Healthcare Professionals' Experiences of Endings in Paediatric Cancer Treatment: An Interpretative Phenomenological Analysis

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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OVERVIEW

Completing cancer treatment is a time of high stress and overwhelming concerns for childhood cancer survivors and their families. Empirical data suggests that during the end-of-treatment period, families are in need of specialist follow-up care and clearer direction around navigating the complexities of the post-treatment period.

Healthcare professionals (HCPs) play a crucial role in patients' wellbeing and clinical outcomes across all stages of the cancer pathway - including the end-of-treatment stage - and yet, research documenting HCPs' perspectives around endings in active treatment is almost non-existent, resulting in the experiences and needs of staff remaining poorly understood. The primary aim of this research is to qualitatively explore the end-of-treatment experience from the perspective of HCPs caring for paediatric cancer patients.

Part One is a qualitative meta-synthesis of findings from 12 qualitative studies exploring HCPs' experiences of providing care to paediatric cancer patients in the UK.

Part Two is an empirical paper reporting the findings from a qualitative study, underpinned by the methodological principles of Interpretative Phenomenological Analysis (IPA). The present study was part of a joint project exploring endings in paediatric cancer treatment from the perspective of paediatric cancer patients, their parents/carers and HCPs providing care to this population. This research was separate from the studies exploring patients and parents'/carers' views and specifically explored the experiences and perspectives of HCPs working in a paediatric hematology and oncology tertiary care centre in the UK. Semi-structured interviews were conducted with seven HCPs from a range of professional groups. Findings are discussed in relation to previous literature, whilst the unique contributions of the present research are also highlighted. Implications and suggestions for further research are noted.

Part Three represents a critical reflection on the project. This part considers the potential impact of the author's previous academic and professional experiences on the present thesis and outlines the steps that were taken towards maintaining reflexivity throughout the research process. The author further discusses some

contextual challenges that were encountered during the research process and how these were experienced and managed.

IMPACT STATEMENT

The present thesis set out to explore the expressed experiences and perceptions of healthcare professionals (HCPs) providing care to paediatric cancer patients in the UK. A particular focus of the present research was to examine how HCPs experience the provision of care around the end-of-treatment phase as well as their perceptions of existing rituals that are currently used to *mark* the ending in paediatric cancer treatment. This thesis comprises of a systematic review and an empirical paper both of which employed qualitative methods.

In terms of the qualitative meta-synthesis, to the author's knowledge, this is the first ever systematic review to have examined all the available qualitative evidence in relation to HCPs' experiences of providing care to paediatric cancer patients. Given that previous reviews have either tended to focus primarily on the experiences of children and their parents or have focused on the experiences of particular professional groups (e.g., nurses), the findings presented here provide unique, in-depth insights into how HCPs across a range of professional groups experience the provision of care within the setting of paediatric oncology. A finding of particular significance is that HCPs reported experiencing both inter- and intrapersonal challenges, highlighting an evident need for additional emotional and system-level support for staff within paediatric oncology. Notably, this review identified that there is a paucity of studies exploring how HCPs experience and navigate the end-of-treatment phase in particular.

The empirical paper aimed to address this gap by qualitatively exploring how HCPs in a tertiary paediatric cancer centre in the UK experience the provision of care around this important phase in the paediatric cancer pathway. Similar to the systematic review, to the author's knowledge, this is the first study to provide an in-depth exploration of this particular phenomenon. The present analysis demonstrates that HCPs perceive the end-of-treatment phase as the beginning of a period characterised by a range of unique and complex challenges not only for children and their families but also for HCPs themselves. A finding of particular significance is that most HCPs expressed reservations over the use of the end-of-treatment bell, a ritualised activity that is currently used in paediatric cancer wards to *mark* the end-of-treatment. HCPs expressed views that bell ringings can be personally and professionally distressing and may negatively impact on other children receiving

treatment on cancer wards, suggesting that it may be important for services to reconsider its use and presence on the wards. This analysis also highlighted some of the relational, ethical and psychological challenges HCPs experience within this setting and how these may be further compounded by the organisational contexts within which HCPs are required to operate. Collectively, this research provides insights into the factors that may influence HCPs in relation to the provision of care and proposes opportunities for developing appropriate strategies to support HCPs, children and families during this significant milestone.

This research is important as it may inform the development of best practices and may contribute to advancements in survivorship care in paediatric oncology. This research may be of particular importance for specialist tertiary paediatric cancer care centres in the UK but is likely to be of broader interest to service commissioners as well, due to its scope for identifying staff support initiatives that could reduce the personal and professional distress HCPs experience within paediatric oncology. Poor staff wellbeing can have serious consequences for HCPs, patients/families and public healthcare systems in general and therefore the current findings have potential to contribute to the development of healthcare policies that will prioritise and address the need for effective healthcare staff support.

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To myself – thank you for embracing all the challenges with a smile.

Ithaka

As you set out for Ithaka
hope your road is a long one,
full of adventure, full of discovery.
Laistrygonians, Cyclops,
angry Poseidon—don't be afraid of them:
you'll never find things like that on your way
as long as you keep your thoughts raised high,
as long as a rare excitement
stirs your spirit and your body.
Laistrygonians, Cyclops,
wild Poseidon—you won't encounter them
unless you bring them along inside your soul,
unless your soul sets them up in front of you.

Hope your road is a long one.
May there be many summer mornings when,
with what pleasure, what joy,
you enter harbours you're seeing for the first time;
may you stop at Phoenician trading stations
to buy fine things,
mother of pearl and coral, amber and ebony,
sensual perfume of every kind—
as many sensual perfumes as you can;
and may you visit many Egyptian cities
to learn and go on learning from their scholars.

Keep Ithaka always in your mind.
Arriving there is what you're destined for.
But don't hurry the journey at all.
Better if it lasts for years,
so you're old by the time you reach the island,
wealthy with all you've gained on the way,
not expecting Ithaka to make you rich.

Ithaka gave you the marvelous journey.
Without her you wouldn't have set out.
She has nothing left to give you now.

And if you find her poor, Ithaka won't have fooled you. Wise as you will have become, so full of experience, you'll have understood by then what these Ithakas mean.

C. P. Cavafy, "The City" (1984) from *C.P. Cavafy: Collected Poems.*

Ἰθάκη

Σὰ βγεῖς στὸν πηγαιμὸ γιὰ τὴν Ἰθάκη,
νὰ εὔχεσαι νᾶναι μακρὺς ὁ δρόμος,
γεμάτος περιπέτειες, γεμάτος γνώσεις.
Τοὺς Λαιστρυγόνας καὶ τοὺς Κύκλωπας,
τὸν θυμωμένο Ποσειδῶνα μὴ φοβᾶσαι,
τέτοια στὸν δρόμο σου ποτέ σου δὲν θὰ βρεῖς, ἂν μέν᾽ ἡ σκέψις σου ὑψηλή, ἂν ἐκλεκτὴ συγκίνησις τὸ πνεῦμα καὶ τὸ σῶμα σου ἀγγίζει.
Τοὺς Λαιστρυγόνας καὶ τοὺς Κύκλωπας,
τὸν ἄγριο Ποσειδώνα δὲν θὰ συναντήσεις, ἂν δὲν τοὺς κουβανεῖς μὲς στὴν ψυχή σου, ἂν ἡ ψυχή σου δὲν τοὺς στήνει ἐμπρός σου.
Νὰ εὔχεσαι νά ΄ναι μακρὺς ὁ δρόμος.
Πολλὰ τὰ καλοκαιρινὰ πρωϊὰ νὰ εἶναι
ποὺ μὲ τί εὐχαρίστηση, μὲ τί χαρὰ
θὰ μπαίνεις σὲ λιμένας πρωτοειδωμένους·νὰ σταματήσεις σ᾽ ἐμπορεῖα Φοινικικά,
καὶ τὲς καλὲς πραγμάτειες ν᾽ἀποκτήσεις,
σεντέφια καὶ κοράλλια, κεχριμπάρια κ᾽ ἔβενους, καὶ ἡδονικὰ μυρωδικὰ κάθε λογῆς, ὅσο μπορεῖς πιὸ ἄφθονα ἡδονικὰ μυρωδικά. Σὲ πόλεις Αἰγυπτιακὲς πολλὲς νὰ πᾷς, νὰ μάθεις καὶ νὰ μάθεις ἀπ᾽ τοὺς σπουδασμένους.
Πάντα στὸ νοῦ σου νἄχῃς τὴν Ἰθάκη.
Τὸ φθάσιμον ἐκεῖ εἶν᾽ ὁ προορισμός σου.Ἀλλὰ μὴ βιάζῃς τὸ ταξείδι διόλου.
Καλλίτερα χρόνια πολλὰ νὰ διαρκέσει.
Καὶ γέρος πιὰ ν᾽ ἀράξῃς στὸ νησί,
πλούσιος μὲ ὅσα κέρδισες στὸν δρόμο,
μὴ προσδοκώντας πλούτη νὰ σὲ δώσῃ ἡ Ἰθάκη.
Ἡ Ἰθάκη σ᾽ ἔδωσε τ᾽ ὡραῖο ταξίδι.
Χωρὶς αὐτὴν δὲν θἄβγαινες στὸν δρόμο.
Ἄλλα δὲν ἔχει νὰ σὲ δώσει πιά.
Κι ἂν πτωχικὴ τὴν βρῇς, ἡ Ἰθάκη δὲν σὲ γέλασε.
Ἔτσι σοφὸς ποὺ ἔγινες, μὲ τόση πείρα,
ἤδη θὰ τὸ κατάλαβες ἡ Ἰθάκες τί σημαίνουν.

Κ.Π. Καβαφης. Από τα *Ποιήματα 1897-1933*, Ίκαρος 1984)

PART 1:

SYSTEMATIC LITERATURE REVIEW

A systematic review of qualitative studies exploring the experiences of healthcare professionals caring for children with cancer in the UK

Abstract

Aims: This systematic review aims: (1) to explore the existing qualitative research on healthcare professionals' expressed experiences and perceptions in relation to caring for paediatric oncology patients, (2) to identify gaps in the existing evidence base, and (3) to discuss the implications for clinical practice and make recommendations for future research.

Method: A systematic review was carried out in July 2020 and involved undertaking a comprehensive and systematic search of the literature, critically appraising the studies and synthesising the data using a thematic synthesis approach. The thematic synthesis process consisted of four main elements: (1) in-depth reading of full-text papers, (2) 'line-by-line' coding of study findings, (3) grouping the initial codes into descriptive themes, and (4) assembling descriptive codes into higher order analytical themes.

Results: Of the initial 3612 identified articles, 12 studies were eligible for inclusion. Healthcare professionals' experiences in caring for children with cancer were mapped to four analytical themes: '*Navigating and managing relational complexity', 'Focusing on the child's unique experience', 'Effective communication, information sharing and shared-decision making'* and '*Coordinated care in a complex health system'*.

Conclusions: Several overlapping descriptive themes were identified across the analytical themes. Healthcare professionals identified a range of challenges they experienced within the setting of paediatric oncology. These included emotional difficulties - such as emotional labour, moral distress, compassion fatigue and occupational burnout - as well as practical and organisational constraints. The ways in which these factors may influence health practice and the delivery of care are noted and the need for additional emotional, professional and organisational support for healthcare professionals is highlighted. The findings discussed here may represent important areas for healthcare organisations to consider when looking to support healthcare professionals in their roles of providing care to paediatric cancer patients and their families.

Keywords: healthcare professionals, paediatric oncology, qualitative research, systematic review

1. Introduction

1.1. Incidence of paediatric cancer worldwide

Globally, paediatric cancer represents a significant cause of morbidity and mortality (Johnston, Erdmann, Newton, Steliarova-Foucher, & Roman, 2021). It is considered rare, and differs markedly from adulthood cancer both in its biology and in its patterns of occurrence (Filbin & Monje, 2019). Paediatric cancer encompasses a range of malignancies that are heterogeneous in their aetiology, tumour characteristics, symptomatology, treatment options, supportive care, survival rates and risk of late effects of treatment.

Over the past five decades, the significant advances in diagnostics and pharmacology combined with the optimisation of anticancer treatments, have led to substantial improvements in survival rates of paediatric cancer. Mortality rates have been steadily declining since the 1960s with recent figures suggesting that approximately 80% of childhood cancer patients in most high-income countries will survive five years post-diagnosis (Cancer Research UK [CRUK], 2021). These data indicate a more than 50% improvement in survival rates compared to the 1960s when only 30% of childhood cancer patients reached long-term survivorship.

With the improvements in paediatric cancer survival rates over time, and as the number of childhood cancer survivors reaching adulthood is steadily increasing, there have been growing concerns about the major long-term risks faced by this growing population. Children's exposure to highly toxic cancer treatment, such as chemotherapy and radiotherapy, at a young age, and particularly during developmentally critical periods, is associated with increased risks of experiencing detrimental acute and toxic side and late effects. These include a range of somatic conditions – for example, second primary tumours and neoplasms, neurocognitive impairments, cardiovascular disease, reproductive concerns and infertility risks, organ toxicities (Gröbner et al., 2018) - as well as a range of mental health conditions including depression, anxiety and PTSD (Allen et al., 2018; Ernst et al., 2021, 2020; Irestorm, Tonning Olsson, Johansson, & Øra, 2020). Moreover, childhood cancer survivors report overall poorer quality of life, and experience greater social and financial hardships compared to people without a cancer history (Nathan, Henderson, Kirchhoff, Park, & Yabroff, 2018). Due to the substantial negative impact of the

physical and psychosocial sequelae of paediatric cancer and its treatment, much attention has been focused on strategies to improve survivors' quality of life; an area that has been an important focus of survivorship and psyhco-oncological research.

1.2. Incidence of paediatric cancer in the United Kingdom

Childhood cancer accounts for less than 1% of all cancer deaths in the UK according to 2016-2018 data (CRUK, 2021). Incidence rates of paediatric cancer in the United Kingdom (UK) show that in 2015 – 2017 there were approximately 1878 new cases of childhood cancer per year (CRUK data, 2021) and 2490 new cases of cancer in teenagers and young adults (TYAs; CRUK, 2021)[1]. In the UK the incidence rate of paediatric cancer has increased by approximately 40% since the 1960s, with a consistent increase of almost 1% per year observed between 1966 and 2000 (CRUK, 2021). Promisingly, similar to the cancer trends observed worldwide, mortality rates for paediatric cancer in the UK have declined by approximately 69% since the early 1970s, with more than 8 in 10 (84%) of children diagnosed with cancer in England surviving their disease for five years or more (CRUK, 2021).

1.3. Types of cancer affecting children and treatment

Cancers in children and young people are rare and complex and their unique composition and distinctive histopathological nature have long been recognised (Kieran, Walker, Frappaz, & Prados, 2010a; Werner, Traulsen, & Dingli, 2016). The most common types of paediatric cancer are the acute leukaemias (i.e., haematological malignancies) including Acute Lymphoblastic Leukaemia (ALL) and Acute Myeloid Leukaemia (AML); combined, the acute leukaemias comprise approximately one-third of cases. Other common cancers include malignancies in the central nervous system (CNS) and spinal cord cancers (approximately one-quarter of cases), whilst the remaining malignancies comprise various solid tumours.

Similar to adulthood cancer, the treatment of paediatric cancer comprises three main modalities: surgery (to remove the tumour), chemotherapy (whether curative or palliative) and/or radiotherapy (whether curative or palliative). The relative use of each modality depends on a range of factors, including the type of malignant

[1] The Office for National Statistics classifies children as aged 0 to 14 years and young people as 15 to 24 years.

condition and the age of the patient; for instance, radiotherapy is strongly influenced by stage at diagnosis, whether the patient is generally well enough to tolerate this treatment, the patient's own treatment preference and the patient's age. For example, radiotherapy tends to be avoided whenever possible in patients under three years old, due to its association to more severe late side effects. Typically, the primary modality of treatment for children with haematological cancers is chemotherapy, whereas children with solid tumours are more likely to require surgery, however, these modalities are frequently used in combination depending on the child's presenting symptoms (National Institute for Health and Care Excellence, [NICE], 2014).

1.4. Delivery of paediatric care in the UK

In the UK, paediatric cancer care has become increasingly centralised and is provided by specialised treatment centres according to guidelines set forth by the Children's Cancer and Leukaemia Group (CCLG); a leading children's cancer charity and the UK and Ireland's leading professional association for paediatric cancer professionals. Paediatric cancer care in the UK is provided and coordinated by a network of 21 regional tertiary centres[2] distributed throughout the UK with one centre in Ireland, known as paediatric oncology Principal Treatment Centres (PTCs). PTCs are specialist centres for diagnosing and treating childhood cancer and hold overall responsibility for coordinating children's cancer care. PTCs also provide the necessary expertise for all types of inpatient and outpatient cancer treatment, across all age groups (i.e., children, adolescents and young adults) and for all types of malignancies.

Guidelines by the National Institute for Health and Care Excellence (NICE, 2014) recommend that all children and young people (CYP) must be referred to the PTC located in their catchment area, as soon as cancer is suspected. In some regions, PTCs may share care with units in local hospitals, known as Paediatric

[2] Royal Aberdeen's Children's Hospital, Edinburgh Royal Hospital for Sick Children, Glasgow Royal Hospital for Sick Children, Great North Children's Hospital (Newcastle), Leeds General Infirmary, Royal Manchester Children's Hospital, Alder Hey Children's Hospital (Liverpool), Sheffield Children's Hospital, Nottingham Children's Hospital, Leicester Children's Hospital, Birmingham Children's Hospital, Cambridge University Hospital, John Radcliffe Children's Hospital (Oxford), The Noah's Ark Children's Hospital for Wales, Bristol Royal Hospital for Children, Great Ormond Street Children's Hospital (London), University College London Hospital, Royal Marsden Hospital , Southampton General Hospital, Royal Belfast Hospital for Sick Children, Our Lady's Children's Hospital (Crumlin).

Oncology Share Care Units (POSCUs). POSCU services are provided by District General Hospitals outside the PTC, and provide supportive care closer to patients' homes. Any child with a cancer diagnosis is allocated to one tertiary centre which conducts all specialist aspects of treatment (i.e., the PTC) and one shared care centre which works in partnership with the tertiary centre and conducts all non-specialist aspects of treatment closer to home.

In line with national governmental policies, services are increasingly focusing on the importance of delivering patient-centred care, defined as ensuring that patients are actively involved in their own care plan and are given the opportunity to have their voices heard at key time points throughout the care pathway. A core element of patient-centred care is to conduct needs-based assessments and for patients to receive support based on their unique and personalised identified needs. In relation to paediatric services in particular, a primary focus is on shaping services in a way that considers the individual needs of children and young people with cancer (aged 0 to 24 years) and their families and to build healthcare services around service users' identified medical and psychosocial needs. Recently published NICE (NICE, 2014) guidance on improving outcomes for children and young people with cancer, further emphasises the importance of commissioning services that: (1) assess patients' individualised needs, and (2) provide specialist psychosocial support based on the patients' identified needs. Paediatric cancer patients and their families present with different needs at different stages of the cancer pathway and individualised care plans should take into account patients' and families' informational needs, communication styles, educational and employment needs, as well as their social, cultural and spiritual needs. Moreover, patient-centred care plans aim to identify ways to support patients and families in developing effective and age-appropriate coping skills and provide financial and practical support wherever possible.

NICE guidelines further suggest that patients' psychosocial needs should be assessed at various key points in their care pathway including: at diagnosis, during active treatment, at the end of active treatment, during long-term follow-up, at relapse, during palliative care and following bereavement (for families and carers; NICE, 2014). Based on patients' identified needs, the provision of appropriate psychosocial support is crucial for improving patients' long-term overall wellbeing (Jones et al., 2018; Peikert, Inhestern, & Bergelt, 2018). Within the NHS,

psychosocial support is defined as supportive care provided to children with cancer and their families during active treatment and long-term follow up, and it may include respite care, palliative care and bereavement counselling for families and carers. These services are mostly provided by allied health professionals (AHPs), from a wide range of specialties and disciplines including physiotherapists, occupational therapists, speech and language therapists, and therapeutic radiographers among others.

1.5. The impact of childhood cancer on healthcare professionals

Providing care to children who are suffering from life-threatening illnesses can lead to emotional and psychological distress for healthcare professionals (HCPs). The medical setting of paediatric oncology has previously been described as a stressful, high-risk and emotionally demanding work environment for HCPs. Some of the challenges experienced by HCPs involve heavy workloads, prolonged exposure to death, dying and suffering, being confronted with complex decisions and moral challenges, and working against various systemic constraints and institutional obstacles including excessive work demands, insufficient staffing, time pressures, and perceived lack of organisational support (Boyle & Bush, 2018). Moreover, HCPs often face multiple challenges associated with multidisciplinary working, such as disagreeing with the opinions of colleagues, communication breakdown within the team and having to consider multiple and sometimes conflicting views regarding the child's best care (Bartholdson, Lützén, Blomgren, & Pergert, 2015).

The advanced medical, nursing and supportive care that paediatric cancer patients require has also been associated with increased moral challenges among HCPs. For example, challenges in truth-telling and communicating transparently with children and families (particularly in the event of poor prognoses), administering toxic anticancer treatment, performing painful medical procedures against the child's will, pursuing futile medical treatment, being unable to meet the needs of patients and their families and not being able to adequately involve children in the decision-making and care-planning processes, have all been associated with moral distress (Bartholdson et al., 2015; Mukherjee, Beresford, Glaser, & Sloper, 2009). Moral distress is a multidimensional concept that has primarily been defined as the negative emotional response that arises from one's perception that one's moral

integrity has been compromised due to not being able to carry out the ethically appropriate action in line with one's professional and personal values (Jameton, 1993). Moral distress has been shown to manifest as depression, anxiety, guilt, powerlessness and helplessness among HCPs (Lazzarin, Biondi, & Di Mauro, 2012), has been associated with greater professional dissatisfaction and greater intent to leave healthcare professions (Trotochaud, Coleman, Krawiecki, & McCracken, 2015) - a finding that has more frequently been reported among nursing staff (Karakachian & Colbert, 2019; Oh & Gastmans, 2015).

Much research has also focused on the concepts of emotional labour and compassion fatigue among paediatric oncology staff; emotional labour is a term originally coined by Hochschild (1983) to describe the discrepancy between the external display of emotion and the internal affective experience. This phenomenon has been primarily observed and examined within the nursing profession and has also been described as 'surface acting' (Hochschild, 1983) – that is, suppressing one's emotions in order to maintain professionalism in line with the wider organisational rules, rather than being able to truthfully express one's internal affective experience. Compassion fatigue - also referred to as the 'cost of caring' - is a term used to describe the physical, emotional and psychological exhaustion and depletion as a consequence of caring for others (Bush, 2009). Although emotional labour and compassion fatigue represent distinct phenomena they are interrelated and together have been shown to contribute to HCPs' overall professional dissatisfaction and negative emotional sequelae, such affective disorders (e.g., depression and anxiety), as well as increased somatic complaints including chronic fatigue, sleep disturbances, insomnia, weight fluctuation and headaches (Boyle & Bush, 2018). In terms of work-related outcomes, such emotional hazards and the continuous exposure to emotionally laden occupational stressors have been associated with increased absenteeism, feelings of isolation in the workplace, withdrawal from colleagues and work activities, higher levels of attrition and poorer professional performance (Delgado, Upton, Ranse, Furness, & Foster, 2017).

1.6. Aim

Effective, safe and high-quality healthcare for children cannot exist without the retention of trained and experienced paediatric HCPs, and therefore the importance

of identifying the factors that may predict or perhaps protect HCPs from moral distress, emotional labour, compassion fatigue, professional burnout and overall job dissatisfaction cannot be understated or overlooked. The gap of available qualitative literature on the experiences of HCPs in relation to the caring process in paediatric oncology suggests that the voices, views and needs of staff tend to have a low profile in research agendas and may reflect a general sense that some of the issues experienced by oncology paediatric providers remain unacknowledged, and therefore inappropriately addressed, within the context of the current healthcare climate.

The overall aim of the present systematic review is to examine and summarise the findings from qualitative studies on the expressed experiences and perceptions of HCPs providing care to paediatric cancer patients in the UK. As indicated earlier, there is a paucity of literature on the experiences of HCPs who provide oncological care for children. Previous reviews have predominantly focused on exploring the experiences of children with cancer and/or their parents/carers/families (Gibbins, Steinhardt, & Beinart, 2012; Jibb et al., 2018; Markward, Benner, & Freese, 2013; Martinez‐Santos, Fernandez‐De‐La‐Iglesia, Sheaf, & Coyne, 2021). Where studies have examined HCPs' perspectives, they have tended to focus on specific clinical specialties within the MDT in isolation – for example the experiences of paediatric oncology nurses (Atout, 2020) – rather than incorporating the views of all healthcare specialties. Moreover, previous reviews have focused on HCPs' experiences of providing end-of-life care to children (McConnell, Scott, & Porter, 2016; Mu et al., 2019) or in other specific paediatric settings such as in neonatal intensive care units (NICU; Gibson, Hofmeyer, & Warland, 2018). Very little is understood about HCPs experiences in providing paediatric oncological care in a variety of hospital-based clinical settings across a range of clinical specialties. To the author's knowledge, this is the first systematic review summarising all the available qualitative evidence on HCPs' experiences of providing paediatric cancer care, in the context of the UK healthcare system, without restricting the search by professional specialty (e.g., nursing staff), particular hospital setting (e.g., ICU) or by a particular phase across the cancer pathway (e.g., end-of-life). The search was however, restricted by country and only aimed to include UK-based studies; although important knowledge and understanding can be inferred from research conducted outside the UK, the wider organisational structures within which HCPs are required to operate and practise will present different challenges depending on the country's healthcare system

organisation, policies, procedures and practices as well as the wider sociocultural context and professional climate within which healthcare systems are embedded (Asch et al., 2006; Mounier-Jack, Mayhew, & Mays, 2017). For instance, in the United States there is an absence of universal health care, unlike the UK were healthcare is provided free at the point of access via the NHS (Friebel et al., 2018). It is important therefore, to gain an in-depth understanding of the concept of paediatric cancer care and how this is experienced by HCPs in the UK.

Initially, the aim of the present review was to focus specifically on how the end-of-treatment phase is *marked* in paediatric cancer care and how this process of *marking* the ending is experienced among HCPs. The initial decision to focus the review on the end-of-treatment phase and ending rituals in particular, was driven by existing evidence suggesting that childhood cancer survivors and their families face a wide range of end-of-treatment difficulties and yet support around this time remains sub-optimal. Moreover, increasingly the end-of-treatment bell – also known as the cancer bell - has been established as a celebratory ending ritual (Gale, 2019) and is rung by oncology patients in both paediatric and adult cancer wards around the world to signify that an important milestone across the cancer pathway has been reached . Despite the prominence of the end-of-treatment bell, the perceptions of HCPs regarding its use and presence on the ward remain under-researched. Focusing solely on the end-of-treatment period and how endings in paediatric cancer treatment are marked could help gain insights into how these rituals are experienced and perceived by HCPs and their patients, which in turn could pave the way towards a greater understanding of the factors that influence the provision of care around that *specific* period along the cancer pathway, and could help identify opportunities for optimising the support children and their families receive as they complete active treatment and transition into survivorship.

The initial search strategy was developed to reflect this primary focus on endings and ending rituals (see Appendix 1.1), however, the first database search that was conducted revealed that there were no relevant qualitative papers in the existing literature that focused on how endings and/or ending rituals in paediatric cancer treatment were experienced by HCPs, either highlighting an important gap in the current evidence base or perhaps indicating that the initial review question was too narrowly defined. Following consultations with a specialist librarian - who was advised throughout this process to help structure and refine the database strategy -

the primary review question was adapted and broadened in order to identify *any* qualitative study exploring the experiences and perceptions of HCPs in relation to the provision of care to paediatric cancer patients in the UK. Casting a 'broader net' was considered more likely to ensure that key results were not missed and increased the likelihood of also identifying any published papers focusing on endings and/or ending rituals. Therefore, a secondary, more narrowly defined review question was also developed that was concerned primarily with endings in paediatric cancer treatment and ending rituals. The development of the review question(s) and database search strategy are outlined in detail in Section 2 below.

2. Method

2.1. Developing the review question

To guide the structuring of the review question the SPIDER mnemonic (Cooke, Smith, & Booth, 2012) was used, which helped identify key aspects of the research question (See Table 2.1). The *Sample* of the study was defined as any healthcare professional working in any paediatric oncology setting in the UK. The *Phenomenon of interest* was the provision of care to paediatric cancer patients from the perspective of HCPs. In terms of *Design* and *Research type*, any qualitative research study was eligible for inclusion (of any design and methodology, including qualitative findings from mixed-methods studies), whereas *Evaluation* related to participants' views, experiences and perceptions of the aforementioned phenomenon.

Table 2.1*. SPIDER Tool*

SPIDER	**Present review**
S – Sample	Any healthcare professional (HCP) providing care to paediatric oncology patients.
PI – Phenomenon of Interest	The provision of care to paediatric oncology patients.
D - Design	Any qualitative design.
E - Evaluation	Views, experiences and perceptions of participants regarding the phenomenon of interest.

R – Research type	Any qualitative research including mixed-methods studies (but only when the qualitative component was reported separately).

Primary Question:

- What are the expressed experiences and perceptions of HCPs providing care to paediatric cancer patients in the UK?

Secondary Question:

- What are the expressed experiences and perceptions of HCPs providing care to paediatric cancer patients during the end of treatment phase and how are end-of-treatment rituals perceived by staff?

2.2. Search strategy

The literature search aimed to identify any peer-reviewed qualitative research exploring HCPs' expressed experiences and perceptions relating to caring for paediatric cancer patients. Three search strategies were employed; first, a preliminary searching and scoping activity was conducted through searching electronic resources (Google and Google Scholar) to get a sense of relevant key words related to the topic in order to inform the subsequent development of the main database search strategy. Secondly, six electronic databases were searched – Ovid EMBASE, Ovid EMCARE, Ovid MEDLINE, Ovid PSYCINFO, CINAHL Plus and Web of Science – from inception to a cut-off date of 13/01/2021 (see Appendix 1.2 for the full database search strategy). Thirdly, the reference lists of all identified research articles were hand-searched for any additional studies. All retrieved datasets from the electronic databases were imported into an EndNote library and de-duplicated. A librarian was consulted across the various stages of developing the review search strategy.

2.3. Screening and selection

The inclusion criteria of studies for the review were: (i) studies explicitly reporting views or experiences of any HCP providing care to paediatric cancer patients in the UK, (ii) any type of childhood cancer, (iii) any date, (iv) published in English language, (v) primary research papers, (vi) qualitative research (of any design and/or methodology, including qualitative findings from mixed-methods studies as long as qualitative findings were reported separately). See Table 2.2. for a summary of the review inclusion and exclusion criteria.

***Table 2.2**. Inclusion and exclusion criteria*

Component	Inclusion Criteria	Exclusion Criteria
Population	Any healthcare professional providing care to paediatric cancer patients in the UK[3]	Children; Young People; Teenagers; Adults; Parents; Caregivers; Families
Disease	All childhood cancers[4]	Other childhood diseases[5]
Language	English	Non-English
Publication Date	Any date	n/a
Papers	Qualitative; Mixed-methods[6]; Peer-reviewed papers; Primary research paper; Studies that have a primary or secondary focus on the experiences of healthcare professionals providing care to paediatric cancer patients	Quantitative; Non-peer reviewed papers; Protocols; Reports; Letters; Editorials; Conference papers/abstracts/presentations; Dissertations; Theses; Thought pieces/discussions; Reviews; Meta-analyses; Studies with a predominant focus on palliative care

[3] Studies focusing on the experiences and perceptions of any healthcare professional providing care for paediatric cancer patients in the UK. Studies that included both patient and professional perspectives were included only if professionals' views were reported independently.

[4] B-Cell Acute Lymphoblastic Leukemia (ALL); Brain and Spinal Cord Tumours; Craniopharyngioma; Ependymoma; Leukemia; Medulloblastoma; Rhabdomyosarcoma; Retinoblastoma; Wilms Tumour

[5] Abdominal and Digestive D isorders; Cardiovascular Disorders; Congenital Abnormalities and Genetic Disorders; Oral Health Problems; Pancreatic Disorders; Lung and Respiratory Problems; Lysosomal Storage Disorders; Mental Health; Metabolic Disorders; Musculoskeletal Problems; Neurological/Developmental Disorders; Skin Disorders; Spasticity and Movement Disorders; Urogenital Disorders; Visual Problems

[6] Mixed-methods studies were considered for inclusion in the review only if qualitative findings were reported separately.

All titles and abstracts identified by the literature search, were examined by the author (AT) for relevance against predefined inclusion criteria. Full-text versions of potentially eligible papers were retrieved and assessed for eligibility by the author (AT). Papers not meeting inclusion criteria were excluded with reasons noted (see Appendix 1.3. for a list of excluded papers with reasons). The author extracted relevant information for the entirety of the studies and the thesis supervisor (HC) independently assessed 20% of the full-text papers for inclusion in the review. Any discrepancies were resolved through discussion.

2.4. Quality assessment

The methodological quality of included studies was assessed using the Critical Appraisal Skills Programme (CASP, 2018) instrument for qualitative studies. The checklist comprises 10 questions that determine the validity, rigour and relevance of included studies. The questions are designed to assist researchers in systematically assessing various methodological aspects of the study including the study aim, methodology, research design, recruitment and sampling, data collection, consideration of the relationship between the researcher and the participants, ethical issues, data analysis, findings and the overall value of the research. Each question was answered with a “yes”, “no”, or “unclear” response (“yes” scored as 1, “no” or “unclear” scored as 0) and an aggregate score was provided to classify the overall quality of each study; higher scores reflected better methodological quality. Studies of all quality were included in the review.

2.5. Data extraction and assessment of relevance

A standardised, pre-piloted Excel workbook (see Appendix 1.4.) was used to extract relevant data from the included studies, for assessment of study quality and evidence synthesis. The data extraction workbook was initially piloted and was modified accordingly to ensure that information was extracted on all relevant points of interest. Relevant domains covered items such as study aim, country, sample, publication language, methodology, methods, data analysis, and setting. Study characteristics were extracted in full by the author. To facilitate the analysis (undertaken in Word and Excel), full-text PDFs were retrieved and all data reported in

the ‘findings/results’ sections of each study were extracted, coded line-by-line and analysed.

2.6. Data analysis and synthesis

Data synthesis was carried out using an inductive thematic approach, as proposed by Thomas and Harden (2008). This iterative process of synthesising qualitative data from multiple studies, involved four stages: (1) in-depth reading of full-text papers, (2) ‘line-by-line’ coding of study findings, (3) grouping the initial codes into descriptive themes, and (4) assembling descriptive codes into higher order analytical themes.

Following the in-depth reading of full-text papers, the themes and subthemes identified by the authors of each included paper were extracted from studies and entered into an Excel spreadsheet (see Appendix 1.5. for a screenshot). Potential similarities among extracted themes were examined and were grouped into an initial colour-coded framework and each grouping was assigned an overarching descriptive code (see Appendix 1.6.). This additional step was done in order to help the reviewer gain an overview of papers included in the review and to facilitate the synthesis process.

The next step - Stage 2 in the Thomas and Harden (2008) approach - involved ‘line-by-line’ coding; this process was performed on any text that was under the ‘findings’ or ‘results’ sections of included papers. All the results of the studies were entered into Word and each sentence was coded according to its meaning and content. Every sentence had at least one code applied and usually each line of text was assigned multiple codes – for example, the sentence “*Instead, doctors emphasised how they worked ‘to keep the family together so they can function tomorrow’ and spoke of how this was in the child’s best interests*” - extracted from Forsey, Salmon, Eden, and Young (2013) - was assigned three codes: (1) keeping the family together, (2) stopping the emotions from taking hold, and (3) redirecting focus on the tangible and practical. Another example extracted from Lea et al (2020) involved two codes assigned to the following sentence: “*Specific professionals identified challenges in leadership, where services lacked the provision of a dedicated individual to lead this aspect of the services*”; the two codes were: (1) improving systems of care, and (2) specialist and dedicated roles to support

adolescents and young adults with cancer at the end-of-treatment. A screenshot of a section of a worked example is in Appendix 1.7. All given codes from this stage were imported into Excel (see Appendix 1.8. for a screenshot), and similar to the approach described earlier, potential similarities among the 21 initial codes that were identified, were further examined and grouped into a colour-coded framework (see Appendix 1.9.). After examining all initial codes for similarities and differences, these were then grouped into descriptive themes, which led to the development of higher-order analytic themes (see Appendix 1.10.). Whilst the development of *descriptive* themes aims to remain 'close' to the original data reported by the authors of the included studies, the development of *analytic* themes requires reviewers to 'go beyond' what was reported in the primary studies – that is, reviewers are required to reflectively examine the data included into the synthesis up until this stage and draw upon their own judgment and insights "to generate additional concepts, understandings and/or hypotheses" (Thomas & Harden, 2008).

3. Results

3.1. Study selection

A total of 3552 relevant papers were identified. After removal of duplicates, 2092 papers remained, and article titles and abstracts were screened against predefined inclusion criteria. Of these, 2044 did not meet eligibility criteria and were therefore excluded, resulting in 43 full-text papers to be assessed for inclusion. Following full-text screening, a total of 12 papers were eligible for inclusion in the review. The PRISMA template was used to produce a flowchart outlining the exclusion and inclusion of studies at each stage of the selection process (see Figure 3.1).

3.2. Study characteristics

Included studies were published between 2009 and 2021, with the majority of studies (n = 8; 66%) being published since 2018, reflecting an overall trend of more recently published studies. The sample sizes ranged from 8 to 58, with a total

combined sample size of 245[7] healthcare professionals. Healthcare professionals from various disciplines were represented in the data, including clinical nurse specialists (CNSs), nurses, hospital doctors, social workers, psychologists and allied healthcare professionals. All included studies reported on data from various disciplines within the MDT, whilst two studies solely focused on nurses (Gray & Smith, 2009; Wright, Norton, & Geary, 2018). All included studies collected data through one-to-one interviews, whilst two of the included studies adopted a mixed-methods design, reporting qualitative findings from the interviews separately to qualitative data collected through cross-sectional surveys (Lea et al., 2020, 2019). One study collected data through a range of methods, including one-to-one interviews, focus groups and via an online forum (Gibson, Kumpunen, Bryan, & Forbat, 2018). One study collected and reported data from parents of children with cancer in addition to healthcare professionals (F. Gibson et al., 2018), however, this study was eligible for inclusion as the data reported for healthcare professionals were sufficiently distinguished from parents' accounts.

Included studies had varied aims, objectives, research questions, analytic approaches and foci, hence the findings of the articles were heterogeneous. Approximately half of the included studies (n = 7) reported on the views of HCPs specialising in providing care for teenage and young adult (TYA) cancer patients. From these, four studies were interested in exploring the informational and communication needs of TYAs with cancer; for instance Lea et al (2020) examined HCPs' perceptions of TYAs' informational needs during the end-of-treatment phase, Lea et al (2019) explored the use of online information and how this may be safely incorporated into TYAs' standard care, Pugh et al (2020) focused on HCPs' perspectives regarding the provision of health behaviour advice in order to improve the provision of holistic care among this patient population, and Day et al (2018) explored the views of professionals regarding the factors that influence TYAs' involvement in shared-decision making. Three studies focused on HCPs' perceptions of how they might support TYAs experiencing and managing various physical and psychosocial sequelae relating to cancer and its treatment; for instance, Coughtrey et al (2019) explored how HCPs may recognise and help treat low mood and

[7] This number does not include HCPs participating in the quantitative components of included studies.

depression in TYAs, Willmott, Loades, Baker, and Spathis (2021) explored HCPs' perceived challenges in supporting TYAs with cancer-related fatigue (CRF), whereas Wright et al (2018) examined HCPs' experiences in undertaking fertility-related discussions with TYAs.

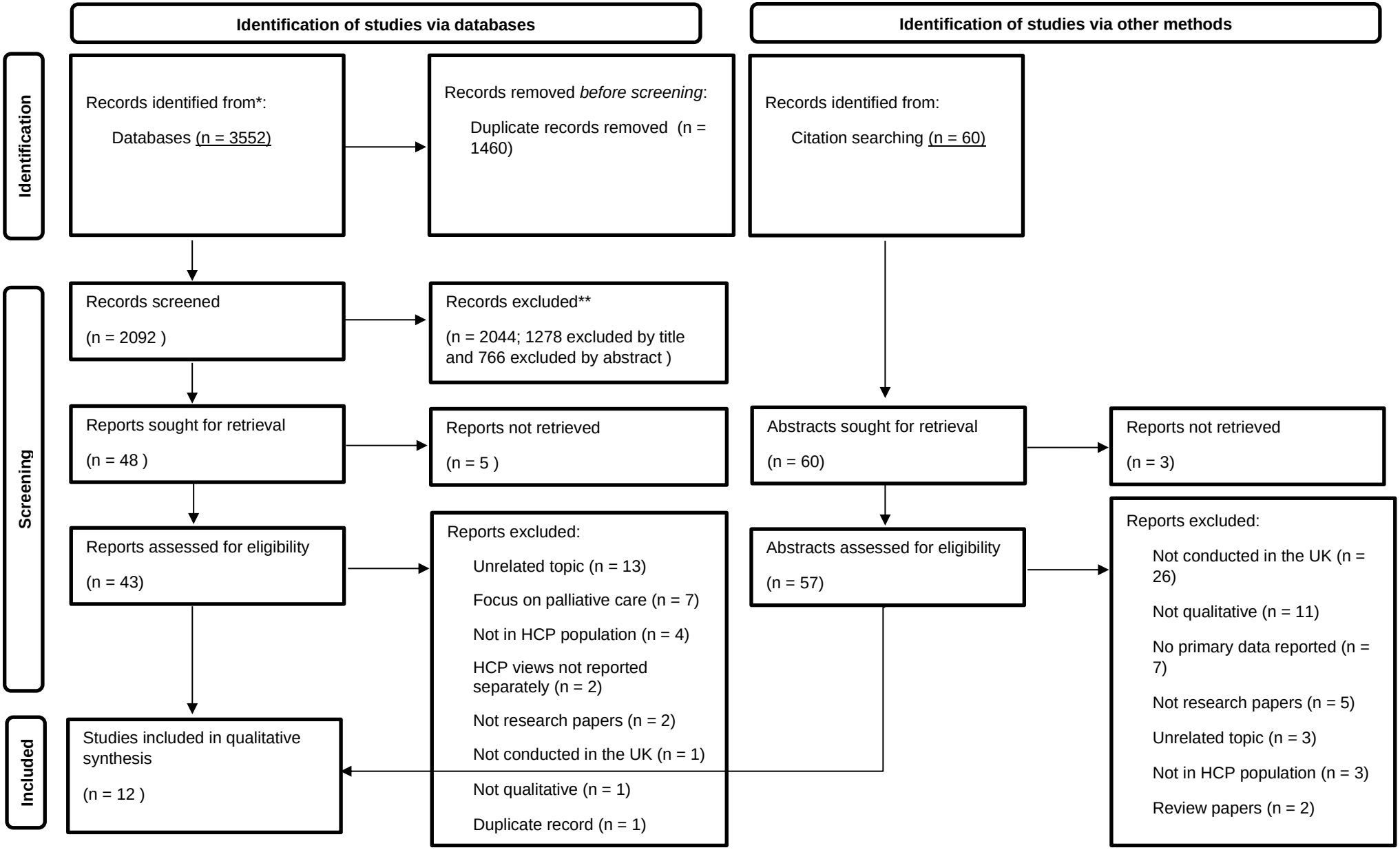

***Figure 3.1**. PRISMA flow chart: schematic overview of the selection process for interventions eligible for full review*

The remaining five studies concerned HCPs' views and experiences in relation to various aspects of providing care to paediatric cancer patients. Three papers focused on HCPs' emotional reactions to caring not only for the physical but also the emotional wellbeing of their patients and their families; for instance, Gray and Smith (2009) examined nurses' experiences in relation to emotional labour, Pye (2013) explored HCPs' perceptions and feelings concerning moral distress and its impact on interprofessional working, whereas Forsey, Salmon, Eden, and Young (2013) focused on exploring how HCPs manage the emotional care of parents of children with leukaemia. Lastly, Gibson et al (2018) explored HCPs' perceptions on how they receive and communicate information with patients and their families at the stages of diagnosis and treatment, whereas Williamson and Rumsey (2016) explored HCPs' views regarding the psychosocial impact of an altered appearance during and following cancer treatment. A detailed summary of study characteristics is presented in Table 3.1.

***Table 3.1**. Characteristics of articles included in the review*

Study No.	Author(s), year	Country, publication language	Methodology, method and data analysis	Phenomena of interest / Study aims	Setting and participants	CASP quality rating
1.	Coughtrey et al., (2019)	UK, English	Qualitative, semi-structured interviews, Thematic Analysis.	To: (1) explore the views of health professionals in recognising and treating low mood in young people with cancer, and (2) identify the key components of an effective online treatment package for depression in this population.	Setting: NHS Teenage and Young Adult (TYAs) cancer service providing treatment to patients aged 13-24 years old. Participants: 18 healthcare professionals, members of the psycho-oncology team; 10 psychologists, psychiatrists and psychotherapists; 3 clinical nurse specialists; 2 play therapists; 1 radiographer; 1 consultant haematologist; 1 activity coordinator.	9
2.	Day et al., (2018)	UK, English	Qualitative, semi-structured interviews, Grounded Theory.	To explore healthcare professionals' perspectives on the involvement of teenagers and young adults (TYAs) with cancer in decision-making.	Setting: A tertiary referral centre in the UK. Participants: Any healthcare professional working in a specialist MDT for Teenage and Young Adult cancer patients. 58 HCPs were recruited; 6 consultants, 19 junior doctors, 9 clinical nurse specialists, 10 ward nurses, 14 allied healthcare professionals.	9

3.	Forsey, Salmon, Eden, & Young (2013)	UK, English	Qualitative, one-to-one interviews, data were analysed interpretatively (but no specific analytical approach was reported).	To describe and compare doctors' and nurses' accounts of managing the emotional care of parents of children with leukaemia, with the overall objective of examining how their accounts might inform training and policy.	Setting: Six UK paediatric oncology and haematology treatment centres. Participants: 16 doctors and 14 nurses from paediatric oncology and haematology units.	7
4.	Gibson, Kumpunen, Bryan, & Forbat (2018)	UK, English	Qualitative, one-to-one interviews, focus groups, and an online forum. Data were analysed using a Grounded Theory approach.	To examine parents' and healthcare professionals' perceptions of roles in receiving and communicating information when a child is diagnosed with and treated for Acute Lymphoblastic Leukaemia (ALL).	Setting: A principal children's cancer treatment centre in a large urban area of the UK. Participants: 1) 28 parents of children who were receiving and who had completed treatment for Acute Lymphoblastic Leukaemia, and 2) 34 healthcare professionals, who parents believed had provided helpful information.	9
5.	Gray & Smith, (2009)	UK, English	Qualitative, semi-structured interviews. No specific analytic approach was reported but the analysis was based on ethnographic approaches.	To discuss the experiences of nurses in relation to their feelings and emotional labour and ask them to invite them to reflect upon their practices and emotions.	Setting: Participants were recruited to the study via the researcher's attendance at several pre- and post- registration classes held at the local East London hospital. Nurses worked across three clinical settings: primary care, mental health and children's oncology. Participants:	2

					16 nurses.	
6.	Lea et al., (2019)	UK, English	Mixed methods, semi-structured interviews/survey, Framework Analysis.	To understand how healthcare professionals perceive online information and support for young people with cancer.	Setting & Participants: Healthcare professionals involved in the care of young people with cancer in the UK were invited to take part in a telephone interviews or survey. A total of 46 healthcare professionals participated; 8 took part in interviews and 38 completed the survey.	9
7.	Lea et al., (2020)	UK, English	Mixed methods, semi-structured interviews/survey, Framework Analysis.	To identify young people's information and support needs when treatment ends from the perspective of healthcare professionals, and to determine whether there is a current model of care that fulfills young people's information and support needs during this period of their cancer timeline.	Setting: Specialist Adolescent and Young Adult (AYA) treatment centres, as well as other cancer settings where young people received care, from across the UK. Participants: Interviews were conducted with 12 healthcare professionals, whereas 49 healthcare professionals completed the online survey.	8
8.	Pugh et al., (2020)	UK, English	Qualitative, semi-structured interviews, Framework Analysis.	To understand teenagers, young adults and healthcare professionals' perspectives on the provision of health behaviour advice and preferences on an intervention to help develop their health promotion skills.	Setting: Participants were recruited through email advertisements sent to several UK-based professional and charitable bodies specialising in Teenage and Young Adult (TYA) cancer patient care. Participants: 26 healthcare professionals took part.	8
9.	Pye (2013)	UK, English	Qualitative, semi-structured, Riley's	To: (1) explore perceptions of doctors and nurses working	Setting:	

			method of qualitative data analysis.	in a paediatric oncology unit regarding their experiences and feelings concerning moral distress, and (2) to gain a deeper understanding of the causes, implications, and effects on the team as well as how this distress affects the relationship dynamics between the members of the team.	Not specified. Participants: 4 nurses and 4 doctors.	3
10.	Williamson & Rumsey (2016)	UK, English	Mixed methods, semi-structured interview/survey, Thematic Analysis.	To gain an insight into healthcare professionals' views of the psychosocial impact of an altered appearance- elated with the intention of identifying ways in which this care might be improved.	Setting: A UK regional paediatric oncology unit (for the interviews) and various UK oncology care settings (for the survey). Participants: 14 healthcare professionals (5 doctors, 5 nurses, 2 social workers, and 2 psychologists).	8
11.	Willmott, Loades, Baker, & Spathis (2021)	UK, English	Qualitative, semi-structured interviews, Thematic Analysis.	To explore clinicians' perspectives, practices and challenges in supporting teenage and young adult cancer patients with cancer-related fatigue.	Setting: A single, regional UK-based Teenage and Young Adult (TYA) MDT providing care to 16- to 24-year-old patients within the NHS. Participants: 10 healthcare professionals from a range of disciplines (1 doctor, 3 nurses, 1 physiotherapist, 3 psychologists, 1 social worker, and 1 youth support worker).	10
12.	Wright, Norton, &	UK, English	Qualitative, semi-structured	To: (1) explore and interpret nurses' experiences, feelings,	Setting:	9

Geary (2018)	interviews, Interpretative Phenomenological Analysis.	and associated meanings attached to undertaking fertility-related discussions with teenagers and young adults with cancer, and (2) to advance an understanding of factors that facilitate or hinder such discussions, to progress clinical practice.	A Teenager Cancer Trust (TCT) Unit in a UK hospital. Participants: 11 nurses.

3.3. Methodological quality

The highest possible score that could be obtained on the CASP measure was 10, indicating the highest methodological quality, whereas the lowest possible score was 0. The scores of included papers ranged from 2 (Gray & Smith, 2009) to 10 (Willmott et al., 2021) with a mean score of 7.6 and a median score of 8.5. Overall, only one of the included studies (Willmott et al., 2021) made clear reference to the relationship between the researcher and the participants, reflecting a general sense that the vast majority of researchers did not critically examine their own role, potential bias and influence during the various stages of the research process. The results of the quality assessment are presented in Table 3.2.

Table 3.2. *Assessment of included studies against the CASP (Public Health Resource Unit, 2013) qualitative research checklist*

No	Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score	Classification of Quality[8]
1.	Coughtrey et al., (2019)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
2.	Day et al., (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
3.	Forsey, Salmon, Eden, & Young (2013)	Y	Y	U	Y	Y	N	N	Y	Y	Y	7	High
4.	Gibson, Kumpunen, Bryan, & Forbat (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
5.	Gray & Smith, (2009)	Y	Y	U	U	N	N	U	N	N	N	2	Low
6.	Lea et al., (2019)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High
7.	Lea et al., (2020)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8	High
8.	Pugh et al.,												

[8] Papers were categorised as high quality (above seven), medium quality (between five-seven) or low quality (under five).

	(2020)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8	High
9.	Pye (2013)	Y	Y	U	U	U	N	N	N	N	Y	3	Low
10.	Williamson & Rumsey (2016)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8	High
11.	Willmott, Loades, Baker, & Spathis (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10	High
12.	Wright, Norton, & Geary (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	9	High

Notes. Abbreviations: Y = Yes; N = No; Q1 = Clear statement of aim; Q2 = Suitable qualitative methodology; Q3 = Appropriate research design; Q4 = Proper recruiting strategy; Q5 = Adequacy in data collection; Q6 = Adequate relationship between researcher and participants; Q7 = Ethical considerations; Q8 = Rigor in data analysis; Q9 = Clear statement of findings; Q10 = Overall value of research. Scoring Key: Y (Yes) = 1, N (No) = 0, U (Unclear/Can't tell) = 0.

3.4. Synthesis of results

The data synthesis revealed 19 descriptive themes in relation to HCPs' expressed experiences and perceptions regarding the provision of care to paediatric cancer patients in the UK. From these, four interrelated analytical themes were identified: *'Navigating and managing relational complexity', 'Focusing on the child's unique experience', 'Effective communication, information sharing and shared-decision making in paediatric oncology'* and '*Coordinated care in a complex health system'*. An overview of the descriptive and analytical themes is shown in Table 3.3 and an example of excerpts and samples of coded text supporting each analytical theme can be found in Appendix 1.11.

Table 3.3. *Overview of analytical and descriptive themes from the meta-synthesis*

Analytical Theme	Descriptive Themes
Navigating and managing relational complexities	*HCPs' difficulties and coping strategies in paediatric cancer care*
	Complex decisions and ethical dilemmas
	Relational factors that matter: interpersonal connection, trust and rapport in the HCP-parent-patient triad
	'Lean on me': providing compassionate care
	Psychosocial support for HCPs
Focusing on the child's unique experience	*Recognising and addressing patients' and families' individualised needs*
	Fluctuations in patients' psychosocial and informational needs along the cancer journey
	HCPs' awareness of the physical, psychosocial and emotional impact of childhood cancer
	TYA-specific challenges and care needs
Effective communication, information sharing and shared-decision making	*Information provision and transparent communication*
	Shared decision-making and collaboration or lack of?

	Use of online resources in paediatric oncology
	HCPs' knowledge deficits
	Skills-based training, education and support for HCPs
Coordinated care in a complex health system	*HCPs' perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings*
	Team-based care
	Systemic and structural factors
	What might help: practical recommendations and possible interventions

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3.4.1. Navigating and managing relational complexity

Five descriptive subthemes were categorised under this analytical theme: '*HCPs' difficulties and coping strategies in paediatric cancer care', 'Complex decisions and ethical dilemmas', 'Relational factors that matter: interpersonal connection, trust and rapport in the HCP-parent-patient triad', "Lean on me': providing compassionate care',* and '*Psychosocial support for HCPs'.*

3.4.1.1. HCPs' difficulties and coping strategies in paediatric cancer care

Narratives portrayed HCPs encountering and managing challenging situations in what was described as an '*emotive and upsetting clinical area'* (Gray & Smith, 2009). Staff described the challenges of being exposed to death, dying and prolonged suffering and the difficult emotions that these situations evoked for them. At the same time, HCPs reported often feeling unsupported in dealing with such emotions and described a process of having to 'push down' or compartmentalise their own emotions in order to respond to patients' needs:

> *The nurse said that she felt ''anger'' and ''despair'' in the situation, which mirrored the emotions of the parents and also related to the issue that the nurse had her own children. She said that her feelings were not dealt with and supported: ''You can't show your frustration if you're a nurse and you just have to sit on your anger''. This dissonance between genuinely felt and displayed emotions was linked with the formation of the ''hard nurse'' and with high rates of ''burnout''.* ***(Paper 5; Gray & Smith, 2009)***

Within HCPs' accounts there was variation in how staff coped with distress and the many negative emotions that cancer and its treatment elicit for children and their families.

Some papers reported that HCPs, and particularly doctors, might refrain from acknowledging and engaging with patients' worries and fears and that instead they might find it preferable to emphasise the 'good news' in order to preserve hope and '*keep the family together'*:

> *All doctors described providing reassurance and explanation for families at the beginning of treatment, focusing on the ability of treatment to cure the child: 'I always start off being very positive, it's ALL, it's the most common childhood cancer we see, the one we know the most about. And the one we're most successful at treating' (B.D4). They did not describe explicitly asking parents about their worries and fears or engaging with such fears. Instead, doctors emphasised how they worked 'to keep the family together so they can function tomorrow' (C.D4) and spoke of how this was in the child's best interests. (**Paper 3; Forsey et al., 2013)***

Perhaps this process of engaging with and prioritising 'good' over 'bad' news on the one hand is used by HCPs to nurture and maintain hope and on the other it might represent a coping strategy that some HCPs adopt in order to navigate the emotionally challenging environment that is paediatric oncology. This process of choosing to disconnect or detach from emotionally difficult material - possibly in order to maintain an emotional balance and retain a sense of self-efficacy - is further highlighted by the excerpt below:

> *Doctors tended not to use emotional language when describing their relationships with families and only rarely discussed situations that they found personally challenging. (**Paper 3; Forsey et al., 2013)***

3.4.1.2. Complex decisions and ethical dilemmas

Challenges encountered in terms of clinical decision-making were reported in included studies. HCPs' accounts reflected the need to consider important contextual factors when making clinical decisions, including patient preferences, disease prognosis, available treatment options, late effects and toxicity of treatment. Although not explicitly stated in included studies, the decision-making process seemed to be further complicated by the triadic communication and interactions that exist when working with children with cancer between paediatric patients, their parents and HCPs. The excerpt below illustrates the ethically complex decisions HCPs encounter in paediatric oncology and provides an underlying sense that HCPs might feel pressurised to prioritise and centre the parents' voices rather than make space to promote children's participation in the decisions concerning their healthcare. Additionally, despite the vital principle of promoting shared-decision making whenever possible, HCPs reported that the final say, and therefore the responsibility, in the decision-making process lies with the clinician:

> *During interviews, HCP discussed a possible shift when disease-directed treatment began to fail and suggested that at this point families and teenagers are pulled into the decision-making*

process, and asked to voice opinions and preferences. However, during MDT meetings and informal discussions, HCP acknowledged that it was difficult to respond to these preferences. In practice, the final authority for such decision-making toward end of life lay with HCP and the clinical consensus. ***(Paper 2; Day et al., 2018)***

The excerpt below also illustrates the complexities of clinical decision-making from the perspective of a nurse, who describes the perceived ethical challenges that arise from parents' wishes to pursue further potentially futile treatment and doctors' inclination to meet parents' needs:

Where you are faced with the parents wanting you to treat and maybe us thinking that we shouldn't treat, you are faced with the consultant and whether they are doing the right thing by offering all these avenues to the parents, that is challenging for us to see because sometimes you feel like they just want to play God. I find it quite a lot when you have got a consultant who just wants to do everything, salvage as much as they can and they do call it salvage therapy a lot of the time don't they. (Nurse 2) ***(Paper 9; Pye, 2013)***

The sense that nurses may be at risk for experiencing burnout was also reflected in some of the HCPs' narratives. This sense that nursing staff in particular may be "running on empty" was further exemplified by a comment from one nurse:

"*I think if you emotionally burnout, you don't give anything emotionally and patients soon caught onto that fact. There are lots of nurses who are burnt out and who don't know how to cope […]. But then if you continually give and give and give and give, […] I might have learnt to say all the right things, but they might not really mean anything to me anymore. Although I was doing what I was supposed to be doing, medically at that point, my emotions weren't engaged at that point and I had to get out."* ***(Paper 5, Gray & Smith, 2009)***

3.4.1.3. Relational factors that matter: interpersonal connection, trust and rapport in the HCP-parent-patient triad

A sense that the provision of care extended beyond patients' physical needs underlay HCPs' accounts. Specifically, HCPs, and nursing staff in particular, highlighted that identifying and responding to patients' emotional and psychosocial wellbeing, as well as their physical wellbeing, was an equally integral part of their roles and responsibilities:

They explained how they shared with parents personal details about themselves to promote relationships 'you can be off for a week, I got married and came back and in and everyone was like "let me see your photos, how was it?"'(C.N19). Nurses therefore wanted to care for families emotionally and to develop close relationships with them, and they thought that this was an essential part of their role (Table 3). They spoke of how they developed intimate knowledge of families and felt this helped them to meet parents' needs 'you know what mum likes, you know what [child] likes, you know how she has her medicines, you can tell if there's something not quite right' (D.N2). ***(Paper 3; Forsey et al., 2013)***

Trust, respect and rapport were also emphasised as essential and seemed to provide the basis upon which strong therapeutic relationships between HCPs-children-parents were formed. More importantly, establishing a trusting relationship with one's physician seemed to

be a critically important factor for ensuring that parents feel their children are in good hands and that HCPs are prioritising the child's best interests:

> *They described at length their efforts to 'earn' (D.D1) parents' trust by being 'honest', 'upfront' or 'straight' (A.D3, B.D1) so that parents understood there would be 'no secrets' and that, as doctors, they would always be 'truthful' (B.D3). Doctors thought that showing their sincerity, 'caring' and 'interest' in the child (C.D4) might help parents to trust them. They also spoke of demonstrating their knowledge and expertise as specialists in the care of children with cancer as a way of showing parents that they could be trusted in their roles.* ***(Paper 3; Forsey et al., 2013)***

3.4.1.4. 'Lean on me': providing compassionate care

HCPs' accounts made reference to compassion as a central pillar of high quality paediatric healthcare. Compassionate care, a term broadly understood as one's ability to empathise with another's distress together with the desire to alleviate it (Strauss et al., 2016), seemed to encompass a range of advanced communication skills, including active listening, validating, giving patients and their families time and space to express their emotions, engaging with and responsively attending to their needs, and providing reassurance:

> *"Most of what I do involves just listening….It's also important not to belittle how they feel, that's the biggest thing, allowing them to have their chance to talk about it and express how they feel about it" (nurse). For patients, particularly boys, who struggled with verbal expression, some advocated the use of written or video diaries: "I just said 'write down how you feel and about how you look'. He wrote 'I'm pissed off… because I look disgusting" (social worker). Other simple psychological interventions included validating rather than dismissing concerns, identifying positive role models with similar appearance changes (including celebrities), and providing positive reassurance about the adolescent's appearance.* ***(Paper 10; Williamson & Rumsey, 2016)***

3.4.1.5.Psychosocial support for HCPs

A theme that emerged among included papers was the need to acknowledge the emotional labour associated with caring for children with cancer. This need was discussed within the scope of institutional and occupational structures generally lacking appropriate systems and strategies to support HCPs with work-related stress and burnout. Some papers made reference to HCPs' capacity to regulate their emotions in the face of stressful events when providing patient care, and that staff are often required to put their own emotions aside and 'get on with it':

> *Such an evocative narrative certainly adds further weight to the argument that we need to extend an appreciation of emotional labour so as to allow a more explicit focus on systems of social and emotional support. James writes: Cancer is a particularly apt disease to review in order to analyse the management, control and 'labour' of emotions in health organizations*

(James, 1993, p. 96). Children's oncology was a protracted and painful event for all those involved. As the nurse said at interview: "People can go through years and years and years of hoping that someone close to them might live, but knowing in the end that they are going to die. I don't know how nurses and relatives can cope with that, really. They just get on with things and have to get on with things". Nurses, patients and relatives were all involved in emotional labour and engaged in reflections of how to manage medical and emotional demands. ***(Paper 5; Gray & Smith, 2009)***

3.4.2. Focusing on the child's unique experience

Four descriptive subthemes were categorised under this analytical theme: '*Recognising and addressing patients' and families' individualised needs', 'Fluctuations in patients' psychosocial and informational needs along the cancer journey, 'HCPs' awareness of the physical, psychosocial and emotional impact of childhood cancer'* and '*TYA-specific challenges and care needs'.*

3.4.2.1. Recognising and addressing patients' and families' individualised needs

Within their accounts HCPs referred to the importance of recognising, responding to and personalising the provision of care to the psychosocial, informational and care needs of patients and their families. Being attuned to and honouring patients' unique needs were considered a fundamental part of clinical practice. This was particularly emphasised in relation to patient-provider communication and the provision of cancer-related information:

Healthcare professionals described how the level of detail in which they provided the spiel was based on their perceptions of a family's knowledge and questions, and degree of a family's reception and acceptance of the disease-related information. Many doctors said they tried to individualise the information given, by suggesting, "If a family wants numbers I give them numbers." ***(Paper 4; Gibson et al., 2018)***

The need to consider patients' individualised needs was further discussed in the context of communicating cancer-related information TYAs; a patient group with different information requirements to those of younger children and with greater independence to access and obtain information via online sources:

Professionals emphasized that young people had different information and support needs, and varying levels of engagement with the internet, therefore the emphasis on online information needed to be tailored to the needs of the individual patient or family. ***(Paper 6; Lea et al., 2019)***

3.4.2.2. Fluctuations in patients' psychosocial and informational needs along the cancer journey

The provision of tailored support and information to the needs of each patient was further discussed within the context of the different stages along the cancer pathway – at

diagnosis, during active treatment, at the end of treatment and at the point of transition into long-term survivorship. HCPs' narratives conveyed that patients and families will have varying needs depending on treatment stage and disease trajectory. For instance, at the point of diagnosis patients and families seemed to engage primarily with cancer-related information seeking, whereas as patients approached the end of treatment phase they required more emotional support and guidance regarding reintegrating back into "normal" life:

> *Professionals reported variation in young people's online information and support needs at distinct stages of their cancer diagnosis and treatment timeline. They felt that young people's needs were contextual and based on individual circumstances, particularly at the latter part of their cancer timeline when they were approaching the end of treatment and moving back into what was sometimes referred to as "normal" life.* ***(Paper 6; Lea et al., 2019)***

Particularly among TYAs who had completed cancer treatment, the provision of more practical advice around management of finances or employment concerns seemed to be more important:

> *Healthcare professionals recognised that young people required advice and support to navigate these various aspects of their life in the months after completing cancer treatment: "Last week I had a patient who's probably two months post-transplant, and just rang me up and asked me for advice on how to get back into work because apparently, her work were being quite tricky about doing a phased return to work, and she asked for advice."* ***(Paper 7; Lea et al., 2020)***

3.4.2.3. HCPs' awareness of the physical, psychosocial and emotional impact of childhood cancer

Several papers made reference to HCPs' awareness of the impact cancer and its treatment have on children's lives. For instance, HCPs discussed the emotional and psychosocial impact of cancer and highlighted that children frequently experienced low mood and depression, both during and following the completion of active treatment. HCPs emphasised that comorbid low mood should be perceived as a normal psychological reaction to a life-threatening illness and painful and complex treatment procedures, indirectly suggesting that it is important not to pathologise distress among children who have been treated for cancer:

> *Almost all participants explained that low mood is a common and understandable reaction to cancer in young people e.g., "Young people go under the duvet, which is a very very common place…It's like just shut your mind and just get through it and I think that is very appropriate. That seems to be completely understandable." Participants described how low mood was a normal and appropriate reaction to a cancer diagnosis and treatment: "I think the majority of young people have low mood at some point, many points, throughout their whole journey. And lots of it is completely normal, they have enough reason to [feel that way]" and "We would very regularly see young people who would be very low in mood just because of what has just happened…so one would really feel that it would be very appropriate to be weeping and very upset….just think about the nature of chemotherapy and how many of us would just*

think 'oh that's ok, I'm fine with this." ***(Paper 1; Coughtrey et al., 2019)***

One paper (Williamson & Rumsey, 2016) primarily discussed the negative impact of temporary or permanent changes in physical appearance and the subsequent appearance-related distress experienced by adolescent cancer patients. Authors perceived psychosocial distress among TYAs to stem primarily from engaging in social comparison with their peers without cancer and their preoccupation of how and to what extent their altered appearance will be noticed or receive negative attention by others:

> *Participants believed that appearance-related distress is common among patients when anticipating treatment, during treatment, as well as following treatment and that this is a major challenge: "how they look and how their peers treat them is one of the biggest angsts for most" (doctor).* ***(Paper 10; Williamson & Rumsey, 2016)***

Apart from appearance-related concerns, HCPs also referred to the long-term physical sequelae of cancer treatment. Specifically, Willmott et al (2021) explored cancer-related fatigue (CRF) - defined as the physical, emotional and cognitive tiredness or exhaustion related to cancer and its treatment – among adolescents with cancer and highlighted that CRF is among the most debilitating, persistent side effects of cancer treatment with little access to fatigue-related support. Traveling to attend hospital appointments was also highlighted as an important factor contributing to CRF:

> *Clinicians' perceptions of patients' fatigue were that it was caused by cancer, its treatments and treatment side and ongoing and late effects. CRF was also linked to TYAs' need to attend regular hospital appointments for treatments, necessitating considerable travel and emotional burden. "I think cancer-related fatigue is usually because of the disease process… fatigue that is caused by either the cancer process or the treatment of cancer. I think treatment-related fatigue can go on for a substantial amount of time, depending on the type of treatment someone had or where their cancer was or still is".* ***(Paper 11; Willmott et al., 2021)***

3.4.2.4. TYA-specific challenges and care needs

The teenage and young adulthood age group was the focus of approximately half of the papers included in the present review. The narratives of included studies portrayed adolescence as a complex developmental stage, however, this complexity was seen as being further amplified by a cancer diagnosis which interfered significantly with TYAs' capacity to manage a range of biological, social and psychological developmental tasks as they moved towards reaching adulthood.

Namely, some of the difficulties faced by TYAs, beyond their cancer diagnosis, included concerns about puberty, their fertility, sexuality, forming and maintaining social and

romantic relationships with peers, appearance-related concerns and body image, completing education and starting employment and achieving emotional independence and autonomy.

> *Participants felt that at the heart of appearance distress is the experience of looking and being treated differently by their peers, feeling unattractive compared to society's beauty norms, and fear of negative evaluation by others, including being teased. For those with extreme or poorly addressed issues, participants observed a psychosocial and behavioral pattern indicative of reduced self-esteem and confidence, together with a failure to access social support leading to isolation, depression, and decreased therapeutic compliance: "He wouldn't receive chemotherapy and steroids because of weight gain and worries about being bullied" (doctor).* ***(Paper 10; Williamson & Rumsey, 2016)***

There was also an overall sense that existing cancer-related resources were not geared towards meeting the unique, age-specific needs of TYAs with cancer and that healthcare services were mostly designed either for younger children of for adults.

> *In terms of provision of information and support that met these issues, healthcare professionals perceived young people to have a variety of unmet needs. They felt that fatigue management, fear of recurrence, late effects, fertility and employment were some of the key issues where young people's information and support needs were unmet (Fig. 1). Furthermore, in the interviews, healthcare professionals referred to 'family needs', recognising that young people's parents, partners, and siblings may have questions, which may require referral to sources of information and support: "Then, also, a lot of partners sometimes ring me up and just-, things like asking advice on things like sex and relationships post-chemo, and again, it's about signposting them to the right things."* ***(Paper 7; Lea et al., 2020)***

3.4.3. Effective communication, information sharing and shared-decision making

Although communication, information sharing and decision-making represent distinct concepts they are interrelated phenomena that were considered essential components of patient-centred care. Five descriptive subthemes were categorised under this analytical theme: '*Information provision and transparent communication', 'Shared decision-making and collaboration or lack of?', 'Use of online resources in paediatric oncology', ''HCPs' knowledge deficits,* and '*Skills-based training, education and support for HCPs'.*

3.4.3.1. Information provision and transparent communication

The importance of effective and transparent communication was among the most frequently mentioned themes among HCPs and was perceived as a central component in the provision of high-quality and patient-centred care. Moreover, the provision of information was considered a critical pre-requisite for promoting participation in shared decision-making and for ensuring that both children and their parents are able to make informed decisions about matters concerning the child's health and future:

Analysis revealed that open communication was a paramount HCP principle of involving teenagers in decision making about care and treatment. At MDT meetings, HCP regarded information provision as an indication that a teenager had been involved in decision-making. ***(Paper 2; Day et al., 2018)***

At the same time, effective communication interactions between providers and patients/families required HCPs to draw on a set of advanced communication skills; for instance, HCPs described the importance of being able to recognise verbal and non-verbal cues from patients themselves to inform their information-sharing strategy and discussed the importance of identifying and honouring the child's unique informational needs:

HCP recognised the importance of establishing and respecting what the teenager wanted and needed to know at different times across the illness. HCP depended on indications from the teenager to do this. ***(Paper 2; Day et al., 2018)***

Additionally, HCPs' accounts highlighted the challenges in maintaining the balance between providing enough information to ensure that children and their families are adequately informed about their illness, its treatment and overall impact, but at the same time ensuring that this information is communicated sensitively and in a way that does not exacerbate children's and parents' distress:

They pointed to how they used non-threatening language and phrasing and carefully selected the information they presented to parents, for example, one doctor thought 'difficult to cure' was kinder to say to parents than 'prognosis is poor' (C.D2), while another indicated that he was 'cautious about saying too much' (C.D4). Doctors did not do this to deny parents' fears; as explained above, they were keenly aware of how anxious parents were. Rather, they perceived that parents 'always hone in on the negative' (B.D4), and because of this, doctors thought that they had a responsibility to avoid contributing to parents' fears and, where possible, take remedial or compensatory steps to help parents manage their fears. ***(Paper 3;Forsey et al., 2013)***

3.4.3.2. Shared decision-making and collaboration or lack of?

Although shared decision-making emerged as an important component of high quality care in included papers, there was an underlying sense that HCPs experienced some barriers that negatively affected optimal involvement of patients and/or their parents in clinical decision making. Professionals described situations in which they experienced reservations to involve teenagers and families in conversations regarding their treatment, particularly when clinicians themselves were uncertain about the course of treatment or the likelihood of its success:

HCP reported how the nature of the disease resulted in difficulty in giving teenagers and families' clear and accurate information about different options and their respective outcomes, one nurse stating 'I think it's much harder to sit down and tell someone this is what's going to happen because you just don't know'. This influenced how, when and to what to extent HCP felt able to involve teenagers in decisions about their care and treatment. HCP often sought clinical guidelines and consulted with other professionals to determine whether a certain treatment or trial should be permitted or excluded. During these periods of uncertainty involvement of other professionals was prioritised in reaching a decision, thus limiting the role afforded to teenagers in the process. ***(Paper 2; Day et al., 2018)***

Other factors that were reported to affect optimal shared decision-making included situations in which patient and family preferences for treatment conflicted with what was recommended by HCPs or in situations where it was critical for treatment to start as soon as possible and families expressed reservations due to not having enough time to process the diagnosis and its impact. The type and stage of cancer as well as whether the decisions were of serious or minimal consequence were also factors that represented potential barriers to shared decision-making and HCPs.

Another aspect of shared-decision making was discussed within the context of the MDT and related to inadequate communication and poor team dynamics that affected whose voices were heard or unheard during clinical decision-making. Specifically, one paper reported that nurses perceived themselves as not being fully involved during decision-making processes and this was aligned with doctors' views who also acknowledged that they did not fully involve nurses in decisions:

Isolation was expressed as a feeling by some participants when making complex decisions. There were also feelings of powerlessness and feeling devalued regarding their perceived lack of input into the process, contributing to moral distress. The weight of responsibility for the person making a decision was highlighted by all participants. ***(Paper 9; Pye, 2013)***

3.4.3.3. Use of online resources in paediatric oncology

The need to further integrate online resources as part of standard clinical care was a theme that emerged from included studies. This was also further supported by the general movement of the NHS towards digitalising health services and was perceived as an increasingly used mode of delivery for cancer-related information:

It was noted that in England digitalization of health services was part of the NHS Five Year Forward agenda and should be embraced as opposed to shied away from. Professionals recognized the need to become comfortable with using and understanding online resources in order to successfully guide and support patients and their families online, they also felt it was part of their role to facilitate safe use and access to online resources. This was supported by survey respondents which showed it was important for the treatment team to facilitate young people's access to health information online. ***(Paper 6; Lea et al., 2019)***

For TYAs in particular the engagement with online resources was better compared to accessing information via more traditional modes of delivery such as written information (e.g., leaflets, brochures etc.):

> *Professionals discussed the need to have an awareness and understanding of the online world that young people used and accessed. It was accepted that most young people engaged well with information and resources that were online, potentially more readily than information in other formats such as leaflets.* ***(Paper 6; Lea et al., 2019)***

The importance of online resources was also highlighted in relation to supporting TYAs with cancer and comorbid low mood and depression, who may experience additional barriers in seeking face-to-face support:

> *Participants suggested that GSH including online and computerized interventions for depression may have the most benefit for young people who do not or cannot currently engage with face-to-face services: "The big issue with them when seeking help is that actually doing the talking, they don't want to do that, whereas if you put them onto something online they are much more likely to engage in that, maybe at an earlier stage."* ***(Paper 1; Coughtrey et al., 2019)***

3.4.3.4. HCPs' knowledge deficits

This theme reflects HCPs' perceived lack of specific knowledge around certain cancer-related topics that patients were concerned with. For instance, the excerpt below illustrates that HCPs' perceived knowledge insufficiencies around fertility preservation among TYAs with cancer, represented an important barrier to raising these issues with patients. Specifically, the authors indicate that HCPs' avoidance was primarily driven by their perceived belief that their lack of knowledge and expertise on this topic would prevent them from being "*effective and useful to TYAs*":

> *Ten/eleven nurses perceived their lack of knowledge to be a significant barrier, resulting in them avoiding raising fertility issues. Knowledge insufficiencies were particularly significant in areas such as policy and guidance and knowledge required to adequately prepare TYAs for the sperm banking process. Their avoidance of FP discussions appeared to reflect their personal belief in their inability to be effective and useful to TYAs.* ***(Paper 12; Wright et al., 2018)***

HCPs' skepticism over supporting and advising patients with certain difficulties due to their perceived knowledge insufficiencies is further highlighted below; in this instance, HCPs

expressed feeling unable to provide TYAs with cancer health behaviour advice as part of routine cancer care due to felling ill-equipped to provide such advice to patients:

> *Health professionals' confusion and conflict over the best advice to provide often stemmed from a lack of specific knowledge relating health behavior to TYA cancer outcomes. Health professionals reported being aware of "emerging evidence in cancer in general," with many noting the lack of TYA-specific evidence* ***(Paper 8; Pye, 2013)***

3.4.3.5. Skills-based training, education and support for HCPs

Given their perceived lack of knowledge, HCPs identified that they would benefit from specialist skills-based training and professional development opportunities in order to be able to support patients with concerns extending beyond standard clinical care. For example, in the paper by Wright et al (2018) HCPs reported wanting more education around fertility preservation and that this was essential in order to participate in such discussions with TYAs. Similarly, Pugh et al (2020) concluded that supporting HCPs in accessing TYA-specific resources and the delivery of specialist skills-based training would facilitate the provision of lifestyle and health behaviour advice (e.g., physical activity, dietary intake, smoking cessation and alcohol consumption). Similar conclusions were reached among other papers included in the review; for instance, Lea et al (2019) reported that HCPs expressed a specific need for more training around how TYAs with cancer use the internet to access information and support in order to be able to support them with staying safe when accessing online resources:

> *Professionals recognized a need for increased understanding of what young people looked for online and why, to assist them in conversations they had with young people about using the internet for information and support. When asked whether professionals had received any training on advising young people with cancer about accessing online resources, the majority, 87% (n=32) of respondents had not received any training. Training for HCPs on advising young people with cancer about accessing online resources could be a facilitator if it was provided and survey data indicated that HCPs would be likely to undertake training if it was offered.* ***(Paper 6; Lea et al., 2019)***

Similarly, Williamson and Rumsey (2016) identified that HCPs' perceived knowledge insufficiencies in how to approach appearance-related concerns with TYAs were a barrier to initiating and engaging in such discussions and further education to improve HCPs' confidence and competence was proposed as an important intervention in order to improve care going forward:

> *Barriers associated with organizational constraints and reluctance to discuss appearance concerns were identified more frequently than barriers associated with personal competence. However, even when individual participants felt personally competent, they stressed that many of their colleagues were not, and 91% of those surveyed requested education to address deficits in knowledge and to provide strategies to improve care.* ***(Paper 10; Willamson & Rumsey, 2016)***

3.4.4. Coordinated care in a complex health system

Four descriptive subthemes were categorised under this analytical theme: '*HCPs' perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings' 'Team-based care', 'Systemic and structural factors',* and *'What might help: practical recommendations and possible interventions'.*

3.4.4.1. HCPs' perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings

Apart from HCPs' perceived lack of knowledge, other challenges relating to services, processes and roles were also reported in included studies as factors that affected optimal patient support. For instance, Lea et al (2020) explored the needs of young people following the end of active treatment and identified a range of barriers to information provision and support, including lack of resources relevant to the needs of young people at end of treatment, lack of local services to refer young people to following treatment, lack of time, and the absence of a dedicated professional to specifically focus and lead end-of-treatment support for young people within the service:

> *A variety of processes, services and roles were described by healthcare professionals to either facilitate or hinder the provision of information and support to young people. Processes were described such as specific meetings about the end of treatment that were used by the MDT, or end of treatment-specific services that were offered, for example, dedicated end of treatment nurse-led clinics.* ***(Paper 7; Lea et al., 2020)***

Williamson and Rumsey (2016) also identified professional and organisational barriers perceived by HCPs that inhibited the provision of appearance-related support to TYAs. Challenges identified by HCPs included the perceived practical barriers associated with providing care for TYAs with cancer as well as organisational constraints such as time pressures, lack of dedicated ward space for private discussions, uncoordinated approach to care within the MDT, limited availability of specialist adolescent staff within the team as well as poor access to specialist psychological support:

Forty-five percent of participants expressed disappointment at the lack of appearance-specific expertise available through hospital-based psychologists or, in the absence of this service, from family doctors. Discrepancies in relation to who should deliver interventions and the timing of their delivery were found. While some believed doctors and nurses should be responsible for delivering medical information and psychosocial specialists responsible for psychosocial interventions, others believed in a multidisciplinary approach, characterized as: "team awareness/experience and support, so that the young person can choose who they feel most comfortable seeking this support from" (doctor). ***(Paper 10; Williamson & Rumsey, 2016)***

3.4.4.2. Team-based care

A theme that emerged from HCPs' narratives was the importance of multidisciplinary care and a range of MDT-related benefits were highlighted, including improved patient management, shared responsibility and inter-professional support between professional groups. Specifically, the excerpt below highlights that HCPs considered it important that all core disciplines within the MDT should have the capacity and ability to provide emotional support to patients and that it should not be one professional group alone that is primarily tending to patients' emotional wellbeing. At the same time, the excerpt below illustrates that doctors may perceive themselves as not 'being the right person' to provide psychosocial and emotional support, directly indicating that such aspects of care are more traditionally associated with nurses:

Rather than individual professionals trying to meet all of parents' needs, doctors also explained that the clinical team as a whole was responsible for providing emotional care for parents. They therefore described how the work of meeting these needs was shared between doctors and nurses, as appropriate to their respective roles. For example, doctors described how they could not provide emotional care 'by themselves' (A.D3) or 'deal with everything' (C.D2), adding that they may not be the 'right' person to help parents but could 'find the right person for them to talk to' (C.D2). ***(Paper 3; Forsey et al., 2013)***

At the same time, results reported by Pye (2013) included a quote by a doctor, which highlights the importance of effective communication in the nurse-doctor relationship and underlines the vital contributions of the nursing team in the provision of high-quality cancer care:

"I realized that if you persisted in making horrendous things happen to patients you so emotionally disturbed the nurses that you lost nursing staff. I realized that you can't look after sick children if you don't have the nurses to look after them, so for me it is incredibly important actually that the nurses haven't go so far off side with you that you are losing them mentally or physically. I have always held that really dear because I think it is such an important issue if you haven't got an adequate number of nursing staff you can't get better the patients who can get better, let alone ones who have gone beyond the point of any chance of that. So that for me is a very important decision-making thing." (Doctor 2) ***(Paper 9; Pye, 2013)***

In some instances, MDT-based care was not always associated with effective decision-making and treatment implementation, suggesting that identifying strategies to support and improve MDT function and team climate could be potential areas for improvement. The excerpt below illustrates some of the challenges HCPs experience in MDT working, including poor communication, insufficient teamwork, uncoordinated care, divergent perspectives and strategies in relation to patient care, as well as disagreements between different professional groups:

> *Situations build up out of control because of different members of the team saying different things to families not together. "Medically we are guilty of going and seeing families on our own and not imparting information. I think because there is not time to go together and support each other, you get a communication breakdown, then the team falls apart. Actually if we had time to do things together then we might be able to present a more structured support package for the families to understand what we are trying to all deal with and I don't think we always value this". (Doctor 4)* ***(Paper 9; Pye, 2013)***

3.4.4.3. Systemic and structural factors

Some of the systemic challenges HCPs described included time constraints, staffing issues and the lack of resources and clear guidelines, all of which represented significant barriers to the provision of high quality care:

> *Clinicians described insufficient time for assessment, consultation and interventions. "We're time-limited and we need clearer guidelines, you know, these are the… interventions that you can call on." (P1) Additional challenges included staffing, TYAs 'straddling' paediatric and adult community services and fatigue and exercise programmes. Other systemic challenges included societal stigma and lack of understanding from TYAs families, friends, education providers and workplaces****. (Paper 11; Willmott et al., 2021)***

In the study by Wright et al (2018), which explored nurses' experiences in undertaking fertility-related discussions with TYAs with cancer, nurses reported that one of the main barriers preventing them from initiating such discussions was the limited time frame to preserve fertility, especially among female patients, prior to commencing cancer treatment. Nurses' narratives portrayed that the importance of starting treatment superseded the need to initiate fertility-related discussions, thereby significantly reducing patients' chances to consider and make informed decisions in relation to their fertility:

> *Nearly, all (nine/eleven) nurses described the limited time frame for females to preserve their fertility before commencing cancer treatment as a barrier to both fertility discussion and fertility preservation. Nurses felt that "time is of the essence", a phrase used by participants themselves and one which aptly captions this theme: "It's not as easy for females … you have got to start the treatment straightaway" (Participant 7); "… Often between their diagnosis and needing chemotherapy there isn't time to do that" (Participant 3). […] There appears to be general agreement here that lack of time is an insurmountable barrier. There is a suggestion*

of resigned acceptance that, in all cases, treatment has priority over fertility preservation, rather than considered on an individual patient basis. ***(Paper 12; Wright et al., 2018)***

Despite the prevailing view that the limited window of opportunity to discuss and undergo fertility preservation procedures with female patients is an insuperable barrier, another nurse supported the view that having fertility-related discussions is a safe and feasible option as long as these conversations happen in a timely manner and are followed by timely referrals to fertility-preservation specialist services. This view opposes what the majority of nurses expressed and suggests that, should fertility-related guidelines provide clearer direction and relevant processes be operationalised in a way that prevent unnecessary delays, more female cancer patients will be able to be informed about their fertility options and make decisions about parenthood in line with their own priorities:

*However, participant one's account challenges many of the assumptions and hints at "excuses" for not talking to females about their fertility: "There is a fair amount of time while you are getting all of the pretreatment scans and investigations and stuff done. So there is no reason why in my head, why you couldn't talk about fertility then, especially for the females" (Participant 1).This account raises the question whether time is used wisely by the healthcare team generally (the nonspecific "you" pronoun) and implies that a failure to address fertility is not always an inevitable consequence of lack of time. (****Paper 12; Wright et al., 2018)***

3.4.4.4. What might help: practical recommendations and possible interventions

A broad range of clinical implications, practical recommendations and possible interventions were proposed by the majority of included studies. Studies focusing on TYAs discussed the importance of personalising interventions to the specific needs of this population rather than attempting to use information resources, services and approaches that had been mostly designed for younger children or adults. Similarly, some studies highlighted the importance of not only adapting resources and services depending on the needs of specific age groups, but also depending on the stage in the cancer pathway; for example, the excerpt below proposes the need for end-of-treatment information evenings as well as peer support initiatives following treatment completion:

It was suggested that services should be reviewed to understand existing follow up processes, there should be provision of more information events and resources tailored specifically towards the needs of young people, such as end of treatment information evenings. Additionally, more services providing support for young people and to promote peer-to-peer support, such as social peer events for those who have finished treatment: "Young people supporting each other, I think, during the treatment, that's one thing that certainly people benefit massively from, or they seem to anyway, is the connections they make with other young people. I guess, a lot of people continue that naturally, but how to

maybe build that into finishing treatment, where they can still, there is still a way to maintain those connections." ***(Paper 7; Lea et al., 2020)***

Another suggestion to ensure that lifestyle promotion is integrated into standard cancer care was to integrate health promotion training as a core professional competency to be acquired at the prequalification stage rather than expecting clinicians to cultivate this skill on the job:

Integrating health promotion into care was viewed as challenging. To shift health behavior advice delivery from an ad hoc basis to a standard element of practice, most believed that health promotion should be introduced as a professional competency during training. ***(Paper 8; Pugh et al., 2020)***

Other priorities identified by HCPs, in relation to improving the quality of care and available support for TYAs with cancer, included recognising, validating and not minimising young people's psychosocial needs, providing psychoeducation for parents/carers in order to promote understanding regarding some of the unique issues faced by TYAs with cancer, establish support provision and access to TYA-specific services during cancer treatment and beyond, and ensure opportunities for specialist HCP training to improve the provision of holistic support for TYAs. The excerpt below summarises some of these recommendations:

Participants' suggestions for improvements have been organized into five main areas. 1. Validating and normalizing adolescents' appearance concerns by raising or encouraging appearance-related discussions through a screening tool or peer-support interventions. 2. Educating parents and significant others about the psychosocial impact of appearance change and how to provide support. 3. A coordinated plan of appearance-related care incorporating a tool to assess for appearance-related support needs and providing guidance on how to escalate care and access psychological expertise as required. 4. Training and education including information regarding communication and support strategies to address psychosocial concerns and opportunities to share experiences of "best practice" with experienced colleagues. 5. A directory of appearance-specific services and organizations within and external to the hospital. ***(Paper 10; Williamson & Rumsey, 2016)***

4. Discussion

This systematic review identified 12 articles and used thematic synthesis to explore HCPs' expressed experiences and perceptions in relation to providing care to paediatric oncology patients.

The first analytical theme '*Navigating and managing relational complexity*' illustrated how staff were often exposed to situations that gave rise to strong emotional reactions and complex ethical challenges due to the frequency of high-stake decisions when caring for children with cancer. Emotional difficulties experienced by HCPs when working in this

setting, primarily stemmed from having constantly to be alert and tend to the needs of clinically vulnerable populations coping with life-limiting diagnoses, whilst having to process and contain their own emotions and maintain professionalism at the same time. Although none of the included studies directly explored emotional labour among healthcare staff, a number of included studies identified links between emotional labour and caring for children with cancer.

Notably, the present review highlights that paediatric cancer does not only affect children and their families, but also emotionally affects the healthcare teams around the child. Particularly, the association between increased emotional distress among HCPs in response to prolonged caregiving and exposure to death and suffering identified in the present review, has also been documented elsewhere (Adwan, 2014; Gallagher & Gormley, 2009; Liakopoulou et al., 2008). Burnout, psychiatric morbidity and indirect trauma among HCPs in paediatric oncology (Mukherjee, Beresford, Glaser, & Sloper, 2009) and adult oncology have also extensively been discussed in the literature (Taylor, Graham, Potts, Richards, & Ramirez, 2005). Some of the coping strategies that HCPs used involved attempting to find a balance between consciously choosing to engage or disengage with emotionally charged discussions; HCPs however described the difficulties of displaying clinical empathy and attentiveness to the psychosocial needs of children and their families on the one hand, whilst being mindful of protecting their own emotional wellbeing on the other. This review also highlighted that HCPs might resort to 'pushing down' or ignoring their own emotional reactions to distressing situations in order to retain their clinical judgment and respond effectively and efficiently to the situation at hand. As indicated earlier in this review, this phenomenon has been described as 'surface acting' (Hochschild, 1983; 2003), a concept directly linked to emotional labour, and has been associated with a significantly increased risk for occupational burnout and compassion fatigue (Kinman & Leggetter, 2016). Future studies examining strategies to support HCPs with their own emotions and prevent burnout in paediatric oncology settings should take into account the relational complexity, uncertainty and ethical distress involved in providing this type of care.

Findings showed that staff experienced varying degrees of ethical distress particularly in relation to conflicting views regarding the treatment plan; for instance, clinical decision making was found to be further complicated due to having to consider and take into account the views of all members of the triad (i.e., parent-child-HCP) but also the views of different professional groups within the MDT. Situations in which further futile treatment was pursued raised important ethical concerns for HCPs and this was associated with increased risk of

experiencing moral distress and also manifested as staff conflict, particularly between doctors and nurses. Moral distress - first coined by Jameton (1993) and defined as the consequence of knowing what is ethically right to do, but being unable to due to institutional constraints – has been identified as a common experience across all healthcare professional groups (Whitehead, Hebertson, Hamric, Epstein, & Fisher, 2015). Although only one study (Pye, 2013) explicitly examined the experience of moral distress among HCPs, a few of the included studies indirectly referred to the various ethical dilemmas and stresses faced by HCPs in paediatric oncology. However, research suggests that paediatric healthcare providers, and paediatric nurses in particular, experience significantly greater levels of moral distress which in turn is a precursor for low job satisfaction, increased risk of burnout and greater intention to leave the profession (Allen et al., 2013; Dyo, Kalowes, & Devries, 2016). Our results confirm that nursing staff are more likely to experience burnout and associated job dissatisfaction in response to occupational stress and prolonged caregiving.

Another finding, which was consistently highlighted across included studies, related to the importance of effective communication in the parent-child-HCP triad as well as the significance of providing tailored information according to the needs of patients and their families. This is illustrated by the second and third analytical themes '*Focusing on the child's unique experience'* and *'Effective communication, information sharing and shared decision-making*'. Across the majority of included studies, appropriate and skillful communication, both between staff and patients/families, as well as within members of the MDT, was described as a pillar of high quality care. In relation to TYAs with cancer in particular, this review illustrates not only the need for personalising resources, services and approaches to care for this population, but more importantly highlights that HCPs are lacking crucial communication skills, knowledge and expertise in certain areas. These deficits in communication skills and knowledge render HCPs unable to adequately address the informational and counseling needs of their patients; for instance, papers included in the review highlighted that HCPs seem to be underskilled in four important areas with regards to TYA-specific cancer care, including assessment and management of comorbid low mood and depression, appearance-related distress in response to cancer and its treatment, cancer-related fatigue and oncofertility-related concerns.

Similar to other age groups, TYAs require the provision of age-specific and developmentally appropriate information and support throughout their cancer journey and beyond active treatment, and for HCPs to be able to provide such specialised support there is an evident need for formal professional training and additional education. Results from the

review highlighted a range of perceived barriers experienced by staff that hindered effective communication and HCPs' narratives portrayed an overall sense that communication was a challenging skill to master, particularly when it concerned sensitive and emotionally charged topics. For example, in the papers by Williamson and Rumsey (2016) and Wright et al (2018) HCPs reported that they felt uncomfortable and ill-equipped to initiate discussions relating respectively to TYAs' appearance-related worries and concerns regarding adolescents' future reproductive capacity.

The notion that transparent and effective HCP-patient communication and shared-decision making are essential components of high quality patient-centred care is widely supported by previous literature (Levit, Balogh, Nass, & Ganz, 2013). Despite HCPs' best efforts to communicate effectively with patients and their families, HCPs consistently reported that identifying and responding to parents'/families' differing informational and communication needs was not without its challenges and required drawing from an advanced set of communication skills. HCPs described having to gauge patients' and their parents' capacity to understand cancer-related information and their willingness and readiness to discuss treatment options and its possible side effects, and at the same time be mindful that their *choice* of words, *tone* of voice and the *timing* they choose to provide information, are all critically important and likely to affect subsequent acceptability of that information. Moreover, HCPs reported the importance of being attentive to verbal and non-verbal cues and having to take these factors into account when planning their communication approach.

These findings are generally in line with previous research where the importance of tailoring biomedical and disease-related information to the unique needs of patients and their families has been repeatedly highlighted (e.g., Anderson, Bloch, Armstrong, Stone, & Low, 2019; Li et al., 2020). However, the findings presented here also show the significance of adopting a personalised approach that expands beyond a solely biomedical focus and that a personalised approach to care should be adopted by HCPs when tending to patients' psychosocial and emotional needs as well - as illustrated, for example, in the paper by Williamson and Rumsey (2016) concerning appearance-related distress and in the paper by Wright, Norton, and Geary (2018) concerning adolescent survivors' future reproductive capacity.

HCPs' accounts also conveyed the sense that it is important to consider the wider organisational, professional and social structures within which they provide care to paediatric cancer patients. This is demonstrated in the final analytical theme '*Coordinated care in a*

complex health system'. HCPs identified a range of professional and organisational barriers and constraints that interfered with the provision of care to varying degrees.

Some of the organisational constraints reported, included the lack of resources necessary for providing tailored and individualised support, as well as having to operate in a time-constrained environment, which often led HCPs having to prioritise primarily biomedical issues leaving little opportunity to discuss other matters concerning patients and/or their families. Studies also discussed that there was a lack of allocated members of staff within MDTs responsible for leading certain aspects of specialist support; for instance, HCPs indicated that teams lacked members of staff with expertise in managing TYA-specific concerns and also indicated that there were limited services to which HCPs could signpost patients for more specialist support and information should they require it. Moreover, one paper (Lea et al., 2020) explored HCPs' perceptions regarding fluctuations in patients' needs at different stages of the cancer pathway and identified that, despite the multiple and well-documented difficulties experienced by patients at the stage of treatment completion and beyond, there is a lack of a structured support plan offered as part of standard care to help patients with end-of-treatment challenges. Such findings, reflect a need to consider the development of interventions at the healthcare-system level that aim to ameliorate some of the practical and organisational hazards HCPs experience.

In addition, this review highlights that difficult dynamics or poor communication within the MDT are likely to negatively impact on subsequent communication between HCPs and patients and their families. The interactions between professional groups within the MDT were not a focus of many of the included papers with only a few (Pye, 2013; Forsey et al., 2013) referring to communication challenges occurring within the team. Given that MDT working is considered the "gold standard" in the provision of high quality care in various countries including the UK (Soukup et al., 2018) it appears important for further research to consider group processes and identify factors that may hinder or facilitate team functioning in paediatric oncology specifically. Of particular importance seem to be the interactions between doctors and nurses primarily, however, this dyadic relationship has been adequately examined and discussed by previous literature (McGrail, Morse, Glessner, & Gardner, 2009; Vivar, 2006).

The mentioning of and attention to other specialties within the MDT, such as allied health professionals and CNSs, were almost non-existent in included studies, potentially reflecting a general sense that the contributions as well as the challenges that these professional groups experience in MDT working may remain unrecognised and undervalued.

Traditional professional hierarchies have been associated with the exclusion of certain professional groups within MDTs (Lamb et al., 2011) with research suggesting that team discussions tend to primarily evolve around biomedical information. This in turn may lead to missed opportunities for other professional groups to showcase the added value they can bring and impair collaboration within the team. Previous research supports that effective multidisciplinary collaboration heavily relies on interpersonal factors, such as trust, recognition of other professionals' expertise and mutual respect between professional groups, as well as having strategies in place – for example, an independent chair – that will help ensure equal input from key professionals within the team in order to prevent clinical decisions from being shaped unequally and promote shared understanding (Haines, Perkins, Evans, & McCabe, 2018).

4.1. Strengths and limitations

The present systematic review is not without its limitations. First, despite the use of a thorough and comprehensive database search strategy, there may be some qualitative or mixed-methods literature on HCPs' experiences that was, unintentionally, not identified. Moreover, the present review was not exhaustive in that it did not include 'grey literature' (i.e., unpublished documents and reports) on this topic.

Second, this review did not include studies conducted outside the UK and therefore the wider, international literature on HCPs' experiences providing oncological care to paediatric patients has not been reflected in the findings. The restriction to include solely UK-based studies was defined by the pragmatic time constraints within which this thesis was completed. At the same time, this restriction by geographical location, ensures that the findings presented here apply directly to the UK's healthcare system, structure, and policies and therefore the evidence synthesised here may provide a useful basis upon which interventions and recommendations for national policies concerning paediatric care can be developed.

An important strength of the present review is that, to the author's knowledge, it represents the first systematic review of qualitative studies on HCPs' experiences of providing care to paediatric cancer patients. As mentioned earlier in this chapter, previous reviews have tended to focus primarily on the experiences of children and their parents and therefore the views of oncology HCPs remain under-represented in the current evidence base.

4.2. Concluding remarks

In summary, the present qualitative systematic review identified a range of factors that may influence how HCPs provide oncological care to paediatric cancer patients and their families and summarised all the available published qualitative literature on this topic within the UK setting. The findings discussed here indicate that there is an unquestionable need to provide additional informational, emotional and systemic support to HCPs to ensure that they can continue to provide the high-quality care that paediatric cancer patients and their families deserve. More importantly, this review identified that there is a paucity of studies exploring how HCPs experience and navigate the end-of-treatment phase, with only one of the included studies examining this. As briefly outlined in the Introduction section of this chapter, the end-of-treatment phase is an important stage of patients' cancer pathway and represents a period of stress for both children and families with little support available to them. The role of HCPs is crucial for ensuring that patients' needs are identified and met during this important phase, and yet the limited available evidence suggests that HCPs face a range of challenges that influence their capacity to provide effective care around this time suggesting a need to invest extra efforts into supporting HCPs. It is to this recognised need within the wider field of paediatric cancer that the second part of this thesis was developed. The following chapter is an empirical study that aims to address this gap in the existing literature by qualitatively exploring how HCPs experience the end-of-treatment phase in paediatric cancer treatment.

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PART 2:

EMPIRICAL PAPER

Healthcare professionals' experiences of endings in paediatric cancer treatment: An interpretative phenomenological analysis

Abstract

Aims: The point of ending active treatment is a period of disruption, transition and heightened distress for paediatric cancer patients and their families. The involvement of healthcare professionals (HCPs) in the identification and management of children and families' difficulties during this phase appears crucial. This study aimed to examine qualitatively the experiences of HCPs providing care to paediatric cancer patients during the end-of-treatment phase.

Method: Interpretative Phenomenological Analysis (IPA) was used to explore the experiences of HCPs. Seven HCPs working in a tertiary paediatric oncology centre in the UK participated in the study. All interviews were conducted via an online videoconference platform and transcribed verbatim.

Results: Four superordinate themes, each with multiple subthemes, were elicited through the analysis: *first*, '*A time of unexpected challenges*', centred HCPs' perceptions around the stresses families experience when completing treatment; *secondly*, '*Good bell, bad bell'* offered insights into how certain ritualised end-of-treatment activities, such as ringing the cancer bell, are perceived by HCPs; *thirdly,* '*Holding too much*' represented some of the emotional demands placed on HCPs in paediatric oncology; and *lastly, 'Organisational culture'* provided insights into some of the system-level factors that HCPs perceived affected provision of care during the end-of-treatment phase.

Conclusion: To the author's knowledge, this is the first study to provide an in-depth exploration of how HCPs experience the end-of-treatment phase in paediatric oncology. The present analysis suggests that HCPs perceive the end-of-treatment phase as the beginning of a period characterised by a range of unique and complex challenges for families and most HCPs expressed reservations over the use of the end-of-treatment bell. This analysis also highlighted some of the relational, ethical and psychological challenges HCPs experience within this setting and how these may be further compounded by the organisational contexts within which HCPs are required to operate. Collectively, these data are discussed to provide insights into the factors that may influence HCPs in relation to the provision of care and to highlight opportunities for developing appropriate strategies to support HCPs, children and families during this significant milestone.

1. Introduction

According to recent 2016-2018 data (CRUK, 2021), approximately 1900 children under the age of 15 and 2500 young people aged 15-24 years are diagnosed with cancer each year in the UK. The acute leukaemias (i.e., Acute Lymphoblastic Leukaemia [ALL] and Acute Myeloid Leukaemia [AML]) central nervous system (CNS) and spinal cord cancers account for more than two-thirds of all cancers diagnosed in children. Promisingly, it is estimated that more than 8 in 10 (84%) children diagnosed with cancer in the UK will survive their diseases for five years or more (CRUK, 2021). Survival rates for childhood cancer have almost doubled in the UK over the past decades, reflecting significant advances in cancer detection and treatment (Miller et al., 2016).

Regardless of prognosis, a wide body of literature acknowledges that children treated for cancer experience a significant level of disease-related and treatment-related symptoms that persist long after the end of active treatment and have a significant psychosocial impact on their long-term quality of life. In addition, the post-treatment period has been recognised as a time of overwhelming concerns for both childhood cancer survivors and their families. The period immediately following treatment completion has been associated with increased fear relating to cancer recurrence, challenges with reintegrating into “normal” life, impaired psychosocial functioning, concerns relating to body image and physical appearance, cognitive changes and increased risk for anxiety, depression and post-traumatic stress (Brinkman, Recklitis, Michel, Grootenhuis, & Klosky, 2018; Friend, Feltbower, Hughes, Dye, & Glaser, 2018; van Erp et al., 2021).

Despite empirical data highlighting the longer-term impact of surviving childhood cancer and the challenges experienced by survivors and their families during the end-of-treatment phase, there is currently little research regarding childhood survivors’ and survivors’ parents’ needs. Studies have shown that parents report a perceived lack of support and overall poor follow-up care around end-of-treatment, which is likely to amplify parental concern during the critical point of treatment completion (Muskat et al., 2017). The completion of childhood cancer treatment has become a topic of increasing interest within healthcare during recent years, and yet despite its raised profile, little research has investigated in-depth the

psychological and social issues of completing cancer treatment. As a result, there is a paucity of practical recommendations on how to support children and their parents during the end-of-treatment phase.

Moreover, despite acknowledgment in the literature about the significant contribution that experienced, oncology healthcare professionals (HCPs) make to patients' wellbeing and clinical outcomes (Wiener, Kazak, Noll, Patenaude, & Kupst, 2015), research documenting the experiences and perspectives of how the end-of-treatment phase is experienced by HCPs is almost non-existent. Given the lack of evidence regarding the needs of survivors and their families during the end-of-treatment phase, the primary aim of this research is to explore qualitatively the perspectives of paediatric oncology HCPs on their experiences in relation to providing care to children around the end-of-treatment phase.

A secondary aim of this research is to describe the perspectives of HCPs regarding the use and meaning of rituals used to *mark* the end-of-treatment phase in paediatric cancer. Multi-disciplinary teams (MDTs) around the UK have implemented a range of strategies to mark the ending of cancer treatment, including psychologically-informed tree of life groups, congratulatory cards to the survivors and their families and parties celebrating this important milestone. More recently, an end-of-treatment ritual that involves ringing a bell – also known as the 'cancer bell' or 'end-of-treatment bell' - has been introduced on cancer wards across the UK and worldwide. Specifically, this celebratory ritual has been implemented in both childhood and adult cancer wards and the ringing of the bell is intended to mark that patients have now completed cancer treatment and are transitioning into survivorship. As highlighted in the systematic review presented in Part One, there is an absence of empirical data exploring the psychological impact of the bell although current narratives - conveyed mostly through videos, blog posts and news articles circulating on the Internet - indicate that this is a joyous moment for all parties involved (i.e., children, families and HCPs). For instance, non-published data, such as videos and blog posts, indicate that this is an emotional day for children and their parents, children are given an end-of-treatment gift and a "certificate" indicating that they have completed treatment and healthcare staff and other families on the ward also participate in the celebration and applaud and congratulate the patient for completing treatment. A recent thought-piece by Gale (2019) suggests that there might also be negative aspects to bell ringings, however an in-depth exploration of

how this end-of-treatment ritual is perceived and experienced by HCPs has not been empirically and thoroughly examined to date.

It is hypothesised that part of the disconnect between the calls for improving post-treatment care for young survivors and their parents and the lack of appropriate and adequately tailored interventions may stem from a lack of strong evidence supporting existing practices and rituals during the end-of-treatment phase. Due to the dearth of knowledge in this area, researching the perspectives of HCPs may provide insights into the unmet needs of paediatric cancer patients and their parents, which can in turn help inform the development of best practices following treatment completion. Complementary to this, this qualitative project may provide insights into possible challenges faced by HCPs in paediatric oncology MDTs during the end-of-treatment phase and thereby identify opportunities for staff support initiatives that could in turn contribute to advancements in survivorship care for paediatric cancer patients and their families.

2. Method

2.1. Overview of study procedures

A qualitative study design was employed and Interpretative Phenomenological Analysis (IPA) was chosen as the method of analysis for the research. Purposive sampling was used and participants were recruited via a single tertiary paediatric cancer treatment centre in the UK. Data were collected through one-to-one semi-structured interviews and were conducted via Zoom, which is a secure and encrypted videoconference tool. Interviews were audio-recorded and transcribed verbatim. All the methodological aspects of the study are described in further detail in the sections below.

2.2. Method of Analysis

The present study adopted a phenomenological epistemological stance to explore participants' unique and subjective experiences. IPA (Smith, Flowers, Larkin, 2009) facilitated an in-depth exploration of narratives detailing the experiences of HCPs providing care to paediatric cancer patients around the end-of-treatment phase. IPA is a methodological approach, which focuses on examining and comprehending the lived experiences of individuals by drawing on three key areas of the philosophy of knowledge: *phenomenology, hermeneutics* and *idiography*. The

main goal of IPA is to attempt to understand the individual's lived experiences through the in-depth exploration of the individual's subjective account of a particular phenomenon.

Phenomenology, developed by philosophers such as Husserl and Heidegger, involves the rigorous and careful exploration of human experience and the way in which this occurs in its own terms (Smith et al., 2009). Husserl argued that as humans we are naturally inclined to categorise perceived phenomena in line with our prior knowledge and our pre-existing understanding of the world around us, rather than separating our perception of that world to focus our attention anew on every *particular thing.* Husserl notably stated that we should endeavour *to 'go back to* things themselves' (cited by Smith et al., 2009, p. 12) – suggesting, that conscious and intentional effort should be made to separate or 'bracket off' our prior understandings, assumptions and pre-conceptions in relation to the world and/or a particular phenomenon in order to be able to explore fully the object of attention. Heidegger further developed Husserl's ideas and argued that it is unlikely that humans are able to completely achieve this and that our perception and interpretation of phenomena are processes that occur in relation to something; meaning that our engagement and interaction with the world around us will naturally colour our meaning-making processes as we are fundamentally and intricately linked to our own experiences. Heidegger's concept of *intersubjectivity* is a central phenomenological concept and refers to the 'shared, overlapping, and relational nature of our engagement in the world' (Smith et al., 2009, p.17). Heidegger's approach to understanding phenomenology is inextricably connected to the second major theoretical influence on IPA, hermeneutics.

Hermeneutics, is concerned with the interpretative process itself and has been defined as 'the theory of interpretation' (Smith et al., 2009, p. 21). According to hermeneutic phenomenology, the interpretation of a phenomenon or experience cannot be achieved simply by listening to another person's account or description of an experience; rather the interpretation of any communication requires the adoption of a more holistic stance and an inevitable part of the interpretative process is that any interpretation will be shaped by the way we position ourselves within the world. Therefore, according to hermeneutics, it is unavoidable that IPA researchers will interpret any new information presented to them in relation to their own preconceptions and past experiences; a process referred to as the 'double

hermeneutic' (Smith et al., 2009), which entails the researcher interpreting participants' own interpretations of their experience.

The third major theoretical underpinning of IPA is *idiography*. Idiography refers to the focus on the particular rather than the general. IPA is not concerned with drawing generalisable conclusions on the basis of a whole sample or population - which is characteristic of the nomothetic approach commonly employed in quantitative psychological research - rather it is committed to gaining an idiosyncratic, in-depth and rich understanding of '*particular* experiential phenomena, that have been understood from the perspective of *particula*r people, in a *particular* context' (Smith et al., 2009, p. 29).

These three philosophical principles – *phenomenology, hermeneutics* and *idiography* – collectively form the foundation upon which IPA's epistemological position is based and elucidate the suitability of using IPA in the present research. This study places emphasis on idiosyncratically exploring HCPs' subjective accounts of a *particular* phenomenon – that is, the delivery of paediatric oncological care – within a *particular* setting – that is, within a tertiary paediatric cancer centre in the UK - during a *particular* time-point – that is, the end-of- treatment phase in paediatric patients' cancer journey. In line with hermeneutics, IPA methodology acknowledges the futility of pursuing 'direct' access to HCPs' experiences; rather the present study fully embraces the 'double hermeneutic' and recognises that the analysis presented below represents the researcher's understanding of HCPs' sense making of their experiences and that the findings discussed will inevitably be viewed from within the prism of the researcher's unique world view and past experiences.

2.2. Participants and Recruitment Procedure

The present study was part of a joint project exploring endings in paediatric cancer treatment from the perspective of paediatric cancer patients, their parents/carers and HCPs providing care to this population. This research was separate from the studies exploring patients and parents'/carers' views and specifically explored the experiences and perspectives of HCPs working in a paediatric hematology and oncology tertiary care centre in the UK.

HCPs were eligible for inclusion in the study if they: (1) had been working for a minimum of six months on haematology and oncology wards at a specialist paediatric

tertiary cancer centre in England, and (2) were actively engaged and involved in the care of paediatric cancer patients. HCPs who had worked for less than six months, who worked in non-oncology wards and who were not actively involved in providing care to paediatric cancer patients were excluded.

As indicated above, recruitment took place in a single paediatric tertiary cancer centre in England. The recruitment procedure was conducted in partnership with a service administrator, who was identified as a local collaborator within the trust. A study recruitment poster (see Appendix 1.1.) containing information about the research was placed in staff common rooms on the cancer wards. Moreover, the local collaborator held a list of all HCPs working in the paediatric oncology service of interest. All HCPs on the list were sent an email invitation by the administrator, on behalf of the cancer matron, informing them about the study (see Appendix 1.2. for email template sent to staff). The email included a participant information sheet (see Appendix 1.3.) and invited any HCP interested in taking part to respond to the advertising email. Any participant who expressed an interest in taking part was directly contacted by the researcher via email in order to gain further confirmation and to clarify any questions. Once HCPs confirmed they wished to proceed with the interview, the researcher forwarded them another email containing a copy of the study information sheet and consent form (see Appendix 1.4.). Once participants confirmed they had read and understood the information provided, a mutually convenient date and time for the interview was arranged. Prior to the commencement of the interview, the information sheet and consent form were verbally explained once more and participants were encouraged to share any concerns and ask any questions before providing informed consent. Due to the interviews being conducted via Zoom, participants were asked to provide informed consent in the following ways: first, by verbally agreeing to take part, and secondly, by sending the researcher an email confirming that they had read the consent form and agreed to proceed with the interview. It was further reiterated to staff that their participation was entirely voluntary, that they could decide to stop the interview at any point without needing to provide a reason and that their employment would not be impacted by their decision to participate in the research.

2.3. Ethical Considerations

The study received ethical approval from the Health Research Authority (HRA), and specifically from the London – Bloomsbury Research Ethics Committee (REC ref: 20/PR/0295; see Appendix 1.5. for ethical approval documents). The research was further reviewed by the Clinical Research Adoption Committee (CRAC) from the Trust in which the present research was conducted. The CRAC is an internal peer review committee that meets to review and endorse any clinical research projects taking place within the Trust.

Among the main ethical issues that needed to be considered in the present study was the potential for HCPs to experience distress whilst talking about their personal experiences with providing paediatric cancer care. Participants were reminded by the researcher to share as much information as they felt able to and were reminded of their option to terminate the interview at any point.

In order to preserve participants' confidentiality a number of procedures were followed. Interviews were digitally recorded and each participant was assigned a unique identification number (ID). Audio recordings were stored on a memory stick that was password protected and interview recordings were identified against the participants' assigned ID. Any personally identifiable information, such as names and addresses, were removed from the transcript (for example, were replaced by [*name of colleague*] and [*name of hospital*]) to ensure anonymity. Once transcribed, the interview transcripts were stored on the shared drive of the Trust's electronic system and all files were password protected using a password only known to the researcher. No transcription services were used for the present study, further ensuring that participants' confidentiality was protected.

2.4. Procedure

Initially, the interviews were scheduled to take place at participants' place of work. However, due to Covid-19 restrictions the interviews were conducted via video call using Zoom. Zoom is a secure and encrypted videoconference tool that allows for scheduling online meetings. Interviews were arranged at a date and time that was convenient for each participant and each participant was emailed a link allowing them to join the video call on the day of the interview. Video links were deactivated once the interview was completed.

Establishing rapport with the participant at the beginning of the interview has been highlighted as one of the most important factors for obtaining good data (Smith, Flowers, & Larkin, 2009). Therefore the interviewer ensured that enough time was dedicated to an 'opening conversation' during which the researcher introduced herself, reiterated the purpose of the study and expected duration of the interview, and gave participants the opportunity to voice any potential concerns they had about the research. An interview schedule was used to help facilitate the discussion of relevant topics. The interview schedule was not followed rigidly; instead it was used in a flexible manner and was mostly referred to as a guide to ensure that the researcher did not completely 'drift' away from some of the central issues pertaining to the research. The order of the questions was adapted in each interview and the line of questioning was predominantly shaped by the concerns and/or topics raised by participants.

All interviews were conducted between April 2021 and June 2021. Interviews were automatically audio- and video-recorded via Zoom. Interview times ranged from 31 to 84 minutes (mean interview time = 62 minutes, standard deviation = 17.5 minutes) and all the interviews combined produced a total of 431 minutes (i.e., approximately 7 hours and 20 minutes) of audio for transcription. All interviews were transcribed by the researcher, which was invaluable in terms of becoming immersed in and familiar with the data. Interviews produced a total of 78023 words of transcribed text (mean word count per interview = 11146, standard deviation: 4226) and word counts ranged between 4956 and 16901 words.

As IPA is primarily an analytical methodology concerned with interpreting the 'meaning of the content of the participant's account' (Smith et al., p74) it does not require the transcription of prosodic, non-verbal features of the recordings (e.g., length of pauses). Table 1.1. below provides an overview of the transcription and reporting conventions used.

Table 1.1. *Transcription and reporting conventions*

Convention	**Meaning**

I:	Interviewer
P:	Participant
[…]	Represents text that has been omitted in the excerpt to make it clearer for the reader or to shorten the quote
(Pause)	Speaker pauses
(Laughs)	Speaker laughs
Underlined text	Underlined fragments indicate speaker emphasis
[Names person]	Removes name of person to protect anonymity
[Names place]	Removes name of place to protect anonymity
[Names hospital]	Removes name of hospital to protect anonymity

2.4.1. Interview Schedule and Interviewing

The interview schedule (see Appendix 1.6.) comprised of pre-set, open-ended questions and topic areas that were explored by the researcher during interviews. Participants were encouraged to share their experiences and express their views on providing care to paediatric cancer patients during the end-of-treatment phase. The principles of semi-structured interviewing outlined by Smith et al (2009) guided the development of the interview schedule for the present study. First, the first two questions of the interview schedule had been carefully selected to initiate the conversation and to support participants in feeling more comfortable with the interviewer – these were: '*What drew you to wanting to take part in this research?'* and '*Can you tell me a little bit about your role at [name of hospital]*?'. It was hoped that these types of questions would allow participants to be more descriptive in their responses, rather than opening the interview with questions that would elicit more affective, in-depth responses from interviewees. As the interview progressed, questions shifted from the '*descriptive to the affective, from the general to the specific, from the superficial to the disclosing'* (Smith et al., 2009, p.68).

Secondly, during the development of the interview schedule, the key topic areas pertaining to the research were identified and the sequence of topics was considered; for example, the primary research question of the present research concerned how HCPs experience endings in paediatric cancer treatment, however, the interviews also aimed to explore HCPs' perceptions regarding ending rituals, such as the cancer bell. It was thought that the most logical sequence would be to start the interview enquiring about endings in cancer treatment more *broadly* and gradually work towards enquiring about *specific* ending rituals as the interview

progressed. In the majority of interviews this sequence was adhered to, however, there were instances where participants themselves referred to specific ending rituals at the start of the interview and therefore the discussion followed the course set by the participant, in line with IPA interviewing principles. Given that the interview schedule was not followed rigidly, not all questions included in the original interview schedule were asked and some of the questions asked were not included in the original interview schedule.

Thirdly, questions were carefully phrased to ensure that they were as open-ended as possible. Broader, more abstract questions relating to each topic were initially asked and were usually followed by probing questions, which acted as prompts to encourage participants to provide more detail and further information relating to what had been shared. Smith et al (2009) describes the process of probing participants as '*going deeper'* and highlights that the use of prompts such as '*Can you tell me more about that?*' or '*How did you feel?*' are likely to lead participants to give more personal and detailed accounts of particular experiences and the associated thoughts and feelings.

The interview schedule was drafted and revised after consultations with the researcher's supervisory team. The interview schedule was further refined following the completion and transcription of the first interview, which sparked important reflections. For instance, some of the researcher's reflections included feeling that some of the questions were a bit more leading or loaded than originally anticipated and that the researcher's interviewing style was slightly rigid and fixed on eliciting the interviewee's responses on certain topics, such as the cancer bell, despite the participant not being overly concerned about this. The researcher also observed some challenges with 'holding silences' as well as making minimal use of probing questions. Following these reflections, and with ongoing input from the researcher's supervisory team, more conscious effort was made to follow each participant's unique rhythm and flow and to use more open-ended and probing questions throughout the interview.

2.5. Method of Analysis

As discussed earlier, interview data were analysed using IPA methodology (Smith et al., 2009). Interviews were analysed one-by-one, in line with the idiographic

nature of IPA, and in chronological order. The following steps were followed for the data analysis: *first*, transcripts were read and re-read several times to facilitate the researcher's familiarisation with their content and audio-recordings were listened to again whilst re-reading the transcript to facilitate immersion in the data. *Second*, line-by-line analysis was conducted and annotations were made in the right-hand margin next to their respective sections of transcribed text. This initial noting phase was done according to the three discrete levels of analysis recommended by Smith et al (2009): *descriptive, linguistic*, and *conceptual*. *Descriptive* comments are defined by Smith and colleagues (2009) as being focused on describing the content of what the participant has shared and stays close to the explicit meaning of this content. *Linguistic* comments are concerned with specific uses of language; for example, the repetition of certain words, or the continuous use of filler words (e.g., um, uh, sort of). *Conceptual* comments are more intended to provide a deeper, more interpretative and conceptual level of analysis, '*moving away from the explicit claims of the participant'* (Smith et al., 2009; p 88). Alongside the initial noting phase, the researcher also noted any particular reflections, responses and reactions to the text. *Third*, the line-by-line analysis gradually led to the development of emerging themes, which were noted on the left-hand margin of the text. The codes developed during the initial coding phase were closely examined with the purpose of mapping out possible connections. To facilitate this process all of the themes were typed in chronological order in the form of a list, were printed out, and the separate pieces of paper were laid out to help the researcher gain an overview of the themes and explore potential inter-relationships and connections (see Appendix 1.7. for a an example of printed themes).

Some of the techniques recommended by Smith et al (2009) for looking for patterns between emergent themes include: (1) *abstraction* – that is the process of placing themes that represent similar concepts together (i.e., putting like with like); (2) *polarisation* – the process of highlighting themes representing oppositional relationships; (3) *contextualisation* – the process of organising themes that relate to a particular narrative; for example organising the participant's key life events according to the temporal moment in which they occurred; (4) *numeration* – that is, taking into account how frequently a theme appeared throughout the transcript; and (5) *function* – the process of identifying clusters of themes by their specific function; for example,

the participant providing a portrayal and/or narrative of the self in a way that elicits certain emotional responses, whether positive or negative, from the interviewer.

As a result of this process, clusters of sub-themes were identified and formed higher-order 'chunks' of data. For example, from the interview conducted with participant 2, there was a series of sub-themes pertaining to the emotional challenges HCPs experience in paediatric oncology. These sub-themes were '*stating the facts, 'bearing witness to challenging situations', 'the highs and lows'*, and '*not alone'* – these sub-themes were subsequently organised under a higher-order cluster labeled '*emotional professionalism'*. This process helped condense findings; for instance, the transcript from participant 2 initially produced 147 emergent themes, which were then clustered into four super-ordinate themes. This process of organising emergent themes and further abstracting them to higher order themes was facilitated using Excel to maintain a digital copy of all the printed sub-themes for each interview. Excel files for each participant also had a corresponding Word document with their relevant excerpts of transcript for each sub-theme to ensure that the analysis remained grounded in the text.

Once individual analyses for all interview transcripts were completed, the next and final stage of analysis involved looking for patterns and connections of themes across all interviews. To facilitate this process a series of mind maps containing the sub-themes and super-ordinate themes for each interview were created in Word (see Appendix 1.8. for an example of a mind map). Similar to previous stages, these mind maps were printed, organised on a large surface and were closely examined to identify patterns across cases. Once connections and similarities/differences were identified, these were further clustered into super-ordinate themes.

A complete analysis for one of the interview transcripts can be found in Appendix 1.9, in which the initial exploratory notes and reflections can be found in the right-hand margin and emergent themes on the left. Appendices 1.10., 1.11. and 1.12. include tables presenting the list of superordinate and emergent themes relevant to three of the transcripts (one for each professional group represented in the data: doctors, nurses, and allied health professionals), alongside their corresponding transcript. The results of the analysis as well as the master table of superordinate themes and subthemes can be found in the Results section.

2.6. Quality and validity assurances

In line with the recommendations by Smith and colleagues (2009) the validity and quality of the present study was assessed using the four broad criteria set forth by Yardley (2008): (1) sensitivity to context, (2) commitment and rigour, (3) transparency and coherence, and (4) impact and importance.

2.6.1. Sensitivity to context

Yardley (2008) suggests that one of the ways whereby the researcher may show sensitivity to context may be achieved by demonstrating awareness of previously published research on the phenomenon explored. The present study was directly linked to the systematic review presented in the first part of the thesis; specifically, the systematic review allowed for a gap in the evidence base in relation to HCPs' experiences of endings in paediatric cancer treatment to be identified. Moreover, additional literature specifically on the importance of the end-of treatment phase in cancer treatment and more broadly on importance of marking endings in general was presented in the introductory part of this section. It is important to mention that the researcher had increased familiarity with the cancer literature in general, due to having conducted previous doctoral-level research concerning the processes that affect cancer screening behaviours in adult populations. In order to amplify the researcher's awareness of and sensitivity to her own context and prior knowledge, a bracketing interview was conducted prior to data collection with a Clinical Psychologist with experience of working in a paediatric cancer care setting. The bracketing interview was informed by previous literature on bracketing (Roulston, 2010); the bracketing exercise involved the researcher taking the position of the interviewee, a process which is proposed to help researchers enhance their awareness of their own subjectivities and promote self-reflection. The bracketing exercise consisted of four key questions: (1) 'What brought you to this topic?', (2) 'Any thoughts on what you might find? What do you think you might find that might be negative, difficult, or clash with your ideas?', (3) 'How do you think you (not) sharing participants' experiences / background will influence recruitment / interviews / analysis?', and (4) 'What assumptions might your participants make about you? How may these influence recruitment / interviews?'. Here, the bracketing interview helped the researcher investigate and recognise her own experience, understanding and presuppositions in relation to the phenomenon of interest. For example, the

bracketing exercise highlighted that the researcher had a particular interest in qualitative methods and that this was partly due to having conducted predominantly quantitative research for her PhD, which had led to an increased awareness regarding the limitations of using quantitative research methods alone. Specifically, the researcher had experienced frustration in relation to the lack of nuance that she felt was more pronounced in using quantitative methodologies in isolation. As a result of the bracketing exercise, the researcher became more aware that qualitative research was more aligned with her own personal values in that 'rich' narratives and gaining an in-depth understanding of the nuances, subtleties and complexities of the experience, as opposed to something that may be a bit more reductionist, is deeply meaningful and important for the researcher, both at a professional and at a personal level. In further exploring the researcher's previous experiences, the bracketing exercise helped elucidate that the researcher's nationality played a role in why she had come to value the 'depth' of qualitative research over the 'breadth' of quantitative research. Specifically, the researcher reflected on her Greek nationality and identified that within the Greek culture there is a tendency to value more 'black and white', dichotomous, pragmatic and practical thinking rather than valuing the importance of examining the various layers of an experience. The researcher experienced this as an internal conflict to a degree - on the one hand there was the powerful influence of her own culture and upbringing and on the other hand there was the influence of having studied and worked for 10 years in the UK in the field of Psychology; a discipline that values the notion of 'going deeper' and requires taking into account the different levels that influence how a person experiences a phenomenon, for example in psychological formulation. The bracketing exercise strongly highlighted that the researcher's professional and academic experience in the UK had really contributed to a felt sense that it is really important to consider the complexity and the individual nuances around an experience. Upon reflecting on this, the researcher became more aware of a potential blind spot, in that she might be more drawn to focus on a very narrow aspect of participants' experiences in order to ensure that the aforementioned complexity and nuance was captured, but that in doing so she might be risking the exploration of other experiences disclosed by participants during the interview. The bracketing exercise helped sensitise the researcher to the potential pitfalls of being overly concerned with depth and acted as a beneficial reminder that it is important to follow the participants' natural rhythm and follow the concerns of the participant as

these evolve during the interview. Overall, bracketing one's own experiences, assumptions and pre-existing concerns is, according to Smith et al (2009), critically important for ensuring that the researcher is able to maintain sensitivity and attentiveness towards what interviewees are sharing and prevent their own biases from being projected onto the data.

Sensitivity to the data was further demonstrated by presenting a detailed account of the analytic process. Supportive documents and screenshots from various stages in the analysis have been included in the Appendices and any findings presented in the Results section below are supported by interview excerpts.

2.6.2. Commitment and rigour

In line with Yardley's (2008) recommendations, commitment to rigour was firstly demonstrated by being mindful of attending closely to what was being said by the participant throughout the interview and by ensuring that participants felt at ease from as early on in the interview process as possible. This degree of attentiveness to the participant is in line with one of IPA's key philosophical principles which is to ensure 'sufficient idiographic engagement' (Smith et al., 2009; p. 181). The rigour and thoroughness of the present study were further demonstrated by: (1) adopting a purposive sampling approach to ensure the appropriateness of the sample in relation to addressing the research question, (2) the iterative development of the interview schedule, which was adapted and refined based on input from the researcher's supervisory team as well as the researcher's own reflection as data collection progressed, and (3) the researcher's supervisory team evaluating and assessing the quality of the analysis at various stages – for example, during initial noting and during the process of identifying emergent and superordinate themes.

2.6.3. Transparency and coherence

In the context of assessing the validity and quality of qualitative research, transparency is defined by Yardley (2008) as the process of the researcher providing a clear description of the various steps and processes involved in conducting the analysis. First, the results from Part One of the thesis clearly and systematically demonstrated that there is a gap in the current evidence base regarding HCPs' experiences in relation to endings in paediatric cancer treatment. Therefore, the identified gap in the literature strongly supports the rationale for the present study.

Furthermore, the researcher has provided a clear argument supporting the appropriateness of IPA as a methodology to analyse the data collected from the interviews with HCPs. In line with the principles of transparency, the shortcomings and potential pitfalls of IPA were also presented. Moreover, the ways in which the sample of participants was selected and recruited, the interview schedule was developed, and the interviews themselves were conducted have all been thoroughly described. Concerning the analysis, the researcher has evidenced substantial complementary material to demonstrate transparently how the analysis was conducted; for instance a worked example of the analytic process for one interview has been included (see Appendix 1.9.) and photos from the printed emergent and superordinate themes have also been included (see Appendices 1.7. and 1.8.). The use of excerpts from interview transcripts supporting each sub-theme identified within participants' individual accounts, further demonstrates transparency and coherence (tabulated examples of these can be found in Appendices 1.10., 1.11., and 1.12.)

2.6.4. Impact and importance

Yardley's (2008) final principle in assessing a study's quality and validity is inextricably linked to its potential to be impactful and to contribute useful and important findings to the subject area(s) within which the research is embedded. As the systematic review in Part One highlighted, research in relation to HCPs' experiences in endings of paediatric cancer treatment is scarce. It is anticipated that by providing an in-depth account of HCPs' experiences around this important stage on the cancer pathway, useful and impactful clinical implications and recommendations can be proposed.

3. Results

Seven HCPs were interviewed in relation to their experiences of providing care to paediatric cancer patients during the end-of-treatment phase. In terms of professional groups represented in the data, two participants were doctors, two were Clinical Nurse Specialists (CNSs), one was a ward nurse, and two were Allied Health Professionals (AHPs).

Table 1.1. below presents the superordinate themes and subthemes that emerged through the analytic process. Four superordinate themes were identified: (1) '*A time of unexpected challenges'*, (2) '*Good bell, bad bell'*, (3) '*Holding too*

much', and (4) '*Organisational culture'*. Each of these are discussed in the following sections.

Table 1*.1. Master table of superordinate themes and subthemes*

Superordinate theme	**Subthemes**	**Participants contributing to subtheme**
A time of unexpected challenges	*It's not over when it's over*	*P1, P2, P3, P4, P5, P6*
	Suddenly left	*P2, P3, P4, P5, P6*
Good bell, bad bell	*A culmination*	*P1, P2, P3, P6, P7*
	A contentious subject	*P2, P4, P5, P6, P7*
Holding too much	*I'm human too*	*P1, P2, P3, P4, P5, P7*
	Unbearable pain	*P2, P3, P4, P7*
	Becoming what families need	*P3, P4, P6, P7*
	Conflict	*P2, P6*
Organisational culture	*The system*	*P2, P3, P5, P6*
	In it together	*P2, P3, P4, P5*
	Like an orchestra	*P3, P5, P6, P7*

3.1. A time of unexpected challenges

This first super-ordinate theme captured the unique challenges that children with cancer and their families face after the completion of active treatment from the perspective of HCPs. It was evident from participants' accounts that when asked about their experiences of providing care during the end-of-treatment phase HCPs mostly spoke about the *parents'* concerns rather than their *own*. Therefore, in this instance, it was not only a case of the researcher interpreting participants' interpretations, but also participants interpreting parents' interpretations of how they experience the end-of-treatment phase, which was then conveyed to the researcher during the interview, suggesting a third level of hermeneutic interpretations.

3.1.1. It's not over when it's over

Most participants expressed that, although the end-of-treatment is typically perceived as the grand finale of the cancer pathway, this perception does not accurately reflect the reality of what children and their families experience around this time. The majority of participants' narratives conveyed a sense of 'endlessness' in relation to paediatric cancer and spoke of families having to manage a whole new set of challenges after the end-of-treatment that they often did not expect to experience. HCPs perceived patients and their families as having a range of issues at the end-of-treatment across multiple domains, including physical, psychological, social, and educational. Moreover, participants spoke about patients transitioning into the post-treatment active monitoring period – that is, a period of five years following the completion of active treatment during which children are required to be actively monitored for possible signs of relapse. HCPs expressed that children and their parents express major and persistent worries about possible cancer recurrence around this time. The excerpt below illustrates this sense of 'endlessness' described above, where Participant 3 describes patients' transition from active treatment to active monitoring, and then from active monitoring to long-term follow-up:

> *"It probably never ends, does it? You know, it.. It's.. I mean for me.. Well.. Is.. Is.. Then, sort of, that next five years off-treatment mark. When we say "Actually, this is <u>never</u> coming back now". Umm, you know, "This leukemia is never coming back and so therefore we're going to refer you into long-term follow-up". Umm.. Where, we're not looking for signs of the disease coming back, where we're making sure there's no late effects of chemotherapy. Umm.. But, you know, so that's another end for me. That's where I stop, in theory, where I stop looking after those patients and refer them*

onto another team. Umm.. But for them that's not the end because, you know, they will continue to.. To long-term follow up and, you know, to be seen sort of life-long.. Umm.. Yeah, yeah." ***(Participant 3, Clinical Nurse Specialist)***

In the above excerpt, the participant describes that one of the ways in which HCPs mark endings with patients is when they are referred onto another team and therefore their input is no longer required. At the same time, the participant clearly identifies that "*for them (i.e., families) that's not the end*" suggesting that the sequelae of paediatric cancer are something that families will, in one way or another, have to deal with *"life-long".* In the excerpt below, Participant 6 describes another form of endings and specifically refers to the death of a patient as being the only "*definite ending*":

"I don't know if I really have a definite ending? And obviously the only.. The only definite ending for me is, when sadly, when that, umm, the child umm.. Dies. So, that is the only really definite ending because I don't see an end of active treatment as an end? Because I know that what lies ahead for this child and family and actually there are.. There aren't that.. […] And particularly when I look.. Particularly looking at children who've had a bone marrow transplants, umm.. […] You know, I can think of children who have leukaemia and they have treatment for three years, and then the leukaemia comes back, and then they have more treatment, and they have relapse treatment, and they have that for another year, and then the leukaemia comes back, and then they come in for a transplant, and this is gonna cure them.. This is what's gonna cure them! And these families come in with so much hope, and it may well cure them of their cancer diagnosis, but what they don't understand is that they've had to have so much treatment to cure them of their cancer, that actually it then causes so many more problems and these families are a bit like, umm.. Feel short-changed. It's like "You never told me it was gonna be like this"." ***(Participant 6, Physiotherapist - Allied Health Professional).***

Here, Participant 6 describes situations where children have relapsed and refers to the various treatment complexities associated with recurrent cancer. Notably, the participant emphasises the likelihood of cancer recurring not only once but multiple times, and describes the efforts of the medical team to provide ongoing curative treatment, including bone marrow transplant, if deemed necessary. At the same time, the participant highlights that continuous treatment - despite the possibility of it being curative - also increases children's risk of long-term physical and psychological cancer sequelae and that parents may be left feeling "*short-changed*". This phrase is followed by "*you never told me it was gonna be like this*" suggesting that parents may place blame on HCPs and perceive them as not being transparent

in relation to the devastating impact childhood cancer treatment can have on children's long-term wellbeing. One practical recommendation proposed by the participant in order to potentially ameliorate the distress parents experience at the end-of-treatment phase involved the possible implementation of "on-treatment days" whilst children are still going through active treatment. Specifically, the participant discussed the importance of having "on-treatment days" that could help ensure that parents / families have access to important information regarding the potential side-effects of treatment and the support available to them prior to the end-of-treatment phase, thereby helping families feel more prepared and better equipped to deal with some of the post-treatment challenges:

> *"So actually, end of treatment is quite a good time for meeting other people but then from a.. You know, then families will say that "If we'd known before" and then they could've meet people going through treatment at the same time then "That would've been really useful for us". So, I mean it has made me think about days whether we should not just wait until end of treatment, that there should be days like on treatment days, which I know have started as well […]"* ***(Participant 6, Allied Health Professional – Occupational Therapist)***

In the excerpt below, Participant 2 presents a slightly different perspective when asked about endings by reflecting on the importance of providing curative treatment to "*large numbers of children*" rather than focusing on individual cases:

> *"What you want is not to allow your sense of "This treatment is successful" being dependent on an individual child having been cured. It's, uh, providing that benefit to large numbers of children. So, I don't think I take, uh.. Any sense of closure (laughs) from having brought one child to that point. It's about an ongoing venture, that is never.. – until I stop working – never going to end."* ***(Participant 2, doctor)***

By focusing on the provision of paediatric cancer care across his whole career, the participant seems to adopt more of a public health lens; again there is a perceived *endlessness* conveyed here, as the participant specifically describes the provision of care as "*an ongoing venture, that is never going to end*" at least until he reaches retirement.

HCPs' narratives also conveyed additional barriers that families experience following the end-of-treatment; for instance, in the excerpt below the participant describes that parents might "*feel torn*", in that a part of them is "*really happy*" that treatment has ended but that this is intertwined with a range of uncertainties and

insecurities surrounding this next phase of the "*journey*", reflecting an overall sense that this is a period of emotional turbulence for families:

> *"And then suddenly when we're all really happy that it's now ended I think a lot of people or families feel torn a little bit? Because of course they are happy that everything has now finished but then this kind of journey starts where they.. They really cannot be quite sure of what to expect."* ***(Participant 1, doctor)***

Apart from the emotional difficulties families experience, participants also spoke of the more tangible challenges children and their parents face around this time; specifically, this is expressed in the following extract when Participant 6 refers to the impact of hospitalisation on children's "*global development*", suggesting that apart from the negative sequelae of anti-cancer treatment, the experience of hospitalisation is in and of itself a stressful experience for the child and has potentially long-lasting effects on a child's psychosocial and cognitive development:

> *"So, we've got specific referral criteria. So, there were some.. So, for example, we now routinely see all children under the age of 1, which I know is quite similar to psychology as well – or try to – umm.. And that's just because, umm.. It's such a huge part of their development and so if they're in hospital for long periods of time then it can have a huge impact on their global development."* ***(Participant 6, physiotherapist – Allied Health Professional)***

3.1.2. Suddenly left

The majority of participants' accounts contributed to this sub-theme, which mainly reflects HCPs' sense that parents experience a sense of "abandonment" after the completion of active treatment. In the excerpt below, this is linguistically expressed through the use of multiple phrases – for example, the participant describes this transition as "*quite abrupt*" and that there is "*no weaning*". Notably, the participant here uses the metaphor of parents experiencing some sort of "*withdrawal syndrome*" – usually a term used to describe the symptoms that occur from suddenly discontinuing substances in the context of drug dependence - which reflects the suddenness and abruptness of this transition for families:

> *"For parents it can seem quite abrupt. Because one day the child is on treatment and being seen quite regularly and with more intense monitoring and the <u>next</u> day the child just stops treatment. There's no weaning. And.. They not only lose that sense of reassurance of the child being on treatment, but also that sense that they're not being as intensively monitored and supported as they were while the child.. Child was on treatment. And some of the parents undergo this, kind of, almost withdrawal*

syndrome of suddenly finding themselves having to go back to a semblance of normality, which they'd forgotten?" ***(Participant 2, doctor)***

This sense that parents feel like they are left to their own devices following the completion of active treatment is further illustrated by the excerpt below:

"And actually they are quite well looked after whilst their treatment is occurring and then end of treatment occurs and they finish and then this huge support network that this family have become very used to having and the child, essentially disappears over night? And that kind of safety bubble of.. Of people to go to and talk to and have questions about, umm.. Disappears? ***(Participant 6, Physiotherapist – Allied Health Professional****)*

Moreover, participants' accounts reflected that this sense of abandonment that families experience around the off-treatment period may be strongly linked to the close bonds families form with HCPs during the active treatment period. In the excerpt below, a number of phrases illustrate the interpersonal connectedness that occurs between families and HCPs during treatment; for example, phrases such as "*we're gonna miss you", "what are we gonna do with you?"* and "*you lose your support network*", all reflect that this transition from active treatment to off-treatment may be experienced as particularly challenging by parents partly due to the relational losses:

"[..] Families will just offer that information and will say umm "Gosh, this is really difficult" umm.. For many different reasons but usually the reasons that are given around are umm "We're gonna miss you", "We're gonna miss our [name of hospital] team" umm.. "What are we gonna do without you there anymore?", "We've got used to coming to hospital all the time, how are we expected just to go back and adapt to normal life?".. Umm.. "We're on chemotherapy and it makes us feel safe and secure that the cancer is under control. Now you're stopping the treatment and what's gonna happen? Will it come back?". Those massive anxieties around stopping treatment. And obviously then you lose your support network, I think we touched upon that before. […] So the parents will often often, often express fears about how are they gonna cope when their support network's gone? How are they gonna go back to normal life? How are they gonna get through the scan anxiety?" ***(Participant 4, Clinical Nurse Specialist)***

3.2. Good bell, bad bell

This superordinate theme primarily captured HCPs' experiences with and perceptions of the end-of-treatment bell, also known as the cancer bell. As described earlier in this section, the bell represents a ritual to signal that a patient has completed their cancer treatment. In other words, endings in paediatric cancer

treatment in many wards nationally and internationally, are marked by ceremonies that involve children and their patients ringing the bell. In assigning the label "*good bell, bad bell",* this superordinate theme aims to convey the many interpretative layers that unfolded during interviews with HCPs with regards to the bell. In essence, this super-ordinate theme reflects the wider sense that the majority of HCPs experience mixed emotions in response to the bell ringing ceremonies and participants' narratives imparted an overall sense that the meaning children, patients and HCPs assign to the bell are not necessarily aligned. HCPs' perceptions of the bell are summarised in the sub-themes '*a culmination'* and '*a contentious subject'* presented below.

3.2.1. A culmination

Etymologically the word culmination is defined as "the highest or climactic point of something, especially attained after a long time". HCPs' narratives often portrayed a sense that the bell ringing represents a symbolic action that takes place within the context of the ward and takes the form of a celebratory ceremony, which serves the purpose of acknowledging the importance of this deeply significant milestone in children's cancer journey. Specifically, the word "culmination" was used by Participant 7 to describe this notion that the end-of-treatment is experienced as some sort of crescendo, where the bell is used as a ritual object to mark this important transition:

> *"It's just, like a culmination of everything, you know? It's all finished and it's all gone and they.. And the.. The poem, it's all about, you know "My treatment's done, and I'm on my way and I'm gonna go off now and I don't need to come back here anymore" type thing and umm, it's just.. It is. You know, it's just.. It's positive."* ***(Participant 7, ward nurse)***

Here, the participant refers to the poem that children and/or their parents read out loud whilst ringing the bell. The poem specifically says "*Ring this bell, three times well, its toll to clearly say, my treatment's done, this course is run and I am on my way!".* The poem itself provides insights into the meaning families might assign to the bell; specifically, in the excerpt above, the participant uses the phrases "*I'm on my way*" and "*I don't need to come back here anymore*" suggesting that the ringing of the bell represents somewhat of an epilogue for the very difficult time families have been through and that these ritualised activities together (i.e., bell ringing and reading of the poem) represent a formalised way for transitioning into survivorship. Moreover,

the bell and poem may allegorically convey to families that this is the last time they find themselves in hospital and that they are ready to start their lives afresh. Another excerpt from the same interview, illustrates the kinds of emotional reactions that HCPs might have during bell ringings:

> *"Well it is.. D'you know it is always.. Like, I think I've cried at every bell ringing I've been too (laughs).. 'Cause it's amazing because you see the children going through everything and then they're at the end […] So, it's a big.. It is a big event."* ***(Participant 7, ward nurse)***

Here, the participant describes that bell ringings are not only an opportunity for families to celebrate the end-of-treatment, but that these ceremonies might represent opportune and appropriate moments for staff also to express their emotions within the professional setting. Moreover, HCPs' expression of emotion during bell ringing ceremonies might signify a somewhat therapeutic activity for staff allowing them to process their own feelings of loss and grief that might be activated when patients no longer require their therapeutic input.

Participant 2 further describes the bell ringing ceremony as a process that is similar to an anniversary or a birthday, indicating that the end-of-treatment likely represents an important milestone that is not unlike other important life events:

> *"And I think it's a good thing. I think it's an important, uh.. For the parents, an emotional uh.. Milestone, which they would.. They would like to mark? Much like an anniversary or a birthday? And some parents continue to mark that as an anniversary subsequently. So, just as celebrating a birthday gives us pleasure, uh.. Or an anniversary of some sort. Celebrating the end of treatment on a certain date.. No matter that it may be arbitrary, umm, is still an important milestone that I think parents get a lot of comfort from marking that."* ***(Participant 2, doctor)***

Another participant highlighted that the bell ringing represents an opportunity for families to be "*proud and happy*" for "*having come that far*". Perhaps this speaks to the notion that during previous phases on the cancer journey – for example, at diagnosis and during active treatment – parents are likely to experience predominantly negative emotions and that the bell ringing ceremony allows parents to experience a moment of joy after a period of prolonged suffering:

"I think it's worth.. I think it's worth.. You know.. Acknowledging and.. And being proud and happy about having gone through all of that treatment and having come that far." ***(Participant 1, doctor)***

The same participant immediately proceeds to express some of her concerns over the fact that families might perceive the bell ringing as a definite ending:

I think that calling it 'an end' and that this is now finished and everything is now… Umm.. You know, I think it's a bit mixed because.. Uhh.. Especially for the neuro-oncology children it's such a long journey ahead still. You know.. It's a.. But it's.. It's.. It's marking something, you know.. And.. And.. And umm.. But it shouldn't be.. It's not the end of that long long road that they are still on.. It really isn't." ***(Participant 1, doctor)***

Here, the participant's account suggests that the bell ringing, albeit an important and worthwhile ritual, does not represent the finale families might hope for in relation to dealing with cancer and its aftermath, but rather it signifies a transition into a different phase, which in all likelihood will present a whole new set of unique difficulties for families.

3.2.2. A contentious subject

The majority of HCPs described the cancer bell as controversial to a degree. HCPs described that bell ringings on the ward might have a range of unintended negative psychological consequences and might be perceived as insensitive for other children and their families who might be really poorly, have no hope for curative treatment or for whom the end of treatment signifies the transition into palliative care. HCPs' accounts indicated that instead of the bell infusing other patients on the ward with hope – which is thought to be the bell's original purpose - it may act as a painful reminder that they will never have the opportunity to reach that milestone in their own cancer journey. In the excerpt below, Participant 4 provides a very vivid description of how the bell ringing ceremonies might be painful for other families on the ward:

"So, it's become a really kind of.. Umm.. Mixed feelings about the bell because umm.. It's hard because they do it on the ward and you'll have a family nearby where their child is dying and hear what goes on because it's not thick walls.. So, in one minute you've got a dying child in that bed and the next minute you have another family cheering and clapping and celebrating their child's finished cancer treatment. You know, the emotional impact on those parents, I think, must be really hard. 'Cause you know – you're hearing that and yet your child.. Your child's gonna die. Your child's never gonna get that experience of ringing that bell. Or.. Umm.. So, I often think that

when I hear.. 'Cause you know. And don't.. Don't get me wrong. They're lovely ceremonies, they're lovely. And the.. You know.. And the cheering and clapping. But in the back of my mind I'm thinking "Well, what about the families that'll never gonna get to do this?" and "What about the families that will never get to experience going home and getting back on with their lives?". ***(Participant 4, Clinical Nurse Specialist)***

Here, the participant's detailed and rich description of such a scenario being enacted on the ward, strongly conveys this sense that this otherwise joyful ritual lacks sensitivity towards those who have no hope for a cure but are somewhat 'forced' to witness these celebrations taking place nearby. The participant's narrative further illustrates the types of thoughts that might arise for HCPs during bell ringing ceremonies – specifically, the participant provides an example of internal dialogue taking place "*at the back of her mind*" and wonders "*Well, what about the families that'll never gonna get to do this?"* which is an indication of the participant's reflexivity and her capacity to empathise with and take the position of "*the other*". The participant also described an internal conflict – she says: "*Don't get me wrong, they're lovely ceremonies*" and then expresses her concerns over the negative impact the bell may have for other families. This participants' narrative potentially represents an example of HCPs' emotional labour within the context of clinical practice, as the participant's account conveys a sense that despite her own reservations, she cannot intervene or change the fact that bell ringings are taking place on the ward, indicating that the participant might be engaging in 'surface acting' (Hochschild, 1983).

This sense that bell ringings can be emotionally taxing for HCPs is further supported by the extract below. Here, another participant recounts an emotionally difficult experience related to the bell that had a lasting impact on her:

"I remember a.. Patient on [name of ward] who, umm.. Who.. Who passed away on [name of ward]. And he had a type of leukemia and he never got to ring the bell. And he was an inpatient for quite a long time? And so both him and his mum and family had witnessed people ring the bell for a long time. And when he died on the ward it was.. Got.. It got quite conflictual towards the end, as generally things tend to these days.. […] Mum was finding (it) very difficult to find that there was no more treatment left to try. And he sadly passed away on the ward. And.. You know, that noise of - I don't know if you've personally heard it - but the, umm.. When fam.. When.. Particularly mums.. The noise of grief.. That.. Just, kind of, raw grief. Is just so.. The kind of inner.. Ahh.. It's just the most horrendous noise. But she ran out of the room after he died and she just hung onto this bell and was just ringing it and ringing it and

ringing it. And everyone was just, kind of, coming out of their rooms to see if somebody's ringing the bell and there's this grief stricken woman.. Was just ringing this bell in quite a, kind of, mad.. It was just.. It was just horrific to watch really. And be part of.. You just think.. I just think.. I don't know how much that bell has had to play a part in.. In all of this.. Or, you know, how much that's, kind of, really got (to) her that he was never able to do it or she was signifying that he'd left this kind of wo.. I don't know what the purpose was but it was.. It was quite harrowing." ***(Participant 6, Physiotherapist, Allied Health Professional)***

The participant uses a number of phrases here that convey the intensity of how this incident was experienced; first, the participant uses the phrase "*the noise of raw grief*" and proceeds to describe this as the "*most horrendous noise*", conveying a sense that witnessing this mother's grief, loss, pain and anguish was quite traumatic for the participant as well. This notion that the participant was extremely distressed by this incident is further supported when the participant says that it was "*harrowing*" and "*horrific to watch*". This extract felt particularly emotionally laden as the participant was speaking. This may have been partly due to the fact that the participant painted a vivid image of this incident through her detailed description, which in turn makes it even more true to life, but at the same time it provided some important insights into how parents, whose children die from cancer on the ward, might feel towards the bell. In this excerpt, a felt sense was that the mother had placed a lot of hope on the bell and following her son's death the mother's immediate response was to instinctively run towards the bell and start ringing it repeatedly. This raises important questions around what the bell might mean to parents, particularly those whose children do not reach survivorship. Although typically, parents and children ring the bell to celebrate the end-of-treatment, here it was rung by a mother in mourning; therefore, in this instance, the bell was not the object of a celebratory ritual but instead became the object of a grieving ritual. Due to the bell-ringing ritual becoming possibly distressing for some families, some participants proposed that it might be best that the bell is removed from the ward and moved to a location where other children and families are not "forced" to witness the celebration:

"And I think that.. It (i.e., bell) definitely has a place, I don't think.. I personally – this is a very personal opinion – umm.. I think that the bell on an inpatient ward is not the right place for it to be. And I.. And I think that you know.. Also because of Covid it's been a really positive thing – so the bell is now portable and the bell gets taken out of the hospital and anyone who wants to go and watch that bell can.." ***(Participant 6, Allied Health Professional – Occupational Therapist)***

The participant's view that the bell should perhaps be moved away from the ward is particularly emphasised in the excerpt below:

> *Some children who are just "I'm never.."- particularly the older children who are much more aware – that they're never gonna get to ring the bell again or have never got to rung the bell is really difficult.. Really difficult. And I've had a few children have those conversations and I just think "Oh my God, get rid of that God damn bell!" (laughs).. I don't want anymore of this bell!"* ***(Participant 6, Allied Health Professional – Occupational Therapist)***

Particularly the phrase "*Oh my God, get rid of that God damn bell!*" conveys a sense that the participant is angry and frustrated that the bell remains on the ward.

3.3. Holding too much

This theme overall includes illustrations of how HCPs may often feel overwhelmed and distressed in response to the emotional burden of care and attempts to elucidate the many ways in which the *'personal'* is inextricably linked to the *'professional'* among HCPs in paediatric oncology. This superordinate theme further captures participants' experiences in relation to some of the psychological demands placed on HCPs due to the highly emotionally and taxing nature of providing care to children who are seriously ill. Overall, participants' narratives portrayed the inevitability of experiencing strong, and often painful, emotions that arise from working in this complex setting. Some participants' reflections around how they might attempt to cope and manage their emotional reactions are also represented within this superordinate theme.

3.3.1. I'm human too

This theme identified that participants often experienced intense emotions in response to working with paediatric cancer patients and their families. The theme aimed to capture some of the emotional components intertwined with clinical practice, and aimed to convey a sense of "humanness" and professional vulnerability among HCPs – that is, that HCPs, similar to everyone else, may experience a range of emotions including stress, anger, fear, shame and guilt.

Participants' narratives illustrated that the relational aspects of providing care to paediatric cancer patients and the experience of human connectedness within this

setting can be an extremely powerful experience for professionals. In the excerpt below the participant describes feelings of deep sadness, both in response to a patient's death but also in response to her relationship with patients and their families coming to an end around the end-of-treatment phase:

> *"But if the child dies, that.. That.. And it is again I think for me it's like a grieving process actually because.. You know, we're only human and often I'll think to myself "God, I'm really gonna miss that child, I'm really gonna miss that mum, I'm really gonna miss that family", you know, and it is.. I think as a health professional you still go through a slight grieving process. If the child dies. Or even if a child then finishes treatment and doesn't really contact you very much. You still miss them.. You still think about them."* ***(Participant 4, CNS)***

Here the participant appears to be slightly hesitant in using the phrase '*grieving process'* and seems to make attempts to justify her choice of words by following this up with "*we're only human*" and "*as a health professional you still go through a slight grieving process*" which provides some insights into possible beliefs the participant may have around managing work-related losses. First, it may indicate that a greater degree of connectedness with patients/families increases HCPs' risk for crossing professional boundaries, which in turn may pose a threat to HCPs' professional identity if this connectedness is perceived as unprofessional. Secondly, by openly acknowledging her grief following a patient's death the participant is, in an indirect way, expressing that she can be emotionally vulnerable as well, which goes against historic narratives and perceptions of HCPs being emotionally invincible and unaffected.

Another excerpt from the interview with Participant 4 further highlights the potential struggles HCPs might experience in relation to maintaining strict professional boundaries. Particularly, the following quote illustrates some situations in which HCPs might in fact experience a degree of over-involvement but that this occurs within the context of a strong bond that has developed through working interpersonally with patients and their families over prolonged periods of time:

> *"Because like, again I'll say the blurred boundaries almost sometimes.. You know, it's the.. This.. The "friendship", which I suppose it.. And that's a really.. I think.. Boundaries are really really difficult.. Really difficult sometimes. […] Especially if you've got a family that you.. We're human and.. And we click with certain people better than we do with others and sometimes it feels like.. That they blur slightly.. The*

boundaries. Not that you'd see them outside of work or anything like that, but sometimes, you know, you're having a conversation and you'll almost forget for a second that you're a health professional. […]" ***(Participant 4, CNS)***

This strong affectional bond with patients and their families was also discussed by a ward nurse:

"All I'm trying to say is.. We all get quite attached to the patients and the families and we build good relationships with them. So, often by the.. You know, by the end of treatment it's quite.. It's a mixture of emotions really.. I think for us and the families, particularly the parents, because you build up.. There's such a relationship an then they.. They obviously go along and they.. They only really get seen every so often for follow-ups and outpatients and things. So.. But it's.. It's.. It's positive ultimately." ***(Participant 7, Ward Nurse)***

Notably, here the participant says "*we all get quite attached to the patient and the families*" and the use of the word "attached" hints towards Bowlby's (1979) attachment theory and how this may be enacted in the HCP-patient relationship. The participant also speaks of this attachment whilst referring to the end-of-treatment phase, suggesting that some of the stronger emotions are more likely to be experienced by HCPs during times of separation. Interestingly the participant says "*they only really get seen every so often*" making use of the passive voice, instead of saying "*we only see them every so often*" perhaps reflecting an unconscious attempt from the participant to distance herself on a linguistic level from certain emotive elements.

3.3.2. Unbearable pain

Most participants expressed experiencing a spectrum of painful emotions in response to distressing situations on the ward. HCPs' narratives conveyed an overall sense of frequently feeling overwhelmed and emotionally scarred particularly following a child's death or in situations where patients no longer responded to treatment. Participants also spoke about the emotional impact and intense feelings that arose from often being the "target" of parents' anger and grief. In the excerpt below, Participant 3 spoke of her experience with providing care to a patient who was no longer responding to treatment and, despite the mother's wishes to pursue further treatment, it had been agreed by the MDT that doing so would be considered medically futile and would have gone against the child's best interests. Here, the

participant describes the emotional distress she experienced after going to see the mother on the ward following her child's death:

> *"Anyway, he died. He died on the wards.. Umm.. A few months ago. And I went and saw her, sort of, around 20 minutes after he died. Umm, and obviously there was lots of whaling and, you know, how upset she was with us that we'd never done the second transplant and.. That she should have left.. She should have left and taken him to [country outside the UK] and that she should have done this and that and.. You know we.. We.. We didn't do the best for him.. Umm... So, I, sort of.. I was just like.. I'm really sorry you know.. I was really sorry that we couldn't get that.. I'm really sorry we couldn't do that for him.. You know, he was lying there beside her.. dead. Umm.. While she's sort of laying on the bed whaling.. So, so it was really really (laughs).. difficult."* ***(Participant 3, Clinical Nurse Specialist)***

Particularly the phrases "*how upset she was with us*" and "*we didn't do the best for him*" provide insights into the painful emotions experienced by the participant and illustrates how HCPs may become the 'vessels' containing parents' intense and overwhelming grief responses whilst at the same time having to maintain their professionalism. This excerpt further illustrates the ways in which grieving parents might place blame on HCPs and that, in response, staff may experience emotions of guilt and internalise the beliefs of parents, despite their best intentions and efforts to be of service and offer the best possible care to patients and their families. This is further exemplified by the fact that the participant repeatedly used the phrase "*I'm really sorry*" to respond to the mother, indicating that perhaps a degree of moral distress and guilt were experienced in this situation. The excerpt below further illustrates the strong emotional impact that arises from being exposed to death, dying and suffering at work:

> *"People get to that.. Parents get to that point in.. in a very different, umm.. At very different times.. You know, some people push, push, push, push, push "There's must be something more you can do" really, really emotional.. Difficult, difficult, difficult conversations "How can you stand there and let my child die?", "What else are you gonna do?", "There must be something else – can I go to America? Can I go to Germany? Can I go to Mexico? Can I go to Barcelona? Can I do this? Can I do that?". You know, it's constant, constant, constant.. Umm.. Or.. And some parents are much more accepting and are like "I know you tried everything you can and I don't want you to put my child through anything else" and there's all of those difficult conversations as well.. […] Where are they going to die? Are they gonna go home? Are they gonna stay in hospital? Are they gonna go to a hospice? And grief.. You know when a child does die, if they die on the ward. Absolutely how people react is completely new.. Sometimes you just can never predict what they do.. You know,*

some parents collapse on the floor, some parents scream and shout, some parents shake the child "Wake up, wake up, wake up, wake up". Umm.." ***(Participant 4, Clinical Nurse Specialist)***

The excerpt above poignantly illustrates the pressures HCPs might experience from parents; this is particularly communicated by the language the participant uses in this excerpt. For instance, the participant repeats a number of words to describe this; she says that parents might "*push, push, push, push, push*" for further treatment and that these are "*difficult, difficult, difficult conversations*". Furthermore, the participant refers to instances where parents might try to pursue other treatment options that involve seeking medical help from countries outside the UK. This might be experienced by HCPs as an indirect way for parents to say that they no longer trust the provision of care this team is providing and that they will seek more specialist and appropriate treatment elsewhere. Other participants also spoke about having to have difficult conversations with families around death and palliative care, however, the excerpt below taken from the interview with Participant 2, illustrates that participants used very different language to describe these experiences:

"Whereas the most difficult conversations, are of patients who may have days or even a week or two before they may die. And there the conversation is more around how parents want the child managed, whether it's in the home, hospice, hospital setting. What the focus will be around symptom care, especially around the use of analgesia, which might cause sedation for that. And that might in itself contribute to death - etc. So, those conversations are the most difficult." ***(Participant 2, doctor)****.*

Here the participant uses phrases such as "*how parents want the child managed*", "*symptom care*", and "*the use of analgesia*" which overall convey a sense that the participant might be distancing himself from the emotional aspects of these conversations, through the use of biomedical terminology and overall more pragmatic, objective and neutral language. Some participants also spoke about another emotionally taxing part of paediatric oncology; that is, the requirement for HCPs to attend patients' funerals and the difficult emotions that HCPs experience within this context. The excerpt below indicates that the participant experienced feelings of guilt stemming from having to "choose" which funeral to go to:

"[…] I find funerals really hard. I do go to some and again I think in my head "What makes me pick that family's funeral to go to over that family's funeral?".. It's hard. That's really, really hard. Umm.. I go to less certainly as I've got older I try and go to

less. Because they are so incredibly difficult! Emotionally they kill me for a few days afterwards. Emotional.. Uh, I find it really really.. Really tricky funerals. But sometimes if the parents say "Look, I'd really want you to come to the funeral, you're a really important part of her life" or whatever they're gonna say then umm.. I do go." ***(Participant 4, Clinical Nurse Specialist)***

It is evident from this excerpt that the experience of moral distress for the participant was multi-layered in this instance; first, the participant describes the moral dilemmas associated to having to "choose" which patients' funerals to go to. The participant's narrative conveys a sense that she experiences guilt for not being able to attend all funerals, and for the ones she does not attend, there is a sense that she feels like there must be a rationale behind this decision – perhaps, a sense that she unconsciously favours certain families over others, which in this instance seems to have given rise to feelings of moral distress and internal conflict. There was a sense that HCPs' understandable distress in response to a patient's death might have been amplified by the lack of adequate institutional support available to staff. Participants' narratives conveyed a sense that there were few system-level processes to ensure staff wellbeing following critical incidents, such as patient death, and that some of the existing support strategies were largely experienced as unhelpful by HCPs. For instance, one participant mentioned that one aspect of institutional support came in the form of debrief meetings, which are offered following a patient's death and/or any other critical incident. In the excerpt below, the participant describes the process of debriefing:

"So, in theory - the research behind debrief obviously is really positive and.. It's something that you should do and.. - but in reality I have to say experiences of them people aren't really that bothered or don't get much out of them. […] The debriefs I've attended have mainly been.. Umm, following.. Following a death. But.. I think we as the nursing staff we would prefer to have it as, umm, like more medical. Like "Right, tell us exactly about what happened, what are the facts blah, blah, blah" rather than all sit around and discuss your feelings.. Is the general consensus. Whereas if it's not as a.. A constructed thing and it's just, you know, a natural conversation that might arise from the team of nurses then that is much more productive." ***(Participant 7, Ward Nurse)***

In the excerpt above, the participant describes that during debriefs staff are encouraged to "*sit around and discuss their feelings*" providing a sense that debriefs are intended to encourage staff to explore their emotions within the safety of the staff

group. The participant acknowledges that the "*research behind debrief is obviously really positive*" but at the same time directly expresses that this is not experienced as helpful by the nursing team. Instead, the participant proposes that such debriefs should be "*more medical*", perhaps indicating that the participant might be unknowingly moving away from allowing herself to reflect on any potentially painful emotions and be vulnerable in the presence of colleagues. The participant's comment that debriefs are a "*constructed thing*" rather than a "*natural conversation*" provides important insights into how the format of such initiatives might affect how debriefs are received by staff. For example, in this instance the participant might be indirectly conveying that debriefs happen rather "mechanically" and in a "tick-the box" format and that this in turn may deter staff from openly expressing their internal affective experience. Among nurses, the lack of clinical supervision was also discussed and was highlighted as a potential factor that further contributed to feelings of distress within the professional setting. Specifically, in the excerpt below, one participant discusses that despite the provision of counselling and emotional support for patients and their families being an integral aspect of her role, nurses do not receive clinical supervision to support them with this part of their job:

> *"Um.. I was.. Ugh.. I don't.. I don't know. People are surprised generally I think if they ask, you know, friends and people that don't know so much about the job they'll say "God, that's a really tough..". All these roles, all nurse specialists, all advanced nurse practitioners, all these are really tough emotional roles so I think people are often surprised when I say it's not mandatory for you to have to have any clinical supervision or somebody to talk to.. They'll say "God that should be mandatory in your job", "You should.. You should be doing that, that should be routine, that should be the day you walk in the door in these roles you should have that". But it's not.. It never has.. Not in my experience. It's never been mandatory to have any support. I think it's a take it or leave it. You want it or you don't want it. I think."* ***(Participant 4, Clinical Nurse Specialist)***

Here, the participant's description conveys a sense that as she was reflecting on the lack of clinical supervision she herself became surprised that such support is not available to nurses. This is not directly expressed but is mostly indirectly relayed to the reader through the participant referring to how others perceive the lack of supervision; the participant describes how others will say "*God, that's really tough*" and acknowledges that "*all these roles*" are "*really tough emotional roles*" for which supervision should be "*routine*" and "*mandatory*". The participant's phrases "*take it or*

leave it" and "*you want it or you don't want it*" provide insights into how HCPs might experience some degree of entrapment within their roles and gives a sense that the system is somewhat rigid and unable to accommodate and flexibly respond to staff's needs to ensure that they have the appropriate support in the workplace.

3.3.3. Becoming what families need

Participants spoke about the importance of identifying and adapting to families' unique care needs. In the excerpt below Participant 3 makes reference to the importance of patients' needs and expectations in regard to information and treatment:

> *"You know, I often say to my guys, or you know, and to myself, "I'm the one who needs to be different going from bed to bed". You know, as I go from different patients I need to, sort of, be, you know, I need to be, different for what that patient needs. Because, sort of, information needs will be different. There's a basic level of information that you've got to get over, umm.. But, you know, the degree of that information will be different for each family and it's for me to be able to read that and.. And.. You know.. And work with, you know, what you've got in front of you."* ***(Participant 3, Clinical Nurse Specialist)***

The language the participant uses here demonstrates that HCPs are required to rely on their own judgment to identify patients' needs; for instance, the participant says "*I need to be different for what the patient needs*", that she must "*be able to read that* (i.e., patients' needs)" and that it is key to "*work with what you've got in front of you*" suggesting that HCPs are required to draw upon a complex set of interpersonal skills in order to provide high-quality care and adapt their communication style in line with patients' and families' needs. At the same time, the participant here acknowledges that despite patients having different information needs, there's a "*basic level of information that you've got to get over*" suggesting that the provision of information is a central aspect permeating all aspects of providing paediatric cancer care. Another participant's account, further supported this notion that high quality care relies greatly on HCPs' advanced communication and interpersonal skills and capabilities; specifically, Participant 6 below underlines the importance of emotional intelligence:

> *So, I think it's about – you know, you're not gonna be able to do the same things for all families and I think it's about.. You know, some of it is real emotional intelligence from that staff member about realising that actually that, yeah, this is the way to go*

with this family and actually, d'you know what, now is not the right time we'll shut this down, or we'll retry it or try a different avenue but, umm.. It's just I guess then that's kind of experience really about knowing when is the right time to persist with something and when it's a different time. And that's like anything with, you know.. Anything within healthcare is emotional intelligence. You know, if you've got that then you're kind of halfway there and if you haven't then it's very difficult to learn (laughs). ***(Participant 6, Physiotherapist – Allied Health Professional)***

Here, the participant's narrative describes emotional intelligence as a cornerstone of effective healthcare, which is particularly emphasised by the phrase "*if you've got that (i.e., emotional intelligence) then you're kind of halfway there*". The participant's definition of emotional intelligence here comprises of the following important elements: first, the participant says "*this is the way to go with this family*", which illustrates her capacity to identify the family's needs and then proceed with a personalised course of action that meets this identified need. Secondly, the participant says "*we'll shut this down, or we'll retry it or try a different avenue"* highlighting the importance of continuously revisiting and adapting the care plan as patients' and families' needs shift and change over time.

With regard to the end-of-treatment phase in particular, some participants discussed that families' support and psychosocial needs can vary greatly. In the excerpt below, the participant discusses instances where families openly communicate a need for ongoing support following the end of active treatment, whereas other families do not express wanting to maintain contact with the care team during this time. Similar to the excerpts above, the following extract demonstrates that staff are required to adopt a case-by-case approach for each patient and family and to be mindful and sensitive to patients' unique needs across the various stages of the cancer pathway, including the end-of-treatment phase:

"You'll get families you won't hear from between the three monthly scans and that is the end for them and you don't really hear from them, or you'll get families that still really, really need you and they will ring for.. They'll.. It's almost like they're making up an excuse to ring you because they miss you there and they'll ring and they'll say something like "I don't really need to ring you for that" but it's their way of, kind of, touching base still. So, I think it depends on the family. […] It could go either way and you never can quite.. Well, you can tell from how certain families behave. You.. You can pretty much guess sometimes but.. Families cope in very, very, very different ways." ***(Participant 4, Clinical Nurse Specialist)***

3.3.4. Conflict

HCPs also spoke about communication breakdowns and disagreements occurring between staff and parents. Participants referred to situations in which parents wished to pursue further treatment despite the medical team's advice that this would not be in the child's best interest and instead could have the opposite effect by prolonging the child's suffering and further compromising their welfare. One participant described a troublesome situation that occurred with the parents of a child who was no longer responding to treatment and the parent was unable to accept that the child's cancer was incurable. In the excerpt below, the participant provides a poignant account of how such conflicts with parents may give rise to important ethical dilemmas that exert additional emotional demands on HCPs:

> *"And what happens in those situations is that.. Inevitably the focus.. How hard you try is distracted by this.. Battle.. Ongoing battle with the family. And that can be quite time, energy and emotionally consuming. Which, therefore you have to constantly remind yourself that you have to try and separate those two things. Is that the child's welfare should remain the paramount focus and you need to separate that from the difficult conversations that you are having with the family. […] Umm. And it isn't always successful. Because often you get pressured into doing things that are not in the child's best interests for the sake of satisfying the parents."* ***(Participant 2, doctor)***

Here the participant uses the metaphor of an "*ongoing battle*" to describe the development of entrenched and conflicting views between parents and providers. The participant describes these disputes as "*quite time, energy and emotionally consuming*" indicating that these situations are draining and require HCPs to draw upon their own internal resources, that are possibly already limited due to the many challenges associated with practicing medicine in paediatric oncology.

The participant proceeds to say that these disputes can become emotionally demanding and draining to such a degree, that he may feel "*pressured into doing things that are not in the child's best interests for the sake of satisfying the parents*", suggesting that such instances are likely to be the associated with increased risk for moral injury. In the excerpt below, the participant describes that one of the most important factors likely to determine dispute resolution within the constraints of non-curable cancer, is trust:

> *"Yeah, and if the parents don't accept that then the critical, uh, measure of a successful, uh, clinical, uh, discourse is trust. Is to build trust between the patient's*

family and the professional. So, if that breaks down, as it does, and as it did in the case of this family, then that brings on a whole different, challenging, uh, scenario in which it's impossible to regain that trust. Because the family often seeks second, third opinions, nationally, internationally. And to deal with that becomes almost a full-time occupation in that period of time." ***(Participant 2, doctor)***

Similar ethical dilemmas and internal conflicts around "what is best?" for the child were discussed by some of the allied health professionals (AHPs) participating in the study but in this instance these dilemmas were more in relation to the provision of *psychosocial supportive* care rather than *medical* care. Specifically, some participants raised concerns over the fact that not all paediatric patients seem to have equal access to psychosocial supportive care services such as OT, physiotherapy, speech and language, psychological support etc. In the excerpt below, the participant describes morally demanding situations in which some children have had consistent and tailored support from AHPs throughout their caner journey, whereas other have had no input at all:

"And I really hope as well that that might improve some of the equity. Because actually some of the feedback, umm, that we've had from families is that if we meet some children early on in treatment they can get a very good service form us because we know them regularly, their medical team then know that we're involved, we get asked to see routinely. And then there are some families who we don't get to see at all. And so when we get to end of treatment days some parents we know very, very well and other parents we haven't. And actually their children's treatment hasn't been that dissimilar but we don't know about them and.. So, like "Wow, if we'd known we could've done this or we could've done that". And so there isn't often a huge amount of equity. […] I just feel a little bit uneasy at times how we know about some children and we don't know about them all." ***(Participant 6, Physiotherapist – Allied Health Professional)***

Here the participant uses the word "*uneasy*" to describe how these inequities she has observed in practice may be linked to increased moral distress. In the excerpt below, the same participant reflects on some of the reasons behind these perceived inequities, and particularly describes that families' capacity to self-advocate will greatly determine whether they are able to access psychosocial supportive care and have their needs met whilst on treatment:

"And unfortunately I think.. Sometimes, that it.. Kind of, then targets the same, kind of, families. It's the families that will ask for help that we all end up getting to see but it's actually the ones that don't feel they're able to or don't realise there's a problem and

that don't tend to not be able to advocate for their child necessarily as well as somebody else might be which is just, umm, really difficult. And that's just not the kind of model we want to.. But naturally I think that's what happens. ***[…]*** *And again, the inequity of some families who shout loudest and gets, versus some families who are in greatest need who don't gets and are quiet and don't know how to advocate, umm.. So, I would describe it.. Yeah, overwhelming and frustrating and.. You know, essentially for lots of the problems you can't.. You can't fix them"* ***(Participant 6, Physiotherapist – Allied Health Professional)***

The language the participant uses here poignantly illustrates the dichotomy between certain families that "*shout loudest and gets*" versus those who "*don't gets and are quiet*" providing insights into whose voices are likely to be heard, centred and tended to and whose voices remain unheard, decentred and unattended. The participant describes this as "*overwhelming and frustrating*" and her phrase "*lots of the problems.. You can't fix them*" provides a glimpse into the demoralisation and hopelessness that NHS staff might experience within a healthcare system that is chronically underfunded and understaffed. Some of these organisational challenges are further explored in the fourth and final super-ordinate theme below.

3.4.Organisational culture

Some of the factors that participants spoke about in relation to providing care to paediatric cancer patients at the end-of-treatment concerned the wider institutional arena within which HCPs operate and the ways in which organisational contexts, processes and protocols can affect, either positively or negatively, the provision of care.

3.4.1. The system

One of the issues raised by participants with regards to systemic challenges concerned continuity of care. As briefly outlined earlier, the way paediatric oncology services are organised in the UK dictate that children will transition from the end-of-treatment phase into a five-year active monitoring period (during which the risk for cancer recurrence peaks), which is then followed by the a long-term follow-up period. Around the stage of long-term follow-up children's cancer is less likely to recur, however treatment-related sequelae that require medical and psychosocial interventions may appear around this time. Based on participants' accounts the five-year active monitoring period is a crucial time for children and families on a range of levels that extend beyond concerns around cancer recurrence in isolation. In the

excerpt, below Participant 6 expresses frustration over the fact that the current model of care often leaves children and families without any psychosocial support with devastating consequences for children's wellbeing:

> *"That will happen every three or six months, umm, and actually, you know, these children were very well supported on treatment and then they've got a five-year gap and then they're going into long-term follow-up clinic and they are just a mess! Umm.. You know, and.. And the families, have, you know, the community services have stopped, these children are in inappropriate schools with not the right, umm, educational healthcare plan in place, umm.. So, I think we need to change our model of.. Of working. Particularly because cancer treatment is changing. Well, it's changing now as we're speaking, but it has changed significantly over the last 5-10 years. More and more children are surviving with different, umm, presentations, umm, and we need to change our model of working to adapt with that. So, why are we waiting five years to see these children when actually probably seeing a year off treatment, umm, when – as I say – at the end of treatment some of these.. Some of the.. Some of the issues are present but not.. But not all. Umm.. And so actually there's sometimes bigger.. Bigger problems down the line."* ***(Participant 6, Physiotherapist – Allied Health Professional)***

The participant's phrase that children are "*just a mess*!" conveys a sense that the participant is feeling deeply frustrated and perhaps quite dismayed by the fact that the current model limits families' opportunities to access the support that they need around this time. Specifically, the participant swiftly moves onto declaring the importance of implementing changes on a healthcare-system level and says "*we need to change our model of working*". The participant further emphasises the importance of organisational change in light of the growing number of children reaching long-term survivorship and presenting with chronic health-related difficulties resulting from cancer and its treatment.

Another participant expressed that the continuity of care during the five-year active monitoring period (also known as the off-treatment period) may be hampered to a certain degree due to the shared care model, which requires children to receive care at hospitals closer to home following completion of active treatment:

> *"So, at [name of tertiary hospital] it is mainly the local hospital that does the off-treatment monitoring. We see them less frequently. We share that off-treatment monitoring with the local hospital. We do see them, but not as frequently and we are not entirely responsible for that."* ***(Participant 2, doctor)***

Here the participant conveys a sense that seeing children less frequently following the completion of active treatment may present with some challenges. The participant doesn't directly express this, however, his sentence "*we do see them, but not as frequently and we are not entirely responsible for that"* communicates that had the shared care model not been the current framework in which HCPs were required to operate, the participant might have preferred to have more frequent contact with patients around this time, presumably due to facilitating continuity of care.

3.4.2. In it together

Colleague support and effective team working emerged as an important protective factor among HCPs participating in the present research. HCPs reported valuing their colleagues and reported feeling fortunate to work alongside people who are compassionate and able to relate to the challenges involved in working in paediatric oncology. Some participants expressed that support from colleagues helped lessen the emotional burden especially during difficult situations:

> *"Ah – colleague.. Colleague support is massive and actually, you know.. Big part of how you do these jobs is working within a team of amazing colleagues as well. And they do.. They get you through.. They get you through some situations. Because it.. Like.. It helps with the emotional burden I think. Talking to other people. And talking to colleagues that understand and it.. It does help." (**Participant 4, Clinical Nurse Specialist)***

What seems to be key in this participant's account is that colleague support operates in the following ways: first the participant mentions that it helps "*talking to people*" suggesting that talking in and of itself can be restorative, and then they mention the importance of talking to "*colleagues that understand*". It appears that these two components together appear particularly important within the context of paediatric oncology. This notion of relying on colleagues also extended beyond emotional support; in the excerpt below the participant expresses her appreciation for working within a team that values each other's roles and contributions:

> *"Oh really comforting. Really comforting. And I guess, I think, that's something that works really well within our team? Is that we all have very defined roles? Umm, but, you know, that compliment each other. But actually we all know what each, sort of, member of the team brings to the table in terms of support for those families." **(Participant 3, Clinical Nurse Specialist)***

Here the participant describes the importance of each member's unique contributions and refers to this as being "*really comforting*". At the same time the participant recognises that members of the MDT recognise what "*each member of the team brings to the table*" and that they are all working towards a common goal which is "*to support those families*".

Participants also seemed to find it reassuring that medical decisions were made in partnership with all members of the team; there was a sense that bringing this combined expertise to children's care planning helped participants feel less 'alone' and that the weight of the responsibility of clinical-decision making was not placed on a single individual but was shared across members of the MDT. In the excerpt below, Participant 2 describes the importance of shared decision-making among staff in relation to patients whose cancer is incurable:

> *"And obviously the starting point there is the multidisciplinary, multiprofessional, team agreeing that we have reached the end of the road. That's the first step. And then once there is consensus around that and that any treatment is futile and potentially will do more harm than good, then that uh.. That information is given to the parents. Even if it's just me having the conversation, usually though it's always me and someone else, it's given as a team decision rather than my decision."* ***(Participant 2, doctor)***

3.4.3. Like an orchestra

Here, the concept of an orchestra is used as a metaphor to illustrate the importance of teamwork and coordination required between the various professional groups within the MDT to ensure the provision of high quality care. Most participants referred, either directly or indirectly, to the importance of working in partnership with the other professional groups from different specialties. A general sense that arose from the interviews was that HCPs felt that each role/discipline was invaluable and uniquely contributed to the wellbeing of patients and their families.

CNSs more frequently spoke of the importance of providing emotional and psychological support to patients and families, a type of support that other specialties spoke less of within the present study. In the excerpt below, the account provided by Participant 3 illustrates how CNSs are required to draw upon a wide range of communication and interpersonal skills, including empathising and identifying with families' feelings as they approach the end-of-treatment, listening to their concerns, reflecting their thoughts back to them, providing reassurance and preemptively

normalising the complex and difficult emotions likely to arise following the end of active treatment:

> *"Some families will say that finishing is as scary as starting, you know, so that support they need is, you know, is almost just as much as what they needed at the start. Umm.. You know.. And I will often just say to families "You just need to be really kind to yourself" and, you know, "Be kind to each other and don't expect .. you know, you will feel worried.. You will.. You know, at times.. You will feel worried and that's.. that's absolutely okay". Just.. And "Don't be surprised if you have a little crumble as you finish treatment", you know "Because you haven't done as you've been on treatment because".. You know.. "Because you've been too busy sort of doing this but, you know, once you finish that might be a point where you need some, sort of, additional support, so just.. Just be aware of that"."* ***(Participant 3, Clinical Nurse Specialist)***

Whilst the excerpt above nicely illustrates how CNSs perceive the provision of psychological support as an integral part of their role, the excerpt below focuses on another critically important aspect of care, the provision of more practical types of support. Specifically, the excerpt below comes from an interview with an occupational therapist (OT), who articulates the importance of seemingly "*simple things*" that have, however, the capacity to empower patients:

> *"We can do quite simple things. Like it might just be giving a wheelchair to someone who's got really deconditioned and can't get to the playground but actually, whilst it's a really simple thing, it can be really empowering, umm, as well. So, I sort of, like we've got these little things that you can tick off quickly, like I say, whether it's a wheelchair or maybe helping somebody in and out of the bath or the toilet, right through to kind of ongoing, weekly developmental support."* ***(Participant 5, OT – Allied Health Professional)***

Despite the benefits of MDT working some participants mentioned that it is not without its challenges. Some participants expressed disappointment and frustration over not feeling that their discipline was valued and acknowledged enough by the team. Particularly a participant working as an OT mentioned that OTs in general are more likely to be confused with physiotherapists; the participant presented a sense that this may be understandable to an extent, due to a certain degree of overlap between the two roles, however, it did cause frustration:

> *"Just in terms of what value OT can bring I think was just really.. Obviously not recognised and there was.. So, we've really spent I guess, you know, all of this time building up the identity of OT again, again like I said, in terms of beyond giving*

wheelchairs, umm.. And actually we can do so much more than that.. [..] And I think that's just historically being an OT.. Everyone thinks we're a physio, you know, all the time, everyone just calls us physios. Umm.. And it's like "No, we're not a physio, we're OT" and, umm, you know, that's from nursing through to consultants through to other profess.. Other AHPs. Umm.. And I think it's just not a very well known profession beyond the basics. And the kind of nuances and subtleties that we can do, I think are just not known so much? […] And, umm.. So, I think that can be difficult and, umm.. Often consultants will automatically go to physios and I think there's just always going to be more physios than OTs and so if there's more people, that raises your profile, umm.." ***(Participant 5, OT – Allied Health Professional)***

Here the participant uses a number of phrases which convey a sense of frustration such as "*everyone just calls us physios*", "*(OT is) obviously not recognised*" and "*we can do much more than that (i.e., giving wheelchairs)".* Here, the participant's frustration appears mainly to stem from others misunderstanding and/or undervaluing the specialist contributions of OT. The data suggested that both OTs and physiotherapists perceived their role as being more practical and involving components aimed to empower parents and help them reclaim some control. In the excerpt below, Participant 6 provides further insights into the role of physiotherapists and discusses how this complements the work of the medical team (i.e., nurses and doctors):

"You know, we're very fortunate in physio that we can often, we have a very positive role to play in.. In a child's cancer journey and often we're.. You know, even when other medical, umm, you know, or other healthcare professionals are having real difficulties with families, we very rarely.. We're very fortunate that we rarely experience that in physio? Because we bring a very positive side and it's generally something families want to do and their child generally, most of the time, wants to to reach their goals? So, we don't really have a lot of, umm.. Conflict or sadness really so, umm.. We're quite.. We're quite – well we are – I think we're quite protected in a way compared to how the nurses sometimes are. Umm, and also really aware that we come and go quite a lot as well, whereas some of the other, you know, nurses who are there for, kind of, 12 hours just looking after families and children is.. Is much more difficult. […] But generally we have a very positive, most of the time, impact." ***(Participant 6, Physiotherapist – Allied Health Professional)***

Here the participant engages in a comparison between the role of physiotherapists and the roles of nursing staff. The participant emphasises that physiotherapy-related interventions are usually welcomed by families and that overall physiotherapists are seen as having a "*very positive role*". Although not directly stated, the participant's narrative conveys a deep appreciation for the nursing staff

and the participant uses validating language to acknowledge how emotionally demanding nursing roles can be; specifically, the participant acknowledges that medical staff often "*have real difficulties with families*" – indirectly implying that perhaps the issues physiotherapists assist with are not as "real" or significant? – and further describes how nurses "*are there for 12 hours just looking after families and children*" and how this is "*much more difficult*" in relation to the responsibilities non-medical staff have.

To illustrate some of the duties and responsibilities of nursing staff, the excerpt below, derived from an interview with a ward nurse, provides a sense of the types of tasks carried out by nursing staff:

> *"We're a 12-bedded unit, umm.. Obviously, inpatient. Umm.. We.. So, I tend to.. Sometimes I take charge of the.. Of the ward. Umm, but we still take patients. So, it's very much patient-facing, yeah. Umm.. So, yeah. And .. Chemo-giver? A bit of everything really. […] CNSs tend to do more of the, umm.. Liaison, I guess between..? So, they're the specific link between the parents and the children? Umm, and then the hospital. […] So, they.. They make sure that all the appointments and the.. The tests and everything are all, umm, done. And we do them (laughs)."* ***(Participant 7, ward nurse)***

In this excerpt, the narrative conveyed by the participant is that nursing staff undertake a wide range of tasks that are critical to patients' cancer treatment; for instance, the participant says that she "*sometimes takes charge of the ward*", indicating that during those times she is responsible for 12 inpatient paediatric cancer patients, that she is a "*chemo-giver*", indicating that she is responsible for administering children's chemotherapy regimens, and she concludes by saying that she does "*a bit of everything*". The participant also makes reference to how the CNS role complements the ward nurse's role, by explaining that CNSs are responsible for much of the liaison and planning involved in providing efficient paediatric cancer care whereas ward nurses are the ones actually performing medical procedures alongside doctors.

4. Discussion

The primary aim of the present study was to explore qualitatively HCPs' experiences with regards to providing care to paediatric cancer patients during the end-of-treatment phase. A secondary aim of the study was to explore how HCPs experience and perceive the ringing of the end-of-treatment bell; a ritualised activity

used across wards in the UK and worldwide to mark endings in paediatric cancer treatment. Participants' narratives provided important insights not only with regard to the end-of-treatment phase, but also in relation to some of the wider challenges that HCPs in paediatric oncology experience.

With regard to endings in particular, HCPs' accounts relayed an overall sense that the end-of-treatment phase, albeit an important milestone, signifies the start of a new phase that entails significant challenges for children and families. Participants' narratives portrayed a sense of endlessness and that, to a degree, the aftermath of cancer and its treatment, will exert a lifelong impact on families. Staff particularly emphasised the various difficulties families experience as they transition from the on-treatment phase to the survivorship phase and HCPs described families as struggling to establish a "new normal"; a finding that has been well documented elsewhere (Lea et al., 2020). Some of the major challenges families face according to HCPs is that they experience the end-of-treatment phase as being "abandoned" and "forgotten" by the healthcare team. HCPs also described endings as being abrupt and sudden and through their accounts they conveyed a sense that it is understandable why families might feel like they are bereft of support around this time. This sense of abandonment experienced by families seemed to be intricately linked to the strong interpersonal relationships and close attachments formed between HCPs and patients/families throughout their cancer journey. Without it being directly stated by HCPs in the interviews, it seemed that the stronger the connectedness between HCPs and families, the more anxiety-provoking and challenging the end-of-treatment phase seemed to be for families, suggesting a dynamic interplay between the *relational,* the *personal* and the *professional*. As briefly mentioned earlier, the fact that parents might experience intensified emotional distress around the end-of-treatment phase, could be better understood with Ainsworth and Bowlby's (Ainsworth & Bowlby, 1991; Bowlby & Ainsworth, 2013) attachment theory in mind. Although attachment theory is primarily concerned with child-parent relationships, it is possible that paediatric cancer patients and their parents might perceive HCPs as their 'secure base' and HCPs might act as an attachment figure for families. This need for an attachment figure around this time is likely to be even more pronounced as children with cancer and their families are typically in a state of anxiety and fear. Within this context, the abrupt and sudden ending that follows the completion of

active treatment might by experienced as the loss of an important attachment figure and could explain parents' consequent reactions of anxiety, denial and sadness.

Apart from HCPs' perceptions in relation to how *parents* experience endings in paediatric cancer treatment, this study adds to our understanding of how *HCPs* themselves navigate this phase. In their accounts, staff bravely explored their own emotional reactions, with the findings presented here suggesting that HCPs might experience a "grieving" period, not only following the death of a patient, but also at end-of-treatment. Participants conveyed a sense that they may also become attached to families and expressed thinking of certain patients and their parents long after their discharge from hospital. The data presented here suggests that HCPs might also experience endings as abrupt, particularly within the context of specialist tertiary cancer centres that operate in line with the shared-care model. As described earlier in this thesis, the shared care model redirects the provision of follow-up care after the completion of active treatment to local hospitals closer to patients' homes, meaning that staff who have provided care during the acute phase of the child's illness have little to no contact with children and their families after they complete treatment. In this study, participants expressed that only being involved in children's care when they are acutely ill and then not seeing patients again after they've reached survivorship, can be emotionally challenging. It is within this context, that initiatives such as "Get Active" days - which are initiatives HCPs spoke of that are organised by tertiary hospitals to encourage children to remain physically active during cancer treatment and beyond - were warmly welcomed by staff as they provided the opportunity for staff members to "reunite" with children and their families that had previously been very ill, but are now happy, healthy and cured of cancer. Although there is currently a lack of research in relation to this, it may be that such initiatives could have a healing, reparatory and restorative effect for HCPs who are exposed to children dying, being in pain and suffering over prolonged periods of time. These findings suggest that such initiatives implemented within healthcare organisations might represent helpful strategies for staff to process and cope with work-related losses, whether these are related to patient deaths or endings in general. The concept of work-related losses in oncology settings has been discussed in previous literature, however, these have predominantly been discussed in relation to patients dying and professional bereavement (Chen, Chow, & Tang, 2018; Jonas-Simpson, Pilkington, MacDonald, & McMahon, 2013) with few studies acknowledging

that successful completion of a patient's cancer treatment may also be experienced by HCPs as a work-related loss (Conte, 2014). Moreover, work-related losses have predominantly been explored among nurses and not among other professional groups within the MDT. Given the relational closeness that develops between HCPs and families within this context, it may be important to consider the implementation of initiatives that formally acknowledge that endings and the absence of the relationship with past patients/families may be experienced as emotionally challenging by staff as well and may be associated with grief responses. Previous research has shown that validation – that is, accepting that another person's experience is real and valid without judgment – is associated with significant reductions in physiological and emotional arousal during stressful situations (Shenk & Fruzzetti, 2011), suggesting that even the simple act of acknowledging and employing more validating responses to HCPs' losses and grief reactions (e.g., "I can see how much this patient/family meant for you", "I understand this is difficult for you") could have a healing effect. Validation has been found to have a buffering effect in that it helps individuals preserve positive affect when faced with interpersonal stressors (Benitez, Howard, & Cheavens, 2020). Based on the finding that HCPs are deeply affected by the losses they witness in this context, it appears that the validation of their experiences and the provision of ongoing psychosocial support to help staff manage work-related loss and professional grief are necessitated in paediatric oncology.

Importantly, the findings presented here conveyed a sense that HCPs were overall hesitant to discuss the more emotional and relational aspects of providing care to paediatric cancer patients. Staff's accounts portrayed a narrative that emotions might be perceived as a sign of unprofessionalism and weakness within the healthcare setting and described there being a fine line between establishing strong rapport – a fundamental requirement for the provision of effective healthcare (English, Gott, & Robinson, 2021) - and emotional over-involvement. Participants spoke of the importance of maintaining professional boundaries, but at the same time expressed that it is challenging to ensure that appropriate emotional distance is maintained at all times. Participants expressed that families might come to perceive HCPs almost as "professional friends", which in turn makes it more challenging for HCPs to maintain an unemotional and objective stance. Moreover, the data presented here highlighted that for certain specialties within the MDT this challenge might be greater; for instance, nursing staff (including CNSs and ward nurses)

seemed to discuss more frequently the emotional demands of their roles compared to doctors and allied health professionals (AHPs). Although generalisable conclusions from the present study cannot be drawn given the small sample size and the qualitative nature of the present study, previous research has also reported that nurses are more likely to experience emotional distress compared to other professional groups (Kinman & Leggetter, 2016). Nurses' narratives in the present study relayed a sense that they might be more likely to be the ones mostly providing emotional support to families; this was conveyed in multiple ways; *first*, nursing staff explicitly recognised the provision of emotional support as an integral part of their role, whereas this was not explicitly communicated by the other two professional groups (i.e., doctors and AHPs); *secondly*, doctors were more likely to use biomedical and objective language when describing some of the more challenging situations related to patient care (e.g., transition into palliative care), reflecting a reasoning process that was more concerned with the *factual* rather than the *emotional*. *Thirdly*, nursing staff were more likely to discuss their own emotional vulnerability as a response to the emotional burden associated with nursing care in paediatric oncology. Specifically, nurses more frequently described feelings of anxiety and guilt and some described that work-related concerns sometimes bled into their personal lives. There was a felt sense that the other professional groups (i.e., doctors and AHPs) were also more likely to perceive nurses as being better positioned to discuss some of the more emotional aspects of paediatric cancer care – for instance, in relation to bell ringings, which are associated with greater expressed emotion by families and staff, doctors conveyed a sense that this is not something that they are usually involved in and advised the researcher to redirect these questions to nursing staff. Moreover, AHPs participating in the present study, described feeling quite protected from the emotional stressors associated with paediatric oncology and they tended to perceive their roles as "positive" – for instance, both the physiotherapist and the occupational therapist described that the types of practical interventions they deliver (e.g., providing equipment, helping patients with physical activity etc.) are usually very much welcomed by families as they provide families with something tangible and practical to do, however nurses were less likely to express similar narratives.

Taken together these data suggest that nurses may require substantial support within the workplace in order to be able to navigate these relational

complexities that will inevitably occur within this setting; it might be of particular importance for nurses to have more guidance and input in relation to how they can manage and regulate their own emotional reactions to distressing situations that occur on the ward. Within the present data, it was conveyed that nurses had little opportunity to safely explore their own emotional responses within the workplace. This in turn may be associated with maladaptive coping mechanisms such as the tendency to repress, over-control or deny their emotions. Repression and inhibition of emotions have long been associated with a range of negative outcomes such as emotional exhaustion and emotional labour, with the latter increasing the likelihood of HCPs engaging in surface acting and refraining from expressing genuine emotions (Kinman & Leggetter, 2016). As discussed earlier emotional labour is associated with negative psychosocial and work-related outcomes among staff, including professional burnout, compassion fatigue, and greater turnover intention (Delgado, Upton, Ranse, Furness, & Foster, 2017). Therefore, possible interventions should aim to support nursing staff in recognising, managing and working constructively with their own emotions and to ensure that they feel adequately supported in the workplace. Apart from staff support being directly beneficial for staff's wellbeing, it is also highly relevant to patient safety and the provision of high quality care; burnout, emotional exhaustion and compassion fatigue among healthcare staff have all been associated with increased medical errors and poorer quality of care and poorer patient safety (Hall, Johnson, Watt, Tsipa, & O'Connor, 2016). There is therefore a need to develop strategies that ensure nurses and all healthcare staff groups are able to provide high quality and compassionate care without sacrificing their own wellbeing.

In the present study, nursing staff reported that although much of their role requires them to provide psychological support to patients and families, they do not formally receive any counselling and/or psychology-related training, suggesting that there is additional pressure placed on individual nurses to acquire this knowledge 'on the job'. Whilst the development of skills through direct professional experience is anticipated, it seems vital that nursing staff receive more formalised training within this domain given that it has been recognised that the provision of psychological support is a key part of the nursing profession. Moreover, nursing staff reported a lack of clinical supervision in relation to providing psychological support to families, and reported relying on each other for emotional support and advice; a finding that

further highlights the urgent need to put strategies in place that will support this professional group in particular. Although peer support has been associated with increased staff wellbeing (Pereira, Radovic, & Haykal, 2021), it seems important that this is combined with more formalised support that is embedded within wider institutional structures.

One example of institutional support discussed by nurses was the offering of debriefs following a patient's death and/or any other critical incident; nurses discussed that during debriefs staff are encouraged to explore their emotions within the safety of the group (although important aspects such as the format of debriefs and/or the presence of a facilitator were not discussed by nurses). Despite previous research supporting the use of Critical Incident Debrief Sessions (CIDS) for professionals caring for children with life-threatening conditions (Keene, Hutton, Hall, & Rushton, 2010), the findings from the present study suggest that nurses in particular did not find these helpful. Some of the reasons mentioned by staff included the fact that debriefs tended to not provide information relating to the circumstances in which the critical incident and/or death occurred; nurses expressed wanting somebody to outline for them some of they key information pertaining the incident, presumably to aid understanding and facilitate the processing of the event. Moreover, it was reported that debriefs felt overly formal and structured, and nurses expressed gaining more comfort from informal conversations with colleagues. Based on these findings, and given that debriefs are widely considered effective, it would be useful to further explore via qualitative means, what factors might affect how debriefs are experienced by different staff groups in paediatric oncology. For instance, key questions that would be potentially useful to explore include: What do HCPs find unhelpful about debriefs? What could make them more helpful? How are these conversations facilitated? By whom? What is their format? How soon after they incident are they delivered?

In terms of wider systemic challenges, participants discussed certain factors that were seen as further amplifying the difficulties that some families experience at the end-of-treatment; one of these factors was the perceived inequity in relation to the provision of psychosocial support. Allied health professionals in particular, described instances where some families received a lot of support throughout their cancer journey for their physio- and OT-related needs, whilst others either received minimal or no support at all, highlighting possible disparities in accessing

psychosocial supportive care along the cancer pathway. Participants partly attributed this to some families being less able to advocate for their needs and voice their concerns and/or treatment-related preferences throughout their treatment, resulting in some children having very little or potentially no input for a range of issues, including mobility-, speech and language-, mental health- and activity-related issues; all of which are known to affect children's long-term quality of life and wellbeing (Ness et al., 2010; Siegwart et al., 2020).

Participants highlighted the importance of shifting towards a *proactive*, rather than a *reactive*, model of care whereby, apart from the medical interventions children receive as part of their anti-cancer treatment regimen, all paediatric cancer patients and their families also receive a baseline level of psychosocial support that is adapted and personalised to meet their needs. Participants expressed experiencing ethical dilemmas and feelings of guilt and 'uneasiness' in response to these inequities, and their narratives conveyed a sense that it feels impossible at times to be an 'agent of change' within a healthcare system that is facing immense economic challenges and therefore is unable to fund more of these services that could in turn prevent the inequitable access observed at present. Participants also highlighted the importance of empowering parents and educating them around both the types of services that are available to them as well as around their child's cancer diagnosis in order to increase the likelihood of having their voices heard and their needs met. Previous research has repeatedly discussed the significance of self-advocacy in oncology (Hagan, Rosenzweig, Zorn, van Londen, & Donovan, 2017). These findings suggest that initiatives that promote self-advocacy and awareness among parents could potentially contribute to the reducing some of the inequities discussed by participants in the present study.

Within the context of the current study, it was proposed that apart from having end-of-treatment days it might be equally important to introduce on-treatment days as an opportunity to get families together and provide them relevant information relating to the psychosocial support available to them in a timely and proactive manner. The importance of making such initiatives accessible to families that are likely to face more barriers in accessing information – for example, health literacy and language-related barriers – was also highlighted.

Another systemic barrier participants discussed within the wider context of endings in paediatric cancer treatment related to challenges arising with regards to

continuity of care. As mentioned earlier in this thesis, in the UK, paediatric cancer patients transition from the end-of-treatment phase into a five-year active monitoring period (during which children's risk for cancer recurrence is at its highest), which is then followed by a long-term follow-up period. Participants described that during that five-year active monitoring period, children primarily undergo medical procedures (e.g., MRI) to ascertain whether there are signs of cancer recurrence, but that the psychosocial support available to families around that time is practically non-existent, possibly increasing children's risk of adverse health-related outcomes. For instance, participants described that it was not uncommon for children to present with a range of developmental difficulties at long-term follow-up at which stage opportunities for early intervention had dissipated. Participants expressed feeling shocked and frustrated that paediatric cancer care is not structured in a way that emphasises the importance of proactive care and early intervention and there was a felt sense that the system is "failing" these children and families.

In relation to the end-of-treatment bell, participants' narratives in their majority conveyed a sense that it is a ritualised activity that evokes conflicting emotions and views among staff. Staff expressed that undoubtedly these celebratory ceremonies were warmly welcomed by parents and children whose treatment had been curative and was a way for families to mark the end-of-treatment as the important milestone that it is. HCPs conveyed a sense that bell ringings were particularly important for parents, as some children were often too young to understand the purpose of the bell. One interpretation for this could be that after going through the multiple difficult stages leading up to the end-of-treatment, parents might feel that they deserve to experience a moment of joy on the ward, which had otherwise been a place associated with fear, pain, illness and anxiety. In relation to how HCPs experienced bell ringings, there was a sense among doctors that they were rarely able to attend these but that when they did they experienced them as pleasant. Some participants described finding bell ringings as being moving and expressed feeling tearful at times; perhaps this formalised ritual activity provides HCPs the opportunity to express their emotions within the workplace. In line with the findings presented earlier, which illustrated that HCPs might be hesitant to allow themselves to express their emotional reactions - particularly with regards to the relational aspects of their role - in fear of being perceived as unprofessional, it is understandable why the use of a symbolic

object such as the ringing of the bell might encourage feeling and expression of emotion.

Previous literature has examined the importance of rituals and symbolic objects particularly in relation to grief; for instance, Romanoff and Terenzio (1998) proposed that grief therapy encourages the use of symbolic objects as they act as a representation of the relationship with the lost loved one. Within this context, bell ringings might provide staff the opportunity to bid children and families farewell as they transition into survivorship. As discussed earlier, the data presented here indicated that staff also experience endings as somewhat abrupt and therefore having the opportunity to attend a child's bell ringing might help facilitate a sense of closure for HCPs and might promote acceptance that their relationship with their patient is also undergoing a transition – that is, accepting that this child no longer requires their input as they are not a *current* patient but an *ex* patient. In other words, bell ringings might not only be a ritual that marks the ending of paediatric cancer treatment but also a ritual of *separation* that resonates strongly with HCPs and families alike.

Another parameter of this ritualised activity participants frequently discussed related to the presence of others during bell ringings. Specifically, HCPs discussed that bell ringings often turned into major celebrations on the ward and were frequently attended by various members of staff, by children's extended families, such as aunts and uncles, as well as by other children on the ward and their families. Through participants' narratives there was a sense that having this ritual witnessed by others was an important aspect of what made them meaningful for children and families. Within the context of death and bereavement, research has shown that including significant others in ritual enactment allows the bereaved person to express publicly their grief - when typically grief is concealed and hidden - and provides opportunities for the bereaved to receive social support and experience a sense of solidarity (Castle & Phillips, 2003, Doka, 2012). In regard to the bell-ringing ritual in particular, the symbol of the bell itself represents the need for it to be heard by others – it is loud and opposes the more widely accepted norm of 'quietness'. Previous ethnographic research has discussed the long use of bells for religious purposes and across multiple religions, such as Buddhism, Orthodoxy, Catholicism, and Taoism, where the ringing of the bell usually signifies the start or the end of a religious ceremony (MacKinnon, 2016; Parker & Spennemann, 2020). Particularly in Christian

countries bells are associated with celebrating events of high emotional significance – e.g., weddings, baptisms, national celebrations, important holidays (e.g., Christmas) as well as times of sorrow, such as funerals or during the Holy Week of Easter (Kovacic, 2006). Bells also have been associated with the function of signalling; for instance, marking time, important events, dangers. Here, the ringing of the cancer bell appears to constitute a symbol of transition from one phase to the next and represents a formal ritual to signify the passage from one status to another (Needham, 1967).

Despite staff unanimously agreeing that it is important for families to have the opportunity to mark the end-of-treatment, there was a felt sense that this ritual might best be placed away from the ward. Staff discussed how such a public statement for achieving curative treatment could be perceived as insensitive by other families who were grappling with acute illness, non-curable cancer and/or transitions into palliative care. Taken together the data presented here suggest that HCPs are mostly in support of the use of bell ringings as a ritualised activity to mark patients' *rite de passage* from the on-treatment to the off-treatment phase, however, its presence on paediatric cancer wards should be carefully reconsidered to ensure that undue distress for other patients and families is prevented as much as possible.

4.1. Limitations

The present study was conducted within a single research site, a specialist cancer tertiary care centre within the context of the UK's national health system. The findings presented here might be reflective of this particular, highly localised context and the insights and understandings documented here may not be generalisable to other cancer settings, whether nationally or internationally. Further exploration of how HCPs experience endings in paediatric cancer treatment and the bell ringing as an ending ritual in particular is required to gain additional insights into this phenomenon.

Another limitation concerns the lack of representation by certain specialties within the paediatric oncology MDT; for instance, other AHPs, such as play therapists and speech and language therapists were not represented in the current data. A greater representation of ward nurses would have been preferable as only one participant from this professional group took part in the study. Despite these limitations, the results presented here make an important contribution towards understanding HCPs' experiences in relation to providing care to paediatric cancer

patients around the end-of-treatment. Moreover, these findings present new-found insights in relation to the bell ringing ritual and how this is perceived and experienced by staff; a phenomenon that has not be explored previously within the literature.

4.2. Conclusions

This qualitative study is, to the author's knowledge, the first to report on the experiences of HCPs in relation to providing care to paediatric cancer patients at the point of treatment completion. The findings revealed that the end-of-treatment phase presents with a range of challenges not only for paediatric cancer patients and their families, but also for HCPs working within this setting. This study revealed some unique experiences of paediatric oncology HCPs particularly in relation to the cancer bell as an end-of-treatment ritual. HCPs' perceptions around the bell have not been documented elsewhere highlighting this study's unique contribution to the field. Additional studies are required to explore further how endings are experienced among HCPs in this setting; it may be of particular importance to explore perceptions of the bell within the paediatric cancer triad – that is, among children, their families and HCPs. Such evidence could provide a useful basis upon which more effective support services are developed to ensure that children and families' needs are met as they transition into survivorship and that HCPs are also adequately supported around this time.

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PART 3

CRITICAL APPRAISAL

1. Overview

Within Part Three of the thesis I, the researcher, reflect upon the experience of undertaking the empirical study presented in Part Two. The reflections presented here were informed both by the bracketing interview that was conducted with a Consultant Clinical Psychologist as well as the reflective journal I kept throughout the research process. The reflections presented here focus on three key sections. The *first* section briefly discusses the concept of reflexivity and describes some of the steps I took towards maintaining reflexivity throughout the research process. Naturally, this section provides a reflection on some of my own experiences, personal interests and presuppositions that were highlighted during the bracketing exercise and considers the impact these may have had on the research process. The *second* section discusses some of the contextual factors that influenced the process of conducting this research; particularly, I discuss how the Covid-19 pandemic affected various stages of the research process including participant recruitment, interviewing and data analysis. The *third* and last section discusses some of my reflections in relation to narratives that may be held in relation to HCPs' professional identity and I present some thoughts around how certain areas of vulnerability may be unrecognised within this professional group. Personal reflections are embedded throughout the various sections.

1.1. Reflexivity and exploring my own position throughout the research

Reflexivity is considered a central practice when conducting qualitative research and refers to the process by which the researcher is able to consider the role of the self in the research process whilst being aware of their own presuppositions, beliefs and assumptions (Berger, 2015). Reflexivity requires the researcher to actively engage with all aspects of the research process and to continuously evaluate their own subjective responses and the impact these may have on the creation of knowledge (Cutcliffe, 2003). Within the context of the present research, issues pertaining to reflexivity included the consideration of the reasons behind choosing to pursue this specific research topic as well as how my personal beliefs, interests and experiences may have influenced the data collection and data analysis processes.

In relation to choosing this research topic, the bracketing interview placed particular emphasis on how my previous familiarity within the area of cancer research, which I developed through conducting a PhD on cancer screening uptake prior to clinical training, may have played an important role in pursuing this topic for my DClinPsy thesis. I reflected that having gained research experience on the topic of cancer during my PhD could have either deterred me completely from wanting to pursue any further research in this area or alternatively it could have represented a motivating factor to continue to conduct research in the same area. Personally, my previous research experiences had reaffirmed that my professional and academic interests are firmly embedded within the areas of health psychology, psycho-oncology and public health. The bracketing interview further highlighted that despite having conducted previous research in the field of cancer, the present study had a substantially different focus to the research I had undertaken previously. In summary, my PhD was concerned with exploring uptake of cancer screening among adult populations, the sample comprised of service-users and data were analysed by using predominantly quantitative methodologies. Contrastingly, the present research was related to paediatric cancer, the sample consisted of service-providers and adopted qualitative methodologies both for the systematic review (i.e., meta-synthesis) and the empirical paper (i.e., IPA).

Undoubtedly, the experience of conducting my PhD highlighted the importance of both quantitative and qualitative methodologies and that both play an invaluable role in the creation of scientific knowledge. However, at the same time my previous research experience strongly instilled in me the sense that I am more deeply invested in exploring and understanding how individuals make sense of their experiences and how one person's account of an experience can be conveyed to another through the process of dialogue. Therefore, the bracketing interview highlighted that my motivation to pursue this research topic was not only driven by my prior research experience in the field of cancer and my particular professional and academic interest in psycho-oncology but also by the fact that I strongly wished to pursue a project that required a qualitative research methodology for my DClinPsy thesis. Therefore, having the opportunity to pursue further research in the field of cancer through the means of qualitative research in particular was the main motivation behind choosing this topic.

In terms of the data collection process, one of the issues identified through the bracketing exercise related to experiencing a slight conflict between my identity as a trainee clinical psychologist on the one hand and my identity as an academic researcher on the other. Previously, alongside my PhD I had also worked as an Assistant Psychologist and there were times when I found it challenging to maintain a strictly research-oriented stance when collecting data for my PhD whilst also working clinically. Within the context of the present research and prior to commencing data collection, I sensed that the challenge of maintaining a balance between these two "identities" would be even more pronounced given that I was even more actively involved in clinical work during my DClinPsy training. Both the bracketing interview and keeping a reflective journal helped me process some of my worries in relation to having this dual identity; prior to starting the interviews, I was particularly worried that I might respond to participants' accounts more as a mental health practitioner rather than a scientist particularly in the event that participants expressed vulnerability. One tangible example of how this manifested during interviews was during instances when participants disclosed experiences that they felt had been distressing. It required a lot of conscious effort to remind myself that within the context of the present research my main responsibility was to promote understanding around the particular phenomenon of interest rather than alleviate distress. I became increasingly aware during interviews that I found it particularly challenging to retain a strictly "researcher" stance and that at times I could not refrain from wanting to ensure that participants felt "held" and safe enough to explore their thoughts and emotions as these arose during the interview. Upon reflection, it required substantial considerable intentional effort to ensure that on the one hand I responded to participants' accounts with empathy and warmth but that on the other I was able to maintain my focus on obtaining rich data that would expand on current understandings in relation to how HCPs experience the provision of care towards paediatric cancer patients at the end of treatment.

Keeping a reflective journal during the data collection process helped maintain reflexivity and self-awareness during instances where perhaps I responded to participants more as a practitioner and during times when I "lost sight" of the key purpose of the research. I was particularly conscious that participants knew of my professional orientation as a mental health practitioner beforehand and that therefore they might have, either consciously or unconsciously, held expectations of me to

respond to their narratives as a therapist rather than a researcher. Upon reflection, I think that my tendency to want to respond to participants' disclosures more as a mental health professional, may have been exacerbated particularly within the context of the Covid-19 pandemic and the evidence that was emerging around the time the interviews were being conducted around increased risk for distress, moral injury, burnout and post-traumatic stress among HCPs providing care to patients with Covid during the pandemic (Heath, Sommerfield, & Von Ungern-Sternberg, 2020). Entries in my reflective journal conveyed a sense that I felt strange to be focusing on endings in paediatric cancer treatment at a time when HCPs nationally and internationally were at the front-line of delivering care to Covid-19 patients during a global public health crisis. Following discussions with my supervisor, it was agreed that should participants' narratives concern experiences related to Covid-19 and how their practice may have been influenced as a result of the pandemic, I would actively remind myself, in line with IPA principles, to consciously engage with the material the participant was bringing rather than being overly concerned with the structure and/or content of the interview schedule. Journaling throughout the data collection process was particularly helpful in this regard in that it encouraged me to reflect on my interactions with participants following each interview and also helped with being mindful of potential pitfalls as I prepared for subsequent interviews.

Active engagement with journaling also helped me maintain a curious stance about my own emotional responses whilst I was analysing the data; for instance, there were times during the interview process where I experienced emotions of frustration and even anger at times particularly with regards to some of the issues relating to inequalities in the provision of healthcare that were raised by some participants. Linking this to my research experiences prior to the DClinPsy, my PhD largely focused on identifying the factors that contribute to racial and socioeconomic inequalities observed in cancer screening uptake in the UK. Due to having studied cancer screening inequalities in such depth previously, I felt that I was particularly sensitised towards any aspect within participants' accounts that concerned inequalities in the provision of healthcare. Some entries in my journal reflected this sense that I had strong opinions and views around this and that I had the urge to particularly focus and 'go deeper' in relation to this aspect in particular. Reflecting on my emotional reactions and keeping a record of some the thoughts I had following each interview helped me resist my tendency to want to express my own views and

consciously ‘checking in’ with myself was helpful in ‘bracketing’ off my prior knowledge, thereby reducing the risk of distorting or “contaminating” the interview with my own assumptions and biases. In favour of transparency, I did not manage to achieve this at all times and there were instances where I found myself expressing some of my personal views during interviews with participants. Therefore, I acknowledge that, to a certain degree, my own feelings, thoughts and views are likely to have influenced the findings presented here.

1.2. Contextual factors

The initial stages of conducting this research - including the formulation of the research question, the development of the study protocol and preparations for applying for ethical approval - took place prior to the outbreak of the Covid-19 pandemic. All subsequent stages, including applying for ethical approval, data collection, data analysis and write-up of study findings, took place following the outbreak of the Covid-19 pandemic. Given that the Covid-19 pandemic has resulted in many changes on various levels (i.e., individual, societal, national, global) and all aspects of human undertakings I felt it important to consider within this section how some of these changes may have impacted on the present research project.

First, one of the challenges directly linked to the pandemic related to delays in gaining ethical approval and therefore commencing recruitment. Due to the unprecedented circumstances we collectively found ourselves in, it was understandable that healthcare research projects directly related to Coivd-19 were prioritised and all scientific resources were dedicated towards clinical trials aimed at identifying strategies to protect the general public from this major public health threat. As a result, the present research study was submitted for ethical approval five months later than originally scheduled and we received confirmation of ethical approval in October 2020 with recruitment commencing shortly after.

Apart from the delays in gaining ethical approval, another challenge that presented itself concerned the inability to conduct interviews face-to-face as initially planned due to the UK government restricting the movement and gathering of people and advising the public to stay at home where possible. A contingency plan was devised suggesting the use of an e-research method, which required the use of video-conferencing tool – in this instance, Zoom – as an alternative to conducting the

interviews face-to-face. Recent data suggest that the pandemic has highlighted an increasing need for conducting health-related research that does not rely on face-to-face contact and that alternative data collection and participant recruitment strategies should be explored (Villarosa, Ramjan, Maneze, & George, 2021). Within the context of the public health emergency we are currently experiencing, the development of alternative e-research strategies may be become particularly vital for ensuring that public health research, which is essential for informing the development and commissioning of services, can continue as we transition into the post-pandemic world.

Although I had not previously undertaken research using e-research methods, I was overall pleasantly surprised by how straightforward and convenient it was to conduct the interviews remotely. In this section I briefly outline the advantages and limitations of conducting the interviews via Zoom. A key advantage was that I felt that participation in the research was made more convenient and accessible to HCPs particularly during a time of increased professional demands due to the pandemic. My own reflection was that it is likely HCPs may have been more inclined to participate in an online interview as this may have been perceived as less time- and energy-consuming and fairly relaxed compared to a face-to-face interview. Moreover, I felt that despite conducting the interviews virtually I was able to collect rich data likely comparable to the data collected face-to-face.

A possible limitation of conducting the interviews online related to the fact that I was not present in the room with the participant, and consequently important non-verbal and contextual information may have been lost. Moreover, despite my own perception of having developed strong rapport with the majority of participants, it is likely that conducting the interviews virtually may have compromised the establishment of rapport with some interviewees, which in turn will have had an impact on how able participants felt to disclose aspects of their experience. Previous research supports that good interpersonal connection during qualitative research is crucial for rapport-building (Pitts & Miller-Day, 2007), however I was unable to identify any research exploring whether rapport is compromised when conducting one-to-one qualitative interviews using e-research techniques. Another possible limitation involves the fact that I was not able to visit the hospital setting myself in order to conduct the interviews. It is likely that being physically present within participants' professional environment and being able to get a sense of the setting myself would

have communicated important contextual information that could have deepened my understanding of HCPs' accounts. Had there not been a global pandemic, I might have also been able to also become an active observer of a bell ringing celebration on the ward or alternatively I might have been able to at least hear a bell being rung or get a visual sense of where the bell was located on the ward. On the one hand this may have been helpful with regards to approaching the data analysis having had this context in mind, however, upon reflection I felt that not having had the opportunity to directly observe the bell ringing ritual or its location on the ward may have had a somewhat protective effect in that it prevented me from developing my own views, beliefs and preconceptions in relation to the bell, thereby further preventing my own biases from infiltrating the data.

1.3. HCPs: Heroes or Humans?

Another central theme in terms of my own reflections during the time I conducted this research, concerned a felt sense that narratives around HCPs portray an image of them being "invincible". Some of my reflections concerned the notion that HCPs hold a unique position in society - on the one hand they are highly respected, acknowledged and privileged figures within the community, yet on the other hand they carry great responsibility and are possibly held to a higher standard compared to other professional groups. Previous research suggests that healthcare workers are at risk of experiencing depression, anxiety, burnout, insomnia, compassion fatigue, moral distress and suicidal ideation (Ahmed, Banu, Al-Fageer, & Al-Suwaidi, 2009; Mata et al., 2015; Tyssen & Vaglum, 2002) and yet despite the evident need for integrating staff support initiatives within existing healthcare structures, there seems to be a research-to-practice gap in that there appears to be a mismatch between what is *needed* and what is *offered* in terms of staff support. For instance, in the present thesis a common finding identified across both the systematic review and the empirical paper was that despite staff reporting experiencing emotional distress in response to work-related stressors and demands, there was minimal support available to them via their organisation. Moreover, staff often reported that they felt they could only rely on colleague support to manage occupational distress and they largely attributed this to the fact that those outside the caring professions would be unable to understand and adequately support HCPs with

the unique challenges they experience within the workplace. Although not explicitly stated by participants during the interviews, I found myself thinking that participants felt apprehensive to openly disclose vulnerability and psychological distress within the workplace in fear that they might be perceived as less competent or as unprofessional. Perhaps this reflects wider organisational and societal discourses that perceive HCPs as being competent, logical, empathic, nurturing and emotionally resilient at all times, without acknowledging and normalising that HCPs, just like everyone else, may experience periods of psychological distress and mental health difficulties.

The wellbeing of healthcare professionals attracted newfound interest within the scientific community particularly within the recent context of the Covid-19 pandemic. Recent data has overwhelmingly suggested that HCPs have experienced immense psychological distress due to the unprecedented demands placed on them as a result of the pandemic. Studies have reported increased occupational burnout , higher suicide rates and higher rates of anxiety and depression (Bryant-Genevier et al., 2021; Young et al., 2021). At the same time, a dominant discourse among the general public and in the media has been the portrayal of HCPs as 'heroes', which unintentionally may have placed additional emotional pressures on staff; perhaps such narratives of being a 'hero' or a 'superhuman' communicates a message to staff that they ought to risk, and potentially sacrifice, their own wellbeing in order to selflessly support others.

The pandemic has highlighted more than ever that staff support should be a leading public health priority given that the very existence of the NHS, and other healthcare organisations worldwide, is contingent on the capacity of its workforce to not only merely function but to thrive. Poor staff wellbeing is a major public health concern in that research has consistently shown that it is inextricably linked to poorer patient safety, higher risk of medical error, increased absenteeism and poorer staff retention. The long-term quality and sustainability of healthcare services greatly relies on its ability to retain highly-skilled and competent healthcare workers, thus highlighting that healthcare organisations should mobilise and dedicate resources towards establishing and integrating effective staff support policies within the healthcare context.

Although attending to the emotional needs and psychological wellbeing of HCPs is as imperative as ever within the context of the pandemic, I feel it is critically

important to not only advocate for the need of effective staff support initiatives during times of crisis, but to also ensure that staff are able to readily access support within their day-to-day professional activity. My personal view is that it is vital that we collectively work towards dismantling the 'hero' narrative and that we are more cautious with the language we use particularly at times of collective distress, grief and fear. The pandemic has been ongoing for approximately 17-18 months now, with its effects likely to be significant in years to come, and a public narrative that emphasises individual heroism is likely to place additional significant pressures on staff to continuously go above and beyond their duty of care during this period, potentially risking their own welfare. Working towards establishing a more realistic narrative that acknowledges that HCPs are human and therefore vulnerable to psychological stressors similar to everyone else might foster greater openness in discussing the difficulties healthcare workers experience and might help us at a societal level to collectively acknowledge that we ought to reciprocally support HCPs as well.

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APPENDICES

PART 1 - SYSTEMATIC REVIEW

Appendix 1.1. Initial search strategy in Ovid databases focused on endings

Stem group 1: Type of population

Children

EMBASE

1. child/ or preschool child/ or school child/
2. or toddler/
3. adolescent/
4. child*.mp.
5. toddler*.mp.
6. adolescent*.mp.
7. teenager*.mp.
8. kid*.mp.
9. or/ 1-8

Number of papers from Stem 1: 4,314,474

PSYCINFO

1. child*.mp.
2. preschool child*.mp.
3. school child*.mp.
4. toddler*.mp.
5. adolescent*.mp. or exp Adolescent Health/
6. teenager*.mp.
7. kid*.mp.
8. or/1-7

Number of papers from Stem 1: 1,025,837

Stem group 2: Type of population

Healthcare professionals

EMBASE

10. health practitioner/
11. pediatric nurse practitioner/ or pediatric nurse/ or nurse/ or oncology nurse/
12. clinician/
13. physician/
14. health* professional*.mp.
15. health* practitioner*.mp.
16. (p?ediatric nurse practitioner or p?edtaric nurse or nurse or oncology nurse).mp.
17. clinician*.mp.

PSYCINFO

9. health practitioner*.mp.
10. (p?ediatric nurse practitioner or p?edtaric nurse or nurse or oncology nurse).mp.
11. exp Clinicians/
12. exp Physicians/
13. Health* professional*
14. clinician*.mp.
15. physician*.mp.
16. doctor*.mp.
17. consultant*.mp.
18. oncologist*.mp.
19. exp Onclogy/ or oncology nursing.mp.

18. physician*.mp.
19. doctor*.mp.
20. consultant*.mp.
21. oncolog*.mp.
22. oncology nursing.mp. or oncology nursing/
23. multidisciplinary team*.mp
24. multi-disciplinary team*.mp.
25. MDT*.mp.
26. cancer MDT*.mp.
27. healthcare team*.mp.
28. health-care team*.mp.
29. or/10-28

Number of papers from Stem 2: 1,785,966

20. nurses.mp. or exp Nurses/
21. Exp Health Personnel Attitudes/ or multidisciplinary team*.mp.
22. MDT*.mp.
23. Cancer MDT*.
24. (healthcare team* or health-care team* or health care team*).mp.
25. or/9-24

Number of papers from Stem 2: 307,637

Stem group 3: Paediatric cancer

EMBASE

30. malignant neoplasm/
31. childhood cancer/
32. oncology/
33. childhood leukemia/
34. leukemia/
35. lymphoma/
36. leuk?emia.mp.
37. malignant neoplasm*.mp.
38. childhood cancer*.mp.
39. oncology/ or oncology.mp.
40. childhood leuk?emia.mp.
41. lymphoma.mp.
42. tumo?r.mp.
43. p?ediatric cancer.mp.
44. or/30-43

Number of papers from Stem 3: 3,375,988

PSYCINFO

26. exp Neoplasms/ or malignant neoplasm*.mp. 27.Childhood cancer*.mp.
28. Oncology.mp. or exp Oncology/
29. childhood leukemia.mp.
30. exp Leukemias/
31. lymphoma.mp.
32. leuk?emia.mp.
33. malignant neoplasm*.mp.
34. childhood leuk?emia.mp.
35. tumo?r
36. p?ediatric cancer.mp.
37. or/26-36

Number of papers from Stem 3: 59,984

4th Stem group: Ending Cancer Treatment

EMBASE

45. (end* adj3 cancer treatment*).mp.
46. (end* adj3 cancer intervention).mp.
47. (end* adj3 cancer therapy).mp.
48. end* cancer treatment.mp.
49. end* cancer intervention.mp.
50. end* cancer therapy.mp.
51. (complet* adj3 cancer treatment).mp.

PSYCINFO

38. (end* adj3 cancer treatment*).mp.
39. (end* adj3 cancer intervention*).mp.
40. (end* adj3 cancer therapy).mp.
41. end* cancer treatment.mp.
42. end* cancer intervention.mp.
43. end* cancer therapy
44. complet* adj3 cancer treatment

52. (complet* adj3 cancer intervention).mp.
53. (complet* adj3 cancer therapy).mp.
54. postcancer treatment*.mp.
55. post-cancer treatment*.mp.
56. (off-treatment adj3 cancer).mp.
57. cancer survivor/ or cancer survival/
58. cancer surviv*.mp.
59. end-of-treatment transition*.mp.
60. (transition adj3 palliative care).mp.
61. post-cancer adjustment*.mp.
62. cancer rehabilitation.mp. or cancer rehabilitation/
63. (transition adj3 cancer).mp.
64. (transition adj3 cancer surviv*).mp.
65. (mark* adj3 end*).mp.
66. (drug therapy adj3 cancer).mp.
67. Chemotherapy/
68. Adjuvant radiotherapy/ or radiotherapy/ or cancer radiotherapy/
69. (surgery adj3 cancer).mp.
70. Immunotherapy
71. Radiation therapy.mp.
72. (adjuvant therapy adj3 cancer)
73. Or/45-72

Number of papers from Stem 4: 1,028,576

45. complet* adj3 cancer intervention
46. complet* adj3 cancer therapy
47. (post-cancer treatment or postcancer treatment).mp.
48. (off-treatment adj3 cancer).mp.
49. (cancer survivor or cancer survival).mp.
50. (end-of-treatment transition or end of treatment transition).mp.
51. (transition adj3 palliative care).mp.
52. palliative care.mp. or exp Palliative Care/
53. terminal cancer.mp. or exp Terminal Cancer/
54. (post-cancer adjustment or postcancer adjustment).mp.
55. cancer rehabilitation
56. (transition adj3 cancer surviv* or transition adj3 cancer).mp.
57. (mark adj3 end*).mp.
58. (drug therapy adj3 cancer).mp.
59. chemotherapy.mp. or exp Chemotherapy/
60. (adjuvant radiotherapy or radiotherapy or cancer radiotherapy).mp.
61. (surgery adj3 cance).mp.
62. immunotherapy.mp. or exp Immunotherapy/
63. exp Radiation Therapy/ or radiation therapy.mp.
64. (adjuvant therapy adj3 cancer).mp.
65. exp Psychosocial Readjustment/ or psychosocial readjustment.mp.
66. or/38-65

Number of papers from Stem 4: 34,766

Stem group 5: Experiences

EMBASE

74. Experience/ or experience*.mp.
75. Perspective*.mp.
76. Narrative/ or narrative*mp.
77. View*.mp.
78. Discourse*.mp.
79. Theme*.mp.
80. Or/74-79

Number of papers from Stem 5: 2,323,894

81. Combine Stems 1-4 = 21,699 papers (20,961 when limited to English language)

PSYCINFO

67. experience*.mp.
68. perspective*.mp.
69. narrative*.mp.
70. exp World View/ or view*.mp. or exp Attitudes/
71. discourse*.mp.
72. theme*.mp.
73. or/67-72

Number of papers from Stem 5: 1,397,579

74. Combine Stems 1-4 = 557 papers (536 when limited to English language)

82. Combine Stems1-4 + Stem 5 = 5,057 papers
(4,918 when limited to English language)

75. Combine Stems 1-4 + Stem 5 = 301 (291 when limited to English language)

Stem group 6: Bell

EMBASE

83. (bell adj3 cancer).mp.
84. Victory bell.mp.
85. Cancer bell.mp.
86. Or/83-85
87. Combine Stems 1-5 + Stem 6 = 0 papers

PSYCINFO

76. (bell adj3 cancer).mp.
77. Victory bell.mp.
78. Cancer bell.mp.
79. Or/78-80
80. Combine Stems 1-5 + Stem 6 = 0 papers

Appendix 1.2. Review search strategy

Database	Search statement	Search Terms	Notes on strategy
EMBASE			
	1	health practitioner/ or health care personnel/ or medical staff/ or nurse/ or nursing staff/ or physician/ or pediatric nurse practitioner/ or pediatric nurse/ or oncology nursing/ or oncology nurse/ or clinician/ or health practitioner/ or pediatrician/ or oncologist/ or pediatric oncologist/ or multidisciplinary team/	/= MeSH term. Subject headings are assigned descriptors used in databases to uniformly describe a concept and help identify relevant items relates to the topic. OR = Boolean operator
	2	experience/ or attitude/ or attitude to death/ or attitude to illness/ or perception/ or narrative/	
	3	1 and 2	AND = Boolean operator
	4	health personnel attitude/ or physician attitude/ or nurse attitude/	
	5	((Personnel or staff or nurs* or physici* or practition* or clinician* or doctor* or consultant* or oncologist* or p?diatrician* or health* professional* or health care professional* or healthcare worker* or health care worker* or allied health professional* or occupational therap* or physiotherap* or multi-disciplinary team* or multidisciplinary team* or MDT or healthcare team* or health care team*) adj8 (experienc* or view* or attitude* or perception* or feeling* or thoughts or emotion* or discourse or narrative*)).mp.	Asterisk (*) = truncation. It is used in advanced searching to find variant word endings e.g. child* finds child, childhood, children Question mark (?) = wildcard symbol. When used inside a word it replaces zero or one character e.g. gyn?ecology or colo?r Adj8 = adjacency operator (also known as proximity operator). Adj8

			finds the words if they are maximum eight words apart from one another regardless of the order in which they appear. For example, ***nurse* adj8 experienc**** will identify results that have a maximum of eight words between the beginning and ending terms. .mp = title, abstract, subject heading
	6	3 or 4 or 5	
	7	paediatrics/ or pediatrics/ or child/ or school child/ or preschool child/ or child/ or adolescent/	
	8	malignant neoplasm/ or leukaemia/ or oncology/ or lymphoma/	
	9	7 and 8	
	10	childhood cancer/ or childhood leukemia/	
	11	((child* or p?ediatric* or adolescen* or young people* or teen* or kid or kids) adj8 (cancer* or leuk?emia* or oncolog* or lymphoma*)).mp.	
	12	9 or 10 or 11	
	13	6 and 12	
	14	qualitative research/ or qualitative analysis/ or interview/ or semi structured interview/ or structured interview/ or unstructured interview/	
	15	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or "semi-structured" or semi structured) adj3 (interview* or discussion* or questionnaire*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw.	Ti.ab. = searchable fields: title and abstract Tw.kw. = the textword (t.w,) field in Embase includes Title (TI), Abstract (AB), and Drug Trade Name (TN). The keyword (k.w.) field contains keywords defined by the author of the article.
	16	thematic analysis/ or phenomenology/ or grounded theory/ or	

		discourse analysis/ or content analysis/
	17	(thematic coding or narrative analysis or interpretative phenomenological analysis or interpretive phenomenology or Foucauldian discourse analysis or critical discourse analysis or conversation analysis).mp.
	18	14 or 15 or 16 or 17
	19	13 and 18

EMCARE

	1	health practitioner/ or health care personnel/ or medical staff/ or nurse/ or nursing staff/ or physician/ or pediatric nurse practitioner/ or pediatric nurse/ or oncology nursing/ or oncology nurse/ or clinician/ or health practitioner/ or pediatrician/ or oncologist/ or pediatric oncologist/ or multidisciplinary team/
	2	experience/ or attitude/ or attitude to death/ or attitude to illness/ or perception/ or narrative/
	3	1 and 2
	4	health personnel attitude/ or physician attitude/ or nurse attitude/
	5	((Personnel or staff or nurs* or physici* or practition* or clinician* or doctor* or consultant* or oncologist* or p?diatrician* or health* professional* or health care professional* or healthcare worker* or health care worker* or allied health professional* or occupational therap* or physiotherap* or multi-disciplinary team* or multidisciplinary team* or MDT or healthcare team* or health care team*) adj8 (experienc* or view* or attitude* or perception* or feeling* or thoughts or emotion* or discourse or narrative*)).mp.
	6	3 or 4 or 5
	7	paediatrics/ or pediatrics/ or child/ or school child/ or preschool child/ or child/ or adolescent/

	8	malignant neoplasm/ or leukaemia/ or oncology/ or lymphoma/
	9	7 and 8
	10	childhood cancer/ or childhood leukemia/
	11	((child* or p?ediatric* or adolescen* or young people* or teen* or kid or kids) adj8 (cancer* or leuk?emia* or oncolog* or lymphoma*)).mp.
	12	9 or 10 or 11
	13	6 and 12
	14	qualitative research/ or qualitative analysis/ or interview/ or semi structured interview/ or structured interview/ or unstructured interview/
	15	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or "semi-structured" or semi structured) adj3 (interview* or discussion* or questionnaire*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw.
	16	thematic analysis/ or phenomenology/ or grounded theory/ or discourse analysis/ or content analysis/
	17	(thematic coding or narrative analysis or interpretative phenomenological analysis or interpretive phenomenology or Foucauldian discourse analysis or critical discourse analysis or conversation analysis).mp.
	18	14 or 15 or 16 or 17
	19	13 and 18

MEDLINE

	1	health personnel/ or medical staff/ or nurses/ or nurses, pediatric/ or nursing staff/ or physicians/ or oncologists/ or pediatricians/ or pediatric nurse practitioners/ or oncology nursing/

2	attitude/ or attitude to death/ or attitude to health/ or health knowledge, attitudes, practice/ or Perception/
3	1 and 2
4	"Attitude of Health Personnel"/
5	((Personnel or staff or nurs* or physici* or practition* or clinician* or doctor* or consultant* or oncologist* or p?diatrician* or p?diatric oncolog* or health* professional* or health care professional* or healthcare worker* or health care worker* or health practitioner* or allied health professional* or occupational therap* or oncolog* nurs* or physiotherap* or multi-disciplinary team* or multidisciplinary team* or MDT or healthcare team* or health care team*) adj8 (experienc* or view* or attitude* or perception* or feeling* or thoughts or emotion* or discourse or narrative*)).mp.
6	3 or 4 or 5
7	Child/ or Child, Preschool/ or Pediatrics/ or Adolescent/ or Child, School/
8	Neoplasms/ or Leukemia/ or Lymphoma/ or Medical Oncology/
9	7 and 8
10	((child* or p?ediatric* or adolescen* or young people* or teen* or kid or kids) adj8 (cancer* or leuk?emia* or oncolog* or lymphoma*)).mp.
11	9 or 10
12	6 and 11
13	qualitative research/ or interview/
14	(qualitative analysis or semi structured interview or unctructured interview).mp.
15	(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or "semi-structured" or semi structured) adj3 (interview* or discussion* or questionnaire*)).ti,ab. or (focus group* or qualitative or ethnograph*

		or fieldwork or "field work" or "key informant").tw,kw.
	16	Grounded Theory/
	17	(thematic coding or thematic analysis narrative analysis or interpretative phenomenological analysis or interpretive phenomenology or phenomenology or Foucauldian discourse analysis or critical discourse analysis or discourse analysis or conversation analysis or content analysis).mp.
	18	13 or 14 or 15 or 16 or 17
	19	12 and 18

PSYCINFO

	1	health personnel/ or medical personnel/ or nurses/ or physicians/ or pediatricians/ or clinicians/
	2	attitudes/ or death attitudes/ or health attitudes/ or perception/ or narratives/
	3	1 and 2
	4	health personnel attitudes/
	5	((Personnel or staff or nurs* or nurs* staff or physici* or practition* or clinician* or doctor* or consultant* or oncologist* or p?diatrician* or p?diatric nurse practitioner* or p?diatric nurs* or oncolog* or p?diatric oncolog* or nurs* or health* professional* or health care professional* or healthcare worker* or health care worker* or health practitioner* or allied health professional* or occupational therap* or physiotherap* or multi-disciplinary team* or multidisciplinary team* or MDT or healthcare team* or health care team*) adj8 (experienc* or view* or attitude* or perception* or feeling* or thoughts or emotion* or discourse or narrative*)).mp.
	6	3 or 4 or 5

	7	pediatrics/	
	8	Neoplasms/ or Leukemias/ or Oncology/	
	9	7 and 8	
	10	((child* or school child* or preschool child* or p?ediatric* or adolescen* or young people* or teen* or kid or kids) adj8 (cancer* or leuk?emia* or oncolog* or lymphoma*)).mp.	
	11	9 or 10	
	12	6 and 11	
	13	qualitative methods/ or semi-structured interview/ or interviews/	
	14	[(("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide or "semi-structured" or semi structured) adj3 (interview* or discussion* or questionnaire*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw.]	
	15	Thematic Analysis/ or Phenomenology/ or Grounded Theory/ or Discourse Analysis/ or Content Analysis/	
	16	(thematic coding or narrative analysis or interpretative phenomenological analysis or interpretive phenomenology or Foucauldian discourse analysis or critical discourse analysis or conversation analysis or qualitative analysis).mp.	
	17	13 or 14 or 15 or 16	
	18	12 and 17	

CINAHL PLUS

	1	((MM "Health Personnel") OR (MH "Pediatric Nurse Practitioners") OR (MH "Nurses") (MH "Physicians") OR (MH "Medical Staff") OR (MH "Pediatricians")) AND ((MH "Attitude") OR (MH "Attitude to Death") OR (MH "Attitude to Health") OR (MH "Attitude to Illness") or	MM = Searches the exact CINAHL Plus subject heading as major concept of an article.

		(MH "Narratives"))	MH = Searches the exact CINAHL Plus subject heading; searches both major and minor headings.
	2	(MH "Attitude of Health Personnel") OR (MH "Nurse Attitudes") OR (MH "Physician Attitudes")	
	3	(Personnel OR staff OR nurs* OR physici* OR practition* OR clinician* OR doctor* OR consultant* OR oncologist* OR p#ediatrician* OR "health* professional*" OR "health care professional*" OR "healthcare worker*" OR "health care worker*" OR "allied health professional*" OR "occupational therap*" OR physiotherap* OR "multi-disciplinary team*" OR "multidisciplinary team*" OR MDT OR "healthcare team*" OR "health care team*") n9 (experienc* OR view* OR attitude* OR perception* OR feeling* OR thought* OR emotion* OR discourse* OR narrative*)	* = Truncation; a search method in which symbols are used in place of letters or words to help broaden the search. In CINAHL, the asterisk (*) represents any group of characters, including no character.
	4	1 or 2 or 3	
	5	(MH "Pediatrics") AND (MH "Neoplasms") OR (MH "Leukemia") OR (MH "Oncology")	
	6	(child* or p#ediatric* or adolescen* or "young people*" or teen* or kid or kids) n9 (cancer* or leuk#emia* or oncolog* or lymphoma*)	
	7	5 or 6	
	8	4 and 7	

	9	(MH "Qualitative Studies") OR (MH "Semi-Structured Interview") OR (MH "Unstructured Interview") OR (MH "Interviews") OR (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guid* or "semi-structured" or "semi structured") n4 (interview* or discussion* or questionnaire*))	N4 = Near Operator (also known as proximity operator). N4 finds the words if they are maximum four words apart from one another regardless of the order in which they appear. For example, ***semi-structured N4 interview*** will identify results that have a maximum of four words between the beginning and ending terms.
	10	(MH "Thematic Analysis") OR (MH "Phenomenology") OR (MH "Phenomenological Research") (MH "Grounded Theory") OR (MH "Content Analysis") OR ("thematic coding" or "narrative analysis" or "interpretative phenomenological analysis" or "interpretive phenomenology" or "discourse analysis" or "conversation analysis")	
	11	("focus group*" or qualitative or ethnograph* or fieldwork or "field work" or "key informant")	
	12	9 or 10 or 11	
	13	4 and 7 and 12	

WEB OF SCIENCE

	1	((TS=((child* OR children OR preschool child* OR school child* OR toddler* OR adolescent* OR young person OR young people OR teen* OR kid* OR p?ediatric*) AND (health practitioner* OR health personnel OR allied health personnel OR medical staff OR nurses OR nursing staff OR physician* OR p?ediatric nurse practitioner OR p?ediatric nurse OR oncology nurse* OR oncology	TS = Topic. Searches for topic terms in the following fields within a record: Title, abstract, author keywords, keywords plus.

nursing OR clinician* OR health* professional* OR health* practitioner* OR p?ediatrician* OR doctor* OR consultant* OR oncologist* OR multidisciplinary team* OR multi-disciplinary team* OR MDT* OR cancer MDT* OR healthcare team* OR health-care team*) AND (child* cancer* OR child* leuk?emia* OR child* oncology OR p?ediatric cancer* OR p?ediatric oncology) AND (experienc* OR perspective* OR attitude of health personnel OR attitude* OR narrative* OR view* OR discourse* OR theme*) AND (qualitative OR mixed methods OR mixed-methods OR case study OR content analysis OR conversation analysis OR critical discourse analysis OR discourse analysis OR ethnography OR ethnographic content analysis OR Foucauldian discourse analysis OR grounded theory OR interpretive phenomenology OR interpretative phenomenological analysis OR narrative analysis OR phenomenology OR thematic coding OR thematic analysis)))) AND LANGUAGE: (English)

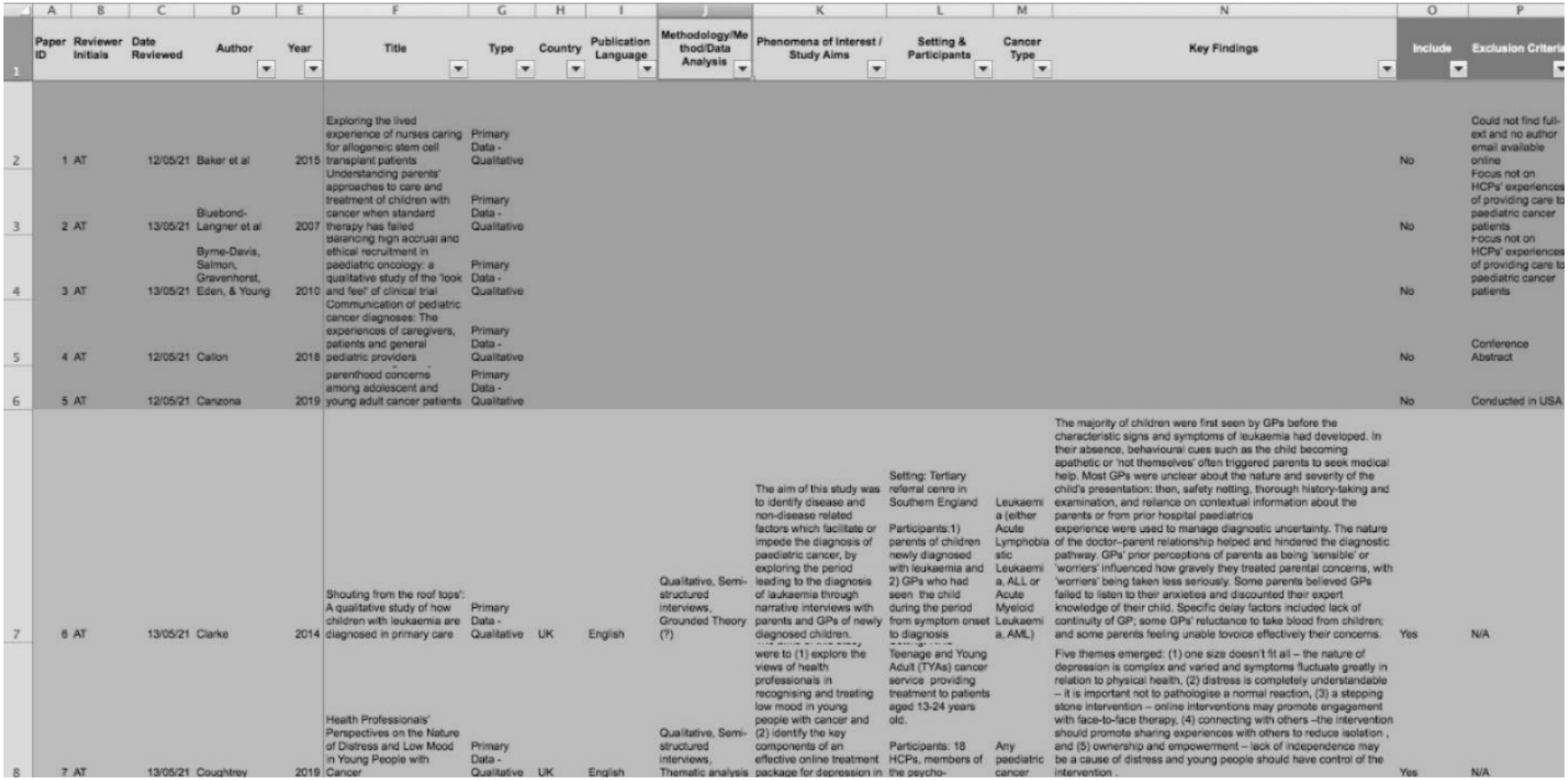
Appendix 1.3. Excluded papers with reasons

No	Study	Reason for Exclusion
1	Baker et al (2015)	Full-text could not be retrieved.
2	Bluebond-Langer et al (2007)	The focus was on examining parents' approaches to care and treatment when standard therapy has failed. There was no data reported on HCPs' personal accounts/narratives/experiences around this.
3	Byrne-Davis, Salmon, Gravenhorst, Eden, & Young (2010)	The focus was on investigating the parent-practitioner relationship to identify how doctors' communication could promote or inhibit optimal recruitment of paediatric cancer patients in clinical trials. There was no data reported on HCPs' personal accounts/narratives/experiences around this.
4	Callon et al (2018)	No full text available - conference abstract only.
5	Canzona et al (2019)	Have emailed first author for the 2019 paper on 14th May but no reply. Could not find the 2019 citation but found a paper published by Canzona et al (2021) on a similar topic which was conducted in the US: https://onlinelibrary.wiley.com/action/authenticateSharedSP.
6	Clarke et al (2014)	Narrative interviews with parents and GPs in primary care. No data reported on HCPs' experiences of providing care to paediatric cancer patients.
7	Davies et al (2018)	HCP views not reported separately from the views of family/partners/friends who were close to TYAs with cancer.
8	Fallstrom et al (1987)	Full-text could not be retrieved.
9	Garnett et al (2003)	Focus is on children's oncology palliative care.
10	Hooker et al (2000)	Focus not on HCPs' experiences of providing care to paediatric cancer patients.
11	Hunter-Jones et al (2003)	Focus not on HCPs' experiences of providing care to paediatric cancer patients.
12	Ignatowicz et al (2018)	Focus not on HCPs' experiences of providing care to paediatric cancer patients.
13	Jestico et al	Focus is on whether nurses feel prepared/equipped to care

	(2017)	for children with cancer immediately after completing their nursing education? No data on their actual experiences in caring for patients in a paediatric oncology setting.
14	Kelly et al (2004)	HCPs' views not reported separately from the views of patients and parents.
15	Kiernan et al (2010)	Not conducted in the UK, conducted in Ireland.
16	Lavender et al (2019)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on understanding the reasons behind reduced participation of adolescent and young adults (AYAs) for clinical trials.
17	Martins et al (2016)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on defining the development and implementation of the specialist nurse/key worker role.
18	McAndrew et al (2014)	Full-text could not be retrieved.
19	McInally et al (2012)	Focus is on exploring the impact of paediatric oncology education on nursing practice and not on nurses' experiences of providing care to paediatric cancer patients.
20	Mulhall et al (2004)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on evaluating the first UK specialist adolescent cancer unit. Also the views of HCPs are not reported separately to those of teenagers and parents.
21	Neilson et al (2020)	Focus is on children's oncology palliative care.
22	Neilson et al (2015)	Focus is on children's oncology palliative care.
23	Neilson et al (2011)	Focus is on children's oncology palliative care.
24	Neilson et al (2013)	Focus is on children's oncology palliative care.
25	Neilson et al (2010)	Focus is on children's oncology palliative care.
26	Norton et al (2020)	Duplicate record - same as the paper by Wright, Norton & Geary (2018).
27	Pearson et al (2012)	Focus is on children's oncology palliative care.
28	Schildmann et al (2012)	Full-text could not be retrieved.
29	Stevens et al (2018)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on factors that are

		important for developing services specifically for teenager and young adult (TYA) patients in the UK. No qualitative data reported for HCPs (i.e., quotes, themes).
30	Taylor et al (2011)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on service development for TYA cancer units. Not qualitative data reported for HCPs (i.e., quotes, themes).
31	Taylor et al (2016)	Not a qualitative study. A modified e-Delphi study.
32	Tomlinson et al (2004)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Focus is on developing a framework for nursing education.
33	Tyler et al (1994)	Not relevant to paediatric oncology-haematology specifically. It does not explicitly state the population studied. Also it does not state the analysis of the qualitative data and does not report any quotes from the interviews. Therefore, no primary data for the qualitative component are reported.
34	Wilson et al (2012)	Full-text could not be retrieved.
35	Young et al (2013)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. More like a case study type of research focusing on physician-parent communications/interactions. No qualitative data reported on HCPs' experiences.
36	Young et al (2011)	Focus not on HCPs' experiences of providing care to paediatric cancer patients. Qualitative data reported on parents' experiences of discussing with oncologists about their child's diagnosis. Very interesting paper for the empirical chapter.

Appendix 1.4. Data Extraction Workbook in Excel



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
1	Paper ID	Reviewer Initials	Date Reviewed	Author	Year	Title	Type	Country	Publication Language	Methodology/Method/Data Analysis	Phenomena of Interest / Study Aims	Setting & Participants	Cancer Type	Key Findings	Include	Exclusion Criteria
2	1	AT	12/05/21	Baker et al	2015	Exploring the lived experience of nurses caring for allogeneic stem cell transplant patients	Primary Data - Qualitative								No	Could not find full-ext and no author email available online
3	2	AT	13/05/21	Bluebond-Langner et al	2007	Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed	Primary Data - Qualitative								No	Focus not on HCPs' experiences of providing care to paediatric cancer patients
4	3	AT	13/05/21	Byrne-Davis, Salmon, Gravenhorst, Eden, & Young	2010	Balancing high accrual and ethical recruitment in paediatric oncology: a qualitative study of the 'look and feel' of clinical trial	Primary Data - Qualitative								No	Focus not on HCPs' experiences of providing care to paediatric cancer patients
5	4	AT	12/05/21	Callon	2018	Communication of pediatric cancer diagnoses: The experiences of caregivers, patients and general pediatric providers	Primary Data - Qualitative								No	Conference Abstract
6	5	AT	12/05/21	Canzona	2019	parenthood concerns among adolescent and young adult cancer patients	Primary Data - Qualitative								No	Conducted in USA
7	6	AT	13/05/21	Clarke	2014	Shouting from the roof tops': A qualitative study of how children with leukaemia are diagnosed in primary care	Primary Data - Qualitative	UK	English	Qualitative, Semi-structured interviews, Grounded Theory (?)	The aim of this study was to identify disease and non-disease related factors which facilitate or impede the diagnosis of paediatric cancer, by exploring the period leading to the diagnosis of laukaemia through narrative interviews with parents and GPs of newly diagnosed children.	Setting: Tertiary referral centre in Southern England Participants:1) parents of children newly diagnosed with leukaemia and 2) GPs who had seen the child during the period from symptom onset to diagnosis	Leukaemia (either Acute Lymphoblastic Leukaemia, ALL or Acute Myeloid Leukaemia, AML)	The majority of children were first seen by GPs before the characteristic signs and symptoms of leukaemia had developed. In their absence, behavioural cues such as the child becoming apathetic or 'not themselves' often triggered parents to seek medical help. Most GPs were unclear about the nature and severity of the child's presentation: then, safety netting, thorough history-taking and examination, and reliance on contextual information about the parents or from prior hospital paediatrics experience were used to manage diagnostic uncertainty. The nature of the doctor–parent relationship helped and hindered the diagnostic pathway. GPs' prior perceptions of parents as being 'sensible' or 'worriers' influenced how gravely they treated parental concerns, with 'worriers' being taken less seriously. Some parents believed GPs failed to listen to their anxieties and discounted their expert knowledge of their child. Specific delay factors included lack of continuity of GP; some GPs' reluctance to take blood from children; and some parents feeling unable tovoice effectively their concerns.	Yes	N/A
8	7	AT	13/05/21	Coughtrey	2019	Health Professionals' Perspectives on the Nature of Distress and Low Mood in Young People with Cancer	Primary Data - Qualitative	UK	English	Qualitative, Semi-structured interviews, Thematic analysis	were to (1) explore the views of health professionals in recognising and treating low mood in young people with cancer and (2) identify the key components of an effective online treatment package for depression in	Teenage and Young Adult (TYAs) cancer service providing treatment to patients aged 13-24 years old. Participants: 18 HCPs, members of the psycho-	Any paediatric cancer	Five themes emerged: (1) one size doesn't fit all – the nature of depression is complex and varied and symptoms fluctuate greatly in relation to physical health, (2) distress is completely understandable – it is important not to pathologise a normal reaction, (3) a stepping stone intervention – online interventions may promote engagement with face-to-face therapy, (4) connecting with others –the intervention should promote sharing experiences with others to reduce isolation , and (5) ownership and empowerment – lack of independence may be a cause of distress and young people should have control of the intervention .	Yes	N/A

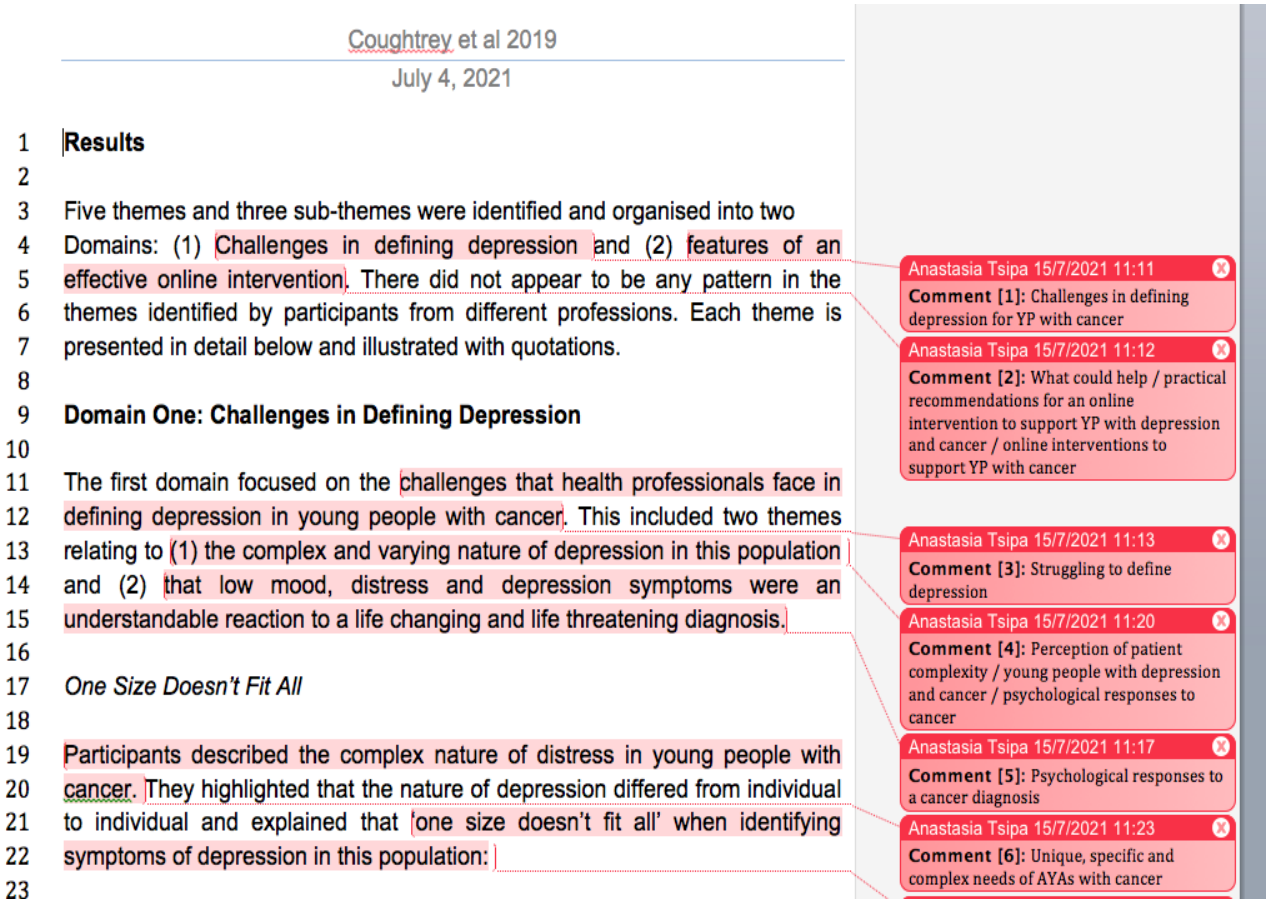
Appendix 1.5. Themes and subthemes identified by authors extracted from included studies (full spreadsheet not depicted)

	Paper	Date	Theme 1	Theme 2	Theme 3	Theme 4	Theme 5	Theme 6	Theme 7	Theme 8	Theme 9	Theme 10
2	Coughtrey	2019	One size doesn't fit all	Fluctuating symptoms	Distress is completely understandable	Don't pathologise distress	A stepping stone intervention	Connecting with others	Therapeutic benefits	Ownership and empowerement		
3	Day	2018	Doing the 'right thing'	Act on the care and treatment preferences of the teenager	Openly disclose information about the teenager's condition, prognosis and treatment	Mediating factor 1: family communication style	Mediating factor 2: stage of the illness	Mediating factor 3: Nature of the disease				
4	Forsey, Salmon, Eden, & Young	2013	Doctors recognise parents' emotional distress	Doctors' strategies for managing parents' emotional distress: sustaining hope & preserving parents' trust	Doctor's authority facilitates boundaries	Nurses' role in emotional care	Parents' dependence on nurses for emotional care can challenge boundaries	Providing emotional care as a team				
5	Gibson, Kumpunen, Bryan, & Forbat	2018	Before diagnosis	Diagnosis talk	First week in hospital	Preparing to go home	Life as an outpatient family	Parents' carer and communication roles	Parents' interactions with health professionals			
6	Gray & Smith	2009	The emotional labour involved in children's oncology and bone marrow transplant									
7	Lea et al	2019	Views about young people's use of online resources	How young people's needs change along the cancer timeline: at diagnosis, during treatment, end of treatment, beyond treatment.	Where professionals refer young people to online	Are young people's online needs currently being met?	Recognition of the emotional relationship between young people and the internet	Barriers and facilitators for professionals when referring young people to online resources	Strategies used in practice: use of caveats	Strategies used in practice:Information exchange with the young person	Strategies used in practice: professionals pre-empting by searching themselves	Education and training
8	Lea et al	2020	Issues experienced by young people at the end of treatment	How end of treatment issues were identified	Facilitators to provision of support and information	Challenges to provision of support and information	Existing resources of support and information	Timing of information and support provision	Additional influencing factors: age, cancer type, personal situation	Changes and improvements		
9	Pugh et al	2020	Discussing health behaviour to support self-management	Health promotion iwthing TYA cancer care	Lack of evidence and resources to support health behaviour promotion in practice	Requirements for implementation and change in practice						
10	Pye	2013	Decision making: role of experience	Decision making: Feelings regarding decision-making	Decision making: Quality of life regarding decision-making	Decision making: the role of the team within decision-making	Conflict over right to treatment and withholding by professionals	The importance of communication within the team				
11	Williamson & Rumsey	2016	HCPs' perspectives on the psychosocial impact of appearance change and interventions to prevent or ameliorate concerns	Barriers inhibiting appearance-related care and perspectives on how to improve appearance-related support								
12	Willmott, Loades, Baker, & Spathis	2021	How do clinicians perceive TYA CRF? 1. Different to tiredness	How do clinicians perceive TYA CRF? 2. Arises from cancer and its treatment	How do clinicians perceive TYA CRF? 3. A common but individual experience	How do clinicians perceive TYA CRF? 4. Invisible and intangible	How do clinicians perceive TYA CRF? 5. Multidimensional impact in the context of TYA development	How do clinicians assess and manage TYAs' CRF? 1. Conversational versus structured assessment	How do clinicians assess and manage TYAs' CRF? 2. Language use	How do clinicians assess and manage TYAs' CRF? 3. Cognitive and emotional support	How do clinicians assess and manage TYAs' CRF? 4. Meeting medical needs and encouraing healthy living	How do clinicians assess and manage TYAs' CRF? 5. MDT and systems working
13	Wright, Norton, & Geary	2018	Recognition of the importance of knowledge: 1. Perceived lack of knowledge	Recognition of the importance of knowledge: 2. Responses to identification of knowledge deficits	Time is of the essence							

Appendix 1.6. Colour-coded framework of themes and subthemes identified by authors extracted from included studies

HCPs perceptions of resources, facilitators and barriers	HCPs' knowledge and understanding	Importance of information and transparent communication	Recognising and addressing patients' needs: tailoring care	Connection and trust in the HCP-Parent-patient triad	Mediating factors	Needs along the cancer journey	Systemic and structural factors	Shared decision-making and collaboration	What might help: skills, techniques and practical recommendations	Team-based care / interprofessional working	Ethical dilemmas
Views about young people's use of online resources	How do clinicians perceive TYA CRF? 1. Different to tiredness	Openly disclose information about the teenager's condition, prognosis and treatment	One size doesn't fit all	Doctors recognise parents' emotional distress	Mediating factor 1: family communication style	Before diagnosis	Where professionals refer young people to online	Decision making: role of experience	A stepping stone intervention	Providing emotional care as a team	Doing the 'right thing'
Are young people's online needs currently being met?	How do clinicians perceive TYA CRF? 2. Arises from cancer and its treatment	Strategies used in practice:Information exchange with the young person	Fluctuating symptoms	Doctors' strategies for managing parents' emotional distress: sustaining hope & preserving parents' trust	Mediating factor 2: stage of the illness	Diagnosis talk	Education and training	Decision making: role of experience	Connecting with others	Decision making: the role of the team within decision-making	Conflict over right to treatment and withholding by professionals
Barriers and facilitators for professionals when referring young people to online resources	How do clinicians perceive TYA CRF? 4. Invisible and intangible	Existing resources of support and information	Distress is completely understandable	Doctor's authority facilitates boundaries	Mediating factor 3: Nature of the disease	First week in hospital	Lack of evidence and resources to support health behaviour promotion in practice	Decision making: Quality of life regarding decision-making	Recognition of the emotional relationship between young people and the internet	The importance of communication within the team	What are the challenges for clinicians working with TYA CRF? 1. Uncertainty
Facilitators to provision of support and information	How do clinicians perceive TYA CRF? 5. Multidimensional impact in the context of TYA development	Timing of information and support provision	Don't pathologise distress	Nurses' role in emotional care	Parents' carer and communication roles	Preparing to go home	Requirements for implementation and change in practice		Strategies used in practice: use of caveats	How do clinicians assess and manage TYAs' CRF? 5. MDT and systems working	Time is of the essence
Challenges to provision of support and information	Recognition of the importance of knowledge: 1. Perceived lack of knowledge	Discussing health behaviour to support self-management	Act on the care and treatment preferences of the teenager	Parents' dependence on nurses for emotional care can challenge boundaries	Additional influencing factors: age, cancer type, personal situation	Life as an outpatient family	How do clinicians assess and manage TYAs' CRF? 3. Systemic challenges		Strategies used in practice: professionals pre-empting by searching themselves		
Barriers inhibiting appearance-related care and perspectives on how to improve appearance-related support	Recognition of the importance of knowledge: 2. Responses to identification of knowledge deficits	Health promotion iwthing TYA cancer care	HCPs' perspectives on the psychosocial impact of appearance change and interventions to prevent or ameliorate concerns	Parents' interactions with health professionals		How young people's needs change along the cancer timeline: at diagnosis, during treatment, end of treatment, beyond treatment.	How do clinicians assess and manage TYAs' CRF? 4. Lack of TYA-friendly measures and resources		Changes and improvements		
			How do clinicians perceive TYA CRF? 3. A common but individual experience	The emotional labour involved in children's oncology and bone marrow transplant		Issues experienced by young people at the end of treatment			How do clinicians assess and manage TYAs' CRF? 1. Conversational versus structured assessmen		
			How do clinicians assess and manage TYAs' CRF? 6. Patient-centred adjustments	How do clinicians assess and manage TYAs' CRF? 3. Cognitive and emotional support		How end of treatment issues were identified			How do clinicians assess and manage TYAs' CRF? 2. Language use		
									How do clinicians assess and manage TYAs' CRF? 4. Meeting medical needs and encouraing healthy living		
									How do clinicians assess and manage TYAs' CRF? 2. Managing expectations and engagement.		
									Therapeutic benefits		
									Ownership and empowerement		

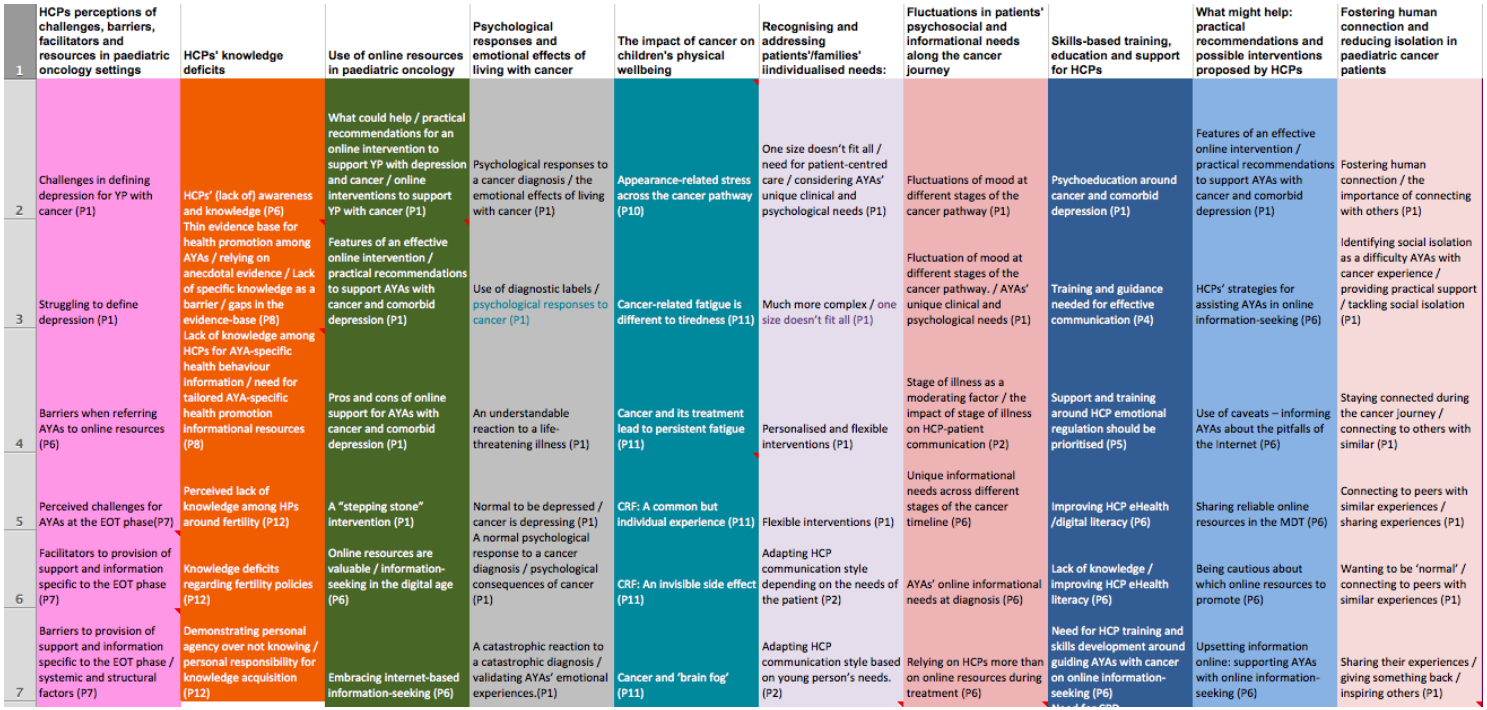
Appendix 1.7. Screenshot of an example of 'line-by-line' coding of included studies (full analysis not depicted)



Appendix 1.8. Screenshot of initial codes assigned to included papers (full Excel spreadsheet not depicted)

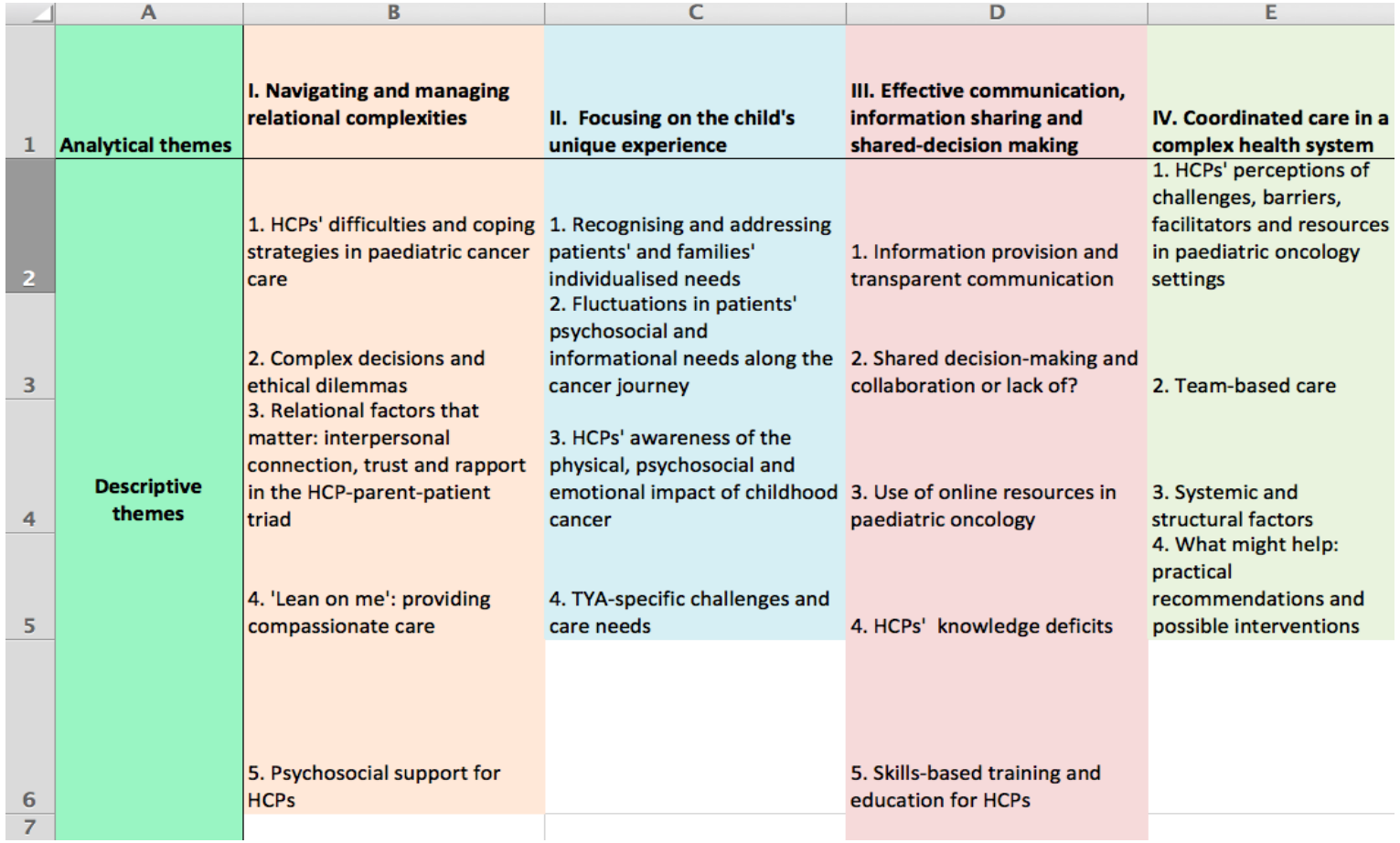
1	Paper	Date	Code 1	Code 2	Code 3	Code 4	Code 5	Code 6
2	Coughtrey (Paper 1)	2019	Challenges in defining depression for YP with cancer	What could help / practical recommendations for an online intervention to support YP with depression and cancer / online interventions to support YP with cancer	Struggling to define depression	Perception of patient complexity / young people with depression and cancer / psychological responses to cancer	Psychological responses to a cancer diagnosis / the emotional effects of living with cancer	Unique, specific and complex needs of AYAs with cancer
3	Day (Paper 2)	2018	Doing the 'right thing'	Clinician responsibility / lack of shared-decision making	Clinician responsibility / the clinician mainly decides	Difficult dilemmas / when should patient participation be implemented in cancer care?	Following the patient's lead where possible	Difficult dilemmas / acting in the patient's best interest despite going against their wishes
4	Forsey, Salmon, Eden, & Young (Paper 3)	2013	Maintaining emotional distance	Recognising patients' emotional difficulties	Focusing on the positives	Moving away from the emotion / Not addressing negative emotions	Keeping the family together / stopping the emotions from taking hold / redirecting focus to the tangible and practical	Focusing on the positive / sustaining hope
5	Gibson, Kumpunen, Bryan, & Forbat (Paper 4)	2018	Managing uncertainty regarding clinical decisions / clinician uncertainty	The diagnosis talk / the spiel / standardised information	Patients'/families' information preferences	Effective and ineffective communication – strategies and approaches	The timing of information provision	Road blocks in communication
6	Gray & Smith (Paper 5)	2009	Exposure to death, dying and suffering	An emotionally complex setting / Emotional labour in nursing	Clinician distress / moral distress / ethical conflicts / emotional burden / identifying and empathising with patients' needs	Empathising with the emotions of the patient/family / emotional burden / moral injury / emotional dissonance / professional boundaries	Emotional dissonance and burnout	Pyschosocial and emotional support for HCPs should be a priority
7	Lea et al (Paper 6)	2019	Online resources are valuable / information-seeking in the digital age	Embracing internet-based information-seeking	Embracing online resources	Facilitating safe online use	Improving HCP eHealth /digital literacy	Greater acceptability of digital information versus traditional modes of delivery
8	Lea et al (Paper 7)	2020	Perceived challenges for AYAs at the EOT phase	Establishing a 'new normal' after the end of active treatment	Practical advice and support needed after completing cancer treatment	Unmet needs of AYAs after treatment completion	Unmet needs of important others supporting AYAs following cancer treatment	Strategies for identifying the needs of AYAs following the completion of active treatment
9	Pugh et al (Paper 8)	2020	Discussing health behaviour to support AYAs' holistic wellbeing	Barriers to health behaviour promotion among TYA-HPs	Need for CPD interventions to promote delivery of health behaviour advice	Factors the motivate HCPs to provide health behaviour advice	The importance of health behaviour promotion / lowering the risk of long-term side effects of cancer	Barriers to discussing health behaviours and lifestyle advice with AYAs with cancer

Appendix 1.9. Screenshot of colour-coded framework of initial codes identified in included studies (full Excel spreadsheet not depicted)



1	HCPs perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings	HCPs' knowledge deficits	Use of online resources in paediatric oncology	Psychological responses and emotional effects of living with cancer	The impact of cancer on children's physical wellbeing	Recognising and addressing patients'/families' iindividualised needs:	Fluctuations in patients' psychosocial and informational needs along the cancer journey	Skills-based training, education and support for HCPs	What might help: practical recommendations and possible interventions proposed by HCPs	Fostering human connection and reducing isolation in paediatric cancer patients
2	Challenges in defining depression for YP with cancer (P1)	HCPs' (lack of) awareness and knowledge (P6)	What could help / practical recommendations for an online intervention to support YP with depression and cancer / online interventions to support YP with cancer (P1)	Psychological responses to a cancer diagnosis / the emotional effects of living with cancer (P1)	Appearance-related stress across the cancer pathway (P10)	One size doesn't fit all / need for patient-centred care / considering AYAs' unique clinical and psychological needs (P1)	Fluctuations of mood at different stages of the cancer pathway (P1)	Psychoeducation around cancer and comorbid depression (P1)	Features of an effective online intervention / practical recommendations to support AYAs with cancer and comorbid depression (P1)	Fostering human connection / the importance of connecting with others (P1)
3	Struggling to define depression (P1)	Thin evidence base for health promotion among AYAs / relying on anecdotal evidence / Lack of specific knowledge as a barrier / gaps in the evidence-base (P8)	Features of an effective online intervention / practical recommendations to support AYAs with cancer and comorbid depression (P1)	Use of diagnostic labels / psychological responses to cancer (P1)	Cancer-related fatigue is different to tiredness (P11)	Much more complex / one size doesn't fit all (P1)	Fluctuation of mood at different stages of the cancer pathway. / AYAs' unique clinical and psychological needs (P1)	Training and guidance needed for effective communication (P4)	HCPs' strategies for assisting AYAs in online information-seeking (P6)	Identifying social isolation as a difficulty AYAs with cancer experience / providing practical support / tackling social isolation (P1)
4	Barriers when referring AYAs to online resources (P6)	Lack of knowledge among HCPs for AYA-specific health behaviour information / need for tailored AYA-specific health promotion informational resources (P8)	Pros and cons of online support for AYAs with cancer and comorbid depression (P1)	An understandable reaction to a life-threatening illness (P1)	Cancer and its treatment lead to persistent fatigue (P11)	Personalised and flexible interventions (P1)	Stage of illness as a moderating factor / the impact of stage of illness on HCP-patient communication (P2)	Support and training around HCP emotional regulation should be prioritised (P5)	Use of caveats – informing AYAs about the pitfalls of the Internet (P6)	Staying connected during the cancer journey / connecting to others with similar (P1)
5	Perceived challenges for AYAs at the EOT phase(P7)	Perceived lack of knowledge among HPs around fertility (P12)	A "stepping stone" intervention (P1)	Normal to be depressed / cancer is depressing (P1)	CRF: A common but individual experience (P11)	Flexible interventions (P1)	Unique informational needs across different stages of the cancer timeline (P6)	Improving HCP eHealth /digital literacy (P6)	Sharing reliable online resources in the MDT (P6)	Connecting to peers with similar experiences / sharing experiences (P1)
6	Facilitators to provision of support and information specific to the EOT phase (P7)	Knowledge deficits regarding fertility policies (P12)	Online resources are valuable / information-seeking in the digital age (P6)	A normal psychological response to a cancer diagnosis / psychological consequences of cancer (P1)	CRF: An invisible side effect (P11)	Adapting HCP communication style depending on the needs of the patient (P2)	AYAs' online informational needs at diagnosis (P6)	Lack of knowledge / improving HCP eHealth literacy (P6)	Being cautious about which online resources to promote (P6)	Wanting to be 'normal' / connecting to peers with similar experiences (P1)
7	Barriers to provision of support and information specific to the EOT phase / systemic and structural factors (P7)	Demonstrating personal agency over not knowing / personal responsibility for knowledge acquisition (P12)	Embracing internet-based information-seeking (P6)	A catastrophic reaction to a catastrophic diagnosis / validating AYAs' emotional experiences.(P1)	Cancer and 'brain fog' (P11)	Adapting HCP communication style based on young person's needs. (P2)	Relying on HCPs more than on online resources during treatment (P6)	Need for HCP training and skills development around guiding AYAs with cancer on online information-seeking (P6)	Upsetting information online: supporting AYAs with online information-seeking (P6)	Sharing their experiences / giving something back / inspiring others (P1)

Appendix 1.10. Screenshot of higher-order analytic themes generated from the data synthesis



	A	B	C	D	E
1	**Analytical themes**	**I. Navigating and managing relational complexities**	**II. Focusing on the child's unique experience**	**III. Effective communication, information sharing and shared-decision making**	**IV. Coordinated care in a complex health system**
2	**Descriptive themes**	1. HCPs' difficulties and coping strategies in paediatric cancer care	1. Recognising and addressing patients' and families' individualised needs	1. Information provision and transparent communication	1. HCPs' perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings
3		2. Complex decisions and ethical dilemmas	2. Fluctuations in patients' psychosocial and informational needs along the cancer journey	2. Shared decision-making and collaboration or lack of?	2. Team-based care
4		3. Relational factors that matter: interpersonal connection, trust and rapport in the HCP-parent-patient triad	3. HCPs' awareness of the physical, psychosocial and emotional impact of childhood cancer	3. Use of online resources in paediatric oncology	3. Systemic and structural factors
5		4. 'Lean on me': providing compassionate care	4. TYA-specific challenges and care needs	4. HCPs' knowledge deficits	4. What might help: practical recommendations and possible interventions
6		5. Psychosocial support for HCPs		5. Skills-based training and education for HCPs	
7					

Appendix 1.11. Overview of thematic synthesis alongside samples of coded text

Analytical Theme *Descriptive Themes*	**Transcript**	**Page / Line**	**Key words**
Navigating and managing relational complexities			
HCPs' difficulties and coping strategies in paediatric cancer care	*Doctors tended not to use emotional language when describing their relationships with families and only rarely discussed situations that they found personally challenging.* ***(Paper 3)***	1 / 5 – 7	Personally challenging
	All doctors described providing reassurance and explanation for families at the beginning of treatment, focusing on the ability of treatment to cure the child: 'I always start off being very positive, it's ALL, it's the most common childhood cancer we see, the one we know the most about. And the one we're most successful at treating' (B.D4). They did not describe explicitly asking parents about their worries and fears or engaging with such fears. Instead, doctors emphasised how they worked 'to keep the family together so they can function tomorrow' (C.D4) and spoke of how this was in the child's best interests. ***(Paper 3)***	1 / 18 – 26	Not engaging with such fears
	In the children's oncology setting, nurses have to deal with issues of dying, death, bereavement and managing a 'good death'. The case of children's oncology was a justifiably emotive and upsetting clinical area in which there was often little hope of a cure and only the possibility of palliative care. Nurses, in particular, have to learn how to manage a 'good death' and emotional labour was a key component for doing this. ***(Paper 5)***	4 / 164 – 170	Emotive and upsetting clinical area
	The nurse said that she felt ''anger'' and ''despair'' in the situation, which mirrored the emotions of the parents and also related to the issue that the nurse had	5 / 191 – 197	Anger and despair

	her own children. She said that her feelings were not dealt with and supported: ''You can't show your frustration if you're a nurse and you just have to sit on your anger''. This dissonance between genuinely felt and displayed emotions was linked with the formation of the ''hard nurse'' and with high rates of ''burnout''. ***(Paper 5)***		
	People can make an extraordinary recovery sometimes you have to make decisions regarding treatment and then these patients they have gone wrong very quickly as a direct consequence of something that you have recommended and decided with the patients. You quite often end up in a situation where you are carrying on, trying new drugs, persisting, you are sending someone for resuscitation but in your heart you actually think that there is a 99% risk that they will die, you feel angry at the situation that you have got into and you wonder whether the decisions you made could you have avoided getting into that situation. (Doctor 2) ***(Paper 9)***	1 / 25 – 33	Gone wrong very quickly
	The participants assume that a level of preexisting knowledge is required for them to be effective and their assessment of their own lack of knowledge appears to act as a decisive factor in preventing their involvement in discussions. By focusing on a justification, such as appearing unhelpful or upsetting patients, participants were able to avoid any sense of self-blame. ***(Paper 12)***	1 / 32 - 36	Avoid any sense of self-blame
Complex decisions and ethical dilemmas	*However, while this principle was advocated for certain decisions (place of care, minor procedures), for others HCP recognised that acting on teenagers' treatment preferences might not be possible, feasible or desirable. This was particularly the case for decisions governed by internationally agreed treatment protocols, or those where there was the likelihood of serious harm, death or suffering (refusal of curative treatment, reduction of chemotherapy dose and escalation of care to intensive care). MDT discussions highlighted how HCP responses to teenagers' care and treatment preferences varied over time and in the context of different decisions. HCP weighed the feasibility of enacting teenagers' care*	2 / 47 – 58	Likelihood of serious harm, death or suffering

and treatment preferences against their clinical responsibility to provide what they judged to be the best care. ***(Paper 2)***		
*During interviews, HCP discussed a possible shift when disease-directed treatment began to fail and suggested that at this point families and teenagers are pulled into the decision-making process, and asked to voice opinions and preferences. However, during MDT meetings and informal discussions, HCP acknowledged that it was difficult to respond to these preferences. In practice, the final authority for such decision making toward end of life lay with HCP and the clinical consensus****. (Paper 2)***	3 – 4 / 125 – 131	Final authority
"Where a patient who has just days and still hasn't got a resuscitation status and I think that's appalling, because the last thing you want to do is have a patient who has the right to die peacefully and then have to jump on them". (Nurse 2)	1 – 2 / 37 – 46	The right to die peacefully
"I do struggle with this whole business about repetitive chemotherapy that is not curative, I really do. I always have done, but the natural law meant that this child would have died long ago and therefore whatever we are doing beyond that is playing God in a sense and doing unnatural things that are often unpleasant for the child." (Doctor 4) ***(Paper 9)***		Playing God
*"Where you are faced with the parents wanting you to treat and maybe us thinking that we shouldn't treat, you are faced with the consultant and whether they are doing the right thing by offering all these avenues to the parents, that is challenging for us to see because sometimes you feel like they just want to play God. I find it quite a lot when you have got a consultant who just wants to do everything, salvage as much as they can and they do call it salvage therapy a lot of the time don't they." (Nurse 2****) (Paper 9)***	3 / 90 – 96	Doing the right thing
Participant three goes beyond a simple acknowledgment of missed opportunities and describes the potential consequences of delaying treatment.	5 / 197 - 206	Consequenc
"Sometimes females don't get		

	offered the opportunity to look into their fertility and look what is available … I think if their life was going to be put at risk because the chemotherapy was delayed, then obviously they wouldn't be fertile in the future anyway" (Participant 3). Here, lack of sufficient time is not viewed as an avoidance approach, but somehow justified by the potentially conflicting necessity to save life. ***(Paper 12)***		es of delaying treatment
			Conflicting necessity to save a life
Relational factors that matter: interpersonal connection, trust and rapport in the HCP-parent-patient triad	*Doctors spoke of how their focus on treatment allowed them to earn parents' trust while being clear about the 'boundaries' (A.D3) of their relationship and avoiding encouraging parents to become overly dependent upon them personally for emotional support. They explained how this was particularly important in case they might at some stage have to challenge parents in order to serve the best interests of the child.* ***(Paper 3)***	3 / 93 – 98	Earn parents' trust
	They explained how they shared with parents personal details about themselves to promote relationships 'you can be off for a week, I got married and came back and in and everyone was like "let me see your photos, how was it?"'(C.N19). Nurses therefore wanted to care for families emotionally and to develop close relationships with them, and they thought that this was an essential part of their role (Table 3). They spoke of how they developed intimate knowledge of families and felt this helped them to meet parents' needs 'you know what mum likes, you know what [child] likes, you know how she has her medicines, you can tell if there's something not quite right' (D.N2). ***(Paper 3)***	5 / 181 – 190	Develop close relationships
	They described at length their efforts to 'earn' (D.D1) parents' trust by being 'honest', 'upfront' or 'straight' (A.D3, B.D1) so that parents understood there would be 'no secrets' and that, as doctors, they would always be 'truthful' (B.D3). Doctors thought that showing their sincerity, 'caring' and 'interest' in the child (C.D4) might help parents to trust them. They also spoke of demonstrating their	2 / 70 -77	Be trusted in their roles

	knowledge and expertise as specialists in the care of children with cancer as a way of showing parents that they could be trusted in their roles. ***(Paper 3)***		
'Lean on me': providing compassionate care	*Doctors perceived that parents needed 'something positive to hang onto' (C.D4) and spoke of the importance of communicating in ways that helped parents be hopeful for their child's survival as hope 'keeps people going' (C.D3). Several doctors talked literally about 'giving the parents hope' (D.D4), but most spoke about hope more indirectly, for example, indicating that they reassured parents by being 'positive' or 'optimistic' (C.D3, C.D4, D.D1, E.D2, F.D2). Doctors pointed to how, as treatment progressed, they encouraged parents to be hopeful based on the efficacy of treatment, and how they reassured parents that treatment was 'going according to plan' (C.D3) or 'on the right road' (C.D4).* ***(Paper 3)***	1 / 32 – 41	Hope 'keeps people going'
	They commonly described how they imagined they might feel in the parents' situation 'I'd be horizontal on the floor, me' (D.N2), particularly regarding the difficulties of treatment 'a little drop of blood for my little girl would be like "Oh my goodness!"' (C.N5). Nurses emphasised how their role entailed responsibility for providing emotional care for parents and described how they talked to parents about whatever they needed, which included overt emotional discussion 'they can phone you up, have a chat and you maybe make them feel better (E.N1). ***(Paper 3)***	5 / 174 – 181	Responsibility for providing emotional care
	Professionals highlighted their practice and provision of advice and support should be sensitive to these negative emotions: ***"****We have to be mindful that when they're first diagnosed, or when they're in the clutches of desperation and there's no more treatment left, they start looking for alternatives."* ***(Paper 6)***	6 / 250 – 255	Be mindful
	"Most of what I do involves just listening….It's also important not to belittle how they feel, that's the biggest thing, allowing them to have their chance to talk about it and express how they feel about it" (nurse). For patients, particularly boys, who	2 / 59 - 68	Just listening

	struggled with verbal expression, some advocated the use of written or video diaries: "I just said 'write down how you feel and about how you look'. He wrote 'I'm pissed off… because I look disgusting" (social worker). Other simple psychological interventions included validating rather than dismissing concerns, identifying positive role models with similar appearance changes (including celebrities), and providing positive reassurance about the adolescent's appearance. ***(Paper 10)***		
Psychosocial support for HCPs	*Such an evocative narrative certainly adds further weight to the argument that we need to extend an appreciation of emotional labour so as to allow a more explicit focus on systems of social and emotional support. James writes: Cancer is a particularly apt disease to review in order to analyse the management, control and 'labour' of emotions in health organizations (James, 1993, p. 96). Children's oncology was a protracted and painful event for all those involved. As the nurse said at interview: People can go through years and years and years of hoping that someone close to them might live, but knowing in the end that they are going to die. I don't know how nurses and relatives can cope with that, really. They just get on with things and have to get on with things. Nurses, patients and relatives were all involved in emotional labour and engaged in reflections of how to manage medical and emotional demands.* ***(Paper 5)***	5 – 6 / 200 – 217	Systems of social and emotional support
	Several health professionals noted the value of motivational interviewing, suggesting that this may help professionals to develop confidence to pursue conversations about lifestyle and prompt patients to change their behavior. There was a strong feeling that CPD resources need to be evidence based to help reduce uncertainty surrounding the best advice to provide. ***(Paper 8)***	4 – 5 / 172 - 177	Help professionals develop confidence
Focusing on the child's unique experience			

Recognising and addressing patients' and families' individualised needs	*However, healthcare professionals described how the level of detail in which they provided the spiel was based on their perceptions of a family's knowledge and questions, and degree of a family's reception and acceptance of the disease-related information. Many doctors said they tried to individualise the information given, by suggesting, "If a family wants numbers I give them numbers."* ***(Paper 4)***	3 / 124 – 129	Individualise the information
	However, it was also highlighted not all young people were immersed in digital technology. Professionals emphasized that young people had different information and support needs, and varying levels of engagement with the internet, therefore the emphasis on online information needed to be tailored to the needs of the individual patient or family: "For some people they may have consulted 'Dr Google' in the build-up to their diagnosis, so they may be less scared to look afterwards, whereas other people would avoid it … I don't know if there's a hard and fast rule as to who uses it for what." ***(Paper 6)***	2 / 52 – 61	Tailored to the needs of the individual
	Clinicians discussed patient-friendly adjustments for TYAs, such as offering telephone appointments to reduce hospital visits, considering the timings of appointments and clinics, and every TYA attending an end-of-treatment clinic in which they could discuss ongoing issues, including fatigue. ***(Paper 11)***	5 / 194 - 197	Patient-friendly adjustments
Fluctuations in patients' psychosocial and informational needs along the cancer journey	*Professionals reported variation in young people's online information and support needs at distinct stages of their cancer diagnosis and treatment timeline. They felt that young people's needs were contextual and based on individual circumstances, particularly at the latter part of their cancer timeline when they were approaching the end of treatment and moving back into what was sometimes referred to as "normal" life. Four key periods of time emerged where unique needs were described: at diagnosis; during treatment; end of treatment; and beyond treatment.* ***(Paper 6)***	2 – 3 / 83 – 90	Variation in young people's needs

	Healthcare professionals perceived young people to have a range of issues at the end of treatment, which fell into the following categories: physical, mental health, emotional, spiritual, social/relationship and education/employment issues. Issues within all of these categories required young people to adapt in some way and needed to be addressed in order for them to establish a 'new normal'. Healthcare professionals recognised that young people required advice and support to navigate these various aspects of their life in the months after completing cancer treatment: "Last week I had a patient who's probably two months post-transplant, and just rang me up and asked me for advice on how to get back into work because apparently, her work were being quite tricky about doing a phased return to work, and she asked for advice." ***(Paper 7)***	1 / 27 – 39	A range of issues at the end of treatment
	Participants were particularly surprised that patients with a terminal diagnosis can also be preoccupied with appearance change: "he's really worrying about these stretch marks and I thought…you know you're dying!" (social worker). ***(Paper 10)***	1 / 29-33	Preoccupied with appearance change
HCPs' awareness of the physical, psychosocial and emotional impact of childhood cancer	*Participants believed that appearance-related distress is common among patients when anticipating treatment, during treatment, as well as following treatment and that this is a major challenge: "how they look and how their peers treat them is one of the biggest angsts for most" (doctor). Participants believed that both girls and boys can experience concerns but boys may be more reluctant to discuss them and therefore appear to struggle less.* ***(Paper 10)***	1 / 17 – 23	The biggest angst
	Clinicians' perceptions of patients' fatigue were that it was caused by cancer, its treatments and treatment side and ongoing and late effects. CRF was also linked to TYAs' need to attend regular hospital appointments for treatments, necessitating considerable travel and	1 / 28 – 37	Fatigue caused by cancer and its treatment

	emotional burden. "I think cancer-related fatigue is usually because of the disease process… fatigue that is caused by either the cancer process or the treatment of cancer. I think treatment-related fatigue can go on for a substantial amount of time, depending on the type of treatment someone had or where their cancer was or still is". ***(Paper 11)***		
	Almost all participants explained that low mood is a common and understandable reaction to cancer in young people e.g., "Young people go under the duvet, which is a very very common place…It's like just shut your mind and just get through it and I think that is very appropriate. That seems to be completely understandable." Participants described how low mood was a normal and appropriate reaction to a cancer diagnosis and treatment: "I think the majority of young people have low mood at some point, many points, throughout their whole journal. And lots of it is completely normal, they have enough reason to [feel that way]" and "We would very regularly see young people who would be very low in mood just because of what has just happened…so one would really feel that it would be very appropriate to be weeping and very upset….just think about the nature of chemotherapy and how many of us would just think 'oh that's ok, I'm fine with this." ***(Paper 1)***	2 / 57 - 73	Low mood as a normal reaction to cancer
TYA-specific challenges and care needs	*Information specific to the needs of young people with cancer was viewed as particularly important: "I suspect it probably needs to be a combination, does not it? Because I think if we are genuinely looking at lifestyle behaviors in its broadest sense, it almost feels like there are too many things to be putting on one poster or one leaflet or within one thing, [but] they could fit on one thing and then you could use individual resources that sit alongside or underneath that perhaps offer a greater level of detail [of information] or different strategies."* ***(Paper 8)***	4 / 159 – 167	Specific to the needs of young people
	Participants felt that at the heart of appearance distress is the experience of	1 / 34 – 42	

looking and being treated differently by their peers, feeling unattractive compared to society's beauty norms, and fear of negative evaluation by others, including being teased. For those with extreme or poorly addressed issues, participants observed a psychosocial and behavioral pattern indicative of reduced self-esteem and confidence, together with a failure to access social support leading to isolation, depression, and decreased therapeutic compliance: "He wouldn't receive chemotherapy and steroids because of weight gain and worries about being bullied" (doctor). ***(Paper 10)***		Feeling unattractive
Clinicians perceived CRF to impact many domains of TYAs' lives including physically, behaviourally, cognitively emotionally and socially. These domains were seen as highly interconnected and mutually reinforcing. Clinicians specifically highlighted the unique developmental stage and associated age-related tasks of TYAs. Physically, clinicians discussed changes in TYAs' sleep patterns, their bodies feeling 'heavy' or 'drained', and limited energy levels. They feel like their body can't do it, the physical heaviness, and… lack of energy; and they might have a flipped sleep cycle where they're awake all night and sleeping all day." ***(Paper 11)***	2 / 63 – 72	Unique developmental stage
In terms of provision of information and support that met these issues, healthcare professionals perceived young people to have a variety of unmet needs. They felt that fatigue management, fear of recurrence, late effects, fertility and employment were some of the key issues where young people's information and support needs were unmet (Fig. 1). Furthermore, in the interviews, healthcare professionals referred to 'family needs', recognising that young people's parents, partners, and siblings may have questions, which may require referral to sources of information and support: "Then, also, a lot of partners sometimes ring me up and just-, things like asking advice on things like sex and relationships post-chemo, and again, it's about signposting them to the right things." ***(Paper 7)***	1 – 2 / 41 - 53	Unmet needs

Effective communication, information sharing and shared-decision making in paediatric oncology

Information provision and transparent communication	*Analysis revealed that open communication was a paramount HCP principle of involving teenagers in decision making about care and treatment. At MDT meetings, HCP regarded information provision as an indication that a teenager had been involved in decision making.* *However, open communication in their view did not always mean explicit verbalisation of every outcome. Sensitive information was often implied or suggested, not stated directly. One consultant explained that when cure was unlikely, they 'might not actually verbalise "and the outcome is you're going to die"' instead, informing the teenagers of test results and the difficulties moving forward.* *HCP recognised the importance of establishing and respecting what the teenager wanted and needed to know at different times across the illness. HCP depended on indications from the teenager to do this.* ***(Paper 2)***	2 / 63 – 81	Open communication
	They pointed to how they used non-threatening language and phrasing and carefully selected the information they presented to parents, for example, one doctor thought 'difficult to cure' was kinder to say to parents than 'prognosis is poor' (C.D2), while another indicated that he was 'cautious about saying too much' (C.D4). Doctors did not do this to deny parents' fears; as explained above, they were keenly aware of how anxious parents were. Rather, they perceived that parents 'always hone in on the negative' (B.D4), and because of this, doctors thought that they had a responsibility to avoid contributing to parents' fears and, where possible, take remedial or compensatory steps to help parents manage their fears. ***(Paper 3)***	2 / 44 - 53	Non-threatening language
	The issue with the spiel was that the agenda of the conversation was in the hands of doctors who had given the same speech numerous times. They saw it as	4 / 172 –	

normal to provide certain pieces of information, and made assumptions about what those were. Parents were given the opportunity to ask questions, but the spiel would continue, with consultants returning to the information they wanted to impart: "before I want to talk about the stuff I want to talk about" (HCP1.05.I1). *At diagnosis parents had very little knowledge about leukaemia, and did not yet understand their communication role within the hospital system. They did not understand that the more they asked of the medical consultant, the more information they would receive. Nor did they know what information outside of the spiel they were missing out on. The burden of guiding conversation and seeking knowledge appeared to be unfairly shifted to parents in the period of time surrounding diagnosis. Despite these heavy criticisms of the spiel, there was also evidence in our data that some healthcare professionals intentionally built up information over time and would continue speaking in detail if parents confirmed that they were happy for them to continue, which contests the general assumptions that parents should guide the diagnosis discussion based on their questions: and may add to an 'increased sense of chaos' when trying to assimilate complex information.* ***(Paper 4)***	192	Certain pieces of information The spiel
There were mixed views surrounding when information and support should be offered to young people in relation to their end of treatment. The difficulties of knowing when to provide information were reported, with issues sometimes not arising until young people were three to 6 months after treatment ended: "I think I tend to see more engagement with them maybe three to six months after treatment ends. That's the time when they try to get back into normal life as much as they can but they, kind of, find that their friends have moved on or that things are different in work. They're not quite as able to do the things they used to, so they, kind of, come back to us maybe three to six months on." ***(Paper 7)***	5 – 6 / 209 - 218	Knowing when to provide information

Mediating factors	*Additional influencing factors: age, cancer type, personal situation. There were additional factors that needed to be considered, which influenced the whole process of young people accessing information and support at the end of treatment. These included their age, cancer type and personal situation.* *"It's something we've probably got to look at. At the moment, they float in their own tumour groups … So, testicular cancer patients, 99% of them will be referred out, so, at their end-of-treatment, they will be at the [DH], so I don't really get involved with them … Skin is a tricky one because a lot of skin, like melanoma, they don't have an end-of-treatment because our link in with the treatment would be the nurse specialist for skin, but a lot of the time, they have it incised and that's it."* ***(Paper 7)***	6 / 230 - 241	Influencing factors
Shared decision-making and collaboration or lack of?	*HCP reported how the nature of the disease resulted in difficulty in giving teenagers and families' clear and accurate information about different options and their respective outcomes, one nurse stating 'I think it's much harder to sit down and tell someone this is what's going to happen because you just don't know'. This influenced how, when and to what to extent HCP felt able to involve teenagers in decisions about their care and treatment. HCP often sought clinical guidelines and consulted with other professionals to determine whether a certain treatment or trial should be permitted or excluded. During these periods of uncertainty involvement of other professionals was prioritised in reaching a decision, thus limiting the role afforded to teenagers in the process.* ***(Paper 2)***	4 / 135 - 151	Period of uncertainty
	The decision-making process needed to be shared and there was evidence of consideration of others feelings and their role in the decision-making process. It is acknowledged within the literature that decision-making within pediatric oncology can be challenging (Oberle & Hughes, 2001; Whitney et al., 2006). With experience came increased	2 / 75 - 84	The decision-making process

	levels of confidence in challenging the decision-making process. Isolation was expressed as a feeling by some participants when making complex decisions. There were also feelings of powerlessness and feeling devalued regarding their perceived lack of input into the process, contributing to moral distress. The weight of responsibility for the person making a decision was highlighted by all participants. ***(Paper 9)***		
Use of online resources in paediatric oncology	*It was noted that in England digitalization of health services was part of the NHS Five Year Forward agenda and should be embraced as opposed to shied away from. Professionals recognized the need to become comfortable with using and understanding online resources in order to successfully guide and support patients and their families online, they also felt it was part of their role to facilitate safe use and access to online resources. This was supported by survey respondents which showed it was important for the treatment team to facilitate young people's access to health information online (Figure 1A).* *Professionals discussed the need to have an awareness and understanding of the online world that young people used and accessed. It was accepted that most young people engaged well with information and resources that were online, potentially more readily than information in other formats such as leaflets.* ***(Paper 6)***	1 – 2 / 32 - 45	Digitalisation of health services The online world
	There was consensus among participants that online interventions could not replace the enormous therapeutic benefits of forming a therapeutic relationship through face-to-face psychological therapy: "There is a huge amount of value in simply being with them [face-to-face] through the whole journey." *Participants suggested that GSH including online and computerized interventions for depression may have the most benefit for young people who do not or cannot currently engage with face-to-face services: "The big issue with them when seeking help is that actually doing the talking, they don't want to do that, whereas if you put them onto something online they*	3 / 107 - 120	Online interventions cannot replace face-to-face

	are much more likely to engage in that, maybe at an earlier stage." ***(Paper 1)***		
HCPs' knowledge deficits	*Ten/eleven nurses perceived their lack of knowledge to be a significant barrier, resulting in them avoiding raising fertility issues. Knowledge insufficiencies were particularly significant in areas such as policy and guidance and knowledge required to adequately prepare TYAs for the sperm banking process. Their avoidance of FP discussions appeared to reflect their personal belief in their inability to be effective and useful to TYAs. This is illustrated in the following quotations:* *"… I don't feel like I have the knowledge to do it … I don't think it's helpful me bringing up the topic of fertility preservation without actually being able to advise them on what's involved or not involved …" (Participant 1)* *"If your knowledge isn't sort of, you know, very solid on the subject, you don't want to risk saying anything that's going to upset someone …" (Participant 2)* ***(Paper 12)***	1 / 17 - 30	Knowledge insufficiencies
	Professionals' knowledge and awareness of what online resources existed for young people was described as both a facilitator and a barrier to referring young people to online resources. Knowledge and awareness of online resources was investigated further in the survey. Professionals were asked to rate their awareness and knowledge of existing resources for cancer-specific, and holistic (e.g., mental health, finances, body image) information and support for young people. Differences were shown between the knowledge and awareness of HCPs around these two types of information and support. The majority of professionals (n=29; 78%) had very good/moderate awareness and knowledge of online information and resources that were cancer-specific, i.e. , related to disease and treatment. Similarly, professionals (n=29; 78%) had very good/moderate awareness of what currently existed online for young people's holistic information and support needs. However, their knowledge of what was available did not correspond with whether	5 / 176 – 190	Both a facilitator and a barrier

	they felt that the internet met young people's information and support needs. ***(Paper 6)***		
	Health professionals' confusion and conflict over the best advice to provide often stemmed from a lack of specific knowledge relating health behavior to TYA cancer outcomes. Health professionals reported being aware of "emerging evidence in cancer in general," with many noting the lack of TYA-specific evidence: There is not as much evidence to date in the specifically TYA population, but there is a lot of anecdotal evidence that it helps and it makes sense that we should be getting people to [lead a healthy lifestyle]. ***(Paper 8)***	3 / 114 - 123	Lack of specific knowledge
Skills-based training, education and support for HCPs	*There was a clear communication hierarchy, where certain information was delegated to be given out by certain professionals, one nurse stating: "….and blurt out a load of medical information…….I wouldn't really feel that is my place" (HCP1.09.I1). The absence of guidance regarding communication, in terms of roles, and who does what, and the timing of supplementing information or follow up on the information received by families may have contributed to the deficiency of information shared during this period, as well as throughout treatment.* ***(Paper 4)***	4 – 5 / 215 – 223	The absence of guidance regarding communication
	The above quotation supports the case that the task of research on emotional labour in the children's oncology setting should involve an assessment of the strategies of emotional regulation that were available to nurses. This includes looking at how nurses manage their own and the patient's emotions, how nurses come to terms with the difficult processes that were an unavoidable part of children's oncology, and looking at examples of successful mechanisms of support and disclosure for patients, relatives and staff. ***(Paper 5)***	6 / 276 – 282	Successful mechanisms of support
	Professionals recognized a need for increased understanding of what young people looked for online and why, to assist them in conversations they had with young people about using the internet for	9 / 358 – 368	Training for HCPs on advising

	information and support. When asked whether professionals had received any training on advising young people with cancer about accessing online resources, the majority, 87% (n=32) of respondents had not received any training. Training for HCPs on advising young people with cancer about accessing online resources could be a facilitator if it was provided and survey data indicated that HCPs would be likely to undertake training if it was offered. If there was official training available, 35 (95%) felt that they would be extremely/very/moderately likely to attend it. ***(Paper 6)***		young people with cancer
	Barriers associated with organizational constraints and reluctance to discuss appearance concerns were identified more frequently than barriers associated with personal competence. However, even when individual participants felt personally competent, they stressed that many of their colleagues were not, and 91% of those surveyed requested education to address deficits in knowledge and to provide strategies to improve care. ***(Paper 10)***	3 / 123 - 128	Address deficits in knowledge
Coordinated care in a complex health system			
HCPs' perceptions of challenges, barriers, facilitators and resources in paediatric oncology settings	*Healthcare professionals perceived young people to have a range of issues at the end of treatment, which fell into the following categories: physical, mental health, emotional, spiritual, social/relationship and education/employment issues. Issues within all of these categories required young people to adapt in some way and needed to be addressed in order for them to establish a 'new normal'. Healthcare professionals recognised that young people required advice and support to navigate these various aspects of their life in the months after completing cancer treatment.* ***(Paper 7)***	1 / 27 - 34	A range of issues
	A variety of processes, services and roles were described by healthcare		

	professionals to either facilitate or hinder the provision of information and support to young people. Processes were described such as specific meetings about the end of treatment that were used by the MDT, or end of treatment-specific services that were offered, for example, dedicated end of treatment nurse-led clinics. Facilitating roles included specific support from YSC, social workers and clinical nurse specialists (CNS), following treatment finishing: "Yes, they can ring us, they have our number, they are always welcome to ring us. We don't ever really stop being a CNS, we have quite a good service and we carry a mobile and they can contact us." ***(Paper 7)***	3 / 106 – 117	Facilitate or hinder the provision of information
	However, personal interest and cognitive biases such as fear of disengaging the patient often affected TYA-HPs' decision to provide advice. Many TYA-HPs reported low knowledge of and limited skills to address health behavior with patients in their care. It was clear that TYA-HPs' capability to provide advice was limited by a lack of available resources and evidence to support health behavior promotion. ***(Paper 8)***	1 / 29 – 34	Personal interest and cognitive biases
	Forty-five percent of participants expressed disappointment at the lack of appearance- specific expertise available through hospital-based psychologists or, in the absence of this service, from family doctors. Discrepancies in relation to who should deliver interventions and the timing of their delivery were found. While some believed doctors and nurses should be responsible for delivering medical information and psychosocial specialists responsible for psychosocial interventions, others believed in a multidisciplinary approach, characterized as: "team awareness/experience and support, so that the young person can choose who they feel most comfortable seeking this support from" (doctor). ***(Paper 10)***	3 / 86 - 95	Disappointment at the lack of appearance-specific expertise
Team-based care	*Rather than individual professionals trying to meet all of parents' needs, doctors also explained that the clinical team as a whole was responsible for providing emotional care for parents. They therefore*	3 / 105 – 112	Shared between doctors and nurses

described how the work of meeting these needs was shared between doctors and nurses, as appropriate to their respective roles. For example, doctors described how they could not provide emotional care 'by themselves' (A.D3) or 'deal with everything' (C.D2), adding that they may not be the 'right' person to help parents but could 'find the right person for them to talk to' (C.D2). ***(Paper 3)***		
Notably, health professionals expressed the importance of peer support from colleagues and highlighted the benefit of interdisciplinary sharing of knowledge. ***(Paper 8)***	4 / 169 – 171	Interdisciplinary sharing
I realized that if you persisted in making horrendous things happen to patients you so emotionally disturbed the nurses that you lost nursing staff. I realized that you can't look after sick children if you don't have the nurses to look after them, so for me it is incredibly important actually that the nurses haven't go so far off side with you that you are losing them mentally or physically. I have always held that really dear because I think it is such an important issue if you haven't got an adequate number of nursing staff you can't get better the patients who can get better, let alone ones who have gone beyond the point of any chance of that. So that for me is a very important decision-making thing. (Doctor 2) ***(Paper 9)***	2 / 60 – 69	If you don't have the nurses
Situations build up out of control because of different members of the team saying different things to families not together. "Medically we are guilty of going and seeing families on our own and not imparting information. I think because there is not time to go together and support each other, you get a communication breakdown, then the team falls apart. Actually if we had time to do things together then we might be able to present a more structured support package for the families to understand what we are trying to all deal with and I don't think we always value this". (Doctor 4) ***(Paper 9)***	3 / 110 – 117	The team falls apart
Clinicians supported TYAs with CRF by referring to other disciplines within the MDT, supported by a weekly MDT	5 / 181 -	Disciplines

	meeting. Clinicians also worked with wider systems, holding discussions with education providers and workplaces and making referrals to local cancer centres and exercise management programmes in the community. "I often will have conversations with teachers or student support services and say actually, 'yep, they have finished their treatment, but fatigue is a big thing and they do need to have a reduced timetable, a phased return, extenuating circumstances." (P6) ***(Paper 11)***	190	within the MDT
Systemic and structural factors	*Numerous challenges that were identified that hindered the provision of information and support at the end of treatment. Specific professionals identified challenges in leadership, where services lacked the provision of a dedicated individual to lead this aspect of their service: "As a hospital no one person is, kind of, leading on it and there isn't a set structure (…) everyone's doing their own, sort of, separate thing in site-specific teams, it's a bit loose." Process challenges included difficulties in knowing where young people had been discharged to, for example, if the young person had returned to university they might have then been in a new city and new hospital. Some participants noted that young people did not need support and they were hard to engage: "The psychology team do a beading day [type of narrative therapy], and I think that can be quite useful at the end of treatment, looking back over things. Again, you can offer it to them all, but not many of them take it up."* ***(Paper 7)***	4 / 142 – 159	Challenges in leadership
	*Clinicians described insufficient time for assessment, consultation and interventions. "We're time-limited and we need clearer guidelines, you know, these are the… interventions that you can call on." (P1) Additional challenges included staffing, TYAs 'straddling' paediatric and adult community services and fatigue and exercise programmes. Other systemic challenges included societal stigma and lack of understanding from TYAs families, friends, education providers and workplaces****. (Paper 11)***	6 / 244 – 253	Systemic challenges

	Nearly, all (nine/eleven) nurses described the limited time frame for females to preserve their fertility before commencing cancer treatment as a barrier to both fertility discussion and fertility preservation. Nurses felt that "time is of the essence", a phrase used by participants themselves and one which aptly captions this theme: *"It's not as easy for females … you have got to start the treatment straightaway" (Participant 7).* *"… Often between their diagnosis and needing chemotherapy there isn't time to do that" (Participant 3).* *"… it was almost like at the time the focus was on just get treatment started … time is of the essence in terms of starting treatment" (Participant 1).* *"The fact that there is not time for the process … with the girls, time is of the essence …" (Participant 2).* *There appears to be general agreement here that lack of time is an insurmountable barrier. There is a suggestion of resigned acceptance that, in all cases, treatment has priority over fertility preservation, rather than considered on an individual patient basis.* ***(Paper 12)***	4 / 151 - 172	Limited time frame
What might help: practical recommendations and possible interventions	*This domain comprised three themes focusing on the features of an effective online psychological intervention: (1) acting as a 'stepping stone' to promote engagement with face-to-face therapy; (2) enabling vulnerable young people to connect with others; and (3) promoting ownership and empowerment of young people with low mood and cancer.* ***(Paper 1)***	3 / 99 – 103	Effective online psychological intervention
	Professionals employed a range of strategies to assist them in managing their anxieties around young people's online activity describing strategies to assist them with referring young people to online resources and that enabled them to feel confident and comfortable in doing this. Furthermore, they employed strategies to protect young people online and assist colleagues in doing this. […] Professionals frequently mentioned using caveats when	7 – 8 / 291 – 311	Strategies to protect young people online

discussing online resources with young people, and they forewarned young people of the pitfalls of searching for information on the internet:

"I tend to say at the beginning, 'the internet is amazing but it's sometimes a very dangerous thing … what you may find is information that's not relevant to you or your diagnosis'."

They also used caveats with trusted websites, to illustrate that not all online information would be relevant to them. If young people accessed social media sites, such as hospital Facebook groups, HCPs reiterated to young people that these were not intended for medical use, and to refer to their treatment team when they required medical information. ***(Paper 6)***

It was suggested that services should be reviewed to understand existing follow up processes, there should be provision of more information events and resources tailored specifically towards the needs of young people, such as end of treatment information evenings. Additionally, more services providing support for young people and to promote peer-to-peer support, such as social peer events for those who have finished treatment:

"Young people supporting each other, I think, during the treatment, that's one thing that certainly people benefit massively from, or they seem to anyway, is the connections they make with other young people. I guess, a lot of people continue that naturally, but how to maybe build that into finishing treatment, where they can still, there is still a way to maintain those connections through the hospital." ***(Paper 7)***

7 / 260 – 273

End of treatment information evenings

Integrating health promotion into care was viewed as challenging. To shift health behavior advice delivery from an ad hoc basis to a standard element of practice, most believed that health promotion should be introduced as a professional competency during training. A number of health professionals felt that endorsement and backing from leading supportive care and charity organizations specializing in TYA cancer care were essential for widespread access to health promotion

5 / 189 – 195

A professional competency during training

materials to be possible. ***(Paper 8)***

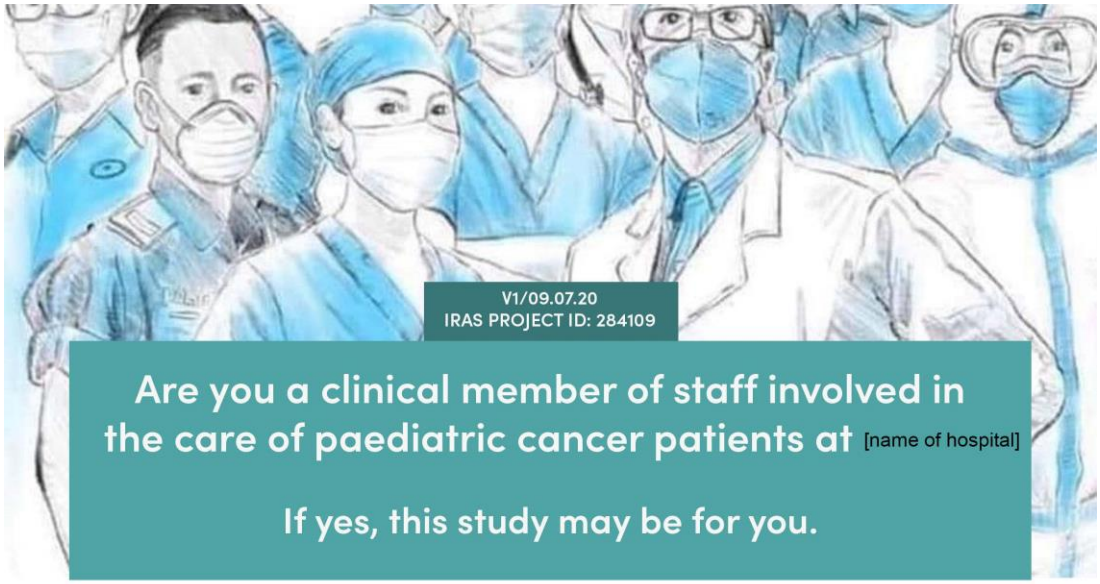
Participants' suggestions for improvements have been organized into five main areas. 1. Validating and normalizing adolescents' appearance concerns by raising or encouraging appearance-related discussions through a screening tool or peer-support interventions. 2. Educating parents and significant others about the psychosocial impact of appearance change and how to provide support. 3. A coordinated plan of appearance-related care incorporating a tool to assess for appearance-related support needs and providing guidance on how to escalate care and access psychological expertise as required. 4. Training and education including information regarding communication and support strategies to address psychosocial concerns and opportunities to share experiences of "best practice" with experienced colleagues. 5. A directory of appearance-specific services and organizations within and external to the hospital. ***(Paper 10)***

3 – 4 / 128 - 141

A coordinated plan

PART 2 – EMPIRICAL PAPER

Appendix 1.1. Study recruitment poster



Take part in important new research in partnership with UCL.
We're looking for members of staff who:

- Have been working for a minimum of six months on [name of ward] at [name of hospital]
- Are actively engaged and involved in the care of paediatric cancer patients at [name of hospital]

UCL

Participants will be asked to participate in a confidential one-hour interview with the study researcher to discuss their experiences and perspectives around ending treatment with paediatric oncology patients.

INTERVIEWS CONDUCTED VIA ZOOM

If you are interested in taking part in this new and important piece of research and would like more information or if you're unsure if you meet the requirements, please email Dr Anastasia Tsipa at [researcher's NHS email]

Appendix 1.2. Email template for invitation to potential participants

Sample email invitation to potential participants (for staff interviews)

Dear colleagues,

We are a team of Clinical Psychologists and Trainee Clinical Psychologists from [name of hospital] and University College London (UCL). We are writing to ask if you would be willing to take part in our project titled "Ending cancer treatment - experiences of children, parents and staff".

We know from the literature that the end-of-treatment phase represents a significant point and transition in the care pathway for children, young people and their families/caregivers, and yet despite this knowledge there is a lack of practical recommendations on how to support children and their families during this phase. Additionally, despite the acknowledgment in the literature about the vitally important role cancer healthcare professionals have in relation to patients' wellbeing and clinical outcomes, the research documenting healthcare professionals' perspectives and experiences in relation to the end-of-treatment phase is almost non-existent.

The purpose of this study is to conduct a one-to-one interview with any healthcare professional who: (1) is actively involved in the care of paediatric cancer patients and (2) is working on any of the cancer wards at [name of hospital].

The interview has two aims:

1) To explore your views and experiences in caring for paediatric cancer patients during the end-of-treatment phase.
2) To seek your perspective on some newly introduced rituals used on cancer wards across the NHS to mark endings in cancer treatment (e.g., ringing the "cancer bell"). To date, healthcare professionals' narratives around the use of this ritual have not been examined.

We anticipate that the information gathered from interviews with healthcare professionals will likely provide insights into the unmet needs of paediatric cancer patients and their parents/caregivers, which should in turn help to inform the development of best practices.

If you choose to participate in this study, please reply to this email and the researcher, Dr Anastasia Tsipa, will contact you to arrange a mutually convenient date and time for the

interview to take place. Interviews are expected to last between 45-60 minutes and will be held on Zoom.

We have attached a study information sheet, which provides further information about this study. This study has been approved by the London - Bloomsbury Research Ethics Committee on 14th October 2020 and the confidentiality of all participants is assured.

Please do not hesitate to contact the researcher (Dr Anastasia Tsipa), her supervisor (Dr Henry Clements) and/or the Principal Investigator (Name of principal investigator) if you have any further queries or concerns about this research. Our contact details are:

Researcher: Dr Anastasia Tsipa, Trainee Clinical Psychologist, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. Email: [researcher's NHS email address at study site].

Research Supervisor: Dr Henry Clements, Principal Clinical Tutor, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. Email: henry.clements@ucl.ac.uk

Principal Investigator: [name of principal investigator at study site], Principal Clinical Psychologist, Psychological Services, [name of hospital]. Phone: [Principal investigator's phone number at study site]. Email: [principal investigator's NHS email address at study site].

Thank you very much for considering taking part in this study.

Yours sincerely,

Dr Anastasia Tsipa (Trainee Clinical Psychologist, UCL)

Dr Henry Clements (Clinical Psychologist/Principal Clinical Tutor & Research Supervisor, UCL)

[name of principal investigator] (Principal Clinical Psychologist, [name of hospital]

Appendix 1.3. Participant Information Sheet

Participant Information Sheet (Staff)

Study Title: Ending cancer treatment - experiences of children, parents and staff

We would like to invite you to take part in a research study. Before you decide we would like you to understand why the research is being done and what it will involve. If you do decide to take part, the researcher will go through this information with you again and answer any questions you may have.

Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen if you take part.

Part 2 gives your more detailed information about the conduct of the study.

Part 1: Purposed of the study and what it involves

1. What is the purpose of the study?

This study explores the end-of-treatment (EOT) phase and how this is experienced by healthcare professionals (HCPs) who are involved in the care of paediatric cancer patients at [name of hospital]. We would like to hear your perspective on this important topic as it is likely to provide insights into the unmet needs of paediatric cancer patients and their parents, which should in turn help to inform the development of best practices.

2. Why have I been chosen to take part?

You have been chosen because you have been working at [name of hospital] for at least six months and have been directly involved in the care of paediatric cancer patients on the Safari, Giraffe and/or Elephant ward(s). Your views and experiences of the end-of-treatment phase are invaluable for understanding how best to support patients and their families during this time.

3. Do I have to take part?

No. It is up to you to decide whether or not to take part. If you choose to take part, the researcher will explain the study and go through this information sheet with you. If you agree to take part, the researcher will then ask you to sign a consent form. You will be given a copy of the information sheet and the signed consent form to keep for your records. You are free to withdraw from the study at any time and without giving any reason. Any data collected with consent will be retained for use in the study, however, if you decide to withdraw you will not be contacted by the researcher again and no further data will be collected from you or about you. You can withdraw from the study by contacting the researcher and stating you want to withdraw: **Dr Anastasia Tsipa**, Trainee Clinical Psychologist, Clinical Psychology Doctoral

Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. **Email:** Anastasia.tsipa.18@ucl.ac.uk.

4. What do I have to do?

By agreeing to take part, you will be required to participate in an interview. This interview will be conducted by Dr Anastasia Tsipa, Trainee Clinical Psychologist, at a mutually convenient time at [name of hospital] premises and will take approximately 45-60 minutes. The interview will be audio-recorded to ensure that the information you provide is accurately reflected in the interview transcripts.

However, if current restrictions due to the Covid-19 pandemic persist, we will conduct the interviews via a video call. This will be arranged in accordance to any preferences you may have.

If during the interview you disclose something that makes the interviewer concerned about a child's safety, the interviewer will have to disclose this information to the appropriately authorised people.

5. How long will the study run for?

Each participant will only need to complete an interview once. Therefore, overall involvement will take approximately 45-60 minutes in total. The study itself will run for approximately six months.

6. What are the possible disadvantages and risks of taking part?

We will be asking you about your own personal experiences of caring for peaditric patients during the end-of-treatment phase. This may understandably generate some distress for some participants. At the end of the interview, we will provide further information on support that can be accessed if needed.

7. What are the possible benefits of taking part?

There will be no direct benefit to participants. However, participants may find it beneficial to have the opportunity to talk about their experiences, and may have a sense of satisfaction that their views are being documented and taken into consideration. It is also hoped that the increased understanding about staff experiences can also help to inform support for staff around how they manage endings, and add to the literature around staff support needs of healthcare professionals working in paediatric oncology. It is known that this is a highly emotive setting with relatively high rates of staff distress and burnout. Better understanding of staff experiences ma provide insights into the challenges faced by healthcare professionals in cancer multi-disciplinary teams during the end-od-treatment phase and thereby identify opportunities for effective intervention that may contribute to advancements in survivorship care for child cancer patients.

8. What happens when the research study stops?

We will collect all the information together and analyse healthcare professionals' experiences of the ending of pediatric cancer treatment. This will help us to identify common patterns and experiences and better support paediatric cancer patients and their families during the end of active treatment phase in the cancer journey.

9. Will my taking part in this study be kept confidential?

All information provided by you will be kept confidential. Any information reported from the interview will not enable you to be recognised. The recording and notes from your interview will be given a unique participant identification number (PIN) to ensure that you will not be identifiable by name. All information which is collected about you during the course of the research will be kept on a password-protected data file on the [name of hospital] network, which has very high standards of security, and will be held securely in accordance with EU General Data Protection Regulations (GDPR) and the Data Protection Act (2008). Access to the information will be limited to the research team and principal investigator only. A copy of the interview transcript will be available to you on request. You will not automatically be expected to take part in any future research.

The only exceptions to confidentiality would be: (1) a disclosure about misconduct that would compromise patient safety, in which case the information you share will be forwarded to Trust management as appropriate; (2) a disclosure which indicated you are at a significant risk of harm to yourself or others, in which case the researcher would speak with the Research Supervisor and/or Principal Investigator and action would be taken to ensure your safety and/or the safety of the other person(s) which might involve breaching your confidentiality, although wherever possible and appropriate this would be discussed with you first.

10. Contact for further information

If you would like any further information about this study, you could contact:

Researcher: Dr Anastasia Tsipa, Trainee Clinical Psychologist, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. **Email:** [researcher's NHS email address at study site].

Research Supervisor: Dr Henry Clements, Clinical Psychologist & Principal Clinical Tutor, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. **Phone (Main Office**): 020 7679 1897. **Email:** henry.clements@ucl.ac.uk

Principal Investigator: [name of principal investigator at study site], Principal Clinical Psychologist, Psychological Services, [name of hospital]. Phone: [Principal investigator's phone number at study site]. Email: [principal investigator's NHS email address at study site].

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.

Part 2 - more detail – information you need to know if you still want to take part.

11. What will happen if I don't want to carry on with the research?

This is entirely up to you and if you wish to withdraw from the study at any point; you do not have to provide a reason. Please note that any data collected from you up to your withdrawal will be retained for the purposes of the study. After you withdraw you will not be contacted again about the research and no further data will be collected from you or about you.

12. What if there is a problem or something goes wrong?

In case you have a complaint on your treatment by the researcher or anything to do with the study, you can approach the principal investigator:

Name: [name of principal investigator]
Designation: Clinical Psychologist
Hospital: [hospital site]
Telephone: [principal investigator's phone number at hospital site]
Email: [principal investigator's NHS email address at hospital site]

Alternatively you can contact the researcher's supervisor:

Name: Dr Henry Clements,
Designation: Clinical Psychologist, Principal Clinical Tutor
Organisation: University College London
Email: henry.clements@ucl.ac.uk.

If you have any concerns about the conduct of this study you can contact [name of hospital and service] on [contact number at hospital] or [email address at hospital].

If you want to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer. The research team can give you details of the right Data Protection Officer.

If you are not happy with their response or believe they are processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

Harm

If something does go wrong and you or your child are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for

compensation – but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

13. Will taking part in this study be kept confidential?

All information provided by you will be kept confidential. Any information reported from the interview will not enable you to be recognised. The recording and notes from your interview will be given a unique participant identification number (PIN) to ensure that you will not be identifiable by name. All information which is collected about you during the course of the research will be kept on a password-protected data file on the [name of hospital] network, which has very high standards of security, and will be held securely in accordance with EU General Data Protection Regulations (GDPR) and the Data Protection Act (2008). Access to the information will be limited to the research team and principal investigator only. A copy of the interview transcript will be available to you on request. You will not automatically be expected to take part in any future research.
The only exceptions to confidentiality would be: (1) a disclosure about misconduct that would compromise patient safety, in which case the information you share will be forwarded to Trust management as appropriate; (2) a disclosure which indicated you are at a significant risk of harm to yourself or others, in which case the researcher would speak with the Research Supervisor and/or Principal Investigator and action would be taken to ensure your safety and/or the safety of the other person(s) which might involve breaching your confidentiality, although wherever possible and appropriate this would be discussed with you first.

14. Will the use of my data meet the General Data Protection Regulation (GDPR) rules?

Yes. Universities, NHS organisations and companies may use patient data to do research to make health and care better. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules.

We have made sure to meet the GDPR rules and protect the privacy of the people who take part. An NHS research committee has checked this and approved the study before the research started.

15. What will happen to the results of the research study?

The results will be written up for the purposes of an education course. We also plan to submit the findings of this study to scientific journals for publication and results may be presented at relevant conferences. You will not be identified in any report/publication and any findings being reported will be completely anonymised. A short summary of the results may also be sent to all the people who have taken part in the research. If you would like to receive a brief summary of the study findings at the conclusion of the project, you can provide your preferred contact details (either email address or mailing address) so the researcher can send you the final report in due course. The study will be registered on the NIHR website and a summary of findings will be publicly available at www.nihr.ac.uk.

16. Who is organising and funding the research?

The study is organised by University College London (UCL) and [name of hospital]. The study is funded by UCL.

17. Who has reviewed the study?

The study has been reviewed and approved by the London Bloomsbury Research Ethics Committee (IRAS ID: 28-4109; Date of Approval: 14th October 2020). The study has also been reviewed by the [research committee at hospital site] (R&D Number: 19SH35).

18. How can we find out more about the research?

To find out more about research at [name of hospital] in general, you can go to [hospital website] or contact the hospital research facility on [contact number].

HRA Information Governance Transparency Statement

[Name of hospital] is the sponsor for this study based in UK. [Name of hospital] will be using information from you in order to undertake this study and will act as the data controller for this study. This means that [Name of hospital] is responsible for looking after your information and using it properly. [Name of hospital] will keep identifiable information about you until 6-12 months after the end of this study after which all identifiable information will be deleted. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. [Name of hospital] will keep a record of your name and contact details confidential and will not pass this information to anyone else. [Name of hospital] will use this information as needed, to contact you about the research study. You can find out more about how [Name of hospital] use your information by contacting [Name of Data Protection Officer at Hospital], at [email contact for Data Protection].

If you decide to take part in this study, you will be given this information sheet and signed consent form to keep.

Thank you very much for considering taking part in this study.

Appendix 1.4. Participant Consent Form

Participant Identification Number:

Staff Consent Form

Study Title: Ending cancer treatment - experiences of children, parents and staff

Ethical Approval Ref: (to be added)

Name of Researcher:
……(Please print clearly)

If you are happy to sign this sheet, please confirm each statement by putting your initials in the associated box.

1. I confirm that I have read and understood the information sheet with the date..... (Version.....) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, up to one month after the date on which I have been interviewed. ☐
3. I understand that the interview will be recorded and that anonymous direct quotes from the interview will be used in study reports / publication. ☐
4. All information supplied will be kept confidential. Any information reported will not enable me to be recognised. I understand that the only exceptions to confidentiality are: (1) if I make a disclosure about misconduct that would compromise patient safety, in which case confidentiality will likely be breached and the information I share will be forwarded to Trust management as appropriate; (2) if I make a disclosure which indicated I am at a significant risk of harm to myself or another person or persons, in which care the researcher would speak with the Research Supervisor and/or Principal Investigator and action would be taken to ensure my safety and/or the safety of the other person(s) which might involve breaching my confidentiality, although wherever possible and appropriate this would be discussed with me first. ☐
5. I agree for the discussion to be audio-recorded and understand that when it is typed up, my name will not be on the document and any identifying features will be removed. ☐
6. I understand if I become upset in any way, I can stop the interview and support will be available to me' ☐

7. I understand that certain phrases or sentences may be quoted in future reports or publications but that my name will not be included and any identifying features will be removed. ☐

8. I understand that if I disclose anything during the interview which makes the interviewer concerned about a child's safety, the interviewer will have to disclose this information to the appropriately authorised people. ☐

9. I agree to take part in the above study. ☐

10. I agree to being sent a summary of the study findings. ☐

My preferred way of contact is ……..

Name of Participant _____

Signature _____

Date _____

Name of Researcher _____

Signature _____

Date _____

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

Appendix 1.5. Ethical approval documents

London - Bloomsbury Research Ethics Committee

HRA RES Centre
Manchester
Barlow House
3rd Floor4
Minshull
Street
Manchester
M1 3DZ
Telephone: 0207 104 8196

14 October 2020

Dr [name of principal investigator]

[address of hospital site where the present research was conducted]

Dear Dr [name of principal investigator]

Study title:	**Ending cancer treatment: experiences of children, parents and staff.**
REC reference:	**20/PR/0295**
Protocol number:	**v1**
IRAS project ID:	**284109**

Thank you for responding to the Committee's request for further information on the aboveresearch and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentationas revised, subject to the conditions specified below.

Recommendation

The Committee recommended that the following changes should be made to the PISs before commencing your research. You do not need to submit these changes back to the REC;

- In the staff consent form: 6 is kept 'in at the end of the phrase when copy & pasting – thisshould be removed.

- Large font size was used for the whole of point 8 – edit this to make it uniform with therest of the document.
- In page 8 of both information sheets for Parents/Guardians, there is a large gap at thetop of the page (1/2 a page worth), please delete the gap. Also, some section headers are at the bottom of pages – please format the document so that the headings correspond with the text they are associated with.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start ofthe study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission forresearch is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with theprocedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from hostorganisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see herefor more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving- research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency- responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annualprogress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied withbefore the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to thestart of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed inthe application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Staffposter]	1	09 July 2020
Covering letter on headed paper [Cover letter]		
Interview schedules or topic guides for participants [Parentinterview]	1	09 July 2020
Interview schedules or topic guides for participants [Child interviewPPI]	1	09 July 2020
Interview schedules or topic guides for participants [Child interview]	1	09 July 2020
Interview schedules or topic guides for participants [Staff interview]	1	09 July 2020
IRAS Application Form [IRAS_Form_06102020]		06 October 2020

Letters of invitation to participant [Email to staff]	1	09 July 2020
Other [Summary of amendments]	1	05 October 2020
Participant consent form [Parent / Guardian Consent for CYP]	2	23 September 2020
Participant consent form [Staff Consent Form]	2	23 September 2020
Participant consent form [Child / Young Person Assent Form]	2	23 September 2020
Participant consent form [Parent / Guardian Consent Form]	2	23 September 2020
Participant information sheet (PIS) [Staff]	2	23 September 2020
Participant information sheet (PIS) [Parents/Guardians]	2	23 September 2020
Participant information sheet (PIS) [11-14 years]	2	23 September 2020
Participant information sheet (PIS) [8-10 years]	2	23 July 2020
Participant information sheet (PIS) [Parents/Guardians on behalf ofCYP]	2	23 September 2020
Research protocol or project proposal [Study protocol]	1	17 July 2020
Summary CV for Chief Investigator (CI) [CV]		01 July 2020
Summary CV for student [Hida Caliskan CV]		22 July 2020
Summary CV for student [Martha Werthern CV]		22 July 2020
Summary CV for student [Anastasia Isavella Tsipa CV]		22 July 2020
Summary CV for supervisor (student research) [Krsistina Soon CV]		22 July 2020
Summary, synopsis or diagram (flowchart) of protocol in nontechnical language [Data colletion protocol]	1	17 July 2020

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality- assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 284109	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Signed on behalf of; Reverend Jim LinthicumChair
Email:bloomsbury.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Vanshree Patel

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr [name of principal investigator]
Principal Clinical Psychologist
[address of hospital site where the present research was conducted]

Email:
approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

14 October 2020

Dear Dr [name of principal investigator]

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Ending cancer treatment: experiences of children, parents and staff.**
IRAS project ID:	**284109**
Protocol number:	**v1**
REC reference:	**20/PR/0295**
Sponsor	**[name of hospital site]**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towardsthe end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Irelandand Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reportingexpectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light ofchanges in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact detailsare below.

Your IRAS project ID is **284109**. Please quote this on all correspondence. Yours sincerely,

Damilola Odunlami

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Dr Vanshree Patel

Appendix 1.6. Interview schedule

Endings in Paediatric Cancer Treatment - Proposed Interview schedule for Staff

1. **Welcome MDT staff to the interview session.**
   Hi! (Introduce self). Thank you for agreeing to take part in this research today. How are you doing?

2. **Give each participant a copy of the study information sheet/consent form.**
   - Ask them to read the forms carefully.
   - Researcher to verbally review sections related to confidentiality and what they are agreeing to when they sign the form.
   - Ask participants if they have any questions and answer them accordingly.
   - Collect signed consent forms. Keep one copy for own file and ask participant to keep a copy for their record as well.

3. **State purpose of interview briefly**
   I am interested in learning about staff's perspectives and experiences around the endings in paediatric cancer treatment. First (SPECIFIC), I would like to explore your experiences and thoughts around any specific rituals/procedures that are implemented in your healthcare organisation to signify the end of treatment (EOT) phase. Second (BROAD), I would like to learn more about your views and experiences of what it is like for you to be caring for paediatric cancer patients during the end-of-treatment (EOT) phase.

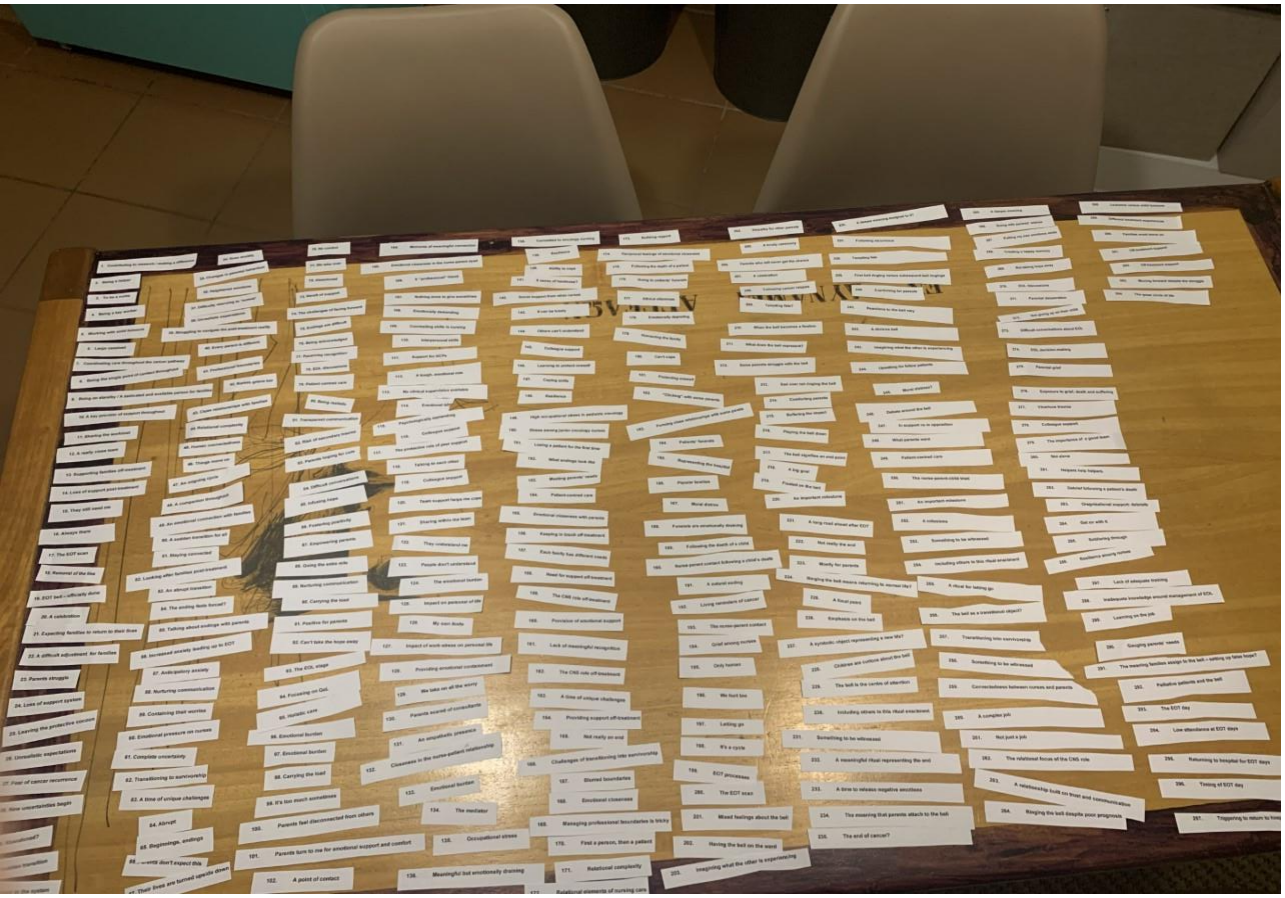
   Note. To be decided through the pilot interviews whether it is best to first examine the broad and then the specific.

4. **Overview of Interview Session**
   - To learn more about your experiences, I will be asking you some questions.
   - Remember, there are no right or wrong answers. If at any time you feel uncomfortable, please let me know right away. You can stop the interview at any time without having to provide a reason.
   - The interview will last approximately 45 minutes.

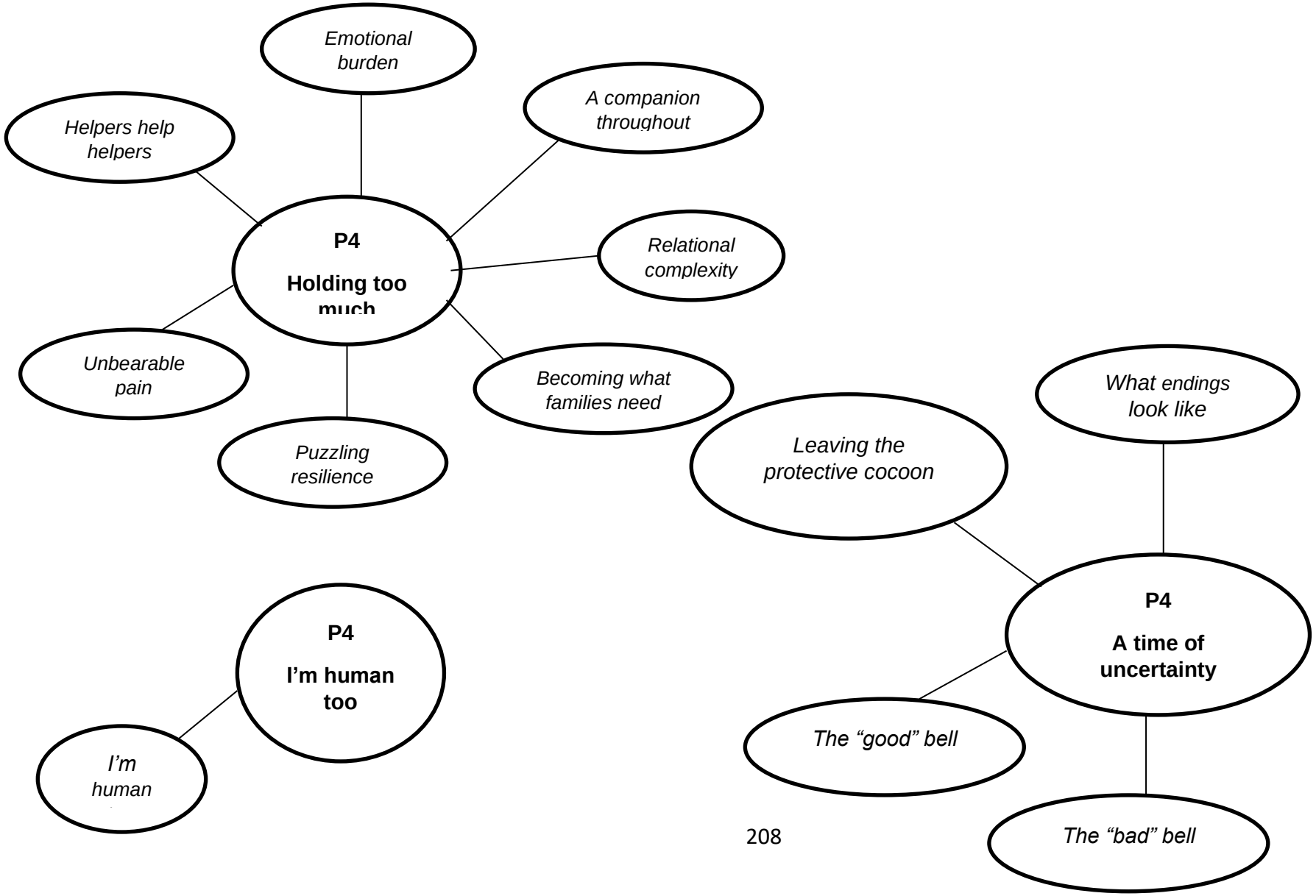
   Research Questions
   - What is it like as a (insert staff's role) to be involved in the care of a child during the end-of-treatment phase (practically, emotionally, mentally)?
   - What are some specific challenges that staff encounter around the EOT phase?
   - What are some specific challenges that staff face in the process of paediatric cancer patients transitioning from paediatric cancer care to cancer survivorship?

- The existing literature highlights that staff often face challenges around having to set expectations for the post-cancer treatment period for patients and their families – what are your thoughts/experiences around this?
- What has been your experience in terms of communicating/liaising with other members of the MDT involved in the patient's care around the EOT phase?
- What does your healthcare organisation do in terms of rituals and/or procedures to signify the EOT phase for paediatric cancer patients?
- How do you experience the existing rituals? What do you understand a ritual to mean?
- **Ask about the cancer bell specifically:**
  - Could you tell me about the first time you heard about/saw the cancer bell on the ward?
  - How was the bell introduced to the ward?
  - What did you think of it when you first heard about the cancer bell?
  - Did you have any concerns or expectations about patients ringing the cancer bell on the ward? (this would be a follow-up question if participants indicated any concerns)
  - What do you like and/or not like about the cancer bell?
  - How do you think the experience of ringing the cancer bell is for the child and for their family?
  - What is the experience like for you?
  - How do you decide whose cancer bell ringing to go to?
- How do the current rituals and/or procedures around the EOT phase affect you?
- When you think about your experiences with patients ending cancer treatment, what are some concerns that have come up for you in terms of the existing EOT rituals?
- What other EOT rituals, if any, would you like to see being implemented on the ward?

Appendix 1.7. Example of emergent themes printed out in chronological order (Participant 4)



Appendix 1.8. Example of mind map depicting emergent themes and superordinate themes (Participant 4)



Appendix 1.9. Worked example of coding data (Participant 4)

P4 Transcript

Date of Interview: 06/04/2021

- Descriptive comments: NORMAL TEXT – paraphrasing, saying in your words
- Conceptual comments: UNDERLINED - it is in the content but it's hidden
- Linguistic comments: ITALICISED – any question marks, laughs, idioms, metaphors

Emergent Themes	Original Transcript	Exploratory Comments
	I: So, hopefully that's recording now! So, I'm just wondering as a disclaimer as well, obviously I will be asking you quite a bit about your role and how you experience endings in a professional kind of way, but I'm also very much interested in how you experience endings as a human being? Umm.. And how, you know.. You're.. You know, you're very welcome to bring in the personal as well, umm.. To the extent you feel comfortable to obviously. Umm.. So, I guess the first question is, umm.. What kind of drew you to taking	

	part in this research today? P: Oooh! Good question! I think.. Well.. We're very driven for research in oncology anyway, so I think anything that you can contribute and may change or help.. Help professionals or children or families in the future is really important and I think.. Umm.. In the sector that we work in we rely heavily on research to.. Whether it's to.. (phone rings). Sorry let me turn this phone off, one second. Whether it's to umm.. Change the future.. Make it better.. So, I think yeah. I just always want to help I think and I think that comes naturally with being a nurse sometimes as well (laughs). You know, like.. You care about other people and you care about making a difference I think. **I: Yeah, of course. Ah brilliant, so it sounds like very much.. Kind of, you're thinking about what this (i.e., research) can contribute to in the wider scheme of things, is one of the aspects?** P: Uh-huh. **I: Okay. And would you be able to tell me a bit about your role in the team and umm.. Obviously I know what your title**	Motivation to contribute to research. Contributing to change in oncology. Making an impact Wanting to help children and families Changing the future. Research is important. Always wanting to help – I am a helper It comes naturally, nurses help people. Nurses = professional helpers? Caring, nurturing, altruistic? Caring about making a difference, being of service to others
Contributing to research / making a difference **Being a helper** **To be a nurse**		

	is but could you tell me a bit more about what you do? P: Uh-huh. Yeah. So, uh.. I start.. I've been a cancer nurse now for uh.. 12-11 years I think? I think I qualified.. I've always worked in cancer pretty much. So when I qualified I started at Birmingham Children's (i.e., hospital) and did a couple of years in cancer, and then moved to Manchester and did six years in cancer and then a couple of years end-of-life stuff in the community. Then I got my first clinical nurse specialist (CNS) post where I worked at the Whittington Hospital for three and a half years and I did.. Uhh.. I ran the service there and did most of my Master's and nurse prescribing and things like that. And then moved to [name of hospital] about.. Gosh, three years ago now. So, I work specifically with umm.. solid tumours. So, there's three in the team, so there's me and two other girls. And we all, kind of, key work, different tumour types. So, I take umm.. The.. Oooh. The, probably some of the really more difficult tumours in terms of prognosis.. So, rhabdoid tumours, rhabdomyosarcomas, Ewing sarcomas, germ cells, umm.. and all the kind of rare and aggressive stuff. So, anybody with that	Working in solid tumours Being a cancer nurse involves key working? Being a key worker The difficult tumours – my expertise Difficult tumours – poorer prognoses Aggressive tumours – a disease thet forms, grows and spreads quickly, more severe, more intense – <u>therefore needing to intervene quite quickly and drastically? More pressure?</u>
Being a key worker **Working with solid tumours**		

Large caseload **Coordinating care throughout the cancer pathway** **Being the single point of contact throughout** **Being on standby / A dedicated and available person for families** **A key provider of support throughout**	diagnosis between, kind of, can go as far down as, kind of, Brighton up to maybe Watford – we've got a big catchment area. Any child with that diagnosis that comes in through hospital they'd get allocated to me as their keyworker. So, I would meet them at diagnosis.. Umm.. Through the, kind of, the initial support work "This is your diagnosis, bla bla bla" and then I'd see them every time they came in for treatment umm.. And then we also carry a mobile phone that goes off a million times a day so that they can call when they're an outpatient as well. So, if they've got a problem or a concern.. They're angry about something, anything, you know, we're very much the point of contact for these families so that they can call between hours of 9-5, Monday to Friday. And then we'll also do all the relapsed things as well. So, they either get to a point where they've finished treatment and that's the end? And then we'll see them umm.. In clinic follow-ups or maybe they've relapsed and we'll pick them back up again? Umm.. And subsequently do the.. The next stage of treatment and when they get to the kind of end-of-life point umm.. They pass over to the palliative care team. So there's usually a kind of crossover towards the end if you're going into palliative care.	Big catchment area – a large geographical area covered Large caseload I am a keyworker – coordinating care? Being the main point of contact for families? My role: initial support work – <u>at time of diagnosis?</u> Being there when they come in for treatment Telephone contact – "*it goes off a million times a day*" – <u>overwhelming? Too much? Always being alert?</u> My role – I'm their point of contact when they're an outpatient too Any problem or concern – they call me. Being the container for anything and everything When they relapse they call me After the end of active treatment – seeing them for follow-up If they relapse I keywork the EOL stuff <u>A companion and supporter across the multiple twists and turns of the cancer journey</u> <u>Provision of ongoing support throughout</u> Not involved in palliative care?

	I: Uh-huh. Okay. Okay. That's all really helpful to know. Umm and I guess up to this point in my research, most of the people that I've spoken to, have umm.. Been working mainly in Advance Lymphoblastic Leukemia (ALL) I think which is, I suppose, is quite separate to.. P: Yeah, very different. **I: Yeah, so you're the first, kind of, person that I am speaking too from the, kind of, solid tumour team. Umm.. So I'm very very keen to hear how, you know, how things are from your side as well. Umm.. And I guess, you said that you work with two other colleagues that work with slightly different tumours – is that right?** P: Yeah, so we split the tumours. We split the tumour types up. So, we each basically got 3 or 4 different tumour types roughly. Give or take. **I: And have you..** P: I think it was just the way..	[own reflection: here I was very aware of the fact that I had only spoken to people working with ALL which is very treatable and is generally considered a low risk cancer. Was just keen to acknowledge this and be transparent with the P] Splitting the tumour types "*we each get 3 or 4 tumour types*" -Quite pragmatic, biomedical language here

	I: Sorry.. Go on.	
Sharing the workload **A really close team**	P: Sorry. No, that's historically.. I think when I came in it was very much set up like that. It's kind of historic.. The tumour.. 'Cause there's too much to do for any one person. But equally it's nice because you can specialise in certain areas. So, Umm.. You have a really good knowledge base about your 3 or 4 different tumour types. But.. We have.. You know, we work as a really close team. So, we do cross-cover. Like, if I'm off next week somebody will have to cover my patient caseload while I'm off. So you do.. You know about all the solid tumours generally. But then you specialise within a certain 3 or 4 roughly.	Set up is "*historic*" – has not been adapted more recently? An outdated model of working? A lot of work – needs to be a shared workload Nice to be able to focus and specialise on one thing Developing a good, in-depth knowledge base A close team – they cover each other when needs be – supportive, <u>tight-knit team?</u> Whole team has broad knowledge of solid tumours but each have a specialty
	I: Okay. And as you were speaking I was thinking that – you know, you said it yourself – that it's quite a lot for one person, you know it sounds like a massive workload and I was just wondering, at any one time approximately how many patients might you have in your care?	
Supporting families off-treatment	P: Umm.. On chemotherapy? Because obviously you've got on treatment and the children that have maybe finished treatment but.. Don't underestimate how	Caring for on-treatment and off-treatment patients Off-treatment patients need a lot of support. "Don't underestimate how much support they need" – The P here feels a need to emphasise this? Almost like it's a common

Loss of support post-treatment **They still need me** **Always there**	much they still need support. They still.. Even when they're at the very end of treatment they contact you a *lot* for reasons, such as they're struggling because their support network drops off, you know? They're.. Maybe they're not needing to come to hospital anymore, not even to go to their local hospital, maybe the community (i.e., team) even stop going umm.. So, I think just because they finish treatment does not mean it's the end of your role for them because they.. They do still contact you and still need you I think. **I: Uh-huh. Okay, that's a really good point actually. So, I guess you're, kind of separating it out, between, you know, the people (i.e., patients) that are still on active treatment and how would we call the other group of patients that have completed treatment but are in that, kind of, other phase? What.. If we could label it what kind of label would we give that?** P: The children are off-treatment. So, off-treatment families I guess. So on treatment and off-treatment probably. **I: Okay, thank you. That's really helpful to.. Kind of, to be able to separate**	assumption nurses hear that children off-treatment don't need much support whereas it's quite the contrary? Loss of support network – it drops off – a sense that this happens quite suddenly? No need for hospital visits anymore Community team does not visit anymore <u>The CNS is perhaps the only person they can contact more readily/convenienty post-treatment? As their keyworker? As the person that has followed them throughout the whole pathway? "*They still need you"* – almost indicating that a lot of pressure is on the CNS to support families off-treatment because all the other support tails off?</u> On-treatment versus off-treatment

	those. And I guess going back to that question about how many patients you might have in your care.. P: Oh, sorry. Umm.. 20-30 maybe? Something like that? **I: Okay, okay. And.. I guess in your experience.. How do you usually experience.. You know, it's a general question – but how you do you experience endings with, you know, patients in your care? Umm.. I guess, in relation to ending treatment how do you experience that emotionally, practically, umm.. Mentally? All those different angles I suppose.** P: Uh-huh. Umm.. So, start with practically I guess. So, they come to a point of time when they've finished their treatment and some of their treatments are.. Umm.. They're varying lengths. So, for germ cell for example it might only be for 4 or 5 months, whereas, a sarcoma might be umm.. Knocking on 2 years? Just under maybe.. Two.. 19 months? Something like that? So, practically, once they've reached the end of their treatment and they have a clear end of treatment scan, that means that there's no disease present or that's	Endings – when patients finish treatment Treatments for sarcoma vary in length End of treatment is when they have clear end-of-treatment scan to show there's no cancer anymore
The EOT scan **Removal of the line**		

EOT bell – officially done **A celebration** **Expecting families to return to their lives** **A difficult adjustment for families** **Parents struggle**	the end of the treatment. Umm.. And then we usually kind of arrange the end of the.. The line to come out and then.. Have you seen the end-of-treatment bells where they can ring the bell to say that it's officially done and that they're finishing treatment and they get a little prize and they get a certificate umm.. And then.. They actually.. They're just pretty much sent off to (laughs), kind of, get on with normal life.. I have to say! And then usually, with the solid tumours, they come back in every three months. And they'll have an MRI scan and a clinic appointment. Umm.. And that's just to keep monitoring the child for the next couple of years afterwards with regular MRI scans to make sure the cancer doesn't return. So, practically that's really how it works.. So they get to a point – chemo's finished.. The line comes out.. They ring the bell.. All done. And then the child is expected really to kind of.. And the family to re-adapt to normal life. To go back to school. Parents to go back to work. *Really* difficult for them. That's practically roughly how it works. It's kind of.. And parents struggle with that. But we can talk about that in a bit more detail. **I: Yeah, and could you tell me a bit more about that as well. And we can come**	The line comes out EOT bell "To say that it's officially done" – proposing that the bell makes it official? To declare it loudly and openly through this ritual/ceremony? Getting a prize/gift – a time to reward the child. <u>Similar ritual to birthday – giving gifts to celebrate the day they were born? Almost like the bell signifies a re-birth? The start of a new life post-cancer?</u> "Sent off to (laughs), kind of, get on with normal life" – the P laughs here, an indication that it's quite surprising to her as well that there is the expectations for families to get on with life? The off-treatment period in solid tumours Finishing chemo Line removal Ring the EOT bell The various processes that mark the ending? Return to normal life – really difficult. Challenging for families. Unrealistic to expect this from families The struggle of parents at the EOT phase

	back to the other aspects of how you, kind of, experience endings, but you kind of.. You said, you know, that "that's it" basically and that they (i.e., families) then return to normal life.. That kind of transition. Can you tell me a little bit more about why you think that might be difficult for families? P: I think.. I think 9 times out of 10 umm.. Families will just offer that information and will say umm "Gosh, this is really difficult" umm.. For many different reasons but usually the reasons that are given around are umm "We're gonna miss you", "We're gonna miss our Great Ormond Street team" umm.. "What are we gonna do without you there anymore?", "We've got used to coming to hospital all the time, how are we expected just to go back and adapt to normal life?".. Umm.. "We're on chemotherapy and it makes us feel safe and secure that the cancer is under control. Now you're stopping the treatment and what's gonna happen? Will it come back?". Those massive anxieties around stopping treatment. And obviously then you lose your support network, I think we touched upon that before. So, you lose your community team, who will come into your house once or twice a week to take	Families often express how difficult it is for them Losing their support network – [name of hospital] not only provides medical treatment but almost becomes their <u>social support system</u> for as long as treatment lasts? Parents experience the loss at different levels so the impact is quite significant? *"What are we gonna do without you*?" – <u>indicates some sort of dependence, inability to think of how life will be without this support, difficulty to envisage how they'll move on? Leaving the protective cocoon?</u> An expectation to just adapt to normal life – too much for parents Chemo makes them feel safe. A sense that the cancer is under control, something tangible is actively keeping the cancer at bay. Without the chemo parents feel insecure? Not knowing what to expect. Fear of cancer recurrence is always with them. <u>Helplessness?</u> <u>New uncertainties begin following cancer treatment</u> <u>Loss of all support networks – a grieving process almost?</u>
Loss of support system **Leaving the protective cocoon** **Unrealistic expectations** **Fear of cancer recurrence** **New uncertainties begin** **Abandoned?**		

A sudden transition **A shock to the system** **Anticipatory anxiety: worried they won't cope** **Not ready for this transition** **Scan anxiety** **Changes in parental behaviour**	blood tests for the child. You lose your local team because you don't need them anymore really. You lose your Great Ormond Street.. You don't see the nurses on the wards anymore and some of these children are in kind of 3, 4, 5, 6 days at a time for chemotherapy.. Even longer periods of times sometimes, depending on whether they're having surgery, you know, or whatever, you know.. Umm.. So they don't see the girls on the ward anymore. And then, they don't need to call me as much anymore. So, some families are very reliant all the way through treatment and they'll call you a million times a week. And then once they've got to the end they don't need you as much anymore and they.. And they.. You know. So the parents will often often express fears about how are they gonna cope when their support network's gone? How are they gonna go back to normal life? How are they gonna get through the scan anxiety? So.. Umm.. The follow-up scans are *hugely, hugely* overwhelming for these families. Umm.. And I find sometimes the parents.. Parents' behaviour changes a lot. They might become angry.. They might constantly ring or text or phone.. "Is the scan clear? Is the scan clear? Is the scan clear?". You know.. They get very very anxious about the	<u>Left alone? Abandoned?</u> <u>On-treatment – families are very reliant, dependent on us</u> <u>Off-treatment – loss of all support systems</u> <u>Very sudden? A shock to the system?</u> Parents worry they will not be able to cope? Are not prepared for the next phase? A lot of anxiety and uncertainty? Anticipatory anxiety? Anxiety about returning to normal life – a process of grieving the life you had before cancer? Everything changes, finding a new normal Scan anxiety – overwhelming for families Scary to wait – what will it show? The fear of cancer recurrence runs deep Parents change Almost "obsessive" about scan results

Heightened emotions **Difficulty returning to 'normal'** **Unrealistic expectations** **Struggling to navigate the post-treatment reality** **Every parent is different**	scans especially for the first scan after you stop the chemotherapy. There's a *lot* of heightened emotions. Amongst parents. And honestly they all say "Oh my God, I'm really worried about stopping treatment" umm.. You know, because of those reasons. Scan, loss of support network.. Umm normal life, how do you pick up and just go back into work again after having a year off treatment.. Ugh (corrects self) a year off work. Some of these parents never work while they're on cancer treatment. How are you expected just to adapt and get back to that? Really difficult. **I: Mmm, extremely difficult. It sounds extremely difficult and I guess it's very very, obviously understandably, really difficult and challenging for families to navigate that and parents in particular but also, I suppose, then you're on the receiving end of kind of many of those anxieties and, kind of, having to contain many of those worries. Umm.. What.. What's that like?** P: It depends on umm.. on umm.. A number of different levels. I think you have different relationships with different families and the boundaries are sometimes really tricky? Being.. Being honest with you. You	Heightened emotions Scan anxiety causes stress Loss of support causes stress Returning to normal life causes stress. Difficulty returning to 'normal' Not seeing staff regularly An unrealistic expectation to just return to normal life – <u>almost impossible? Setting parents up for failure? Deep waters? Unable to navigate the post-treatment reality?</u> Different relationship with parents – every parent is different therefore the nurse-parent relationship will differ too?

Professional boundaries **Nurses grieve too** **Close relationships with families** **Relational complexity**	get to know some of these families and they.. You know they're not your friends, you absolutely know, you're a professional, but some of them, you just get on really well with and actually it's a grieving process for us sometimes because you really miss those families. *Really* miss them. 'Cause they've been a *massive*ly big, important part of your life for 18 months or whatever. The same also if the child dies. It's a definite grieving process I think for end-of-treatment and for death. You definitely feel it. I do. Certainly. Umm. And I think it's different with different families because sometimes they really invest in you and really need your time and really really need you throughout the course of treatment and some families just use you for the bare minimum. So, it depends on.. I think.. As a human being you develop different relationships with different people. I think. **I: Mmm. Okay. And I guess how do you.. How have you experienced perhaps this, kind of, transition or ending with a family that you felt that you were quite close to? Do you have an example that comes to mind about perhaps how you experienced such an ending?**	Tricky to maintain boundaries Professional nurse-patient boundary A grieving process for us as well? My loss too? Emotional attachment Relational complexity in paediatric oncology More than just a patient I miss them too Developing close human connections. They need me Different relationships with different people

Human connectedness **Things move on** **An ongoing cycle** **A companion throughout** **An emotional connection with families** **A sudden transition**	P: I think on a.. On a.. On a rudimental basis you know.. You miss some of them and you feel it s bit "Gosh, I've missed not seeing them this week" but then as awful as it is life goes on and then the next 8 families come through and then.. And then suddenly you're really busy again and there's lots of new.. All new families and there's lots of.. And it's like a vicious.. It's like a vicious cycle. You get those families through treatment, you give them lots and lots of support, you get them through the treatment, they finish, and then God, there's eight other families. And.. You know. You're back to square one. Rebuilding that relationship again. Umm.. Giving the families your.. Umm. They invest in you as much as you invest in them I think as well. You.. You know. Umm.. And I think it's.. It's a.. Yeah. I think.. You get.. You get used to these things and I think experience tells you that this is what happens and.. You'll.. You get to love these families but umm.. They move on and they get on with their lives and then the (laughs).. The next set of families come through. I think that's how it works really. **I: Uh-huh. Okay.**	Miss seeing the families post-treatment Developing a closeness, forming a bond with patients and their families, human connectedness transcends the strict nurse-patient boundary sometimes? Hit by reality – the next set of incoming patients that need your focus and attention. Life goes on? Things move on? Continuous process. An ongoing cycle – incoming patients – treatment – completion of treatment – new patients. A vicious cycle "you get them through x/y/z" – <u>a trusted confidant throughout the cancer trajectory?</u> Back to square one. Having to go through this emotive and sometimes deeply personal process again and again? <u>Giving a piece of myself to each family every time? Mental load?</u> <u>A personal investment from both sides? We're in this together? A team? Reciprocal feelings of emotional closeness?</u> "You get to love these families" – extreme closeness and emotional involvement Back to being pragmatic. Everything moves on.

for all **Staying connected** **Looking after families post-treatment** **An abrupt transition** **The ending feels forced?**	P: And I think you do still see them. So.. I try and make it at least a couple of times a year. 'Cause they're only in after that for 3 months later – this is solid tumours. Very different with leukemia follow-up. But for solid tumours they come in every 3 months to clinic so I'll make.. I usually make a habit of trying to see them at least a couple of times a year when they're just off-treatment just to make sure they're alright and to mop up the bits and pieces that umm they may have questions about or they may be worried about or.. So, you do still see them it's just that it goes really really intensive to.. Umm.. Massive breaks in time before you might speak to them. **I: So, what you're kind of.. What I'm hearing from you is that it's quite abrupt.** P: Uh-huh. It is quite abrupt yeah. I mean you know it's coming because of treatment pathways generally are.. You know, they're research driven.. There's an exact pathway that these children will follow. Sometimes you deviate, sometimes you change things round. But roughly, you know when they're gonna start and roughly when they're gonna finish.	A sudden transition for CNSs as well. Off-treatment you see patients rarely Arrange to see them when they're in clinic. Important for the P to feel that they are still connected? Misses them and wants to see them again. Making sure I see them in case they need anything? Being present for their needs even off-treatment. The carer.. The helper.. There to be of service. Quite protective? From really intensive to really infrequent – a sudden, abrupt transition for families and HCPs Massive breaks in time where both parties hold each other in mind but are not in contact? The ending is not layered? (thoughts for discussion: Challenges of separation and loss arise for both? A forced ending? On the one hand they want treatment to end but on the other hand it feels forced and sudden? Mixed feelings? For HCPs past losses/grief might be evoked when a patient ends treatment?) "*You know it's coming*" – <u>but despite knowing it almost feels like nothing can prepare you or prevent the feelings of separation and loss arising? When logic defies emotion?</u>

	I: Umm.. And do you feel that they know – you know, parents – from their perspective are they aware of how, kind of, sudden that change in the provision of care is after the end of (active) treatment or do you feel they often end treatment and then expect, you know, almost for there to be an additional level of support after they're off treatment? What's your experience?	
Talking about endings with parents	P: Umm… Ohh.. It's difficult. I think they get a vague idea because I will talk about end of treatment and a bit what that looks like quite.. Quite.. That's quite.. I talk about that at the beginning, in the middle and the end. I kind of space it out. So, I don't think it's a massive shock to *hear* it, but to *experience* it I think is a very different thing. So, I get the anxieties start to play in usually around a couple of months before the end of treatment. They will start to say.. - and most families do this. It's not common not to get a family to say "I'm quite worried about the end of treatment and how I'm gonna feel and how I'm gonna cope with this". Umm.. And then we'll talk.. We'll talk more and more about that and what it looks like.. And.. We just try.. It's just the case of being positive with them. Because I mean this has been.. They ask	We talk about the endings with parents Parents have a vague idea Difference between hearing it and experiencing it Anxiety leading up to the EOT Most families worry about how they're going to cope afterwards Talking about their worries Listening to them – becoming the container. Counselling skills in nursing? "Being positive with them" – positivity. Being strong for them
Increased anxiety leading up to EOT		
Anticipatory anxiety		
Nurturing communication		
Containing their worries		

Emotional pressure on nurses **Complete uncertainty** **Transitioning to survivorship** **A time of unique challenges** **Abrupt**	you all the time and you know you can't give this to them, but they want a guarantee that that cancer is not gonna come back and it's gonna be alright. So, you know, and that.. Nobody can guarantee that. *Absolutely* nobody and so like I said before a lot of this is them living with the *complete* uncertainty still and the no guarantee. They're not going to chemotherapy anymore, you know, they're not having any network or support really.. I mean, they can still call but they lose an *awful* lot of their support network as soon as they finish treatment. Quite abruptly, like you say, as soon as that line comes out no community team, you don't need to go through the local hospital 'cause they don't need blood transfusions.. They don't need antibiotics anymore. And they.. they don't see the nurses here and they don't see the daycare staff here. It is quite an abrupt ending for them I think. It's hard. It's *really* hard. **I: Yeah, it sounds really really tricky I suppose. And, I guess, what really struck me with what you said is that.. You know, it seems that you have some end of treatment chats quite, you know, frequently, you know, during the active treatment but when they're actually**	need for certainty, asking the nurse for a guarantee – <u>extreme emotional pressure on nurses?</u> On the one hand possibly feeling the "pull" to offer reassurance but at the same time knowing that they can't/it's not helpful/ethical to do so? Living with complete uncertainty No guarantees Heightened anxiety Loss of support whilst transitioning into survivorship The line comes out and suddenly everything changes. Very abrupt – loss of not only biomedical support but social support as well. A time of unique challenges and little guidance for parents how to navigate this. <u>Here the P is probably quite strongly identifying with the parents?</u>

	experiencing it, it's a completely different, umm, story.	
Beginnings, endings	P: Ahh – *definitely. Absolutely*. They can't even contemplate at the beginning what end of treatment.. They want to know the questions and they ask "When am I gonna finish?", "How long am I going to be here?", "How often is my chemo?" "What.. You know, what do I expect?" and then.. But right at the beginning it's a *total* contrast to how they feel at the end. Their life is *completely* turned upside down because they follow our rules – so they can't make.. You can't plan chemotherapy, you can't plan treatment, I mean you can't plan your *life*. You know.. They'll plan to go away for a weekend for example and the child will get temperature and they won't be able to go and they can't go.. You know, time at school is intermittent and they can't umm.. If they get a temperature they're in hospital for 4-8 hours.. I mean for chemo it's definitely 4 days a week. And I.. I say that in the beginning.. You can't – sadly with cancer treatment – you can't plan your life anymore, you know. "You have to be with me all day almost!" – I don't say that, but they do, they have to. If they get a temperature they go to hospital if they do this, they do this. If the do this,	Beginnings and endings Looking forward to the end but experiencing it is a shock to the system
Parents don't expect this		How parents feel at the start is completely different to how the feel at the end
Their lives are turned upside down		Their lives have completely changed during this time – <u>life interrupted? Life turned upside down?</u>
No control		Following our rules. No control. Unable to plan their lives
Cancer dictates everything		Cancer treatment dictates everything
No control		Loss of control Can't plan your life anymore
We take over		The cancer assumes control of everything Dominates their lives

	they do this! If they do this, they do this! You know. It's almost like we've taken over their lives for a little while. It feels like that sometimes. **I: And then to kind of be asked to, you know.. Live life again.. You know.**	"almost like we've taken over their lives for a little while" - HCPs are in control. HCPs are their "guides" during this time – <u>a power dynamic here? Parents do what they are told?</u>
Abandoned	P: Yeah! And then they struggle! And it's like 'Ugh! We've got used to you telling us what to do!" (laughs). I mean that's not exactly how it works, but you know.. **I: Yeah I know what you mean.**	HCPs provide structure and guidance and parents feel up in the air, unsettled, uncertain, anxious
Bereft of support **The challenges of facing forward**	P: They're used to this.. The "cancer life" (makes movement with hands to signify quote-on-quote) umm, and expectations on them. And then suddenly it's all, you know.. It drops away. Yeah, "Go back your normal life again! You're finished now, off you go!" you know.. "See you later, well done!", you know, and it's hard it's really hard. **I: Mmm.. Okay. So it sounds like almost.. Maybe.. Perhaps in the beginning they, kind of, anticipate the ending to be a time of relief but then as it approaches..**	The cancer life "It drops away" – bereft of all their support? Repeated phrases "of you go" and "go back to your life" - an emphasis of how abruptly parents might experience this. <u>Almost aggressive? Being sent away before feeling ready and without having the proper support in place?</u>

Endings are difficult **Being acknowledged** **Receiving recognition**	P: It's *not*. It's not a time of relief I don't think. Not in my experience. Some.. They're all obviously really grateful and umm.. And there's lots of tears and cards and it's.. It's a beautiful end sometimes, you know, and when they.. For me as well it's just the thank you. Sometimes a card with a little message – I've got some lovely cards - and they just make such a massive difference to.. To you as a health professional because you think, "God, you know.. I must have really helped that family". I must have been.. And you do, you get them through the treatment. And subsequently sometimes they'll finish treatment and.. And they'll try and get back to a normal life and then the cancer will sadly come back and then they're on a completely different journey. And that's equally *really* hard. **I: Mmm. Yeah. And I guess, as you were speaking before, you said something about parents, kind of, asking you almost to guarantee that the cancer will not come back.. Almost, kind of, they engage in some sort of reassurance seeking, which is completely understandable, and I guess how hard is it for you to actually not provide that reassurance, because obviously as you**	Endings are difficult Not feeling relief Parents are grateful and show their gratitude "just the thank you" – being seen, acknowledged, feeling validated by parents Acknowledgment from parents make such a massive difference. Feeling valued The importance of being appreciated and receiving recognition Being valued for their contribution I get them through it If cancer recurs then it's a difficult journey

	said, you can't.. You can't really guarantee anything but I guess there's some level or reassurance being provided. Umm.. How do you navigate that? It sounds difficult.	
EOL discussions	P: Yeah. So I think it depends on the treatment type, so my tumour types range from umm.. Not offering treatment to "Do you just want to go home and just live, you know, the rest of your life?", to an 8% prognosis, to a 20% prognosis, to a maybe as much as like 50%, 60% or 70% prognosis. So, I navigate it very differently depending on, really, the survival outcome that that child has got. So like.. You know, so the children with very very little.. So, you know, the 8%, 7%, 6% prognosis, which sadly some of my children do have, umm.. I think we're quite realistic? And I think.. And I think – I often talk about this with my consultants – there's a particular type of tumour umm which carries an 8% prognosis if it's.. If it's spread and if it's a certain type of genetics into it, so.. Umm.. But what it does this tumour, is it completely melts away. So, you start with a child that's riddled with it and then you give maybe 3 or 4 cycles of chemotherapy and sometimes you may never see – you might not see – a speck of cancer on the scan	Some cancers are so severe that no treatment is offered. Focus shifts primarily to palliative care and quality of life at the EOL stage
Patient centred care		Being adaptive, responding to the patient's/family's needs – patient centred care
Being realistic		Being realistic
Transparent communication		A dangerous tumour – solid tumour management
		Unpredictable cancer
		The tumour melts away

Risk of secondary trauma **Parents hoping for cure** **Difficult conversations**	after that. It might *completely* disappear. And this is what it does. And then you kind of go through the treatment and then you may offer some radiotherapy and you give a low dose of chemotherapy for a year and it keeps it at bay. And so the parents almost forget the very conversation we've had with them at the beginning that this is not really survivable, this is 8% here. But, because the cancer's completely disappeared, the child is *completely* well, back to their normal self, going back to school it's like another grieving process when the cancer comes back, because it always always does, it's just a matter of time but they *forget* that. So, it's like.. Almost like you're introducing a completely new concept to them when it comes back again. Umm.. Because they forget, you know, they forget that this is really bad because the child is *extremely* well. That's *really* really challenging. **I: How do you experience that type of stuff emotionally? I suppose, because on the practical side, you know, you have the conversations, you kind of, outline the treatment pathway, you contain some of the parents' anxieties during those chats, you, kind of, walk them through the whole process – how**	Parents forget that the cancer is high risk because scans come back clear The cancer is not survivable. <u>Secondary trauma? Difficult for the P being exposed to this?</u> The child seems completely well, back to normal self Grieving all over again when the cancer recurs This cancer always returns A matter of time Parents hoping for cure Stories from nursing A difficult profession Managing and navigating life and death

	do you, kind of, internally experience that process?	
Infusing hope **Fostering positivity** **Empowering parents** **Going the extra mile** **Nurturing communication**	P: Uhhh.. I think it. Ugh. I think you just want to do the best for that family and I think.. In my head, even with a 10% prognosis, I do often say this, you know, "Somebody has got to be in that 10% to survive, and that might be 1 in a 100 but there's got to be.." and I say this to parents if they decide to have treatment, if they decide to go for treatment, I will say, you know, "As much as this is a bad situation, to get *through* this and to live each day, you know, you've got to try and get yourself in the mindset that why couldn't your child be in that survivor group?". Because if you.. Some parents do that quite well, and actually they really rise to the occasion and they get on and they live their life and they do fun things and I encourage parents at all times to try and go away if you can for the weekends, you know, or to try and do.. It's the small things, it's the family time, "Let me move your chemo to a Monday so you're not in over the weekends, you can be together as a family for the weekend".. You know. Uhh.. And I will often say, you know, "Somebody has got to be in that survivor group, so we're going to give it our very	Doing my best to support the family Maintaining hope Giving them hope, infusing hope Cultivating a positive mindset Empowering parents Encouraging parents to do as much as they are able to It's the small things. Going the extra mile? Nurturing families, giving them what they need

	best shot and, sometimes that's not good enough, but we're gonna give it a go and we're gonna try and see where we get to."	Giving it our best shot Maintaining hope for parents
	I: Yeah.	
Carrying the load **Positive for parents** **Can't take the hope away** **The EOL stage** **Focusing on QoL** **Holistic care**	P: I think I'm positive with them even though sometimes it's.. The percentage is rotten because how do you get through the average day if you.. If you.. If you.. If you've not got some degree of positivity and.. And hope! I can *never* take somebody's hope away even if they're gonna die. Umm.. I just don't take that hope away.. I can't take that hope away. And I think parents would never forgive you if you took that hope away.	I've got to be positive so that they can get through this. Positive for them. Emotionally challenging Cannot take hope away – keeping the hope alive for families is important. The importance of hope. Repetition – "*I can't take that hope away*" – a lot of emphasis on this by the P. Seems absolutely crucial to the P to encourage parents by having faith that they will get through it. "*They would never forgive you if you took that hope away*". A moral obligation to maintain hope? It's what keeps them going? What sustains them?
	I: Yeah.. Yeah.. It's what keeps them going.	
	P: Yeah. Exactly. It keeps them going. And if you know that that child's gonna die but they've got 18 months where you can give them a really good quality of life, and they're cancer free for a while, God yeah, you know, you do, you drive it forward, you.. You know, you ughh.. Do as much as you can. There's lots of charities out there that do, like, umm.. Shows and holidays and caravan things.. So it's supportive	The goal of care shifts from cure to comfort and QoL At EOL the important outcome is QoL – the new goal for this stage Charities

	care, so it's kind of, the holistic care, which is *massive* in this role. Because 9 times out of 10 the person they're gonna ring if they're feeling a bit.. If they are having a bad day is me. And the emotional burden of this job is *enormous*. Enormous. **I: Tell a little bit more about that.** P: The emotional burden? Ughh… **I: If you're able to. I guess, you know, many people, kind of.. We think we know what emotional burnout means in, kind of, oncology because there's lots of research around it, but I guess we don't really.. You know, it's very important to hear from people that are actually experiencing it.** P: Umm. Burden. Burden, burnout – is it the same thing? I dunno. **I: Yeah, that's a good point.**	Supportive/holistic care is important – they can also support families It sounds like the P feels overwhelmed by being the main supporter for this families and relieved that there are charities that are also able to provide some support too? Enormous emotional burden [own reflection: I paraphrased what the participant said here thinking what she was describing was emotional burnout when she was actually referring to emotional burden]
Emotional burden **Carrying the load** **It's too much**	P: Emotional burden.. Umm. Emotional burden is I think umm.. A lot of these families put a lot of their thoughts and their feelings and their emotions onto.. Onto.. Onto my shoulders if they're under me umm.. Because I'm the person that will.. I	Emotional burden Families rely emotionally on us – <u>it is overwhelming? Too much? It feels heavy?</u> I'm a parent too

sometimes **Parents feel disconnected from others** **Parents turn to me for emotional support and comfort** **A point of contact** **A 'professional' friend?**	mean I don't.. I've not.. I have got a child.. I've got one, but I've never been through this as a parent. But they know.. I mean, I do understand because I've seen this for how many years did I say? 12 years or whatever (laughs) or even maybe longer than that, 16 or whatever it is, umm.. and I think they, often families say, you know, that "We can't talk to other people because people don't understand, people don't know what to say to us, people..". People stop communicating with them or they find that their best friends tail off a bit because they just don't know what to say or to do. **I: Mmm, so they're quite lonely in that experience.** P: Yeah, lonely. Sometimes. Not.. Not for every family. Some families have *amazing* support networks but there are families that have no support network at all. And they're *really* reliant on emotional support from their key worker because I am.. They see me every time they come in, they ring the phone, they text the phone, *so* much contact. Umm.. And when they're in for 5 or 6 days at a time I'll usually, if I can, make a point of going into their room every day to just.. Even if it's just for 10 minutes to have a chat "How're you doing?" and	Parents feel disconnected, alone – like others don't understand them Parents lose their social network whilst on cancer treatment for their child Some families have no support network. [Own reflections: I'm sensing here that the P is specifically talking about these families because it these families that require the most emotional support? Greater input from her and therefore more emotionally demanding? Especially if the P tends to identify and come closer with some of her patients? Risk of over-identifying?] A lot of contact with me – on the phone with them frequently. Possibly the sense that she can be contacted so easily – at the other end of the line – makes it even harder to maintain boundaries? Almost like a 'professional friend'?

Moments of meaningful connection **Emotional closeness in the nurse-parent dyad** **A "professional" friend**	you build it up on a personal level as well I think so they ask you about your life and you end up talking a bit about your life, like "My little boy did this this week" or.. And you know it's that kind of umm.. Professional but mixed in with like.. I think they want you to give them a bit back.. I don't think you can be completely professional, they're looking for you to invest in.. They want to know about you! **I: Of course, of course. It makes complete sense because they're connecting.. You know, they're experiencing something extremely umm, you know, life-altering with you, you know, by their side so you're almost like a friendly companion apart from a healthcare professional.** P: Well, and I think they see you as their friend. Even though that isn't what it is.. They do.. I think a lot of parents would.. Would.. And I think that's another reason they struggle at the end, is that they're losing a.. A.. A - inverted commas – their "best friend" that's been there for them every step of the way for 18 months. So, I think it's a grieving process for them. I think. I think.. Umm.. But yeah the emotional burden. If you times one (x1)	Building strong and close relationships with families – risk of boundary-crossing Self-disclosure Moments of meaningful connection Relational complexity in pediatric oncology nursing I'm a professional but also a human being More than just a patient – difficult to be strictly professional [own reflection: perhaps validating the P here a bit too much? Possibly going a little bit too much into therapist mode?] They see me as a friend Developing an emotional attachment with the CNS They see me as their "best friend" – a "professional friend"? Every step of the way A grieving process for them? <u>But also probably for the nurse too?</u>

	family by, you know - we maybe have whatever 20 or 30, whatever, you've got.. on the wards and things – and each person.. It sometimes feels like they suck the living *soul* out of me. And I'll go home some nights, and I think, "Jesus, I haven't got *anything* else to give anybody. If anybody asks of anything else of me today I just won't budge".	Big caseload
Nothing more to give sometimes		Very emotional demanding and overwhelming Giving everything I have – a piece of myself to every single one. Feeling drained? My mental resources are finite – nothing more to give
Emotionally demanding	**I: Uh-huh.**	
	P: It's not like that everyday.	
	I: Yeah, and I can completely hear what you're saying and I guess uhh.. You know, it's almost like part of your role is to – you know, a very key part of your role – is to provide some sort of "informal" counseling as well, you kind of..	
Counselling skills in nursing	P: Oh yeah! Yeah! *Absolutely*! Counselling, yeah. Without any official qualification, but yes! Yes!	A counselor but without the qualification – a lot of emotional support provision Like a counselor
	I: Is that recognised as part of your role do you feel like widely? Is that something that people know that as a specialist nurse that is something that you do or is it almost like.. You know,	

	it's expected from you to do it..	
Interpersonal skills	P: I think it's a big part of the role but without actually.. (laughs).. If you looked at a job specification of a Clinical Nurse Specialist I'm not sure counselling would be there (laughs) but I think it is. I think.. It's a massive role.. It's a *big* part of the role. A really big part of the role.	Interpersonal skills are central to the role – listening and attending to families' needs, containing emotions, managing anxieties, being a constant and stable presence throughout
	I: And I guess how do you kind of manage that because I guess you know some days can be really difficult, what support is available to you to perhaps, kind of, navigate some of the difficult emotions that, you know, come up for you?	
Support for HCPs	P: I have to say, I don't access any support around that. I think.. I think there is available – I mean, we have a great team of clinical psychologists – and there's the wellbeing cupboard in the hospital, and there's various things you can access if you wanted to but I'm not one of those people that does that.	We have support but I don't access it – [Own reflection: What is a wellbeing cupboard? I noticed myself feeling angry when I heard this. Such a difficult and emotionally demanding job and the NHS puts things like this in place?!]
	I: But it's not a standard part of like.. You know, for example, you having an allocated hour every week, for example, to speak to somebody about some of	"I'm not none of those people that does that" – <u>perhaps an indication that it would be a low point if she did? That's it's almost a bad thing if she did? It would mean that she is not capable of managing herself?</u>

	the difficulties that have come up for you? P: No. No. I think you have to ask if you want it. Umm. But not it's not.. **I: What do you make of that?**	You have to ask for help if you want it – the person must actively choose to seek out support. Not something that is part of standard practice for staff.
A tough, emotional role	P: Um.. I was.. Ugh.. I don't.. I don't know. People are surprised generally I think if they ask, you know, friends and people that don't know so much about the job they'll say "God, that's a really tough..". All these roles, all nurse specialists, all advanced nurse practitioners, all these are really tough emotional roles so I think	Others think my job is really tough A tough, emotional role – nursing is hard
No clinical supervision available	people are often surprised when I say it's not mandatory for you to have to have any clinical supervision or somebody to talk to.. They'll say "God that should be mandatory in your job", "You should.. You *should* be doing that, that should be routine, that should be the day you walk in the door in these roles you should have that". But it's not.. It never has.. Not in my experience. It's never been mandatory to have any support. I think it's a take it or leave it. You want it or you don't want it. I think. **I: Yeah. And do you kind of find that.. You know, when you speak to**	Surprising that support and/or clinical supervision is not mandatory in this profession Other think clinical supervision should be mandatory – <u>perhaps the P is also thinking this should be offered? An evident need for formalised support?</u> <u>Importance of clinical supervision in supporting nurses' wellbeing – important not only for nurses' wellbeing but also for their clinical practice more broadly? Important in relation to quality of patient care?</u> Take it or leave it

	colleagues that this is kind of a shared experience, where, you know, people often feel that emotional burden? Is that something that you, kind of, have heard other people in your line of work saying and talking about?	[own reflection: circular questioning. Wondering how other nurses might feel]
Emotional labour **Psychologically demanding** **Colleague support** **The protective role of peer support** **Talking to each other**	P: Oh yeah! *All* the time. I think we all say the same things and there are different.. There's always politics in these jobs as well, in big Trusts like here, I think there's lots and lots of politics but we've got.. Actually I have to say, we've got a great little office here and we'll do something slightly different. There's a couple of ward managers umm that cover the CNSs and Advanced Nurse Practitioners (ANPs) and we all sit together, and we do.. I mean I think it's that's the thing about shared offices – you do chit chat and talk through different problems "Oh, that's really upset me today" or "What do you think about this?" – and by default it's almost clinical supervision. It's .. Because.. You talk to each other, this is what the nice thing about these offices is.. You do – and we often do – we *all* do it! We'll come in here and have a rant for 10 minutes about something particular challenging that day..! **I: That's massively important – that**	Nursing is an emotionally demanding profession NHS politics Relying on each other Emotional support from colleagues The protective role of peer support Talking to other nurses is almost like clinical supervision Venting is a protective factor Close relationships in the workplace

	support from colleagues! Yeah, absolutely.	
Colleague support **Team support helps me cope** **Sharing within the team** **They understand me**	P: Ah – colleague.. Colleague support is massive and actually, you know.. Big part of how you do these jobs is working within a team of amazing colleagues as well. And they do.. They get you through.. They get you through some situations. Because it.. Like.. It helps with the emotional burden I think. Talking to other people. And talking to colleagues that understand and it.. It does help. **I: Yeah. It sounds like there's something really valuable about being able to share that kind of experience and being able to feel understood and heard by somebody who's experiencing similar things umm.. And yeah.. I guess, because otherwise it can feel quite isolating if you feel like you can't really speak to anybody about the struggles of the job.**	Colleague support is crucial They get me through it – the protective role of peer support <u>Colleague support mitigates the impact of compassion fatigue and the emotional burden</u> Talking to others who understand. Feeling less alone.
People don't understand **The emotional burden**	P: Yeah. I mean you can talk to – I mean I can talk to my boyfriend – but he doesn't, you know, he's amazing – but he doesn't.. He still doesn't understand what ugh.. What the.. The kind of the impact of the emotions. And as awful as it is as well,	Talking to my loved ones sometimes It's not helpful – they don't get it Emotionally draining work

Impact on personal of life **My own limits**	there sometimes is umm.. I find that how.. What kind of day I have sometimes reflects in my behaviour at home with my.. With my little boy. Sometimes I've got really little tolerance for anything because I'm just up to here with umm.. How my day's been or the emotions of it. I have less tolerance. I'm a little bit more snappy with him or less tolerant. And he's only a little seven-year old boy but I really do find sometimes that if I've had a bad day and somebody's died or umm.. Difficult conversations or been too busy, not enough time in the day scenario, too big a caseload, can't give anybody the time I need to give them, I find that it does sometimes affect how I behave at home. I don't know if other people would say the same. But, I'm *really* conscious of that sometimes. **I: I think yeah, absolutely it sounds like from.. You know.. I can't really.. My job is kind of similar in the way because I provide a lot of emotional support to people but not in cancer obviously, so I guess you often are the container for many people's, you know.. Emotions and quite intense emotions so then you obviously have a certain amount of capacity umm.. yeah. Yeah. Or else it overflows doesn't it?**	The emotional burden bleeds into my home life Reduces my tolerance to personal life things Less tolerance – emotional exhaustion I get snappy Stressors in nursing are constant. A task-oriented environment My own limits "*Really conscious"* - <u>A sense if guilt here?</u> [own reflection: In that moment I really identified with the P because this emotional burden and demanding nature of the job is something that I have also felt. And I disclosed this to the P in this moment. Not sure whether I should have said this? Maybe I didn't maintain the interview frame here?]

Impact of work-stress on personal life	P: Yeah, it does, it does, it does. I'm really good... It's not every day, it's not even once a week that that happens to me, maybe like what – once or twice a month – maybe I'll be a bit more and I'll think after when put him to bed "Oh God, I was a bit harsh there", you know, or "I didn't need to be..", you know.. It's nothing extreme it's just I'm *conscious* of it that I'm.. I'm a bit more snappy with him. **I: Yeah. Absolutely.**	It happens rarely but it happens Conscious that I become more snappy Losing my patience sometimes due to work-related stress Impact of work-related stress
Providing emotional containment	P: And you do, like you say, containment is a massive, *huge* part of this role. Is containing people's anxieties, containing everything really. **I: Yeah.** P: And we'll do that for the consultants 'cause we work *really super* close with the consultants, so, there's two that I.. And I love them dearly both, actually they're great, umm.. But you do.. You do a lot of containing for them.. A *lot* of containing. **I: In what way?** P: Umm.. Umm.. In what way? Well,	Containment as part of the provision of compassionate care "Doing containing for them" – not sure whether the P here means that nurses do a lot of containing on behalf of the consultants or containing consultants' emotions as well <u>Having to be a tower of strength for everyone?</u>

We take on all the worry **Parents scared of consultants** **An empathetic presence** **Closeness in the nurse-patient relationship** **Emotional burden**	because you.. The people these parents phone isn't the consultant. They see the consultant once in a blue moon sometimes – the person they consistently see is me. So, it will be me that takes on the worries and the stresses. Most of the time, because they'll only see the consultant every now and then. And actually you get sometimes to the point where they're like.. Umm. They're petrified of seeing the consultant for the scan results, but when I walk in the room it's like sheer relief and I get that often they'll say "Thank God it's you! I'm really, really scared about seeing the consultant because I don't know what he or she is going to say to us, whereas, you you're really consistent!" (laughs). D'you know? And they're not.. They.. They love you but they find it really hard seeing the consultant (laughs). Strange, but yeah. **I: Yeah, it really strikes me, the emotional labour that you're actually talking about. It sounds umm.. Like a huge part of the role.** P: Yeah. *Massive*. Massive emotional burden. Massive, massive, massive. **I: And it sounds almost that you're the link between uhh.. You know,**	Absorbing families' worries intended for consultants The point of contact Consultants do not deal with emotional stuff – we do it for them Parents have more contact time with me Consultants versus nurses? The intermediary Families sometimes scared of consultants Families are relieved to see me The closeness in family-nurse relationships A trusted confidant Emotional closeness Massive emotional burden in nursing – <u>emotional labour and exhaustion?</u>

The mediator	**connecting the consultant to the patient as well, so, you're kind of the person..** P: ..Yeah. We are. Yeah. Very much. We work *really* closely with the consultants umm.. Really, really closely. Sit in all the clinics.. Umm. We go to their office and chat about certain patients, you know.. And we have a great relationship with the two I work with.. You know, umm.. I really, really do. And on.. On the side of this I'm doing.. We've just set up a cancer genetics clinic, which I'm also doing this, kind of on the side from.. From this role as well with one of the consultants, where we umm.. So some ch.. families have genetic predisposition to cancer? It's called a TP53 mutation and if they've got this predisposition then.. Umm.. They are.. They've got like a 40-50% chance of getting cancer by they time they're.. They're 40 years old. So, we've just set up a clinic now where – which it's today actually, this afternoon – where these families come into clinic and they have, umm.. Three monthly ultrasounds scans looking for cancers and a full body MRI scans which.. And we hope that if we find cancers we'll pick them up earlier because we've been looking for them. It doesn't mean they're going to develop cancer –	Liaison work The link between families and consultants? The intermediary

Occupational stress **Meaningful but emotionally draining**	they've got 40% chance – but we hope to catch it early and that is also another new emotional burden that, you know.. I love it, it's a great clinic, but it comes with such high anxiety levels as well that people are coming into clinic for scan results that .. They haven't got cancer, but they're gonna be told "Oh, no your scans are fine, so.. " **I: It could potentially be a life-altering moment for them.** P: Yeah. So, it's another whole level of emotional burden, I think as well. I mean it's *great* and it's really interesting and really, really exciting but again it's kind of adding to the workload and just stretching that emotional… (laughs).. A little bit more. **I: Of course. And yeah, I guess what I'm hearing from you sometimes – you kind of said that it's very, kind of, emotionally difficult but then actually you're saying "but it's great" – and I'm just.. What I'm hearing from you is that these two can co-exist, right? It can be great and very meaningful and extremely interesting but at the same time be extremely uhh.. Difficult on an emotional level.**	Work-related stresses High anxiety levels in nursing Emotional burden Meaningful work but is often emotionally draining [own reflection: went into therapist mode a little bit here?]

What makes me do this? **Committed to oncology nursing** **Resilience** **Ability to cope** **A sense of**	P: Yeah. But I think.. It probably takes.. And I don't know what makes me do this job.. I don't what.. 'Cause lots of people could never do this job and I think – you can think that for any job – but makes me be able to do it? And I don't know.. And I think.. I've always had a bit of a fascination with umm.. Umm.. Life-limiting things and things that can change your... And.. And I don't know.. I don't know why I do this job or why I can get… you know, years and years and years of doing this now, but I've *never* ever really once felt the point where I've had such a bad emotional burnout that I can't function. I have bad days – *absolutely* – where I'm like "Ugh!" but I've never got to the point where I thought "I can't do this anymore, this isn't for me". I've *never* ever felt like that in 16 years of cancer. **I: Wow. Wow.** P: But I don't know why. This is the thing I don't know why I can just cope with it. And I think.. Um, you know.. And.. And I have a very normal life outside work where I see friends, I have drinks, like I said, it can influence how I behave sometimes at home, yes, it can sometimes, but only for like a couple of hours or an evening and	"*What makes me do this"* – interesting that the P used the phrase "makes me". Almost like there it is not a conscious choice? Draw to doing this work? Almost like the P is not in control but something else "makes" her do it? Almost like she is saying "I don't know why I do it?" Link for discussion to external versus internal locus of control? Fascinated by life-limiting things? Discuss with HC about how to link this to psychodynamic theory? Emotionally demanding and draining but never thought of quitting <u>Despite the difficulties I'm invested in this career? A commitment to helping others?</u> <u>Finding meaning in what I do?</u> <u>Surprised with myself that I can cope?</u> A normal life outside of work My work sometimes affects me in my personal life

hardiness?	then the next day it's fine again. Yeah. I don't know why.. I don't know why I can do that. I don't know..I don't know the answer to that. **I: It's fascinating actually and I guess, you know, that's a whole, kind if, new are of research potentially about what kind of people are.. Actually uhh.. Choose this line of work as their career because, you know, I'm sure there will be some very interesting findings there in terms of, you know, kind of, the personality qualities that you might possibly have in order to be able to contain all this.** P: Yeah! **I: And still carry on day after day, right?** P: Yeah. Yeah. Yeah, if I told people one story about my average day. Like a maybe a really sad story they'll be like "Ugh!! God! I don't know how do you do that?", you know, you get that kind of reaction, don't you from a lot of people. **I: Do you feel like outside of work it's quite difficult to talk a little bit about what you, kind if, face on a daily basis?**	"I don't know why I can do it" – the P is almost quite shocked about how she is able to keep working in this field despite the massive emotional challenges? Almost like she is realising how difficult it is as she is speaking to me? Sad stories part of an average day in nursing <u>Others would not be able to cope?</u> <u>Something quite unique about people who choose nursing?</u>

Social support from other nurses **It can be lonely** **Others can't understand** **Colleague support** **Learning to protect oneself** **Coping skills**	P: Yeah, because I think people don't.. I do.. Ugh I've got some.. – by default, some of my best friends are nurses because I did my training with them – but I think umm.. I wouldn't want to burden (audio not clear at this point).. Actually how shit it can be sometimes because they don't understand and also.. Usually you'll get a response of.. – I don't do.. I used to do it a bit.. I don't really do it anymore – because you usually get a response of "Oh my God, that's horrendous! How do you cope with that?" and that's not very helpful. **I: Yeah, that's not very helpful. Yeah. Yeah.** P: So.. So, I don't really bother anymore. Yeah. I talk to me colleagues, yeah. **I: So, I guess what you're saying basically is that apart from your team and your colleagues most of the stuff that you deal with you kind of have to learn how to manage yourself.** P: Cope yourself. Uh-huh. Yeah. I've got *really good* coping skills and I think that runs into my normal life anyway, I think, umm.. I cope with things pretty well. And I	Some of my best friends are nurses by default It can be shit sometimes People who are not in nursing cannot understand Feeling lonely in my experience Other nurses can relate to what I go through Colleague support is important Other nurses get it Coping strategies to protect oneself Really good coping skills

Resilience	don't know why again, I mean I don't know why I do, but I do. I.. I.. I'm pretty good at coping with bad situations even at the average.. Not even work-related. Personal life related. I think I'm.. I'm pretty good. I think. **I: Okay. Well, massive respect to you basically because what I'm hearing from you is that you've had to very much, kind of, cultivate some of these coping skills and you almost need them in your toolbox in order to carry on day in day out. Umm. (participant nods) And I'm just wondering, as you were speaking, your experience of nursing or providing care to paediatric cancer patients is coloured a little bit by the fact that you work with high risk tumours? I suppose do you feel that colleagues working in leukemia might experience things very differently? Umm..**	Good at coping with bad situations [own reflection: validating what the P has shared up to this point but also wanting to understand the unique challenges that the P might face in working with high risk tumours]
High occupational stress in pediatric oncology	P: Uhh.. Not necessarily because.. So the girl that sits there (participant points to a desk in the office) is a Leukemia Nurse Practitioner, uhh.. She's amazing. *She* had some really.. Like some children with leukemia.. Is you know, even though.. The workload is.. Is.. Umm.. Huge in leukemia.	Working in cancer is difficult for everyone Huge workload in leukemia

	Lots of them do really well but there's a *definite* population of these children that don't do well. So bad site of genetics or umm.. Down syndrome children or.. So, she (i.e., colleague) has some *really* sad cases as well, so I don't.. I think we all umm.. I think we all have bad times.. Some.. My cases I think particularly is a quite high population of death rates. But umm.. But sometimes..	All nurses have difficult cases A difficult profession in general Higher death rate in solid tumours though
	I: So, across the board it's quite difficult..	
Stress among junior oncology nurses	P: Oh, oh yeah it is. Across the board it's really difficult. I don't think anybody has a better time than anybody else. I think we all have.. And actually, you know, some of them umm.. – the two girls in my team are more.. Are more junior than me and umm.. Recently one of them had.. It was her first.. She'd just.. She's umm.. Quite new to the role I would say, like 8 months now – she's great, she's doing really well – but she had a first really bad bout of umm.. A couple of deaths and a couple of relapse treatments, and actually blimey I rarely.. You know, you forget.. She *really* struggled. *Emotionally really* struggled. So, you.. And then you support them through it.. And you think gosh, you know, actually, yeah.. This	It's difficult across the board Harder for junior nurses – another difficult transition from being a student nurse to qualifying? Emotional struggles for newly qualified nurses Dealing with patient deaths as a junior nurse
Losing a patient for the first time		

	is really really tough and it's such a big part of the job that I almost.. I know it's going to come and I just get through it whereas she.. It's the first time she's experiencing it..	
	I: So, let's add to the list.. Support towards colleagues as well.	Supporting my colleagues
	P: Yeah, oh yeah, yeah, yeah.	
	I: So.. Supporting patients, being the link between consultants and patients, umm, support to other colleagues that are struggling with things.	Being of service to others. Supporting everyone.
	P: Yup. All of that.	
	I: Yeah. All of that. Wow. That's a lot. Umm. So, I'm guessing in terms of.. How.. What do you consider an *ending* to be with a family? If we could.. If you could, you know, kind of, explain what an ending is. Is that a word that is, I guess, reflective of what happens or is it more of a transition?	
What endings look like	P: Oooh. A bit of both I think. I think it.. Umm.. I think.. It is often quite a.. A .. They know it's coming obviously because we talk about it but going through it is a very	Endings and transitions

Meeting parents' needs **Patient-centred care** **Emotional closeness with parents** **Keeping in touch off-treatment** **Each family has different needs** **Need for support**	different experience for them. I think it is quite a.. I think an ending looks like end-of-treatment, line out and then coming into clinic once every three months. I think that.. That typically.. Sometimes.. I mean like the.. You'll get families you won't hear from between the three monthly scans and that is the end for them and you don't really hear from them, or you'll get families that still really really need you and they will ring for.. They'll.. It's almost like they're making up an excuse to ring you because they miss you there and they'll ring and they'll say something like "I don't really need to ring you for that" but it's their way of, kind of, touching base still. So, I think it depends on the family. Sometimes there's a very.. There's an ending that's abrupt, it's the end of treatment, see you in three months time, get on with your life.. Sometimes. Sometimes it's very much.. They'll still call you and they'll still contact you, and they'll come back to the ward to visit, they'll come back and bring sweets in, they'll do this, they'll do that to maintain that link and that contact with the hospital and I think it.. It could go either way and you never can quite.. Well, you can tell from how certain families behave. You.. You can pretty much guess sometimes but.. Families cope in very, very, very	What an ending looks like Each family is different – patient centred care Giving each family what they need Being adaptive Wanting to keep in touch with me Endings with each family ar different depending on their needs Maintaining the link with us Relational complexity in pediatric nursing Families cope in different ways

off-treatment **The CNS role off-treatment** **Provision of emotional support**	different ways. And some really don't ring some really really do need your support even after treatment. So, I think.. It's difficult because, you know, I think it's.. It's difficult.. Even for key workers because everyone thinks "Oh, that's the end of treatment, that's another one off X's caseload, that's fine" or "That's off from X's or X's caseload, oh they're finished now!".. Mmm.. Not really! They don't see the behind the scenes work that goes on and they don't see the phone calls you're still taking and they don't see the emotional support that you're still giving to these families.. It's not a simple.. I think people don't see that sometimes.. They don't see.. **I: When you say people do you mean, umm.. Who do you mean when you say "people don't see that"?** P: Maybe.. Maybe.. Maybe other.. Other.. Other colleagues and things – not necessarily the people in these roles.. **I: Yeah, yeah, yeah. We're just kind of openly talking a little bit about who might.. Who might it be important.. Hmm sorry.. I want to phrase this question correctly. Who should know that this is going on behind the scenes?**	Support doesn't end with EOT Behind the scenes work Transition from EOT to off-treatment is difficult A lot of emotional support is needed People don't acknowledge how much is required from us during the off-treatment period. <u>More than meets the eye? Frustration with the lack of recognition?</u> Other colleagues – perhaps managers, team leads don't really acknowledge or validate difficult parts of the role? [own reflection: trying to understand who the Ps referring to here. Who should

	Who would it be helpful to know that this.. That all this work, this emotional support.. Who should know about it? P: I don't.. I'm not really sure. I think.. I think.. Perhaps the managers and things. They often don't.. They don't appreciate that actually just because they're at the end of treatment it doesn't mean that that's the end of the CNS role. By any stre.. Some families absolutely yes it is (i.e., the end of treatment) and you don't hear from them, you genuinely don't hear from them very much. But that's *definitely* definitely not the case in a *lot* of.. A lot of the caseloads. **I: It sounds like in the majority of caseloads that's not the case..** P: I think.. Yeah, and I think if you asked or interviewed my other two colleagues you'd.. You'd find that they'd probably would have said the same, that the end of treatment, doesn't necessarily mean end of treatment in terms of the support, the telephone calls, the text messages, the.. **I: So, it's the end of one round of treatment but on the flipside it's the beginning of a different type of support**	acknowledge this? How would it be important?]
Lack of meaningful recognition **The CNS role off-treatment** **A time of unique challenges** **Providing support off-treatment**		Managers don't appreciate/realise how much CNSs do post-EOT Lack of meaningful recognition/acknowledgment/validation – <u>a further factor possibly contributing to the emotional burden?</u> In the discussion link this to literature relating to poor leadership? Good working relationships and leadership? See paper by Theodosius et al (2021) – "Collegial surface acting emotional labour, burnout and intention to leave in novice and pre-retirement nurses in the UK: A cross sectional study" Most families need a lot of support after the EOT A difficult time for families. A time of unique challenges. Families require a lot of input and emotional support. Many roadblocks after the EOT A new set of challenges after treatment stops

	that is needed.. So, it's not really an end..	
Not really an end	P: Yeah. No, it's not really an end. But it's difficult because for some families yes it is and then they see that as an end and actually.. And they do get on with normal life and they don't really come into the hospital unless they really need to and they don't want to speak to you. Because, sometimes they associate you with shit times let's say. And cancer, yeah! Sometimes, absolutely sometimes. But I think percentage-wise there'd be a much greater percentage of families that actually still want some contact with you. Because like, again I'll say the blurred boundaries almost sometimes.. You know, it's the.. This.. The "friendship", which I suppose it.. And that's a really.. I think.. Boundaries are really really difficult.. *Really* difficult sometimes.	It's not really an end Some families get on with normal life
Challenges of transitioning into survivorship		Most families require a lot of support during the off-treatment phase Transitioning into survivorship is uniquely challenging
Blurred boundaries		Blurred boundaries
Emotional closeness		Close relationship with parents A bit like friends?
	I: Yeah, yeah.	
Managing professional boundaries is tricky	P: Especially if you've got a family that you.. We're human and.. And we click with certain people better than we do with others and sometimes it feels like.. that they blur slightly.. The boundaries. Not that you'd see them outside of work or anything	We're human
First a person, then a patient		Risk of boundary crossings is high in this line of work

Relational complexity

Following the death of a patient **Going to patients' funerals** **Ethical dilemmas** **Emotionally depleting** **Honouring the family**	whole different grieving process – oh my God it's hard! **I: Can you tell me a bit more about that kind of scenario when you have a child that has sadly died? What.. What happens then with those relationships with parents I suppose?** P: (Sigh) It depends on the families. So, pre-Covid times.. I find funerals really hard. I do go to some and again I think in my head "What makes me pick that family's funeral to go to over that family's funeral?".. It's hard. That's really really hard. Umm.. I go to less certainly as I've got older I try and go to less. Because they are *so incredibly* difficult! Emotionally they *kill* me for a few days afterwards. Emotional.. Uh, I find it really really.. Really tricky funerals. But sometimes if the parents say "Look, I'd really want you to come to the funeral, you're a really important part of her life" or whatever they're gonna say then umm.. I do go. **I: Okay. And is that something that you kind of.. I guess, you said that you find it really difficult to choose which ones to go to and which ones not to go to – and sorry if this is a silly question but**	If a child dies. The EOL phase is hard. Following the death of a patient. Funerals are really hard. Choosing which funeral to attend is difficult Moral injury? Ethical dilemmas? Emotionally challenging "They kill me" – extreme personal discomfort, emotionally very demanding, depleting <u>Facilitates the grieving process for parents if HCPs attend?</u> <u>Going for the parents – demonstrating respect to the family by attending? Extending the relationship?</u>

Can't cope **Protecting oneself** **"Clicking" with some parents** **Forming close relationships with some parents**	**why is it, kind of, difficult to choose? Do you kind of feel..** P: Well, I can't go to them all. Because.. Umm.. Work-wise.. I mean you can.. You can go to as many as you want but realistically if I was gonna go to a funeral I'd go.. But.. But, I mean, I can't go to them all because just the emotion, I can't cope with that. Can't cope with that. Umm.. And I think as a human being you tend to go to the families – it's awful! – that you.. That you have a particularly good relationship with or if they ask you to go. So if they directly reach out, which they often do, to be honest. They often do, they'll reach out and they'll say "We'd really like you to come to the funeral, we'd really like you to be there". Some of it.. **I: And I guess if you decline an invitation to go that must be also quite difficult.. I suppose.** P: Yeah, but they understand. I usually phrase it around "I'm really really sorry but I've uh.. I've.." Whatever – something to do with work. I'll say something about work.. I really.. "I'm the only one in, I really can't get out.." If I can't go I'll generally write a card? And post it to them?	Can't go to all of them *Noticing some hesitation & incomplete sentences here* – approaching a difficult subject for the P? Difficult to explain why it's challenging? Perhaps some shame/guilt attached to this topic? Can't cope with the emotion – really challenging emotionally *"it's awful"* – feeling embarrassed admitting that the P is likely to go to the funerals of the families that she was close to? Again highlighting the relational complexity interwoven into the fabric of nursing? Families understand if you can't attend the funeral Finding an excuse not to go sometimes

	I: I guess from [name of hospital] do you have any, kind of, advice or any, kind of, umm.. Support about how to navigate those types of situations when you're invited by a family to go to a funeral or when you're attending a funeral - do you have any support?	
Patients' funerals **Representing the hospital** ***Popular* families** **Moral distres**	P: No. No, I think the ward girls.. You tend to go with the junior workforce on the ward umm.. Here. They tend to want to go to the funeral. So, I think as long as 1-2 people are going, somebody's going to represent the hospital.. It doesn't feel quite as bad if you kind go individually 'cause you'll always find that.. And again as *awful* as it is it's families.. If the family is a really popular family and really great then *loads* of nurses will want to go but it shouldn't be that way. Whereas if the family is not as much as a popular family or perhaps they've been challenging and difficult then umm.. You know, one of those families that people don't want to look after, you'll find that nobody really goes. So, it's all.. It definitely is a..	Junior ward nurses more likely to attend funerals No formal support/guidance provided around attending funerals Somebody to represent the hospital – <u>yet no support in place for staff around how to navigate this? Options for grief support training for HCPs?</u> Popular families – again the participant here uses the word "awful" to refer to something that – I personally feel – <u>is quite a natural, human reaction. Feeling more connected to some families than others.</u> "It shouldn't be that way" – <u>a sense that it almost unethical to not be exactly the same with ALL families? Moral distress?</u> "Popular" versus "challenging" families own reflection – <u>what might be a "challenging" family? How is this perceived/experienced by HCPs?</u>
	I: Like another dilemma there.	
Funerals are	P: Yeah. But they're difficult and they are	Funerals are emotionally really difficult – <u>perhaps attending funerals triggers</u>

emotionally draining **Following the death of a child** **Nurse-parent contact following a child's death** **A natural ending** **Living reminders of cancer**	emotionally really difficult and I think some.. Often.. So, sometimes if a child has died and you go to a funeral that's often the end point. Umm.. And I find that actually families.. When the child.. *Most* commonly, I.. I don't hear that much from families that children have died. Even if I had a really nice relationship with them. I don't hear very much. **I: It kind of ends there.** P: Yeah, often. And it's always been the way throughout my whole career and I think it's probably the same for most people. There are some families, though, that will still drop my a text message or an email umm.. Or will come up to the hospital sometimes. You'll see that. But most of the time after a death, after the funeral there isn't that much contact after that. Maybe it's a natural ending, I don't know. **I: Why do you think.. Yeah, it's a natural ending.** P: They're trying to pick up the pieces of their life I think. And they don't need a constant reminder of.. of cancer. Of the.. of the.. Umm. What they went through, of the nurses.	<u>thoughts of own losses or traumatic separations from loved ones?</u> Death of a child is a definite end point Families whose child has died don't keep in touch Following the death of a child <u>Too traumatic for parents to contact HCPs following the death of their child? Brings back memories of a time that was unbearable? Parents want to forget anything to do with the time of being at hospital and cancer treatment?</u> Not much contact with parents following the death of a child Death = a natural ending Picking up their pieces following their child's death Nurses remind parents of cancer

	I: Of their loss.	
The nurse-parent contact	P: Yeah the loss. I think so. And it's weird, because like I said even.. If the child's alright the families cope.. Don't cope in a very different way, they (i.e., families) constantly want to be in touch. But if the child dies, that.. That.. And it is again I	A paradox? When child dies parents cease all contact. When the child recovers parents want constant contact.
Grief among nurses	think for me it's like a grieving process actually because.. You know, we're only	A grieving process for me as well. Secondary trauma.
Only human	human and often I'll think to myself "God, I'm really gonna miss that child, I'm really	We're only human I miss them – these families become a big part of HCPs' lives too
We hurt too	gonna miss that mum, I'm really gonna miss that family", you know, and it is.. I think as a health professional you still go	The grieving process for nurses
Letting go	through a slight grieving process. If the child dies. Or even if a child then finishes treatment and doesn't really contact you very much. You still miss them.. You still think about them.	Difficulty of letting go <u>An expectation that nurses just "deal with it" – but there is a personal cost that goes unacknowledged?</u> <u>Difficult to let families/patients go?</u>
	I: Of course. Again, isn't it. Although, you know.. It's based on the fact that, you know, it's a happy ending, I suppose because the child has recovered and what not but again it's almost like a loss on a personal level of that contact that you had with that patient.	

It's a cycle	P: Yup. Yup. And then as I said.. Something will happen and 85 new people come to the ward and you'll have loads more kids and it's a cycle! It starts again and you start again, and you meet new families.. **I: I think you're touching on something really important which is the kind of the grieving process on the side of the professionals, which I'm not sure we kind of hear often about. I think that's massively important what you're commenting on. And yeah, thank you so much for those insights because I think, yeah.. It's really really important that we hear from professionals about how they experience that. Umm.. And I'm just wondering you know.. You touched on this a little bit earlier as well.. But you mentioned the bell.** P: Umm.. Yeah (laughs). *The* bell! **I: Could you tell me a bit more about the bell? (laughs)** P: Umm.. **I: Where does that come in? When does that happen, I suppose? When does the**	It's a cycle The bell

	bell ringing happen? P: Uhh. So families can pick and choose a little bit about the bell. So they can umm.. It's usually.. Either they'll do it after.. After their last dose of chemotherapy before they go home or they'll do it when they've had a clear scan and their line comes out.. I encourage not to ring the bell until you've had a *clear* end of treatment scan and usually when the line comes out I'll.. I usually will try and say to parents "You know, try and wait until that point if you possibly can". **I: Is it after the three-month scan that you're talking about?** P: No, like maybe the end. So, once they've finished treatment they get a scan pretty much at the end of treatment.. For most treatments. Solid tumour. **I: On the same day or?** P: What a same day scan? **I: Do they get their line taken out and then they have a scan? Maybe a few..** P: They.. They have a scan after chemo.. It	
EOT processes **The EOT scan**		When is the bell rung After last chemo After a clear scan When the line comes out Importance of a clear end-of-treatment scan [own reflection: focusing too much on the EOT protocol here but I think I'm trying to understand in order to inform the types of questions I might ask the P]

	could be.. It's not usually the same day, it might be after a week or two later, to check that everything's clear and that's your clear end of treatment scan. And at *that* point the line could come out. So, it's usually a couple of weeks after that. **I: Okay, and then you encourage them to ring the bell after that.**	Some parents do not want to ring the bell
Mixed feelings about the bell	P: Yeah, and like I said, some parents do not want to go anywhere near that bell umm.. So, it's become a *really* kind of.. Umm.. Mixed feelings about the bell because umm.. It's hard because they do it on the ward and you'll have a family nearby where their child is dying and *hear* what goes on because it's not thick walls.. So, in one minute you've got a dying child in that bed and the next minute you have another family cheering and clapping and celebrating their child's finished cancer treatment. You know, the emotional impact on those parents, I think, must be really hard. 'Cause you know – you're hearing that and yet your child.. Your child's gonna die. Your child's never gonna get that experience of ringing that bell. Or.. Umm.. So, I often think that when I hear.. 'Cause you know. And don't.. Don't get me wrong. They're *lovely* ceremonies, they're *lovely*.	Mixed feelings about the bell
Having the bell on the ward		Ringing the bell on the ward is tricky
Imagining what the other is experiencing		Thinking about the other patients that are dying – what is it like for them? Taking the position of the other, the P is being reflective here Stark contrast – EOL/death/dying versus celebration/clapping on the same ward
Empathy for other parents		Emotionally really difficult for parents – <u>can stir up really complex emotions I suppose?</u>
A lovely ceremony		Lovely ceremonies

Parents who will never get the chance	And the.. You know.. And the cheering and clapping. But in the back of my mind I'm thinking "Well, what about the families that'll never gonna get to do this?" and "What about the families that will never get to experience going home and getting back on with their lives?".	Thinking of the families that will never get the opportunity
	I: Yeah.	
A celebration	P: So, it's quite loud on the ward. And the people often come out of the cubicles and they'll put their heads out of the cubicles to have a look at what's going on because there's so much clapping and cheering. So that's one thing.. And I think umm.. You've also got the fact that if you ring that bell and then four weeks later the child relapses and the cancer comes back, often parents don't want to tempt fate? So, I hear every now and then "I'm not ringing that bell, that's tempting fate that is, I'm not doing that". And then you've got the families that umm.. That very much, their fixation, and that *massive* goal of the *whole* of the cancer treatment, is to get to the end point where they can ring that bell. So, there's *so* many different ways you can look at it. There's so many.. Yes, it's supposed to represent good times but I'm not sure it is.. I'm not sure that it always	A celebration on the ward A moment during which people come together You can't really avoid it When a child relapses A sense that ringing the bell is like tempting fate Families fixate on the bell An important moment for parents The bell supposedly represents something good The bell: helpful or harmful?
Following cancer relapse		
Tempting fate?		
When the bell becomes a fixation		
What does the bell represent?		

	does. (laughs). **I: Yeah, yeah. It sounds umm.. You know, you're touching on some really really important things there. Because I think you're, kind of, really empathising with the parents that, you know, might have a poor prognosis for their child and then at the same time, you know.. A few meters away somebody's celebrating uhh.. The recovery of their child.** P: Yes. **I: Have parents ever, you know, in that kind of position, have you had any parents telling you that they've found it difficult to…**	
Some parents struggle with the bell	P: Yeah. Yeah, definitely. *Definitely*. Yeah, definitely. Definitely I've had that. **I: What might they say? How might that be expressed? From parents?**	Parents have disclosed they struggle with the bell
Sad over not ringing the bell **Comforting parents**	P: Umm.. I had one a while ago say "That makes me really sad that I know I'll never get to that point".. "I know my child will never ring that bell".. And I'll play that down. I'll play that down.	Sad to never reach that point – another thing to be sad about? Seeing other celebrate reminds parents that their child will never recover? Might even make the thought of death more prominent? Put further emphasis on that even more? Playing things down. Being positive and strong for parents. Lean on me.

	I: Okay, what might you say?	
Buffering the impact **Playing the bell down**	P: "Hey, listen that treatment bell isn't the be all, end all. It.. You know, it doesn't have to signify anything".. You know, "Don't worry about that bell" and I'll play it down. Because, you know, what else can you do?	It's not the be all, end all. Buffering the impact
	I: Yeah.	
	P: Umm. But it is..	
	I: So, I guess do you agree with the fact that the bell is on the ward?	
The bell signifies an end point	P: Umm.. Yes, because there are *so* many families that.. Well.. This is another thing, you're talking about end of treatment – it signifies an end point. For lots of families. And obviously there'll be some relapses after the scan and there'll be children that don't ring it but there'll be a lot of those children that ring it and that is.. That signifies to the child, psychologically as well, and as well as the families, that that's the end point. Ringing that bell is *often* a big goal. Not for all families, like I said before, but for a lot of them their *whole* cancer journey – and they talk about it	Should it be on the ward? The bell signifies an end point - the EOT bell Psychologically for parents and patients it means they've reached the end point Ringing the bell is a big goal Fixated on the bell throughout the cancer journey
A big goal **Fixated on the bell**		

An important milestone **A long road ahead after EOT** **Not really the end**	constantly through the journey – their endpoint is.. Is ringing that bell, and they'll frequently say that; "We're just living for the day that we'll come ring that bell and we'll walk out of here". But again, I can roll it back into, but actually they ring the bell and walk out of here but it.. You know, emotionally that's not the end and like I said before they'll ring and the anxiety and.. With the end of treatment comes a *whole* different level of anxieties. Very different. So.. **I: What do you think that bell symbolises in parents' minds and in children's minds?** P: As two separate things you mean? **I: Yeah – so.. I guess.. I mean, how do you think children experience that bell ringing and what do you think that bell means for them?**	Living for the day they ring the bell Ringing the bell is not the end – it is still a long road ahead for families EOT: A time of increased anxiety A time of unique challenges
Mostly for parents **Ringing the bell means returning to *normal* life?**	P: I think a big emphasis is put on children by their parents.. You know "You just need to ring that bell and that's it. That's the end of treatment for you, that means it's the end and we can go back, you can go back to nursery and you can go back to running around grandpa's house.." or whatever. I	The bell is mostly emphasised by parents "That's it" – <u>parents give their child the sense that once the bell is rung cancer is over?</u> Ringing the bell means you can go back to normal life

A focal point **Emphasis on the bell** **A symbolic object representing a new life?**	think, psychologically, the parents instill that in the children that those children know, if they're old enough to understand that concept obviously, if they're not old enough, then hey. But if they're old enough to understand the concept of the bell then it very much is.. A focus on "you concentrate on ringing that bell!". That bell means you've finished and you can go back to your life again. So, they put the emphasis on that bell as being the end of treatment. Which rightly or wrongly I'm not sure. **I: Yeah, yeah. So, I guess you're kind of saying parents' perceptions of the bell really colour how the child also perceives the bell?**	Ringing the bell becomes a focal point, an important goal, a milestone for the child to focus on Ring the bell and go back to your life again A lot of emphasis on the bell Rightly or wrongly? Helpful or not? Uncertainty.
Children are curious about the bell **The bell is the centre of attention** **Including others in this ritual enactment**	P: (participant nods) And sometimes though.. So, if the child happens to see another child ring that bell, sometimes the child will ask questions "What does that mean?" but actually having said that as soon as you walk on the wards people are talking about that bell. It's a highly uhh.. Talked about thing. 'Cause each bell.. Each ward has got a bell, and the daycare unit has got a bell and they get a choice about where they ring that bell.. You know, and they get a present and they get a	Children influenced by what they see on the ward Curious about the bell when they see other children ring it The bell is highly talked about. Attracts lots of attention. Children get a present and a certificate – like a graduation almost?! Some sort of ceremony?

Something to be witnessed	certificate, and they get 2 or 3 presents or whatever they get, the families are allowed to come in, granny, grandpa.. Not it Covid times obviously.. But yeah. **I: It sounds like a celebration doesn't it?**	A chance for the whole family to get together and celebrate. Something to be witnessed? Perhaps an opportunity to overcome the solitude that cancer brought? A big moment
A meaningful ritual representing the end **A time to release negative emotions**	P: Yeah! And sometimes *whole* families come in. Like Uncle Jeff, Aunty whoever.. 8 or 9 people will come in and it takes about 4 minutes but for them it's got a highly.. It signifies something really.. And it signifies an end point. I think. **I: Okay. And do you think it also kind of.. Parents might translate it as in "Cancer is not coming back after you've rung that bell"?**	The bell signifies an end point. Own reflection: A time-limited activity that provides containment? Having had not control all this time, perhaps parents feel it is a moment that is very structured, a moment during which they can channel their emotions? Allowing themselves to show emotion? Acceptable for them to show emotion? Some sense of control during all the "chaos"? [own reflection: a bit of a leading question here]
The meaning that parents attach to the bell **The end of cancer?** **A deeper meaning assigned to it?**	P: *Yes*. Oh yeah, yeah, yeah. Parents don't ring that bell with the expectation that cancer is gonna come back. No, they ring it to say "you're done". And obviously then the *really* hard thing is there's a percentage population that will come back and the cancer will come back and they have to go through the whole process again and be admitted onto the ward for whatever chemotherapy and.. Umm.. Yeah.	parents ring the bell anticipating that cancer is gone for good. Bell means the end of cancer in parents' minds – has a deeper meaning? In the event of a relapse Going through the whole cancer journey again – really difficult

Following recurrence Tempting fate	**I: And that second time round after they've relapsed do you think families want to ring the bell again?** P: (Laughs) Sometimes. Sometimes absolutely not. Then you'll get the "tempting fate". **I: Yeah, and is that something that parents say? Have they talked about that.. You know, that idea of tempting fate.** P: Yeah. Yeah. Yeah, yeah yeah. Definitely tempting fate. People talk.. Yeah, absolutely people talk about that.. Umm.. "And I don't want to tempt fate.." And I think.. The bell gets an.. The bell's been around now for.. Oh, I don't know.. Like 6 years, -ish. So, it's a *well* recognised bell and it.. I don't know if you saw the advert a while ago. It was a Morrison's advert, they did umm.. Uhh – you can Google it – I'll send you the link. **I: Yes please, that would be great thank you.** P: And it was a Morrison's supermarket and they called it.. I think they called it The Bells? And they had children that were	Tempting fate Not sure they want to ring the bell again after cancer recurrence Parents don't want to tempt fate Ringing the bell again post cancer recurrence sparks anxiety. Not so much a focal point the second time round? The first bell ringing versus subsequent bell ringings The Morrison's ad
First bell ringing versus subsequent bell ringings		

	either all finished cancer treatment or umm.. Or going through cancer treatment and they were talking about The Bells like the Big Ben bell and the importance of the bells and then the they.. Then they showed a few clippets of children on various different cancer wards around Britain – 'cause this bell is massive now. They're even doing it for neonates when they've finished their time on the neonatal intensive care unit. Massive. Umm.. **I: So, obviously there they're not really doing it for the child, right? They're doing it for the..**	The importance of the bell The bell is massive across the UK
Comforting for parents	P: Nooo, parents! Yeah! And I think sometimes it *is* for the parents. Absolutely, sometimes. If the child is 8 months old they're not going to care if they ring a bell at the end of treatment.. It's.. It's.. It's for the parents. But it's interesting because, I did some teaching last year at a university about umm.. About cancer and tumour types and things like that and I showed that video umm.. Of the end of treatment bell and umm.. And these nurses and doctors had never worked in cancer before particularly, so they didn't really have a clue what this bell was, and the reaction to that video was *really* diverse. Some people	The bell is mainly for the parents Comforting for the parents Children can't always understand what it symbolises – age-related as well.
Reactions to the bell vary **A divisive bell**		Mixed views about the bell from HCPs in other non-cancer disciplines

Imagining what the other is experiencing **Upsetting for fellow patients** **Moral distress?**	were like crying watching it.. I mean because it's so emotionally driven isn't it? And but yeah.. A number of them said, quite rightly so, 2 or 3 of them said "God, well, what about the families that never get to experience that?". So, you know.. It's *really* emotive that bell. Really, really emotive. **I: And I guess it causes a lot of uhh.. I suppose, conflicting views about it.**	Thinking about the other families who don't get to ring the bell A sense that some HCPs find it morally quite wrong? Or provocative? Thoughtless? Insensitive? Rude? The bell sparks a debate. A debate around the bell. An emotive topic
Debate around the bell	P: Yeah, and the longer it's around and the more times goes on.. Because now, evidently, all the people that would have rung the bell and it would have been an amazing thing like "Yeah, you finished treatment!" but then, you know, the longer you carry on the more children are likely to have relapsed after ringing the bell. Umm.. Or never get to ring the bell. So, I think the more it goes on, the more you hear more conflicting views about it. Some people do	More conflicting views with time Increasing numbers of children relapsing after ringing the bell
In support vs in opposition	not like it *at all.* Parents and colleagues. Some people think it's the best thing ever. Some people.. They hold it *hugely* important. It's a very very emotive thing. **I: Yeah, no. It sounds like.. Very very complex. And, I suppose, as I'm hearing you speak, we're talking a little bit**	Some parents and HCPs disagree with the ringing of the bell For some it is hugely important. Quite strong reactions re the bell? Unlikely to be sort of neutral about it? Has strong supporters and strong opponents. A sense that the bell means much more than just the EOT? More like ringing the bell creates and expectation that it is the end of cancer and that it won't come back?

	about.. A lot about mixed feelings and do you feel that you hold mixed feelings or do you have kind of a very.. Do you, kind of, sit on one side – is it a positive thing, is it, you know.. A problematic thing? Or do you, kind of, have a little bit of both?	[own reflection: trying to redirect the focus specifically on the P. What are her own personal thoughts and feelings re the bell?]
	P: I think a bit of both. I don't express my opinions about it to parents. So, if they want to ring the bell I make it a positive thing, if they say they don't want to ring the bell I'll say I completely understand. So, I think I just uhh.. I would go along with the wishes of the parents. I don't really have huge opinions about it either way. I think it does represent for parents the.. – and some children – the.. You know, the end and you know, I think it's an important milestone to some..	Keeping my opinion about the bell to myself
What parents want		Adapting to parents' needs and wishes. Patient-centred care. Almost like the primary focus is sometimes the parent rather than the child? The nurse-parent-child triad?
Patient-centred care		Go along with parents' wishes
The nurse-parent-child triad		It represents the end
An important milestone		An important milestone
	I: Yeah, it's a milestone, it's a good word that you're using.	It's a milestone
A milestone	P: It's a milestone yeah.	
	I: And do you attend those bell ringings?	
	P: If I'm around yes, yes. Yes. Because.. But often parents will want you to be there	It's opportunistic – I'll attend if I can

Something to be witnessed **Including others in this ritual enactment** **A ritual for letting go**   **The bell as a transitional object?** **Transitioning into survivorship**

parents **A complex job** **Not just a job**	you know, it's a complicated, complex job I think. It's so… **I: Yeah, it's so much more than providing medical care isn't it?** P: Oh! Yes! Yeah, absolutely! And talking about it.. 'Cause I'm thinking about it.. Like.. Some of these things I've not thought about for a long time 'cause you just get on with the job.. But if somebody's asking you questions and you're talking about the role, it's like.. God, yeah! It really is more than just a job.. It's so much more and it's a *really* complicated job as well. Emotional.. Every.. **I: Yeah. As you were speaking, I guess the metaphor that comes to mind is a little bit like the tip of the iceberg.. And sometimes what we see and what's underneath that.. Umm. It sounds like, you know, there's so much more that we are unaware of as outsiders.. You know, now speaking to you, umm and I'm, kind of, realising how many different levels there are around, you know, providing care in this line of work.** P: Mmm.. 'Cause we're not like, you know,	A friendly, stable, supportive companion throughout – understandable they want be there during the bell ringing A complicated, complex job <u>Relational complexity. Hard to maintain boundaries. Risk of boundary crossing is high due to the emotional closeness parents-nurses develop?</u> I just get on with it. Talking and reflecting on it makes me realise. More than just a job. A complex, emotionally challenging job. [own reflection: validating, summarising and checking my understanding of what the participant has shared. A little but too therapist mode?]

The relational focus of the CNS role **A relationship built on trust and communication**	sometimes.. We don't do that many medical things actually in these roles, not really. I mean, I can prescribe and I can do things like that but.. I think in this role.. Umm.. I can't remember the last time I gave a dose of chemotherapy, I don't think I knew what I was doing, can't remember the time I've worked on the ward, it's many, many, many.. It's a really.. Its kind of a.. A really niche job, I think. A lot of talking. A lot of talking. **I: Yeah, yeah. Wow absolutely. And I guess with uhh.. Sorry, going back to the bell a little bit, I'm thinking have you ever been to a bell ringing where you felt really uncomfortable? For example, if you knew the child's poor prognosis..**	The focus of the CNS role is not biomedical It is relational – a lot of talking At the core of the CNS role is good communication, liaison, supporting parents
Ringing the bell despite poor prognosis **A deeper meaning**	P: Yes, absolutely! Yes! Yeah, ah yeah! *Loads* of times. You've gone onto a bell ring and then you.. You.. Almost on the side you tell your colleague "Oh God! Just.. That cancer will be back in about two months' time!". Yeah! But it's important for the parents. **I: So, the parents, knowing that poor prognosis they still kind of.. Do they usually know that poor prognosis and still want to ring the bell? How does..**	Felt uncomfortable during bell ringings When children with poor prognoses ring the bell Important for the parents (sometimes despite poor prognoses). <u>Perhaps parents want the image of their child ringing the bell? An important moment despite what might happen next?</u>

Going with parents' wishes **Putting my own emotions aside** **Creating a happy memory**	**How does that, kind of, usually go?** P: Sometimes. Yeah, sometimes they know. And umm.. In my.. And interestingly in my really, really metastatic children that.. You know, the 8% to 10% prognosis, can't remember the last time one of them rung the bell, but I think perhaps it's because they've died before the got to the end or.. Umm.. So yeah. I think it's.. I think, yeah sometimes the parents do know that there's a very high chance or percentage of the cancer will come back and still want to ring the bell. And you can argue it either way, can't you? I just don't think there's a right or wrong in this bell. I think it causes a *lot* of emotions. Umm.. I'm not sure. **I: And I guess for you as well, when you know all the, kind of.. I guess all the aspects of, you know, their prognosis and you have all that information and you still kind of have to be happy for that family ringing the bell, it must be a very difficult position for you to be in emotionally.** P: (Nods) But then you know, uhh.. It's a happy.. It's a memory isn't it? It's a memory of that child and.. I think it.. You have to, a lot of the time roll with what..	Parents often want their child to ring the bell despite poor prognoses Can't argue with parents Important to value and go with their wishes Must put personal opinions and emotions to the side No right or wrong – each family is different Ringing the bell is an opportunity to create happy memories Roll with parents' wishes Not about what I think, but about what the parents want

Not taking hope away **EOL discussions** **Parental desperation** **Not giving up on their child**	Roll with the parents' wishes. 'Cause I just don't think there's a right or wrong and I don't think.. And it's about, like I said before, it's about taking away hope. I don't I could ever *ever* do that.. to a family. So, if they wanna ring that bell with the hope that that cancer never comes back, who am I to take that away? Like, you *can't* take away hope, even when a child is actively dying. I just don't think you can take away hope. That's not what they wanna hear. They don't want you to walk in that room and talk about.. **I: … Death.** P: I dunno. Yeah, you know, no, not necessarily. Because.. And.. And.. People get to that.. Parents get to that point in.. in a very different, umm.. At very different times.. You know, some people push, push, push, push, push "There's must be something more you can do" really, really emotional.. Difficult, difficult, difficult conversations "How can you stand there and let my child die?", "What else are you gonna do?", "There must be something else – can I go to America? Can I go to Germany? Can I go to Mexico? Can I go to Barcelona? Can I do this? Can I do that?". You know, it's constant, constant,	Maintaining hope Can't take hope away Parents' reactions during the EOL phase Aggression/blame from parents? Difficult moments in nursing Parental desperation Pushing for more treatment Hopeful that there must be something else to be done for their child to be saved. Not giving up on their child

Difficult conversations about EOL	constant.. Umm.. Or.. And some parents are much more accepting and are like "I know you tried everything you can and I don't want you to put my child through anything else" and there's all of those difficult conversations as well.. **I: Yeah.**	Some parents are more accepting Every parent is different The difficult conversations we have in pediatric oncology
EOL decision-making	P: Where are they going to die? Are they gonna go home? Are they gonna stay in hospital? Are they gonna go to a hospice? And grief.. You know when a child does	EOL decision-making
Parental grief	die, if they die on the ward. Absolutely how people react is *completely* new.. Sometimes you just can *never* predict what	Parental grief Grief is unpredictable
Exposure to grief, death and suffering	they do.. You know, some parents collapse on the floor, some parents *scream* and *shout*, some parents shake the child "wake up, wake up, wake up, wake up". Umm.. **I: And again you're there witnessing that, aren't you?** P: Well.. **I: If you're there..**	Ongoing exposure to suffering, death and grief <u>Increased risk for secondary trauma?</u>
Vicarious trauma	P: If.. If I'm there, yeah! If I'm there. And *nothing* can prepare you for the things that you see in this job and the outpouring of	<u>Witnessing death and dying in the oncology context – high levels of occupational stress. Secondary trauma.</u>

	grief and the difficult emotions and the death and how parents behave. And *nothing* can prepare you for the things that you see and that you witness. **I: And for these very difficult things that you witness and you see, do you have any, kind of, space for reflection within the team? For example, for the difficult cases do you find that there is, you know, the chance to reflect with other members of the team about some of the difficult aspects of the case? Is that something that happens?** P: Yeah, yeah absolutely. And again, it comes into talking a lot in these umm.. Within this.. With friends, with colleagues – your colleagues are your friends you know.. You could never get through the average day sometimes without your colleagues by your side having a chat.. You know, and having lunch together sometimes if you get time (laughs) or.. You know! At the end of the day, you couldn't do this job if you didn't work in a good team and I think I'm very lucky because the whole three of us.. Four maybe. Umm.. We're a really good little.. A really good little team. And actually coming to work is easier 'cause you know that you've got	Nothing can prepare you for it. [Own reflection: And yet there is no formal support following such incidents? How can that be safe for HCPs and also the quality of care they provide? What is the impact of not having the right level of support?]
Colleague support **The importance of a good team** **Not alone** **Helpers help helpers.**		Colleague support – who helps the helper? Other helpers help helpers. Colleagues are your friends. Mutual support among nurses The importance of a chat with colleagues Not alone The importance of a good team Sharing the burden Relying on each other, leaning on each other

	your colleagues there I think as well. **I: Uh-huh. No, massively important. It sounds..** P: I think also, they do.. When.. So, the psychologists here they do offer umm.. Like a debrief for each child that dies.. They do offer that. Umm.. And most of the time I don't tend to go to them – 'cause I think a lot of the ward nurses go and I think.. I don't know.. It.. I don't know.. I don't think I'd want that. Sometimes I just don't feel the need to attend a debrief even though what I've just witnessed is particularly awful perhaps, you know.. But, I don't really go to those. You can go to them and they are offered, and the psychologists definitely do offer it every single time a child dies, they offer a debrief, which I tend to find the more junior nurses go.. So, like the more.. Like the Band 5 on the ward and things.. **I: Did you attend them more when you were more junior as well? Do you remember?** P: I don't.. I don't think so.. 'Cause I think back then.. 'Cause we're talking.. So, 16-17 years ago – I don't think we ever had	Colleague support – a hugely important protective factor against the stresses of the work Psychologists offer debriefs following a patients' death I don't find debriefs helpful. They don't offer what I need emotionally in that moment? A very task-oriented environment perhaps? Like a tick the box type of thing? Thought for discussion: what is the evidence for the use of debrief following a patient's death? Junior nurses are more likely to attend debriefs
Debrief following a patient's death **Oragnisational support: debriefs**		

Get on with it **Soldiering through** **Resilience among nurses**	that.. back then. I think there was that emphasis that they just really expected you to get on with it really, aren't you? Which is I think maybe that's why I've got the mentality that I have as well "Yeah, I'm alright!". (Laughs). **I: Yeah, yeah. And, do you find that with years of experience it becomes.. I mean does it change how uhh.. You're able to cope with these types of things.. Or.. I mean was it more difficult when you started off or does it remain difficult, you know, across the your career?** P: I think it remains difficult.. I don't think anybody ever teaches you how to deal with these things.. So, there's no formal teaching that makes you a good CNS.. Or there's no formal teaching that teaches you how to.. How to talk to a family after a their child has died and.. And there's no formal teaching about how to talk to a family when their child is diagnosed with cancer or they've got a problem.. I think it just comes with experience and you learn umm.. And obviously, each different family.. You could say something to a family.. Well, to one family.. But you know you could never say that to another family. But you have to gauge what you can and can't say, I think?	Then versus now. Used to be the expectation to just get on with it An unspoken expectation that one must handle whatever is thrown their way Stiff upper lip? Putting on an act that nothing phases you? It remains difficult throughout. Can never really get used to it. No support/training/input on how to cope as an HCP following a patient's death No formal teaching can teach you how to be a good CNS No training on how to communicate with parents after their child has passed? Lack of adequate training – may create feelings of fear and uncertainty? A sense of being incompetent in their therapeutic communications with parents? Inadequate skills and knowledge around managing EOL situations? Learning on the job Experiential learning Being flexible and adaptive. Patient-centre care. Gauging the needs of families and parents
Lack of adequate training **Inadequate knowledge around management of EOL** **Learning on the job** **Gauging parents' needs**		

	I: Yeah. P: And that.. That comes with experience. **I: Yeah, yeah. Thank you so much for talking about all this stuff and I think I am conscious that you've spoken about some quite difficult things and umm.. You know, difficult aspects of the role, umm.. And I'm just wondering, if you did feel a bit vulnerable and required some support yourself, do you know where to kind of find that support within [name of hospital]?** P: Oh yeah! Yeah, yeah, yeah! Yeah, I'd just ask one of the psychologists. Um.. Yeah, no. **I: Because it sounds like, you know.. I definitely have felt, you know, speaking to you that there are so many other elements and aspects to the job that I hadn't really, kind of, considered before. You know.. We spoke a little bit about it and umm you know.. And you touched recently.. Just now on palliative care and I'm just wondering do patients that transition into palliative care do they ever have the request or**	

The meaning families assign to the bell – setting up false hope? **Palliative patients and the bell**	**wish to ring the bell?** P: Ooohh. No. Not that I know of. Not.. I can't think of an example of that. Although you could argue, couldn't you, you know.. An end of li.. An end of.. A bell.. Does it have to signify you know.. Umm.. It sometimes still means, even though the child is going to die that they have finished their active treatment so.. you could argue, why couldn't they get the opportunity to ring that bell? It doesn't have to signify that they're gonna live forever and they're gonna get on with their life.. It sometimes, it just signifies it's the end of cancer treatment.. So, you could argue that. But no, I don't think.. And actually I don't think.. If you'd ask me to find a family that would want to ring the bell when they enter palliative care I don't think many people would. **I: So, it sounds like the meaning that people assign to the bell is really important because from.. I guess from the professional's perspective you're thinking it signifies the end of active treatment but often parents assign the meaning to it that it's.. You know, cancer is never coming back. Umm.. So it's quite different how people make**	A further sense that people perceive the bell as indicating the end of cancer once and for all? Palliative care patients do not express wanting to ring the bell The P seemed a little bit conflicted here – if the bell signifies the EOT, why should palliative care patients not ring the bell after they finish active treatment? Is the bell rung only at the end of curative treatment? A bit of an oxymoron

	sense of the bell. P: I think so.. I think it's *really* individual. **I: Yeah, really individual. That's a good word. Yeah.** P: Yeah. Yeah. **I: And umm.. Thank you so much. Is there anything that you think, you know.. We've spoken about a lot of things, but is there anything that you feel that I should have asked that's quite important umm.. That I haven't asked? Anything around the end of treatment?**	The meaning people assign to the bell is really individual
The EOT day **Low attendance at EOT days**	P: I think what I didn't mention – you probably know this – there's an end of treatment day, which is run by.. (name of colleague) actually runs it.. Umm.. And umm. They can come after they've finished treatment, they can come along to that day.. I think there's a psychology session, there's a dietitian session, there a CNS – I often do the CNS bit – umm.. I don't know.. The numbers never appear that high to me in that.. It's a really good day. *Really* good day, it's well run.	The EOT day People don't tend to attend EOT days A well-organised, useful day but parents don't attend

Returning to hospital for EOT days **Timing of EOT day**	**I: Okay, so you think what's on offer (i.e., on the day) is important?** P: *Really* important! It's whether.. It's why lots of people – you tend to find that the leukemia patients access it but not so much the solid tumours. And I don't know why.. and I don't know why. And I think again it comes down, it boils down, to how.. Do parents really want to go in? For a full day? And I think it's a really useful session, but do they want to go in and talk about umm.. What they've just been through? Not necessarily. But even though it's so important and it offers them access to psychologists.. Umm.. But yeah, so there is that day that parents can attend. **I: Do you think, umm.. Why do you think solid tumour patients might not… What barriers – what additional barriers might they face and not, kind of, show up?** P: No, I don't know 'cause they get a standard letter that's written to them. Every parent gets the letter.. Umm. If they're.. They're all eligible. Unless a child's died or relapsed what have you.. But umm.. Maybe we.. Maybe we run it too late. Maybe. For example, maybe we offer.. Six months down the line and maybe it's just..	More likely that leukemia patients will attend Solid tumour patients less likely to attend Confusion as to why – what dictates attendance? What factors influence this? Another thing for parents to do? Potentially traumatic for parents to have to return to hospital after treatment has been completed? Access to psychological support during the EOT day Maybe the timing of the EOT day is not convenient – too late? Six months down the line – parents have already had to deal with the difficult transition? Not helpful at that point to have an EOT day.

Triggering to return to hospital?	Maybe by that point parents are like "Well, I'm alright now, six months down the line I'm alright". Maybe, I dunno. Or whether it's just that they don't feel like they want to come back into hospital and they don't want to revisit what they've been through. Maybe. I don't know. **I: A bit triggering.** P: Sorry say that again. **I: Perhaps, it's a bit triggering for them, kind of.. It's a reminder of some of the difficult times that they've been through as a family.** P: Yeah, yeah, I think so. **I: And I guess that's more common in solid tumours isn't it, because I guess you know the relapse rates are higher, or the risks are higher? I don't know. Perhaps it's quite different to leukemic patients.**	Not wanting to revisit what they've been through. <u>Triggering for parents? Bring back difficult memories?</u>
Leukemia versus	P: Yeah. Very. The inpatient treatments are massive. Like you have leukemias, if you've got ALL, and you're, you know, you've got a 90% cure rate. You.. You have one.. Usually one admission at the	In leukemia you're mainly an outpatient throughout the treatment

solid tumours **Different treatment experiences**	beginning of diagnosis and then normally you're an outpatient or you go to daycare. Or you go to local hospital. Whereas these.. Some of the solid tumour patients.. Maybe, you're right – they come in and they're in hospital for weeks at a time having chemo or 3 or 4 or 5 days at a time every three weeks. That they're in.. Umm.. Maybe. I don't know, I don't know the answer to that. But, it's just that just looking at the numbers, that I've attended.. The last couple that I've been to – it's a while ago now because of Covid – but there's was only.. I maybe had 1 or 2 solid tumours and maybe there were 7 or 8 leukemia patients. The ratio seemed to be. Or maybe.. Maybe it's just because leukemia is massively common in the cancer world and there's more.. It might just be a simple as that. There's more patients and therefore more people attend. It might just be as simple as that. I dunno. **I: Yeah, yeah, interesting. More questions arise as we speak uh.. And one last question I suppose – yeah what was it sorry. It was just here. Umm.. Yeah sorry. I forgot that last one. Sorry, it happens sometimes, doesn't it? (laughs)**	Solid tumour patients stay in hospital for weeks Patients in these two groups have very different treatment experiences therefore how they feel about the hospital in general will have been coloured by these experiences and might influence whether they feel able to attend or not?

	P: Oh, God yeah, yeah (laughs)! **I: Thank you so much.. Do you have any.. Oh, no, no, I got it, I got it! So, the last question was, do you think – I guess because we touched a little bit on how abrupt those endings are – and how you know, from having lots of support, parents.. You know, after the end of active treatment, don't have much support. Do you think anything else could be done or anything else could kind of be in place to provide more support for parents after the end of active treatment?**	
Families must move on	P: Uhh. I don't know. Because to a certain degree they have got to get on with life and life has got to go on. And they're.. You know, they're offered psychology every step along the way.. I think I offer it a lot.. Because umm.. I think it's important. **I: Yeah.**	They have to get on with it The must move on. Not sure whether there's anything else we can do? They have to let go? Make this transition Psychological support is offered along the way <u>There is a bit of a contradiction here to what the P has said – on the one hand she has mentioned a few times that the EOT phase is really difficult and parents lose much of their support network and yet here states quite firmly that parents "have to get on with life"</u>
Off-treatment support	P: Umm.. So, they're offered that and they're offered it even at the end of treatment they've still got option for that. They get CLIC Sargent and social support who are a really important team as well.. They do some of the emotional support,	Parents have off-treatment support from various teams Financial support following cancer treatment? Important aspect of returning to

	they do the practical stuff, the finances.. That's a whole different topic of conversation. **I: Yes, yes of course.** P: Umm.. Umm.. And they get end of treatment day and.. And they get.. Still get.. Access to me and they still get to.. You know.. If they're concerned then they just pick up the phone. So, I think, even though the support is.. They lose a *big* section of it there's still quite a lot there.. And.. And.. And I think.. Awfully, life goes on and they've got to.. They've got to.. They've got to get back into life as hard as that is.. *Absolutely* challenging and we expect *so* much from these families. But I think.. You know.. Life goes on. **I: Yeah, it moves on. And it's what you said earlier as well about, you know, you have these patients that are ending but then you have this new set of patients that are just starting so you, kind of, have to shift that focus to this new set of patients.** P: Yeah. Yeah. I think.. I call it the great circle of life actually, isn't it?	normal life? The impact of cancer on a family's finances? EOT day Access to me throughout the whole off-treatment period They lose a lot of support but there are options for parents following treatment [own reflection: what barriers might parents face to access the available support during the off-treatment period?] Very challenging for parents but life goes on. We expect a lot from them. But the reality is they must move on. The great circle of life in pediatric oncology. Things move on. An ever-changing landscape.
Off-treatment support **Moving forward despite the struggle** **The great circle of life**		

	I: Yeah! P: I often use that phrase. It's the great circle of life. **I: It's a beautiful phrase and I think it really nicely reflects what we've been talking about a little bit. Yeah. Well.. Thank you so much.. It's been such a privilege to, kind of, get to hear some of your experiences and uh.. Do you have any questions at all or any concerns that you'd like to share with me.. Anything that you'd like to ask?** P: No. **I: Okay.** P: No, I was gonna say.. It's been really good. It's made me think about things that I've not thought about for a looong time. **I: Okay. In a good way? (laughs)** P: Yeah, in a really good way! Sometimes, you think God actually, my job, bloody hell, how do I do this? It makes you think, God.. It's really.. It makes you really reflect on things!	

	I: Absolutely, I have so much respect for what you do and umm.. I'm just kind of wondering.. Would you be interested in receiving a copy of the findings? P: Yeah! I'd really *love* to. **I: Okay.** P: How many people are you gonna interview? **I: So, I'm hoping.. I've interviewed.. So you're my fourth person that I've been interviewing and I'm hoping to interview around 9 members of staff.. Because I'm doing quite an in-depth analysis of the findings. It's not so much about a massive sample of people.. We're very much interested in, kind if, depth over breadth I suppose. So yeah! So, hopefully after I finish with the analysis I'll be coming and presenting to you guys.** P: Amazing! **I: So hopefully, we'll have a chance to speak about the findings and.. yeah. Hopefully we'll meet again.**	

	P: I'd love to.. I'd love to see a copy of that. **I: Yeah, brilliant. Okay, so I'll note that down and I'll send you a copy once we're done with everything.** P: Perfect! **I: Well, (name of participant) thank you ever so much.** P: No thank you, nice to talk to you. **I: Have a lovely day. You too.** P: And you. **I: Brilliant. Thank you, bye bye.** P: Bye! Bye!	

Appendix 1.10. Super-ordinate themes and subthemes for participant 2 (Doctor)

Super-ordinate Theme *Subtheme*	**Transcript**	**Page / Line**	**Key words**
"The End?"			
Endlessness	*"What you want is not to allow your sense of "This treatment is successful" being dependent on an individual child having been cured. It's, uh, providing that benefit to large numbers of children. So, I don't think I take, uh.. Any sense of closure (laughs) from having brought one child to that point. It's about an ongoing venture, that is never.. – until I stop working – never going to end."*	12 / 482 - 487	An ongoing venture
The system	*"So, at [name of hospital] it is mainly the local hospital that does the off-treatment monitoring. We see them less frequently. We share that off-treatment monitoring with the local hospital. We do see them, but not as frequently and we are not entirely responsible for that."*	3 / 90 - 93	Not entirely responsible
An antithesis	*"[…] some children unfortunately develop very late side effects.. We are giving poisons to these children, who are growing, have a lot of growing to do, and those poisons might affect that growth, development, cause second cancers.. So.. Heart problems.. So, they.. […]"*	19 / 781 – 784	Poisons
	"So.. I think it's really important at that very early stage to say "Look, <u>now</u>, except for the fact that your child is taking medicines, you should basically return to your normal family dynamics", as well as return to some, uh.. Uh, sense of giving that child, uh.. A normal environment in which they feel they are not sick."	17 / 678 - 682	Not sick

The bell as a marker	*"And I think it's a good thing. I think it's an important, uh.. For the parents, an emotional uh.. Milestone, which they would.. They would like to mark? Much like an anniversary or a birthday? And some parents continue to mark that as an anniversary subsequently. So, just as celebrating a birthday gives us pleasure, uh.. Or an anniversary of some sort. Celebrating the end of treatment on a certain date.. No matter that it may be arbitrary, umm, is still an important milestone that I think parents get a lot of comfort from marking that."*	10 -11 / 409 - 415	Like a birthday
An important milestone	*"I <u>expect</u> that they see it as an important milestone that <u>they</u> look forward to reaching and therefore it builds that sense of anticipation of "When am I going to ring the bell?" and yes, I have heard one or two children say that, uh.. And they really are excited of that prospect of uh "I will do the same one day"."*	13 / 533 - 537	Important milestone
It's a mixed bag	*"But I imagine for the child who's been very unwell with side effects of treatment et cetera, seeing that (i.e., another child ringing the bell) that could give them a sense of uh.. Uh.. Having missed out on something. Or might feel that they don't deserve this. You know, a sense of "This child deserves this and I don't deserve this"."*	14 / 551 - 556	I don't deserve this
The parent's experience			
Parental perspective	*"P: Umm. We could also probably, umm.. Identify those parents who are going to struggle more than others. And proactively put in place some additional support for them.* ***I: How might you identify those parents?*** *P: Well, we <u>know</u> the parents who (laughs) cope less well than others. It's.. That is a subject of uh.. Uh.. MDT conversations often. Is that this family for various reasons.. Social.. Psychological.. Are coping less well than some other families."*	16 / 625 - 634	Struggle more

Suddenly left	*"For parents it can seem quite abrupt. Because one day the child is on treatment and being seen quite regularly and with more intense monitoring and the next day the child just stops treatment. There's no weaning. And.. They not only lose that sense of reassurance of the child being on treatment, but also that sense that they're not being as intensively monitored and supported as they were while the child.. Child was on treatment. And some of the parents undergo this, kind of, almost withdrawal syndrome of suddenly finding themselves having to go back to a semblance of normality, which they'd forgotten?"*	2 / 53 - 61	No weaning Withdrawal syndrome
Support for parents	*"What are the important considerations for not only what we call the end of treatment but also how exactly we mark it and the way we should be supporting families when they make that transition."*	15 / 609 - 611	Supporting families
A conflict			
Battle with the parents	*"And what happens in those situations is that.. Inevitably the focus.. How hard you try is distracted by this.. Battle.. Ongoing battle with the family. And that can be quite time, energy and emotionally consuming. Which, therefore you have to constantly remind yourself that you have to try and separate those two things. Is that the child's welfare should remain the paramount focus and you need to separate that from the difficult conversations that you are having with the family. […] Umm. And it isn't always successful. Because often you get pressured into doing things that are not in the child's best interests for the sake of satisfying the parents."*	8 / 301 – 313	Ongoing battle
	"Yeah, and if the parents don't accept that then the critical, uh, measure of a successful, uh, clinical, uh, discourse is trust. Is to build trust between the patient's family and the professional. So, if that breaks down, as it does, and as it did in the case	7 / 282 - 288	Building trust

	of this family, then that brings on a whole different, challenging, uh, scenario in which it's impossible to regain that trust. Because the family often seeks second, third opinions, nationally, internationally. And to deal with that becomes almost a full-time occupation in that period of time."		
Moral distress	*"[…] the main issue there is that you might think that what the parent is asking for may not be in the child's best interest and yet you are almost compelled to compromise on that, because the parents are insisting on it. Uh, often expressed in a very angry, hostile way, which can uh.. Be difficult then to reestablish a sense of.. "Look, we're both trying for the same thing, which is the child's best interest". And it is assumed that the parents are the ones who know what is in the child's best interest, yeah? And when the parents think that what we are doing isn't in the child's best interest, then you're always going to come behind what the parents want."*	8 / 320 - 328	Compelled to compromise
Emotional professionalism			
Stating the facts	*"Once you've done it several times – and I've done it hundreds of times – what you have to be conscious of, that you don't do it on autopilot. 'Cause you have a spiel in your head and you just go boom, boom, boom.. Fact-based. You have to be mindful of the fact that the child is the most important thing for those parents and that you're not doing it in a more bureaucratic formality. That you engage with the parents to address their anxieties and concerns and ensure that they have fully, not only understood the factual information and the logistics, but also around the, uh, support they will continue to have and the reassurances around the chances of cure. So, you just got to be mindful of that."*	4 / 126 - 135	Bureaucratic formality
Bearing witness to challenging situations	*"Whereas the most difficult conversations, are of patients who may have days or even a week or*	6 / 213 - 219	Days before they

	two before they may die. And there the conversation is more around how parents want the child managed, whether it's in the home, hospice, hospital setting. What the focus will be around symptom care, especially around the use of analgesia, which might cause sedation for that. And that might in itself contribute to death - etc. So, those conversations are the most difficult."		die
The highs and lows	*"And as we've developed newer and newer ways of treating children who have failed the standard treatment, uh, there will be the occasional child who in, even two or three years ago, we would have said is incurable but we've tried these almost experimental treatments and have been successful, and where a year later you can pronounce them cured after that experimental treatment. Now that gives you a sense of "Yes, you've done something here, which you weren't able to do even two years ago"."*	12 / 489 – 495	Experimental treatments
	"Well, as a physician obviously you always feel that if you haven't managed your patient, that you fail as a professional.. Uh, but equally over the years you come to reconcile yourself for that, because you're never going to be 100% successful with anything in your life."	6 / 224 - 227	You fail as a professional
Not alone	*"And obviously the starting point there is the multidisciplinary, multiprofessional, team agreeing that we have reached the end of the road. That's the first step. And then once there is consensus around that and that any treatment is futile and potentially will do more harm than good, then that uh.. That information is given to the parents. Even if it's just me having the conversation, usually though it's always me and someone else, it's given as a team decision rather than my decision."*	7 / 263 - 269	Consensus

Appendix 1.11. Super-ordinate themes and subthemes for participant 4 (Nurse)

Super-ordinate Theme *Subtheme*	**Transcript**	**Page / Line**	**Key words**
Holding too much			
Emotional burden	*"Well, and I think they see you as their friend. Even though that isn't what it is.. They do.. I think a lot of parents would.. Would.. And I think that's another reason they struggle at the end, is that they're losing a.. A.. A - inverted commas – their "best friend" that's been there for them every step of the way for 18 months. So I think it's a grieving process for them. I think. I think.. Umm.. But yeah the emotional burden. If you times one (x1) family by, you know - we maybe have whatever 20 or 30, whatever, you've got.. on the wards and things – and each person.. It sometimes feels like they suck the living soul out of me. And I'll go home some nights, and I think, "Jesus, I haven't got <u>anything</u> else to give anybody. If anybody asks of anything else of me today I just won't budge"."*	12 / 477 - 487	Their "best friend" Suck the living soul out of me
A companion throughout	*"Umm.. Umm.. In what way? Well, because you.. The people these parents phone isn't the consultant. They see the consultant once in a blue moon sometimes – the person they consistently see is me. So, it will be me that takes on the worries and the stresses. Most of the time, because they'll only see the consultant every now and then. And actually you get sometimes to the point where they're like.. Umm. They're petrified of seeing the consultant for the scan results, but when I walk in the room it's like sheer relief and I get that often they'll say, "Thank God it's you! I'm really, really scared about seeing the consultant because I don't know what he or she is going to say to us, whereas, you you're really consistent!" (laughs). D'you know? And they're not.. They.. They love you but they find it really hard seeing the consultant (laughs). Strange, but yeah."*	15 – 16 / 619 - 630	Sheer relief

Relational complexity	*"Because like, again I'll say the blurred boundaries almost sometimes.. You know, it's the.. This.. The "friendship", which I suppose it.. And that's a really.. I think.. Boundaries are really really difficult.. <u>Really</u> difficult sometimes. […] Especially if you've got a family that you.. We're human and.. And we click with certain people better than we do with others and sometimes it feels like.. That they blur slightly.. The boundaries. Not that you'd see them outside of work or anything like that, but sometimes, you know, you're having a conversation and you'll almost forget for a second that you're a health professional and it feels like, you know, you're chit-chatting about – I don't know – life! What you did that weekend and.. And.."*	21 / 855 - 868	Blurred boundaries
Becoming what families need	*"You'll get families you won't hear from between the three monthly scans and that is the end for them and you don't really hear from them, or you'll get families that still really, really need you and they will ring for.. They'll.. It's almost like they're making up an excuse to ring you because they miss you there and they'll ring and they'll say something like "I don't really need to ring you for that" but it's their way of, kind of, touching base still. So, I think it depends on the family. Sometimes there's a very.. There's an ending that's abrupt, it's the end of treatment, see you in three months time, get on with your life.. Sometimes. Sometimes it's very much.. They'll still call you and they'll still contact you, and they'll come back to the ward to visit, they'll come back and bring sweets in, they'll do this, they'll do that to maintain that link and that contact with the hospital and I think it.. It could go either way and you never can quite.. Well, you can tell from how certain families behave. You.. You can pretty much guess sometimes but.. Families cope in very, very, very different ways."*	19 – 20 / 794 – 808	They miss you
Puzzling resilience	*" 'Cause lots of people could never do this job and I think – you can think that for any job – what makes me be able to do it? And I don't know.. And I think.. I've always had a bit of a fascination with umm..*	17 / 677 - 691	What makes me able to do it?

	Umm.. Life-limiting things and things that can change your... And.. And I don't know.. I don't know why I do this job or why I can get… you know, years and years and years of doing this now, but I've never ever really once felt the point where I've had such a bad emotional burnout that I can't function. I have bad days – absolutely – where I'm like "Ugh!" but I've never got to the point where I thought "I can't do this anymore, this isn't for me". I've never ever felt like that in 16 years of cancer […] But I don't know why. This is the thing I don't know why I can just cope with it."		
Unbearable pain	*"People get to that.. Parents get to that point in.. in a very different, umm.. At very different times.. You know, some people push, push, push, push, push "There's must be something more you can do" really, really emotional.. Difficult, difficult, difficult conversations "How can you stand there and let my child die?", "What else are you gonna do?", "There must be something else – can I go to America? Can I go to Germany? Can I go to Mexico? Can I go to Barcelona? Can I do this? Can I do that?". You know, it's constant, constant, constant.. Umm.. Or.. And some parents are much more accepting and are like "I know you tried everything you can and I don't want you to put my child through anything else" and there's all of those difficult conversations as well.. […] Where are they going to die? Are they gonna go home? Are they gonna stay in hospital? Are they gonna go to a hospice? And grief.. You know when a child does die, if they die on the ward. Absolutely how people react is completely new.. Sometimes you just can never predict what they do.. You know, some parents collapse on the floor, some parents scream and shout, some parents shake the child "Wake up, wake up, wake up, wake up". Umm.."*	32 / 1319 - 1337	Screaming and shouting
	(Sigh) "It depends on the families. So, pre-Covid times.. I find funerals really hard. I do go to some and again I think in my head "What makes me pick that family's funeral to go to over that family's funeral?".. It's hard. That's really, really hard. Umm.. I go to less certainly as I've got older I try	22 / 889 – 897	They kill me

	and go to less. Because they are so incredibly difficult! Emotionally they kill me for a few days afterwards. Emotional.. Uh, I find it really really.. Really tricky funerals. But sometimes if the parents say "Look, I'd really want you to come to the funeral, you're a really important part of her life" or whatever they're gonna say then umm.. I do go."		
Helpers help helpers	*"Ah – colleague.. Colleague support is massive and actually, you know.. Big part of how you do these jobs is working within a team of amazing colleagues as well. And they do.. They get you through.. They get you through some situations. Because it.. Like.. It helps with the emotional burden I think. Talking to other people. And talking to colleagues that understand and it.. It does help."*	14 / 563 – 568	They get you through
A time of uncertainty			
Leaving the protective cocoon	*"I think.. I think 9 times out of 10 umm.. Families will just offer that information and will say umm "Gosh, this is really difficult" umm.. For many different reasons but usually the reasons that are given around are umm "We're gonna miss you", "We're gonna miss our Great Ormond Street team" umm.. "What are we gonna do without you there anymore?", "We've got used to coming to hospital all the time, how are we expected just to go back and adapt to normal life?".. Umm.. "We're on chemotherapy and it makes us feel safe and secure that the cancer is under control. Now you're stopping the treatment and what's gonna happen? Will it come back?". Those massive anxieties around stopping treatment. And obviously then you lose your support network, I think we touched upon that before. So, you lose your community team, who will come into your house once or twice a week to take blood tests for the child. You lose your local team because you don't need them anymore really. You lose your Great Ormond Street.. You don't see the nurses on the wards anymore and some of these children are in kind of 3, 4, 5, 6 days at a time for chemotherapy.. Even longer periods of times sometimes, depending on whether they're*	4 – 5 / 161 - 185	You lose your support network

	having surgery, you know, or whatever, you know.. Umm.. So they don't see the girls on the ward anymore. And then, they don't need to call me as much anymore. So, some families are very reliant all the way through treatment and they'll call you a million times a week. And then once they've got to the end they don't need you as much anymore and they.. And they.. You know. So the parents will often often, often express fears about how are they gonna cope when their support network's gone? How are they gonna go back to normal life? How are they gonna get through the scan anxiety?"		
What endings look like	*"They know it's coming obviously, because we talk about it, but going through it is a very different experience for them. I think it is quite a.. I think an ending looks like end-of-treatment, line out and then coming into clinic once every three months. I think that.. That typically.. Sometimes.. I mean like the.. You'll get families you won't hear from between the three monthly scans and that is the end for them and you don't really hear from them, or you'll get families that still really, really need you and they will ring for.. They'll.. It's almost like they're making up an excuse to ring you because they miss you there and they'll ring and they'll say something like "I don't really need to ring you for that" but it's their way of, kind of, touching base still."*	19 – 20 / 791 - 800	Going through it
The "good" bell	*"But if they're old enough to understand the concept of the bell then it very much is.. A focus on "You concentrate on ringing that bell!". "That bell means you've finished and you can go back to your life again". So, they put the emphasis on that bell as being the end of treatment. Which rightly or wrongly I'm not sure. […] And sometimes though.. So, if the child happens to see another child ring that bell, sometimes the child will ask questions "What does that mean?" but actually having said that as soon as you walk on the wards people are talking about that bell. It's a highly, uhh.. Talked about thing. […] You know, and they get a present and they get a certificate, and they get two or three presents or whatever they get, the families are*	27 – 28 / 1119 - 1143	Concentrate on ringing that bell

	allowed to come in, granny, grandpa.. Not in Covid times obviously.. But yeah. […] And sometimes whole families come in. Like Uncle Jeff, Aunty whoever.. Eight or nine people will come in and it takes about four minutes but for them it's got a highly.. It signifies something really.. And it signifies an end point. I think."		
The "bad" bell	*"So, it's become a really kind of.. Umm.. Mixed feelings about the bell because umm.. It's hard because they do it on the ward and you'll have a family nearby where their child is dying and hear what goes on because it's not thick walls.. So, in one minute you've got a dying child in that bed and the next minute you have another family cheering and clapping and celebrating their child's finished cancer treatment. You know, the emotional impact on those parents, I think, must be really hard. 'Cause you know – you're hearing that and yet your child.. Your child's gonna die. Your child's never gonna get that experience of ringing that bell. Or.. Umm.. So, I often think that when I hear.. 'Cause you know. And don't.. Don't get me wrong. They're lovely ceremonies, they're lovely. And the.. You know.. And the cheering and clapping. But in the back of my mind I'm thinking "Well, what about the families that'll never gonna get to do this?" and "What about the families that will never get to experience going home and getting back on with their lives?".*	25 / 1029 - 1042	It's hard
I'm human too			
I'm human too	*"But if the child dies, that.. That.. And it is again I think for me it's like a grieving process actually because.. You know, we're only human and often I'll think to myself "God, I'm really gonna miss that child, I'm really gonna miss that mum, I'm really gonna miss that family", you know, and it is.. I think as a health professional you still go through a slight grieving process. If the child dies. Or even if a child then finishes treatment and doesn't really contact you very much. You still miss them.. You still think about them."*	24 / 965 – 972	We're only human

Appendix 1.12. Super-ordinate themes and subthemes for participant 6 (Allied Health Professional)

Super-ordinate Theme *Subtheme*	**Transcript**	**Page / Line**	**Key words**
Difficult dilemmas			
Those who gets and those who don't	*"And I really hope as well that that might improve some of the equity. Because actually some of the feedback, umm, that we've had from families is that if we meet some children early on in treatment they can get a very good service form us because we know them regularly, their medical team then know that we're involved, we get asked to see routinely. And then there are some families who we don't get to see at all. And so when we get to end of treatment days some parents we know very, very well and other parents we haven't. And actually their children's treatment hasn't been that dissimilar but we don't know about them and.. So, like "Wow, if we'd known we could've done this or we could've done that". And so there isn't often a huge amount of equity. Now I would hope that you know, - all of our children have got CNSs and they're all seeing consultants and medics all the time – that if there was real problems then we would know about them. But umm.. It does.. Just doesn't create.. I just feel a little bit uneasy at times how we know about some children and we don't know about them all."*	6 / 218 – 232	Uneasy
	OR *"And unfortunately I think.. Sometimes, that it.. Kind of, then targets the same, kind of, families. It's the families that will ask for help that we all end up getting to see but it's actually the ones that don't feel they're able to or don't realise there's a problem and that don't tend to not be able to advocate for their child necessarily as well as somebody else might be which is just, umm, really*	6 / 246 – 252	Not able to advocate

	difficult. And that's just not the kind of model we want to.. But naturally I think that's what happens." *OR* *"And again, the inequity of some families who shout loudest and gets, versus some families who are in greatest need who don't gets and are quiet and don't know how to advocate, umm.. So, I would describe it.. Yeah, overwhelming and frustrating and.. You know, essentially for lots of the problems you can't.. You can't fix them? Because they're.. They're here for an hour appointment and often that's a Zoom at the moment, either as well, which is just even worse, umm.. And so, I guess we've, kind of, had to readdress what.. What the.. What the purpose is of.. Of.. Of.. What's our role in that clinic?"*	15 / 613 - 619	Inequity
The time in between	*"That will happen every three or six months, umm, and actually, you know, these children were very well supported on treatment and then they've got a five-year gap and then they're going into long-term follow-up clinic and they are just a mess! Umm.. You know, and.. And the families, have, you know, the community services have stopped, these children are in inappropriate schools with not the right, umm, educational healthcare plan in place, umm.. So, I think we need to change our model of.. Of working. Particularly because cancer treatment is changing. Well, it's changing now as we're speaking, but it has changed significantly over the last 5-10 years. More and more children are surviving with different, umm, presentations, umm, and we need to change our model of working to adapt with that. So, why are we waiting five years to see these children when actually probably seeing a year off treatment, umm, when – as I say – at the end of treatment some of these.. Some of the.. Some of the issues are present but not.. But not all. Umm.. And so actually there's sometimes bigger.. Bigger problems down the line."*	14 / 549 - 563	Just a mess
Not the end	*"I don't know if I really have a definite ending? And obviously the only.. The only definite ending for me*	18 – 19 / 739 - 761	Lifelong difficulties

	is, when sadly, when that, umm, the child umm.. Dies. So, that is the only really definite ending because I don't see an end of active treatment as an end? Because I know that what lies ahead for this child and family and actually there are.. There aren't that.. It's hard, because I guess, the families that we will always remember and get involved with are the ones that.. Who will have lifelong difficulties and I'm sure that there are families who will, kind of, go through treatment relatively unscathed and be able to.. You know, move on. With a relatively normal life and childhood. But, umm. There are also many many families that don't. And particularly when I look.. Particularly looking at children who've had a bone marrow transplants, umm.. They're.. Where you might see that - and I think some families do see – that they've had.. You know, I can think of children who have leukemia and they have treatment for three years, and then the leukemia comes back, and then they have more treatment, and they have relapse treatment, and they have that for another year, and then the leukemia comes back, and then they come in for a transplant, and this is gonna cure them.. This is what's gonna cure them! And these families come in with so much hope, and it may well cure them of their cancer diagnosis, but what they don't understand is that they've had to have so much treatment to cure them of their cancer, that actually it then causes so many more problems and these families are a bit like, umm.. Feel short-changed. It's like "You never told me it was gonna be like this"."		
It feels wrong	*"Yeah, I think so but I think it probably.. It kind of gets to like a crisis point. Where.. You know.. For example, how we, kind of, we're looking at the oncology, umm, clinic and trying to change.. The neuro-oncology, and trying to change that, is because we had, kind of, two or three patients in a short space of time that had been, what I perceived - I called them failed - umm, quite spectacularly, unnecessarily as well. And it felt like we were really… And I felt quite responsible for that even though, you know, as.. As one physio as part of a massive team you.. We can't take individual responsibility, but it seems such an unnecessary*	17 / 689 - 699	An unnecessary failure

	kind of failure. Umm.. And, you know, for.. For one the child, for example, it was just, umm.. <u>Complete</u> communication breakdown."		
The system we operate in	*"You know, some of these children, really complex children, don't have pediatricians, for example.. Just, just.. Crazy. Or, you know, getting them involved in transitional services, you know, to kids that are going up to.. Towards adult services and things like that. So, it's much more of a liaison post than.. Than I guess we, kind of, imagined it would be? Umm, and I guess the hope would be though that if you manage to change our way of working and we don't have a long-term follow up at five years and we have something a bit more proactive that you maybe wouldn't see this kind of extremeness of some children who have lots and some children who have nothing. And, you know, there are really some situations where, you know, as I say children are really failing in mainstream schools and it's just really quite unbelievable that nobody has picked up or been helping the family to advocate for children.. It's just.. And.. You know, I'm really aware as well that we're in a tertiary centre, at a [name of hospital] bubble sometimes, umm.. And we want the world for our children and we think that they deserve everything and it's just.. The fact is that there is limited resources so, you know.. It's just.. It can just be quite frustrating, umm.. Place I think."* *OR*	15 – 16 / 625 – 641	Children who have nothing
	"These children move from a neurosurgical ward here, to UCLH for radiotherapy, back to here to a different ward, to the States for something, to come back to community services in for.. You know, here back to.. You know, they are <u>all</u> over the place! And so, it's not surprising, umm, that's.. You know, that.. This child had a referral that had been done for the neurosurgical team here.. As far as they were concerned the child had been picked up.. Umm.. The community services said they'd picked him up and then the child went to the States, they missed their appointment, they came back.. So, it was just a logistical error but this child had	17 – 18 / 699 - 720	A disaster

	received no therapy for two years? Umm.. And the mum was kind of.. She didn't know that wasn't.. She knew everyone was busy and was stretched and, you know.. She was still undergoing treatment and, you know, she was seeing professionals, so you know.. Kind of, thought well, you know.. Anyway, it was just a bit of a disaster. And there were.. I think then we got three patients for, kind of, similar stories in a short space of time and then you, kind of, then react and think.. This isn't.. Okay, and then you try and make changes but then fatigue, kind of, sets in and then you're, kind of, battling because we need to do this and it's quite organizationally quite difficult and it involves lots of different people and.. Then I guess different priorities set in and then it has to wait for something else to happen again.. So, it feels.. Sometimes it feels a bit cyclical, like we're talking about the same thing and the same things are happening and how do you make it better.."		
Something specious			
Cancer bell, never rung	*"I'm quite interested in.. About, umm.. The ringing of the bell. Because umm.. For lots of families umm.. That umm.. Signifies lots of very positive things but actually I've experienced not a lot of positives? Umm.. The, kind of, more negative side of it actually? And so I've actually spoken to X (name of PI) a few times, umm.. About, umm.. Why that was introduced and how such a big thing was introduced without really any kind umm, of discussion? It just suddenly appeared on the ward one day? With a very, very well meaning intent, umm.. But we have lots of families who will never be able to reach that point in treatment? Umm.. And it just signifies, umm.. Lots of difficulties for some families and we've seen that very visually on the ward a few times in the last few years? Umm.. And I just have very mixed feelings about the use of it, umm, on the ward."*	1 / 14 - 25	Negative side
The mourning bell	*"I remember a.. Patient on Elephant ward who, umm.. Who.. Who passed away on Elephant ward.*	24 / 962 - 982	Harrowing

	And he had a type of leukemia and he never got to ring the bell. And he was an inpatient for quite a long time? And so both him and his mum and family had witnessed people ring the bell for a long time. And when he died on the ward it was.. Got.. It got quite conflictual towards the end, as generally things tend to these days.. A family wanting more treatment and it wasn't in the child's best interest and more treatment, and more treatment.. And mum was finding very difficult to find that there was no more treatment left to try. And he sadly passed away on the ward. And.. You know, that noise of - I don't know if you've personally heard it - but the, umm.. When fam.. When.. Particularly mums.. The noise of grief.. That.. Just, kind of, raw grief. Is just so.. The kind of inner.. Ahh.. It's just the most horrendous noise. But she ran out of the room after he died and she just hung onto this bell and was just ringing it and ringing it and ringing it. And everyone was just, kind of, coming out of their rooms to see if somebody's ringing the bell and there's this grief stricken woman.. Was just ringing this bell in quite a, kind of, mad.. It was just.. It was just horrific to watch really. And be part of.. You just think.. I just think.. I don't know how much that bell has had to play a part in.. In all of this.. Or, you know, how much that's, kind of, really got her that he was never able to do it or she was signifying that he'd left this kind of wo.. I don't know what the purpose was but it was.. It was quite harrowing."		
An important focus	*"So, yeah, the bell is really interesting because for some families and some children it's a really important focus. Like, so things are really, really difficult at the end but, you know, "Remember that bell" and "Remember you saw so and so ring the bell" and blah blah blah.. It's.. And I think that.. It definitely has a place […]"*	20 / 830 - 834	Remember that bell
Off the ward	*"I don't think.. I personally – this is a very personal opinion – umm.. I think that the bell on an inpatient ward is not the right place for it to be. And I.. And I think that you know.. Also because of Covid it's been a really positive thing – so the bell is now portable and the bell gets taken out of the hospital*	20 – 21 / 834 - 850	Not the right place to be

	and anyone who wants to go and watch that bell can.. […]. But they are not enforced to.. To have to listen to that bell. Because I've been on the wards where a family.. Umm.. You know, in good and bad situations.. So, you know, a child has reached the end of treatment and for them it's very, very special and they've got presents and there's lots of people around and it's really, really positive.. But literally two rooms down you've got a family who've just been given a, you know, very devastating diagnosis with no chance of cure and I've literally seen them, like, sobbing in the rooms and having to shut curtains so that they.. They can't hear that."		
Conflicted about the bell	*"D'you know what? I don't know! I don't know! I just remember it going up? And everyone was like "What a great idea!". And I.. I have to admit when I first saw it.. It went up a similar time as we did Beads for Courage.. It arrived.. 'Cause I think actually the two – Beads of Courage and the lady who set up the bell – might have been in contact with each other, I think. But essentially arrived at the same time. And they were both received massively positively and I have to say, when I saw it I was like "This is amazing!" like this is, you know, really really positive. And then obviously, as time goes on and you get to see the kind of the.. Not so positive sides of it or how it can affect, umm, families and children, I was a bit like, how did we just let this..? Like.. What's the research behind this? What do families and patients actually want? Do they want it? Or is it just something that they, kind of, have to do? That's just what.. You get to ring the end of treatment bell, there is.. Almost there isn't a choice! It's just "Yeah! You're ringing the end of treatment bell!". I don't know how much choice families feel they actually have in doing it to be honest."*	22 / 904 - 919	Do they want it?
The post-treatment journey			
Impact of hospitalisation	*"So, we've got specific referral criteria. So, there were some.. So, for example, we now routinely see*	3 / 112 - 117	Huge impact

	all children under the age of 1, which I know is quite similar to psychology as well – or try to – umm.. And that's just because, umm.. It's such a huge part of their development and so if they're in hospital for long periods of time then it can have a huge impact on their global development."		
Loss of support overnight	*"And actually they are quite well looked after whilst their treatment is occurring and then end of treatment occurs and they finish and then this huge support network that this family have become very used to having and the child, essentially disappears over night? And that kind of safety bubble of.. Of people to go to and talk to and have questions about, umm.. Disappears? Umm.. And also I think for some families they really think that that treatment has finished now, we go back to normal life and that, kind of, isn't the case for lots of families who had quite life changing diagnoses and treatments. And I'm not entirely sure.. We have end of treatment days and.. And that has certainly improved things, but the feedback we get from families is that at the end of treatment days they actually wish that they'd received a lot of the information that we give them at the end of treatment at the beginning of treatment?"*	1 – 2 / 31 - 43	Disappears overnight
Specialist physio			
A positive role	*"You know, we're very fortunate in physio that we can often, we have a very positive role to play in.. In a child's cancer journey and often we're.. You know, even when other medical, umm, you know, or other healthcare professionals are having real difficulties with families, we very rarely.. We're very fortunate that we rarely experience that in physio? Because we bring a very positive side and it's generally something families want to do and their child generally, most of the time, wants to to reach their goals? So, we don't really have a lot of, umm.. Conflict or sadness really so, umm.. We're quite.. We're quite – well we are – I think we're quite protected in a way compared to how the nurses sometimes are. Umm, and also really aware that*	29 – 30 / 1202 - 1220	A very positive side

	we come and go quite a lot as well, whereas some of the other, you know, nurses who are there for, kind of, 12 hours just looking after families and children is.. Is much more difficult. […] But generally we have a very positive, most of the time, impact."		
Early intervention	*"And actually what we've moved now to a model of seeing them at the very beginning and seeing if we can then through education and experience try and prevent some of those problems? And it's had a really positive, umm, impact but that.. You know, we were really fortunate after a long battle of getting more staff we were able to be a bit.. We were able to move to a model of doing a bit more proactive work rather than this constant reactive, umm.. Kind of fire fighting of patients, and we're now probably gonna try and do that with a different population – the children with ALL, Acute Lymphoblastic Leukemia - which is the most common type of childhood cancer, umm.. Because we.. Umm, there are so many of them umm.. And we all seem to be getting referred these children at very similar time points. So, we want to try and get in there beforehand and educate families and CNSs and doctors about, you know, how they will go with their activity and mobility through treatment just to see if we can try and prevent again what tends to be happening, this kind of reactive, umm.. Referrals."*	5 – 6 / 198 - 212	Proactive work