



**“The End” of Paediatric Cancer Treatment: A Qualitative Study of
Parents’ Experiences and Needs**

Hida Izel Caliskan

D.Clin.Psy. thesis (Volume 1), 2021

University College London

A thesis submitted for the degree of Doctor of Clinical Psychology

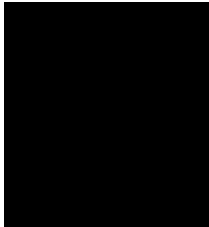
Division of Clinical, Educational and Health Psychology

UCL Doctorate in Clinical Psychology

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.

Signature:



Name: Hida Izel Caliskan

Date: June 14th, 2021

Overview

This thesis explores parents' experiences and needs at the end of paediatric cancer treatment (EoT), focusing on the ringing of the bell ritual (RTB) which is a widespread public ceremony in paediatric oncology wards to mark the end of successful treatment.

Part One is a qualitative meta-synthesis which aims to provide a comprehensive understanding of the experiences, expectations and needs of parents when approaching and at the EoT. The sample consists of twenty qualitative studies. The analysis reveals three analytic themes which are: *discrepancies and dualities: a cautious celebration and desolation, the end is not the end* and *voice, choice, and guidance: informational and support needs*. The study highlights needed future directions for research and clinical practice to better orchestrate the EoT transition and support the needs of parents and families.

Part Two is a qualitative study which uses Interpretative Phenomenological Analysis (IPA) to explore parents' experiences of marking the end of their child's treatment through rituals, particularly the ringing of the bell (RTB) tradition. It is part of a joint project which aims to understand parent, child, and staff perspectives at the EoT. The analysis for the current project reveals six super-ordinate themes which are: *making sense of when "the end" is, meanings attached to marking the end(s), a bell that bonds and divides, for whom the bell tolls: a multi-vocal symbol, the role of staff in ringing the bell, and after the bells are rung*.

Part Three is a critical appraisal which focuses on the meaning and impact of conducting end of treatment research interviews on participants and the researcher during the COVID-19 pandemic. It also discusses issues of power and ethical dilemmas during the research design and analysis stages.

Impact Statement

Over recent decades, there has been an increase in the number of children who successfully transition from active cancer treatment to post-treatment care (Miller et al., 2019). The end of paediatric cancer treatment (EoT) is a critical milestone for parents and a unique point of the cancer trajectory, warranting its own review (Keller et al., 2020). Parents describe the importance of staff marking and acknowledging the EoT milestone which is commonly done through the ringing of the bell ritual (RTB) in oncology wards (Björk et al., 2011). To date, there are no studies exploring parents' experiences of EoT rituals, including the RTB.

Part One of the thesis is a systematic review which identifies the challenges parents' face when approaching and at EoT. This is the first qualitative meta-synthesis to highlight parents' informational and support needs, including the preferred content, source, format, and timing of information delivery. The review makes direct recommendations to hospitals and oncology staff for improving service delivery to promote positive outcomes for parents of children transitioning off active cancer treatment. These include conducting review meetings to identify and assess parents' concerns, fears, and needs prior to EoT; providing formalized education sessions to prepare for the end; delivering individualized support/guidance through directing parents to helpful resources and signposting to relevant organizations. The findings illustrate that the marking of EoT through formal meetings and informal celebrations by staff is an unidentified need with implications for parents' emotional experiences and perceived capacity to cope with the end. It highlights the gap in the literature surrounding marking endings in paediatric cancer. The identified need for further research on marking endings can help elucidate the meanings parents attribute to EoT rituals and celebrations including the widespread tradition of the ringing of the bell (RTB) in oncology wards.

Part Two, the empirical paper explores parents' experiences of marking the end of their child's treatment through rituals, with a focus on RTB. It is the first qualitative study to generate insights into the positive and negative experiences surrounding the bell in paediatric oncology settings. Therefore, the study has implications for the clinical use of bells on a local level i.e., the hospital where the research was conducted, but also more broadly as RTB rituals are common across paediatric oncology wards in the U.K and other countries. The study discusses the critical considerations in implementing the bells which includes the physical location of the bells, witnesses present during the ceremony, and the support available for families affected by the RTB as well as those that wish to ring the bell with planning and carrying out the ritual. It also highlights a need to conduct a Health Impact Assessment (HIA) prior to deciding whether to install or keep the bells and to develop a guide for how staff can support parents with EoT celebrations as well as the period following the RTB. The researcher aims to deliver the study findings to oncology staff at the research site and to disseminate the research through publishing in an academic journal; this has implications for the current care delivered to families.

Table of Contents

Thesis Declaration Form	2
Overview	3
Impact Statement	4
Table of Content	6
List of Tables & Figures	9
List of Appendices	9
Acknowledgements	11
Dedication	12
Part I: Systematic Literature Review	13
Abstract	14
Introduction	15
Previous reviews	17
Current review	18
Defining the End of Treatment (EoT) transition.....	19
Method	20
Inclusion and exclusion criteria	20
Search strategy and study selection	21
Quality appraisal	23
Data extraction and synthesis.....	25
Results	27
Characterisation and quality of the studies	27
Findings	33
Discussion	47
Strengths and limitations.....	50
Implications for practice	51
Conclusion	53
References	54
Appendices	63
Part II: Empirical Paper	70
Abstract	71
Introduction	72

Terminology and definitions.....	73
Marking endings in healthcare settings.....	74
Marking the end of paediatric cancer treatment. – “the end of treatment bell”	75
To ring or wring the bell	76
Rationale for the study	78
Method	79
Epistemological position.....	79
Methodological position	79
Interpretative Phenomenological Analysis (IPA)	80
Background and participants.....	82
Ethical considerations	84
Data collection	85
Data analysis	87
Validity and quality.....	89
Results	92
Introduction.....	92
1. Making sense of “when the end” is.....	94
Multiple and personal endings	94
Port-removal: “the end of the end”	96
COVID-19: the loss of the anticipated end.....	98
2. Meanings attached to marking the end(s)	100
Separating from cancer	100
Dissolving a tension: being a “good” parent.....	102
Forgetting and remembering.....	104
3. A bell that bonds and divides.....	107
An unspoken bond	107
A reminder of the sick and the well.....	109
4. For whom the bell tolls: a multi-vocal symbol	113
Sustenance and hope	113
A (false) sense of security	115
Freedom and return to “normal”	116
Recognizing achievements.....	118
5. The role of staff in ringing the bell	121
“Not just another patient”: Feeling special to staff.....	121
Needing guidance and “a party planner”	124

6. After the bells are rung	126
“Hit” by emotions	126
Loss of support and reassurance	127
Discussion	129
Making sense of when “the end” is.....	129
Meanings attached to marking the end(s)	130
A bell that bonds and divides.....	131
For whom the bell tolls: a multi-vocal symbol	132
The role of staff in ringing the bell	133
After the bells are rung	134
Implications for practice and recommendations	135
Strengths and limitations.....	139
Future directions	140
Conclusion	142
References.....	143
Appendices.....	152
Part III: Critical Appraisal.....	185
Introduction.....	186
Impact and ethical issues.....	186
Methodological concerns	195
References	197

List of Tables & Figures

Part 1 – Systematic Literature Review

Table 1: Search terms.....	22
Table 2: Characteristics of the qualitative primary studies.....	29
Table 3: Quality appraisal of primary studies using the CASP Qualitative Checklist Criteria (Critical Appraisal Skills Programme)	32
Figure 1: Defining the end of treatment transition	19
Figure 2: PRISMA flowchart of sample selections	24
Figure 3: Diagram of themes and sub-themes	28

Part 2 – Empirical Paper

Table 1: Number of participants with demographic information	84
Table 2: Overview of master table for all participants.....	93

List of Appendices

Part 1 – Systematic Literature Review

Appendix A: Master table of themes, subthemes, and codes	63
Appendix B: Table for Theme 2, Subtheme	65
Appendix C: Illustration of ethnographic work for face validity	68

Part 2 – Empirical Paper

Appendix A: Trainee’s contribution to the joint study	152
Appendix B: Ethical approval letter	153

Appendix C: Participant information sheet (PIS).....	155
Appendix D: Participant consent form	163
Appendix E: Interview schedule.....	165
Appendix F: Illustration of exploratory questions/interview extract.....	166
Appendix G: Script for participant research feedback sessions	167
Appendix H: Illustration of feedback received on findings	171
Appendix I: Illustration of colour coded comments in original transcript	173
Appendix J: Illustration of developing super-ordinate/sub-themes for a single participant	174
Appendix K: Illustration of developing super-ordinate/sub-themes across cases.....	178

Acknowledgements

There are many incredible humans I am thankful for as I mark the end of my three-year doctoral journey. I am grateful to all the parents who took part in my research and trusted me with voicing their experiences. I hope with all my heart that I did your stories justice.

I would like to thank my supervisor Kat Alcock for helping me become a reflexive researcher and all the tears and laughter we shared while thinking and feeling together. Thank you to Becky Sweet and Henry Clements for being their caring selves and grounding me during times of uncertainty with this research. Thank you to Kristina Soon for all her support with ethics. Martha von Werthern and Anastasia Tsipa – I couldn't have done this without you.

Thank you to my parents who gave me endless love and support as I pursued this path, across different countries, time zones and distance. I will forever cherish the little desk you bought for me just so I could keep working during the months I stayed with you. Thank you for being the hard-working and caring role-models that you are. I only hope that I can be the same for my own children someday. Sizi seviyorum.

I am grateful to Goodenough College and the community that made London “home” – a feeling I have been searching a long time for. I am thankful for the conversations over dinner at Great Hall, the study breaks outside the London House library, the laughter in our fourth-floor buttery and many more. Thank you to my small common room girls for keeping me company as I wrote this thesis day and night. To name a few of the people who will always have their place in my thoughts and heart: Anupriya Sharma, Erhan Kucuk, Gabriela Cromhout, Inoué Vong Séguy, Rebecca Fox, André Van Parys, Reena Gupta, Jasmine May Cachia Mintoff, Anjali Bhat and Karan Nisar.

Thank you to my friends, colleagues and family who gave me support, both directly and indirectly as I completed this doctorate: Praku Gupta-Stelk, Celeste WanYee Teo, Charlie Cole, Maya Bowri, James Pamment, Irem Ata, Eylul Ozcan, Defne Gabay, Areej Jaffrani, Abigail Enlander, Jasmin Meier, Chloe Thimonier, Omara Baig, Emily Akdogan, Orhun Bergel and Timothy Singham.

To Anne – thank you for helping me to look within myself and all the care and sense of continuity you have given me.

Dedication

This thesis is dedicated to everyone going through their own endings and transitions in their life journey.

Part I: Systematic Review Paper

**Parents' expectations, experiences, and needs at and approaching the end
of paediatric cancer treatment: a qualitative meta-synthesis**

Abstract

Aims: The study aims to synthesize qualitative evidence about the experiences and needs of parents when approaching and at the end of their child's cancer treatment (EoT).

Methods: A qualitative meta-synthesis was conducted from searching five databases. The search identified 660 articles. Forty-two articles were selected for full-text reading and assessed for eligibility; a total of 20 studies conducted across seven countries were included in the final sample and subjected to quality appraisal. The thematic synthesis method was used to analyse the data and the software NVivo® was utilized to support the analytic process.

Results: Three analytic themes were constructed: (1) discrepancies and dualities: a cautious celebration and desolation (2) the end is not the end (3) voice, choice, and guidance: informational and support needs. The end of treatment was experienced as a milestone met with mixed feelings and unexpected losses including the loss of security, safety, and protection. There were feelings of disorientation, fear of relapse and a strong wish to return to "normal". Participants wanted individualized anticipatory guidance at the EoT, psychosocial support to prepare for the emotional challenges ahead and to have the end of their children's treatment be marked and acknowledged by hospital staff.

Conclusions and Implications: Synthesizing the experience and needs of parents when approaching and at the end of paediatric cancer treatment is essential to improve the support families are given. This support can include assessing parents' needs prior to end of treatment phase, providing formalized education to prepare parents and give them voice and choice in relation to marking the end.

Introduction

Childhood cancer survival rates have improved markedly over the recent decades. As of 2018, cure rates as measured in five-year survival increased from 77.1% in 2001 to 85.5 % in paediatric cancer (Office for National Statistics, 2019). This has meant an increase in the number of children and parents transitioning from successful active treatment to post-treatment care (Darcy et al., 2014; Miller et al., 2019). Current guidelines and improvements in survival rates have led research to focus on how families deal with and cope at different transition points in the child cancer care pathway, from diagnosis to treatment, and eventually to survival (Castellano et al., 2010; Hosoda, 2014; Lazar & Musek, 2020; Patterson, Holm & Gurney, 2003). One of the most critical, yet less comprehensively studied transitions in the care practice of childhood cancer is the end of treatment (EoT) period when a child successfully transitions off active cancer treatment (Grassi, Spiegel & Riba, 2017; Stam et al., 2006). While many families report the experience of active treatment as being distressing and look forward to its completion, studies have shown that the EoT can be a period of heightened anxiety, crisis and need for families, particularly for parents and carers (Hosoda, 2014; Keats et al., 2019; Labay, Mayans & Harris, 2004). During the end of treatment, parents report coexisting, and contrasting emotions such as relief and joy, alongside fear and uncertainty (Norberg & Steneby, 2009; Stam et al., 2006). There is a perceived loss of support as the frequency of visits to the hospital decreases and contact with hospital staff is reduced (Labay, Mayans & Harris, 2004). Parents experience worries about having to readjust and recreate everyday life patterns and renegotiate their roles at home and in the community (Hosoda, 2014; Labay, Mayans & Harris, 2004; Maurice-Stam et al., 2007). There is also heightened parental stress and fear around relapse once treatment finishes (Norberg, Lindblad & Boman, 2005; Krivoy et al., 2012); this can leave parents vulnerable to experiencing poor quality of life in psychosocial and physical

health domains during the post-treatment phase (Maurice-Stam et al., 2007; Stam et al., 2006). The ability for parents to deal with different stressors at the EoT may depend largely on the supportive care and information available to them (Hovén et al., 2018). It is critical to understand parents' experiences and needs at the EoT, as parental functioning and coping are critical contributors to the successful adjustment of paediatric patients at transitions (Norberg & Steneby, 2009; Van Dongen-Melman, Van Zuuren & Verhulst, 1998). Parents often act as the child's advocate and the interface between the child and broader system of care e.g., school, medical care. Additionally, they can protect their child from psychological distress if they employ effective coping strategies (Blotcky et al., 1985; Fuemmeler et al., 2003). Parents' experiences and coping will also likely influence the quality of life of other family members, including siblings, not only the child with cancer (Patterson, Holm & Gurney, 2003). In addition, parents have more than a caring role, and are individuals with their own emotional lives, needs, and vulnerabilities; as such, it is important to consider them in their own right (Semple & McCance, 2010). NICE Guidelines (2005) for paediatric cancer care highlight the importance of family-centred care and recommends that parents and carers should be given psychosocial and information support by healthcare staff during the transition from active treatment. Despite the existing recommendations and growing recognition of parent's emotional stress and vulnerability at the end of treatment, there exists a paucity of research exploring the expectations and needs when approaching the transition and completing the treatment (Lie et al., 2015).

Previous systematic reviews

Many reviews have investigated the impact of cancer on parents at the time of diagnosis, during treatment and post-treatment (Gibbins, Steinhardth, & Beinart, 2012; Van Schoors et al., 2015). There has also been extensive research on experiences during the long-term survivorship phase i.e., two years post-treatment or 5 years from cancer diagnosis (Ljungman et al., 2014; Vetsch et al., 2017). Research focusing on the time between approaching the EoT, time of receiving the last active treatment and transitioning to follow-up care is less comprehensive and a unique point of the childhood cancer trajectory that warrants its own review; anxiety and fear are most heightened during this transition from active treatment to early post-treatment, compared to late post-treatment and survivorship phase where parents feel more reassured (Wakefield et al., 2009). There are to date only three reviews on the topic. Previous reviews that explored the completion of childhood cancer treatment focused on psychological functioning of children and adjustment of parents (Wakefield et al., 2009; Wakefield et al., 2011). One review, Wakefield et al. (2011) highlighted parents' experiences between treatment completion and achievement of long-term survivor status, without a focus on the transition from active treatment. The review excluded studies where children had not yet completed treatment and those who were not in remission; this meant that it was not possible to identify parents' expectations and anticipatory experiences when approaching the EoT. Walker & Lewis (2011) looked at adolescent, adult survivors, and parents' experiences at the end of treatment and early post-treatment. The study did not include perspectives of parents of younger children; it is possible that the child's age and developmental stage may play a role in the experiences and needs reported at the EoT. Their review solely reported on studies that looked at negative experiences of ending treatment; there is a need to capture all types of experience including positive experiences for a more inclusive and balanced review.

Most recently, Keller et al., (2020) addressed this limitation and used a narrative synthesis approach to explore the impact and experiences of completing childhood cancer treatment on children, adolescents, and families. Their review focused mainly on family, rather than parents' perspectives, and the early post-treatment phase rather than the end of treatment transition. The review included qualitative, quantitative and mixed-methods studies, which meant that data collection techniques were not uniform across studies. This was limiting in terms of capturing the complexity of parental experiences. Furthermore, the review did not include studies from non-English speaking countries, which resulted in limited cultural diversity. Although the study highlighted the importance of the content, timing and format of information given at the EoT, there was limited knowledge reported regarding what parents wanted this information to look like.

Current review

The current review addressed the limitations identified in previous reviews by including studies from non-English speaking countries, focusing solely on parent perspective during the end of treatment transition and reporting on the content, timing and format of information parents wanted. The review had three key aims: to develop a comprehensive understanding of experiences and expectations of parents when approaching and at the EoT; to identify the informational and support needs of parents and to suggest needed future directions for research and clinical practice to better orchestrate the EoT transition and support the needs of parents and families. Understanding the particularities of the parental experiences contributes to more individualized, family-oriented care practice. The review questions were:

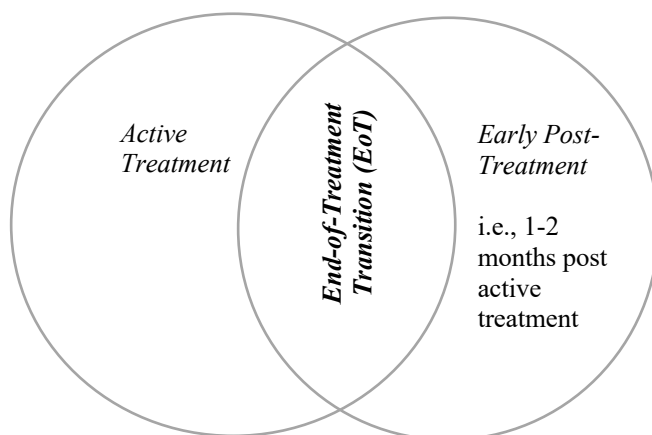
- 1) What are parents' expectations and experiences at and approaching the end of paediatric cancer treatment?
- 2) What are parents' informational and support needs at and approaching the end of paediatric cancer treatment?

Defining the End of Treatment (EoT) Transition

The current review used the end of treatment theoretical framework by Walker & Lewis (2011) as a foundation for defining the EoT transition period. In this framework, EoT was defined by the final dose of active treatment when something is done to fight the cancer and disengagement from healthcare providers to follow up visits. The current study extended this period to include the time from 1-2 months prior to the last treatment and early post treatment (1-2 months post-active treatment) as literature highlights how EoT may not be a definite moment in time but rather a transitional, subjective phase of approaching, completing treatment and moving into post-treatment care (Wilkins et al., 2014).

Figure 1

Defining the end-of treatment transition



Method

The current study is a qualitative meta-synthesis which follows the steps proposed by Sandelowski & Borroso (2003): Formulating the review question, defining the limits of the study, systematic search of literature, selection of articles for analysis, detailing selected articles, evaluating the quality of included articles and creating the meta-synthesis. The researcher followed the recommendations of the ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) to achieve transparency, consistency, and credibility with the meta-synthesis (Tong et al., 2012). The systematic review was recorded on the PROSPERA platform on 23/10/20 (CRD 42020213761).

Inclusion and Exclusion Criteria

Primary studies with methods of collecting and analysing qualitative data that explored the experiences, needs and/or expectations of parents of children and young people (between the ages of 0-18 at the end of treatment) were included. Studies were included if they referred to the end of treatment (EoT) even if the primary focus of the study was not the EoT phase. Studies were included if they explored anticipatory experiences and needs from 1-2 months prior to the end of treatment to the last active treatment. Studies were included if the mean time for treatment completion was between few weeks to a maximum of five years; this was to ensure participants could recall the end of treatment clearly. Researcher included studies if they used semi-structured interviews, focus groups or case studies as the primary method; this was seen to be the most fitting with the aim of the research, which was to provide a rich understanding of parental experiences. The researcher included studies published after 1970. This time period marked increasing success in treating childhood cancers, alongside the

development of formal definitions of family-centred care, leading to a change in the way paediatric departments recognized and incorporated parent and family members into a child's care delivery (Kuo et al., 2012; O'Leary et al., 2009). Researcher excluded studies that focused on parents of children who were now adult survivors (more than 18 years of age); studies that looked at parental experiences at the end of a child's life or unsuccessful treatment; studies that explored the time of the diagnosis, active cancer treatment, early post-treatment and survivorship if they did not include a section, theme or sub-theme related specifically to the EoT period. Exclusion criteria included studies that were not peer-reviewed, and were literary reviews, meta-analyses, secondary analyses, and grey literature (thesis, dissertations, abstracts, posters, editorials). In addition, articles published in other languages than English were included if articles were translated.

Search Strategy and Study Selection

The Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA) framework was used to guide the search and screening process (see Figure 2; Moher et al., 2009). The identification of eligible studies was conducted in a systematic search of the literature and was performed by the researcher across five databases: PsycINFO, EMBASE, CINAHL, MEDLINE and PubMed. The electronic search was complemented by the manual identification of studies through berry-picking and hand searching research literature in paediatric oncology journals and reference lists of relevant articles. The SPIDER tool (Cooke, Smith, & Booth, 2012) was used to develop a search strategy and identify relevant search terms (see Table 1) based on the research question. The first search strategy was developed for the PsycInfo database using combinations of the medical subject heading terms, their synonyms and keywords using the Boolean operators of AND and OR. Researcher consulted an expert

librarian on the search strategy for different databases once they were finalized. Modifications to the search strategy were made depending on the database used as they had different specificities. The search in the database was performed in October 2020. The initial database search resulted in 660 articles. Hand-searching identified 8 additional studies. There was a total of 623 non-duplicated articles. The initial 623 titles and abstracts were screened by the researcher. The eligibility criteria were applied at this stage and from these only 42 were selected. These articles were read in full, along with articles where review was not possible from the abstract alone. Of these, 22 articles were eliminated based on exclusion and inclusion criteria (Figure 1). The three most common reasons for elimination were the lack of a theme or sub-theme related to the EoT phase (n=11), studies having relied on questionnaire or survey data (n=5) and studies being categorized as “grey literature” (n=4).

Table 1

Search terms

Component 1	Component 2	Component 3	Component 4	Component 5
Mother*	Paediatric cancer	End of treatment	Qualitative	View*
OR	OR	OR	OR	OR
Father*	Pediatric cancer	Treatment end*	Interview*	Need*
OR	OR	OR	OR	OR
Caregiver*	Leukemia	Transition	Case stud*	Experience*
OR	OR	OR	OR	OR
Parent*	Brain tumour	Off-treatment	Semi-structured	Persp*
OR	OR	OR	interview*	OR

continued

Table 1

Continued

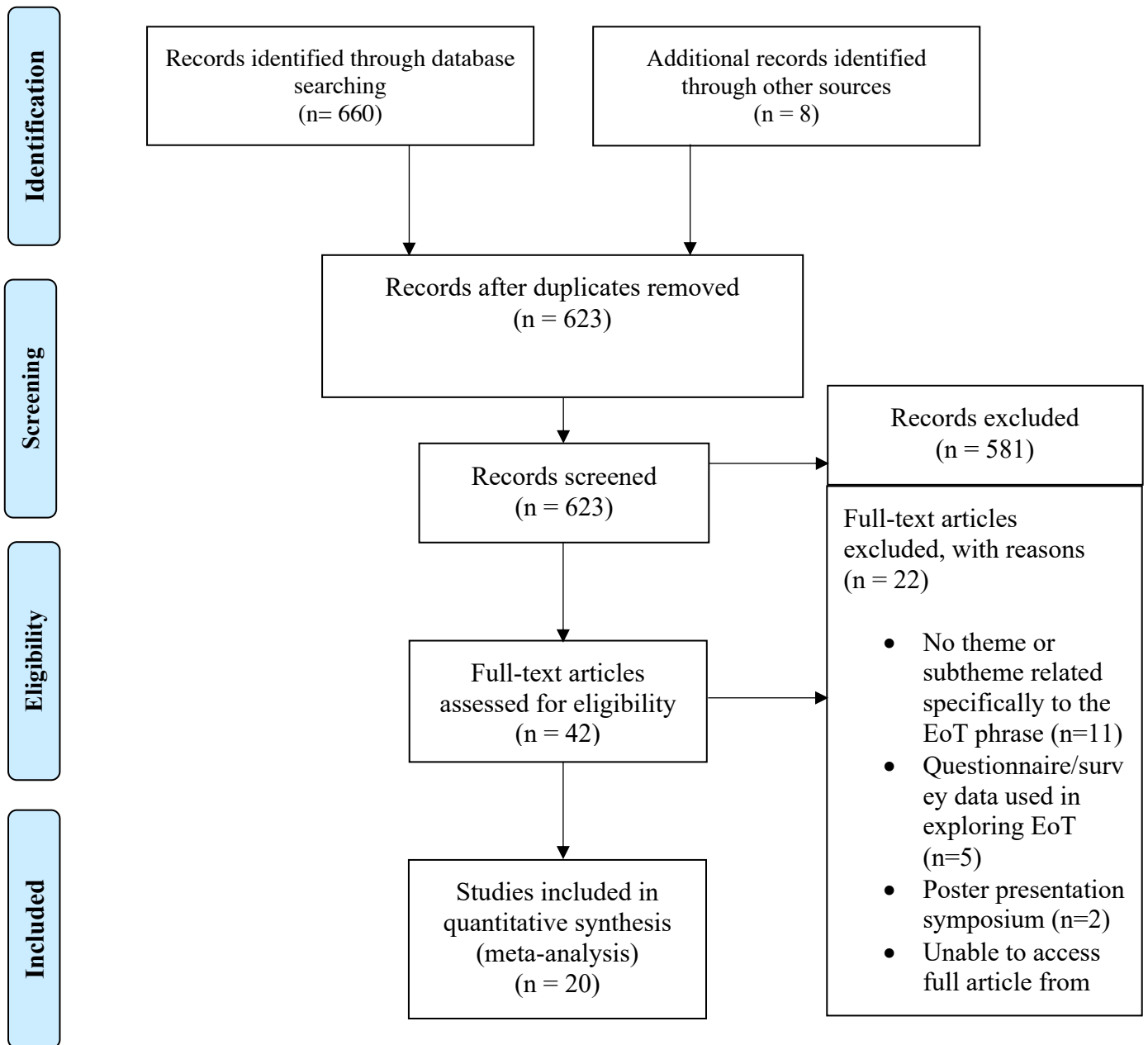
Family	OR	Treatment complet*	OR	Understanding
OR	Brain tumor	OR	Focus group*	OR
Families	OR	Ending		Expectation*
	Lymphoma	OR		
		Finish		
		OR		
		Discharge		

Quality Appraisal

The main researcher and another researcher with expertise in qualitative research independently assessed the quality of the selected papers. The appraisal was conducted using the Critical Appraisal Skills Programme Qualitative Checklist Criteria (CASP, 2018). Divergent results were discussed and, when necessary, a third reviewer was consulted. The outcome of the appraisal did not have implications for the inclusion of the studies as it was solely conducted for the purpose of enhancing transparency and credibility of the research.

Figure 2

PRISMA Flowchart of Sample Selections



Data Extraction and Synthesis

The researcher prepared a data extraction form which included the following information: author(s), place of study, publication year, title of the article, perspective included (e.g., parent perspective or family perspective), characteristics of participants and the child, time since end of treatment, aims of the study, methodology, data collection and synthesis. The thematic synthesis method was used to analyse the data (Thomas & Harden, 2008). Thematic synthesis (TS) allowed the researcher to “go beyond” the primary studies and generate new interpretative constructions and hypothesis. TS was chosen for three reasons: First, it was found to be fitting with the aim of the review which was to aggregate existing evidence and identify patterns within and across qualitative studies that explore parental perspectives near and at EoT. Second, TS allowed to synthesize qualitative data with varying methodologies and reporting styles including thin descriptions and multiple quotations. Third, it offered good transparency and made outcomes accessible to multiple audiences including parents, researchers, and healthcare staff.

The first stage of analysis was to use line-by-line coding with the help of NVivo Qualitative Data Analysis Software. Researcher entered the findings of the studies into the database and free-coded each line of text that referred to the period approaching, and the EoT. These codes were compared and integrated into a common set of codes, staying close to original findings of studies. The second stage involved developing descriptive themes; the researcher explored similarities and differences between the codes when organizing the descriptive themes (see Appendix A). A draft summary of the descriptive themes was shared with another researcher with expertise in TS, to ensure credibility; the discussion led the researcher to make modifications to themes and subthemes until consensus was attained. The

final stage included generating analytic themes; “going beyond” the findings of the primary studies, i.e., third order interpretations (see Appendix B). Analytic themes were once again discussed with another qualitative researcher. To strengthen the analytic process, quotations from parents across different studies were used to ground the findings in the data.

Results

Characterisation and quality of the studies

The sample of this meta-synthesis consisted of 20 studies conducted in seven countries: The United States of America ($n = 7$, 35%), Sweden ($n = 4$, 20%), Canada ($n = 3$, 15%), Australia ($n = 2$, 10%), United Kingdom ($n = 2$, 10%), Brazil ($n = 1$, 5%) and Puerto Rico ($n = 1$, 5%). Studies varied in the qualitative approach used, with a predominance of phenomenology ($n = 10$, 50%) and grounded theory ($n = 6$, 30%). The most commonly used techniques of data collection were semi-structured interviews ($n = 17$, 85%) and focus groups ($n = 2$, 10%). A total of 430 parents of children who finished treatment were included in this meta-synthesis. The time between the EoT and completion of interviews ranged from 2 weeks to 5 years since the final active treatment. One study included interviews that were conducted 1-2 months prior to EoT. Most studies highlighted views and experiences at both EoT and post-treatment phases ($n = 8$, 40%), six focused on experiences at EoT alone ($n = 6$, 30%), and six highlighted the EoT experiences in the context of the child's cancer trajectory ($n = 6$, 30%). Four studies focused exclusively on identifying the educational and support needs of parents at EoT. Details on the characteristics of the studies are presented in Table 2.

The evaluation of the quality of the studies showed that all studies had clear aims that were appropriate with qualitative methodologies. All had research design appropriate to address the aims of the research. Most reported on ethical considerations ($n = 14$, 70%). Only one study reported on reflexivity i.e., the relationship between researcher and participants. Details on the quality of studies are presented in Table 3.

The thematic synthesis allowed for the construction of nine descriptive themes that represent the expectations, experiences, and needs of parents at the end of their child's cancer

treatment. These experiences and needs were later grouped into three analytic themes, that is, *discrepancies and dualities: a cautious celebration and desolation, the end is not the end* and *voice, choice, and guidance: informational and support needs* (see Figure 3).

Figure 3

Diagram of themes and sub-themes

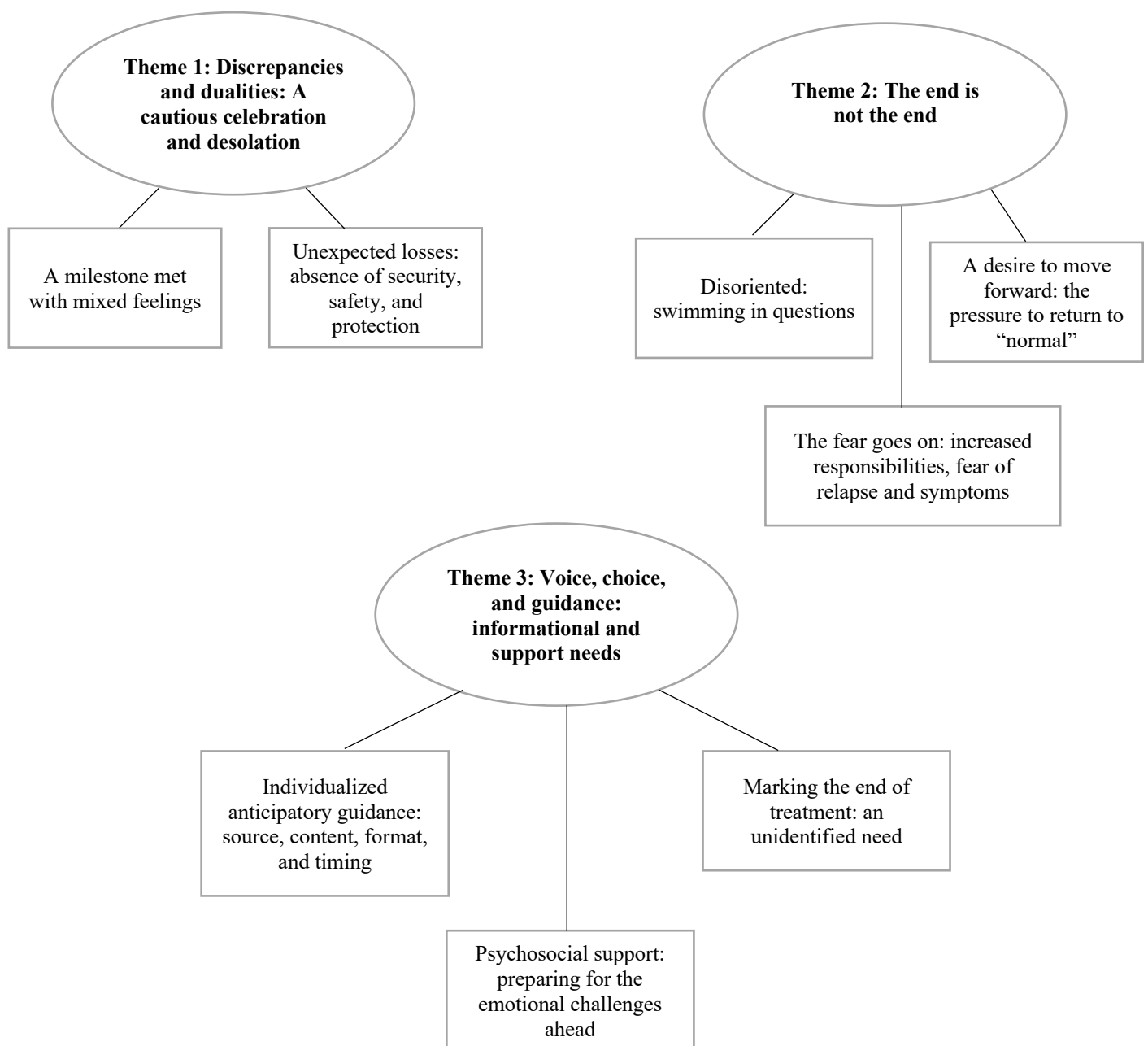


Table 2

Characteristics of the Qualitative Primary studies (N=20)

(Author, year), country	Purpose of the study	Design and methods	Cancer type	Time since EoT	Characteristics of parents and children
(Duffey-Lind et al., 2006), USA	To identify needs and concerns of recently treated adolescent cancer patients and their parents.	Qualitative study; included parent and young people (YP) perspectives; parent focus group (FG) interviews; phenomenological; Content Analysis (CA)	Solid tumours (100%)	1-5 years; median 2.5 years	N=7 parents of adolescents between ages 14-17
(Ortiz & Lima, 2007), Brazil	To understand how parents of children and young people (CYP) with cancer experience the EoT in order to support them to cope with this and future periods.	Phenomenological; study included family perspectives; descriptive, exploratory study; parent semi-structured interviews (SSi)	N/A	N/A	N=9 mothers and N=2 fathers.
(Baenziger et al., 2020), Australia	To explore parents' reflections on their experiences during their child's past, ongoing and future cancer care.	Co-constructivist perspective; parent perspective; inductive, hypothesis generating approach; parent SSi; Grounded Theory (GT)	Most commonly solid tumours(34%), Leukaemia (32.3%).	Average 1.9 years	N=52 mothers, N=6 fathers, age range 22-55 yrs., mean age 40.1 yrs.
(Muskat et al., 2017), Canada	To explore the experiences, feelings, and emotional states of parents of paediatric cancer patients shortly after completion of cancer therapy and to understand the support parents receive and their needs during this time period.	Qualitative methodology; interpretative description; parent perspective; parent SSi; CA	Acute lymphoblastic leukaemia (ALL)	2 months	N=14 mothers, N=3 fathers of children between ages 2-13 yrs., parents age range 32-47 yrs.
(Martinson & Cohen, 1989), USA	To expand knowledge of the impact of childhood cancer on parents and healthy siblings	Longitudinal qualitative study; parent perspective; individual SSi	All cases of childhood cancer	N/A; 5 years since diagnosis	N=5 finished cancer treatment; interviews conducted annually for 5 years after initial diagnosis
(Hobbie et al., 2010), USA	To determine the educational needs of parents as their children complete cancer treatment and begin surveillance and off-therapy follow-up	Parent perspective; FG; CA	All cases of childhood cancer	11-15 months	N=10 parents (7 mothers and 3 fathers)
(Björk & Hallström, 2011), Sweden	To illuminate the families' lived experience after completing a child's cancer treatment	Hermeneutic phenomenological approach: family perspectives; inductive longitudinal design; SSi	Leukaemia, solid tumour, brain tumour	2-11 months	N=10 mothers median 37 yrs., N=8 fathers 36 yrs. of children 7 months-12yrs.
(Wilford, Hopfer & Wenzel, 2019), USA	To identify parent perceptions of clinical survivorship care relationships and to support and develop a thematic model on parent experience after EoT and into LTS	Inductive GT approach: parent perspective; thematic model generated; SSi	Leukaemia, brain tumour, sarcoma	1-5 years	N=20, median age 38.7, child median age 8.2
(Woodgate, 2003), Canada	To discover what it is like for children with cancer and their families to experience cancer trajectory	Interpretative interactionism; longitudinal qualitative research; GT; study included family perspectives; parent SSi	Leukaemia, lymphoma	N/A	N=15 families, children between ages 4-18 yrs.

(continued)

Table 2

Continued

(Author, year), country	Purpose of the study	Design and methods	Cancer type	Time since EoT	Characteristics of parents and children
(Woodgate, Canada 2006),	To describe how childhood cancer shapes a child's and his/her family's way of life	Interpretative qualitative design; GT; study included family perspectives; parent SSi	Leukaemia, lymphoma	N/A	N=39 families, children between ages 4-18 yrs.
(Wakefield et al., 2012), Australia	To explore experiences of young cancer survivors and their parents in receiving information first year after treatment; needs and preferences for information delivery	Phenomenological; thematic; descriptive, exploratory study; included parent and YP perspectives; parent SSi	All cases of childhood cancer	12 months	N=44 mothers and N=35 fathers, parent average 42.5 years, mean child age 16 years
(Walker, Lewis & Rosenberg, 2020), USA	To describe challenges parents experience in the first year after the completion of their adolescent's cancer treatment and what parents did to manage	Inductive CA; parent perspective; SSi	Hodgkin lymphoma, bone tumours, ALL, AML	<12 months	N (mothers)=28 and N (fathers)=2, mean adolescent age 15 years
(McKenzie, et al., 2012), UK	What are parents' experiences of the end of treatment (EoT) transition?	SSi; parent perspective; GT	ALL, solid tumour, osteosarcoma	0-12 months post-treatment	
(Enskär et al., 2020), Sweden	To describe young children with cancer and their parents' experiences of nurses caring practices over a 3-year period, from diagnosis to follow-up	Longitudinal study; included parent and YP perspectives; deductive approach; qualitative CA; parent SSi	Leukaemia, brain and solid tumours	N/A	At maintenance period and follow up N (mother and father) =26
(Rivero-Vergne, 2010), Puerto Rico	To explore reintegration of families into the community after their child's cancer treatment	Phenomenological approach: study included family perspectives; parent SSi; GT	ALL	N/A	N=7 mothers of children who completed treatment for ALL
(Norberg & Green, 2007), Sweden	To increase the understanding of parents' experiences of going back to normal after completed cancer treatment of a child	Inductive thematic method; parent perspective; SSi	Lymphoma and brain tumour	9 and 11 months	N (families)=2, children ages 16 and 13
(Carlsson, Kukkola, Hoven, von Essen, 2019), Sweden	To explore psychological distress experienced by parents who express a need for psychotherapy after curative treatment for their child's cancer	Inductive latent qualitative analysis; parent perspective; parent SSi	All cases of childhood cancer	<1-5 years, median 2 yrs.	N (mothers, median age) =8, 42; N (fathers, age) = 7, 45 median age 38.7, child median age 12
(Karst et., 2018), USA	To determine priorities, unmet needs and survivorship related concerns of CYP and their caregivers at the time of transition to after treatment care	Included parent and YP perspectives; parent SSi	Leukaemia, bone and soft tissue tumours, lymphoma	Time 1(1-2 months prior to EoT; Time 2 (3-7 months post EoT)	N (mother)= 37, N(father)= 10, child average age 10.9

(continued)

Table 2

Continued

(Author, year), country	Purpose of the study	Design and methods	Cancer type	Time since EoT	Characteristics of parents and children
(Firth, Davies & Skinner, 2013), UK	To understand individual needs, the reasons why young people do or do not desire treatment summaries, and the views of family members	study included family perspectives; parent SSi	ALL, extracranial malignancy, tumour	Mean time 4.5 years	N (parents) =49
(Lewis & LaBarbera, 1983), USA	To learn specifically about the psychological experience of terminating chemotherapy, within the context of the whole experience with their child's cancer from diagnosis to present status	Open ended interviews; parent perspective	Leukaemia	A minimum of few weeks to a maximum of 5 years prior to interview	N (mothers)=19, N(fathers)=1

Table 3

Quality appraisal of primary studies using the CASP Qualitative Checklist Criteria (Critical Appraisal Skills Programme)

(Author, year)	CASP questions									
	1	2	3	4	5	6	7	8	9	10
(Baenziger et al., 2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Björk & Hallström, 2011)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Carlsson, Kukkola, Hoven, von Essen, 2019)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Duffey-Lind et al., 2006)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Enskär, 2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Firth, Davies & Skinner, 2013)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Hobbie et al., 2010)	Y	Y	Y	Y	Y	N	C	N	Y	Y
(Karst et., 2018)	Y	Y	C	Y	Y	N	N	Y	C	Y
(Lewis & LaBarbera, 1983)	Y	Y	N	Y	C	N	N	N	N	Y
(Martinson & Cohen, 1989)	Y	Y	N	Y	Y	N	N	Y	Y	Y
(McKenzie, 2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Muskat et al., 2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
(Norberg & Green, 2007)	Y	Y	Y	Y	Y	N	C	Y	Y	Y
(Ortiz & Lima, 2007)	Y	Y	C	Y	Y	N	C	N	Y	Y
(Rivero-Vergne, 2010)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Wakefield, Butow, Fleming, Daniel & Cohn, 2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Walker, Lewis & Rosenberg, 2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Wilford, Hopfer & Wenzel, 2019)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Woodgate, 2006)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
(Woodgate, 2003)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Note. Y= Yes; N=No; C=Can't tell. 1= Was there a clear statement of aims of the research? 2= Is the qualitative methodology appropriate? 3= Was the research design appropriate to address the aims of the research? 4=Was the recruitment strategy appropriate to the aims of the research? 5= Were the data collected in a way that addressed the research issue? 6= Has the relationship between the researcher and participants been adequately considered? 7= Have ethical issues been taken into consideration? 8= Was the data analysis sufficiently rigorous? 9= Is there a clear statement of findings? 10= How valuable is the research?

Findings

Theme 1. Discrepancies and dualities: A cautious celebration and desolation.

The first analytic theme relates to how parents experience the end of treatment in a dual way; whilst the end of curative treatment is experienced as a time of celebration and relief, it is simultaneously experienced as a time of loss and desolation. There is a marked discrepancy between how parents expect to feel versus how they feel at the EoT. The two descriptive themes encompassed by this analytic theme are *a milestone met with mixed feelings* and *unexpected losses: absence of security, safety, and protection*.

A milestone met with mixed feelings

Parents report that they view the EoT as a landmark which they expect eagerly during the intensive treatment phase (Norberg & Green, 2008; Wilford, Hopfer & Wenzel, 2019). Many describe joyfulness, relief, and gratefulness that the EoT is approaching (Björk et al., 2011; Lewis & LaBarbera, 1983; Norberg & Green, 2008; Ortiz & Lima, 2007; Muskat et al., 2017; Walker, Lewis & Rosenberg, 2020), as illustrated by the following quote:

“When we got the news, it caused great joy for me” (Ortiz & Lima, 2007)

Feelings of relief and joy are related to not being compelled to watch their child suffer physically and emotionally from taxing treatment procedures, and the child surviving and being in remission (Norberg & Green, 2008; Walker, Lewis & Rosenberg, 2020; Wilford, Hopfer & Wenzel, 2019), with one parent saying,

“Well, uh I am very happy because things turned out that my son has zero leukaemia in his body. That is what makes us happy” (Walker, Lewis & Rosenberg, 2020). Alongside the expected joy and relief, parents report unexpected emotions like emptiness, disappointment, and vast tiredness at EoT (Carlsson et al., 2019; Norberg & Green, 2008; Muskat et al., 2017; Walker, 2020; Wilford, Hopfer & Wenzel, 2019; Woodgate & Degner, 2003). In the words of one parent,

“When it’s over, it just feels empty, you feel weak, you kind of haven’t landed yet” (Carlsson et al., 2019).

Parents describe feeling disappointed and anticlimactic when treatment finishes (Muskat et al., 2017; Norberg & Green, 2008), with one parent saying

“... the turmoil and... the complete whirlwind and the earthquake that... shattered our lives... and then, you just take this little pill, like that’s it, that’s done? OK. Like it’s just so kind of anticlimactic.” (Muskat et al., 2017).

Many parents describe how the sense of tiredness and feeling weak does not enable them to enjoy the EoT (Norberg & Green, 2008; Woodgate & Degner, 2003). One parent uses the metaphor of running a marathon,

“We had made it but at the same time we had not – we stood there at the winning post, worn out, but got no sustenance” (Norberg & Green, 2008).

The exhaustion and disappointment are further exacerbated if there are treatment related symptoms that linger near the end of treatment. During active treatment, children and their families tend to believe that symptoms will fully resolve when treatment is completed (Woodgate & Degner, 2003).

In contrast to parents who experience positive or juxtaposing emotions, in one study some parents report consistent negative feelings associated with their children ending treatment, without any report of positive emotions (Duffey-Lind et al., 2006). Some parents say the end of treatment marks the beginning of a difficult time, due to having to confront difficult feelings previously shelved (Norberg & Green, 2008; Walker, Lewis & Rosenberg, 2020; Wakefield et al., 2012) as illustrated in this quote,

“Oh dear, when I received the news that the treatment was over... [lowers her head and remains silent] that’s when I started a difficult phase in my life” (Ortiz & Lima, 2007).

Parents talk about how they begin to reflect on their own psychological experiences of the cancer experience at EoT (Norberg & Green, 2008; Ortiz & Lima, 2007; Walker, Lewis & Rosenberg, 2020; Wakefield et al., 2012). One parent describes this as:

“When it ended, it was just such a weird emotion. You’re excited... You finally have a chance to like, breathe. It’s such a let-down...I think it was just so exhausting at the end because ... you just had to keep going during the treatment. When it ended... I finally started realizing what had just happened, what we had actually gone through...”
(Walker, Lewis & Rosenberg, 2020).

Unexpected losses: absence of security, safety, and protection

One of the most frequently reported EoT experiences is related to the distressing loss of felt security and safety that had accompanied the child's active treatment (Enskär et al., 2020; Lewis & LaBarbera, 1983; Ortiz & Lima, 2007; Rivero-Vergne, Berrios & Romero, 2011; Wilford, Hopfer & Wenzel, 2019). Although parents experience active treatment as a difficult time, they report unexpected feelings of "safety" and "security" associated with treatment, seeing the active treatment, regular visits, monitoring and oncology staff as a secure base and means of protecting the child from the disease (Enskär et al., 2020; Lewis & LaBarbera, 1983). The termination of treatment meant less frequent contact with the hospital and team, the loss of a secure base and the relinquishing of the predictor of safety leaving parents to feel threatened by the absence of the team (Enskär et al., 2020; Lewis & LaBarbera, 1983; Ortiz & Lima, 2007; Rivero-Vergne, Berrios & Romero, 2011; Wilford, Hopfer & Wenzel, 2019). One parent says:

"I left the hospital unwillingly. I felt so safe there!" (Rivero-Vergne, Berrios & Romero, 2011).

Parents experience a sense of abandonment by staff and feel they are thrown into a reality far away from the safety of the hospital at the EoT (Baenziger et al., Carlsson et al., 2019; Duffey-Lind et al., 2006; McKenzie & Curle, 2012; Walker, Lewis & Rosenberg, 2020), as captured by this quote

"When they're going through treatment, they are surrounded by everybody. Doctors, nurses, family, everybody... They're the focal point. And as soon as she got the scan that she didn't have cancer any more um, everybody celebrated: it's okay now we are going on to our

life. So, it's almost like when somebody dies and you, you surround that person who's left for the funeral and for the preparations and as soon as the funeral's over and the person's buried, everybody goes back to their normal lives and the person who lost that person is all alone. And it's kinda like that. All of a sudden, you're all alone." (Walker, Lewis & Rosenberg, 2020). Although the experience of loss comes through strongly in the analysis, some parents in one study report gains that they carry to the end and beyond treatment, taking away with them the connections and acquaintances they made with other parents of children with cancer (Björk et al., 2011).

Theme 2. The end is not the end

This theme highlights parents' experience of the end of treatment as not an end as such, but rather a liminal phase – finding themselves 'betwixt and between' different states and roles. At the point of finishing treatment, parents' transition from the certainty that the treatment has, at that point in time, "cured" the disease, to a perpetual state of managing uncertainty and the unknown, as they fear bringing the child home, cancer recurrence and short- and long-term effects of treatment. Parents describe feeling unprepared for the EoT, experiencing the end as abrupt and feeling unprepared in managing the challenges ahead. They describe how the cancer is cured but that the fear continues; there is a sense of feeling trapped between two discrete constructs: illness and health. Parents describe being given the message that their lives should return to "normal", and there is a subsequent sense of feeling invalidated and isolated as a result of both their own and others' expectations. The following descriptive themes consists of *disoriented: swimming in questions; the fear goes on: increased responsibilities, fear of relapse and symptoms; and a desire to move forward: the pressure for things to return to "normal"*.

Disoriented: swimming in questions

Parents report that treatment and support ends very abruptly, leaving them feeling vulnerable and disoriented in an uncharted territory (Baenziger et al., 2020; Carlsson et al., 2019; Duffey-Lind et al., 2006; Mckenzie & Curle, 2012; Wilford, Hopfer & Wenzel, 2019), with one parent saying

“You stop treatment cold turkey, it’s weird” (Muskat et al., 2017).

They describe feeling unprepared to manage the discharge from the hospital (Carlsson et al., 2019; Ortiz & Lima, 2007), the emotional challenges of the transition (Wilford, Hopfer & Wenzel, 2019) and the effects of the end on their sense of identity as a family and a parent (Mckenzie & Curle, 2012). They talk about swimming in questions about EoT and post-treatment, including questions on when life would get back to normal and the possibility of relapse (Duffey-Lind et al., 2006; Muskat et al., 2017; Walker, Lewis & Rosenberg, 2020). They experience subsequent feelings disappointment as illustrated by the following quote

“...but we were a little bit . . . disappointed that we don’t get much...cause the doctor thinks it’s OK, so it’s very normal, it’s very easy, off is off.” (Muskat et al., 2017).

The fear goes on: increased responsibilities, fear of relapse and symptoms

Parents describe how although the active treatment comes to an end, they experience “a fear that will not end” (Björk et al., 2011; Carlsson et al., 2019; Duffey-Lind et al., 2006; Hobbie et al., 2010; Martinson & Cohen, 1989; Mckenzie & Curle, 2012; Muskat et al., 2017;

Norberg & Green, 2008; Ortiz & Lima, 2007; Rivero-Vergne, Berrior & Romero, 2011; Wilford, Hopfer & Wenzel, 2019). One of the most commonly reported fears is about bringing the child home - managing the contrast between having the child be taken care of by healthcare professionals and having to take care of their child on their own (Carlsson et al., 2019; Ortiz & Lima, 2007; Rivero-Vergne, Berrior & Romero, 2011). Parents report finding the shift in responsibility frightening as they question their capacity to cope with the child's health state without the daily support and contact with hospital staff (Carlsson et al., 2019; Ortiz & Lima, 2007; Rivero-Vergne, Berrior & Romero, 2011), as described by this parent

“I think it will be harder after we bring her home, to be honest with you, because I think I will worry more than I do right now, knowing she's in such good care whereas at home, it will be my responsibility” (Martinson & Cohen, 1989).

There is fear that the disease might return when treatment ends as well as worries about not having the child be frequently monitored by doctors and the possibility of missing signs of reoccurrence as parents (Duffey-Lind et al., 2006; Hobbie et al., 2010; Carlsson et al., 2019; Mckenzie & Curle, 2012; Muskat et al., 2017; Rivero-Vergne, Berrior & Romero, 2011; Wilford, Hopfer & Wenzel, 2019; Woodgate, 2006), as illustrated by the following quote

“Why is it depressing to me not to go to the cancer clinic? Why am I so scared? Some of it is if you're not looking at him every week, who knows what's happening.” (Duffey-Lind et al., 2006).

Parents describe having to manage difficult feelings associated with uncertainty, hesitancy and having to manage the unknown regarding the potential for relapse in their child (Mckenzie &

Curle, 2012; Rivero-Vergne, Berrios, & Romero, 2011). Parents also experience the EoT as uneasy and frightening due to increased worries about the short- and long-term side effects of treatment like possibly lasting sequelae implying certain restrictions in daily life (Björk et al., 2011; Enskär et al., 2020; Norberg & Green, 2008; Ortiz & Lima, 2007; Walker, Lewis & Rosenberg, 2020).

A desire to move forward: the pressure for things to return to “normal”

Parents describe a wish, expectation and need for EoT to be “the end”, to move forward from the illness and get back to life as it was before the diagnosis (Björk et al., 2011; Carlsson et al., 2019; Mckenzie & Curle, 2012; Muskat et al., 2017). It feels important to families to “normalize family life” as quickly as possible before the end of treatment and restore pre-diagnosis routines and relationships (Carlsson et al., 2019; Hobbie et al., 2010; Martinson & Cohen, 1989). Although some parents describe regaining their old ways of living (Woodgate, 2006), the vast majority report that their expectations are met with disappointment as they realize that the end of treatment is not the end and that the cancer experience would “never be over with, always a waiting game” (Björk et al., 2011; Walker, Lewis & Rosenberg, 2020; Woodgate, 2006). One parent says:

“I thought everything would be fine, back to normal and it hasn’t been... it’s just surprisingly hard. I just did not anticipate this at all. I thought it would be like flipping a switch, life would be pretty much just, be okay and everything’s back normal.” (Walker, Lewis & Rosenberg, 2020).

Parents express feeling as though they are in a type of continuing care, rather than at the end:

“I think emotionally and mentally the treatment hasn’t ended yet, so all that happened is that he stopped taking his drugs” (Mckenzie & Curle, 2012).

Even those who do not experience the EoT as the end have doubts about whether they will ever be fully over it (Mckenzie & Curle, 2012). Parent’s report how friends and family expect the end to be the end and for them to go back to “normal” (Björk et al., 2011; Mckenzie & Curle, 2012; Walker, Lewis & Rosenberg, 2020). One parent says

“Other people expect that everything should be as it was before. The only thing that has happened is that treatment has stopped, the anxiety is still there and nobody can say... he has not been given a clean bill of health, it will take many years” (Björk et al., 2011).

Others’ expectation for things to return to normal puts further pressure on parents and a sense of isolation as well as feeling misunderstood (Björk et al., 2011; Mckenzie & Curle, 2012).

Theme 3. Voice, choice and guidance: informational and support needs

This theme captures parents’ and families' need for voice, choice and guidance in relation to information and support at the end of treatment. Overall, parents report a need for increased, individualized and anticipatory education and support to prepare for the EoT transition. The content, source, timing and format of information and support is central to the perception of feeling prepared and successfully navigating the transition period. There is a desire to have psychosocial support and to be warned about the physical and emotional

challenges of the EoT transition and post-treatment. The marking of the end of treatment by staff is as an unmet need for some parents and a potential way to allow families to process and get closure on the treatment. The following descriptive themes consist of *individualized anticipatory guidance: the source, content, format, and timing of information*; *psychosocial support: preparing for the emotional challenges* and *marking the end of treatment: an unidentified need*.

Individualized anticipatory guidance: the source, content, format, and timing of information

Parents feel insufficiently prepared, informed and supported by staff when approaching the end of treatment (Baenziger et al., 2020; Carlsson et al., 2019; Duffey-Lind et al., 2006; Mckenzie & Curle, 2012; Wilford, Hopfer & Wenzel, 2019). There is little recommendation given regarding early post-treatment (Baenziger et al., 2020; Mckenzie & Curle, 2012), with one parent saying,

“We weren’t given any guidance or anything, you know, about when he finishes treatment and what to expect... I think there is lack of support...” (Mckenzie & Curle, 2012).

Parents report a desire to have direction and a “guide” for the end of treatment (Duffey-Lind et al., 2006; Hobbie et al., 2010; Muskat et al., 2017; Karst et al., 2018), as illustrated by this parent

“... you’re getting out of jail and you’re let go and... you’re wandering around... If someone would just lead you a bit.” (Muskat et al., 2017).

Parents identify wanting to receive transition-related guidance from their treating oncologist (Duffey-Lind et al., 2006; Karst et al., 2018; Wakefield et al., 2012). Parents appraise information provided by their oncologist positively and express high levels of trust in the information (Duffey-Lind et al., 2006; Wakefield et al., 2012), with one parent saying

“I had a really strong sense of trust in him [the oncologist] and getting the information from him. I got a lot of printed stuff, but mainly I listened to what he told me.” (Duffey-Lind, et al., 2006).

Parents want the guidance they receive to potentially include practical information and suggestions about disease-specific information (Duffey-Lind et al., 2006; Hobbie et al., 2010; Muskat et al., 2017; Wakefield et al., 2012), a point of contact once treatment finishes (Hobbie et al., 2010), education regarding child’s lifestyle behaviours e.g., health and physical restriction (Karst et al., 2018), education regarding their role as parents following the end of treatment (Hobbie et al., 2010), symptom management and potential side effects of their child’s treatment e.g., when do I worry about fever now? (Duffey-Lind et al., 2006; Hobbie et al., 2010; Muskat et al., 2017; Karst et al., 2018; Wakefield et al., 2012), information about a follow-up plan and future tests (Duffey-Lind et al., 2006; Karst et al., 2018) and anticipatory guidance related to emotional adjustment and coping once treatment is completed (Karst et al., 2018; Wakefield et al., 2012).

The preferred format for receiving information at EoT is a combination of verbal explanations, face-to-face discussions with the named oncologist and printed material (Duffey-Lind et al., 2006; Firth, Davies & Skinner, 2013; Wakefield et al., 2012). Some of the most commonly preferred forms of receiving written information include information booklets, pamphlets, online resources and frequently asked questions sheets which they want their named

clinician to go through with them (Duffey-Lind et al., 2006; Firth, Davies & Skinner, 2013; Muskat et al., 2017; Wakefield, 2012). Some parents express a wish to receive a written individualized treatment summary combined with a verbal explanation of what the treatment summary entailed (Duffey-Lind et al., 2006; Firth, Davies & Skinner, 2013). Parents want the treatment summary for practical reasons like being able to show the document to other healthcare professionals when needed, to take the document on holiday in case of an emergency, and also due to finding it a helpful memory aid, as one parent says

“because if someone explains something, I understand things but then I walk out and forget it”
(Firth, Davies & Skinner, 2013).

There is variability in the desired timing of EoT guidance and information (Duffey-Lind et al., 2006; Hobbie et al., 2010; Karst et al., 2018). Only one study reports on the precise timing and content of information (Karst et al., 2018). Most parents in the study want to receive transition related information 1-2 months before the end of therapy (Karst et al., 2018). The desired information 1-2 months prior to and at the EoT includes distinguishing symptoms of reoccurrence from the potential side effects of treatment (Karst et al., 2018). Parents also want to receive emotional adjustment information prior to finishing treatment (Hobbie et al., 2010; Karst et al., 2018). There is uncertainty about the timing of survivorship information i.e., specific issues that might affect their child in the future, once they get to the five-year survival milestone; although parents are interested in wanting to know, they do not feel they have to know specifics at the time of completing therapy as this information can feel overwhelming at the time (Duffey-Lind et al., 2006; Hobbie et al., 2010).

Psychosocial support: preparing for the emotional challenges ahead

Parents identify the need to be warned about the difficulty of the treatment completion phase in order to cope better with the unexpected emotional challenges at the transition and post-treatment (Wakefield et al., 2012; Wilford, Hopfer & Wenzel, 2019). There is also an expressed need to be informed about the emotional support available to help repair the emotional damage from treatment and EoT (Wilford, Hopfer & Wenzel, 2019; Wakefield et al., 2012). Parents identify the need for continued support at EoT and a desire to know that there will be continued connection with the healthcare team (Hobbie et al., 2010; Muskat et al., 2017). The desire for continued support is related to having a shared experience with staff about their child's cancer therapy and need for reassurance due to persistent fear of relapse (Hobbie et al., 2010; Muskat et al., 2017). Despite the wish for continued support at EoT, parents are conflicted in asking for help as they think about the hospital's resources and do not want to limit care delivery to families just beginning or in the middle of their child's treatment (Muskat et al., 2017), as one parent describes

“You know how thinly spread everybody is, you don't want to take away that person [staff member] from somebody who's just started.” (Muskat et al., 2017)

Some parents report that an important source of emotional support at EoT is connection with other parents of children with cancer, marking this as a potential need at the end (Enskär et al., 2020).

Marking the end of treatment: an unidentified need

Parents mention that the marking of the end of treatment by oncology staff carries implications for their experience of the EoT transition, with some parents describing this as an unmet need (Björk et al., 2011; Enskär et al., 2020; Wakefield et al., 2012). One study reports that majority of parents remember informal experiences of their last treatment being acknowledged, such as celebration parties on the ward on the day of their last treatment and being informed they could go back to their normal lives (Wakefield et al., 2012). There are reported feelings of disappointment when parents feel that staff do not explicitly mark the EoT milestone, that the child's tough treatment regime is finished; this is an implicitly identified need for one parent who identifies the lack of ending being marked as something she would have liked:

“Actually, I got a little sad when we were here for the last time. I thought I was going to be glad, but I got sad. On one hand it was as if it was only, we who knew, although it was not so, it was how it felt. We have made it and you wanted to feel positive about that. But it was just like any other appointment.” (Björk et al., 2011)

Few participants recall having participated in a formal meeting in preparation for treatment completion and although most do not report participating in a formal meeting as a necessity, some report it as an unmet need (Wakefield et al., 2012). Some parents want to have a formal end of treatment/off-treatment reviews with the paediatric oncology team so that both themselves and their children can reflect on the entire cancer trajectory to process and achieve closure on what had happened, illustrated by this quote, just

“Have a meeting and talk about it” (Enskär et al., 2020)

Discussion

This study synthesized the evidence on parental expectations, experiences and needs in the specific context of the end of their child's cancer treatment. The thematic synthesis presented in the review highlighted the discrepancies and dualities parents experienced at the end of treatment, which was both a cautious celebration and experience of desolation, uncertainty, and fear. It described how parents did not experience the end as an end but rather a liminal experience in which they had various informational and support needs. Themes were mirrored across studies that explored experiences of parents and those that looked at informational and support needs. For example, studies looking at parental experience highlighted the feeling of loss of staff support, and studies looking at parental needs emphasized the need for continued support from and contact with staff. The mirroring is an indication of validity, with experiences and needs paralleling each other.

The results presented in the thematic synthesis showed that there was a discrepancy between how parents expected to feel at the EoT phase, namely positive emotions, and how they actually felt which was a duality of positively valenced emotions such as, excitement and happiness alongside negatively valenced emotions such as disappointment, tiredness and anxiety. Dichotomous emotions are commonly described in end of treatment transitions in cancer care (Knobf, 2007; van Dongen-Melman, van Zuuren & Verhulst, 1998). Results also showed that the end of treatment is a time of unexpected feelings of vulnerability and emotional challenges; these findings are consistent with other reviews which explore the end of treatment phase (Keller et al., 2020; Walker & Lewis, 2011).

One of the novel findings of this review was parents expressed need to be warned about the potential difficulty of the transition period and where to turn for support regarding emotional adjustment and coping once treatment finishes. It is possible that becoming aware of the potential emotional challenges of the transition for parents, could be a normalizing experience, thus alleviating distress (Young, 2018).

The review showed that parents experienced the EoT as feeling abrupt, and there was a sense of loss. These were connected to feeling unprepared to manage the transition and receiving little recommendation and guidance. There was a wish to receive anticipatory guidance and preparation when they approached the ending period. The counselling and psychotherapy literature talks about the importance of seeing the ending as a stage or part of a process and not a sudden cessation, so that it is part of a well-planned withdrawal (Roy, 1985; Wilson, Elkan & Cox, 2007); a planned ending to the relationship can help address issues of loss and abandonment raised by the ending itself (Davis, 2008). The current study shows that this could also be an important consideration in paediatric medical oncology settings, where parents and families experience unexpected feelings of loss and abandonment at the end of cancer treatment.

The systematic review highlighted that the amount, type and desired timing of preparation and information regarding the EoT varied between different studies and parents. It is possible that this variation was influenced by type of cancer, nature, duration of treatment and parental readiness. The varying needs at the EoT and desired guidance could be understood as a need for voice, choice and individualized guidance, requiring professionals to explore the needs of parents on an individual basis when they approach the end of treatment. The varying needs could also relate to the methodology of the review, specifically the inclusion of papers from different countries which could reflect differences in healthcare delivery and provision. It is

possible that the different models of end of treatment practice and care post-treatment has implications for families experiences and needs at the end of treatment.

It is important to highlight how results suggested that parents may desire but struggle to ask for support at the end of treatment. It is possible that using similar models of survivorship support, like survivorship care plans (Hewitt, Greenfield & Stovall, 2006; Stricker & O'Brien, 2014) and passport for care (Harowitz et al., 2009) which includes a summary of individuals diagnosis, treatment, journey, follow-up plan and resources for support may be beneficial for parents of children completing treatment.

The results showed that many parents did not experience the end of treatment as the end but rather as a transitional, liminal phase marked by disorientation, sense of loss and uncertainty. Liminality can be defined as a state of transition between one stage and the next, especially between major stages in one's life (Turner, 1967); the concept has previously been explored in adult cancer literature and other types of chronic illnesses (Blows et al., 2012; Dauphin et al., 2020; Little et al., 2007). Studies suggest that individuals with a serious condition and their families can enter a state of acute liminality where they feel disorientated and experience losses with the diagnosis (Little et al., 2007). This study suggests that parents may also enter a state of acute liminality when their child transitions-off active treatment. This can be explained in the way parents described the ambiguous state of moving from the certainty that the active treatment had cured their child at that point in time to the uncertainty of finishing treatment and not knowing what is to happen in the future i.e., fear of reoccurrence. This is indicative of a sense of being trapped between two states which are often constructed as being discrete illness and health; a common concern for parents of children completing treatment (Cupit-Link et al., 2018; Adorno, 2015). Liminality is also evident in the way parents experience confusion in regard to their parental role and identity once their child finishes treatment. Furthermore, it also becomes apparent in the desire and pressure to return to "normal

life” and finding it difficult to do so, questioning what will “normal” be now. The study shows that there is no rapid shift to return “ordinary life” without the ambiguity of liminality.

This was the first systematic review to highlight parents’ wish for the end of treatment to be marked by staff; this could include informal ways of marking it like a party on ward or formal, like having an end of treatment meeting or going over a treatment summary with their oncologist. The wish to have the ending be marked could be related to a need to have a ritual, a tangible marking for closure and making sense of the experience (Donley-Hayes, 2006). Studies show that closure can facilitate psychological movement through different stages of disease and treatment, allowing patients and families to mark and make sense of ending of a chapter in their illness (Wilson, Elkan & Cox, 2007). Despite the current review highlighting the importance of the marking of cancer treatment, there were to date no studies that explore parents’ and families’ experiences of ending rituals and the marking the end of paediatric cancer treatment.

Strengths and Limitations

The meta-synthesis was the first review to highlight in detail, the information and support needs of parents at the end of paediatric cancer treatment. It used quotations from the included studies, which not only allowed the researcher to support the generated themes and sub-themes, but also enabled parents’ voices to be heard. The review included studies from multiple countries and those that were not originally published in English; these allowed for a culturally diverse sample and for the results to be representative of parents from non-English speaking countries. The inclusion criteria for the review allowed the study populations and data collection techniques to be uniform across studies, which strengthened the ability to generalize results. Furthermore, the researcher attempted to ensure face-validity of the research by conducting additional ethnographic work and applying the thematic analysis method to

generate themes on parent blogs and website resources for parents of children ending treatment. These were later matched with the themes from the review (see Appendix C). One of the limitations of the review was the exclusive focus on parents as carers; ending treatment is likely to have a significant impact on a wider range of individuals caring for the child including grandparents. Another limitation was the exclusion of studies that did not use semi-structured interviews, case studies and focus groups; the inclusion of studies that used survey data to explore the educational and informational needs of parents at the EoT could have provided additional information for the review. Additionally, given the rarity of different types of childhood cancers and associated small sample sizes, the study could have explored potential differences in needs and experiences across different types of childhood cancer. Due to the included qualitative studies focusing on individual experience, there was limited exploration of how social factors such as socio-economic status and social support might have mediated the experience of ending treatment and expressed needs. It is well known that these factors can affect psychological adjustment, coping and experience of parents of children with serious health conditions (Grootenhuis & Last, 1997; Litzelman et al., 2013).

Implications for practice

The systematic review adds to the body of knowledge related to current practice at EOT for families. In line with the findings of the review, there are approaches that could promote positive outcomes for parents of children ending cancer treatment.

Assessing parents' needs

The review highlighted that although there were common information and support needs expressed by parents, the content and timing of the information could vary. Thus, it is important for oncologists to assess for parental needs prior to the end of treatment phase in order to provide individualized support and appropriate resources and referrals. The assessment can include a meeting that involves an exploration of parents' feelings about approaching the end of treatment, their hopes, fears and questions about the future.

Providing formalized education to prepare

The review highlighted the importance of providing anticipatory education to address parents' difficult transition experience. Oncology wards could provide a formalized education to prepare parents for dealing with emotions and feelings, practical issues, useful organization and information resources for the end of treatment and post-treatment phases; this can help normalize the challenges that can come with the transition. The education can be delivered in the form of an end of treatment event invitation coordinated by members of staff at the hospital. This could take place in both an individual and group setting. As highlighted by the review, the group setting could allow parents to find other parents of children ending treatment as an important source of emotional support. Additionally, hospitals can make use of existing end of treatment guides, such as the "*My child has finished treatment. What happens next?*" (CCLG, 2017) to verbally go over the information with them prior to or at the end of treatment depending on their preference.

Marking the end

The review described the need for parents and families to be given voice and choice in regard to whether they wish to mark the end of their treatment and ways they would like for this to be acknowledged. It is important for staff to encourage conversations with parents about the EoT and provide choice regarding marking the end. This can include providing a treatment summary, an end of treatment meeting with oncologist or more informal acknowledgements on the ward including rituals to celebrate the ending e.g., a party on the ward.

Conclusion

In conclusion, this systematic review explored the expressed expectations, experiences and needs of parents at the EoT. It identified the discrepancies in parents' expectations versus lived experiences, the challenges faced with the transition and ways they could be supported with these challenges. Informational, psychosocial support and the marking of the end of treatment have been shown to impact parents' experience of the end.

References

- Adorno, G. (2015). Between two worlds: liminality and late-stage cancer-directed therapy. *Journal of Death and Dying, 71*(2), 99-125.
- Baenziger, J., Hetherington, K., Wakefield, C. E., Carlson, L., McGill, B. C., Cohn, R. J., . . . Sansom-Daly, U. M. (2020). Understanding parents' communication experiences in childhood cancer: a qualitative exploration and model for future research. *Supportive Care in Cancer, 28*(1), 4467-4476.
- Björk, M., Nordström, B., Wiebe, T., & Hallström, I. (2011). Returning to a changed ordinary life - families' lived experience after completing a child's cancer treatment. *European Journal of Cancer Care, 20*(1), 163-169.
- Blotcky, A. D., Raczynski, J. M., Gurwitch, R., & Smith, K. (1985). Family influences on hopelessness among children early in the cancer experience. *Journal of Pediatric Psychology, 10*(4), 479-493.
- Blows, E., Bird, L., Seymour, J., & Cox, K. (2012). Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *Journal of Advanced Nursing, 68*(10), 2155-2164.
- Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & von Essen, L. (2019). Psychological distress in parent of children treated for cancer: an explorative study. *PLoS One, 14*(6), 1-18.
- Castellano, C., Toledo, J., Blasco, T., Gros, L., Ortis, L. C., & Perez-Campdepadros, M. (2010). Parental coping and emotional distress in relation to the quality of life of adolescent cancer in remission. *Psicooncologia, 7*(2), 415-531.
- Children's Cancer and Leukaemia Group. (2017, July 1). *Publications*. Retrieved from Children's Cancer and Leukaemia Group:

https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/My_Child_Has_Finished_Treatment_June_2017.pdf

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research, 22*(10), 1435-1443.

Critical Appraisal Skills Programme. (2018). *CASP Qualitative Checklist*. Retrieved from CASP UK: <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>

Cupit-Link, M., Syrjala, K. L., & Hashmi, S. K. (2018). Damocles' syndrome revisited: update on the fear of cancer recurrence in the complex world of today's treatments and survivorship. *Hematology/Oncology and Stem Cell Therapy, 11*(3), 129-134.

Darcy, L., Björk, M., Enskär, K., & Knutsson, S. (2014). The process of striving for an ordinary, everyday life, in young children living with cancer, at six months and one year post diagnosis. *European Journal of Oncology Nursing, 1*(5), 605-612.

Dauphin, S., Wolputte, S. V., Jansen, L., Burghgraeve, T. D., Buntinx, F., & Akker, M. v. (2020). Using liminality and subjunctivity to better understand how patients with cancer experience uncertainty throughout their illness trajectory. *Qualitative Health Research, 356-365*.

Davis, D. D. (2008). *Terminating therapy: a professional guide to ending on a positive note*. New Jersey: John Wiley & Sons.

Donley-Hayes, K. (2006). At face value: a piece of my mind. *Journal of the American Medical Association, 295*(1), 2701-2702.

Duffey-Lind, E. C., O'Holleran, E. O., Healey, M., Vettese, M., Diller, L., & Park, E. R. (2006). Transitioning to survivorship: a pilot study. *Journal of Pediatric Oncology Nursing, 23*(6), 335-343.

- Enskär, K., Darcy, L., Björk, M., Knutsson, S., & Huus, K. (2020). Experiences of young children with cancer and their parents with nurses' caring practices during the cancer trajectory. *Journal of Pediatric Oncology Nursing*, 37(1), 21-34.
- Firth, E. R., Davies, N., & Skinner, R. (2013). Views of childhood cancer survivors and their families on the provision and format of a treatment summary. *Pediatric Hematology Oncology*, 35(3), 193-196.
- Fuemmeler, B. F., Brown, R. T., Williams, L., & Barredo, J. M. (2003). Adjustment of children with cancer and their caregivers: Moderating influences of family functioning. *Families, Systems, & Health*, 21(3), 263-276.
- Gibbins, J., Steinhardt, K., & Beinart, H. (2012). A systematic review of qualitative studies exploring the experience of parents whose child is diagnosed and treated for cancer. *Journal of Pediatric Oncology Nursing*, 29(5), 253-271.
- Grassi, L., Spiegel, D., & Riba, M. (2017). Advancing psychosocial care in cancer patients. *F1000 Research*, 6(2), 1-9.
- Grootenhuis, M. A., & Last, B. F. (1997). Adjustment and coping by parents of children with cancer: a review of literature. *Supportive Care in Cancer*, 5(6), 466-84.
- Hewitt, M., Greenfield, S., & Stovall, E. (2006). From cancer patient to cancer survivor: Lost in translation. *From cancer patient to cancer survivor: Lost in translation* (pp. 1-534). Washington: The National Academies Press.
- Hobbie, W. L., Ogle, S. K., Reilly, M., Ginsberg, J. P., Rourke, M., Ratcliffe, S., & Deatrck, J. A. (2010). Identifying the educational needs of parents at the completion of their child's cancer therapy. *Journal of Pediatric Oncology Nursing*, 27(4), 190-195.
- Horowitz, M. E., Fordis, M., Krause, S., McKellar, J., & Poplack, D. G. (2009). Passport for care: implementing the survivorship care plan. *JCO Oncology Practice*, 5(3), 110-112.

- Hosoda, T. (2014). The impact of childhood cancer on family functioning: a review. *Graduate Student Journal of Psychology, 15*(1), 18-30.
- Hovén, E., Lannering, B., Gustafsson, G., & Boman, K. K. (2018). Information needs of survivors and families after childhood CNS tumor treatment: a population-based study. *Acta Oncologica, 57*(2), 649-657.
- Karst, J. S., Hoag, J. A., Chan, S. F., Schmidt, D. J., Anderson, L. J., Englebert, N. E., . . . Bingen, K. M. (2018). Assessment of end-of-treatment transition needs for pediatric cancer and hematopoietic stem cell transplant patients and their families. *Pediatric Blood and Cancer, 27*(1), 1-7.
- Keats, M. R., Shea, K., Parker, L., Stewart, S. A., Flanders, A., & Bernstein, M. (2019). After childhood cancer: a qualitative study of family physician, parent/guardian, and survivor information needs and perspectives on long-term follow up and survivorship care plans. *Journal of Cancer Education, 34*(2), 638-646.
- Keller, C. M., King, C., Hart, L., Engelke, K., Needham, A., Holden, E., . . . Lucas, R. (2020). The end of cancer treatment experience for children, adolescents, and their parents: a systematic review of the literature. *Journal of Psychosocial Oncology, 2*(14), 1-18.
- Knobf, M. K. (2007). Psychosocial responses in breast cancer survivors. *Seminars in Oncology Nursing, 23*(1), 71-83.
- Krivoy, E., Jenney, M. E., Mahajan, A., & Nahum, M. P. (2012). Survivorship in childhood cancer. In S. Kreitler, M. W. Ben-Arush, & A. Martin, *Pediatric Psycho-Oncology: Psychosocial Aspects and Clinical Interventions, Second Edition* (pp. 187-195). Oxford: John Wiley & Sons.

- Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centred Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal Child Health, 16*(2), 297-305.
- Labay, L. E., Mayans, S., & Harris, M. B. (2004). Integrating the child into home and community following the completion of cancer treatment. *Journal of Pediatric Oncology Nursing, 21*(3), 165-9.
- Lazar, M. B., & Musek, J. (2020). Well-being in parents of children with cancer: The impact of parental personality, coping, and the child's quality of life. *Health and Disability, 61*(5), 652-662.
- Lewis, S., & LaBarbera, J. D. (1983). Terminating chemotherapy: another stage in coping with childhood leukemia. *The American Journal of Pediatric Hematology/Oncology, 5*(1), 33-37.
- Lie, H. C., Loge, J. H., Fossa, S. D., Hamre, H. M., Hess, S. L., Mellblom, A. V., . . . Finset, A. (2015). Providing information about late effects after childhood cancer: Lymphoma survivors' preferences for what, how and when. *Patient Education and Counseling, 98*(2), 604-611.
- Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. (n.d.). Liminality: a major category of the experience of cancer illness. *Social Science and Medicine, 47*(10), 1485-1494.
- Litzelman, K., Barker, E., Catrine, K., Puccetti, D., Possin, P., & Witt, W. (2013). Socioeconomic disparities in the quality of life in children with cancer or brain tumors: the mediating role of family factors. *Psychooncology, 22*(5), 1081-1088.
- Ljungman, L., Cernvall, M., Grönqvist, H., Ljótsson, B., Ljungman, G., & von Essen, L. (2014). Long-term positive and negative psychological late effects for parents of childhood cancer survivors: a systematic review. *PLoS ONE, 9*(7), 1-12.

- Martinson, I., & Cohen, M. H. (1989). Themes from a longitudinal study of family reaction to childhood cancer. *Journal of Psychosocial Oncology*, 6(3), 81-98.
- Maurice-Stam, H., Grootenhuis, M. A., Brons, P. P., & Caron, H. N. (2007). Psychosocial indicators of health-related quality of life in children with cancer 2 months after end of successful treatment. *Journal of Pediatric Hematology Oncology*, 29(5), 540-550.
- Mckenzie, S. E., & Curle, C. (2012). 'The end of treatment is not the end': parents' experiences of their child's transition from treatment for childhood cancer. *Psycho-Oncology*, 21(1), 647-654.
- Miller, K. D., Nogueira, L., Mariotto, A. B., Rowland, J. H., Yabroff, K. R., Alfano, C. M., . . . Siegel, R. L. (2019). Cancer treatment and survivorship statistics. *CA Cancer*(69), 8.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, 6(7), 1-6.
- Muskat, B., Jones, H., Lucchetta, S., Shama, W., Zupanec, S., & Greenblatt, A. (2017). The experiences of parents of pediatric patients with acute lymphoblastic leukemia, 2 months after completion of treatment. *Journal of Pediatric Oncology Nursing*, 34(5), 358-366.
- Norberg, A. L., & Green, A. (2008). Stressors in the daily life of parents after a child's successful cancer treatment. *Journal of Psychosocial Oncology*, 25(3), 113-122.
- Norberg, A. L., Lindblad, F., & Boman, K. K. (2005). Parental traumatic stress during and after paediatric cancer treatment. *Acta Oncologica*, 44(4), 382-388.
- Norberg, L. A., & Steneby, S. (2009). Experiences of parents of children surviving brain tumour: a happy ending and a rough beginning. *European Journal of Cancer Care*, 18(2), 371-380.

- O'Leary, M., Krailo, M., Anderson, R., & Reaman, G. H. (2009). Progress in childhood cancer: 50 years of research collaboration, a report from the children's oncology group. *Seminars in Oncology*, *35*(5), 484-493.
- Ortiz, M. A., & Lima, R. A. (2007). Experiences of families with children and adolescents after completing a cancer treatment: support for the nursing care. *Rev Latino-am Enfermagem*, *15*(3), 411-7.
- Patterson, J. M., Holm, K. E., & Gurney, J. G. (2003). The impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, *13*(6), 121-126.
- Rivero-Vergne, A., Berrios, R., & Romero, I. (2011). The return to the community after cancer treatment: from safety to reality check. *Journal of Psychosocial Oncology*, *19*(1), 67-82.
- Roy, L. (1985). *Coping with loss - an introduction to loss and loss counselling*. Birmingham: Pepar.
- Sandelowski, M., & Borroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*, *1*(2), 1-23.
- Semple, C. J., & McCance, T. V. (2010). Parents' experience of cancer who have young children: A literature review. *Cancer Nursing*, *33*(2), 110-118.
- Stam, H., Grootenhuis, M. A., Brons, P. P., & Last, B. F. (2006). Health-related quality of life in children and emotional reactions of parents following completion of cancer treatment. *Pediatric Blood Cancer*, *47*(3), 312-319.
- Stricker, C., & O'Brien, M. (2014). Implementing the commission on cancer standards for survivorship care plans. *Clinical Journal of Oncology Nursing*, *18*(1), 15-22.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45), 1-10.

- Thompson, K. (2007). Liminality as a descriptor for the cancer experience. *Illness, Crisis & Loss*, 15(4), 1-14.
- Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(181), 1-8.
- Turner, V. (1967). Betwixt and between: the liminal period in rites of passage. In V. Turner, *The forest of symbols: aspects of ndembu ritual* (pp. 93-111). Cornell: Cornell Press.
- Van Dongen-Melman, J., Van Zuuren, F., & Verhulst, F. (1998). Experiences of parents of childhood cancer survivors: A qualitative analysis. *Patient Education and Counseling*, 34(3), 185-200.
- Van Schoors, M., Caes, L., Verhofstadt, L. L., Goubert, L., & Alderfer, M. A. (2015). Systematic review: family resilience after pediatric cancer diagnosis. *Journal of Pediatric Psychology*, 40(9), 856-868.
- Vetsch, J., Frdell, J. E., Wakefield, C. E., Signorelli, C., Michel, G., McLoone, J., . . . Cohn, R. J. (2017). "Forewarned and forearmed": Long-term childhood cancer survivors' and parents' information needs and implications for survivorship models of care. *Patient Education and Counseling*, 100(2), 355-363.
- Wakefield, C. E., Butow, P., Fleming, C. A., Daniel, G., & Cohn, R. J. (2012, 58). Family information needs at childhood cancer treatment completion. *Pediatric Blood Cancer*, 621-626.
- Wakefield, C. E., McLoone, J., Goodenough, B., Lenthen, K., Cairns, D. R., & Cohn, R. J. (2009). The psychosocial impact of completing childhood cancer treatment: A systematic review of the literature. *Journal of Pediatric Psychology*, 35(3), 262-274.

- Walker, A. J., & Lewis, F. (2011). Adolescent and young adult cancer survivorship: a systematic review of end-of-treatment and early post-treatment. *Nursing and Palliative Care, 1*(1), 1-6.
- Walker, A. J., Lewis, F. M., & Rosenberg, A. R. (2020). Walking on eggshells: parents' first year after their adolescent completes their cancer treatment. *Journal of Pediatric Oncology Nursing, 37*(4), 233-243.
- Wilford, J. G., Hopfer, S., & Wenzel, L. (2019). Perceptions of changes in clinical, informational, and supportive relationships after end of treatment among parents of young childhood cancer survivors. *Psycho-Oncology, 28*(9), 913-919.
- Wilkins, K., D'Agostino, N., Penney, A. M., Barr, R. D., & Nathan, P. C. (2014). Supporting adolescents with cancer through transitions: position statement from the canadian task force on adolescents and young adults with cancer. *Pediatric Hematological Oncology, 36*(7), 545-551.
- Wilson, E., Elkan, R., & Cox, K. (2007). Closure for patients at the end of a cancer clinical trial: literature review. *Journal of Advanced Nursing, 59*(5), 445-453.
- Woodgate, R. L. (2006). Life is never the same: childhood cancer narratives. *European Journal of Cancer Care, 15*(1), 8-18.
- Woodgate, R. L., & Degner, L. F. (2003). Cancer symptom transition periods of children and families. *Journal of Advanced Nursing, 46*(4), 358-368.
- Young, T. L. (2018). Counseling parents of children with cancer: therapeutic considerations and strategies. *Journal of Mental Health Counseling, 40*(3), 185-198.

Appendix A: Master table of themes, subthemes, and codes for the review

Theme	Subtheme	Title of code	Frequency of code (number of articles)
Discrepancies and dualities: A cautious ‘celebration’ and desolation	<i>A milestone met with mixed feelings</i>	Code A: sense of joy, relief, happiness and gratefulness Code B: sense of disappointment and emptiness Code C: sense of tiredness and overwhelm Code D: beginning to confront feelings previously shelved	6 6 4 4
	<i>Unexpected losses: absence of security, safety and protection</i>	Code E: active treatment and oncology staff as a secure base, end of treatment as the loss of this base – active curative agent Code F: feeling abandoned by staff and alone at the end Code G (contradictory finding): gains at the end of treatment – social support	6 5 1
The end is not the end	<i>Disoriented: swimming in questions</i>	CODE H: Abrupt ending, lost and unprepared CODE I: Insufficient information, unanswered questions CODE J: Confusing time with shift in parental role	6 6 2
	<i>A desire to move forward: the pressure to return to “normal”</i>	CODE K: Wish for lives to return to normal CODE L: Expecting EoT to be the end and for things to return to normal CODE M: Other people don’t understand CODE N: Experiencing a different normal	3 3 2 2
	<i>The fear goes on: increased responsibilities, fear or relapse and symptoms</i>	CODE O: Fear about bringing the child home/increased responsibility CODE P: Fear of relapse CODE Q: Fear and worries about symptoms, recovery	4 8 5

Continued

Voice, choice and guidance: informational and support needs	<i>Individualized anticipatory guidance: source, content, timing and format of information</i>	CODE R: Lack of information making transition difficult CODE S: Content of guidance/type of information needed CODE T: The source of information i.e. the who CODE U: The timing of the guidance and information i.e. the when CODE V: The format of the information delivery i.e. the how	5 3 3 4 4
	<i>Psychosocial support: preparing for the emotional challenges ahead</i>	CODE W: Desire to know there will be continued connection with healthcare team CODE X: Wanting to be warned about the difficulty of the end of treatment period CODE Y: Struggling to ask for support CODE Z Meeting other parents in the same situation, finishing treatment	2 2 1 1
	<i>Marking the end of treatment: an unidentified need</i>	CODE 1: The need for formal and informal acknowledgement of the end of treatment	3

Appendix B: Table for Theme 2, Subtheme 3

A desire to move forward: pressure to return to ‘normal’

Code	Article reference(s)	Evidence/Description	Quote (if available)
Code K A desire for lives to return to normal	(Hobbie, et al., 2010)	Present day focused on the completion of therapy. Desire to get their lives “back to normal” was foremost on their minds	N/A
	(Carlsson, Kukkola, Ljungman, Hovén, & von Essen, 2019)	Parents wished to get back to life as it was before the diagnosis when treatment ended and to move forward as a family. Getting back to work was seen as an important part of getting back to life as it was before the diagnosis. However, great difficulties were described related to trying to balance family life and work.	N/A
	(Martinson & Cohen, 1989)	Subtheme is ‘the need to normalize family life’: parents had a compelling need to normalize family life as quickly as possible and to try to restore pre-diagnosis routines and relationships.	<i>“My main concern is to bring our daughter home and try to lead as normal a lifestyle as we possibly can, knowing at the same time that it will never be the same. But I would like to try, very hard, just to have it as close to normal as I can.”</i>
Code L An expectation for EoT to be the end and for things to return to normal	(Björk et al., 2011)	Parents and others expectation to go back to their ‘normal’ lives.	<i>“other people expect that everything should be as it was before. The only thing that has happened is that treatment has stopped, the anxiety is still there and nobody can say... he has not been given a clean bill of health, it will take many years”</i>
	(Mckenzie & Curle, 2012)	It’s not going to go away: In contrast to this sense of “life is very normal” is the ongoing threat of childhood cancer. Even those who saw the EOT as ended had doubts about whether they would ever be fully over it. Suppose you don’t really in some respects, it’s always there in the background” Parents were left with a sense that childhood cancer would be forever a part of their lives for the foreseeable future, whether it was in the background or the forefront of their minds, it would not disappear.	<i>“I think emotionally and mentally the treatment hasn’t ended yet, so all that happened is that he stopped taking his drugs”</i>

Continued

	(Walker, Lewis, & Rosenberg, 2020)	Thinking everything would be back to normal, both parents, friends and family expected families lives to go back to normal with the end of treatment. Parents described a type of continuing care rather than the end of as the end.	<p>“I thought everything would be fine, back to normal and it hasn’t been... it’s just surprisingly hard. I just did not anticipate this at all. I thought it would be like flipping a switch, life would be pretty much just, be okay and everything’s back normal.</p> <p>“I think that people sort of have a perception that oh, well child is in remission, everything’s find and that’s just not the case”.</p> <p>“it’s almost like, it just feels like we’re just still continuing, we’re still in, like nothing totally ended, other than it sort of ended”. Similarly, a parent said, “it doesn’t feel like we’re at the end of treatment. It just feels like we just transitioned to kind of continuing care”</p>
Code M Other people don’t understand	(Mckenzie & Curle, 2012)	Feeling that friends and family did not understand. Parents were left with a sense that childhood cancer would be part of their lives for the foreseeable future, whether it was in the background or the forefront of their minds, it would not disappear.	“other people think, oh it’s all finished now, and that’s it, whereas... you are still going to have it at the back of your mind that it could come back”.
Code N What is normal?	(Muskat, et al., 2017)	The theme of returning to “normal” following the end of their child’s treatment was experienced in a variety of ways among the parents, with a range of definitions of what “normal” meant for them. Some spoke of a return to a similar life to what existed prior to their child’s treatment. Some parents spoke of a “new normal” that included issues that did not exist in their lives before their child’s diagnosis. Other conceptualizations of a “new normal” included new perspectives on life that had developed after experiences with their child’s cancer. One parent described the experience of returning to “normalcy” following treatment.	<p>“Getting your life back, it’s like coming up for air after being held underwater for so long... you just come to that knowledge that you’ve put in a lot of hard work for the past 21/2 years and now</p> <p><i>Continued</i> 1 to... gaining ur normal life”</p>

	(Woodgate R. L., 2006)	<p>It's never over with... always a waiting game: near the end of cancer treatment, most families expressed that they were regaining their old way of living. For Families I and II, this included Denise and Gail going back to work on a part-time basis and the children attending school on a regular basis. Both Families I and II were now moving forward into the future by making long-term plans for such things as vocations. The families were now redirecting their goals on life. However, despite their ability to move forward and regain much of what they had lost, they could never be completely free from the experience of childhood cancer. While getting their life back the way it was before the cancer diagnosis was important, this was not possible because as families realized at the beginning of the cancer experience, 'life would forever be different'.</p>	<p>"I looked at him and I said 'in actual fact it is as normal as it is ever going to get'. And he said 'what do you mean by that?' and I said 'it will never be what it was before the cancer hit him'. Normal as families knew it in the past was now experienced as something different for them, families needed to create a 'new normal'. Interestingly, Family II dealt with the never-ending cancer experience by never claiming to be a 'normal family'.</p>
--	------------------------	--	--

Appendix C: Illustration of ethnographic work for face-validity – Thematic overview on an EoT Guideline

My child has finished treatment (CCLG, 2017)

Themes/headings from document	Evidence i.e., quote/text from CCLG document	Matching theme/subtheme in current review
Mixed feelings/emotions	<p>Parents may feel happy and relieved your child or teen has completed their treatment, but you may also feel anxious the cancer may come back. It can be a very unsettling time.</p> <p>Parents may also have time to think about the impact on practicalities such as work, their child’s education and finances. Families are often exhausted after months or years of treatment.</p> <p>Parents may think about the past and the diagnosis</p>	A milestone met with mixed feelings
Celebrating	<p>Parents often find friends and families are overjoyed their child has reached the end of treatment. They are greeted with big smiles and told how well their child looks. “Isn’t it great he’s finished his chemo?” Yet most parents find their own reactions are much more cautious. Many parents say they cannot allow themselves to feel joy at having reached the end of treatment and can sometimes feel more insecure and lost. For other families, a celebration feels very appropriate. Your child and family have just got through the huge challenge of treatment. That in itself is a great achievement. The celebration might be nothing more than going to the park on what would previously have been a clinic day. Some families choose to have a family party or a celebration at school. Others find planning a holiday or some other enjoyable event gives them something positive to focus on. Whatever you and your child choose will be right providing it feels right to you.</p>	Marking the end of treatment: an unidentified need
Wondering where everyone went	<p>During active treatment, families are regularly seeing professionals and other parents at the hospital. Professionals can reassure parents their experiences are not unusual. Other parents are in the unique position of knowing how it feels to go through treatment with a child. Yet suddenly, at the end of treatment, fewer hospital visits mean parents have much less access to these sources of support, often at a time when they really need it. Parents sometimes find even people who seemed to have understood what the family was going through during treatment, now become less available and act as if life is now back to normal. It can be particularly hard at this time to find people who realise the pressures and fears you still feel. With a little explanation, or perhaps by lending them this booklet, friends and relatives can be helped to appreciate the fact you still have concerns and what some of these may be.</p>	Unexpected losses: absence of security, safety and protection

Continued

Scared cancer might come back	Parents often tell us the end of treatment feels like the removal of their child's safety net. While the treatment is being given, families feel everything possible is being done to beat the cancer. No-one can tell you the disease will not return. Parents sometimes feel they would prefer their child to remain on low dose chemotherapy for life, if it could guarantee the disease would not return.	The fear goes on: increased responsibilities, fear of relapse and symptoms
Difficulty coping	Sometimes, once treatment finishes and it is 'all over', the enormity of the whole cancer experience can hit parents hard when they are trying to get things back to normal. Strong feelings can be pushed down during treatment but are then released afterwards or even some time in the future. It is normal to feel emotional at this time but, if your feelings are too overwhelming and you are finding it hard to cope or are experiencing ongoing symptoms such as anxiety or depression, you may benefit from some further help to talk about how you are feeling.	Psychosocial support: preparing for the emotional challenges ahead
Finding a new normal	Although life may not return to exactly how it was before your child was ill, most parents feel that, in time, the family reaches a new normal. For children, this involves returning to nursery or school and, as much as possible, to a full range of leisure activities. For parents this may be getting back to normal activities such as work or home. For some parents, returning to work can feel like a huge hurdle. If you have not seen colleagues since before your child was ill, coping with their reactions, however kind, can be a challenge. Some parents have found it helpful to visit their work place or meet up with colleagues before their first official working day. A new normal might involve a return to usual discipline within the family. When a child is ill it is natural that family rules slide. However, insisting on good discipline now sends a positive message to all children that things are starting to get better. It can be very encouraging to plan a holiday at this stage. If you want to travel abroad, you will need to seek advice about insurance. 2	A desire to move forward: a pressure to return to normal
Sources of help and support	Some people find the end of treatment a positive time when they need much less support. But for others it is very important to have people who understand that although treatment has stopped, their worries have not. Try to find people who will let you be very open and honest about how you are feeling. Talking can help to make your own thoughts clearer. Some parents, however, find it is helpful to have some time to themselves.	Individual <i>Continued</i> anticipate : source, content, format and timing.

Part II: Empirical Paper

Marking Endings in Paediatric Cancer Treatment: An Interpretative Phenomenological Analysis (IPA) of Parents' Experiences

Abstract

Background: The end of paediatric cancer treatment (EoT) is a significant milestone for parents. Rituals and celebrations that mark EoT can impact parents' experiences of the end and capacity to cope with the transition. One such ritual is the ringing of the bell ritual (RTB) which involves ringing a physical bell upon the successful completion of treatment in oncology wards.

Aims: The study aimed to explore the meanings parents attribute to and experiences of marking the completion of paediatric cancer treatment, with a particular focus on the ringing of the bell ritual (RBT) in oncology wards.

Methods: Eight online semi-structured interviews were conducted with eleven parents of children aged 8-11. The interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results: The end of treatment was described as a continuum with multiple milestones to be marked. Marking the milestones allowed parents to achieve a separation from the cancer, dissolve tensions between being the parent one wants to be and the parent one has to be during treatment, and to forget the difficulties and remember the positive experiences. The EoT bell was a symbol of hope and sustenance, achievement, a (false) sense of certainty and security, freedom and return to "normal". It formed an unspoken bond of understanding between families, but also created a divide between the sick and the well. Parents identified needing active staff support with planning/carrying out the RBT and wanting to feel special to staff. The post-RBT and celebration period was a time of vulnerability and loss.

Implications: The study discusses critical considerations when implementing rituals like the end of treatment bells in hospital wards. Future research should explore the effect of rituals like RTB on parents of children with poor cancer prognosis.

Introduction

Throughout the paediatric cancer journey, children and parents face many transitions as they move from one space (e.g., state, condition, circumstance) or time (e.g., life phase) to another (Wilkins et al., 2014). Each transition begins with an ending, meaning that individuals leave their familiar ways of being to reach somewhere different. One of the most critical transitions in the paediatric cancer pathway is the end of treatment (EoT) where the child finishes active treatment (Walker & Lewis, 2011). Parents describe this transition as a long-anticipated milestone filled with heightened feelings of fear and joy (Björk et al., 2011; Muskat et al., 2017; Norberg & Green, 2008). There are unexpected losses of staff and the hospital (Carlsson et al., 2019), feelings of disorientation (Duffey-Lind et al., 2006) and a strong sense that “the end is not the end” (Mckenzie & Curle, 2012). Research shows that the marking and acknowledgement of the EoT milestone by hospital staff can have implications for parents’ feelings and perceived capacity to cope with the transition (Björk et al., 2011; Enskär et al., 2020; Wakefield et al., 2012). The current study aims to explore how parents of children with Acute Lymphoblastic Leukaemia (ALL) experience the marking of the end of their child’s cancer treatment, with a particular focus on the ringing of the bell ritual (RBT) in oncology wards. The introduction chapter will provide definitions and terminology for the concepts mentioned. It will then provide an overview of psychological perspectives into marking endings in healthcare settings. This will be followed by discussing the RBT and previous research as well as the study questions.

Terminology and Definitions

Paediatric Acute Lymphoblastic Leukaemia (ALL) and treatment pathway

Acute Lymphoblastic Leukaemia (ALL) is the most common paediatric cancer with a survival rate of 80-90% (Cooper & Brown, 2015; Kato & Manabe, 2017). In the UK, the treatment pathway for ALL takes approximately two years for girls and three years for boys to complete (CCLG, 2021). At the beginning of treatment, a central venous access device e.g., a port or PICC line is usually implanted/inserted into the child's body to take regular blood samples for testing and for giving medicines such as chemotherapy on a long-term basis (CCLG, 2014; NCCN, 2021). The treatment involves three phases: induction phase, consolidation, and maintenance (NICE, 2016). During induction, ALL is treated with chemotherapy and involves an inpatient admission; this lasts between four to six weeks until there are no detectable leukaemia cells (NICE, 2016). The consolidation phase involves another course of short-term intensive outpatient chemotherapy, lasting between four to eight weeks. During maintenance, low dose chemotherapy is used typically consisting of weekly and daily tablets at home for an extended period between two to three years prevent relapse (NCCN, 2021). Following this, the central venous access device is removed and there is transition to long term follow-up care.

Marking the end of treatment transition

Research defines the end of paediatric treatment as the final dose of active treatment (Walker & Lewis, 2011). The current study acknowledges the subjective experience of time

and endings in cancer care thus hopes to explore parents' understanding of the end rather than providing a conclusive definition (Rovers et al., 2019).

Marking the end of paediatric cancer treatment has been discussed in the context of staff preparing families through formal EoT meetings and informal celebrations like a party on the ward on the day of the last treatment (Wakefield et al., 2012). The current study uses a broader definition and describes the marking of the end as any individual/group engagement in repeated or one-time acts, rituals, events, and celebrations to acknowledge the child's transition off-cancer treatment. The study uses the terms "marking the EoT" and "EoT rituals" interchangeably across the paper. In contrast to previous studies, it acknowledges that the marking of the end can be led and marked multiply by hospital staff, parents, children, extended family, and friends. It can be marked by behaviours that may be considered mundane, such as an ordinary dinner that could be non-ritualistic in nature, but at the point of the EoT acquires a symbolic meaning.

Marking endings in health care settings

There is a growing body of literature that explores the value and function of marking endings in healthcare settings from a psychological perspective. Psychotherapy and counselling research highlights the importance of acknowledging endings with patients and the benefits of using documents such as "goodbye letters" to contribute to the rite of passage accompanying the end of the therapeutic work with the clinician (Fox, 2003; Turpin et al., 2011; Wilson, Elkan & Cox, 2007). Evidence suggests that marking endings can encourage patients to reflect on their treatment journey and cope better with the complex range of emotions that can come with the ending and the loss of the therapist, thus allowing patients to achieve a sense of "closure" (Hamill, Ried & Reynolds, 2008; Simmonds et al., 2020;

Wilson, Elkan & Cox, 2007). The experience can encourage a feeling of a “clean slate”, allowing individuals to move on and deal more easily with the new state, role, and tasks the next phase brings (Schworer, Rebekka & Oettiengen, 2019). In paediatric inpatient mental health settings, the experience of marking the end of admission with staff and other patients can allow difficult feelings, including feelings of loss, to be processed and can help children and parents to feel a sense of accomplishment that the child is “well” (Haen, 2005). Research on marking endings in physical paediatric care is scarcer with studies focusing predominantly on the meaning and function of rituals in the context of end of life in palliative care (Kochen et al., 2020). There is less known about rituals and marking the EoT when the child survives and successfully transitions off-cancer care. Although this is an under-researched area, there is evidence to suggest that the marking of the end of treatment by staff is an important subject to explore (Björk et al., 2011). Studies show that parents experience feelings of disappointment, difficulties processing the end and getting closure from treatment when staff do not mark the EoT milestone that the child’s tough treatment regime is finished (Björk et al., 2011; Enskär et al., 2020). The marking of the EoT is therefore experienced as an unaddressed need (Björk et al., 2011).

Marking the end of paediatric cancer treatment – “The end of treatment bell”

For some years, a wide-spread bell-ringing ritual has been used to mark the end of cancer treatment across adult and paediatric healthcare settings in different countries. The ritual first began in 1996 in the United States when an adult cancer patient, a former navy rear admiral installed a “victory bell” at a treatment centre to mark the successful completion of his treatment (Gale, 2019). For him, the bell was like those that sailors rang when they came to

the end of a mission and a job was successfully completed (Gale, 2019). He recited a poem as he rang the bell. The poem is now engraved next to all end of treatment bells:

“Ring this bell three times well,
its toll to clearly say, my treatment’s done
this course is run, and I am on my way”

The ritual was introduced to the UK in 2013, when the parent of a child in a paediatric hospital setting wanted her daughter to ring it to mark the end of treatment. Since then, 85 bells have been situated in paediatric oncology settings across the UK and are named as “End of Treatment Bells” (End of Treatment Bells, 2021). The bells are also commonplace across adult oncology settings. The ritual is optional and often involves a celebration between the child, friends, family, and staff members. Individuals gather in the corridor where the bell is situated, the child rings the bell three times whilst reading the poem and he/she/they is clapped for and cheered on by others (End of Treatment Bells, 2021). The ritual is also witnessed by other patients, carers and parents who are receiving care at the ward. Despite the widespread use of the bells, there are no guidelines regarding how the bell should be introduced to children and parents and how a decision can be reached regarding the ritual e.g., with whom it should be discussed and who rings the bell i.e., the parent, the child, both.

To ring or wring the bell

There are to date no guidelines on the practice and implementation of end of treatment bells in oncology wards i.e., how it can be introduced, how a decision is reached and who

rings the bell. There has been a recent increase in the attention paid to the ringing of the bell ritual (RTB) and its potential psychological impact on patients and witnessing others.

In his personal reflection piece, Subbiah (2011) discusses the positive experience of his patients who ring the bell, describing the ceremony as a “heart-warming” and “memorable event”. He highlights the difficult journey of cancer treatment, for the patient and the family and that recovery and the completion of treatment deserves appreciation, kudos, and applause (Subbiah, 2011). A contrasting opinion is expressed in an anecdotal piece by Gale (2019) who describes the bell ringing as an “inappropriate” ritual specifically in relation to patients with poor diagnosis witnessing the ceremony. Gale (2019) talks about how the bell creates a false premise that ringing it marks the end of cancer, neglecting the possibility of relapse and reoccurrence. A recent survey conducted in an adult oncology service (YCC, 2019), highlights both positive and negative feelings towards the bell and its use in the outpatient clinic. Despite the wide clinical use of the bell and mixed opinions, there is a paucity of research concerning RTB. Bridarolli, Spiers & Putuskin (2020) published the first qualitative study on the topic. The study focuses on an adult population and investigates experiences of adult cancer patients and caregivers exiting treatment. It uses Interpretative Description (ID) which is a small-scale qualitative method; the study includes four participants. The study does not provide an interview schedule. The study illustrates that RTB is experienced positively in the transition out of active treatment, and creates a sense of community, representing an important milestone that was symbolic of returning to “normal life” after cancer treatment. The paper highlights the need for research to examine the experience of rituals including the ringing of the bell amongst diverse patient populations, including paediatric settings (Bridarolli, Spiers & Putuskin, 2020).

Rationale for the study

This qualitative study aims to understand parents' experiences of rituals at the end of paediatric cancer treatment, with a focus on RTB. Previous literature explores the meaning of rituals such as the RTB in adult cancer care settings and rituals in the context of paediatric palliative care. There are to date no studies that focus on rituals at the end of successful paediatric cancer treatment. This is a critical area of research, for a number of reasons, including: increased survival rates and number of children transitioning off active treatment (Office for National Statistics, 2019); the meaning and function of rituals at successful treatment completion being different to experiences at the end-of-life transition (Myers, 2003); and the increasing number of bells being situated and rung across paediatric oncology settings in the UK, despite mixed evidence of its impact and a lack of research understanding individual experiences (Gale, 2019). The focus on parent perspectives and experience is critical due to parents' important role in navigating the EoT transition, as well as their active role in forming celebrations, ceremonies, and rituals for the child, themselves, and the family (Santos et al., 2015; Patterson, Holm & Gurney, 2003). The findings of the study have implications for both research and clinical practice/service delivery, in relation to the use of rituals such as RTB and ways in which parents and families can be supported with marking their endings during the EoT transition.

The current research questions are:

1. How do parents understand and experience rituals at the end of their child's cancer treatment i.e., the marking of the end of their child's cancer treatment?
2. What meaning do parents attribute to the ringing of the bell ritual (RTB)?

Method

This section begins with a discussion of the epistemological and methodological positions of the research. It provides the theoretical underpinnings of and rationale for using Interpretative Phenomenological Analysis (IPA). The section gives an overview of methodology and discusses the rigour and quality of research which includes a reflexivity statement.

Epistemological position

In carrying out the study, the researcher commits herself to exploring, describing, interpreting, and situating how parents make sense of their experiences of marking the end of their child's treatment and the ringing of the bell (RTB) ritual. Madill, Jordan & Shirley (2000) describe this as a "contextualist position". In contrast to the naïve or scientific realist framework, the position rejects the notion of there being one reality and accepts that all knowledge is local, provisional, and situation-dependent i.e., results can vary according to the context in which the data is collected and analysed (Larkin, Watts & Elizabeth, 2006). In the production of knowledge, the researcher should exercise subjective judgement and be aware of personal beliefs and conceptions that can impact knowledge produced (Madill, Jordan & Shirley, 2000; Pidgeon & Henwood, 1997; Tuffour, 2017).

Methodological position

The current research is embedded in qualitative methodology. Qualitative approaches are widely used to bring insight into the research domain of health and illness (Yardley,

2000). They allow researchers to peer deeply into the world of human experience (Guest, Namey & Mitchell, 2013) and enable in-depth exploration of the meaning people attribute to their experiences (Brookes, 2007; Merriam & Tisdell, 2015; Tuffour, 2017). One of the advantages of qualitative approaches is the use of open, exploratory questions that enable unlimited and emergent descriptions to come forth, making it particularly helpful when little is known about a research area or when the topic is highly complex (Anderson, 2010; Elliott & Timulak, 2005); the current study fulfils both of those requirements.

Interpretative Phenomenological Analysis (IPA)

To gain an understanding of parents' lived experiences, the researcher applied the inductive qualitative methodology of Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). IPA is one of the most widely used approaches to qualitative enquiry in health psychology (Brocki & Wearden, 2006; Reid, Flowers & Larkin, 2005). It enables researchers to explore individuals' "lived experiences" (Brocki & Wearden, 2006) and is therefore acknowledged as a suitable approach for capturing "what it is like to be experiencing this or that for this particular person" (Eatough & Smith, 2008).

IPA has been informed by ideas from three key areas of the philosophy of knowledge including phenomenology, idiography and hermeneutics (Smith, Flowers & Larkin, 2009). IPA is phenomenological as it thinks about experience in relation to what is important to the individual and how individual comes to understand what their experiences of the world constitute (Smith & Shinebourne, 2012). It enables to "give voice" to the concerns of participants (Larkin, Watts & Elizabeth, 2006). IPA pursues an idiographic commitment, as it is interested in thinking about individuals in their contexts, understanding their personal views, which begins with a detailed exploration of each participant before moving to more

general claims (Smith & Osborn, 2015). It corresponds to hermeneutics as IPA from the outset is an interpretative process and claims that participant's cognitive world can be accessed through the analytic process (Smith, Flowers & Larkin, 2009). The approach is committed to contextualizing and "making sense" of individuals claims from a psychological perspective (Larkin, Watts & Elizabeth, 2006).

The choice of IPA for current study

IPA is often concerned with exploring experiences which are of a particular moment or significance to the person (Smith & Osborn, 2015). This is applicable to the current study as marking the end of treatment has been shown to carry a significance for parents, though the meanings attached to these experiences have not yet been explored (Björk et al., 2011; Enskär et al., 2020; Hobbie et al., 2010). IPA is recommended for understanding experiences during times of change and transitions (Smith & Osborn, 2015). The end of cancer treatment is an important transition and time of change in the care pathway of children and families (Hosoda, 2014; Keats et al., 2019; Labay, Mayans & Harris, 2004). The idiographic focus of IPA is also fitting with the current research as marking endings and rituals carry individual meaning through personal interpretation, requiring one to understand the unique context and story of each participant (Nelson-Becker & Sangster, 2019). The selection of IPA is further supported by its applicability to other studies exploring the experiences of parents of children living with chronic illnesses like cancer (Schweitzer, Griffiths & Yates, 2012; Tutelman et al., 2019).

Background and Participants

The current study is a part of a joint project which aims to understand the experience of marking the end of cancer treatment from the perspective of parents, children, and staff members (von Werthern, 2021; Tsipa, 2021; see Appendix A). The study focuses solely on the views of parents.

Participant Inclusion and Exclusion Criteria

Parents were recruited from the oncology department of a national referral children's hospital in the UK. In line with IPA guidelines, purposive and homogenous sampling was used for the recruitment of participants (Smith, Flowers & Larkin, 2009). Participants were included if they were parents of children aged 8 to 14 years who finished cancer treatment 6 to 24 months prior to the time of recruitment. Children above the age of 14 were excluded, due to this age marking a transition from the hospital where the study was conducted to another oncology service. All children had received treatment in the haematology department of the same hospital that had the "end of treatment bell". Exclusion criteria included: parents of children with significant learning difficulties, either through pre-existing syndromes or due to cancer treatment as they may have had a different journey through cancer treatment; parents of children for whom there were known safeguarding issues; parents of children who were unwell medically or in a relapse phase to an extent that it would be deemed inappropriate to try to interview them.

Recruitment Procedure

Potential participants were identified based on inclusion and exclusion criteria by the administrator of the oncology ward and a Clinical Nurse Specialist. An assistant psychologist (AP) who was an existing member of the treating team sent information packs to the 26 identified potential participants. The AP contacted parents by telephone between one and two weeks after the information packs were mailed, to identify participants who were interested in participating in the study. Sixteen participants agreed to being contacted further by the primary researcher and thereafter agreed to take part in the research. In line with recommendations for IPA sample size for a professional doctorate (Smith, Flowers & Larkin, 2009), eight participants were contacted to arrange a date and a time for interviews (see Table 1). Others were informed that recruitment had been stopped due to reaching the required number of participants; they were given the option to contribute by providing feedback on the initial study findings.

Five participants chose to attend their interview alone i.e., five individual interviews and three wanted to attend with their partner i.e., three dyad interviews with six parents. Thus, eleven parents from eight families took part in this study (see Table 1). By chance, all were parents of children who finished treatment for Acute Lymphoblastic Leukaemia (ALL) which allowed to have a homogenous sample in line with IPA guidelines (Smith, Flowers & Larkin, 2009). At the time of the interviews, participants ranged in age from 40 to 61 [$m=45$] and children's ages ranged from 9 to 12 [$m=10$]. Four participants were male/fathers, and seven were female/mothers. Four participants were White British/Other and seven were Asian/Asian British. The range for time off treatment was 6-19 months [$m=14.5$], and for treatment duration 26-40 months [$m=27.5$].

Table 1

Number of participants with demographic information

Demographic factors	Variants	Participant numbers
Parent gender	Males	4
	Females	7
Parent ethnicity	White British/White Other	4
	Asian/British Asian	7
Parent interview participation	Mother and father	6
	Mother only	4
	Father only	1
Child gender	Males	3
	Females	5
Time in ALL treatment	26-28 months	5
	36-40 months	3
Time since treatment completion	6-12 months	4
	12-20 months	4

Ethical considerations

Ethical approval for the study was granted by the local NHS Foundation Trust in December 2020 (see Appendix B). To obtain informed consent, participants were sent an Information Sheet (PIS; see Appendix C) which they were asked to read prior to being contacted for participation and signing the consent form (see Appendix D). The PIS contained information about the study aims, voluntary participation, the procedure involved, data storage and usage, and potential benefits and disadvantages of taking part. A screenshot of the signed consent form was taken at the beginning of each video call. All electronic recordings including consent forms, video-recordings and transcripts were stored on an encrypted USB. To protect confidentiality, names of participants, children, and places, as

well as certain identifying details were changed in the original transcripts of transcribed sessions, the write-up of the study and all electronically stored documents. The Data Protection Act (1998) and General Data Protection Act (2018) were followed to maintain data protection rights of parents. Interviews took place on ZOOM, a virtual platform that complies with the European General Data Protection Regulation (GDPR, 2018; ZOOM, 2020). The secure link and password for the meetings were sent to participants via secure NHS Trust e-mail the day before the interview. Once transcribed the video recordings were deleted. Participant wellbeing was considered in the application for ethical approval; this included a protocol on emotional distress, withdrawal, and complaint procedures. There was no report of distress and request to access psychological support following the interviews.

Data Collection

In line with IPA guidelines (Smith, Flowers & Larkin, 2009), data was collected through semi-structured interviews. This method invites participants to offer a rich account of their own experiences and provides flexibility to explore matters that are important to them (DeJonckheere & Vaughn, 2019). The researcher acknowledged that there may be different family contexts and structures, thus in the case of children having more than one parent interested in participating parents had the option to attend the interviews separately or as a dyad. This was to ensure ethical and inclusive research.

Interview Schedule

The interview schedule (see Appendix E) was carefully developed through discussions with primary and secondary supervisors. This process integrated Patient and Public Involvement (PPI), with a draft of the interview questions being discussed with the parent of a child who finished cancer treatment for ALL at the same health care service. This enabled the researcher to check the sensitivity, acceptability, and relevance of the questions (Muller et al., 2019). There were no proposed changes and questions were found to be “appropriate” and “phrased sensitively”. The interview schedule had eight open questions, along with possible prompts and lasted between 45-90 minutes; questions such as “why?” and “how did you feel?” were used repeatedly to go deeper into participants experiences (see Appendix F).

COVID-19 Pandemic

The COVID-19 pandemic had significant implications for the data collection phase; there were long delays in being granted ethical approval for the study, which resulted in limited time for recruitment and data collection. All eight interviews were completed in the span of two weeks. Due to the UK Government restrictions, the interviews could not take place face-to-face as and were completed on a virtual communication platform.

Feedback Interviews

Participants were given the opportunity to be contacted for a follow-up video conference call to discuss and give feedback on the general findings and recommendations of

the study (see Appendix G). Seven participants agreed to be contacted at the time of their interviews, but only three were reached prior to the submission of the thesis. All three participants said that the findings captured the essence of their EoT experiences (see Appendix H).

Analysis

There are no set of fixed procedures for conducting IPA, however there is a framework for analysis that can be used in a flexible manner (Smith, Flowers & Larkin, 2009). The first step involved transcribing the interviews verbatim by the researcher who listened to the audio recordings. The analysis involved four key steps: re-reading transcripts and taking initial notes; identifying emergent themes and developing super-ordinate themes and developing super-ordinate themes across cases. Given the idiographic commitment of the approach, interviews were analysed separately before moving to the next and same steps of analysis were applied to all. Discussions with the research team took place throughout the process of analysis, to cross-check and assist with bracketing.

Re-reading and initial noting

The initial step involved listening to the audio recording and simultaneously reading the transcript and re-listening to the recording. A reflective diary was used to bracket off initial observations and ideas, to avoid rapid meaning-making and slow down the process and focus back on the participant. The transcripts were moved into a table in Word, the left-hand margin consisted of the transcription, and the right-hand margin contained the initial line-by-

line comments. The notes were colour coded into descriptive, linguistic, and conceptual comments (see Appendix I).

Identifying emergent themes and developing superordinate themes

The second stage involved working primarily with initial notes and mapping out connections across emergent themes within each interview (see Appendix J). Some themes were discarded depending upon the scope of the research question e.g., talking about sibling experiences during chemotherapy diverted from the explicit area of exploration of the end and rituals. In mapping out the themes, the researcher printed out all the emergent themes and cut them to be placed on separate pieces of paper. The floor was used to move the themes around. The researcher used methods like abstraction, subsumption, polarization, and contextualization when identifying patterns to condense and cluster emergent themes into super-ordinate themes (Smith, Flowers & Larkin, 2009).

Developing super-ordinate themes across cases

The final stage involved looking for patterns across emergent superordinate themes from all eight interviews using the same procedure outlined in the section above (see Appendix K). All eight mind maps were printed and put next to each other on the floor, to look for connections across them and clustering themes together to represent higher-order themes.

Validity and Quality

Smith, Flowers, & Larkin (2009) suggest using the four principles identified by Yardley (2000) when assessing the validity and quality of qualitative research. These principles include Sensitivity to Context, Commitment and Rigour, Transparency and Coherence, and Impact and Importance.

Sensitivity to context

Yardley states that quality research should demonstrate sensitivity to context (Yardley, 2000). The researcher's choice of IPA showed sensitivity to context through taking an idiographic approach and focusing on the context and experiences of individuals. The interview schedule was carefully developed through supervisory discussions and integrating Patient and Public Involvement (PPI). Sensitivity to context was demonstrated through allowing participants to attend the interview individually or together as a couple. It was also shown in the analysis of the data, through providing original verbatim extracts from interviews that corresponded with initial notes and codes; this allowed the researcher to support the claims made, make interpretations transparent to the reader and allow parents' voices to be captured. Sensitivity was also achieved through providing participants with a summary of key findings.

Commitment and rigour

As a researcher novel to IPA, I showed commitment to the study by enhancing my knowledge on the methodology through readings, attending an IPA masterclass and seeking support from researchers with expertise. Commitment was also illustrated through the extensive time given to the analysis stage and carrying out a thorough analysis despite delays in NHS ethics and limited time to conduct analysis with other requirements of the course, all in the context of the COVID-19 pandemic.

Transparency and Coherence

Transparency was achieved through providing a clear description of the stages involved in data collection and analysis in the study write-up e.g., participant tables, copy of interview schedule, and examples of the analytic process. Yardley (2000) discussed that reflexivity is critical in achieving transparency. To engage in reflexivity, I kept a reflexive diary, recording my thoughts, feelings towards undertaking the research prior to and during data collection, analysis, and write-up. I used existential bracketing reflecting on my theoretical orientation, presuppositions, cultural background, and experiences might influence how I approach the research (Gearing, 2004). I completed a bracketing interview prior to conducting the study, with another researcher (Tufford & Newman, 2008). The bracketing interview was used to inform the reflexivity statement below:

I identify myself as a healthy young woman without a history of chronic illness. I grew up with a parent who had a serious health condition and underwent multiple surgeries due to malignant tumours. I have vague memories of the time, but I remember my strong wish to

protect my parent from being unwell and the worry and anxiety I felt. Although I know what it is like to be in the position of a child with a sick parent, I have no lived experience of being the parent of a child with an illness. Through my bracketing interview, I recognized that similar protective feelings re-surfaced as I talked about the upcoming research interviews. I became aware of my wish to protect the parents from reliving and talking about difficult experiences regarding their child's illness. This was a reflection I was mindful of throughout my research journey. Although I made the choice to research a topic on endings and transitions, I also became aware of my sensitivity towards experiencing and talking about endings. Growing up, I went through many transitions in the context of changing physical location and countries. Transitions often signified loss, particularly the loss of relationships. It was therefore important for me to be aware of my personal beliefs about what it means to transition and leave a familiar way of being in the world. Another important recognition was my social constructionist stance as a clinician and the implications of this for the research process. I was aware of my discomfort in making assumptions about individuals' thoughts and feelings without being able to check my assumptions with them.

Impact and Importance

Yardley (2000) stated that the decisive criteria by which any qualitative research must be judged is its usefulness, relevance, and applicability. The researcher hopes to demonstrate the impact and importance of research in the discussion section where she talks about the theoretical and practical implications of the research for community, and health workers.

Results

Introduction

The analysis reveals six superordinate themes and sixteen sub-themes (see Table 2).

The super-ordinate themes are explored in the following chapters and are as follows:

- **Making Sense of When “The End” is**
- **Meanings Attached to Marking the End(s)**
- **A Bell that Bonds and Divides**
- **For Whom the Bell Tolls: A Multi-Vocal Symbol**
- **The Role of Staff in Ringing the Bell**
- **After the Bells are Rung**

There is an over-arching theme of *ambivalence* across the first three super-ordinate themes but not all accompanying sub-themes. There is ambivalence in making sense of and knowing when “the end” is as the end of treatment is not the end of difficulties. Participants express feelings of ambivalence as they mark the end to close a difficult chapter that cannot be fully closed. There are also feelings of ambivalence towards the end of treatment bell as the bell bonds yet divides children and parents of children who are sick i.e., on treatment and those who are well i.e., transitioning off treatment.

Table 2

Overview of the master table for all participants

	Superordinate Theme	Sub Themes
<i>Ambivalence</i>	Making Sense of When “The End” is	Multiple and Personal Endings Port-removal: “The End of the End” COVID-19: The Loss of the Anticipated End
	Meanings Attached to Marking the End(s)	Separating from Cancer Dissolving a Tension: Being a “Good” Parent Forgetting and Remembering
	A Bell That Bonds and Divides	An Unspoken Bond A Reminder of the Sick and the Well
	For Whom the Bell Tolls: A Multi-Vocal Symbol	Sustenance and Hope A (False) Sense of Security Freedom and Return to “Normal” Recognizing Achievements
	The Role of Staff in Ringing the Bell	“Not Just Another Patient”: Feeling Special to Staff Needing Guidance and “A Party Planner”
	After the Bells are Rung	“Hit” by Emotions Loss of Support and Reassurance

1. Making Sense of When “The End” is

This super-ordinate theme captures parents’ trying to make sense of when “the end” is and the milestones that get marked and celebrated. There are feelings of ambivalence with the end of treatment not feeling like “the end”. All parents describe having one more than one ending and highlight that these are personal to their child’s cancer journey. The EoT milestones often signify the end of obstacles and difficulties faced by the child and parents. The removal of the port carries a particular significance for the perceived sense of an ending. Finishing treatment during the COVID-19 pandemic is experienced as the loss of the imagined end, blurring the line between being on active treatment and at the end. The sub-themes include: *Multiple and Personal Endings*, *Port-removal: “The End of the End”* and *COVID-19: the loss of the imagined ending*.

Multiple and personal endings

Eight parents talk about how the end of treatment is not a single moment in time but rather a continuum with multiple milestones. Jennifer says:

No more medicine [chemotherapy] but hospital appointments were still kind of happening so maybe not, I guess there was like two ends of, there were three end of treatment dates?

The quote captures Jennifer’s ambivalence and confusion about when the end of treatment is. This is illustrated through her hesitant speech and the question she directs at

herself. The end of chemotherapy tablets and loss of contact with the hospital are some of the multiple endings important to her.

Similarly, Josephine also talks about there being multiple endings:

it was probably the last time I administered anything to him, end of steroids and medicine? finishing the medicine, having his port removed and leaving the hospital (...) once he gets to the five years, that will be another thing, there is still the five-year remission isn't there. We got ages again, it's a long process, that is leukaemia, but he did it and he had a good finish to it

Josephine tries to make sense of the end of treatment and names some of the milestones that are important to her. The milestones signify the end of foreign substances entering the child's body, invasive procedures, and loss of contact with the hospital. There is hesitation in her language, which could indicate uncertainty and difficulty in knowing when the end is. There is ambivalence about the end; although there is a finish to the treatment, the cancer experience is not over with. She speaks about waiting for the five-year remission and how they continue to be on the end of treatment continuum. This could suggest that the end of her son's treatment is not experienced as "the end" but as one in a series of endings, milestones, or transitional points.

In addition to describing multiple endings, six participants talk about how these endings are personal to their child's cancer journey and the struggles they faced. Daisy says:

An important one was when she finished this medication called Cotrimoxazole. That was every Monday and Tuesday for the whole of the two and a half years, and she hated that, like with a passion, it was quite hard to get her to take it.

This quote illustrates how an important ending for Daisy is the completion of the long and traumatic journey with a medication “hated” by the child and herself. The medication is the source of many physical and emotional challenges for the parent-child dyad. The difficulty for Daisy is having to get her daughter to swallow pills that are critical for her health but are nevertheless disliked.

Port-removal: “The End of the End”

Five parents talk about the importance and meaning of the removal of the central venous access device e.g. port-removal i.e., a device placed under the skin to draw blood and give treatment, for the perceived sense of an end. Jennifer says:

Yes, he finished his tablets, but you still need to remember he's got his port and you have to be very careful if he gets a temperature, he still gotta go into the hospital and you still worry about this machine (...) you want that out even though that's been like just perfect for his treatment, you don't want that in when it's finished because it's not finished whilst that's in, but then once that's out, we have nothing to do with anyone anymore, we are on our own.

There are feelings of ambivalence towards the port and its removal. The port is seen to have a positive and critical role in the child's treatment journey, and at the same time

maintains ties to sickness, danger, and the hospital. It is experienced as a foreign “machine” that continues her worries past the point of ending medication. Although the chemotherapy tablets are finished, there is no sense of an end with the port in; the child continues to be at risk. There is a sense of wanting the port to be out and ending treatment but then feeling that they are out. With the port-line being removed, the ties with the hospital are cut. There is an experience of being alone without the support of staff.

For some parents, the removal of the port carries less ambivalent and more positive meanings as it signifies freedom and the child’s return to “normal”. Ina says:

The most special was when her port line was removed that’s the end of the end because she was free from everything and she could swim like the other children again.

Ina describes how port-removal is a strong signifier of the end of a restricted life and transition to a new social status of being a “normal” child. Her child can now engage in ordinary and everyday activities like swimming. This represents a sense of returning to normality. This is echoed in another account by Josephine:

When he got his port out, he did say to me, I can be like all the other boys now? And I said yeah David you’re alright (...) that was really the end you know (...) if he had a temperature, he would now have Calpol like the other children.

This quote illustrates the shared understanding between the parent and the child that the port-removal is the true end to the treatment. It signifies the transition to a more “normal”

childhood. From Josephine's perspective, her child can now be like other children, who can have ordinary fevers and be treated with everyday medicines at home.

COVID-19: The Loss of the Anticipated End

Five participants talk about pre-anticipating and constructing an imagined ending in their minds prior to finishing, i.e., what they want the end of treatment to look like and when they want it to happen. Finishing during the time of the COVID-19 pandemic deconstructs the sense they had made of the end, leaving some parents to feel as if there was no end. Hemal describes the loss of the imagined ending:

I felt absolutely gutted because there was so much that I wanted to do. From the second year I started thinking about how I wanted my last visit to hospital look like, but I couldn't do anything (...) I wanted to give nurses a box of chocolates, but they would have to sanitise it and everybody was treading on just eggshells, they just wanted her in and out.

Hemal daydreams about the end of treatment, long before it takes place. There are strong feelings of disappointment and upset that accompany her unfulfilled wishes and perceived lack of control in marking the milestone. There is experience of loss that comes with the dangers posed by the pandemic. Hemal is not able to show gratitude towards staff in the desired way, as gift giving becomes a dangerous act of kindness. She feels rushed and there is the loss of time and space to say goodbye. Similarly, Dipa also talks about the loss of the imagined end and adds what that means for the perceived sense of an ending:

There is a lot of negatives to what's happened with COVID-19. We couldn't do any of the things we wanted, and it does feel like there has not been this line that we can put through treatment.

This quote illustrates how ending treatment during the pandemic is a difficult experience that leaves the parent to feel as though they have not been able to cross off and be done with treatment. There is a sense of finishing treatment but not feeling like it has ended. The quote also indirectly highlights the importance of marking the end to achieve a sense of closure from treatment and leave it behind.

Jennifer echoes this by talking about how COVID-19 blurs the line between her child being on active treatment and at the end:

We were going to take a proper holiday at the end and then it's like we are going into a lockdown (laughter) alright, well we were already kind of in a lockdown, so let's just scrap this year as well (...) it's like did it really end?

There is an unexpected and interrupted transition to normality following cancer treatment with the pandemic. Jennifer describes a sense of their lives being put on hold during cancer treatment, which unexpectedly continues to be the case beyond the end of treatment. As a restricted life continues with COVID-19, Jennifer experiences ambivalence and confusion about whether her child's treatment has ended.

2. Meanings attached to marking the end(s)

All participants talk about marking the end of their child's treatment. Some of the rituals and events include, taking an EoT trip as a family, gatherings and informal EoT parties on the ward/at home, the ringing of the bell, dedicating time to throw out chemotherapy medication etc. For eight parents marking the end of treatment has multiple meanings. For many, it is a way to achieve separation from the cancer and close a difficult chapter; there are feelings of ambivalence with the recognition that the cancer experience cannot fully be left behind. For some, rituals signify the end of the tension felt between being the "good" parent one has to be and wants to be while the child is on treatment. Additionally, marking the end is a way to remember the child as a happy child rather than a child in pain. The sub-themes include *separating from cancer, dissolving the tension: being a "good" parent, and forgetting and remembering.*

Separating from cancer

For six parents, marking the end through celebrations and rituals is a way to separate from and leave the cancer behind. Josephine says:

I made sure all celebrations were in the same year, I mean it was hectic, did a trip, his birthday, parties. We finished that year saying that's the end, all the bells are rang (laughter) it's done, that stays there, and it doesn't come with us into the new year. I was like it's got to be done, need to close that chapter and open a new door, for him and for us (...) Now I see doing all that was great, and he was fine, kids move on very quickly don't they but not parents.

There is a strong need to shut the door on cancer and transition to a cancer free life; this is to be achieved through celebrations. The strong need is conveyed through throwing multiple celebrations, despite finding this to be a “hectic” experience. The parties and the end of treatment trip serve the function of communicating and providing certainty and reassurance that the cancer is “done” and over with. It is unclear whether this communication is towards themselves, others, or both. The bell is a strong signifier of the end with all the different celebrations being labelled as other bells being rung. From her eyes, there are differences between the child and parent positions in relation to how easily the cancer chapter can be closed. From her perspective, the child easily separates from the cancer and moves on, whilst she does not. There is a degree of uncertainty regarding the child’s experience, directing a question to the interviewer whom she knows is a psychologist. There is a recognition that despite the efforts to celebrate and leave the difficult cancer experience behind, this cannot be fully achieved.

Daisy also talks about her need to close the cancer chapter but in a different way:

I did a book for her, an end of treatment book with all like pictures of her treatment and the end. I think it was closure, really (...) I felt like a massive relief because it was something to look back at. I just feel like it's all in there now, this was, well this is our life.

Daisy tries to achieve closure and make the cancer journey a distant memory through marking the end with a picture book “to look back at”. Despite her efforts, the cancer experience remains to be in the present. This is evident in the ambivalence in her language as

she describes feelings of closure and relief, yet switches from past tense i.e., “this was” to present tense i.e., “this is our life”. This suggests that the cancer experience cannot be fully left behind and remains a part of the family’s life story.

Dissolving a tension: a “good” parent

For five parents, marking the end and celebrating signifies the end of a difficult tension between being the parent one wants to be and the parent one has to be during the child’s treatment. Jennifer talks about the meaning of marking the end through throwing out chemotherapy drugs:

The day that was big for me was when I dedicated that time to throw out the medication in the cupboard. Every time I went into that cupboard, it said it’s a toxic substance with all these warnings on it, you can’t even touch surfaces with it and I’m giving it to my child and she’s swallowing this toxic thing, and she lost her hair too (...) I didn’t have to do that and be that anymore.

This quote captures the felt tension between having to keep the child well by giving her tablets yet making her unwell through administering toxic drugs. The drugs are perceived to be so toxic that they are harmful even to inanimate objects. Guilt is an unnamed yet described feeling, as she talks about the side effects of the medication like the changes in her child’s appearance. Throwing out of the medication is thus an important event that marks the transition to no longer having to live with this tension and being able to be a different parent. This is also captured in the following quote by Daisy who describes her child’s end of treatment party:

I was always like we can't do this; we can't do that, and my girls would always tell me off and say, 'oh come on, stop being so over-the-top, you are being too controlling!' there was a lot of time away from people so she wouldn't get sick. That big celebration at the end was like it was okay to have fun and relax without me saying to everyone have you washed your hands, who just sneezed, coughed (laughter) because I was really over the...

Daisy describes her daughters experience of her as a parent who was “controlling” throughout treatment. She shows agreement with her daughters through describing her hypervigilant behaviour. There is a tension between two types of “good” parent – the good parent of a child without cancer who focuses on supporting the child’s overall development (social, emotional, physical etc.) and the good parent of a child with cancer who must prioritize the child’s health perhaps to the detriment of everything else. Although she wants to be a good parent and keep her daughter well by keeping her away from infections, she becomes a “controlling” parent who limits her life and keeps her away from others. The celebration and party thus help to dissolve this tension and mark the transition to being a less limiting and more “fun” parent. Josephine echoes this as she talks about marking the end with a Make-A-Wish trip:

you've got bad cop, good cop, my husband let him have exactly what he wanted whereas I didn't. When we started treatment, you had to wait an hour before and after medication for food, it was a nightmare. That was the toughest thing ever saying you can't eat that for an hour, you can't do this, you can't do that. It was really nice to go away on that trip at the end and not have to do that anymore.

Josephine talks about the difficult experience of having to be the “bad cop/parent” who implements strict measures and rules to keep her child well while her husband is the “good cop” and the more permissive parent. The end of treatment trip allows to achieve a physical and mental separation from this role and represents the end of the tension between having to limit her child to keep him well and being positioned as the bad cop.

Forgetting and remembering

Four parents talk about how marking the end through celebrations and the bell is a way to forget the pain of the treatment, share mutual enjoyment with the child and acquire and recall happy memories. Jennifer talks about what is to be remembered through celebrating:

It's just nice to mark it, it needs marking and that's why we did it, it was a big day with lots of celebrations and happy moments for everyone to remember and it's one that he won't forget and that we won't forget (...) how happy we were...

For Jennifer, the function of marking the end is about having a special and “happy” day to be remembered by her son, herself, and other family members. Celebrating the end is described as a “need”, which could potentially be reflective of a need to acquire happy memories to hold onto. This is elaborated on in the following quote by Dipa as she talks about what she would like to remember and forget through celebrating the smaller endings in her child’s treatment journey:

Treatment is just mixed up with so much negativity, constantly seeing her in pain but then these little glimpses of happiness, you need that as a parent that we can make her happy, otherwise it's just shit. I think back and it's not only pain I think about, but also not only all the negativity, I think about how all the celebrations and it puts a smile on my face (...) rather than remembering the pain and the medicine and how awful things were and losing her hair we wanted her to remember the happy moments.

During treatment, there is a sense of loss in not being able to be the parent of a child who is happy and well. There is the potential loss of a happy childhood and parenthood during the cancer journey. Marking allows Dipa to find “a glimpse of” what is lost in witnessing her child’s happiness and perhaps instals a sense of hope. The celebrations are a reminder to her that she is a parent who can make her child happy. The celebrations are perhaps the only way to remember the journey in a more balanced way, with its negatives and positives. They are also a way for her to ensure that her daughter’s memories are not clouded with the losses and the pain of treatment and that she also remembers the happy moments of celebrating and having fun together as a family.

Hemal talks about the missed opportunity to witness and remember her child as a happy child, as she did not want to celebrate and ring the bell at the end:

It's like anybody wants to see their child happy and remember them being happy (...) treatment is full of negative things and the bell is like taking your child to a theme park and they sit on one ride and they're ecstatic and the parents are happy because

their child is happy. But with my daughter, unfortunately, she doesn't like any rides, she fears heights.

The celebration and bell ringing are an opportunity to witness and remember the child as a happy child after a difficult and “negative” treatment journey. The theme park analogy captures how celebrations are a way to experience shared excitement and contagious joy between the parent and child dyad. The feared and disliked rides could symbolise her child’s dislike and fear of ringing the bell to celebrate. This is experienced as a missed opportunity and disappointment as Hemal is not able to witness her child being happy while celebrating.

3. A Bell that Bonds and Divides

This super-ordinate theme portrays parents' feelings of ambivalence towards the end of treatment bell as the bell bonds yet divides children and parents of children who are receiving active treatment and transitioning off treatment. This is illustrated in the following contrasting themes: *The bell as an unspoken bond* and *A reminder of the sick and the well*.

The bell as an unspoken bond

Eight participants refer to the bell as an unspoken bond of understanding and pain between witnessing and experiencing individuals. Some describe how the bell is a bond between parents. Harun says:

The bell is like this bond you know (...) when they ring the bell, we know all the crap that these parents have had to deal with you know the amount of time and effort it takes for people to look after their kids, receiving these injections and medicine.

Hearing children ring bell evokes a bond of understanding between parents, through their shared experience. It is an unspoken communication and reminder of the shared and collective pain, as they all witness and look after their children undergoing invasive procedures and take medication. A similar account is given by Jennifer:

You see others ring the bell and you didn't really have to say much to them, you just knew. You became one, like I didn't even know the people, but you are all in the same boat, all of you, like zombies walking around.

Jennifer describes how the bell bonds and brings together parents of children on the unit through an understanding of shared experiences and difficulties. The bell reminds her that she is a part of a community of fatigued parents who walk around the unit “like zombies”. The zombie analogy could represent a liminal state between life and death as well as a separation from the rest of humanity who perhaps fear contagion. When she witnesses others ringing the bell, it reminds her that she is not alone and on the “same boat” i.e., difficult situation as other parents who have now come to the end of their child’s treatment.

Some participants talk about how the bell is also a bond of understanding between children ringing the bell and parents of children undergoing treatment as they witness the ceremony. This is illustrated in the following quote by Hazel:

We’ve seen other children ring that bell and that’s quite an emotional day and these were children we didn’t even know but watching them ring that bell, just means a lot because you know what they’ve been through.

There is a sense of knowing and feeling for the children ringing the bell without knowing them. Hazel describes how when she witnesses the ceremony, there is an understanding of the pain that a child with cancer goes through. This stirs up emotions in Hazel, perhaps being reminded of her own child’s experience and pain.

A reminder of the sick and the well

Six parents talk about how the bell creates a divide and acts as a reminder of who is sick and who is well on the ward. There are different yet consistently ambivalent emotions towards witnessing and experiencing the bell. The feelings change depending on where the child is at in the cancer treatment. Ina describes her experience of hearing the bell at the start of her daughter's treatment:

I was crying when I first saw a kid, happiness obviously that the other child is going home, they are happy now (begins sobbing) and at the same time I was waiting, waiting when will my kid come for his bell ringing? (Continuous to sob) It was emotional, it was happy, both, their child is free, but we had to wait.

There is a sense of hearing the bell and being reminded of other children getting better while her daughter is sick. Ina describes having to wait in line for her turn to celebrate the freedom and recovery of her daughter, without an end in sight. Happiness is the "obvious" emotion to feel, however there are ambivalent feelings which are re-experienced in the interview; she sobs while describing her happiness for others and having to wait for their turn. This statement is echoed by other parents. Daisy says:

You feel quite envious of them, that they've got to that stage (...) you think wow that's amazing like that's such an achievement (...) but then you think argh, we actually came in for chemo today so it's a kick in the teeth at the same time. It's a horrible feeling, it's like you are happy for them but then you're like gutted for yourself because you are like oh flipping out, we've just, we got so long to go before we finish.

The witnessing of the bell ringing induces a comparison between where they are at in the treatment journey in relation to other families who are at the end of treatment. For Daisy, the bell ringing appears to be an unwelcome reminder of her child's ill state and the long and dreaded journey ahead of them. The perceived burdensome length of the journey is conveyed in her speech, as she slows down and "so long" is elongated. There is something shocking and painful as they are "kicked in the teeth" which might relate to unfair, disappointing, and upsetting experiences of having to go through treatment. There are ambivalent feelings, as Daisy experiences both happiness for others, but also difficult and unwanted feelings of envy.

The more difficult feelings towards the bell and the divide between the sick and the well become less stark as the child progresses in the cancer treatment. Alex says:

I think the resentment left after a while, it becomes a really happy sound later on that someone has gotten through and your child will get well too, but you know it depends, because the whole treatment is up and down regarding emotions.

Alex describes feelings of resentment towards those who ring the bell at the beginning of his daughter's journey. There is a shift in how he feels towards witnessing others with more positive feelings being amplified. This is due to getting to a point in the treatment where he can imagine his daughter coming to an end and being in the category of the "well". Feelings of ambivalence remain, as he describes how the turbulent emotional journey has an impact on how he experiences the bell ringing ceremony.

Josephine also describes her changing feelings and experience in witnessing others ring the bell as they approach the end:

It was when we got closer to finishing, I was like oh that's going to be us, that's going to be us, that's going to be us, so that was encouraging then (...) it was exciting.

This quote illustrates how with her child coming to the end of treatment, there is less perceived divide between her family and others ringing the bell. The bell becomes a symbol of hope and evokes feelings of excitement that their family can now be like others who successfully finish treatment.

The divide becomes visible again when participants' own children come to the end of treatment and ring the bell. Daisy says:

You do feel guilty like when you're the ones that are ringing the bell because you are looking around and you think we are finished, but we were where you were and some of them may have just been starting or in the middle, you just don't know what stage they are at (...) it's a weird feeling because you're happy but then you feel (begins sobbing) you just feel guilty.

Ringling the bell evokes a duality of feelings as Daisy experiences guilt and happiness. The bell is a reminder of their changing status and transition as a family. She wants to celebrate her child's successful ending and recovery but is also reminded of past experiences of hearing the bell when she was the parent of a sick child. She describes her confusion and perhaps worry about where others are at in the cancer journey and empathizes with their pain.

For some parents, the duality of emotions and empathizing with families with sick children on the ward influences how the end is celebrated. Jennifer says:

you're happy because you're finished, but it's like it's you don't want to rub it in too much, so you have to kind of still conserve it a little bit. So maybe it was good that we had that party at home afterwards because then we could just like, be ecstatic and feel happy.

There is a dilemma; wanting to celebrate yet having to strike a balance for others for them to not be reminded of the ill status of their child and experience feelings of envy. There is an expressed need to mask the feelings felt with true feelings and happiness needing to be preserved to be released when the family leave the hospital.

4. For Whom the Bell Tolls: A multi-vocal symbol

This super-ordinate theme captures meanings that are unique to the EoT bell. The bell is a multi-vocal symbol that allows different announcements to be made and for messages to be conveyed. Parents experience the bell as ringing for multiple individuals, including themselves, their child, and witnessing others which includes parents, children, and staff. The power of witnessing and being witnessed and the physical presence of the bell on the unit becomes apparent in the sub-themes which include *sustenance and hope, a (false) sense of security, freedom and return to “normal”, recognizing achievements*.

Sustenance and hope

Eight parents describe the bell ringing ceremony as an announcement of hope. Ina says:

You know, you celebrate it so that the hospital, the ward knows that, you know, there's one person who's successfully finished treatment... it's possible.

From Ina's perspective, the bell rings for those who are on treatment and witness the ceremony. It is a communication device that lets families on treatment know that someone successfully finished treatment. It provides reassurance and hope that successful recovery and positive endings are possible. Alex has a similar understanding of the bell and describes how the bell rang for him and his child when they witnessed the ceremony on the ward:

I could say to Hailey, look there is someone ringing the bell, there is another person getting better, that sound gives you that support during treatment and then that you can then support your child and say you have people are getting better all the time.

The bell is perceived as a direct source of support for Alex and an indirect source of support for his daughter. The more it rings, the more proof that children recover from cancer. This helps him to actively draw his daughter's attention to the bell and communicate the important message that like other children, she will also survive cancer and get better.

Some parents describe how this announcement of hope can be made even in the presence of a silent bell on the unit. Dipa and Harun and say:

Dipa: It's that hope, you walk past it and there is a possibility, because when you're at the beginning it feels like you can't get through, it feels like a massive weight, surrounding your aura, watching your child disappear from your eyes, personality, looks. So, the bell being there, it's something you can hold onto it's that hope that there is an end to this, even though it feels like a lifetime away. You can get through this; others get through this

Harun: Yeah, there's the possibility and it's like this thing you look forward to, this hope, it sounds strange, it's just an object or an idea but it gives you hope.

The physical presence of the bell is a source of hope and sustenance during a time of hopelessness and loss. Dipa communicates the felt hopelessness through describing being weighed down and her whole existence being captured by the experience of having her child

undergo treatment. At a time of significant loss which is the loss of the child she once knew and had, the bell gives her hope that her child will reappear again as herself and recover. The bell provides reassurance and gives both parents a future time to look forward to. Although it feels inexplicable and perhaps surreal to Harun, the bell represents more than an object.

A (false) sense of certainty and security

For three parents the bell is a strong symbol of security that ringing it marks the end of the treatment journey. Alex describes the meaning of the bell for the end of his daughter's treatment:

It's the trust in the nurses and doctors that we wouldn't be ringing this bell unless it was over, you know, it is a big thing. It's not a piece of paper that you read that says her treatment is over, it's the sound and sight of something happening that, you know, it's telling us that it's over. It's done, you know, it's a two-way thing you know, it is over, we are showing you it's over

From Alex's perspective, the bell is a powerful multi-sensory object which can be heard and seen by witnessing and experiencing individuals. Being witnessed by medical professionals allows them to have trusted allies that reassure him that the treatment is done and that his child is well. This instils a sense of security and certainty. The comparison between ringing the bell versus receiving an end of treatment letter illustrates the perceived power of witnessing and being witnessed by others; the end feels more real when others are seeing, hearing, and witnessing.

Three participants describe how they feel the bell evokes a false sense of security and certainty that ringing it means the end. This is illustrated in the following quote by Daisy:

A part of me was quite nervous, so I was like she's ringing the bell this should be the end, I hope this is the end, like I really want it to be the end. Erm, you can't really, it's just always going to be in the back of our minds, but it... it's difficult. It's like, we want to relax but we can't fully relax even now.

While her daughter is on treatment, the bell communicates certainty to Daisy that “this should be the end”. When her daughter is at the end of her treatment and ringing the bell, Daisy doubts its meaning and becomes less certain, which is mirrored in her unsure and hesitant language. She recognizes how ringing the bell may be the end of treatment, which brings some relief, but that it is not the end of experiencing worry; this could be related to a fear of relapse in the future.

Freedom and return to “normal”

Eight parents talk about how the bell signifies freedom from the disease, the restrictions imposed by the treatment and a return to normality. Alex uses the analogy of wartime bell ringing to illustrate this:

it's a bit like when I think of you know what people do after real misery, like after a war, they ring bells, it's the end of misery, we now move forward with our lives.

Here, Alex talks about the end of treatment bell as being like wartime bells that are rung at the end of a battle and are symbolic of end of conflict and sense of freedom. The war metaphor is used to describe a state of suffering that is the result of cancer which brings misery to their lives. The bell ringing is an announcement of the end of their suffering, freedom from the disease and transition to living as fully as they can, in the face of what they have experienced.

Ahmad and Ina also talk about the bell ringing as an announcement of freedom:

Ahmad: I think that bell is like, you let people know, okay I am free now. I don't need to have anything go in my body and I can go anywhere I can do anything I want, because for the two years, she wouldn't be able to swim at all, she's not allowed.

Ina: Yeah, it means treatment is finished and she is free now, she can do things other children do, enjoy her life now.

For Ahmad, the bell ringing ceremony is about his daughter making an announcement to others that she is free from cancer. At first, it is hard to tell who makes the announcement of freedom, whether it is the child or the parents. The freedom is liberty from toxic substances entering the child's body, and the end of a restricted life. The bell is an announcement of returning to normality and being able to do the things ordinary children can do. Ina agrees and adds how this goes beyond returning to a normal life, but also means that life can now be more enjoyable for her child.

The following extract by Shah and Hazel, illustrates how the child ringing the bell is an announcement of their freedom as parents:

Shah: It's a celebration for parents, we can say to people we can enjoy our life, nothing to worry about, everything is back to normal life, we can enjoy life now, no more hospital, medicine, and things all those.

Hazel: It's the same feeling for me, we can now enjoy our life because for three years, there was so much Shah and I couldn't do

Although it is the child who rings the bell and stops the treatment, the bell is a way for Shah and Hazel to announce to others their freedom as parents. For Shah, this is freedom from the worries and anxieties he felt while his child was on treatment, and a sense of returning to a “normal” and more “enjoyable” life. For Hazel, the freedom is about living a less restricted life and being able to do things they were not able to do as individuals.

Recognizing achievements

For seven parents, the bell ringing ceremony is a way to recognize and acknowledge the achievements of the child, parents and others who helped the family across the treatment journey. Josephine talks about celebrating the achievement of her son:

It was like wow you did it [the bell ringing] it was an achievement for him to have done all of that, and I'll show you something else as well, he got two certificates [from the ceremonies].

The bell ringing ceremony is about acknowledging her son's recovery which she sees as his achievement. Through presenting her son's bell ringing certificates on camera and smiling, she shows me how proud she feels of his success.

In addition to seeing the bellringing as a celebration of the child's success, some participants view it as a celebration of their accomplishments and efforts as parents. This is illustrated in the following quote by Ahmad:

When she is ringing the bell, it's a success, and the satisfaction, that okay you did the hard work of the two years, and the end result is that your daughter is cured.

Here, the bell speaks to and rings for Ahmad as a parent. The bell has a voice that acknowledges the hard work he put into caring for his daughter and how his efforts helped his daughter to be cured. The bell rewards him as a parent and evokes feelings of gratification.

For some participants, the bell ringing ceremony celebrates the parents' efforts, but this is something difficult to accept and acknowledge as the bell ringing is meant to be about the child. This is illustrated in the following quote by Daisy:

Everyone said to me when she rang the bell, oh, you're amazing, but you just think, not really you don't have a choice. It's just not about us, it's about them. I had to keep myself well to take care of her so maybe that's an achievement.

For Daisy, the bell rings for her child rather than herself. Her achievements and efforts are lost, and hard to acknowledge, being perceived as something she must do as a parent rather than by “choice”. Even when the achievements are acknowledged i.e., being attentive to her self-care throughout treatment, looking after herself becomes something she does for her child.

Some parents talk about how the bell rings not only for their child and themselves but also for others who supported them throughout the journey. For example, Jennifer says:

It was him ringing the bell, but it was all of us you know. We had such great neighbours and family, when David craved something one of them was bound to bring it and that's why I wanted everyone to see, like we've all done that, we've all helped each other and got him through this and now he's ringing that bell.

This quote captures how the bell ringing ceremony is a celebration of joint success. The bell ringing ceremony is a way to acknowledge the efforts of the support network around the child and to show them that this joint effort made the child's recovery and getting through cancer possible. The invitation to witness the ceremony could be interpreted as being way to give the support network around the family a gift in return – the child's successful recovery - and to show gratitude for their efforts.

5. The role of staff in ringing the bell

Eight participants talk about the important role of staff in planning and being present in the ringing of the bell ritual. Participants report a range of experiences, with some receiving extensive support and attention from staff, and some describing a sense of being on their own and left in the dark. The sub-themes include: *“Not just another patient”*: *Feeling special to staff* and *Needing guidance and a “party planner”*.

“Not just another patient”: Feeling special to staff

All parents talk about their wish to feel important and special to staff at the end of treatment. The way staff mark or do not mark the end and parents’ perception of staff’s feelings towards the bell ringing ceremony have implications for how the end of treatment is experienced. Daisy says:

It was just so sweet and special they even made time in their diary, they wanted to be there, her nurse said I'm going to come just for this and be there. It just shows it's special for them too you feel like oh wow they've taken time out of their day to come and watch her ring the bell, even the doctors have come out and it makes you happy.

This quote illustrates how staff are an important part of the bell ringing ceremony, and the end of treatment. The end feels special when staff make an active effort to make space for the bell ringing and the family, both emotionally and physically through putting the event down in their diary. Being in the diary of staff members is a communication to Daisy that the bell ringing is an event that is important and personal to staff too. Daisy has the experience of

being kept in their main nurse's mind and recognises her desire to be there, as she comes into the hospital for the bell ringing on a day she is not paid to be there and in her nursing role.

This communicates an experience of feeling like her and her child are more than a patient to staff.

Alex describes a contrasting experience of not feeling special and important to staff at the end of treatment and the bell ringing:

It's such a special moment, but it was a bit like us saying [on the day of last visit to hospital] will she be ringing? yeah she will be ringing [laughs]. It was a little bit kind, of yeahhhhh fineeeee (rolls eyes) [laughs] There was no build up as it were and you just stand there, you just go straight there, you just do it and off you go (...) it was like matter of fact, it was sad (...) We built up relationships with certain nurses, and just a little bit of we understand how special this is, for all of us and you just a little bit more kind of empathy there on how special it is.

This quote captures Alex's desire to matter to staff and his subsequent disappointment about feeling insignificant to them. His enthusiasm, excitement and question about the bell ringing, something that is important to him is met with staff's lack of pre-emptive enthusiasm and emotion. He imitates staff's response and rolls his eyes which shows how he perceives the bell ringing ceremony to be an insignificant and burdensome task for staff; something that is done only because the family wish to do it. His laughter conveys a sense of embarrassment about the perceived mismatch between his and staff's enthusiasm towards the ceremony. The staff are perceived as being "matter of fact" i.e., without emotion about the ceremony which leads Alex to experience the bell ringing as something that is almost mechanical. The long-awaited moment now feels anticlimactic. There are feelings of disappointment as staff, who

play an important role in their lives, do not understand the importance of the ceremony for his family.

Dipa and Varun also talk about their wish to feel important to staff, particularly as their child was not able to ring the bell due to the COVID-19 pandemic:

Dipa: I felt quite sad about it, just that recognition like maybe a letter to say 'we haven't been able to do the bell ringing, but we just wanted to say how pleased we are that she got to the end' so you're not just another patient, it's a feeling of being just another statistic (...) because we've been at the hospital every three months, we've had conversations with them often and the nurses they were such a massive part

Harun: Its relationships ending

Dipa: Yeah, and it's just like it's shut down, it would have been nice to have someone acknowledge that.

Dipa refers to feelings of sadness and disappointment about the ending of their treatment not being acknowledged by staff. She describes the imagined acknowledgement; wanting them to acknowledge the loss of the bell ringing ceremony and that the end of the treatment is also important to them. Feeling like “a statistic” conveys a cold, and impersonalised end to the treatment journey; a perceived feeling of not been seen. This is especially difficult due to feeling as though they had built personally meaningful relationships with staff. Harun agrees with Dipa but to him, the loss that needs to be acknowledged is the loss of the relationships with staff. This is followed by Dipa describing how, beyond feeling like the end was not acknowledged, there is a felt sense of an active rejection, with being “shut down”.

Needing guidance and a “party planner”

Seven parents talk about wanting the active guidance of staff in relation to marking the end of treatment, including but not restricted to the bell ringing ceremony. This is illustrated in the following quote from Josephine:

It's always done in passing if you like, maybe somebody to come in and say [enthusiastic, fast voice] right okay I've looked at your file, you've only got this left, what are we going to do now? and when are we going to do it? Let's plan! Almost like, like a party planner person who gives you that, because you're just so exhausted (...) it would be nice to have someone say like it's time to get excited because you've got none of this rubbish go through your child's system anymore. It's something to celebrate.

Josephine highlights the need for staff to take an active role in terms of the end of treatment celebrations; her experience is staff taking a passive approach, treating the end of treatment as something casual. There is an expressed need to be informed about approaching the EoT and for a collaborative EoT celebration plan to take place. The desire is for their wants and needs to be considered in the planning. The switch to a fast paced and louder tone, conveys the want to have enthusiastic and energetic staff member i.e., ‘party planner’. When approaching EoT, there is exhaustion and subsequently limited motivation to plan the celebrations. There is a need to be energized and motivated by staff and to be reminded of the importance of the milestone, that it is something positive. The need for guidance and planning is also captured in the following quote by Alex:

Because it's so important the bell ringing, it would be nice to have them say this is when we plan on this happening, not just on the day, because we didn't know when it was going to happen and there was no guidance on that. So that was one thing I remember, the unknown there (...) it was you know; we knew it was going to happen when it was going to happen but no one telling us when, just waiting around for them to be ready.

Alex conveys feelings of powerlessness and being left in the dark and uncertain about the bell ringing ceremony. This could also reflect the broader confusion and uncertainty about the end of treatment, and when the end is. There is a wish for staff to help navigate the uncertainty and provide a sense of certainty about the end through planning the ceremony. He feels insignificant to staff, having to wait around to be informed about the bell ringing ceremony and for the staff to get ready.

Dipa gives further suggestions about what staff support could look like, both in relationship to the bell and other EoT celebrations:

You know a little pack at the end to say you've done it, here is what you can do if you want to talk to someone, here is this to celebrate it, these are the places you might want to phone, the support, the charities, holiday homes in England or a network of places that you can use to celebrate the EoT.

Dipa highlights the importance of being informed and guided in relation to marking the end but also what comes after the bell is rung and treatment is over. The quote highlights her wish to be given a range of options.

6. After the Bells are Rung

Seven parents talk about what happens once the end of treatment bells are rung, and the celebrations are over. For many parents, the period after the bell ringing signifies the beginning of a time where they face previously held emotions and multi-layered losses.

“Hit” by emotions

Four parents talk about the experience of being hit by previously held emotions after the bell ringing ceremony. For Josephine, the period following the ringing of the bell is experienced as a comedown:

you are over the clouds celebrating but once the bell rings, it all kind of comes down (...) I felt like the sort of rock, getting him through treatment and I found that from a mother's point of view and obviously fathers if they play that role depends on your family, I went downhill from that ringing of the bell I which I knew was coming, the trauma hits you.

Josephine describes a deterioration in her mood and coming back down from a euphoric state of celebrating after the bell. She uses the metaphor of the rock to describe the transition from being a strong, solid, and unbreakable parent whom the child relies on during treatment to gradually feeling weak after the end of treatment celebrations are over. There is a perceived gendering in emotional experiences and the trauma is seen to be unique to the position of the mother as the primary caregiver in her family. There is an element of expecting yet being “hit” by difficult feelings. The switch to a second-person language is an indication of the

need to create an emotional self-distance from the trauma experienced. Alex also talks about being hit by previously shelved emotions after the bell ringing ceremony but describes a contrasting experience:

it's tears, like an emotional synopsis after the bell rings; a synopsis of everything that's happened just coming out and came out for many days afterwards, which was good to get it all out. It's like you are hit by so many emotions (...) I can let go, I can finally let go.

Here, Alex describes how when the bell rings, this marks the beginning of a period of releasing and experiencing emotions that were bottled in throughout treatment. It is a time he can reflect on and think about what they went through with the treatment. He experiences this as a positive and healthy process, being able to let feelings out.

Loss of support and reassurance

Seven participants talk about the unexpected loss of staff support and reassurance after the ringing of the bell.

it was quite scary because once she rang the bell, we didn't have that kind of knowledge that we would have been looked after all the time and we were left to our own devices (...) and we got used to all the nurses it just became like a second home.

The quote captures an experience of disillusionment about the end after the bell ringing ceremony. There is an unexpected loss of relationships with staff, safety, and security as they

leave their “second home”. There is a sense of feeling abandoned and fearful about no longer been seen regularly at the hospital and the reassurance being gone. Josephine also describes the loss of reassurance after the bell ringing:

it's all great that day but then you feel very lost after once he's rung the bell, it's like wow he doesn't need blood tests you sure? No, he doesn't. What? Don't you want to see him next week, are you sure you don't want to see him, it's like no ring the GP [looks surprised].

The routine medical appointments and contact with staff during treatment is a source of reassurance for Josephine. There is disbelief and surprise that they are no longer looked after by staff once the bell rings and the ending is marked. Josephine's repeated questions to staff conveys the strong need for continued reassurance after treatment finishes. There is a sense of feeling abandoned and potentially dismissed with the transition to primary care and being asked to contact the GP instead of the nurses and doctors Josephine has gotten used to.

Discussion

This study aimed to explore parents' experiences of marking the end of their child's cancer treatment, with a focus on the ringing of the bell ritual (RTB). The researcher completed eight semi-structured interviews with eleven participants and used an Interpretative Phenomenological Analysis (IPA) approach. Six super-ordinate themes were identified: *Making Sense of When "The End" is*; *Meanings Attached to Marking the End(s)*; *A Bell that Bonds and Divides*; *For Whom the Bell Tolls: A Multivocal Symbol*; *The Role of Staff in Ringing the Bell* and *After the Bells are Rung*. The section will discuss each of the super-ordinate themes with reference to the relevant literature. Furthermore, it will consider the clinical implications of the findings and suggest recommendations for future clinical practice and research.

Making sense of when "the end" is

Many parents expressed ambivalence in knowing when "the end" was. They described how finishing active treatment was one of many endings which were personal to the family's cancer journey and signified the end of different obstacles faced throughout treatment. For some parents, the end of active treatment was not "the end" as they waited for the five-year survival milestone. Previous studies report similar findings that parents feel "the end is not the end" but rather a liminal and uncertain space (Mckenzie & Curle, 2012; Muskat et al., 2017; Walker, Lewis & Rosenberg, 2020). To the researcher's knowledge, the current study was the first to highlight the significance of the port-removal for the perceived sense of an ending. The port was like a "transitional object" that maintained ties to the hospital and served as a communicative link to the nurses and doctors after the end of active treatment. It was a reminder to the parents that the child was different to other children and neither sick

nor well; thus, there was no end without its removal. When the port was out, the child transitioned to primary health care e.g., GP in the case of temperatures or taking medication at home instead of being seen at the specialist hospital. This was thus experienced as a significant loss of support and relationships with the staff that the family had become accustomed to. The study adds to existing research as it highlights how the commonly reported loss of safety and security may distinctively occur after the port-removal rather than the end of active treatment.

The study took place during the time of the COVID-19 pandemic, as such it was able to capture the unique experiences of parents of children who finished treatment during the global crisis. Parents reported experiencing loss and disappointment due to not being able to mark the ending in the anticipated and desired way e.g., not being able to ring the bell or having staff acknowledge the end through other informal celebrations. This left them without a sense of an ending and closure as the line between being on-treatment and off-treatment was blurred. The inability to mark endings due to the prohibition of public gatherings and rituals is a crucial stressor in the COVID-19 pandemic, leaving individuals without a sense of closure (Fernández & González, 2020; Cardoso et al., 2020).

Meanings attached to marking the end(s)

Marking the end of treatment through rituals allowed parents to achieve a sense of separation from the cancer and to begin to redefine their identities and status as parents as well as redefining the parent-child relationship. Parents described how they experienced a tension between being a “good” parent and keeping the child well and at the same time having to be restrictive and limiting during treatment. This tension and threats to self-identity as adequate parents is commonly reported in parents of children with cancer (Bury, 1982; Young et al., 2002). In the current study, rituals and celebrations served to dissolve the felt

tension allowing participants to begin to adopt a preferred parental identity and narrative, for example by celebrating the EoT with a party and being a permissive parent who allowed the child to have fun and be surrounded by others. Earlier research highlights how engaging in rituals during life transitions can help an individual's identity to be shaped and for identity connections to be developed or restored (Nelson-Becker & Sangster, 2019). This finding can further be explained by the anthropological term "rites of passage" (Van Gennep, 1960). The term refers to rituals that mark different life transitions which involve a separation phase meaning that individuals participating in the rite or celebration detach from a previous status (Mahali, 2016). This is relevant to the current study as rituals and celebrations are a way for parents to detach from their status as parents of children with cancer and reintegrate into society as parents of children who were well.

A bell that bonds and divides

Many parents talked about how the bell divides and bonds children and parents of children who are on and transitioning off-treatment. The bell bonds individuals as it creates a sense of community and shared connectedness. This finding is supported by previous research which claims that RTB creates a unifying sense of community for patients and carers (Bridarolli, Spiers & Putuskin, 2020). The study adds to existing research as it highlights how the sense of community can form through the act of witnessing without language i.e., the bell forming an (un)spoken bond of understanding and empathic connection. Anthropological research highlights how rituals in a community of concern or a therapeutic environment can create a sense of collected unity during times of transition, serving as a reminder of individuals connectedness and belonging in a circle of care (Garrick, 1994; Richardson, 2012). The study is the first to illustrate how the bell not only creates a sense of community but also simultaneously disrupts one. Parents report holding two

conflicting emotional experiences, being both happy for and envious of other families as the bell ringing reminds them of their child's "sick" status and the long journey ahead i.e., "a kick in the teeth". Transition rituals can be a reminder of the status of individuals e.g., between being on treatment and "well" (Lewin & Green, 2009). Previously, Gale (2019) stated that this reminder evoked by the bell can cause difficult feelings in witnessing patients with poor outlook and prognosis and their carers. The current study adds an additional layer, indicating that the bell can also stir ambivalent and conflicted feelings in carers/parents of children with a good prognosis when they are at the beginning of the treatment journey and in the early stages of being "sick".

For whom the bell tolls: a multi-vocal symbol

The bell was a multi-vocal symbol with different meanings. It acquired meaning through witnessing and being witnessed. For many parents, having their child ring the bell in-front of witnesses made the ceremony meaningful, evoking a sense of certainty, security, and validation that treatment was over. Being witnessed by others during rituals can be a way to acknowledge, validate and authenticate endings and individuals experiences during times of transition (Garrick, 1994; Nelson-Becker & Sangster, 2019). For some the bell ringing evoked a false sense of security and certainty as ringing it does not mean "the end" and there are worries about the future and relapse. It is possible that the bell creates a false premise that its ringing marks the end of the cancer experience (Gale, 2019; Williams et al., 2019). This is further supported by the final super-ordinate theme which captures parents' difficult experiences and losses after the bell.

Nearly all parents talked about how the bell ringing provides hope and sustenance to families who are on treatment. It is important to note that the parents involved in the study were parents of children with a good cancer prognosis, as such the bell was a source of hope

for parents of children with a hopeful cancer trajectory. For many, it was an end goal to aim towards during a difficult and uncertain time. This suggests that, like other rituals, the bell ringing might play an important role in preparing and energizing parents for a future and context that is motivationally relevant like the child finishing treatment (Hobson et al., 2018). Furthermore, many parents talked about how the bell allows children finishing treatment, and their parents, to announce their freedom from invasive procedures, medicine and strict treatment regimens and a return to normality. The wish for freedom and return to normality is a commonly reported need for parents of children who are transitioning off active treatment (Björk et al., 2011; Carlsson et al., 2019; McKenzie & Curle, 2012; Muskat et al., 2017). Previous research on the RTB also suggests that the ceremony is a pivotal moment in the cancer journey, mainly symbolizing a transition to a “normal life” (Bridarolli, Spiers & Putuskin, 2020). Lastly, the current study indicates that the bell rings to acknowledge the joint achievements and successes of the child, parents, and the family support network. Parents expressed feeling proud of their children and themselves for surviving the difficult journey of cancer treatment. Subbiah (2011) highlights a similar idea and discusses how the bell ringing is about patients and carers receiving appreciation, kudos, and applause for recovery and success in completing treatment.

The role of staff in ringing the bell

Parents described the important role of staff in planning and carrying out the bell ringing ritual. Some spoke about receiving extensive support and enthusiasm from staff in relation to the bell, thus feeling special, whilst others felt left in the dark and insignificant as if they were “just a statistic”. Previous research has highlighted how parents often express their wish to have the staff mark the end of treatment through informal celebrations (Björk et al., 2011; Enskär et al., 2020; Wakefield et al., 2012). The current study support this finding

and shows that having staff acknowledge and mark the end has implications for how parents feel at the end of treatment. The study adds to existing research as it talks about parents' perspectives on what staff support can look like in the marking of the end. Parents want staff to take an active role in initiating anticipatory conversations about the EoT milestone and discussing different options for celebrating including the RTB e.g., timing and scheduling in of the bell ringing, determining who will be there to witness etc.

After the bells are rung

Many parents talked about an experience of “coming down” and being hit by emotions once the bells were rung and the celebrations were over. Some parents described this as a positive experience where they could process and digest their feelings, whereas others described it as being a traumatic experience. Parents commonly report that the EoT is a time where they begin to reflect on what they went through during the child's cancer treatment (Norberg & Green, 2008; Ortiz & Lima, 2007; Walker, Lewis & Rosenberg, 2020; Wakefield et al., 2012). Several studies have found EoT to be a difficult time where parents confront previously shelved emotions (Norberg & Green, 2008; Walker, Lewis & Rosenberg, 2020; Wakefield et al., 2012). The current study thus contributes to existing research by showing how rituals and celebrations at the end can distinctively mark the beginning of this process of reflection and integration. The current study also showed how, when the celebrations were over, parents felt the abrupt and unexpected loss of staff and safety. This finding is supported in literature which discusses how EoT is a period where parents experience the loss of felt security and safety that had accompanied the child's treatment (Enskär et al., 2020; Wilford, Hopfer & Wenzel, 2019).

Implications for practice and recommendations

The current study adds to the limited body of knowledge related to end of treatment rituals, particularly the ringing of the bell ritual (RBT) in paediatric oncology wards. There are clinical and research approaches that could improve the experience of parents and promote positive outcomes.

Exploring and anticipating personal EoT milestones with families

Although the bell ringing ritual frequently takes place at the end of active treatment, the current research suggests that there could be different and equally important milestones to mark at the EoT; the port removal being a particularly important milestone that follows the end of active treatment. It is important for staff, such as the child's clinical nurse specialist, to show curiosity about and understand the milestones that are personal to each family and the landmarks they look forward to whilst on treatment. This will help staff to subsequently motivate, give sustenance to families and help them pre-plan the EoT rituals and celebrations. The removal of the port was a milestone that evoked a duality of feelings in parents and marked a period of loss. It is important for staff to recognize the potential impact and meaning of this procedure for parents and to be attentive to and normalize mixed emotions that can come with it as well as prepare parents for what may come after. Furthermore, staff can encourage the bell ringing ceremony to take place following the removal of the port as well as the end of active treatment. It is also important to consider and provide choice in relation to what happens to the port itself, for example whether families wish to and can keep the port as a symbol of this period of their life.

Considerations for implementing EoT bells in hospitals

The study findings showed that there are critical considerations when implementing end of treatment bells in hospital wards. These include the physical location of the bells, the witnesses present during the ceremony, and the support available to families affected by the RTB as well as those that wish to ring the bell with planning and carrying out the ritual. For many parents, witnessing and being witnessed by others during the ritual was preferred over private end of treatment celebrations; however, when the bell ringing was witnessed at the beginning of the child's treatment and the end felt like it was too far out to reach, the bell evoked mixed and predominantly negative emotions. It is possible that witnessing the ceremony might have further negative implications for parents of children who may never have a successful end to reach due to poor prognosis and outlook. This is supported by Gale (2019) who suggests that cancer wards should consider the impact of the bell ringing tradition on terminally ill patients and use private and personal alternatives e.g., gifts and cards signed by the oncology team. The current study highlights how there is value in the witnessing and being witnessed as it provides sustenance and hope but that hospitals should question and re-consider where the bells are positioned and rung in terms of who is being treated on the ward and witnessing e.g., are the bells rung in places where both children with good and poor cancer prognosis are treated? The study recommends hospitals to conduct a Health Impact Assessment (HIA) prior to deciding whether to install or keep the end of treatment bells (Lock, 2000). This would allow to understand the benefits and drawbacks of the RTB and to determine whether benefits outweigh the costs and for whom. The study also recommends a public acknowledgement on wards of the rationale behind the RTB ceremony, the benefits and the conflicting or negative emotions that may be evoked for those at the start of treatment or those with a poorer prognosis. This can be done through an information plate

alongside the bell or a wall with quotes about the positive and negative impacts. It is also important for hospitals to consider support for those who may be negatively impacted by the bell.

The study showed that parents had a range of experiences regarding the level of support they received from staff with the bell ringing ceremony. There are to date no guidelines for how the bell should be introduced to families or health professionals' role in planning for and carrying out the ritual. The study points to a need for consistent and standardized staff support with the bell ringing ceremony if families choose to ring it; this will help ensure that families receive equal support at EoT. This could be through having a policy/standardized guideline within the oncology unit to help staff support patients and families better and more consistently. In line with the expressed needs of parents from the study, future guidelines can include the following recommendations regarding EoT celebrations and the RTB:

- Staff to check in with families prior to the end of active treatment to note the milestones they may wish to mark and discuss options. It is critical to take an active role as parents can feel overwhelmed and fatigued at EoT. This includes taking a collaborative stance and supporting parents with pre-planning the celebrations which can include the RBT e.g., the date and time of the ceremony, the audience parents wish to be present including the multi-disciplinary team members (MDT), gifts and foods to organize for the day.
- Staff to take an empathic, caring stance and recognize and reciprocate the potential importance of the EoT milestones and celebrations for families through informal discussions.

- Staff to support families through signposting to charitable organizations that can provide practical and financial support with the EoT celebrations.
- Staff to provide anticipatory guidance, information, and support regarding life after the bell and celebrations. This can include an EoT meeting to discuss the common challenges and difficulties parents face after treatment as well as point of contact for emotional support.

In the case that children finish treatment during the time of COVID-19, it is important for staff to think of ways endings can be acknowledged and marked safely during the pandemic. Staff can show flexibility and find alternative ways to mark the end and facilitate the bell ringing e.g., portable bells families can ring in outdoor spaces near the hospital or having bells being sent to family's homes.

Providing support after the bells are rung

The ringing of the bell was a critical and joyful moment for all parents which signified leaving the cancer experience behind. The time after the bell was a period of subsequent disappointment and loss as parents faced different challenges and difficulties. It is important for staff to prepare parents for the period after the EoT celebrations. This preparation can include normalizing feelings of ambivalence about the end and common experiences of disappointment and loss as well as providing information regarding post treatment life and psychological impact.

Strengths and limitations

The current study had several strengths and limitations to its methodology and analysis. It was the first study that explored parents' views on the end of treatment bell in paediatric oncology settings. Through a chance occurrence, all recruited participants were parents of children with ALL which is a cancer with good prognosis (Kato & Manabe, 2017). Although this allowed for a more homogenous sample, it also limited the range of experiences captured by the study and was not inclusive of the voices of parents whose children finished treatment for types of cancer prognosis and outlook. This is a significant consideration when capturing views about the ringing of the bell ritual as patients with a more difficult treatment journey and prognosis as well as their carers may have more adverse and negative reactions to the ceremony (Gale, 2019). In developing the interview schedule, the researcher used Patient and Public Involvement (PPI) to consult a parent instead of involving co-production with paid experts by experience. Involving co-production would have allowed for a more equal sharing of decision making and power (Mayer & McKenzie, 2017). Due to the COVID-19 pandemic, interviews had to be completed virtually instead of face-to-face. While this made it feasible to conduct the study and enabled parents to share their experiences, it is possible that the virtual context had an impact on the information shared, dynamic between the researcher-participant and researchers subsequent understanding of the participants experience (Salmons, 2012). During the interview stage, participants were given the flexibility to attend the interviews alone or as a parental couple, thus the researcher conducted a mixture of individual and dyad interviews. Joint interviews with parental couples had the benefit of conveying the experience from the perspective of both individuals in the parenting relationship, allowing individuals to complement or disagree with each other and remind each other of certain experiences the researcher could not have thought of (Bjørnholt & Farstad, 2012; Mavhandu-Mudzusi, 2018).

They also allowed multiple perspectives to be considered at once e.g., that of mothers and fathers (Larkin, Shaw & Flowers, 2019). Furthermore, they were helpful in the case that one of the parents in the parenting couple had language difficulties. There were also limitations to using a combination of individual and dyadic interviews within the same study. IPA is committed to exploring the detailed experience of each participant through individual interviews before moving onto the next case (Larkin, Shaw & Flowers, 2019). Although there are studies that use and discuss the added benefit of dyadic interviews within IPA studies, conducting interviews with two individuals can mean there is less opportunity to focus on one individual's experience and go deeper in the interview and analysis stages. This might have been the case particularly in interviews where one individual was more vocal than the other. The results revealed the importance of context and time in relation to the meaning of and experiences with the bell e.g., the bell was a symbol of hope and sustenance during treatment and symbol of achievement and return to normality at the end; there was a changing relationship with witnessing the bell over the course of treatment. Although IPA is suitable for shedding light on lived experiences, it is possible that Grounded Theory Analysis would have captured the nuances and changes in experience over time and transition/life change better (Padgett, 2017).

Future directions

The current research had a homogenous sample and focused on parents of children with Acute Lymphoblastic Leukaemia. Future research can recruit from the population of parents of children who have poor cancer prognosis to understand the impact of witnessing the EoT treatment bell on families where there is little prospect of recovering and ringing the bell. Future research can also focus on the experiences of parents of adolescents who ring the

bell as their involvement in planning and carrying out the rituals and celebrations thus experiences might be different. Additionally, studies can explore the relative impact of different EoT rituals on parents, for example public versus private RTB's or end of treatment letters.

Conclusion

Parents experience multiple endings and ambivalence as they come to the end of their child's treatment; the end does not feel like "the end" and the child's cancer is a chapter that cannot be fully closed. Marking the end of treatment through rituals and the ringing of the bell can have profound meanings, function, and impact on parents. Some of these include separating from the treatment experience and leaving it behind, dissolving a tension and adopting a more preferred parental identity, and forgetting the pain of the treatment and remembering the happy moments. There are both positive and negative experiences surrounding the ringing of the bell. The bell symbolizes hope and provides sustenance to parents during treatment. It also creates a sense of a community between different families. The bell provides some parents with a sense of security that treatment is done, it also allows families to recognize the joint achievements of the child, themselves, and their support network. It also symbolizes the transition to a more free and "normal" life. As well as the positive, there are also negative experiences surrounding the bell. It is a reminder of who is sick and who is well on the ward which evokes mixed feelings of happiness, envy, resentment, and guilt. The staff have a critical role in the RTB ritual; parents express needing staff to take an active role in the planning and executing the bell ringing. Parents describe how the ringing of the bell is not the end and that the period following the ceremony is a time of significant loss and disappointment. Future research can explore the impact of RTB on diverse parent groups including parents of children with poor-prognosis cancer.

References

- Anderson, C. (2010). Presenting and evaluating qualitative research. *American Journal of Pharmaceutical Education*, 74(8), 141.
- Björk, M., Nordström, B., Wiebe, T., & Hallström, I. (2011). Returning to a changed ordinary life - families' lived experience after completing a child's cancer treatment. *European Journal of Cancer Care*, 20(1), 163-169.
- Bjørnholt, M., & Farstad, G. R. (2012). 'Am I rambling?' on the advantages of interviewing couple together. *Qualitative Research*, 14(1), 1-12.
- Bridarolli, A., Spiers, J., & Pituskin, E. (2020). To ring or not to ring: an interpretative description of cancer patients and caregivers exiting treatment. *Canadian Oncology Nursing Journal*, 30(1), 38-42.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87-108.
- Brookes, D. (2007). Understanding qualitative research and its value in healthcare. *Nursing Times*, 103(1), 32-33.
- Cardoso, E. A., Silva, B. C., Santos, J. H., Loterio, L. S., Accoroni, A. G., & Santos, M. A. (2020). The effect of suppressing funeral rituals during the COVID-10 pandemic on bereaved families. *The Revista Latino-Americana de Enfermagem*, 28(2), 1-20.
- Carlsson, T., Kukkola, L., Ljungman, L., Hovén, E., & von Essen, L. (2019). Psychological distress in parent of children treated for cancer: an explorative study. *PLoS One*, 14(6), 1-18.

- Chapman, G. E. (1983). Ritual and rational action in hospitals. *JAN Leading Global Nursing Research*, 8(1), 13-20.
- Children's Cancer and Leukaemia Group . (2014). *Children and young people with cancer: A parent's guide*. Leicester: Children's Cancer and Leukaemia Group .
- Children's Cancer and Leukaemia Group. (2021, December 1). *Acute Lymphoblastic Leukaemia (ALL)*. Retrieved from Children's Cancer and Leukaemia Group: The experts in childhood cancer: <https://www.cclg.org.uk/Acute-lymphoblastic-leukaemia-ALL>
- Cooper, S. L., & Brown, P. A. (2015). Treatment of pediatric acute lymphoblastic leukemia. *Pediatric Clinics*, 62(1), 61-73.
- DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family Medicine and Community Health*, 2(4), 1-8.
- Duffey-Lind, E. C., O'Holleran, E. O., Healey, M., Vettese, M., Diller, L., & Park, E. R. (2006). Transitioning to survivorship: a pilot study. *Journal of Pediatric Oncology Nursing*, 23(6), 335-343.
- Eatough, V., & Smith, J. (2008). Interpretative Phenomenological Analysis. In C. Willig, & W. Stainton-Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 1-22). London: SAGE.
- Elliott, R., & Timulak, L. (2005). Descriptive and interpretive approaches to qualitative research. In P. Gilbert, & J. Miles, *A handbook of research methods for clinical and health psychology* (pp. 147-159). Oxford: Oxford University Press.
- End of treatment bells. (2021, April 1). *Celebrating Milestones* . Retrieved from End of treatment bells : <https://endoftreatmentbells.com/>

- Enskär, K., Darcy, L., Björk, M., Knutsson, S., & Huus, K. (2020). Experiences of young children with cancer and their parents with nurses' caring practices during the cancer trajectory. *Journal of Pediatric Oncology Nursing, 37*(1), 21-34.
- Fernández, Ó., & González, M. G. (2020). The dead with no wake, grieving with no closure: illness and death in the days of coronavirus in Spain. *Journal of Religion and Health, 12*(3), 1-10.
- Fox, H. (2003). Using therapeutic documents: a review. *The International Journal of Narrative Therapy and Community Work, 4*(2), 26-36.
- Gale, K. J. (2019). Inappropriate celebration in the presence of patients with poor prognosis - The cancer center victory bell. *JAMA Oncology, 5*(2), 146-148.
- Garrick, D. A. (1994). The work of the witness in psychotherapeutic rituals of grief. *Journal of Ritual Studies, 8*(2), 85-113.
- Gearing, R. E. (2004). Bracketing in research: a typology. *Qualitative Health Research, 14*(2), 1429-1451.
- Guest, G., Namey, E. E., & Mitchell, M. L. (2013). *Collecting qualitative data: a field manual for applied research*. London: SAGE.
- Haen, C. (2005). Group drama therapy in a children's inpatient psychiatric setting. In A. Weber, C. Haen, & S. Bloom, *Clinical Applications of Drama Therapy in Child and Adolescent Treatment* (pp. 199-201). New-York: Brunner-Routledge.
- Hamill, M., Ried, M., & Reynolds, S. A. (2008). Letters in cognitive analytic therapy: the patient's experience. *Psychotherapy Research, 18*(5), 573-583.
- Hobbie, W. L., Ogle, S. K., Reilly, M., Ginsberg, J. P., Rourke, M., Ratcliffe, S., & Deatrck, J. A. (2010). Identifying the educational needs of parents at the completion of their child's cancer therapy. *Journal of Pediatric Oncology Nursing, 27*(4), 190-195.

- Hobson, N. M., Schroeder, J., Risen, J. L., Xygalatas, D., & Inzlicht, M. (2018). The psychology of rituals: an integrative review and process-based framework. *Personality and Social Psychology Review, 22*(3), 260-284.
- Hosoda, T. (2014). The impact of childhood cancer on family functioning: a review. *Graduate Student Journal of Psychology, 15*(1), 18-30.
- Kane, N., & Sheldon, L. K. (2016). After the bell: lifestyle transformation after cancer treatment. *Clinical Journal of Oncology Nursing, 1*(20), 459-460.
- Kato, M., & Manabe, A. (2017). Treatment and biology of pediatric acute lymphoblastic leukemia. *Pediatrics International, 60*(1), 4-12.
- Keats, M. R., Shea, K., Parker, L., Stewart, S. A., Flanders, A., & Bernstein, M. (2019). After childhood cancer: a qualitative study of family physician, parent/guardian, and survivor information needs and perspectives on long-term follow up and survivorship care plans. *Journal of Cancer Education, 34*(2), 638-646.
- Kochen, E. M., Jenken, F., Boelen, P. A., Deben, L. M., Fahner, J. C., van den Hoogen, A., . . . Kars, M. C. (2020). When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief and loss theories. *BMC Palliative Care, 19*(28), 1-22.
- Labay, L. E., Mayans, S., & Harris, M. B. (2004). Integrating the child into home and community following the completion of cancer treatment. *Journal of Pediatric Oncology Nursing, 21*(3), 165-9.
- Larkin, M., Watts, S., & Elizabeth, C. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.
- Lewin, S., & Green, J. (2009). Ritual and the organisation of care in primary care clinics in Cape Town, South Africa. *Social Science & Medicine, 68*(8), 1464-1471.

- Lock, K. (2000). Health impact assessment. *Education and debate*, 320(7246), 1395-1398.
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: realistic, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91(1), 1-20.
- Mahali, A. (2016). Rites of passage: separation, liminality and an initiation into being in Mamela Nyamza's hatched. *South African Theatre Journal*, 29(1), 1-14.
- Mavhandu-Mudzusi, A. H. (2018). The couple interview as a method of collecting data in interpretative analysis studies. *International Journal of Qualitative Methods*, 17(2), 1-9.
- Mckenzie, S. E., & Curle, C. (2012). 'The end of treatment is not the end': parents' experiences of their child's transition from treatment for childhood cancer. *Psycho-Oncology*, 21(1), 647-654.
- Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation*. Jossey-Bass.
- Muller, I., Santer, M., Morrison, L., Morton, K., Roberts, A., Rice, C., . . . Yardley, L. (2019). Combining qualitative research with PPI: reflections on using the person-based approach for developing behavioural interventions. *Research Involvement and Engagement*, 5(34), 1-8.
- Muskat, B., Jones, H., Lucchetta, S., Shama, W., Zupanec, S., & Greenblatt, A. (2017). The experiences of parents of pediatric patients with acute lymphoblastic leukemia, 2 months after completion of treatment. *Journal of Pediatric Oncology Nursing*, 34(5), 358-366.
- Myers, G. E. (2003). Restoration or transformation? Choosing ritual strategies for end-of-life care. *Mortality*, 8(4), 372-387.

- National Comprehensive Cancer Network. (2021). Pediatric Acute Lymphoblastic Leukemia. *NCCN*, 1-90.
- National Institute for Health and Care Excellence. (2016). Inotuzumab ozogamicin for treating relapsed or refractory B-cell acute lymphoblastic leukaemia. *NICE*, 1-5.
- Nelson-Becker, H., & Sangster, K. (2019). Recapturing the power of ritual to enhance community in aging. *Journal of Religion, Spirituality & Aging*, 31(2), 153-167.
- Norberg, A. L., & Green, A. (2008). Stressors in the daily life of parents after a child's successful cancer treatment. *Journal of Psychosocial Oncology*, 25(3), 113-122.
- Ortiz, M. A., & Lima, R. A. (2007). Experiences of families with children and adolescents after completing a cancer treatment: support for the nursing care. *Rev Latino-am Enfermagem*, 15(3), 411-7.
- Padgett, D. K. (2017). Choosing the right qualitative approach(es). In D. K. Padgett, *Qualitative and Mixed Methods in Public Health* (pp. 31-55). London: SAGE Publications.
- Patterson, J. M., Holm, K. E., & Gurney, J. G. (2003). The impact of childhood cancer on the family: a qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, 13(6), 121-126.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.
- Richardson, C. (2012). Witnessing life transitions with ritual and ceremony in family therapy: three examples from a metis therapist. *Journal of Systemic Therapies*, 31(3), 68-78.
- Rovers, J. J., Knol, E. J., Pieksma, J., Nienhuis, W., Wichmann, A. B., & Engels, Y. (2019). Living at the end-of-life: experience of time of patients with cancer. *BMC Palliative Care*, 18(40), 1-8.

- Santos, S., Crespo, C., Canavarro, C., & Kazak, A. E. (2015). Family rituals and quality of life in children with cancer and their parents: the role of family cohesion and hope. *Journal of Pediatric Psychology, 40*(7), 664-671.
- Schouten, J. W. (1991). Personal rites of passage and the reconstruction of self. *Advances in Consumer Research, 18*(2), 49-51.
- Schweitzer, R., Griffiths, M., & Yates, P. (2012). Parental experience of childhood cancer using Interpretative Phenomenological Analysis. *Psychology & Health*(27), 1.
- Simmonds, J., Allen, K. L., O'Hara, C. B., Bartholdy, S., Renwick, B., Keyes, A., . . . Johnson-Sabine, E. (2020). Therapist written goodbye letters: evidence for therapeutic benefits in the treatment of anorexia nervosa. *Behavioural and Cognitive Psychotherapy, 48*(4), 419-431.
- Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain, 9*(1), 41-42.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE.
- Smith, J., & Shinebourne, P. (2012). Interpretative phenomenological analysis. In H. Cooper, *APA handbook of research methods in psychology* (Vol. 2). New-York: American Psychological Association.
- Subbiah, V. (2011). To ring or wring the bell? *Journal of Palliative Medicine, 14*(8), 968-969.
- Tsipa, A. (2021). *Healthcare Professionals' Experiences of Endings in Paediatric Cancer Treatment: An Interpretative Phenomenological Analysis*. London: UCL.
- Tufford, L., & Newman, P. (2008). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research Methods, 19*(4-5), 583-590.

- Turpin, C., Adu-White, D., Barnes, P., Chalmers-Woods, R., Delisser, C., Dudley, J., & Mesbahi, M. (2011). What are the important ingredients of a CAT goodbye letter? Reformulation. *Winter*, 30-31.
- Tutelman, P. R., Chambers, C. T., Urquhart, R., Fernandez, C. V., Heathcote, L. C., Noel, M., . . . Stern, M. (2019). When "a headache is not just a headache": a qualitative examination of parent and child experiences of pain after childhood cancer. *Psycho-Oncology*, 28(9), 1901-1909.
- von Werthern, M. (2021). *Endings in paediatric cancer treatment: A qualitative analysis of children's perspectives*. London: UCL.
- Wakefield, C. E., Butow, P., Fleming, C. A., Daniel, G., & Cohn, R. J. (2012). Family information needs at childhood cancer treatment completion. *Pediatric Blood Cancer*, 58(2), 621-626.
- Walker, A. J., & Lewis, F. (2011). Adolescent and young adult cancer survivorship: a systematic review of end-of-treatment and early post-treatment. *Nursing and Palliative Care*, 1(1), 1-6.
- Walker, A. J., Lewis, F. M., & Rosenberg, A. R. (2020). Walking on eggshells: parents' first year after their adolescent completes their cancer treatment. *Journal of Pediatric Oncology Nursing*, 37(4), 233-243.
- Wilkins, K., D'Agostino, N., Penney, A. M., Barr, R. D., & Nathan, P. C. (2014). Supporting adolescents and young adults with cancer through transitions: Position statement from the canadian task force on adolescents and young adults with cancer. *Journal of Pediatric Hematology Oncology*, 36(7), 1-7.
- Williams, P. A., Hu, J., Yang, D., Cao, S., & Jennelle, R. L. (2019). The cancer bell: Too much of a good thing? *International Journal of Radiation Oncology*, 105(2), 247-253.

Wilson, E., Elkan, R., & Cox, K. (2007). Closure for patients at the end of a cancer clinical trial: literature review. *Journal of Advanced Nursing*, 59(5), 445-453.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, 15(2), 215-228.

Yorkshire Cancer Community. (2019). *End of treatment bell survey: Key findings 2019*. Yorkshire: Yorkshire Cancer Community.

Appendices

Appendix A: Trainee's contribution to the joint study

Ethics application: As mentioned in the overview and methodology sections, the current study was a part of a joint project with two other DClinPsy trainees who focused on child and staff perspectives at the end of treatment. The title for the overarching project was "*Ending cancer treatment: experiences of children, parents and staff*". All trainees shared equal responsibility in writing and submitting the joint NHS ethics application for the project. The shared responsibilities included: completing a comprehensive online ethics application which included a literature review, outline of methodology, ethical considerations etc., creating participant information sheets and consent forms, and completing the revisions suggested by the ethics board. The trainee leading the current parent study and the trainee conducting the child study co-produced the parent and child information and consent sheets.

Recruitment: The initial phase of recruitment was completed by the hospital staff where the research was conducted. The trainee was responsible for calling and e-mailing participants who agreed to take part, in order to arrange and carry out the parent interviews on a virtual platform.

Analysis and write up: The trainee was responsible for carrying out the analysis and the write up of the study alone. Once all three studies i.e., parent, child and staff are completed, the findings of the study are to be brought together by the trainees in a single publication.

Appendix B: Ethical Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Dr Rebecca Sweet
Principal Clinical Psychologist



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

14 October 2020

Dear Dr Sweet

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

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

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

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

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

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

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

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

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

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

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

Yours sincerely,
Damilola Odunlami

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Dr Vanshree Patel

Appendix C: Participant Information Sheet (PIS)

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

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

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

Before you decide if you would like 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 and their parents/caregivers. We want to know what it is like for parents and carers to come to the end of active treatment, as well as their experiences of events such as the bell ringing ritual, if the family chooses to do this.

2. Why have I been chosen?

We are approaching parents / guardians of young people aged eight to 14 years, who have finished their cancer treatments at Great Ormond Street Hospital in the past three to eighteen months.

3. Did you consult parents about doing the research?

Yes. We have worked together with parents at X Hospital to check whether they think we are doing the study properly and get their suggestions and advice.

4. Do I have to take part?

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

You will be given a copy 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 to continue. Your decision will have no bearing on your child's ongoing clinical care at X Hospital. We will continue to do our best for you and your child.

5. What will happen if I agree 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 your feelings and experiences during this transition period. The care your child receives will be unaffected by your decision to enter or not enter the study.

The study duration is only the time required to answer questions (maximum of 60 minutes). A translator will be provided should you require one. Working with an interpreter may extend the interview by a further 15 minutes.

The interview will be done either at X Hospital on a day when you are 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 you that is convenient so as not to interfere with you attending the appointment or disrupt your daily schedule. The researchers will have access to a private area in the hospital, such as a clinic room, for you 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.

6. What will I have to do?

You will be asked to take part in an interview. The interview will take up to 60 minutes (1 hour) without a translator, and 75 minutes (1 hour 15 minutes) with a translator.

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 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 you. The researcher will email you a link on the day of the interview. Following the link will

allow you 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 you participated or witnessed the bell-ringing ritual and how you understood and experienced this.

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

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 60 minutes. The study itself will run for approximately six months or until a minimum of four parents have taken part. We aim to contact families 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. You are welcome to stop if you feel too upset. The researcher, who is a trainee psychologist, is there to support you if this happens.

9. What are the possible benefits of taking part?

The study will help us understand how it feels to finish cancer treatment and subsequently improve how we look after patients and their families when their treatment at X Hospital finishes.

We do not anticipate that you 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 X Hospital. We hope that this study will help us improve how we look after patients when their treatment at X Hospital finishes.

10. What happens when the research study stops?

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

11. What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you 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:

Dr Rebecca Sweet
Principal Clinical Psychologist, Lead Investigator

If you remain unhappy and wish to complain formally, you can do this through the normal hospital complaints procedure and contact X Hospital PALS:

X Hospital (PALS)
Phone number provided here
pals@Xhospitalnhstrust

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

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

Harm

If something does go wrong and you are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for compensation – but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

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. What do I do now?

You can discuss whether you wish to take part in this study with anybody you would like. You can also see what else you would like to know about the study before you decide whether to take part.

14. Contact for further information

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

Researchers:

Hida Izel Caliskan, Trainee Clinical Psychologist, Clinical Psychology Doctoral Programme, Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London, WC1E 6BT. **Email:** hida.caliskan.15@ucl.ac.uk

Research Supervisors:

Dr Kat Alcock, 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.alcock@ucl.ac.uk

Principal Investigator:

Dr Rebecca Sweet, Principal Clinical Psychologist, Psychological Services, X Hospital NHS Foundation Trust

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

Part 2: More information/details about the study

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

You 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 your 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 you. 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, you might feel that meeting with a trained mental health practitioner would be helpful. The researcher can discuss options for support with you.

Any complaint about the way you 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:

Dr Rebecca Sweet

Principal Clinical Psychologist, Lead Investigator

If you remain unhappy and wish to complain formally, you can do this through the normal hospital complaints procedure and contact X Hospital PALS:

X Hospital Advice and Liaison Service (PALS)
pals@NXhospital.nhs.net

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

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

Harm

If something does go wrong and you or your child are harmed during the research and this is due to someone's negligence, then you may have grounds for a legal action for compensation – but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

15. 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 parents. The interviews will be audio recorded and all the information will be stored electronically on the X 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).

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

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

Yes. Universities, NHS organisations and companies may use 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.

17. What happens to my 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 name, and how long they will keep it.

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

When the study is completed, we will share our findings with X 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.

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

19. Who is organising and funding this study?

This study is organised by X NHS Foundation Trust. The researchers will not be receiving any extra money, over and above their normal salary, for conducting this research.

20. 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 (Registration No:), and the X Hospital Research Adoptions Committee (Registration No...).

HRA Information Governance Transparency Statement

X NHS Trust 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. X 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.

X Trust will keep your child's name, hospital number and contact details confidential and will not pass this information to anyone else. X Trust 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 X Trust 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 X, Data Protection Officer for X Hospital, at your.data@XTrust.com

If you decide 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 D: Participant Consent Form

Participant Identification Number:

Parent / Guardian Consent Form

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

Ethical Approval Ref: (to be added)

Name of Researcher: Hida Izel Caliskan

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 participation is voluntary and that I am free to withdraw at any time without giving any reason, without my child's medical care or legal rights being affected.
3. I understand that the information collected about me will be stored anonymously.
4. I agree that my participation in the study will be noted in their hospital medical records.
5. I understand if I become upset in any way, I can stop the interview and support will be available to me.
6. I agree for the discussion to be audio recorded and understand that when it is typed up my name will not be on the document and any identifying features will be removed.
7. I understand that certain phrases or sentences during my interview may be quoted in future reports or publications, but that my name will not be included and any identifying features will be removed.
8. I understand that 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 the hospital, where it is relevant to me taking part in this research.
9. I understand that if I disclose 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 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 E: Interview Schedule

End-of-treatment

1. What does the “the end of treatment” mean to you?

Prompting questions:

- a. When you think about the end treatment, what feelings/thoughts/events, and experiences come to your mind?
2. What do you remember about the end of treatment and your experience of it?

Prompting questions:

- a. Can you tell me about the feelings/thoughts you had when your child was finishing treatment?
- b. Can you tell me about moments/feelings/thoughts that were important to you?
- c. Can you tell me about the day your child finished treatment and what that looked like for you?
- d. How was it similar and different from other days while your child was on treatment/other hospital visits?

Marking the end of treatment

3. What (if anything) did you do when your child came to the end of treatment?

Prompting questions:

- a. Do you remembering doing anything on the day your child finished treatment? Anything different, or the same?
4. Why was it important/not important to you to mark the end of treatment?
 5. What might be some of the advantages and disadvantages of marking the end of treatment?

The ritual of the bell ringing (RTB)

6. Can you tell me about the first time you witnessed or heard about the bellringing?

Prompting questions:

- a. How did you feel?
 - b. What did you think?
7. Tell me what it was like when it was time for your child to ring the bell?
 8. What do you think the bell rings for?
 9. What would have made your experience of the end and bellringing different/better?

Appendix F: Illustration of exploratory questions/interview extract (Participant 4/Josephine)

Josephine: the bell ring, ehm it was just so special and important. The hospital said we could have people there, well so it was like how many can we have, and they're like as many as you want so because you're a big family. And then I threw him a party afterwards, I just said, let's make a big deal of it.

Researcher/myself: Why did you want to make a big deal of it? Why did it feel important have the celebrations and for him to ring the bell?

Josephine: When he finished, that's the finishing one, that's like "Oh, my God David look you did it like " Because during treatment you watch other kids ringing the bell and then finally, he gets to do it.

Researcher/myself: How did you feel feel when you were shown the bell or when you saw other children ringing it during treatment?

Josephine: When we were first shown it, we went "sigh, ugh, that's ages away" Because you're shown that bell, you know they ring that at the end of treatment, you know, he's got three and a half years in front of him before he can even ring that. So it's like that. That's what I said at the beginning bit, you just forget that, forget that you gotta get through this treatment first because it's intense at the beginning and that's when you get to the maintenance. But then you still got two years of that so it's soooooo far away, that bell ring, you have so many obstacles in your way to get there. That's why it's such a wow look you've done it, you've done it. You can ring that bell now, after waiting three and a half years and having to go through all of that you can ring that bell.

Appendix G: Script for parent research feedback sessions/summary of findings

Introduction to the findings. Eleven parents of children who finished treatment for ALL participated in the research. There were six broad themes/areas parents talked about that I would like to walk you through. It is possible that some experiences will resonate with you, some might be different to what you experienced at the end of your child's treatment. Regardless, it would mean a lot to us to get your thoughts what we found and get your feedback.

Theme 1. Making sense of when “the end” is (this captured how parents perceived or understood the end in terms of when and what the end was)

Many parents tried to make sense of when the end was and described how the end did not feel like a single moment in time but rather a continuum with many endings and milestones. For some, they were still on a continuum waiting for the five-year survivorship period. Some of the important milestones was end of active treatment i.e., chemotherapy/tablets and the removal of the port. The port removal carried a lot of importance for some parents. The port was a device that represented something helpful for the treatment but also meant in the case of a temperature, the child needed to be taken to the hospital. So, it maintained ties to the hospital and its removal meant loss of staff, loss of the contact that parents once had to the hospital – being on your own. There were some families who finished treatment during COVID-19 and that was experienced as the loss of the anticipated end, of the imagined ending to the treatment. Some parents couldn't ring the bell, have celebrations the way they wanted or say goodbye to staff the desired way and they weren't able to do this. It also felt

like there couldn't be a line put through treatment, feeling a bit anticlimactic and like the end hadn't really come.

Theme 2. Meanings attached to marking the ends (This captured the different functions and meanings of marking the end of treatment).

There were different meanings attached to marking the end. Celebrating for many parents was about putting the cancer experience behind and separating from it. It also carried some significance in terms of dissolving a tension as a parent, there was a sense that during treatment there was a certain parent one had to be, having to impose restrictions to keep the child safe for example without wanting to do so. Celebrating meant parents could be the parents they wanted to be, being able to allow themselves and the child to do what they wanted and be "normal". Marking the end and celebrating was also about forgetting the pain of treatment and what families went through and remembering some happy moments of being together, seeing a happy child and being the parents of a happy child.

Theme 3. A Bell That Bonds and Divides (This captured ambivalent feelings towards the bell and experiences witnessing and experiencing it)

We talked a lot about the end of treatment bell in interviews with parents. One of the key findings was how there were ambivalent feelings towards the end of treatment bell. The bell bonded people and created a sense of community but also divided one because it was a reminder of who was sick and who was well on the unit. When the bell rang, parents had an unspoken bond between them, of understanding each other and empathizing with one another in terms of what it was like to look after a child go through cancer treatment as parents. At

the same time, the bell evoked difficult and ambivalent feelings particularly when parents witnessed other children ringing the bell when their own child was at the beginning of the treatment journey. The bell was like this difficult reminder of the long and dreadful journey ahead, reminding parents others were getting better while their child was sick. Therefore, there were mixed feelings of happiness, envy, and resentment. For some parents, this reminder was also present when their own child rang the bell – while parents were happy that their child got to the end, there were some feelings of guilt that others were still on treatment.

Theme 4. For Whom the bell Tolls: A multi-vocal symbol (This was about what the bell symbolized and represented to the parents)

The bell represented different things to different parents but there were some common themes across interviews. The bell was a symbol of sustenance and hope, it gave hope to parents that children were being cured and that it was possible that their daughter/son would also get there. It kept them going and have a goal, an aim to look forward to as they went through cancer treatment. The bell also gave parents a sense of security, for some this was a false sense of security. This means for some parents, ringing the bell gave them certainty that treatment was over, having witnesses there especially trusted doctors was reassuring that the cancer was over. For some parents, there were worries about relapse, about the future and recognition that ringing the bell did not necessarily mean the end when their worries continued, and they went through a difficult period after the bell ringing. The bell was a symbol of achievement, achievement of the parent for the effort, energy they put into looking after their child, for the child to keep going through a difficult treatment regimen for many years, and the joint achievement of the family as well as the support network who helped the family get through.

Theme 5. The role of staff in ringing the bell (This was about the important role of staff for the bell ringing ceremony and end of treatment celebrations)

Parents wanted to feel special to staff and had mixed experiences, some parents felt well supported in planning end of treatment rituals and bell ringing, but some parents were left in the dark and felt unsupported. Parents wanted active guidance and support and pre-planning with the bell, also wanted staff's enthusiasm which helped to energise them too.

Theme 6. After the bells are rung (This was about experiences following the end of treatment bell)

Although the research was not about what happened after the bells were rung and celebrations were over, many parents talked about the period following the bell as being a critical time of requiring support. Parents talked about being hit by emotions that they were shelved while the child was on treatment, to be able to keep going. For some parents being hit by emotions was experienced as a healthy process, the processing of emotions and experience. While for others, this was experienced as being traumatic and difficult. In addition, there was the loss of support and reassurance from staff which felt unexpected and hard.

Suggestions for future: Guidance from staff about the end of treatment which includes planning the bell ringing ceremony and other type of celebrations, as well as thinking about the period following the bell to prepare families. End of treatment review meetings to plan and support parents. Guidance for staff to support families consistently with the end of treatment and the bell. Considering the location of the bells and where they are rung and who witnesses it.

Appendix H: Illustration of feedback received on findings

Participants 6 and 7 (couple) Feedback session

“Participant 6: Everything you said resonated completely with me, it was exactly, I can’t add more to that, it mirrors exactly our feelings. Like the separating and closing the chapter, like you said you try but I don’t think that can ever be fully closed, as years go on the anxiety gets less thought. But there isn’t a yes, we finished we can move on fully now (...) I think celebrating different milestones helped it didn’t have to be the final end, all those little happy memories, moments to remember (...) You know everything that goes into the point leading up to the ringing of the bell and only cancer parents can truly understand that and like you said the bell you understand other parents (...) I think also it’s true about the after treatment period, facing feelings and it feeling traumatic.

Participant 7: It all resonates, about the bell and the staff. It’s interesting to hear some parents had negative thoughts about the bell, like I never had a negative thought about someone ringing the bell, it was always thinking the day will come my child will do it and being happy for the family, it was hope to keep us going.”

Participant 2 Feedback Session

“I think this captured a lot of what I was saying, it captured that like the part that stuck out for me like the end as being different points but also the finish of stopping of medication as an important end like that routine stopping, and what happens after the bell, wanting support, reassurance after because you finish but you are not finished. Also, the other thing was how matter of fact it felt the bell ringing and not having the staff help plan, that’s really really

really important to think about the pre-planning and your suggestion about end of treatment reviews to have a build up to the end and know what to expect. What you said about hearing other people ring it when your child is at the beginning of treatment too, it's like yes at the beginning it is hard to think about because you have so long to go..."

Appendix I: Illustration of colour coded comments in original transcript (Daisy; Page 14, Lines 607-614)

Blue – Descriptive

Green – Linguistic

Red – Conceptual comments

<p>Erm...at the beginning you just, you feel quite, quite envious of them, that they've got to that stage, feel a bit jealous, but then you're really happy that they got there and you just think, wow, that's amazing like that's such an achievement, you are just really, really happy and then you think, argh, we have we've actually come in for chemo today, so it is a kick in the teeth at the same time.</p>	<p>Both happiness for and envy towards others ringing the bell when her daughter is at the beginning of his daughter's treatment. Duality of emotions and ambivalence while witnessing others ring the bell. The bell as a reminder that they are far away from the finish line. The bell is a symbol of success and achievement for the family. Cancer narrative, beating the cancer/winning against cancer – bell ringing as a symbol of achievement. The bell reminds her of the long journey ahead of them, that they are far from the end. The bell evokes a social comparison between the sick and the well. Kick in the teeth can communicate something about the unfair disappointing and upsetting experiences of having to go through treatment.</p>
<p>It's a horrible feeling [laughter] it's like you are happy for them but then you're like gutted for yourself because you are like oh flipping out, we've just, we got sooooo long to go [emphasis on the so long to do] before we finish, but then when we got closer to finishing, we were excited that, that was going to be us and we were encouraged to keep going to get there.</p>	<p>The ambivalence is a “horrible feeling” to have. Envy as an unwanted emotion (perhaps one should not be allowed to feel resentment or envy due to having to feel happy for others that they get to ring the bell). Guilt due to feeling resentment towards others ringing the bell. Use of swearing, the slowing down of the speech and emphasis on “far away” mirrors the perceived burdensome length of the treatment. With time progressing on treatment, she describes a changing relationship towards the bell and feelings. Changing and a more positive relationship with the bell as they get closer to being in the category of the “well”. Bell gives sustenance to push through to the end and is encouraging. Less envy towards others at this stage.</p>

Appendix J: Illustration of developing table of super-ordinate/sub- themes for a single participant (Participant Daisy)

Super-ordinate theme	Transcript
<i>Sub-Theme</i>	
Making Sense of Endings	
<i>Ambiguity around when "the end" is</i>	"It was finishing giving her the medication but there were the hospital appointments, there was the port in too. There were I don't know how many ends, different ones many really yeah I don't know"
<i>Multiple end points in the end of treatment journey</i>	"the first one was when she actually finished her chemo, which was on the 18th of August 2019. Erm, the second one was when she finished the medication called Cotrimoxazole, so that was like the second one and for the third one was when she had her port removed"
<i>Endings personal to the family's journey with cancer</i>	"Erm, an important one was when she finished this medication called Cotrimoxazole, which is a medication she has to take for six weeks after her treatment just because it kind of prevents her getting a kind of type of pneumonia. So that was every Monday and Tuesday for the whole of the two and a half years. And she hated that, like with a passion, it was really quite hard to get her to take it. it was just that one medicine that she just really, she, that was her weakness"
<i>"The end" of the end: Removal of the port</i>	<p>"so, she [child] was like, well, I finished treatment, so why do I have to do this mom? No, so just six weeks and then we'll finish that, she goes so have we finished? and then I'm like, no you still have to have your port out [laughs] so it was like, well, when have I finished then? It was like well now you finished, you know now you had your port out and that's all done."</p> <p>"Because she still had that in if she got temperatures, then she would still need to go into hospital for treatment, erm so it didn't feel like the end. It was the end, but it wasn't quite the end and that felt like, OK, you know, it's finished"</p> <p>"erm but I think that port-removal, it was the most emotional one of all because she still had a, even though she finished her treatment in August, you still get worried because it's still this foreign thing in her body."</p>
Super-ordinate theme	
<i>Sub-Theme</i>	
Marking the end: a false sense of security	
<i>Repeatedly marking it to make it more real, but it is still not real</i>	"It was we did lots of parties, I did a book for her, she rung the bell, then her port was out and she rang the bell again after that and then it really it was quite emotional, actually, that we got to the end. we got to the last celebration, and it registered then, what had happened that she'd actually finished but still even when she rang, kept feeling like it wasn't real"
<i>Ring the bell and doubting its meaning: not the end</i>	"A part of me was quite nervous, so I was like she's ringing the bell this should be the end, I hope this is the end, like I really want it to be the end. Erm, you can't really, it's just always going to be in the back of our minds, but it... it's difficult. It's like, we want to relax but we can't fully relax even now."

Trying to make cancer a memory, but still in the present

“I did a book for her erm an end of treatment book, or a treatment book, should I say erm I did like a photo book for her with all like pictures of her treatment... I think it was closure, really. I felt like a massive relief once I'd done it erm because it was something to look back at. I just I just feel like it's all in there now, to look back at, this was, well this is, this is our life”

Super-ordinate theme

Transcript

Sub-Theme

Meaning and function of the bell ringing ritual

Forgetting and remembering; holding onto the good

“I didn't want this to be forgotten, a lot of people are like just forget what you've gone through it's too traumatic to keep thinking about it but it was good to celebrate and have fun, I'm just proud of what she's achie, what she, how she dealt with everything, and I wanted us to remember all the fun we had.”

To acknowledge the joint achievement of the child and parent

“I think just getting through something like this, so hard, because the medicine the list of medicines she needs to take is ridiculous. So, I think we had to work it. I think we had to kind of I kind of the bell and the party and say okay we've done that, done that.”

To acknowledge child's achievement

“This is just something that she can look back on and say, look, I did that. I did that. And she's got certificates in her room. She got an award for bravery.”

“So, yeah, that's why I felt that we needed to celebrate [pause] each like milestone because it was an achievement for her”

Others acknowledging parents' achievements: Difficult to accept

“everyone said to me when she rang the bell, oh, you're amazing, but you just think, not really you don't have a choice. It's just not about us, it's about them. I had to keep myself well to take care of her so maybe that's an achievement”

Super-ordinate theme

Transcript

Sub-Theme

Marking the end: being a different parent and a child

Being a less restrictive, fun parent

“it felt like I was always, oh, we can't do this, we can't do that, like my girls would always tell me off, they'd be like “ohhhh come on, it's like stop being so over-the-top”, you know, cause they would always say to me, oh, you are just, you know, you are being too controlling and we'd have to stay away from people that were sick so there was a lot of time away from people, away from school, the hospital appointments, so it had been a while since we kind of had a big celebration because I was worried about infections and things and she'd only gone to part of a wedding and a christening, two christenings in the whole time because I was trying to keep her away from people so this felt like it was okay to just have fun and relax without me saying to everyone have you washed your hands [laughter], who just

sneezed, who just coughed [laughter] you know without that, because I was I was really over the..."

Child being a "normal" free child again

"it meant, it felt like she could run around, be with other children in her party, like them play like them without having to be told to stop because I was always worried about her, about her getting infected. "

Super-ordinate theme

Transcript

Sub-Theme

Feeling special and important to staff

Being kept in staff's mind

"It was just so sweet and special they even made time in their diary, they wanted to be there, her nurse said I'm going to come just for this and be there. It just shows it's special for them too you feel like oh wow they've taken time out of their day to come and watch her ring the bell, even the doctors have come out and it makes you happy"

Ceremony as being special to staff

"it just it shows that it's special for them, too. And like, you feel you feel like, oh, wow, they've taken time out of their day to come and watch her ring her bell. That's really like, oh, OK. Even the doctors have come out, makes you happy"

Super-ordinate theme

Transcript

Sub-Theme

The bell as a bond and divide between families

A bond between parents

"When others ring the bell it's like you know what they have gone through, it doesn't matter what type of cancer it is you are all in like the same boat, you understand them and where they are coming from."

Reminded of child's "sick" status: happy and envious

"You just, you feel quiet, quite envious of them, that they've got to that stage, feel a bit jealous, but then you're really happy that they got there, and you just think, wow, that's amazing like that's such an achievement, you are just really, really happy and then you think, argh, we have we've actually come in for chemo today, so it is a kick in the teeth at the same time"
"It's a horrible feeling [laughter] it's like you are happy for them but then you're like gutted for yourself because you are like oh flipping out, we've just, we got sooooo long to go till we finish[emphasis on the so long to do]
"you're really happy for that family, you know, you're really, really, really happy for them. But at the same time, you're like, ugh okay we've still got, it just felt at the beginning it felt like ages [emphasis on the word]. It felt like ages away erm at the time."

Reminded of other children's "sick" status when own child rings it: guilt

"But you do feel guilty like when you're the ones that are finishing [sight] that was quite emotional because you are looking around and you think we are finished, but we were where you were and some of them may have just been starting or, you know, in the middle, you just don't know what stage they are at until you talk to them but it's a weird feeling because you're happy but then you feel sad you know, for the other children [begins crying] you do, you feel guilty, you just feel guilty"

Super-ordinate theme

Transcript

Sub-Theme

After the party is over

Registering experience and emotions when the party was over

“but it is only really started to register afterwards what we went through and erm just how hard it was, but at the time, you just kind of get on with it, you don't really have a choice but to but to get on with it.”

Letting go of putting on a brave face in front of others

“I could kind of just be myself instead of having to put a brave face on, so I kind of had a little cry [begins crying] but yeah it was an emotional day, I do remember that]. Maybe when I was alone, I was allowed to reflect a bit on what had happened whereas in celebrating, there was all the family, all the nurses then back home at the party, eating celebrating, cake it was full on like there was no time to think about things, it was just fun”

Facing the losses

"it was quite scary because once she rang the bell, we didn't have that kind of erm knowledge that we would have been looked after all the time and we were kind of left to our own devices, if you like. So, we had that security of knowing that the doctors were there, we could just go in whenever we wanted, and they would get seen. And she was she got used to all the nurses in the hospital on the wards and just became like a second home, really.”

Appendix K: Illustration of developing super-ordinate/themes across cases

2. A Bell That Bonds and Divides

2.1 An Unspoken Bond (8 participants)

Participant	Theme	Extracts
Harun	A bond of understanding other parents' pain	"The bell is like this bond you know, when they ring the bell we know all the crap that these parents have had to deal with you know the amount of time and effort it takes people to look after their kids, receiving these injections and medicine."
Jennifer	An unspoken bond of shared experience between parents	"You see others ring the bell and you didn't have to say much to them, you just knew. You like became one like I didn't even know the people, but you are all in the same boat"
Daisy	A bond of empathy	"When others ring the bell it's like you know what they have gone through, it doesn't matter what type of cancer it is you are all in like the same boat, you understand them and where they are coming from (...) you understand how hard it was what they went through."
Alex	Forms a bond through a shared goal	"You know it just seems like a real bond to everyone, including parents and other children who are going through treatment, it's like something we all want to do, it's a reciprocal joy us as parents, our child, nurses, doctors, whoever is there. A goal. Also, other children and parents who witness what is happening"
Josephine	Shared experience: knowing the child's pain	"When you see them ring the bell, it's like tears because I know what she, because as a parent, you know what she's been through because you're going through that with your son, so that's happy like she's done. She's finished. She doesn't need to go through this no more, you look around and everyone is crying"
Ina	A bond and shared experience	"It was like a bond or something with them you know when they are ringing the bell when you see them because you are all going through similar things and now, they get to ring the bell"
Dipa	A bond between "cancer mum/dads"	"When you think of the end of treatment, you think of the bell you know something that as cancer mum and cancer dads when they see others ringing it you know what that means to them, what they went through and it's like this bond you have"

Hazel	A bond of understanding and empathy/towards child	“We’ve seen other children ring that bell and that’s an emotional day and these were children we didn’t even know but watching them ring that bell, just means a lot because you know what they’ve been through”
-------	---	--

2.2 A Reminder of the Sick and the Well (6 participants)

Participant	Theme	Extracts
Ina	Sick and waiting in line for freedom: mixed emotions	“I was crying when I first saw a kid, happiness obviously that the other child is going home, they are happy now (begins sobbing) and at the same time I was waiting, waiting when will my kid come for his bell ringing? (Continuous to sob) It was emotional, it was happy, both, their child is free, but we had to wait”
Daisy	Reminded of the long and dreadful journey ahead: mixed feelings	“You feel quite envious of them, that they've got to that stage (...) you think wow that's amazing like that's such an achievement (...) but then you think argh, we actually came in for chemo today so it's a kick in the teeth at the same time. It's a horrible feeling, it's like you are happy for them but then you're like gutted for yourself because you are like oh flipping out, we've just, we got so long to go before we finish”
	Reminder of the sick children: guilt	"You do feel guilty like when you're the ones that are ringing the bell because you are looking around and you think we are finished, but we were where you were and some of them may have just been starting or in the middle, you just don't know what stage they are at (...) it's a weird feeling because you're happy but then you feel (begins sobbing) you just feel guilty."
Jennifer	A divide between the sick and the well: waiting your turn	“so it's sort of like a bit of like there's an argh, you know they ring the bell and you you just want it to be your turn. But that's just natural. I think it's human nature, isn't it? But you just need to keep waiting to be where they are”
	A divide between the sick and the well: guilt	“as the parent of a child who rings the bell, you are really happy obviously and so grateful and thankful but on the other hand, you feel enormous guilt, other children who do not make it who don't get well like your child”

	Not wanting to remind families of the child's sickness	“you're happy because you're finished, but it's like it's you don't want to rub it in too much, so you have to kind of still conserve it a little bit. So maybe it was good that we had that party at home afterwards because then we could just like, be ecstatic and feel happy (...) you don't want to remind them they are still on treatment you know”
Hemal	A reminder to the child of sickness and status	“the biggest disadvantage is that I thought was the fact it's like saying oh yeah, the person that was lying on the next to me had finished treatment and they're so happy. And here I am taking my medication and I'm being injected.”
Alex	Evokes a social comparison: far behind in the treatment journey	“There was joy and probably some resentment there as well. I think of the personally, you know shit we got all this to go through, we got all these years to go through. We aren't anywhere near there, we are so, so far away [emphasis on the far away]. So, a little bit of resentment creeping in there”
	Changes in the felt divide between sick and well	“I think the resentment left after a while, it becomes a really happy sound later on that someone has gotten through and your child will get well too, but you know it depends, because the whole treatment is up and down regarding emotions”
Josephine	Changing feelings towards the bell: Close to being “well”	“It was hard hearing it at the beginning because it's like you are so far away but then, it was when we got closer to finishing, I was like oh that's going to be us, that's going to be us, that's going to be us, so that was encouraging then (...) it was exciting”

3. For Whom the Bell Tolls: A Multi-Vocal Symbol

3.1 Sustenance and Hope (8 participants)

Participant	Theme	Extracts
Josephine	Hope and possibility of child getting better	“It made me feel good when I heard it because I knew that it's possible to get to the end.”

Ina	Announcing hope to others	“You know, you can celebrate it so that the hospital, the ward knows that, you know, there's one person who's successfully finished treatment it's possible”
Dipa	Possibility of hope and sustenance to keep going getting through the difficulties and cancer	“It's that hope, you walk past it and there is a possibility, because when you're at the beginning it feels like you can't get through, it feels like a massive weight, surrounding your aura, watching your child disappear from your eyes, personality, looks. So, the bell being there, it's something you can hold onto it's that hope that there is an end to this, even though it feels like a lifetime away. You can get through this; others get through this.”
Harun	Hope for the future	“There's the possibility and it's like this thing you look forward to, this hope, it sounds strange, it's just an object or an idea but it gives you hope.”
Alex	Helps parent install hope in the child	“I could say to Hailey, look there is someone ringing the bell, there is another person getting better, that sound gives you that support during treatment and then that you can then support your child and say you have people are getting better all the time”
	Provides sustenance to keep going	"Hearing and seeing people, especially as you go through treatment and you hear it more and more, then it'll happen, it'll happen, it will happen keep going and you will be there, you will get there"
Daisy	Reminder of a hopeful future and sustenance to get through	“I think it's nice where it's situated in the corridors because you are walking past it all the time and you're, that's like a reminder that, it's hard but you know, we're going to ring that soon, it will end soon”
Jennifer	Gives sustenance and a goal to aim towards	“Just really really happy that she finally rang it, that she got there, because that was like the aim throughout, keep going to get there to the bell”
Hemal	Hope of successful endings and cure	“It made me feel good because I knew that it's possible to get to the end. It's possible that children were being cured so it's sort of like a bit of hope I thought”

3.2 A (False) Sense of Certainty and Security (6 participants)

Participant	Theme	Extracts
Ahmad	Security that cancer can be left behind	“The bell is like, it’s a very strong signifier of you know it is over, that it is done and over with”
Ina	Certainty that difficult times are over	“It is a big thing that bell, you know it that when you ring it, it is finally finished, it is the end of the hard times”
Alex	Reassurance and certainty: a multi-sensory symbol	“It’s the trust in the nurses and doctors that we wouldn't be ringing this bell unless it was over, you know, it is a big thing. It’s not a piece of paper that you read that says her treatment is over, it's the sound and sight of something happening that, you know, it’s telling us that it's over. It's done, you know, it’s a two-way thing you know, it is over, we are showing you it’s over”
Josephine	Recognizing the bell ringing is not the end: false reassurance	“It’s like you look forward to this bell ringing so that you can leave it behind, that once that’s rung it’s finished done, but it’s not actually done, things stay with you, and you still worry”
Daisy	Ringling the bell and doubting it’s meaning/certainty	“A part of me was quite nervous, so I was like she’s ringing the bell this should be the end, I hope this is the end, like I really want it to be the end. Erm, you can't really, it's just always going to be in the back of our minds, but it... it's difficult. It's like, we want to relax but we can't fully relax even now.”
Jennifer	Ringling the bell does not mean it is the end: relapse fear	“It’s disappointing a bit, you look forward to your child ringing the bell and are sure that will be the end, but you don’t know what happens in the future, if it comes back”

3.3 Freedom and Return to “Normal” (8 participants)

Participant	Theme	Extracts
Shah		

	Return to normality/a life without worry	“It’s a celebration for parents, we can say to people we can enjoy our life, nothing to worry about, everything is back to normal life, we can enjoy life now, no more hospital, medicine, and things all those”
Hazel	Return to a more enjoyable life	“It’s the same feeling for me we can now enjoy our life because for three years, there was so much Shah, and I couldn’t do”
Ahmad	Child announcing freedom from toxicity and return to normality	“I think that bell is like, you let people know, okay I am free now. I don’t need to have anything go in my body and I can go anywhere I can do anything I want, because for the two years, she wouldn’t be able to swim at all, she’s not allowed.”
Ina	Child being free and “normal” again	“Yeah, it means treatment is finished and she is free now, she can do things other children do, enjoy her life now”
Alex	Freedom from misery	“it’s a bit like when I think of you know what people do after real misery, like after a war, they ring bells, it’s the end of misery, we now move forward with our lives.”
Hemal	Freedom from a restricted burdensome life	“It’s celebrating freedom, no more appointments, no more appointments, no more driving down at six a.m. and being there for eight a.m. and, you know, finishing the day. Feeling exhausted”
Josephine	Free from restrictions imposed by treatment	“When the bell rings it’s like they are free, free from taking medication not being able to eat two hours before, two hours after, just free”
Jennifer	Return to a life with more autonomy and freedom	“There were so many restrictions, safety restrictions on what we can do, where we can go, keeping her away from infections things that could hurt her, and when she rang the bell it’s like we could do what we wanted, and she could do what she wanted.”

3.4 Recognizing achievements (7 parents)

Participant	Theme	Extracts (pages/lines)
-------------	-------	------------------------

Daisy	<p>Bell rings for child's accomplishment</p> <p>Bell rings for the joint accomplishment of the family</p> <p>Others acknowledging parents' achievements: Difficult to accept</p>	<p>"So, yeah, that's why I felt that we needed to celebrate [pause] each like milestone because it was an achievement for her"</p> <p>"I think just getting through something like this, so hard, because the medicine the list of medicines she needs to take is ridiculous. So, I think we had to work it. I think we had to kind of I kind of had the bell ringing and say okay we've done that, done that."</p> <p>"Everyone said to me when she rang the bell, oh, you're amazing, but you just think, not really you don't have a choice. It's just not about us, it's about them. I had to keep myself well to take care of her so maybe that's an achievement"</p>
Josephine	Acknowledging and letting child know their success	"It was like wow you did it [the bell ringing] it was an achievement for him to have done all of that, and I'll show you something else as well, he got two certificates [from the ceremonies]"
Dipa	Recognizing the child making it through a difficult journey/achievement	"You have so many obstacles in your way to get there. That's why it's such a wow look you've done it and having to go through all of that you can ring the bell, you did it well done you!"
Hazel	Acknowledging making it through as a couple/accomplishment	"It's like we did it together and the bell ringing is like you did it. When you're going through that, I mean, I know a lot of parents get divorced and things because of the pressure is just immense. It's just it's amazing how something can survive through that kind of trauma, it's a success"
Ahmad	Bell rings to acknowledge parents' achievements/effort	"When she is ringing the bell, it's a success, and the satisfaction, that okay you did the hard work of the two years, and the end result is that your daughter is cured"
Jennifer	Acknowledging the support/success of support network around the child	"It was him ringing the bell but it was all of us you know. We had such great neighbours and family, when David craved something one of them was bound to bring it and that's why I wanted everyone to see, like we've all done that, we've all helped each other and got him through this and now he's ringing that bell"
Ina	Coming together and recognizing the joint achievement/success	"we all did it made it together you know. Yes, it was him ringing it there, but it's like everyone should ring it, they're all my family, it's everyone, you know that's why I wanted everyone to see, like we've all done that, we've all helped each other and now he is ringing the bell at the end"

Part III: Critical Appraisal

Introduction

This critical appraisal will focus on the possible meaning and impact of conducting end-of-treatment research interviews during the COVID-19 pandemic, for both participants and for myself. It will begin with an appraisal of some of the positive and negative effects of conducting and participating in semi-structured research interviews, as well as the benefits and challenges of occupying a dual position as a clinical psychology practitioner-researcher. This will be followed by a discussion of ethical issues such as power and positionality during the research design, interviewing and analysis stages, and a reflection on my thoughts and feelings in relation to conducting an interpretative analysis. Finally, the appraisal will elaborate on different methodological issues faced during the pandemic, including delayed ethics approval, limitations in the data collection phase, shift to virtual research interviews and the impact of these issues on the quality of my research.

Impact and ethical issues

Potential impact on research participants

The current research took place during the time of the COVID-19 pandemic. In interviews, many parents talked about the loss of the anticipated end and a sense of not having closure from treatment. There were missed opportunities to say goodbye to staff, the hospital, and in one case not being able to have the bell ringing ceremony. There were multiple accounts of the end feeling anticlimactic, and not feeling important to staff due to a rushed ending. During the debriefing at the end of the research interviews, many parents talked about how the research interview left them feeling and the impact on them. This

included the “therapeutic” benefit of participating in the interviews, as illustrated in this quote from participant:

“it’s good to just talk everything out and get it out your system because we weren’t able to do that, I think it’s therapeutic”

The therapeutic value in the research interview process is reported in studies that discuss the role of qualitative research and qualitative researchers (Rossetto, 2014). While doing the interviews, I wondered about the meaning of participating in the interviews, particularly when the ending of the child’s treatment was not marked in the anticipated and desired way. This wondering is captured in an extract from my reflective journal:

“... I felt saddened by her expressed disappointment about the ending; she felt rushed and, in a hurry, leaving the hospital and staff without properly saying goodbye and marking the milestone with nurses they were used to seeing. I wondered what it meant to be doing this interview now, taking the time to think about the end and reflect on her experience. It felt as though the end was almost being marked in the interview, retrospectively.”

Research highlights how semi-structured interviews can make a positive difference by giving participants space to have a dialogue about their experiences, particularly if there was a missed opportunity to talk (Dearnley, 2005). In relation to cancer patients and caregivers it has been discussed how talking about feelings and experiences at length can be therapeutic, when there is no chance to do so in a time-pressured healthcare system (Adams, 2010). This pressure was evident during the COVID-19 pandemic, with hospitals wanting to minimize

the time patients spent in the hospital to avoid unnecessary infections. Another therapeutic benefit of doing the interviews could be to get a sense of closure on treatment and give parents “a retrospective completeness” (Roger, 1974). This could be particularly relevant for parents who expressed a lack of closure, due to not being able to mark the end of treatment and celebrate in the desired way. Wilson, Elkan & Cox (2007) discuss how conducting exit interviews after a cancer chemotherapy trial helped nurses facilitate closure at the end of patients’ participation.

From an anthropological perspective, the interviews could have been analogous to a “rite of passage” that marked the change in a parent’s role or status, interviewing them as parents of children who were now off treatment. The interview, like a rite of passage, could have assisted the process of acceptance and advancement by providing a closing of what had gone before. Another potential function of interviews could be to empower respondents and give them a sense of control (Husband, 2020). Many parents talked about a lack of perceived control in marking the end, due to COVID-19. Giving parents a chance to discuss their experiences in an open interview format, being led by them and providing autonomy in relation to attending the interview alone or as a parent couple could have provided some sense of control over the process. The debriefing at the end, and frequent checking in about feelings that came up in the interview could have gone some way towards repairing the rupture between participants and the healthcare system, through having a health care professional attend to and acknowledge their feelings and experiences regarding the end. Being thanked for their participation at the end and being shown gratitude for their contribution might have enabled parents to feel important and valuable to the hospital and research, which might have been meaningful to them, given expressed accounts of feeling insignificant and unimportant to staff.

It is also important to consider the potential negative impact and ethical implications of conducting the research interviews. Although there were no reports of distress or requests to receive follow-up support and counselling after the interviews, many parents talked about how the interview stirred up a lot of emotions. This was evident in the way in which participants sobbed and laughed at different points. Studies talk about how in-depth interviews can raise issues that are sensitive and make them emotionally intense experiences (Adams, 2010). This made me reflect continuously on ethical data collection and the impact of conducting in-depth semi-structured interviews where respondents are asked to re-live their experiences of a point in time that is important to them. The way I addressed this ethical issue was to use the beginning of the interviews to have an open dialogue about how participants could and would let me know if they did not want to answer a question or if they wanted to stop at any time. I also addressed it by using my clinical skills and monitoring the effect of my questions and interview on the participants, through verbal and non-verbal accounts (Smith, Flowers & Larkin, 2009). There were moments where I decided it was inappropriate to delve deeper into areas of experience e.g., recognizing participants' difficulty talking about a particular time and gently moving on to different questions.

Impact on researcher

Conducting research interviews evoked powerful emotions in me, often leaving me thinking about participants post-interview. The impact of collecting sensitive data on qualitative researchers is a topic widely discussed in the literature (Johnson & Clarke, 2003). Although I had reflected on my interest in transitions and endings in my bracketing interview and reflexive statement I recognized, during the process data collection and analysis, that my emotional responses were more powerful than I had predicted. Throughout the research

process, I thought about how conducting research on endings during a pandemic led me to face my own existential fears, particularly in relation to illness and loss. The experience of doing all eight interviews in the span of two weeks also contributed to the intensity of my feelings and the frequency in which I thought about endings. I used different strategies to support myself throughout the interview process. This included journaling about my experience of the interviews and debriefing with my supervisor - discussing transcripts and coding but also reflecting on the emotions stirred in me and my thoughts (Rossetto, 2014). During these discussions, I recognized how the role-conflict I felt, and power and positionality were important contributors to the wave of emotions stirred in me during the interviewing and analysis stages.

Dual roles and involvement

It is possible for in-depth research interviews to have a dual aim of information gathering and providing therapeutic support as questions often target experience and feelings (Allmark et al., 2009); thus, researchers may find themselves taking on the dual role of researcher and therapist. The dual role conflict is a widely reported experience in health research (Hay-Smith et al., 2016). Throughout the research journey, I was aware of my dual position of being a trainee clinical psychologist and a doctoral researcher.

As a researcher, I had a desire to obtain good quality material from the interviews and to draw out rich information. This encouraged me to use many prompting questions, particularly in the presence of “hot cognitions”. As a trainee psychologist, I had ambivalent feelings towards delving deeply into experience and emotions, without being able to normalize, reassure and validate. This dilemma became more apparent during moments where parents talked about difficult experiences and feelings regarding the end of treatment. I

experienced feelings of guilt as I was not able to “help” participants, a common feeling reported by researchers who are also health care practitioners (Johnson & Clarke, 2003). I could often feel myself being drawn towards the role of a psychologist and away from that of researcher, wanting to provide reassurance and containment. This can be seen in an extract I wrote in my reflective journal:

“I was tempted to let her know that the mixed and unwanted emotions when hearing others ring the bell was something a lot of other parents said. She expressed a sense of guilt and shame about how she felt towards others ringing the bell. I wanted to normalize this and give her a peace of mind. Then I thought about the implications of making this comment, for the interview and analytic process, stopping myself from making a comment and nodding in what I hoped was a compassionate way.”

This extract shows how non-verbal communication was a powerful tool for me in responding to participants during moments of intense emotion. Another dilemma I faced with my dual role was when parents approached the interviews as though they were a service evaluation, demonstrating hesitancy in discussing feelings and experiences. As a researcher, I tried to find different ways to ask questions to elicit cognitions, feelings, and experiences to obtain rich data. As a trainee psychologist, I was mindful that the participants I interviewed came from different contexts and backgrounds and that perhaps talking about feelings and experience was harder for some parents than others. Here, I tried to strike a balance between trying to elicit information and trying to be respectful and non-intrusive.

Power and Positionality

Both the researcher and participants are inseparable parts of the research project and have significant levels of involvement (Karnieli-Miller, Strier & Pessach, 2009). Research highlights how it is important for qualitative researchers to reflect on this involvement and issues of power during the research design, interviewing and analysis stages of the research (Allmark et al., 2009). There were various skills I used and adopted to try to minimize the power imbalances inherent in the process of research.

While developing the interview schedule for my research, I used Patient and Public Involvement (PPI) and consulted the parent of a child who had finished cancer treatment. This allowed me to ensure that the questions were appropriate and relevant to participants' experiences. For more equal sharing of power and decision-making, the research questions, aims, design and interview schedule would ideally be co-produced with paid experts-by-experience, rather than the questions being developed by myself as a researcher and then "approved" by parents (Mayer & McKenzie, 2017). However, genuine co-production is rarely achievable within the scope and timeframe of a DClinPsy thesis.

In the participant recruitment phase, I tried to ensure that parents had some power and control over their participation, through enabling them to decide whether they attended the interviews as a couple, separately or not at all. During the data collection/interview phase, I tried to establish an atmosphere of equality through creating a welcoming, nonthreatening environment in which participants could share their stories. I tried to make sure that the interviews felt informal, anti-authoritative, and non-hierarchical. Additionally, although I had a structured interview schedule with prompts, I allowed myself to be led by participants and their stories, rather than purely pursuing my own agenda as a researcher.

During the analysis and write-up phases, I was aware of being in a position of power in interpreting what was said in the interviews, choosing which quotes were used and in deciding how they were used. This is an important reflection in which to engage when one is conducting qualitative research (Allmark et al., 2009). From this stage onwards the stories shared with me were in some sense “separated” from the participants, and I became the “storyteller” (Karnieli-Miller, Strier & Pessach, 2009). I was mindful that, in interpreting participants’ experiences retrospectively, I was not able to check my interpretations and understanding with them. It is possible that, as participants read the findings of studies in which they have participated, they may feel misrepresented (Dennison, 2019). To address this issue, I provided participants with the option to attend a virtual feedback session and additionally offered to send a written copy of the findings of the study in the future. This allowed us to discuss participants thoughts and opinions on my general interpretations of the data and proposed clinical recommendations. All participants who provided feedback said their experiences were captured by the various themes listed in the findings with no proposed changes or comments on how findings could be represented differently. Furthermore, to ensure I did justice to the participants’ stories and captured their voices fairly, I cross-checked my interpretations with my supervisor at each stage of analysis, including the final write-up. Additionally, I was transparent and reported on the number of participant accounts under each super-ordinate and sub-theme included in the findings.

Capturing all stories and voices

During the write up of the research, I was aware of the dilemma I faced in wanting to do justice to all participants stories and voices in the write up of the research. One dilemma was my wish to present all the super-ordinate themes that emerged from the analysis and

having to keep within the scope of a DClinPsy project e.g., limit to word count. For example, the research project did not aim to focus on the period following the end of treatment bell, however nearly all parents talked about what life had been like when the child finished treatment and rang the bell. Although this super-ordinate theme did discuss the direct meaning of rituals and marking the end, I felt it was critical to capture what was important to the participants and highlight how parents can feel vulnerable and at a loss after the rituals and the bell ringing at the end.

While some couples complemented each other and took equal turns in the dyadic interviews, some individuals within parent couples took a more active or passive stance compared to their partners. As semi-structured interviews follow the participants lead, I noticed how there were times I was drawn into focusing more on the experiences of parents who took an active stance and engaged more vocally with the interview questions. To address this, I tried to encourage both individuals in the couple dyad to have a voice; I directed similar questions in both quality and quantity as I tried to alternate fairly between the individuals. I was aware that parents who were quieter and more hesitant in vocalizing their experiences were also less presented in the write-up of the study. This made me wonder what the quality of the interviews would be like if they were conducted as individual rather than dyadic interviews.

Methodological concerns

The COVID-19 pandemic posed unprecedented challenges for my research. This included delays in receiving NHS ethical approval, seriously restricting the time available for conducting the research interviews. It was also necessary to carry out all interviews remotely. A recent article talks about time limits in doctoral research and stress and anxiety experienced due to challenges of conducting qualitative research during the pandemic (Sah, Singh, & Sah, 2020). Completing the interviews in a short span of time and consecutively meant that there was less time and space available to reflect on and process the interviews. To address this, I used my reflective diary after each interview. Additionally, I had a conversation with a member of the research team after conducting the first three interviews, to think about how the interviews went, as well as sharing some examples and extracts.

During the data collection phase, I continuously reflected on the implications of conducting remote research interviews during the time of COVID-19. There can be multiple drawbacks and disadvantages to doing the interviews remotely. IPA guidelines recommend the use of face-to-face semi-structured interviews for data collection (Smith, Flowers & Larkin, 2009). Although videoconferencing can closely resemble the natural back-and-forth of face-to-face communication, I experienced conflicted feelings. During emotionally charged moments, I felt limited in my ability to respond to participants nonverbally, due to being physically distant from them (Foley, 2021). I wondered whether building trust, and the quality of the interaction would have been different if the interviews were face-to-face. I thought about how the subtle human qualities that are important in an interview like eye contact and gaze, facial expressions and body movements may not have been captured as

well in remote interviews. It is possible that this limited me from gaining a more nuanced understanding of the participants' words and experience (Pierre, 2008; Salmons, 2012).

It is important to mention that there could also have been benefits to conducting remote interviews in the context of paediatric cancer research. Firstly, remote interviews made it possible to carry out safe and feasible research during a pandemic. It is also possible that they enabled interviewees to be more open to sharing their stories. Some studies suggest that online interviews and taking part from a familiar space like one's home can make it more comfortable for research participants to share sensitive information (Hanna, 2012; Sipes, Roberts & Mullan, 2019). In the context of illness and health research, completing the interviews in one's own surroundings can enable feelings of control and a sense of safety rather than being at the hospitals (Sipes, Roberts & Mullan, 2019).

To conclude, research on "endings" is likely to have positive and negative effects on both the researcher and research participants. Through critical appraisal, I considered the emotional impact of the study, as well as issues of power, and ethical dilemmas. This enabled me to take a reflexive approach and enhance research integrity.

References

- Adams, E. (2010). The joys and challenges of semi-structured interviewing. *Community Practitioner*, 83(7), 18-21.
- Allmark, P., Boote, J., Chambers, E., Clarke, A., McDonnell, A., Thompson, A., & Mary, A. (2009). Ethics issues in the use of in-depth interviews: literature review and discussion. *Research Ethics Review*, 5(2), 48-52.
- Dearnley, C. (2005). A reflection on the use of semi-structured interviews. *Nurse Researcher*, 13(1), 1-12.
- Dennison, M. (2019). The black swan of qualitative research. *Qualitative methods in psychology bulletin*, 27(2), 1-20.
- Foley, G. (2021). Video-based online interviews for palliative care research: a new normal in COVID-19? *Palliative Medicine*, 35(3), 625-626.
- Hanna, P. (2012). Using internet technologies (such as Skype) as a research medium: a research note. *Qualitative Research*, 12(2), 239-242.
- Hay-Smith, J. C., Brown, M., Anderson, L., & Treharne, G. J. (2016). Once a clinician, always a clinician: a systematic review to develop a typology of clinician-researcher dual-role experiences in health research with patient-participants. *BMC Medical Research Methodology*, 16(95), 1-17.
- Husband, G. (2020). Ethical data collection and recognizing the impact of semi-structured interviews on research respondents. *Education Sciences*, 10(206), 1-12.
- Johnson, B., & Clarke, J. M. (2003). Collecting sensitive data: the impact on researchers. *Qualitative Health Research*, 421-434.
- Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research*, 19(2), 279-289.

- Mayer, C., & McKenzie, K. (2017). '...it shows that there's no limits': the psychological impact of co-production for experts by experience working in youth mental health. *Health and Social Care, 25*(3), 1181-1189.
- Pierre, E. A. (2008). Decentering voice in qualitative inquiry. *International Review of Qualitative Research, 1*(3), 319-336.
- Roger, G. (1974). *The language of the rite*. London: Darton, Longman & Todd.
- Rossetto, K. R. (2014). Qualitative research interviews: assessing the therapeutic value and challenges. *Journal of Social and Personality Relationships, 31*(4), 482-489.
- Sah, L. K., Singh, D. R., & Sah, R. K. (2020). Conducting qualitative interviews using virtual communication tools amid the COVID-19 pandemic: a learning opportunity for future research. *Journal of Nepal Medical Association, 2*(3), 1103-1106.
- Salmons, J. (2012). Designing and conducting research with online interviews. In J. Salmons, *Cases in online interview research* (pp. 1-25). London: SAGE.
- Sipes, J., Roberts, L. D., & Mullan, B. (2019). Voice-only Skype for use in researching sensitive topics: a research note. *Qualitative Research in Psychology, 4*(8), 12-15.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE.
- Wilson, E., Elkan, R., & Cox, K. (2007). Closure for patients at the end of a cancer clinical trial: literature review. *Journal of Advanced Nursing, 59*(5), 445-453.