

**Endings in paediatric cancer treatment: A qualitative analysis of children's
perspectives.**

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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

Advancements in paediatric oncology and subsequent increased survival rates have made life after cancer increasingly clinically important. The following thesis aimed to explore children and young people's (CYP) experiences of ending their cancer treatment. It sat alongside two further DClInPsy theses, exploring endings in paediatric cancer treatment for parents and staff respectively.

Part 1 describes a systematic review, synthesising literature on CYP's experiences of ending cancer treatment. Sixteen qualitative studies were included and analysed using thematic synthesis. Themes included '*the continuity of cancer*', '*ambivalence of needs*', '*the end as a marker of making sense of the experience*' and '*the sense of self following the ending*'. Findings highlight the complexity of endings, suggesting increased thought needs to be placed on managing such endings.

Part 2 describes an Interpretative Phenomenological Analysis of children's experiences and meaning-making of the end of their cancer treatment, with a focus on how endings have been marked, including ringing the end of treatment bell. Seven children took part in semi-structured interviews. Identified themes were '*the omnipresent end*', '*the punctuation of endings*', '*that which is remembered, that which is forgotten*', '*the voiced and the unvoiced*', and '*freedom from cancer*'. Findings highlighted the importance of celebrating the end of treatment in considered ways, allowing children to understand and process their experiences.

Part 3 describes a reflection on issues pertinent to conducting the research. Within this, personal assumptions brought into the research, interpreting children's voices, and the silence of cancer are discussed.

Impact Statement

The current study sits within a paediatric psychological preventative health model (PPPHM; Kazak et al., 2015), a framework that aims to identify psychosocial need and reduce harm that result from serious childhood illnesses, including cancer. It promotes the view that across treatment, all parts of service delivery need to be provided with the aim of facilitating and optimising psychological wellbeing for children. With increasing numbers of children reaching the end of their cancer treatment, this study aimed to increase the understanding around a significant point in the treatment pathway, namely ending cancer treatment, which currently remains largely under-researched. It is hoped that the outcomes from each part of the thesis will inform service delivery in providing considered endings, which may reduce distress and improve outcomes for children who have been treated for cancer.

Part one generated insight into the emotional complexity children and young people face when ending their cancer treatment as well as the ambivalence around their identity and their own need that follows. The findings further demonstrate a need for services to provide clearer communication around the practical, physical and emotional implications of ending cancer treatment. Furthermore, the findings challenge the current construction of the end of treatment as final, and suggest services may need to consider alternate ways of constructing the end and managing cancer care that reflects the continuity of cancer described by young people in the paper.

Part two emphasises the importance of punctuating and celebrating the end of treatment for children, whilst equally helping them understand, process and find the space to voice their experiences of the end. Within this, the findings suggest increased thought needs to be placed around the practice of ringing the bell that currently often marks the end of treatment, including its positioning within the ward and how the bell ceremony is performed.

Taken together, these findings imply that children are currently left with the emotional burden of ending cancer treatment. They therefore highlight the need for practice changes in

order to scaffold and support children and families with the emotional complexity of the end. It is hoped that attending to the end in this way may make transitioning from cancer treatment easier and ultimately contribute to children's emotional wellbeing, as well as having positive impacts on long-term engagement with services.

Contributing to the current research base around endings in paediatric medical treatment, and the use of the end of treatment bell specifically, it is hoped that the dissemination of these findings will facilitate discourse about cancer management and service provision, in order to consider redeveloping practices of ending medical treatment. However, importantly, these conversations and reconsiderations cannot be held without the children and families completing the treatment.

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Part 1. Review Paper

The continuity of cancer. Children and adolescent's experiences of the end of cancer treatment: A systematic review.

Abstract

As the research and treatment of childhood cancer steadily progresses, so has the interest in children's needs, not only throughout such treatment, but also following completion. Whilst there is increased literature focusing on the long-term psychosocial impact of treatment completion, little is currently known about how children and young people (CYP) experience the more immediate end of their cancer treatment. **Aim:** The current review seeks to examine CYP's experiences of the end of their cancer treatment. **Method.** Sixteen studies were retrieved using a systematic search strategy across five databases, all of which used qualitative methodology. Thematic synthesis was chosen to analyse the data. **Results.** Four overarching themes were generated, which encompassed '*the continuity of cancer*', '*ambivalence of needs*', '*the end as a marker of making sense of the experience*' and '*sense of self following the ending*'. **Conclusions.** The end of treatment is a time of complexity for CYP, yet it is currently largely overlooked. In order to scaffold these endings for CYP, increased emphasis and thought needs to be placed on the end of treatment and the support that is provided within it.

Introduction

Around the world, cancer is the principle cause of death for children and young people (CYP), with approximately 300,000 young people receiving a diagnosis each year (Steliarova-Foucher et al., 2017). However, within high-income countries, significant progress in cancer research and treatment has meant that survival rates have improved substantially over time, resulting in approximately 80% of children surviving cancer (World Health Organisation, 2021).

CYP and their families' cancer journeys are marked by several key milestones, which – following a cancer diagnosis – often include commencement of treatment, completion of treatment, entry into long-term follow-up care and exit from specialised oncology into primary healthcare settings (Nathan et al., 2011). This journey may not be linear and young people may move between such milestones, with some facing a final transition into palliative or end-of-life care. Therefore, rather than merely moving between binary notions of sickness and health (or death), the cancer journey unfolds along a continuum, with CYP and their families facing several transitions and distinct challenges at each turn (Lea et al., 2018).

Much has been researched and written about CYP and their families' experiences immediately following diagnosis and whilst undergoing treatment (e.g. Jibb et al., 2018; Long & Marsland, 2011). The progression into long-term survivorship, however, has shifted the focus away from being solely on diagnosis and treatment, leading to the recognition that needs extend beyond treatment completion. Whilst the literature in this area is steadily growing, large parts of such research focus on the long-term psychosocial impact of CYP surviving cancer (see the following reviews for long-term survivors and quality of life – Cantrell 2011; Macartney et al., 2014; cancer identity – Cheung & Delfabbro, 2016; post-traumatic growth – Duran, 2013; and mental health – Friend et al., 2018). Consequent to their findings, highlighting in part the negative physical and psychosocial sequelae of cancer treatment, long-term follow-up (LTFU) clinics have been set up across the world to continuously support CYP and their families beyond

cancer treatment. However, comparatively less is known about the end of cancer treatment itself as well as CYP's experiences surrounding it.

End of cancer treatment

The end of active cancer treatment is a major milestone in and of itself. Once the cancer is seen to have subsided or where no further treatment options remain, treatment is ceased and/or chemotherapy is stopped (Children's Cancer and Leukaemia Group, 2014). The central line or port through which chemotherapy was administered is removed under general anaesthetic. The time point of this varies; however it is aimed to be removed as soon as possible following treatment. For CYP in remission, visits to the clinic continue, in order to monitor for signs of cancer recurrence and later for long-term side effects of treatment. Such visits commonly occur every 4-6 weeks following the end of treatment, with the length between visits increasing as time goes by. Once five years without cancer recurrence is reached, CYP continue to be seen once a year for a further number of years (Children's Cancer and Leukaemia Group, 2014). Whilst active treatment may be completed, often leading to the end as being constructed as somewhat 'final', the involvement and process of clinical care continues, therefore blurring the meaning of the end.

The end of treatment is further characterised by a shift away from monitoring illness and treatment and the active fight against cancer, towards an increased focus on general health and wellbeing, along with its maintenance (Lea et al., 2018; Nathan et al., 2011). To date, much of the current literature reports the experiences and concerns of parents, or of adult survivors at this point in their cancer journey (Brauer et al., 2017; McLoone et al., 2011). Described as a time of contradiction, it has been associated with a range of psychosocial reactions including post-traumatic growth and relief attributed to the end of both invasive treatment and disruption to ordinary life, alongside emotional distress, fears of cancer recurrence and the renegotiation of 'normality' (e.g. Labay et al., 2004; McKenzie & Curle, 2012).

The more limited literature base focusing on young people's (often including young adults') own experiences following their cancer treatment further brings together paradoxical feelings at the end (Wakefield et al., 2010), and has shown similar accounts of psychosocial hardiness, met with uncertainty and felt vulnerability following treatment (Fern et al., 2013; Thompson et al., 2009). However, how the ending is understood by CYP and the meaning it therefore carries is currently left unheard. Considering the emotional demand of the end of treatment, alongside the current unclear meaning of the end, increased attention may need to be given to this time point within CYP's cancer experience. Whilst most research to date has focused on the understanding of the psychosocial impact of completing cancer treatment and the experiences that follow for young people, there is currently no such synthesis to further the understanding of the experience of the ending itself.

Aims

The current systematic review aims to synthesise and express a range of views held by CYP concerning the end of their cancer treatment, thereby focusing on developing current understandings around and perceived management of this end. It is hoped that attending to this may inform how services can assist CYP on their cancer journey, no matter which pathway they have and will continue to travel.

Method

A systematic review following PRISMA guidelines (Moher et al., 2009) was conducted between September 2019 and May 2020 (PROSPERO Registration Number: CRD42020182092)

Inclusion and exclusion criteria

Studies were included if they (a) reported on experiences of CYP aged 0-18 at the time of research. Studies involving a wider age population (i.e 18+) were also included if the overall

sample included younger ages; (b) focused on the end of cancer treatment. Studies that focused on wider timelines (e.g. long-term survivorship), yet reported separately on the end of treatment phase were included; and (c) reported on primary data. Whilst inclusion criteria at the point of the search did not specify any particular methodological approach, it should be noted that the focus on CYP's subjective experiences lent itself more strongly to qualitative research designs. Indeed, once included papers were finalised, the resulting papers were largely qualitative in methodology, with only one having a mixed methods design. As such, it was decided to only focus on the qualitative content.

Studies were excluded if they (a) did not report specifically on the end of cancer treatment, instead focusing on the cancer journey more broadly; (b) focused on adjustment following treatment only; (c) provided adult accounts of their previous childhood cancer experiences; (d) provided parental accounts of the end of their child's cancer treatment only; and (e) focused on medical reports at the of end of treatment only.

Search strategy

Relevant literature was identified through electronic searches of Embase, PsycInfo, Medline, CINHAlPlus, and Emcare. Limits were set to English language only. No further restrictions applied. Following several scoping searches, search terms relating to 'cancer', 'children and young people', 'end of treatment', 'experiences' and 'psychology' were combined. These were purposefully broad and inclusive to maximise retrieval of relevant studies as, based on the scoping searches, it was anticipated that retrieval of final papers would be relatively low. A full list of search terms is presented in Appendix A. Titles of articles were screened for relevance followed by an abstract review to identify studies to be accessed in full. If the outcome of the abstract review remained unclear, the study was retrieved in full. Full texts were assessed to verify eligibility according to the above criteria. A subset of abstracts (10%) and full texts (30%) were screened by a second independent reviewer (GG), resulting in inter-rater reliability of $k=0.88$ (almost perfect agreement, 94%) and $k=0.52$ (moderate

agreement, 80%) respectively (Landris & Koch, 1977). Discrepancies were resolved by discussion. Supplementary to electronic searches, reference lists of all included studies were hand-screened for further papers.

Quality assessment

Qualitative research covers a multitude of approaches as well as reflecting a plurality of epistemological positions. The idiosyncratic and inherently subjective nature of analyses further complicates assessing the quality of interpretations made (Dixon-Woods, 2004). As such, quality appraisals of qualitative research have prompted much controversy and a lack of consensus concerning procedures continues (Cohen & Crabtree, 2007; Dixon-Woods et al. 2007). Nonetheless, arguing that quality should be appraised to avoid inferring unreliable conclusions, the qualitative Critical Appraisal Skills Programme Checklist (CASP-QC, 2018) was chosen to assess studies meeting inclusion criteria (see Appendix B) and was used as a framework to flexibly guide the assessment process, whilst fitting various epistemological stances. As the CASP-QC focuses largely on adult populations, it was modified to include questions around the appropriateness for qualitative research with children. Each domain was rated as ‘no features present’ (0), ‘some features present’ (1), ‘most features present’ (2), or ‘not relevant’, following which total scores were divided by the number of relevant domains (see p. 26 for breakdown of scores). Half of the articles were independently rated by a second rater (GG). Accuracy and mutual agreement was reached by discussion. Rather than excluding papers based on a quality rating, the CASP-QC was used to allow for the weighting of individual papers as well as the exploration of their relative contributions to the synthesis as a whole. Following the quality analysis, a sensitivity analysis was conducted to re-analyse the data with the exclusion of studies rated as low in overall quality (<1), in order to ensure they had sufficient conceptual richness to add to the synthesis.

Data extraction

The following data was extracted from included studies: publication year, study design, methodology including method of analysis, country of study, participant demographics (age, ethnicity), clinical characteristics (cancer type, time since treatment completion), exclusion and dropouts, and outcomes (see Table 1). To keep consistency and to compare findings, half of the studies were randomly sampled to be double-extracted (GG).

Analysis

Various methods have been suggested in order to synthesise qualitative research, each underpinned by the question under review as well as its own epistemological position. Such syntheses include meta-ethnographies (Campbell et al., 2011), meta-syntheses (Paterson et al., 2001) and thematic syntheses (Thomas & Harden, 2008). A thematic synthesis approach was selected for the following review, aligning itself with the author's epistemological stance of critical realism – namely the idea that reality is mediated by an individual's perceptions and beliefs. Further, being originally developed out of necessity to compose reviews addressing intervention need, as well as appropriateness and acceptability of such interventions, thematic synthesis views itself as yielding outputs which can directly inform policy and practice (Barnett-Page & Thomas, 2009). This was seen to encapsulate experiences of the end of cancer treatment and its subsequent impact on how services can manage such endings. Further, this synthesis was chosen to go beyond summarising the content of primary studies, instead allowing for the generation of new concepts according to the question under review, whilst also allowing to appraise the quality of papers within its framework.

Reviewing papers in chronological order beginning with the oldest publication, the following phases of analysis, as described by Thomas & Harden (2008) were utilized: (1) initial line-by-line coding of results relating to experiences specifically around the end of treatment, followed by the re-reading of texts and the 'translating' of concepts across studies; (2) configuration of codes into broader level descriptive themes; and (3) construction of

overarching analytical themes. This allowed new themes to be generated, alongside the elaboration of themes identified in primary papers. Study findings were defined as any text labelled ‘results’ or ‘findings’ within primary studies, including quotations. Once generated, the themes were reviewed and finalised with the supervisors (KS, RS). NVivo 12-Pro software was used to enhance data management and analysis.

Author’s background and preconceptions

The following analysis needs to be understood within the context of the author’s own experiences and perceptions, which inevitably contribute to the process of making sense of the data. As a trainee clinical psychologist, the author is very much drawn to understand experiences through a psychological lens – with an interest of how meaning is given to experiences and what stories are privileged within the broader cultures and societies we live in. Whilst guided by clinical psychologists in the field of paediatric psychology, the author had no prior experience of working within paediatric health settings. Though not having experienced many health-related endings themselves, the author experienced multiple other endings within childhood which they perceived to be abrupt and out of their control, leaving them often finding endings and change difficult. Although attending to their own preconceptions and assumptions around endings and of a bias of drawing attention to psychology, it is likely for these to be reflected within the themes, just as it is likely that a researcher from another discipline or profession may have identified different, yet equally valid themes.

Results

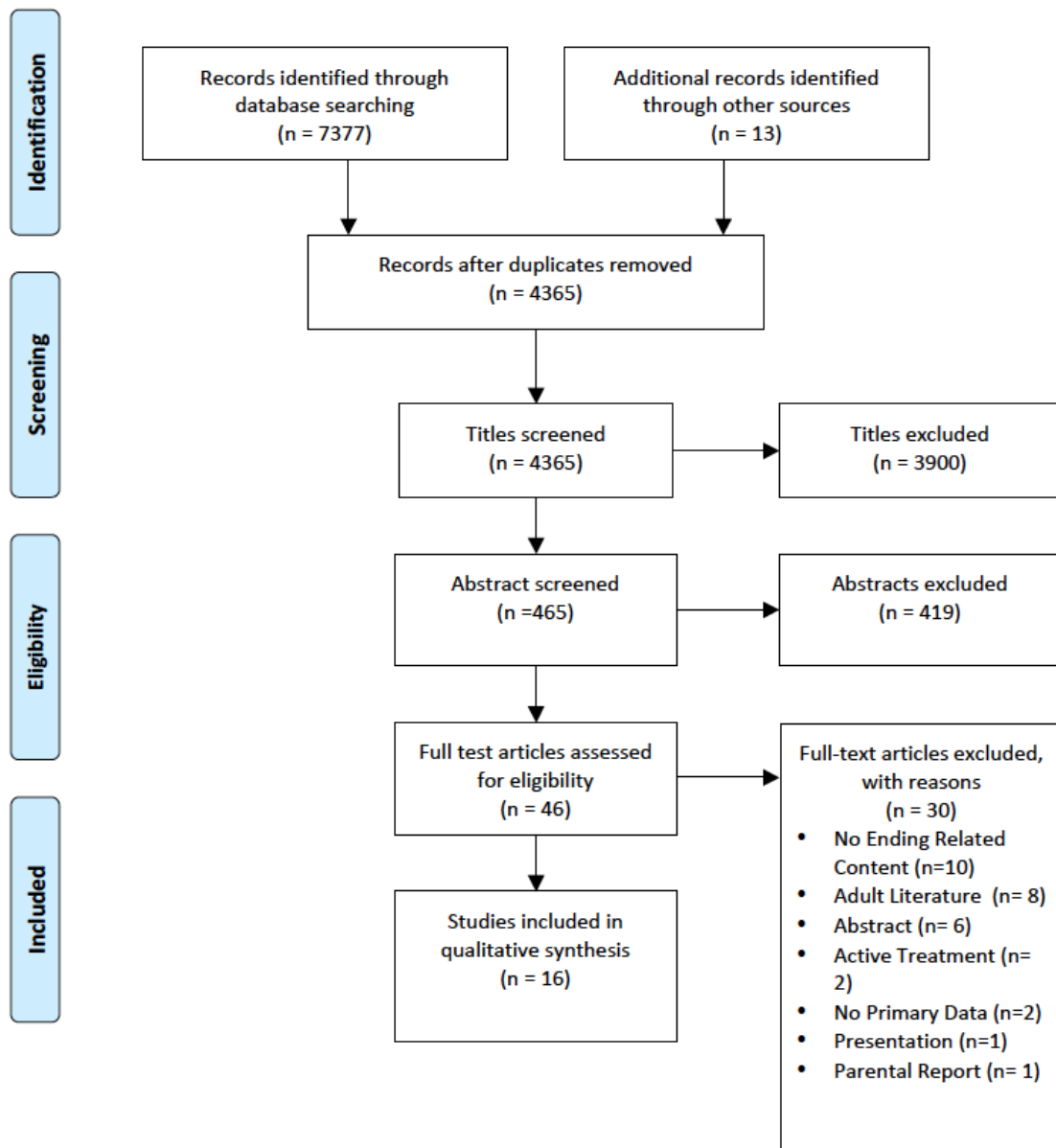
Overview of results

The search retrieved 4365 articles. Titles followed by abstracts were read and reviewed against the inclusion/exclusion criteria, yielding 46 eligible articles. As the search terms were kept quite broad, most papers at this stage were excluded due to reporting on medical literature or the long-term effects of cancer treatment, rather than expressing CYP’s subjective

experiences of the end of their treatment. The reference lists of all 46 papers were hand-searched for further papers. After reading the 46 eligible articles in full, 30 were further excluded on the basis of lacking ending related content, reflecting adult voices only, and having been conducted during active cancer treatment, as well as reporting on secondary data or representing presentations and abstracts only. The final review included 16 articles (see Figure 1. for selection process).

Figure 1

Flow Diagram of Search Strategy



Description of reviewed studies

Sixteen studies reporting on the experiences of 217 CYP with various types of cancers were included in the review. Three of these studies further reported on experiences of families alongside those of the CYP. Two studies directly explored children’s perspectives of experiencing the end of their treatment itself, whereas all other studies featured the ending of treatment within broader discussions around experiences that closely followed treatment completion. These included exploring CYP’s adaptation processes and transitions following

treatment, their post-treatment needs, coping strategies and sense of identity, as well as end of treatment information provision and survivorship care delivery.

The ages of CYP ranged from four to twenty-five, with one study looking specifically at younger ages (8-13years), three studies at adolescents (14-17years), three studies at adolescents and young adults (14-25years) and eight across ages (4-22years, however, most clustering around adolescence). One study gave an average age of 20.6 years. Where results were reported separately by age group (n=8), only the results of those under age 18 were considered. Time since treatment completion ranged from two months to thirteen years. Three studies did not report on time since completion. Fifteen studies reported on qualitative findings, one used a mixed-methods design. Across studies, the chosen methodologies included individual interviews (n=12), focus groups (n=3) and written accounts (n=1), which were analysed using various frameworks. Studies were conducted across several countries, most of which were anglocentric (n=13). Key characteristics and details of the included studies can be found in Table 1.

Table 1.

Key characteristics of articles included in the review.

First author	Code	Year	Aim	Data collection & analysis	N	Country	Demographics	Cancer type	Time since treatment	Exclusion
An	A	2019	To investigate the experience and adaptation process of adolescent and young adult leukaemia survivors during their return to social life in the sociocultural context of Korea	SSI, GT	14	Korea	Age: 14-22 Gender: 11 female, 3 male	ALL, AML, CML	0.2-7 years	Not provided
Ander	An	2018	To provide an in-depth exploration of cancer-related psychological distress experienced by young survivors of cancer during adolescence reporting a need for psychological support	SSI, CA	10	Sweden	Age: 15-25 Gender: 4 female, 6 male	Leu-U, CNST, Lym-U, STS, other malignancy	1-8 years	On going psychotherapy; severe psychiatric symptoms
Björk	B	2011	To illuminate the families' lived experience after completing a child's cancer treatment	SSI, HP	4*	Sweden	Age: 8-13	Leu-U, ST, BT	2-11 months	Chronic complications; awaiting further decisions re treatment
Duffey-Lindt	DL	2006	To identify and describe the experiences of adolescent cancer survivors from the completion of therapy to the first few years off of therapy	FG, CA	4*	US	Age: 14-16	ST	1-5 years	Not provided
Firth	F	2013	To investigate views of childhood cancer survivors on the provision and format of a treatment summary	SSI, analysis unknown	24	UK	Age: 4-22	ALL, AML, extra cranial malignancy, CNST	0.5-13 years	Non-survivors
Haase	H	1994	To explore the child's perspective of experiencing completion of cancer treatment	SSI, PA	7	US	Age: 5-18 Ethnicity: 5 Caucasian, 2 Hispanic	Leu-U, Sar-U, Lym-U	4-12 months	English not first language
Jones	J	2011	To provide a descriptive analysis of the ways that adolescent cancer survivors develop their identity post treatment and understand how survivors seek support, respond to their health and transition to survivorship after facing cancer	SSI, CCM	12	US	Age: 12-20 Gender: 7 female, 5 male Ethnicity: 9 White, 2 Hispanic, 1 African American	Not provided	Not provided	Not provided
Lopez	L	2014	To gain an in-depth understanding of the adolescent cancer survivors' individual perceptions and the meanings they assigned to the transition to early survivorship	SSI, TOS	8	US	Age: 14-17 Gender: 3 female, 5 male Ethnicity: All Caucasian	ALL, AML, BL, HL	6 months -3 years	History of relapse; BT; English not first language
Palmer	Pa	1997	To explore the experiences of adolescent cancer patients and identify areas of unmet physical, psychological and social need	FG, GT	6	Australia	Age: 20.6 (mean)	HL, NHL, M, BT, ES, STS	3 years (mean)	Not provided
Perez	Pe	2019	To describe a young man's personal experience moving from treatment to survivorship	Case study	1	US	Age: Young adult	Not provided	Not provided	N/A
Psihogios	Ps	2019	To elucidate adolescent and young adult experiences and preferences for survivorship care delivery	FG, CA	14	US	Age: 15-25 Gender: 4 female, 4 male Ethnicity: 100% non Hispanic, 75% White/Caucasian Engaged in LTFU: 8 Not engaged in LTFU: 6	Leu-U, Lym-U, ST	0.9-2.8 years (engaged in LTFU) 12-26 years (not engaged in LTFU)	Not provided
Wakefield	Wa1	2013	To explore the perceptions of adolescents and young adults who had recently completed treatment in terms of satisfaction and unmet need for medical and emotional support after cancer treatment	SSI, M&H	19	Australia	Age: 12-20	ALL, AML, CML, HL, NHL, ES, OS, GCT	5.4-66.9 months	History of relapse
Wakefield	Wa2	2012	To investigate experiences of young cancer survivors in receiving information in the first year after treatment	SSI, M&H	19	Australia	Age: 12-20	ALL, AML, CML, CNST, WT, HL, ES, GCT, OS RS, NHL,	1.9.27.7 months	Not provided

								GCT, OS RS, NHL, H		
Walker	Wal	2019	To describe the experience of adolescents in the first year after completing chemotherapy and/or radiation, incl. challenges they faces as they attempt to return to their lives ad adolescents	SSI, GT	29	US	Age: 12-18 Gender: 62% male Ethnicity: 81% White	HL, ES, OS, ALL; AML, NHL, TC	Mean: 5.6 months (SD: 4)	BT; neuropsychiatry/cognitive rehabilitation; hematopoietic cell transplants; surgical resection only; English not first language
Weekes	We	1994	To explore and describe adolescents' experiences and associated changes in coping strategies 6 months after completion	SSI, CCM	13	US	Age: 11-18 Ethnicity: 95% White	ALL, ES, OS, RS	6 months	Developmental disability; history of relapse
Woodgate	Wo	2006	To describe how childhood cancer shapes a child's way of life as depicted in the narratives they construct	SSI, NA	39	Canada	Age: 4.5-18	Leu-U, Lym-U	Not provided	Not described

KEY: *Overall sample include parents, siblings and/ or healthcare professionals. However, not included in given N and their voices not included in current review; **ALL:** Acute Lymphoid Leukaemia; **AML:** Acute Myeloid Leukaemia; **BL:** Burkitt lymphoma; **BT:** Brain Tumour; **CA:** Content Analysis; **CCM:** Constant Comparative Method; **CML:** Chronic Myeloid Leukaemia; **CNS:** Central Nervous System Tumour; **ES:** Ewing Sarcoma; **FG:** Focus Group; **GCT:** Germ Cell Tumour; **GT:** Grounded Theory; **H:** Hepatoblastoma; **HL:** Hodgkin Lymphoma; **HP:** Hermeneutical Phenomenology; **Leu-U:** Leukaemia unspecified; **LTFU:** Long Term Follow Up; **Lym-U:** Lymphoma unspecified; **M:** Melanoma; **M&H:** Miles & Huberman's conceptual framework; **NA:** Narrative Analysis; **NHL:** Non-Hodgkin Lymphoma; **OS:** Osteosarcoma; **PA:** Phenomenological Approach; **RS:** Rhabdomyosarcoma; **Sar-U:** Sarcoma unspecified; **SSI:** Semi-structured Interview; **ST:** Solid Tumour; **STS:** Soft Tissue Sarcoma; **TC:** Testicular Cancer; **TOS:** Template Organising Style; **US:** United States; **UK:** United Kingdom; **WT:** Wilms' Tumour

Quality assessment

Quality ratings ranged from 0.6 to 1.7 out of 2. An overview of the quality assessment can be found in Table 2. Of note, whilst the choice of qualitative methodology was appropriately discussed in the majority of papers, most papers did not describe whether the methodology was adapted to child populations. Only two papers specifically described such adaptations (Haase & Rostad, 1994; Woodgate, 2006). Studies represented a wide range of cancers diagnoses, treatments, and experiences. However, the demographic make-up of samples was not sufficiently reported in 10 papers, often only including age and/or gender (An & Lee, 2019; Ander et al., 2018; Björk et al., 2011; Duffey-Lindt et al., 2006; Firth et al., 2013; Palmer et al., 2007; Perez & Greenzang, 2019; Wakefield et al., 2012; Wakefield et al., 2013; Woodgate, 2006).

A position of particular interest within evaluating qualitative findings is the space that is afforded to subjectivity within such findings (Madill et al., 2000). Despite reflexivity being considered a cornerstone of qualitative research, none of the authors explicitly stated nor acknowledged their positioning with view to their research. Further, exploring inter-subjective meanings – for completeness of analysis rather than convergence – has been encouraged. All but three analyses were conducted by more than one researcher, either in part (Wakefield et al., 2012; Wakefield et al. 2013; Walker et al., 2019) or in full (Ander et al., 2018; Björk et al., 2011; Duffey-Lindt et al., 2006; Haase & Rostad, 1994; Jones et al., 2011; Lopez et al., 2014; Palmer et al., 2007; Psihogios et al., 2019; Weekes & Kagan, 1994).

To improve the quality of qualitative research, researchers are often encouraged to report findings that appear to contradict emergent explanations (Mays & Pope, 2000). All but three studies (An & Lee, 2019; Björk et al. 2011; Duffey-Lindt et al., 2006) presented contradictory data from CYP's experiences. All studies provided sufficient information in terms of quotations to facilitate the determination of whether interpretations and themes were

supported by the data. Of further importance within qualitative research is the use of credibility checks, namely sharing the findings with the research participants in order for them to validate them. Credibility checks were conducted within three studies (Lopez et al., 2014; Haase & Rostadt, 1994; Woodgate, 2006), whilst a further two validated their findings against the opinions of expert clinicians (Björk et al., 2011; Weekes & Kagan, 1994).

Table 2

Quality assessment ratings across studies

	A	An	B	DL	F	H	J	L	Pa	Pe	Ps	Wa1	Wa2	Wal	We	Wo
Aim	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Qualitative methodology	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Child considerations	○	●	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Design	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Recruitment	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Data collection	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Relationship	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Ethical issues	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Analysis	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Findings	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○
Total	1.4	1.7	1.3	1.2	0.6	1.6	1.3	1.6	1.2	0.8	1.7	1.3	1.2	1.3	1.4	1.6

Key: ○ no features present / unknown (0); ○ some features present (1); ○ most features present (2) ● not applicable

Thematic Synthesis

A thematic synthesis of the research generated four overarching analytical themes, each with a subset of descriptive themes – a summary of which can be found in Table 3 along with their patterns of occurrence. Supporting quotes from primary papers are presented in italics

throughout; direct quotes from participants within papers are written in apostrophes (‘) and marked with an asterisk (*). Superfluous material within quotations has been replaced with an ellipsis (...).

Table 3

Overarching themes and their patterned occurrence.

Overarching Analytical Theme	Descriptive Theme	A	An	B	DL	F	H	J	L	Pa	Pe	Ps	Wa1	Wa2	Wal	We	Wo	
Continuity of cancer experience	Definition of ending																	
	Inescapability of cancer																	
	Reminders	Of cancer treatment																
		Of treatment completion																
	Fear of recurrence																	
	Others misperceiving ending																	
Ambivalence of needs	Lack of clarity / explanation																	
	Communication of information																	
	Need for support	Support following treatment																
		Accessing support																
Felt responsibility																		
The end as a marker of making sense of cancer experience	Revisiting cancer experiences																	
	Survivors guilt																	
	Loss																	
	Conflicting emotions	Variety of emotions																
		Difficulty understanding emotions																
Sense of self following ending	Defined by cancer																	
	Change in focus away from cancer																	
	Patient vs. survivor/ sickness vs. health																	
	Findings the words																	

1. Continuity of cancer

Participants within all papers bar one reflected on the continuity of their cancer experiences. Within this, difficulties of defining the end of treatment became apparent, alongside a felt inescapability of cancer, reminders, fear of recurrence, and others’

misperceiving endings. All in all, the end was described as embedded within the broader cancer experience.

1.1. Definition of ending. Many CYP reported feeling left with an undefined ending and uncertainty of what such an ending truly meant. For some, the end was defined as moving forward into a new life or returning to an old life, rather than being framed as an ending. For others, it was a more clearly marked end.

Adolescents described this shift to early survivorship in a variety of ways, including: 'closing a chapter and moving on,' 'moving on to the next stage,' 'stepping back into the story or page of a book,' and 'continuation of the journey'. (Lopez et al., 2014)

Many papers characterised the ending as a transition. Participants within one paper, however, felt that such label was inappropriate as a transition signified a larger change than what they perceived the end of their treatment to be. Others spoke of the ending in more definite terms. Implicit in such narratives was a feeling of disbelief that the treatment had indeed come to an end. Within this, a small number of CYP described ways of marking the end including celebrations or ward parties. The timing, nature and extent of such celebrations was built on the certainty that treatment had indeed come to an end.

'I just screamed out: I'm going to stop with the pills, I'm going to stop with the pills, I'm recovered! It felt so good that I have done all this.' (*314P in Björk, 2011)

'The moment your oncologist tells you the date of your final treatment, you realize that your cancer has an expiration date.' (*Perez in Perez & Greenzang, 2019)

1.2. Inescapability of cancer. Although treatment had ended, the majority of CYP described a sense of inescapability or permanence of cancer; that their life remained on trial and that cancer had left its marks on them. Some claimed the end not to be an end.

Participants described the disease as a handicap and expressed frustration and grief by not being able to escape or erase its lifelong impact. (Ander et al., 2018)

The cancer experience would never be over with. The veil of cancer while not covering them completely still remained with them. (...) Because of the cancer, life had changed and would continue to change, hence the cancer experience was never ending. (Woodgate, 2006)

1.3. Reminders. Conversations around the ending were grounded in reminders of cancer treatment and treatment completion.

1.3.1. Of cancer treatment. On-going reminders of treatment made the end difficult to comprehend for some CYP. Reminders included continued treatment side effects, changes to their appearance, experiences of symptoms/feelings similar to those during treatment, physical limitations, as well as the need to attend follow-up appointments and undergo procedures.

'It's, like, difficult for me to just lie in bed and take it easy, because I get, I become, it, like, stresses me out. (...) It's because that was all I did then and that feeling is like really, it's really associated with, with, like, how I felt then.' (*ID 5 in Ander et al., 2018)

1.3.2. Of treatment completion. Fewer CYP reflected on reminders that treatment was over. These included tangible signs such as cessation of medication, the removal of the central line, moving out of hospital and returning to school, fewer follow up appointments, as well as increased mental and physical capacity.

1.4. Fear of recurrence. The continuity of cancer was further spoken about in terms of fear of recurrence. Whilst one paper noted a reluctance in participants to speak about recurrence, most CYP spoke about worries of the cancer returning and of their inability to withstand further treatment. They noted that this fear heightened or resurfaced around follow-up appointments or illness, or upon hearing about other CYP they knew relapsing or dying from cancer. Whilst fear of recurrence reduced over time, some CYP resisted viewing the cancer experience as complete until they reached the 5-year mark.

'I constantly wonder if it is ever coming back, and if I'm going to die tomorrow. I have this weird feeling that I'm going to have a heart attack sometime.' (*17 year old in Jones et al., 2011)

'There seems to be this constant worry about recurrence right before going to the hospital. Every once in a while if I feel suddenly dizzy or something. . . . I can't help but think, why is this happening.' (*Participant E in An & Lee, 2019)

'When you get five years [with no recurrence], all the doctors consider you all of the way cured. I mean I'm cured . . . but nobody past five years [without a relapse] has gotten their cancer back.' (*Carrie in Haase & Rostad, 1994)

Only one participant across studies made reference to having experienced a relapse, alluding to difficulties the recurrence and subsequent return to hospital brought with it.

'I have to say it was really hard at first because when I first got out of the hospital I ended up going back for a little while. That made things, it made things a little bit harder.' (*Participant in Walker et al., 2018)

1.5. Others misperceiving endings. Some CYP expressed their frustration at others not understanding the on-going impacts of their cancer experiences, be it family or friends. They further felt angered at others for framing the end as an opportunity to learn from their experiences.

The adolescents expressed feeling that other people did not understand that just because treatment was over did not mean that the cancer experience was over. (Duffey-Lindt, 2006)

Others' expectations about positive cancer-related consequences, e.g., 'having learned so much from cancer', caused frustration and made participants feel different and judged. (Ander et al., 2018)

2. Ambivalence of own needs

Many CYP expressed an overall ambivalence of their needs at the end of treatment. Many felt caught between wanting explanations and continued support, whilst at the same time wanting to move past the cancer. Some expressed a sense of responsibility over others needs in relation to their own.

2.1. Lack of clarity/explanation. Echoing the undefined end, participants spoke of the lacking clarity and explanation around the end of their treatment. While some CYP felt knowledgeable about the ending, others expressed feeling unclear around what the ending meant, what aspects of treatment would continue (e.g. monitoring), why treatment had ended, and what would follow. Missing such clarity complicated the transition off treatment and left CYP unclear about their needs at the end of and beyond treatment. Within one study which elucidated the experiences of young people who engaged in long-term follow up (LTFU) and those that did not, the lack of clarity contributed to CYP often not understanding the need for LTFU, as well as lacking motivation to pursue LTFU.

‘That was the scariest thing. I didn’t know if I was going to have three more, or one more, or if the current treatment was it.’ (*David in Haase & Rostad, 1994)

‘There was no information at all, even what I had, never mind what I could expect.’
(*Participant in Lopez et al., 2014)

‘I somehow got this in my head that once I get into remission, I’ll be immune from cancer forever. I don’t know where I got that idea, but I never asked anyone about it.’
(*Participant not engaging in LTFU in Psihogios et al., 2019)

CYP also felt that the lack of explanations left them unprepared for challenges faced post-treatment, including late effects. They expressed a wish to be more prepared, however remained ambivalent on what this would look like.

Participants described a sense of shock when faced with numerous challenges post-treatment, and reported being warned about these might have assisted them to cope better. (Wakefield et al., 2012)

2.2. Communication of information. CYP expressed differing needs regarding communication of information upon completion of their treatment. Within this, participants described informal review meetings during which the ending was acknowledged and children and their families were encouraged to return to their normal lives. Whilst some welcomed information (for example around side effects, prognosis or as treatment summaries), most found it unnecessary or did not want to concern themselves with such information/data, wanting instead to put their cancer experience behind them. Rather than communicating about illness and risk prevention, participants within one paper called for survivorship to be framed around wellbeing and health promotion.

‘I guess I don’t want to know like that I am more likely to get this kind of cancer, I’m more likely to get that. I’d rather just live happily now and not have to think about like those things they would say. (...) Yeah, they would just probably cause me to worry. Yeah, but I never wanted to hear like any side effects or any of that kind of stuff.’
(*Participant in Lopez et al., 2014)

‘My oncologist asked if I wanted to hear the statistics and rates of relapse for my type of cancer, and as usual, I said no.’ (*Perez in Perez & Greenzang, 2019)

2.3. Need for support. CYP varied in their expressed need for and access to support at the end of treatment, as well as in their experiences of such support.

2.3.1. Support following treatment. Some children welcomed the received support, which ranged from emotional to practical and medical support from families and healthcare providers, perceiving it to be sufficient. Others did not share such need for support, instead preferring to proceed independently. However, most participants shared a strong sense of a marked decline in and lack of support following treatment, which starkly contrasted the careful care received during treatment. Within this, some expressed a particular absence of and need for psychological support.

'Everything is related to getting better, but not past that point (ending). There is no one there to look after you after that.' (*Participant in Palmer et al., 2007)

'You kind of feel forgotten even if you are not.' (*314P in Björk et al., 2011)

'When I finished treatment, and I think I was just kind of thrown out there, like, 'You're done, here you go. Have fun.' That type of thing.' (*Participant in Duffey-Lindt et al., 2006)

'It's like a trauma for the whole family... I would have liked the whole family to have some support.' (*Participant in Psihogios et al., 2019)

2.3.2. Accessing support. A small number of participants felt unclear who to approach to access support, particularly around health concerns. Others did not want to access the support when given the option, wanting to distance themselves from their cancer experience.

'All I remember is I had an option to do I think the survivorship clinic and I didn't want to because it just made me think about cancer more. I know it's probably very helpful. Maybe I could have benefitted from it. But I just didn't want to.' (*Participant not engaged in LTFU in Psihogios et al., 2019)

Within one paper, CYP declined accessing support following treatment, so as not to take support and resources away from those continuing to be under treatment.

Participants reported a reluctance to request support during this period, as they felt this would deflect resources away from patients still receiving treatment. (Wakefield et al., 2013)

2.4. Felt responsibility. Some CYP felt responsible for shaping the end, feeling ambivalent of their own needs in relation to those of others. Some felt responsible to ease other's distress when talking about the cancer, especially their families, hiding any difficult thoughts and feelings. This appeared to be driven by not wanting to continue being a burden to the family.

'The thought of cancer relapsing had crossed my mind and concerned me. But I did not voice my concerns that day, because I did not want my family to see those worries.' (*Perez in Perez & Greenzang, 2019)

Some (...) tried to alleviate other's distress by assuring them everything was fine, irrespective of how they felt and sometimes avoided certain people or situations because they felt too tired of handling others' reactions. (Ander et al., 2018)

A few participants found solace in volunteering within cancer organisations, whereby finding an opportunity to talk about their experiences in ways that felt acceptable whilst simultaneously being able to support others, a wish many were left with at the end of treatment. Others stressed the importance of peer support for themselves and their families. This helped CYP feel truly understood, further giving them the opportunity to extend themselves and help others.

Other participants made reference to the pressures and responsibility they faced from their families to feel happy, to be strong, move on with their life and 'live life to its fullest' following the ending. Similar messages were received from healthcare professionals, encouraging CYP to return to life as normal.

'[My parents] are kind of pushing me all the time and it kind of gets me mad. They just tell me 'You've got to think about the future'. My dad gets mad because I sleep all the time. [He says] 'You're not sick anymore'. I rely too much on my family.' (*Jose in Haase & Rostad, 1994)

'You're just expected to go back I think just like going about everything normally. Um, school and spending time with friends, and, um, I think just acting like a normal teenager.' (*Participant in Walker et al., 2018)

3. The end as a marker of making sense of the cancer experience

The end of cancer treatment functioned for many as a point to reflect on their cancer experience and its overall impact. This included revisiting their cancer experiences, reflecting on survivor's guilt and loss, and processing the conflicting emotions the ending brought about.

3.1. Revisiting cancer experiences. CYP spoke of involuntary reminders of the cancer, which they tried to avoid as best they could by not thinking about their experiences – a technique which had helped them during treatment.

‘Just constantly trying to tell yourself that it’s over, you beat it, and so try not to put any negative thoughts in your head.’ (*Participant in Walker et al., 2018).

‘I try not to think about it, but even if I try not to think of it, the thoughts keep coming, so I let them come.’ (*Participant E in An & Lee, 2019).

However, at times they felt they could no longer ignore their thoughts, instead, feeling the need to talk about and make sense of them, yet struggling to know whom they could turn to for such conversations.

3.2. Survivors guilt. Alongside questioning why they got ill, some CYP further questioned why they had survived cancer when others had not. This survivor’s guilt was also implicit in the reluctance to access support following cessation of treatment.

‘One of my old friends died, so it kinda makes me wonder why God took her life and not mine.’ (*12 year old participant in Jones et al., 2011)

‘On the day that was supposed to be one of the happiest of my life, I could not help but feel confused and guilty as to why the same disease had left us with opposing results.’
(*Perez in Perez & Greenzang, 2019)

3.3. Loss. Alongside the loss of others, the end of treatment also brought about reflections on the loss of time, the loss of a future, the loss of friendships, and the loss of the body (e.g. hair, sight).

'Realizing how much I missed out on last year, its tough to think about where I could have been if this didn't happen.' (*Participant in Walker et al., 2018)

3.4. Conflicting emotions. The end of treatment was felt by some as a time of conflicting emotions.

3.4.1. Variety of emotions. CYP expressed a multitude of emotions including appreciation, happiness, relief, hopefulness, thankfulness, excitement, eagerness, energy, determination and pride at having reached the end of their treatment; alongside feelings of fear, guilt, shame, anger, disbelief, uncertainty, confusion, worry, anxiety, disheartenment, and sadness. These not only stood in conflict with each other, but also with participants' own and others' expectations of how they should be feeling at the end of their treatment. Knowing families had been eagerly awaiting the end, they felt unable to express the more negative feelings around the conclusion.

They expected to feel happy or relieved e.g. when treatment was completed or when everything was fine at follow-ups, but instead they felt sad or depressed. (...) Moreover, feelings of guilt, shame and anger about not being happy and doubt about their right to feel the way they did were expressed. (Ander et al., 2018)

3.4.2. Difficulty understanding emotions. Such contradiction in emotions left some CYP unable to understand or communicate their emotions more generally, highlighting again the need for psychological support following treatment.

Participants described how they dismissed and did not understand their reactions and feelings. They sometimes had difficulties identifying and articulating, and trusting them, let alone difficulty knowing how to act on them. (Ander et al., 2018).

'Well, I am in the process of getting counselling. But I don't really feel comfortable talking freely about myself, because I don't really get, like, myself.' (*16 year old participant in Jones et al., 2011).

4. Sense of self following ending

The ending brought on a changed sense of self as well as a change in how CYP were perceived by others. Participants reflected on both remaining defined by cancer and moving away from cancer following the end. This further spoke to the paradox of being both patient and survivor, and manifested itself in difficulties finding words when discussing their experience with others.

4.1. Defined by cancer. In line with perceptions that the cancer experience continued beyond the end of treatment, there was a felt sense that CYP continued to be defined by cancer. They felt their identity had been merged with that of cancer, when wanting to be viewed as independent from their illness – both within personal and professional relationships. This often left CYP feeling odd or different, particularly when comparing themselves to peers.

'I felt like an animal at the zoo since friends would openly stare, or when passing they'd look at me a certain way...or I'd feel like they are thinking, oh, is s/he the one.'
(*Participant D in An & Lee, 2019).

4.2. Change in focus away from cancer. However, following treatment cessation, a smaller number of CYP equally noted that the cancer – which had previously taken up most of the attention – no longer was the sole focus of others. This again was seen as a sign that the treatment had ended.

For Carrie, the fact that her family no longer made her illness a frequent topic of family discussions was profound evidence that the ordeal was ending (Haase & Rostad, 1994)

'While I was on therapy, my mom drove me crazy. She was always on my case about my treatments – how they were going, when was the next one, and what the test showed. If I tried to talk about something else, she'd get mad and say I was not paying attention to my condition. Now that my therapy is over, maybe we can talk about something else and she can pay attention to me.' (*15 year old participant in Weekes & Kagan, 1994)

4.3. Patient vs. survivor/sickness vs. health. As a result, a few CYP described feeling caught between identifying themselves as cancer patients and survivors – caught between sickness and health. This felt particularly pertinent for those participants who felt they were still recovering both mentally and physically from the cancer.

Adolescent cancer survivors had a collective identity that is paradoxical in nature, because they identify with both their cancer social group and their survivor social group. (Jones et al., 2011).

4.4. Finding the words. Changes to their sense of self and how CYP viewed themselves, as well as how they were viewed by others, further elicited difficulties in finding the words to describe their experience and in discussing such experiences with others. There was a reluctance amongst most participants in disclosing their cancer experience to others once treatment had come to an end. They feared others' reactions e.g. being pitied, victimised or avoided, anticipating others being scared or hesitant around them if they knew. In addition, they did not want to feed into narratives of being defined by their experiences. However, not discussing their experiences with others equally left some CYP feeling dishonest. Participants further felt reluctance from others wanting to talk about the cancer experience, including family members.

'Because, if I don't directly tell them, they won't know that I was sick and I don't have any friends who would tackle that or ask me because they are curious.' (*Participant N in An & Lee, 2019)

'I don't feel uncomfortable telling people that I had cancer, but I noticed that they kind of feel uncomfortable hearing it sometimes. So the hardest thing for me is when I meet someone new, trying to bring it up, and say, "Oh yeah, I had cancer." It's like you always get so many different reactions, but most of them are, "Oh, I don't know if I want to talk about this with you." I have met people and brought it up right away, and they don't really want to talk to me anymore.' (*Participant in Jones et al., 2011)

Discussion

The current literature on the experience of endings of childhood cancer treatment paints a picture of complexity, within which the completion of cancer treatment sits on a continuum of meaning and perception. For some CYP, the ending was expressed as positive and somewhat uncomplicated, yet the vast majority alluded to a more nuanced and convoluted ending; complicated by a sense of continuity to their experiences, feeling caught between victim- and survivorhood, and the ambivalence of needs that followed.

The continuity of cancer

The felt continuity of the cancer experience beyond the end of treatment gave rise to an unclear definition of the ending itself; raising questions about what CYP perceive and understand such endings to be; as well as begging the questions whether the experience of cancer ever comes to an end. Taking this together with the emotional complexity and range of emotions evidenced around the end of treatment, it suggests that the end was left unfinished and unprocessed for many, and was experienced against an abrupt termination of care. There was a sense of CYP being left to cope with and make sense of their experiences including the difficulties of loss and guilt, with many simultaneously being driven to avoid the topic, to move on and leave the cancer behind. Indeed, for many there was a wish for movement towards recovery, without always knowing how to achieve this.

Such description is in keeping with broader, culturally preferred narratives of illness, which centre health as the normal condition that is to be restored (Frank, 1995). Within this, it is the social role of the sick person to recover, cease to be a patient and resume their prior commitments (Parson, 1951). Such dominant restitution narratives are mirrored within family, healthcare, and social structures that give words and meaning to illness experiences, being featured across everyday images as well as within modernist expectations of cure. Whilst an important narrative to tell, the shared idea or expectation of a 'happy ending' and a return to

health makes alternative stories such as of chaos, struggle, relapse or poor prognosis more difficult to tell (Frank, 1995). Similarly, little room is left for a continued cancer experience.

Meaning making: Cancer victim or survivor

Rather than viewing illness and the cancer experience on a continuum, health is often idealised whereas illness is pitied, and both are set against the other. For CYP, this meant the ending brought about a sense of self caught between sickness and health, between being a patient and a survivor – thereby becoming *a master of two worlds* (Campbell, 2008), yet left unsure how to position themselves within either. This was amplified by unclear communication from services about what the end meant and what changes would follow. Whilst the end itself allowed the illness to be somewhat shaded into the background, CYP felt interruptions to this, such as at follow-up visits, which brought the illness back into the foreground. This brought with it a fear of recurrence, accentuating how near to the surface cancer memories continue to sit.

Somewhat unsurprisingly within this context, this split further brought forth ambivalence amongst CYP's roles and needs following treatment completion. Many felt conflicted about what feelings and support they were entitled to, and what responsibilities they held; stuck between wanting to help and be helped. Lacking support, it may be that some children attempted to remove their own pain of the ending by helping and supporting others to take their pain away. Without a place to process and put words to their experiences, CYP were left to shoulder the enormity of their experiences at the end without structures provided by systems to scaffold or support this.

Management of cancer care

The management of illness further deepens the divide between sickness and health. Medical spaces are built on a binary definition, around which movement is orchestrated and responsibility is associated to (Obholzer & Roberts, 1994). This means that care ends as soon

as the patient's treatment ends. Whilst there is comfort in the thought of ridding oneself of illness and moving on with life, CYP with cancer may not hold this privilege. Even though their blood may be clear of cancer markers, their cancer experience continues. Whilst long-term support exists, it currently focuses on the medical long-term effects of cancer and may be blind to other ways in which the cancer experience continues. Questions are therefore raised around how CYP can be supported on this lengthy process and whether services need to broaden their focus around the end. Moreover, consideration needs to be made around how the end of treatment can be attended to and marked in a meaningful way, whilst allowing the ending to find its place.

Limitations of review

The review was constrained by various limitations as set out below. Although the search terms used were broad, these mainly reflected psychological understandings of the end of treatment. Bridging the field of psychology and medicine, different terminology unknown to the author may have been used to refer to the same constructs, and may have led to missing papers.

Furthermore, within eight papers, it was not possible to separate the responses of CYP from those of young adults (18+). Whilst themes did not differ between papers including young adults and those that did not, it is not entirely clear whether younger participants had differing responses to those above 18. Indeed, albeit reflecting a wide age-range, the voices of adolescents were most strongly represented within papers, leaving a gap in understanding younger children's experiences of the end. Further, the restriction to English language within the search undoubtedly led to the predominantly anglocentric focus of this paper, at the exclusion of the experiences of CYP from different communities, whose voices are often left unheard.

Finally, qualitative research is bound to its context, time, participants, and researchers. As such, synthesising qualitative research threatens its very explanatory context (Thomas & Harden, 2008), and risks separating bodies from their cultures. Whilst the current paper does not dispute this, it argues that in order to contribute to and highlight the value of qualitative research, its evidence needs to be summarised and made available in comprehensive ways, whilst acknowledging the difficulties in doing so. For the current synthesis, it should be noted that studies were held across various geographical locations, their subsequent healthcare structures and broad timeframes within which cancer treatment has seen substantial medical and social change; within which endings may have been experienced differently. However, there was no apparent difference in contributions to themes according to country of study or time, apart from the themes ‘lack of clarity/explanation’, and ‘communication of information’ which drew more heavily, yet not exclusively on US papers (n=4 and n=5 respectively).

Weighting of papers under review and their limitations

Analysis

Grounded in constructivist thought, researchers play an active role in constructing the meaning of qualitative data and as such, cannot be fully separated from that which is being researched. However, there was a clear absence of authors stating their positioning towards the data and its analysis. It should be noted, however, that all but three analyses were conducted by multiple researchers, therefore providing increased confidence in the rigour and completeness of the analyses (Barker et al., 2016; Yardley, 2000). Further, only half of the papers included examples of interview questions, making it difficult to determine the extent to which themes mirrored the questions themselves. Based on the available examples, it seems that where papers were looking into evaluations (e.g. of treatment summary), the derived themes echoed the questions more closely; whereas papers that took a broader approach to understanding CYP’s experiences seemed to demonstrate increasingly developed analyses,

contributing to the synthesis to greater extents. This is further reflected in the number of quotes used from each paper, with more quotes taken from those papers that contributed more strongly to the synthesis.

Sample Representativeness

In terms of participants, the majority of papers focused on a variety of cancer experiences and ages. However, most studies lacked sufficient demographic information, especially regarding ethnicity of participants. Where provided (n=6), the vast majority was White (70%-100% within papers), with many studies requiring English as a first language. Such lack of including other voices, such as of minoritised communities, is a larger reflection of not only of biases and inequalities within research, but also within cancer treatment itself. Whilst knowledge regarding cancer is advancing and survival rates are climbing, knowledge, care and survival of minoritised individuals falls far behind (Aziz & Rowland, 2002).

With regards to further exclusion criteria, two papers explicitly stated that they excluded those who had relapsed. More broadly, however, there was only one account within which a participant made reference to having relapsed. The added complexity of ending treatment multiple times or with a negative prognosis is therefore not reflected within this paper. Similarly, other exclusion criteria such as accessing psychological therapies, having continuing chronic complications and/or a developmental disability, may have contributed to missing the voices of those most vulnerable or increasingly complex at the end of treatment.

End of Treatment

Whilst all papers included sections on or made reference to the end of treatment within wider discussions on the cancer experience, only two papers directly posed questions to CYP about the ending as an experience. The rich accounts regarding the ending that emerged, however, indicate that further research into this area is needed.

Clinical implications and further research

The current review highlights the difficulties experienced by CYP at the end of their cancer treatment. Therefore, the following clinical implications and areas for future research are suggested:

- To provide clearer communication around what CYP can expect at the end of treatment. This may cover continued clinical involvement, the ongoing physical impacts of having had treatment, as well as the range of emotional reactions CYP may experience at the end.
- To consider providing structures/services to support young people with the emotional burden of ending cancer treatment. This could include peer groups and/or psychological spaces that address and contextualise paradoxical feelings, as well as any ambivalence around their needs.
- To consider different ways of constructing the end of treatment which allows for a continued cancer experience that does not end with treatment end, as well as consulting CYP on how the end of treatment can be addressed and celebrated within this context.
- To advance research by asking CYP directly about their experiences of the end of treatment incl. how this has been marked and managed; particularly attending to voices of younger participants and those of minoritised backgrounds.

Conclusion

In conclusion, the current review has brought together current knowledge around CYP's experiences of the end of their cancer treatment. Within this, the end has paradoxically emphasised a continuity of CYP's cancer experiences and their resulting ambivalence of needs, as well as positioning the end as a marker for CYP to make sense not only of the cancer experience but also of their identity. The resulting emotional complexity of the ending has

highlighted the need to (re)consider how the end of active treatment is constructed and what support is made available to CYP at this stage.

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Part 2. Empirical Paper

‘You can’t just continue going through treatment and never end’. Endings in paediatric cancer treatment: An Interpretative Phenomenological Analysis of children’s perspectives.

Abstract

Medical advancements in paediatric oncology have made quality of life after cancer increasingly clinically important. Despite this, few guidelines outlining the need and support for children around the end of treatment exist. Moreover, little is currently known about children's experiences, either of the ending itself, or of how they perceived such endings to be managed. **Aim.** The current study seeks to explore children's experiences of the end of their cancer treatment and the meaning they give to such experiences, particularly how endings have been signified and marked. **Method.** Semi-structured interviews were conducted with seven children who had completed their cancer treatment. Each interview was analysed using an Interpretative Phenomenological Analysis (IPA) framework. **Results.** Five superordinate themes were generated: '*the omnipresent end*', '*the punctuation of endings*', '*that which is remembered, that which is forgotten*', '*the voiced and the unvoiced*', and '*freedom from cancer*'. **Conclusion.** Within their narratives, children highlighted the importance of punctuating and celebrating the end of their treatment, whilst drawing attention to the need of doing this in ways that help children process their experiences and provides space for their voice within this.

Introduction

‘Saying good-bye hurts. Grief hurts. But to be allowed to say good-bye with gratitude and love as well as with sadness and loss is a privilege.’ (DeYoung, 2003, p. 203)

Over the past few decades, paediatric oncology has seen one of the greatest medical successes, with survival rates reaching approximately 80% (Izraei & Rechavi, 2004; World Health Organisation, 2018). This has meant that life after cancer has become clinically important for an increasing number of patients. For children and young people (CYP), this move away from active treatment has been characterised by complex and contradicting emotions (Duffey-Lind et al., 2006; Wakefield et al., 2010), with CYP transitioning from an identity of being a patient to a survivor (Jones et al., 2011), and reporting being unprepared and feeling ambivalent around their needs both at the end of, and following treatment (Lea et al., 2018; Psihogios et al., 2019). Further, due to continued medical involvement, and the physical and psychological effects of cancer continuing past treatment completion, the end of cancer treatment has been described by some not as a final end, but rather as an ending sitting within a continuity of the cancer experience (Ander et al., 2018; Björk et al., 2011). Whilst the psychological complexity of treatment and subsequent need for long-term support for CYP has been recognised and incorporated into best practice guidance (Labay, 2004), the end of active treatment itself has not yet received much attention within research or practice. As such, CYP’s experiences of the end of active cancer treatment and how it relates to subsequent adjustment remains poorly understood.

Endings in child psychotherapy

Little is currently known about CYP’s experiences of ending medical treatment. Most of the current understanding of treatment endings is located in the child psychotherapy literature (Gil & Crenshaw, 2016), which hypothesises that treatment endings activate previous

experiences of pain, loss and separation (Lemma, 2003). As such, endings can elicit a mix of strong emotions such as excitement, apprehension, relief and frustration (Finlay, 2016), making it the role of the therapist to help CYP tolerate and process the paradox of the ending with all its ambivalence and anxiety (Lanyado, 1999). Endings in mental health are therefore positioned as therapeutic opportunities for growth and healing.

Further, the emotional tone of the end depends partly on how endings are managed. Sensitive and predictable endings may facilitate feelings that the pain of the end can be overcome; whilst negative or premature endings may leave CYP confused and fearful (Gil & Crenshaw, 2016). Whilst endings do not necessitate particular techniques, instead calling for attunement to its individual meaning for CYP, some therapeutic approaches have embedded ending rituals such as gift exchanges or goodbye letters into their practice (e.g. BJORoy et al., 2016; Finlay et al., 2016). These can be thought of as transitional objects (Winnicott, 1953), which may help the child separate from one thing and move on to another. Whilst recognising the differences between ending cancer treatment and psychotherapy, the emotional salience across the two raises questions about how the end of cancer treatment can be similarly attended to.

End of treatment bell

The end of treatment bell is an increasingly common ritual used to mark the end of cancer treatment, signifying the completion of chemotherapy/radiation therapy. Originating in the USA, the bell and its accompanying poem (see Appendix C) have been widely introduced to oncology wards across the UK to celebrate the joy of ending treatment and has since been rung by thousands of patients. However, the tradition has been implemented and continued with little understanding of its impact. More recently, the bell has elicited conflicting opinions within the adult oncology literature. In a small study looking into experiences of the bell, it was perceived as positive by patients and their carers, creating felt connection, community and

determination in their journeys through treatment (Bridarolli et al., 2020). By contrast, a study measuring distress of patients ringing the bell at treatment completion versus those unable to, found worsened distress in the bell ringing group, highlighting potential unintended consequences of the practice (Williams et al., 2019). Moreover, others, often those who are terminally ill and/or their carers, have named the felt insensitivity and negative effects the bell has on patients with poor prognoses, who continually hear the bell (Gale, 2019; Taylor, 2019), and question who really benefits from it; the patient, family or staff.

Whilst the interest in the utility of the end of treatment bell is growing, the existing research is contradictory and there is currently little understanding of the experiences of CYP at the point of ending their cancer treatment and the ways in which the ending is marked.

Children's voices within stories of illness

In the fields of medicine and health, a single story of illness presides. Often, a patient's chart becomes their illness story, told primarily by medical staff (Frank, 1995). Similarly, it reflects a practice built heavily on quantitative research. However, with a developing focus on patient-centred care (Broyard, 1993), there is an increasing recognition for the place of qualitative research that privileges the voice of the patient.

Despite the increasing value placed on service user perspectives, the voices of children are missed and undervalued. Until recently, assumptions of children's limited capacity, understanding and communication of their experiences have led to excluding CYP from research, instead relying on parents and caregivers to provide a lens through which children's experiences are understood (Woodgate, 2000a; 2001). More recent advocacy for qualitative paradigms in child research has shifted towards the view of qualitative methods as facilitating access to children's lived experiences (Teachman & Gladstone, 2020; Woodgate, 2000b). It is therefore believed that methods of phenomenology may allow for the identification of meaning

that children give their cancer experience and it's ending, as well as their sense-making process behind it.

Aim

The current research sought to explore children's experiences of the end of their cancer treatment and the meaning they give to such experiences – particularly how endings have been signified and marked, including by ringing the end of treatment bell.

Method

This thesis sat alongside two further DClinPsy theses, which explored the experiences of ending paediatric cancer treatment for parents (Caliskan, 2021) and staff (Tspia, 2021) respectively (see Appendix D for an outline of contributions).

Interpretative Phenomenological Analysis (IPA)

Qualitative research, whilst sharing an underlying aim of understanding individual experience, unifies differing approaches informed by overlapping yet distinct assumptions, theoretical underpinnings and purposes (Barker et al., 2016).

IPA was the chosen framework for guiding the current research. It was chosen for its focus into the particular significance and meaning that everyday lived experience takes on for individuals, thereby seeking to engage with and examine the sense-making process behind such experiences (Smith et al., 2009). With much of the IPA literature originating within health psychology, it has often been used to understand how people perceive and give meaning to experiences of health and illness (Brocki & Wearden, 2006).

IPA builds on hermeneutic and phenomenological thought, focusing on how the researcher makes sense of the participant making sense of a given experience (Spiers & Smith, 2019). As such, IPA accepts that analysis cannot be understood without interpretation, and that the knowledge produced is only ever an interpretation of the participants' experiences gained

through the researcher's own interpretive frame. It further draws on ideographic tradition, aiming to understand *the particular* within its context, reflected in the detail and depth of analysing each participant's contribution within its own right (Smith et al., 2009). It does so whilst also drawing attention to the shared aspects of participants' experiences.

Semi-structured interviews are frequently used to allow for the above. They aim to collect rich descriptions and reflections from a small sample of participants who share an experience and are otherwise a fairly homogenous group. Although the use of IPA on children's accounts has been queried based on the depth and detail of their accounts, it has been increasingly recognised within child research (e.g. Griffiths et al., 2011.), as well as used more widely within equally contested research with people with learning disabilities (Rose et al., 2019). It is therefore argued that IPA has the potential of contributing substantially to current understandings of the lived experiences of CYP with cancer and its ending.

Participants and Recruitment

The study was conducted at a children's hospital in London. A purposive and homogenous sample was chosen in line with IPA principles, which, for the purpose of the study, was defined as: CYP who had recently completed the end of their cancer treatment within the said hospital, as set out below.

Inclusion criteria

CYP were included if they (1) were between eight and 14 years old, (2) had completed cancer treatment involving chemotherapy, and (3) completed this within three to 24 months prior to the study. The lower age limit was set as it was thought that younger children (who would have started cancer treatment around the age of five) might have a significantly different experience of treatment. Due to service structures, CYP above 14 years old transition to a different hospital and would not have experienced their end of treatment at the hospital the research was conducted at.

Exclusion criteria

Exclusion criteria were (1) CYP who received surgical treatment only, as they would not have had an extended period of treatment, (2) CYP with significant learning or other communication difficulties which would have made it difficult for them to participate in the interview format, (3) CYP for whom there were known safeguarding issues, and (4) CYP who were deemed medically unwell to the extent that participating in a study would be unethical. CYP were not excluded on the basis of the type of cancer or their prognosis at the end of their treatment.

Recruitment procedures

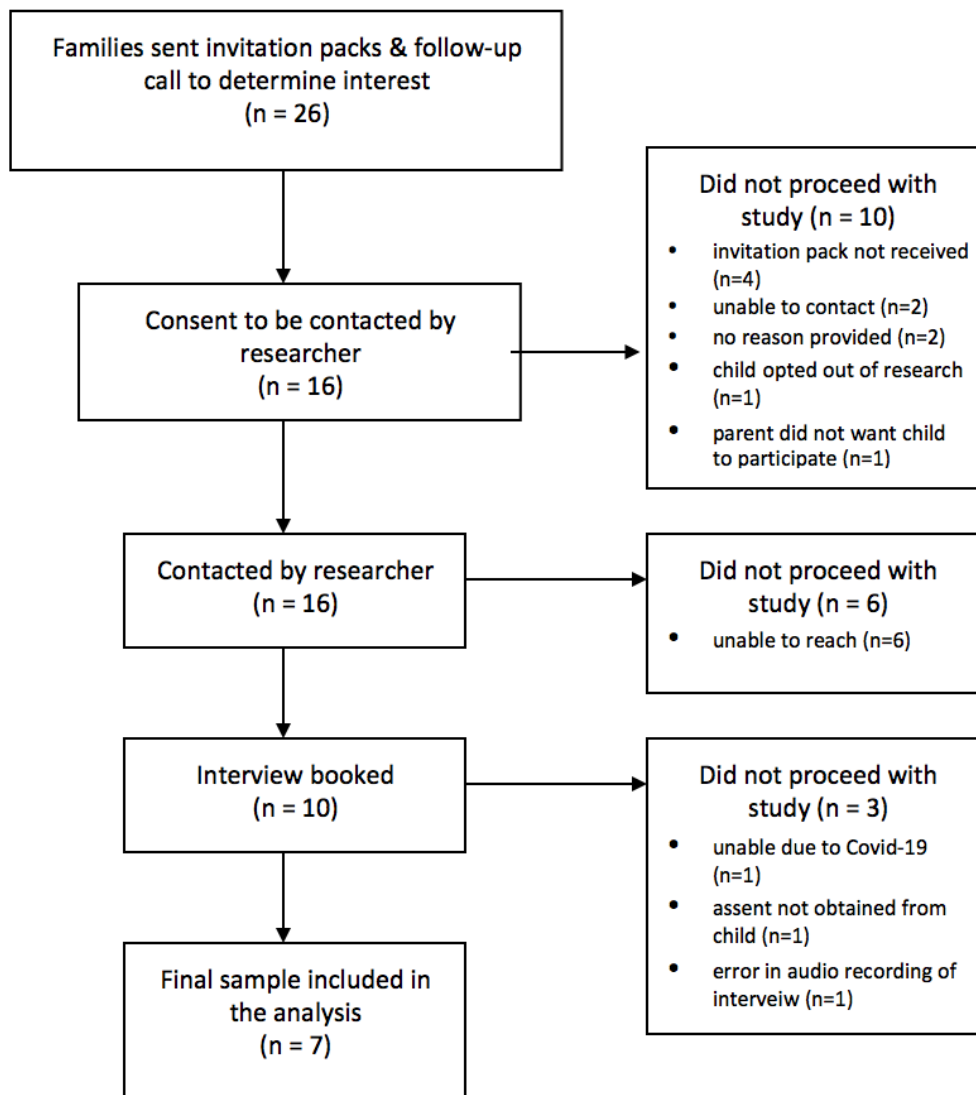
Potential participants were identified by members of the Haematology and Oncology treating team. Twenty-six potential participants and their families were posted invitation packs regarding the study (incl. invitation letter, information sheets, consent/assent forms; see Appendices E-J). This was followed-up by a telephone call from a further member of the treating team to offer clarifying information, and, if appropriate, to gain verbal consent to be contacted by the researcher to take part in the study. Ten families did not proceed after this point (n=4 invitation pack was not received within needed timeframe; n=2 unable to contact; n=2 no reason given; n=2 child opted out of research due to not wanting to talk about the end). Sixteen families consented to be contacted by the researcher. Of these, six were not contactable by the researcher. There was no difference in treatment length or treatment outcome between those that declined participation/were unable to be reached and those who participated. However, those that did not participate reflected a broader age range (range: 7-13 years) and were predominantly male.

Ten interviews were arranged, of which two did not proceed: one child was unable to provide written assent and the other was unable to attend due to having COVID-19. One completed interview was not included in the analysis due to an error in the audio recording.

The final sample consisted of seven participants (see Figure 2 for overview of recruitment process), keeping in line with the recommended sample size when conducting IPA as a doctoral study (Smith et al., 2009).

Figure 2

Flow chart of recruitment process.



Ethical approval

Ethical approval was obtained both from the Clinical Research Committee (R&D number: 19SH35) at the study hospital, and the NHS Health Research Association (REC Reference: 20/PR/0295; see Appendix K for approval paperwork).

Data Collection

Due to COVID-19 restrictions, all interviews were held via video call. Interpreters were offered where appropriate. Prior to the interview, formal written assent and consent was obtained from the CYP and their caregivers respectively. This included consent to be contacted for credibility checks following the analysis. All CYP decided to be interviewed with one or both caregivers present. The interviews lasted up to 40 minutes. None of the CYP required an interpreter. Following the interview, participants were debriefed as appropriate and the researcher checked whether the participant was left with any distress or questions. Those who agreed to credibility checks were contacted at a later date to discuss initial interpretations. Finally, all participants were sent a certificate for their participation (see Appendix L).

Interview Schedule

Aiming to explore participants' experiences of the end of their treatment, a semi-structured interview (see Appendix M for full interview schedule) was developed in conjunction with clinical psychologists in the field of paediatric psychology including oncology, as well as being informed by the hospital's Young People's Forum which consists of a group of young people who consult on a range of issues regarding treatment at the hospital. Whilst questions within IPA are ordinarily kept fairly abstract (Smith et al., 2009), questions in the current schedule were kept more concrete for the purpose of interviewing CYP.

To build rapport prior to the interview, both participants and the researcher brought a personal item, which they talked about. Considerable time was taken to ensure participants felt at ease and engaged before starting the interview by following their lead and checking in with

them whether they felt ready to begin. As well as their personal item, CYP were encouraged to bring a memento of their cancer treatment if they wished. Participants were further asked to bring pens and paper, in case it was easier to communicate through drawings.

A semi-structured design was chosen to flexibly guide the dialogue, ensuring a balance between the content driven by the participants and by the researcher. It began with questions asking participants to remember their treatment, before turning to questions aimed at elucidating themes for analysis including the meaning of the ending, experiences of the ending, and ways of marking the ending. Questions were adjusted according to participants' individual responses, allowing the researcher to follow up topics as they arose (Smith et al., 2009). Questions were scaffolded by visual prompts e.g. pictures of different emotions, star rating scales to determine the CYP's evaluation of their experience (see Appendix N).

Following the first interview, both its structure and content were reflected on with one of the research supervisors (RS), drawing attention to any prior experiences, assumptions, biases and preconceptions held by the author (Heidegger, 1962).

Analysis

The analysis followed IPA guidelines as set out by Smith et al. (2009). All interviews were initially transcribed verbatim by the author, following which any identifying information was redacted and recordings were deleted. In keeping with the ideographic commitment of IPA, each transcript was analysed separately following the steps below, before turning towards the collective patterning across transcripts.

In turn, each transcript was read and re-read, allowing the author to immerse themselves in the data. Following this, initial notes of descriptive, conceptual and linguistic interest were compiled, alongside noting initial thoughts regarding interpretation. Whilst IPA traditionally focuses on commissions rather than omissions, attention was equally focused on silences and non-verbal communication (Spyrou, 2016). Initial notes were then translated into

comprehensive emergent themes, bridging a reflection of the data itself and the interpretation of such. Next, superordinate themes were developed by searching for connections across themes within the transcript, whereby clustering and condensing themes by use of abstraction, subsumption, polarisation, contextualisation, numeration and function. Individual tables for superordinate themes were drawn up for each participant before turning to the next transcript. Finally, patterns across cases were attended to, searching for connections across tables of themes, and creating an overall master table of themes. Following each stage of the analysis, themes were discussed with both supervisors (KS, RS).

In order to preserve the children's voices within the analysis, member checks were conducted with those who provided consent. Keeping with IPA's ideographic nature, themes were discussed with corresponding participants. As recommended when conducting interviews with children, repeated opportunities to meet with the researcher improved trust and confidence in the research process creating an environment in which the participants felt able to speak openly (Woodgate, 2000), whilst remaining consistent with the idea of multiple interviews within IPA (McCoy, 2017).

Validity and quality

At present, there is no one way of evaluating the validity and quality of qualitative research. However, there is a considerable amount of overlap in the suggestions put forward within the literature (Barker et al., 2016; Yardley, 2000). Some of these, namely sensitivity to context, rigour of analysis, transparency and coherence, which align themselves to the epistemological and methodological assumptions of IPA, are discussed below.

The sensitivity to context within which qualitative research occurs refers to the context of theory and previous literature, as well as the context of power and its balance throughout the research process (Yardley, 2000). The author drew on previous knowledge and theory to inform both the interview and to support analysis, as well as seeking consultation from

members of the hospital's Young People's Forum (YPF), who had completed medical treatment and were of similar ages to the participants. The interview schedule was discussed to gain sensitivity to children's perspectives, whereby attempting to attend to power dynamics, to gain advice on the general interview and the appropriate use of language, as well as on how to engage young people in complex conversations and build rapport. Following a lively discussion, the interview and engagement process as well as the schedule was amended in line with the YPF's suggestions. This included changes to the interview questions themselves, the addition of the researcher bringing a prop to introduce themselves to match the participant, as well as attending to the ending process of the research by providing participants with a certificate and, upon completion of the research, a summary of the findings. Further, participants of the study were invited to complete credibility checks, namely to check the results in the initial stages of analysis and offer their views on the interpretations made, in order to guard against reflecting a purely adult interpretation of children's worlds and experiences within them (Kirk, 2007). Three participants undertook credibility checks, and their contributions were further included in the analysis (see Appendix O for example extract).

In terms of rigor of analysis, several levels of analysis as outlined above were conducted. Each step was followed by discussions with the supervisors (KS, RS), ensuring that interpretations and themes both linked back to the data and transcended 'common' understandings (Yardley, 2000). This allowed for completeness of the interpretation, rather than double-coding or claiming inter-rater reliability, which does not lend itself to the epistemological assumptions underpinning the current research (Madill et al., 2000).

Finally, to ensure transparency and coherence, the author has presented excerpts of the data analysis for readers to discern themes from (see Appendix P) and has used quotations throughout the text to exemplify such themes. Of equal importance, consistent with the view that researchers' engagement with data is shaped by their preconceptions (Heidegger, 1962),

the author conducted a bracketing interview prior to the study interviews and kept a reflective journal across all stages of the research. This was done with the intention of allowing the author to notice and to move away from their own perceptions and towards the essence of children's experiences at the end of their cancer treatment. Some of these are shared in a brief reflexive statement below.

Overall, as a white, able-bodied woman, the author is speaking from a white and able-bodied frame of reference and worldview. The author has experienced multiple (health-unrelated) endings, particularly in childhood, which she often perceived to be abrupt and beyond her control. More recently, she has been directly confronted with close others' experiences of cancer, one of which resulted in surgery and a positive prognosis, the other ended in death. Both were perceived by the author as 'being over' quickly. Within clinical practice, the author has felt drawn to therapeutic approaches that place emphasis and consideration on the ending, marking it in several ways including ending letters. The author has not previously worked or engaged with children in oncological settings.

Results

Seven children took part in the study (see table 4 for key characteristics), together with their parent/s. The following quotes therefore reflect not only the children's voices, but where children communicated through their parents, also their parents' voice. Where appropriate, quotes have been edited for readability. Pseudonyms have been chosen to reflect the gender and ethnicity of the children. However to ensure confidentiality, names are not matched to participant characteristics.

Table 4*Participant characteristics*

Participant characteristics	
Age	Range: 8-11 years
Gender	Female (n=5) Male (n=2)
Ethnicity	Asian Bangladeshi (n=1) Asian Indian (n=2) Mediterranean (n=1) White British (n=3)
Diagnosis	Acute Lymphoblastic Leukaemia (n=5) Pre-B Acute Lymphoblastic Leukaemia (n=2)
Length of Treatment	Range: 2.5-3.5 years
Time since treatment completion	Range: 9-19 months

Five superordinate themes were generated through the analytic procedure, each with a set of subthemes, an overview of which can be found in table 5 along with their patterns of occurrence according to participant.

Table 5

Superordinate themes, subthemes and patterns of occurrence.

Superordinate Themes	Subthemes	Aaliya	Sadia	Wayne	Hera	Lola	Riaan	Noa
The omnipresent end	Endlessness of treatment							
	The tantalising bell							
	Self-reassurance							
	Disbelief at the end							
The punctuation of endings	Multiple ends							
	Celebrating the end as an achievement							
	The privacy of experience							
	Interrupted and incomplete ends							
That which is remembered, that which is forgotten	Remembering support and togetherness							
	The pain of remembering							
	Memorialising the end and leaving it behind							
The voiced and the unvoiced	Voicing difficulties							
	Keeping experience to oneself							
	Parents as voices and gateways to experience							
Freedom from cancer	Lack of agency and control							
	Ridding the self of cancer							
	Separation from cancer and the return to self							

The following notations were utilised throughout:

Omission of intervening material (...)

Anonymised information [*Hospital Name*]

Explanatory information (*the bell*)

Non-verbal communication *pause

Speech emphasis underlined

The omnipresent end

Permeating all accounts, children made reference to the end of their treatment as something omnipresent. For most, thoughts about the end were present from the first treatment day, setting the scene from the very beginning and providing a thread throughout. This was captured by the following subthemes: ‘*endlessness of treatment*’, ‘*the tantalising bell*’, ‘*self-reassurance*’ and ‘*disbelief at the end*’, moving in and out of the belief that treatment will and will not end.

Endlessness of treatment. Aaliya, Sadia, Wayne, Hera and Lola all painted a picture of the endlessness of their treatment and its associated waiting. To be cured meant to endure continuous hardship and the children expressed a desire to get to the end of the endlessness.

Sadia: ‘This time passed, I want to say quickly, but this time has passed so slowly, but now it is finished!’

R: ‘So it was a long time waiting for this moment.’

Sadia: ‘Yeah I just feel like (change in tone of voice) oh my gosh, I’ve had that for two and a half, yeah, two and a half years. Two and a half years of my life I’ve had treatment.’

Sadia’s emphasis on her perception of time draws attention to the slow movement through treatment, almost as though moving in slow motion. She finishes off with a reminder to herself that the treatment is now truly over, before reflecting on how much of her life has been consumed by cancer. The felt length of time is extended by her repetition. Further, the sudden change to an adult-like, almost artificial ‘*oh my gosh*’ may imply the need to have been

mature during the process and a subsequent sense of her childhood being taken away in those two and a half years.

Hera's mother: 'And he (favourite toy) came into every single operation, every time we stayed in [Hospital Name], monkey always came. Monkey has been everywhere.'

Talking about a toy monkey that accompanied Hera throughout the process, Hera's mother recounts the numerous appointments and procedures both Hera and the monkey had to experience to reach the end. Similar to Sadia, Hera's mother's repetition, here of '*every operation, every time, everywhere*' conveys the seemingly unending and arduous process of treatment.

The tantalising bell. The end of treatment bell was seen by most children as a tangible symbol of the end. All but one child commented on the bell as being ever-present; always in sight, always tantalising, and leaving the children yearning to ring the bell. Within their narratives, many children compared themselves to those they heard ring the bell, envying their positions of having reached the end.

Wayne: 'I knew it (the bell) because when I used to walk by sometimes in the hospital and I went to the playing area, and the playing area is, and its kinda near to the playing area, the bell. (...) And I read it (the poem) and then I wanted to you know ring it, and then I knew that, then I read it and I knew that it was only for end of the treatment.'

Wayne describes his numerous encounters with the bell, as well as his recognition of the bell as being reserved for the end, almost framing it as forbidden or sacred. His longing is

shared by Lola, who describes the temptation of touching the bell's rope, which hangs torturously within reach every time she passes. Her comment of '*when will this end*' gives a further nod to the gravity of enduring treatment and the pain and desperation of not knowing what it is like to get to the end.

Lola: 'It felt good because every single time I walked past it I thought 'when will this end?' I want to ring that bell. And one time I just touched the rope and it nearly rang. (...) I wanted to know how it felt, I wanted to know how it felt. And when I was in the hospital, I could hear the bell being rung and I was like 'One day, that will be me.'

Describing a very different experience of the bell, Noa appears to reject the importance of it, whilst acknowledging its looming presence from the start of her treatment.

Noa: 'When we went in, I saw it.'

R: 'You saw it? And what did you think about the bell when you saw it?'

Noa: 'I thought it was a bell.'

Her account here remains very matter-of-fact, but turns more vulnerable later in the interview.

R: 'And how did it feel to hear somebody ring their bell?'

Noa: 'I didn't really hear them. I just saw my mum and them talking.'

R: 'So how did that feel, to hear them talking about the bell?'

Noa: 'Uhm ,um, uh, hm, I don't really mind. (muffled)'

R: 'Sorry, I didn't quite hear that.'

Mother: 'She said she didn't really mind or care, all she wanted was to go home.'

Noa describes not hearing, or not wanting to hear others ring the bell. She hesitates, her voice becomes muffled and closed off. She is unable to get her words out. At this point, her mother steps in, maybe as to protect her, and explains all Noa wanted was to get to the end, go home and leave anything to do with the cancer behind.

Self-reassurance. Most children spoke of the end with a certainty, reassuring themselves throughout treatment that they too would come to the end of it. Consequently, the bell became a symbol of their determination, spurring them on and providing strength. Like Lola above, Aaliya and Sadia spoke of 'one day' ringing the bell.

Aaliya's mother: 'You used to hear people ring it didn't you. And you used to say you were going to ring it one day, yeah?'

Aaliya: 'Yeah.'

Sadia: 'In a way it (hearing others ring the bell) felt like, it made me feel like I can get through this. I can get through this and one day I will ring that bell good and gold.'

For Aaliya and Sadia, hearing others ring the bell becomes a reminder that they too would recover. Sadia speaks about it in a final way; good and gold, resembling done and dusted. Similarly, anticipating his own turn, the excitement and happiness of witnessing others ring the bell made Riaan happy for himself.

Riaan: 'I was so happy for them and also happy for me that I was going to be ringing the bell.'

The very possibility of not recovering seemed unfathomable to most, as expressed by Lola.

Lola: 'Its like everybody, everybody, people go through treatment and everybody finishes, then those people have to finish it. Like you can't just continue going through treatment and never end.'

She describes an order to treatment, that it begins and that it ends. Implicit through the focus on 'everybody' may be the fear of considering that her own treatment may not end; repeatedly telling herself that it must.

Sadia goes a step further and asks herself 'What if that never happens to me?', placing the bell as a reminder of her own mortality. She quickly moves on to speaking about ringing the bell (p.74), not allowing the thought to sit in the air for too long.

Disbelief at the end. Riaan, Wayne, Hera, Lola, and Sadia all described responding with surprise upon hearing about their treatment end, despite their deep longing for it. They described not quite believing that their treatment had indeed finished, instead only grasping or allowing themselves to grasp the end once it was actually there.

Hera: 'Uhm, happy. And surprised.'

R: 'Surprise. And why do you think you felt surprised?'

Hera: 'Because I didn't think my port would come out then.'

For Riaan, the disbelief was stronger, more likened to shock.

Riaan: 'The first time I found out, I thought my dad was joking.'

R: 'Really? And why did you think he was joking?'

*Riaan: 'Because he said it in such a normal... *pause. I don't know, I just thought he was joking.'*

R: 'And when did you realise that it wasn't a joke?'

Riaan: 'When everyone kept saying 'It's true, it's true, it's true.' I felt shocked.'

Riaan's initial reaction is that the end cannot be true, that it must be a joke. He refers to the way his dad spoke about it, implying that the normality in his father's voice does not match the significance of completing treatment. Riaan almost needs convincing to believe it is true. For Wayne, the disbelief lingers.

Wayne: 'And stop all the medicine, so you don't need to take them anymore. You can throw them.'

R: 'You can just throw away the medicine because you are finished.'

Wayne: (in quieter voice) 'Yeah, I still have them actually, but I don't need them.'

By holding onto the medicine, Wayne is holding onto the disbelief and the safety that the medicine represents, should he need to return to it. He moves from speaking more generally that 'you don't need them' to making it more specific about himself 'I still have them', allowing a glimmer of uncertainty about his own end of treatment to surface. The shared disbelief may bring into question how much the children believed they would reach the omnipresent end, implying a fragility in this belief in the first place.

The punctuation of endings

Ways in which the ending was constructed and signified were woven into all children's narratives. This highlighted both the importance and the complexity /complication of such punctuations, which are captured through the themes: '*multiple ends*', '*celebrating the end as an achievement*', '*privacy of experience*', and '*interrupted and incomplete ends*'.

Multiple ends. Rather than having a single end point, children differed in their definition of the end, with some referring to multiple endings across multiple hospitals. Endings were defined by final procedures such as the last lumbar puncture, last injection, removal of the port/line and the final use of medication. For Aaliya and Noa, the meaning of the end took a more abstract form; that is the end of continuous pain and the end as a feeling of safety.

Aaliya: 'I didn't have to go. I didn't have to keep going and getting needles. They hurt'

Mother: 'What about when your port was taken out? Do you think that was the end of your treatment?'

Noa: 'Yeah, port taken out.'

(...)

Mother: 'Did it feel weird?'

Noa: 'No. I thought the bed was really warm.'

Whilst Noa acknowledges the removal of the port as the end, her thoughts turn to the comfort and containment of waking up in a warm bed following her procedure. Together with

the return home as the most important marker of the end, it may symbolise Noa's relief and the felt safety of the end.

Celebrating the end as an achievement. For all children, the end (or endings) was constructed as an achievement, which called for celebration and reward from both services and families. Celebrations ranged from making a wish come true¹ (e.g. swimming with dolphins, trips to Disneyland), to having parties with friends and family on the ward (incl. bell ringing ceremonies, receiving certificates) as well as at other locations (incl. driving in limousines, having bouncy castles, going on water slides, visiting London dungeons, ringing a bell at school). Contrasting the passivity during treatment, presents as well as chosen activities to mark the end appeared to be active, pushing boundaries of safety and becoming a marker of strength and bravery at having overcome cancer. For Lola, whose parents arranged a piñata for the end of her treatment, which represented the taste of her medicine, 'beating cancer' took a more literal form.

Lola: 'Its like when I am really annoyed, I get to smash some stuff. And then I got really annoyed at the banana (i.e. medicine) so I got to smash it. (...) I was like 'I hate you banana medicine!'

R: 'And I wonder whether that let you let out all the anger on the cancer as well?'

Lola: 'Yeah, it did. Because, because it was part of it'

Not only was Lola able to express that she had beat the cancer, having the power to break it into tiny pieces, she was also allowed to express the frustration, anger and hatred

¹ Make a wish: Charity granting life-changing wishes to children with critical illness. <https://www.make-a-wish.org.uk/>

towards the cancer. Now that treatment was over, there appeared to be an emotional safety in doing so.

The privacy of experience. However, alongside speaking of celebrations, most children expressed a felt intrusion to the privacy of their endings. This was particularly the case for the bell ringing ceremony, which was often held the same day as the port removal. For Sadia and Aaliya, there was a discrepancy between the pain and exhaustion they felt from their procedures and the need to celebrate shortly after. Others spoke of being overwhelmed in a different way, of feeling burdened by the attention they received and by feeling exposed.

Sadia: 'I remember you had to, I had to read this poem and they were like go on read the poem and I was like I read that? I am normally quite confident but because there were so many people watching, I just got a bit shy and then they all started reading it with me and I was trying to be as quiet as possible and they were all like, I was like that's it, take over my voice'

Here, Sadia compares her usual confident self to a much shyer, smaller, almost shrunken self. Whilst others are encouraging her to find her voice, she loses her voice in the process. There is an expressed relief to be able to step out and relinquish the control, which may mirror the cancer treatment itself and being taken care of within it.

Riaan: 'It felt weird, because my mum was taking pictures everywhere. Everyone was staring.'

R: 'Everyone was staring, who was staring?'

Riaan: 'Uhm, all the nurses and doctors and people who were there.'

Riaan adds to the feeling of being watched or observed with a tone of embarrassment. He feels stared at; not only by staff but also by other people he does not know, invoking a similar sense of wanting to hide. Wayne, on the other hand, appears to welcome the attention.

Wayne: 'The bell is kinda high, so my mum helped me and then I ring it and it was the most fun time ever. Because you know the audience, the whole audience comes. (...) And they are clapping.'

He recalls the fun of jointly ringing the bell with his mother. By referring to those who attended as *'the audience'*, he evokes a scene of coming to the end of a play, whereby treatment has become the stage upon which he is expected to perform, to get better, to thrive, to survive; for which he is being applauded.

Interrupted and incomplete ends. Where the end was not possible in its original form due to COVID-19, children experienced a felt loss of the end. The incomplete and interrupted ends for Hera and Wayne highlighted the importance of such endings, their celebrations and the ringing of the bell as a form of closure. Wayne, who was only able to ring the bell with his mother, felt hopeful to be allowed to ring the bell again with both his parents present, in order for his father to join the celebration. For Hera and her mother, the ending seemed to slowly shrink and eventually disappear with COVID-19 restrictions tightening.

R: 'So it sounds like ringing the bell is actually really important. Is that right?'

Hera nods.

R: 'And why do you think it's important?'

Mother: 'Are you excited to do it? Yeah, we were excited to do it. It was very sad that she didn't get to do it, but she will do it if she still wants to.'

R: 'So did you feel a bit disappointed as well when you found out you couldn't ring the bell when you wanted to?'

Hera nods.

Similar to Wayne, both Hera and her mother felt the end had not been fully reached without ringing the bell and both were keen to complete the tradition. The use of 'we' implies the shared experience and importance of the bell. However, without the fanfare of the bell, an unexpected intimacy of celebrating life was created between the two.

In contrast, Noa, who had her final procedure on a different ward and was therefore unable to ring the bell, did not appear to be affected by the change, whereas her mother expressed finding closure difficult without it.

R: 'So that must have been really tricky to be on a new ward and unfamiliar.'

Mother: 'Did it feel weird?'

Noa: 'No.'

R: 'Your mum said that it felt like it wasn't the ending you were expecting. Did it feel unfinished to you as well or is that more how mum felt?'

Noa: 'Mum.'

Mother: 'So it feels like, to me anyway, maybe not to Noa, it doesn't seem like she is affected too much, but it doesn't feel like there is closure.'

That which is remembered, that which is forgotten

Over the course of the interviews, there was a stark contrast between parts of the treatment and its ending that were remembered and parts that were forgotten. This is expressed

through the subthemes: ‘*remembering support and togetherness*’, ‘*the pain of remembering*’, and ‘*memorialising the end and leaving it behind*’.

Remembering support and togetherness. All children recalled happy memories from their time in hospital, centred around feeling supported, protected and close to family and staff. They spoke of their allies throughout treatment and the felt connection and togetherness this period of their life brought about.

Aaliya: ‘I got something after from a box when I finished. And daddy took me to the gaming bit.’

Riaan: ‘I remember that once, I wasn’t allowed to go to the playground, because I had to stay in my room, one of the nurses they came and played with me and kept me company.’

Lola: ‘So someone who was always here was my mum. My mum was always there for me so I could always talk to her about everything. Uhm., like we could get into her bed and we could talk and watch some TV.’

The pain of remembering. By contrast, all narratives were interspersed with several reports of ‘I can’t remember’, particularly when reflecting on the difficult moments in treatment. There was a sensed pain to remembering, or a not knowing how to remember, instead repressing the memories. ‘Not remembering’ further became part of two children’s broader sense of identity.

Riaan: ‘I’m sorry, I don’t have the best memory. I have a small memory.’

Noa: ‘I’m not a good rememberer’

Many were able to remember experiences, but were left unable to recall their feelings and thoughts connected to these, for example when hearing others ring the bell.

R: 'And did you ever hear anybody ring the bell when you were in treatment?'

Hera: 'Yeah once.'

(...)

Mother: I cried. It was so sweet. (...) Were you happy, were you excited, were you sad?

*What were you when you heard her ring the bell? *Pause. Or you don't remember.'*

Hera: 'Don't remember.'

Hera's mother provides Hera with several possibilities of how she might have felt, before offering her a way out by asking whether she doesn't remember, which she accepts. Aaliya similarly does not remember her thoughts when hearing the bell being rung, as well as at other points of treatment. This differs from Aaliya's mother's own inability to forget.

Mother: 'We were there for so long, that by the time we got home, it was so late. (...)

There was a lot of waiting around that day. You were so good. Bless you.'

R: 'Do you remember all of this?'

Aaliya: 'No.'

Mother: 'I do.'

Differing from all other accounts, Wayne shows his keenness to speak about all the things he knows in response to a question of what he remembers.

Wayne: 'I actually know a lot more.'

On beginning the interview, Wayne's' parents appeared hesitant about his participation, as the cancer was something that had not been talked about widely amongst them. Wayne's statement of knowing a lot more seems to cut through that, implying that he knows more than he is given credit for or is allowed to admit.

Memorialising the end and leaving it behind. Most children felt a pull between memorialising the ending and wanting to leave it behind. Ways of keeping hold of the ending included certificates and pictures of the ending celebrations, the presents they received at the end, having a bell of their own, and beads of courage, which symbolise the treatment and its procedures in its entirety by individual beads. Interestingly, none of the children received an end of treatment bead.

Hera: Where are they (the beads)?

Mother: I don't know, where are they? Maybe, hold on, I'll see if they are in the kitchen'.

Hera's dialogue with her mother creates a sense of not quite knowing what to do with and where to keep the memorabilia, which may echo a wider not knowing of what to do with and where to keep the memories and feelings related to treatment. Without this, the beads find their place in a kitchen drawer, creating a sense of disconnection. Hera further goes on to demonstrate the weight of treatment and with it the weight of remembering.

(Hera takes all beads together and holds them into the camera.)

Mother: 'Are they heavy?'

Hera: 'Yeah.'

The ambivalence of how to position himself following treatment completion is further demonstrated by Riaan, who speaks about a necklace he received from a nurse for the end.

Riaan: 'I put it on, then I took it off, then I lost it, then I found it, then I put it on again, then off again, then lost it, then found it. And then I thought you know what, I am going to keep it on for the rest of my life.'

He begins by changing between wanting to keep the necklace and its memory close and wanting distance, between losing and finding himself in relation to the cancer. This sequence is repeated with a sense of rhythm, before Riaan decides to keep the necklace on for the rest of his life, emphasising the impact the cancer has had and will continue to have on him.

The voiced and the unvoiced

Similar to remembering and forgetting, there were differences in what children spoke about, and what was kept unsaid. This is elaborated on in the themes: *'voicing difficulties'*, *'keeping experience to oneself'*, and *'parents as voices and gateways to experience'*.

Voicing difficulties. There were moments of hesitation and silence throughout all children's accounts, within which some experiences were left unvoiced. Of note, in terms of naming the cancer, Sadia was the only child to say 'cancer' within her interview. Moreover, when asked about worries at the end of treatment, all other children closed off the conversation, either by changing their demeanour, the subject, asking to turn their camera off or withdrawing from the conversation.

R: 'Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having?'

*Aaliya: 'Yeah.' *Pause*

R: 'Yeah and do you remember what these worries were about?'

Aaliya: 'No.'

*Lola: (in response to asking about worries at the end of treatment) Uhm *pause uh, I don't know. I don't (...) Uhm, yeah (in quieter voice) that feels like a difficult question.'*

(Noa's mother making inaudible suggestion in background)

R: 'Do you think your mum thinks there is something that was not so good?'

Noa: 'No.'

Neither Noa, Lola nor Aaliya seem to be able to or want to find the words to describe their worries. Noa's mother appears to make a suggestion of something that may have been difficult for her. However, turning the question back to Noa, Noa's rapid 'no' stops the conversation from going any further.

Rather than finding anything in particular difficult to talk about, Hera remains fairly silent throughout, communicating in whispers through her mother and by holding different items including her toy monkey and beads of courage into the camera. To this, her mother responds *'To make sure you have seen everything.'* To have her experience witnessed appears important to Hera, who lays out her beads of courage and carefully shows them one by one, pausing at the important beads.

Sadia is the only child who feels able to speak of her difficulties within and following treatment.

Sadia: 'I found that being free of cancer, in a way hard. (...) It was hard to be like, I am free, I can actually do stuff. I could go to school if somebody had chicken pox. (...) I, every now and then get a bit worried. Cause like, ugh, I do not want to get it.'

*Father: 'I think it has also been recent with what's going on as well *pause. So it's been, you know, linked to the corona virus.'*

Sadia: 'You can say COVID, you don't need to say 'what's going on'.'

Father: 'I am saying it, I am not holding back, am I?'

Sadia begins by speaking of the complexities of returning to the world after having had cancer, not quite knowing how to be in this world within which previous dangers are no longer dangers. She goes on to express a fear of the cancer returning, implying a dreariness or repulsion with the 'ugh'. Next, her father interjects, explaining the role of COVID in Sadia's fears, to which she responds with a call to communicate frankly and for difficulties to be voiced.

Keeping experiences to oneself. Continuing the silence, most children felt a need to keep their experiences from others, including their families and staff.

R: 'Was there anybody who you felt you could talk to about your worries?'

Aaliya: 'Mum.'

M: 'You don't really talk to me about it at all, do you?'

Aaliya: 'No.'

Aaliya is resistant to share her worries with her mother, maybe out of fear of not wanting to burden her. She later makes reference to a school counsellor with whom she has discussed her treatment end.

Lola: 'Yeah, whatever they (doctors) asked me, I'd answer. But I wouldn't like, say anything that isn't, that they didn't, if they didn't have a question, but I had an answer, I would just keep that until they asked that question.'

Here, Lola explains that she would only share information with doctors when asked directly. She is the bearer of her answers, holding onto them until space is made for her to offer them. The difficulty in expressing herself here *'that isn't, that they didn't, if they didn't'* may mirror the broader difficulty of knowing how to share her experiences.

Parents as voices and gateways to experience. All children chose for their parent/s to remain with them during the interview, providing a sense of safety. The interviews with Noa, Aaliya, Hera, and Lola in particular draw attention to their mothers' role in gatekeeping their experiences, being facilitative and protective, not only within the interview, but also the treatment. Aaliya frequently turns to her mother when unsure of a question and repeats her mother's words throughout. For Hera, her mother almost becomes her translator, putting a voice to her whispers and gently steering the interview when sensing difficult questions. For most, their mothers are the containers of their worry, whilst also framing their experiences.

R: 'Would you have liked to have rang the bell if you could have? Would that be something you would have chosen to do?'

Noa: 'My mum would have chosen to.'

R: 'Yeah, and what about you?'

Noa: 'I don't mind. I am a simple person.'

Noa centres her mother in her own experience and positions herself around her, describing herself as a '*simple person*' in comparison. Hera exhibits a similar agreeableness and, upon seeing her mother cry at hearing another child ring the bell, does not know how she herself feels or should feel (p.83).

Freedom from cancer

Finally, a move away from being consumed by cancer to being free from cancer became evident across narratives. These are reflected in the subthemes: '*lack of agency and control*', '*ridding the self of cancer*', and '*separation from cancer and the return to self*'.

Lack of agency and control. Most children associated their treatment to a time of restriction and lacking control. The dominance of cancer and its physical, social and psychological demand meant that children were stripped of agency, instead having to do things they actively disliked such as taking their medication and relinquishing themselves to procedures.

Aaliya: 'I always tried to stay awake. When I had to have something to make me go to sleep.'

Here, Aaliya tries to stay awake, to resist and stand up to the treatment. Wayne describes a different struggle.

Wayne: 'The worst part was actually when you had to, you know, wait, because you need the injection. So that was the worst part for me, to stay hungry for 3 hours. Also

I thought water would be okay, not food, but I thought water would be good, but there wasn't water too.'

Wayne is stripped of even bare requirements fundamental to existence. By being denied food and water, he evokes an image of being held hostage by the treatment and maybe by extension the cancer. Following a prolonged period of treatment, Sadia expressed her felt lack of agency by questioning whether she would have sufficient muscle to even ring the bell.

Ridding the self of cancer. Children's ports, which accessed their bloodstream, became the symbol of their restriction, and its removal was one step in ridding themselves of cancer. No longer having to ingest oral medication was a further token of clearing themselves and their bodies from the impact of cancer.

*Riaan: 'I wanted to get rid of the line so I could do stuff I wasn't able to do. (...)
Because I wasn't able to go swimming for such a long time because of it. I really wanted to, but I wasn't able to.'*

Riaan goes on to describe being able to return to jumping and having showers without fear of infection. In another description of the port, Lola illustrates a visceral image of it ripping, were she to be too active.

Lola: 'That port, I couldn't go on the monkey bars and I was really upset. Because then my port would rip.'

Wayne: 'I didn't feel it being taken out because I had to have a magic, I think it's like a milk. So that's why I couldn't feel it. I got a photo of how it looked.'

Wayne on the other hand describes the removal of the port and the magic milk, which helped him not to feel. Following the procedure, he is shown a picture of what has been taken out of his body, almost as though needing proof it is no longer within him.

Separation from cancer and the return to self. For Sadia, Wayne, Hera and Lola, the end of cancer treatment also meant reclaiming a self-identity that was separate from the illness.

Sadia: 'I was cancer free!'

With her exclamation, Sadia returns to being her brave self, sliding down water slides, going to the London Dungeons and being brave for both herself and her father. For Wayne, the return to self takes the form of being independent, helping others, be it classmates or baking with his mother. Similarly, Lola describes a role reversal with her elder sister, whom she now supports when having injections; holding, comforting and containing her.

Lola: 'My sister gets scared. And she needs to hold me. Instead of I need to hold her.'

Hera, who was accompanied by her toy monkey throughout the entirety of her treatment, receives an adoption for a real monkey at the end. It is a striking representation of Hera awaking, reclaiming her self and returning to life.

Discussion

Both in their independent and group form, children within the current study told a story both of the joy and the complexity/confusion of reaching the end of their treatment, an end which felt present throughout. Within this, there was a strong sense of ambivalence and contradiction, a push and pull towards and away from the end and its bell, possibly mirroring

the liminal state of neither being sick nor healthy (Frank, 1995). This was further mirrored by the opposition within themes, including remembering and forgetting, the voiced and unvoiced, and the lack of agency and freedom. Nevertheless, to have the end punctuated, marked and celebrated was clearly evidenced as important, yet equally raised significant considerations of how this is done in a nuanced and sensitive way, and in a way which hears children's voices.

The weight and the silence of the end

For all children, the end carried enormous weight. It was deeply longed for by all, yet disbelieved when it finally came. The fragility in the belief of the end was wrapped in self-reassurance as well as silence. Children voiced their certainty that their treatment would come to an end and kept worries regarding treatment completion largely to themselves. Not knowing the place for worry, children were guided by the social repertoire of narratives not only around acceptable ways of speaking about illness (Frank, 1995), but also acceptable ways of speaking about illness as a child (Spyrou, 2016).

Within psychotherapy, endings are often said to elicit anxiety, aggression or silence (Murdin, 2000). Children expressed feeling disempowered and lacking agency during their treatment, and without having their voices actively welcomed at the end, may have fallen into further silence. Their passivity may additionally be a reflection of how much children's environments, be it familial or healthcare structures, encourage and invite the expression of concern (Sisk et al., 2016). If adults around them are unable to voice these and put processes of closure into place, children will follow their lead (Yalom, 2008). By contrast, if given the opportunity, children have been seen to have unprompted conversations about treatment, cure and long-term survival when amongst other children with cancer (Bluebond-Langner et al., 1990). Indeed, children and adolescents have called for peer spaces at the end of their treatment in order to feel understood and jointly make sense of their experiences (Duffey-Lindt et al., 2006, Psihogios et al., 2019). However, without these and without adults making space for the

end in its entirety, children may be left with abrupt and silent endings, having to do the ‘ending work’ and carry its emotional weight in solitude (Finlay, 2016). There is then a danger that need is only picked up at long-term follow up several years later.

Children’s endings cannot be understood without also understanding parent’s endings. Seeing their child come to the end of their treatment may reactivate parent’s own feelings of loss, grief and confusion alongside feelings of relief (Gil & Crenshaw, 2006). This may leave them not knowing what to and what not to discuss with their child. Further, parents shape children’s understanding, appraisals and re-appraisal of their past experiences and how these are remembered (Noel et al., 2019). Particularly when considering the age of participating children and the parental role of mediating and acting as a gateway to their children’s experiences, parents need to be supported to support both their child and themselves. Whilst there is currently thought and resources put into supporting parents to have conversations with their child at the beginning of treatment (e.g. how to communicate diagnoses, Ranmal et al., 2008; children’s cancer story books, CLIC Sargent, 2021), there is currently little such consideration at the end.

Remembering and forgetting

As well as being unable or not wanting to voice certain aspects, children were not always able to remember parts of their treatment and its end. Whilst developmentally appropriate, this may be understood in several, overlapping ways. First, it may communicate the pain of remembering and the consequent avoidance of doing so. Further, periods of prolonged stress (incl. medical traumatisation) can often interfere with the process of memory consolidation, making it difficult to process memories as a cohesive whole (Marsac et al., 2014; Streeck-Fischer & van der Kolk, 2000). Finally, cancer treatment itself has shown to have neurotoxic effects on brain development, leading to poorer cognition and memory in survivors of cancer (Kazak & Noll, 2015; Siegwart et al., 2020). However, the patterns of remembering

the positive and forgetting the more difficult parts of treatment points towards the former hypotheses. The gaps in children's memories therefore indicate a need to help children consolidate and process their experience of treatment once it comes to an end.

The construction and celebration of the end

Across all children, the end was constructed as an achievement to be celebrated in various ways. It was clear that celebrations were important to children, symbolising freedom, a chance to have fun and be active once again. However, the sole focus on and expectation of celebrating the end may have further prevented children from expressing and being able to process other emotions brought about by their end of treatment. Particularly, subtle hints of uncertainty about cancer recurrence and questions whether cancer ends with treatment end were left unattended (Ander et al., 2018; Patenause & Last, 2001).

Moreover, framing the end as an achievement brings into focus questions of what narrative is constructed for those children who do not come to the end of their treatment or those who relapse. Does this imply they were any less brave or did not fight hard enough to achieve? Completing treatment both deserves recognition and celebration and it needs to remain mindful of constructing it as a result of individual personal effort or attributes for those who are faced with different or multiple treatment endings.

The end of treatment bell

The end of treatment bell was further seen as integral to ending treatment by all but one child. Although the cultural meaning behind the bell, which is often connected to religion and tradition (Parker & Spennemann, 2020) and may therefore evoke different emotional responses in children from differing backgrounds, was not explored within the study, the bell's importance was notable. This was particularly highlighted by COVID's interruptions to endings, with some children feeling they had not fully reached the end without ringing the bell. However, they also expressed a level of pain associated with the bell. As well as providing

determination throughout treatment, the bell created a deep sense of longing and envy. Moreover, it should be noted that this pain can only be understood within the context of recovery, again questioning the experiences of children who hear the bell, yet do not get to ring it.

For most children the bell ceremony brought about a level of discomfort. Children experienced feeling intruded upon and exposed during the ceremony, especially when feeling tired or weakened from the medical procedures earlier that day or by not knowing everybody who attended the ringing. The nuanced intimacy of celebrating life appeared to get lost against a brash celebration of the end. Taking together the conflicting feelings of hearing the bell and of the ceremony surrounding it, services may need to reconsider where the bell is best placed, when celebrations are held and who joins the child in these celebrations. Within this, individual preference of the child cannot be forgotten nor assumed.

Considering the complexity of feelings children are left with at the end of their treatment, questions need to be asked as to whether the bell is sufficient in terms of service provision and who it currently serves most. At present, not much more space or closure is given to children the end, with end of treatment beads not being awarded despite children receiving these for all other treatment milestones, and children being discharged and losing regular contact with some of the people closest to them during their treatment. It further raises questions about staff's own experiences of their patient's treatment endings and any difficulties they may face associated to this, which may lead to endings receiving the little attention they currently do. More thought needs to be placed on how endings are managed, allowing a certain freedom from cancer and an ability to move on against a backdrop of uncertainty. One must ask oneself, does the bell currently abdicate responsibility for thinking about the complexity of this?

Limitations

The current study is not without its limitations. All children who participated were referred by the haematology team and had acute lymphoblastic leukaemia, a cancer with the best prognosis for recovery. Whilst not excluded on its basis, none of the children had histories of relapse or poor prognoses. Combining this with the exclusion of those with safeguarding issues, being too unwell, and/or communication difficulties, the sample may have been biased in favour of less complex treatments and endings. Two families decided against participating, explicitly stating not wanting to discuss their experiences, potentially indicating the difficulty in doing so. Without detracting from the pain and suffering experienced by the participating children, the experience of the ending represented here can therefore only be understood within the context of positive treatment outcomes and a willingness to reflect on experiences. In line with IPA principles, the study does not attempt to generalise its findings beyond its participants.

All children asked for their parent/s to remain present during the interviews. Whilst this undoubtedly facilitated the conversation, it may have simultaneously contributed to the silence of not knowing what to voice with parents present. If the timeframe had allowed, more time could have been spent meeting children and building confidence in completing parts of the interview on their own. Although children were asked to bring drawing materials, these were not used, with the online format making it more difficult to encourage this. The interviews therefore relied more heavily on spoken communication.

Finally, credibility checks were completed to minimise losing the children's voices within the research. However, considering the power imbalances inherent within child-adult dyads, children may not have felt able to contradict the author, instead confirming their interpretations.

Clinical implications and further research

The current study highlights the complexity of children completing cancer treatment as well as the need to consider how endings are appropriately marked and celebrated. As such, the following clinical implications and areas for future research are suggested:

- To consider providing services that support children with the range of emotions such as joy, confusion, envy, fear and shock at the end of treatment and the silence that follows, so that the ending is managed in ways that align to children and help them understand what is happening.
- To consider providing parents with support to manage both their child and their own endings. Further research may be needed to explore what support parents would find most helpful.
- To continue to research and consult children, families and staff on matters of the end of treatment bell. Whilst participants have raised the dilemma of the bell being both a symbol of determination and of pain, the current research has generated more questions into the positioning of the bell (for example whether the bell should remain visible and audible on the ward or whether it should be moved to a more private space), as well as how the bell ceremony is performed (first, how children are invited to choose for or against partaking in the ceremony, as well as at what timepoint the ceremony is held and who is invited to attend). These questions have not been posed in the current research, yet need to be further researched in order to ensure that specific preferences of children are carefully elicited and honoured and services are provided in line with such preferences.
- To conduct research into experiences of children with differing ending experiences, including those who have relapsed or transitioned into palliative care.

Conclusion

In conclusion, speaking of the long-awaited end, children highlighted the importance of punctuating and celebrating the end of their treatment. However, their responses simultaneously call attention to the need of ending treatment in a considered and appropriate way, which allows children to understand, process and find space to voice their experience and what is to follow once treatment has come to an end.

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Part 3. Critical Appraisal

Critical Appraisal

The following critical appraisal comprises of a summary of the main reflections that occurred whilst conducting the research as well as upon its completion. It will reflect on personal assumptions brought into the research, including endings as loss, the dichotomy of the ending, the construction of the end as finite, and the value of endings in therapy, before turning to thinking about interpreting children's voices and the silence of cancer.

Personal assumptions

Within the Interpretative Phenomenological Analysis (IPA) framework, it is understood that any attempt to make sense of data will include projection (Smith et al., 2009). As such, the interpretations made cannot be understood without my preconceptions (Heidegger, 1962), namely prior experiences, assumptions and biases that may shape how I perceived the data (see reflexive statement p.68). It therefore should be noted that another author, with different personal and clinical experiences, may have arrived at other, yet equally valid, interpretations.

Although understanding that preconceptions can only ever be arrived at in part, I conducted a bracketing interview with a clinical psychologist prior to the study interviews (excerpts of which will be presented in italics below), as well as keeping a reflective journal throughout, in order to increase my awareness of my own perceptions. Further, I regularly checked in with my supervisors throughout the interview and analysis stages of research, to reflect on my assumptions and, in keeping with IPA, to ensure a balance between my own interpretations and staying close to the participant's accounts. By attending to my own assumptions throughout, I hoped to be more receptive of novel perspectives and those that differed from my own, as well as being able to move into providing an increasingly contextualised account of children's experiences of ending cancer treatment. The most pertinent thoughts and assumptions are discussed below.

Endings as loss

Reflecting on my own position towards endings, I came into the research with an assumption that with endings comes change and with change comes loss. The trauma and difficulty I believed to be inherent in endings within cancer treatment was further part of what initially drew me to the research area. Whilst engaging with the wider literature on paediatric oncology, I realised that most studies centralised distress and maladjustment, at the expense of telling stories of resilience and coping (Wakefield et al., 2010). Indeed, there seemed to be a dominant narrative of vulnerability within children with cancer, which matched my own assumptions of cancer.

'I was reading a systematic review and one of their limitations was around how cancer and its endings are perceived quite negatively. And I think it clicked with my perceptions of endings being quite difficult.'

The difficulty of endings in my own life made me aware that I too could be biased towards exploring and giving more space to negative or difficult endings. Given that the difficulties within endings became a large part of what children spoke about or communicated, I had to remain aware of whether difficulty was the only thing I was hearing during the interviews and seeing within the analyses because of my own preconceptions, and continuously reflected on how much space I chose to give this within my write up.

At the same time, during the interview process as well as during various other points including attending a cancer sports day, I became acutely aware of the resilience inherent in every single child I spoke to, no matter where in treatment they were. It made me wonder why fewer spaces are given to resilience stories, outside of the more 'obvious' recovery stories. It further made me reflect on how the association between resilience and successful treatment

(and the subsequent construction of the end as an achievement) may overshadow other examples of resilience during and outside of treatment. It further made me wonder whether there is a shared fear of recognising children as resilient until the end of treatment, which may feel like a more emotionally safe time to do so.

The dichotomy of the ending

Within the process, I noticed myself being pulled into framing the end as dichotomous, namely thinking of the end as being either difficult or easy, or either good or bad, particularly when thinking about the bell.

‘I’ve just realised even my language in the interview is binary, asking about anything good that happened and anything bad that happened. That already frames the end as dichotomous.’

However, rather than changing the wording within my interview, I decided to keep the structure (which had also been reviewed and approved by the Young People’s Forum) and to attend to following up on children’s responses as they arose. Being aware of my binary thinking allowed me to recognise the very nuanced ways that endings were both ‘good’ and ‘bad’ and somewhere in between for children, in complex and intertwined ways.

In hindsight, I recognise that binary discourses about the bell exist in the wider society, with the charity’s advertisements for the bell portraying it as something wholly positive, and the adult literature on the bell being split between those arguing for its use and those arguing against it. I also wonder whether societal, and by extension my own, ideas of the ending or the bell being either good or bad reflect the wider binary notions of sickness and health and the opposition these are often placed in (Frank, 1995).

The construction of the end as finite

Within my own life, endings have often felt somewhat final. They felt almost boundaried, with clear ends and clear beginnings. It was only when analysing the data for the systematic review that I realised my construction of the end as finite, which contrasted and was challenged by children and adolescents' on-going experiences of cancer. The initial title 'Children and adolescent's experiences of the end of cancer treatment' suddenly felt it was portraying the end as too concrete, and so 'The continuity of cancer' was added to its beginning.

However, the continuity expressed by adolescents within the systematic review did not seem to match the more definite end children expressed within the empirical paper. This difference may be understood developmentally, with adolescents understanding the end in abstract terms, whereas children viewed the very concrete removal of the port as cancer being over. This further led to children reassuring themselves that there must be an end to the endlessness. Thinking about it now, just like the children, my own construction of the end as finite may have created a sense of safety for myself, one that may have made researching the otherwise incomprehensible phenomenon of childhood cancer more tolerable for myself.

The value of endings in therapy

During my training, I was struck by how much time and space was given to endings within some therapeutic approaches, with some focusing on the end from the very beginning (Finlay, 2016). I felt myself particularly drawn to the use of goodbye letters as a way of retelling the story of therapy, reflecting on the process as a whole, and bringing therapy to a close (e.g. Denman, 2001).

'I think this training was the first time I maybe thought about giving endings a bit more space and time. Because I think before training, the concept of endings wasn't a thing,

you do your Assistant Psychologist work and then that comes to an end, but I never thought of the meaning of that ending.'

The importance I placed on attending to endings increased over training and with some clients, it felt like the most impactful part of therapy. I was particularly struck by the power of clients writing their own goodbye letters and being able to recount their experiences of therapy. Again, I was aware that these experiences could shape the meaning I found children to give their ending, potentially looking for confirmation that they too needed space at the end, and was cautious to lay my experiences aside as much as possible to explore what significance children gave their ending and how they would like these to be marked.

Interpreting children's voices

With a shifting view that research should be done *with* children rather than *on* them, increased effort has been placed on giving children a voice, particularly by use of qualitative methodology (Facca et al., 2020). However, how this voice is heard (methods) and understood (analysis) highlight both the importance of thinking about the analytic process and the power within this, which give meaning and value to the voices of children (Spencer et al., 2020). There is therefore a possibility that without a reflexive stance to conducting research with children, the data may merely re/present adult researchers' aims rather than allowing space for the multi-layered and complex voices of children. Further, the very notion of 'giving voice' to children may be problematic, implying that children do not already own a voice or an opinion, and therefore the voice and its truth need to be found by the researcher (James, 2007). As evidenced within the current research, children very clearly have a voice, including when this is expressed through silence, and so I saw it as my position to provide a space for this voice, rather than claiming to give voice. As part of this, and in order to view children as individuals

within their own right, I chose to give participants names to remind the reader of the characterful children behind the data.

Following on from the above reflections on my assumptions, I believe the worlds of children presented in the current research to be co-constructed. Within this, I was cautious not to lose the essence of children's voices when making interpretations. At times, I found it difficult to balance my 'adult' interpretations with children's accounts, yet continuously tried to ground myself in their developmental context and brought any dilemmas into conversations with my supervisors. As an example, I struggled to know whether children's perceptions of time warranted being a theme. I was deliberating whether misplacing stickers received from doctors during treatment could be interpreted as children wanting to leave their experiences behind, or whether it was indeed quite typical of any eight-year-old not to keep hold of something they received in previous years. Further, some children expressed feeling like their treatment ended a long time ago and again I debated whether this was related to wanting distance from the experience, or whether one and a half years in the life of a nine-year-old did feel like a long time. Being an adult who has also been a child, I tried to hold on to my own experiences to make sense of children's stories, as well as being able to put these to one side in order to move closer towards what the children were saying. At the same time, interpretation is key to understanding any child's voice (Carnevale, 2020) and so I was cautious not to simplify their experiences by staying at face value.

Further, although transcripts varied substantially in length, I took care to give each participating child similar space within the paper – a focus which aligned itself to the ideographic ideas of IPA. Within this, I was mindful to attend to silences as much as to spoken words, with the belief that silences and non-verbal communication may in fact tell us equally if not more about children's perspectives and contribute to a thick description of their experiences (Carnevale, 2020; Facca, 2020).

Finally, the interpretation of children's voices cannot be understood without thinking about the impact of COVID-19. The pandemic may have intensified children's worries, particularly around sickness and health. Equally, it may have brought experiences and memories of being unwell, needing to stay in isolation and being categorised as vulnerable closer to the surface, possibly adding to the silence.

Power within the context of child research

Whilst aiming to attend to power imbalances inherent in participant-researcher and child-adult interactions, the co-produced voices of children within the current study remained defined by my own power and adult framework. What could and what could not be expressed within the interview was, in part, based on how I asked my questions and responded to children's answers (Spencer et al., 2020). However, I took care to jointly develop children's narratives, taking turns to lead and follow the conversation and remain attuned to children. This also meant diverting from interview topics at times and taking children's leads, for example having conversations about my favourite chocolate when asked this by a child in the context of her describing the chocolate cake she made for the end of her treatment.

It should be noted, however, that the use of semi-structured interviews ended up relying more heavily on children's ability to articulate, conceptualise and remember their experiences of the end of their treatment, and I wonder whether this format amplified or made it more difficult for children to both voice and remember these. Recognising the limitations imposed by the power differential, research on conducting studies with children is increasingly calling for art-based communication to be considered within study designs to allow children to express themselves outside of verbal communication (Cladairou-Bessetter et al., 2020). Would the format have allowed me to support children to use drawings, a different, possibly fuller, sense of children's experiences and perspectives may have been gained.

It is further unclear what effects conducting the interviews via video call rather than in person due to COVID-19 had on the children. On the one hand, it may have been more difficult to build rapport and encourage children to speak. On the other hand it may have given children more choice, for example, the choice of turning off the camera at points where they felt overwhelmed.

Further, within the analysis, the choice of what would be featured in the results was mine (e.g. excluding the above described perception of time), again highlighting the power of adult voices choosing and shaping findings within child research (James et al., 2007). In order to address this, in part, member checks were conducted with three children. This allowed the children to verify any initial interpretations made, in the hope that this would keep the child's voice at the centre of the findings and move away from a dominant academic voice (Liebenberg et al., 2020). This further allowed children to expand on and clarify their previous descriptions, adding richness to their accounts.

The silence of cancer

In the very first interview, I was struck by how little was said, yet how much was being communicated. This silence wove itself through all interviews, becoming part of various superordinate themes. However, it was not until one of the children spoke the word 'cancer' out loud, that I noticed nobody had said it before her, including myself. I noticed the word becoming a shared taboo, not only within the interview, but seemingly within wider systems, creating a context that shaped children's expectations of what to talk about and what to keep to themselves.

Own silence

Throughout the interviews, I found myself feeling cautious, not knowing how far to take my questioning, particularly around the content of worries or difficulties surrounding children's treatment and its end. Not wanting to distress children and keeping ethical

boundaries of conducting research with children in mind (Kirk, 2007), I found myself hesitant to follow up on questions, particularly when children said they did not know or could not remember. Keeping the above-mentioned power dynamics in mind, I kept the balance between gently exploring difficulties and respectfully moving the conversation on when children signalled wanting to stop.

Prior to the interviews, I also wondered whether death would be something that children would choose to talk about and how I would facilitate the conversation, both if they did and if they did not.

‘Something I was struck by is the absence of talking about death in the literature and my own hesitation about how to go about it if it does come up, or how much to invite it.’

Death was not a topic that children brought to the interviews, however it also remained uninvited by me, both in the interviews and in my interpretations. In retrospect, there is a duality in the end, comprising of both the omnipresent end of treatment and the omnipresent end of life. I imagine that for some children, the end they expected or prepared themselves for was death and that by coming to the end of their treatment, the meaning of the word ‘end’ changed from death to life.

I wondered whether my feelings of caution and shared reticence are reflections of both parents’ and professionals’ feelings around speaking about death (Fredman, 2018) as well as the end with all its complexity; wanting the end to be a final and left behind. However, I also believe that as adults, we must enter children’s worlds gingerly and respectfully and not contribute to and collude with their silence. Indeed, studies, particularly those working with children who are facing their death, have evidenced that death is something children are trying

to make sense of, and are left to do so in lonely ways if adults do not join them (Bluebond-Langer, 1978).

Team silence

Whilst recruitment was completed across both haematology and oncology teams at the study hospital, only the haematology team referred children into the study. The oncology team remained silent. This is somewhat unsurprising, as the haematology team had been more involved in thinking about and setting up the study, with the Clinical Nurse Specialist expressing a special interest in thinking about the end of cancer treatment. However, it is notable that within oncology, treatments and prognoses do not see the same successes as within haematology. The silence may therefore be interpreted as resistance or fear of asking children and their families to talk about their experiences, as many of these may be deeply painful and reflect suffering in ways that differ from haematology (Bartholdson et al., 2014). Oncology staff may have been faced with different, possibly larger ethical concerns when considering recruiting into the study. However, the haematology team was also selective in whom they invited to the study and for whom they deemed the study inappropriate, creating a fine balance between burdening and silencing, and between taking fragility into account and assuming it. Whilst unarguably essential to practice ethically, such risk-based discourses influence whose voices are privileged and made space for within research and whose voices are left unheard (Spencer et al., 2020).

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Appendices

Appendix A. Full list of search term

1 st Stem Group: Type of Population - Children				
Embase	PsycInfo	Medline	CINHALPLUS	Emcare
1. Pediatrics/ 2. Child/ 3. Adolescent/ 4. (child* or kid* or adolescen* or teen* or youth or young person* or young people* or p?ediatric*).mp 5. 1 or 2 or 3 or 4	1. exp Pediatrics/ 2. (child* or kid* or adolescen* or teen* or youth or young person* or young people* or p?ediatric*).mp 3. 1 or 2	1. Pediatrics/ 2. Child/ 3. Adolescent/ 4. (child* or kid* or adolescen* or teen* or youth or young person* or young people* or p?ediatric*).mp 5. 1 or 2 or 3 or 4	1.(MH "Child") 2.(MH "Adolescence"). 3. child* 4.kid* 5.adolescen* 6. teen* 7. youth 8. young person* 9. young people* 10. p?ediatric* 11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9	1. Pediatrics/ 2. Child/ 3. Adolescent/ 4. (child* or kid* or adolescen* or teen* or youth or young person* or young people* or p?ediatric*).mp 5. 1 or 2 or 3 or 4
2 nd Stem group: Cancer				
Embase	PsycInfo	Medline	CINHALPLUS	Emcare
6. malignant neoplasm/ 7. oncology/ 8. childhood cancer/ 9. childhood leukemia/ 10. (oncolog* or cancer* or leuk?emia or tumo?r* or malignan* or lymphoma* or childhood cancer* or p?ediatric oncolog* or p?ediatric cancer*).mp 11. 6 or 7 or 8 or 9 or 10	4. exp Neoplams/ 5. exp Oncology/ 6. exp Leukemias/ 7. (oncolog* or cancer* or leuk?emia or tumo?r* or malignan* or lymphoma* or childhood cancer* or p?ediatric oncolog* or p?ediatric cancer*).mp 8. 4 or 5 or 6 or 7	6. Neoplasm/ 7. Medical Oncology/ or Psycho-oncology 8. Leukemia/ 9. oncolog* or cancer* or leuk?emia or tumo?r* or malignan* or lymphoma* or childhood cancer* or p?ediatric oncolog* or p?ediatric cancer*).mp 10. 6 or 7 or 8 or 9	12. (MH "Neoplasm") OR (MH "Childhood Neoplasm") 13. (MH "Oncology") 14. oncolog* 15 cancer* 16.leuk?emia 17. tumo?r* 18. malignan* 19. lymphoma* 20. childhood cancer* 21. p?ediatric oncolog* 22. p?ediatric cancer* 23. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22	6. malignant neoplasm/ 7. psycho-oncology/ or oncology/ 8. childhood cancer/ 9. childhood leukemia/ 10.(oncolog* or cancer* or leuk?emia or tumo?r* or malignan* or lymphoma* or childhood cancer* or p?ediatric oncolog* or p?ediatric cancer*).mp 11. 6 or 7 or 8 or 9 or 10
3 rd Stem Group: Ending Treatment				
Embase	PsycInfo	Medline	CINHALPLUS	Emcare
12. cancer survival/ 13. cancer survivor/ 14. cancer surviv* 15. end* adj3 cancer treatment.mp	9. cancer surviv* 10. end* adj3 cancer treatment.mp 11. end* adj3 cancer intervention.mp	11. Cancer survivors/ 12. cancer surviv* 13. end* adj3 cancer treatment.mp	24. (MH "Cancer Survivors") 25. cancer surviv*	12. cancer survivor/ 13.cancer survival/

<p>16. end* adj3 cancer intervention.mp 17. end* adj3 cancer therapy.mp 18. cancer adj3 complet*.mp 19. (cancer adj3 transition*).mp 20. end of cancer treatment transition* 21. transition* adj3 palliative care 22. (cancer adj3 end*).mp 23. (cancer adj3 off treatment).mp 24. (cancer adj3 post treatment).mp 25. (cancer adj3 posstreatment).mp 26. (mark* adj3 end*).mp 27. cancer bell.mp 28. bell adj3 cancer.mp 29. victory bell.mp 30. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29</p>	<p>12. end* adj3 cancer therapy.mp 13. cancer adj3 complet*.mp 14. (cancer adj3 transition*).mp 15. end of cancer treatment transition* 16. transition* adj3 palliative care 17. (cancer adj3 end*).mp 18. (cancer adj3 off treatment).mp 19. (cancer adj3 post treatment).mp 20. (cancer adj3 posstreatment).mp 21. (mark* adj3 end*).mp 22. cancer bell.mp 23. bell adj3 cancer.mp 24. victory bell.mp 25. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24</p>	<p>14. end* adj3 cancer intervention.mp 15. end* adj3 cancer therapy.mp 16. cancer adj3 complet*.mp 17. (cancer adj3 transition*).mp 18. end of cancer treatment transition* 19. transition* adj3 palliative care 20. (cancer adj3 end*).mp 21. (cancer adj3 off treatment).mp 22. (cancer adj3 post treatment).mp 23. (cancer adj3 posstreatment).mp 24. (mark* adj3 end*).mp 25. cancer bell.mp 26. bell adj3 cancer.mp 27. victory bell.mp 28. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26</p>	<p>26. end* adj3 cancer treatment.mp 27. end* adj3 cancer intervention.mp 28. end* adj3 cancer therapy.mp 29. cancer adj3 complet*.mp 30. (cancer adj3 transition*).mp 31. end of cancer treatment transition* 32. transition* adj3 palliative care 33. (cancer adj3 end*).mp 34. (cancer adj3 off treatment).mp 35. (cancer adj3 post treatment).mp 36. (cancer adj3 posstreatment).m p 37. (mark* adj3 end*).mp 38. cancer bell.mp 39. bell adj3 cancer.mp 40. victory bell 41. 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40</p>	<p>14. cancer surviv* 15. end* adj3 cancer treatment.mp 16. end* adj3 cancer intervention.mp 17. end* adj3 cancer therapy.mp 18. cancer adj3 complet*.mp 19. (cancer adj3 transition*).mp 20. end of cancer treatment transition* 21. transition* adj3 palliative care 22. (cancer adj3 end*).mp 23. (cancer adj3 off treatment).mp 24. (cancer adj3 post treatment).mp 25. (cancer adj3 posstreatment).mp 26. (mark* adj3 end*).mp 27. cancer bell.mp 28. bell adj3 cancer.mp 29. victory bell.mp 30. 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29</p>
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4th Stem Group : Experience				
Embase	PsycInfo	Medline	CINHALPLUS	Emcare
<p>31. experience/ 32. narrative/ 33. attitude/ 34. (experience* or perspective* or narrative* or view* or attitude* or opinion*).mp</p>	<p>26. exp Narratives/ 27. exp Attitudes/ 28. experience* or perspective* or narrative* or view* or attitude* or discourse* or theme* or opinion*).mp</p>	<p>29. Attitude/ 30. (experience* or perspective* or narrative* or view* or attitude* or discourse* or theme* or opinion*).mp</p>	<p>42. (MH 2Narratives") 43. (MH "Attitudes") 44. experience*</p>	<p>31. experience/ 32. narrative/ 33. attitude/ 34. (experience* or perspective* or narrative* or</p>

discourse* or theme* or opinion*).mp 35. 31 or 32 or 33 or 34	29. 26 or 27 or 28	31. 29 or 30	45. perspective* 46. narrative* 47. view* 48. attitude* 49. discourse* 50. theme* 51. opinion* 52. 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51	view* or attitude* or discourse* or theme* or opinion*).mp 35. 31 or 32 or 33 or 34
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5th Stem Group: Psychology

Embase	PsycInfo	Medline	CINHALPLUS	Emcare
36. child psychology/ 37. psychology/ 38. mental health/ 39. "quality of life" 40. adjustment 41. psych*.mp 42. mental health.mp 43. quality of life.mp 44. adjust*.mp 45. need*.mp 46. 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 47. 5 and 11 and 30 and 35 and 39 48. limit 47 to English language	30.exp child psychology/ 31. psychology/ 32. exp mental health/ 33. exp "quality of life" 34. exp adjustment 35. psych*.mp 36. mental health.mp 37. quality of life.mp 38. adjust*.mp 39. need*.mp 40. 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 41. 3 and 6 and 25 and 29 and 40 42, limit 41 to English language	32. Psychology/ or Psychology, Child/ 33. Mental Health/ 34. "Quality of Life"/ 35. Psych* 36. mental health* 37. quality of life 38. adjust* 39. need* 40. 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 41. 5 and 10 and 28 and 37 and 40 42. limit 42 to English language	52. (MH Psychology) or (MH Child Psychology) 53. (MH Mental Health) 54. (MH Quality of Life) 55. psych* 56. Mental health 57. quality of life 58. adjust* 59. need* 60. 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 61. 11 and 23 and 41 and 52 and 60 62. limit 61 to English language	36. child psychology 37. psychology/ 38. mental health/ 39. "quality of life" 40. adjustment 41. psych*.mp 42. mental health.mp 43. quality of life.mp 44. adjust*.mp 45. need*.mp 46. 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 47. 5 and 11 and 30 and 35 and 46 48. limit 46 to English language

Appendix B. Modified Critical Appraisals Skills Programme Checklist

Overall score: 0 = no features present; 1= some features present; 2 = most features present; not relevant

Domain	Features	Comments & Score
1. Was there a clear aim of the research?	<ul style="list-style-type: none"> There is a clear statement of the aims of the research 	Score:
2. Is the qualitative methodology appropriate?	<ul style="list-style-type: none"> Qualitative methodology is appropriate Actions and/or subjective experiences of participants are sought to be interpreted 	Score:
3. Was the methodology appropriate for qualitative research with children?	<ul style="list-style-type: none"> Where younger participants were interviewed, questions were adapted to be developmentally appropriate Methods to engage younger participants were outlined 	Score:
4. Was the research design appropriate to address the aims of the research?	<ul style="list-style-type: none"> The research design has been justified The decision regarding use of methodology has been discussed The decision regarding the use of analysis has been described 	Score:
5. Was the recruitment strategy appropriate to the aims of the research?	<ul style="list-style-type: none"> Selection of participants has been discussed Recruitment issues (e.g. biases) have been discussed Exclusion discussed? 	Score:
6. Was the data collected in a way that addressed the research issue?	<ul style="list-style-type: none"> The setting for data collection has been justified The approach to data collection has been outlined clearly (e.g. semi-structured interview, focus group etc.) Methods of data collection are detailed and explicit (e.g. use of interview schedules, topics etc.) Data recording has been outlined (e.g. audio recordings etc.) Saturation of data has been discussed 	Score:
7. Has the relationship between the researcher and participants been adequately considered?	<ul style="list-style-type: none"> The role of the researchers has been critically examined incl. preconceptions, potential biases during various stages of the study 	Score:
8. Have ethical issues been taken into consideration?	<ul style="list-style-type: none"> Explanation of research to participants clearly outlined and consistent with appropriate ethical standards Ethical issues raised by the study have been discussed (e.g. informed consent, confidentiality etc.) Approval from an ethics committee has been sought 	Score:
9. Was the data analysis sufficiently rigorous?	<ul style="list-style-type: none"> Analysis processes are described in depth e.g. how categories / themes were derived from the data Data analysis completed by multiple reviewers 	Score:

10. Is there a clear statement of findings?

- Findings have been explicitly stated
- Sufficient data are presented supporting the findings
- Data presentation has been justified
- Contradictory data have been presented and taken into account
- Credibility of findings have been explored (e.g. respondent validation, peer review)
- Subjectivity of findings have been discussed (e.g. contextualization, consideration of co-creation of findings, analysis of researcher-participant relationship)
- Limitations of findings have been acknowledged

Score:



Appendix C. End of treatment bell poem

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!

Appendix D. Joint project contributions

The current thesis sat alongside two further DCLinPsy theses by Hida Caliskan and Anastasia Tspia, which explored the experiences of endings in paediatric cancer treatment for parents and staff respectively. All three theses were supervised by separate internal supervisors, however they shared the same external supervisor.

A joint ethics application was submitted, which was put together by all three trainees under the supervision of Dr Kristina Soon and Dr Rebecca Sweet. This included jointly writing participant information sheets to ensure consistency. In line with the ethical requirement set out in this application, the recruitment of participants into the child and parent study was conducted by Ramsay Lochhead Devaraj, the Psychology Placement Student within the treating team. The recruitment into the staff study occurred separate to this. Once Ramsay had obtained consent from families to be contacted by the researchers, names and contact details were passed on to myself and Hida. I contacted families to arrange interviews with the children and Hida contacted families to arrange separate interviews with the parents.

All interviews, the following data analyses and the write-ups were conducted completely independently by all three trainees. Results were purposefully not discussed in order to preserve the individual viewpoints of participants, namely those of children, their parents and staff.

Appendix E. Invitation Letter

3rd November 2020

Dear families,

End of Treatment research project.

Firstly, I hope this finds you all as well as possible in the current circumstances.

I am writing to invite you and your child to participate in research exploring your experiences about your child reaching the end of their cancer treatment. We already know that the end of treatment is a time for families that might be full of mixed emotions. We hope that this research will give us a better understanding of how we can support children and young people and families as they approach the end of their treatment and beyond.

Please find further information about the research enclosed, including details of who to contact should you have any more queries.

A member of the team will contact you in around a week's time to check if you have received this invitation, and whether you have any questions.

Yours sincerely,

signed by

Matron/Lead Cancer Nurse

Haematology/Oncology/Palliative Care

Blood, Cells and Cancer Directorate

Participant Information Sheet (8-10 years)

To be shown and read by parent/carer if required.

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



1. What is Research?

Research is a careful experiment to find out the answer to an important question.

2. Why is this study being done?

We are doing this study to find out how children and young people felt when they finished their cancer treatment.

We also would like to know whether they did anything different or special because it was the end of their treatment.

3. Why have I been asked to take part?

You and your parents or carers have been asked to take part, because you have been coming to (*study hospital*) and have finished your cancer treatment.

4. Did anyone else check the study is OK to do?

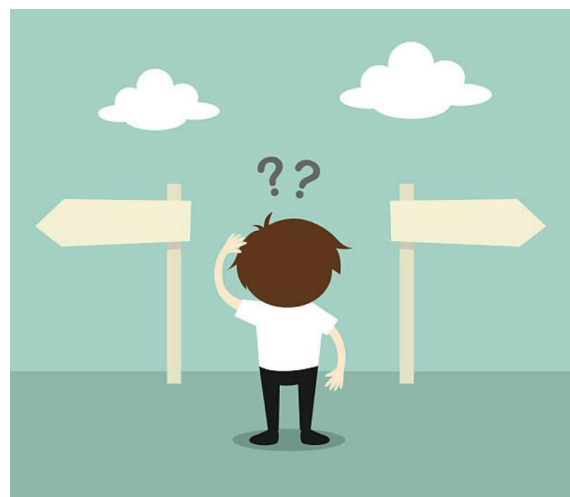
Before any research gets the green light to go ahead, it has to be checked by a group of people to make sure the research is fair.

We have also worked together with a group of young people from the Young People's Forum at (*study hospital*) to check whether they think we are doing it properly.

5. Do I have to say yes?

No – not at all. It is up to you! Just tell us if you don't want to join in. No one will be upset or cross.

Your doctors and nurses will still work with you in the same way and treat you exactly the same as if you were / were not doing the study.



6. What will happen if I want to take part?

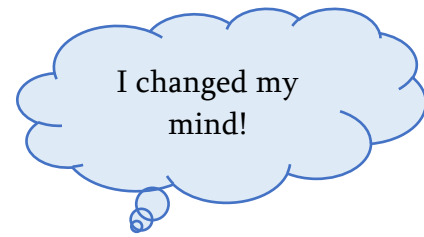


If you want to take part, we will ask you to write your name on a form. This is to tell us that you understand the study.



Then, we will find a time to meet with you at (*study hospital*) or at your home. You can decide!

If the restrictions of the COVID-19 pandemic carry on, we will meet with you via a video call instead. We will send you and your parents an email with a link to start the call.



When we meet with you, we will check if you still want to take part.

You can say no if you have changed your mind.



If you still want to take part, we will ask you questions about what it was like for you to finish your treatment.

This will take about 20 minutes.

Your parents or carers will stay close by and the researcher will be there to help you if you have any questions.





You will get a certificate!



7. Will anything about the research upset me?

Sometimes, when people talk about personal things, it can be a bit sad. So you may feel a bit sad when answering the questions.

You can decide to stop the interview at any point.

Your parents or carers and the researcher (who is also a trainee psychologist) are there to help you feel better if that happens. If you would like more support than that, we can talk about making a referral to the (*study hospital*) psychology team with you and your parents or carers.

If in the interview you talk about something that makes us worried about your safety, we will talk to the right people to help you.

8. Will taking part in this study help me?

Taking part might not help you directly.

Some people have said it has helped them understand their own feelings a bit better and helped them talk to others about how they feel.

We hope that the information we get from this study will help us look after girls and boys who are finishing their treatment at (*study hospital*).



9. What happens when the research study stops?

The research will be talked about and written down, but no one will know that you took part.

10. What if something goes wrong?

If there is a problem, you can talk to your parents or any of the researchers.

11. What if I don't want to do the research anymore?

Just talk to your mum, dad, or carer at any time. They will not be cross with you. You will still have the same care whilst you are at the hospital.

12. What if I wish to complain about the study?

If you want to complain you or your mum, dad or carer can talk to the research team first. If you are still not happy, then we will help you to talk to someone at the hospital.



13. Will my information be kept private? Will anyone else know I am taking part?

All of your information will be kept private. We will only tell your parents.

We might use sentences you have told us, but nobody will know that you said them.

14. Who can I ask if I have questions about this study?



If you have questions or worries about this study you can:

- Ask your parents or carers. They have also been given lots of information.
- You or your parents or carers can talk to the lead researcher on this study:
 - *(name of lead researcher)*, Clinical Psychologist at *(study hospital)*, on *(telephone number)*; *(email)*
- You or your parents or carers can also talk to the researcher and their supervisors:
 - Dr Kristina Soon, Clinical Psychologist and Principal Clinical Tutor, on 020 7679 1897; email: k.soon@ucl.ac.uk
 - Martha von Werthern, Trainee Clinical Psychologist, on 020 7679 1897; email: Martha.werthern.15@ucl.ac.uk

Thank you very much for taking the time to read this. Please ask us any questions if you need to.

Participant Information Sheet (11-14 years)

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

Invitation

We would like to see if you and your parents/carers would like to take part in our research study.

Before you decide if you would like to join in, we would like you to understand what our study is about and what you have to do if you take part.

Please read the information below. If anything is unclear, please feel free to discuss it with your parents/carers. We have sent them some information about our study too.

One of us will be phoning you and your parents/carers in a few days' time. We can answer any questions or worries you have about taking part then.

Our telephone number and email address are written at the bottom of this information sheet. You can phone us with your questions if you prefer.

Part 1 will give you first thoughts about the project.

Part 2 will give you more detail and information you need to know if you still want to take part.

Part 1 – to give you first thoughts about the project

1. Why is this research being done?

We want to try and find out about young people's felt when finishing their cancer treatment. This includes whether they did anything differently or special because it was the end of their treatment.

We hope that talking to you will help us improve the end of cancer treatment.

2. Why have I been invited to take part?

You and your parents/carers have been chosen because you are a patient at (*study hospital*) and have finished your cancer treatment.

We would like to find out more about what it was like for you to finish your cancer treatment.

3. Do I have to take part?

No! It is entirely up to you!

No one will be upset or cross. Your doctors and nurses will still work with you in the same way and treat you exactly the same as if you were / were not doing the study.

If you do decide to take part:

- You will be asked to sign a form to say you agree to take part (this is called a assent form)
- You will be given this information sheet and a copy of your signed assent for to keep.

You can decide to stop talking at any part during the research without telling us why, without anybody getting cross.

4. What will happen if I take part?

We will find a time to meet with you. We can either meet the next time you come to (*study hospital*) for an appointment or we can meet you at your home. We want to know what you prefer!

If the current restrictions due to the COVID-19 pandemic carry on, we will arrange for a video call using a secure platform called Zoom instead. We will send you an email with a link and a password on the day of the interview. Clicking on the link will start the video call and the link will disappear when we finish. If you have any questions about this or want to know more, we will find a time for you and your parents to talk to the researcher about this.

When we meet with you we will check that you are still happy to take part. You can say no if you've changed your mind.

If you are happy to continue, we will start an interview asking you some questions about what it was like for you to finish your treatment. This will take about 20 minutes. Your parents / carers will stay nearby and the researcher will be there to help you if you have any questions.

At the end, you will get a certificate for having taken part.

5. What will I be asked to do?

You will not be asked to do anything extra as a result of the study. You will just be asked to answer the questions as openly and honestly as you can.

6. Is there anything else to be worried about if I take part?

Sometimes when people talk about personal things, it can be a bit sad. So it is possible that you may feel a bit sad when you are answering the questions. Remember, you can stop the interview at any time you want.

If you do feel upset, your parents/carers and the researcher (who is also a trainee psychologist) are there to support you and to help you to feel better. If you would like more support than that, we can talk about making a referral to the (*study hospital*) psychology team with you and your parents/carers.

If we find out something that we think might be important for your health and care, we will talk to your parents or carers and ask them if they want to speak to the team at (*study hospital*) about it. Similarly, if in the interview you tell us something that makes us worried about your safety, we will talk to the right authorised people about this to help you.

7a. Will taking part in this study help me?

Taking part might not help you directly. However, some people who take part in interviews tell us that it can help them to understand their own feelings a bit better and help them to talk to others about their feelings.

We also hope that this study will help us to improve how we look after patients when their treatment at (*study hospital*) finishes.

7b. How will taking part in this study help others?

Helping us to understand how it feels to finish cancer treatment will help us to look after the feelings of other patients at (*study hospital*) who are finishing their treatment, who might feel the same way. We hope that this study will improve how we look after patients in (*study hospital*) when their treatment is coming to an end.

8. What happens when the research stops?

We will collect all the information that young people tell us together and write it up in a report. Nobody will know that you were one of the young people who took part.

9. Who can I ask if I have questions about this study?

If you have questions or worries about this study you can:

- Ask your parents/carers. They have also been given information about this study and they might be able to help.
- You or your parents/carers can contact the lead researcher on this study:

Name: (*name*)

Designation: Clinical Psychologist

Site: (*study hospital*)

Telephone: (*telephone number*)

Email: (*email*)

- You or your parents / carers can contact the researcher and their supervisor:

Name: Dr Kristina Soon

Designation: Principal Clinical Tutor / Clinical Psychologist

Site: University College Hospital

Telephone: 020 7679 1897

Email: k.soon@ucl.ac.uk

Name: Martha von Werthern

Designation: Trainee Clinical Psychologist

Site: University College Hospital

Telephone: 020 7679 1897

Email: martha.werthern.15@ucl.ac.uk

Thank you for reading so far – if you are still interested, please go to part 2 (next page).

Part 2 – More detail and information you need to know if you still want to take part

10. What if I don't want to do the research anymore?

Just tell the researcher or your parents / carer. Nobody will be cross with you. You will still get the same care from your team.

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

Tell us if there is any problem at all and we will try to sort it out straight away. You and your parents / carer can also talk to the project coordinator about this.

Name: *(name)*

Designation: Clinical Psychologist

Site: *(study hospital)*

Telephone: *(telephone number)*

Email: *(email)*

If you have any concerns about the conduct of this study you can contact *(study hospital)* Patient Advice and Liaison Service (Pals) on *(number)* or *(email)*.

12. Will anyone else know I'm doing this?

The people who are part of the research team will know what you are talking about. All information that is collected about you in the study will be kept strictly confidential. This means that you will be given a number which will be used instead of your name. Any information that leaves the hospital will not have your name or address on it so nobody will know it is you.

Once the study is complete, all information will be kept for 6-12 months or kept in your own confidential notes.

Other people who work at the hospital may also look at your medical notes to check that the study is being carried out correctly.

13. Will any genetic or other tests be done?

No tests will be done during or as a result of the study.

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

Once the study has finished, we will write up what we have found in a report. We will present our findings to the team at *(study hospital)* and also put it into a journal so other cancer teams can also read about what we have found.

In our report, we might use sentences you have told us, but nobody will know that you said them.

15. Who is organising and funding the research?

The research is being organised by practitioners at *(study hospital)*. Nobody will get any extra money for doing this research.

16. Who has checked the study?

Before any research goes ahead, it has to be checked by a Research Ethics Committee. This is a group of people who make sure that the research is okay and give it a green light to go ahead. This study has been looked at by a Research Ethics Committee.

We have also worked together with a group of young people from the Young People's Forum at *(study hospital)* to check whether they think we are doing it properly.

17. How can I find out more about research?

To find out more about research at *(study hospital)* in general, you can go to *(website)* or contact the hospital research Facility on *(number)* .

Thank you very much for taking the time to read this. Please ask any questions if you need to.

Appendix H. Participant information sheet (Parent)

Participant Information Sheet (Parents/Guardians – for participation of their child)

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

We would like to invite your child to take part in our research study.

Before you decide if you would like them to join, we would like you to understand what the research is about, why the research is being done and what it will involve.

One of our team members will contact you by telephone in a few days' time and answer any questions you may have. Feel free to discuss this study with your friends and family or healthcare professionals.

Information Sheet Part 1: The purpose of the study and what it will involve

Information Sheet Part 2: Further details and information about the conduct of the study

Part I – Purpose of the study and what it involves

1. What is the purpose of the study?

We know that the end of active cancer treatment marks a significant point and transition in the care pathway of children and young people with cancer. We want to know what it is like for children and young people to come to the end of active treatment, as well as their experiences of events such as the bell ringing ritual, if they chose to do this.

2. Why has my child been chosen?

We are approaching all young people aged eight to 14 years, who have finished their cancer treatments at (*study hospital*) in the past three to eighteen months.

3. Did you consult children and young people about doing the research?

Yes. We have worked together with a group of young people from the Young People's Forum to check whether they think we are doing the study properly and get their suggestions and advice.

4. Does my child have to take part?

No. It is entirely up to you and your child to decide if you want them to participate. We will explain the study and go through this information sheet with you. If you agree to your child's participation, we will ask you both to sign a consent form.

You will be given copies of the information sheet and the signed consent forms to keep for your records.

You can change your mind at any point if you don't want your child to continue. Your decision will have no bearing on your child's ongoing clinical care at (*study hospital*). We will continue to do our best for you and your child.

5. What will happen to my child if I agree for them to take part?

This study involves detailed questions of when your child came to the end of his/her active cancer treatment. It wants to document their feelings and experiences during this transition period. The care your child receives will be unaffected by your decision for them to enter or not enter the study.

The study duration is only the time required to answer questions (maximum of 30 minutes). A translator will be provided should your child require one. If working with an interpreter, the interview is likely to take up to 40 minutes.

The interview will normally be done either at (*study hospital*) on a day when your child is attending an out-patient appointment, or we can visit you at home – whichever you prefer. Members of the research team can arrange a time to meet with your child that is convenient so as not to interfere with them attending the appointment or disrupt their daily schedule. The researchers will have access to a private area in the hospital, such as a clinic room, for your child to complete the interview.

We are also able to carry out video-interviews remotely, if this is more convenient for you and if the current restrictions regarding COVID-19 persist.

If during the interview your child discloses something that makes the interviewer concerned about their safety, the interviewer will have to disclose this information to the appropriately authorised people.

6. What will my child have to do?

Children will be asked to take part in an individual interview. A member of the research team will arrange to meet your child at a time and date that would suit them. If you would like to join your child's interview, we can arrange that.

If the interview is carried out remotely, an online platform called Zoom will be used. Zoom is a secure and encrypted video conference tool that allows to set up meetings and chats online. It is one of the most commonly used modes of online communication used in healthcare. A member of the research team will arrange to meet via the platform at a time and date that is convenient for your child. The researcher will email you a link on the day of the interview. Following the link will allow your child to join the video call. The call will be password protected to ensure security. This link will be deactivated once the interview is completed.

The interview will involve questions around feelings and thoughts regarding the end of cancer treatment as well as whether your child participated or witnessed the bell-ringing ritual and how your child understood and experienced this.

7. How long will the study run for?

Each participant will only need to complete one interview at one time. Therefore, for each participant, their involvement will be over within 30 minutes. The study itself will run for approximately six months or until a minimum of four young people have taken part. We aim to contact patients between October 2020 and February 2021.

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

Sometimes, when people talk about personal thoughts, feelings and experiences, they can start to feel quite emotional. Your child is welcome to stop if they feel too upset. The researcher, who is a trainee psychologist, is there to support your child if this happens.

If you feel your child needs further support, we can discuss making a referral to the (*study hospital*) psychology team with you and your child.

9. What are the possible benefits of my child taking part?

The study will help us understand how it feels to finish cancer treatment and subsequently improve how we look after patients when their treatment at (*study hospital*) finishes.

We do not anticipate that your child will benefit directly from taking part. However, participants in our previous studies have told us that taking part in interviews can help them to understand their own feelings a bit better and to feel ok about having those feelings.

Helping us to understand how it feels to finish cancer treatment will help us to develop our services so that we can help all patients finishing their treatment at (*study hospital*). We hope that this study will help us improve how we look after patients when their treatment at (*study hospital*) finishes.

10. What happens when the research study stops?

We will collect all the information together and analyse children and young peoples' experiences of the ending of paediatric cancer treatment. This will help us to see common patterns and experiences and better support patients during the end of active treatment phase in the cancer journey.

11. What if there is a problem?

Any complaint about the way your child has been dealt with during the study or any possible harm your child might suffer will be addressed. If you have concerns about any aspect of this study, you should speak to the lead investigator of the research team in the first place:

(name of lead investigator)

Principal Clinical Psychologist, Lead Investigator

(study hospital)

(telephone number)

If you remain unhappy and wish to complain formally, you can do this through the normal hospital complaints procedure and contact (*study hospital*) PALS:

(study hospital) Patient Advice and Liaison Service (PALS)

(telephone number)

(email)

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) (*email and telephone number*).

Harm

If something does go wrong and your child is 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.

12. Will taking part in the study be kept confidential/private?

Yes. We will follow ethical and legal practice and all the information in the study will be held in confidence. You can find the details in Part 2.

13. Will we receive a payment for my child's participation in this study or be reimbursed for travel expenses?

If the interview takes place face-to-face on (*study hospital*) premises, we will reimburse for travel expenses. No other payments will be made for participating in the study.

14. What do I do now?

Talk to your child to discuss whether they wish to take part in this study. You can also see what else you and/or your child would like to know about the study before you decide whether to take part.

15. Contact for further information

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

Researchers:

Martha Freiin Von Werthern, Trainee Clinical Psychologist, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. **Email:** Martha.werthern.15@ucl.ac.uk

Research Supervisors:

Dr Kristina Soon, 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:** k.soon@ucl.ac.uk

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

Part 2: More information/details about the study

13. What will happen if I don't want my child or if my child themselves doesn't want to carry on with the research?

Your child can stop being part of a research study at any time, without giving a reason, but the research team will keep the research data about you that they already have. You can find out what would happen with their data before you agree to take part in a study.

Researchers need to manage your records in specific ways for the research to be reliable. This means that they won't be able to let you see or change the data they hold about your child. Research could go wrong if data is removed or changed.

14. What if there is a problem and who can I contact if I have a complaint?

After taking part in a study like this, your child might feel that meeting with a trained mental health practitioner would be helpful. The researcher can discuss options for support with your child.

Any complaint about the way your child has been dealt with during the study or any possible harm you or your child might suffer will be addressed. If you have concerns about any aspect of this study, you should speak to the lead investigator of the research team in the first place:

(name of lead investigator)

Principal Clinical Psychologist, Lead Investigator

(name of hospital)

(telephone number)

If you remain unhappy and wish to complain formally, you can do this through the normal hospital complaints procedure and contact (STUDY HOSPITAL) PALS:

(study hospital) Patient Advice and Liaison Service (PALS)
(email and telephone number)

If you want to complain about how researchers have handled your child's 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) *(email and telephone number)*.

Harm

If something does go wrong and your child is 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.

16. Will taking part in the study be kept confidential?

Participant confidentiality is very important to us. All the information that we gather will be stored using a code number for each participant instead of their name so that it cannot be linked to individual patients or parents. The interviews will be audio recorded and all the information will be stored electronically on the *(study hospital)* network which has very high standards of security, for 15 years, in line with the EU General Data Protection Regulations (GDPR) and the Data Protection Act (2008).

A note will be made in your child's *(study hospital)* patient records that they have participated in this study. The details of their involvement and content of their responses will not be stored in their patient record.

If your child withdraws from the study, we will keep and continue to use all the data that we have already collected from your child. We will not collect any further data.

17. Will the use of my child's 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.

18. What happens to my child's research data after the study?

Researchers must make sure they write the reports about the study in a way that no-one can work out that you took part in the study. Once they have finished the study, the research team will keep the research data for several years, in case they need to check it. You can ask about who will keep it, whether it includes your child's name, and how long they will keep it.

19. What will happen to the results of this study?

When the study is completed, we will share our findings with (*study hospital*) healthcare professionals. We may also present our study at a conference for healthcare professionals and publish the study in a professional research journal. All results shared will be anonymous and will not identify individual participants.

At the end of their participation, your child will also be asked whether they would like to receive a summary of the study findings. If they would, they can provide their preferred contact details (either email address or mailing address) to the researcher who will send you the report in due course.

20. Who is organising and funding this study?

This study is organised by (*study hospital*). The researchers will not be receiving any extra money, over and above their normal salary, for conducting this research.

21. Who has reviewed this study to make sure that it is of sufficient quality?

This study has gone through several reviews. It has been approved by the NHS Health Research Association, and the (*study hospital*) Clinical Research Adoptions Committee

HRA Information Governance Transparency Statement

(study hospital) is the sponsor for this study based in UK. We will be using information from you and your child in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. *(study hospital)* will keep identifiable information about you and your child 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.

(study hospital) will keep your child's name, hospital number and contact details confidential and will not pass this information to anyone else. *(study hospital)* will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from *(study hospital)* and regulatory organizations may look at your child's medical and research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you or your child and will not be able to find out your or your child's name, hospital number or contact details.

You can find out more about how we use your information by contacting *(data protection officer)* at *(email)*

If you and your child decide for them to take part in this study, we will give you this information sheet and the signed consent and assent forms to keep.

Thank you for taking the time to read this information sheet.

Appendix I. Child assent form

Child / Young Person Assent Form

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

Ethical Approval Ref:

Name of Researcher:(Please print clearly)

Child / young person to circle all they agree with:

- | | |
|---|----------|
| Has somebody else explained the project to you? | Yes / No |
| Do you understand what this project is about? | Yes / No |
| Have you asked all the questions you want? | Yes / No |
| Have you had your questions answered in the way you understand? | Yes / No |
| Do you understand it's okay to stop taking part at any time? | Yes / No |
| Do you understand that if you become upset in any way, you can stop the interview and support will be made available to you? | Yes / No |
| Do you understand that anything about you will not have your name or any other identifying information on it? | Yes/ No |
| Do you understand that the interview will be audio recorded? | Yes / No |
| Do you understand that some sentences you say might be used in the report, but nobody will know you said them? | Yes / No |
| Do you understand that if you tell us something that makes us worried about your safety, we will have to speak to the right person to make sure you are helped? | Yes / No |
| Do you want the researchers to contact you so that you can have a look at what the researchers have written and check whether it is right? | Yes / No |
| Are you happy to take part? | Yes / No |

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name _____

Date _____

The researcher who explained this project to you also needs to sign:

Name of Researcher _____

Signature _____

Date _____

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

Appendix J. Parent consent form

Parent / Guardian Consent Form on Behalf of the Children

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

Ethical Approval Ref:

Name of Researcher:(Please print clearly)

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without my child's medical care or legal rights being affected.
3. I give permission for relevant information from my child's medical notes may be passed onto the researchers by the clinical team at my hospital.
4. I understand that the information collected about my child will be stored anonymously.
5. I agree that my child's participation in the study will be noted in their GOSH medical records.
6. I agree to my child's interview being audio recorded and understand that when it is typed up my child's name will not be on the document and any identifying features will be removed.
7. I understand that certain phrases or sentences during my child's interview may be quoted in future reports or publications, but that my child's name will not be included and any identifying features will be removed.
8. I understand that relevant sections of my child's medical notes and data collected during the study may be looked at for monitoring and auditing purposes by authorised individuals from regulatory authorities or from Great Ormond Street, where it is relevant to my child taking part in this research.
9. I understand that if my child discloses anything during the interview which makes the interviewer concerned about my child's safety, the interviewer will have to disclose this information to the appropriately authorised people.

10. I agree to my child taking part in the study.

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

My preferred way of contact is.....

Name of Participant _____

Name of Signatory _____

Relationship _____

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 K. Ethical Approval Paperwork

09/03/2020

PI: [REDACTED]

R&D number: 19SH35

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

Dear [REDACTED]

Thank you for your resubmission to the Clinical Research Adoptions Committee (CRAC) which was reviewed on 6th March 2020. We recognise that you have discussed in detail with [REDACTED] from the [REDACTED] who has now agreed to support the study in particular with some training provision.

The committee have no major objections to the conduct of this project at [REDACTED] although some issues arose in discussion:

1. Please work with the R&D team to clarify some inconsistencies in the patient information sheets and consent forms, e.g. add a check box on each parents / staff consent form for recording of the interview (currently on one but not the other), add a specific box for consent to be re-contacted by the research team, clarify on the parent information sheet whether they are consenting for themselves to be involved, or their child, or in some instances both?
2. If parents and children are to both participate in your study, but the child requested the parent is present during his or her interview, have you considered how or when to interview the parent separately? Presumably in advance of the child interview.
3. Please reconsider including data on those children who do not ring the bell. They should either be included in the research group and their opinions noted, or if they are excluded then please collect some data on the number of exclusions on this basis, to put your final study group into perspective / context.

Decision: Conditional Approval

You will shortly be contacted by R&D Governance who will support you through the process of obtaining the necessary approvals (including UCL ethics) before your project can begin. You must not commence your project before receiving R&D approval. Please find attached further information regarding the next stages in the research administration process.

Regards,

[REDACTED]

Dr Owen Arthurs
Chair, Clinical Research Adoption Committee

[REDACTED]



London - Bloomsbury Research Ethics Committee

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

14 October 2020

[REDACTED]
Principal Clinical Psychologist

Dear Dr [REDACTED]

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 above research 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 documentation as 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;

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

It is the responsibility of the sponsor to ensure that all the conditions are complied with before 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 the start 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 in the 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:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Staff poster]	1	09 July 2020
Covering letter on headed paper [Cover letter]		
Interview schedules or topic guides for participants [Parent interview]	1	09 July 2020
Interview schedules or topic guides for participants [Child interview PPI]	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 of CYP]	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 Werthem 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 non technical language [Data collection 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
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With the Committee's best wishes for the success of this project.

Yours sincerely



**Signed on behalf of;
Reverend Jim Linthicum
Chair**

Email: bloomsbury.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: 

Appendix L. Participation certificate



Certificate of Participation

This award is presented to:

For outstanding participation in a research study about the end
of your cancer treatment

Date:
Signed:



Appendix M. Interview Schedule

Endings in Paediatric Cancer Treatment Proposed Interview Schedule following consultation (*study hospital*) Young Peoples Forum

General introductions to make participant feel at ease

- Researcher to bring a prop to talk about themselves
- Participants to bring a prop to talk about themselves or to bring in memento or photograph of cancer treatment if they so wish
- Adapt wording according to age of participant and include play (e.g. drawings, stars to rate experience) with younger participants

Topics / Key questions

Involvement in study

- Why did you decided to take part in the study?
- What drew you to take part in the study?

Generic questions to remind participants of their treatment / time at (*study hospital*)

- Conversation around what it was like, what they remember
- Prompts: Do you remember the nurses' names, the colour of their uniforms etc.
- Props: e.g. Photographs of the hospital / ward accompanied by questions asking to recall what photograph depicts; medical equipment.

Experience of the Ending

- What does the 'end of treatment / last day of treatment' mean to you?
- When did you find out about your treatment ending?
- How did you find out? Who told you and what did they tell you?
- Do you remember your last day of treatment at the hospital?
- What was it like?
- Was there anything during your treatment that made the end of treatment / last day easier or more difficult?
- **Prompting questions around Feelings**
 - How did the last day of treatment feel for you? [Use feeling images as prompt?]
 - Do you know how family / parents felt?
 - Was it a happy time or a sad time or a mixture?

- **Prompting questions around Thoughts**
 - Was there anything that was good about your last day of treatment?
 - Was there anything that was not so good your last day of treatment?
 - Some kids sometimes feel worried or have other different feelings around the last day of treatment / ending their treatment; did you feel worried?
 - Was there anything anyone did to help with these worries? Is there anything you would have liked people to have done to help with these worries?

- **Prompting questions around Behaviours**
 - Did you do anything or did anybody do anything differently or special because it was your last day of treatment? For example did your family or the staff do anything differently or special?
 - Would you have liked to do something special because it was your last day of treatment? Why or why not?

Marking the ending

- Introduction to bell on (study hospital) ward
 - Did you know about the bell? If yes, how did you find out about it?
 - Did you hear others ring the bell while you were still having treatment?
 - What was that like?
 - Do you think that would be a nice way of finishing treatment?
 - Did you ring the bell at the end of your treatment?
 - Why did you decide for / against ringing the bell?

- Looking back, are there any other ways you would have liked to mark the end of your treatment?

Debrief

Appendix N. Visual Prompts

How Do You Feel Today?

 <p>jealous</p>	 <p>bored</p>	 <p>proud</p>
 <p>happy</p>	 <p>excited</p>	 <p>surprised</p>
 <p>shy</p>	 <p>tired</p>	 <p>sad</p>
 <p>angry</p>	 <p>frightened</p>	 <p>sorry</p>

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Appendix O. Credibility check example extract

Extract 1

R: 'So one theme I thought was about moving away from being taken over by the cancer to finally feeling free of cancer.'

Sadia: 'And yeah, I found that, in a way hard. Do you know what I mean?'

R: 'What do you mean by that?'

Sadia: 'It was hard to be like, oh my god, I'm free, I can actually do stuff. I could go to school if somebody had chicken pox.'

R: 'Mhh, and what do you think was hard about that?'

Sadia: 'I'm not sure, I just wasn't very used to it.'

R: 'So it sounds like you were a bit scared of all the possibilities you now had.'

Sadia: 'Yeah.'

Extract 2

R: 'When I was reading back on what you were saying, it reminded me, almost as if the cancer was a dementor² and it was taking over while you were in treatment, but at the end, it was no longer a part of you.'

Sadia: 'Yeah! So it was like it was a dementor, and in a way I was doing the patromus charm³, which is the charm that keeps them away. Because they can still come back. But sometimes I do that charm in a way.'

R: 'So you are keeping them away.'

Sadia: 'Yeah.'

Extract 3

R: 'And I just had another question around the bravery. So sometimes when we are brave, so when we feel brave, its very easy to feel more and more brave. And sometimes we feel brave when we feel a bit vulnerable or a bit frightened. Do you know which one it was for you at the end?'

Sadia: (Pause) 'Probably vulnerable.'

² Dementor: phantom species who gradually deprive human minds of happiness within Harry Potter novel.

³ Patronus charm: defensive spell which produced a silver, animal guardian, used to protect against dementors.

Appendix P. Excerpts from data analysis

Original transcript with initial notes – Aaliya

Note colours of notes: description (blue), conceptual (purple), linguistic (orange) & parent (green).

Original Transcript	Exploratory Comments
<p>R: You can't remember? That's okay! Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having?</p> <p>P: Yeah.</p> <p>R: Yeah. And do you remember what your worries were about?</p> <p>P: No.</p> <p>R: No? And was there anybody who, who you felt you could talk to about your worries?</p> <p>P: Mum.</p> <p>R: Your mum? Yeah. <i>(pause)</i>. And do you feel like there should have maybe been another person to talk to about your worries? <i>(pause)</i> Or was it enough to talk to mum about it?</p> <p>P: Yeah, mum.</p> <p>M: You don't really talk to me about it at all, do you?</p> <p>P: No.</p> <p>M: He has a counselor at school who he talks to.</p> <p>R: And did you talk to the school counselor about the end of treatment at all?</p> <p>P: Yeah.</p> <p>R: Yeah. And was that helpful?</p> <p><i>(Nods)</i></p> <p>R: Okay good. <i>(pause)</i>. So I can hear in some ways it was the best day of your life because you knew you didn't have to come back to poked and prodded anymore. But there were maybe some difficulties that you spoke to your school counselor</p>	<p><i>Confirmation of worries but worries not voiced. Reminder of cancer and difficulties of treatment? Forgetting. Forgetting difficulties.</i></p> <p><i>Mum as holding worries. Mum between YP and cancer? Position of mum in ending.</i></p> <p><i>Mum as only person needed. Mum as universe.</i></p> <p><i>Difficulty talking to mum re experiences. Cancer experience not talked about. Reluctance to talk openly. Keeping hold of on own.</i></p> <p><i>Speaking to school counselor about end of treatment. Picked up on emotional demand of cancer experience? Space outside of family to talk? Privacy of talking.</i></p>

<p>about. And its quite difficult to talk to other people about.</p> <p>P: Yeah.</p> <p>R: Yeah. That makes sense to me. And you told me a little bit about the bell already. So before we move to the bell, was there anything that anybody did that was special or different on the last day? <i>(pause)</i>. So this could be your family that did anything different, or the staff.</p> <p>M: You rang the bell and they gave you a present.</p> <p>P: Yeah.</p> <p>R: So do you want to tell me a little bit about the bell then. How did you hear about the bell? How did you know about the bell?</p> <p>P: Uh, uh, I saw it.</p> <p>M: You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?</p> <p>P: Yeah.</p> <p>R: And how did you feel when you heard these other people ring the bell?</p> <p>P: Uhm, ah, uh.</p> <p>M: How did it make you feel? Happy, sad, upset, envious?</p> <p>P: What is envious?</p> <p>M: Like when you really want to do it and they are already doing it. Or did it make you happy when someone else was ringing it?</p> <p>P: Envious.</p> <p>R: Envious, yeah, so it sounds like it way quite hard to maybe hear other people ring the bell. Is that right?</p> <p>P: Yeah.</p>	<p><i>Difficulty sharing experience.</i></p> <p><i>Mum jumps in.</i></p> <p><i>Ringing the bell + present.</i></p> <p><i>Seeing bell on ward. Bell as visible. Knowing of bell through seeing and hearing. Hearing bell being rung.</i></p> <p><i>You used to say – more than once. Endless? One day – determination, endlessness, tediousness, longing</i></p> <p><i>Certainty of ringing bell. Self-reassurance</i></p> <p><i>Hesitation</i></p> <p><i>Mother giving 'negative' options – sad, upset, envious.</i></p> <p><i>Happy or sad doesn't quite cut it.</i></p> <p><i>Envy at others ringing the bell. Difficulty of hearing others ring the bell.</i></p> <p><i>Repetition of mothers words.</i></p>
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Emergent Themes	Original Transcript
<p data-bbox="204 510 448 573">Voicing of worries Forgetting difficulties</p> <p data-bbox="204 723 512 752">Mum as containing worries</p> <p data-bbox="204 1003 427 1032">Importance of mum</p> <p data-bbox="204 1144 632 1240">Cancer experience as not talked about Keeping cancer experience to self Not wanting to burden mum</p> <p data-bbox="204 1391 603 1420">Privacy of talking about experience</p> <p data-bbox="204 1877 560 1906">Difficulty of sharing experience</p>	<p data-bbox="810 232 1422 367">R: You can't remember? That's okay! Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having?</p> <p data-bbox="810 405 903 434">P: Yeah.</p> <p data-bbox="810 472 1378 539">R: Yeah. And do you remember what your worries were about?</p> <p data-bbox="810 577 879 607">P: No.</p> <p data-bbox="810 645 1417 712">R: No? And was there anybody who, who you felt you could talk to about your worries?</p> <p data-bbox="810 750 903 779">P: Mum.</p> <p data-bbox="810 817 1406 958">R: Your mum? Yeah. <i>(pause)</i>. And do you feel like there should have maybe been another person to talk to about your worries? <i>(pause)</i> Or was it enough to talk to mum about it?</p> <p data-bbox="810 996 975 1025">P: Yeah, mum.</p> <p data-bbox="810 1064 1401 1093">M: You don't really talk to me about it at all, do you?</p> <p data-bbox="810 1131 879 1160">P: No.</p> <p data-bbox="810 1198 1347 1227">M: He has a counselor at school who he talks to.</p> <p data-bbox="810 1265 1406 1332">R: And did you talk to the school counselor about the end of treatment at all?</p> <p data-bbox="810 1370 903 1400">P: Yeah.</p> <p data-bbox="810 1438 1155 1467">R: Yeah. And was that helpful?</p> <p data-bbox="810 1505 887 1534"><i>(Nods)</i></p> <p data-bbox="810 1572 1417 1794">R: Okay good. <i>(pause)</i>. So I can hear in some ways it was the best day of your life because you knew you didn't have to come back to poked and prodded anymore. But there were maybe some difficulties that you spoke to your school counselor about. And its quite difficult to talk to other people about.</p> <p data-bbox="810 1832 903 1861">P: Yeah.</p> <p data-bbox="810 1899 1422 2033">R: Yeah. That makes sense to me. And you told me a little bit about the bell already. So before we move to the bell, was there anything that anybody did that was special or different on the last day? <i>(pause)</i>. So this</p>

<p>(In)visible bell / Presence of bell</p> <p>Certainty of ringing bell Longing to ring bell</p> <p>Endlessness of treatment</p> <p>Voicing difficulties</p> <p>Envy</p>	<p>could be your family that did anything different, or the staff.</p> <p>M: You rang the bell and they gave you a present.</p> <p>P: Yeah.</p> <p>R: So do you want to tell me a little bit about the bell then. How did you hear about the bell? How did you know about the bell?</p> <p>P: Uh, uh, I saw it.</p> <p>M: You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?</p> <p>P: Yeah.</p> <p>R: And how did you feel when you heard these other people ring the bell?</p> <p>P: Uhm, ah, uh.</p> <p>M: How did it make you feel? Happy, sad, upset, envious?</p> <p>P: What is envious?</p> <p>M: Like when you really want to do it and they are already doing it. Or did it make you happy when someone else was ringing it?</p> <p>P: Envious.</p> <p>R: Envious, yeah, so it sounds like it way quite hard to maybe hear other people ring the bell. Is that right?</p> <p>P: Yeah.</p>
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Individual table of themes – Aaliya

Superordinate Theme <i>Sub-Theme</i>	<i>Transcript</i>	Page / Lines
Remembering / Forgetting		
<i>Remembering good bits</i>	<ul style="list-style-type: none"> • 'Oh yeah. And I got something after from a box when I finished.' • 'And daddy took me to the gaming bit. There was an Xbox there and things. (<i>inaudible</i>)' 	2/4 2/11

<i>Difficulties remembering</i>	<ul style="list-style-type: none"> • 'P: Uhm, uhm. M: What can you remember? P: Uhm, like what?' • M: 'You had a big party. Can you not remember anything?' P: 'No' 	1/9 11/8,9
<i>Forgetting difficulties</i>	<ul style="list-style-type: none"> • R: Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having? P: Yeah. R: Yeah. And do you remember what your worries were about? P: No. 	8/1-4
<i>Inability to forget</i>	<ul style="list-style-type: none"> • R: Do you remember all of this? P: No. M: I do. 	14/1-3
Voiced / unvoiced		
<i>Silence</i>	<ul style="list-style-type: none"> • YP does not speak for a while 	5-6
<i>Not wanting to speak</i>	<ul style="list-style-type: none"> • M: She can't understand you if you have your hand there (<i>in front of mouth</i>). • 'I don't know.' Overall hesitation in speaking 	4/7 7/14
<i>Not knowing what to say</i>	<ul style="list-style-type: none"> • 'P: Uhm, uhm. M: What can you remember? P: Uhm, like what?' • 'I don't know.' 	1/9 7/14
<i>Voicing difficulties / worries</i>	<ul style="list-style-type: none"> • Confirmation of worries, but worries not voiced. R: Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having? P: Yeah. R: Yeah. And do you remember what your worries were about? P: No. 	8/2;4
<i>Privacy of experience</i>	<ul style="list-style-type: none"> • M: He has a counselor at school who he talks to. R: And did you talk to the school counselor about the end of treatment at all? P: Yeah. R: Yeah. And was that helpful? (<i>Nods</i>) 	8/11
<i>Keeping experience to self/ not wanting to burden</i>	<ul style="list-style-type: none"> • M: 'You don't really talk to me about it at all, do you?' P: 'No.' • R: 'And do you remember what you thought when you heard other people ring the bell?' P: 'Uhm, uh. Don't know.' 	8/9,10
<i>Cancer experience as not talked about</i>	<ul style="list-style-type: none"> • M: You don't really talk to me about it at all, do you? P: No. 	8/9,10
<i>Expectation of how to react</i>	<ul style="list-style-type: none"> • 'Best day ever' • 'R: And how did you feel at your party?'. P: Happy (<i>inaudible</i>) 	7/3 12/9
<i>Distance from experience</i>	<ul style="list-style-type: none"> • M: 'You have your own bell, haven't you?' P: 'Oh, but I don't know where that is!' 	11/5;6
Mum as gateway to experience		
<i>Experience mediated through mum</i>	<ul style="list-style-type: none"> • Unsure of question, so turns to mum. Repetition of mother's words • Appealing for mum to step up. Mum whispers answer. • (<i>In response to asking who told P about end</i>) Mum.' 	4/2 5/3 5/8
<i>Mum as containing worries/ Importance of mum</i>	<ul style="list-style-type: none"> • R: And was there anybody who, who you felt you could talk to about your worries? P: Mum. 	8/6
<i>Divergence between mum and P – not shared experience at end?</i>	<ul style="list-style-type: none"> • R: Do you remember all of this? P: No. M: I do. • M: So my view would be completely different, because he still doesn't sleep even now and stuff like that. I notice things like that. 	14/1-3 15/5
Agency / Control		
<i>Endlessness of treatment / Waiting</i>	<ul style="list-style-type: none"> • 'I didn't have to go. I didn't have to keep going and getting needles. They hurt.' • M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' • M: (<i>Day of port removal</i>) 'We were there for so long, that by the time we got home, it was so late.' 	7/5 9/10 13/9
<i>(In)visible bell</i>	<ul style="list-style-type: none"> • (<i>in response to knowing of bell</i>) Uh, uh, I saw it.' 	9/9
<i>Longing to ring bell</i>	<ul style="list-style-type: none"> • M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' 	9/10
<i>Envy</i>	<ul style="list-style-type: none"> • 'Envious.' 	10/6
<i>Self-reassurance</i>	<ul style="list-style-type: none"> • M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' 	9/10
<i>Standing up to cancer / Resisting</i>	<ul style="list-style-type: none"> • 'Oh and I always tried to stay awake... When, when I had to have something to make me go to sleep.' 	3/10;1 2
<i>Separation from cancer?</i>	<ul style="list-style-type: none"> • 'I had my port removed and it felt weird.' 	4/8

Messiness of ending / Contradiction of ending		
<i>Multiple ends</i>	<ul style="list-style-type: none"> Port removal Lumbar puncture 	
<i>Ways of marking the end (or Ways of marking multiple ends)</i>	<ul style="list-style-type: none"> Make a wish M: 'You had a big party.' 	4/12 11/8
<i>End as good / End as best day ever</i>	<ul style="list-style-type: none"> 'Best day ever' (practiced, rehearsed) 	7/3
<i>Celebrating with friends and family</i>	<ul style="list-style-type: none"> R: And who came to that party? P: Friend, family. Yeah. I think that's it. School friends. 	12/3,4
<i>Return to activity</i>	<ul style="list-style-type: none"> P: 'In a big hall. There was a bouncy castle.' M: 'Car machines....Driving simulators, a photo booth.' 	11/14, 16
<i>End of pain</i>	<ul style="list-style-type: none"> 'I didn't have to go. I didn't have to keep going and getting needles. They hurt.' 	7/5
<i>Physical discomfort at end</i>	<ul style="list-style-type: none"> 'I had my port removed and it felt weird.' 	4/8
<i>Keeping hold of ending</i>	<ul style="list-style-type: none"> M: 'You have your own bell, haven't you?' M: 'Driving simulators, a photo booth.' 	11/5 12/2

Overall master table of themes – Aaliya's themes within it

Superordinate Theme Sub-Theme	Transcript	Page / Lines
The omnipresent end		
<i>Endlessness of treatment</i>	<ul style="list-style-type: none"> 'I didn't have to go. I didn't have to keep going and getting needles. They hurt.' M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' M: (<i>Day of port removal</i>) 'We were there for so long, that by the time we got home, it was so late.' 	7/5 9/10 13/9
<i>The tantalising bell</i>	<ul style="list-style-type: none"> M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' 	9/10
<i>Self-reassurance</i>	<ul style="list-style-type: none"> M: 'You used to hear people ring it didn't you. And you used to say that you were going to ring it one day, yeah?' 	9/10
<i>Disbelief at end</i>		
The punctuation of endings		
<i>Multiple ends</i>	<ul style="list-style-type: none"> Port removal Lumbar puncture 	
<i>Celebrating end as an achievement</i>	<ul style="list-style-type: none"> Make a wish R: And who came to that party? P: Friend, family. Yeah. I think that's it. School friends. 	4/12 11/8
<i>The privacy of experience</i>		
<i>Interrupted and incomplete ends</i>		
That which is remembered; that which is forgotten		
<i>Remembering support and togetherness</i>	<ul style="list-style-type: none"> 'Oh yeah. And I got something after from a box when I finished.' 'And daddy took me to the gaming bit. There was an Xbox there and things. (<i>inaudible</i>)' 	2/4 2/11
<i>The pain of remembering</i>	<ul style="list-style-type: none"> R: Some children tell us that they feel quite worried or have different feelings at the end. Was that something you remember having? P: Yeah. R: Yeah. And do you remember what your worries were about? P: No. 	8/1-4
<i>Memorialising the end and leaving it behind</i>	<ul style="list-style-type: none"> M: 'You have your own bell, haven't you?' M: 'A photo booth.' 	11/5 12/2
The voiced and the unvoiced		
<i>Voicing difficulties</i>	<ul style="list-style-type: none"> R: And do you remember what your worries were about? P: No. 	8/2
<i>Keeping experience to self</i>	<ul style="list-style-type: none"> M: 'You don't really talk to me about it at all, do you?' P: 'No.' 	8/9
<i>Parents as voices and gateways to experience</i>	<ul style="list-style-type: none"> Unsure of question, so turns to mum. Repetition of mother's words Appealing for mum to step up. Mum whispers answer. 	4/2 5/3

	• <i>'(In response to asking who told P about end) Mum.'</i>	5/8
Freedom from cancer		
<i>Lack of agency and control</i>	'Oh and I always tried to stay awake... When, when I had to have something to make me go to sleep.'	3/10
<i>Ridding self of cancer</i>	'I had my port removed and it felt weird.'	4/8
<i>Separation from cancer and the return to self</i>	P: 'In a big hall. There was a bouncy castle.'	11/14