Children and Young People's Experiences of the Transition Period from On- to Off-treatment for Childhood Cancer

Submitted by Sophia Arina Christina Broere, to the University of Exeter

as a thesis for the degree of Doctor of Clinical Psychology, 30th April 2019

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

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EMPIRICAL PAPER

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Abstract

The transition period from on- to off-treatment has been described as one of the major stressors faced by children and young people with cancer. Few UK studies, however, have explored this stressful period with a particular focus on identity. A grounded theory study of 9 children and young people going through this transition period was conducted. Findings revealed the core theme of ‘stepping into the unknown’ and reflected the continued process of role and identity changes that participants faced. During treatment participants adopted a ‘cancer identity role’, which was managed by ‘adapting’ and ‘increasing support’. After treatment they adopted a ‘survivor identity role’. Finally, an integration of their pre-cancer identity, ‘cancer identity role’ and ‘survivor identity role’ took place, forming a ‘new identity’, however this pathway appears to be age and condition dependent. Understanding of this process may help to prepare patients for the impact and challenges that finishing treatment may pose.

Keywords: *adolescents, cancer, children, identity, psychosocial aspects, transition*

Introduction

More than 80% of children and young people (CYP) in the UK survive cancer for at least five years (Office of National Statistics, 2018; O'Hara et al., 2015). The physical and emotional long-term effects of childhood cancer are well documented, demonstrating substantial risk of adverse health status and psychological and social adjustment problems (Eiser, 2007; Oeffinger, Hudson & Landier, 2009; Vuotto et al., 2017). Few studies have assessed the issues CYP face when they complete cancer treatment, despite this transition being acknowledged as a major stress in the paediatric cancer journey (Chesler & Barbarin, 1987; Kreitler, Ben-Arush, & Martine, 2012; National Institute of Clinical Excellence, 2005; Woodgate & Degner, 2002).

Current Department of Health (DoH) legislation such as 'Improving Outcomes: Strategy for Cancer' acknowledges the limited focus on enabling individuals to return to active lives post treatment (DoH, 2011). As a result, a document 'Living with and beyond cancer: taking action to improve outcomes' was launched to support cancer survivors to live as healthy and active a life as possible, for as long as possible (DoH, Macmillan Cancer Support & NHS Improvement, 2013).

Transition implies "the process of changing from one state to another" (Hawkers, 2002, p.654), and within this study refers to a new phase of life after completing treatment for childhood cancer (Duffey-Lind et al., 2006). This period involves unique challenges for CYP when they attempt to successfully reintegrate into family, school and community life (Labay, Mayans, & Harris, 2004). Developing an increased understanding of this transition could assist in making it less stressful, and promote successful long-term adjustment.

Identity

Identity can be defined as “who or what someone is” (Hawker, 2002, p.303). Cancer, a stressful enduring disease process with a succession of new social interactions (i.e. medical staff and other ill children and their families) and emotions, is likely to threaten the individual’s pre-cancer identity. An experience of cancer could also result in the integration of a new and potentially permanent identity (Brennan, 2001; Haslam, Jetten, Cruwys, Dingle, & Haslam, 2018; Stewart, 2003; Woodgate & Degner, 2002; Zebrack, 2000).

Personal identity refers to a person’s internalised sense of their individuality (Turner, 1982). The person categorizes the self as occupying various roles (role identities), which have meaning and expectations (Jackson & Hogg, 2010; Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). Individuals can have multiple role identities as a result of membership of different groups.

There is much debate regarding the use of the terms ‘cancer patient’ and ‘cancer survivor’ (Cheung & Delfabbro, 2016; Surbone, Annunziata, Santoro, Tirelli, & Tralango, 2013). Within this study ‘cancer identity role’ refers to participants on active cancer treatment, and ‘survivor identity role’ includes participants living beyond the end of treatment with no evidence of disease. ‘Pre-cancer identity’ refers to pre-cancer life and functioning.

Cognitive and identity development models

As this research study is focused on CYP, it is important to consider influential developmental theories of cognitive and identity development.

The cognitive development depends on the child actively attempting to adapt to the world, assimilating new knowledge into existing schemas or accommodating it into new or more complex schemas. Through the stages of cognitive development, self-descriptions of identity evolve in sophistication (Carr, 2006; Damon & Hart, 1988; Erikson, 1968; Piaget, 1932).

Piaget (1932) and Erikson (1968) both highlight the importance of acknowledging different child developmental stages. Between the ages 7-11 thinking patterns are relatively concrete, with a focus on cause, effect and fairness. Children live in the ‘here and now’, and want to learn and master new skills. They also start to compare themselves against their peers, and have increased interest in developing friendships.

Thought processes of adolescents (12 years onwards) are more abstract, they have mental capacity to be more philosophical towards life events and give more hypothetical self-descriptions (Brand, Wolfe, & Samsel, 2017; Carr, 2006). Additionally, they are concerned with finding a peer group with which to become affiliated without sacrificing individual and personal goals and aspirations (Carr, 2006).

Although the criticism of Piaget’s and Erikson’s work concerns the boundaries between the stages, it is suggested that children at each stage of their development have characteristics important to keep in mind in interview (Vasta, Haith, Miller, 2003; Carr, 2006), and how they might view their cancer experiences.

Bosma and Kunnen (2001) developed a model encompassing the process of identity development in adolescents (Figure 1). This model specifies that identity consists of personal commitments, values and beliefs, against which new information is compared. When the information is concordant, it would be a fit. When information is in conflict with one’s existing identity (cognitive dissonance), psychological distress results (Festinger, 1962). People attempt to resolve this conflict by adjusting their interpretation of the situation (assimilation). If assimilation is impossible, people will try to change the internal model to incorporate new information (accommodation). The process of accommodation is complex and requires repetition to weaken existing commitments over time, opening possibilities for change (Bosma & Kunnen, 2001). Finding equilibrium between assimilation and accommodation is important for development and adaptation.

Assimilation protects our existing worldview, whilst accommodation assists in learning from new information (Joseph, 2011). When completing cancer treatment individuals may either assimilate their new experience into their current identity, values and beliefs (returning to normal) or incorporate them to formulate a new identity (Bosma & Kunnen, 2001). Joseph (2011) argues that accommodation could result in experiencing posttraumatic growth (PTG). PTG refers to “positive psychological change experienced as a consequence of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004, p.1).

Although this model is complex, and was developed for adolescents rather than children, research reports that facing a life-threatening illness may accelerate the developmental progress (Woodgate & McClement, 1997). Consequently this model could provide an understanding how new experiences and information, via the processes of assimilation and accommodation, could be incorporated into the children as well as young people’s identity.

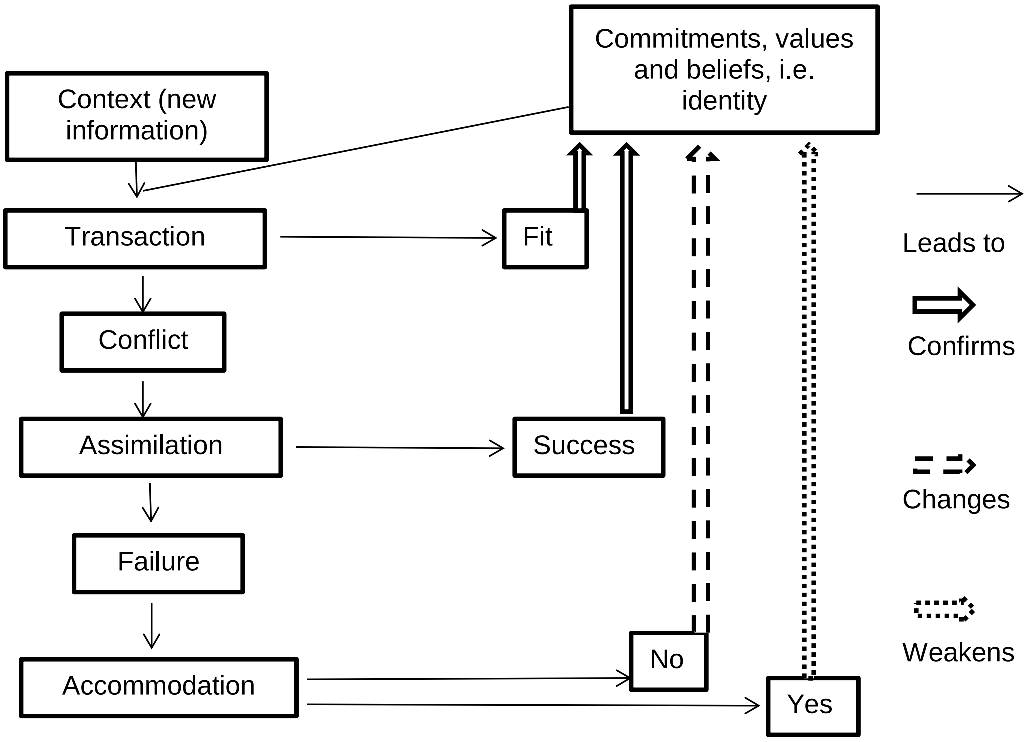

Figure 1. Schematic representation of identity development, adapted from Bosma & Kunnen (2001).

The transition from on-to off-treatment for childhood cancer: What we know so far

Wakefield et al. (2010) carried out a systematic review exploring the psychosocial issues of CYP, who had completed cancer treatment within 5 years. This review included 19 studies (13 quantitative, four qualitative and two mixed methods). They concluded that completing treatment can be a psychologically complex time with both positive and negative psychosocial outcomes. Positive outcomes included good behavioural conduct, high self-worth, and psychosocial hardiness; negative outcomes included low levels of psychosocial well-being, mood, self-esteem, motor and physical functioning, as well as increased anxiety, sleeping difficulties, and problem behaviours (Wakefield et al., 2010).

Importantly, Wakefield et al. (2010) emphasised a lack of relevant, methodologically rigorous studies in this area. None were carried out in the UK which has a unique healthcare service. Moreover, the focus was not specifically related to the immediate transition from on- to off-treatment. Information about this specific time period may help identify possible barriers and solutions for reintegration into family, school and community life (Labay et al., 2004).

The quantitative studies included in Wakefield's review (2010) and others have reported that the largest negative impact of treatment is physical (Al-Gamal & Long, 2016; Engelen et al., 2011; Gotte, Kesting, Winter, Rosenbaum, & Boos, 2015; Reinfjell, Lodstad, Nordahl, Vikan, & Diseth, 2009; Ruccione, Lu, & Meeske, 2013). Quantitative questionnaires might restrict the breadth of response of the participants and fail to capture the complexity of the experience of completing treatment. Additionally, these studies predominantly focused on maladjustment or distress, rather than examining evidence of resilience or coping. To consider the illness experience and impact, research methods that provide CYP the opportunity to represent experiences within their social context should also be used.

The qualitative studies from Wakefield's review and more recent studies suggested that completing treatment is psychologically complex. Studies remained at a descriptive level, and did not develop a more conceptual theory (Straehla et al., 2017; Thompson, Palmer, & Dyson, 2009; Wakefield, McLoone, Butow, Lenthen, & Cohn, 2013; Wakefield et al., 2010). The development of a theoretical framework could allow a better understanding of how the complex elements of the experience of finishing treatment link together, facilitating improved support and outcome in CYP patients.

Finally, Wakefield’s review did not identify data on whether the completion of cancer treatment could impact participants’ identity. A systematic literature search (Appendix A) covering the period following Wakefield’s review identified only three studies focusing on identity transformation when making the transition from on- to off-treatment for childhood cancer (Choquette, Rennick & Lee, 2016; Jones, Parker-Raley & Barczyk, 2011; Stegenga & Macpherson, 2014). All three studies used qualitative methodologies.

Jones et al. (2011), using constant comparative analysis, identified three themes describing the experience of adolescent cancer survivors: finding meaning, identity paradox and the need to belong. Twelve adolescents took part in this study. The time from treatment completion was not documented and was not focused on the transition period.

Stegenga and Macpherson’s (2014) longitudinal study assessed 15 adolescents through the cancer trajectory from diagnosis for one year. Participants engaged in adolescent identity and cancer identity roles and integrated the two into an adolescent with a cancer identity. Again, the focus was not on transition following treatment.

Using a constant comparison method Choquette et al. (2016) explored how returning to school affects adolescents’ beliefs about themselves, their self-identity and social relationships. They found three main themes: establishing a new life at school, being on the right track, and bridging the two worlds. However, as some parents attended the interview the quality and content of their narratives might have been contaminated. Moreover, this study only focussed on transitioning back to school, omitting other transitions such as reintegrating into community settings.

All studies were conducted outside the UK and only included adolescents, with younger children excluded. Whilst cancer at any age introduces major stressors, adolescents, compared with children face unique challenges due to the interference of the cancer experience with developmentally normative tasks of this period such as separation from parents, decisions of future goals, and developing a positive body image and sexual identity (Bleyer & Barr, 2007; Shama & Lucchetta, 2007; Zebrack, Chesler, & Kaplan, 2010). Attention should also focus on understanding the differing perspectives of younger children in addition to those of adolescents (Woodgate, 2000).

The present study

This study aimed to address the gap in the literature by including younger as well as older children. Based on developmental models (Carr, 2006; Erikson, 1968; Piaget, 1932) ‘younger children’ will include children 8-11 years old, and ‘older children’ 12-18 years old. A grounded theory (GT) approach was utilized. GT is a rigorous method, enabling theory generation and a potential model to understand the meanings that CYP give to their experiences of the completion of treatment for childhood cancer (Charmaz, 2006).

The purpose of this study is to explore the CYP’s experience of the transition period from on- to off-treatment for cancer in the UK. The information and model created is intended to inform healthcare providers with potential approaches to better support CYP during the transition from on-to off-treatment.

Method

Design

This study used a GT design to develop theory from the data collected from semi-structured interviews. Constructivist GT by Charmaz (2006) was chosen it views knowledge as socially developed, takes a reflective stance toward our actions, situations and participants in the field setting as well as our analytic constructions of them, and acknowledges multiple standpoints of both the research participants and the grounded theorist. I considered using traditional Interpretative Phenomenological Analysis (IPA; Smith, 1996). As IPA places greater emphasis on the individual's personal experience rather than focussing on social processes and 'change', GT was considered more suitable for this study in order to ground my analysis to concepts of transition (Willig, 2001).

Researcher's Position

This research was inspired by my personal experience with cancer (both my brother and I had lymphoma in childhood) as well as professional experience.

Following data collection in 2007/2008, I was diagnosed and treated for cancer twice (2009 and 2013), my Mother died of cancer (2012) and I became a Mother (2012). Consequently, the final analysis and write up of the data took place in 2018/2019. These personal experiences changed my world view, which might have influenced my analytical interpretation of the data. To ensure credibility of the emerging theory, I used a personal reflective journal (Appendix B), line-by-line coding, personal therapy, and supervision to reflect on the process. In addition, I wrote extended memos (Appendix C) to remain aware of my contribution to the emerging theory.

Participants

Purposive sampling was used to identity participants. Nine CYP (3 female, 6 male) aged between 8 and 18 years old participated. Participants were British Caucasian and treated for any form of cancer in the South West of England (Table 1). All potential participants approached by the Nurses and Social Workers agreed to take part.

Table 1.

Demographics and medical variables of the participants

Demographic Factors	**Situational variants**	**Number of participants and gender** **N=9**
Age & gender participants	8-11 years old (younger children)	Female: 1, male: 3
	12-18 years old (older children)	Female: 2, male:3
	Mean age: 13.7 years	
Type of cancer	Solid Tumour	5 (1 CNS tumour)
	Acute lymphoblastic leukaemia (ALL)	2
	Lymphoma	2
Type of treatment	Chemotherapy	9
	Radiotherapy	3
	Surgery	8
Length of treatment	< 1 year	6
	> 1 year	1
	> 2 years	2
Time off-treatment	2-6 months	3
	6-12 months	6
Number of siblings	0	4
	1	4
	4	1
Stage of education at the time of interview	Primary school	3
	Secondary school	2
	Completed GCSE's, commencing further education or working	4

Recruitment

Nurses and Social Workers at a single specialist centre identified potential research participants and their families, and introduced them to the study. They gained verbal consent to distribute the information packs and assent/consent forms (Appendices D, E and F).

*Inclusion criteria***.** Eligible participants were:

(a) 8-19 years old at interview

(b) 2-12 months off-treatment at the time of data collection to ensure that the CYP had sufficient time to experience and recall the situation fully (Haase & Rostad, 1994).

(c) In first remission

(d) Fluent in English

(e) In full-time education when diagnosed with childhood cancer (Children are only treated in the Children's hospital if they are diagnosed when 16 years or under, or are in fulltime education aged 17 years old and living at home)

(f) Living at home with their family/guardian at the time of interview as this research study was part of a wider approach exploring both parents' and children's experiences (McKenzie & Curle, 2012).

*Exclusion criteria***.** Exclusions were:

(a) Parental insistence on being present at interview (McCrum & Hughes, 2001).

(b) Severe learning difficulties to the extent that they could not converse, and other co-morbid conditions that could prevent participation in an interview

(c) CYP not in full-time education when diagnosed

(d) CYP living independently at the time of interview. Young People living independently are likely to have different issues to CYP living with parents, potentially affecting the usefulness of the study.

Service User Involvement

The views of two CYP (female aged 9, male aged 14) who had completed cancer treatment were sought and incorporated into the study methodology, recruitment process, participant information and interview schedule.

Ethical Approval

Ethical approval was granted by local NHS Research Ethics Committee (Appendix G).

Ethical considerations

Informed consent. As per standard practice young people aged 16 and over signed consent forms; individual assent and parental consent forms were obtained from participants under 16 years of age (Gibson, Aldiss, Horstman, Kumpunen & Richardson, 2010; Spinetta et al., 2003; DoH, 2001).

Confidentiality. The confidentiality and anonymity of the participants was addressed in the information pack (Appendices D & E) and during the visits.

Freedom from coercion or deception. The power imbalance between CYP and researcher was taken into account; as well the CYP’s desire to please the researcher. Open questions were used as much as possible (Greene & Hogan, 2005). In addition, the participant could choose the time and place of the interview. Participants were clear that they could withdraw at any time without this affecting their treatment. Following the service users' suggestions, and after discussions with the Ethics Committee and supervisors, should the participant show an interest in my personal experience, I would then share this with the participant. This occurred in one interview, and the participant did not appear adversely affected by this information.

Some strategies had been adopted to successfully interview the participants; such as avoiding tiredness and anxiety, and responding appropriately to emotional reactions (Sartain, Clarke, & Heyman, 2000). As an icebreaker, participants were offered to draw a picture representing their experience on-treatment and off-treatment. Only one participant took up this offer. Data from the drawing discussion was embedded within the interview data (Bradding & Horstmand, 1999).

*Debriefing and addressing sensitive topics***.** Supervisors were available to debrief or to discuss any personal or socially sensitive topics with both the interviewee and the interviewer. Conducting research into both the CYP's experience alongside the parents' experience reduced the risk of lone working, as the researchers sought to carry out the interviews at the same time.

*Use of research results***.** All names were replaced with a number and pseudonyms. All tapes were wiped after I was sure that all information had been transcribed verbatim. The study findings will be disseminated to service providers and wider research community (Appendix H).

*Participation of vulnerable groups***.** Some CYP displayed distress when talking about their cancer experiences. When this occurred, I provided immediate emotional support and empathy, and contacted parents where appropriate. They were also verbally reminded of the contact details of the research team mentioned in the information sheets (Appendices D & E).

Interviews

A semi-structured interview (Appendix I) consisting of open-ended, non-directive questions was derived directly from the relevant childhood cancer literature (Green, Bradwell, & Griffiths, 2007; Kyngas et al., 2001; Labay et al., 2004; Weekes & Kagan, 1994), service user consultations and discussions with clinicians.

Based on participants’ personal preference, all interviews were conducted in the participants’ homes. The interviews ranged in length from 21 minutes to 67 minutes. All participants were debriefed after the interview.

Data Analysis

I conducted all nine interviews in 2007/2008. The transcripts were analysed using GT following Charmaz’s (2006) social constructivist approach. Data collection and analysis occurs simultaneously to facilitate expansion and elaboration of codes (figure 2).

Open codes were applied line-by-line to each transcript to capture units of meaning. I maintained data integrity by using ‘in vivo’ codes where possible and tried to see actions and meanings in each segment of the data (Charmaz, 2006). The openness of initial coding allowed new ideas to emerge (Glaser, 1992).

Focused coding, which involved merging common recurring themes and larger segments of data to refine the emerging categories followed (Appendix J). Codes within and between each transcript were constantly compared to each other for similarities and differences. Memos were written during all stages (Appendix C) to identify and describe categories and to search for underlying assumptions within participants' accounts in order to define categories further (Charmaz, 1995). This ensured remaining open to new ideas and maintaining transparency regarding my pre-conceptions. Memo writing led directly to purposive sampling.

Purposive sampling was used to seek and collect pertinent data to elaborate and refine categories (Charmaz, 2006). Charmaz (2006) emphasised that purposive sampling is not about representing a population or increasing statistical generalisability, but to serve the purpose of conceptual and theoretical development. Theoretical saturation implies that collection of new data adds no further theoretical insights to the emerging analysis (Charmaz, 2006). While in GT the concept of theoretical saturation is an ideal, it was not possible within the constraints of this doctoral research project.

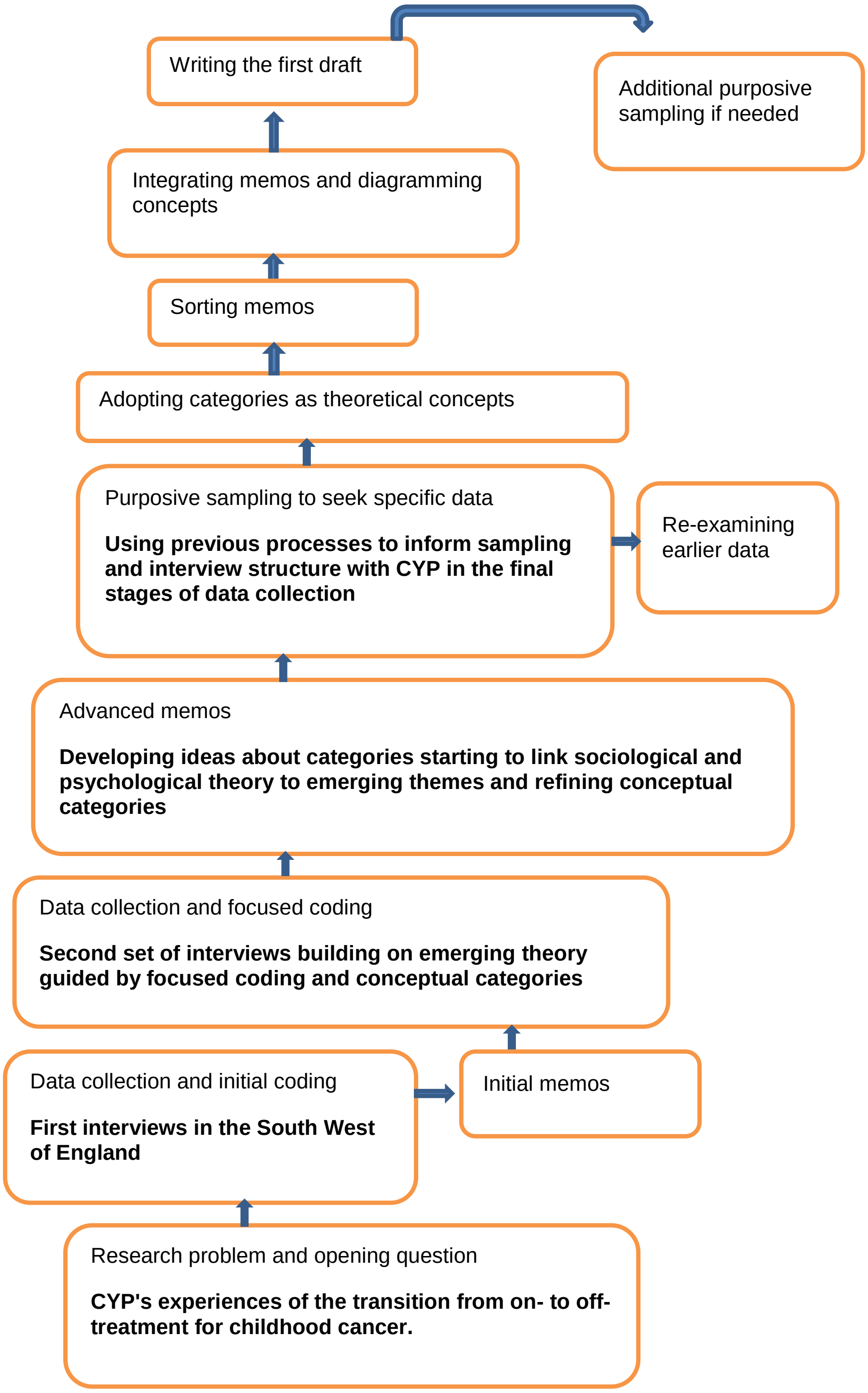

Figure 2. The basic grounded theory processes by Charmaz (2006).

Results

A model was constructed to capture CYP's experiences, as described in the interviews, of the transition from on- to off-treatment for childhood cancer (figure 3, page 28).

This section starts with an overview of the model, followed by a detailed description of categories and subcategories. Quotes from participants have been selected to best illustrate a concept.

Model Overview

'Stepping into the unknown' emerged as the core category, encapsulating participants' pro-active approach when dealing with a great uncertainty during the transition from on- to off-treatment for childhood cancer. All participants viewed the end of treatment in the context of the overall experience of childhood cancer and 'stepping into the unknown' captured the sense of uncertainty when starting treatment, developing a 'cancer identity role', as well as the immediate time following the completion of treatment resulting in a 'survivor identity role'.

Throughout and immediately after treatment, there was a continued tension between their pre-cancer identity and stressors that disrupted it. Each period had its unique challenges. Negative feelings were experienced when the participants' pre-cancer identity was not supported. In contrast, experiences that enhanced their pre-cancer identity seemed to be linked to positive feelings, for example a sense of achievement and overcoming adversity.

During treatment, the tension between the disrupted identity stressors and pre-cancer identity enhancing experiences appeared to be alleviated by 'increasing social support' and 'adapting their lifestyle' and this process resulted in their 'cancer identity role’. After treatment, the tension between their ‘cancer identity role’ and ‘pre-cancer identity’ was mediated by a ‘shift in social support’ and ‘adapting their lifestyle’, forming their ‘survivor identity role’.

After the initial recovery phase, most participants began to integrate their pre-cancer identity, cancer identity role, and survivor identity role. The two youngest participants treated for ALL returned to their pre-cancer identity, whilst the other participants formed a new identity.

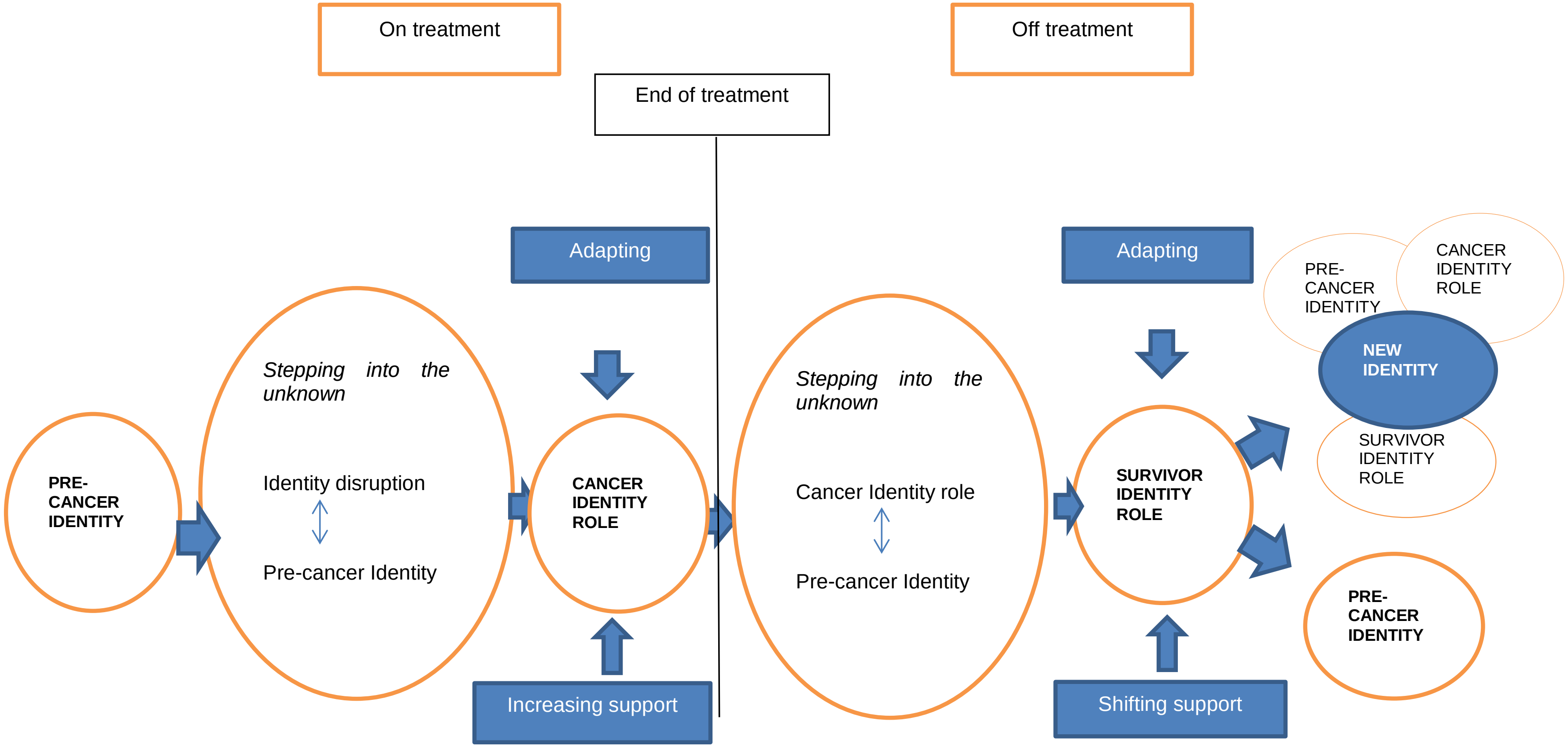

Figure 3. Grounded theory model: ‘Stepping into the unknown’: Children and Young People’s experiences of the transition period from on- to off-treatment for childhood cancer

Pre-cancer Identity

It was important for all participants to talk about elements of their lives before receiving the diagnosis and treatments. The pre-cancer identity represents their ‘normal life’, life before the cancer diagnosis: “I was quite an active person before [diagnosis]. I used to see my friends all the time and going out” (Kelly, age 18).

Stepping into the unknown on treatment

After the initial shock of receiving the cancer diagnosis, all participants accepted the need to undergo treatment: “[During treatment] I was normally in and out [of hospital]” (Daisy, 8). Most participants adopted a pro-active approach providing them with a sense of control in this uncertain time: “I think it made me a bit more ambitious to beat it in a sense because no-one knew anything about it [as prognosis for this rare cancer was unclear]” (Jane, 15).

They had to undergo many invasive medical treatments including chemotherapy, surgery, and radiotherapy. Consequently, they appeared to lose control of their lives: “[The hospital] feels like a prison” (Matthew, 11).

Identity disruption

As cancer disrupted their pre-cancer identity and their ‘normal’ activities were curtailed, a feeling of alienation was expressed.

Participants talked about the impact of the intense treatment on their physical and emotional well-being, including appearance change, reduced sense of freedom, and increased sense of vulnerability. For example, they all received a central line for chemotherapy administration: “[I could not play football] just in case somebody would grab my line and pull it” (Chris, 10).

Older participants experienced a loss of newly gained independence and autonomy, disrupting their adolescent identity role and resulting in feelings of frustration: “I felt totally useless when I was in treatment, because I could not really do anything. . . I was always in the house” (Kelly, 18).

The extent to which participants were able to keep a sense of normality seemed to be dependent on both treatment intensity and external demands. For example, some older participants temporarily lost their student identity due to increased academic demands: “I was hoping to manage to fit it [cancer treatment] in around, but it was just getting too much really so I had to drop out [of college]” (Richard, 17).

Pre-cancer identity during treatment

Maintaining a sense of normality, despite treatment-related stressors, highlighted the participants’ resilience. Resilience and focussing on their achievements gave a sense of control and had a positive effect on psychological well-being: “When I was in chemotherapy, I could go [to school] for a week at the time . . . It was nice” (Matthew, 11).

The aim was “to get through” (Jane, 15) to the end of treatment whilst trying to maintain a sense of normality, continuing their pre-cancer identity whenever possible.

Cancer Identity Role

From diagnosis, the participants’ identity role changed from being a healthy person to someone with an illness. They were unable to carry out various roles they felt were important to their identity. Cancer became, at least temporarily, an important component of who they were: “I don’t think I actually realised how serious it was like up until I did start going through the chemo” (David, 17), and “My hair was falling out” (Daisy, 8).

Adapting during treatment. Despite experiencing the threat to their pre-cancer identity, all participants tried to keep a sense of normality. Adjusting their coping strategies helped them to deal with treatment demands.

Participants used a variety of practical coping strategies. As a result of restrictions, participants kept themselves busy with physically less demanding activities. They had to negotiate which identity roles to perform and to what degree: “Even when I couldn’t play football, I have been playing golf” (Mark, 10). Distraction was used, giving a sense of purpose and helping to maintain a positive outlook. For example, younger participants spent time catching up on homework when possible: “I did it sometimes [going to hospital school]” (Chris, 10), whilst older participants reported using digital gadgets to distract themselves and prevent boredom: “I played video games” (Zachary, 17).

Participants also used psychological coping strategies such as ‘focusing on the positives’ which made it easier to cope with challenging situations: “Everybody else might run and stuff, but I can’t so I stand out a bit, which is quite nice really because I can always find my friends and they can find me” (Mark, 10). This coping strategy was often used by older participants, who in contrast to younger participants expressed awareness that they could potentially die from their cancer. They actively avoided these thoughts and focused on the positives: “My aunty who had been on treatment [for cancer] passed away. That wasn’t so good but it made me feel that I was quite lucky” (Jane, 15).

For some older participants, sharing experiences with others in a similar position, helped to reframe cancer in a less threatening way and gave them a sense of purpose:

> One mum used to ask me how it felt because as her son is so young, he couldn’t explain to her how he was feeling… it’s just nice being able to talk to other people because at first you feel like you are the only one but then you realise that it really not like that, there’s loads of people (Jane, 15).

Increasing social support during treatment. Support and visits from family and friends were treasured and played a key role in keeping a sense of normality, reminding them of their pre-cancer life: “My cousin loved it [visiting me in hospital]. He could play with all the Lego stuff so he wanted to stay there, and my cousin slept there” (Daisy, 8).

All participants disclosed their cancer diagnosis to close friends and family, and they felt supported by them. Disclosing their illness could be viewed as accepting their cancer identity role: “I sort of let them [friends] know what was going on, they were all pretty supportive really” (David, 17). However, some older participants reported changes in how they were viewed, challenging their desire to feel normal and fit in: “I found some friends quite patronising” (David, 17).

Medical staff provided vital support and were mainly viewed as ‘nice, helpful and supportive’, providing age-appropriate care, practical support, and hope, encouraging them to maintain a sense of normality whenever possible: “The doctor said that by September next year . . . I should be able to do contact sports, so that’s good” (Mark, 10). Younger participants were informed of the end of treatment via parents, whilst older participants were prepared by the medical staff: “I think I had enough [preparation for end of treatment] because there is only so much you can be told and other stuff you want to know for yourself" (Jane, 15).

Most participants managed to make new friends on the ward. They reported a sense of belonging which helped them to normalise feelings and symptoms related to their cancer identity role. This connectedness could be costly if fellow patients passed away: "Yes I did [meet other people with cancer], yeh. It was kind of nice cuz like they're in the same boat as you. But um, she died last year" (Zachary, 17).

End of treatment

Stepping into the unknown after treatment

The transition from on- to off-treatment is characterised by conflicting emotions. Relief and happiness that treatment had finished, conflicted with having to deal with the aftermath of the treatment and a sense of uncertainty.

Apart from one younger participant, participants expressed uncertainty on how /if their health, fitness and appearance would recover and return to their pre-illness identity: "[When I finished treatment I felt] Happy actually, because I did not have all these wires [central line] attached, but I am going to have an operation soon to straighten it [my leg]. So after that, than who knows, I don't know" (Mark, 10).

Participants expressed fear of relapse. Whilst older participants seemed to carry this fear themselves, for many younger participants it seemed to be carried by the parents: "I was quite happy but mum said no parties [to celebrate the end of treatment] in case it [cancer diagnosis] happens again" (Daisy, 8). This fear, which could lead to hyper-vigilance, increased when participants experienced similar symptoms as before diagnosis: "I sometimes worry [about a relapse], like if I have stomach ache [a similar pain as before cancer diagnosis]" (Jane, 15). Additionally, some respondents (and their family) felt lost without the hospital structure:

> Coming off the treatment is worse than going on it, because when you come off you don't have that security blanket of having chemo all the time and [on treatment] you have sort of a schedule to stick to, so you know what is coming and you know what has been planned whereas now everything is more uncertain (Kelly, 18).

Another concern expressed by participants was catching up with missed schoolwork. In particular, older participants sometimes found this impossible. This led to performing below their expectations which could affect their future careers and identity: "I'm just working for bits. I would have carried on [with school] but I didn't do too well in my AS's" (David, 17).

Some adolescents expressed a sense of uncertainty when re-establishing friendships after a long absence and used a pro-active approach when dealing with this worry:

> I felt like I was stepping out into the unknown again because I'd missed so much with my group of friends. They were still friendly with me but they had moved on a bit . . . It gave me something to work on, so now I don't have that feeling anymore (Jane, 15).

Cancer Identity role after Treatment

In addition to feelings of uncertainty, participants had many reminders of their cancer treatment. Continuing medical problems made it challenging for all participants to fully return to their pre-cancer identity.

All, except the two youngest participants, experienced fatigue. Fatigue, like other medical problems, could affect their social identity: “I can’t go down there for the day [to see friends], because I know that by the time I get off the train I will be shattered” (Kelly, 18).

A reduction in physical abilities and a change in physical appearance appeared to impact negatively on their self-esteem, increased feelings of anxiety, anger and insecurity, and left some participants open to threats such as bullying by strangers: “It is not nice that people calling you names. [They said] ‘Why do you walk like an old granny?’, and they did (he shows an old granny walking), which I didn’t like at all” (Mark, 10). These negative comments were reminders of his cancer identity role and that he was not the same as his healthy peers.

Pre-cancer identity after immediate treatment

Several changes heralded a return to normalcy. These included the cessation of demanding treatments and procedures, returning to previously restricted activities, and a healthy physical status, restoring parts of their pre-cancer identity roles: “I can go swimming now, and jump around in the bedroom” (Daisy, 8). This illustrates that participants felt a sense of freedom when treatment finished and the central line was removed. Consequently, this return to normality gave them hope for the future and improved their emotional state: “[I feel] Like happy and everything, as I’ve got no more treatment” (Zachary, 17).

Returning to full-time education was an event that particularly highlighted a sense of normalcy. “I just went in for maybe 2 days a week first of all, and now I’m back full time. It was good to be back [at school after 11 months] as it made you feel a bit more normal” (Jane, 15).

Older participants highlighted that it was important to increase their sense of independence after treatment as this gave them a sense of control and achievement, restoring their adolescent identity role:

> Learning to drive, that's what I enjoy most at the moment. If I do this than this is my step back to independence, because I have been so dependent on everyone else and I was not like that before (Kelly, 18).

Survivor Identity Role

At the end of treatment, their life and consequently their identity changed from cancer patient to cancer survivor. The survivor identity role is characterised by the tension between reminders of the cancer treatment and restoring their pre-cancer identity: "[During treatment] you would plan your life around the treatment, but now you plan the treatment around your life" (Kelly, 18).

The aim during this period was to decrease the potential gap between their 'cancer identity role' and 'pre-cancer identity'. This process was mediated by 'adapting after treatment' and 'shifting social support'

Adapting after treatment. As when on treatment, all participants used a variety of practical and psychological coping strategies.

For all but the two youngest participants with ALL, it was impossible to return to some pre-cancer activities, and they therefore had to adapt their life trajectory: "[When diagnosed] I was going to college, I was doing my AS levels, but this all cropped up so I stopped that, but hopefully in September I am going to do a foundation course at university" (Kelly, 18).

Similar to during treatment, all participants continued to use psychological coping strategies such as ‘focusing on the positive side’: “I had some absences [from school] but a lot fewer than I was having when I was having all the chemo and stuff. So things are going up” (Mark, 10). In addition, some older participants actively avoided thinking about their time during treatment to maintain a positive outlook: “I try not to think about everything that has happened. Focus on things that you can do rather than things that you cannot do” (Kelly, 18). This quote illustrates that participants acknowledged treatment-related difficulties, but chose to focus on their achievements. This gave them a sense of achievement and control.

Most participants found it beneficial to talk to others who understood their cancer journey: “Only when I am in a bad mood [I worry about cancer coming back]… I talk to my mum… when I am in a bad mood, I just want to talk, get it all out of me” (Matthew, 11). This quote implies that talking helped to reduce worries and rumination.

Comment [A1]: . . .: dots further apart??

Shifting support after treatment. Participants described receiving support from various people. During treatment, the main support came from family and medical staff, while after treatment it appeared to be from family and friends.

While clinics were less frequent, participants found attending them reassuring, helping them to deal with the fear of recurrence and other medical problems: “It made me feel a little bit more like not so much of a worry and it is reassuring that they’re there looking after me” (Jane, 15).

Some participants struggled with reduced support from the healthcare professionals and sought support from survivors who were coping well and served as ‘role models’. This contact appeared to normalise their current feelings and symptoms, increasing their sense of control and reducing the threat to their future lives: “I met somebody who had got the same sort of thing as me. He has been to lots of nice places, which means that he can still go out” (Mark, 10).

Participants had more time to spend with friends. All participants had managed to keep their pre-cancer friendships; however some friendships had weakened. Friends often adjusted their own activities to meet the needs of the participants: “My friend was doing it [swimming] at the same pace as me [slower], even though she was really good and quite a strong swimmer” (Jane, 15).

One participant, however, expressed that the support did not match his needs. On one hand he felt that his mum was holding him back “She [mum] wraps me up in cotton wool” (Matthew, 11), on the other hand he said that his friends had not adapted their behaviour which left him feeling isolated and alone. However his friends might have found it difficult to understand his situation as he did not provide them with information:

> I don’t say anything to my friends, because I would rather get on with school than I would talk about it [cancer experience]. They still joke around me really, but all my friends run off without me and I am left on my own (Matthew, 11).

This quote showed that he preferred to focus on his pre-cancer identity rather than his survivor identity; though this could have made it harder for peers to relate to him.

Creating a new Identity

All participants exhibited a great sense of resilience by accepting their situation. For most, a new identity was formed by incorporating the pre-cancer identity, cancer identity role, and survivor identity role.

The two youngest participants with ALL felt that life after treatment was similar to their pre-cancer identity despite ongoing physical changes. Other participants reported their cancer experiences had stimulated them to re-evaluate their former state of normality which often resulted in a changed perspective of themselves, their lives and their relationships with others. This was viewed as a positive experience:

> It [cancer experience] is like an adventure. I would not say life is the same. I think it changes your perspective on everything like I think it changes your perspective on everything like big things that you thought were big before don’t really become important. It brought me a lot closer to my family and we talk about things a lot more. It is really good (Kelly, 18).

Older participants reported that having cancer enabled priorities to be reset and helped them to realise what mattered most. For example, three older participants reported that they adopted a healthier lifestyle than before treatment: “I’ve gone away from that [smoking and drugs] because I didn’t want to end up getting hooked into that kind of thing” (Jane, 15). Ordinary events became infused with positive meanings: “I used to see my friends and think nothing of it, but now when I get back I think what a good time I had and how lucky I am” (Jane, 15). Moreover, the cancer journey gave some younger and older participants a new sense of meaning and purpose in their lives:

> After school, I suppose I would like to be a scientist, because since I have been cured, I have been taught about cells and energy and all that so . . . I want to research more on everything I have been through to try to find a cure for it, a quick cure (Matthew, 11).

Discussion

The current study aimed to provide a theoretical framework of CYP's experiences of the transition period from on- to off-treatment for childhood cancer in the UK. Using a GT approach, a conceptualised model was developed based on the accounts of nine CYP who had gone through this transition within the previous 12 months. The model suggests that this transition cannot be separated from the treatment process and post treatment experiences. It reflects the continuous role and identity changes that participants experienced related to their place in the cancer treatment trajectory.

Stepping into the unknown: Identity and role changes

As in previous studies (Stewart, 2003; Woodgate & Degner, 2002), participants experienced uncertainty due to cancer diagnosis and treatment. Feelings of uncertainty can threaten pre-cancer identity values and beliefs, and may be a trigger for action (Bosma & Kunnen, 2001). In this study it resulted in a pro-active approach leading to a (temporary) 'cancer identity role' and subsequently a 'survivor identity role' depending on their stage in the cancer trajectory. The present study findings add to Bosma and Kunnen's model in that the development of the 'cancer identity role' and 'survivor identity role' occurred in younger participants as well as adolescents.

Adapting

Adapting to the demands of cancer helped to maintain a sense of pre-illness identity and a positive outlook, both within active- and post-treatment phases.

Distraction. During treatment, participants used distraction to maintain a positive outlook. Distraction, combined with active acceptance, could be adaptive, but might be maladaptive when combined with avoidance strategies (Wolgast & Lundh, 2017). In my study, distraction appeared to improve well-being and could be considered an adaptive strategy.

Focussing on the positives. Positive refocussing can assist in minimising the significance of the illness, and in regaining a sense of mastery over one’s life (Fife, 1994). In addition, higher optimism has been associated with better emotional and behavioural functioning in children with cancer (Williams, Davis, Hancock, & Phipps, 2010).

Talking to others. Talking to understanding others, such as parents or survivors, helped participants reduce their worries and reframe their cancer in a less threatening way. Maintaining bonds with peers who experienced cancer, can provide an important source of shared understanding (Mitchell, Clarke, & Sloper, 2006), and help integrate novel experiences with pre-illness assumptions (Calhoun & Tedeschi, 1999). This might encourage reflective rumination that allows new ways of looking at the world (Joseph, 2011) thereby facilitating accommodation and development of a new identity.

Avoidance. Older participants’ use of psychological defences such as avoidance of negative thoughts complements the social-cognitive transition model of adjustment by Brennan (2001). This model suggests that when an experience is too painful or incompatible with the individual’s expectations, cognitive avoidance and denial might result. Denial and cognitive avoidance are usually temporary adaptive strategies, but might become maladaptive in the long-term if it prevents incorporation of new information into their previous assumptions (Brennan, 2001; Parkes, 1988).

Support

Support and validation from others was important to the participants and increased their confidence when dealing with changing circumstances and identity roles, and highlights the importance of the perceptions of others and society in the formation of identity (Carr, 2006; Erikson, 1968). Social support has been linked to coping, and support networks that provide tangible emotional support may act as a stress buffering effect (Cohen & Wills, 1985; Haslam et al., 2008; Kyngas et al., 2001; Woodgate, 2006).

Previous studies showed a decline in support after treatment end (Duffey-Lind et al., 2006; Jones et al., 2011). My study findings suggested that support after treatment often shifted from healthcare professionals to other sources, such as classmates and fellow survivors. Some participants struggled with reduced healthcare support and hospital structure. Identifying patients who require more support is essential to facilitate optimal return to pre-cancer lifestyle and well-being (Bessell, 2001; Choquette et al., 2016; Wakefield et al., 2013).

Physical disability limited one participant (re)joining peer groups after treatment. His symptoms were not obvious and could be concealed. He chose not to disclose them to his school friends and focused on his ‘healthy’ identity. Non-disclosure, avoiding perceived stigma or discrimination, has been shown to assist in maintaining a positive view of the self in adults with a brain injury (Jones, Jetten, Haslam & Williams, 2012), but in this case, led to social isolation which could also lead to reduced well-being (Jones et al., 2012).

A new identity

The process of creating a new identity after initial recovery appeared to complement Bosma and Kunnen's model of identity development (2001); however, unlike the identity formation during treatment, there appeared to be a difference between younger and older participants. The two youngest participants with ALL (aged 8 and 10) appeared to assimilate their experiences, returning to their pre-illness identity, whilst the other participants appeared to accommodate their experiences, creating a 'new identity'. This distinction could be due to the difference in cognitive development, with the youngest participants accommodating the information into a new identity but not recognising that as different to their pre-cancer identity (Brand et al., 2017; Carr, 2006; Piaget, 1932). It might however be the cancer type that could be the reason for this difference, as these youngest participants both had ALL which has generally a good prognosis with a survival rate over 90% (Cools, 2012). Unlike in most solid tumours, treatment for ALL is relatively intense for a few months, followed by two to three years of less intense maintenance treatment when most normal, pre-illness activities are usually possible, making the transition from on- to off-treatment less significant.

Most participants accommodated their experiences, developing a 'new identity'. Joseph (2011) relates the process of accommodation to PTG. Three broad categories were identified: changes in self-perception, changes in interpersonal relationship and changes in philosophy of life (Tedeschi & Calhoun, 1996). In contrast to studies reviewed by Wakefield et al. (2010), the results of the current study demonstrated that most participants were not only resilient but also talked about having derived benefit as a result of dealing with their difficulties. Subsequent studies confirmed this finding in CYP with cancer as well as other life-threatening illness (Jessup & Parkinson, 2010; Phipps et al. 2014; Tillery, Howard Sharp, Okado, Long, & Phipps, 2016). The experience could however set them apart from their peers as their worldview and priorities might have changed which could result in isolation, and affect their social identity (Parry & Chesler, 2005).

In summary, despite the ongoing experiences of uncertainty and changes within their identity during and after treatment, the outcomes of their childhood cancer trajectory are not equivocally negative. With the exception of the youngest participants with ALL, their identity emerged permanently altered but not necessary damaged as they embraced what lies ahead of them.

Developmental differences

In line with developmental theories (Erikson, 1968; Piaget, 1932), the data highlighted important developmental differences between older and younger participants. For example, in my study, only the two youngest participants (aged 8 and 10) did not express concerns around dying or fear of recurrence. This distinction could be due to the difference in cognitive development or illness trajectory as previously discussed (Brand et al., 2017; Carr, 2006; Piaget, 1932).

The older participants expressed concerns consistent with their complex developmental life stage. As in previous studies, (Choquette et al., 2016; Jones et al., 2011; Stegenga & Macpherson, 2014) they felt that they had lost their independence during treatment and feared the potential effects of the cancer treatment on their future, including career and friendships, threatening their adolescent identity.

With regards to identity formation in adolescents with cancer, our study findings appear to complement the results found by the USA studies by Jones et al. (2011)

and Stegenga and McPherson (2014). Their data demonstrated that the adolescents felt the need to accommodate both the cancer patient and cancer survivor identities into the identity of an adolescent who had survived cancer. Our study adds that there might be a different process for youngest children with ALL.

Critical Reflections and Future Research

To appraise quality of the study, Charmaz (2006, 2014) advocates the criteria of originality, usefulness, credibility, and resonance.

The model developed provides a contribution to the field of childhood cancer by including the voice of the younger participants. Due to my personal life events, the results presented here were analysed 10 years after collection. During that time, changes in young peoples' lifestyles could affect the usefulness of this study. For example, social media was not discussed within the interviews as it was not relevant at the time, however it may play an important role for many CYP with cancer now (Chou, & Moskowitz, 2016).

It is important to acknowledge that these findings represent just one person's interpretation on the participants' experiences going through the end of treatment transition for childhood cancer. In line with Charmaz's perspective (Charmaz, 2006), the emerging model provides an analysis of the studied participants experiences rather than an exact picture of it. Researcher biases were rigorously explored (see researcher's position).

There are limitations to this research in terms of relating it more widely to other populations and contexts. Sample size was small and participants were all White British from the South West UK. The model may fail to account for differences in socio-cultural background. In addition, the majority of the participants were male, which could have skewed the results in a more positive direction as research suggest females report more adverse outcomes (Hudson et al., 2003).

Moreover, although all potential participants who were approached agreed to take part, professionals may have been biased in recruitment of participants. It was also a heterogeneous CYP group in terms of diagnosis, nature and intensity of treatments, and prognosis. In addition, this was a retrospective, cross-sectional, single-site study. Future qualitative longitudinal research, including one cancer type, could validate CYP reports and add new insight into the lived experience of CYP throughout their cancer journey and beyond 12 months post treatment. Drawing from alternative larger samples from different geographical areas, and ethnic minorities might improve generalisability.

At this initial stage in the investigatory process this study focused purely on CYP's experiences of the on- to off-treatment transition period. Including the voice of younger participants has been especially important as their voice has often been ignored in the past (Sartain et al., 2000).

Cancer affects the whole family. Considering the wider experiences of other family members and staff may provide a more holistic picture of the transition period. As stated previously, a parallel project focusing on the parent's experience of the transition period was performed in conjunction with this study (McKenzie & Curle, 2012). Combining both self and parent experience might provide a richer picture of the families' experiences. Including the voice of the sibling, grandparent and medical staff could further strengthen the credibility of the emerging model.

*Practical limitations***.** As this data was collected 10 years ago and ethical approval expired, it was impossible to check if the theory resonated with the participants' experience.

Clinical Implications

The model highlights challenges that CYP face during and after treatment. In addition, it shows that developing a new identity could vary according to age, tumour type and treatment. An age-appropriate, person-centred approach is vital when working with CYP of different ages and abilities.

The results demonstrated that to understand the transition period it is important to consider the patients' experiences during treatment. For example, promoting patients to continue contact with pre-illness friends during treatment, and providing information for these friends on how to assist might facilitate attaining 'normal life' once treatment has ended (http//:www.clicsargent.org.uk; Olsen & Harder, 2009).

Feelings of being abandoned by healthcare professionals reinforce the need for careful planning throughout the cancer trajectory. Healthcare professionals can assist CYP by preparing them for lessened support as well as plan for appropriate support provision.

Social or professional support might also help individuals reconstruct their identities, values and beliefs. Therefore, individuals should be given the opportunity to talk about their experiences, how they see themselves, their losses and potential gains. This will validate and normalise their experiences and assist them making sense of them (Zebrack, 2000).

Conclusion

The findings of this study highlighted a central process of continuing change in identity and roles for CYP throughout active and post treatment phases. The overall emergent theme ‘stepping into the unknown’ revealed that the disruptions to their identity roles as a result of cancer caused uncertainty. For the youngest participants with ALL the identity disruption appeared temporary, whilst the older participants had to renegotiate valued identity roles. Recommendations have been made as to how healthcare professionals could support CYP in light of these findings.

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Appendix A: Literature search

Although I passed the ‘literature review’ in 2007 as part of my Doctorate in Clinical Psychology, I have systematically searched the literature for recent articles related to my study in December 2018.

Objectives

The aim of the literature search was to identify any research study published in a peer-reviewed journal that examined the children and young people’s (CYP) experiences of the transition period from on- to off-treatment for childhood cancer.

Eligibility criteria

Focus. Qualitative studies focusing on the identity of CYP who are going through the transition period from on- to off-treatment were included.

*Population***.** All CYP had (a) had been diagnosed with a malignant form of childhood cancer (b) between 8-18 years old at treatment completion (c) had completed treatment less than 5 years ago and therefore had not reached the status of a long-term survivor (d) in first remission

*Exclusion***.** Studies including young adults were excluded as they often face different issues relating to the next stage of psychosocial development, such as living independently and intimate relationships (Carr, 2006). Studies including non-Western countries were excluded as their different culture and ethnic background can impact adolescent resilience as they face challenges such as cancer (Haase, 2004; Wallace et al. 2007).

Information sources

The electronic databases from Pubmed, and PsycINFO (2008-2018) were searched.

Search strategy

An online search was carried out of peer review articles published before December 2018. The first group of key words consisted of ‘child, adolescent, paediatric and paediatric’. The second group used the terms ‘oncology, cancer, leukemia, leukaemia, tumour and tumor’. The third group used the terms ‘post-treatment, off treatment and survivor’. The final group included ‘identity and identities’. In addition, the reference lists of all included studies were searched manually. Qualitative studies published in English were only included (see figure A1). Finally, the quality of the resulting cohort of studies was assessed, using the critical appraisal skills programme (CASP) qualitative checklist (CASP, 2013). Each criteria fully met was awarded one point (See table A1).

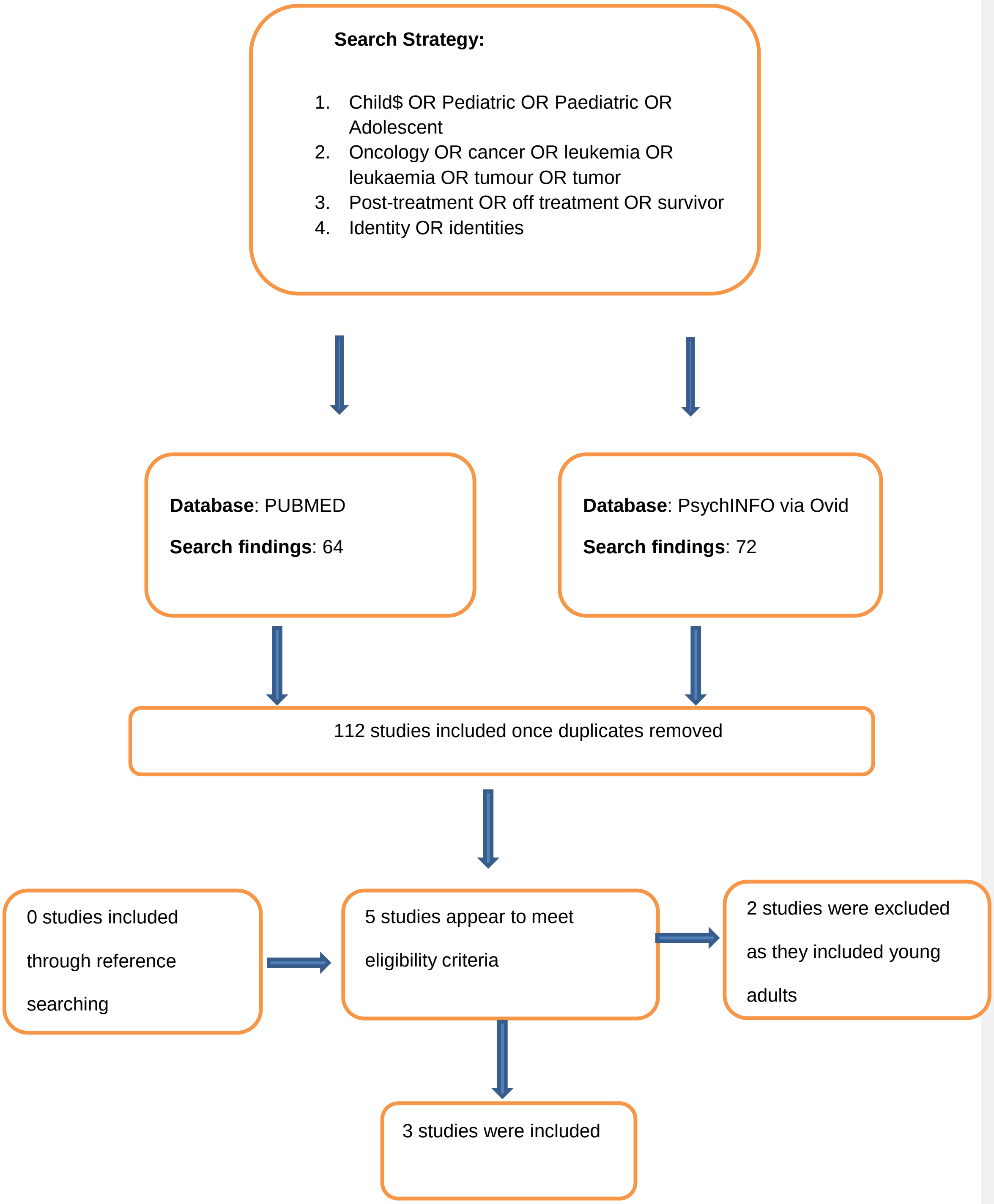

Figure A1. Flow diagram showing the number of records included and excluded through the different phases of the literature search

Table A1. *A Summary of the main findings of the three qualitative studies, using the CASP Tool (2006)*

Reference	**CASP Score**	**Aim**	**Design and Analysis**	**Country**	**Data**	**Risk of bias/ Limitations**	**Findings and Clinical Relevance**
Jones, Parker-Raley & Barczyk, (2011). Adolescent Cancer Survivors: Identity Paradox and the Need to Belong	7/9	To understand the experiences of adolescent cancer survivors, with a particular focus on identity, health promotion, and meaning making	Qualitative study. Constant comparative analysis	USA	Semi structured interviews with 12 adolescent survivors of childhood cancer aged 12-20 (7 female, 5 male), had received a cancer diagnosis before age 18, and posttreatment at the time of the study	Unclear how long ago participants finished their treatment; unclear why they chose ‘constant comparative analysis’; unclear if eligible adolescents had refused to take part as this could lead to selection bias; Lack of consideration of the influence of the researcher on the interviews and analysis	Three first-level codes emerged: finding meaning, identity paradox, and need to belong. Seven second-level codes were revealed; appreciation; personal growth; survivor identity; cancer identity; isolation; importance of family; friends, and health care providers; and lack of support as a survivor. Clinical relevance: Healthcare professionals should be conscious of the difficulty adolescents have transitioning to the end of treatment, and emphasize the social support network (i.e., family, friends, and teachers), as well as external support services available in the community, prior to the finishing treatment. Social workers could organise social events either face-to-face or via social media. In addition, they could provide training to family members on how to assist adolescents through this transition.
Stegenga & Macpherson, (2014). ‘‘I’m a Survivor, Go Study That Word and You’ll See My Name’’. Adolescent and Cancer Identity Work Over the First Year After	8/9	To explore and describe common themes of the cancer experience across the first year after diagnosis in a cohort of adolescents	A longitudinal qualitative study. Participants were interviewed up to four times during the first year after diagnosis Inductive	USA	Semi structured interviews with 15 adolescents aged 12-17 (10 female, 5 male, diagnosed with cancer	Some interviews were missed and some attrition happened over the year; many female participants; Lack of consideration of the influence of the researcher on the interviews and analysis	The most salient themes related to the development of adolescent identity, cancer identity and integration of the two into an adolescent with cancer identity. Clinical Relevance: Understanding of this process assists practitioners to pro-actively provide guidance for adolescent experiencing cancer, understanding their need for peer support as well as the need to normalize the cancer experience whenever

Diagnosis			content analysis		within the past 2 months.		possible.
Choquette, Rennick, & Lee, (2016). Back to School After Cancer Treatment Making Sense of the Adolescent Experience	8/9	To describe how the return to school affects adolescents' beliefs about themselves, their self-identity, and their social relationships in order to explore the meaning of returning to school for adolescents who have finished active cancer treatment.	A qualitative study Interpretive description inclusive purposive sampling and saturation of the data	Canada	Semi structured interviews with 11 adolescents aged 13-17 (3 female, 8 male), completed cancer treatment between 6 months and 2 years prior, and were attending high school fulltime	Many male participants; Lack of consideration of the influence of the researcher on the interviews and analysis; unclear why Inductive description was chosen as a method; unclear if eligible adolescents had refused to take part as this could lead to selection bias; some parents present during the interview which might have influenced the quality and content of the interviews.	Three main themes: being on the right track, bridging two worlds and establishing new life at school. Return to school hallmarked the end of an illness episode and a welcome return to a sense of well-being, however nearly all adolescents described being negatively impacted by the cancer experience. Clinical implications: recommendations are made to promote healthy psychosocial development to better support adolescents during the integration to school.

Appendix B: Researcher reflexivity

In common with Professor Brad Zebrack (Zebrack, 2003), this research study was inspired by my personal experience, and professional involvement and interaction with many childhood cancer patients and survivors (Broere, 2007). Working as an Assistant Psychologist and Trustee of a large Childhood Cancer Charity, I have met many cancer patients and survivors with unique, personal stories.

Initially I wrote up my research project in 2008; however major changes were required. During the viva in 2008, it was suggested to link the data to the concepts of ‘identity’ and ‘sense of the world’. Initially I found it hard to relate identity in regards to the younger participants as identity seemed like a permanent concept, and a child’s identity seemed flexible. After reading articles regarding children and identity and seeing my 6-year old daughter growing up whilst coping with various life events myself, I have now realised that children learn about themselves and construct their own identity within the context of their families and communities. Re-reading and analysing my data in 2018, I could now understand how, after initial and focused coding, theoretical codes could emerge relating to identity and their sense of the world.

As in 2008, memo-writing, a reflective journal, supervision and personal therapy sessions assisted me to distinguish my own experiences from the participants’ experiences. The line-by-line coding helped me to stay close to the data and to generate fresh ideas (Charmaz, 2006).

Throughout this process, I have also learnt about the complexity of research methodology, and particularly the differences in objective and subjective approaches. This has taught me to be mindful of the particular experience of an individual and the importance of the nuanced version of more generalised, objective models and theories.

Completing this research has made me realise how a changing situation can influence someone's identity role. Receiving support and feeling validated appears vital when undergoing this change, and could assist them to grow from this life experience.

Appendix C: Example of a memo

Early on in the analysis, memos allowed for spontaneous thoughts that directed subsequent coding. Advanced memos helped to link codes in order to produce theoretical categories, and also to interrogate and fill out the dimensions (subcategories) of these categories (Charmaz, 2006).

Reflections on a concept within the ‘identity disruption’

3.108 I had to stop playing football because of the [central] line. Obviously stuff like that had to stop just in case it got pulled out (third interview, line 108) (Code ‘Experiencing restrictions due to demanding treatment’)

Do all participants receive a central line when on treatment? How did they feel about receiving this line? On one hand receiving this line might be a relief. The line may help to receive fewer needle punctures, as bloods withdrawal could take place via this line and the chemotherapy could be administered through this line. However, it could be frustrating as well as in between the chemotherapy courses the line would stay attached to the body and could cause many restrictions. For example, they might not be allowed to carry out contact sports as this could damage the line, and the line could not get wet so having a shower might be tricky. The line could also change their appearance which could affect someone’s self-confidence as it can make them feel quite vulnerable.

How did they adapt their lives to deal with these restrictions? How would these and other restrictions affect their identity? How would other people deal with their change in appearance?

Will participants question the necessity of the line? In theory they could refuse the line nevertheless the medical staff might recommend this line. Do they trust the advice of the medical staff or would it be too hard to judge what the best way in dealing with the chemotherapy is? Do they feel out of control, and powerless against the medical staff? Or would they accept their situation, decide not to complain and ‘just get on with it’?

The restrictions of the line could be a metaphor for all that is ‘not normal’ in their lives, and like hair loss, it could function as a tangible outward sign of their cancer diagnosis.

What was their experience after the transition from on- to off-treatment had taken place, and their line was removed? How did they feel after the line was removed? Was the removal of the line a sign that life was ‘normal’ again or did other factors play a role? How was it having blood taken without a line when attending follow-up appointments? As restrictions related to the line would be lifted, does it affect their identity?

Appendix D: Parents/Guardian Information Sheet

Parent/Guardian Information Sheet

Study title

Young people's changing experiences and associated coping strategies during the transition period from on- to off-treatment for childhood cancer

Research supervisors

XXXX, Clinical Psychologist, University of Exeter

XXXX, Clinical Psychologist, Bristol Children's hospital

Research Worker

XXXX, Trainee Clinical Psychologist

Thank you for reading this short information sheet. Your child has been invited to take part in this research project.

What is the purpose of this research project?

Seven out of ten children survive childhood cancer (www.clicsargent.org.uk), and much research has been done about long-term survivors. However, little is known about the effects of finishing cancer treatment. Therefore, I would like to know what it is like for children to finish their cancer treatment and if there is anything to make this transition easier.

Why has my child been chosen?

Your child has been chosen as he/she is almost finishing treatment. Besides your child, 8-12 other children will participate in this study.

Who is doing the research?

Picture	**XXXX** is running the project. She is studying to be a Clinical Psychologist at the University of Exeter.
Picture	**XXXX** a Clinical Psychologist, at the University is supervising the project
Picture	**XXXX,** a Clinical Psychologist,
Picture	and **XXXX,** a Consultant Oncologist from Bristol Children's hospital are helping her to plan it.

The study has been approved by Local NHS Ethics Committee and is funded by Exeter University.

Does my child have to take part?

No. It is up to your child to decide whether to take part. You are both free to withdraw from the research at any time without giving any reason. Your decision about this will not affect the standard of care your child will receive.

What will my child need to do if I agree to take part?

If you are happy to take part, and are satisfied with the explanations from your research team, you will be asked to sign a consent form. If your child is able to understand the research, is happy to take part, and can write their name, they will be asked to sign an "assent" form with you, if they want to. You will be given a copy of the signed information sheet and consent/assent forms to keep for your records.

What does my child have to do if I agree to take part?

XXXX would like to visit you and your child for around 40 minutes in your home or in the hospital (whatever you and your child prefer). XXXX would like to talk to your child about their experience of finishing treatment. If your child likes to draw, it will also be possible to make a drawing about their experience.

What will happen if my child or I do not want to carry on with the research?

If at any time, your child or you do not want to do the research anymore, you can stop. Should your child withdraw from the study, any data collected from your child would be returned to your child, if they request it.

Will anyone else know I am taking part?

If your child is interested in taking part, your social worker, nurse or consultant will pass their contact details on to XXXX. If your child decides to take part, they will not be informed unless you tell them yourselves.

However if for any reason your child feels unable to participate please could you inform one of the above professionals and they will contact XXXX to let her know. If your child decides later that they do not want their interview data to be included in the research, this can be destroyed at any stage in the process.

What are the possible benefits of taking part?

I cannot promise the study will help you and your child but the information I get might help other young people who will finish treatment in the future. However, young people often find it helpful to be able to talk about their experiences to a sympathetic listener.

What if my child wants to talk to someone after taking part?

Sometimes, people may want to talk to someone after having an interview. They may feel sad or angry, or just want to talk more about it. If they would like to talk to someone outside the family, you can arrange to speak to a Clinical Psychologist, either XXXX (tel. XXXX) or XXXX at Bristol’s Children Hospital (tel. no.XXXX).

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to XXXX who will do her best to answer your questions (01392 264695). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Will my child’s taking part in the research project be kept confidential?

All information, which is collected, about your child during the course of the research will be kept strictly confidential. Any information about your child, which leaves the hospital, will have their name and address removed so that your child cannot be recognised from it. One exception to confidentiality is when your child or some else is at risk.

What will happen to the results of the research study?

After I have analysed the data I will provide feedback about the findings. The data will be kept anonymous and will be available to the hospital and university. I also have the intention to publish the data. Your child will not be identified in any report/publication unless you have consented to release such information.

Contact details

If you would like any further information, please contact your social worker, nurse or XXXX (01392 264695), email: XXXX

Thanks for reading this – please ask any questions if you need to.

Appendix E: Children and Young People's information sheets

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Information sheet for children ages 8 to 12 year old

Study title

The young person's experience of the transition from treatment for cancer

I would like **to invite** you to take part in this research to find out what it's like for you to finish your treatment.

Before you decide if you want to join, it is important to understand why the research is being done and what it will involve for you. So please read this leaflet carefully. You might want to **talk** about it with your family, friends, doctor, social worker or nurse before deciding. Your mum and dad will also have some information about the research and they can help you read this booklet. Please ASK if you have any questions or would like to know more. **Think carefully** and take **time** to decide whether or not you want to take part.

What is research?

People do **projects** when they want to find out more about something. This is called doing **research.**

What is the research about?

The project is about what is it like for children and adolescents to finish their cancer treatment.

Why have I been chosen to take part?

You have been asked to take part because you are finishing your cancer treatment. 8-12 other children will also be asked to take part in this study.

Who is doing the research?

picture

XXXX is running the project. She is studying at the University of Exeter to become a Clinical Psychologist.

picture

XXXX, a Clinical Psychologist, at the University is supervising the project

picture

XXXX, a Clinical Psychologist,

picture

and XXXX**,** a Consultant Oncologist from Bristol Children’s hospital are helping them to plan it.

What will I be asked to do if I take part?

You will be asked to meet XXXX once for around 40 minutes. During the visit, XXXX will first check if you understood everything in this booklet. If you do and still say ‘yes’, you will sign a form to agree to take part. XXXX will ask you if you would like to start making a drawing. Then XXXX will **interview** you. She will ask you some questions about what your life is like. What you say is important, so your interview will be **recorded on tape.** You will not have to say anything that you do not want to say; XXXX is only interested in the things you want to tell her. If you want to finish the interview at any time, **just tell XXXX and it will stop right away.** After a few weeks, XXXX may ask to talk to you again so that she can check that she understood you and in case you have something else to say.

XXXX is also a cancer survivor and understands what it can be like to go through the transition period. However, during this research it is important that you tell her about your experience.

Where will the interview happen?

It's up to YOU were the interview happens. You may want it to happen in a room at home. If not, XXXX will organise a room at the clinic. Young people do not often get to say what they think and feel, so XXXX would like to speak to you without your parents in the room. Your parents can be in the next room. You can ask to STOP the interview and see them at **any** time without giving a reason.

It there a downside to taking part?

Taking part will not affect your treatment you receive, or any other appointments. **It is your choice**. Sometimes, talking about things can make people feel **sad** or **angry**. It is OK to feel like this and XXXX will be there to listen if you need more help. It is important to know that this could happen to you. **Please think carefully about this before deciding whether to take part.** If you change your mind at any point, just tell XXXX you want to STOP. You do NOT have to give a reason. If you do not want your information to be used in the project, it will be destroyed.

What are the possible benefits of taking part?

It is a chance for you to say what you think and feel, including **good things and ways to cope.** I hope that the research will help people to UNDERSTAND more about what it is like to finish cancer treatment. I cannot promise the study will help you, but the project may help services to **understand how best to** help young people finishing treatment in the future.

What if I want to talk to someone after taking part?

Sometimes, people may want to talk to someone after having an interview. They may feel sad or angry, or just want to talk more about it. If you want to talk to someone outside your family, you can arrange to speak to XXXX at Exeter University (tel. no. 01392 264695), or XXXX at Bristol's Children Hospital (tel. no.0117 9276998).

What will happen to the information I give?

Your name will NOT be put on any of the information you give, just a number. XXXX will listen to the tapes and type out the interview, but **all the names of people and places will be removed or changed.** After the interview is typed out, she will send it back to you so you could check it or add anything. When XXXX is sure that she has typed all the information correctly, the **tape will be wiped blank.** When XXXX writes up the project, she may want to include some of the things people said, but she will always use a **pretend name** rather than your real name, so no-one will be able to tell it was you.

There is only one different situation. If you or someone else is in danger, I need to give this information to someone else.

Will anyone else know I am taking part?

If you are interested in taking part your social worker or nurse will pass your contact details on to XXXX. If you decide to take part, they will not be informed unless you tell them yourselves.

What if I want to know more before I decide?

You can ask your nurse or social worker about the study or you can contact XXXX on tel.no.: XXXX or by email: XXXX. She can also meet or telephone you so you can ask any questions before a decision is made.

If you would like to take part, tell your parents and ask them to help you cut out the slip below, fill it in, and return it in the freepost envelope provided. If you decide to take part, please keep this booklet. If you lose it, or would like another copy, please ask your social worker or your nurse.

Name:……………………………………………………………………………………

Address:…………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………
…………………………………………………………………………………………

Tel:……………………………………….

☐ Yes I would like to take part in the project

☐ I am thinking of taking part in the project but I would like to know more first

Thanks for reading this – please ask any questions if you need to.

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Information sheet for young people aged 13 to 19 years old

Study title

The young person’s experience of the transition from treatment for cancer

Thank you for reading this short information sheet.

I would like **to invite** you to take part in this research project to find out what it’s like for you to finish your treatment. Before you decide if you want to join it is important to understand why the research is being done and what it will involve for you. So please read this leaflet carefully. You might want to **talk** about it with your family, friends, doctor, social worker or nurse before deciding. Please ASK if you have any questions or would like to know more. **Think carefully** and take **time** to decide whether or not you want to take part.

What is research?

People do **projects** when they want to find out more about something. This is called doing **research.**

What is the research about?

The project is about what it’s like for young people to finish their cancer treatment.

Why have I been chosen to take part?

You have been asked to take part because you are finishing your cancer treatment. 8-12 other young people will also be asked to take part in this study.

Who is doing the research?

picture

XXXX is running the project. She is studying at the University of Exeter to become a Clinical Psychologist.

picture

XXXX, a Clinical Psychologist, at the University is supervising the project

picture

XXXX, a Clinical Psychologist,

picture

and XXXX**,** a Consultant Oncologist from Bristol Children's hospital are helping them to plan it.

The study has been approved by the Local NHS Ethics Committee and is funded by Exeter University.

What will I need to do if I take part?

You will be asked to meet XXXX for around 40 minutes. During the visit, XXXX will first check if you understood everything in this booklet. If you do and still say 'yes', you will sign a form to agree to take part. Then XXXX will **interview** you and you will be asked to talk about your expectation finishing treatment. What you say is important, so your interview will be **recorded on tape.** You will not have to say anything that you do not want to say; XXXX is only interested in the things you want to tell her. If you want to finish the interview at any time, **just tell XXXX and it will stop right away.** After a few weeks, XXXX may ask to talk to you again so that she can check that she understood you and in case you have something else to say.

XXXX is also a cancer survivor and understands what is can be like to go through the transition period. However, during this research it is important that you tell her about your experience.

Where will the interview happen?

It's up to YOU were the interview happens. You may want it to happen in a room at home. If not, XXXX will organise a room at the clinic. Young people do not often get to say what they think and feel, so XXXX would like to speak to you without your parents in the room. Your parents can be in the next room. You can ask to STOP the interview and see them at **any** time without giving a reason.

It there a downside to taking part?

Taking part will not affect your treatment you receive, or any other appointments. **It is your choice**. Sometimes, talking about things can make people feel **sad** or **angry**. It is OK to feel like this and XXXX will be there to listen if you need more help. It is important to know that this could happen to you. **Please think carefully about this before deciding whether to take part.** If you change your mind at any point, just tell XXXX you want to STOP. You do NOT have to give a reason. If you do not want your information to be used in the project, it will be destroyed.

What are the possible benefits of taking part?

It is a chance for you to say what you think and feel, including **good things and ways to cope.** I hope that the research will help people to UNDERSTAND more about what it is like to finish cancer treatment. I cannot promise the study will help you, but the project may help services to **understand how best to** help young people finishing treatment in the future.

What if I want to talk to someone after taking part?

Sometimes, people may want to talk to someone after having an interview. They may feel sad or angry, or just want to talk more about it. If you like to talk to someone outside your family, you can arrange to speak to a Clinical Psychologist, either XXXX at Exeter University (tel. no. 01392 264695), or XXXX at Bristol's Children Hospital (tel. no.0117 9276998).

What will happen to the information I give?

Your name will NOT be put on any of the information you give, just a number. XXXX will listen to the tapes and type out the interview, but **all the names of people and places will be removed or changed.** After the interview is typed out, she will send it back to you so you could check it or add anything. When XXXX is sure that she has typed all the information correctly, the **tape will be wiped blank.** When XXXX writes up the project, she may want to include some of the things people said, but she will always use a **pretend name** rather than your real name, so no-one will be able to tell it was you.

Everything that will be said will be confidential. One exception is when you or someone else is at risk.

Will anyone else know I am taking part?

If you are interested in taking part your social worker, nurse or consultant will pass your contact details on to XXXX. If you decide to take part, they will not be informed unless you tell them yourselves.

However if for any reason you feel unable to participate please would you inform one of the above professionals and they will contact XXXX to let her know. If you decide later that you do not want your interview data to be included in the research this can be destroyed at any stage in the process.

What if I want to know more before I decide?

You can ask your nurse or social worker about the study or you can contact XXXX on tel.no.: XXXX or by email: XXXX and she can also meet or telephone you so you can ask any questions before a decision is made.

If you would like to take part, tell your parents and ask them to help you cut out the slip below, fill it in, and return it in the freepost envelope provided. If you decide to take part, please keep this booklet. If you lose it, or would like another copy, please ask your social worker or your nurse.

Name:…………………………………………………………………………………

Address:………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

……………………………………………………………………………………….

Tel:……………………………………….

☐ Yes I would like to take part in the project

☐ I am thinking of taking part in the project but I would like to know more first

Signature…………………………………………………………………………….

Thanks for reading this – please ask any questions if you need to.

Appendix F: Consent/Assent forms

Assent form for children younger than 16

Research project: Young people’s changing experiences and associated coping strategies during the transition period from on- to off-treatment for childhood cancer

Researcher: XXXX, School of Psychology, University of Exeter

Supervisor: Dr. XXXX, School of Psychology, University of Exeter

	Please circle	
Have you read (or had read to you) the booklet about this project?	Yes	No
Has somebody else explained this project to you?	Yes	No
Do you understand what this project is about?	Yes	No
Have you asked all the questions you want?	Yes	No
Have you had your questions answered in a way you understand?	Yes	No
Do you understand it’s OK to stop taking part at any time?	Yes	No
Are you happy to take part?	Yes	No

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

If you do want to take part, please write your name and today’s date

Your name ____

Date____

Your parent or guardian must write their name here too if they are happy for you to do the project

Name____

Sign____

Date____

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

Name____

Sign____

Date____

Thank you for your help

UNIVERSITY OF EXETER

Parent’s Consent form

Research project: Young people’s changing experiences and associated coping strategies during the transition period from on- to off-treatment for childhood cancer

Researcher: XXXX, School of Psychology, University of Exeter

Supervisor: Dr. XXXX, School of Psychology, University of Exeter

Please circle

I have read the Information letter and I understand it Yes No

I have had the opportunity to ask questions about the study Yes No

I know who to contact if I want more information about the study Yes No

Do you understand that your child is free to withdraw from the study:

- At any time?
- Without having to give a reason?
- Without it affecting their doctor’s appointments? Yes No

I agree my child to be interviewed without me in the room Yes No

I understand that I can be in the next room, and that my child can ask to stop the interview and see me at any time Yes No

I understand that my child’s interview will be audiotaped, but that strict confidentiality will be maintained Yes No

I……………………….(name in capitals) agree to my child taking part in the Young people's experiences of the transition from treatment for cancer Project

Signed………………………………….. Date……………….

Signed (researcher)………………….. Date……………….

Consent form Young Person 16 and over

Research project: **Young people's changing experiences and associated coping strategies during the transition period from on- to off-treatment for childhood cancer**

Researcher: XXXX, School of Psychology, University of Exeter

Supervisor: Dr. XXXX, School of Psychology, University of Exeter

Please circle

I have read the Information letter and I understand it Yes No

I have had the opportunity to ask questions about the study Yes No

I know who to contact if I want more information about the study Yes No

Do you understand that you are free to withdraw from the study:

- At any time?
- Without having to give a reason?
- Without it affecting your doctor's appointments? Yes No

I agree to be interviewed without my parent in the room. Yes No

I understand that they can be in the next room, and I can ask to stop the interview and see them at any time Yes No

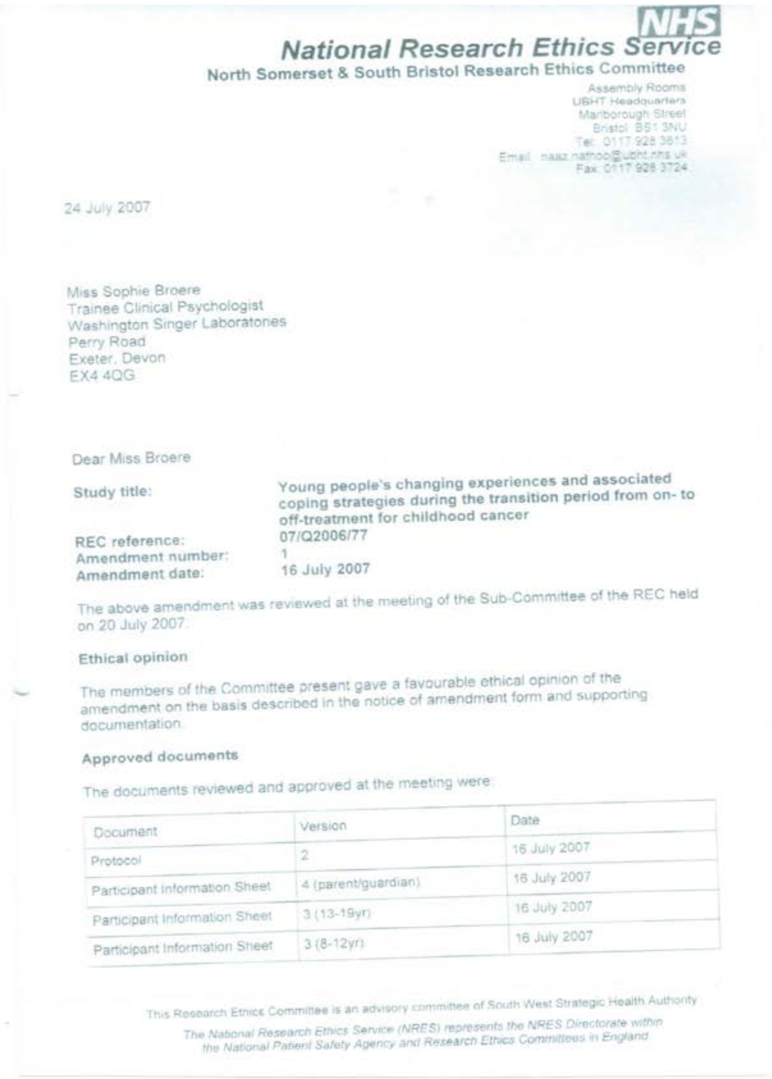
I agree to my interview being audiotaped. I understand that my name will not be used, so no-one will be able to tell it was me. Yes No

I……………………….(name in capitals) agree to take part in the Young people's experiences of the transition from treatment for cancer Project

Signed………………………………….. Date……………….

Signed (researcher)………………….. Date……………….

Appendix G: Ethical Approval Form



NHS
National Research Ethics Service
North Somerset & South Bristol Research Ethics Committee
Assembly Rooms
UBHT Headquarters
Marlborough Street
Bristol BS1 3NU
Tel: 0117 928 3613
Email: naaz.nathoo@ubht.nhs.uk
Fax: 0117 928 3724

24 July 2007

Miss Sophie Broere
Trainee Clinical Psychologist
Washington Singer Laboratories
Perry Road
Exeter, Devon
EX4 4QG

Dear Miss Broere

Study title: **Young people's changing experiences and associated coping strategies during the transition period from on- to off-treatment for childhood cancer**
REC reference: **07/Q2006/77**
Amendment number: 1
Amendment date: **16 July 2007**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 20 July 2007.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

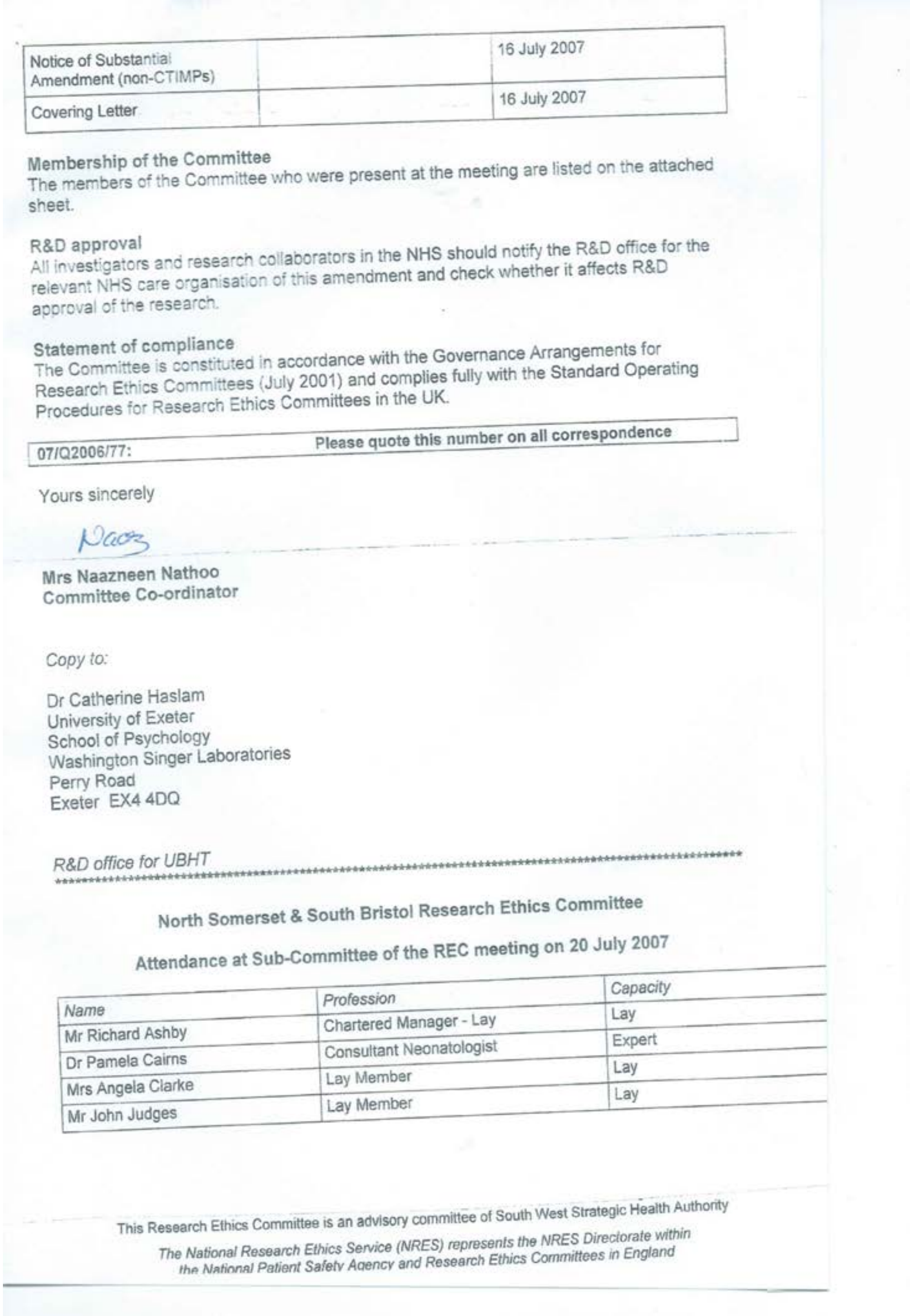
Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	2	16 July 2007
Participant Information Sheet	4 (parent/guardian)	16 July 2007
Participant Information Sheet	3 (13-19yr)	16 July 2007
Participant Information Sheet	3 (8-12yr)	16 July 2007

This Research Ethics Committee is an advisory committee of South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



Notice of Substantial Amendment (non-CTIMPs)		16 July 2007
Covering Letter		16 July 2007

Membership of the Committee
The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q2006/77:	**Please quote this number on all correspondence**

Yours sincerely

Mrs Naazneen Nathoo
Committee Co-ordinator

Copy to:

Dr Catherine Haslam
University of Exeter
School of Psychology
Washington Singer Laboratories
Perry Road
Exeter EX4 4DQ

R&D office for UBHT

****

North Somerset & South Bristol Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 20 July 2007

Name	*Profession*	*Capacity*
Mr Richard Ashby	Chartered Manager - Lay	Lay
Dr Pamela Cairns	Consultant Neonatologist	Expert
Mrs Angela Clarke	Lay Member	Lay
Mr John Judges	Lay Member	Lay

This Research Ethics Committee is an advisory committee of South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix H: Dissemination Strategy

Publication

It is planned that the study will be written-up for publication in the journal ‘Qualitative Health Research’ (impact factor 2.413) and opportunities to present the findings at relevant conferences and research events will be explored.

Presentations

The raw data were presented in June 2008 to the research team, Chief Executive and Director of Services of a large childhood cancer charity where I was a Trustee. In April 2019 I presented the re-analysed version of the results to University of Exeter, students and staff.

Appendix I: Interview schedule

All questions were adapted to the developmental level of the young person

Demographic and situational information

Age and gender of the young person

Type of cancer

Length of time the young person has been in treatment

Kind of treatment

Siblings

Family members

School class

Ethnic origin

The main question is highlighted in bold and this question will be explored via the prompts below.

Interview

Before we start the interview, would you like to make a drawing?

(if yes; could you make a drawing to show me how it was when you were on treatment and when you were off treatment)

*** Can you describe your experiences of what the period from on-treatment to off-treatment for cancer has been like?**

* What is it like to be finished with your cancer treatment?

* How has your life changed since your treatment has finished?

- at home
- at school
- with friends
- with your siblings (if any)
- with your parents

* Now that your treatment has finished, how are things the same or different for you? (what is better, what is not as good or worse)

* Were you prepared for the transition, and how would you have done things differently?

* What was your experience of the doctors and nurses during this period?

* What are your hopes and fears for the future?

* What kind of help have you had?

- medical

- family

- friends

* Did any particular things or strategies that you used/did help when treatment ended?

* Can you tell me what you enjoy most at the moment?

* Besides having cancer, are there any other important things happening at this time in your life? (at school, at home, in the family)

* Has the relationship with your family/friends been affected since you finished your treatment?

* Can you tell me what do you feel was the best part of finishing treatment?

* Can you tell me what do you feel was the worst part of finishing treatment?

* Are there any other things that you found helpful during on to off treatment?

* Do you have any advice for other children?

<u>Questions added during the analysis</u>:

- Is life after treatment as you expected it to be?
- Someone described the treatment as an adventure. What do you say about it?
- How do you look at life at the moment?
- When you compare your life before and after treatment, would you say things have changed? If yes, how have they changed?
- Has your view of the future changed? If yes, how has it changed?

Appendix J: Development of Coding and Analysis

Table J1.

Development of Coding and Analysis: The content of theoretical categories; subcategories and codes (initial and focused coding)

Theoretical Category	**Sub-categories**	**Initial and focused codes**	**Examples of quotes**
Pre-cancer Identity		Life before cancer diagnosis	I used to play hockey and football (Matthew, 11)
Stepping into the unknown when diagnosed and treated for childhood cancer	On treatment	Undergoing invasive medical procedures	I had one big operation and a few little biopsies (Mark, 10)
	Lack of control	Lack of information and support	I wanted to look on the Internet because I wanted to find out a little bit more (Jane, 15)
		Not going as planned	My temperature was higher so I had to go to the hospital (Daisy,8)
		Accepting the situation	You are so used to being at the hospital all the time, and it becomes part of your normality (Kelly, 18)
	Pro-active approach	Being pro-active	From my first ever chemo I was counting it down until the chemo was finished (Matthew, 11)

Stepping into the unknown when finishing treatment	Off treatment Lack of control	Experiencing mixture of emotions	I suppose a relief, but um, at the same time you don't really know whether it's worked (David, 17)
		Sense of uncertainty	It's a bit strange, the top is quite straight normally and the bottom tends to be really curly so I straighten the curls at the bottom, so the back of it is curly and the front's straight so it's a bit peculiar (Jane, 15)
		Fear of relapse	If I have stomach ache… it's always in the back of your mind that what happens if it's this [cancer returns] (Jane, 15)
	Pro-active approach	Not going as planned	I got blood poisoning from the line, the last time I went in they flushed my line (David, 17)
		Being pro-active	I have been doing stuff like swimming to help me (Matthew, 11)
Identity disruption on treatment	On treatment	Experiencing impact treatment on physical and emotional well-being	It [treatment] made me so ill each time (Jane, 15)
	Experiencing losses	Experiencing restrictions due to demanding treatment	When I was in hospital I used to get stir-crazy. You get this like urge of energy and you like can't release it and you just like want to get out but you know you can't because you're attached to all these like wires and stuff …it's just like a frustration like feeling (David, 17)
		Feeling different	I could not play football, I just had to be like careful (Richard, 17)
		Passage of time	In the end [after 9 months treatment], I think, my body could not take anymore (Kelly, 18)

Cancer Identity Role after treatment	<u>Off treatment</u>	Worrying about the future	I wouldn’t say I’m far behind anyone else, my grades aren’t quite as good as they could be. I’m not sure I will get what I was hoping to get originally (Jane, 15)
	Experiencing losses	Experiencing impact past illness on current functioning	I decided to go [to the party] in my wheelchair because it would a bit far for me to walk (Mark, 10)
		Feeling different	My hair was growing…everybody would say ‘wow’ and for the whole day they said they didn’t expect it. That made me mad, I didn’t want them to say it every day (Daisy, 8)
Pre-cancer identity	<u>On treatment</u>	Keeping a sense of normality	Get to sleep in your own bed (Mark, 10)
	Maintaining a sense of normality	Experience positive impact of normality on mood	When they say you can go a smile immediately arises to face whenever they said I could leave from the chemotherapy (Matthew, 11)
		Being resilient	I carried on doing that, playing with my band and just going out and doing stuff (David, 17)
		Experiencing sense of achievement	I was told by the doctor that it would take at least a year for me to walk and run again, but I showed them wrong (Matthew, 11)
		Making your own choices	I had a choice to be treated on an adult ward, but I chose the adolescent ward. I think psychologically it would have been a bit tough on the brain [to be treated on an adult ward] (Richard, 17)

	<u>Off treatment</u>	Regaining a sense of normality	It is a lot better at the moment. I feel a lot more freedom (Kelly, 19)
	Regaining a sense of normality	Experience positive impact of normality on mood	I have been back to school fulltime since I finished my chemo. It is nice. (Matthew, 11)
		Being resilient	She [teacher] did not think I had it, because I was so good with my work (Daisy, 8)
		Experiencing sense of achievement	I’ve met lots of new people at college and I’m doing quite well with my studies (Richard, 17)
		Increasing sense of independence	I went to X with a few friends, well with a lot of friends (Richard, 17)
Cancer Identity role = summary of push-pull conflict on treatment between ‘identity disruption’ and ‘pre-cancer identity’			
Survivor Identity role = summary of push-pull conflict after			

treatment between ‘identity disruption’ and ‘pre-cancer identity’			
Adapting	On Treatment	Looking forward	I did think about it [the future] a lot. I just couldn’t wait until the chemo had finally finished and I could run out of the hospital and stay out there (Matthew, 11)
		Having future aspirations	What I hope to do is playing rugby for the England rugby team (Mark, 10)
	Dealing with treatment demands	Focussing on the positive side	[Medication] made me fall asleep and it like relaxed me (Zachary, 17)
		Distraction	I had to spend a lot more time at home I just watched football loads (Richard, 17)
		Providing support	He [fellow patient] was feeling quite scared, he didn’t really know what to expect and stuff and I think, I think I spoke to him (David, 17)
	Off treatment	Accepting the situation	I got used to the idea and obviously now [finishing college a year after my friends] (Richard, 17)
	Dealing with the aftermath of treatment	Focussing on the positive side	I’m still not completely top notch but I’m a lot better than I used to be and I don’t feel as useless (Jane, 15)
		Coping	[Before treatment] I played football for a team. I used to really like that. [Now] I can’t join in [due to my wonky leg]. I just ref,

			which I like doing (Mark, 10)
		Forgetting	You just forget that you've been through it (Zachary, 17)
		Talking to others	It is really nice to be able to speak about it [cancer experience] (Jane, 15)
Support	On treatment	Keeping a sense of normality	It was good to see my friends because it was a bit of normality (Jane, 15)
	Increasing support	Disclosing information	All my friends knew about it [cancer diagnosis] (Mark, 10)
		Experiencing impact of cancer on whole family	If I went into hospital, normally one of them [parent] was there" (Mark, 10)
		Receiving support	They [medical staff] were always really lovely. They said you can always ask any questions" (Kelly, 18)
			You can make new friends. Yes [I made new friends in hospital] (Chris, 10)
		Others treating participant differently (negatively)	I got some nasty remarks [about hair loss] (Jane, 15)
	Off treatment	Receiving support	Not really [more medical support needed], I would just try it (Matthew, 11)
	Shifting support	Experiencing impact of cancer on whole family	My family – it's a lot stronger. Me and my mum didn't really get on, we got on, but not as well as what we should do really, but now we're really close compared to what we used to be and my dad, I've always been close to my dad (I am a bit of a daddy's girl) but now we're really, really close (Jane, 15)
			Just when it comes up really [I will tell them about my cancer

		Disclosing information	experience] (Zachary, 17)
New identity	Getting on with life	Being resilient	She [teacher] said even though I missed out on a lot of lessons I learnt a lot really (Mark, 10)
		Experiencing sense of achievement	I am in the youth football team [since finishing treatment] (Chris, 10)
		Changing perspective	I appreciate like going out more because when I was ill obviously I couldn’t go out much at all (Richard, 17)
		Changing priorities	I used to always want to be a lawyer, but then I was debating whether to be a lawyer or a teacher and then getting cancer made me realise that if I were to take Law than that would be like 20 years of my life wasted doing school when it could just be 3 or 4 and I thought life is for living so I might as well make the most of it (Jane, 15)
		Personal interpretation of cancer treatment	Basically you’re healthier than you was before really. Just you’re mainly healthier than you were before cuz basically the chemo all it does is just kill all the bad cells and all that, so your body’s much more cleaner. Just basically had a big MOT (Zachary, 17)

Appendix K: Instructions for Authors ‘Qualitative Health Research’

https://www.sagepub.com/sites/default/files/upm-binaries/25187_QHR_Manuscript_Guidelines_11_08.pdf (retrieved March 25th 2019))

Aims and scope

Qualitative Health Research (QHR) is an international, interdisciplinary, journal for the improvement of health care. Published monthly, it is designed to improve the development and understanding of qualitative research methods in health care settings. The journal is an important resource for professionals and others in health and social care.

Preparing your manuscripts

In general, QHR follows the guidelines of the Publication Manual of the American Psychological Association [“APA”], 5th edition (ISBN 1-55798-791-2.

Elements of a manuscript

Each manuscript should consist of these elements compiled in the following order:

1. Title page (as a separate document)
2. Abstract & Key words (page 1)
3. Main body of the manuscript (page 2and onwards)
4. References

These elements are optional:

A. Notes/footnotes/endnotes (after the main body of the text, before the reference list)

B. Tables (at the end of the document)

C. Figures (submit in a separate document)

D. Appendices; only in certain circumstances, at the editor’s discretion (after the reference list, before any tables)

<u>Order of the elements</u>

Compile the elements of your main manuscript document in the following order.

Each element (except notes) should begin on a new page:

A. Abstract and keywords - required

B. Main manuscript text - required

C. Notes/footnotes - optional

D. References - required

E. Appendices - optional

F. Tables - optional

Document set-up

Document file type: only submit documents created in Microsoft Word with the regular file extension of “.doc”.

- Paper size: Letter, 8.5” x 11”
    - Margins: 1” on all sides
    - Ellipses/Ellipsis Points. The proper way to create ellipsis points is as follows: space/dot/space/dot/space/dot/space (. . .); that is, 3 dots, preceded, divided, and followed by spaces. Font Size: 11 point font, including font used for titles, regular text, section headings, and quotations; however, fonts between 8 and 10 points in size should be used in tables and figures
    - Use Times New Roman font.
    - Avoid using italics for emphasis
    - Avoid using underlining for any purpose other than conversation analysis (conversation analysis does not refer to regular participant quotations).
    - Bolded font may be used for section headings, as appropriate according to these guidelines, and (sparingly) in tables and figures.
- Arial is the preferred style for font style of
- Use only one font style be used in each figure
- Line spacing: double
    - All text should be left-justified
    - Indent the first line of every new paragraph by .5” (½ inch; do not use two, .25” indentations).
    - Avoid inserting additional line spaces between paragraphs, or between paragraphs and headings; the exceptions are (a) an extra line space (hard return) between the abstract and the keywords, and (b) after (not before) each excerpt/block quotation, numbered or bulleted list, or section of conversation analysis.
    - Headings: avoid following APA guidelines for headings. QHR uses 4 distinct levels of headings (H = level), including:
        - H1: Centered, Bold, Uppercase and Lowercase Text in Title Case
        - H2: Flush Left, Bold, Uppercase and Lowercase Text in Title Case

- H3: Indented (.5”), Italicized, Uppercase and Lowercase Text in Title Case
- H4: Indented (.5”), italicized, lowercase text in sentence case and ending with a period. At this level, the paragraph text begins immediately after the heading, instead of on the next line.

Use at least two heading levels:

For manuscripts with 2 heading levels, use H1 and H2 For manuscripts with 3 heading levels, use H1, H2, and H4 For manuscripts with 4 heading levels, use H1, H2, H3, and H4

- Quotations: Quotations of 40 or more words should be set as separate paragraphs, with the entire quotation indented .5” from the left margin (this is also referred to as a “block quote”). All other quotations should be contained within regular paragraphs, along with regular text.
- Quotation Marks: In general, use double quotation marks (e.g., “Xxxx.”) to set off quotations appearing within regular paragraphs, and to set off words being used with “special” meaning (or unusual spelling to convey special meanings within the text; e.g., “busy-ness”). In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., “Xxx, ‘Yyy,’ xxxx.”).

Avoid using any quotation marks for block quotes unless there is a separate quote contained within the larger quote. In such a case, use double quotation marks (e.g., Xxxxxx, “Yyyy,” xxxxx.) only for the separate quote within the larger quote.

- Spelling: The spelling of English words varies among the many English-speaking countries of the world. QHR is published in U.S. English. Use Word’s spell check feature to ensure that you have used U.S. English spellings throughout your manuscript. Exceptions to this include (a) direct quotes from written, published material, and (b) as appropriate for titles in the reference list.

Preparing the required manuscript elements

A maximum of three types of documents must be submitted: (1) title page; (2) main manuscript; and (3) figures (if any). Abstract, tables and references should not be submitted as separate documents.

Refer to the Sample Manuscript for additional information.

1. **Title Page** (submitted as a separate document)

The title page should include:

- A running header; less than 40 characters + spaces in length. The running header should only be in the title page, not in the main document. Do not actually format the text as a header.

- Acknowledgements are optional

- Capitalize all important words in the title, and all words with four or more letters.

- The name and affiliation of each author, including the organization (not department or division information); city of the organization; and country.
- Contact information for all authors, including mailing address, primary e-mail address, secondary e-mail address (if any), and telephone number
- A 1-sentence biographical statement about each author.

Manuscript title: A title should convey the main idea of the article. Avoid unnecessary words, such as “A Qualitative Study of”. A good title is generally 10 to 12 words (or fewer) in length. Avoid titles with a colon or a quotation unless it/they is necessary to convey an important concept or a particular meaning about the article.

Avoid (a) typing your title in ALL CAPITAL letters, or (b) placing a period (.) at the end of your title.

2. Abstract

The abstract should be placed on page 1.

Requirements:

- A single paragraph
- Less than 150 words in length
- A brief description of the article; purpose of your research, the main findings, and primary conclusions.
- The abstract should “match” the voice in the manuscript.
- Do not (a) indent the first line of the abstract, (b) include in-text citations, (c) show the word count, or (d) include the manuscript title.

3. Keywords (See QHR Keyword List)

Keywords should follow on the same page as the abstract; leave a blank, double-spaced line between the abstract and the keywords.

4. Main Manuscript Text

Following the abstract and key words, the main text should start on page 2. Preferably the article is written in the first person, active voice, but articles written in the third person will be considered.

Use U.S. English translations of non-English quotations. Exclude the manuscript title in the main document. Attending to copyright regulations is important.

Using section headings, the main text of the document should be broken into appropriate sections. Sections should flow in a logical sequence, including, at least, Method(s), Results, and Discussion (level-1 headings); other headings and subheadings may be used at the author's discretion. Do not use any headings (such as "Introduction" or "Background") at the beginning of the document.

For using and formatting in-text citation, please refer to refer to the APA Publication Manual, 5th edition. Each in-text citation should have a corresponding reference in the reference list, and vice versa.

5. References

The reference list should contain complete references for the sources used in the document manuscript and cited in the text. You must cite and reference relevant articles published in QHR 12-14 months immediately preceding submission of your manuscript.

The reference list; start on a separate page following the last page of manuscript text. References need to be formatted in accordance with the precise guidelines contained in APA.

Other requirements:

- Hanging paragraph format
- In alphabetical order by the last name of the first author.
- Use italics, rather than underlining, for titles.
- Non-English titles should be translated into U.S. English, with the English translation following immediately after the original title, in [brackets].
- Avoid using unnecessary references and over-long reference lists.
- Only include the "essential" or key references

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