected against spiritual distress. For others, it was regarded as irrelevant or unhelpful.

All work packages revealed barriers to children's/young people's and parents' spiritual needs being met. Healthcare staff's accounts revealed a lack of understanding and an uncomfortableness with raising and exploring religious needs and spiritual distress and, for some, a mistrust of chaplaincy services. Survey findings indicated that chaplaincy services are less likely to have a routine presence in paediatric compared to adult settings. Key reasons for this were staff capacity and gatekeeping by healthcare staff.

**Limitations:** Minority faiths are under-represented in the samples recruited to the qualitative components.

**Conclusions:** Having a life-threatening or life-shortening condition brings multiple threats to the spiritual well-being and lived experiences of children/young people and their parents. There are a number of barriers to National Health Service staff recognising and responding to these needs. These include workforce training and adequate resourcing of chaplaincy services and ensuring spiritual care is integrated into care pathways.

**Future work:** Priority topics for future research include effective training for clinical staff on spirituality and spiritual care and integrating spiritual care into care pathways.

**Study registration:** This study is registered as Current Controlled Trials ISRCTN41288313.

**Funding:** This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR128468) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 16. See the NIHR Funding and Awards website for further award information.

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# List of supplementary material

**Report Supplementary Material 1** The survey of UK children's hospices on spiritual care provision and practices (Work package 1)

**Report Supplementary Material 2** Children's hospice heads of care and spiritual care leads views on the provision of spiritual care

**Report Supplementary Material 3** Children's hospice staff's views on the threats to spiritual well-being faced by children/young people and parents

**Report Supplementary Material 4** Work package 1: survey instrument

**Report Supplementary Material 5** Examples of recruitment materials: Work package 3

**Report Supplementary Material 6** Study topic guides: Work packages 2, 3 and 4

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/ZMLF1648).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

# List of abbreviations

| | |
|---|---|
| COVID | coronavirus disease |
| EoI | expression of interest |
| ICU | intensive care unit |
| LLC | life-limiting condition (comprising life-threatening and life-shortening conditions) |
| LYRO | Leeds Young Research Owls |
| MDT | multidisciplinary team |
| NIHR | National Institute for Health and Care Research |
| PPI | patient and public involvement |
| R&D | research and development |
| SLA | service-level agreement |
| SPRU | Social Policy Research Unit |
| WP | work package |

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# Plain language summary

As humans, we need to make sense of what happens to us and to have meaning and a purpose in life. We also need to feel we matter to others and that we feel connected to ourselves, others and the wider social and natural world and, for some, a 'higher power'. This aspect of our humanness is called our spirituality. For some, religious beliefs are important to their spiritual lives.

Being diagnosed, and living with, a life-shortening or life-threatening condition affects our spiritual well-being as well as our physical well-being. However, patients (and their families) often say that their spiritual needs and suffering are not fully recognised and their spiritual needs remain unmet.

The focus of this study was the spiritual needs and care of children and young people with such conditions, and their parents. We wanted to generate evidence that the National Health Service could use to improve the spiritual care they receive. Included in our study was a focus on National Health Service chaplaincy services. This was because chaplains are the National Health Service's spiritual care specialists.

We collected data via a survey of National Health Service chaplaincy services, interviews with young people with a life-shortening or life-threatening condition and their parents and focus groups with staff based in National Health Service services that care for such children and young people.

We found that having a life-shortening or life-threatening condition affects children's and young people's spiritual well-being (and their parents) in multiple ways. They spoke of struggling to make sense of what has happening to them, fears and questions about dying and feelings of despair, guilt and worthlessness. Many said they had not shared these thoughts and feelings with anyone and that they had no support for managing or resolving their feelings and fears. Furthermore, healthcare professionals reported feeling uncomfortable and unskilled in relation to responding to spiritual needs. We also found that chaplaincy was less available in paediatric services than adult services. This means children/young people, parents and staff do not have access to specialist spiritual care and support that could be helpful to them.

# Scientific summary

## Background

Core to our human experience is the need to make sense of and find meaning in life, to feel our lives have purpose, to feel we matter and have value and to feel connected to ourselves, others, the wider social and natural world and, for some, a sacred/transcendent being. This aspect of our humanness is collectively referred to as our spirituality. For some, religious beliefs offer a framework by which we make sense of life, achieve and express connectedness with ourselves, others and 'God'.

Our spirituality is not something we may be particularly conscious of on an everyday basis. However, people do become more conscious of their spirituality at turning points in their lives and at times of change, trauma, challenge, danger, uncertainty and crisis. Such times can challenge the values and beliefs about life, and there can be a heightened awareness of mortality. Spiritual well-being can be threatened, and spiritual distress experienced. People who are spiritually distressed describe feeling sad, afraid, desperate, vulnerable, lonely, empty, useless, guilty and helpless. They may describe existential crises and feel life is without meaning and they do not matter. It is widely accepted that the diagnosis of, and living with, a life-threatening or life-shortening condition [we collectively refer to these as life-limiting conditions (LLCs) forthwith] threatens spiritual well-being.

Historically, the recognition of and attention to patients' spirituality and spiritual needs were regarded as core to health care. However, rapid advances in medicine's ability to treat disease caused a narrowing in the understanding of both what health care is and what constitutes health, particularly in Western countries. The past 20 or so years have, however, seen the beginning of a recalibration away from a biomedical model of health and illness to one that advocates a more holistic approach, including attention to the spiritual needs and care of patients and their families. Indeed, there is extensive evidence that people (patients and family members) need and want healthcare systems to attend to their spiritual needs. Equally strong is the evidence that such needs are frequently unmet.

Spiritual care has been defined as care 'which recognises and responds to the needs of the human spirit', with all healthcare staff implicated as having a role to play in preventing and responding to spiritual distress. In the NHS, chaplaincy services are identified as the spiritual care specialist service and care for patients, family members and staff. With patients and families, much of that work is achieved through their 'presence': defined as an encounter, fleeting or more prolonged, which may include both silence and verbal exchange. It conveys a willingness to sit with a person in their suffering and, in doing so, assumes and shares the load of suffering. The approach taken is person-centred, empathetic and non-judgemental. Chaplains do not seek to provide answers but rather support sense-making by providing a space for individuals to articulate their thoughts, feelings and existential concerns.

At the moment, what we understand about how having a LLC threatens the spiritual well-being of children and young people (and their parents) is limited and patchy, with much of the existing research conducted in the USA or relying on proxy informants. Equally, we know little about their spiritual support needs, where they go for comfort and support, their experiences of how NHS services respond to their spiritual needs and their experiences of chaplaincy services. The overall aim of this study was to support evidence-informed approaches for the spiritual care of children/young people with LLC, and their parents, including the role of chaplaincy services in that care.

## Objectives

The study objectives were as follows:

- to 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
- to investigate the equity of access to chaplaincy services for children and parents and the factors affecting access

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- to describe the spiritual needs of children and parents, preferences regarding sources of support and their experiences of having those needs met or remain unmet
- to understand the differences between providing chaplaincy services to children, parents and adult patients and the implications for service provision and staff training
- to describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services
- to identify the (potential) roles of clinical teams in identifying and responding to the spiritual needs of children, young people and parents and the barriers and facilitators to these roles being fulfilled.

## Study design and methods

The lack of existing evidence demanded that we took an exploratory and descriptive approach to addressing the study objectives. A multiple component study was designed, organised under the following work packages (WPs):

- WP 1: cross-sectional survey of heads of NHS chaplaincy services in acute NHS trusts in England
- WP 2: qualitative research with NHS chaplaincy teams
- WP 3: qualitative research with children, young people and parents
- WP 4: qualitative research with NHS clinical teams/staff and children's hospice care staff

An additional component of this study collected data on children's hospices' spiritual care provision and the views and experiences of hospice staff. However, most findings from this work are specific to hospices and reported as *Report Supplementary Material 1* only.

## Findings

Almost three-quarters of chaplaincy services (*n* = 98/136) took part in the WP 1 survey. Seventy-seven chaplaincy staff, recruited from 13 purposively sampled chaplaincy services, took part in WP 2. Nineteen young people and 62 parents, recruited via NHS clinics, hospices and charities, were interviewed for WP 3. Finally, 48 doctors, nurses and allied health professionals – drawn from a range of services caring for children/young people with a LLC – took part in a focus group for WP 4. Target sample sizes were achieved except for the young people's sample.

Our qualitative research revealed the multiple threats to spiritual well-being faced by children/young people and parents. These included: struggling to make sense and find meaning in their situation; existing belief systems (or personal philosophies) found wanting, existential worries and concerns; a sense of disconnectedness from others and 'normal life'; a lack of pleasure and joy; and feelings of insignificance and invisibility. In addition, and perhaps unique to this population, was the moral distress experienced. Either through helplessly witnessing the suffering of their child or, in the case of young people, witnessing the distress they were causing to their parents. Many study participants described periods of significant spiritual distress and suffering, even as young children.

In terms of sources of support, young people and parents described drawing comfort from connecting with others in the same situation as themselves, moments of compassionate care from healthcare staff and, for some, the support of friends, family or communities to which they belonged. Some described their faith as a key source of resilience, comfort and hope. Among those without faith, the offer of prayers (from friends, chaplains, etc.) was described as a comfort. However, despite these sources of support, most children/young people and parents described hiding their distress and deepest fears and concerns from themselves and others. The overall picture is one of suffering in isolation. Almost all described wishing for people on whom they could unburden themselves and who were prepared to witness their suffering.

For some, chaplains had been such a source of support. Some spoke of a chaplain's involvement or support as highly significant and deeply meaningful, both among those identifying with a religious faith and those not. For others, it was the human connection and listening presence, from someone separate to the clinical team or ward staff, which was valued.

Clinical staff are invariably present with children/young people and their parents at significant and difficult moments and episodes as well as during regular clinic contacts. Yet, the majority of staff who took part in this research described feeling uncomfortable and incompetent with respect to identifying, raising and responding to spiritual issues and needs.

All WPs revealed issues related to children/young people and parents accessing chaplaincy services. Survey findings indicate that chaplaincy services are less likely to have a routine presence in paediatric compared to adult settings. This emerged as critical to supporting access to chaplaincy support because routine presence (as opposed to only attending following a referral or staff request) appears to be important in terms of patients, families and staff properly understanding for whom the chaplaincy services are for and what they can offer. It also increases their availability for spontaneous conversations.

Staff gatekeeping and a lack of recognition of the spiritual suffering of children's/young people's, and families', were identified as the key barriers to accessing chaplaincy. Children's/young people's access could be further compromised by parental gatekeeping. In addition, chaplaincy staff reported that their capacity to devote time to paediatric settings was limited by the size of their teams, with many describing competing demands and priorities. Chaplaincy staff's confidence and competence to work with children/young people emerged as another reason due to which the chaplaincy services may not proactively seek to reach into paediatric settings. Regarding capacity and competency, the research found that providing spiritual care in paediatric settings can be more complex because chaplains may be working with multiple family members at the same time. In addition, the work carries even greater significance, given the unnatural and untimely nature of a child's death, or possibility of such. Furthermore, developmental differences within the population, the potential presence of significant impairment and the cultural gaps between children/young people and adults mean that connecting with and working with this population can be more challenging and unpredictable.

## Conclusions and implications

Study findings are relevant to a number of different bodies and organisations as well as clinical teams and chaplaincy services. Key implications are set out below, followed by suggested priorities for future research.

### *Implications*

- In response to our findings that health professionals lacked an understanding of spirituality and spiritual care, or felt uncomfortable with exploring and supporting this aspect of children's and parents' lives, we suggest that *national professional bodies* specify or review the spiritual care competencies and training required at each qualification level. In doing so, we recommend that they draw on the expertise of healthcare chaplains, particularly paediatric chaplaincy. Investment in developing training resources and courses is likely to be required. This should be informed by evidence on the content and teaching approaches taken by existing training programmes and any evaluations conducted. We note, however, that much of this work is taking place in other countries, and the degree to which content and training approaches translate to the UK should be carefully considered.
- *NHS trusts* should, at minimum, adhere to the guidance published by the Chaplaincy Forum for Pastoral, Religious and Spiritual Care in Health on chaplaincy staffing ratios in paediatric and neonatal settings. We also suggest that *NHS England* evaluates the adequacy of these indicative staffing ratios, given the: (1) degree of spiritual distress reported, *from the point of diagnosis*, by children/young people *and* parents; (2) valued and unique roles chaplains were described to have played and that, for almost all young people and parents who took part in this research, access to such support would have been appreciated; and (3) roles chaplaincy services can play in supporting the multidisciplinary team (MDT), both the team itself and in the clinical care of the child.
- Furthermore, study findings identify the need for *NHS trusts* to review the policies and strategies they have in place with respect to workforce training, the profile of spiritual care within the organisation's ethos, vision and objectives, and investment in the creation and maintenance of 'faith spaces'.

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- We also suggest *national condition-specific professional bodies* use the study findings to review their coverage on the spiritual needs and care of their patient group and to review any current guidance and recommendations. They may also wish to use study days and conferences to increase the profile of spirituality and spiritual care within their specialism.
- Our findings also support the argument for *clinical and service leads* of services that care for children/young people diagnosed with a LLC to consider assigning the role of 'spirituality/spiritual care lead/champion' to a member of the MDT, with protected time to work on developing or improving: (1) staff understanding, skills and practices; (2) reviewing systems and processes by which spiritual needs (including religious support needs) may be identified or assessed; and (2) developing relationships with the chaplaincy teams.
- In terms of improving access to chaplaincy services, our findings suggest chaplaincy services need to work proactively to develop relationships with clinical teams and ward staff. While recognising the constraints under which chaplaincy services are working, we recommend *heads of chaplaincy services in trusts with a children's hospital* (in particular) should seek to invest time in developing relationships with the clinical teams and wards caring for children and young people with LLC. We also recommend they review the training offered or available to the team on paediatric healthcare chaplaincy.
- Our findings highlight three issues unique to chaplaincy in paediatric settings: (1) developmental differences (within the population and compared to adults); (2) the uniqueness of parental spiritual distress; and (3) different family dynamics and sensitivities. We would suggest that the *UK Board of Healthcare Chaplaincy* and *chaplaincy training providers* review the content of *generic* training programmes in terms of whether curricula sufficiently cover chaplaincy in paediatric settings, including direct work with children/young people, working with individual family members and family-centred working. In addition, providers offering *specialist* training in paediatric healthcare chaplaincy should review curricula in terms of coverage of the whole childhood–adolescent age range, family dynamics and family-centred ways of working.
- Finally, this study was the first that the *National Institute for Health and Care Research (NIHR)* commissioned on spiritual care and, to date, remains the only study on this topic. We suggest that NIHR should consider how they might further support developing the evidence base in this area.

### *Research recommendations*

- Development and mixed-method evaluations of postqualification training courses/programmes on spirituality and spiritual care competencies for healthcare professionals; such work should investigate the impacts on healthcare professionals' understanding, confidence and practice and whether/how such outcomes affect children/young people and parents. The factors affecting assimilation and implementation of learning should also be investigated, including comparisons of alternative teaching/training approaches.
- Process evaluations of efforts to embed and integrate spiritual care into the care pathways of children/young people with LLC.

## Study registration

This study is registered as Current Controlled Trials ISRCTN41288313.

## Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR128468) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 16. See the NIHR Funding and Awards website for further award information.

# Chapter 1 Background and study overview

## Background and context

### *Spirituality as a core dimension of the human experience*

Core to our human experience is the need to make sense of and find meaning in life, to feel our lives have purpose, to feel we matter and have value and that we feel connected to ourselves, others, the wider social and natural world and to a 'higher power' and/or the sacred.[1] This aspect of our humanness is collectively referred to as the spiritual aspect of being human, or spirituality. While, for some, religious beliefs offer a framework by which spirituality is expressed and experienced, and sense is made of life.[2] Spirituality is a universal human experience.[2] This dimension of the human experience coexists and interconnects with the physical, psychological and social dimensions of our lives, with each affecting the other (*Figure 1*).

Our spirituality is not something we may necessarily be particularly conscious of on an everyday basis, or we may not label this aspect of our human experience as such. However, we know that people become more conscious of their spirituality at turning points in their lives, and at times of change, trauma, challenge, danger, uncertainty and crisis. Such times can challenge the values and beliefs about life (and death), and there can be a heightened awareness of mortality. Spiritual well-being can be threatened, and spiritual distress can be experienced. People who are spiritually distressed describe feeling sad, afraid, desperate, vulnerable, lonely, empty, useless, guilty and helpless.[3–5] They may describe existential crises and feel their life is without meaning and they do not matter. It is widely accepted that the diagnosis of, and living with, a life-threatening or life-shortening condition [we collectively refer to these as life-limiting conditions (LLCs) forthwith] threatens a person's spiritual well-being. Equally, our spirituality (and within this, for some, religiosity) can be a resource that supports coping.[6,7]

### *Spirituality and health*

Historically, recognition of and attention to patients' spirituality and spiritual needs was regarded as core to health care.[8] However, rapid advances in medicine's ability to treat disease caused a narrowing in the understanding of both what health care is and what constitutes health, particularly in Western countries. The past 20 or so years have, however, seen the beginning of a recalibration away from a biomedical model of health and illness, to one which recognises health and well-being as being about the whole person – physical, psychological, social and spiritual – with each

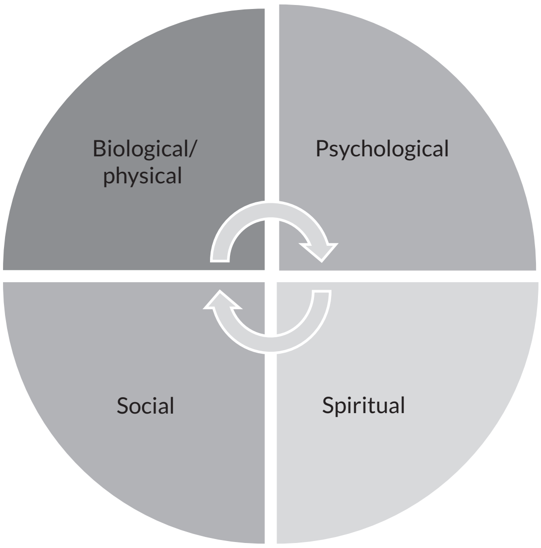

**FIGURE 1** Dimensions of the human experience.

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component of the human experience interrelated to and impacting the others.[7,9,10] This necessarily advocates a more holistic approach to health care, including attention to the spiritual needs and care of patients and their families. Indeed, there is extensive evidence that people (patients and family members) need and want healthcare systems to attend to their spiritual needs.[7,11–15] Equally strong is the evidence that such needs are frequently unmet.[7] The growing evidence on the ways in which spirituality and religiosity affect the physical and mental health outcomes adds further support to the argument that health care should adopt a biopsychosocial–spiritual approach.[7,16,17]

### *Spiritual care*

Spiritual care has been defined as care 'which recognises and responds to the needs of the human spirit'.[18] Recent years have seen an explicit positioning of spiritual care as an interprofessional endeavour[7,19,20] arguing that health professionals should be trained in spirituality and equipped to assess spiritual needs and respond to some degree to spiritual distress. The term spiritual care generalists[21] is used to describe this, with chaplains serving a spiritual care specialists. (*Note*: throughout this report, we use the term 'chaplain' as a generic term to describe qualified staff whose role is specifically defined as spiritual care.) Critically, underlying this has to be a recognition and understanding that *all* aspects of health care, ranging from the way staff interact with patients[22–24] through to hospital architecture,[25,26] have a spiritual impact.

As spiritual care *specialists*, chaplains' work is exclusively in providing spiritual care to patients, family members and staff.[27] Much of that work is through their 'presence': defined as an encounter, fleeting or more prolonged, which may include both silence and verbal exchange. It conveys a willingness to sit with a person in their suffering and, in doing so, assume and share the load of suffering. The approach taken is person-centred, empathetic and non-judgemental. Chaplains do not seek to provide answers but rather support sense-making by providing a space for individuals to articulate their thoughts, feelings and existential concerns.[27–29] If asked, chaplains will also offer prayers, conduct or organise religious rites and rituals, and they will support a patient to practice their faith. Alongside direct work with patients, family members and staff, part of chaplaincy's role is to train and support other staff groups in spirituality and spiritual care.[30–32] Clinical guidance also identifies chaplains as a possible resource when managing clinical issues, such as pain and agitation.[33] They also advise clinical teams on ethically difficult decisions and also may act as mediators between the team and family,[34] and they tend to be members of the hospital's ethics committees[27] and are included in groups or committees overseeing patient care.

Recent years have seen a growth in the interest and engagement in chaplaincy research – both within the profession and out with. This has partly been driven by the need for chaplaincy to evidence its impact (though some question whether orthodox approaches to evaluation are possible or appropriate to spiritual care[35]) and greater awareness and recognition of spiritual care and chaplaincy, something which coronavirus disease (COVID) accelerated.[36] Existing bodies of work include conceptual frameworks that articulate what chaplaincy does,[28,37,38] the value patients place on chaplaincy services[39] and the impacts of chaplaincy on patient's quality of life and well-being[40,41] and staff's well-being.[42–44]

### *National Health Service chaplaincy services*

The NHS England[45] defines chaplaincy services as the specialist provider of pastoral, spiritual and/or religious care to NHS patients, families and staff.[46,47] The inclusion of both 'spiritual' and 'religious' in this definition is intentional, explicitly signalling the modernisation and broadening of NHS chaplaincy into a service[46,48] for all patients and staff, regardless of whether or not they have a religious faith. Thus, chaplaincy staff cannot confine themselves to only supporting people of the same faith as theirs. At the same time, they are not 'expected to perform rituals or ceremonies from religions which are not their own, or to give advice counter to their beliefs'.[46] Chaplaincy teams include chaplains (Bands 5–8), chaplaincy support workers (Band 4) and chaplaincy volunteers. In addition, most trusts have honorary chaplains, typically local faith leaders, and bank chaplains. All chaplaincy staff must be accredited by the religious organisation to which they are affiliated, or in the case of those not holding a religious belief, Humanists UK. Recent years have seen a growing professionalization[49] of chaplaincy in many countries, including the UK. Here, there has been work to establish spiritual care competencies and improved governance and accountability systems and structures.[50]

### *The population of children/young people with life-limiting condition*

In England, there are approximately 40,000 babies and children (0–18 years) living with a LLC.[51] This represents a wide range of diagnoses, including, for example, cancer, neurodegenerative conditions, kidney and heart diseases, some chromosomal and metabolic disorders and children with profound and global impairments. It also includes premature babies. Together, they cause of half of childhood deaths.[52] The illness trajectory of some conditions is predictable; for others, there is a great uncertainty. Some may be curable, but this often requires intensive or unpleasant treatment regimes. For others, efforts to minimise the impacts of the disease or degeneration may involve long-term or invasive interventions. In any year, approximately 4000 children will die and, estimates suggest, approximately 10,000 will face death due to a medical crisis or inexorable deterioration.[33,53]

### *Threats to spiritual well-being faced by children/young people with life-limiting condition*

There is a substantive body of work on the implications of cognitive and psychosocial development when considering the spirituality of children and young people generally.[54,55] Such work confirms that children and young people have spiritual needs[56] and also highlights the ways in which development affects how spirituality is experienced and expressed.[57–62]

A qualitative meta-synthesis on studies investigating the spirituality of children and young people with chronic (and including life-limiting) conditions drew the following conclusions.[63] The ways in which children and young people make meaning of their situation may be different from the ways of adults. Relationships and communication with others are key to this process. Religious beliefs may be an important coping resource. Access to spiritual care in healthcare settings was unusual. However, the authors note much of this body of evidence comes from North American studies. Others have observed the illness experience may cause either a regression or acceleration of maturity (including understandings of death), making the provision of ‘developmentally appropriate’ spiritual care complex and challenging.[64,65]

A recent systematic review[66] on the symptoms, concerns and outcomes that matter to children and young people with LLC confirms the importance of acknowledging and attending to children and young people’s spiritual needs. It found that spiritual issues were reported by over half of the included studies ($n$ = 37/68). These included experiences of existential loss (e.g. loss of past ways of being in the world and loss of a future), existential vacuum (i.e. an inability to find or create meaning in life), not being at peace, longing, worry about the future and/or death, needing sources of hope and to be remembered. Other studies reported children’s, young people’s and parents’ descriptions of feeling ‘connected’ to something larger than self, and this supported resilience. Again, most of these studies were North American. A systematic review, drawing on a similar body of literature, specific to children and adolescents with cancer,[67] was carried out with the objective to inform the scope of the American Psychosocial Oncology Society’s Standards for the psychosocial care in paediatric oncology.[68] It concluded that the quality of the evidence was sufficient to make a strong recommendation for early spiritual needs assessment and support for children and families.

Existing research also points to the specific and distinctive issues for children and young people with LLC compared to adult patients. Their fragile mortality and the untimely nature of their possible or certain death are particularly distressing and challenging for (older) children and parents to reconcile.[60,69] There are generational differences in the extent to which formal religion is seen as relevant to meeting spiritual needs, and beliefs held by children may differ from their parents.[69,70] With respect to parents, evidence reviews and more recently published research also highlight the deficiencies in recognising and responding to their spiritual needs.[71–73]

### *Meeting the spiritual needs of children/young people with life-limiting condition*

Most existing research, as well as policy and practice guidance, focuses on the spiritual care of adult patients and their families. Typically, there is little recognition of possible differences between the adult and paediatric populations and the implications this may have for practice.[74–76] Differences between countries in degree of secularisation, religions practised, the diversity of interpretation and belief within religions and societal changes over time constrain the degree to which practices and approaches to paediatric spiritual care implemented in other countries translate to the UK context.[77–79] It is perhaps, therefore, not surprising that spiritual care has been identified as a research priority for this population.[80–82]

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## Study objectives and study design

### *Study objectives*

The overall aim of this study was to generate evidence that the NHS (and children's hospices) can use to guide how they meet the spiritual needs of children/young people with LLC and their families, including how chaplaincy services can best care for and support them. Specific objectives were as follows:

- to describe the organisation and delivery of NHS and hospice chaplaincy services and to identify differences in the nature of provision for children, parents and adult patients
- to investigate equity of access to chaplaincy services for children and parents and factors affecting access
- to describe the spiritual needs of children and parents, preferences regarding sources of support and their experiences of having those needs met or remain unmet
- to understand the differences between providing chaplaincy services to children, parents and adult patients and the implications for service provision and staff training
- to describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services
- to identify the (potential) roles of clinical teams in identifying and responding to the spiritual needs of children, young people and parents and the barriers and facilitators to these roles being fulfilled.

### *Study design*

The lack of existing evidence demanded that we took an exploratory and descriptive approach to addressing the research objectives. Multiple sets of data collection were undertaken and were organised under the following work packages (WPs):

- WP 1: cross-sectional survey of NHS chaplaincy services and equivalent survey of children's hospices
- WP 2: qualitative research with NHS chaplaincy teams and staff assuming an equivalent/similar role in children's hospices
- WP 3: qualitative research with children, young people and parents
- WP 4: qualitative research with NHS clinical teams/staff and children's hospice care staff.

*Table 1* sets out how the WPs contributed to the research objectives.

Further details on the design and methods of each WP are described in the next chapter.

## Patient public involvement in conceiving and executing the research

This study responded directly to the work we conducted on research priorities for children/young people with LLC. Young people and non-clinical professionals identified spiritual care as a top research priority.[81] Two specific

**TABLE 1** Contribution of WPs to study objectives

| Objective | WPs |
|---|---|
| Describe the organisation and delivery of NHS and hospice chaplaincy/spiritual care services and identify differences in the nature of provision for children, parents and adult patients | 1, 2 |
| Investigate equity of access to chaplaincy services for children and parents and the factors affecting access | 1, 2 |
| Describe the spiritual support needs of children and parents, preferences regarding sources of support and their experiences of having those needs met or remain unmet | 2–4 |
| Understand the differences between providing chaplaincy services to children, parents and adult patients and the implications for service provision and staff training | 2, 3 |
| Describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services | 2–4 |
| Identify (potential) roles of clinical team in identifying and responding to spiritual needs of children, young people and parents and the barriers/facilitators to these roles being fulfilled | 2–4 |

questions/issues were identified: 'What are children and young people's cultural, spiritual and religious needs, and are/how are they being met?' and 'bereavement support – post and pre – with the real emphasis on providing spiritual and religious support'. This was the first time spiritual care had been identified as a topic for research, perhaps due to the virtual absence of children/young people and parents, and non-clinical professionals, in previous research prioritisation exercises.[83]

It was not possible to fully implement the patient and public involvement (PPI) strategy planned for this study. We believe this was partly due to the impacts of COVID (a particularly worrying and distracting time for young people/families with LLC) and the fact that the topic itself carries ambiguities and sensitivities. Thus, despite efforts to recruit a young people's advisory panel, this did not prove possible. Instead, we worked with one of NIHR's Generation R groups: Leeds Young Research Owls (LYRO). The membership of the group includes some young people with significant chronic conditions, and a range of age, ethnicity and religiosity was represented. We did manage to recruit a smaller-than-hoped parent advisory group, with three different religious faiths that represented, fathers and mothers and included members from minority groups.

We worked closely with both these groups with respect to recruitment strategies, how we should convey the study objectives and the words and phrasing we should use to describe spirituality and spiritual care. Examples of the ways in which their input shifted our approach include creating videos, use of social media to support recruitment and using the phrase 'spiritual and emotional care' in recruitment materials in an attempt to convey the research as being relevant to all patients and families and not just to those with a religious faith. We also consulted with the groups about data collection approaches and techniques to facilitate interviews and, for parents, the fine-tuning of the topic guide.

Face-to-face meetings did not prove possible due to COVID and caring responsibilities. We believe this affected the depth of work we could do with the groups. These issues also constrained how much parents had the capacity to input in between meetings. A final impediment to the PPI work occurred, during the early months of the study, when our university paused all PPI work until a payments policy for PPI work had been devised and implemented.

## Equality, diversity and inclusion statement

### *Participant representation*

The study actively sought to recruit participants from a range of ethnic groups and religious beliefs, or none. This was partially successful. Future studies should explore recruiting via community faith organisations and online networks.

### *Research team and wider involvement*

Co-applicants and the research team were predominantly White British. Researchers working on the project included a junior researcher, who led on the day-to-day management and data collection for one WP. They attended all project planning meetings, meetings with co-applicants and the Study Steering Committee. During their time on the project, they were supported to attend training and apply (successfully) for a postdoctoral fellowship.

## Report content and structure

Across the four WPs, this study has generated a considerable amount of rich and novel data. Mindful of NIHR's core objectives, this report focuses on findings relevant to the NHS and NHS context. A summary of research we conducted with children's hospices, and specific to that setting, is presented in *Appendix 1* (with *Report Supplementary Material 1*–*3* offering more detail).

Within the main body of this report, *Chapter 2* describes the study's different WPs. *Chapter 3* concerns our survey of heads of chaplaincy in NHS acute trusts in England (WP 1). *Chapter 4* presents the qualitative research with NHS chaplaincy teams (WP 2) designed to follow-on and further explore survey findings. *Chapters 5* and *6*, respectively, report on our qualitative research with young people and parents (WP 3). Findings from our research with NHS professionals based in, working into, clinical teams and services who care for children/young people with LLC (WP 4)

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are described in *Chapter 7*. All chapters reporting findings conclude with a discussion of the findings, placing them in the context of existing research evidence. Finally, *Chapter 8* offers a synthesis of the findings against the research objectives, considers the implication of the findings for the NHS and makes suggestions for the direction of future research.

# Chapter 2 Methods

## Registration and ethical review

The study was registered on the ISRCTN registry (ref: ISRCTN41288313) prior to the commencement of WPs 2–4 (https://doi.org/10.1186/ISRCTN41288313). It was approved by an NHS Research Ethics Committee (REC) (Ref: 21/YH/0072; 15 April 2021) and the Health Research Authority (HRA).

## Work package 1: survey of acute National Health Service trust chaplaincy services

The purpose of WP 1 was to describe the current provision of chaplaincy services for children/young people with LLC, and their parents, within acute NHS trusts in England.

### *Design*

A cross-sectional survey was used to collect data.

### *Survey content and survey development*

The survey was developed in consultation with NHS chaplains and clinical staff and was piloted with three heads of chaplaincy services. It comprised 26 questions, split across 6 sections, which collected data on the following: trust characteristics; organisational structure of the chaplaincy service and the settings it works in; characteristics of the chaplaincy team, including salaried staff, chaplaincy volunteers and honorary and bank chaplains; qualifications, skills and experience of team members specific to working with children; reach of the chaplaincy services into different sections of the trust, including frequency of visits and relative time spent with patients, families and staff; and data collected on referrals and ward visit. Most questions used a fixed choice response format. A final question asked if the respondent would be interested in taking part in WP 2 online [hosted by Qualtrics®, software (Qualtrics, Provo, UT, USA; www.qualtrics.com survey)], and hard copy versions were created (see *Report Supplementary Material 4*), with the planned strategy being to use the postal version if no response was received via electronic administration.

### *Survey recruitment and administration*

Acute trusts were identified via systematic searches of NHS England websites, followed by web searches to confirm that the trust was still in existence and that it had a chaplaincy service. At the time of the survey, there were 140 acute trusts, of which 16 were specialist trusts. Of these, 139 had a chaplaincy service, the exception being a specialist trust.

The survey was launched in late October 2020, just prior to the second wave of the COVID pandemic in the UK. An e-mail inviting participation in the survey, including a link to the online version of the questionnaire, was sent to the heads of chaplaincy services with a study information leaflet attached. Where the e-mail address of head of the chaplaincy service was not publicly available, the e-mail was sent to the chaplaincy team's general e-mail address. The first page of the questionnaire comprised the consent form. An e-mail reminder was sent to non-respondents 10 days later. A postal version of survey was distributed to non-respondents 2 days after this reminder. A second e-mail reminder was sent 24 days after the initial distribution apart from where the e-mail address of the head of chaplaincy was not available. In these instances, a postal reminder was sent 10 days after the initial postal distribution.

### *Data analysis*

Data from postal questionnaires were entered into Qualtrics. The Qualtrics data file was downloaded into Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA) for data cleaning and was then transferred into Stata® (StataCorp LP, College Station, TX, USA) (version 17.0) for data analysis. Numerical data were analysed using descriptive statistics, including frequency analyses, cross-tabulation, chi-square (where required Yates correction was applied) and Pearson's correlation. Free-text response data were analysed using conventional content analysis.[84]

The NHS trusts represented in the survey were categorised as follows:

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- Generic acute: a trust providing secondary and emergency health care to the local population, including combined trusts also providing community and/or mental health services.
- 'Other specialist': a tertiary trust specialising in a particular diagnosis or patient group but not a children's trust.
- Children's trust: a tertiary trust specialising in the care of babies and children (0–18 years).

For most analyses, data were analysed according to the type of trust and well as for the total sample.

### *Adherence to/deviation from the protocol*

The survey was conducted as per the protocol. No target sample size was set.

## Work package 2: focus groups with National Health Service chaplaincy teams

The objective of WP 2 was to generate qualitative evidence on chaplaincy staff's views on the spiritual needs of children/young people with LLC and parents, how chaplains work with families and experiences of working into paediatric and neonatal settings.

### *Design*

A cross-sectional qualitative study design was used with the data collected via a series of one-off, 90-minute focus groups with purposively sampled NHS acute trust chaplaincy teams. Salaried chaplains, chaplaincy volunteers (with experience of working in paediatric settings) and honorary and bank chaplains were eligible to participate. Data collection took place between April and September 2021: the period in which the NHS began to revert back to usual ways of working following the second wave of the COVID pandemic. During this period, some chaplaincy services had not resumed using chaplaincy volunteers and some of their time was spent working remotely.

### *Sampling and recruitment*

Using WP 1 survey data, a purposive sampling frame identified sites which represented teams of different size, degrees of faith/belief diversity, reported reach into and practices in paediatric settings and the type of trust (generic acute vs. children's). Focus groups were conducted via video conferencing.

Recruitment was iterative to ensure that the sampling framework was populated. In total, 17 chaplaincy services were approached, with 13 agreeing to take part. Heads of the chaplaincy service acted as the lead contact in each site, liaising with the research team with respect to focus group arrangements and forwarding e-mail invitations to their staff and subsequent communications confirming arrangements. All focus group participants completed an electronic consent form and, if they chose, a short background details questionnaire, before taking part in a focus group.

### *Data collection*

Focus groups were facilitated by two researchers, with four members of the team taking this role on at least two occasions. One researcher assumed the lead role in facilitating the discussion and the other chose monitoring coverage of the topic guide, time-keeping and alerting the lead facilitator if they had not noticed a participant was wishing to make a contribution. The same topics were covered with each focus group (see *Report Supplementary Material 6* for topic guide). However, the time allocated to the different topics, or emphasis of probing, varied according to the type of trust (e.g. generic acute vs. children's trust) and reach into paediatric services. After an introduction from the research team and brief introductions from each participant, the following topics were explored: observations of spiritual distress and threats to spiritual well-being in children/young people; experiences of working with paediatric wards/services compared to other services; aspirations regarding the development of the chaplaincy service and continuity of spiritual care following discharge and working with local faith leaders/communities. Probes were used to elicit further details and explanations. A few days prior to a focus group, participants received an e-mail reminder that included a reminder of the topics to be covered.

### *Adherence to/deviation from the protocol*

The protocol specified focus groups would last 2 hours. However, this was reduced to 90 minutes, partly due to demands on staff time and the fact the focus groups were not held in person. We anticipated recruiting around 12 focus groups comprising, on average, 5–8 participants, thus yielding a total sample size of 60–96. In the event, 13 focus groups were held to achieve the target sample size. This was due to chaplaincy teams in smaller, single-site trusts comprising just three to four salaried staff. Seventy-six chaplaincy staff were recruited and the sampling framework was populated.

### *Data analysis*

See *Data analysis: work packages 2–4*.

## Work package 3: research with children/young people and parents

The purpose of this WP was to hear directly from children/young people, and parents, about their spiritual care and support needs, sources of support and their experiences of accessing and using chaplaincy services. For ethical reasons, we did not seek the direct involvement of children/young people at end of life. Children/young people and parents' accounts were regarded as the primary source of data on these issues, with that data being triangulated[85] with the data collected from focus groups with chaplaincy (WP 2) and clinical staff (WP 4).

### *Design*

A cross-sectional, generic,[86,87] qualitative study design was used, drawing on the narrative and phenomenological approaches. It comprised one-off, in-depth interview with three subsamples of children/young people and parents.

- Subsample A:
    - Children/young people with LLC whose health status/disease trajectory indicates they may die in the next 12 months but are not at end stage/dying.
    - Parents of such children/young people.

- Subsample B:
    - Children/young people/young adults treated for cancer as children.
    - Parents of such children.

- Subsample C:
    - Bereaved parents where their baby/child died of a LLC.

The rationale for including subsample B was that the immediate threat of the diagnosis had passed and the elapse of time since then will have allowed for reflection and sense-making.[88] Furthermore, they would, perhaps, be more able to talk about their feelings and experiences more openly when compared to subsample A. The rationale for subsample C included that these parents would be able to speak about their child's end stage and death and the time following this.

### *Sampling: inclusion criteria and target sample sizes*

Inclusion and exclusion criteria and target sample sizes are set out in *Table 2*. For subsamples A and B, we did not require that a child/young person and parent(s) had to both participate.

### *Sampling and recruitment*

The NHS clinics/services and children's hospices were intended as the main recruitment pathways. However, the COVID pandemic significantly impacted the local research and development (R&D) and clinical teams' capacity to support the study. As a result, the recruitment strategy was revised to incorporate partnering with a number of relevant national and regional charities who agreed to publicise the study via social media posts on Facebook (Facebook, Inc., Menlo Park, CA, USA) and Instagram and via electronic newsletters. In total, eight NHS services, four children's hospices and nine charities supported recruitment. NHS services and children's hospices were situated across a number of English regions and included locations with higher levels of ethnic and religious diversity. Written study information, brief information videos (one for each subsample) were also created (see *Report Supplementary Material 5* e.g. of recruitment materials). A QR code on study information sheets opened the relevant video. Given ambiguities and differing understandings of what 'spirituality', 'spiritual needs', etc. mean, including that some may interpret this as confined to religious beliefs, all recruitment materials referred to 'spiritual and emotional' needs/care.

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**TABLE 2** Work package 3: inclusion and exclusion criteria

| | |
|---|---|
| ***Subsample A*** | |
| Children and young people (target sample size: 20–25) | • Approximately 10–25years<br>• Diagnosed with:<br>◦ relapsed cancer, or cancers, with ≤ 75% survival rate (e.g. metastatic bone tumours, high-risk neuroblastoma and very high-risk leukaemias)<br>◦ degenerative genetic, neurological or neuromuscular conditions (e.g. spinal muscular atrophy and Duchenne muscular dystrophy) and evidence of significant deterioration within past 12 months<br>◦ kidney failure<br>• Does not have a significant cognitive impairment<br>• Is aware of the (potentially) life-limiting nature of the condition<br>• Not at end stage/dying |
| Parents (target sample size: 20–25) | • Parents of children (0–18 years) with above characteristics<br>• Parents of children with above characteristics except<br>◦ child has significant cognitive impairment<br>◦ and/or child is unaware of (potentially) life-limiting nature of condition |
| ***Subsample B*** | |
| Children/young people (target sample size: 10–15) | • Children and young people (12–18 years) and young adults (19–25 years)<br>• Have transferred to LTFU within the past 12 months and within 10 years of the end of treatment (Note: transfer to LTFU is locally defined by primary treatment centres and ranges from approximately 2–5 years post end of active treatment.)<br>• Cancer diagnosis occurred between ages of 5 and 17 years<br>• Does not have significant cognitive impairment |
| Parents (target sample size: 10–15) | • Parent of child/young person as above<br>• Child may have significant cognitive impairment |
| ***Subsample C*** | |
| Bereaved parents (target sample size: 20) | • Child diagnosed with a LLC<br>• Child died not before 3 months and not more than 3 years previously<br>• Child's age at death: 0–18 years |

LTFU, long-term follow-up.

### *Recruitment via National Health Service and children's hospices*

Staff in research sites identified children/young people eligible to take part in the study via scrutiny of electronic records and case notes. Sites distributed recruitment packs, comprising covering letter from research site, brief information sheet, 'expression of interest' (EoI) form (i.e. consent to contact) and reply-paid envelope. This was done in clinic/at the hospice and via post. Where posted, some sites chose to telephone the family beforehand to check whether they were happy to receive such information. Individuals interested in taking part in the study returned the EoI form directly to the research team.

The form offered potential participants two options:

- request for the full study information sheet plus response form to be posted to them
- request to be contacted by the research team by telephone, with the full study information sheet also posted to them.

The specific process varied slightly according to the age of the child/young person:

- Up to 15 years: parent(s) and child/young person were jointly approached with separate versions of the brief information sheet and joint EoI form.
- 16–18 years: young person and parent(s) were approached independently.

On receipt of an EoI form, a member of the research team contacted the respondent via their preferred means of communication, provided an opportunity to ask questions about the study and taking part and, if agreed, make arrangements for an interview.

### *Recruitment via social media*

Charities posted brief information about the study, including a hyperlink to an information video and EoI form. The EoI form included a brief screening questionnaire on study inclusion criteria.

### *Data collection*

Participants were offered the choice of an in-person, telephone or video call interview. Where a mother and father both wished to participate, they could choose a joint interview or individual interview. Participants either completed an electronic consent form prior to the interview or the consent process was audio-recorded at the start. For young people aged ≤ 15 years, parental consent was also obtained. Two members of the research team carried out all the interviews. Both interviewed young people, parents and bereaved parents.

The structure of the interview was the same across all subsamples, with topic guides used to ensure consistency and comprehensiveness (see *Report Supplementary Material 6* e.g. of topic guides). Opening questions gathered sociodemographic information (including any religious beliefs and the extent to which these are relevant in day-to-day life) and current living and health situations. The substantive part of the interview was structured around the participant being invited to briefly tell their story, focusing on key turning points and events, from around the point of diagnosis to the current time (or in the case of bereaved parents, at a point of their choosing after their child's death) and the impacts having a LLC/being a parent of such a child has had on their life. They were then asked to choose moments or periods of times that were particularly difficult and to describe what made those times difficult, their thoughts and feelings at those times and coping strategies and sources of support (formal and informal). Regardless of religious beliefs, we probed turning to religious rituals (e.g. prayer) and seeking connection with 'God' or higher other. The interview also explored experiences of sense-making and the degree to which they had resolved this. Finally, interviews explored experiences of and views about chaplaincy services. If a participant was unaware of chaplaincy services, we offered a brief explanation.

Interviews with young people ranged between 30 and 90 minutes. Interviews with parents lasted for 50–90 minutes (subsamples A and B) and 70–150 minutes (subsample C). Duration of joint interviews was consistently longer than individual interviews. Throughout the interviews, we were careful not to impose concepts and/or phrasing/language – thus, we avoided the use of the word 'spiritual' or, if needed, used the phrase 'spiritual and emotional' (e.g. spiritual and emotional needs).

### *Data analysis*

See *Data analysis: work packages 2–4*.

### *Adherence to/deviation from the protocol*

The COVID pandemic significantly impacted clinical teams' capacity to engage with and support the study. It also resulted in significant delays in securing local R&D approvals. This meant fewer NHS services supported recruitment, particularly to subsample A, where just four clinics/services acted as participant identification centres as opposed to around eight (as per the protocol). Target sample sizes were not achieved for children/young people in subsample A ($n$ = 6/20), whereas they were achieved for all other subsamples.

### *Methodological and ethical reflections*

Fieldwork for this component of the study raised challenges and risks. We were conscious that there was potential for the interview to lead to questions being raised or 'lids lifted' on thoughts and feelings that parents/young people may not have even acknowledged or never articulated before. We were therefore tentative in our approach, with our questions very much led by each person's individual situation, the story they told us and the extent to which their answers were closed or invited further questions and exploration. As a consequence, the topics were not covered consistently across the whole sample. Furthermore, we held back from probing unless we felt confident it would not risk distress. Thus, the depth of data also varies. In the protocol, we noted that we might use visual methods/facilitatory exercises to facilitate interviews with younger participants. The decision not to use them was primarily because the 'story-telling' approach (see *Data collection*) proved to be highly effective, rather than because the dominant mode of interviewing was via video-conferencing.

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## Work package 4: research with clinical staff

The purpose of this WP was to generate qualitative evidence on: medical and nursing staff and allied health professionals (e.g. clinical psychology and physiotherapy) understanding and use of chaplaincy services and their perceived impacts; their observations of the spiritual needs of patients and their parents; and their roles (perceived or actual) in identifying and responding to these needs. Forthwith, we use the term clinical staff/teams to refer to this sample.

### *Design*

A cross-sectional qualitative study design was used with the data collected via a series of one-off, 60-minute focus groups with clinical staff based in, or working in, teams/services which care for children/young people with LLC. Data collection took place between June and August 2022.

### *Sampling and recruitment*

We had planned to recruit staff from the same sites as WP 3. However, delays in securing NHS teams' involvement, and the involvement of fewer sites in WP 3, led us to use additional recruitment pathways. This included professional groups and networks, and NHS services supporting recruitment to WP 3. We purposively sampled to ensure representation of relevant professions (medical, nursing and allied health) and setting (e.g. inpatient vs. community; clinic/outpatient vs. inpatient ward). The target sample size was approximately 80 staff, with approximately 10 focus groups anticipated.

Lead contacts in each site liaised with the research team with respect to focus group arrangements. They also forwarded e-mail invitations from the research team to staff along with subsequent communications related to taking part in the study. All focus group participants completed an electronic consent form and, if they chose, short background details questionnaire, before taking part in a focus group.

### *Data collection*

Topics covered in focus groups included:

- experiences and observations of spiritual distress among patients/parent and expressions of the need for spiritual care and support
- practices and experiences around identifying and responding to spiritual needs/distress
- knowledge and understanding of chaplaincy services
- barriers and facilitators to their involvement
- observations of chaplaincy involvement and perceived outcomes
- use of chaplains to support clinical work
- use of chaplains for staff support.

(See *Report Supplementary Material 6* e.g. of topic guide.)

### *Data analysis*

See *Data analysis: work packages 2–4*.

### *Adherence to/deviation from the protocol*

The target sample size was achieved.

## Data analysis: work packages 2–4

All interviews and focus groups were audio-recorded, and the recordings were transcribed.

The approach to data analysis was thematic,[89] and the constant comparative method (internal/within interview, within a participant group and between participant groups)[90] was used to support the analytical process. The Framework

Method[91,92] was used to facilitate systematic data management, data display and data interpretation and to ensure audit trails of the data management process; and the NVivo software (QSR International, Warrington, UK) supported the analytical process. Analysis of WP 2 was led by Bryony Beresford, WP 3 by Natalie Richardson and WP 4 by Suzanne Mukherjee. All members of the team contributed to the analytical processes across data sets.

Coding frameworks for each WP were developed through an iterative process of reading, rereading and comparing transcripts, in which the conceptual clarity and coherence of codes (and higher-level themes/concepts), and the comprehensiveness of the coding framework, were developed, refined and tested using all relevant data sources. Existing notions and conceptual frameworks regarding spirituality were used.

Once finalised, the transcripts were coded and the relevant data were extracted, which was organised in line with the coding framework into tables and word documents. In addition, for WP 3, extended summaries (or ‘pen portraits’) of each interview were created, which was organised under high-level concepts/topics, including a brief chronology of key events and moments. Scrutiny of extracted data and summaries were used to identify explanatory, meaningful concepts (informed by existing conceptual/definitional frameworks of spirituality)[93–95] that served to convey the meaning of the data. Cycles of analytical note-making recorded researchers’ observations of the data (including verbatim quotes) and patterns within and between participants. Visual displays[96] were used to support data analysis (including where relevant, within- and between-group comparisons),[90] data synthesis and conclusion drawing.

## Reflexivity statement

Researchers were applied social science researchers with academic background in psychology (BB, SM) and sociology (NR). None held any clinical qualifications. All had worked on previous research topics with this population (patients, family members and/or staff). BB has a religious faith, SM is a humanist, and NR does not have a religious faith.

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# Chapter 3 Survey of chaplaincy services based in National Health Service acute trusts

## Introduction

This chapter reports findings from the survey of heads of chaplaincy services in NHS acute trusts in England (WP 1). The objective was to gather data on the characteristics of services (e.g. size and make-up), reach into the different sections/services in the trust and policies and practices in relation to working in paediatric departments. The survey was conducted in the autumn of 2020. Nearly three-quarters (*n* = 98/136) of eligible NHS chaplaincy services took part, representing a response rate of 72.1%.

## The trusts represented in the survey

### *Trust characteristics*

The recruited sample comprised heads of chaplaincy services from 86/124 (69.35%) of NHS generic acute trusts, 3/4 of NHS children's trusts and 9/11 of NHS 'other specialist' trusts in England, (see *Appendix 2*, *Table 20*). Among the generic acute trusts, 25/86 had a children's hospital. Size of the trust, as indicated by the total number of beds, varied within and between the types of trust. Generic acute trusts were larger than the 'other specialist' and children's trusts. Overall, 'other specialist' trusts were the smallest. The survey represented chaplaincy services across all the NHS regions in England, but the response rate varied by NHS region.

### *Types of departments and services provided by trusts*

All generic acute trusts had an all-age emergency department, adult inpatient wards, outpatient departments and an adult intensive care unit (ICU) (see *Appendix 2*, *Table 21*). All but one had a maternity department and at least one neonatal service. Almost all had at least one children's ward and/or paediatric outpatient departments, and almost two-thirds had a children's emergency department. Over a quarter had a cancer ward for children and/or teenagers and young adults.

## The chaplaincy service

### *Name of service*

An analysis of the concepts contained in the name of the service revealed that all included the words 'chaplaincy' and/or 'spiritual' (see *Appendix 2*, *Table 22*). Most services (*n* = 69/88; 78.41%) used the word 'chaplaincy'. For some (*n* = 29/69; 42.02%), this was used alongside one or more other concepts, the most common being 'spiritual care/support' (*n* = 24/69; 34.78%). Half of the services (*n* = 45; 51.14%) included the term 'spiritual'. In almost all cases (*n* = 41/45), it occurred alongside one or more other concepts.

### *Postdischarge spiritual care*

The survey asked respondents if their trust *permitted* them to provide support post discharge. Well over half of respondents (*n* = 56/97; 57.73%) reported this was the case, including all the chaplaincy services in the specialist children's trusts (see *Appendix 2*, *Table 23*). Invited to describe the circumstances in which they may offer or consider supporting a patient or family following discharge, 54/56 respondents provided brief details. These indicated that an ongoing contact was not offered routinely. Rather, it was restricted to particular groups (e.g. bereaved parents and patients at end of life who were transferred to home or to a hospice) and/or if specifically requested by a patient or family. In the latter instance, respondents typically noted this followed intensive support from the chaplaincy service during the admission and/or concerned support with funeral arrangements. Visits to the chaplaincy service when attending outpatient appointments was another way in which contact was maintained. In addition, among those responding 'no' to this question (*n* = 41), 16 provided further information indicating they also provided postdischarge support. Again, this was in particular circumstances (e.g. bereaved parents, where readmission was expected) or, exceptionally, for other patient groups. Across the whole sample, therefore, there is evidence that many, and perhaps all, felt they have discretion to make decisions on offering postdischarge support to patients and/or their families.

### *Connections with other services*

The majority of chaplaincy services ($n$ = 91/97; 93.81%) were separate to the trust's bereavement service. This included the three children's trusts. Chaplaincy services in 11 generic acute trusts and 1 non-paediatric specialist trust had a service-level agreement (SLA) to provide spiritual care at a local hospice. In one instance, the chaplaincy service in a generic acute trust had a SLA with a children's hospice (see *Appendix 2*, *Table 24*). This included a part-time presence at the hospice (5 hours/week) and 24/7 on-call availability.

### *Dedicated chaplaincy provision in children's hospitals or wards/departments*

Survey respondents based in generic acute trusts with a children's hospital ($n$ = 21) were asked to report whether their chaplaincy service had dedicated spaces or team members working in that setting. Just one reported there was a dedicated team working only in the children's hospital (*Table 3*). Seven (28%) reported there was a chaplaincy office in the children's hospital and nine (36.0%) reported that there was a multifaith space. For generic acute trusts without a children's hospital, over a third (37.7%) of respondents reported that they had dedicated salaried chaplains working in children's wards/departments. A smaller proportion (15/61; 24.6%) reported that they had one or more dedicated chaplaincy volunteers working in children's wards/departments.

## The chaplaincy team

### *Size*

Data on the number of salaried staff in the chaplaincy teams are summarised in *Table 4*. The total number of salaried staff varied, ranging from 1 to 18 (for further details, including band and whether full- or part-time, see *Appendix 2*, *Tables 25–27*).

There was a strong positive correlation between the size of the trust (as indicated by the total number of beds) and the number of salaried chaplaincy staff [Pearson's $r(96) = 0.668$, $p < 0.001$].

In addition to salaried staff, NHS chaplaincy teams typically included bank chaplains, honorary chaplains and chaplaincy volunteers. Thus, over half of services employed bank chaplains ($n$ = 54; 55.10%) working on an 'on-call' basis to widen the faith/belief groups represented in the staff team. However, their use varied, with some services having a few through to a small proportion (7/98) having 10–30 bank chaplains (see *Appendix 2*, *Table 28*). Most chaplaincy services also reported having one or more honorary chaplains ($n$ = 55/98; 56.12%), that is, religious/community leaders or accredited representatives of a belief group who the chaplaincy teams call on for specific purposes (see *Appendix 2*,

**TABLE 3** Dedicated chaplaincy provision for children in generic acute trusts

| | Number with provision | Per cent with provision |
|---|---|---|
| Generic acute trusts with children's hospital ($n$ = 25/25)<br>Dedicated chaplaincy provision in the children's hospital | | |
| Dedicated chaplaincy team working only in children's hospital | 1 | 4.0% |
| Chaplaincy offices | 7 | 28.0% |
| Multifaith and belief space/sanctuary | 9 | 36.0% |
| Generic acute trusts without children's hospital ($n$ = 61/61)<br>Specific members of team working in children's wards/departments | | |
| Dedicated salaried chaplains | 23 | 37.7% |
| Dedicated chaplaincy volunteers | 15 | 24.6% |

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**TABLE 4** Number of salaried staff[a] in the chaplaincy team

| Type of trust | Minimum | Maximum | Mean | Median |
|---|---|---|---|---|
| Generic acute ($n$ = 86/86) | 1 | 18 | 6.1 | 6 |
| Other specialist ($n$ = 9/9) | 0 | 6 | 2.7 | 3 |
| Children's ($n$ = 3/3) | 2 | 8 | 5.7 | 7 |
| Across all trusts | 1 | 18 | 5.8 | 5 |

a Full-time (> 30 hours/week) and part-time chaplains, Band 4 chaplaincy support workers.

*Table 29*). Again, these were typically being used to ensure that the patients'/families' religious needs are met. In terms of chaplaincy volunteers, the reported number of volunteers ranged from 0 to 160 (see *Appendix 2*, *Table 30*). However, the analysis of free-text responses indicates that some respondents reported having no volunteers at the time they completed the survey (when most NHS trusts were operating under COVID restrictions) and rather provided pre-COVID figures (as per survey instructions). Thus, figures on the number of volunteers in chaplaincy teams should be treated with caution. Overall, as with salaried staff, there was a strong correlation between the size of the trust (as indicated by the total number of beds) and the number of non-salaried members of the chaplaincy team (Pearson's $r(6) = 0.483$, $p < 0.01$).

## *Religions and beliefs represented in chaplaincy services*

### Range of religion and belief groups represented in chaplaincy services

Less than half of chaplaincy services [$n$ = 42/96 (43.7%)] had salaried chaplains from more than 2 religious/belief groups, and less than 1 in 10 services ($n$ = 8/96; 8.3%) had salaried chaplains from 5 or more groups (see *Appendix 2*, *Table 31*). Among chaplaincy services that used honorary chaplains ($n$ = 54), over a third 21 ($n$ = 21, 38.8%) had honorary chaplains from a single religion/belief and a similar proportion ($n$ = 22; 40.8%) from two or three different religions/beliefs. However, one in five ($n$ = 11; 20.4%) had honorary chaplains representing four to eight different religions/beliefs. Bank chaplains (used by 57 services) tended to represent one or two religions/beliefs, with three-quarters ($n$ = 42; 73.6%) reporting this. Finally, chaplaincy volunteers (being used by 88/96 services) were the staff group likely to be the most varied in the religions/beliefs represented with half of respondents reporting four or more religions/beliefs represented among their chaplaincy volunteers.

### Religious or belief affiliations of salaried chaplains

Protestant denominations [Church of England (88.5%), Free Church (72.9%)] were the most commonly represented religious affiliations among salaried staff in the NHS chaplaincy services (*Table 5*). Two-thirds (66.7%) of chaplaincy teams had a Roman Catholic salaried chaplain, and 45.8% had a Muslim salaried chaplain. Less than 1 in 10 had salaried chaplains who were Jewish (9.4%), Hindu, (8.3%), Sikh (6.3%) and/or Buddhist (2.1%). The presence of a non-religious/humanist salaried chaplain was unusual ($n$ = 5/96; 5.2%). Among smaller size chaplaincy teams (which included almost all non-generic acute trusts), Protestant, Roman Catholic and Muslim faiths were the only religions represented ($n$ = 45/49; 91.8%) (*Table 6*). However, non-religious/humanist chaplains were found across different size teams.

Unsurprisingly, therefore, almost all chaplaincy services [$n$ = 94/96 (97.9%)] had at least 1 Protestant salaried chaplain, and in 25 chaplaincy services (26.0%), all salaried chaplain(s) were Protestant, including one of the children's trusts (see *Appendix 2*, *Table 32*). However, all but one of these (a generic acute trust) had at least one other religion/belief represented among its non-salaried staff (honorary and/or bank chaplains, and/or chaplaincy volunteers) (see *Appendix 2*, *Table 33*).

### Religions/beliefs represented by non-salaried staff

The relative representation of different religions/beliefs among honorary and bank chaplains was broadly similar to salaried chaplains (*Table 7*). However, the profile of chaplaincy volunteers differed, with non-religious (including humanist) and Buddhist chaplaincy volunteers reported more frequently among chaplaincy volunteers compared to other staff groups.

**TABLE 5** Representation of different religions/beliefs among salaried chaplains by type of trust

| | Number of respondents reporting salaried staff with religion/belief | | | |
|---|---|---|---|---|
| | Type of trust | | | |
| Religion/belief | Acute generic ($n$ = 85/86) | Specialist other ($n$ = 8/9) | Specialist children's ($n$ = 3/3) | Total sample |
| Church of England | 75 | 7 | 3 | 85 |
| Free Church[a] | 64 | 5 | 1 | 70 |
| Roman Catholic | 58 | 5 | 1 | 64 |
| Muslim | 39 | 3 | 2 | 44 |
| Jewish | 9 | 0 | 0 | 9 |
| Hindu | 8 | 0 | 0 | 8 |
| Sikh | 6 | 0 | 0 | 6 |
| Non-religious[b] | 5 | 0 | 0 | 5 |
| Buddhist | 2 | 0 | 0 | 2 |
| Bahai | 0 | 0 | 0 | 0 |
| Jain | 0 | 0 | 0 | 0 |

a Includes Methodist, Baptist.
b Includes humanist.

**TABLE 6** Representation of different religions/beliefs among salaried chaplains by size of team

| | Number of respondents reporting salaried staff with religion/belief | | | |
|---|---|---|---|---|
| Religion/belief | 1–5 ($n$ = 49) | 6–10 ($n$ = 36) | 11–18 ($n$ = 11) | Total sample ($n$ = 96/98) |
| Church of England | 41 | 33 | 11 | 85 |
| Free Church[a] | 31 | 28 | 11 | 70 |
| Roman Catholic | 25 | 29 | 10 | 64 |
| Muslim | 9 | 27 | 8 | 44 |
| Jewish | 0 | 6 | 3 | 9 |
| Hindu | 0 | 5 | 3 | 8 |
| Sikh | 0 | 2 | 4 | 6 |
| Non-religious[b] | 2 | 1 | 2 | 5 |
| Buddhist | 0 | 1 | 1 | 2 |
| Bahai | 0 | 0 | 0 | 0 |
| Jain | 0 | 0 | 0 | 0 |

a Includes Methodist, Baptist.
b Includes humanist.

### *Age profile*

All respondents reported on the age profile of salaried staff. Overall, less than 1 in 10 (8.2%) had a salaried chaplain aged ≤ 30 years and nearly a third had no salaried chaplains aged < 51 years (see *Appendix 2*, *Table 34*).

Respondents also reported on the age of their youngest and oldest volunteers. The age of the youngest volunteer ranged from 18 to 69 years (see *Appendix 2*, *Table 35*). This figure was lower for children's trusts. The age of the oldest volunteer in a chaplaincy service ranged from 42 to 93 years. Across the three children's trusts, the oldest volunteer was 79 years.

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**TABLE 7** Frequency rank distribution of different religions/beliefs by staff group

| | Staff group | | | |
|---|---|---|---|---|
| | Salaried chaplains | Honorary chaplains | Bank chaplains | Chaplaincy volunteers |
| Church of England | 1 | 2 | 1 | 1 |
| Free Church[a] | 2 | 5 | 2 | 3 |
| Roman Catholic | 3 | 1 | 3 | 2 |
| Muslim | 4 | 4 | 4 | 4 |
| Jewish | 5 | 3 | 6 | 9 |
| Hindu | 6 | 8 | 5 | 8 |
| Sikh | 7 | 6 | 7 | 7 |
| Non-religious[b] | 8 | 6 | 9 | 5 |
| Buddhist | 9 | 8 | 8 | 6 |
| Bahai | 10 | 10 | 10 | 10 |
| Jain | 10 | 11 | 11 | 11 |

a Includes Methodist, Baptist.
b Includes humanist.

## Qualifications and training in working with children and families

### *Staff with specialist qualification in paediatric healthcare chaplaincy*

In generic acute trusts, it was unlikely that the chaplaincy team included a member of salaried staff specialist qualified in paediatric healthcare chaplaincy (*Table 8*). Trusts with children's hospitals were no more likely to have such staff compared to those without a children's hospital ($\chi^2$ (1, 86) = 0.32; $p = 0.56$). None of the chaplaincy teams in 'other specialist' trusts reported having staff with such qualifications. In the three children's trusts, two had at least one staff member with these qualifications.

### *Qualifications, skills or experience required for working directly with children*

Chaplaincy services in most generic acute trusts and 'other specialist' trusts did not require staff working directly with children to have any particular qualifications, skills or experience (*Table 9*). Chaplaincy teams in generic acute trusts with a children's hospital were no more likely to require this compared to those without a children's hospital [$\chi^2$ (with Yates correction) (1, 86) = 0.22; $p = 0.64$].

Those services reporting that they required staff working directly with children to have relevant qualifications, skills or experience were asked to briefly describe about that. All relevant respondents provided this ($n = 33$). None required a qualification in paediatric healthcare chaplaincy. Instead, relevant professional qualifications or experiences of working with children in a related setting was the dominant theme in the respondents' descriptions. Respondents gave examples of team members (salaried or volunteers) with professional qualifications (e.g. midwifery, paediatrics, teaching, children's counselling and children's social work) or experiences of working with or supporting children in other settings (e.g. schools). Others highlighted the need for highly developed communication or creative skills.

### *Team training on the spiritual care of children and young people*

Chaplaincy teams (or relevant sections of the team) in generic acute trusts with a children's hospital were no more likely to have received training in the spiritual care of children and young people in the past 5 years compared to those without a children's hospital [$\chi^2$ (with Yates correction) (1, 86) = 0.38; $p = 0.55$] (*Table 10*). None of the chaplaincy teams in 'other specialist' hospitals reported that such a training had been delivered. However, chaplaincy teams in children's trusts had all received training of this nature in the past 5 years.

**TABLE 8** Chaplaincy team includes staff with specialist qualification[a] in paediatric healthcare chaplaincy

| | Type of trust | | | |
|---|---|---|---|---|
| | Generic acute with children's hospital | Generic acute without children's hospital | 'Other specialist'[b] | Children's trust |
| Yes | 4 (16.0) | 7 (11.4) | 0 | 2 |
| No | 21 (84.0) | 54 (88.5) | 8 | 1 |
| Total | 25 (100) | 61 (100) | 8 | 3 |
| Missing | 0 | 0 | 1 | 0 |

a Survey defined as 'postgraduate certificate, diploma or master's in paediatric healthcare chaplaincy'.
b None of the specialist trusts had a children's hospital.

**TABLE 9** Qualifications, skills or experience required for working directly with children

| | Type of trust | | | |
|---|---|---|---|---|
| | Generic acute: with children's hospital | Generic acute: no children's hospital | 'Other specialist' | Children's |
| Yes | 7 (28.0%) | 22 (36.1%) | 2 | 2 |
| No | 18 (72.0%) | 39 (63.9%) | 6 | 1 |
| Total | 25 (100.0%) | 61 (100%) | 8 | 3 |
| Missing | 0 | 0 | 1 | 0 |

**TABLE 10** Receipt of training in children and young people's spiritual care in past 5 years

| | Acute with child hospital | Acute, no child hospital | Specialist, no child hospital | Children's trust |
|---|---|---|---|---|
| Yes | 9 (36.0%) | 18 (29.5%) | 0 | 3 |
| No | 16 (64.0%) | 43 (70.5%) | 8 | 0 |
| Total | 25 (100.0%) | 61 (100.0%) | 8 | 3 |
| Missing | 0 | 0 | 1 | 0 |

Analysis of descriptions of the training ($n = 36/37$) received by chaplaincy staff in generic acute trusts found that the most frequently reported source of training was via the UK Paediatric Chaplains Network ($n = 11/36$). Four respondents reported within-team training from staff specialist trained in children's spiritual care, or with extensive experience of working with children and young people. Specific training in parental bereavement ($n = 6$), play/creativity (e.g. Godly Play) ($n = 2$) was also described. A small number ($n = 3$) reported accessing training for some of its staff on neonatal or paediatric palliative care, and a similar number reported drawing on generic training courses on working with children and young people.

## Reach into different sections of the trust

Respondents were asked whether staff visited departments and units routinely (i.e. they were present in that setting whether or not a specific request/referral had been received), or only when requested. 'Other specialist' trusts were not included in this analysis, given that, due to their specialist nature, many do not have the departments/units found in most acute trusts. Data were collected for salaried staff and chaplaincy volunteers. However, considerable differences between trusts in the number of volunteers used and apparent anomalies in reporting (see *Size*) mean we only report on the reach of salaried chaplaincy staff into generic acute and children's trusts.

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### *Reach into specific departments/units: salaried chaplaincy staff*

Across all generic acute trusts, a greater proportion of respondents reported that salaried chaplains were routinely present in all age emergency departments (53/84) compared to children's emergency departments (24/28) (*Table 11*). A similar pattern was observed for ICUs. Thus, 69/84 (82.2%) respondents said their staff were routinely present in their adult ICU compared to 18/37 (48.6%) respondents reporting this was the case for their paediatric ICU. By contrast, salaried chaplaincy staff were routinely present in paediatric ICUs in children's trusts.

In terms of maternity and neonatal services, the proportion of respondents reporting salaried chaplaincy staff's routine presence was lower for maternity services (29.2%) and special care baby units (30.7%) compared to high dependency, local neonatal units (47.5%) and neonatal care units (39.2%). Where these services were located in a children's trust, chaplaincy staff were routinely present. Finally, and by contrast, more than half of the respondents reported that the salaried chaplaincy staff were routinely present in children's (65.2%) and teenage/young people's (73.7%) cancer wards. Overall, the presence of a children's hospital in the trust did not appear to influence in a consistent way the nature of the salaried chaplains' presence in these settings.

### *Reach into inpatient wards and outpatient departments: salaried chaplaincy staff*

The routine presence of salaried chaplaincy staff in all or some adult/older people's inpatient wards was almost universal practice in generic acute trusts (*Table 12*). Furthermore, over three-quarters of respondents (79.5%) reported that this was the case for all, rather than just some, adult/older people's wards. By contrast, 13/77 (16.8%) of respondents reported that they only visited children's ward when requested. In addition, where visits were routinely made, a smaller

**TABLE 11** Nature of salaried chaplains' presence in specific departments/units

| | **Nature of presence** | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **Generic acute: with children's hospital (*n* = 25/25)[a]** | | **Generic acute: no children's hospital (*n* = 59/61)[a]** | | **All generic acute (*n* = 84/86)[a]** | | **Children's trust (*n* = 3/3)[a]** | |
| **Department/unit** | **Routine** | **Request** | **Routine** | **Request** | **Routine** | **Request** | **Routine** | **Request** |
| ***Emergency departments*** | | | | | | | | |
| All age | 17 | 8 | 36 | 23 | 53 | 31 | | |
| Children's | 6 | 16 | 18 | 12 | 24 | 28 | 1 | 1 |
| ***ICUs*** | | | | | | | | |
| Adult | 22 | 3 | 47 | 12 | 69 | 15 | | |
| Paediatric | 11 | 7 | 12 | 7 | 18 | 19 | 3 | |
| ***Maternity and neonatal services*** | | | | | | | | |
| Maternity | 14 | 10 | 39 | 19 | 24 | 58 | 1 | |
| SCBU[b] | 15 | 9 | 39 | 15 | 24 | 54 | 1 | |
| LNU[c] | 11 | 8 | 22 | 9 | 19 | 21 | 1 | |
| NICU[d] | 12 | 8 | 21 | 10 | 20 | 31 | 2 | |
| ***Children's and young people's cancer wards*** | | | | | | | | |
| Children | 10 | 5 | 6 | 2 | 15 | 8 | 3 | |
| Teenage | 9 | 5 | 3 | 2 | 14 | 5 | 1 | 1 |

LNU, local neonatal unit; NICU, neonatal ICU; SCBU, special baby care unit.
a For each type of trust, row totals vary as trusts varied in the departments/units they had.
b Low dependency.
c High dependency.
d Specialist, complex care.

**TABLE 12** Reach into inpatient wards and outpatient departments: salaried chaplaincy staff

| | Nature of presence | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Generic acute: with children's hospital ($n$ = 25/25)[a] | | | Generic acute: no children's hospital ($n$ = 59/61)[a] | | | All generic acute ($n$ = 84/86)[a] | | | Children's trust ($n$ = 3/3)[a] | | |
| | Visit routinely | | Only by request | Visit routinely | | Only by request | Visit routinely | | Only by request | Visit routinely | | Only by request |
| | All | Some | | All | Some | | All | Some | | All | Some | |
| ***Inpatient wards*** | | | | | | | | | | | | |
| Adult[b] | 19 | 5 | 1 | 47 | 12 | 0 | 66 | 17 | 1 | | 1[c] | |
| Children | 13 | 8 | 3 | 35 | 8 | 10 | 48 | 16 | 13 | 3 | | |
| ***Outpatient departments*** | | | | | | | | | | | | |
| Adult[b] | 4 | 5 | 15 | 8 | 14 | 36 | 12 | 19 | 51 | | 1[c] | |
| Children | 2 | 2 | 21 | 6 | 6 | 40 | 8 | 8 | 61 | 1 | | 2 |

a For each type of trust, row totals vary as trusts varied in the departments/units they had, see *Table 11*.
b Includes older people's/geriatric wards and outpatient departments.
c Includes specialist women's and children's trust.

proportion reported that this was the case for all their children's wards (62.3%). In children's trusts, salaried chaplains were routinely present on all wards.

Patterns of presence in outpatient departments in generic acute differed, with almost two-thirds of respondents (62.1%) reporting that they only visited adult outpatient departments when requested. This figure rose to 79.2% with respect to paediatric outpatient departments. Two children's trusts reported that they were routinely presented in outpatient departments, and one trust only when requested. Overall, the presence of a children's hospital in the trust did not appear to influence in a consistent way the nature of salaried chaplains' presence in these settings.

### *Frequency of referrals/visit requests from paediatric, neonatal and maternity departments*

Respondents reported the frequency of referrals or request to visit a patient/parent in paediatric, neonatal and maternity settings (*Table 13*). Among chaplaincy services in generic acute trusts, there was a considerable variation in the frequency at which referrals were received from specific services/departments. However, over half of respondents with such services reported receiving referrals from maternity (90.4%), neonatal intensive care (62.0%) and/or high-dependency neonatal units (local neonatal units) (56.9%) a few times a month or more frequently. With respect to paediatric departments, referrals or requests to visit outpatient clinics were unusual – a few times a year or less – for almost respondents (92.1%). By contrast, around half of the respondents reported receiving referrals from inpatient wards (48.7%) and paediatric ICU units (54.0%) at least a few times a month. Finally, referrals from teenage cancer wards/treatment centres appeared to be less frequent compared to referrals from children's cancer services.

The pattern of responses from children's trust chaplaincy services ($n$ = 3) suggests that referrals from different departments are received more frequently than that observed in generic acute trusts. The exception was outpatient clinics, where, similar to generic acute trusts, requests to meet with a patient/family only occurred a few times a year.

### *Relative amounts of time spent with patients, families and staff*

Respondents were asked to rank four groups (patients, families, individual staff and clinical teams) in order of the amount of time their chaplaincy service spent with them relative to the other groups. They conducted this ranking exercise separately for adult and paediatric services/departments. In terms of adult services, almost all respondents (93.5%) reported that the group they spent most time with was patients, and just two reported that they spent most time with family members (*Table 14*). None reported they spent most time with individual staff.

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**TABLE 13** Frequency at which chaplaincy service receives referrals/requests for visits

| Name of service/ department | Number of respondents: More than once/ week | Few times a month | Few times a year | Once a year or less | Total number of respondents/total sample[a] |
|---|---|---|---|---|---|
| ***Generic acute trusts (n = 86)*** | | | | | |
| *Maternity and neonatal* | | | | | |
| Maternity services | 25 | 50 | 8 | 0 | 83/85 |
| Special baby care unit | 12 | 24 | 37 | 4 | 77/79 |
| Local neonatal unit | 8 | 21 | 15 | 2 | 51/56 |
| Neonatal ICU | 11 | 20 | 18 | 1 | 50/53 |
| *Paediatrics (excluding oncology)* | | | | | |
| Child inpatient wards | 11 | 27 | 33 | 7 | 78/81 |
| Child outpatient clinics | 2 | 4 | 23 | 47 | 76/82 |
| Paediatric ICU | 8 | 12 | 15 | 2 | 37/38 |
| *Paediatric and teenage oncology (ward/treatment centre)* | | | | | |
| Children's | 3 | 7 | 5 | 7 | 22/25 |
| Teenagers' | 2 | 3 | 10 | 7 | 22/25 |
| ***Children's trusts (n = 3)*** | | | | | |
| *Maternity and neonatal* | | | | | |
| Maternity services | 1 | 0 | 0 | 0 | 1/1 |
| Special baby care unit | 1 | 0 | 0 | 0 | 1/1 |
| Local neonatal unit | 1 | 0 | 0 | 0 | 1/1 |
| Neonatal ICU | 2 | 0 | 0 | 0 | 2/2 |
| *Paediatrics (excluding oncology)* | | | | | |
| Child inpatient wards | 2 | 0 | 1 | 0 | 3/3 |
| Child outpatient clinics | 0 | 0 | 3 | 0 | 3/3 |
| Paediatric ICU | 2 | 1 | 0 | 0 | 3/3 |
| *Paediatric and teenage oncology (ward/treatment centre)* | | | | | |
| Children's | 1 | 2 | 0 | 0 | 3/3 |
| Teenagers | 0 | 1 | 0 | 1 | 2/3 |
| ***Other specialist trusts***[b] | | | | | |
| *Paediatrics (excluding oncology)* | | | | | |
| Child inpatient wards | 2 | 0 | 3 | 0 | 5/5 |
| Child outpatient clinics | 0 | 0 | 2 | 3 | 5/5 |

a Number of respondents and total sample sizes differ for each row, as trusts varied in the maternity, neonatal and paediatric services provided.
b Reporting restricted to wards and outpatients due to the specialist nature of services.

**TABLE 14** Group with whom chaplaincy service spends most time

| Group respondent reports chaplaincy team spends most time with | Type of trust: Generic acute: with children's hospital | Generic acute: no children's hospital | 'Other specialist' | Children's trust | All respondents |
|---|---|---|---|---|---|
| ***Adult services*** | | | | | |
| Patients | 20 | 46 | 6 | n/a | 72 (93.5%) |
| Family members | 1 | 1 | 0 | n/a | 2 (2.6%) |
| Individual staff | 0 | 0 | 0 | n/a | 0 (0.0%) |
| Clinical teams | 3 | 0 | 0 | n/a | 3 (3.9%) |
| Total | 24/25 | 47/61 | 6/9 | - | 77[a] |
| ***Paediatric services*** | | | | | |
| Patients | 2 | 6 | 0 | 0 | 8 (10.1%) |
| Family members | 11 | 21 | 2 | 3 | 37 (46.8%) |
| Individual staff | 6 | 6 | 2 | 0 | 14 (17.7%) |
| Clinical teams | 5 | 13 | 2 | 0 | 20 (25.3%) |
| Total | 24/25 | 46/61 | 6/9 | 3/3 | 79[a] |

[a] Lower total sample size due to some respondents joint ranking two groups, which was therefore excluded from the analysis.

By contrast, when reporting on their work in paediatric services, only a small proportion (10.1%) reported that they spent most time caring for and supporting patients (i.e. children/young people), but nearly half (46.8%) said they spent most time with family members. Furthermore, 17.7% said they spent most time with individual staff, and a quarter (25.3%) informed that most time was spent supporting clinical teams.

## Work with children/young people and parents: additional practice and care

Survey respondents (excluding those based in children's trusts) were asked if, when working with babies, children, young people and their families, they did anything additional for them compared to adult patients and their families. A greater proportion of respondents in generic acute trusts reported this was the case compared to those who did not (*Table 15*). While this figure was greater for respondents based in trusts with a children's hospital compared to those without, this difference was not significant [$\chi^2$ (with Yates correction) (1, 84) = 1.14; $p = 0.28$]. Fewer specialist trusts reported additional practice or provision than those reporting none.

Those reporting additional types of care and support were invited to briefly describe what that comprised. All provided this information.

**TABLE 15** Additional practice or provision for paediatric patients/families

| | Generic acute: with children's hospital | Generic acute: no child hospital | All generic acute | 'Other specialist' |
|---|---|---|---|---|
| Yes | 17 (68.0%) | 31 (52.5%) | 48 (57.1%) | 3 |
| No | 8 (32.0%) | 28 (47.5%) | 36 (42.9%) | 5 |
| Total | 25 | 59 | 84 | 8 |
| Missing | 0 | 2 | 1 | 1 |

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Bereavement support (immediate and/or longer-term) was most frequently mentioned. Some respondents noted such support was available to all patients but was more likely to be requested or provided to bereaved parents. Others reported that postdischarge bereavement care was only offered within maternity, neonatal and/or paediatric services. The types of bereavement support offered included supporting decision-making around funeral arrangements, liaising with local funeral directors and taking funerals. With the respect to the latter, this was often described as being offered to parents experiencing early pregnancy loss, stillbirth and neonatal death. Many also referred to providing an annual baby loss memorial or thanksgiving service and the provision of a 'memorial book'. Other ways in which chaplaincy services offered support to bereaved families included: carrying out required ritual washing and shrouding, accompanying parents to view the body, decision-making around post-mortems, being present when the baby/child's body left the hospital premises and the offer of memory boxes and bereavement support leaflets and books for parents and siblings. Conducting rituals at birth were also described, such as baptisms and blessings, including the provision of mementos such as baptism candles and certificates.

Some respondents reflected on the differences in ways of working with children/young people, and their parents, compared to adult patients. This included descriptions of the use of play, creative resources and activities. These were described not only as a means of bringing fun and enjoyment to the ward (e.g. treasure hunts, visits from Father Christmas) but also as a way of creating or providing opportunities for dialogue or expressions of thoughts and concerns. Some described coworking with other specialisms to provide spiritual care and support to children and young people (e.g. hospital school staff and play specialists) and parents (e.g. support group for bereaved parents corun with psychologists). A couple of respondents noted the slower pace on children's wards, alongside a more holistic approach to care, allowed more time to be spent with patients and their families. This supported more creative approaches to identifying and meeting spiritual needs.

Finally, a couple of respondents referred to dedicated spaces for children and families within their sacred or quiet reflective spaces (e.g. children's books or colouring pencils in a corner of the hospital chapel or multifaith space), and another referred to a baby and children's memorial garden in the hospital grounds.

## Support to staff and clinical teams: adults versus children's services

Overall, acute trusts without a children's hospital were less likely to report differences between children's and adult services in the level of demand or types of support requested by individual staff or clinical teams (*Table 16*). This difference was not significant, however [$\chi^2$ (with Yates correction) (1, 84) = 0.19; $p = 0.66$].

Those reporting differences in the level of demand or types of support provided to staff in adult services compared to paediatric services were invited to briefly describe the differences. All provided this information.

In terms of the level of demand for staff-directed support, respondents differed in whether they found paediatric staff (as individuals or as a team) more or less likely to be open to or seek support from their chaplaincy service. A number noted that the extent to which staff requested support for themselves mirrored how much these staff sought the chaplaincy's involvement in the care of their patients and families. Where demand was greater than experienced from adult teams, this was typically attributed to the emotional demands of caring for babies, children and young people, and their families, including facing the possibility of end of life and the untimely nature of such deaths. Some respondents also noted the emotional stresses and strain on staff caused by safeguarding concerns and disagreements with families about care and treatments.

Respondents described two ways in which they supported staff: attending to personal spiritual needs and supporting staff in their roles. The latter included providing advice on meeting or responding to faith-based needs, contributing to clinical ethics and best interests in decision-making processes, contributing to staff inductions and advising on communication around death and dying with children and families. Staff support was typically provided to the whole team (e.g. formal team debriefs, participation in multidisciplinary team (MDT) meetings and incidental discussions) rather than one-to-one conversations or individual appointments with staff. A few respondents noted that the size of their chaplaincy team precluded them from proactively seeking to increase the support they could offer staff.

**TABLE 16** Differences in demand or types of support requested by individual staff or clinical teams: adult vs. children's services

| | Generic acute: with children's hospital | Generic acute: no child hospital | All generic acute | 'Other specialist' |
|---|---|---|---|---|
| Yes | 10 (41.7%) | 29 (50.0%) | 39 (47.6%) | 2 |
| No | 14 (58.3%) | 29 (50.0%) | 43 (52.4%) | 5 |
| Total | 24 | 58 | 82 | 7 |
| Missing | 1 | 3 | 4 | 2 |

## Monitoring access to chaplaincy services

In generic acute trusts, over two-thirds of respondents (69.1%) said their chaplaincy service did not routinely record the age of patients referred to their service (see *Appendix 2*, *Table 36*). This was also the case for one of the three children's trusts, and four-sevenths of 'other specialist trusts'. However, the types of ward visited were routinely recorded by a large majority (91.5%) of chaplaincy services in generic acute trusts and, where a referral or visit was made to a family member, the nature of their relationship to the patient (87.8%) was recorded. The three children's trust all recorded this information routinely.

## Discussion

This survey of heads of chaplaincy services in NHS acute trusts in England had two main objectives. First, to scope and describe the nature and characteristics of chaplaincy services (e.g. size, age and religious/belief profile), to map their reach into wards, services and departments in the trust and to explore whether this was associated with patient age (i.e. adults/elderly patients vs. paediatric vs. neonatal and maternity) and specialist paediatric provision (as indicated by the presence of a children's hospital). The second objective was to describe the team policies and practices around working with children and young people and paediatric specific provision. Again, here, we were interested in whether specialist paediatric provision in a trust influenced this. Both objectives generated critical contextual evidence to inform subsequent qualitative WPs in terms of fine-tuning decisions around recruitment and data collection, data interpretation as well as the implications drawn from study findings. Generally speaking, existing evidence on NHS chaplaincy services is extremely limited and we could identify none that had explored the differences between paediatric and adult populations in terms of access, practice and provision.

### *Features of the chaplaincy service*

The survey began by collecting data on basic features of the chaplaincy service, including service name, postdischarge support and any paediatric-specific facilities. There was a considerable variety in terms included in service names, though chaplaincy featured in most cases. The introduction of terms such as 'pastoral' and 'spiritual' in addition to chaplaincy or, in some cases, the loss of it altogether, is likely to be a relatively recent. It perhaps reflects a desire to convey the inclusiveness and relevance of the service to all patients and staff, regardless of religious faith or not. While most respondents reported they felt being able to continue providing spiritual care post discharge, this was typically presented as being in exceptional circumstances due, at least in part, to capacity issues. However, continued contact with bereaved parents was something frequently referred to, as was ongoing support to patients discharged elsewhere for end-of-life care.

A chaplaincy office and dedicated faith space/sanctuary in children's hospitals was not commonplace. This may partly reflect the fact that many children's hospitals are colocated with a 'general', all-age hospital offering one or more faith spaces. Furthermore, some children's hospitals are not contained in a physically separate or distinct area in that setting. Survey findings also suggest differences between chaplaincy teams in whether specific staff are allocated to (or work exclusively in) paediatric settings. What we do not know from our survey data whether the differences between trusts are deliberate, with heads of service holding different views regarding paediatric–specialist chaplains, or whether these

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are imposed by available resources or constrained by the multiple demands on chaplaincy services. These are the issues that our subsequent qualitative research with chaplaincy teams explored.

### *The size and make-up of chaplaincy teams*

Regarding the findings on the size and make-up of chaplaincy teams, as expected, there was a strong correlation between the size of the trust and the number of salaried chaplains. The number of non-salaried staff (honorary and bank chaplains and chaplaincy volunteers) was also strongly correlated with the trust's size.

Team size inevitably impacts the chaplaincy teams' diversity. Here, we explored diversity in terms of age and religions/beliefs. Our findings indicate that younger salaried chaplains (< 30 years) are highly unusual in NHS chaplaincy. In addition, almost one in three chaplaincy teams had no salaried chaplains younger than 51 years of age. To our knowledge, there is no existing work on the possible impacts of the age of chaplaincy staff on the acceptability and take-up of spiritual care among children/young people and patient/family experiences and outcomes. Wider evidence on the impacts of age disparity on patient–practitioner relationships is, perhaps surprisingly, extremely limited. However, a handful of studies has found that substantive differences in the therapist and patient age *may* affect the therapeutic alliance achieved.[97–99]

Regarding the religious/belief profiles of chaplaincy teams, as expected, the size of the team determined the diversity of religions/beliefs represented in a chaplaincy team. Existing data on the religious/belief profile of NHS chaplaincy staff are sparse.[45,47,100–102] However, our findings appear to align with existing evidence in that, across trusts, salaried chaplains were most likely to be affiliated to the Anglican or Roman Catholic church. Though difficult to directly compare with existing evidence, our findings do suggest a notable increase in the number of chaplaincy services with Muslim salaried chaplains since 2016 and the emergence of non-religious/humanist chaplains. With respect to the latter, this change is at least in part due to a clear 'uncoupling' of NHS chaplaincy from religion in the 2015 NHS chaplaincy guidelines, in which chaplaincy was defined as 'a service and a profession working within the NHS that is focused on ensuring that all people, be they religious or not have the opportunity to access pastoral, spiritual or religious support when they need it' (p. 6).[45] While the historical roots of NHS chaplaincy in the Christian faith[103] offer some explanation for its dominance in NHS chaplaincy in the early 2020s, the lack of a significant shift in the religious/belief profile of the NHS chaplains has been criticised. However, in terms of salaried staff, it is difficult to see how this can be rapidly or substantially addressed, given it is inextricably linked to the size of chaplaincy teams.

Unfortunately, there are no comparative data available to examine whether the profile of non-salaried posts has increased in diversity. However, it is clear from our findings that, in some NHS trusts, the faith/belief profile of patients and their families, or staff, is not replicated in the make-up of those working for the chaplaincy service. These findings are highly relevant to the population with which this study is concerned. We know that minority ethnic groups are over-represented among families of children with LLCs and parents experiencing baby loss.[104–106] Furthermore, babies and children with LLCs from minority ethnic groups experience more hospital admissions, have poorer prognoses and are more likely to die in hospital.[33,107,108]

### *Comparing chaplaincy in adult and paediatric settings*

Findings from the survey make it clear that chaplaincy teams are less likely to be routinely present on paediatric wards compared to adult wards. Across trusts, paediatric wards, where chaplaincy teams are most likely to be routinely, were neonatal care (particularly, higher-intensity settings) and children and young people's cancer wards/departments. Overall, these findings suggest an inequity of access to spiritual care for children and young people, and their parents, compared to adult patients. The fact that most chaplaincy services do not routinely record the age of patients referred to their service indicates an absence of systematic monitoring of this issue. Over and above this, our findings also point to potential inequities of access to spiritual care between diagnostic groups and trusts.

In terms of the routine presence of chaplaincy staff in outpatient departments, this was unusual in paediatric and adult service departments. This setting is underexplored by research,[109] and reasons for the lack of chaplaincy involvement are not understood. However, there is some work (with adult patients) that suggests the presence of chaplaincy or offer of a meeting may be welcomed by some.[110,111] It is also interesting to note that the 2015 NHS Chaplaincy Guidance only refers specifically to outpatients in the section on specialist palliative care, suggesting that it is not recognised as a context where spiritual needs may be expressed or can be met.

### *Volume of referrals from paediatric, neonatal and maternity services*

More detailed data on the frequency of referrals/requests from paediatric, neonatal and maternity wards and services indicate that this varies between trusts. However, the data do present an almost universal picture of frequent referrals from maternity services and many chaplaincy services also receiving multiple referrals in a month from neonatal intensive care. In addition, around half of chaplaincy services in trusts with children and teenage cancer services reported a similar level of referrals. The small number of children's trusts in our survey (3/4 of all children's trusts) means we should be careful in drawing comparisons. However, the volume of referrals reported by chaplaincy services in children's trusts was consistently higher, suggesting that rates of referral reported by chaplaincy services in generic acute trusts may not reflect the level of need.

### *Paediatric specific provision and practices*

Moving on to paediatric specific provision and practices, our findings suggest that very few chaplaincy staff in England are specialists trained in working with children and young people. Furthermore, few chaplaincy services had provided (or supported team members to access) training on the spiritual care of children and young people. In addition, most chaplaincy services did not require staff to have particular skills or transferrable qualifications or experience to work in paediatric settings. These findings were the same for chaplaincy teams in trusts with and without a children's hospital. Overall, these findings indicate that many chaplaincy services may not be aware of, or struggle to adhere to, the recommendation that chaplains working in paediatric settings should have an enhanced training.[47,112]

Almost all respondents reported that, in adult settings, their chaplaincy team spent most time with patients. When asked about paediatric settings, the response was markedly different. Here, 9 out of 10 respondents reported that they spent most time with people *other than* the patient. Thus, just under half said their team spent most time with parents, a quarter said most time was spent with clinical teams and nearly one in five reported that most time was spent with individual staff. Moreover, most survey respondents reported that the way in which they worked with patients and families in paediatric settings was different because of the unique needs and situations arising in these settings and as spiritual distress is more acute, particularly for families and staff. Different ways of working with patients was also described, including, as has previously been reported, creative approaches to facilitate the expression of spiritual issues and concerns and coworking with other professions.[113,114]

Taken together, these findings paint a picture of the different nature of chaplaincy work in paediatric settings. As such, it raises questions about the suitability of calculating recommended staffing levels on the basis on inpatient numbers alone.[47] This may not only fail to take into account of the need and demand for spiritual support from parents but also from clinical teams and individual staff. In terms of the latter, our findings reiterate existing evidence on the role chaplains play in supporting clinical teams in the care of their patients as well as providing spiritual care to the staff themselves.[115–118] Thus, just under half of survey respondents said there were differences between the adult and paediatric teams and staff in the level of demand and types of spiritual support requested. Some highlighted the threats to staff's spiritual well-being, which arise from having to face suffering and death in babies and children and observing the impacts this has on families. Others reported the work they did to support and advise clinical teams on specific religious beliefs and requirement, or with respect to ethically complex cases, in team meetings, case conferences and hospital ethics boards.

### *Methodological reflections and survey limitations*

The survey achieved a high response rate, and the number of missing responses within the data set was low. While the majority of respondents completed the electronic version of the survey, a sizeable minority used the paper version, supporting the decision to offer two ways heads of chaplaincy services could complete the survey. The recruited sample represented the different types of acute trusts though response rates that varied by region. This may, in part, be explained by the fact that the survey went live just as the second wave of the COVID pandemic was starting to build, beginning in North West England (one of the two regions with the lowest response rate). Furthermore, regional differences in the infection and fatality rates during the first wave may have meant that, at the time of the survey, chaplaincy services differed in how they were operating and their capacity to engage in non-essential activities.[119,120]

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When designing the survey, we sought to strike the correct balance between the depth of information collected and respondent's burden and fatigue. In particular, we avoided questions that required respondents to look up information. This means some of our data are less specific than what we would prefer (e.g. we did not ask for details of the hours of part-time posts). We also did not include all the questions we wanted to ask: a good example here is the absence of data on staff gender.

# **Chapter 4** Working in paediatric versus adult settings: chaplains' experiences

## Introduction

This chapter reports findings from our focus groups with chaplaincy staff (WP 2). One aim of the focus groups was to collect more detailed data on some of the issues covered by the survey of heads of chaplaincy services (see *Chapter 3*). Another objective was to investigate chaplains' views about threats to the spiritual well-being of children/young people and parents associated with living with a LLC, and the findings from these discussions are reported in later chapters.

To briefly summarise our methods, using WP 1 survey data, purposive sampling was used to identify the chaplaincy services that represented: teams of different size, degrees of faith/belief diversity, reported reach into and practices in paediatric settings and type of trust (generic acute vs. children's). Of the 17 services approached, 13 agreed to take part, with a total of 77 chaplaincy staff taking part. Details of the recruited sample can be found in *Appendix 3*, *Tables 37* and *38*.

We present our findings using the following structure:

- access to and involvement in paediatric compared to adult settings
- factors affecting families' access to or use of chaplaincy services
- supporting reach into paediatric departments
- differences between working in paediatric and adult settings
- providing spiritual care and support to children and young people
- the organisation and delivery of paediatric chaplaincy
- postdischarge spiritual care and the role of local faith leaders.

## Access to and involvement in paediatric compared to adult settings

Chaplains from chaplaincy services in generic acute trusts consistently identified paediatric wards and departments as the settings where their service had struggled the most, or were still struggling, to have a routine presence, or where referrals were more unusual than would be expected. Even in children's trusts, chaplains reported that their level of involvement differed between paediatric wards and departments.

> *I have an 'Access all Areas' badge. I can get into anywhere. I can go into any x-ray, … I can go right away into the surgical areas. Where's the one bit in the hospital I can't get access to? Children's. I cannot get in there.*
>
> *M?, Site E*

The lack of a routine presence in many paediatric settings (i.e. visiting routinely regardless of whether a specific referral or request to visit had been received) was regarded as key barrier to families accessing spiritual care and gaining maximum benefit from it.

> *Unless you inhabit that space you will never be a fully effective chaplain because you're not part of that world.*
>
> *F2, Site E*

> *Chaplaincy is a ministry of presence: being there whether those people need us in that moment or not, and when they do need us, the relationship is already there.*
>
> *F1, Site B*

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The consequence of this, chaplains argued, was that the care was not holistic and the spiritual needs remained unmet. In making this point, chaplains often pointed to the paradox that these were settings where spiritual needs may be more acute and more complex, and the risk of long-term consequences of failing to meet such needs will be greater.

By contrast, when they were routinely present, chaplains described spiritual care becoming normalised, and introducing or connecting families to chaplaincy services was the usual practice.

> *… and because of visibility of chaplaincy, staff feel very comfortable addressing us, and then the fact that staff feel so comfortable they feel more comfortable sharing us with the patients and families. And they [patients/families] think well if the staff are OK with them then they can't be too bad, you know?*
>
> *M1, Site F*

## Fathers

Chaplains expressed concerns about the additional barriers to meeting the spiritual needs of fathers, including their access to chaplaincy services. They highlighted their relative invisibility compared to mothers, who tended to be the ones attending clinics and cared for and stayed with the child during admissions.

> *… often they're on the periphery of anything that's done within the ward, we often tend to focus on the mother and child, not on the dads.*
>
> *M2, Site E*

> *It's the man's baby as well, you know. For a man to lose a child is … can be as devastating as it is for the woman. And I think there is something that a man can offer another man possibly in that situation, just identifying man-to-man … it's something that can be brought to that situation as well.*
>
> *M2, Site J*

Potential gender differences in the ways people relate and establish and develop relationships was regarded as another barrier to fathers' accessing chaplaincy. Furthermore, in sites where there were no or fewer male chaplains available, some wondered if this acted as a further reason why fathers' spiritual needs may go unrecognised and unmet.

> *… if there is a dad in, you know, we might send [male honorary chaplain] to go and have a chat with them because we are aware that actually, we are quite aware that a man wants to speak to a man.*
>
> *F2, Site G*

## Factors affecting families' access to or use of chaplaincy

Chaplains believed multiple factors influenced whether or not a family requested or took up the offer of chaplaincy support. Some were generic, applying to all patient groups, and others were regarded as unique to, or more pronounced in, paediatric settings.

### *Public understanding and awareness*

Poor public awareness and understandings of chaplaincy were frequently identified as a barrier to any patient, family member or staff accessing chaplaincy services. Specifically, the perception was that chaplaincy was only for people with a particular or any religious faith, or that chaplains were wanting to impose their beliefs on others. This engendered suspicion or unease around, or resistance to, their involvement.

> *Many people don't really understand what we do and why we do what we do.*
>
> *M2, Site C*

> *… so this conception can be, oh I thought you only visited when people are dying.*
>
> *M3, Site C*

Chaplains noted that previous first-hand experiences of religion or religious organisations may also affect people's feelings about chaplains.

> *Sometimes, because of people's history in church, you have to undo what the church may have done. … it's getting past the preconception of what church is like because of what happened to them in their childhood.*
>
> *M2, Site J*

### *Practices around recording faiths/beliefs*

Inconsistencies in recording faith/beliefs on admission were identified as another generic barrier to patients and families being offered chaplaincy involvement. The perceived uneasiness of staff to ask questions about faith and beliefs was questioned, given the information about other potentially sensitive personal details were collected more consistently.

> *… and the idea of religion or faith for families is a taboo subject: that's one of the reasons that that question is not asked … it's almost seen as an intrusive personal question that has no place, which is ironic because you can be asked quite freely what your sexual orientation is …*
>
> *F6, Site F*

However, chaplains stressed that an improved recording of religion/faith should not be regarded as the main way to improve access to chaplaincy services, given religious support was just one facet of the spiritual care they provided.

### *Spiritual distress understood as psychological distress*

Another barrier to patients and families accessing chaplaincy services was that emotional distress was interpreted or understood by healthcare staff as indicating mental ill health rather than, possibly, being a manifestation of spiritual distress and unmet spiritual needs. This resulted in referrals being made to psychology departments, with chaplaincy involvement not considered.

> *And I think sometimes if a staff member has a particular view or doesn't see that spirituality matters I think sometimes that can be a block. And, you know, I go to one meeting where so often they'll say [we need] psychology to work but the team say the family have declined psychology but they are seeing chaplaincy every day. And then [member of staff] says, no, it is must psychology. These particular doctors can't seem to hear that we've got anything helpful to bring. So I think sometimes the prejudices and biases of others can be a block.*
>
> *F4, Site F*

> *Some clinicians, they have a preference or an expectation that it would be a clinical psychologist or a counsellor or a qualified therapist … because they would prefer a more clinical model. … They want to go down the pathologised route very early …*
>
> *M1, Site H*

### *Staff as gatekeepers*

There was strong agreement that gatekeeping by staff was much more likely in paediatric settings.

> *… If I go on a Monday I won't get in, if I go on a Tuesday I will, if I go on a Thursday forget it because certain people are on. So it's all down to the members of staff that are on and how they view chaplaincy or religion or whatever.*
>
> *M2, Site E*

This was partly attributed to staff not seeing the relevance of chaplaincy services to children/young people or parents due to misunderstandings of the role of chaplaincy services.

> *I was passing and went in to just to say 'Hello, hi, how are you guys doing?' And one of the staff members said 'Yeah, really sorry, we don't really get much interaction with you guys, we've not had a reason to call you, we've not had any deaths in a while'. And I said 'We do deal with a lot more than deaths'. And then she quickly retorted and said 'Oh yeah, yeah, but then, you know, we don't know about people's religions either'.*
>
> *M2, Site M*

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However, chaplains also believed the additional vulnerabilities associated with the age of the paediatric population heightened fears and concerns that chaplaincy involvement with children/young people may be unhelpful.

> *… there'll be staff members that might have faced religious abuse in the past, so there will be, you know, some biases, unconscious biases, and I think it's working with that.*
>
> F2, Site G

## Supporting reach into paediatric departments

There was a strong consensus that developing good relationships with staff/clinical teams was the most effective way to ensuring families accessed to chaplaincy services. This was because staff were regarded as crucial advocates for chaplaincy and could serve to affirm the credibility and value of the service.

> *So if the staff know us and feel comfortable, they'll feel more confident at the time they're doing their care plans or whatever, to 'sell us', you know. … they're not pushing, they're not selling Jesus, they're not trying to convert anybody, they're just here to support, and they've got some experience and some wisdom, hopefully, to bring with it.*
>
> M1, Site B

> *I think our biggest hurdle – and why staff are so critical – is how staff introduce us, how they make us seem and appear.*
>
> F1, Site G

As a result, almost all of the chaplaincy teams had been proactive in seeking to build strong connections with clinical teams and wards.

> *… So we've had to do the legwork, we've, we've made ourselves more visible on the ward, we've done general visiting, just showing our faces more to staff …*
>
> F2, Site C

> *I've seen that a few times over my years here that people that were just very, initially 'we'll call yer if we need yer' have kinda welcomed us. … I think it's about taking time and building relationships.*
>
> F2, Site G

Some services reported that, to start with, they were invited to provide support to staff (e.g. non-clinical de-briefs and well-being interventions) before being invited to work with families. They believed these personal experiences of chaplaincy, and its positive impacts, meant staff not only better understood spiritual care but also trusted the chaplaincy team.

> *So I think sometimes staff will hold back from referring to us until they actually know who we are and they know what we do and they've experienced it.*
>
> F3, Site D

However, the process of building such relationships was sometimes explicitly described as uncomfortable and effortful: it was easier to spend time in settings where they were welcomed and there was plenty of demand for their time.

> *… it takes that getting out of the office, getting out the chapel, getting out of your comfort zone.*
>
> M1, Site B

Finally, within some chaplains' accounts, there was a sense of ongoing scrutiny by clinical staff and a pressure to always 'do well'. Thus, it appeared a degree of fragility could remain in the relationships chaplaincy staff had with paediatric teams which, potentially, could be lost through a single incident.

> *… you're only as good as your last time, I guess, you know, so it only takes me to mess up once. I sometimes feel if I'm in … that this is an audition, you know, and actually if you, if you don't screw it up then you haven't, you know, damaged the reputation of the chaplaincy for next time.*
>
> *M2, Site B*

## Differences between working in paediatric and adult settings

Overall, chaplains believed that working in paediatric settings was more complex than adults' settings because of the differences in family roles and family dynamics. Multiple factors and issues contributed to this complexity.

### *Working with multiple members of the family*

Chaplains were clear that the impact of having family member diagnosed with a LLC differed according to the nature of relationships involved. There were multiple reasons why parents were identified as being much more likely to be highly distressed compared to, for instance, spouses/partners or adult children. Furthermore, the child's mother and father may be responding differently and have different needs. As a result, chaplains could end up working individually multiple members of the same family.

> *Often when we go to a family we are recognising that we're actually there for each member.*
>
> *F1, Site K*

> *There'll be one conversation with the mother, there's different conversation you have with the father, there's different conversation you have with the child, and they're all personal confidential conversations.*
>
> *F1, Site G*

### *The child's reliance on parents as a key source of comfort and support*

While concerned that children's/young people's access to chaplaincy services may be restricted, some believed it was appropriate that they spent more time supporting parents than working directly with children. This was because of the central place parents have in most children's lives, which is further magnified during inpatient admissions. They therefore argued for the importance of chaplaincy support for parents so that they were better able to support their child.

> *That's been my experience that supporting their parents, helping helps them hold on to those internal resources so they can support their child.*
>
> *M1, Site B*

> *So I think [spiritual care] is really important for the children but actually, from my perspective, I see [chaplaincy] as much more as a parental support role because of all the questions it raises with them. … it's just because where the parent is, where the parent sits in relationship to their child, that I just think it helps for them to have an extra support or outlet.*
>
> *F1, Site G*

### *The hiding of distress from each other*

The hiding of distress from other family members was something chaplains said they frequently observed in adult and paediatric settings. However, chaplains believed this issue could be more acute or complex paediatric settings, with the intensity of parents' distress and the child's developmental age/stage contributing to ambiguities or uncertainties around the extent or nature of the child's distress.

> *They just don't want to upset each other, they don't want to hurt each other.*
>
> *F2, Site G*

### *Parental gatekeeping*

Across all focus groups, multiple references were made about the issue of parents' gatekeeping their child's access to chaplaincy services. Even when a child/young person had expressed a wish to meet a chaplain, securing parental permission to visit a child could be difficult to negotiate.

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> *And there's always that tension about does the young person have needs? And are you able to address those needs on the ward? And can you get permission to talk to that child on their own, would they like that?*
>
> *F1, Site I*

> *… it's how you have that conversation in a way with the parents' permission but not with the parents there. That can be tricky.*
>
> *F1, Site G*

Some noted that it was understandable that parents could be cautious or resistant to their child meeting with a chaplain. They believed these concerns were often located in a misunderstanding of what chaplains are and do (particularly, fears around religious indoctrination), not knowing the chaplaincy team themselves, and fears any conversation would be unhelpful or upsetting for the child.

A further reason for parental resistance to chaplains working directly with their child was that the conversation may turn to death and dying. This was something some parents did not want their child to know, or they did not want to face the fact that their child was aware of this. Even in situations where parents had agreed to, or requested, the chaplaincy team to visit their child, parental control over the content of that encounter might need to be navigated.

> *A mother had actually asked specifically to see me on her own first because she'd wanted me to talk to her son.*
>
> *F2, Site D*

## Providing spiritual care and support to children and young people

In this section, we turn to reporting the chaplains' experiences and views on working directly with children and young people, looking both at commonalities with other patient groups and areas of difference.

### *Commonalities with other patient groups*

Overall, there were strong commonalities across all patient groups – young and old – in chaplains' descriptions of spiritual care. These included: presence and human connectedness; providing a non-judgemental and non-directive space in which, if wished, thoughts, concerns and sense-making can be articulated; and, where requested, fulfilling of religious requests.

> *In my experience it's about presence and being that person that can hold the silence. Because so many times I've found that a child needs that space where you're not just simply filling it, and I've had experiences where children have then opened up and talked about what is on their heart, what they're worried about.*
>
> *F6, Site F*

> *I was involved with a young man who was going through a very difficult time, and his parents kept trying to, and understandably, you know, kept saying to him, you'll be all right, you'll be all right. But actually, he just wanted somebody to hear him say, I'm not all right, I'm really not all right, and I can't see being all right ever again.*
>
> *F1, Site F*

### *The heightened vulnerability and fragility of children/young people*

A common theme in all the focus groups was that, as one chaplain put it, the stakes were higher when working with children and young people. This appeared to be grounded both in the powerlessness of children and young people and in their relative lack of robustness, or internal resources, to draw on in the situation they found themselves in.

> *I'd say there just seems like there's a lot more at stake, they're a lot more fragile, they're a lot more vulnerable, volatile.*
>
> *F1, Site E*

### *The diversity within the paediatric population*

In all focus groups, the enormous diversity within the paediatric population in terms of cognitive, linguistic and psychosocial development was discussed. However, it was stressed that, in noting these differences, the chaplains did not want to appear that they were problematising this patient group. Rather, they wanted to be able to understand and work with this diversity.

> *… we're dealing with children at very different stages and in their understanding.*
>
> *F2, Site G*

> *… but just do you work differently with children and young people because you have to take into account their developmental stages. You'd use different language, you'd use different concepts and ideas, you'd structure your speaking quite differently.*
>
> *F2, Site E*

A few chaplains made particular reference to the spiritual needs of children with severe disabilities and neonates. They noted that these babies/children had as much need for human–human connection, to be treated with dignity and to feel valued as other patients. Chaplains stressed the importance of spending time with them, conveying human presence through their voices (talking, singing) and, with parents' permission, touch. Some described the particular way they supported the baby/child's relationship with their mother through the use of 'bonding squares'.

> *So, when you're talking about those with limited capacity or those who are so small that they can't communicate. …., it's [the same as] when somebody is at that point of end of life. ….If that person can't see you and consciously and cognitively understand what that means, then the act of holding a person's hand communicates something in a way … touch can convey so much that words cannot.*
>
> *F2, Site A*

> *We have interchangeable knitted squares. So mum wears one close to her skin and the baby has the other, and then they swap them over so the baby in the cot can smell mum even when she's not there. So you might think it's not possible to provide spiritual care to a baby but that's one of the ways we do.*
>
> *F1, Site I*

### *Differences in connecting and relationship-building*

A dominant theme in discussions was the additional work and skills that may be required when building relationships with children/young people so that they reach a point where, if they wished, a child/young person felt able to fully express themselves.

> *… it's all of those skills that you need to employ with adults but even more so. Building that level of trust, as it's important with an adult isn't it … and even, even more important with a, a child.*
>
> *M1, Site E*

In addition to developmental differences within the population, three further issues were articulated, which could impede building relationships with children/young people.

First, children's/young people's life worlds were quite different to their own, making it harder to identify or find points of connection. At the same time, many believed that the window of opportunity for establishing a connection was often shorter for paediatric patients when compared to adult patients.

> *But you have to be able to walk in and in, literally in a second try and work out how you're going to connect and, and that, and I think sometimes it's, sometimes you've got to make that decision far faster with a young child than you do with an adult.*
>
> *M1, Site A*

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Here, chaplains described using information provided to them by a member of staff (e.g. hobby and interest) and visible cues (e.g. objects on the locker and logos on clothing) to identify a possible point of connection, or conversation opener, with a patient they had not met before. An additional or alternative approach used by chaplains was to bring something (e.g. a creative activity), which they hoped would spark interest and engagement.

Second, chaplains believed that children and young people could take longer to get to a point where they were ready to express existential distress or find a way to articulate it.

> *When you're with an adult, there are potentially at least milestones, landmarks that they can find a frame of reference to kind of frame the experience that they are currently experiencing, some solid ground, if you like, under their feet, even though the world seems to be shifting and changing. I think for young people, for children, even if there are those landmarks it may be difficult for them to recognise or articulate them and we can help facilitate some of that.*
>
> *M1, Site K*

While this holds true for all patients, some chaplains were clear that the opportunity to develop a relationship with a child/young person over time, through a series of visits, was more necessary if they were to be able to fully respond to their spiritual needs.

> *… so it doesn't have to happen in the first session, you know, or even the second or third day, you've got time to build a relationship with the parents and the teenager. But unfortunately, my experience is by the time they come to [hospital end of life suite] they're really within hours or days of death.*
>
> *M1, Site B*

Finally, within discussions on this issue, there emerged descriptions of carefully sensitive persistence in visiting even when the child/young person was not overtly welcoming or wanting to engage in conversation.

> *And sometimes like with the teenagers … I can remember one in particular, they were in a very long time. And most of the time you went you weren't really sure whether they were glad you were there or not. … you didn't get a lot out of 'em at the time. But then it transpires that actually they really valued you just being there and them being able to, you know, have a bit of a moan or, or just the fact that you were bothered and that you kept turning up even when they were grumpy actually meant a lot more to them than you thought.*
>
> *F2, Site G*

### *A greater use of creative approaches*

Creative activities familiar to the age group (e.g. painting and simple cookery) were described as useful for fostering connections and supporting expression. The use of specially designed resources and activities were frequently referred to and were regarded as a means of 'bringing normal life' into the hospital which, in turn, supported the child to relax and, if they wished, open up about their thoughts and feelings. Constructing these encounters to minimise the need for eye-to-eye contact and offering a means for non-verbal expression were regarded as critical. Furthermore, some activities being used were specifically designed to provide openings for conversations.

> *so to do some sort of activity, some sort of play with them, which enables that relationship of trust to be built. And then they say incredible things, they open up. And [in doing these activities] often, they'll talk 'sideways'… we're not eyeballing them and asking them things. You're actually doing something that enables them to relax … and then they begin to realise this is stuff I can talk about … what's going on in my life.*
>
> *F1, Site D*

### *Working with other non-clinical professions*

A further distinctive feature of chaplaincy in paediatric settings was coworking with other non-clinical professions who work routinely with children. Many teams described getting involved with their hospital schools (e.g. doing a session on religious festivals) and saw this as a way to informally introduce themselves and their service to children/young people.

> *… [at the hospital school] we tend to pick up a lot of multi-faith stuff. So we'll often go down and talk to kids there about different religions and their beliefs, including around illness, health, well-being, whatever. And it kinda integrates chaplaincy into what they're doing. It's joined-up working.*
>
> *M2, Site E*

Frequent reference was also made to the drawing on the specialist skills and knowledge of play-workers, particularly in sites where direct work with children/young people was more unusual. Finally, there were also examples of joint-working with a family or codelivery of spiritual and psychological care (e.g. parent bereavement support groups corun with clinical psychology).

> *… Her parents were working with a psychologist. They didn't know how to tell her that she was dying, they didn't know how to deal with her diagnosis and the psychologists were working with them to come to that point. But it was interesting that she had already raised it with me: she just said 'I know that I'm dying and I'm sure me mum and dad know that I'm dying and I'm OK with that. But I don't know how to bring this situation up, I don't know what to talk about, but I know that I'm dying'. So again, that's when we worked with the psychologist. … We coined it 'chapology' – we found a way forward together in that.*
>
> *F2, Site G*

### *Working in the presence of parents*

Regarding gatekeeping children's/young people's access to chaplaincy per se (see *Differences between working in paediatric and adult settings*), chaplains described a further layer of parental gatekeeping. This related to whether parents were willing for the chaplain to meet with the child/young person alone.

> *Some parents can be overbearing, they might answer on behalf of their children … you have to be sensitively be persistent.*
>
> *M2, Site J*

> *But also, if you have older children there is an issue of privacy and being able to engage with that child. If you can imagine, a teenager in hospital, they need to trust you before they can open up about their spirituality and their anxieties and … the big questions. And they're not necessarily gonna do it with mum sitting on the chair just a foot away.*
>
> *F1, Site I*

Some described experiences of working towards a situation where the parent withdrew. Important to this was gaining the parents' trust, something which could require them initially observing an encounter(s) and choosing when they felt sufficiently at ease to step away.

> *he was kinda like looking at mum all the time and trying to find the right answers to say, as opposed to actually letting whatever was inside come out. He was eighteen, we talked about football and then we started talking about other things … But it took the mum to decide to leave the room for him to start speaking.*
>
> *F2, Site D*

### *Children/young people communicating with parents via the chaplain*

Chaplains also described cases where a child/young person appeared to deliberately use a chaplaincy visit to raise an issue (often, their impending death) that, so far, had remained unexpressed within the family. Chaplains believed children/young people did this either to enable further conversations with their family, or as a means of reassuring their parents.

> *Sometimes they want their families to hear the elephant in the room: the parents cannot talk with children that they are dying, but the child knows that they are dying. We had a sixteen-year-old girl, her mother could not tell her [she was dying] and she could not tell her mother [she knew she was dying], so there was a lot of obstruction: not to talk the dying word. All the times she asked to see me with her mum there, all she would ask is about heaven and the end of life. … So sometimes children use us as like a bridge for them to speak to the parents, or to hear each other at these difficult conversations.*
>
> *F7, Site F*

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## The organisation and delivery of paediatric chaplaincy: chaplains' views

### *The need for dedicated chaplaincy staff in paediatric settings*

None of the generic acute trust chaplaincy services represented in our focus groups had chaplains working *exclusively* in paediatric settings. This was principally due to the size and capacity of the chaplaincy team. That said, many had one or more specific team member(s) allocated to establishing a regular presence on children's wards and/or picking up referrals from paediatric settings. However, there was a general consensus that other members of the chaplaincy team need to be able to work in such settings, because of both staff availability and the fact that children/young people may request a chaplain from a specific faith background.

> *Horses for courses, some people take to particular environments more than others and we recognise that. … But I think part of chaplaincy is living in sometimes uncomfortable situations. So everyone should have at least a little bit of exposure and opportunity to go the children's hospital.*
>
> *M1, Site K*

At the same time, it was acknowledged that not all chaplains would be comfortable or effective in this setting.

> *But I think you do have to acknowledge, don't you? Not all chaplains would be good at working with children and young people, in the same way not all chaplains would be good at working with renal patients or with patients with heart failure. … There are some things that, we're human beings and we have gifts and abilities and there are some things we're good at and some things we're not.*
>
> *F2, Site E*

While having staff allocated or, even, dedicated to paediatric settings was consistently regarded as something they would aspire to, chaplains drew attention to the often multiple limitations of their service in terms of faith representation and lack of capacity to meet the needs of other (and larger) populations who might benefit from specialist care, such as patients with dementia. Indeed, something referred to in many of the focus groups was the underinvestment in chaplaincy by the NHS. This was regarded as running counter to its founding principles and current rhetoric around holistic care.

> *I really like the way the NHS was set up originally that a hospital needed a doctor and a chaplain. And so it's been recognised right from the word go the importance of spiritual/pastoral as well as the physical, right from the beginning of the NHS.*
>
> *M1, Site I*

> *But we keep talking about the word 'holistic' and it's all over the NHS in terms of documentation, it's all over their strategy documents. What do they actually mean by that? And I want to keep interrogating that because I don't think pastoral and spiritual is understood or well placed to stand up for itself.*
>
> *F1, Site H*

### *The need for specialist training to work with children and young people*

There was a difference in opinion regarding the need for chaplains working in paediatric settings to have specialist training. Among those who had been specialist-trained, reference was frequently made to its enormous value, including the resources and creative approaches training had exposed them to.

However, some of the chaplains who expressed a comfortableness and confidence in working with children/young people had not received specialist training (though, that is not to say they would not welcome such an opportunity). Instead, they typically described deliberately drawing on relevant professional skills and experiences to inform their practice (e.g. teaching, social work, paediatric healthcare roles and parish ministry), volunteering or personal family experiences (e.g. parenthood and grandparenthood).

By contrast, staff with little experience of direct work, or wider life experiences, with children/young people tended to express unease or uncertainty around working with this group. This appeared to arise from both a sense of the unfamiliar and feeling insufficiently knowledgeable or equipped to accommodate the developmental difference, both those between children/young people and adults and within the paediatric population

> *Young people, they may tell you in different ways, and you need to be able to understand those ways. So I think additional training would be, will always be of, of value. And I think there is a whole area about spiritual development. … Yes, of course, we all have spiritual needs, but they may be different.*
>
> *M3, Site H*

> *… so if I was engaging directly with a child [with learning difficulties] I would probably refer to [family member], as a teacher of special needs and, you know, talk about the best way to engage.*
>
> *M2, Site A*

It was this group, in particular, that expressed a need for some sort of specialist training, in terms of both child development and the practice of healthcare chaplaincy with this population. However, alongside advocating for the need for training, there was a strong consensus that this alone cannot foster and support connections with paediatric patients, particularly older children and teenagers. For this, familiarity with children's/young people's life worlds was also regarded as important.

## Postdischarge care and the role of local faith leaders

Chaplains frequently expressed concerns about having to cease involvement with families at discharge, particularly given the absence of community-based chaplaincy services in most areas.

> *It's sad that there's not a kind of follow-on into the community, because, you know, for all the other disciplines we do, you know, you have district nurses, physios, and actually people are dealing with awful stuff and then we're gone. … I think for some people, they kind of feel bereft, they feel abandoned.*
>
> *F1, Site M*

All sites felt powerless to address this, given the staffing levels and pressures and demands on the team.

> *In terms of continuity of care and in terms of actually handing people on to someone that we recognise, can trust, have some relationship with … I'd love to if someone would give me the time and bodies to do it, but they haven't.*
>
> *M1, Site J*

Their concern was greatest for bereaved parents.

> *They're so desperate, but my job's done when I've finished that funeral and I don't choose to walk away, but it's my job to walk away.*
>
> *M2, Site C*

> *So we've walked this really difficult path with families and it's ended up in a bereavement, and I often feel there's quite an abrupt end to it. Sometimes we do funerals and sometimes we'll meet them in the [mortuary viewing room] and things like that but longer-term support I think it is a massive concern.*
>
> *F3, Site D*

Local faith communities were identified as a potential source of spiritual care and support. However, chaplains were clear that it should not be assumed that local faith leaders and communities have the knowledge, skills or confidence to do this even when families were already members of a community. This was particularly the case if the chaplaincy staff had not had previous contact with a leader or community, either as chaplains or through other roles they had in the locality.

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> *But there's some funny people out there in religious institutions and faith belief groups and I want to be sure of who I'm referring a family to before I do that. They're vulnerable enough. … Quite rightly, you know, we've had to demonstrate that we are helpful, that we are honest, that we are transparent, we have no agenda, and that we are them – focused. I'm not sure you can say that in for some of the institutions that are out there.*
>
> *M1, Site K*

> *We have referred to churches here and there but, I hope I won't offend anyone in saying this, it's very hit and miss as to how a church might pick that up and how they may deal with that situation.*
>
> *F3, Site D*

Chaplains stressed the need to make careful judgements about whether it would be helpful to connect a family to a particular community. A few described supporting and upskilling local faith leaders and communities but also noted that they were constrained in how much they were able to do this.

> *… the religious leader of that community setting might not have the best understanding of the clinical space. So a chaplain then exists in that hopefully perfect multidisciplinary role of being able to bridge both of those spaces between the clinical and the community.*
>
> *M1, Site H*

## Discussion

This chapter has reported findings from focus groups with chaplaincy services purposively selected to represent the range of the services in acute NHS trusts in England (including children's trusts) in terms of size and make-up of the chaplaincy teams and reach into paediatric settings. The focus groups allowed us to further understand some of the issues covered in our survey of NHS chaplaincy service and explore the chaplains' views on the differences between working in adult and paediatric settings and postdischarge spiritual care.

Chaplaincy teams often described being a routine presence in paediatric wards as more difficult to achieve when compared to adult wards. They believed multiple factors contributed to this and the degree to which wards/departments proactively supported families' access to chaplaincy services or involved chaplains in the care of patients and families. Most are not unique to the paediatric setting (e.g. poor understanding of spirituality, spiritual needs and spiritual care/chaplaincy among staff; staff's personal experiences and attitudes towards religious faith; staff's uncomfortableness and inconsistent practices around recording religious faith; and public's misunderstandings of chaplaincy).[20,48,121–126] What is different is that, in paediatrics, chaplains need the permission and cooperation of staff to be routinely present. Thus, staff beliefs, understandings and attitudes play a far greater role in determining whether a child/young person or parents have the opportunity to choose whether or not to draw on chaplaincy services. A consistent story emerged on how chaplaincy teams had overcome these barriers: the importance of developing trusting relationships with staff and providing staff with opportunities to experience, for themselves, the care and support chaplains can offer. Achieving this required time and commitment and a willingness to be put in a place of vulnerability.

As noted previously, research on chaplaincy in paediatric settings is relatively sparse.[74] However, the distinctive nature of family in the paediatric context has been described,[127] and it is represented in practice handbooks.[114] While research on chaplaincy in other settings also reports the tensions that can arise from working with multiple family members, and the skilled work required to manage these,[128] the uniqueness of the parent–child relationship adds a further layer of complexity. There are two reasons for this: the intensity of parental distress and the high degree of dependency of the child on the parent, often in multiple ways. Our findings also reveal parents as potential gatekeepers to chaplaincy services offering and providing spiritual care to children/young people. Together, these findings point to the complexity and sensitivities of the paediatric context and the increased risk that children's/young people's spiritual needs may remain unrecognised and unmet.

Our findings on chaplains' experiences of working directly with children/young people suggest further sources of difference to working with adult patients and their families. This is not unexpected, given developmental differences which, in themselves, have driven the burgeoning of creative approaches within chaplaincy to providing and supporting spiritual care.[129] Furthermore, it was clear that chaplains were deeply aware of the cultural differences between themselves and children/young people. Indeed, while this was a dominant theme in the discussions, it is noteworthy that differences in religious or ethnic culture were *not* mentioned as potential challenges. Our survey findings suggest chaplains tend to be older adults (see *Chapter 3*). However, wider research is equivocal on whether age is relevant to how easily and how well child/youth practitioners connect with and receive the confidences of children/young people. Instead, the importance of child-/young person-centred, age-appropriate practice is emphasised.[130–132] This would point to the value of specialist training in paediatric chaplaincy, particularly if chaplains have no transferrable skills to draw on. At the same time, while first-hand experiences may render someone feeling comfortable, or even confident, to work with a child or young person, this cannot be taken to indicate *competence* and points to the need for specialist training.

None of the chaplaincy teams based in generic acute trusts had chaplains dedicated to working in paediatric settings. While there was no argument against the value of this, chaplaincy staff consistently presented their services as underserving all patient groups. This raised questions about the acceptability of prioritising, or resourcing, the development of their paediatric provision over and above other and often larger patient groups. Against this argument, there is evidence on the increased threats to spiritual well-being experienced by children/young people with LLC and their families which chaplains described, and we consider this in more detail in later chapters.

The focus groups also generated interesting reflections on the spirituality of neonates and children with significant cognitive impairments. These are both groups where their spirituality and need for spiritual care may not be understood or recognised.[133,134] Chaplains who worked with these patients, however, stressed the importance of recognising and responding to their spiritual needs reflecting on parallels in their practice with other patient groups such as people with severe dementia and those not fully conscious. Importantly, there was no evidence of an unease of caring for this patient group. Rather, focus group discussions yielded examples of the creative and multi-sensory ways chaplains sought to meet their spiritual needs.

Finally, we also used the focus groups to explore the issue of postdischarge spiritual care for children/young people and/or their parents and bereaved parents. This was an area of concern for chaplains, particularly where they had been a key source of support during the admission, and they knew that the need for spiritual support would continue post discharge. Our findings challenge a possible assumption that handing over families to local faith communities and their leaders is always appropriate and without risk. While this can work well, the degree of outspokenness in the verbatim quotes included in this chapter are highly representative of the views expressed across all focus groups and serve to illustrate their unease around this unless leaders/communities were well known and well informed. Other research supports this position,[135,136] though this body of evidence needs to be held alongside a separate set of evidence that reports the positive role and value which local faith communities and spiritual leaders can play.[137]

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# Chapter 5 Young people's stories and reflections

## Introduction

In this chapter, we turn to our research with young people (WP 3) which sought to identify and describe the ways having a LLC may threaten the spiritual well-being or create spiritual needs, and the things which support or speak to those needs, including chaplaincy services. We also triangulate the data on threats to spiritual well-being with that collected from NHS chaplains, clinical staff and children's hospice staff in WPs 2 and 4.

*Appendix 4*, *Table 39* provides details on the recruited sample. To summarise, it comprised 19 young people; 6 were under active treatment or had a degenerative condition, and 13 were under the care of a cancer late effects service. Ten participants said they had a religious faith, with five of these describing their faith as important to their everyday lives. Across the sample, five recalled at least one encounter with an NHS chaplain. Most of the sample ($n$ = 15/19) were White British.

Findings are organised as follows:

- threats to spiritual well-being
- the need to talk
- sources of spiritual care and support.

## Threats to spiritual well-being

### *Facing own mortality and living with uncertainty*

All the young people described moments of realisation that there was a possibility they could die, and, for some, experiences of medical crises when they felt they were facing death. Descriptions of feelings of intense fear and anxiety were threaded through these accounts.

Most of those diagnosed as older children and teenagers had vivid memories of the moment they heard about their diagnosis. Some recounted high levels of emotional distress at the time.

> *I was just about two weeks away from dropping dead, basically, so it all came on quite quick, you know? So, as you can imagine, like you're probably a bit on the emotional side of things, that was quite intense. … my mental health was just completely in the gutters.*
>
> *AYP06*

> *I was pretty distraught. I did cry at that point because though I'm ten, you'd still hear the news, you'd still see the fatalities and stuff. It's still all very real. It hits you quite hard when you find out.*
>
> *BYP16*

However, for some, the full realisation of seriousness of their situation did not come until a while afterwards.

> *I think at first I was kind of just numb to it. It wasn't until I was like, you know, hooked up to all the paraphernalia and the hospitals and the drip stands and everything that I got, it, it kind of hit me.*
>
> *BYP01*

Among those diagnosed at an early age, the realisation of possibility of a shortened life, or what death meant, were not things they fully understood or were fully aware of at the time.

> *… as a child there was no sense of the gravity of what was happening.*
>
> *AYP08*

However, most recalled knowing at the time that something was wrong and their health was at risk in some way.

> *I've got quite, quite vivid memories really. It was scary, but at the same time people tried to obviously cover it up quite a bit. … But obviously you still know that there's something off, you know that there's something going on.*
>
> *BYP11*

All the young people talked about the strain and burden of living with the uncertainty of the future course of their condition.

> *It's always hanging over your head like.*
>
> *AYP06*

Medical crises or evidence of significant deterioration were always described as times of great anxiety and distress when deep fears surfaced, which were usually less dominant or suppressed. A number of young people noted the absence of recognition of the trauma of these experiences among those who looked after them. Some also referred to experiencing the deaths of others they knew with the condition, or at the hospice they used. Events such as this served to emphasise their own mortality and the reality of the threat of death.

Among those discharged to oncology late effects services following 'successful' treatments, many referred to heightened levels of stress and anxiety around whether their treatment would be (continue to be) successful. For some, these surfaced in the time leading up to check-ups. For others, this was described as being ever present in their lives.

> *And you're there just thinking, what if it comes back tomorrow? How would I tell my family that? How I would go about telling my boyfriend … it's just such a part of my life now to think about it … kind of impulsively.*
>
> *BYP01*

### *The need to make sense and find meaning*

The need to make sense of and find meaning in the situation they found themselves in, as well as the meaning of life more generally, was observed in almost all young people's accounts.

> *… it's kind of cos my entire world view has been ripped from under me and I'm kinda floating.*
>
> *BYP01*

> *Yeah, well you definitely don't need to be religious, even if you're completely atheist you could be asking like, oh why me, like why is this happening to me kinda thing? And like everything's bad, everything's horrible, like life's terrible. … It's hard to see the light when you're going through all that stuff.*
>
> *AYP06*

However, most of those diagnosed, or who became aware of their diagnosis, as young children did not remember actively engaging in sense-making when they were younger. They felt this was either because they did not appreciate, or were unaware, of the significance of their diagnosis, or because an acceptable explanation and way of looking at things had been offered them by a parent.

Making sense was described an internal and gradual process, and it was something that fluctuated in how much and how often their thoughts turned to it. The involvement of family or friends in sense-making was highly unusual. Looking back to earlier in their lives, some believed they consciously avoided, or had not being ready, to engage in this process of meaning-making. It was also clear that a state of acceptance, and constructing some type of meaning from their situation, could be fragile and easily shattered by a medical crisis or unexpected medical news, if only temporarily.

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Some believed they had reached a point where they were comfortable with, and drew comfort from, the sense they had made of their situation and the way they had been able to reframe it in a positive way.

> *I definitely think [when ~18 years] I definitely did grapple with that question of like meaning of life. What does my life mean and stuff? And I actually, I honestly became very grateful for the life that I have, grateful for the circumstances that I've been given in my life: my education, my family and things.*
>
> *AYP08*

Others described not being able to find sense in why it had happened to them. For these, the language was more around acceptance of the fact there would be no answers.

> *… like it's definitely something that you like think about. And obviously there is the question of like why does God do like this, and is there a point? Like I do sometimes do think, did I go through cancer because it was meant to give me a lesson or it's meant to give me a new way of living or whatever? … it is kinda like an uncertainty.*
>
> *BYP05*

## Religious beliefs and finding meaning

Among those identifying themselves as having a religious faith, this emerged as relevant to their process of sense-making. For some, their faith had proved a positive resource, providing a means by which they could positively reframe their situation.

> *But then again, from like a religious point of view, I feel like it's [dependency on others] also a blessing in a way as well because I feel like I've been protected by a lot of like bad things that maybe in this generation of youngsters accidentally get into or are kind of drawn towards. Whereas I've sort of been sheltered by that, so I'm like Yay! But it's also yeah, it's annoying.*
>
> *AYP04*

Equally, while not wanting to renounce their faith, some described needing to find out for themselves how their faith and beliefs spoke about their situation rather than passively accepting the teaching they had received from parents or community faith leaders.

> *… over the years there've been like so many questions, and I'll be like who do I ask? But it's hard to find someone who's religious but open-minded as well. … But yeah, it would be nice for someone to kind of understand your religious perspective and not be critical if that makes sense?*
>
> *AYP04*

However, there were some who found they could not reconcile about what had happened to them with the beliefs and notions of God taught by their religion which they had previously believed and accepted, if only in a nominal way.

> *I think I have every reason under the sun to not have that faith anymore … it's perfectly justified … because actually like let's look at what's happened. It can be hard to keep the belief that this is someone's plan. Because actually why would someone who is supposedly so good to us plan for something that's so nasty.*
>
> *BYP02*

However, some felt sad or conflicted about relinquishing a set of beliefs and the community that went alongside this.

> *But I don't know … it's weird, cos it goes completely against everything that I've always like done all the way through like school and stuff. I've not been to church now, except from like special occasions, like Holy Communions and funerals.*
>
> *BYP12*

Finally, among those who said they had no religious beliefs, notions of a 'supernatural, higher other' sometimes featured in their accounts.

> *I think I'm in one of those things where it's kind of like, almost like a spiritual thing and it's like, God, I've been given this time, I should make the most of it.*
>
> *BYP01*

### Threats to sense of self-worth

Three main threats to self-worth were observed in the young people's accounts: interactions with staff, dependency and a perceived lack of purpose.

Accounts of occasions when the actions of staff had made the child/young person feel 'de-humanised' or that they did not matter were found across all the sample.

> *… they would just treat yer as you're a patient, not a person. [They should] just to try and be a bit more like person-to-person and like everybody's different and they've got their own like feelings and fears and stuff like that, and that's got to be part of it.*
>
> *AYP06*

Everyone we interviewed also referred to experiences of dependency on others and reflected on how that made them feel about themselves. For some, dependency was a temporary experience. However, for many of those with conditions that progressively impacted their physical functioning, the experience was permanent.

> *I have a very independent mind but a very dependent body, which can be hard because it's difficult to kind of find out who you really are. Cos one side you have your own opinions, your own thoughts, your own feelings, and then the other, the other side you have like a body that means you rely on others to do basic things.*
>
> *AYP04*

It was among this latter group that we also observed references to the struggle to feel their lives had purpose.

> *I don't know, it just feels that there's no like, there's nothing out there for us to, you know, like there's nothing there for us to use or like, you know, be of service of. So I think something, more, more options need to be out there for us.*
>
> *AYP05*

### The inpatient experience

Over and above what an inpatient admission might signify in terms of their health, study participants' descriptions of their inpatient experiences (which, in some cases, were for many weeks and months) revealed multiple ways in which it could threaten their spiritual well-being. Reasons for these negative impacts and experiences varied between participants and between stays. For some, their dislike of being an inpatient cannot be overemphasised.

A dominant theme across young people's accounts was that being away from their homes and their everyday lives resulted in an acute sense of being dislocated or removed from normality, which for many had already been disrupted by the diagnosis or treatment regimes.

> *I think it's because we're like trapped in like a, like a small environment and, you know, being bed-bound. It like takes a knock-on like on mental health, on my mental health, basically, and being away from my home.*
>
> *AYP05*

Those with experiences of having to shield from other people, or because their health was so fragile, described the heightened sense of disconnection that separate rooms engendered.

> *I was quite isolated because of how unwell I was … isolated from people and society and all that … [the ward] was quite cornered off when you're in that situation cos like you can't really see much of outside and it's quite like, quite cornered off.*
>
> *BYP15*

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However, we note that others preferred private rooms and struggled with the lack of space and privacy on a multiple bed ward. This meant efforts to maintain connections with peers could feel uncomfortable and did not offer as much support as they could potentially do.

In addition, experiences of being exposed to patients sicker than themselves were frightening and upsetting, serving to reinforce or emphasise to the young person the life-threatening nature of their condition.

> *… I really didn't like it, because there was people who were a lot more seriously ill that kind of, you know, made me more aware of things. I didn't like seeing other people in the situation, if you get what I mean? So as soon as I got to my bed I'd shut the curtains around me, because I didn't like seeing other people.*
>
> *BYP17*

Among those with experiences of staying in wards where they were not the same age of others, a dominant part of their experience was a sense of not belonging, of being out of place.

> *I was the youngest there by like forty years … I felt like I'm the only person in the world that's my age with this disease.*
>
> *AYP06*

> *I wasn't quite young enough to appreciate a clown but I wasn't really old enough to appreciate sort of the massive screens and stuff in the teenage ward. So I was in a bit of a grey area, I think. … I felt like it wasn't really made for me.*
>
> *BYP03*

Lastly, those dependent on others for moving about and care regarded hospital wards as places that further took away the autonomy they had and increased their sense of dependency.

> *… because we can't do as much ourselves as the next person can with our like muscle wasting conditions. Sometimes it can be really like hours on end for a nurse to come when you buzz 'em.*
>
> *AYP05*

### *Witnessing parents' distress*

Almost all the young people described witnessing moments when their parents were greatly distressed. A key moment when this happened was around the time of diagnosis. Here, even those diagnosed as young children recalled their parents' distress. For some, it was a vivid memory. Regardless of age, observing such distress in their parents was upsetting and unsettling. Some expressed feeling a sense of responsibility and guilt that they were the cause of this distress. For many, these feelings of guilt persisted.

> *And it's difficult to separate knowing that it wasn't me who made them sad, it was this thing within me. I knew that, but it was still almost something I'd done, right? So it was kind of like they are directly sad because of me in some twisted way.*
>
> *BYP01*

### *Disturbed relationships with parents*

Most young people described some sort of disturbance or change in the relationship they had with their parent(s). This arose in two ways. First, in a desire to prevent further distress to their parents, they hid their own distress.

> *… because it can be very difficult for the child to speak frankly to the parents, they may want to reassure the parents, they may gloss over the details of how they actually feel and the actual worries and stresses that they have. I certainly did that: I didn't want to worry my parents.*
>
> *AYP08*

> *I felt this overwhelming need to protect them … they couldn't deal with me not being well, whether it's mentally or physically. So I just hid it and I hid it and, and I suffered for that, so, but in my mind it was a protection thing.*
>
> *BYP01*

Second, particular topics or issues were avoided. Descriptions of talking with their parents about end of life and death were highly unusual and had only happened where there was a shared religious faith and, therefore, shared beliefs about an afterlife.

### *Disrupted relationships with peers*

None of those interviewed described having a friend(s) they could or wanted to talk to about their most private thoughts, fears and feelings. Instead, disrupted relationships with peers were reported by most interviewees, with friendships lost or circles of friends reduced in size.

> *So I found that a lot of my friends just kinda dipped out and disappeared and stuff. … I just was totally isolated, apart from a few people, you know.*
>
> *AYP06*

Multiple causes for this were identified, including times away from friends and usual activities due to extended inpatient stays, the requirements of treatment regimes or not feeling well enough to join in usual activities.

> *I wasn't able to go to the sleepovers and the birthday parties and things like that … and I just remember feeling really left out at the time. I wasn't allowed to play on the main playground in case anyone bumped into me, so I had to play on the nursery one. I hated that, cos again it just felt really separate.*
>
> *BYP11*

In addition, the quality or nature of remaining relationships could change, leaving the young person feeling let down and isolated.

> *… their reactions weren't always ideal, shall we say.*
>
> *BYP02*

### *Feelings of differentness*

Separate, but related to experiences of disrupted relationships, were feelings of being different. Often, this was experienced most acutely in relation to feeling different to peers. Underlying these feelings were three issues. First, they felt different because the psychological and emotional experience of having a LLC is something others cannot step into or imagine. Second, their condition had resulted in changes to their perspective on life and priorities, which did not align to those of their peers. Finally, the physical effects of treatments or surgery – particularly those visible to others and their reactions to them – contributed to feelings of differentness.

> *They have normal lives and, you know, lives like not as complicated a life as me, with medical needs and all that. I think that's what makes me feel a bit, sometimes a bit upset sometimes cos I feel like I can't relate to people my age. It makes me feel like I don't get understood.*
>
> *BYP165*

> *I was in a [school] changing room once and someone gagged when they saw my stomach [scarred from surgery]. I was just stood there like … I didn't know, I didn't say anything, I just stood there looking at them. And then [said] 'OK, well sorry', I think I actually apologised.*
>
> *AYP03*

Within our sample, experiences of feelings of differentness, and the distress associated with this, were more strongly expressed by those who previously had healthy, independent lives. Importantly, for those successfully treated for life-threatening illnesses, these feelings of differentness had not dissipated.

> *Even after the transplant, I still wasn't like a normal person.*
>
> *AYP06*

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### *An absence of pleasure and joy*

Notions of a lack of joy or pleasure in their lives was observed in some young people's accounts. For some, this occurred during periods when they were feeling unwell or suffering from the effects of treatments.

> *… cos like there is always like the longingness to go and play again with other people, but you just can't and that's really upsetting.*
>
> *BYP16*

For others, it appeared to be an everyday experience and was attributed to social isolation, dependency, physical/environmental barriers and parental concerns.

> *… but, you know, it's quality or quantity. So it's them [parents] understanding that they do want to make their child's life a bit more colourful, rather than just protecting them in the bubble and them staying alive. … Yeah, I've never really been able to see life as like, hey, it's good kinda thing.*
>
> *AYP04*

### *Threats to children's/young people's spiritual well-being: professionals' views*

This section triangulates the young people's data with the views of healthcare professionals and chaplains professionals who took part in WPs 2 or 4. They offer additional or further observations regarding the threats to spiritual well-being faced by children/young people (*Table 17*).

**TABLE 17** Additional or further insights from professionals

| Threat to spiritual well-being | Additional observations/insights from professionals |
|---|---|
| Facing own mortality and living with uncertainty<br>The need to make sense and find meaning | • Fears about dying observed across wide age range. May be expressed directly or indirectly<br>• Lack of life experience/wisdom compared to adults increases risk to negative impacts on spiritual well-being<br>• Age further increases struggles as 'personally owned' belief frameworks/world views may not have been established<br>• The inadequacy of held beliefs can be a source of resentment and sadness |
| Threats to sense of self-worth | • Inpatient setting likely to be a setting where sense of self-worth particularly threatened<br>• Teenagers are particularly vulnerable to effects of increasing dependency, or divergence away from peers in terms of trajectory to independence |
| The inpatient experience | • Besides disconnectedness from social/'normal life', children/young people are at increased risk of feelings of invisibility and insignificance due to minority status and parental needs/distress diverts attention<br>• Threat believed to be even greater for teenagers |
| Witnessing parents' distress | • Witnessing conflict between parents over treatment may be a further source of guilt experienced by children/young people |
| Disturbed relationships with parents | • A turning away from religious beliefs handed down by parents is a further threat to the child–parent relationship<br>• Dependency on family and guilt about being a burden may further disturb the relationship with parents<br>• Besides hiding distress, children/young people hide their knowledge of their prognosis |
| Disrupted relationships with peers<br>Feelings of differentness | • Some experience extreme disconnectedness and loss of 'normal life' due to impacts of condition on physical health, functioning, appearance, prolonged inpatient stays or demanding treatment regimes |
| An absence of pleasure and joy | • Basic living activities can be highly effortful and time-consuming. Communication differences can make it hard to convey wishes and preferences. Sources of pleasure and joy may not be easily accessible |

## The need to talk

All but one of those we interviewed said that, throughout their 'illness journey', there were often multiple times when they wanted to have the chance to explore and discuss unshared thoughts, feelings, fears and concerns with someone outside of their family and informal support network. None said they consistently had people in their lives with whom they could confide in this way. In fact, for most, this had never been available to them. The exception was a small number who had received counselling. Though typically useful, this was time-limited in its availability and/or benefit.

> *… it all ties back to if you had someone there to keep you on the straight and narrow and walk you through it a wee bit. …*
>
> *AYP06*

> *There was nothing. I just needed someone to talk to.*
>
> *BYP09*

While the clinical team was consistently identified needing to better appreciate what children/young people may be going through, the young people did not identify them as potential confidantes. With respect to other NHS staff they encountered (e.g. play therapists and hospital school staff), many valued their company and the activities they offered as useful for distraction. However, none said these staff had opened up opportunities for them to express themselves or have deeper conversations, nor were they seen as potentially having that role.

> *… but they didn't, never really asked me like how I was feeling or anything. It was mostly they would just come in and like give me stuff to do and that'd be it really, I didn't really get asked a lot like how I was feeling at the time.*
>
> *BYP15*

### *Meeting the need to talk*

Study participants made a number of observations around the need for someone to listen and talk to. First, the majority believed children/young people may not initially necessarily recognise their need to talk or would not think to request this sort of support.

> *… but I think at that point you've got that many things going round your head that you don't think to ask for the support, you're just too swamped down in it.*
>
> *BYP01*

They also noted the unpredictable nature of when young people are ready to, or feel the need to, talk. Consequently, there is a need for children/young people to have access to people who are comfortable responding 'in the moment'.

> *… if you're in like in a booked one-to-one thing, you're kinda just pressurised to like say things it at that time you may want to, or like bring things up. Whereas if like you naturally do it, it feels more natural and it feels more like less forced.*
>
> *BYP05*

With respect to the characteristics of the people with whom they wanted to have such conversations, an expertise in emotional/mental health well-being was stressed, as were skills in engaging and working with children and young people and adjusting their practice according to developmental stage.

> *… definitely someone who spends their time with children, cos then you kind of know how certain behaviours impact certain things. Stuff like that.*
>
> *AYP04*

### *Securing engagement and trust*

While desiring opportunities to talk, physical symptoms, mood and emotional distress itself could mean young people may be, or appear to be, resistant to, or seem indifferent, to staff reaching out to them in this way.

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> *… I was a typical kind of don't look at me, don't talk to me, don't kind of … And I do like I think back now and sometimes I kinda cringe at the way I was. Cos I was like a typical … grunting, impolite, rude, slightly arsey teenager.*
>
> *BYP02*

> *… there's some days, especially during diagnosis and like during treatment where you, cos you feel so rubbish you don't really want to see anybody … [you don't want] people to come over and for me to chat to them or whatever.*
>
> *BYP14*

Interviewees reflected on the skilled and nuanced work required in establishing connections and discerning when a young person was wanting and ready to pursue deeper conversations. They also noted that staff should not be deterred by initial rebuffs and persistence may be required.

> *… they would have had to come at me from the right direction. If they just came in like … I might just go, oh no, no, no. Cos I'm trying to shut everybody out, like I'm angry or sad about I'm going through it all. So it would have to be like kinda delicate, if you know what I mean? They'd have to come at it the right way.*
>
> *AYP06*

> *They need to have that almost resilience … OK, this young person's pushed me away and knocked me back now but I'm gonna try again next time I see them, rather than kind of actively avoiding that young person again.*
>
> *BYP02*

## Sources of spiritual care and support

### *The comfort of small acts of kindness and human connection from staff*

Weaved within the interviewees' stories was at least one account of an incident where, as an inpatient, a member of staff had done something that was a great source of comfort. Characterising these moments were actions and behaviours that were perceived as reaching beyond their formal clinical role to one of human connection.

Importantly, these were, on the face of it, brief or insignificant gestures. But, for the young people, they had remained with them vividly, sometimes for many years. Such acts can broadly be characterised as the giving of time and presence, and fleeting physical touch. Examples young people gave us included staff spending time with them once a procedure had been completed, or when there was no clinical reason for being with them, and a light touch on the arm. For the children/young people, such apparently small acts communicated recognition of both of their suffering and their unique worth and value.

> *It was just little things like she just gave me a hug before she pushed me down to the thing [MRI scanner] … it made you feel not just like a random patient. Like they actually did care and that they were gonna do everything that they possibly could for yer. And then a bit later on the nurse came back and she just came and like sat down, just like for five minutes just to talk to me about what was on the telly or whatever. Whereas like usually, if they're not giving out medications or something they might not think that's important to come into your room. But just 5 minutes … I'd say that's just as important as giving out medication … to know that someone's there who cares about you: definitely it's important.*
>
> *BYP12*

### *Comfort and resilience gained from others with the same condition*

Among those interviewed, those who had connected with an individual, or a group of young people/young adults with the same condition, spoke of this very positively. They described the comfort derived from spending time with others with the same condition and spoke of a sense of belongingness.

> *Cos it makes you not feel as weird. Cos you go your entire life without meeting anyone that's ever had anything like you and you're always the different one. But it was like everyone there just got everything, like they just understood everything that you were saying.*
>
> *AYP03*

Some described connecting with such groups as a stand-out moment or turning point in how they viewed themselves or their situation.

> *and that was like absolutely revolutionary, meeting so many young people. It was absolutely phenomenal to meet other young people who have gone through the same journey that I have. … I've never felt so like accepted and understood by so many people.*
>
> *AYP08*

Importantly, in almost all cases, these connections were not with other young people they had met at their clinic or on the ward or clinics. Indeed, these settings were typically described in terms of avoiding contact.

> *But I never really spoke to any other children, if you know what I mean.*
>
> *BYP17*

### *Religion and rituals as sources of comfort and hope*

In an earlier section, we reported on the role played by religious beliefs in young people's search for meaning and sense-making. In this section, we focus on their accounts of religious beliefs and rituals as sources of comfort and hope as they *lived with* their condition.

#### Religious beliefs as a source of comfort and strength

All those who said their faith was important to them reported that their religious beliefs meant they regarded God as a source of hope and comfort.

> *… just that peace it brings you that, you know, the outcome will be worth it, no matter how difficult it may be. And also that, you know, God knows you truly and exactly how you feel.*
>
> *AYP04*

Though that is not to say sometimes that faith faltered in the face of challenging developments in their conditions.

> *… when things progressively got sort of worse I think I wasn't really sure where I stood with it [faith]. But it's normally that initial hit of, oh God, here, here's another thing to deal with, but when you kind of settle down and they talk you through what's gonna happen and things like that, it kind of comes back, if that makes sense.*
>
> *BYP14*

Among those nominally affiliated to a religion, there were also descriptions of drawing on understandings of God and an afterlife as sources of comfort and hope.

> *… you sort of like to think that there's something there. And especially in the sense of like heaven and things … that's a massive part of not fearing the end kinda thing. Cos, yeah, it's something to expect afterwards. So it's not a massive part of my life, I wouldn't say, but I do think I have elements of it.*
>
> *BYP11*

#### Seeking connections with religious beliefs from a position of unbelief

Among the young people without a religious belief, one spent time in the interview reflecting on whether this might have been helpful to her. They also remarked on how they had found themselves being drawn to people they knew who had a faith.

> *… but basically like almost it can be a relief for people who are religious because they can say, well my God wanted to save me, and that's a comfort for them, and fair enough, if that's what you believe, you know … but in a way I'm jealous cos if I had something that could just put me at peace like that that'd be lovely, but I just don't. … I became quite close with my RE teacher at the time.*
>
> *BYP01*

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### Use of prayer and feelings about prayer

All those with a faith described praying and knew that others were praying for them. Prayer was described as a source of comfort and strength. Where the condition was potentially curable, some described prayers for healing.

> *I try to pray as much as I can, purely as reassurance, to be honest.*
>
> *BYP16*

> *Yeah, so I don't practise it, I should do, but I still believe there's a God and, yeah … I don't pray five times a day, but I do pray, yeah, to like, pray to God. I do that pretty much all the time.*
>
> *AYP05*

Among those who had rejected an existing faith, or described themselves as non-religious, many described experiences of someone offering to pray for them, or that they knew people were praying for them. This was not unwelcome, though one described feeling awkward about this. Typically, it was described as comforting, conveying that they mattered and someone/others cared about them.

> *But I don't think I ever thought: right, I'll be all right because they're praying for me and God will make it all right. But just the idea of all those people are actually thinking about me and taking time out to like wish me the best: that's a really nice feeling when you're going through something bad.*
>
> *BYP12*

> *It's like I appreciate the sentiment, it's nice that you're gonna dedicate your thoughts to me, but … it just feels a bit weird.*
>
> *BYP01*

## Experiences of and views about chaplaincy

### *Encounters with chaplaincy staff*

Just five of our sample candidates recalled being offered an opportunity to meet a chaplain or a chaplain approaching them because they were routinely present on the ward.

Three chose to engage with the chaplaincy service and all spoke positively of this contact, one of whom identified themselves as having a religious faith. All valued the interest being taken in them as individuals, for the company they offered and the opportunity for conversation. The young person with a faith also valued that the chaplain was of the same religion and praying together with him.

> *… he [chaplain] was like a man without motive. He was very easy to approach, like he's not medical staff, he's not trying to sell me his religion. He was just kind of a nice person to like randomly see on the weekend, just to have a chat. … and that was enough for me. I didn't need him to say me a prayer or anything like that, or give me any kind of spiritual advice. … So it was kind of quite easy … and, you know, someone who chooses the life work of a chaplain is someone who is, you know, caring and that's someone that is easy to talk to.*
>
> *AYP08*

The reasons why two of the young people chose not to engage with the chaplaincy service were different. One felt the support (e.g. prayers, messages and visits) they were receiving from their local faith community and faith leaders was sufficient. The other, who at the time was on a children's ward as a young teenager, described refusing to engage because she felt the craft activities the chaplain brought were too childish. The need for parental presence further strengthened her resistance and also engendered feelings of being let down by the service.

> *… very much like they'd come round with their like crafts box or whatever, and I was kind of like, I'm a teenager, I'm too cool for this. … And they were very insistent that we had adults with us. And I do understand that, but at the same time I didn't. So to me it was just like you're failing me even further, you're saying that I can't have a conversation without an adult.*
>
> *BYP02*

### *Views on the chaplaincy services among those without experience*

#### The possible value of chaplaincy

Among those who did not recall meeting chaplaincy staff, most said they were unaware of this type of service. (Where this was the case, we provided a brief explanation of the role of chaplaincy during the interview.) When asked, most thought such a service was something they would definitely, or might be, interested in using.

> *Thinking back to when I was on treatment, I think it could have definitely been worthwhile speaking to somebody about that, and I think possibly a chaplain would have been the best person. … I think being able to just express those surface level emotions of I'm scared and I'm in pain to someone who would listen … yeah, they [chaplain] probably would have been able to help with that.*
>
> *BYP01*

> *Yeah, someone who isn't like there for me medically, if that makes sense, cos obviously the doctors and nurses, they're there to look after you from a medical point of view. Whereas there's nobody for like your mental healthcare kind of thing or emotional support.*
>
> *BYP09*

#### Misunderstandings about chaplaincy as a barrier to access or engagement

Some young people understood the word 'chaplain' as referring to people who actively brought their religious faith into their encounters with patients. Religious clothing and symbols worn by some chaplains were seen as reinforcing this belief. Such (mis)beliefs were regarded as a barrier to young people engaging with chaplaincy. This view was expressed by those who described themselves as having a religion and those who did not. Reasons for this viewpoint included assumptions that chaplaincy staff would seek to proselytise, could not offer them anything different to their community faith leaders or that chaplaincy is not relevant to someone without religious beliefs.

> *… I might have just dismissed it: oh, that's just for if you're religious, it's not for me kinda thing. And then I [would have] missed out on maybe having someone to help me, you know what I mean? … If it comes like packaged in like, oh it's for religious people, and I'm not religious so I might just go, oh that's not for me, you know?*
>
> *AYP06*

> *I feel like my immediate reaction would have been, oh they're just gonna dump a load of religious things on me, or say they'll pray for me … and that's not what I'm into.*
>
> *BYP*

#### The need for the clinical team to introduce and endorse chaplaincy services

Recognising the challenges faced by chaplains seeking to connect with paediatric/teenage patients, interviewees noted the importance of the clinical team normalising or presenting spiritual care as a core element of care and facilitating initial contacts.

> *… and just make it as normal as having a nurse that comes in to do your bloods or to do whatever. Cos if they say to you, oh you've got blah … we're gonna have like a lung specialist come in: you're not gonna turn that down. … Yeah, I just kinda feel like when someone's really ill they are quite skittish, they'll try and shut everybody out and like, oh I don't want to talk to anybody and all that. But if it's coming from a doctor first, I feel like they've got a bit of trust at the start.*
>
> *AYP06*

> *I think if a priest just turned up to my room, I'd have thought that means that I'm dying. So they'd just have to do it in a sensitive way, like if a nurse or something said, 'Oh we have whoever coming onto the ward, do you want to speak to them?', rather than them just coming straight over to you when you're already overwhelmed, yeah.*
>
> *BYP12*

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## Discussion

This chapter has presented the findings of our analysis of young people's accounts of being diagnosed and living with a LLC. We have sought to understand the implications and impacts of this experience on spiritual well-being and the spiritual needs it may generate. We have also presented data on young people's experiences of, and feelings about, chaplaincy.

Some of the materials reported in this chapter are not novel in that they align with wider evidence on human spirituality and spiritual distress in the context of living with a life-threatening or life-shortening condition (e.g. the need to make sense and fears around dying). However, as we go on to present, there are many distinctive and unique experiences that previous research on this population has not described, or has been unable to explore in any depth.[57,63,138–144] This is partly due to the use of mixed samples (e.g. children/young people, parents and/or professionals and chronic and LLC) and, crucially, not analysing the data for each group *separately*. Other studies, while framing their research as being about spiritual needs, have adopted a relatively narrow definition, with a focus on religious needs or existential concerns.

Thus, the work reported in this chapter makes a number of important new contributions. These include:

- investigating all dimensions of spirituality and spiritual well-being and across childhood and adolescence and multiple conditions
- focusing children and young people's voices, triangulated by professionals' observations
- further exploring age/developmental differences on threats to spiritual well-being and spiritual needs
- seeking to understand the inter-relatedness of spiritual distress within families
- further developing our understanding of the place and role of religious beliefs
- for the first time, an investigation of the experiences of and views about chaplains and chaplaincy services.

Overall, what is clear from our findings are the multiple ways in which having a LLC as a child or young person have the potential to threaten spiritual well-being and the significant spiritual needs it may generate. The young people's accounts include vivid descriptions of facing their own mortality and living with uncertainties around this. The need to make sense of what is, or has happened to them, was also powerfully expressed and, for some, remained unresolved. Furthermore, feelings of disconnectedness were a dominant theme caused by altered or disrupted relationships with families and peers as well as physical separation. Poignant descriptions of feelings of not mattering, and the absence of joy and pleasure in their lives, were also shared with us. Importantly, it was clear from young people's and professionals' accounts that these threats to spiritual well-being are present from the moment of diagnosis, making a persuasive case for spiritual care to be integral to the care and support of children and young people from the outset.

While, overall, no marked differences in young people's accounts were observed according to the type of condition, those with degenerative conditions may be at an increased risk of threats to self-worth and an absence of pleasure and joy in the lives. For those treated for cancer, what is clear is that the impacts on their spiritual well-being continue and, at least for some, appear to intensify. The characteristics of the sample we recruited do not allow us to fully explore whether there are differences in spiritual needs and distress between children/young people with different faiths.

Together, these experiences generated a profound need to talk. Crucially, this was a different or unique sort of 'talk': not something which did or could happen with family, friends or, indeed, the team caring for them. It is vital to emphasise here that this desire was never expressed as a need to be given answers. Rather, it was centred on them having the opportunity to articulate and work through hidden thoughts, feelings and concerns of, literally, sharing the burden of them (if only fleetingly) with someone else and being able explore and find, *for themselves*, the answers to the existential questions being faced. However, responding to this need is complex – there are moments of readiness to open up and times when this need is more or less pressing. Neither are necessarily predictable.

Importantly, it is clear there is no single solution to the multifaceted nature of spirituality and distress. The 'antidotes' to spiritual distress revealed in the young people's accounts illustrate this. The actions and gestures of hospital staff which convey to a child or young person that they matter and their suffering is recognised cannot be overemphasised. Equally, the way in which experiences of differentness and disconnection can be offset by making connections with others in the same situation highlights the importance of supporting young people to do this. Crucially, our findings suggest that some aspects of children's/young people's spiritual distress can, to some degree, be ameliorated or prevented by addressing their parents' distress. This is because almost all the young people described feeling responsible for, or guilty about, the distress they had caused their parents. While recently used to describe the experiences of parents of children/young people with LLC,[145] the notion of moral distress has not been previously applied to children's and young people's experiences. We would suggest this concept may have some value in further understanding their experiences. Religious beliefs and connections to a local faith community emerged as having the potential to be helpful or unhelpful with regard to sense-making and as a source of strength, comfort and hope.

This was the first time young people's views about and experiences of chaplaincy services have been investigated. It was explored and understood within the context of the young people's religiosity, or not. What has emerged is that chaplaincy – in terms of the way it works and what it offers – was regarded as relevant and, for almost all, opportunities to access it were welcomed. However, there were strong caveats around chaplaincy staff being suitability skilled in working with children and young people and having the capacity to individualise the way in which work across the wide age range was represented in the paediatric population. Notions of normalising and routinely integrating spirituality and spiritual needs into their care were supported.

Finally, a key message from this work is that receiving a diagnosis of a LLC as a young child threatens spiritual well-being. To date, this has been poorly understood.[63] Here, the witnessing of parental distress, fears around dying, disruptions to assumptions of what life is like and experiences of differentness were described. Critically, these were often described alongside an acknowledgement that, at the time, they did not fully understand the implications of their diagnosis. This serves to highlight the importance of recognising spiritual needs and distress among younger patients: even if the understanding of their situation may be limited, it may still have significant impacts.

### *Limitations*

We did not reach our target sample size of young people living with the possibility of death within the next 12 months. In terms of the recruited sample, there was a mix of those reporting they had a religious faith and those who did not, and among those with a faith, there were young people where their faith was more and less important to them. However, the number of faiths represented was limited, as was the ethnic diversity of the sample. Only a small number of our sample had an experience of chaplaincy services. This is, perhaps, unsurprising, given the lack of reach of chaplaincy services in paediatrics and reported gatekeeping by staff and parents (see *Chapter 3*). We note that identifying and recruiting children and young people with an experience of chaplaincy to research is challenging. Clinical teams/services may not be aware of chaplaincy involvement, and chaplaincy services do not hold the contact details of patients post discharge.

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# Chapter 6 Parents' stories and reflections

## Introduction

This chapter reports the second component of WP 3: qualitative research with parents. The objective was to explore the ways in which being a parent of a child/young person with LLC threatens the parents' spiritual well-being, sources of spiritual comfort or support and experiences of using, or views about, chaplaincy services.

*Appendix 5*, *Table 40* provides details on the recruited sample. To summarise, 62 parents were recruited, of whom 9 were fathers. The majority (*n* = 44) were White British. Two-thirds described themselves as having a religious faith, though for some, this was more nominal. Those with a faith other than Christianity were much more likely to describe it as being important to their everyday lives. Within our data analysis, we explored the similarities/differences in parents' accounts in terms of the nature of the child's condition and disease stage, religiosity and between mothers and fathers.

Findings are organised as follows:

- threats to spiritual well-being and spiritual needs
- hidden distress
- the need for people to walk with them
- religious beliefs as a source of comfort, hope or strength
- personal prayer and the prayers of others as a source of comfort and peace
- use of hospital faith spaces
- experiences of and views about chaplaincy services
- connections with other parents.

## Threats to spiritual well-being and spiritual needs

Multiple threats to spiritual well-being were expressed (*Table 18*). We describe each in turn.

### *Thrust into a liminal space*

The period when it became clear their child was seriously unwell, or they had a condition which had significant implications for the child's life, was vividly described by parents as a time of profound uncertainty and a sharp realisation that their lives had irrevocably changed.

**TABLE 18** Threats to parents' spiritual well-being

- Thrust into a liminal space
- The visceral fear of their child's death
- Anticipating and experiencing the loss of their child
- The need to make sense and find meaning
- Feeling responsible for the child's condition
- Moral distress
- Witnessing de-humanising treatment or care of their child
- Imagined futures are bleak
- Witnessing greater suffering and death of others' children
- Family relationships disturbed or under strain
- Disrupted relationships with the extended family
- Disrupted or lost relationships with peers
- Withdrawal from or loss of their faith community
- Disconnected from local communities and wider society
- The loss or shrinking of identity
- Interactions with healthcare professionals threaten self-worth

> *… in this bizarre, bizarre world that you've just suddenly been removed from reality and kinda placed into this other place. … and just full of kinda fear and worry and, all the time and …*
>
> *BP17*

> *It's when we started becoming different to everybody else and it's where our own world ended and this, this new awful nightmare world began, and we had to navigate our way through it, and we still do, without anybody's help.*
>
> *CP18b*

The notion of parents being thrust into a 'liminal space' captures this experience. It conveys how parents found themselves in a world which was alien to them, knowing that the life they knew (i.e. their normality) would never be returned to, and the future was deeply uncertain. Crucially, and central to their distress, there was nothing they could do directly to change the situation: they felt utterly disempowered.

> *And after I learn everything I cry a lot, cry a lot at night thinking, oh my God. Cos I'm a single mum, I'm thinking oh my God. … And I'm thinking, oh my God what am I gonna do?*
>
> *AP19*

> *And the hardest thing to deal with was the sense of helplessness, that you weren't in control of events.*
>
> *BP06*

A key theme in parents' accounts, and core to notions of liminality, was the process of transitioning to a 'new normal', albeit not one they wished to inhabit.

> *… it's life changing, is because of the treatments. It's life changing and nothing can prepare you for it.*
>
> *AP21*

Central to this 'new normal' was the place taken by the child's treatment regimes, meeting their care needs, dealing with systems and services never previously encountered and, for many, spending extended periods of time in hospital settings. Another core feature of the 'new normal' was the constant presence of fear.

> *And just learning to live in that new world was probably one of the biggest challenges.*
>
> *AP28*

Importantly, for many parents, this distressing and disturbing experience of liminality did not happen once. The first discharge home from hospital following diagnosis, the transfer from active treatment to monitoring and the death of their child were all events which rethrust parents into a liminal space in which they existed until a new, 'new normal' was established.

> *… but when you lose a child … it somehow brings up a lot of deep fear. It shifts your world on its axis and it makes you feel unsafe in the world because, in a nutshell, because everything that you thought was real and normal has changed.*
>
> *CP02*

### *The visceral fear of their child's death*

Experienced alongside being thrust into a liminal space of uncertainty was the sharp and unavoidable fear that their child might, or will inevitably, die before they did. It was repeatedly described as the ultimate fear for a parent and one they never imagined they would face.

> *So the fear was just enormous at that point … like I couldn't listen to anything they were saying to me because just absorbing that was just horrific.*
>
> *AP28*

Crucially, this fear never left them though periods of good health or positive responses to treatment offered hope that death was not imminent. They also described carrying this fear wherever they were and across all their roles.

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> *… what has also been quite painful has been the kind of schizophrenia that you then end up developing because you are trying to both present a kinda competent side at work but then you're also conscious that … you're conscious your child could be dying at any minute …*
>
> *AP07b*

Many of the parents we interviewed had experienced multiple occasions when their child was acutely life-threatened and then had survived. These were times when they went to the brink and faced their child's death close-up. They were exhausting and draining.

> *… I've got this black ball of fear in my stomach. And at the beginning it was massive and I could barely breathe because it was so big, and then it shrinks and you get on with things and then it, it gets bigger and smaller, depending on the things that go on.*
>
> *AP12*

Weaved into many parents' accounts were notions of the totality of the fear they experienced, with references made to physical sensations and symptoms, and vivid memories of the place where difficult, unwanted news was imparted. Returning to such places could, in itself, be traumatic.

> *I can still remember every inch of all of these rooms. There's usually one room on the ward that's the one that you get your bad news in. Having to go into these rooms again and again where you got the most devastating news of your life. So whenever we went into these rooms we kinda weren't ourself because we were like sitting on the edge of our seat thinking what are you gonna hit me wi' this time?*
>
> *CP10*

Some reported being averse to particular smells which they associated with a time when the fears for their child's life were dire and overwhelming. One parent described needing to dispose of the clothes he had worn when his child first became acutely unwell.

> *… the clothes that I wore in the ambulance the night, I couldn't even bear to look at the them again, and I put them in a black bag and they went off.*
>
> *BP08b*

### *Anticipating and experiencing the loss of their child*

Parents described the suffering of living with the anticipation, or expectation, of their child's death.

> *… for years was such a daily trauma for me, going in to him in the morning and would he … would he be still alive? Even at times when he was well. I found it really hard….*
>
> *CP13*

> *… to live every day of your life, your child's life, for fifteen years knowing that this could be the day.*
>
> *CP02*

Included in many bereaved parents' accounts was a description of the moment towards the end of their child's life when hope was lost or relinquished. Often, this was the most difficult thing for them to share with us. Many also described, both before and after their child died, grieving over the teenager or adult their child would never become and the experiences which they would never have as their parent.

> *I suppose cos you start grieving straightaway, that form of grief straightaway, your hopes and dreams for this child, I immediately actually realised this is not going to be the baby and the daughter or the sister that we thought she was gonna be.*
>
> *CP04*

### *The need to make sense and finding meaning*

Weaved into descriptions of the time around the diagnosis were accounts of the 'why?' questions this raised: why me, why my child, why our family and, for many, why 'God'?

> *How do you deal with a terminal diagnosis for your child? How do you deal with the fact that your child is going to die? Because it's not the order of things that we expect to happen in life.*
>
> *CP01*

> *You've got this five-/six-week-old baby and planning her funeral and it was just the most horrendous. I just still think the word that comes to mind, is perverse. It just is not the way the world should be.*
>
> *CP04*

Some parents we interviewed described being unresolved regarding this matter and that they were still in the process of sense-making.

> *Father: … the thing we both struggled with in this journey is that it just obliterates any planned kind of value systems you ever had. … It's the really cruel thing about the degenerative and fatal conditions: all you ever want is someone to tell you it's going to be all right, but fundamentally it won't be. So then the idea of having to accept that things won't be right leads you into quite an existential void really. And I think spiritually it's an absolute spiritual void as well because if all hope is lost then really what's the point now?*
> *Mother: … yeah, I think the problem is you want to search for a meaning and you want this experience to positively impact your life … and we both feel like we want this to mean something, but I feel like we're a bit too close to the eye of the storm to know what that may be.*
>
> *AP07*

Others believed what had or was happening would never make sense.

> *I was trying to make sense of it perhaps at the beginning, but nothing does make sense and never will. You see, what do … what are we? What's our purpose in life? It's to create other human beings and keep sustaining life. Well, when that little life is taken away it doesn't make any sense really.*
>
> *CP19*

Critically, sense-making was not a one-off process and had no final end point. A medical crisis, a turning point in their child's condition and the death of their child could challenge the sense which had been made, or the state of acceptance a parent had reached. Sometimes, beliefs, which had previously sustained, faltered.

> *… it felt massively unfair and I was like 'We haven't got space in our heads and our lives to manage something else'. And that all just leads to like questions and anger and I just was like 'Why, why on earth would God let him have another problem?' And it just made no sense and, you know, it doesn't really make any sense.*
>
> *AP08*

### The role of belief frameworks in sense-making

For some, their sense-making was firmly contained and articulated within the religious beliefs and teachings they practised. In some cases, however, this had not been without a period of questioning and struggles to reconcile their beliefs and understanding of God with what was happening.

> *I think it was probably the first six months we probably did keep questioning of God, why would you do this to us? Why, why, why would you give us the child and then possibly take him away? … But a year down the line we're in a different place … but in those deep, dark moments, yes, we did question God, why would you do this to us?*
>
> *AP16*

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Among those parents whose faith was more nominal, some found themselves surprised in how strongly they drew on the religious frameworks they were brought up with.

> *Of course I think everybody's faith is shaken when something huge like this happens. But then instead of going … well I'm no longer gonna believe in God because of this. It's kind of made me a bit more steadfast in it. There's a reason, I don't know what it is but there's obviously a reason.*
>
> *AP17*

Others, however, both those with previously strong and nominally held beliefs, found their religious beliefs inadequate or unhelpful or, in their eyes, had been proved to be wrong.

> *… I can definitely see that actually if you had a much stronger faith that would be very supportive in this situation, but yeah, it's just not quite worked for me.*
>
> *APO7b*

By contrast, one or two reported turning to a religious faith for the first time in their desire to make sense of their situation. A further group made no reference to religious concepts in the sense they had made of their situation and did not describe feeling the need to explore beyond quite simple, personal philosophies of, for example, 'bad things happen'. Finally, some of those identifying as being non-religious (sometimes using the term 'atheist') described wishing they were religious because of the belief frameworks, and hope, they offer.

> *In a way I envy them that.*
>
> *BP06*

### *Feeling responsible for the child's condition*

Around the time of diagnosis, a few parents specifically recalled worrying and feeling guilty about the fact that they might be the cause of their child's diagnosis. Sometimes, this was located in something they had done (e.g. not breastfeeding). In other instances, the condition's genetic nature could cause feelings of guilt.

> *I blamed myself cos what I'd read said it was like something to do with being in the womb and because I didn't breastfeed him and that. And for a long time I thought well, it's my fault. I felt like it was some sort of punishment for me.*
>
> *BP08a*

### *Moral distress*

A dominant theme in all parents' accounts was the experience of moral distress. Originally proposed to refer to the distress experienced by healthcare professionals in the face of suffering they cannot alleviate, or causing suffering in order to treat a disease, its relevance to parents' experiences is beginning to be explored.[145] Core to this concept are the notions of the witnessing of suffering and a desire to relieve or remove that suffering but being powerless to do so.

Multiple causes of moral distress were identified in parents' accounts. These included seeing their child in physical pain or very unwell, or enduring treatments that made them feel very unwell or altered their physical appearance. Here, the parents' distress was centred on being unable themselves to relieve that physical suffering or, in some cases, identifying themselves as the cause of that suffering because of decisions they had taken, or contributed to, with respect to the child's treatment.

> *It hurts me what he has to go through every day …*
>
> *AP01*

> *I felt guilty for everything that she went through on treatment. How ill she was and it was me that consented to it all. I really did feel guilty seeing her suffer so much for something that I said, yeah, yeah, she can have it.*
>
> *BP19*

Among bereaved parents, some described the distress of living with the fact that their child's end of life had not been what had been planned. They felt they had let their child down.

> *It wasn't the best death we could give him. It wasn't what we would have chosen for him.*
>
> *CP09*

Being limited in the extent to which they could soothe the child's fears, and provide reassuring answers to their questions, were additional sources of moral distress.

> *… the morning of the operation, I do remember him saying to me 'I'm scared' and that was really horrible. It was just horrible to hear, horrible to not be able to do anything about it. Obviously you can reassure but you didn't really know.*
>
> *BP09*

Further was their sense of powerlessness in remediating the impacts on their child of the lost weeks or years of 'normal' childhood, including the isolation and disconnection from their peers which they had experienced. All these situations and experiences sat utterly against the desires and compulsions of parenthood, and feelings of guilt, wretchedness and despair were widely evident in parents' accounts.

> *… and he was like last [at school sports day]… and he was trying to jump with this sack, he couldn't do it. And he was so tiny, his school shorts were coming down. And I was sat on the opposite side and I hated it. I just couldn't stand it.*
>
> *BP08*

In addition, those with other children also referred to the distress of living with the knowledge that siblings were being neglected (in terms of time and attention) and were themselves confused or distraught by what was happening to their brother or sister. In this extract, a parent describes the unresolvable paradox of wanting and fearing their child's survival, with this partly located around the child's survival negatively impacting their other child's life.

> *Cos also there was the other fear as well, which I haven't really mentioned. Which was what if she does survive? What if she does live long? And then we are, I mean we would gladly do it, but our lives would be extremely different if we were caring for a child with these huge needs. [Sibling's] life would also be impacted. So it was that double-edged sword of, yeah, we're afraid of losing her, but we were also afraid of her living, to be very honest.*
>
> *CP04*

Finally, among bereaved parents were descriptions of the most acute moral distress. These centred on experiences of making decisions which, in essence, brought on the end of their child's life (e.g. withdrawing treatment or life-sustaining technologies). These were moments of great anguish. While being sure it was in their child's best interests, many described acute feelings of the guilt of giving up on their child that they were complicit in their death, something which was utterly contrary to a parents' instincts.

> *I think as times progress, I think I start to be a bit kinder to myself. I knew it was the right decision but when you feel guilty it's there, isn't it? I used to cry every time I think about it. Now it's still there but it's not as prominent, it's not twenty-four/seven, you know.*
>
> *CP22*

### *Witnessing de-humanising treatment or care of their child*

Some parents described the distress of witnessing their child being treated in a way that de-humanised them or conveyed that they did not matter. Such experiences included significant decisions around their care as well as in the way staff interacted with them.

Descriptions of such interactions were characterised by an apparent a lack of interest in the child as a child, or no effort being taken to establish a human-to-human connection with them. This could be subtle or more overt, with taciturn communication, brusque touching and a failure to treat their child with dignity and respect.

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> *Those are the things for me as a parent that make a difference, that somebody is noticing that she's not just a piece of paper.*
>
> *BP10*

> *She wasn't clean, the bed was soaking wet, she was in her own mess, and I was very angry, I was very angry.*
>
> *CP12*

Witnessing such encounters hurt and angered parents, and they grieved over the way this could impact their child's sense of self-worth.

A further way in which parents experienced dehumanising treatment of their child was when their wishes and desires – what mattered to them – were ascribed less importance than medical protocols or hospital policies and practices.

> *… that become a big thing for [child] and that really mattered to him. Having to get a cannula in was a big deal … and this is where I sometimes feel hospitals don't really listen and it's very medicalised. Because what matters to the children, what's big for them, should be what matters. They shouldn't have to have a cannula in when they've got a perfectly good Hickman Line that could be used. … There needs to be more of like: what matters to the kid here? Let's get all the medical stuff aside, what do they want to do and want to happen.*
>
> *CP10*

### *Imagined futures are bleak*

The 'imagined futures' of some parents of children with 'non-curable' conditions were presented as being bleak: there was nothing to look forward to. This was not only in terms of the certainty of their child's death but also because they knew further medical crises and deteriorations would be faced and that these were likely to cause further suffering. Furthermore, they knew the daily demands of care and keeping their child as comfortable, content and well as possible were relentless and there would be little, if any, respite from them.

### *Witnessing greater suffering and the death of others' children*

Noticed specifically in the accounts of some parents of children treated for cancer were feelings of guilt, which arose from witnessing other children on the ward or in clinic who were sicker or had worse prognoses than their child.

> *When you're in the children's ward there with children dying: it will never leave me. You literally were hearing children die in the night, in the same room and there's no support or talk about that. That was just horrific.*
>
> *BP07*

Almost all also referred to, and used the term, 'survivors guilt': a paradoxical feeling of joy and relief of their child's treatment appearing to be successful and a mental unease that this was not the case for others. Some parents referred to this as reraising 'why' questions; in this case, why has my child survived but not others?

### *Family relationships disturbed or change*

Parents described disturbances and blockages in their relationships with their partner, their child and any other children. As a consequence, the family's overall way of being and relating to each other was also disturbed.

### The relationship with their partner

There were multiple reasons for disturbance to relationships with partners, including physical separation, new demands on their time, changes in or reallocation of parenting roles and responsibilities and different and incompatible coping ways of coping. Crucially, many described not revealing their fears, concerns and feelings to their partner. This could be in order to protect their partner or, as we report later, not feeling unable, to face or articulate their own distress. Such experiences served to increase or sharpen parents' sense of loneliness.

> *… Emotionally he's not there. I mean he never talk about the boys' condition, and he let me carry the weight. … He's not there emotionally so I feel like 'out' of the relationship, like I'm more lonely than a single person actually is how I feel.*
>
> *AP02*

### The relationship with their child and other children

Parents also described altered relationships with their children – both the affected child and any siblings. This was typically attributed to changes in parenting roles driven by inpatient admissions or the child's intense care needs and the hiding of distress from each other. The hiding of distress threatened the honesty and authenticity of relationships.

> *I don't know whether she [child] keeps things from me cos she doesn't want to upset me.*
>
> *BP05*

> *.cos when I'm talking to her, when we're in front of her, you have to put your game face on, we called it. Keep everything normal and positive and happy for her. And so you had to hide your own emotions until the evening, when everybody's asleep.*
>
> *AP12*

### The disruption of 'unspoken' things

In addition was the disruption caused by there being 'unspoken' things between family members. For example, some reported their partner avoiding direct discussions about the possibility of their child's death.

> *I did say to him once, I said '[Child] could have died couldn't he?' And he went, he said to me 'No, no, no, no, he couldn't, because if this, if this had happened then this would happen' de-de. And I wanted him to say, 'Yeah, you're right, he could have done', you know. And there's all sorts of emotions tied up in that isn't there? But, but for me, it was kind of like, you're not really recognising, because that is a possibility and I want to kind of talk about that.*
>
> *BP09*

The possibility of death, dying and beliefs about the afterlife were things that typically remained unspoken between parents and children. Among the few where this was not the case, the child and parent had the same religious beliefs which provided both a shared vocabulary and the 'safety' and comfort of their shared beliefs.

> *… I think she only ever said that [Am I going to die?] to me. I think she just said that to me, yeah … and it was is a really difficult one, and I can't even remember what I said, I think I probably said 'Hopefully not, and that, and, and, and I'm certainly praying that you don't' that sort of thing, because I couldn't say no … it seemed to comfort her at the time, and then we'd sometimes pray together as well at that point, you know, and that seemed to help.*
>
> *BP23*

### Impacts on the family unit

So far, we have presented disturbed relationships in the family as unidimensional: between parents and between a parent and child. However, it is important to note these disturbances are happening in the wider context of family unit. Thus, the threats to parent–parent or parent–child relationships have implications for the family as a whole, its dynamic and how it functions and how this is experienced by individual family members.

> *… with the family you're avoiding speaking the unspeakable. You don't want to be the one that mentions the elephant in the room and you don't want to display your own weakness, you have to be the strong father and the strong mother and, and the strong child.*
>
> *BP06*

#### *Disrupted relationships with the extended family*

An additional domain of disrupted relationships was relationships with the extended family. Some parents described expecting their own parents to be a source of strength and support, but this was not the case because their own distress was too great. Indeed, in some instances, parents described having to act as a source of support to their parents, but this was not being reciprocated. As a result, some parents avoided contact or censored their conversations.

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> *… there are things you don't want to or can't say to your family because they're going through the same thing. With my parents now … I'm always honest with them but I try and, I think I try and flower it up a little bit when I tell them, because you don't want to hurt them.*
>
> *AP11*

### *Disrupted or lost relationships with peers*

All parents described changes in some or all of their friendships that had formed prior to the child's diagnosis. This was partly attributed to a lack of time, energy or, quite simply, child care. However, alongside this was a sense of disconnection or discordance in priorities and values which had not existed before. This acted as a disincentive to invest in such relationships, particularly given the effort it could involve.

> *We chat a little bit but then, you know, they don't understand…. they don't know what it like.*
>
> *AP05*

### *Withdrawal from or loss of their faith community*

Among parents connected to a local faith community, the impacts of having child with a LLC on their connections with this community differed. Some described feeling highly supported – both in prayer and practically. Some parents also described having someone from their faith community with whom they could be honest and open about their fears and struggles with faith. A few specifically described treasuring how the community embraced and accommodated their child.

> *… they've been so welcoming, and particularly the Priest: he considers disabled children as, you know, something really special.*
>
> *AP01*

Others, however, had found their faith community unhelpful or their actions hurtful (e.g. insisting on praying for miraculous healing and not accommodating the child's needs at places of worship). This had resulted in some parents stopping attending or moving their place of worship.

### *Disconnected from local communities and wider society*

All parents described experiencing some degree of separation from communities which they had previously been part of and had contributed to their sense of purpose and place in the world. These included neighbourhoods, workplaces and parenting communities. This was partly due to inpatient episodes and also that the child's health and care needs meant parents were simply not in the spaces where these connections were created, sustained and experienced.

> *… the rest of the world is just completely shut out.*
>
> *BP10*

More unusual were experiences of stigmatisation and exclusion by people of their culture due to false beliefs about health and disability.

Some parents also described feeling invisible or avoided by wider society. They attributed this to others' uncomfortableness with their child's complex needs. That this caused their experiences of parenthood, and family life, to be different further separated them. Their lives and situation were not something society wanted to dwell on.

> *… I didn't want to withdraw from the world and hide her away. But when you walk into a situation and you know you're going to make people uncomfortable it's very, very hard … it's not a nice feeling.*
>
> *AP09*

### *The loss or shrinking of identity*

Mothers, in particular, spoke of feeling that they had no identity apart from being their child's parent. This was attributed to being unable to pursue their activities and interests and exercise their skills in work and/or outside or work. The consequence was that their identity was no longer multifaceted and, instead, was dominated by the role of mother. That health professionals tended to refer to them as 'mum' further reinforced this. Some described feeling that their child's diagnosis and the experiences they had undergone served to label them; for example, the mother of a child who is seriously ill, the mother whose child had cancer and the mother whose child had died. This also threatened their sense of self.

### *Interactions with healthcare professionals threaten self-worth*

Connected to the notion of loss of identify were encounters with health professionals which left parents feeling isolated, diminished or insignificant. This was experienced in the degree of empathy and human connection professionals conveyed and the degree to which parents' felt their suffering and the enormity of what they were going through was recognised or acknowledged.

> *… because at times the staff would make you feel like you weren't human because you were having like a bad time, and you were getting upset a lot, and it was just like you were a nuisance.*
>
> *BP20*

Their sense of self-worth was also affected by whether their unique knowledge and expertise regarding their child was valued and recognised.

> *So when the nurses listened to me saying 'He's in pain' or 'He's waking up' and then dealt with it: that was really important, you know.*
>
> *CP05*

## Hidden distress

A dominant theme across parents' stories was the 'hiding' of their emotions, feelings, thoughts and fears, both from themselves and others.

Typically, parents were very aware that they were not, or had not, faced their darkest thoughts and fears, nor were acknowledging their distress to themselves: this can be understood as disconnectedness from their self. Reflecting on the reasons for this, parents described not daring to 'lift the lid' for fear of losing control of their emotions and not having the time and space to fully process them. They feared doing so would leave them in a position both of heightened vulnerability and being less able to devote themselves to their child.

> *I think I kept it to myself and mainly because I had to find strength for [child] to get through all of this. I just didn't have time for me to think of me.*
>
> *AP21*

> *I literally didn't even look in the mirror for two years because I was so completely not interested in how I was. There was a part of me that thought I can't even go there because there's so much pain in there and I don't have time to do all that pain just now. I need to just get through this stuff.*
>
> *CP10*

Some noted the immediate distractions and demands of treatment regimes and looking after their child; and, the physical exhaustion associated with this meant the parents simply did not have the capacity to turn their attention to themselves. Some parents also disclosed having what they admitted as an irrational belief that if their deepest fears remained unspoken, they would not happen.

> *… yeah, if you don't speak it, it's not gonna happen kinda thing …*
>
> *BP23*

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However, many also described either allowing contained moments of emotional release, or their distress surfacing unexpectedly in moments of quiet and when their minds were not distracted.

> *I've done it before, and I'm not someone who cries a lot, I've sat in the car in traffic and then just streamed. And you think where did that come from?*
>
> *AP11*

> *I remember being in the shower and tears just rolling. … and it was like I knew my body needed to cry so I just said 'Right, OK, we're cleaning our teeth and we're having a shower so we can just do some crying just now'. It was like getting through your to-do list: right, I've got one hour of crying to get through and then I'll go and put the smile on …*
>
> *CP10*

Unique to a few fathers' accounts – all of whom had continued working – were descriptions of uncharacteristic emotional 'breakdowns', or outbursts, of anger or despair in the workplace or elsewhere.

> *… but a few occasions at work where I wasn't able to control the feelings anymore. I had some kind of embarrassing need to withdraw from meetings or from discussions because I just couldn't, just couldn't contain myself. … the veil would drop and I'd just lapse into uncontrolled emotion.*
>
> *BP06*

## The need for people to walk with them

All parents described feelings of loneliness, desolation, fear and despair. Aside from their partner (and this was not always the case), many felt no one had accompanied them in their journey and the suffering they had experienced or were enduring. Some, however, did identify one person who had been willing to 'walk with them' – for parts or all of their journey – and hear their deepest fears and concerns. Among those described were a close friend, family member, member of their faith community, family support worker, chaplain or hospice staff.

Times when they were in hospital were often identified when such feelings were most acute, though that is not to say these were not a constant presence in the parents' lives. However, fears and concerns about their child's health and the heightened sense of isolation, disconnection and disempowerment associated with being in hospital served to intensify these feelings and experiences. In these times and moments, parents described wishing, yearning even, for someone sit with them, spend time with them, to chat with and, should they want to, to give them space to express their thoughts, feelings.

> *So, do you know what, all I need[ed] at that time was just for someone to talk to me, to just sit and listen to me.*
>
> *AP34*

> *After the long, long weeks, you sometimes just need to talk, and not necessarily just to family or to visitors because you are trying to keep it together and be strong for everybody else really.*
>
> *CP15*

> *… somebody who's just kind of nurturing and just like give you a hug kinda thing, you know, not, you know, not necessarily physically … but just kinda somebody who you could just relax with and just kind of talk to.*
>
> *BP09*

Parents described being acutely aware of clinical staff not having the capacity to simply spend time with them, nor did they want to divert their attention away from their child. Some parents explicitly said they wanted to connect with someone separate to their child's clinical team. However, all parents wanted clinical staff to (better) recognise their need for people who would 'journey with' them in that suffering and for care and support to be in place to meet that need. Furthermore, they regarded clinical teams as playing a role in connecting parents to such support.

> *… people were caring towards us, but sometimes you just want to cry and let it all out. But you felt you couldn't burden the staff who were caring for your daughter with that, because you wanted them to care for your daughter.*
>
> *AP12*

## Religious and personal beliefs as sources of comfort, hope or strength

We reported earlier that religious or personal belief frameworks, or life philosophies, played a significant role in parents' making sense and finding meaning in, their situation. Alongside this, parents with a religious faith typically described their beliefs and faith in their God as an important ongoing coping resource. This centred on notions of their God caring about them and their child.

> *… we have this consolation that God is there, he'll give us the peace and the strength to carry through the situation at difficult times, no matter how difficult it is. I believe he kept me positive.*
>
> *AP34*

> *I need to believe in God. God is gonna give me the strength to help my son. … is gonna give me, gonna put more strong, is gonna give me more knowledge to deal with this situation.*
>
> *AP19*

In addition, the beliefs they held about death and the afterlife were a source of comfort and hope.

> *… there was always the knowledge that (child) would eventually end up in heaven and that we would meet her again.*
>
> *CP04*

Some parents, while not aligning to a particular religious faith, also described beliefs in a 'supernatural other' as sustaining them.

> *I know I have a tough time and God is always, always been there with, with me, always because I believe in God. I believe in God and I'm thinking OK, always God has been there with me.*
>
> *AP19*

## Personal prayer and others' prayers as sources of comfort and peace

In this section, the findings on parents' descriptions of personal prayer and the prayers of others as sources of comfort and peace are reported. For coherence, parents' descriptions of prayers offered by, or praying with, chaplains are reported in *The comfort of hearing prayers being spoken or praying with another* which reports on parents' experiences of chaplaincy services.

### *Personal prayer*

Many parents described praying and had found that the act of praying, in itself, brought peace and comfort.

> *When she's in bad condition in intensive care. … at that time we feel very emotional so we pray a lot at that time. Cos there is [no-one else], you know. You can't talk everything with your family …*
>
> *AP14*

Among those who described themselves without a faith, some reflected on how they found themselves praying. Some regarded this as a venting of their distress or desperation, while others saw it more as plea to a higher being, although their understanding of this and what it might achieve was unformed.

> *I remember holding him in my arms and walking up and down this field and screaming at the sky 'Help us, help us' just in desperation. Yeah, so … I was going to the big man in the sky again then, [saying] just please help us.*
>
> *BP08*

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### *The prayers of others*

Many of those who were part of a faith community described the comfort of knowing that community was praying for them and their child. Some spoke of this in terms of a sharing of their burden of suffering.

> *… just knowing other people are praying for you … that gave me quite a lot of peace really. I could give some of it away … I was allowed to kinda give some of it away, you know, some of the angst away.*
>
> *BP23*

Among those who did not have a religious faith, being told by friends or relations that they were praying for their child were typically welcomed – either through the comfort they drew from others' concern for and valuing of their child, or, on the off-chance there was a God, prayer may have some positive effect.

> *… people will say 'I'll pray for you', and it just seems the most obscure, ridiculous thing to me to say … talking to a cloud is not going to do anything. But I always still appreciate that their sentiment came from a good place, and you think actually that's a nice thing to do because thinking nice things and thinking warmly about someone, just saying you're in my thoughts, is kind of a nice thing to do.*
>
> *AP11*

## Use of hospital faith spaces

Regardless of religious beliefs or not, a number of parents talked about visiting the hospital chapel or multifaith space. All valued the quietness and calm such spaces imbued, finding it a solace and a marked contrast to the oppressive nature of the ward. Many, including those without a faith, described praying there.

> *I don't know why I went there. I don't know if it was praying. I don't know if it was to talk to someone. It almost felt like we knew that the surgery that she was going through was going to be so major that it was almost like you would kinda try everything. So I did go to the chapel the night before and said things, you know, 'please let her be OK'. And that's probably the closest I've got, that moment, that evening is probably the closest I've got to religion in my whole life, actually.*
>
> *BP17*

Among parents who had not spent time in such spaces, many said they wanted to but could not permit themselves this time, or did not feel able to leave their child for an extended period of time.

> *… there are so many times when I've walked past and thought: I'm gonna go in there. And then I've thought: no, I just need to get back to the ward, I've already been gone for 20 minutes or whatever. I don't religiously go to church or anything like that, but it is actually quite nice knowing that there is that space there and the people available if needed.*
>
> *AP09*

## Experiences of and views about chaplaincy services

Less than half our sample ($n$ = 25/62) had had some contact with a NHS chaplain. This included seven parents without a religious faith. Within these accounts are descriptions of a number of different functions or roles played by chaplaincy staff.

### *Ways in which chaplains had supported parents*

#### Companionship and distraction

Some described enjoying the chaplain's company and interest in them and the absence of any 'agenda'. The distraction afforded by the visit was also welcome.

> *… Yeah, she was nice, she'd come and have a chat. I wouldn't say it was extremely helpful. Mostly about just, you know, how the family were, how things were doing, and then she'd always end with a prayer, which was nice.*
>
> *AP28*

> *He was a very social person, he always had kind words but he had a sense of mischief about him too. And so he was, in an environment where things are very serious and, you know, there's death all around … It was nice to have someone who took your mind off all the medicine. Took your mind off the beeps and the bleeping and the charts and the endless ward rounds and, you know, … the stress.*
>
> *CP19*

### The opportunity to express and explore thoughts and feelings

For some, it was clear that the time spent with a chaplain had, in some way, been very significant. They described the encouragement, comfort, resolution and peace that time with the chaplain had brought them.

> *So they will come to pray, encourage us, teach … and I find that really, really helpful … I am ever so grateful they were there to support and, you know, to encourage, to keep you.*
>
> *AP34*

Within these parents' accounts were descriptions of conversation(s) in which they had expressed things not shared with others or even articulated among themselves.

> *It was just that lovely non-judgemental kind of conversation that you can just open your. … Actually I don't think he did say much, he just was there.*
>
> *CP22*

> *I think often times it's not what you hear, it's the fact that you're able to speak. For so long during treatment and with the family you're avoiding speaking the unspeakable. … Anyway I went to see the chaplaincy service and I saw a really kind and attentive lady there. And really, she didn't say an awful lot, she just gave me the opportunity to let it all out and speak about what had been on my mind, and remarkably I had not done anything like that before. I couldn't do it within the family, I didn't feel I had close enough friends that I could do that with. And it was beneficial … it was a turning point. It wasn't a solution entirely because it didn't take the problems away. It's just, you know, as the old adage goes: a problem shared is a problem halved … because I'd managed to off-load some of these fears and things to somebody else then it diminished the problems.*
>
> *BP06*

### The comfort of the chaplain's presence in the darkest times

One family described the chaplain's presence during their child's final hours as being very precious. For both parents, their faith was important to them. Their account of how the chaplain supported them during that period includes references to her attention to the child, the provision of meaningful objects and mementos and feeling that her presence meant God was present. This incident occurred during the COVID pandemic.

> *Mother: … she sat down, she touched (child) through the rubber gloves. She said the prayers. She spoke to us. She was just with us and alongside. She stayed for a fair while, did a little service.*
> *Father: She brought little carved crucifixes, didn't she? And little knitted hearts. …*
>
> *Mother: Yeah, they were very precious things … So just her very presence, for me, was probably the highlight of that whole last day, because I suppose it was like bringing God into that room … and in that last hour before he died I was on my own and I felt very supported.*
>
> *CP14*

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Other parents also specifically made reference to the value and regard a chaplain had given their child which, in itself, was a comfort.

> *Sometimes, even when I'm not there, she will go there, sing for (child), pray for (child): it's a very nice feeling.*
>
> *AP34*

### The comfort of hearing prayers being spoken or praying with another

Threaded through all these parents' accounts were stories of how they were comforted by the prayers of a chaplain and, for some, praying with a chaplain. Parents with and without a religious faith described this.

> *They have a lady from our religion. We meet one time, she's come in and, gives advice and pray, and pray for us as well. [My wife says]... it's feeling better that somebody else come in to visit us and pray for us, for my daughter, thinking of us this way is very good.*
>
> *AP14b*

> *... if somebody wants to pray for my son then I wasn't gonna stop them. ... and I'd just sit quietly and say Amen at the end and that's fine. It didn't offend me at all, in fact I found it quite comforting actually.*
>
> *CP19*

> *But whenever I go to church, praying together, I don't know, it gives me like a little buzzy feeling. ... And he [chaplain] would be praying in English and I would be praying the same thing but in [first language]. Perhaps it's just because I felt so lonely and it was nice someone to do something with you. It was something that we were doing together.*
>
> *CP22*

### The comfort of rituals

A couple of parents described the comfort and solace they had found in a religious ritual, particularly christenings/ baptisms and blessings. In both instances, they knew their child was close to dying.

> *... and I was like 'Oh so are you a Priest?' And he say 'Yes, I am, I'm Catholic'. And I say 'How lovely'. And just by chatting, and he just turn around and say 'Would you like to baptise your child?' And I say 'Oh yes, I'd love to'. So he's gone off and then come back with all his little bits and bobs and ... he did at the cot-side, just myself and him. And it was lovely, it gave me some peace and, you know, and hope.*
>
> *CP22*

> *... we realised we had to let him go. I said to [partner] 'I want to go down to the chapel and pray'. And while we were there the chaplain ... she heard us cry and she came up to us, she said 'Is there anything I can do?' And I said 'Well if you do christenings I would love to have him christened'. And within an hour ... so that was another thing I'd share that was very, very positive for us. She was a really lovely, beautiful soul, very caring and kind and, yeah, I think that even gave [father] comfort probably, even though he's not religious at all.*
>
> *CP02*

### Journeying with parents

A number of parents highlighted the comfort drawn from a continuity of relationship with the same chaplain which was resumed at each inpatient admission. Their ministry of presence and the knowledge that *their* chaplain would journey with them was of enormous comfort.

> *And then when [after child's first admission] I left obviously I'd still got her hospital number so I asked if I could keep it, cos obviously then we were waiting to find out like the results [of tests] ... So I rang up and I just said 'Can I keep in touch, cos I'm gonna need you along this journey ...'. And that's been really good for me, yeah, most definitely.*
>
> *AP29*

TABLE 40 Parents recruited to WP 3 (*continued*)

In this second illustrative extract, a parent describes her relationship with a chaplain over the period of her child's short life that had been punctuated by multiple hospital admissions and, finally, the decision to switch off the child's life support.

> *And then because he was always that presence, whenever I was in hospital and I felt lonely and then he's always come to cheer me up; and we would talk about anything, you know. … He was there every time we were there at hospital. Whenever we were there he would turn up and he would come every afternoon and we have a little chat. It was something I really look forward to. We would have a little chat about life and things and then we would have a little prayer. … It was easy to have him around. And he knew that we were coming in for that surgery and he was there, and he knew [child] was being taken to ITU and he was there. He would come all the time. And then he was there when they turned the machines off, which was very comforting … he was just there [nearby] … he was waiting in the room when we came to the room. And it was just a nice warm hug, and then he walked with us … it is a horrible feeling when you walk out of the hospital: we walked in with a child and then you come out [without]. And it just like … is that it? It's just weird. It's like that's it, now what, you know, what do I do? And in hospital it's so busy, it's just like boom, boom, boom, boom, boom, that page has been turned, next patient. And then when you walk out you feel. … And it was lovely that he walked with us, he walked all the way to the hotel and then he sat on the outside and we have a little chat and it meant a lot. He just sat and cried and had a little chat and then he gave us a big hug and, and then I felt like … it gave me some sense of closure really because I left the hospital, I just felt completely lost. And, yeah, it was just that little walk to the hotel and sitting with us for a bit outside, have a little debrief, it was kind of a little debrief, and it, it, it really helped.*
>
> *CP22*

### *The views of parents not offered but welcoming of chaplaincy support*

Among the parents who had not been offered chaplaincy support, views were split in terms of whether this would have been welcomed. Some were certain that, if it was/had been offered, they would it accept it. This included those who had a religious faith and those who did not.

> *… if I had that opportunity then, yes … because there was not a time or opportunity to step back and go, why is this happening? Don't understand. Is it my fault? And I don't mean that medically. You know, you do need someone there separately.*
>
> *BP07*

> *At the times when it was really, really hard, yes, I do I think I would have … I think I would have found some kinda comfort in that, yeah.*
>
> *BP19*

Some said they would have welcomed it for the religious support it could have offered them.

> *Yeah, that will have been helpful, because the way they [medical team] leave you with no hope. So I think that will have been nice, you know … after they [medical team] said all of those things, everything that was wrong, then you had someone else after that to come and just sit by you and tell you it will be OK and then tell you, remember the [religious teachings] … to get that reassurance that ultimately it's God's decision, I think that will have been really helpful.*
>
> *AP22*

For others, it was the offer of presence – of someone being with them – which particularly appealed.

> *… in those sort of darkest times, we've never been offered. … But actually, just having someone sat there with me … if they'd have been offered, I would have said yes.*
>
> *AP01*

> *… for me, that would have been a great source of support. And even if they didn't know what to say at the time, just knowing that person was there probably would have helped quite a lot.*
>
> *AP17*

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### *Reasons why chaplaincy would not be welcomed*

Other parents were certain they would not have welcomed seeing a chaplain. This was because they understood chaplains as always having a religious faith and that the support they offered would be religious. In some cases, this meant non-religious parents did not regard chaplains as relevant to them.

> *A chaplain is pretty much, in my head, religious support …*
>
> *BP13*

Some were more firmly against their involvement, assuming they would seek to proselytise or offer unhelpful religious platitudes.

> *I probably would have sent them flying, because, for me, a chaplain signifies God and this, that and the other. And, you know, with a two year old, three year old, four year old, five year old, whatever, battling cancer, I'm like don't be giving me any of this shit that it's God's will. Like do not come near me with any religious crap about God not giving you more than you can cope with or, you know, whatever such crap. Yeah, I probably would have sent them flying.*
>
> *CP09*

### *Supporting access to chaplaincy services*

A few parents expressed frustration at how long it had taken for chaplaincy services to be notified about them. Others queried why they had not been offered this service. Some noted that hospital staff should not wait for parents to request the involvement of the chaplaincy service. This was primarily because they did not have the mental space or capacity to seek out or initiate contact.

> *When you are faced with a diagnosis like that … yes, we have a relationship with God but practically you don't feel that there's time in the day to go and search for these things.*
>
> *AP35*

Parents called for clinical and ward staff to be more proactive in introducing parents to the chaplaincy service and for a greater presence of chaplaincy services on the ward.

> *They need to be on show rather than just a little notice on their door or a sticker on wall of the ward. We're in there, we're stressed, we're tired, worried about our child, the nurse is busy. And the last thing we wanna be doing is saying can you ring the chaplain and make an appointment. I just think that service shouldn't be something you have to book a timeslot for. And I think it needs to be on the booking-in process as well … would you like to see the chaplain?*
>
> *AP35*

## Connections with other parents

There was a wide range of views on the value, or not, of seeking to connect with other parents in the same situation. Some found comfort in being with others with a shared experience.

> *Well, it's like it's absolute empathy isn't it?*
>
> *BP21*

However, none described such connections as being ones where darkest thoughts and feelings were shared. Furthermore, a number of parents described times when such connections had been very important and other times when they did not need them or avoided them. Others had never felt the need for, or avoided, such encounters. This was typically due to fears of being exposed to parents whose children were either less or more severely affected, or because they did not have the capacity to take on another's suffering.

> *And then you hear their stories and for me it was heart-breaking. You carry your own story but then I found I was being a bit of an empath: I was taking on all their grief as well.*
>
> *CP14a*

## Discussion

Parents' stories reveal the *multiple* threats to their spiritual well-being and contain descriptions of, we would argue, both chronic and acute spiritual distress.

Thus, there were accounts of the stripping away of life's certainties, the testing and questioning of religious beliefs and personal philosophies in the face of what was happening and the need to find or make sense of this. There was also the pervasive fear, and anticipation of, their child's death. It was the 'perverse-ness' of this potential (or actual) loss that intensified its impacts on their spiritual well-being and the spiritual distress experienced.

Other threats to their spiritual well-being were also intrinsically tied to being a parent: the moral distress of being powerless to make things better for their child, feeling that their child did not matter to the healthcare team, and, for a few, believing that, in some way, they had caused their child's condition. Layered on top of these experiences were further threats to their spiritual well-being because their sense of connectedness to others was disturbed, disrupted or lost. Critically, this was typically experienced across all spheres of parents' lives. Multiple threats to identity and self-worth were also described due to the narrowing of their life worlds and careless interactions with healthcare professionals. Finally, there were times when their lives felt joyless and there was no sense of hope: for some, this was a constant feature of their lives.

Critically, these threats to their spiritual well-being, and the feeling of guilt, helplessness, despair, fear, sadness and desolation they engendered, were endured privately. This notion of hiddenness was multifaceted: parents hid from facing their spiritual distress (clear evidence of a disconnectedness from self) and they hid it from others. It was buried,[146] with any emotional release confined to private spaces. Together, these descriptions convey the tortuous nature of parents' experiences and the deep suffering they experienced.

Many of these experiences map onto existing models of the multiple ways in which serious illness and inpatient settings threaten spiritual well-being.[7,93,147,148] This is noteworthy because this literature has been predominantly developed from the *patient's* perspective. Thus, there is a sense that, in some ways, parents' experience their situation *as the patient*. Furthermore, the handful of studies considering the threats to spiritual well-being experienced by family members of adult/elderly patients[94,148] suggest that parents' experiences are very different.

There is widespread recognition that parents are likely to be at a greater risk of spiritual distress than those living with the possibility or facing the death of a spouse or other family member. However, aside from writing around the utter differentness of facing the death of a child, there is little work that has sought to identify the causes of that spiritual distress, or to specify the types of spiritual need, which are *unique* to parents. Recent work[145] which applied notions of moral distress to the experiences of parents of children with LLCs is useful here. However, and in accordance with the wider literature,[149,150] we would contest that *all* the dimensions of parent moral distress (intrapersonal, interpersonal and existential) described by the authors are grounded in human spirituality and are relevant to spiritual well-being. Finally, our findings highlight the unique of complexity of the family context when understanding the sources of spiritual distress and considering the spiritual care of children and parents.

Following our description of the threats to spiritual well-being, we moved on to report parents' desire to have someone/people walking with them in their suffering: of being present and available to listen. Notions of walking alongside or 'companioning' are central to descriptions of spiritual care. Crucially, while the notion of walking alongside may convey being alongside for the entire journey (and few parents spoke of having this), this is not its only meaning. It also has relevance to more transitory interactions where comfort and solace can be drawn from an acknowledgement of, and compassionate response to, suffering, or from a one-off encounter where darkest thoughts and fears are unburdened.[8]

Our findings in relation to the role of religious beliefs accord with wider research on the role of beliefs in meaning-making and faith in 'God' as a common coping strategy. Again, not novel,[151] but important to note, is that accounts of the comfort, strength and hope drawn from prayer and faith in a supernatural 'other' were not only confined to those with a faith (practised or more nominal) but were also described by parents not affiliated to a particular religion. Similarly, religious beliefs, or not, did not determine the use of faith spaces in hospital.

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The final sections of this chapter were devoted to two particular sources of spiritual care and support: chaplaincy services and other parents. Existing evidence on parents' experiences of healthcare chaplaincy services is extremely limited.[152,153] To our knowledge, this is the first study conducted in the UK. It revealed a range of ways in which encounters with a chaplain responded to parents' spiritual needs. Among those who had not met a chaplain, the common perception was that it was, primarily, a religious role or had religious motivations. For some, this rendered chaplaincy services either irrelevant or positively unwelcome. For others, however, there was a wistfulness that they had not met with a chaplain, believing that they would have found this helpful. Finally, parents noted the need for chaplains to be routinely present on wards: this speaks of not only increasing their visibility to parents but also being there to meet parents' spiritual needs in the moment. They also called for clinical/ward staff to introduce and signpost to chaplaincy services.

Our findings suggest that the child's diagnosis and stage in the illness trajectory are relevant to understanding spiritual needs and where threats to spiritual well-being may be more likely to be located. Furthermore, as was clear in the accounts of parents of children treated for cancer in childhood, spiritual distress endures and may, indeed intensify, following discharge after 'successful' treatment.

We also note our findings regarding the differences between fathers' and mothers' experiences. These differences appear to be located in fathers' (relative) absence – from inpatient episodes and the day-to-day demands of care – due to work responsibilities. Societal expectations were also perceived as a source of pressure to 'manage' and not display their distress. Wider work on the experiences of fathers with LLCs[154] also identify these issues.

Finally, readers may have observed a lack of reference to findings on the difference in experience with respect to parents' religious beliefs. While noting the limitations of our sample, this did not emerge in our data. The only exception was that one or two reported that their child's condition/diagnosis had led to them being stigmatised by their cultural or faith communities.

### *Limitations*

The sample achieved was predominantly White British and, among those identifying with a religion, most had a Christian faith. However, the study was successful in recruiting those with and without a religious faith and those with and without experiences of using hospital chaplaincy services. Finally, while it was still a small proportion of our sample, compared to other research seeking to recruit both mothers and fathers of children with LLCs, this study experienced relatively greater success in recruiting fathers.

# **Chapter 7** Healthcare staff's views and experiences

## Introduction

This chapter reports findings from the research with NHS staff based in, or working with, the clinical (or multidisciplinary) teams that care for children with life-threatening or life-shortening conditions (WP 4). The objectives of this WP were to understand: (1) staff's experiences of, and views about, identifying and responding to spiritual needs and distress; (2) the views about chaplaincy services and (3) their experiences of working with chaplaincy services. *Appendix 6*, *Table 41* provides details on the recruited sample. In summary, it comprised 48 medical, nursing and allied healthcare professionals drawn from a range of services that typically support children/young people with a LLC.

We have organised the findings under the following sections:

- staff's views on whether spiritual care is part of their role
- the perceived relevance of spiritual needs to the patient group
- practices around identification of spiritual needs at assessment or clerking
- barriers to identifying or discussing religious beliefs
- factors affecting expressions of spiritual distress
- staff's views on the role of chaplaincy
- staff's descriptions of the support chaplaincy services provide to families
- staff's descriptions of the support chaplains provide to clinical teams.

## Staff's views on whether spiritual care is part of their role

Staff varied widely in whether they regarded spiritual care as part of their role, particularly when it concerned matters beyond identifying and responding to religious needs. A minority of study participants described themselves as intentionally regarding people as spiritual beings and that this influenced how they worked and interacted with families.

> *We're trying to care for people ultimately. We're trying to care for other human beings. You can't do that without having some understanding of how they see things, and that to me, overlaps with spirituality.*
>
> *FG4, Doctor A*

Others found spiritual care as fitting within the remit of their role, but it was not something they practised intentionally. A further group acknowledged that such issues may arise or present themselves, but they did not regard identifying and responding to spiritual needs (over and above religious needs) as a part of their role.

## The perceived relevance of spiritual needs to the patient group

Whether or not spiritual needs were a relevant issue to all their patients was discussed by staff. The majority believed that age and cognitive function affected this. Younger children and those with significant cognitive impairment were regarded as having no or a limited awareness of the significance of their diagnosis and, as a consequence, spiritual concerns were less relevant.

> *If I'm sat with a five- or six-year-old, they're not going to have an understanding about sort of death and dying. … But certainly with the older children it is something that I explicitly feel that needs to be discussed.*
>
> *Int 5, Clinical psychologist*

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> *Our patient population do not have the competence even to understand religion, you know, because they are so neurologically impaired. The patient population that we are able to explore the [spiritual] issues with are under the oncology team.*
>
> *FG6, Doctor A*

Many staff also regarded that the stage in the condition trajectory was relevant to the considerations of when children/young people, or parents, may need spiritual care and support. Indeed, many reported that they only proactively offered an opportunity for families to discuss spiritual issues/concerns, or the involvement of chaplaincy services, at end of life.

> *It's not the thing that's most forefront in our minds until we actually get to the end of life stage.*
>
> *Int 2, Occupational therapist*

Exploring spiritual issues earlier on was perceived as much more challenging. Staff spoke of a tension they felt between conveying a sense of positivity with families, which worked against offering a space to explore sober and serious issues.

> *You're trying to have a positive outlook, aren't you ...?*
>
> *FG2, Nurse specialist*

> *I struggle with how to offer it early on in treatment cos I feel like that kind of gives a bad message, that there is a good chance your child won't make it. ... they would automatically assume I am predicting a bad outcome.*
>
> *FG1, Doctor A*

## Identification of spiritual needs at assessment or clerking

There was general agreement that practices around identifying children's/young people's and parents' spiritual needs during the first appointment with their service, or on admission, was superficial, limited and not done consistently. There was consensus that, if done at all, any assessment of spiritual need focused on religious beliefs only and, less consistently, a desire for chaplaincy involvement. There was also agreement that such questions were usually directed at the parent even when the patient was a teenager.

> *It almost is like a bit of housekeeping.*
>
> *Int 5, Clinical psychologist*

> *I think possibly we often hear the dominant voice within a family unit.*
>
> *FG3, Social worker*

## Barriers to identifying or discussing religious beliefs

The majority of staff described feeling awkward and uncertain when asking about religious beliefs and exploring whether religious beliefs may be relevant to the situation a family is facing or decisions being made about treatment and care. Previous experience(s) of religious beliefs causing the family and clinical team to have very different views around a child/young person's treatment was often referred to as a reason why staff were ambivalent about seeking this information.

> *Lots of our colleagues have had challenging cases because of very strong religious beliefs, so whether that's why we back off a little bit from bringing religion in.*
>
> *FG1, Doctor B*

However, a number of other factors were also identified as contributing to this sense of discomfort. These included a lack of training or easy access to information about some or all of the religions of the families they cared for and fears about appearing discriminatory or critical.

> *There's a slight anxiety about touching a raw nerve or maybe straying into territory where you don't want to appear to be discriminating or judgemental about people's religious views.*
>
> *FG2, Doctor A*

Another area of concern was that, in raising issues of religious beliefs, a child/young person or parent might disclose experiencing a crisis of faith, or that their faith offered no sense or comfort. Most staff said they would be deeply uncomfortable if that happened and would not know how to respond. As a result, they managed conversations to avoid this happening. Those prepared to engage in such discussions found it challenging, with unease around boundaries being crossed in terms of their role and their relationship with the families.

> *Some of the families have a bit of a fight or flight with their religion. So they either cling onto it and seek really a lot of comfort, or they question it. And I find that's a hard bit. Sometimes you feel kind of involved in that support, trying to support them with decision-making [about their beliefs].*
>
> *FG4, Specialist nurse A*

Staff were also concerned that asking about religious beliefs may lead to a child/young person or parent asking about their own faith and beliefs. For staff with a religious faith, this typically felt very uneasy territory, particularly if their faith differed from that of the family. They described monitoring themselves to ensure personal beliefs were not revealed in their encounters with families.

> *These people are very vulnerable. You mustn't … you know … we can't steer them towards anything or push them towards anything.*
>
> *FG4, Specialist nurse B*

> *It's quite difficult to actually not be biased and bring my own sort of beliefs or, you know, my own understanding of things to those conversation and I find that particularly tricky.*
>
> *FG2, Doctor B*

## Barriers to raising and exploring spiritual distress

Staff identified multiple reasons for conversations about spiritual needs and distress not taking place between them and families, such as struggles with making sense, existential crises, fears and questions about dying, feeling life is meaningless and loss of hope. These included factors such as:

- staff uncomfortableness
- the setting and nature of the encounter
- the quality of the relationships between families and staff
- patient and parent readiness
- for children/young people, parental presence.

### *Staff uncomfortableness*

Many staff described feeling very uncomfortableness with the idea of exploring or responding to expressions of spiritual distress. As a result, they sought to avoid initiating conversations that might reveal this. This uncomfortableness was multidimensional.

First, hearing families' spiritual concerns and distress could be deeply unsettling because it forced staff to confront themselves and demanded a personal engagement in exploring and understanding their own beliefs and facing their own mortality. This was not necessarily something staff had purposively explored and articulated. Some staff believed not having a personal faith (and the belief frameworks and language that offered) made this more difficult to resolve.

> *I think engaging in these conversations involves some kind of reflection on your own beliefs about spirituality and religion and also life and death. And I think there's nothing more uncomfortable than having to sit there and reflect on your own*

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> *feelings about death and mortality. I think particularly when people are focused on a practical job, trying to keep people alive and keep them going, actually these slower conversations I think are really, really difficult for some.*
>
> *FG5, Clinical psychologist A*

> *… spirituality is difficult for us to cover and I think, you know, it's difficult to express as an adult isn't it? I mean I, I would struggle to sit down and tell you what my spirituality was.*
>
> *FG2, Doctor A*

Feeling underinformed and insufficiently skilled were other key contributors to this sense of uncomfortableness. Staff consistently noted the absence of teaching on spirituality, spiritual well-being and distress in their professional training.

> *I think a lot of people feel really kind of inadequate to have those conversations or are worried that they're not kind of equipped to kind of delve into those kind of conversations with people, or that they have the skills to continue that conversation or, you know, follow where they're going.*
>
> *FG5, Clinical psychologist A*

> *It's something I find difficult and I think many people find difficult. It's finding the words to ask the right questions to allow people to share what their spiritual needs are.*
>
> *FG4, Doctor B*

Alongside this, some noted an absence of specialist support to help them manage such situations, or specialist services to refer patients and parents to. Such views were held by staff with no or limited experiences of chaplaincy services.

> *When you haven't got a service to support them, that's difficult for a professional, because you highlight a need and then you've got nowhere to go with it.*
>
> *Int 1, Occupational therapist*

### *The setting and nature of the encounter*

Staff described being very reluctant to engage in conversations with families around more significant personal issues and concerns during outpatient appointments. They believed that the time-limited nature and 'task-oriented' focus of appointments, alongside the general pressures and busyness of the clinic environment, were not conducive to initiating such conversations or providing opportunities for children/young people or parents to raise such issues.

> *It's a pressured environment, we're usually running late and there's always that sense of you've got to the get the patient through. So I think exploring issues such as spirituality and those kind of things need time and need the right place and the right environment. And I don't think an outpatient clinic is the place for that.*
>
> *FG1, Advanced nurse practitioner*

> *We're in a clinic, the focus is on how they're getting on, trying to support them, it's not on maybe those other areas which would need more time. You can't just ask that question and then go, oh right, you're worried about dying, well we'll pick that up in three weeks, do you know what I mean?*
>
> *FG2, Physiotherapist*

By contrast, inpatient admissions were times when staff found that children/young people and parents did raise spiritual issues. While this could be because the admission itself heightened or raised such concerns, staff also believed that the relationships that developed between staff and families during such stays, and the lack of time constraints, supported this happening. They also afforded opportunities for children/young people to talk to staff when their parents were not present. Indeed, a number of staff described instances where a child/young person raised spiritual issues with ward staff on night duty.

### *The quality of relationships between families and staff*

Staff with experience of children/young people or parents raising spiritual issues with them reflected on how this typically happened after they had been involved in their care for many months, or even years. They believed children/

young people or parents used this time to work out whether they felt they connected with and could trust a particular member of staff.

> *We're going out once or twice a week [for home visits], we're spending time with them [child/young person] and we've been doing that for months, and then you get to a point where they go, 'Will you be honest with me? Are you always going to tell me the truth?'*
>
> *FG6, Clinical nurse specialist A*

> *I mean those are conversations across time … you develop a relationship and when you've established what role you play for them and how you might be of benefit to them and their child, that then tends to lead into, you know, more conversations where you explore … perhaps their emotional needs and then that might widen out to things like making sense of why things are happening and also trying to help to make sense of what is happening, and how their child may feel, particularly if their child can't express themselves directly.*
>
> *FG4, Doctor A*

However, it is important to stress that a long-standing and trusting relationship is not a requirement. We point to our finding that children/young people turn to ward staff they may not know well. Equally, there are many cases where the child's health or the acuteness of a medical crisis makes the duration of the relationship irrelevant. In these circumstances, what is critical is the staff's willingness to recognise and engage with children's/young people's or parents' spiritual needs and concerns.

> *There's some people you meet that you'll talk to about one thing and you'll talk to someone else about something else. There's no rhyme or reason to why you connect with that person.*
>
> *FG6, Clinical nurse specialist A*

### Patient and parent readiness

Finally, staff also felt that children/young people and parents varied in their readiness to express spiritual needs and concerns than others. This was ascribed to both individual differences and stage in the condition trajectory.

> *Some people will be very much more open than others … for some people they absolutely don't want to think about that sort of thing.*
>
> *FG2, Physiotherapist*

> *For me the biggest time I come across it [families raising spiritual issues] would be the more acute intensive care setting where perhaps we are in a situation where we're very concerned about the long-term prognosis for a child.*
>
> *FG1, Doctor A*

### Parental presence

Parental presence was frequently mentioned as a barrier to older children and teenagers raising spiritual issues with staff. Staff believed this could be due to a desire for personal privacy or to save their parents from further distress.

> *Sometimes it works better if the parent isn't there. We find that children will open up to us and they'll talk about things. We've had teens before who have shared thoughts around their funerals and their plans and all kinds of questions.*
>
> *Int 2, Occupational therapist*

> *When I'm separate with those children they sometimes start to talk about these things, and their fears and their fear of dying. Especially with the teenagers … they protect their parents and don't say anything to their parents.*
>
> *FG1, Doctor A*

### Staff's views on the role of chaplaincy

There was considerable variation in how much staff knew about and had been exposed to chaplaincy services. A key reason for this was the degree of reach of chaplaincy into their department or ward, something determined by the

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clinical/ward team, capacity within the chaplaincy team and their confidence with working in paediatric settings (see *Chapter 4*).

Within our sample were individual staff and teams who thought very highly of the chaplaincy service in their hospital and regarded them as key to their endeavour to provide holistic care. Some specifically referred reaching this point had been a gradual process, with time spent getting to know chaplains and observing how they worked.

> *I think it's been really valuable getting to know the chaplain. We've had a really strong relationship with [name] who's our chaplain. Knowing her and knowing how she works gives me the confidence in introducing her to people.*
>
> *FG4, Doctor C*

There were others who, in essence, regarded chaplaincy a last resort for when the clinical team was feeling uncomfortable. Evidence of this can be found in the fact that some staff did not seek to involve chaplaincy until end of life, or only called them in when they had been unable to resolve religion-based disagreements between families and staff around a child's treatment, or where the team could not agree on the best course of treatment for the child/young person.

> *In reality for me that [involvement of/referrals to chaplaincy] has really only been at times of, you know, probably critical decision-making in the ICU setting.*
>
> *FG2, Doctor A*

Other staff did not seek or encourage their involvement unless requested by the family. They expressed concerns that chaplains might impose their own religious beliefs and views on families or offer to pray with families who were not religious.

Finally, some were unclear as to what chaplaincy offered over and above the care and support their MDT offered to families. They therefore did not regard chaplaincy as being able to offer anything unique or different to families.

> *Within oncology there's a lot of MDT roles available that could provide a similar kind of support to what chaplaincy do.*
>
> *FG3, Social worker*

## Staff's descriptions of the support chaplaincy provides to families

Very few study participants were aware of, or had observed, chaplains working directly with children and young people under their care. Where staff had observed this, examples of their involvement were confined to offering companionship and activities that served to distract from the tedium of being an inpatient and the opportunity to engage in creative activities.

More staff had, however, witnessed chaplains working with parents and identified a number of different ways in which they offered support and care to parents. These included the following:

- offering a safe space to talk
- a presence in the darkest moments
- companionship during long inpatient stays
- supporting medical decision-making
- praying for and praying with
- rites and rituals
- bereavement support
- access to sacred or reflective spaces.

We go on to briefly describe each of these in turn, noting that cutting across all of the forms of care and support was the fact that chaplains were available 24/7.

> *Just their flexibility and availability cos they're on the site. So if you've got a family that need someone to come and talk to them now and they're in the hospital they can go [to them] now.*
>
> Int 6, Clinical psychologist

### A safe space to talk

Chaplains were often described by staff as someone offering parents a safe space in which the latter could express their feelings and discuss their worries. The fact that they were familiar with the child's diagnosis and treatment plan but were separate to the clinical team and had no 'agenda', were considered to be particularly helpful in this regard.

> *You might have a nurse or a doctor or an allied health professional that you really trust and can talk to but that's still somebody who's medicalised. I think sometimes having someone from chaplaincy just takes away that element that some families find quite restrictive in being able to be completely open about what they're scared about, without worrying about it being fed back to the medical team.*
>
> FG6, role unavailable

### A presence in the darkest moments

Staff also saw a key role for chaplains in being with families during their darkest moments: the times when they are overwhelmed with fear and sadness.

> *He was there at their point of greatest need and their darkest moment in their child's treatment. And I think that's often when the chaplains do step in: at those dark moments. You know, they're brilliant, they go around the ward and they meet the families offer their services but I think what the families remember are [their presence in] the deepest darkest moments of the treatment.*
>
> FG1, Doctor B

They described the individualised and responsive way in which chaplains worked at such times. Sometimes offering a prayer or blessing, or simply sitting with parents in silence, or sharing a cup of tea, or other acts of kindness that staff believed had offered parents comfort (e.g. singing to the child and bringing a small gift).

### Companionship during long hospital stays

Chaplains were also seen as a source of companionship for parents whose child was in hospital for a long time. Staff believed having someone to talk to who is interested in them (as a person, and not just as a parent) helped to reduce parents' sense of isolation. Within these regular conversations, there was also the opportunity to explore spiritual issues.

> *... these families are still going to be isolated on a hospital ward for three to six months with very limited access to their support network. And actually the chaplain is a sort of an additional person who can come in and visit them, spend time with them. And I just had such wonderful feedback from families about how valuable that was for them, and how much they gained from being able to have those more faith, spiritual based conversations.*
>
> Int 5, Clinical psychologist

### Supporting decision-making

Staff also described examples of chaplains supporting parents facing difficult decisions around their child's treatment and care. This was particularly the case when the options advocated by the clinical team conflicted with their religious beliefs. Those in clinical roles explained that much of what chaplains did during such instances was to work to absolve parents' feelings of guilt, either by helping them to see there were other interpretations of religious doctrines, or by mediating between parents and the clinical team and explaining the clinical and legal responsibilities that clinical teams were under. In this regard, chaplains were considered to be much more helpful than local faith leaders who, staff had found, did not always understand the legal frameworks which medical teams worked within.

> *They seem quite good at giving good advice and alleviating people's worries or guilt about maybe compromising their own personal beliefs.*
>
> FG3, Social worker

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> *[Chaplains help parents see …] … it's not them not doing the right thing, but that there are barriers doing the right thing.*
>
> *Int 6, Clinical psychologist*

### *Praying for and praying with*

The offer of prayer, or praying with parents, was another activity which staff were clear that parents valued and found to be a source of comfort. They noted that the need for prayer appeared to cut across whether a parent had any religious beliefs. Some participants gave examples of the inclusive ways in which chaplains approached praying with parents without a religious faith.

> *They have kind of have learnt different ways. So they'll maybe bring very tactile tools that they use and they maybe say 'shall we just sit with some silence for a while? Is there anything here you want to hold or feel while we, and we'll just sit together?' And just kinda doing it in a different way for them which it's more acceptable.*
>
> *Int 3, Clinical nurse specialist*

### *Rites and rituals*

Being able to offer parents religious ceremonies and rituals (e.g. blessings, last rites and funerals services) was a further way in which staff believed chaplaincy services supported families. They were keen to point out that the need for rituals and rites were expressed by both parents with a religious faith and those who were not religious.

> *Some of NICU families actually say 'I'm not religious at all', but sadly if the baby's not going to survive they'll say '… but I think I want them baptised or a blessing of some sort'. And we've heard parents say 'I can't believe I'm doing this, but actually it feels really important that we do that'.*
>
> *Paed Pall Care FG 2*

> *I had a family that weren't religious at all, they were pagan, but they were very spiritual. Their child spent a month up in PICU and went home to die, but they had a blessing through our chaplain and that was very important to them.*
>
> *FG4, Specialist nurse B*

### *Bereavement support*

Chaplains were also frequently identified as playing a key role in supporting bereaved parents. This included supporting the family to care for their child's body according to their faith traditions, talking to families about sensitive topics such as post-mortems and helping parents to plan and arrange funerals, including advising on religious traditions and requirements, and connecting them with local faith leaders.

Multifaith memorials run by chaplaincy services were consistently described by staff as being highly valued parents. Some particularly remarked on the skilled way that their chaplaincy team created and conducted these ceremonies in order that they were inclusive, even though that require them to depart from their own personal beliefs.

### *Access to sacred or reflective spaces*

Finally, healthcare professionals were consistent in their view that hospital chapels/multifaith spaces were well used by families, particularly by those facing extended inpatient stays. They believed their value lay in fact that they were calm and peaceful environments (with this contrasting sharply with the ward environment) in which parents could spend time away from the ward for reflection and prayer.

## Staff's descriptions of the support chaplains provide to clinical teams

Where chaplains were actively present in their departments, staff also described the support provided by chaplains to the clinical team. This support was typically described as being unique (i.e. it could not be sourced from elsewhere) and highly valuable. Across our data, we identified a number of different ways in which chaplains supported clinical teams.

## An intermediary when the family and clinical team disagree

Staff described valuing the intermediary, or mediating, role chaplains could play in situations where the clinical team and family disagreed over the child's treatment due to the family's faith or wider spiritual beliefs.

> *Chaplaincy are brilliant and we have had some really difficult situations and, you know, in our experience, I think our chaplaincy are vital to act as that intermediary.*
>
> *FG1, Advanced nurse practitioner*

They also reported involving chaplains early in discussions with families where they were concerned that parents' religious beliefs might have implications around decision-making.

> *… even if there's not actually been a conflict in that decision-making … but if there's anxiety from the treating teams about parental religion and how that might impact on the conversation, we have pre-emptively suggested having one of the chaplains present that work with the family.*
>
> *FG6, Doctor*

In situations such as these, chaplains spent time with parents explaining the child's clinical status alongside sharing different interpretations of religious teachings. Staff believed that, in some cases, simply having a chaplain deliver the clinical information was enough to, sometimes radically, shift parents' position.

> *… the parents just wanted everything done. And we called the chaplain in … He'd (already) been shown the scan, and he walked into the room and he just went 'I can see her, she's in the throes of death, we can stop now'. And the parents are like 'OK, we can stop now'.*
>
> *FG6, Doctor A*

Importantly, as well as supporting parents to reframe or change their views, staff also spoke about the way in which chaplains also helped the clinical team to have a better understanding of the parents' perspective and the factors affecting their views and decisions. They believed this could help prevent or resolve conflict.

> *… understanding their [parents] decision-making, even if I disagree with it, is sometimes helpful as a kind of de-escalation of conflict.*
>
> *FG6, Doctor*

### *Supporting the team with complex clinical decision-making*

Some staff described instances where team meetings with a chaplain had helped them explore and discern the right next step in a child's care. This had been found to be particularly valuable in situations where staff felt weighed down with the significance of the decision they faced.

> *We really appreciate it with patients whose symptomology is really complex and difficult to manage, or they've been with the team a long time and they've deteriorated over a long period of time. Chaplaincy come to our meetings, and just being able to talk through our decision-making … and also just giving staff the space to say how they feel, and what the impact on them is on caring for an incredibly complex child when they're not sure that they're doing the right thing.*
>
> *FG6, Doctor*

### *Advice on providing clinical care that is respectful of faith*

Outside of decision-making situations, staff frequently referred to the value they placed on having chaplains' advice on providing care which respected religious beliefs, particularly where a family's religion was not familiar to them.

> *They've been particularly helpful with less common religious faiths … where there's an ignorance within the team around what to do, how to best support. So that's very, very helpful when they give that kind of practical advice.*
>
> *FG3, Social worker*

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### *A point of contact when difficult questions are asked*

Staff described the uncomfortableness they often felt when parents disclosed existential distress or said their religious beliefs were offering them no comfort. Others described times when a child or young person had asked questions about what happens after death and they felt unsure how to respond. In such instances, staff reported being grateful for the support and advice chaplains could provide or were reassured by the fact they could offer to involve a member of the chaplaincy team.

> *… It's hard sometimes when people have a really strong faith and then they talk about, well why would God be doing this? They're kind of almost bringing you into that conversation and I think I find that every hard. That's when, I'd seek advice from the chaplain.*
>
> *FG6*

### *Enabling the clinical team to withdraw at end of life*

Staff acknowledged that their presence was not necessarily needed or wanted by parents at end of life. In such situations, they valued the way in which chaplains would sit with and be alongside the parents, leaving members of the clinical team feeling able, where clinically appropriate, to withdraw.

> *But I always feel that on the last day, on the day when ventilation is withdrawn, often it's our chaplaincy colleagues who are more around, especially for families who really want it. And well actually it feels we kind of back off sometimes at those times, not on purpose, but that's often what ends up happening.*
>
> *FG6, Clinical Psychologist*

## Discussion

This chapter has reported findings from our research with clinical staff involved in the care of children/young people with LLC and their families. Their views and experiences highlight the complexity of seeking to provide holistic care that incorporates recognising and responding to spiritual needs. Multiple challenges or barriers to doing this were identified. Importantly, there were differences between those identified with respect to meeting religious needs compared to spiritual needs, such as existential distress. Critically, the latter emerged as something staff had poorer understanding of and felt less comfortable with. In line with the existing literature,[124,141,155] multiple reasons were identified as causing this discomfort. Furthermore, while paying attention to religious needs was not contested as falling within their remit, this was not necessarily the case for spiritual issues. Again, this aligns with the wider evidence on UK clinical staff.[156,157]

Even where staff believed they had a role to play in meeting spiritual needs, their accounts revealed the challenge of ensuring their encounters with children/young people or parents, including the time, space and privacy for spiritual distress and concerns to be expressed and responded to. Again, these are issues already documented for the wider patient population. However, the issue of parental gatekeeping has not been reported previously, but this is, perhaps, similar to what we already know about the possibility of parental gatekeeping with respect to advance care planning.[158]

Study participants' discussions around spiritual needs and distress, and the involvement of chaplaincy services, revealed that staff may have a tendency to regard this as only relevant at the end of life. This runs counter to children's/young people's and parents' accounts on the significant threats to spiritual well-being associated with receiving and living with a diagnosis of a LLC (see *Chapters 5* and *6*). There is, perhaps, a possible disconnect between staff being aware that a LLC is likely to affect spiritual well-being and when, if at all, they feel they should seek to incorporate spiritual care into the support they provide a family, including seeking the involvement of chaplaincy services. This runs counter to the argument for routinely integrating early spiritual assessments and ongoing support in the care provided to children/young people with a LLC.[67]

Finally, the reported absence of any teaching, or even reference to, spirituality/spiritual care in professional training is concerning. Existing UK research suggests that, if included, its coverage is typically superficial, though this evidence is not available for all the professional groups involved in the care of child/young people with LLC.[12,159,160]

Our investigation into staff's attitudes and views about chaplaincy services was novel in its focus on paediatric settings, but it does align to the wider evidence base in terms of the different positions staff took with the respect to this.[27,116] Thus, we found a lack of understanding of spirituality and spiritual care and what chaplains do. Unsurprisingly, this appeared to influence attitudes and beliefs about chaplaincy services. This is critical, given that staff are a key gatekeeper to children/young people and parents accessing chaplaincy services.

To our knowledge, this study is the first to explore NHS staff's experiences of the way in which chaplaincy services can support parents of children/young people with LLC. Their descriptions align strongly with the accounts of parents and chaplains themselves. Few, however, had observed chaplains supporting children/young people. This is not unexpected, given our findings regarding the way staff and parents may gatekeep children's/young people's access to chaplains. While unlikely to have directly observed families' use of hospital chapels and multifaith spaces, in line with previous research,[161] these spaces were consistently identified by staff as being important to families.

Staff's descriptions of the support their MDT has received from chaplains are illuminating and novel. Rich data were generated on this issue and conveyed, where this was happening, a clear appreciation of their care and support: the notion of chaplains 'holding' the clinical team is apt here. It is likely that such support serves to maintain or bolster staff's empathic capacity.[162,163] This is important, given our findings on the comfort that children/young people and parents derived from the empathetic care from staff and, conversely, the impact of dehumanising care on their spiritual well-being.

Finally, while our findings on the role and contribution of chaplaincy present a positive picture, it is important to stress that this is dependent on the skills, expertise and capacity of chaplaincy teams to work into these settings.

### *Limitations*

A key limitation is that it was a self-selected sample. Given the topic area, and what is known about personal sensitivities or uncertainties around notions of spirituality, our sample is likely to be biased towards people who are comfortable discussing these issues. That said, study participants did vary in their understandings, attitudes and experiences. The choice of a focus group methodology worked well in terms of hearing whole teams discuss issues together (and thus reveal areas of difference and agreement). However, it may have restricted participants' openness, particularly around their struggles or discomfort with respect to spiritual and religious care and the extent to which this was neglected in their practice. Finally, we note the absence of data on encounters with chaplains, which caused concern or was unsatisfactory in some way. We therefore do not know whether this is an issue.

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# **Chapter 8** Synthesis and implications

## Introduction

In this final chapter, we bring together findings from the different WPs and summarise how they speak of the study' objectives. We then move on to consider the implications of the findings for decision-makers and, finally, put forward recommendations regarding the focus of future research.

## Synthesis

The study's objectives are presented below. To support coherence, we have grouped some of the objectives together under a single, high-order theme.

- Differences in the practice of, and access to, chaplaincy in adult and paediatric settings:
    - to describe the organisation and delivery of NHS and hospice chaplaincy services and identify the differences in the nature of provision for children, parents and adult patients
    - to investigate the equity of access to chaplaincy services for children and parents and factors affecting access
    - to understand the differences between providing chaplaincy services to children, parents and adult patients and the implications for service provision and staff training

- to describe the spiritual needs of children and parents, preferences regarding sources of support and their experiences of having those needs met or remain unmet
- to describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services
- to identify the (potential) roles of clinical teams in identifying and responding to the spiritual needs of children, young people and parents, and the barriers and facilitators to these roles being fulfilled.

### *Paediatric versus adult settings: differences in chaplaincy practice and access*

Findings from the WP 1 survey revealed that, compared to adult and older people's services/wards, when working in paediatric settings, chaplaincy services were more likely to be spending most time in supporting parents, clinical teams and staff than patients themselves. Our focus groups with chaplains (WP 2) revealed a consistent view that meeting the spiritual needs of parents was critical, given both what parents were facing and having to endure and because they are their child's main source of support. Findings from WPs 3 and 4 support this position. However, this does not diminish the need to also meet the spiritual needs of children/young people. In the next section, we explore why chaplaincy services may be spending most time working with parents rather than children/young people because of gatekeeping by staff and parents.

In terms of why some chaplaincy teams reported finding themselves working mostly with clinical teams, findings from WPs 2 and 4 revealed the multiple ways in which chaplaincy services can support clinical teams, both in the care of their patients and as a staff team, and the value teams drew from this support. Acting as a mediator and advocate emerged as key roles in preventing or de-escalating potential conflicts between the clinical team and parents and this was an area where religious expertise emerged as critical.

Our findings (WPs 1 and 2 in particular) also point to further differences in practice and provision between paediatric and adult settings. Thus, rites and rituals were more likely to be requested in paediatric setting, and not necessarily situated within a specific religious tradition. In addition was the bereavement support to parents. Support with funeral planning or officiating at the funeral, as well as memorial events, was not a unusual request where chaplains had been closely involved. Over and above this was, in exceptional circumstances, some sort of ongoing contact with bereaved parents was maintained. Their capacity to do this and degree to which this was 'authorised' were limited. Knowing that newly bereaved parents may receive limited support once back home was a source of great concern among chaplaincy staff.

All WPs also revealed issues related to children/young people and parents accessing chaplaincy services. Survey findings (WP 1) indicate that chaplaincy services are less likely to have a *routine* presence in paediatric settings compared to adult settings. This is critical because routine presence (as opposed to only attending following a referral or staff request) appears to be important in terms of patients, families and staff properly understanding who chaplaincy services are for and what they can offer. It also increases their availability for spontaneous conversations.

A key factor affecting access appears to be gatekeeping/resistance amongst staff. This was regarded as *more likely* to occur in paediatric settings than other settings. Findings from WPs 2 and 4 indicate that a lack of knowledge and appreciation of spirituality and spiritual distress as well as misunderstandings about chaplaincy are the two main factors affecting children's/young people's and parents' access to chaplaincy, or that access is restricted to end of life or moments of crisis. It is possible that gatekeeping may arise from staff's concerns about the particular vulnerabilities of children/young people (which may explain why chaplaincy services report fewer or no issues regarding access to maternity and neonatal services). We would argue that this need not be a concern where chaplains are skilled and competent. Indeed, findings from WP 4 clearly demonstrate the significant role chaplains can play in supporting children's/young peoples' well-being and easing suffering. But, aside from this, it is important to remember that such a position also restricts *parents'* access to chaplaincy. WP 3 findings paint a picture of the multiple threats to spiritual well-being faced by parents, the intense spiritual distress they face and the desire to have people – separate to the clinical team – to come alongside them. We would argue that findings from WPs 2–4 also indicate that, for some – both those with and without religious faiths – chaplaincy services can offer or contribute to this. Given that parents are likely to be the main source of support to their children, and parental distress is a source of moral distress for children/young people, ensuring parents' spiritual well-being is expected to become even more imperative.

Further findings (WPs 1 and 2) suggest two other factors may affect *children's/young people's* access to NHS chaplaincy services. First, chaplaincy services' capacity and, with respect to direct work with children/young people, perceived competence. Chaplaincy services have few staff compared to the size of the population they serve and often referred to shortcomings in terms of the size and make-up of the team. They were believed they were underserving a number of different patient groups and, even in trusts with children's hospitals, having staff dedicated to working in paediatric settings was not possible. The fact that paediatric departments will always be a minority in a generic acute trust emerged as a key reason for this. Finally, findings from WP 2 indicate that chaplains may not feel adequately skilled to work in paediatric settings and therefore avoid this. Some identified a need for specialist training in paediatric chaplaincy, and those who had received this training spoke highly of it. However, as our research with chaplains and young people (WPs 2 and 3) revealed, relational skills and youth/cultural understandings are also important if chaplains are to connect with young people.

A second barrier specific to children's/young people's access to chaplaincy services, reported by chaplains and NHS staff, was parental gatekeeping. Data from WPs 2–4 all paint a picture of the complexity of family dynamics and the hiding of distress and knowledge between family members. It is not surprising perhaps that parents may have concerns about their child meeting a chaplain. This points to the role of the clinical team and ward staff in introducing and vouching for chaplaincy services: something which parents noted would be of value. As our focus groups with chaplains and healthcare staff both revealed, this requires good, trusting relationships between them.

### *Spiritual needs and sources of support*

Our interviews with children/young people and parents (WP 3) revealed the significant and multiple threats to spiritual well-being, associated with being diagnosed and living with a LLC. This was observed across the different components of human spirituality: our need to understand and make sense of life, to have meaning and purpose, to feel and express connections to self, others, the wider world and the sacred/supernatural. Parents' and young people's accounts also contained rich descriptions of spiritual distress. There was also clear evidence that the suffering endured by parents is different to that of family members of other patient groups.

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Some key overarching messages emerge from this WP. First, threats to spiritual well-being are located in both seemingly small (e.g. a brusque or uncaring encounter) and significant (e.g. being told a significant diagnosis) things. This reinforces the notion that spiritual care should not be seen as the sole domain of chaplaincy services. Rather, it is about ethos and a recognition that holistic care requires all healthcare staff to have an appreciation of and ability to recognise and respond to spiritual concerns. Second, children who were diagnosed when they were quite young experienced threats to their spiritual well-being: they recalled being afraid for their health and frightened by their parents' distress. These findings challenge assumptions that younger children may be relatively unaffected.

Third, and perhaps unique to the paediatric setting, was the experience of moral distress by children/young people and parents. Importantly, this did not emerge in descriptions of threats to spiritual well-being and distress reported by chaplains or NHS staff, suggesting this is an aspect of spiritual distress that is particularly likely to remain hidden. Fourth, inpatient episodes and living with significant disability – both common features of having a LLC – were significant threats to spiritual well-being. These findings, alongside the descriptions of acute distress around the time of diagnosis and medical crises, further make the case for a 'whole trajectory' approach to the spiritual care of this population, rather than regarding spiritual issues as only becoming relevant at end of life. Finally, our sample included young people treated for cancer in the past and now under the care of a late effects service, and their parents. What was clear in many of these interviews was that, while the cancer might be been successfully treated, there had not been a recovery to full health.

In terms of sources of support, young people and parents described drawing comfort from contacts with others in the same situation as themselves, moments of compassionate care from healthcare staff and, for some, the support of friends, family or communities to which they belonged. Some described their faith as a key source of resilience, comfort and hope; and, among those without faith, the offer of prayers (from friends, chaplains etc.) was described as a comfort and affirmation that they and their child matter. However, despite these sources of support, most children/young people and parents described hiding their distress and deepest fears and concerns from themselves and others. The overall picture is one of suffering in isolation. Almost all described wishing for people on whom they could unburden themselves – either at critical moments or to 'journey' with them. For some, as we discuss in the next section, chaplains had been such a source of support.

### *Young people and parents' understanding and experiences of chaplaincy*

Our qualitative research with young people and parents (WP 3) also explored understandings and experiences of using chaplaincy services. Among those who had no contact with chaplaincy, many said the support that chaplaincy could offer in terms of presence and listening ear, and for some prayers and rituals, would have been welcomed. Not all had come across this service, and others had understood or assumed that chaplaincy was only for people with a religious faith. However, others said they would not have welcomed contact with chaplaincy. This was also rooted in beliefs that chaplains would proactively bring their religious beliefs to any encounter, something which they found offensive.

Among parents who had used chaplaincy – and this included those with and without a religious faith – the value and support drawn from contact with chaplains varied considerably. Their separateness from the clinical team – but (some) knowledge and understanding of their child's condition and care as well as being embedded in the hospital setting – were consistently identified as features that made such support appealing. Among these accounts were descriptions of encounters which were clearly highly significant. What is striking about these is their highly person-centred nature, with chaplains discerning and responding in the moment. However, while some encounters were less significant (e.g. stopping by for a chat about everyday things), they should be regarded as responding to spiritual needs such as our need for human connection and reducing the sense of disconnection from life beyond the ward. While very few young people taking part in this study had experiences of chaplaincy support, some of the health professionals who took part in this study (WP 4) described instances where chaplains had supported children/young people with existential concerns, acted as an advocate for the child within the family context and supported communication between the child and young person.

In terms of improving access to chaplaincy, and in addition to the points already made, what emerges from the WP 3 data are: (1) the need for chaplaincy to be presented as an integral part of the care offered from the point of diagnosis onwards (and at all significant admissions) and (2) that it should be offered to all families, regardless of whether or not they have a religious faith. There is an important caveat to this, however. All the accounts of chaplaincy involvement recorded by this research were highly positive: it may not be the case that all chaplaincy services are of the same standard or competencies as those represented or spoken about in this research.

### *Clinical teams' roles in identifying and responding to spiritual needs*

Earlier sections have already described how WP 4 found that the great majority of staff felt uncomfortable and incompetent with respect to identifying, raising and responding to spiritual issues and needs. This included enquiring about religious beliefs and exploring with families how such beliefs may be relevant to how they are understanding and experiencing their situation and decisions about care and treatment. Health professionals are the staff who are invariably present and with children/young people and their parents at significant and difficult moments and episodes as well as during regular clinic contacts. It is for this reason that, in terms of the implications of the findings from this study, a key area of focus should be on the training and competencies of clinical and allied health professionals with respect to spirituality and spiritual care.

## Implications for decision-makers

Based on this synthesis of the study findings, we set out below implications for decision-makers, both those based in national policy and professional bodies, as well as strategic leads in NHS trusts and heads of paediatric services, clinical teams and chaplaincy services.

1. Many of the healthcare staff (e.g. clinical staff, allied health professionals) who took part in this research, while conscious that the care they provided to patients and families did not adequately include spiritual issues, felt significantly constrained in being able to respond to this. A key reason for this was not feeling comfortable or competent to venture into issues of spiritual care, including religious support. At the same time, other healthcare staff who took part in this study had a poor understanding and appreciation of spirituality and spiritual care. In response to these findings, we would suggest that *national professional bodies* specify or review the spiritual care competencies and training required at each qualification level, and in doing so, draw on the expertise of healthcare chaplains, particularly paediatric chaplaincy. Investment in developing training resources and courses is likely to be required. This should be informed by evidence on the content and teaching approaches taken by existing training programmes and any evaluations conducted.[160,164–170] We note, however, that much of this work is taking place in other countries and the degree to which content and training approaches translate to the UK should be carefully considered.
2. Indicative staffing ratios for chaplaincy services (per patient/number of beds) published by the Chaplaincy Forum for Pastoral, Religious and Spiritual Care in Health[171] suggest that staffing ratios in specialist paediatric settings should be the around the same as for mental health trusts and increased where sites have paediatric or neonatal ICUs. However, the ratio is lower for staff (1 chaplain/2000 staff in mental health trusts vs. 1/3000 in specialist paediatric settings). *NHS trusts* should look to ensuring they should, at minimum, adhere to this guidance. We also suggest that *NHS England* seeks to evaluate the adequacy of the indicative staffing ratios, given: (1) the degree of spiritual distress reported, *from the point of diagnosis*, by children/young people *and* parents; (2) the valued and unique roles chaplains were described to have played and that, for almost all young people and parents who took part in this research, access to such support would have been appreciated; and (3) the roles chaplaincy services can play in supporting the MDT, both the team itself and in the clinical care of the child.
3. Furthermore, study findings identify the need for *NHS trusts* to review the policies and strategies they have in place with respect to workforce training; the profile of spiritual care within the organisation's ethos, vision and objectives; and investment in the creation and maintenance of 'faith spaces'.
4. We also suggest that *national condition-specific professional bodies* use the study findings to review their coverage on spiritual issues and review any current guidance and recommendations. They may also wish to use study days and conferences to increase the profile of spirituality and spiritual care within their specialism.
5. Our findings also support the argument for *clinical and service leads* of services that care for children/young people diagnosed with a LLC to consider assigning the role of 'spirituality/spiritual care lead/champion' to a member of the MDT, with protected time to work on developing or improving: (1) staff understanding, skills and practices; (2) reviewing systems and processes by which spiritual needs (including religious support needs) may be identified or assessed and (3) developing relationships with the chaplaincy teams.

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6. In terms of improving awareness of (and, related to this, access to) chaplaincy services, our findings suggest that proactive work to develop relationships with clinical teams and ward staff is likely to be more successful in removing barriers to children/young people and parents being supported by chaplaincy services. While recognising the constraints under which chaplaincy services are working, our findings suggest that *heads of chaplaincy services in trusts with a children's hospital* (in particular) should look for ways in which time can be invested in developing such relationships and whether the case can be made for staff to have dedicated time (or designated posts) to work in paediatric settings. We also recommend they review the training offered or available to the team on paediatric healthcare chaplaincy.
7. Our findings highlight three issues unique to chaplaincy services working in paediatric settings: (1) developmental differences (within the population and compared to adults); (2) the uniqueness of parental spiritual distress and (3) different family dynamics and sensitivities compared to adult settings. Given that any member of the chaplaincy team may be required to attend a child/young person or their family, we would suggest that the *UK Board of Healthcare Chaplaincy and chaplaincy training providers* review the content of *generic* training programmes in terms of whether the training adopts a whole life course approach (i.e. includes chaplaincy with children/young people) and working with individual family members and family-centred working. In addition, those providers offering *specialist* training in paediatric healthcare chaplaincy should review curricula in terms of coverage of the whole childhood–adolescent age range, family dynamics and family-centred ways of working.
8. Finally, we note that this study was the first which the *NIHR* commissioned on spiritual care and, to date, remains the only study on this topic. We would suggest that NIHR considers how they might further support developing the evidence base in this area.

## Research recommendations

We make the following recommendations for research relevant to the way the NHS responds to and meets the spiritual needs of children/young people with LLC and their parents:

- Development and mixed-method evaluations of postqualification training courses/programmes on spirituality and spiritual care competencies for healthcare professionals. Such work should investigate impacts on healthcare professionals' understanding, confidence and practice and whether/how such outcomes affect children/young people and parents. The factors affecting assimilation and implementation of learning should also be investigated, including comparisons of alternative teaching/training approaches.
- To support evidence-informed change, process evaluations of efforts to embed and integrate spiritual care into the care pathways of children/young people with LLC.

# Additional information

## CRediT contribution statement

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**Emese Mayhew (WP 1 only):** Data curation (supporting), Formal analysis (supporting).

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## Acknowledgements

We wish to express our sincere thanks to all those who took part in this study, and particularly, the young people and parents. We also want to thank the two advisory groups who we worked and consulted with during the study. These were NIHR's Generation R LYRO and a subgroup of the Martin House Research Centre's Family Advisory Board.

We also acknowledge the contributions to the study made by Lucy Stuttard (contributed to development of the survey of acute NHS trust chaplaincy services (WP 1) and Emese Mayhew (supported data input, cleaning and analysis of the survey of heads of care of UK children's hospices). Both had research posts in the Social Policy Research Unit (SPRU), University of York, during the period in which they were involved in the study. Our thanks also go to Lizzie Chambers (Together for Short Lives) who contributed to the conceptualisation of the study and was a co-applicant and advised on the survey of children's hospices (WP 1). Finally, Teresa Frank (SPRU) provided excellent administrative support to the study for which we are very grateful.

## Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

## Ethics statement

The study was approved by the Yorkshire and The Humber – South Yorkshire REC (Ref: 21/YH/0072; 15/04/2021) and the HRA.

## Information governance statement

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## Disclosure of interests

***Full disclosure of interests:*** Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/ZMLF1648.

***Primary conflicts of interest:*** Karl Atkin is a Board member for Sickle Cell Society and UK Thalassemia Trust. No other authors have any conflict to declare.

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# **Appendix 1** Overview of children's hospice research

## Introduction

Aside from NHS services, children's hospices are one of the key providers of care to some children/young people with LLC, and their families, including palliative and end-of-life care. All UK children's hospices align to international definitions of palliative care as whole person care, including spiritual care. Given this, it was important that the study included a component that looked at spiritual care provision in children's hospices and investigated staff's observations and reflections on the spiritual needs and spiritual care of families which use their services.

In this appendix, we provide an overview of what this research compromised, offer headline findings and report where fuller accounts of this work can be found. We note that most of the findings of this research are *specific* to children's hospices. It is for this reason that we have chosen not to include this work in the main body of the report, where the focus is on NHS provision and implications of the research findings for the NHS and NHS services. The exceptions are data collected from hospice staff, which contributed to our triangulation of data collected directly from children/young people and parents regarding threats to spiritual well and experiences of spiritual distress (see *Chapter 5*).

## The different components of the research with children's hospice staff

There were three components to our research on or with children's hospice staff.

1. A cross-sectional survey of heads of care of all UK children's hospices regarding spiritual care provision in their hospice (situated in WP 1 of the study).
2. Qualitative research with heads of care and spiritual care leads and specialist spiritual care staff (situated in WP 2).
3. Qualitative research hospice care team staff (situated in WP 4).

The contribution of this work to the overall study objectives is described in *Table 19*.

## Reporting the research on or with children's hospices

*Report Supplementary Material 1*–*3* present our research with children's hospice staff as follows:

- *Report Supplementary Material 1*: the survey of heads of care of UK children's regarding their spiritual care provision (Component 1);
- *Report Supplementary Material 2*: senior hospice staff and spiritual care staff's views on spiritual care provision in UK children's hospice (Component 2);
- *Report Supplementary Material 3*: hospice staff views on the threats to spiritual well-being faced by children/young people with LLC and their parents (Components 2 and 3).

## High-level findings from our research with hospice staff

- Most children's hospices do not have staff in dedicated spiritual care posts. Where such posts exist, they are confined to one member of staff, and the posts are part-time, sometimes less than a day/week. There are, therefore, likely to be inequities of access to spiritual care between hospices and between families using the same hospices.
- There is evidence of varying degrees of understanding of spirituality and spiritual care among senior hospice staff, and this was regarded as influencing spiritual care provision and practices in hospices.

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- Competing demands for funding and an increased emphasis on clinical care were regarded as barriers to developing or extending spiritual care provision.
- In hospices with staff specialist in spiritual care (e.g. chaplains), staff believed these roles significantly impacted and supported a hospice's spiritual care offer, particularly with respect to staff understanding of spirituality and spiritual care and recognition of their role in meeting spiritual needs and responding to children's/young people's and parents' spirituality. However, this impact was significantly constrained by the fact that spiritual care specialists were employed in part-time posts.
- Furthermore, spiritual care specialists' ability to get involved in direct work with children/young people and parents was restricted by time constraints and a lack of routine presence in the hospice.
- Hospice staff shed particular insights on the spiritual experiences and needs of children with profound disabilities, the way children/young people may express existential distress (including very young children) and factors which supporting expressions and explorations of spiritual distress.

**TABLE 19** Contribution of research with hospice staff to study objectives

| Objective | WP contributing to objective | Includes hospice data? |
|---|---|---|
| Describe the organisation and delivery of NHS and hospice chaplaincy/spiritual care services and identify differences in the nature of provision for children, parents and adult patients | 1, 2 | Yes |
| Investigate equity of access to chaplaincy services for children and parents, and factors affecting access | 1, 2 | Yes |
| Describe the spiritual support needs of children and parents, preferences regarding sources of support and their experiences of having those needs met or remain unmet | 2–4 | Yes |
| Understand the differences between providing chaplaincy services to children, parents and adult patients and the implications for service provision and staff training | 2, 3 | No |
| Describe children's and parents' attitudes, understanding and experiences of accessing and using chaplaincy services | 2–4 | No |
| Identify (potential) roles of clinical team in identifying and responding to spiritual needs of children, young people and parents and the barriers/facilitators to these roles being fulfilled | 2–4 | No |

## Adherence to/deviations from the study protocol

All three components of the research with children's hospice staff achieved target sample sizes. Recruited samples were not diverse in terms of ethnicity or religion: we would argue that this reflects the current UK children's hospice workforce, rather than being a failure of the research to recruit a diverse sample.

## Researcher reflections

As noted above, the level of understanding of spirituality and spiritual care, the extent to which children's hospices invested in and attended to spiritual care strategically and the degree to which spiritual care was intentionally provided by children's hospices was less than anticipated. This limited the extent and richness of data collected.

# **Appendix 2** Work package 1: additional tables

**TABLE 20** Characteristics of NHS trusts represented in the survey (*n* = 98)

| | | | ***n*** | **%** |
|---|---|---|---|---|
| ***Type of trust*** | | | | |
| Generic acute[a] | | | 86 | 87.76 |
| With children's hospital | | | 25 | 25.51 |
| No children's hospital | | | 61 | 62.25 |
| 'Other specialist'[b] | | | 9 | 9.18 |
| Children's[c] | | | 3 | 3.06 |
| Total | | | 98 | 100 |
| ***Size of trust (total number of beds)[d] (n = 98)*** | | | | |
| **Type of trust** | **Minimum** | **Maximum** | **Mean** | **Median** |
| Generic acute (*n* = 86) | 280 | 2508 | 824 | 759 |
| 'Other specialist' (*n* = 9) | 52 | 481 | 176 | 134 |
| Children's trust (*n* = 3) | 166 | 409 | 280 | 264 |
| All trusts | 52 | 2508 | 748 | 719 |
| ***NHS region*** | | | | |
| | **Number of responses** | **Proportion of survey sample (%)** | **Number of acute trusts at survey[e]** | **Regional response rate (%)** |
| London | 19 | 19.39 | 22 | 86.36 |
| Midlands | 17 | 17.34 | 20 | 85.00 |
| South West | 13 | 13.26 | 14 | 92.83 |
| South East | 12 | 12.25 | 19 | 63.16 |
| East of England | 7 | 7.14 | 14 | 50.00 |
| North West | 14 | 14.29 | 28 | 50.00 |
| North East and Yorkshire | 16 | 16.33 | 22 | 72.72 |
| Total | 98 | 100 | 139 | – |

a Includes two trusts combining acute, community and/or mental health services.
b Specialist trust include: burns and plastic, cardiothoracic, orthopaedics, neurological, oncology and women's. All have paediatric outpatient departments and wards.
c Includes specialist women's and children's trust.
d Data obtained from trust websites.
e Excludes specialist trust with no chaplaincy service.

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**TABLE 21** Types of departments and services provided ($n$ = 97/98)

| | Type of trust | | | |
|---|---|---|---|---|
| | Generic acute ($n$ = 86) | 'Other specialist' ($n$ = 8/9) | Children's[b] ($n$ = 3/3) | All ($n$ = 97/98) |
| | $n$ (%)[a] | $n$[a] | $n$[a] | $n$ (%)[a] |
| ***Emergency departments*** | | | | |
| All age | 86 (100.0%) | 2 | 0 | 88 (90.7) |
| Children's | 54 (62.8%) | 0 | 2 | 56 (57.7) |
| ***Inpatient wards*** | | | | |
| Adults/older people | 86 (100.0%) | 7 | 1 | 94 (96.9) |
| Children | 81 (94.2%) | 5 | 3 | 89 (91.8) |
| ***Outpatient departments/services*** | | | | |
| Adults/older people | 85 (98.8%) | 7 | 1 | 93 (95.9) |
| Outpatient: children | 82 (95.3%) | 5 | 3 | 90 (92.8) |
| ***ICUs*** | | | | |
| Adult | 86 (100.0%) | 6 | 0 | 92 (94.8) |
| Paediatric | 38 (44.2%) | 2 | 3 | 43 (44.3) |
| ***Children and young people's cancer wards*** | | | | |
| Children | 25 (29.1.5%) | 1 | 3 | 29 (29.9) |
| Teenage/young people | 23 (26.7.5%) | 1 | 2 | 26 (26.8) |
| ***Maternity and neonatal services*** | | | | |
| Maternity services | 85 (98.8%) | 4 | 1 | 90 (92.8) |
| Special care baby unit: low dependency[c] | 79 (91.9%) | 1 | 1 | 81 (83.5) |
| Local neonatal unit: high dependency[c] | 56 (65.1%) | 3 | 1 | 60 (61.9) |
| Neonatal ICU: specialist, complex care | 53 (61.6%) | 2 | 2 | 57 (58.8) |

a % figures only provided for acute generic trusts and total sample, given small number of specialist other and children's trusts.
b Includes a specialist women's and children's trust.
c Some respondents selecting local neonatal unit did not also select SCBU although is always part of local neonatal unit provision.

**TABLE 22** Concepts used in name of service/department ($n$ = 88/98)

| Concepts used in name of service/department | Number of services | % |
|---|---|---|
| Chaplaincy | 40 | 45.45 |
| Chaplaincy + spiritual[a] | 24 | 27.27 |
| Chaplaincy + pastoral[a] | 3 | 3.40 |
| Chaplaincy + spiritual + pastoral[a] | 2 | 2.30 |
| Pastoral + spiritual[a] | 12 | 13.64 |
| Spiritual | 4 | 4.54 |
| Pastoral + spiritual + religious[a] | 3 | 3.40 |
| Total | 88 | 100 |

a Ordering of concepts varies.

**TABLE 23** Permitted to offer care/support after discharge? ($n$ = 97/98)

| | Yes | No |
|---|---|---|
| Acute generic | 47 | 39 |
| Specialist other[a] | 6 | 2 |
| Specialist children's | 3 | 0 |
| Total sample | 56 | 41 |

[a] Missing data = 1.

**TABLE 24** Service contracted to provide spiritual care to local hospices

| | No | Yes | Total |
|---|---|---|---|
| Acute generic | 73 | 11 | 84 |
| Specialist other | 7 | 1 | 8 |
| Specialist children's | 3 | 0 | 3 |
| All trusts | 83 | 12 | 95 |

**TABLE 25** Number of full-time, salaried chaplains

| Number of FT salaried chaplains | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 2 | 0 | 0 | 2 |
| 1 | 24 | 3 | 2 | 29 |
| 2 | 23 | 1 | 0 | 24 |
| 3 | 14 | 0 | 1 | 15 |
| 4 | 10 | 0 | 0 | 10 |
| 5 | 2 | 0 | 0 | 2 |
| 6 | 5 | 0 | 0 | 5 |
| 7 | 2 | 0 | 0 | 2 |
| Total | 82 | 4 | 3 | 89 |

FT, full-time.

**TABLE 26** Number of part-time, salaried chaplains

| Number of part-time, salaried chaplains | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 6 | 1 | 0 | 7 |
| 1–2 | 27 | 4 | 1 | 32 |
| 3–5 | 41 | 4 | 1 | 46 |
| 6–12 | 12 | 0 | 1 | 13 |
| Total | 86 | 9 | 3 | 98 |

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**TABLE 27** Number of chaplaincy support workers (Band 4)

| Number of chaplaincy support workers | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 71 | 9 | 3 | 83 |
| 1 | 11 | 0 | 0 | 11 |
| 2 | 3 | 0 | 0 | 3 |
| 7 | 1 | 0 | 0 | 1 |
| Total | 86 | 9 | 3 | 98 |

**TABLE 28** Number of bank chaplains

| Number of bank chaplains | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 37 | 6 | 1 | 44 |
| 1 | 11 | 1 | 1 | 13 |
| 2–9 | 31 | 2 | 1 | 34 |
| 10–30 | 7 | 0 | 0 | 7 |
| Total | 86 | 9 | 3 | 98 |

**TABLE 29** Number of honorary chaplains

| Number of honorary chaplains | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 39 | 4 | 0 | 43 |
| 1 | 9 | 2 | 0 | 11 |
| 2 | 14 | 1 | 1 | 16 |
| 3–9 | 18 | 2 | 1 | 21 |
| 10–35 | 6 | 0 | 1 | 7 |
| Total | 86 | 9 | 3 | 98 |

**TABLE 30** Number of volunteers

| Number of volunteers | Acute generic | Specialist other | Children's | All trusts |
|---|---|---|---|---|
| None | 9 | 2 | 0 | 11 |
| 1–10 | 18 | 6 | 2 | 26 |
| 11–20 | 19 | 0 | 0 | 19 |
| 21–30 | 11 | 0 | 0 | 11 |
| 31–50 | 12 | 1 | 1 | 14 |
| 51–80 | 8 | 0 | 0 | 8 |
| 81–160 | 9 | 0 | 0 | 9 |
| Total | 86 | 9 | 3 | 98 |

**TABLE 31** Number of religions/beliefs represented in team by staff role ($n$ = 96/98)

| | Type of trust | | | |
|---|---|---|---|---|
| **Total number of religions/ beliefs represented[a]** | **Acute generic ($n$ = 85/6)** | **Specialist other ($n$ = 8/9)** | **Specialist children's ($n$ = 3/3)** | **All respondents** |
| ***Salaried staff*** | | | | |
| 1 | 20 | 3 | 1 | 24 |
| 2 | 26 | 3 | 1 | 30 |
| 3 | 25 | 2 | 1 | 28 |
| 4 | 6 | 0 | 0 | 6 |
| 5 | 6 | 0 | 0 | 6 |
| 6 | 2 | 0 | 0 | 2 |
| ***Honorary chaplains (Number of chaplaincy services with honorary chaplains = 54)*** | | | | |
| 1 | 18 | 2 | 1 | 21 |
| 2 | 12 | 1 | 1 | 14 |
| 3 | 7 | 1 | 0 | 8 |
| 4 | 1 | 0 | 1 | 2 |
| 5 | 3 | 0 | 0 | 3 |
| 6 | 2 | 0 | 0 | 2 |
| 7 | 2 | 0 | 0 | 2 |
| 8 | 2 | 0 | 0 | 2 |
| ***Bank chaplains (Number of chaplaincy services using bank chaplains = 57)*** | | | | |
| 1 | 15 | 2 | 1 | 18 |
| 2 | 23 | 1 | 0 | 24 |
| 3 | 5 | 0 | 0 | 5 |
| 4 | 1 | 0 | 0 | 1 |
| 5 | 4 | 0 | 1 | 5 |
| 6 | 1 | 0 | 0 | 1 |
| 7 | 0 | 0 | 0 | 0 |
| 8 | 0 | 1 | 0 | 1 |
| 9 | 1 | 1 | 0 | 2 |
| ***Chaplaincy volunteers (Number of chaplaincy services using chaplaincy volunteers = 88)*** | | | | |
| 1 | 7 | 3 | 0 | 10 |
| 2 | 12 | 1 | 0 | 13 |
| 3 | 20 | 0 | 1 | 21 |
| 4 | 15 | 1 | 0 | 16 |
| 5 | 6 | 0 | 1 | 7 |
| 6 | 9 | 1 | 0 | 10 |
| 7 | 5 | 0 | 0 | 5 |
| 8 | 1 | 0 | 0 | 1 |
| 9 | 2 | 1 | 0 | 3 |
| 10 | 2 | 0 | 0 | 2 |

a Maximum number of religions/belief groups = 10, including 'other' (Church of England and Free Church merged into Protestant).

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**TABLE 32** Number of trusts with Protestant faith represented in chaplaincy team

| | Acute generic | Specialist other | Specialist children's | Total number of trusts with Protestant faith | All trusts (100%) |
|---|---|---|---|---|---|
| Salaried chaplains | 84 (87.5) | 7 (7.3) | 3 (3.1) | 94 (97.9) | 96 |
| Chaplaincy volunteer | 74 (77.1) | 6 (6.3) | 2 (2.1) | 82 (85.4) | 96 |
| Honorary chaplain | 27 (28.1) | 2 (2.1) | 2 (2.1) | 31 (32.3) | 96 |
| Bank chaplain | 42 (43.8) | 4 (4.2) | 1 (1.0) | 47 (49.0) | 96 |
| *Sample size* | *85* | *8* | *3* | | *96* |

**TABLE 33** Number of trusts with ONLY Protestant faith represented in chaplaincy team

| | Acute generic | Specialist other | Specialist children's | Total number of trusts with only Protestant faith | All trusts (100%) |
|---|---|---|---|---|---|
| Salaried chaplains | 21 (21.9) | 3 (3.1) | 1 (1.0) | 25 (26.0) | 96 |
| Chaplaincy volunteer | 12 (12.5) | 5 (5.2) | 1 (1.0) | 18 (18.8) | 96 |
| Honorary chaplain | 46 (47.9) | 5 (5.2) | 0 | 51 (53.1) | 96 |
| Bank chaplain | 49 (51.0) | 6 (6.3) | 1 (1.0) | 56 (58.3) | 96 |
| Protestant faith only across all roles | 1 (1.0) | | | 1 (1.0) | 96 |
| *Sample size* | *85* | *8* | *3* | | *96* |

**TABLE 34** Age of salaried staff ($n$ = 98/98)

| | Type of trust | | | |
|---|---|---|---|---|
| | Generic acute ($n$ = 86) | 'Other specialist' ($n$ = 9) | Children's ($n$ = 3) | All ($n$ = 98) |
| *Age bands represented in chaplaincy services (years)* | | | | |
| 18–30 | 6 (6.9%) | 1 | 1 | 8 (8.2%) |
| 31–50 | 62 (72.0%) | 3 | 3 | 68 (69.4%) |
| 51–65 | 80 (93.0%) | 8 | 2 | 90 (91.8%) |
| ≥ 66 | 46 (53.4%) | 3 | 2 | 51 (52.0%) |
| *Youngest age band represented in chaplaincy service (years)* | | | | |
| 18–30 | 6 (7%) | 1 | 1 | 8 (8%) |
| 31–50 | 56 (65%) | 2 | 2 | 60 (62%) |
| 51–65 | 22 (26%) | 5 | 0 | 27 (28%) |
| ≥ 66 | 2 (2%) | 0 | 0 | 2 (2%) |
| Total | 86 (100) | 8 | 3 | 97 (100%) |

**TABLE 35** Age of chaplaincy volunteers

| | Type of trust | | | |
|---|---|---|---|---|
| | Generic acute ($n$ = 78/86) | 'Other specialist' ($n$ = 5/9) | Children's ($n$ = 3/3) | All ($n$ = 86/98) |
| ***Age of youngest volunteer in service (years)*** | | | | |
| Lowest age | 18 | 18 | 18 | 18 |
| Highest age | 69 | 61 | 48 | 69 |
| Average across respondents | 41 | 42 | 33 | 41 |
| ***Age of oldest volunteer in service (years)*** | | | | |
| Lowest age | 42 | 75 | 72 | 42 |
| Highest age | 93 | 83 | 79 | 93 |
| Average across respondents | 79 | 79 | 74 | 79 |

**TABLE 36** Routine recording of information on use of/access to chaplaincy service

| | Type of trust | | | | | | |
|---|---|---|---|---|---|---|---|
| | All generic acute trusts | | | 'Other specialist' | | Children's | |
| Type of information | Yes | No | Total | Yes | No | Yes | No |
| Patient's age | 25 (30.1%) | 58 (69.1%) | *83* | 3 | 4 | 2 | 1 |
| Types of ward | 75 (91.5%) | 7 (8.5%) | *82* | 5 | 2 | 3 | 0 |
| Relationship between family member and patient | 72 (87.8%) | 10 (8.2%) | *82* | 4 | 3 | 3 | 0 |

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# **Appendix 3** Work package 2: site and sample characteristics

**TABLE 37** Number of participants per site (WP 2) and site characteristics

| **Number of participants/site and key site characteristics** | | | |
|---|---|---|---|
| **Site ID** | **Number of participants** | **Type of trust** | **Has children's hospital** |
| A | 5 | Generic acute | No |
| B | 4 | Generic acute | No |
| C | 6 | Generic acute | No |
| D | 10 | Specialist children's | N/A |
| E | 5 | Generic acute | No |
| F | 9 | Specialist children's | N/A |
| G | 3 | Specialist children's | N/A |
| H | 6 | Generic acute | No |
| I | 12 | Generic acute | Yes |
| J | 5 | Generic acute | Yes |
| K | 6 | Generic acute | Yes |
| L | 1 | Generic acute | No |
| M | 4 | Generic acute | No |

N/A, not applicable.

**TABLE 38** Work package 2: sample characteristics

| **Sample characteristics** | **Number of participants** |
|---|---|
| ***Participants' role*** | |
| Salaried chaplain | 50 |
| Salaried chaplaincy support worker | 1 |
| Honorary chaplain | 8 |
| Bank chaplain | 8 |
| Chaplaincy volunteer | 7 |
| *Missing* | *3* |
| ***Years in healthcare chaplaincy*** | |
| < 1 year | 6 |
| 1–2 years | 5 |
| 3–5 years | 16 |
| 6–10 years | 24 |

**TABLE 38** Work-package 2: sample characteristics (*continued*)

| Sample characteristics | Number of participants |
|---|---|
| 11+ years | 19 |
| *Missing* | *5* |
| ***Age band*** | |
| < 30 years | 2 |
| 31–50 years | 17 |
| 51–65 years | 38 |
| 65+ years | 14 |
| *Missing* | *6* |
| ***Gender*** | |
| Female | 37 |
| Male | 39 |
| *Missing* | *1* |
| ***Religious faith/beliefs*** | |
| Church of England | 32 |
| Free church | 12 |
| Roman Catholic | 9 |
| Other Christian | 3 |
| Muslim | 8 |
| Jewish | 4 |
| Buddhist | 1 |
| Hindu | 1 |
| Sikh | 1 |
| Humanist/non-religious | 2 |
| *Missing* | *5* |
| ***Ethnicity*** | |
| White British | 40 |
| White other | 12 |
| Asian/Asian British | 8 |
| Black/Black British | 8 |
| Mixed ethnicity | 4 |
| Other (not specified) | 1 |
| *Missing* | *4* |

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# **Appendix 4** Work package 3: sample characteristics (young people)

**TABLE 39** Young people recruited to WP 3

| ID | Age at interview | Gender | Type of condition | Age at diagnosis | Recruited via | Religion | Faith important to everyday life? | Ethnicity | Contact with NHS chaplain |
|---|---|---|---|---|---|---|---|---|---|
| *Subsample A: may face death in next 12 months* | | | | | | | | | |
| AYP03 | 17 years | Female | Cancer | < 6 months | NHS | None | – | White British | No |
| AYP04 | 20 years | Female | Neuromuscular | < 5 years | Hospice | Muslim | Yes | Asian/Asian British | No |
| AYP05 | 20 years | Male | Neuromuscular | < 1 year | Hospice | Muslim | Yes | Asian/Asian British | Yes |
| AYP06 | 23 years | Male | Renal disease | 17 years | Charity | None | – | White British | No |
| AYP08 | 25 years | Female | Renal disease | 8 years | Charity | None | – | Chinese/ Chinese British | Yes |
| AYP07 | 16 years | Female | Cancer | 16 | Charity | Christian | Yes | White British | No |
| *Subsample B: 'survived' life-threatening illness* | | | | | | | | | |
| BYP01 | 21 years | Female | Bone | 13 | NHS | None | – | White British | No |
| BYP02 | 24 years | Female | Lymphoma | 13 | NHS | Christian | No | White British | Yes |
| BYP03 | 17 years | Male | Lymphoma | 10 | NHS | None | – | White British | Yes |
| BYP05 | 14 years | Female | Bone | 11 | NHS | Christian | No | White British | No |
| BYP06 | 14 years | Male | Leukaemia | 4 | Charity | None | – | White British | No |
| BYP09 | 25 years | Female | Solid (CNS) | 17 | Charity | None | – | White British | No |
| BYP10 | 25 years | Female | Leukaemia | 4 | Charity | None | – | White British | No |
| BYP11 | 24 years | Female | Solid (non-CNS) | 5 | NHS | Church of England | No | White British | No |
| BYP12 | 24 years | Female | Leukaemia | 4 | Charity | Catholic | No | White British | No |
| BYP14 | 23 years | Female | Solid (CNS) | 15 | NHS | Anglican | Yes | White British | Yes |
| BYP15 | 17 years | Female | Leukaemia | 9 | NHS | Catholic | No | White British | Unclear |
| BYP16 | 16 years | Male | Lymphoma | 10 | NHS | Muslim | Yes | Asian/Asian British | No |
| BYP17 | 16 years | Female | Lymphoma | 10 | NHS | None | – | White British | No |

CNS, central nervous system.

# Appendix 5 Work package 3: sample characteristics (parents)

**TABLE 40** Parents recruited to WP 3

| ID | Relationship to child | Type of condition | Age at diagnosis | Age at interview | Recruited via | Religion | Faith important to everyday life? | Ethnicity | Contact with NHS chaplain? |
|---|---|---|---|---|---|---|---|---|---|
| *Subsample A: end of life possible in next 12 months* | | | | | | | | | |
| AP01 | Mo | Degenerative | Pre-birth | 8 years | Hospice | Catholic | Yes | White British | No |
| AP02 | Mo | Degenerative (x2) | Pre-birth; 7 months | 7 years; 8 years | Hospice | None | – | Asian/Asian British | No |
| AP03 | Mo | Degenerative | Approximately 18 months | 11 years | Hospice | Catholic | No | White Irish | Yes |
| AP05 | Mo | Degenerative | < 1 month | 6 years | Hospice | None | – | South Asian | No |
| AP07a | Mo | Degenerative | Approximately 6 months | 2 years | Charity | Church of England | No | White British | No |
| AP07b | Fa | Degenerative | Approximately 6 months | 2 years | Charity | Church of England | No | White British | No |
| AP08 | Mo | Degenerative | Pre-birth | 11 years | Hospice | Christian | Yes | White British | Yes |
| AP09 | Mo | Degenerative | < 6 months | 13 years | Hospice | Church of England | No | White British | No |
| AP11 | Mo | Degenerative | Approximately 1 year | 17 years | Hospice | Church of England | No | White British | No |
| AP12 | Mo | Cancer | Approximately 3 years | 4 years | Charity | Catholic | Yes | White British | No |
| AP14a | Mo | Degenerative | < 1 month | 12 | Hospice | Muslim | Yes | Other | Yes |
| AP14b | Fa | Degenerative | < 1 month | 12 | Hospice | Muslim | Yes | Other | Yes |
| AP15a | Mo | Degenerative | < 1 month | 14 months | Charity | Hindu | No | Asian/Asian British | No |
| AP15b | Fa | Degenerative | < 1 month | 14 months | Charity | Catholic | No | White Other | No |
| AP16 | Mo | Degenerative | < 1 month | 17 months | Charity | Christian | Yes | White British | No |
| AP17 | Mo | Degenerative | < 1 month | 16 months | Charity | Catholic | Yes | White British | Yes |
| AP19 | Mo | Degenerative | Approximately 5 years | 7 years | Charity | None | – | Black/Black British | Unclear |
| AP21 | Mo | Renal disease | Approximately 2 years | 10 years | Charity | Christian | Yes | White British | No |
| AP22 | Mo | Degenerative | < 1 month | 2 years | Hospice | Muslim | Yes | Black/Black British | No |
| AP24 | Mo | Degenerative | At birth | 14 months | Charity | Church of England | No | White British | No |

continued

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**TABLE 40** Parents recruited to WP 3 (*continued*)

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| AP27 | Mo | Degenerative | Approximately 1 year | 2 years | Hospice | Muslim | Yes | Asian/Asian British | No |
| AP28 | Mo | Degenerative | Approximately 6 months | 6 years | Charity | Christian | Yes | White British | Yes |
| AP29 | Mo | Heart disease | At birth | 15 years | Hospice | Church of England | No | White British | Yes |
| AP34 | Mo | Degenerative | < 6 months | 2 years | Hospice | Christian | Yes | Black African | Yes |
| AP35 | Fa | Degenerative | < 6 months | 10 years | Hospice | Christian | Yes | White British | No |
| ***Subsample B: parents of children who have completed cancer treatment*** | | | | | | | | | |
| **ID** | **Relationship to child** | **Type of cancer** | **Age at diagnosis** | **Year of diagnosis** | **Recruited via** | **Religion** | **Important to everyday life?** | **Ethnicity** | **Contact with NHS chaplain?** |
| BP02 | Mo | Leukaemia | 4 years | 2017 | Charity | Church of England | No | White British | No |
| BP05 | Mo | Bone cancer | 11 years | 2008 | Charity | Church of England | No | White British | No |
| BP06 | Fa | Bone cancer | 13 years | 2014 | NHS | None | – | White British | Yes |
| BP07 | Mo | Leukaemia | 4 years | 2015 | NHS | None | – | White British | No |
| BP08a | Mo | Leukaemia | 2 years | 2007 | NHS | None | – | White British | No |
| BP08b | Fa | Leukaemia | 2 years | 2007 | NHS | Catholic | No | White British | No |
| BP09 | Mo | Tumour (CNS) | 17 years | 2018 | Charity | None | – | White British | No |
| BP10 | Mo | Tumour (CNS) | 3 years | 2011 | Charity | Christian | Yes | White Other | No |
| BP11 | Mo | Tumour (CNS) | 19 months | 2019 | Charity | None | – | White Other | Yes |
| BP13 | Mo | Tumour (non-CNS) | 3 years | 2021 | Charity | None | – | White British | No |
| BP15 | Mo | Tumour (non-CNS) | 9 years | 2017 | Charity | None | – | White British | No |
| BP17 | Fa | Tumour (CNS) | 9 months | 2009 | Charity | None | – | White British | Yes |
| BP19 | Mo | Tumour (non-CNS) | 5 years | 2003 | NHS | Church of England | No | White British | No |
| BP20 | Mo | Leukaemia | 9 years | 2013 | NHS | Roman Catholic | Yes | White British | No |
| BP21 | Mo | Leukaemia | 11 years | 2008 | NHS | None | – | White British | Yes |
| BP23 | Mo | Tumour (CNS) | 15 years | 2008 | NHS | Christian | Yes | White British | No |

**TABLE 40** Parents recruited to WP 3 (*continued*)

| ***Subsample C: bereaved parents*** | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **ID** | **Relationship to child** | **Type of condition** | **Age at diagnosis[a]** | **Age when died** | **Recruited via** | **Religion** | **Important to everyday life?** | **Ethnicity** | **Contact with NHS chaplain?** |
| CP01a | Mo | Genetic syndrome | Approximately 2 months | 4.5 months | Hospice | None | – | White British | No |
| CP01b | Fa | Genetic syndrome | Approximately 2 months | 4.5 months | Hospice | None | – | White British | No |
| CP02 | Mo | Neurol. degenerative | Approximately 2 months | 15 years | Hospice | Other | Yes | White Other | Yes |
| CP04 | Mo | Genetic syndrome | Pre-birth | 7 weeks | Hospice | Christian | Yes | White Other | No |
| CP05 | Mo | Born prematurely | At birth | 7 weeks | Hospice | None | – | White British | Yes |
| CP09 | Mo | Cancer (CNS) | 2 years | 8 years | Charity | None | – | White British | No |
| CP10 | Mo | Cancer (CNS) | 4 years | 11 years | Charity | Other | Yes | White British | Yes |
| CP11 | Mo | Cancer (CNS) | 13 years | 13 years | Charity | None | – | White British | No |
| CP12 | Mo | Complex neurological | < 1 month | 14 years | Charity | Christian | Yes | White British | Yes |
| CP13a | Mo | Complex neurological | < 1 month | 12 years | Charity | Christian | No | White British | No |
| CP13b | Fa | Complex neurological | < 1 month | 12 years | Hospice | Christian | No | White British | No |
| CP14a | Mo | Genetic syndrome | < 1 month | 15 years | Hospice | Christian | Yes | White British | Yes |
| CP14b | Fa | Genetic syndrome | < 1 month | 15 years | Hospice | Christian | Yes | White British | Yes |
| CP15 | Mo | Genetic syndrome | 3 and 5 years | 6 and 9 years | Hospice | Christian | Yes | White British | Yes |
| CP17 | Mo | Genetic syndrome | Approximately 2 months | 4 years | Hospice | Muslim | Yes | Asian/Asian British | Yes |
| CP18a | Mo | Leukaemia | 11 years | 15 years | Charity | None | – | White British | Yes |
| CP18b | Fa | Leukaemia | 11 years | 15 years | Charity | None | – | White British | No |
| CP19a | Fa | Major organ disease | Approximately 3 months | 9 months | NHS | None | – | White British | Yes |
| CP20 | Mo | Leukaemia | 1 year | 5 years | NHS | Christian | No | White British | Yes |
| CP22a | Mo | Major organ disease | Approximately 3 months | 9 months | NHS | Catholic | Yes | Mixed ethnicity | Yes |
| CP23 | Mo | Born prematurely | At birth | 13 days | NHS | Christian | Yes | Black/Black British | Yes |

CNS, central nervous system; FA, father; Mo, mother.

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# **Appendix 6** Work package 4: sample characteristics

**TABLE 41** Characteristics of NHS staff recruited to WP 4

| | *n* |
|---|---|
| ***Religion*** | |
| Christian[a] | 23 |
| None | 15 |
| Daoist | 1 |
| Hindu | 1 |
| Humanist | 1 |
| Jewish | 2 |
| Muslim | 1 |
| Prefer not to say | 3 |
| Missing | 1 |
| ***Ethnicity*** | |
| White British | 42 |
| Asian or Asian British | 2 |
| Chinese or Chinese British | 1 |
| Mixed ethnicity | 1 |
| ***Setting work in*** | |
| Inpatient | 37 |
| Outpatient | 38 |
| Community (NHS) | 32 |
| Hospice | 1 |
| ***Profession/role*** | |
| Nursing | 20 |
| Medicine | 12 |
| Clinical psychology | 9 |
| Neuromuscular specialist care advisor | 1 |
| Macmillan health and well-being coordinator | 1 |
| Occupational therapy | 1 |
| Pharmacy | 1 |
| Physiotherapy | 1 |
| Social work | 1 |
| Speech and language therapy | 1 |

**TABLE 41** Characteristics of NHS staff recruited to WP 4 (*continued*)

| | *n* |
|---|---|
| ***Duration in current post*** | |
| < 1 year | 4 |
| 1–5 years | 20 |
| 6–10 years | 7 |
| 11–20 years | 10 |
| > 20 years | 7 |
| ***Diagnostic groups work with*** | |
| Mixed | 33 |
| Oncology only | 10 |
| Neurodegenerative only | 5 |

a Includes: Anglican, Free Church, Roman Catholic.

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