

The Education Engagement, Coping and Well-being of Teenagers with Cancer

Simon Pini

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The candidate confirms that the work is his own and that the appropriate references have been made where the work of others has been used.

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Abstract

Introduction: Every year approximately 2000 teenagers are diagnosed with cancer in the U.K. alone (Brierley et al. 2009). Being diagnosed with cancer during this important developmental stage has been described as a “double penalty” for young people, as they adapt to their changing developmental situations alongside the psychological and social impact of their cancer (Lombard et al. 2013). Many teenagers have been shown to desire continued engagement with their education after a diagnosis of cancer (Gibson et al. 2005), but how do they experience this and what factors are involved?

Aims: There were three main aims of this thesis 1) to investigate the experiences of teenagers as they try to maintain engagement with their education following a diagnosis of cancer; 2) to produce an evidence base for the area of education engagement that was centred on the perspectives and experiences of teenagers with cancer; and 3) to provide evidence and recommendations for the future development of services to appropriately support teenagers with their education following a diagnosis of cancer.

Methods: The main study recruited 12 teenagers (aged 13-16) to participate in interviews and complete questionnaires at 3 time-points over the 9 months following their diagnosis of cancer. Participants were asked to engage in a visual interview approach, where they provided images to represent their experiences, which were then used as a stimulus for discussion. Interviews were transcribed verbatim and qualitatively analysed using Interpretative Phenomenological Analysis.

Findings: Participants experienced their ongoing engagement with education as a complex interaction of different versions of themselves moving through intersecting timelines related to education, treatment and adjustment to cancer. Underpinning their education experiences was a fluctuating desire to be treated normally alongside the often contradictory need for special consideration as a young person with cancer. Engagement with education was hindered by many factors including; telling others about their cancer, altered peer group dynamics, not feeling part of the school community and the perception of changes in themselves over time.

Conclusion: Education is an important issue for young people, even in the context of a cancer diagnosis. School is an environment where changes caused by cancer to peer dynamics, appearance, mobility, ability, and a personal sense of self are brought into sharp focus. The work presented in this thesis has implications for future research, but more importantly for the way that services are designed and implemented to support young people with their education after a diagnosis of cancer.

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Abbreviations

TYA	Teenage and Young Adult
TYAC	Teenage and Young Adult Cancer Research Group
TCTMDF	Teenage Cancer Trust Multi-Disciplinary Forum
FYSOT	Find Your Sense of Tumour
QLM	Qualitative Longitudinal Methods
I.P.A	Interpretative Phenomenological Analysis
SRR	Systematic Research Review
RWR	Relationship with reality
P.A.S.S	Pupil Assessment of Self and School
SWEMWBS	The Warwick Edinburgh Well-Being scale short version
A-COPE	The Adolescent Coping Orientation for Problem Experiences

Chapter 1 - Introduction

School and education are an important part of the lives of young people and when their involvement is disrupted by a catastrophic event like a diagnosis of cancer, significant challenges and stressors present themselves. Does education matter to young people after being diagnosed with a life threatening illness like cancer? Haven't they got more important things to worry about? If they are still interested in their education, how do they carry on with it during illness and treatment? What do young people think about this issue and how do they experience their education after being diagnosed with cancer? This thesis attempts to investigate and answer these questions. This chapter will provide an overview of the thesis, some contextual background to the area of teenage oncology including statistics and current service provision, a reflexive account of my professional and personal position in relation to the research area, and a summary of the main aims of the research. The chapter concludes by providing a summary of the content that is presented in each chapter of the thesis.

1.1 Who are teenagers with cancer?

1.1.1 Statistics

Cancer is the most common cause of non-accidental death amongst teenagers and young adults (TYAs) worldwide and every year approximately 2000 teenagers are diagnosed with cancer in the U.K. alone (CRUK , Brierley et al. 2009). One in 312 males and one in 361 females will get cancer before they are 20 years old (Teenage Cancer Trust 2011). Different cancers are more prevalent in different age groups; leukaemia, lymphomas and brain tumours in 13 to 18 year-olds and lymphomas, carcinomas (soft tissue cancers) and germ cell tumours in 19 to 24 year-olds (Teenage Cancer Trust 2011). Figure 1.1 details the incidence of these diagnostic groups in the U.K during the period 2000-2009 and shows the inconsistent rate of occurrence of certain cancers for males and females. Lymphomas are the most commonly diagnosed cancers in the TYA age range. Although bone tumours are not the most common TYA cancer, they do have their peak incidence in this age range when considered in the full spectrum of younger children through to older adults.

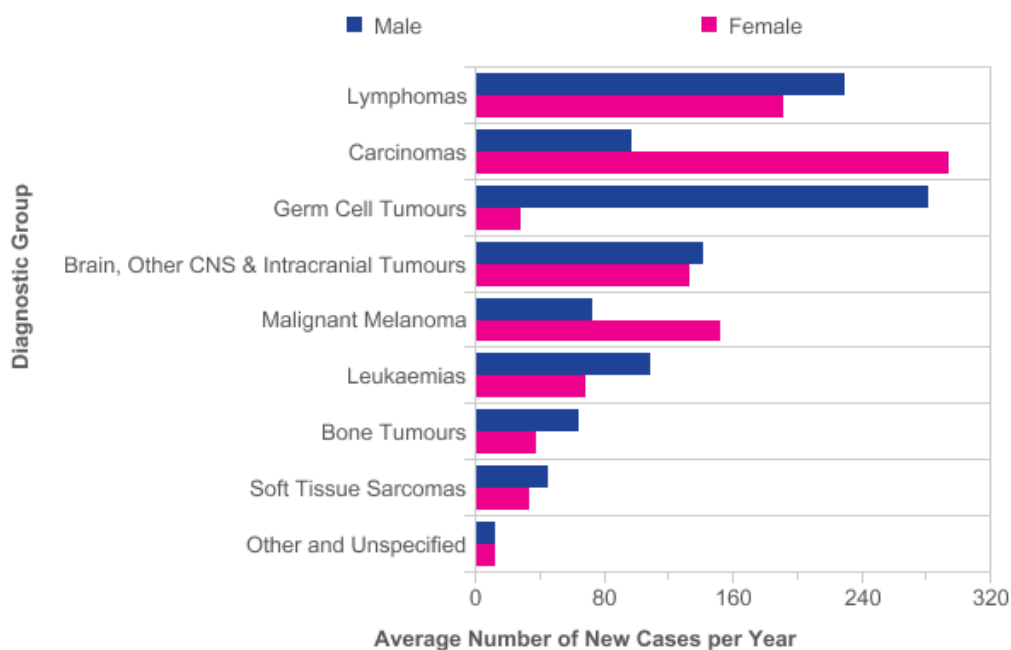


Figure 1.1 – TYA cancer incidence by diagnostic group in the U.K. 2000-2009 (CRUK)

During the period 1979-2003, in the U.K., the incidence of the most prevalent TYA cancers increased over time, whereas the number of stomach and bladder cancers in this age group decreased (Alston, Geraci et al. 2008). Alston et al. (2008) attributed these increases to environmental and behavioural changes in young people. During the last two decades, there have been significant improvements made in the treatment and subsequent survival rates for cancer in young children and older adults, but the same improvements have not been seen in TYA cancers worldwide (Coccia, Altman et al. 2012). However, recent published data has shown that cancer survival in TYAs in Northern England has improved greatly, from 46% in 1968-1977 compared to 84% in 1998-2008 (Basta, James et al. 2014).

1.1.2 Unique from children and adults

The notion of ‘adolescence’ was introduced as a distinct stage of development as early as 1904 (Hendry 2002) and has since been firmly established as a distinct and important developmental period (Erikson 1968, Havinghurst. 1972). Being diagnosed with cancer during this important developmental stage has been described as a “double penalty” (p. 49) for young people, as they adapt to their changing developmental situations alongside the psychological impact of their cancer (Lombard, Mallardeau et al. 2013). They are often faced with tension between their emerging capabilities as they move through adolescence, and their reduced capabilities imposed by their illness and treatments (Freyer 2004). Experiencing cancer and treatments during adolescence can trigger a range of psychosocial difficulties (Abrams, Hazen et al. 2007). Some of these difficulties reflect a

compounding of normative developmental concerns, such as those relating to body image (Fan and Eiser 2009), peer relationships (Meltzer 2005) and developing a sense of self (Woodgate 2005). Teenagers with cancer may also face non-normative psychosocial issues, such as those relating to the development of an illness identity (Albritton 2003), a loss of self (Lombard, Mallardeau et al. 2013), an altered experience of time, the impact of illness on romantic and sexual intimacy and the effects of reduced engagement with school life and education (Thomas, Seymour et al. 2006). Teenagers often express a need to be more involved than younger children in communications with their care teams, information sharing and decision making, with their parents taking more of a background role (Gibson, Aldiss et al. 2010). In comparison with adult and child populations, teenagers with cancer have an experience of cancer and associated quality of life that is specific to their developmental stage and requires special attention (Taylor, Gibson et al. 2008).

1.2 How are teenagers with cancer cared for?

Within healthcare services in the U.K. the specific and complex needs of teenagers with cancer were acknowledged as early as 1959 in the *Platt Report* (1959). This report recommended that teenagers who were admitted to hospital were a group of people that ‘requires special study’. Over the past 50 years, the focus of care of teenagers with cancer has changed from preparing for death to an emphasis on living with and beyond cancer (Eiser 1994, Woodgate 1999). Since the 1990s, an increasingly holistic approach has been taken incorporating, not just good physical care, but also wider psychological and social aspects of patient care (Eiser 1994, Ishibashi 2001, Pearce 2009, Morgan, Davies et al. 2010, Wright 2012, Taylor, Pearce et al. 2013). This progressive stance has emphasised that empowering teenagers to develop the coping strategies and skills needed to deal with issues precipitated by a cancer diagnosis, such as teasing at school and dealing with painful treatments, can be beneficial for teenagers as well as parents and staff (Eiser 1994, Barling, Stevens et al. 2014). The most recent documentation to address psychosocial aspects of care for teenagers with cancer was the publication by the National Institute for Health Clinical Excellence (NICE) guidance, *Improving Outcomes for Children and Young People with Cancer* (Zaza, Sellick et al. 2005). Alongside issues of developing disease specialisms and age-appropriate surroundings for teenagers with cancer, the guidance stated that there should be a team on offer to deliver expert psychosocial support. This echoes previous recommendations in documents such as the *Calman Hine Report* (Calman and Britain 1994). However, despite the increasing recognition of the specific needs of young people with cancer, they have still been described as being in the “no man’s land” (p. 43) (Hollis and Morgan 2001), “grey zone” (p. 302) (Thomas 2006), or “orphaned in the system” (p. 1) (Phillips 2009) in between paediatric and adult services.

1.2.1 Teenage Cancer Trust units

The importance of TYAs with cancer being treated together, and separate from children and older adults, has been increasingly recognised over the past two decades (Lewis 1996, Whelan 2007, Pearce 2009, Taylor, Pearce et al. 2013). The benefits of this fall into two main categories, which are; the ability to centralise and develop TYA specific medical care to improve treatment and clinical outcomes; and bringing young people together to encourage peer support and to provide developmentally tailored psychosocial care in an appropriate setting (Lewis 1996, Whelan 2007, Pearce 2009, Coccia, Altman et al. 2012). The first Teenage Cancer Trust unit opened in Middlesex Hospital in 1990. Since then the Teenage Cancer Trust have opened 28 specialist units around the U.K. designed specifically to care for TYAs with cancer. These units were designed to provide a place where young people with cancer could be treated together and support each other in an environment that was more suitable for their unique developmental stage. The units were also designed to be a place where practitioners with expert medical and psychosocial skills and experience could work together to achieve optimum care for this population. Teenage Cancer Trust units are often a hub for specialist peripartetic services, which provide outreach to TYAs with cancer who do not or cannot attend the units themselves.

1.2.2 Current education support

Many teenagers have been shown to desire continued engagement with their education after a diagnosis of cancer (Gibson, Richardson et al. 2005, Gibson, Aldiss et al. 2010, Tsangaris, Johnson et al. 2014). Services for teenagers with cancer are developing in the U.K, but the provision of dedicated education support is inconsistent. The Teenage Cancer Trust provides education about cancer, but do not currently provide education support to TYAs with cancer. Currently, teenagers with cancer have variable access to education support depending on where they are treated within the U.K. The majority of Teenage Cancer Trust units have access to a hospital school or hospital based education teams, as well as home tuition services that are in place through local education authorities. Hospital school services offer education support, but only when teenagers are inpatients and often only for limited periods of time, and there is some evidence that young people find the work in these settings is not at their level (Gibson, Richardson et al. 2005, Gibson, Aldiss et al. 2010). Continuity of education achieved through multi-disciplinary working throughout the cancer journey of teenagers is difficult within restricted timeframes and requires individual tailoring of care, which a specialist educational practitioner is in a good position to achieve (Harris 2009, Pini 2009). However, only the Teenage Cancer Trust units in Leeds, Birmingham and the South West have a specialist education practitioner specifically for teenagers with cancer. This person does not always have education as the sole focus of their role and often has large geographical areas to cover resulting in substantial caseloads.

1.2.3 The involvement of teenagers in research and trials

Over the past two decades, since the 1989 ‘United Nations Convention on the Rights of the Child’ (Unicef 1989), research into the experiences and needs of children and teenagers has increasingly sought the perspectives of the young people themselves (Weller 2012) and considered them as “active beings” (p. 29) (Balen, Blyth et al. 2006). In 1996, Mayall recommended three fundamental changes necessary to enable research to focus on the perspectives and experiences of young people:

1. Regarding them as competent and reflexive in reporting their own experiences;
2. Giving them a voice and taking seriously what they say; and
3. Working *for* them and not *on* them, in ways that may lead to the betterment of their social worlds.

(Mayall 1996)

Since this time there has been increasing onus on hearing the voices of young people in research that is about them and will affect the lives of young people in the future, although this is often not always facilitated by issues of consent and research governance (Balen, Blyth et al. 2006). In many different disciplines researching into the lives of young people, common themes of inclusion and empowerment have arisen (Christensen 2008, Coad 2008, Weller 2012, Coad, Gibson et al. 2014, Gibson 2014). As a result, research that uses adults as proxies to the perspectives of young people has come under increasing criticism during this time (James 1998, Holloway 2000, Barker 2003, Gibson, Aldiss et al. 2010, Gibson 2014). The increased focus on the inclusion of young people in research that affects them, has resulted in a reassessment of the methodological approaches used to facilitate this inclusion (Weller 2012). Creative approaches have been encouraged to address the imbalance in the power dynamics between researchers and younger participants in research. To address power imbalances, research has looked to develop methodologies that allow young participants to express themselves clearly, but also to involve young people in the design of research (Weller 2012).

1.3 This research – why and how?

1.3.1 Reflexivity in the research process

Within qualitative and qualitatively-led research, it is common to make transparent the involvement that the researcher has in the construction and interpretation of the accounts of participants (Smith 2007). This transparency is an effort to acknowledge that the researcher influences the motivation, data generation, analysis, and proposed implications of a piece of research. Whilst some researchers have called for greater reporting of reflexivity within qualitative health papers (Newton, Rothlingova et al. 2012), others feel that reflexivity is for “privileged academics engaged in the erotics of their own language games” (p. 64) (Patai 1994). Shaw argues that researchers have a responsibility to assess

how they might impact the collection and analysis of data and that this process is “a necessary yet complex task in experiential qualitative research” (p. 242) (Shaw 2010). Reporting of reflexivity within qualitative health psychology research has been said by some to enhance the quality of research, but can risk alienating other sections of the research community who believe “personal narrative is synonymous with a stream of consciousness” (p. 881) (Newton, Rothlingova et al. 2012).

Thus, there is debate within qualitative research about how to be reflective, what constitutes reflexivity and whether reflexivity results in better research. Woolgar (1988) proposed a continuum of reflexivity, from radical constitutive reflexivity through to simple reflection. Woolgar (1988) saw reflection as an acknowledgement of different positions and perspectives with the aim of ensuring accuracy, truth and quality within a research situation, whereas reflexivity involves “turning your gaze to the self” (p. 234) (Shaw 2010) to address the contextual co-construction of experiences and meanings, which are uniquely situated in a research interaction between a participant and researcher in one place at one time.

Pillow (2003) discussed four primary reflexive strategies that have been regularly employed in qualitative research; reflexivity as recognition of self; reflexivity as recognition of other; reflexivity as truth; reflexivity as transcendence. However, the most widely used reflective approach has been described by Macbeth as “a deconstructive exercise for locating the intersections of author, other, text, and world” (p. 35) (Macbeth 2001). In answer to the question posed by Patai - “Does all this self-reflexivity produce better research?” (p. 69) (Patai 1994) - it seems that in this PhD research the acknowledgement of the positioning of the researcher in reference to professional background and the potential influence this could have over the co-construction of meaning with participants was important to acknowledge, report and discuss. Therefore, reflexivity will be applied at points throughout this thesis in line with the approach described by Shaw.

1.3.2 Statement of how reflexivity will be used

Reflexivity is used throughout this thesis at points when the acknowledgement and discussion of my position in relation to the research was thought to provide context that could have influenced the research and would otherwise have been concealed from the reader. Reflexive sections of the thesis are provided in clearly labelled sections (as in the one below) or in boxes where shorter comments are made about a specific issue within a chapter.

1.3.3 Reflexive section about my background in TYA oncology

Prior to commencing this PhD I had worked with teenagers and young adults with cancer for five years from 2004-2009. I was employed as a learning mentor, which consisted of providing education

support to patients 13-25 years old who were referred to the TYA cancer service at a large cancer centre in the north of England. This learning mentor role was the first of its kind and therefore I had to assess the individual needs of young people, their families and schools, and develop the workings of this role without a pre-existing template. Because of the unique and personal way that this role developed, it became very important to me, and its success was a source of personal and professional pride. The role developed to have a broad scope in reference to how education support was determined and provided, which included many aspects of the young person's personal, emotional and social development, alongside strictly academic and educational needs. During the five years of employment in this role, it seemed to me that well-rounded education support of this kind was desired by this population and that the role I had developed was valued by the majority of patients, families and practitioners. From involvement in practitioner networks it also appeared that education support varied across the country and that not every young person with cancer had access to this type of support. I wanted to share the good practice that I felt I had developed and presented my work at several conferences and practitioner network meetings, as well as publishing my first professional article, which detailed the learning mentor role (Pini 2009).

Prior to commencing my PhD, my professional experience of the learning mentor role had given me the idea that maintaining engagement with education could be beneficial for young people who were diagnosed with cancer, but also showed me some of the difficulties and barriers that were involved. I had worked with approximately 500 young people with cancer during my employment and had been a part of their journey through the intersection of their cancer and education experiences. To some extent, I had helped to shape these experiences through the guidance and interventions I offered them, so my personal influence was present in these experiences as it is in my PhD research. I observed the interrelation of education engagement and psychological factors, such as peer relationships, self-esteem, confidence, and coping. These experiences and observations provided some of the motivation for studying this area within my PhD, as I was hoping to further investigate these issues and illuminate their possible interactions.

The learning mentor role involved a considerable amount of multi-disciplinary working. Throughout my contact with various health, charity and educational organisations it became clear that nobody else was working in a similar role and that there seemed to be very limited research and evidence in this area. This was further illuminated for me through feedback to the presentations and publication I disseminated. I therefore saw an opportunity to do a piece of research that was novel, desired by people with an interest in TYA oncology and could provide the impetus for improvements in an underdeveloped area of research and practice.

I think the preceding paragraphs show that I have professional investment in the development of knowledge and services in this area. I have prior conceptions about what is involved in the ongoing maintenance of education engagement for teenagers with cancer and I acknowledge that my professional background has driven the development of this research, with all the agendas that are described above. However, I also believe that this background made me a good person to conduct this research. At the outset, I hoped that my experience would help me to make informed decisions about directions to follow in the research, especially in light of the limited evidence base and therefore absence of a theoretical model specific to the area. Once the research commenced, I hoped that my previous work with young people with cancer would help me to be sensitive to the needs of participants and enable me to successfully navigate the various administrative, practical and professional difficulties that can occur when researching this population.

1.3.4 Aims of the thesis and chapter overview

There were three underlying aims that motivated the design of this research and inform the development of literature reviews, research studies, specific research questions and discussion of the findings:

Aim 1 - To investigate the experiences of teenagers as they try to maintain engagement with their education following a diagnosis of cancer.

Aim 2 - To produce an evidence base for the area of education engagement that was centred on the perspective and experiences of teenagers with cancer.

Aim 3 - To provide evidence and recommendations for the future development of services to appropriately support teenagers with their education following a diagnosis of cancer.

The remainder of this thesis is motivated by these aims, as well as more specific research questions, through the following chapters. Chapter two provides coverage of a systematic review of the literature relevant to the education engagement of teenagers with cancer, as well as reviews of associated areas of coping and well-being, and a discussion of the limitations of the existing literature base. Chapter three describes two preliminary questionnaire studies (study one and study two), which aimed to survey the current experiences and opinions of teenagers with cancer and practitioners in teenage oncology, regarding current education engagement and support services. Chapter four details the theoretical base for the chosen qualitatively led mixed methods longitudinal approach adopted for the

main study (study three) and the consultation exercise that was conducted with teenagers and practitioners. In chapter five, two pilot studies are presented, the first allowed me to experience the planned methodology as a participant, and the second recruited a single teenager with cancer to engage in a single interview in order to pilot the methodology. Chapter six then builds on the previous two chapters to detail the practical application of the methods of data collection and analysis undertaken in study three. The results of the quantitative measures collected during study three are presented in chapter seven, along with pen portraits of the participants. Chapter eight provides details of the interpretative phenomenological analysis (I.P.A) of the interviews from study three, and elaboration of a conceptual map of their experiences. In chapter nine the results of all three studies are discussed in relation to the literature and an assessment of the research aims and questions. Study three is evaluated using quality assessment criteria appropriate to I.P.A and this final chapter concludes with recommendations and implications for practice and overall conclusions.

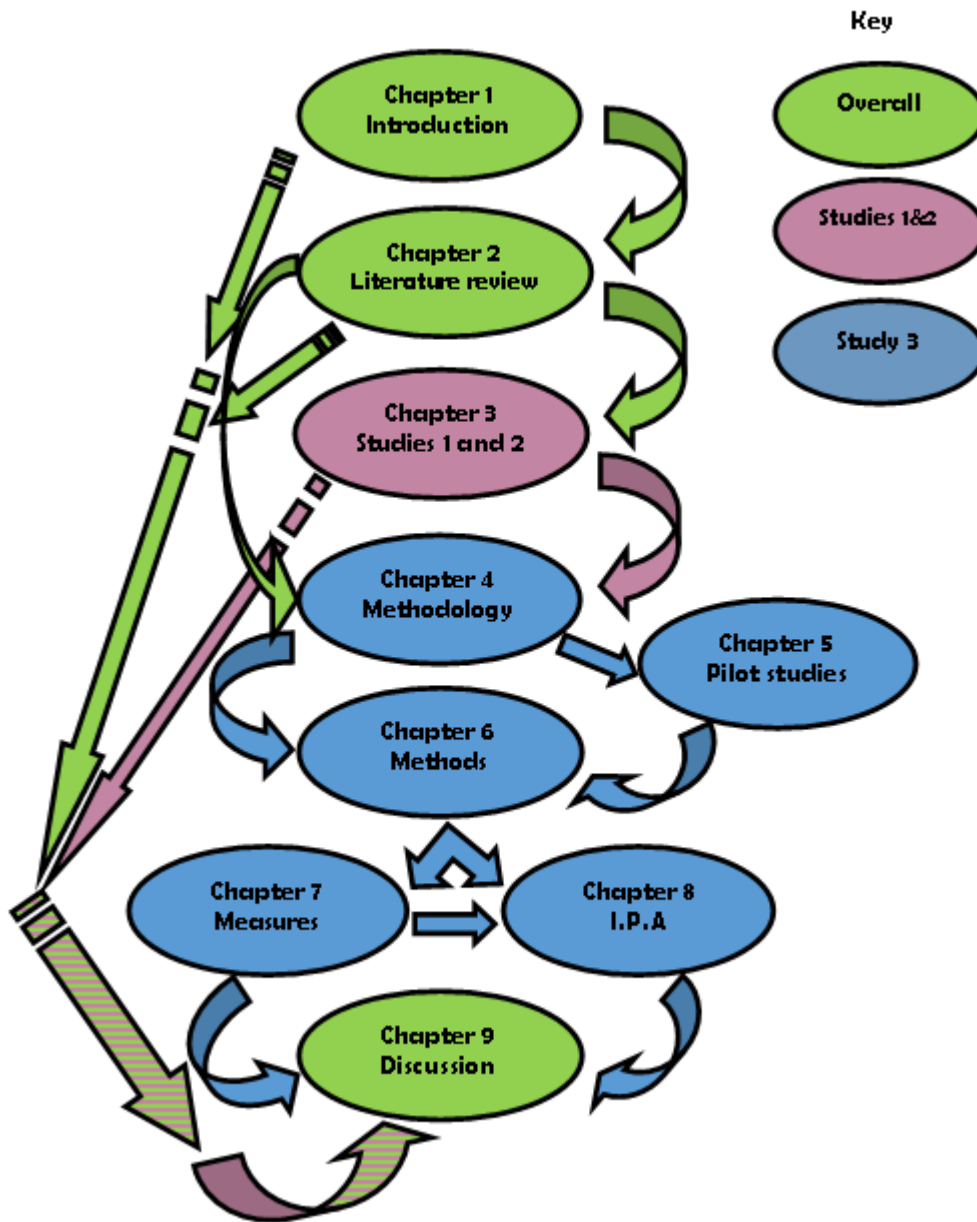


Figure 1.2 - Chapters flow-chart

Figure 1.2 shows a diagram that will be returned to and developed at the outset of every subsequent chapter to show how each chapter informs and is informed by the other chapters.

Chapter 2 - Literature review

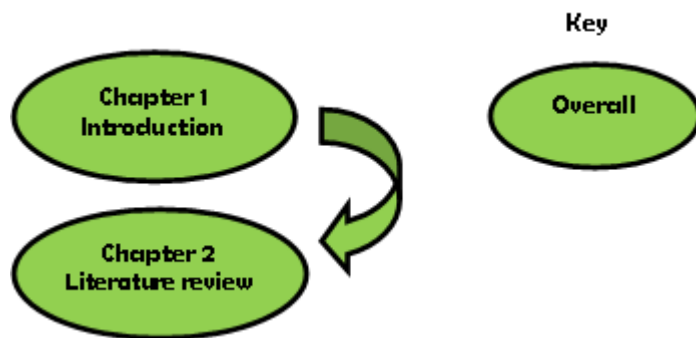


Figure 2.1 - Chapters flow-chart

Chapter one provided some background about teenagers with cancer, teenage cancer services and the motivation for and aims of this PhD research. The first stage in the investigation of the questions posed in the introduction was to assess the current literature. This chapter reports a systematic research review (SRR) of the literature pertaining to the education engagement of teenagers following a diagnosis of cancer. The SRR is reported in detail, including a description of the SRR search methods, inclusion criteria for articles, results, quality assessment of the articles and the methodology used by included studies. The main themes within the findings of the studies in the SRR are then discussed in detail. Following the SRR, two further areas of pertinent literature are reviewed, which are coping and well-being.

2.1 The education of teenagers with cancer – SRR (Pini 2012)

2.1.1 SRR Methods

The following databases were searched electronically; MEDLINE, EMBASE, *PsycINFO*, CINAHL and ASSIA. The search strategy involved using the MeSH terms for the TYA age group ('teenage', 'adolescent', 'young adult'). Age groups are not consistently defined within the literature and these three terms were used to capture any articles that could include teenagers (13-19 year olds). This group was then combined with the MeSH terms for cancer (usually 'neoplasm'). This 'teenage cancer' group was then combined with MeSH terms relating to education ('education', 'school', 'mentoring', 'teaching') and an additional group relating to psychosocial support ('social support', 'psychosocial'). The terms "psychosocial" and "social support" were included due to the fact that some psychosocial research includes education as a sub-section and had the potential to contribute relevant findings. Alongside the MeSH terms, a truncated keyword search (educat*, teenage* etc.) was also carried out to maximise inclusion. An additional search of *PsycINFO* was conducted using

‘academic self-concept’ in place of ‘education’ as this is a term often used in research within education and would maximise inclusion at this stage.

2.1.2 Inclusion criteria

Studies were included in the review if they focussed on any aspect of the education of teenagers diagnosed with cancer between 13 and 19 years of age, regardless of the time since diagnosis. To be included, the study sample could have extended beyond these age parameters provided the results for the target age range were clearly identifiable. Papers must have reported empirical studies, in peer reviewed journals and have been available in English. Studies with non-English samples were included with acknowledgment that education and support systems vary between countries.

2.1.3 Exclusion criteria

Studies were excluded if they failed to meet any one of the inclusion criteria. Therefore, studies were not included if they involved a sample who were not between 13-19 years at the time of diagnosis. Non-English language articles and studies relating to animals were used as exclusion criteria from the outset. Studies that focused solely on the impact that having a teenager with cancer had on the family were excluded. Studies concerned with educating teenagers about cancer were regularly returned in the search given the selected keywords; following initial screening these were excluded due to lack of relevance. Systematic and other review articles were also excluded as they do not directly report empirical studies. Studies focussing on teenagers with brain tumours were excluded due to the well-defined specific education implications of this diagnostic group (Langeveld 2002, Koch 2004).

2.1.4 Results

A large number of articles were returned due to the wide search terms used. The titles of all articles were initially screened using the defined inclusion criteria, and subsequently abstracts and full articles were assessed to refine the final selection by reviewing and establishing further exclusion criteria. The literature search produced a total of 3209 articles, including duplicates (*PsycINFO* – 200, Medline – 2440, Embase – 90, CINAHL – 213, ASSIA – 127, *PsycINFO* – 139). This number was reduced to 115 after screening the titles for suitability using the specified inclusion and exclusion criteria. The abstracts of these papers were examined and, where relevance was indicated, the full paper was reviewed. Only 20 articles remained for inclusion within the review at this stage (Table 2.1). The original completion date of the literature search was 30/11/2009 and since this date two further articles were included in the review after being identified through monthly email alerts from the OVID databases, bringing the final inclusion total to 22 articles at the conclusion of the SRR which was the end of 2011 (Figure 2.2).

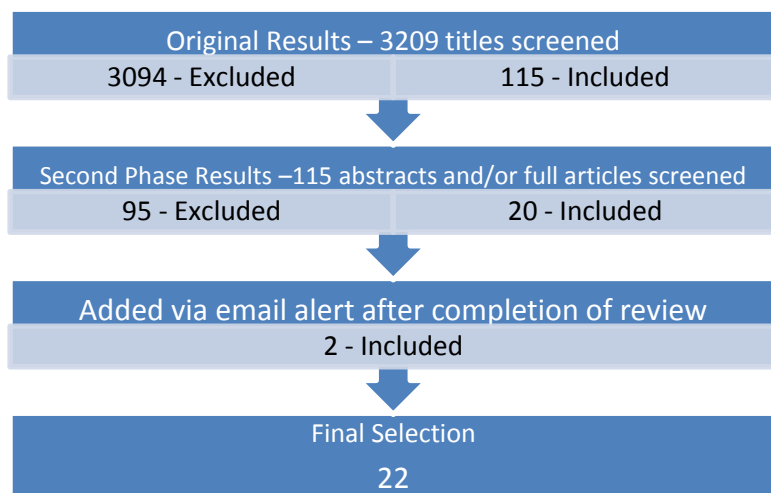


Figure 2.2 - SRR article inclusion flow-chart

Of the 95 articles excluded in the second phase, 35 included age ranges outside the target parameters or were unclear about the age of the sample at diagnosis; 27 were not related to education; 17 were not published in peer review journals; 8 did not focus on the experiences of the teenagers themselves; 7 involved a sample of patients with brain tumours; and 1 was excluded following quality assessment (detailed below). Out of a possible 3209 articles returned in the search, only 22 articles met the criteria for full review. That only 22 articles remained after the application of inclusion and exclusion criteria suggested that there was a scarcity of research focussing specifically on teenagers with cancer and their engagement with education. If articles focussing on other psychosocial or information needs of teenagers with cancer, or the education of paediatric cancer patients had been included, then the number of articles eligible for the review would have been considerably higher.

2.1.4 Quality assessment

To assess the methodological quality of the 22 studies in this review, a validated quality assessment tool was used (Sirriyeh 2012). This tool allowed equitable comparison of empirical studies that utilised quantitative or qualitative methodologies. Each paper was rated on a scale of 0-4 on the following criteria; aims, theoretical framework, sampling, data collection, recruitment, measures, analysis, user involvement, strengths and limitations (Sirriyeh 2012). Using this method each paper was assessed and allocated a quality score, with a maximum score of 42 and a minimum of zero. The total quality score of papers in this review ranged from 6 to 34. Despite the absence of an official ‘cut-off’ score for the quality assessment tool, the lowest scoring paper (Pini 2009) was subsequently removed from the review as it was significantly lower than the other articles due to having only a limited empirical component. Scores of the remaining articles ranged from 22-34 and received high ratings for study design, sampling and appropriate analytical methods. However, some papers scored less well on explicit justification for the measures chosen for data collection and the method of

analysis chosen and there was often a lack of user involvement in the research process, with 16 studies demonstrating no patient involvement.

2.1.5 Methodology of included studies

Studies included in this review originated from a range of countries including, the United States, Sweden, U.K, Canada, Germany, France, Finland, Denmark and Australia. There was not a dominant methodological approach in this area and studies used either quantitative, qualitative or mixed methods approaches. Qualitative studies included semi-structured interviews, grounded theory interviews, focus groups, written narratives and group therapy sessions; quantitative studies utilised standardised measures and questionnaires and mixed methods studies were typically a combination of interviews and standardised measures. Measures and questionnaires were completed from the perspective of different groups alongside teenagers. For example, Moore (2009) invited parents, school personnel and nurses to provide an assessment of barriers to education, whereas Stern (1991) used a range of questionnaires completed by teenagers alone to assess the impact of cancer on career progression. There were also considerable differences in sample size within the studies. Qualitative studies ranged in number of participants from 1 to 35; quantitative from 34 to 14,054 and mixed method studies from 10 to 76.

Table 2.4 - Details of studies included in the SRR

Author	Year	Country	Participants	Time since diagnosis	On/off treatment	Methodology	Summary of findings	QAT score
Bonneau et al	2011	Fra	N= 148 children in remission mean age of 15-/-5.3 years	Mean 6.3 years	Off	Phone questionnaires about school career of the patient and their siblings. The primary outcome was the rate of repeating a grade.	More patients than siblings repeated a grade (33% versus 21%; P = .02), with a mean delay since diagnosis of 2 years. Risk factors were an older age at diagnosis, attending a secondary school, low education level of parents, bone marrow transplantation, cerebral surgery, and physical sequelae. In multivariate analysis, risk for repeating was associated with low educational level of the father, attending secondary school at diagnosis, and requiring school-organized educational support on return to school	22
Cassano et al	2008	Can	N=11 14-20yo	Not specified	On = 4 Off = 7	Grounded theory interviews with patients Field notes of peer support group	Adolescent's feel supported when they are among others in similar circumstances while engaging in normal activity	30
Decker et al	2004	US	N=127 11-21yo N=74 11-19yo	0-3 years	Both	The Information Preferences for Adolescents (IPA) questionnaire.	Of those items rated the highest for the newly diagnosed adolescents, 6 had a mean of 3.5 or greater. These items were (1) dealing with procedures, (2) relationships with friends, (3) getting back into school, (4) relationships with family, (5) finishing treatment, and (6) adjusting to the diagnosis	30

Dieluweit et al	2011	Ger	N=820 adult survivors of cancer during adolescence (age at onset 15-18 years)	age at follow-up: mean = 30.4	Off	Questions on graduation from school, professional education, age at first employment, current employment, and other social outcomes (e.g., family status)	Compared to peers from the general population, survivors of cancer during adolescence achieved higher educational and vocational levels. A higher proportion of survivors was employed; however, survivors were significantly older when starting their first occupation.	33
Drew	2007	Aus	N=57 (N=39 11-16yo)	5-20 years	Off	In-depth study-specific questionnaire, followed in some cases by interview. Grounded theory and Narrative analysis	Patients interviewed described being teased at school because of changes in body image and not being able to maintain previous performances at school because of the effects of cancer and treatment.	34
Duffy-Lind	2006	US	N=4 adolescent survivors N=7 parents N=14 young adult survivors N=3 paediatricians	1-5 years	Off	Focus groups of TYA and parents Semi-structured interview with 3 primary care providers	Most of the adolescents revealed concerns related to going back to school and feeling different than peers. Similarly, many young adult survivors recalled experiencing a range of feelings from elation to abandonment, especially around school re-entry.	27
Enskar et al	2007	Swe	N=54	<1 year - >10 years	Both 15 TYAs on treatment and 39 off	Life Situation Scale for Adolescents (LSS-A)	Adolescents need relationships with friends and support from family, school and health care staff. However, a third of the adolescents and young adults undergoing treatment reported problems with school work and more than half reported receiving no support from others in the same situation. Problems with school might be a predictor of life satisfaction as well as future problems.	30
Grinyer	2007	UK	N=35 (20 - from specialist units 15 - from non-specialist) 5 - written accounts 15-25 yo	Not specified	Both	In-depth interviews and 5 written narratives	Many aspects of the participants' lives were affected [by a cancer diagnosis], including education, careers, life plans, friendship networks, appearance, sexuality and fertility.	26
Hedstrom et al	2005	Swe	N=56 13-19yo TYA	n/a	On	Interview. HADS. SF-36	Worry about missing school (62% of participants) was second only to missing leisure activities in most prevalent psychosocial concerns. This concern was also rated among the highest in terms of impact as well as prevalence.	26
Hokkanen et al	2004	Fin	N=20 13-18yo TYA	1 - >10	Both	Focus group and content analysis	Some teens described their teachers' attitudes as negative. Teens listed more information to classmates as a necessary improvement. Patients reported being bullied at school because of physical appearance and poor PE performance	30
Koch et al	2004	Den	N=2384 diagnosed before 20 Randomly sampled age match control group	1-40 years	Off	Multiple regression analysis of education data	These findings confirm that only survivors of CNS tumours in childhood experience significant educational deficits. The deficit was mainly seen among persons whose tumour was diagnosed before they reached the level of secondary education.	31
Manne et al	1998	US	N=50 12-20yo	n/a	On	Network of Relationships Inventory (NRI) The Psychological Distress scale of the Mental Health Inventory-18-item form The Cancer Rehabilitation Evaluation System	Unfortunately, the day-to-day management of cancer may cause disruption to family and school routines. Although more aggressive management of treatment side-effects (e.g., anti-emetic therapy) and a greater emphasis on outpatient care has reduced school absence and thus allowed teenagers increased opportunities for peer interactions, recent evidence suggests that teenagers continue to report that they are not able to perform the same activities as peers.	31
Mattsson et al	2007	Swe	N=38 15-21 years old	Two years	Off	Telephone interviews Short Form 36 (SF-36) and the Hospital Anxiety and Depression Scale (HADS)	The respondents describe that the school work takes a lot of effort and energy, work is necessary to catch up on missed time at school and that their cognitive ability has deteriorated	27
Meltzer et al	2005	US	N= 34	Up to 17 years	Both	Questionnaires on the first and last day of camp; Peer comparison, Self-Perception Profile for Adolescents, Children's Loneliness and Social Satisfaction Questionnaire.	The results indicate that adolescents felt more similar to peers at a camp for teenage cancer patients than home peers and that these peer comparisons were related to social acceptance, physical appearance, global self-worth, and loneliness	30

Mitchell et al	2006	UK	Three age groups (0–5, 6–11 and 12–18 years) N=75 12–18yo N=102 parents of 12–18yo	Three treatment stages (on treatment, off treatment and 5 years post-treatment)	Both	Parent and patient study-specific questionnaires.	Talking to peers was also important for children and young people at all stages of the illness, in particular, talking to school peers (78%) and other children in hospital with cancer (71%). Seventy-three per cent felt that school and college staff had helped them to catch up with their studies and 74% felt that staff had been understanding about changed appearance, such as wearing a cap or bandana in class. An educational co-ordinator to oversee their child's return to school and liaise with service providers would also be welcomed (46%).	27
Moore et al	2009	US	N=118 nurses N=49 school personnel (counsellors and teachers) N=59 parents The children of parents in the sample ranged in age from 3 years to 19 years at the time of diagnosis	Three years or more	Off	Study specific questionnaire	Communication among nurses, school personnel, and parents was a major barrier to providing effective services to students and their parents. Nurses were unsure of how to help parents navigate the school bureaucracy, school personnel felt they needed more information and parents felt that their children were not receiving all the school re-entry services needed. Individuals in this study recommended that a liaison position be created to coordinate services.	30
Nagarajan et al	2003	US	N=14,054	Five years or more	Off	Baseline demographic and medical information were obtained	Education was a significant positive predictor of employment, having health insurance, and being currently in their first marriage. Male gender predicted ever being employed and female gender predicted having health insurance and marriage. When compared with siblings, amputees had significant deficits in education, employment, and health insurance.	32
Palmer et al	2000	US	11-19 y/o TYA	Not specified	Not specified	Supportive–Expressive Group Therapy sessions with adolescents and their parents. Sessions were weekly over 6-8 weeks	Many children said that their worst pain was to be teased about their appearance (i.e., baldness, extreme pallor, weight loss, etc.) when they returned to school. Several of our adolescent group members reported that they withdrew from peers out of frustration of not being understood. Considering the obstacles that these adolescents have encountered in getting support from their peers at school and in their communities, the value of a support group can be substantial, and joining a support group can significantly reduce feelings of isolation.	23
Searle et al	2003	US	N=10 12–17 years of age at diagnosis, their parents and their teachers	n/a	On	A qualitative, ethnographic, case-study method. Semi-structured open-ended interview questions.	High achieving students engaged in extracurricular activities prior to diagnosis performed well academically in all three schooling situations. Those less engaged in school prior to diagnosis did poorly in homebound schools, better in their community schools, and best in the hospital school.	24
Sorgen et al	2002	US	N = 76 TYA The mean age of the participants was 14 years	n/a	On	Semi-structured interview, immediately followed by study-specific questionnaire relating to coping and control, and Beck Depression Inventory, Children's Depression Inventory, State Anxiety Inventory [SAI] and Child Behavior Checklist (CBCL)	School problems included "concerns about being held back a school year" and "worries about missing too much work". Based on the current research findings, it appears that it may be beneficial to educate children with cancer to recognize and identify controllable and uncontrollable situations in relation to school- and hospital-related problems and to teach them types of coping that may match the appraisals of control	30
Stern et al	1991	US	N=48 cancer patients N=40 healthy adolescents M age at diag = 13.9 years	2 months - 12 years	Both	Vocational Rating Scale (VRS). Career Planning scale (CPS). Career developmental task scale (CDTS). Tendency to Foreclose scale (TTF). Career development assessment inventory (CDAI). Offer Self-image Questionnaire (OSIQ). Social Provision Scale (SPS). Individual interviews were conducted with each participant The semi structured CDAI interview was also conducted at this time.	This study found few differences as a function of health status alone. Career maturity was found to differ between the two groups as a function of age. For younger adolescents, healthy subjects were more advanced in their career maturity than were cancer patients. Among older adolescents, however, cancer patients were well ahead of healthy adolescents on career maturity progress. One important difference was that, as a whole, adolescent cancer patients showed a greater tendency to prematurely foreclose on a career choice than did healthy adolescents. Interview data suggest that this tendency to foreclose may be adaptive in adolescent cancer patients.	31

Woodgate	2006	Can	N=39 families N=15 had an adolescent between 12 and 18 years of age. The mean age of the adolescents was 14 years	Not specified	Off	Longitudinal qualitative research design Open-ended interviews Two focus group interviews were scheduled near the end of the study to help validate emerging themes	In helping adolescents feel like they have a life, it was important for their special friend to help them keep close ties with their peers and school.	24
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2.1.6 SRR Findings

Literature regarding the education engagement of teenagers with cancer focussed on four key areas; school attendance, reintegration, peer relationships and long term impact. The findings of the studies in this SRR will be discussed below under these four headings.

2.1.6.1 School absence

Previous research has shown that teenagers with cancer were more likely than healthy peers to have school absences (Bonneau, Lebreton et al. 2011, Manne and Miller 1998, Mattsson, Ringner et al. 2007, Moore 2009) and to repeat a year at school (Barrera 2005, Gerhardt 2007). A cancer diagnosis resulted in more absences than other chronic diseases (Eiser, Vance et al. 2002) and teenagers have been shown to be a particularly high risk group for extended school absence compared to younger children with cancer (Bonneau, Lebreton et al. 2011). Absences were a particular problem in the year after diagnosis (Eiser, Vance et al. 2002), averaging 40 to 60 days (Moore 2009). Attendance could continue to be irregular for up to three years after diagnosis (Moore 2009) and difficulties in catching up with work missed were experienced by some teenagers up to two years later (Mattsson, Ringner et al. 2007). Despite the increased likelihood of school absences presented by a diagnosis of cancer, Manne et al. (1998) reported that through more successful management of side-effects and a greater emphasis on outpatient care, the extent of school absences by teenagers with cancer had begun to be addressed in the late 1990s.

Teenage patients experienced the possibility of school absence as a primary concern as early as at the point of diagnosis; along with concerns about not getting well, mucositis, nausea and painful procedures and treatments, these anxieties reached the cut-off scores for potential clinical anxiety in 12% of the sample and in 21% for potential clinical depression (Hedstrom, Ljungman et al. 2005). Teenagers reported that increased school absence could be for numerous reasons including; decreased energy and concentration (Mattsson, Ringner et al. 2007), decreased cognitive ability (Mattsson, Ringner et al. 2007) and sometimes the 'intolerant attitude' [p270] of school staff regarding their reintegration (Grinyer 2007). However, this did not necessarily equate to long-term poorer academic outcomes. Moore (2009) reported no significant relationship between perceived academic performance / ability and days absent from school when using parental perception as an indicator. Dieluweit et al. (2011) showed, in a sample of German survivors of teenage cancer, that survivors

actually achieved higher educational and vocational levels than healthy controls, even though the survivors did not enter higher education or employment until later in life.

2.1.6.2 Reintegration

Returning to school after a diagnosis of cancer has been shown to be a major challenge for teenagers and school staff (Koch 2004) and a primary concern for teenagers as early as diagnosis (Decker 2004). This concern could have stemmed from teenagers' fears about being accepted back into their peer group and having to build new friendships (Decker 2004, Duffey-Lind 2006), alongside worry about being teased or bullied about their appearance due to hair and weight loss (Manne and Miller 1998, Drew 2007, Grinyer 2007). Palmer (2000) found that, out of all the possible pains associated with having cancer, 'being teased about their appearance when returning to school' [p50] was rated by teenagers as the worst. This negative effect has been shown in other studies where teenagers have expressed being bullied at school due to negative body image (Hokkanen 2004). Searle et al. (2003) reported that this negative body image could lead teenage patients to request home or hospital schooling during treatment, which could be very beneficial to patients in this group, especially if restricted to the short-term. However, many patients found that the reality of returning to school was not as difficult as they had imagined (Searle, Askins et al. 2003) and that some education staff could be understanding and would facilitate their return (Mitchell 2006).

As well as concerns about peers and body image, research showed there could be specific academic concerns (Searle, Askins et al. 2003). Teenage patients who had been in hospital schools were sometimes concerned that the work in those settings was 'too easy' [p352] and worried about their ability to catch up with their regular school curriculum (Searle, Askins et al. 2003). Despite these concerns, Searle (2003) found that the majority of patients who had been enrolled in hospital schools successfully reintegrated into their regular schools, although the article did not include data relating to the length of absence as a moderating factor.

A moderating factor for reintegration was the ability for education staff to make adjustments and facilitate reintegration of teenage patients back into school through collaborative planning with medical staff (Searle, Askins et al. 2003, Mitchell 2006, Moore 2009). Both families and professionals identified the need for a designated co-ordinator of education for teenage cancer patients (Mitchell 2006, Moore 2009). Moore (2009) reported unsuccessful communication between parents and staff was a major barrier to successful reintegration and that staff were often uncertain how to help parents negotiate school systems. This appeared to place the emphasis on parents being in control and healthcare staff supporting, whereas it has been shown elsewhere (Pini 2009) that a specialist co-

ordinator could relieve some of the pressure on parents to organise their child's education and reintegration.

As well as providing medical information to school staff, peers and the school community, healthcare professionals have been shown to have an important role in encouraging teenagers to engage in education where possible (Searle, Askins et al. 2003). It has also been shown that a significant role for healthcare professionals was in helping to decide the most appropriate environment for education when considering the medical and health needs of the teenager. This could be homebound, hospital or community based education and healthcare professionals were advised to take into account 'social, emotional and academic, as well as health factors' [p383] (Searle, Askins et al. 2003) when making these recommendations. The absence of specialist teenage oncology staff from education co-ordination has been shown to increase the stress experienced by teenagers going through treatment, through a lack of understanding of their needs (Grinyer 2007). However, Moore (2009) reported that nursing staff performed 'few services to facilitate re-entry' [p90], that these services were 'moderately helpful' [p92] and that additional services including technology, educational support and hospital tuition would have improved services.

Patients have reported low levels of satisfaction with the support they received from teachers (Enskar, von Essen et al. 2007). The reasons for this included; negative staff attitude (Hokkanen 2004), that school staff did not think the patient could pass their courses (Grinyer 2007) or that teachers ignored health plans (Moore 2009). Moore (2009) found that parents felt that teachers were not willing to help 'one child when they have so many others' [p95]. Other studies, however, found that school personnel were flexible and supportive within their capabilities (Mitchell 2006). From the teachers perspective, it has been found that they did not always rate the support they gave as particularly helpful (Moore 2009) and have been shown to know what services would have supported patients, but were not clear who had responsibility for implementing this support when so many people were involved in the teenager's care (Moore 2009).

Perhaps as a result of incomplete knowledge of the cancer experience, teachers have been shown to have lower expectations of the academic ability of patients compared with healthy controls (Koch 2004). Collaborative planning and information sharing clearly increased the understanding of the ability of young people with cancer to engage in education activities (Hokkanen 2004, Mitchell 2006).

2.1.6.3 Peer relationships

The importance of peer relationships as a moderating factor in the ability of teenagers to engage in education was reported in a variety of research (Manne and Miller 1998, Palmer 2000, Searle, Askins

et al. 2003, Decker 2004, Hokkanen 2004, Meltzer 2005, Duffey-Lind 2006, Mitchell 2006, Woodgate 2006, Grinyer 2007, Mattsson, Ringner et al. 2007, Cassano, Nagel et al. 2008). Findings suggested that a diagnosis of cancer leading to absence from school could adversely affect a teenager's interaction with their peer group (Manne and Miller 1998, Palmer 2000, Searle, Askins et al. 2003, Decker 2004, Hokkanen 2004, Meltzer 2005, Mitchell 2006, Woodgate 2006, Grinyer 2007, Mattsson, Ringner et al. 2007). Decker (2004) found that 'relationships with friends' [p331] was second only to 'dealing with procedures' [p331] in the concerns of newly diagnosed teenagers. Manne (1998) reported that teenagers diagnosed with cancer had, on average, smaller social networks compared to healthy controls. Illness related differences between patients and their pre-diagnosis peer group also contributed to teenagers feeling socially isolated (Mattsson, Ringner et al. 2007) and teenagers who felt different from their pre-diagnosis peer group were shown to report more loneliness, reduced social acceptance and lower self-worth, as well as being less satisfied with their physical appearance (Meltzer 2005). When teenage patients did try to maintain contact with their peer group it could be demoralising if repeated attempts to engage were thwarted by their illness and treatment (Grinyer 2007).

Teenage patients often expressed feelings of not being understood by their pre-diagnosis peer group (Palmer 2000) and of being 'left-behind' [p220] as their peers moved on with their lives (Grinyer 2007). Although maintaining contact with peers was important, sometimes patients stated that it could 'hurt to be reminded' (Searle, Askins et al. 2003) of the activities they were missing out on. In this situation, teenage patients could intentionally 'cut off relationships' [p382] by not allowing friends to visit while they were unwell (Searle, Askins et al. 2003). Woodgate (2006) noted the potential importance of a 'special friend' [p125] in maintaining this contact with peers at school, which was usually a lifelong friend.

2.1.6.4 Long term impact on education and employment

A diagnosis of cancer can be disruptive at any stage of life, but individuals in TYA years have been described as being on the 'threshold of fundamental change in their circumstances' [p269] (Grinyer 2007). Treatment and illness experiences could lead to chronic post-traumatic stress for patients extending into remission affecting their subsequent experiences (Grinyer 2007). This ongoing 'narrative wreckage' [p282] (Drew 2007) made it difficult for patients to identify appropriate pathways and plan their future (Drew 2007). This effect, in relation to employment, varied between individuals and could be moderated by the stage of career exploration they were in when diagnosed (Stern 1991). Those at early stages of career exploration were shown to be affected more negatively by a cancer diagnosis than those with more developed career plans, who demonstrated a positive effect (Stern 1991). Survivors of teenage cancer were often older when first employed, but this did not

lead to lower levels of vocational achievement compared to healthy controls (Dieluweit, Debatin et al. 2011). Education attainment was a significant predictor of future employment for cancer survivors (Nagarajan, Neglia et al. 2003) and teenagers with cancer were identified as a group with a greater chance of future unemployment (Langeveld 2003, Gurney 2009). The precise impact of a cancer diagnosis on future employment has been shown to be moderated by age at diagnosis, with the career maturity of younger teenagers with cancer significantly less developed than healthy comparators, whereas older teenagers showed tendencies to prematurely foreclose on career decisions (Stern 1991).

With regard to the effects of cancer and treatment in relation to long-term educational difficulties, it appeared that survivors of central nervous system cancers were the only group reported as differing significantly from healthy controls in education attainment (Bonneau, Lebreton et al. 2011, Koch 2004) and employment (Dieluweit, Debatin et al. 2011). Problems with school were predictive of future social difficulties and life satisfaction (Enskar, von Essen et al. 2007) and those patients experiencing social isolation during treatment continued this into longer term survivorship (Drew 2007).

A number of studies have examined the psychosocial outcomes of continued engagement or non-engagement with education following a diagnosis of cancer. For example, sustaining regular involvement with school appears important for well-being (Searle, Askins et al. 2003) and global self-worth (Seitzman 2004), whilst limited engagement can lead to feelings of social isolation (Searle 2003, Barrera 2005) and difficulties with peer interactions (Barrera 2005), especially among teenagers who require extended periods of home schooling (Searle, Askins et al. 2003).

2.1.7 Summary

Emerging from the SRR were key issues surrounding the engagement of teenagers with education after a diagnosis of cancer. Despite the literature showing that school absences do not necessarily result in a reduction in educational and vocational attainment, absence was clearly an issue felt acutely by some teenage patients. It seemed important to involve health care and education professionals, as well as parents and the teenagers themselves, in school reintegration if it was to be successful. This appeared to be facilitated through encouraging maintenance of existing peer groups and sensitivity towards issues surrounding body image and the effect this could have on reintegration and peer groups. It proved difficult for existing research to demonstrate any clear and consistent quantitative outcomes when analysing the relationship between a cancer diagnosis and education engagement. Therefore, further research is needed to investigate the overall impact of successfully maintaining education engagement for teenagers, the role that peer groups play in this process, and how education engagement contributes to the overall coping and well-being of teenagers with cancer.

The difficulty with establishing consistent quantitative findings suggests that a qualitative approach may be the most appropriate to investigate the nuances of the interaction between education engagement, cancer and psychological experiences. Previous literature has also highlighted the need for further qualitative research into the perspectives that teenagers with cancer have about their experiences (Woodgate 1999, Taylor, Pearce et al. 2013).

2.2 Coping and Well-Being for Teenagers with Cancer

Associations between education, coping and well-being have been identified in previous research and literature in these areas. Difficulties with school have been shown to be a significant cancer-related stressor (Eiser 1994) and one that can influence approaches to coping in young people and the effectiveness of coping strategies (Sorgen and Manne 2002). Previous research into the well-being of young people has included educational well-being as an important component of overall well-being (UNICEF 2007) and teenagers have been shown to have a unique perspective on their well-being at school, which is often in contrast to their parents and teachers (Waters et al. 2003). The education SRR revealed only limited previous attempts to qualitatively assess relationships between academic and any psychological variables in this group. Looking further into these areas would also reflect a move within teenage cancer care and research towards understanding what contributes to positive outcomes, rather than exclusively focussing on pathways to risk and negative outcomes.

To develop an understanding of education engagement of teenagers with cancer, a systematic research review was required to identify and assess the vast majority of the existing research. The review of literature related to coping and well-being was systematic, but was not strictly a SRR. The aim of assessing the literature in this area was to investigate existing approaches to understanding and researching these abstract concepts. Electronic databases (MEDLINE and EMBASE) were searched by using terms related to teenagers and cancer in combination with terms related to coping and well-being. The resulting articles were initially screened for suitability by reading titles and then, if appropriate, reading abstracts and full articles. The findings of all the relevant identified articles have been used to produce the following two main sections (2.3 and 2.4), which will provide an overview of the literature in these areas.

2.3 Coping in teenagers with cancer

In 2006, Decker reviewed the literature related to coping in teenagers with cancer (Decker 2006). In this review, Decker (2006) identified the main conceptual models of adolescent coping presented in the literature as; problem-focused versus emotion-focused coping models, primary and secondary control coping models, engagement (approach) versus disengagement (avoidant coping) models, empirically derived models and additional multidimensional models. Decker (2006) also showed that

the literature did not report any consistent relationship between the coping styles listed above demonstrated by teenagers and developmental or demographic features. The literature did show that teenagers with cancer used different coping strategies when on and off treatment, as well as using different strategies compared to healthy controls dealing with normative stress (Decker 2006). The review also showed that, in the cancer population, older teenagers used a greater variety of coping strategies compared to younger teenagers (Decker 2006).

In 2002, Sorgen and Manne conducted semi-structured interviews with 76 young people with cancer (mean age 14 years and 10 months). The aim of this study was to assess the impact of congruency between coping styles and perceived levels of control on psychological distress. Table 2.2 shows the definitions of coping styles used in this study and shows that Sorgen and Manne used problem-focused and emotion-focused as overarching categories for five different approaches to coping.

Table 2.5 - Definitions of Coping Categories – Taken from Sorgen and Manne (2002)

Problem-Solving (problem-focused)	Analysed and took measures to correct a situation or problem; information seeking to better understand a situation, e.g., made a plan of action and followed it; gathered information about the illness
Distraction (emotion-focused)	Cognitive or behavioural active attempts to think about something other than the negative stimuli, e.g., participated in an activity to avoid thinking about or experiencing a negative experience; watched TV.
Cognitive Restructuring (emotion-focused)	Positive reappraisal; tried to see the positive side of things and/or minimized the negative, e.g., thinking eventually it will end; rediscovered what is important in life; thought at least I am alive.
Seek Support (emotion-focused)	Sought information and emotional support, e.g., talked to others, held someone's hand.
Avoidance (emotion-focused)	Tried to ignore or deny an existing problem; wishful thinking and behavioural efforts to escape or avoid, e.g., hoped for a miracle, avoided being with people, went to sleep. The coping effort "went to sleep" is only used in this category when it is not used in the context of sleep/diversion in which patient goes to sleep during painful procedures or episodes.
Other (emotion-focused)	Prayed to God; accepted it because there was nothing else to do; cried, wrote in journal; yelled at someone; sleep/diversion.

Within the interviews participants were asked to identify examples of cancer related stressors in four areas of their lives: school, friendships, family and hospital treatment (Table 2.3) (Sorgen and Manne 2002). Participants then discussed what they did, if anything, to make these situations easier for themselves. Once they had identified any strategies for coping, they rated how successful that strategy was and how much control they thought they had over the situation, on a 5-point scale.

Table 2.6 - Examples of stressors – adapted from Sorgen and Manne 2002

Category	Examples given by participants
School problems	“concerns about being held back a school year” “worries about missing too much work”
Cancer-related friendship problems	“friends not knowing how to act” “not being able to go to the prom”
Family problems	“having to be in the hospital for Christmas” “sibling scared patient might die”
Treatment problems	“feeling nausea and vomiting” “not being able to eat before medical procedures”

Findings indicated that the use of problem-focused coping strategies was associated with higher appraisals of control, and the use of emotion-focused coping was associated with lower appraisals of control (Sorgen and Manne 2002). Older teenagers had a greater ability to match their strategies to appraisals of control, which is perhaps because they had a greater variety of coping strategies as demonstrated in the review by Decker (2006). For example, older teenagers were more likely to use emotion-focused coping in situations where they perceived they had less control (Sorgen and Manne 2002). They found that the congruence between the selected coping strategy and the perception of control of the situation affected the level of psychological distress experienced by the participants, as measured by the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) or the Children’s Depression Inventory (Kovacs,1992) depending on the age of the participant. Therefore, teenagers who did not match their coping efforts to their perceptions of controllability over the stressor had higher levels of psychological distress. This was found to be particularly significant for mismatches between control and problems related to school and treatment in hospital, which significantly correlated with higher scores of distress (Sorgen and Manne 2002).

In their review of the outcomes of using avoidance coping and repression as a defence mechanism in a variety of populations, Gil (2005) found that teenagers who were classed as “repressors” showed similar tendencies to those in adult samples, which were that they tended to exhibit; self-deception, biased self-reporting, and inhibition of signals of distress. Gil (2005) reported patterns of self-reporting from studies of children and teenagers, whereby those identified as using a repressive coping style reported less anxiety, less depression, and less anger than young people who were classed as “non-repressors” or from normative populations. This finding was consistent for “repressors” with chronic illnesses and those who were free from illness, indicating that the finding was a consistent result of the coping style across different health statuses. Canning et al. (1992) investigated repressive coping in young people with cancer and found that repression was a more prevalent coping strategy in their sample than in healthy controls, although the article does not specify the demographics of the healthy control sample. Regression analysis of their data showed that variation in self-reported depression was significantly explained by the use of repressive coping by participants, meaning that

those who were repressors were less likely to self-report distress (Canning, Canning et al. 1992). These findings were replicated by Phipps and Srivastava (1997) in their research into teenagers with cancer.

The review by Gil (2005) also reported studies showing that repression was a coping strategy that provided young people with a way to function on a day to day basis in the face of difficult circumstances. Phipps and Srivastava (1997) showed that young people with cancer who used repression coping were able to continue to engage in school, engage with peers and withstand difficult procedures. However, the mixed methods study by Erickson and Steiner (2000) showed, in a sample of forty people who were at least five years into remission, that survivors of cancer who demonstrated repression or avoidance coping were more likely to demonstrate post-traumatic stress and psychological distress in survivorship.

The review by Gil (2005) showed that adults with cancer, as well as those with HIV, MS and other serious conditions, who used repression as a coping strategy, had heightened physiological and biochemical responses to stressful situations, which were linked to worse disease progression, more recurrence and increased mortality. The review by Gil highlighted that there was a lack of research into this aspect of repression coping for young people, but if this finding was consistent between adults and young people, as with other aspects of repression coping, then it could mean that despite the reduced presence of self-reported distress and the benefits of short-term day to day engagement, young people using repression coping could still be at risk of longer term physiological problems, alongside post-traumatic stress and psychological distress.

Wu et al. (2009) conducted a qualitative interview study with ten teenagers aged 10-18 to investigate their experiences of coping with cancer. Wu found that the coping experiences of participants were informed by two underlying themes: losing confidence and rebuilding hope. These two themes were comprised of important sub-themes. Losing confidence had sub-themes related to physical and psychological suffering. Rebuilding hope had sub-themes of thought restructuring, re-evaluating what I have, and envisioning hopeful images of the future. Wu concluded that participants moved their focus between these two areas of coping depending on their experiences at the time, but that a focus on rebuilding hope helped young people to cope with distressing events associated with their cancer experiences. Wu reported that issues concerning school were particularly relevant to the sub-theme of thought restructuring, whereby young people abandoned the idea of academic achievement and focussed instead on the consequences of losing their health. Part of this restructuring was the realisation of participants that they would need to sacrifice previous goals to work towards survival.

Palmer et al. (2000) also investigated the coping experiences of teenagers with cancer, but through two support groups held with young people (11-18 years old) and their parents. The number of group members was not specified in the article. There were four main themes that arose from their work in the support group. The first theme was the challenge of improving family support and open communication. Palmer reported that young people discussed the impact that they could see their diagnosis was having on their family, especially their parents. They talked about being scared by the strong emotional reactions of their parents, but also saw these reactions as a sign of the amount their parents cared for them. This led to some young people not wanting to disclose how they were feeling to their parents for fear of further upsetting them. Palmer also highlighted the increased likelihood of conflict between the young person and their parents because of changing dynamics in relation to uncertainty from parents about how to continue parenting post-diagnosis and the heightened levels of stress from all involved.

These parent-child dynamics are important because literature has consistently shown that parental coping is positively correlated with child coping (Trask 2003). Despite the fact that some studies have not found any significant effects of cancer on family functioning compared to healthy controls (Banner, Mackie et al. 1996, Kinderziekenhuis 1998), Kazak (1989), in a self-report survey of survivors of childhood cancer and their families, reported that family adaptability was positively linked to psychological adjustment, social acceptance and scholastic competence in teenagers. These results were replicated in a similar self-report questionnaire study by Trask (2003) using a sample of 28 teenagers with cancer and at least one of their parents. The cohesion of the family of young people with cancer was also rated by teachers as the most important element in adjustment to cancer in a study by Levin et al. (2000). In this same study, parents rated the amount of time that their child was absent from school as the most important element in this adjustment to cancer. This is interesting because it shows that parents and teachers each rate the other as providing the most important element in adjustment to cancer and highlights a potential difficulty when parents interact with their child's school.

The second theme from Palmer's (2000) analysis of the support group discussions was the challenge of overcoming others' discomfort with discussing the realities of cancer. Palmer reported that young people did not feel comfortable broaching the subjects of death, dying and relapse because they perceived these topics as forbidden as others did not discuss them. However, once these topics were raised in the support group, they became the main focus and young people reported feeling "liberated" (p. 47) through these discussions. Palmer (2000) said that there was a sharp contrast between the young people's willingness to discuss these subjects and their parent's "relief" (p. 47) at the perception that their children had not thought about these issues. Young people in these groups

reported feeling isolated and alone when they were not able to discuss “the bad things” (p. 47) with the people closest to them.

The third theme was the obstacle of gaining peer support (Palmer 2000). Young people in the group reported that their peers were uncertain about how to interact with them now that they had cancer and that they missed their normal interactions with peers. Young people often said that their social groups had reduced and that this was partly due to missing time from school, but also out of their own frustration at not being understood. They often reported feeling like they did not fit into their peer groups anymore and increasingly identified with the adults in their lives, instead of other young people.

The fourth theme was overcoming the challenge of feeling betrayed by one’s body (Palmer 2000). Young people discussed not feeling intact anymore and having to adjust to a new unsatisfactory body image. They also reported frustration at bodily changes limiting their engagement in previously enjoyed activities like sports. Losing control over their bodies gave some young people a “nothing to lose” attitude and could lead to extreme or sometimes reckless behaviour, whereas for others it resulted in them deferring control to parents and other authority figures in their lives. Both of these approaches could lead to the young person relinquishing hope and, as demonstrated above by Wu, rebuilding hope can be an important part of coping for young people with cancer.

In summary, the literature showed that there are a wide variety of coping styles used by young people with cancer. The extent to which young people match their coping style to their perceived controllability of the stressor can affect their experience of distress. Young people with cancer often use repression or avoidance coping as a means of reducing the impact of present stressors and to allow them to more easily carry on with day-to-day activities, but this coping style can result in longer term vulnerability to psychological distress and post-traumatic stress. Peers, parents and teachers can all affect the success of a young person coping with cancer when faced with cancer related stressors such as body image, changing relationship dynamics and loss of hope.

2.4 Well-being

The previous two sections of the literature review have looked at the engagement in education and the coping of teenagers with cancer. It seemed that well-being was an area that could have underpinned certain elements of these previous two sections of literature, or could have been an outcome of successful engagement with education and/or successful coping. Therefore, the following section reports an assessment of the literature on the well-being of teenagers. Teenagers are moving through a period of rapid change and development and therefore the notion and components of well-being are

likely to differ from those of the adult population (McCullough, Huebner et al. 2000, Blum, Astone et al. 2014).

2.4.1 What is well-being?

Well-being has been defined as “a positive and sustainable state in which we can thrive and flourish” (p. 246) (Huppert, Baylis et al. 2005). On a macro-scale, well-being can be affected by the interaction between national-level factors, such as national wealth, inequality, education, and employment (Lancet 2013, Blum, Astone et al. 2014). Blum et al. (2014) highlighted that these macro-factors provided a framework within which other factors that have a more direct influence over the well-being of young people are developed, such as community, family, school and peers.

The subjective concept of well-being has been described as containing specific constructs, which correlate with each other to comprise the overall feeling of well-being (Diener, Suh et al. 1999). Diener et al. discussed these specific constructs as being reflected in; people’s emotional responses, domain satisfactions and global judgements of life satisfaction. People’s emotional response could clearly be pleasant (happiness, joy, affection) or unpleasant (guilt, stress, depression), and a distinction has been made between the experience of these as momentary emotions or long-term moods (Diener, Suh et al. 1999). The satisfaction that people feel in domains of their lives including; work, family, leisure, health, finances, self and one’s group, provide a separate component of well-being to their emotional responses (Diener, Suh et al. 1999). These are more applicable to an adult population than a teenage population, as teenagers would be likely to replace work with school/education and would likely not be as acutely concerned about finances. Global judgements of life satisfaction are a more generalisable component in Diener’s (1999) paper and include satisfaction with life in the past, present and future, as well as people’s perception of how others view their life. Diener et al. (1999) add to this conception of subjective well-being by highlighting the important variability offered by personality factors, coping and adaptation, societal wealth, close relationships and having the resources needed to pursue identified goals.

Well-being has also been defined as the opposite of mental disorders such as depression and anxiety (Huppert and So 2013). By using this idea Huppert & So looked at the components used to assess the presence of anxiety and depression, and identified the opposite of these components to construct an assessment of well-being. A major difference between this conception of well-being and that proposed by Diener is the inclusion of functional aspects as well as feelings. Huppert & So devised a ten component measure of well-being that included; competence, emotional stability, engagement, meaning, optimism, positive emotion, positive relationships, resilience, self-esteem, and vitality (Huppert and So 2013). Using this measure they investigated the well-being of 43,000 people from 23

European countries and found marked differences in well-being between countries (Huppert and So 2013). Figure 2.2 shows data from the 2007 UNICEF report on childhood and adolescent well-being in a variety of economically advanced nations from around the world (Unicef 2007). This report provides an assessment of well-being across six domains; material well-being, health and safety, educational well-being, family and peer relationships, behaviours and risks, and subjective well-being. European countries, especially those in northern Europe, were ranked consistently high across domains. Despite this, no country was in the top third for every domain and therefore no one domain could be used as a reliable guide for overall well-being (Unicef 2007). The U.K. was ranked in the lower third for all domains except for health and safety for which it was in the middle third. UNICEF also concluded that there was no measurable correlation between the well-being of young people and the GDP of the country (Unicef 2007).

		Dimension 1	Dimension 2	Dimension 3	Dimension 4	Dimension 5	Dimension 6
Dimensions of child well-being	Average ranking position (for all 6 dimensions)	Material well-being	Health and safety	Educational well-being	Family and peer relationships	Behaviours and risks	Subjective well-being
Netherlands	4.2	10	2	6	3	3	1
Sweden	5.0	1	1	5	15	1	7
Denmark	7.2	4	4	8	9	6	12
Finland	7.5	3	3	4	17	7	11
Spain	8.0	12	6	15	8	5	2
Switzerland	8.3	5	9	14	4	12	6
Norway	8.7	2	8	11	10	13	8
Italy	10.0	14	5	20	1	10	10
Ireland	10.2	19	19	7	7	4	5
Belgium	10.7	7	16	1	5	19	16
Germany	11.2	13	11	10	13	11	9
Canada	11.8	6	13	2	18	17	15
Greece	11.8	15	18	16	11	8	3
Poland	12.3	21	15	3	14	2	19
Czech Republic	12.5	11	10	9	19	9	17
France	13.0	9	7	18	12	14	18
Portugal	13.7	16	14	21	2	15	14
Austria	13.8	8	20	19	16	16	4
Hungary	14.5	20	17	13	6	18	13
United States	18.0	17	21	12	20	20	–
United Kingdom	18.2	18	12	17	21	21	20

Figure 2.2 - Child well-being data taken from (Unicef 2007)

Although there are differences in the prevalence of well-being in different countries, a study of two very different cultures, using a sample of Russian and American teenagers, found that some components of well-being were consistent cross-culturally (Chirkov and Ryan 2001). This finding supports the idea that while there may be cultural and societal influences that can affect well-being, there must also be universal facets.

Research into the well-being of young people has investigated specific aspects that contribute to well-being as well as the more general domains discussed so far. One specific aspect of the well-being of young people that is present in the literature is the way that young people orientate themselves in time. The ability of teenagers to orientate themselves in the future when making decisions in the present, by setting goals, plans and milestones that have longer term positive ambitions, has been shown in the literature to have a positive relationship with well-being, mental health and healthy developmental outcomes (Johnson, Blum et al. 2014). Future orientation of this kind has also been developed as an intervention to help teenagers positively adjust to present difficulties (Johnson, Blum et al. 2014). In his chapter covering the well-being of young adults, Baylis (2005) described the importance to well-being of the relationship with reality (RWR) that young people develop throughout their lives. RWR involves three fundamental orientations to reality in the face of difficulties; reality evading, quick-fixes, reality investing (Huppert, Baylis et al. 2005). A negative RWR is categorised by unhelpful and frequent deployment of quick fixes and reality evading. “Late bloomers” (p.244) in the TYA years were categorised by Baylis (2005) as often having a negative RWR, which subsequently changed when they encountered nurturing circumstances made up of positive relationships, achievable meaningful goals and seeing their ability to change their reality. Baylis argued that RWR can form the overriding feature of an individual’s personality, which can affect their approach to coping and subsequent well-being (Figure 2.3).

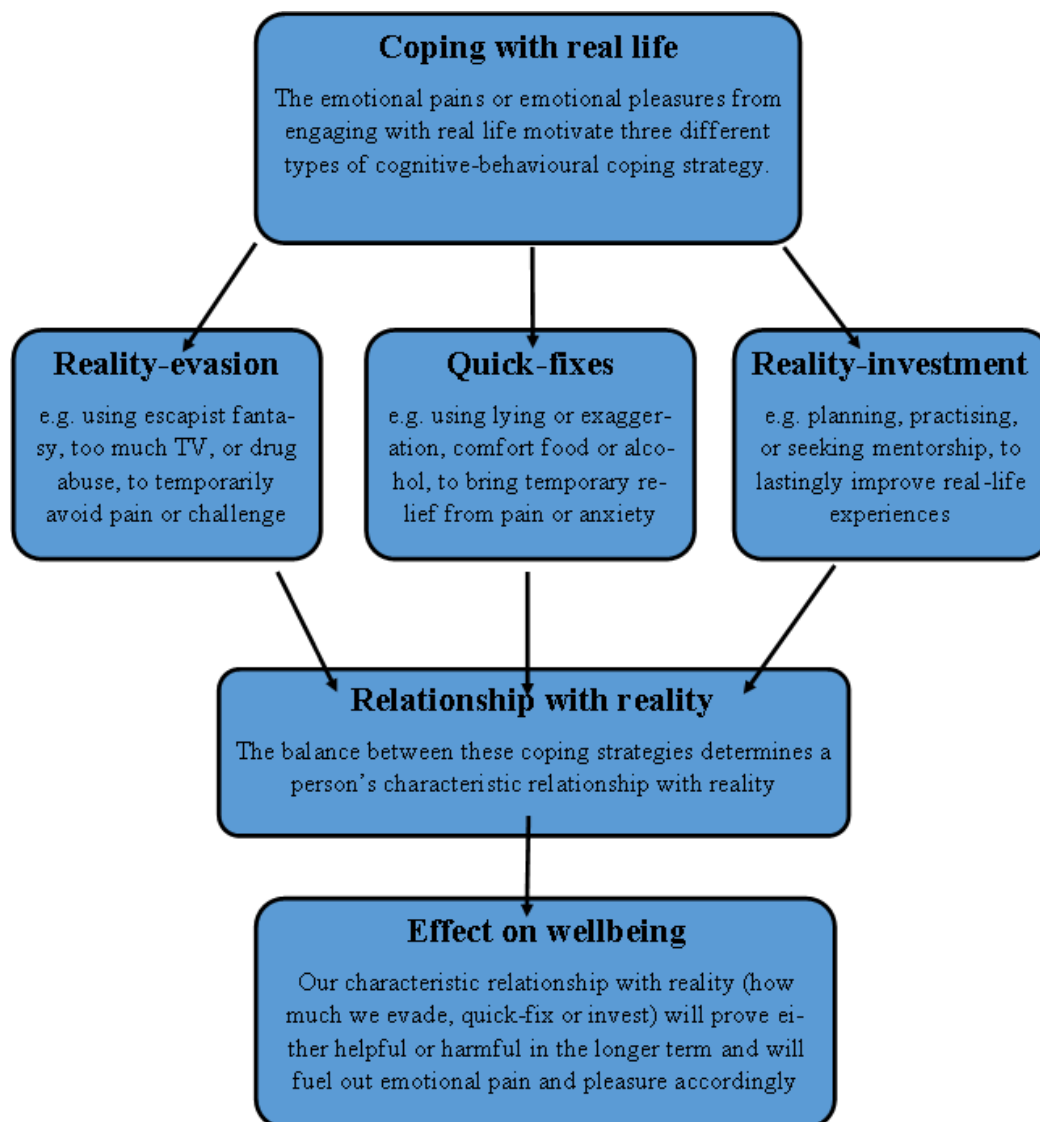


Figure 2.3 - The link between RWR, coping and well-being, adapted from (Huppert, Baylis et al. 2005)

Figure 2.3 suggests that the balance in the coping strategies of an individual contributes to their overall RWR and that this overall RWR impacts their well-being. For example, Baylis argued that quick fixes provide short-term relief from stressors, but are often at the expense of long-term well-being because of the development of a dominant short term relationship with reality. There seems to be a link here with the findings of the repression and avoidance coping literature presented earlier. It may be that using an avoidant or repression coping style is a quick fix to alleviate the impact of the current stressors being experienced, but could perhaps influence the young person's relationship with reality and have longer-term consequences for well-being, such as the previously mentioned psychological distress and PSD.

It has been shown in previous research that everyday difficulties, as well as major life events, also contribute to the well-being of teenagers, with everyday difficulties having more of a significant impact than major life events (Rowlison and Felner 1988, McCullough, Huebner et al. 2000). Everyday difficulties were found to explain the most significant variance in three identified aspects of well-being (life satisfaction, positive affect and negative affect). This is not unique to teenagers and has also been shown in adult populations, where the negative affect associated with daily stressors was shown to be related to general affective distress and symptoms of an affective disorder 10 years later (Charles, Piazza et al. 2013). McCulloch et al. (2000) stated that minor everyday life events in the lives of young people, such as fights with friends, doing poorly on an exam, enjoying a hobby, and helping other people, had a cumulative positive or negative effect. McCulloch et al. (2000) concluded that these 'external' events had more of an impact on well-being than internalised ideas of self or personality. It seemed that everyday difficulties and major life events provided distinct categories of experience for young people and both had the ability to impact well-being in distinct ways, and therefore both should be attended to when addressing the well-being of young people (Rowlison and Felner 1988, McCullough, Huebner et al. 2000).

2.4.2 What part does well-being play in education?

It has been argued that the recent trend in education policy in England has been to focus on the academic attainment of young people and wider issues of well-being and developmental health have become marginalised (Bonell, Humphrey et al. 2014). This is evidenced by league tables, and a reduction in Ofsted focus on student well-being, and personal, social, and health education (PSHE) programmes being an optional, rather than statutory, part of the curriculum (Bonell, Humphrey et al. 2014). In comparison to schools in England, schools in Australia, Finland, Sweden and Singapore all achieve better academic results, whilst also placing more emphasis on wider developmental aims and well-being (Humphrey 2013, Bonell, Humphrey et al. 2014). The literature suggests that academic attainment and personal well-being are not two separate entities and that they work in harmony (Bradley and Greene 2013, Bonell, Humphrey et al. 2014). Chirkov et al. (2001) found that well-being could be enhanced when young people perceived that the components important to their well-being, particularly autonomy, were being supported by parents and teachers. As well as an enhanced sense of well-being, when their need for autonomy was supported by significant others, participants in this research were more autonomously motivated in their academic environments (Chirkov and Ryan 2001). It has been shown that seemingly unconnected academic and personal aims actually influence each other over time (Masten and Cicchetti 2010, Bonell, Humphrey et al. 2014), and that schools who achieve better than expected academic success also achieve better health status for their pupils (Bonell, Farah et al. 2013, Bonell, Humphrey et al. 2014). The school community can be very important to the well-being of teenagers and the extent to which a young person feels like they belong

to a school has been shown to be a predictor of positive well-being and successful school outcomes (Ahmavaara and Houston 2007).

2.4.3 What is unique about the well-being of teenagers with cancer?

With the increase in survival rates amongst teenagers with cancer, issues of psychosocial adjustment and maintenance of well-being are becoming ever more important and relevant within the literature and care practices (Bitsko, Stern et al. 2008). Survivors of teenage cancer have been shown to experience less satisfaction with their lives compared to healthy controls up to six years post diagnosis and this was predicted by less post-traumatic growth and enduring physical and emotional difficulties (Seitz, Hagmann et al. 2011). Young people with cancer have demonstrated a need for ongoing psychological and emotional support in the survivorship phase, but this need does not always result in seeking support and survivors often “suffer in silence” (p. 530) or rely heavily on the support of friends and family (Wakefield, McLoone et al. 2013). However, despite the potential for well-being related difficulties post-treatment, a study of bone tumour survivors showed that there was also the possibility that survivors would show a more optimistic view of the future than matched controls (Smorti 2012). Bitsko et al. (2008) found that happiness was a more successful predictor of quality of life in teenagers with cancer than the intensity of treatment protocols. Even though happiness does not equate to well-being it suggested that the ongoing well-being of teenagers with cancer was important, not only for their ability to adjust to the presence of cancer in their lives, but also to their longer term quality of life in survivorship. Adjustment to the presence of cancer in their lives is complicated by the shifting uncertainty that teenagers with cancer experience (Woodgate and Degner 2002, Stewart, Mishel et al. 2010), especially when they have experienced “rough spots” (p. 191) in their treatment (Woodgate and Degner 2002). This uncertainty has been shown to be higher for teenagers than children, especially when they are closer to diagnosis, have less cancer knowledge and when their parents report higher degrees of uncertainty about treatment and prognosis information (Stewart, Mishel et al. 2010).

As discussed, young people with cancer can experience alterations to their peer group dynamics. This change in dynamic is important when considered in the context of the moderating effect of peers on subjective well-being. Cancer presents young people with experiences that are not shared by their peers, an often increased level of wisdom and insight compared to their peers, and can “profoundly shape how young people conduct their relationships” (p. 1) (Lewis, Jordens et al. 2013). Compared to males, female teenage patients have been shown to report significantly lower ratings of support from peers and a higher presence of negative emotions and feelings (Wesley, Zelikovsky et al. 2013). This is a particular problem because the study also showed that high ratings of peer support were correlated with feelings of well-being (Wesley, Zelikovsky et al. 2013). As well as factors that had a negative

effect on the well-being of teenagers with cancer (such as loss of control), the positive effect of cancer has also been shown through factors such as improvement to personal attributes and strengthened relationships (Wicks and Mitchell 2010).

Appearance changes associated with cancer and treatments have been shown to be a major concern for young people after diagnosis (Williamson, Harcourt et al. 2010). The anxiety surrounding appearance changes can be compounded by being in public places, or through the negative reactions of others. Research has shown that there are gender differences in the way young people react to appearance changes related to cancer. Male patients have a marked reaction to loss of body hair, with it representing a feminisation of the body and an outward disclosure of their cancer status, though they are less likely to receive guidance on how to disguise or prevent hair loss (Hilton, Hunt et al. 2008). Female patients were less anxious about weight loss, which was attributed to media pressure on females to be thinner and for males to be more muscular (Hilton, Hunt et al. 2008). This supports the thematic findings of other studies with young male cancer patients, which provided evidence of experiences linked to loss of masculinity in this population (Carpentier and Fortenberry 2010, Campbell-Enns and Woodgate 2013).

Teenagers seemed more able to adjust to these body image difficulties when they were well supported by friends and family (Williamson, Harcourt et al. 2010). Three themes of support that were reported as valued by participants in this study were; friends and family still telling them they were beautiful, peer-shielding and parental shielding. Unconditional positive reinforcement from parents was an important part of adjustment to changing appearances, but young people found the positive opinions and comments of peers more valuable to their feelings of well-being regarding their body image and confidence about “removing camouflage” (p. 172) (Williamson, Harcourt et al. 2010). Both parents and peers provided shielding that was valued by the young people, which involved protecting the young people from negative reactions of others, or situations where they might encounter negative reactions. Parents provided additional shielding by helping their children to maintain their peer shield through facilitating their ongoing engagement with their peer group (Williamson, Harcourt et al. 2010).

The issue of orientation in time as an important factor in the well-being of teenagers is complicated by cancer and is discussed by Lombard et al. (2013). A diagnosis of cancer produces a break in the young person’s normal developmental process and establishes a before and after. Lombard et al. (2013) described the role of a therapist of teenagers with cancer is to help with “putting signifiers back in a temporality in order to restore a continuous feeling of existence” (p. 49). In contrast, it has been shown that there could be a role for mindfulness based interventions for teenagers with cancer that could have a positive impact on the well-being and quality of life in this population (Jones,

Blunda et al. 2013). Mindfulness training could benefit teenagers with cancer by orientating them in the present, rather than focussing on the “un-fixable past” or the “fearfully imagined future” (p. 2150) (Jones, Blunda et al. 2013). This is in contrast with the future orientation approach seen in non-cancer areas of the well-being literature and reflects the unique needs of the teenage cancer population.

In summary, the literature suggests that well-being is multi-faceted, involving internal and external influences across a range of life domains. The personality and approach to reality of the young person seem like important factors in the maintenance or development of well-being, but also the behaviours and attitudes of peers, parents and teachers. It seems unclear whether young people with cancer should orientate themselves in the present or the future to enhance their well-being in the face of cancer-specific stressors and everyday challenges. Both approaches seem to have advantages and disadvantages. It appears that engaging in education and feeling part of a school community with peers could be a factor in the well-being of young people, but that perhaps this is not equally encouraged or recognised in different countries.

2.5 Limitations of existing research

The literature review showed that there was the need for further research specifically focusing on the education engagement of teenagers with cancer, compared to younger children, as they inhabit distinct psychosocial contexts, generating unique challenges and support needs. Extant research that has focussed on the educational engagement of teenagers does so only as a small sub-section of broad psychosocial investigations of the population. This has led to intriguing findings such as; the worst pain associated with having cancer was, ‘being teased about their appearance when returning to school’ (Palmer 2000). However, including education in this type of broad context is limited in so much as the research does not have the specific focus and detail to examine the intricacies of this area and further develop the more general findings.

There was also inconsistency within the limited evidence available in this area. It was unclear whether successfully maintaining education during treatment had a direct impact on education and vocation. It also proved difficult for existing research to demonstrate any clear and consistent quantitative results relating to academic and vocational outcomes for teenagers with cancer compared to healthy controls.

There have been some studies reported in this chapter that have allowed teenagers to express their views on their experiences. However, because there is limited research focussing specifically on the education engagement of this population, and no detailed investigation of the intricacies of the qualitative experiences of these young people, the literature is still missing a clear teenage voice. This further reinforced the second overall aim of this thesis, which was to provide a patient-centred

evidence base in this area. Since the 1980s researchers have been increasingly interested in the perspectives of young people (Cook and Hess 2007) and the 1989 'Convention on the Rights of the Child' stated that 'the child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child . . .' (Unicef 1989). More recently, the U.K's National Service Framework for Children and Maternity Services prioritised the active involvement of young people in the development of services (Health 2004). Also, the children's rights movement and research associated with the inter-disciplinary new social studies of childhood (N.S.S.C) have included the views of teenagers and children on decisions affecting policy, practice and research (Weller 2012).

When there is a lack of research in an area it seems logical to begin with collecting information directly from the main people involved in that area, in this case that is teenagers with cancer. By using appropriate methods to collect this information, this teenage voice should provide increased authenticity to the research and subsequent conclusions. The idea of offering teenagers with cancer the opportunity to directly report their experiences and therefore have a central role in developing research in this area, is also in keeping with the developing philosophy of the clinical and support services offering care to this group (Fern, Taylor et al. 2013, Gibson 2014).

There was a lack of research aiming to understand education engagement in a wider context of coping and well-being for this patient population. The school environment provides teenagers with everyday opportunities for personal development, peer interaction, social activities and emotional experiences. There are obviously other avenues for young people to engage with these opportunities as well, such as family relationships and friendships not linked to education. However, if a diagnosis of cancer impacts a teenager's ability to engage with their education, then it seems worthwhile to assess how, and if the level of this impact affects psychological and emotional variables. Observations within my professional experience showed that teenagers who were more successful in maintaining engagement with their education during their treatment appeared to feel less isolated, seemed more confident and less solely focussed on their illness and treatment. There were many variables that seemed to influence how successful teenagers were in this endeavour and therefore it offered an interesting avenue for research.

Data collection from questionnaires distributed in the early stages of this research (see Chapter 3), as well as aspects of the literature review, also demonstrated that support for teenagers with cancer to continue engagement with their education after being diagnosed was felt by to be unsatisfactory. This conclusion was drawn from teenagers as well as practitioners and further highlighted the need for service development in this area. The need for service development coupled with the lack of research

literature in this area provide a significant proportion of the motivation and justification for this research.

Chapter 3 - Studies One & Two, Questionnaire studies (Pini, Gardner et al. 2012)

Figure 3.1 shows the flow-chart developing the linkage between the chapters and shows that the findings of the previous chapter were carried forward into the development of the studies present in the current chapter.

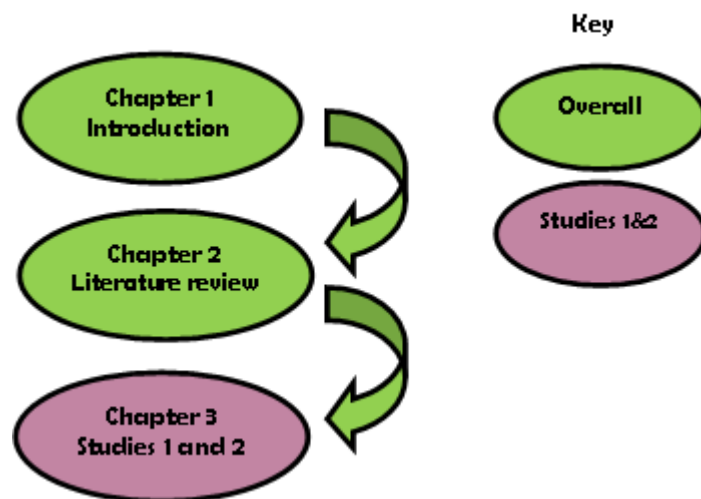


Figure 3.1 - Chapters flow-chart

The literature review in the previous chapter pointed to the importance of assessing the current state of education engagement for teenagers with cancer and the relative importance of psychological variables. Some of the findings from chapter two have been used as the foundation of question development in the studies reported here in chapter three. These studies were conducted with two groups: study one was with teenagers with cancer; and study two involved practitioners working in TYA oncology.

The research questions that are addressed in this chapter are as follows:

- 1- What are the current opinions and experiences of teenagers with cancer regarding their experiences of education and the support they have received?
- 2- What are the experiences of TYA oncology practitioners around education engagement with young people with cancer?
- 3- Is there any evidence of relationships between different factors involved in the ongoing education engagement of teenagers with cancer?

3.1 Methodology

The data in these two studies was solely collected using questionnaires, with separate questionnaires used for each sample.

3.1.1 Sample – study one

To participate in this research, teenagers needed to be 13-16 years of age at the time of diagnosis. This age range was selected because the homogeneity of the educational pathways experienced by the majority of this group allows for greater generalisation of findings.

One of the initial difficulties with study one was access to a substantial population of teenagers with cancer. The 'Find Your Sense of Tumour Conference' (FYSOT) is an annual conference organised by the Teenage Cancer Trust to which young people with cancer from across the U.K, and from teenage cancer organisations across the world, are invited to attend. It is unique in its focus on young people as opposed to the practitioners working with them. It offers a variety of presentations, information, discussions and activities all aimed at improving young people's understanding of cancer and to offer a chance for them to interact with each other and specialist practitioners. The conference averages an attendance of 300-400 TYAs with cancer and therefore provided the ideal location for recruiting participants for this study.

As well as the previously described elements of the FYSOT conference, there are also research sessions. In these sessions the Teenage Cancer Trust survey the conference attendees on a range of issues linked to teenage cancer. Education issues have not previously been explored in depth at this conference, with the conference focussing more on medical issues such as delays in diagnosis and location of treatment. However, education was briefly addressed at the 2004 FYSOT conference, where it was discovered that 36% of respondents reported difficulties in communicating with others following their cancer diagnosis and returning to school, and 81% reported that no healthcare professional came to their school to provide information to staff and peers (Smith 2007). This information was primarily gathered to assess the need for and effectiveness of one of Teenage Cancer Trust's awareness raising services, rather than an assessment of education in its own right. Therefore, there was no existing education data to be drawn upon from previous FYSOT conferences. The questionnaire for study one was included in the survey session at the 2010 FYSOT conference (Appendix 1).

3.1.2 Sample – study two

A similar access problem was possible for the recruitment of practitioners from this area. Teenage and young adult cancer services are distributed across the country and this distribution is not equitable. Fortunately there were two organisations that operated e-mail circulation lists for TYA oncology practitioners for research and professional purposes. These organisations were; the Teenage Cancer Trust Multidisciplinary Professional Forum (TCTMDF) and the Teenage and Young Adult Cancer

research group (TYAC). The practitioners in this study were approached through these networks and a copy of the initial email can be seen in Appendix 2. For inclusion, they needed to have been working within teenage oncology for at least six months to be able to adequately reflect on the experiences of teenagers with cancer.

3.1.3 Data collection

Ethical approvals for both study one and study two was obtained through the University of Leeds before data collection could commence (Appendix 14a). Both studies required the one-off completion of a questionnaire, which did not pose considerable ethical issues or risk of harm to participants in itself. The main ethical issues were the degree to which informed consent could be obtained and the rights of the participants to withdraw their data. Participants in study one were informed that they would be asked to take part in a research survey at the FYSOT conference and that their participation would be optional. Their consent was implied by their choice to complete the survey. If participants in study one wanted to withdraw any of the data they provided at the conference they could contact the FYSOT organisers or practitioners from their local Teenage Cancer Trust unit. Participants in study two were invited to participate via email that contained clear information about the study and advised them that their consent was implied in their choice to complete the survey. They were given my details so that they could contact me for any reason, including to request withdrawal of their data. As this email was sent via professional networks, participants could also contact the administrators of these networks with any concerns or questions.

The teenage and practitioner questionnaires (Appendices 1 and 2) were developed using outcomes generated from a SRR of literature regarding the education engagement of teenagers with cancer (Pini 2012) described in chapter 2. The review implicated the following as key areas for further research; school attendance, reintegration, maintaining peer groups and long-term effects on attainment and employment. To help provide focus within this study apprenticeships and other vocational pathways have not been included. These are important pathways for some teenagers and will need to be researched within this topic in the future, but for the current research project their inclusion will dilute what can be concluded about the sample. Questionnaire items were then discussed with practitioners from local TYA oncology services, who approved the content and advised on tailoring response options to facilitate teenagers' comprehension. For example, response options to a question about time missed from school included quantifiable amounts of time ("several weeks") as well as more general responses ("very little"). For teenagers, the questionnaire items relating to education were incorporated into a larger questionnaire administered at the FYSOT conference, which included items pertaining to diagnosis, health service evaluation and treatment experiences. Teenagers responded to the questionnaire via hand held devices that assigned each respondent a number, making it possible to

link their answers to socio-demographic items whilst keeping their responses anonymous. All of the education questionnaire items (Table 3.1) were completed consecutively and at one sitting in which participants were shown questionnaire items on a large screen and were asked to select from multiple choice options presented using Likert ratings.

Table 3.1 - Teenage questions

<p>47) How much of a priority is it for you to continue with your education at the moment?</p> <ol style="list-style-type: none"> 1. Very important 2. Quite important 3. Not that important 4. Not important at all 5. I have finished my education 6. I am not a cancer patient
<p>48) How much education did you miss during treatment?</p> <ol style="list-style-type: none"> 1. Very little – a matter of days 2. Some –several weeks 3. Quite a bit- a few months 4. A lot – I missed a about a year 5. I was not in education when I was diagnosed 6. I am not a cancer patient
<p>49) Have you returned to full time education?</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. I haven't finished treatment 4. I had already finished my education when I was diagnosed 5. I am not a cancer patient
<p>50) Has missing time from education affected your friendships?</p> <ol style="list-style-type: none"> 1. My friends have all been supportive 2. I have lost some friends 3. I have lost a lot of friends 4. I was not in education when diagnosed 5. I am not a cancer patient
<p>51) What was it like going back to education?</p> <ol style="list-style-type: none"> 1. Easy, I didn't have any problems 2. Took a while to settle back in 3. Quite hard 4. Very hard, I really struggled 5. I haven't gone back to education 6. I'd left education when diagnosed 7. I am not a cancer patient
<p>52) Does the way you feel about yourself or the way you think you look, affect whether you go to school/college/university?</p> <ol style="list-style-type: none"> 1. No, I always go when I can 2. Not really 3. Sometimes 4. Yes 5. I was not in education when diagnosed 6. I am finished education 7. I am not a cancer patient
<p>53) The education support you received during treatment was...</p> <ol style="list-style-type: none"> 1. Very good 2. Okay 3. Not good enough 4. Non-existent 5. I was not in education when diagnosed 6. I am not a cancer patient
<p>54) Where did the majority of your education support come from during your treatment?</p> <ol style="list-style-type: none"> 1. Teachers at school/college/university 2. Other staff at school/college/university 3. Education staff at hospital 4. Health staff at hospital 5. Parents 6. Home tutor 7. Other 8. I received no help 9. I was not in education during diagnosis
<p>55) Have your education plans changed since you were diagnosed?</p> <ol style="list-style-type: none"> 1. Yes, they are now completely different 2. Yes, they are slightly different 3. No

- | |
|--|
| 4. I was not in education when I was diagnosed |
| 5. I am not a cancer patient |

Practitioners in study two were invited to complete an online version of the questionnaire (Figure 3.2) via the TCTMDF or TYAC email circulation lists. The questionnaire items covered the same areas as the young people’s questionnaire, but were worded to capture responses from a professional viewpoint. The practitioners were asked to reflect on their experience of working with teenagers with cancer in relation to maintaining their education. They were also asked to rank order the issues identified in the SRR in terms of the impact they felt each issue has on the education engagement of patients (Figure 3.3). Open ended questions regarding the major barriers to education and what could facilitate engagement for teenagers were also included.

1. In general, how much of a priority do you think it is for patients to continue with their education during their treatment?
2. Below is a list of factors that could influence a patient’s satisfaction with education. Please rank these factors in order of importance by putting a number in each of the boxes
3. If possible, could you please provide an example from your experience to illustrate your selections?
4. What are the main barriers to patients continuing with education during their treatment?
5. In your experience, what facilitates patients continuing with education during their treatment?
6. What do you think of the standard of education support available to patients during their treatment?
7. Who do you think provides the most valuable education support to patients during treatment?
8. What changes could be made to minimise the impact of a cancer diagnosis on a teenager’s education?

Figure 3.2 - Practitioner Questions

Below is a list of factors that could influence a patient’s satisfaction with education. Please rank these factors in order of importance by putting a number in each of the boxes.	
Please give each factor a different ranking score (1 = the most important, 10 = the least important).	
School attendance	Self-esteem
Independence	Academic achievement
Future education/career plans	Reintegration after treatment completion
Relationships with peers at school	Behaviour at school
Reintegration during treatment	Body image in relation to school

Figure 3.3 - Ranking Educational Issues

3.1.4 Data analysis

Questionnaire data were investigated through a statistical software package (SPSS 18.0) using Spearman’s correlation, frequencies and descriptives. Data generated by the open ended questions in the practitioner questionnaire were subjected to content analysis whereby key themes were identified.

3.2 Results

3.2.1 Study one demographics

Approximately 400 TYAs with cancer attended the 2010 FYSOT conference, 259 of whom engaged in the research survey session. One hundred and eighteen delegates from this sample were diagnosed between 13 and 16 years of age and were therefore eligible for this research. Eighty-eight teenagers, aged 13-16, (M=14.49, SD=1.29) completed the education questionnaire and were entered into the analysis. The sample consisted of males (n=39) and females (n=47) and a range of diagnoses were represented (Table 3.2).

Table 3.2 - Participant Demographics

	n	%		n	%
Gender			Age at diagnosis		
Male	39	44.3%	13	22	25%
Female	47	53.4%	14	23	26.1%
Missing	2	2.3%	15	21	23.9%
			16	22	25%
Age of participant			Cancer type		
14	3	3.4%	Leukaemia	22	25%
15	5	5.7%	Lymphoma	18	20.5%
16	9	10.2%	Bone	15	17%
17	26	29.5%	Brain/spine	15	17%
18	20	22.7%	Other	17	19.4%
19	13	14.8%	Missing	1	1.1%
20	4	4.5%			
21	3	3.4%			
22	4	4.5%			
Missing	1	1.1%			

3.2.2 Study two demographics

Members of the TCTMDF and the TYAC were invited to participate. Consent was indicated in their response to an email invite to participate and anonymity was offered by making the identifiable information (e.g. workplace and job role) optional. Forty healthcare practitioners from a variety of disciplines and with varying degrees of experience (Table 3.3) completed the online questionnaire. Only eight of the practitioners chose not to offer demographic information.

Table 3.3 - Healthcare Practitioner demographics N= 40

Experience	n	Job role	n
6mth – 1 year	4	Clinical/Lead Nurse Specialist	10
1 year – 2 years	6	Youth Worker	5
2 years – 5 years	5	Consultant	5
5 years – 10 years	8	Ward/ Clinic Nurse	4
10 years +	9	Social Worker	3
Not given	8	Other Health Professional	5
		Not given	8

3.2.3 Study one data

In this section the main findings from the FYSOT conference education questionnaire will be reported.

Sixty-five per cent (n = 57) of teenage participants felt that it was 'very important' to continue with education during treatment, with only 7% (n= 6) responding 'not important at all'.

Over 50% (n=48) of respondents had missed a year from school, with a further 28% (n=25) missing at least a few months. Regarding reintegration after missing time from school, only 17% (n=14) of respondents said that their reintegration had been easy for them, with the remainder saying that it had taken them a while to settle back into school or it had been a difficult experience. The impact that body image had on reintegration was evenly distributed across the sample with 39% (n=32) saying that they always went to school when they were able to and 41% (n=34) saying that body image had some effect on their willingness to attend school.

In terms of the supportive factors experienced by teenagers there was an even distribution with 26% (n=23) saying their education support was very good and 23% (n=20) saying that it was non-existent, the remainder saying it was okay (33% n=29) or not good enough (16% n=14). The majority reported that their main source of education support came from school teachers (37% n=31), hospital education staff (15% n=13) or home tutors (15% n=13). When the sources of support were grouped into school, hospital and other, school showed the most support (41% n=35), followed by other (25% n=21) and hospital (17% n=15). Within this question there was also an option for participants to report that they had received no support, and unfortunately this was reported by 15% (n=13) of the sample.

The effect that their cancer diagnosis had on their peer group was again evenly distributed with 44% (n=38) saying that their friends had all been supportive, 34% (n=29) saying they had lost some friends and 21% (n=18) saying they had lost a lot of friends.

Another interesting result was that only 24% (n=20) said that their educational and vocational plans were still the same as pre-diagnosis, with the remainder saying that their plans were slightly (37% n=31) or completely different (37% n=31).

Correlations were investigated using Spearman's rho and the main findings are reported (Table 3.4). Teenagers who reported well maintained peer groups were significantly more likely to also report: easy reintegration to school ($r=.364$, $p=.001$), low impact of body image on reintegration ($r=.282$, $p=.011$) and high ratings of education support ($r=.273$, $p=.012$). Teenagers who reported easy

reintegration into school were significantly more likely to also report high ratings of educational support ($r=.443$, $p<.001$) and fewer absences from school ($r=.312$, $p=.005$). An additional factor related to reintegration was the significant relationship between the priority placed on education by a patient and whether they had returned to full time education ($r=.393$, $p=.000$).

Table 3.4 - Correlations in teenage data

Variable 1	Variable 2	Spearman's r	Sig. P - value
Peer Support	Reintegration	$r = .364$	$p = .001$
Peer Support	Body Image	$r = .282$	$p = .011$
Education Support	Peer Support	$r = .273$	$p = .012$
Education Support	Reintegration	$r = .443$	$p = .001$
Reintegration	School Absence	$r = .312$	$p = .005$
School return	Education Priority	$r = .393$	$p = .000$

Relationships between the demographics and the responses to the research questions were investigated using the Chi-square statistic. Responses to the question 'who provided the majority of education support' were grouped into three categories; 'school' (teachers and other staff at school), 'hospital' (education or health staff at hospital) and 'other' (home tutors, parents and other). When teenagers identified school as providing the majority of education support they were significantly more likely to report that their peer groups had been well maintained ($\chi^2=17.71$; $df=6$; $p=.007$). The relationship between gender and priority given to education approached significance ($\chi^2=7.7$, $df=3$, $p=.053$) with slightly more girls placing a high priority on education than boys. There was no significant effect of cancer type on any of the questionnaire responses.

3.2.4 Study two data

In this section the results of the practitioner questionnaire will be reported.

Q. In general, how much of a priority do you think it is for patients to continue with their education during their treatment?

Practitioners considered it very important for teenagers who are undergoing treatment to continue with education ($M = 1.3$, where 1 = 'very important' and 5 = 'not important at all').

Q. What do you think of the standard of education support available to patients during their treatment?

Practitioners did not perceive teenagers were getting the educational support they required, with a mean score of 2.2 (1 = No support, 2 = Not good enough, 3 = Satisfactory, 4 = Good and 5 =

Excellent). No practitioner said that educational support was ‘non-existent’, but neither did any say it was better than ‘satisfactory’.

Q. Below is a list of factors that could influence a patient’s satisfaction with education. Please rank these factors in order of importance by putting a number in each of the boxes.

Practitioners were asked to rank ten factors identified by the SRR by ordering them from 1-10 (1 = most important, 10 = least important). ‘Relationships with peers’ was rated by practitioners as the most important factor influencing teenagers’ satisfaction with education. This variable had the lowest mean ranking score (3.9) and the highest frequency of practitioners ranking it as the most important factor (n=8) (Table 3.5).

One participant reinforced their selection by saying that:

“I think that the vast majority see education as a link with friends and the social side of ‘normal’”

Another stated that:

“In my experience tackling reintegration while on treatment by engaging the school and peers leads to an environment where the young people feel safe going back to school”.

Table 3.5 - Factors in education satisfaction

Item	Mean ranking	No. 1 rankings
Relationships with peers at school	3.9	8
Self-esteem	4.1	6
Independence	5.2	0
Body image in relation to school	5.4	2
Future education/career plans	5.5	0
Reintegration after treatment completion	5.6	1
Reintegration during treatment	5.9	2
Academic achievement	6.5	0
School attendance	6.8	2
Behaviour at school	7.6	3

Q. What are the main barriers to patients continuing with education during their treatment?

The key perceived barriers to teenagers accessing education whilst undergoing treatment were:

- i) unrealistic expectations from patients/parents/schools (n=15)
- ii) toxicity/hospitalisation (n=9)
- iii) practicalities of accessing education (n=6).

Q. In your experience, what facilitates patients continuing with education during their treatment?

Practitioners felt that education engagement was improved when there was effective liaison between hospital, home and school (n=11), as well as informed support from family and peers (n=10). The flexibility of the school staff was also perceived as important (n=12) as one respondent stated:

“Committed teaching staff at schools- people who are willing to fight for the patient and to give a bit more time to their education and to understand their needs [can facilitate education]”.

The potential for body image to impact the self-esteem of the teenagers, and for this in turn to affect peer interactions and school attendance, was commented on by four practitioners. This was highlighted by the following extract:

“body image / self-esteem is high on the teenager’s agenda and needs to be recognised by us workers and taken seriously”.

However, the positive impact returning to education could have on body image and self-esteem was raised by a participant:

“re-joining the course improved her self-esteem and body image after an amputation and boosted her confidence immensely”.

Q. Who do you think provides the most valuable education support to patients during treatment?

There was no consistency from practitioners from different geographical areas in response to this question. The variety of responses included; family (n=4), friends (n=2), home tutor (n=1), learning mentor (n=1), hospital school (n=4), health care practitioners (n=4), youth support worker (n=2), school teachers (n=4), social worker (n=2), head of year (n=1), pastoral care staff (n=1) and the patient themselves (n=1).

A participant commented:

“This varies as to patients’ needs from both an educational and health perspective - best approach is multi-agency. I can't answer the question below as it varies from County to London Borough, to school/college/university and no two are the same!”

Three respondents to the above question acknowledged that support should be individually tailored to the needs of the individual teenager, and should involve multi-disciplinary working encompassing school, hospital and home.

Q. What changes could be made to minimise the impact of a cancer diagnosis on a teenager’s education?

Six respondents highlighted the need for a specialist practitioner who could solely focus on facilitating education engagement for teenagers.

A participant commented:

“Having someone in post to concentrate on that specifically...not sufficient to have it just as a small part of someone’s role”.

Five respondents said that they were limited by an inflexible education system and that increased flexibility for teenagers with cancer would allow them to tailor their education provision more successfully. Five respondents felt that education issues should be more successfully integrated into routine clinical practice and be understood and considered by healthcare professionals from diagnosis onwards. Four respondents thought that community schools who were more considerate and flexible towards the specific needs of teenagers with cancer would improve education engagement.

3.3 Discussion

A range of factors involved in the education engagement of teenagers with cancer were explored in studies one and two, including; school attendance, reintegration, maintaining peer groups and long-term effects. Education is an important element of the psychosocial care of teenage cancer patients and an area where there is a need to further develop services to facilitate teenagers’ ability to engage with education during and after treatment.

Findings from study one point to a potentially important interaction between the maintenance of peer groups, successful reintegration into school and the primary source and quality of education support.

It appears that teenagers with cancer who have more successfully maintained peer groups find it easier to reintegrate back into mainstream school. Where school personnel themselves have provided the primary source of support, and this support is reported as being successful, this also has a positive impact on reintegration and the maintenance of peer groups. This affirms the importance of the teenagers' community school as being an integral part of ongoing education engagement. Ensuring that the community school plays a leading role in education support can improve peer group maintenance and ultimately contribute to successful reintegration. Further research will be needed to assess the direction of cause and effect, as it is unclear from the findings of the questionnaire what factors have the strongest influence on successful outcomes in this area. In study one, higher rates of absences from school correlated with poorer experiences of reintegration, indicating that this could also be an important factor in successful reintegration, however, study one did not probe any potential reasons for absences. Previous work has shown that returning to school after a diagnosis of cancer can be a major challenge for young people and staff (Koch 2004) and a primary concern as early as diagnosis (Decker 2004). This concern can stem from young peoples' fears about being accepted back into their peer group and having to build new friendships (Decker 2004, Duffey-Lind 2006). Alongside peer group issues young people have been shown to worry about being teased or bullied about their appearance due to hair and weight loss (Drew 2007). Interestingly this is a factor from the teenage questionnaire which significantly correlated with reintegration and peer group maintenance.

The practitioners in study two clearly articulated the need for successful liaison between education institutions, hospital and home, in order to facilitate the education engagement of teenagers. Previous research has also showed that without this collaboration, services for teenagers are likely to be compromised (Moore 2009). Practitioners in study two identified flexibility and realistic expectations of education staff as being a potential barrier to successful collaboration. Successful collaborative planning and information sharing has previously been shown to increase the understanding of the ability of teenagers with cancer to engage in education activities (Hokkanen 2004, Mitchell 2006). Even though the present study suggests the teenagers' mainstream school as a good primary source of education support, specialist teenage oncology practitioners need to be involved in collaborative planning with schools, as their absence has been shown to increase the stress experienced by teenagers undergoing treatment through a lack of understanding of their needs (Grinyer 2007). This collaborative planning should include strategies to maintain academic studies whilst in hospital and at home, whilst identifying and facilitating appropriate access to mainstream school where possible. Alongside academic studies, planning should include approaches to maintain meaningful contact with peers and early-stage planning for eventual successful reintegration. To facilitate a smooth and effective reintegration, parents have previously said they would like teachers and peers to be better informed about their child's cancer (Mitchell 2006).

In different areas of the U.K. there are currently a wide variety of practitioners providing education support to this population of young people, which was highlighted by responses in the practitioner questionnaire in study two. Despite this variety of practitioners, it was still reported by teenagers and practitioners in this research that support was unsatisfactory, and indeed some teenage participants still reported receiving no support at all. This may be due to confusion arising about the responsibility practitioners have for specific areas of education support (Moore 2009) or because of the time available for practitioners to understand the specific needs of individual young people and tailor plans accordingly, when many have other responsibilities. Several practitioners in this research felt that a specialist practitioner dedicated to providing education support and co-ordination would improve the service provision in this area. It has previously been shown that where there is no practitioner specifically assigned to co-ordinate education for teenagers with cancer, it is desired by families as well as practitioners (Mitchell 2006, Moore 2009). A specialist learning mentor role has been successfully implemented in Leeds and has demonstrated benefit to TYAs with cancer, staff and families through clear coordination of individualised education plans and increased advocacy for the educational needs of young people (Pini 2009).

3.4 Limitations

The population of teenagers with cancer engaged in study one were exclusively sampled from the FYSOT conference. It is possible that teenagers attending the conference could have had homogeneity of characteristics that may have biased the results. This research sample could have been more motivated and engaged than a sample of teenagers not willing to attend the conference. This has potential implications for the engagement with and experience of education expressed in this research. Some teenagers may not have been clinically well enough to attend the conference and therefore this research sample may not have included those teenagers with more acute symptoms and side-effects. Participants at the FYSOT conference were responding to questionnaire items in a group situation, which may have elicited different responses than in a one to one situation where there would be less potential influences on responses e.g. answers provided by friends. The questionnaire also limited respondents to a predetermined set of response options and did not allow any depth of detail or room for individual circumstances.

It is perhaps reflective of the predominantly healthcare based sample used in the practitioner questionnaire in study two, that factors associated solely with education were rated as the least important ('academic achievement', 'school attendance' and 'behaviour at school'). It must also be acknowledged that some respondents to the practitioner questionnaire will have known that I have previously been employed as a specialist learning mentor within TYA oncology services and this may in turn have affected their responses.

3.5 Re-visiting the overall aims

Aim one, as stated at the end of chapter one, was to assess the current state of education engagement for teenagers with cancer and the relative importance of psychological variables. Studies one and two have shown that education engagement is an important psychosocial issue for teenagers with cancer and practitioners in this area. The current support available to teenagers is not experienced as adequate to the needs of this population and has the potential to be improved. In accordance with findings from the literature review, the findings of studies one and two highlight the importance of psychological and social variables as well as academic variables in successful engagement with education and overall satisfaction with education experiences.

Aim two was to produce an evidence base for the area of education engagement that is centred on the opinions and experiences of teenagers with cancer. Study one has contributed to this aim by providing data gathered directly from teenagers with cancer. This data has highlighted some potentially interesting relationships between variables associated with education and these need to be investigated further to be understood in more detail. Data from studies one and two has been published in a peer reviewed journal and is therefore forming part of a fledgling literature base in this area.

Aim three was to provide evidence and recommendations for the future development of services to appropriately support teenagers with their education. Studies one and two have contributed to this aim to some degree, but further detail is required. Successful reintegration into mainstream schooling seems to be an outcome of collaborative planning between hospital and mainstream education practitioners to address important non-academic issues, primarily peer group maintenance and body image, alongside academic variables. Collaborative planning should be initiated when a teenager is diagnosed with cancer and aim to address the variety of academic and non-academic variables that can influence successful maintenance of education engagement and ultimately facilitate successful reintegration into mainstream schooling.

3.6 Implications for study three

Based on the findings of studies one and two further research is needed to understand the nature of the relationship between education engagement and teenagers' cancer experiences as a whole, as well as gaining a more in depth understanding of how teenagers experience their education after a diagnosis of cancer. To achieve this, the next study in this research may benefit from adopting a qualitative interview based methodology that would allow teenagers to describe their experiences and express themselves in their own words. Further assessment of psychological variables for this group would enhance the assessment of the importance of these issues in relation to education engagement.

Overall what is missing from the literature and the findings of studies one and two of this research is an in depth understanding of the qualitative impact a diagnosis of cancer has on an individual teenager or group of teenagers. The interdependency of the academic and non-academic variables associated with education engagement for this group is hinted at, but not assessed in any detail, and this will be an important contribution to the current evidence base. This will be essential for a more complete understanding of the impact a diagnosis of cancer has on the education engagement of teenagers and for making informed recommendations for future service developments in this area.

Chapter 4 - Study Three, Methodological Framework

Figure 4.1 shows the flow-chart developing the linkage between the chapters and shows that a combination of the findings of the studies presented in the previous chapter and the literature presented in chapter two have been used to develop the methodology presented in the current chapter.

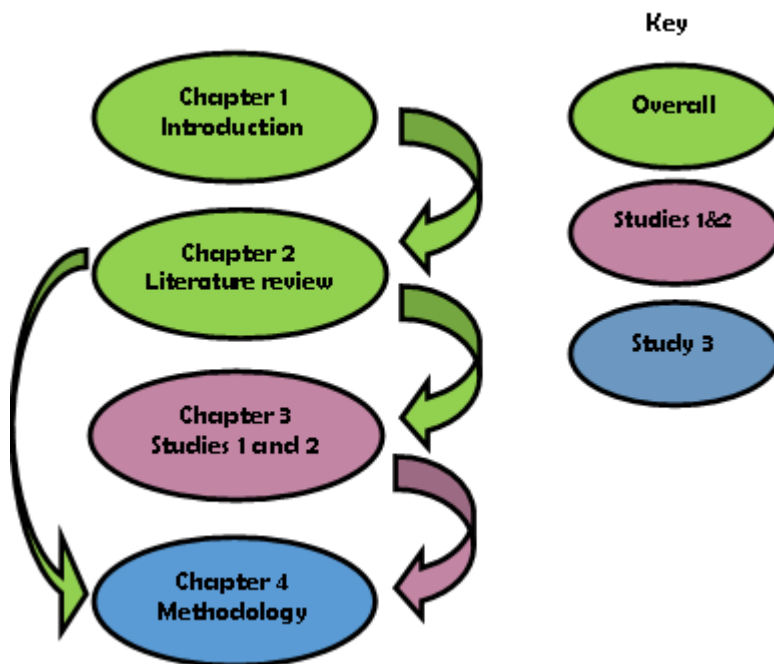


Figure 4.1 - Chapters flow-chart

The literature review, detailed in chapter two, showed that there was very limited research published that focussed on the education engagement for teenagers with cancer and the psychological and social processes involved. Studies one and two, reported in chapter three, showed that education engagement was important to teenagers after a cancer diagnosis and that teenagers and oncology practitioners did not think that the support offered to patients in this area was sufficient. Giving teenagers with cancer the chance to report their experiences via the survey in study one provided the first step towards a teenage voice in the literature in this area. Study three aimed to add to the findings reported in chapters two and three by providing a more in depth qualitative understanding of the education experiences of teenagers with cancer, how these experiences affected their overall cancer experience and to what extent these experiences changed over time. This chapter will detail the methodological theory underpinning the research carried out in study three, but the practical application of this methodology will be detailed further in chapter six.

Study three adopted a qualitatively led longitudinal mixed methods approach combining visual/’go-along’ interviewing with psychometric measures. Each aspect of this research design will be covered

in this chapter along with the underlying epistemology, the method of analysis and the quality assessment procedures. There will also be a report about a pre-study consultation phase with teenagers and practitioners. This chapter concludes with the specific research questions that will be investigated in study three.

4.1 Theoretical foundations of study three

4.1.1 Epistemology

Epistemology refers to “what we regard as knowledge or evidence of things in the social world” (p. 16) (Mason 2002). The decisions that researchers make about what research to conduct, what questions to ask and what methods to employ, all reflect underlying epistemological stances regardless of whether these are overtly stated (Feilzer 2010).

Alongside the personal and academic benefits of conducting this PhD research, I aim to arrive at outcomes that can be used in the future to better understand the experiences of teenagers with cancer and practically develop and improve services designed to care for and support them. Alongside these aims I would also like the data that leads to the research outcomes to be primarily generated directly from the opinions, perspectives and experiences of the population in question, as this is a significant gap in the literature and in keeping with the patient-centred philosophy underpinning teenage cancer care. However, I think that my existing experience and knowledge in this area also has the ability to positively contribute to the co-construction, and subsequent understanding, of the participants’ accounts of their education experiences.

Adopting a pragmatic epistemological stance seems in keeping with research that has the aims outlined above. This pragmatic framework has been used to develop a methodological approach that is appropriate to produce outcomes that are useful to achieving these aims. Traditionally the main epistemological paradigms that are opposed to each other in research are positivism/postpositivism and constructivism/interpretivism (Feilzer 2010). Positivism deals with the discovery of objective realities and has traditionally underpinned quantitative research, whereas constructivism claims that reality is primarily constructed subjectively and is therefore more allied with qualitative methodological approaches. A pragmatic approach is anti-dualist (Rorty 1999) in nature, accepting that there are both singular and multiple realities, and looks to bring together quantitative and qualitative methodology to best answer real world questions and address real world problems (Dewey 1958, Rorty 1999, Creswell and Clark 2007, Cornish and Gillespie 2009, Feilzer 2010). Pragmatism is a philosophical standpoint that was developed over a century ago by American philosophers Charles Sanders Peirce, William James, John Dewey and George Herbert Mead (Cornish and Gillespie 2009). Pragmatism adopts a common sense approach to the research methods selected for the investigation of

a subject and this 'toolkit' approach is a view that seems to be endorsed in applied medical and health research (Shaw 2011). By adopting a pragmatic approach researchers can avoid becoming entangled in debates about relativism and realism, and instead enable action and outcome (Cornish and Gillespie 2009). This focus on action and outcome extends beyond the design and execution of the research and becomes the test of the knowledge that has been generated. Therefore, for pragmatism, knowledge is "judged according to its consequences in action" (p. 802) (Cornish and Gillespie 2009). So, a pragmatic approach to epistemology in research changes the question from 'does this knowledge accurately reflect the underlying reality?' to 'does this knowledge serve our purposes?' (Rorty 1999). Indeed, pragmatists argue that there is little to be gained by worrying about how accurately statements made in research represent ultimate abstract realities outside of the context of action (Rorty 1999, Cornish and Gillespie 2009).

In the context of the aims of this research and the pragmatic stance adopted, a co-constructed, but participant led study is the most appropriate methodological approach to explore the primary research questions. This can be achieved through employing methods that allow the participants to have control over the initial generation of data and the structure of the accounts of their experiences. The understanding and meaning of this data is then co-constructed through discussions that allow the participant and researcher to contribute to the articulation of the participant experiences. The researcher can then continue the active interpretation of the data through the analysis and writing up process.

To achieve the above aims, this research will employ visual interviewing as the primary data collection method to explore the education experiences of teenagers with cancer. These interviews will be conducted at three time points over the first nine months of the participants' cancer treatment, which will allow an assessment of change over time and offer a more complete analysis of patient experience. Alongside this primary qualitative method, participants will also complete psychometric measures assessing coping strategies, well-being, self-perception and perception of school, which will create a qualitatively led mixed methods approach.

4.1.2 Mixed methods

Study three is adopting a mixed methods approach including visual interviewing and psychometric measures. Ontologically speaking the measures could be said to assume there are fixed constructs of coping, self-perception and well-being that can be detected by measuring, which would contradict to some extent the constructionist assumptions of the qualitative component of the method. However, pragmatically, the measures offer a previously tested and validated way of gathering additional data

regarding participant's perceptions of themselves in these areas, which can be used in conjunction with the interview data to address the research question.

The 1959 article by Campbell and Fiske (1959) is often credited with formally introducing the practice of mixed research methods (Johnson, Onwuegbuzie et al. 2007). Campbell and Fiske (1959) described triangulation and multiple operationalism where more than one mode of assessment is employed as a way to encourage results that reflected the underlying issues at work in a research topic, as opposed to reflecting the constrictions imposed by the framework of a single method. Mixed methods has been described as both old and new, with a long history in social science, but with a new set of terminology and methods employed by a new and growing community of researchers (Tashakkori and Teddlie 2010). The increasing attention given to mixed methods research has led to a greater understanding of the complexities involved in combining quantitative and qualitative methodologies (Bryman 2007).

Mixed methods have been used to address research questions in a wide range of areas including; education, nursing, demography and development economics (Green and Thorogood 2004), counselling (Hanson, Creswell et al. 2005), political science and comparative politics (Harrits 2011), cultural anthropology sociology (Johnson, Onwuegbuzie et al. 2007), psychology and health sciences (O'Cathain 2009). The percentage of studies commissioned within health services in the U.K. classified as mixed methods was 17% in the mid-1990s, but rose to 30% in the early 2000s (O'Cathain 2009).

Mixed methods has developed significantly in recent years (Bryman 2007) and is considered to be the third major methodological movement, following on from quantitative and qualitative methods (Green and Thorogood 2004, Johnson, Onwuegbuzie et al. 2007, Tashakkori and Teddlie 2010). In fact, it has been argued that mixed methods research provides an answer to the debate surrounding the preferred use of quantitative or qualitative methods (Tashakkori and Creswell 2007, Feilzer 2010). In some areas of health research that focus on quantitatively dominant areas such as clinical drug trials, qualitative methods had previously been dismissed as "poor science" (p. 3) (O'Cathain 2009), until it was shown that they could be employed in combination with the more quantitative elements of clinical research to further understand the subtleties of the application of health interventions (O'Cathain 2009).

Harrits (2011) argues that mixed methods cannot be considered as one single paradigm and follows previous researchers that recognise the presence of different epistemological positions, methodological stances, methods, and practicalities within mixed methods research (Tashakkori and Creswell 2007, Denscombe 2008, Alise and Teddlie 2010). Mixed methods research approaches a

research question with both quantitative and qualitative tools (Johnson, Onwuegbuzie et al. 2007) and attempts to synthesise methodologies that are influenced by different epistemological and ontological perspectives, different approaches to questioning, different data gathering and different analytical methods (Green and Thorogood 2004, Creswell and Tashakkori 2007, Johnson, Onwuegbuzie et al. 2007). Even though quantitative and qualitative research come from different philosophical paradigms they can be “combined in a single study if it is done for complementary purposes” [p50] (Sale 2002). Despite encompassing multiple influences, mixed methods research can be defined by distinctive methodological and practical processes (Green and Thorogood 2004). However, it has also been said that there is disagreement within the mixed methods community about the nature of the mixed methods paradigm (Feilzer 2010). Feilzer (2010) described how different methodologists variously detail one (Tashakkori and Teddlie 1998), three (Creswell and Clark 2007) or four (Greene, Benjamin et al. 2001) alternative stances available within the mixed methods paradigm. It seems that this plethora of approaches to the underlying principles of mixed methods research highlights the flexibility of the approach and therefore further reinforces the previously stated pragmatic epistemological stance of study three. Indeed, Feilzer’s (2010) review of the paradigms underpinning mixed methods research confirms the dominance of pragmatism.

Pragmatism, as detailed earlier in this chapter, provides the main philosophical and methodological underpinning for the mixed methods paradigm (Johnson, Onwuegbuzie et al. 2007, Feilzer 2010).

Table 4.1 - A Pragmatic Alternative to the Key Issues in Social Science Research Methodology

	Qualitative Approach	Quantitative Approach	Pragmatic Approach
Inference from data	Induction	Deduction	Abduction
Connection of theory and data	Subjectivity	Objectivity	Intersubjectivity
Relationship to research process	Context	Generality	Transferability

Table 4.1 taken from Morgan (2007) shows how the pragmatic approach adopted by mixed methods research differs from the singular use of quantitative or qualitative methods in terms of making inferences from the data gathered, the connection of theory and data, and the relationship to the research process. Morgan organises this table by distilling the paradigmatic differences down to three fundamental issues relating to social sciences research. Regarding the ‘inference from data’ row of the table, Morgan acknowledges that in practice no research is conducted in a purely inductive or deductive fashion and that it is impossible to be purely theory or data driven. The abductive approach

adopted in pragmatism is to convert data into theory and then to test theory in action. This abductive approach is often seen in sequential mixed methods studies where the inductive outcomes of a qualitative phase are used to inform the development of deductive quantitative measures or vice-versa. Morgan also describes the traditional differences in quantitative and qualitative research in subjectivity and objectivity as essentially artificial in practical research. The idea of being completely subjective or objective does not seem to apply to conducting research and Morgan claims that researchers “work back and forth between various frames of reference” [p71] (Morgan 2007) and that the term intersubjectivity adequately represents this duality. Intersubjectivity also captures the commensurability that pragmatism strives for, in that in pragmatism there is no difficulty with asserting that an objectively real world exists and that individuals interpret and create their understanding of this world independently (Morgan 2007). The final distinction put forward in Morgan’s table is the applicability of the research to other situations. Morgan does not believe “it is possible for research results to be either so unique that they have no implications whatsoever for other actors in other settings or so generalized that they apply in every possible historical and cultural setting” [p72] (Morgan 2007). The transferability Morgan refers to in relation to pragmatism is the desire to find ways of appropriately applying what is learned in one situation to benefit and inform another.

Over the years researchers and methodologists have tried to define the reasons for using a mixed methods approach. Rossman and Wilson (1985) described three reasons for using mixed methods as; “to enable confirmation or corroboration through triangulation”, “to provide richer data”, and “to initiate new modes of thinking” (p. 115) (Johnson, Onwuegbuzie et al. 2007). Green et al (1989) developed this reasoning by adding the idea that mixed methods could also be implemented by using the results of one method to inform the other within the same research, or expand the breadth and range of the inquiry (Johnson, Onwuegbuzie et al. 2007). This list was updated by Collins et al. (2006) who described four primary reasons for conducting mixed methods research;

- participant enrichment (e.g., mixing quantitative and qualitative research to optimise the sample using techniques that include recruiting participants, engaging in activities such as institutional review board debriefings, ensuring that each participant selected is appropriate for inclusion),
- instrument fidelity (e.g., assessing the appropriateness and/or utility of existing instruments, creating new instruments, monitoring performance of human instruments),
- treatment integrity (i.e., assessing fidelity of intervention), and
- significance enhancement (e.g., facilitating thickness and richness of data, augmenting interpretation and usefulness of findings).

Taken from (Johnson, Onwuegbuzie et al. 2007)

It is this last point of significance enrichment and to provide richer data that is the primary reason for employing mixed methods in study three of this research. Assessing the individual meaning of a cancer diagnosis and the impact this had on the education engagement of a teenager could have been achieved solely through qualitative interviewing techniques. However, the assessment of psychological variables, such as well-being and coping strategies, will be enhanced through the addition of quantitative measures. These psychological variables may well have been discussed in the qualitative interviews, but the measures would have enhanced the data collected in assessment of these variables or provided data in cases where these variables were not discussed.

It has been said that mixed methods can be used when it is acknowledged that the complexities of the phenomenon in question mean that it exists on different levels, and by investigating some of these levels with quantitative methods and some with qualitative methods, mixed methods research provides a more comprehensive approach than using either method in isolation (Green and Thorogood 2004, Tashakkori and Creswell 2007, O'Cathain 2009, Feilzer 2010). Researchers can choose to use a mixed methods approach when the different levels of their research require both generality and particularity (Green and Thorogood 2004) and when there is a need to establish regular patterns, but also to shed light on the variations (Green and Thorogood 2004). Because of the potential complexities of the interactions between the medical variables (cancer, treatment, hospitalisation), individual variables (age, gender, personality), educational variables (individual school, academic ability, educational support) and social variables (friends, family, socio-economic demographics) present in study three, this further contributes to the justification for a mixed methods approach. It was unknown at the outset of this study the degree to which each of these sets of variables would be involved in this dynamic and therefore a multi-layered mixed methods approach seemed to offer the best opportunity to fairly explore all of them.

When setting up a mixed methods study Hansen et al. (2005) describes three main steps;

- Deciding on a theoretical lens
- Deciding how to collect and prioritise the data
- Deciding when data integration and analysis will occur

The theoretical lens in this example is the philosophical underpinning of the research and involves ontological and epistemological assumptions. The choices made in this first step influence the decisions made in the subsequent two steps and the research project as a whole. In study three a pragmatic approach has been adopted to arrive at outcomes that can be useful in understanding and advancing the fields of teenage cancer care and research.

In mixed methods research deciding how to collect and prioritise the data refers to the order in which quantitative and qualitative data will be collected and the priority each of these data sets will have. This can be influenced by two factors; status and sequence (Morse 1991, Johnson, Onwuegbuzie et al. 2007, Harrits 2011). Status refers to the extent to which qualitative or quantitative methods are dominant and sequence refers to the order in which these two methods of data collection are used (Harrits 2011). Figure 4.2, taken from Hansen et al. (2005), shows the nine different possible outcomes when deciding on the status and sequence of qualitative and quantitative methods within a research study. The third step, data integration, refers to the different points within the study where the analysis of the quantitative and qualitative elements will be separate and when it will be combined.

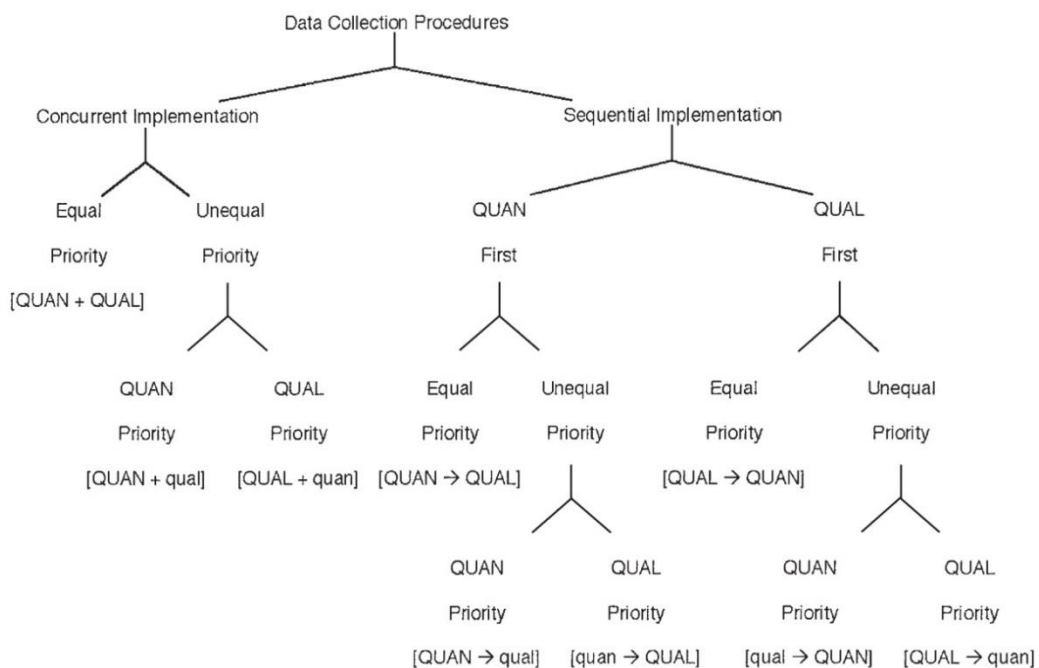


Figure 1. Options related to mixed methods data collection procedures. QUAN = quantitative data was prioritized; QUAL = qualitative data was prioritized; qual = lower priority given to the qualitative data; quan = lower priority given to the quantitative data.

Figure 4.2 - Options for Quantitative/Qualitative balance in mixed methods taken from (Hanson, Creswell et al. 2005)

In study three of this research the quantitative and qualitative data will be collected concurrently, with quantitative measures completed at each time-point by each participant alongside the qualitative visual interviews. The priority within study three is for the qualitative data. The interviews provide the most in depth analysis of the individual experiences of the participants and this is the main contribution that this research will have to the existing evidence base and the future development of services. The quantitative measures are useful in assessing secondary research questions and provide additional data and depth to primary research objectives. This is especially important in study three,

where participants will be dictating to a large degree the content of the interviews and therefore collecting the quantitative measures will ensure that these psychological variables are assessed regardless of whether they are initiated by the participants.

Walker et al. (2009) provided a good example of how a mixed methods approach can be used to engage a teenage population and to understand their experience of an aspect of their lives. Walker et al. (2009) recruited a sample of 30 young people (12-14 years old) to study their well-being and movements on their journeys to and from school. Data were collected using mobile telephones provided to the participants by the research team. These mobile telephones monitored the routes that teenagers took to and from school via a GPS tracker, but also allowed the teenagers to upload photographs and blog entries about their observations and how they were feeling on these journeys. The participants were subsequently interviewed about the GPS, photographic and textual information they had provided, which allowed the researchers to understand why certain items had been recorded. Walker et al. (2009) concluded that the disadvantages of their mixed methods approach were that it produced a considerable amount of data that was difficult to manage, was time consuming and required considerable co-operation between teenagers, schools and researchers. However, the advantages of this mixed methods approach appeared to significantly outweigh the disadvantages. The use of a variety of methods and media enabled teenagers with a wide range of skills and from different backgrounds to participate and the use of technology kept them engaged throughout the study. The triangulation of data from the different methods provided a successful way of capturing the complexities of teenagers' experience of journeys to and from school, and led to a better insight into the complex personal and social context of a school journey than previous research had been able to. They also concluded that whilst the GPS, photos and messages had provided content and context, it was the interviews that produced the greatest level of insight into the individuality of the participants' experiences. This was a qualitatively led mixed methods study with the emphasis of interpretation and conclusion placed on the data derived from the interviews and provides a good example of how this approach can be used successfully to investigate experiences within a population of young people.

One of the main issues within mixed methods research is whether the end result of mixing qualitative and quantitative methods is greater than the sum of its parts (Bryman 2007). Green et al (1989) reviewed 57 studies that used mixed methods and found that 44% did not integrate quantitative and qualitative data within the research. Similar findings were obtained in a more recent review conducted by Niglas (2004) in mixed methods education research. However, Bryman (2007) highlights the fact that integration of the quantitative and qualitative components of research may not always be the most important part of the analysis and in some cases may not be appropriate. For example, in the conception of a mixed methods study, the quantitative and qualitative components may be included to address distinct research questions. Therefore, the integration of the data produced by these

approaches may not be a primary concern, although it could still produce interesting findings (Bryman 2007).

Bryman (2007) went on to provide nine main barriers to the integration of quantitative and qualitative components:

- 1- Different Audiences
- 2- Methodological Preferences
- 3- Structure of Research Projects
- 4- Role of Timelines – quant and qual completed and analysed at different speeds
- 5- Skill Specialisms
- 6- Nature of the Data – more interesting data given priority
- 7- Bridging Ontological Divides
- 8- Publication Issues
- 9- Problem of Exemplars – No gold-standard

Bryman states that these nine barriers can be further grouped into three main themes. The first theme is barriers that relate to the nature and qualities of the methodologies and these include barriers 3, 4 and 7. The way that study three is structured means that the qualitative data can be analysed as the project progresses i.e. the analysis can begin in time-point one before time-point two has been completed and so on. Therefore, the extra time that it takes to perform in depth qualitative analysis compared to quantitative analysis is counteracted to some extent. The quantitative data will be analysed once it has all been gathered at the end of the study and therefore both sets of data should be completed at approximately the same time. The ontological divides of the two methods are addressed by the pragmatic approach being adopted by this study and therefore the integration of data analysis will be driven by a practical purpose and application.

The second theme is barriers that relate to the wider institutional context of mixed methods research and these include barriers 1 and 8. These barriers refer to the expectations held by consumers and publishers of research that favour a certain type of data over another. These barriers do not relate significantly to the production of a PhD thesis, but may influence the destination of the dissemination and publication of the findings. Therefore this is not an immediate barrier in the current research study and should not affect future publications as the research area is still in its infancy.

The third theme comprises of barriers 2, 5 and 6 and this theme is concerned with the skills and preferences of the researchers themselves. It seems clear that this barrier theme does influence the structure of this research study and the priority given to certain aspects of the analysis. I am primarily a qualitative researcher and am employing what I consider to be a novel and interesting qualitative

method of visual interviewing. Therefore, my preference is for the data that is being produced by this strand of the research. However, I do believe that to best address the aims of this PhD as a whole, the priority given to the qualitative methods reflects the limitations of the current literature and the need to provide detailed understanding of the meaning making and experience of the sample population.

Barrier 9, ‘‘problem of exemplars’’, is not categorised with the other themes as it was thought to cross them all. It refers to the problem that there is no ‘gold-standard’ for mixed methods researchers to follow as an example. The complex nature and contextual variance in mixed methods studies makes this gold-standard difficult to achieve and therefore there are likely to continue to be a great variety of applications of mixed methodologies.

With no obvious exemplar to follow in this area, the pragmatic approach taken by study three of this research is to use a qualitatively led longitudinal mixed methods approach, comprising visual interviewing and psychometric measures. Aspects of this methodology will be detailed further in the remainder of this chapter.

4.1.3 Visual interviews

The method of data collection used within study three is photo elicitation/visual interviewing. Photo elicitation is the most commonly used term to describe interviews that use an image as the stimulus for an interview, but as participants in this study were able to select the type of visual media they used, the broader term of visual interviewing will be used predominantly throughout this thesis. Photo elicitation was first named in an article by Collier (1957) and developed out of the field of anthropology. It is a method that has been used previously to investigate young peoples’ attitudes towards education (Harper 2002) and is flexible enough to be appropriate for the investigation of an open phenomenon like experience (Smith, Gidlow et al. 2012). This versatility of method allows for comparable data to be gathered utilising a range of different mediums from participants from diverse personal and cultural backgrounds (Jordan, Adams et al. 2009, Smith, Gidlow et al. 2012).

In recent literature, photo elicitation interviewing has been employed as the primary method for data collection in populations including; adolescents suffering from obesity (Lachal, Speranza et al. 2012), young people undergoing renal replacement treatment (Wells, Ritchie et al. 2012), teenagers’ attitudes to bullying (Walton and Niblett 2013), teenagers’ experiences of education (Smith, Gidlow et al. 2012), children’s’ experience of school (Pyle 2013), education engagement (Cremin, Mason et al. 2011), patient experiences of chemotherapy (Frith and Harcourt 2007) and more widely in psychological adjustment (Sustik 1999), education (Dempsey and Tucker 1991, Smith and Woodward 1999), ethnography (Pink 2001) and organisational studies (Buchanan 1998).

It has been suggested that visual interviewing is a method that may be more developmentally appropriate than a more formal semi-structured interview for research with teenagers and children, (Smith, Gidlow et al. 2012, Pyle 2013). Smith et al. (2012) concluded that participant generated photographs provided a successful way of engaging adolescents in discussions about their experiences. Pyle (2013) highlights that using participant generated photographs improved engagement in the interview by reducing the difficulties children have in understanding the questions of adults. Responding to a visual stimulus can elicit more of an emotional response than verbal questioning alone and is a way to improve the interaction between the researcher–observer and the researched–observed (Prosser 2006). The inclusion of photographs in research with teenagers has been shown to successfully increase the researcher participant rapport (Smith, Gidlow et al. 2012) and allow young people to have control over the presentation and discussion of their experiences in a way which may be more problematic in a standard interview, where the researcher decides the subject matter and the order of presentation (Wells, Ritchie et al. 2012).

This method removes some of the barriers of verbal interviewing alone as it is “anchored in an image that is understood, at least in part, by both parties” [p20] (Harper 2002). By asking the participant to record the images that provide the focus and structure of the interview, visual interviewing works to reduce power differentials within the research by positioning the participant as an active and central part of the research process (Wells, Ritchie et al. 2012). As well as addressing power issues, adopting a participant led approach such as visual interviewing can promote participant engagement, by offering freedom of expression (Wells, Ritchie et al. 2012) and a level of control over the process (Pyle 2013). Wells et al. (2012) report that there was no attrition in their study and felt that this was due to the high level of engagement the teenagers had with the visual methods. Teenagers are generally engaged in a wide range of image based media (social networking, film, music videos, magazines, video games etc.) and therefore visual interviewing is seen as appealing to teenagers because of the level of media engagement regularly present in this population (Thomson 2012, Walton and Niblett 2013).

Having photographs to refer to in the interview can provide a focus for the participants and offers them a visual memory aid when recounting their experiences (Pyle 2013). This increases the likelihood of a more comprehensive discussion of their experiences. By allowing the participants to creatively control the focus of the photographs, the use of visual methods can elicit unexpected and novel directions for the research to follow (Meo 2010, Pyle 2013), which can lead, in some cases, to a more detailed discussion of participant experiences than more traditional methods (Cappello 2005, Thomson 2012, Mandleco 2013, Pyle 2013).

The visual images themselves are not the focus of visual interviewing techniques, it is the meaning that participants attach to the imagery that generates data and allows them to convey their more abstract thoughts, feelings and experiences (Carlsson 2001, Pink 2001, Smith, Gidlow et al. 2012). In previous research with young people, photo elicitation has been an appropriate interview technique because it enabled teenagers to 'introduce aspects of their lives that they felt might appear obscure or abstruse to their audience' (p. 353) (Croghan 2008). Croghan (2008) shows in her paper an example of a participant demonstrating the abstract concept of belonging by presenting a photograph of them with their band. Croghan (2008) claims that this image demonstrates the concept of belonging far more clearly than would be possible with any verbal account alone. The ability for visual methods to help young people to articulate the abstract is one of the primary benefits of this methodology for the current research. Having a photograph as a starting point can help young people to introduce difficult and complex subject matter and facilitate recollections and verbal communications with the researcher (Lachal, Speranza et al. 2012). Lachal et al. (2012) selected photo-elicitation as the primary data collection method for their research into the experiences of teenagers with obesity. This method was chosen as the researchers reported that, in their clinical practice, teenagers suffering with obesity often have difficulty with putting their experiences with food and subsequent relationships into words. It was felt that asking participants to take photographs would help them to start reflecting on their experiences before the interview and that this would in turn help them to articulate these experiences during the interview.

One of the main problems with visual interviewing is the ethical issues associated with recording images. Difficulties can arise when participants want to capture images depicting people (Wiles, Prosser et al. 2008) and whether these images should be included in publication and presentation of research findings (Smith, Gidlow et al. 2012). As well as potentially identifying individuals who have not consented to their images being used, there is the possibility that the participants themselves could be revealed through their photographs (Pyle 2013). Although the images are not the focus of the research, their inclusion can help to illustrate the methodology and add depth to the discussion of research findings, and therefore their inclusion in publications and presentations is justifiable as long as precautions are taken to ensure anonymity (Smith, Gidlow et al. 2012, Pyle 2013).

There are also a number of practical issues to consider when employing this method. Self-censorship can be a problem with visual interviewing, as with any participant led research methods (Smith, Gidlow et al. 2012). Participants may not be willing to discuss certain aspects of their experiences and may therefore not want to record images that will elicit questions around these issues (Mandleco 2013). This self-censorship can be a particular problem when research questions provide limited restrictions on what participants record (Frith and Harcourt 2007, Smith, Gidlow et al. 2012), as with this research, but this needs to be balanced against the desire to allow participants to have control over

the research process. Smith gives an example of a participant who used two different cameras during the research period; one for the study and one for personal reasons. In their interview this participant said that they knew the researcher would be looking at the photographs on the research camera and therefore kept more personal or 'embarrassing' photographs on their other camera (Smith, Gidlow et al. 2012). Participants may also forget to take the photographs during the time allocated by the researcher (Mandleco 2013). This can lead to difficulties if the researcher is assessing a particular time-point, for example, if the researcher is investigating a two week period but the participant only remembers to take the photographs in the last two days, then the research is assessing two days rather than two weeks (Mandleco 2013).

4.1.4 Longitudinal

To allow for the assessment of changes in education engagement and psychological variables over time, the visual interviews described above will be employed on a longitudinal basis over the first nine months of the teenagers' cancer experience.

The dominant data collection method within qualitative research is the interview, but the relative merits of employing interviews in a longitudinal structure are not commonly explored in research texts (Vincent 2012). However, qualitative longitudinal research methods (QLM) are increasingly being employed in social and health research over the past ten years and are attracting more scrutiny (Calman, Brunton et al. 2013). QLM studies are based upon the investigation and assessment of changes over time and consider those changes within a context (Holland, Thomson et al. 2006, Holmbeck, Bruno et al. 2006, Weller 2012, Calman, Brunton et al. 2013). The introduction of time as a key component of the research design in QLM approach distinguishes it from other qualitative methodologies (Calman, Brunton et al. 2013) and makes it the most appropriate methodology for studying change over time, mechanisms of change and critical moments or turning points (Holmbeck, Bruno et al. 2006, Calman, Brunton et al. 2013).

Holland et al. (2006) identifies four main methodological models within QLM; mixed methods approaches, planned prospective longitudinal studies, follow-up studies and evaluation studies. The mixed methods approach is where the majority of QLM research is located within the healthcare domain (Calman, Brunton et al. 2013). This prevalence of longitudinal research in healthcare could be due to the importance of understanding transitions for patients in the healthcare system, so that care pathways can be more accurately mapped and services and support delivered in a more timely fashion. This benefit of longitudinal methods is closely linked to the aims of this PhD research and will provide useful data to this end.

Not all areas of healthcare regularly employ longitudinal methods. A review of articles published on psychopathology research conducted with children and adolescents between 1983 and 1992 demonstrated that only 4% employed longitudinal methods (Wierson and Forehand 1994). The need for greater use of QLM has been regularly documented in the recommendations for future research in paediatric psychology (Holmbeck, Bruno et al. 2006). Not all research questions allow for a longitudinal design, but Wierson and Forehand (1994) suggest that these cases are in the minority and that most of the papers they reviewed pointed towards the need for longitudinal research in their conclusions. Wallander et al. (1998) go as far as to say that developmentally orientated longitudinal research should be the norm in any paediatric healthcare research.

There have been examples of QLM research occurring in young people experiencing cancer, spinabifida, traumatic brain injury, juvenile rheumatoid arthritis (Holmbeck, Bruno et al. 2006), pregnancy during school years (Vincent 2012) and stem-cell transplants (Parsons. S 2006). More recently in the U.K the “Timescapes” project examined the complexities and changes in young peoples’ lives as part of a wider project including seven separate longitudinal studies (Neale, Henwood et al. 2012). A project on this scale demonstrates the interest in and potential scope of QLM. The use of QLM has been said to be particularly informative when employed at critical transition or developmental stages throughout childhood and adolescence (Holmbeck, Bruno et al. 2006). When investigating these transition and developmental stages in combination with chronic health problems, QLM can help to provide understanding of a young person who is changing and developing as an individual, but in the context of changing and developing health difficulties (Holmbeck, Bruno et al. 2006). Alongside these individual and health changes, the family, peers and social world of the young person will be in a state of change and adaptation that will again have the possibility of affecting change over time, which can be highlighted through QLM.

It has been claimed in some of the existing literature that a QLM approach can be particularly effective with young people because it allows the participants to develop trust and rapport with the researcher that can lead to richer and more open expression of experiences and emotions than an individual data collection point (Walker, Whyatt et al. 2009, Vincent 2012, Weller 2012). This is a difficult point to provide supportive evidence for because rapport and levels of expression are hard to measure and can also potentially be achieved through singular interviews. Also, even though a longitudinal design offers more time for rapport to be built, this does not necessarily lead to a more positive rapport.

Another benefit to serial interviews is that the content of preceding interviews can be reflected upon before conducting subsequent interviews with the same participant (Vincent 2012). This approach can be taken in a longitudinal format or with any approach that uses multiple interviews with the same

participant. This idea can assist with building a rapport with the participant, reorienting the researcher to the context of the individual participant and allowing follow up and validation of previous lines of enquiry (Vincent 2012). Within study three of this research the ability to modify and adapt lines of enquiry as participants move through the time-points has hopefully facilitated a more in depth assessment of the meaning that individuals have made out of their experiences.

With the potential for an increasing rapport to build between the researcher and the participant, there is also the increased possibility that participants may be exploited within the research context by sharing more about their lives than they would otherwise feel comfortable doing in a standalone interview (Holland, Thomson et al. 2006, Weller 2012). Qualitative research can be emotionally challenging for researchers as well, and this can be intensified when a participant-researcher relationship is developed over multiple data collection points with people in vulnerable positions (Calman, Brunton et al. 2013). Researchers need to be aware of the potential for blurred boundaries when building relationships with participants over time and how to manage the cessation of these relationships at the conclusion of the research (Wray, Markovic et al. 2007). The idea of blurred boundaries is certainly something that was a concern at the outset of this research because of my previous role within TYA cancer services. In my previous role, I provided support, care, information and guidance to teenagers and their families, so that when problems were discussed with me I could give advice and offer practical help and solutions. To manage the boundaries of my research role, I have used the support of my supervisors and the practitioners working with my participants.

There are a number of considerations to be aware of when planning and conducting QLM research. Issues such as the use of theory, analytic methods and practical and ethical considerations should all be assessed at an early stage (Calman, Brunton et al. 2013). Issues around confidentiality of participant data can be increased when research is longitudinal (Calman, Brunton et al. 2013). Data is often in use more regularly than in single time-point research as researchers and participants are exchanging information at a higher frequency and often in more depth (Calman, Brunton et al. 2013). Within study three of this research the participant identifiable data was securely stored and was not needed to be shared with any external agencies or other health professionals. This minimised the confidentiality issues, alongside the need to thoroughly anonymise the data which were brought about initially by the use of visual methods.

Cohort effects are possible when research participants are sampled from different places at different times, and in a health setting this is often related to differences in the availability and standards of care (Holmbeck, Bruno et al. 2006, Calman, Brunton et al. 2013). Cohort effects are not an issue for the current research, but were a factor in the decision to only recruit participants from a single centre.

Longitudinal research can also create practical problems for the researcher related to continuity of research funding and the turnover of research or allied staff within the timeframe of the research (Calman, Brunton et al. 2013, Koro-Ljungberg and Bussing 2013). This can be a particular problem where research projects need to be extended due to previously mentioned issues of attrition. Within this PhD research this problem arose when initial charity funding expired and alternative funding had to be sought. Applications for funding or additional funding have consumed a significant amount of time, especially when considering the part time nature of this PhD.

The number of data collection points have an impact on the extent to which patterns of change over time are detectable and can be critically assessed (Holmbeck, Bruno et al. 2006, Calman, Brunton et al. 2013). The number and nature of data collection points needs to be balanced with the understanding of the amount of time a participant is happy and willing to give to the research (Weller 2012). Two data points can detect changes over time, but more data points are generally recommended (Willett, Singer et al. 1998). Data collection in QLM research is also prone to missing data due to attrition and the difficulties with collecting data at every time-point (Parsons 2006). Three data points were selected for study three of this research to attempt to assess three different stages of the education experiences of teenagers with cancer; the first stage was an experience of diagnosis; the second stage was an experience of the impact of treatment; and the third stage was a reflection on the overall experience. Attrition is also a factor that can be a particular problem for QLM research due to the length of the data collection process and the potential gaps in between data collection points (Holmbeck, Bruno et al. 2006, Koro-Ljungberg and Bussing 2013). This problem is intensified by recruiting a paediatric sample with health difficulties (Holmbeck, Bruno et al. 2006, Parsons 2006). Those young people who are suffering with illness may be too unwell to participate, whereas those who improve may consider themselves as no longer unwell and therefore would not want to continue their participation (Patenaude and Kupst 2005). Attrition was addressed by offering clear information at consent about the amount of time involved, using age appropriate and engaging methods, having interim contact with participants between time-points and by offering remuneration at the second two time-points.

QLM research needs to be flexible and creative in the execution of methodology throughout the duration of the research project (Weller 2012). The ideas of flexible and innovative research approaches have also been seen to be key elements of successful research with children and teenage populations (Weller 2012). This flexibility can be achieved by offering participants a degree of choice over study activities and control over the interview process (Weller 2012). QLM research utilising serial interviews is in a uniquely advantageous position to offer flexibility by using previous interviews, and the content and preferences expressed within, to individually tailor the subsequent interviews (Farrall 2006). Alongside the need to assess potential changes over time, this notion of

flexibility offered by a longitudinal approach is a primary reason for employing this method. The previously stated appropriateness of visual interview methods for assessing an open phenomenon like experience combines nicely with the flexibility of longitudinal methods to produce a methodological approach that is participant centred and can adapt to the iterative nature of the data collection process and therefore follow and expand upon novel areas of interest to create a more thorough and accurate assessment of the research questions.

4.1.5 'Go Along' interview

Leading up to the concluding time-point of this project a discussion was held with participants about engaging in a 'go along' interview. This possibility was also raised with the participants in the information given at the point of consent. If a participant felt uncomfortable with this or thought it was inappropriate, then a visual interview was conducted as per the previous time-points.

The way in which an individual perceives themselves in an environment can be said to be 'richly differentiated into places or centres of special personal significance' (Relph 1976) and these places can be current, remembered or imagined (Lynch 1960, Kusenbach 2003). Interviewing a participant in a location selected by the participant can produce a more empathetic understanding of their experience by placing this experience in a context where the participant has the opportunity to create personal meaning (Pink 2007). By interviewing a participant in a dynamic location the researcher adopts a spatial rather than chronological approach to allow investigation of the symbolic qualities of the everyday spaces of participants (Kusenbach 2003).

Sit-down face-to-face interviewing has several disadvantages. Even when using additional stimuli, as with the visual interviewing method adopted by this research, it is not possible to transcend the framework of a narrative driven interaction between researcher and participant (Kusenbach 2003). Traditional interviews also restrict the possibility for natural context driven reactions of both the interviewer and interviewee (Kusenbach 2003). The static nature of sit down interviews tends to separate individuals from their everyday lives, normal routines and experiences of their natural environments (Kusenbach 2003).

'Go along' interviewing is a qualitative approach that has been primarily employed in ethnographic and sociological research. It involves "walking with participants as they experience, tell and show their material, immaterial and social environments in personally, socially and culturally specific ways" (p. 250) (Pink 2007). It is important that a 'go along' occurs in a situation that the participant would be engaging in regardless of participating in the research, so that the situation is as natural as

possible (Kusenbach 2003). It was thought that teenagers in this research may have liked this interview to happen as they returned to school or attended a follow-up appointment at the hospital.

The 'go-along' interview method is essentially a fusion of interviewing and observation, which has the potential to exploit the benefits of each method whilst using the one method to minimise the limitations of the other (Carpiano 2009). For example, traditional interviewing offers the opportunity to engage with the inner world of the participant and construct meaning with them, but will always be abstracted from their environment, which is off-set in 'go-along' interviews by conducting the interviews in the environment of the participant.

The interview proceeds through the researcher asking questions, as well as making observations, as the participant moves through their environment (Kusenbach 2003). In keeping with the visual interview method adopted in this research, 'go-along' interviews are primarily participant driven and focus on the participant's reaction and interaction with the environment. This interview technique is a means of getting away from the restrictions of a static face-to-face interview and allowing the location to act as the stimulus for the collection of interview data. It is a unique tool for examining "how physical, social, and mental dimensions of place and space interact within and across time" (p. 264) (Carpiano 2009). This frees the researcher from "having to rely on photos and objects brought into the interview room" (p. 256) (Anderson 2004) and allows the interview to move "in productive and sometimes entirely unexpected directions" (p. 160) (Jones 2008).

Epistemologically a 'go-along' interview method is consistent with the idea that understanding an individual's experience is more successfully achieved by observing them in interaction rather than abstraction (Carpiano 2009). In this way the 'go-along' interview compliments the previous use of visual interviewing, which looks to understand participant's experiences of education through their visual interaction with the research questions and subsequent discourse with the researcher. Pragmatically the 'go-along' interview has the potential for placing the previous two time-point interviews in a wider context and offering the participant a greater opportunity for reflection on their first nine months of treatment by discussing how their interaction with their educational environment has changed during that period.

The 'go-along' method also fits with the visual interviewing and longitudinal approach due to the flexibility it offers to adapt to the requirements of individual participants (Carpiano 2009). Again like the visual interviewing method, 'go-along' interviews can use an unstructured or semi-structured approach that can be constantly adapted depending on the confidence of the participant (Carpiano 2009).

A 'go-long' interview has a possible benefit for the egalitarian approach to the power balance within research. By allowing the participant to act as a 'tour guide' introducing the researcher to aspects of their life and environment they are given a degree of control over the experience (Carpiano 2009). The participant is likely to feel more comfortable in a familiar environment than they would in an unfamiliar research context. However, at the outset of this research there were concerns that this might not be the case for teenagers returning to school. Returning to school could well be a source of anxiety for participants who had missed long periods of time and this could potentially be exacerbated by the presence of a researcher who would not usually be part of that environment. Therefore, this 'go along' method was offered as an optional alternative to the visual interviews and the location was decided upon by the participant.

4.1.6 Analysis

Interpretative Phenomenological Analysis (I.P.A) was selected as the prime method of analysis for the interview data in study three. Epistemologically, I.P.A is derived from phenomenology, hermeneutics and idiography (Smith 2011). Phenomenology is the philosophical movement that is concerned with the study of experience as a discreet structure, whereas hermeneutics and idiography refer to interpretation and the study of the individual respectively. I.P.A combines these three philosophical perspectives to focus on how individuals interpret and experience their personal and social world, and aims to explore the meanings particular events or states hold for individuals and how they make sense of these experiences (Smith, 2008). Whilst aiming to gain an insider perspective into participants' lived experiences, I.P.A acknowledges that this cannot be achieved directly or completely. Instead Smith describes a double hermeneutic (Smith 2011) where the researcher is interpreting the participant's interpretation of their own experience.

I.P.A is most commonly conducted as a method of interrogating data presented in the verbatim transcripts of semi-structured interviews (Smith 2011). I.P.A is interested in examining divergence and convergence in smaller samples, and as such is willing to produce in-depth analyses of peoples' accounts in keeping with the aim of qualitative research (Smith, Flowers et al. 2009). This in-depth analysis of the experience of individuals can sometimes result in the presentation of single case studies (Smith 2011), but more commonly leads to a thorough analysis and subsequent understanding of each individual transcript, followed by an assessment of themes and commonalities across the entire sample or within sections of the sample (Smith 2011). The emphasis that the I.P.A approach places on thorough analysis of individual accounts allows for a detailed examination of particular extracts within an interview or corpus where those extracts are especially potent (Smith 2011). Smith refers to these extracts as "gems" (Smith 2011). The gem in this context is a single utterance within a the account of a participant that can have "analytic implications disproportionate to its size" (p. 7)

(Smith 2011). These gems, when discovered and their meaning examined, can offer increased insight into the phenomenon in question. The meaning of gems, however, is not always immediately accessible and researchers using I.P.A are encouraged to engage in hermeneutic circling (Smith 2011) whereby the analysis of the whole sample can illuminate the meaning of individual utterances, which can then in turn provide depth of meaning to the overall findings. Smith discerns three distinct categories of gems; shining, suggestive and secret. The shining gem is clearly stated and is easily understood by participant and researcher. The suggestive gem is partially understood by the participant and requires more interpretative work by the researcher to uncover its meaning. The secret gem is something that is out of the awareness of the participant and requires more extensive analytical work by the researcher to unlock the depth of meaning it holds for the interpretative process.

With its grounding in phenomenology, idiography and hermeneutics, I.P.A is in a good position to investigate the experiential and meaning making possibilities of metaphor in the conceptualisation of illness experiences (Eatough, Smith et al. 2008, Shinebourne and Smith 2010). I.P.A has been employed in recent times as a method for investigating the use of metaphor in articulating and understanding the experience of addiction (Shinebourne and Smith 2010), breast cancer (Bennett, Laidlaw et al. 2006) and depression (Rhodes and Smith 2010). The psychological study of metaphor as a way of articulating and translating experiences of the world was pioneered by Lakoff and Johnson (1980). They believed that metaphor is an important method for partially understanding experiences and practices that cannot be understood completely (Lakoff 1980). In a later work Lakoff (1993) suggested that people use “basic bodily understanding of places, movement, forces, paths, objects, and containers as sources of information about life and about abstract concepts” (Shinebourne 2010). Lakoff (1980) says that what the person experiences is not totally separate from the metaphors they use and therefore the metaphors can give the researcher valuable information about the inner world of the participant. However, despite the ability of metaphors to facilitate clearer understanding of these phenomena, they can also limit the potential for alternative conceptualisations that do not fit the metaphor (Lakoff 1980). Rhodes (2010) believed it possible that “the greatest moments of suffering come imbued with metaphor or other forms of figuration” (p. 407) and therefore metaphor seemed like an appropriate area of interest in relation to the experiences of teenagers with cancer in this research. Indeed, metaphor has been highlighted previously as a successful way of communicating and understanding experiences in a health psychology and medical context (Kirmayer 1992, Radley and Chamberlain 2001).

In her research into addiction Shinebourne (2010) claims that “suffering and the experience of illness may be presented metaphorically rather than literally, precisely because it is not fully specifiable and cannot be communicated through description alone” (p. 60). Shinebourne (2010) also noted that her participants may not have previously expressed the experiences and feelings they described in the

interviews with her and therefore may have used metaphors more frequently to try and articulate their experiences in a way that could be understood by them and the researcher. Metaphors have also been said to convey multiple meanings in a concise and vivid way that can facilitate shared understanding and increase rapport (Fainsilber and Ortony 1987).

The following are examples of the metaphors used by participants in recent health related research. Shinebourne (2010) found that her participants' use of metaphor could be categorised into four main themes: addiction as affliction, addiction as support, recovery as growth, and addiction and recovery as a journey. Bennet et al. (2006) found that breast cancer patients often employed a military metaphor to conceptualise their cancer experiences, whereas people with depression used metaphors including pit, hole, light/dark and hinge to describe their experiences (Rhodes and Smith 2010)

It is possible to use I.P.A to investigate any type of experience, but in reality it is used primarily to assess experiences that have some existential import to the participant (Smith 2011). I.P.A is widely used in the area of health psychology (Smith 1996) and is said to be an approach that lends itself well to exploring peoples' experiences of life transforming or threatening events (Smith 2004). In the period from 1996 to 2008 there were 293 papers published that explicitly stated the use of I.P.A methodology (Smith 2011). This figure has been steadily increasing since 2003, with the largest volume of papers published originating in the U.K. (Smith 2011). This increase in published I.P.A work within the U.K coincides with increased recognition of the validity of qualitative methods, which is supported by the British Psychological Society making qualitative methods a requirement for all accredited undergraduate programmes and a required skill for Chartered Psychologists (Shaw 2011). The increased recognition and popularity of I.P.A has led to it becoming a 'default' option for many students employing qualitative methods, which has the negative consequence of producing I.P.A research that is descriptive and not representative of the nuances of the method (Hefferon and Gil-Rodriguez 2011). Nearly a quarter of this sample of 293 published papers focussed on the experience of illness (Smith 2011). The successful application of I.P.A to understanding health experiences can make it a good method for providing insight for people wanting to generate guidelines for good practice and guidelines in healthcare settings (Shaw 2011). In keeping with aim three of this research, this last point resonates well with the potential application of the findings of this PhD research to inform and develop services within teenage oncology.

The evidenced successful application of I.P.A to the study of health related problems combines well with the same successful application of longitudinal methods described earlier. Analysing the data from a longitudinal piece of research can be complex, with the possibilities of both cross-sectional and longitudinal approaches (Saldaña 2003, Weller 2012, Calman, Brunton et al. 2013). In study three participants could be compared cross-sectionally to each other at each time-point, or longitudinally to

compare within each individual's timeline. The cross-sectional approach would allow conclusions to be drawn about the experiences of the teenage cancer group at each time-point and potentially compare some aspects of the teenage cancer group to normative data. This may be particularly useful with the Pupil Assessment of Self and School (P.A.S.S), as there is a substantial volume of normative data available. In contrast, the longitudinal approach would allow an assessment of each individual's timeline, which will be more appropriate to assess changes over time and to provide an understanding of the meaning of individual's experiences in keeping with I.P.A. Longitudinal timelines could subsequently be compared cross-sectionally to assess convergence and divergence within the sample as a whole and to begin to draw conclusions about the population, individual differences and to make recommendations for future practice.

The issues produced by the longitudinal aspect of the research are further complicated by the mixed methods approach incorporating the quantitative measures. With mixed methods research there is always the question of how qualitative and quantitative data will be brought together through the analysis process, if this will occur at all and if so at what point will this happen (Hanson, Creswell et al. 2005). Data analysis may occur by analysing the data separately, through transformation of data, or by combining the analyses (Caracelli and Greene 1993, Onwuegbuzie and Teddlie 2003, Hanson, Creswell et al. 2005, Tashakkori and Teddlie 2010).

4.1.7 Assessing the Quality of Research

Assessing the quality of qualitative research methods and publications is an area that has received increased attention over the past decade. As previously discussed in Chapter 2, Sirryeh et al (2012) have developed a quality assessment tool that allows the comparison of qualitative and quantitative methodology. Previous to this, Yardley (2000) developed four main principles for assessing the quality of qualitative research: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Since Yardley published her guidance for assessing qualitative research, Meyrick (2006) offered an alternative method that stems from two fundamental concepts; that good quality qualitative research should be transparent and systematic. This assessment method works by applying these two principles to the various stages of the research process including: epistemology, methods, sampling, data collection, analysis, results and conclusions. Because Meyrick's assessment method focusses on underlying principles it allows for assessment of a diverse range of qualitative methods and comparisons to be drawn between methods with very different approaches. Carter and Little (2007) offered another alternative way of assessing the quality of qualitative research. They proposed a set of guiding principles for producing good quality qualitative research that centred on the internal consistency of epistemology, methodology and method. They

believed that this approach could transcend a more traditional checklist approach to assessing quality and therefore be more applicable to a wider range of qualitative research.

Shaw (2011) believes that Yardley's quality assessment criteria allow for an accurate assessment of whether the results and conclusions of a piece of research can be trusted based on what is included in the paper. Yardley's approach is also favoured by Smith (2011). However, Madill et al (2000) believe the applicability of quality assessment frameworks depend on the underlying epistemology and ontology of the research in question. For example, the assessment of reliability and objectivity are only appropriate within qualitative research when it is conducted from a naive or scientific realist position (Madill, Jordan et al. 2000). Madill claims that the breadth of psychological approaches to research makes it important that any evaluations of research quality be consistent with the approaches of that research.

Smith (2011), although complimentary of general quality assessment criteria such as that offered by Yardley, agrees with Madill and asserts that for specific individual analytic methods, such as I.P.A, specific individual assessment criteria need to be developed and implemented. Smith (2011) has developed a quality assessment tool for I.P.A studies that categorises research into "acceptable", "unacceptable" and "good", based on categories including: theoretical basis, transparency, coherency, plausibility, interesting nuanced analysis, appropriate sample size and conclusions supported by data. Overall Smith concludes that a good I.P.A paper should have the following:

- The paper should have a clear focus
- The paper will have strong data
- The paper should be rigorous
- Sufficient space must be given to the elaboration of each theme
- The analysis should be interpretative not just descriptive
- The analysis should be pointing to both convergence and divergence
- The paper needs to be carefully written

(Appendix 15)

It is with these I.P.A specific quality assessment criteria that the quality of the I.P.A sections of study three will be assessed.

4.2 Consultation with practitioners and patients

An important part of the development of the methodology for study three was the involvement and feedback of practitioners and patients. As well as gathering some initial feedback on the

methodological approach being taken in study three, it was also important to engage with the study population for the development of study documents and information.

Involving the public, and particularly the patient population under study, is an important and widely recognised component of health research within the U.K. (Health 2006, Boote, Wong et al. 2012). In England, patient and public involvement in health service development has been championed by INVOLVE (2004), who are a national advisory group that promote public involvement in the NHS. INVOLVE argue that if the public are to be involved in research it should be “an active partnership between the public and researchers in the research process, rather than the use of people as the “subjects” of research” (INVOLVE 2004). Patients should be involved in all stages of the research process where appropriate as this ensures that the development of new initiatives is not just based on professional opinions (Boote, Wong et al. 2012). However, Thompson et al. (2012) highlight that public and patient involvement in health research rather than health policy is more of a recent phenomenon. Patient involvement in health research can include various stages of the process; planning, conduct, funding and dissemination. In a qualitative study of patient involvement in research, Thompson et al. (2012) found that patients thought their “experiential expertise” (p. 6) was the primary benefit of their contribution to the research process. Thompson et al. (2012) also highlight the phenomena of the “professionalised” (p. 1) patient, whereby patients who are regularly involved in the research process can lose their authenticity as a patient through adopting too much of a professional approach.

The proposed qualitatively driven mixed methods approach using visual interviewing was discussed with teenagers with cancer and with TYA oncology practitioners. Teenagers with cancer were approached via an email circulation list held by the Activities Co-ordinator of the TYA service. A brief description of the planned study was outlined and the teenagers were asked to provide answers to the questions shown below. A total of eight teenagers responded and were happy to provide feedback. The respondents did not have to provide demographic or clinical details, but were from a population currently receiving treatment or those who had completed treatment. As well as being asked to comment on methodological issues, the teenagers were also asked to provide some insight into their own education experiences. The feedback relating to the methodology was used to refine and shape the design of study three. The insights into their experiences were used in conjunction with the literature review and questionnaire studies to help design aspects of the interview schedule and study information, but also to engage them in the consultation process.

At the time of submission there are plans to include participants from study three in the future dissemination of the research findings. Participants were asked in their final interview whether they would be interested in seeing a summary of the findings of the research. The majority responded

positively and research summaries will be distributed to them after which they will be given the opportunity to comment on the findings. Following the submission of this thesis those participants that are interested could be invited to contribute to conference presentations and/or write a piece for inclusion in future journal articles arising from this research. The contribution of participants to either of these aspects of dissemination will increase the authenticity of the research findings and contribute to the aim of creating a teenage voice in the literature.

The involvement of patients and professionals in the design stage of study three was essential because of the corroboration they were able to provide to the aspects of the research they agreed with and the suggestions they were able to make for the aspects they did not favour. One of the difficulties of consulting with patients and professionals is the boundary between their experiential expertise and the expertise of the research team. Having consulted with them, are you then obliged to act on the information that they provide you with? Within this consultation phase I tried to incorporate everything that was fed back to me that was concerned with 'experience' and then to more critically assess the feedback I received that was concerned with research design or methodology. This approach seemed to reflect the competencies of all involved in the consultation process.

4.2.1 Patient Feedback

Below are the questions that were distributed to patients prior to developing the methodology. Each question has a summary of the feedback below.

1. *Do you think that you would have been able to do this in the first month after being diagnosed, or is that too soon? If you think it's too soon, then when do you think you would have felt able to take part in this kind of project?*

The majority of patients said they would have found it difficult to participate within the first month of diagnosis. This was due to factors including: shock, intensive treatment, numerous practitioners to meet, illness and other concerns apart from education.

2. *What do you think you would have recorded/taken photos of?*

Suggestions included: teacher, work, home tutoring sessions, medication, hospital bed, meals, Facebook, hair, different drugs, nurses, places in hospital, the facilities, friends, and text books from school.

3. *Do you think you would have recorded/taken photos of different things at different times? E.g. would it have been different after 3 months and after 9 months?*

All respondents thought their images would change at the different time-points. This was true for those who were predicting their future experiences as well as those reflecting on their past.

4. *If you were being interviewed about what you had recorded, would you have liked to be interviewed on your own, or would you have liked the option to have a parent, or somebody else with you?*

There was a mix of responses to this issue. Some said that they would definitely not want a parent and others said that they would, even if it was just at the beginning. Overall, respondents acknowledged that everyone would be different and that participants should be given the option.

5. *What do you think was the biggest thing you missed about school?*

Respondents mainly reported missing friends and the “social side” of school. This often led to them feeling left out of their social networks. Some also reported missing school work and falling behind their peers in education. Some even missed the routine.

6. *What was the biggest help and the biggest barrier to carrying on with education after you were diagnosed?*

Support to continue with school work at home and in hospital was regularly reported as helpful and this support came from home tutors, hospital teachers, school teachers, parents and MacMillan Nurses.

The barriers reported included: illness, fatigue, substandard teaching, doing different work to peers, falling behind, lack of cancer knowledge from school staff and peers, and personal courage to return to school

7. *Any other comments.....?*

There were only limited additional comments, but these included a teenager’s belief that technology was very important in helping to maintain education engagement and another teenager suggesting using other mediums in addition to photography e.g. scrapbooks or diaries.

4.2.2 Practitioner Feedback

Practitioners from the TYA service were contacted and given a similar outline to the proposed study and asked to provide their feedback. The practitioners included: a nurse consultant, two clinical nurse

specialists, a learning mentor and an activities co-ordinator. The main change described by the practitioners was for the initial time-point to be extended from one month to two months, to allow participants more time to move passed difficult initial medical stage and emotional and psychological adjustment. This echoed the feedback from the patients.

4.3 Research questions

Using the information gained as a result of the literature review, initial study aims, preliminary studies one and two, and the patient and practitioner consultation, study three of this research has been designed to answer one primary research question and several secondary questions. The collective findings associated with answering the secondary questions will all contribute to the exploration of the primary research question.

Primary research question

From the perspective of young people, what influences the impact that a cancer diagnosis has on their education?

Secondary research questions

- What are the main factors that hinder or facilitate education engagement for teenagers with cancer?
- To what extent do the education experiences of teenagers with cancer change over the first nine months of their diagnosis?
- What is the impact of education engagement on the overall coping and well-being of teenagers with cancer?
- Does cancer have an effect on teenagers' perceptions of themselves?
- Does cancer have an effect on teenagers' perceptions of school?
- Does education engagement affect the extent and nature of relations with pre-diagnosis peers?

The following chapter details two studies designed to pilot the methodological approaches that have been outlined in this chapter. The combination of chapters four and five have shaped the methods that were used in study three and are described in detail in chapter six.

Chapter 5 - Study Three, Pilot Studies

Figure 5.1 shows the flow-chart developing the linkage between the chapters and shows that the methodological literature presented in the previous chapter has been used to develop an initial method to be trialled in the pilot studies presented in the current chapter.

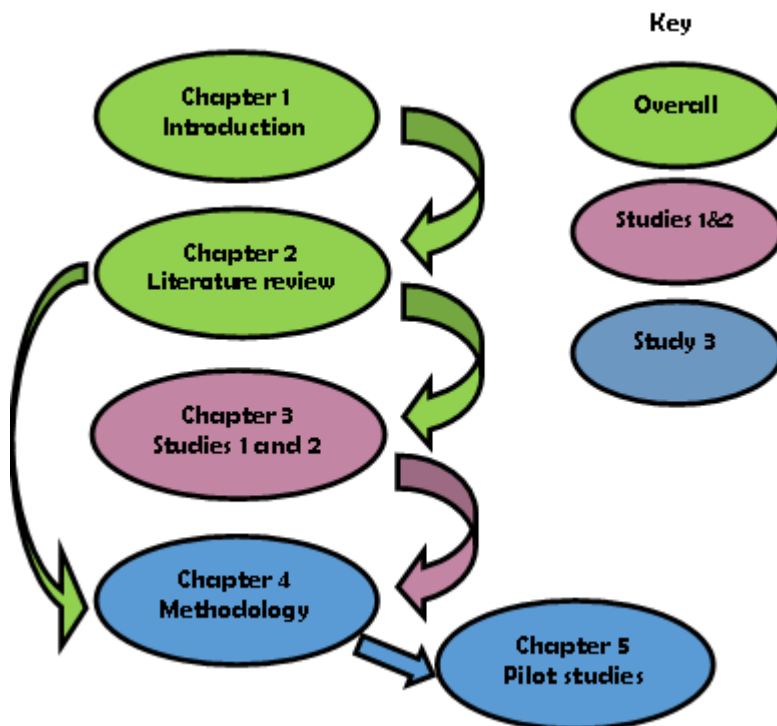


Figure 5.1 - Chapters flow-chart

5.1 Aims

This chapter presents the rationale, design and procedure for the pilot work carried out prior to commencing study three of this research. The methodological theory for study three, which these pilot studies refer to, is detailed in chapter four and the practical description of the method is described in chapter six. Pilot studies are conducted for two main reasons in social science research; as reduced versions of a main study for feasibility purposes, or for pre-testing of a new instrument or technology (van Teijlingen and Hundley 2001). The primary reason for the pilot studies in this research was to assess feasibility. Alongside the feasibility and appropriateness of the methods and the practicalities of recruiting in the clinical environment, when designing the pilot studies it was also hoped that the more subtle issues of researcher positioning and power relationships would be addressed by allowing the researcher to experience the role of the participant.

Visual interviewing is a methodological approach that has not previously been used in this population and is a method that was not familiar to me at the outset of this project. Therefore, in preparation for

study three, two pilot studies have been conducted. Pilot Study 1 involved positioning me as the participant and for Pilot Study 2 a teenager with cancer was recruited to participate in a one-off visual interview.

5.2 Pilot study 1: self-pilot

5.2.1 Context

The concept of a self-pilot is very rarely written about within psychological literature. The self-pilot study allowed me to experience the methodology in order to better understand what a participant might need to know to effectively engage with the novel methods of study three. As well as information needs, engaging in this pilot allowed me to better understand how it felt to be faced with this task and the questions it may raise for the participants. When giving the participants study information and guiding them through the consent process for study three, I would then be able to relay to them my experience within teenage oncology as well as my participation in the pilot study. This self-pilot addressed power within the research through the researcher being willing to undergo the same process as the participants.

5.2.2 Research question

Because I was not a teenager with cancer, a different topic had to be selected as the focus of the pilot project. I wanted to select a topic that would be allied to the content expected from the participants in study three in terms of setting, as well as personal and emotional challenges. I had been working in an oncology environment in various roles for nine years at the time of the pilot study and during this time had experienced a variety of professional and personal challenges linked to this setting. The emotional, psychological and practical impact of cancer provided a link between real experiences in my life and the experiences of my future participants and was therefore deemed an appropriate area to focus on within the first pilot study. The specific research question was set by the supervisory team after discussion and one of the assigned PhD supervisors (SHJ) also acted as the interviewer for the pilot.

Research question - What are the challenges of working in an oncology setting?

Once the question was set I was then left to proceed with the project based on the information that was contained within the study documents. This was a very useful exercise in trying to objectively interpret and practically implement the study information. The materials produced as a result of this pilot study were not analysed in their own right and only contribute to the overall aims and findings of the thesis through the modifications made to the methodology and the experience and insight I gained

as a participant researcher. The following sections detail the insight obtained during and after my participation in the pilot study.

5.2.3 Reflections on taking the photographs

The photographs were taken over the two week period before the scheduled interview, which was consistent with the planned methodology for study three. When faced with this situation I realised that it was quite a daunting task to try to convert the issues and experiences relevant to the research question into photographs. Despite being confident in the discussion of personal feelings and experiences, I also became aware that anything I recorded visually I would have to elaborate on in the interview with my supervisor. This did not pose a great deal of anxiety for me within the pilot study, but it did clearly highlight the real issue of self-censorship that was identified in the visual interviewing literature in chapter four. I also realised that my motivation for taking individual photographs was to have a visual prompt in the interview to remind me of a pre-decided issue that I wished to discuss. This was interesting because prior to participating in the pilot I had imagined that participants would take photographs throughout their two week period to document whatever happened to them during that time and then bring all of these images to the interview. On reflection, both options were available to participants and could be presented as examples, if necessary, in the information and consent periods.

5.2.4 Reflections on consent

When presented with the consent form at the outset of the interview I realised that the nine point consent form was an unhelpfully formal document. The use of visual methods allowing the participants control over the content and structure of the interview had the aim of keeping the process informal. It was hoped that this would facilitate an open and accessible process to encourage the comfort of the participants and allow them to feel in control of the situation. Presenting the consent form at the start of the interview did not seem consistent with these aims. As a participant, I also felt that the consent form delayed my desire to commence the interview and begin the discussion of my photographs. Because of the number of issues requiring consent from the participant, it was not possible to simplify the consent form to a significant degree, so the decision was taken to move through all of the formal written consenting prior to the two week period of image recording and then to verbally reiterate some of the relevant sections at the start of the interviews.

5.2.5 Results in brief

The two week image recording period resulted in me bringing five photographs to the interview (Figure 5.2). Each image was a symbol of an area of difficulty associated with the research question and used within the interview to stimulate conversation about these issues.

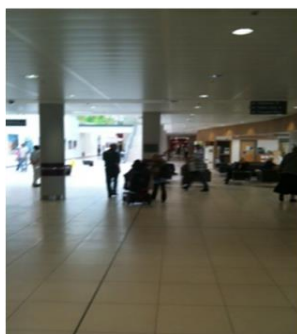


Image 1 – This photograph is an image of the main entrance lobby of the cancer centre. It was used in the interview as a symbol of the environment of working in an oncology setting and the difficulties presented by being surrounded by different aspects of cancer on an everyday basis.



Image 2 – This photograph is an image of cancer support leaflets and information. This image was used in the interview as a symbol of the difficulty with maintaining a strict research role when meeting cancer patients and not providing help or advice outside of the parameters of this role.



Image 3 – This photograph is an image of a nurse's uniform. Within the interview this image was used as a symbol of the difficulties of working in an academic research role within an oncology setting where other professionals are providing more direct care to patients.

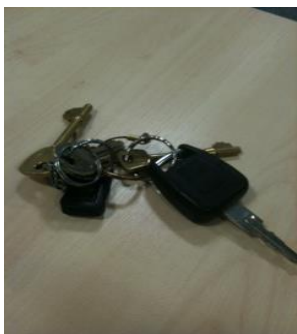


Image 4 – This photograph is an image of car keys and was used in the interview to symbolise the importance of regulating the degree to which oncology related experiences affect life outside of work.

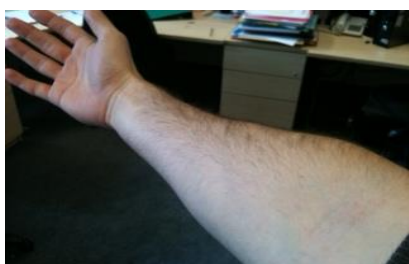


Image 5 – This photograph is an image of my arm. This image was used to symbolise the way in which working in an oncology setting can lead to a level of hyper-vigilance with regards to my own physical symptoms and those of family and friends.

Figure 5.2 - Images from pilot study one

5.2.6 Reflections on the interview process

As previously stated, one of the primary aims of using visual interviewing methodology was to encourage in the participant a level of control over the research process and the interview in particular. This was something that I experienced significantly throughout the pilot interview. By bringing the photographs to the interview and using these as the stimulus for discussion, the control felt as though it was with me throughout and that the interviewer was prompting and encouraging elaboration where necessary. I felt that it also reduced the degree to which the interviewer asked questions that did not feel relevant to the issues I wanted to discuss and the experiences I had. Although this has the benefit of hopefully engaging the participants in the research questions, I realised that it could also be daunting for some young people to have this much control over a fairly open research question, when trying to visually represent their experiences. Therefore, it was understood that I would have to provide good information and explanation of the research aims to participants and be available to answer questions throughout the research process.

Having participated in the interview I discovered that there was a level of catharsis in discussing, within an interview, experiences and issues that were sometimes difficult and challenging. This catharsis was something that I was hopeful would be experienced by those participants in study three who had found their education experiences difficult. I was also hopeful there may be a degree of catharsis with participants who had very positive education experiences and would benefit from reflecting on this. So, for example, a teenager who had successfully kept in contact with their peers, achieved academically and was moving onto the next stage of their education happily, might feel a sense of satisfaction having discussed these positive experiences. For those at the final time-point this reflection may provide a useful sense of closure, whereas for those still going through treatment it may help to motivate them and encourage a positive feeling.

Following participating in the self-pilot I was confident that using a visual interview method would be an appropriate way of addressing the research aims and questions for study three. The way that the method encouraged my engagement with the aims of the process prior to the interview and gave me something tangible to take with me to the interview, were both positive factors in favour of this method. This method offered me an opportunity to shape the content of the interview to a greater extent than would have been possible with a standard semi-structured interview and I felt empowered to address the research question in a way that was personal and satisfying. I was interested to take this forward to the second pilot study to see if a young person with cancer would feel that the visual interview method was similarly positive and engaging.

5.3 Pilot study 2: Participant pilot

In addition to the first pilot study, a second pilot study involving a teenager with cancer as the participant was conducted. This allowed an assessment of the feasibility of the methodology for the study population, as well as giving me some experience of conducting the research process from recruitment through to interview. Experience of conducting this type of visual interview was particularly important prior to commencing study three because this interview technique was something with which I had no previous experience

5.3.1 Participant

It was not essential that the participant in this pilot study fulfilled all of the inclusion criteria. They did need to be from the correct age group of 13-16, so that the feasibility of the materials and methodology could be tested for the appropriate age group. To ensure an accurate pilot the participant also needed to be without any of the exclusion criteria; a brain tumour diagnosis, palliative care, psychopathology, non-English speaking and learning difficulties. However, it was not essential for this pilot interview that the participant was within two months of diagnosis, only that they were within nine months of diagnosis. The nine month period was important because this was the furthest from diagnosis that a participant would be within study three. Because the methods in study three would be consistent across the different time points, it was not considered necessary to pilot the methods for teenagers fitting each of the three main time-point categories. The variation across the time-points was expected to be in the content and not in the application of the methodology.

The participant for this pilot was identified by the TYA service, who identified six potential participants attending a paediatric and teenage oncology outpatient clinic. The participant was the first young person I approached in the clinic on that day and, as they agreed to participate, none of the remaining five were approached at that time. The participant was approached by a member of the clinical staff to ask if they would be happy to speak to me about participating in some research. This participant was a 14 year old female with leukaemia and fitted the inclusion criteria for study three, which are expanded upon in chapter 6. Once she had agreed to participate, I discussed the pilot project with her and her family members who had attended the clinic appointment with her. When the participant and parent agreed to participate, an appropriate time was arranged where I could meet them again to sign consent forms and discuss the research process further. The pilot proceeded once written consent had been obtained.

5.3.2 Research question and interview schedule

Research question - "Tell me about your education experiences since you have been diagnosed and what has helped or made it more difficult to carry on with school"

The above research question provided the primary focus for the participant in taking photographs to describe her education experiences. Other issues of interest to the research project (e.g. peer relationships, body image, education support and well-being) were explored further in the interview, but always in relation to the images provided by the participant.

5.3.3 Taking the photographs

The participant had taken a total of sixteen photographs, using a mobile phone camera of her own, although one could have been provided for her. These photographs were printed for the participant to bring to the interview. This was not something that was suggested to her, but something that she had decided would be useful so that we could both clearly see what she had recorded. The Activities Co-ordinator for the TYA service had reported that the participant had struggled in the beginning to think about what issues and experiences she had faced. The Activities Co-ordinator subsequently worked with the participant to construct a spider-diagram to help her generate ideas and reflections. These ideas then formed the starting point from which the participant began taking photographs. This was a different manifestation of the same experiences I had during the self-pilot, where I had thought about the issues I wished to discuss before visually representing them.

5.3.4 Results in brief

The participant's photographs covered the following broad issues that were all primarily concerned with factors that hindered her access to education (Figure 5.3):

- Restrictions on what she could eat and drink due to infection risks
- Fatigue and spending a lot of time in bed
- Treatment
- Low blood pressure
- Taking medication in school
- Scans and tests
- Access and mobility around school
- Being an inpatient
- Attending clinic appointments
- Doctors changing their minds about treatment and hospital attendance
- Friendly people at the hospital (not a barrier)

Photographs of medical signage representing areas of the hospital



Photographs of medical professionals

Photographs representing restrictions and limitations



Figure 5.3 - Images from pilot study two

5.3.5 The interview process

The interview lasted for 40 minutes and the participant was interviewed alone. Using the photographs as a way of moving through the interview provided a good structure to the session. The participant seemed confident when discussing the photographs that she had brought to the interview and the well organised nature of her comments led me to think that she had thought about what she wanted to say about each photograph in advance. Therefore it seemed that the photographs had provided an effective way of her structuring her thoughts about the subject. I attempted to explore each photograph in as much depth as possible, but it was sometimes difficult for the participant to make the connection between the practicalities of the situation (e.g. “stairs make it difficult for me to get around school”) and the resulting emotional and psychological impact (e.g. “it makes me feel like I stand out”). I attempted to facilitate this by asking her to give me an example of a specific time that she had experienced what she was discussing and then to use this example to contextualise her experience and hopefully recall some of the feelings at this time. This was successful in some instances, but was something that I would need to develop further in the methodology of study three. After all of the photographs had been discussed, there was an opportunity to explore some more generic questions from a draft interview schedule (detailed in chapter six), which was developed based on the findings presented in chapters two and three. Where possible, these questions were referred back to the issues that had been discussed based on the photographs and this process felt like it naturally flowed successfully.

5.3.6 Practicalities

A number of practical issues were raised during this pilot study. The room which had been highlighted as a good interview space was in use on the day of the interview and therefore a less private room had to be substituted. This resulted in the interview being interrupted on two occasions. Another practical issue was the fact that the participant had forgotten to take the photographs up until two days before the interview. This was only discovered through a brief discussion with the clinical staff about booking a room and was attributed to the amount of treatment and appointments the participant had during this time.

5.3.7 Feedback

Once the interview had been completed there was an opportunity to ask the participant for some feedback about the structure of the project and the information she had been given. She reported that she found it difficult to visually represent in photographs the issues that she wanted to discuss. She said that examples would have helped her to better understand what was being asked of her. She also reported that the spider-diagram activity had been a useful way of getting started and could be suggested to future participants at the outset of study three. The participant did feel that she

understood the aims of the research and how her participation fitted into the project as a whole. She also reported liking the visual interview methodology and preferring it to a more traditional interview situation.

5.3.8 Changes

This pilot study proved very useful and resulted in several changes to the planned methodology. Firstly, participants would be shown examples of how to visually represent their experiences and ideas. Participants would also be advised to use a spider-diagram or similar method if they were struggling to think about how their diagnosis had impacted their education engagement and were provided with a template for this purpose. Emails or texts would also be sent to participants during the two weeks before the interview to remind them to record their experiences. Where possible, a private room would be secured in advance to minimise disruption to the interviews and maximise the quality of interview recordings.

5.3.9 Reflection on the positives

Despite some of the initial difficulties the participant had in producing images, it was pleasing to hear that the use of those images as a focus and structure of the interview was a positive experience for her. As an interviewer, the experience of using the images was also very positive and created an interview situation that felt more dynamic and interesting than a traditional interview. I also felt that through the images there was an increased level of engagement with the participant and a rapport that developed through sharing the images she had created and the discussions surrounding these images. It also seemed that the participant had a sense of satisfaction with the images they had produced and the contribution this had made to the interview process and the shared nature of the research experience.

The experiences and findings from the two pilot studies discussed in this chapter have been used to inform the practical development of the methods for study three that will be detailed in chapter six. After a theoretical assessment of the literature in chapter four and the pilot work of the current chapter, visual interviewing remains a viable main data collection technique that can be taken forward for use in study three.

Chapter 6 - Study Three, Methods

Figure 6.1 shows the flow-chart developing the linkage between the chapters and shows that the methodology described in chapter four has been used to develop the methods that will be detailed in the current chapter and used for study three. These methods were piloted in the previous chapter and these pilot studies added additional understanding of the methods as well as some practical alterations.

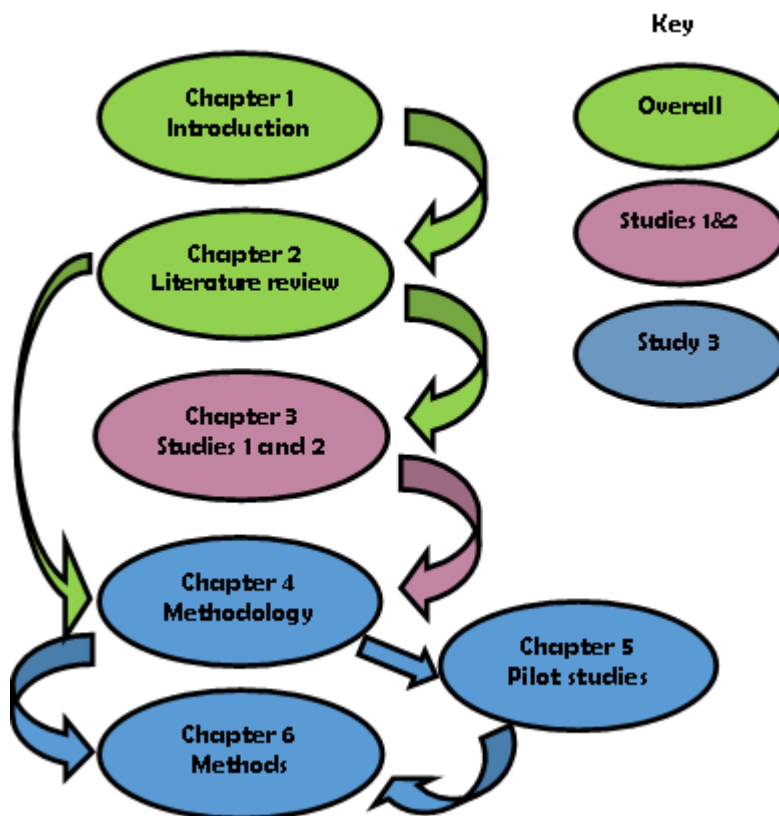


Figure 6.1 - Chapters flow-chart

Following the experience gained in pilot study one and the feasibility demonstrated in pilot study two (reported in Chapter five), the visual interview methods (described in Chapter four) were taken forward into study three, with some minor adaptations. The aim of this chapter is to detail the way in which the visual methods and the other components of this QLM study were used to address the research questions in study three. To assess the research questions, teenagers with cancer had the option to participate in visual or 'go-along' interviews (see Chapter four for details), along with the completion of quantitative measures, at three different time-points over the first nine months of their cancer diagnosis. The findings of the qualitative and quantitative components were analysed separately and comparatively to comprehensively address the primary research question. Secondary research questions were addressed by specific individual methodological components or a combination of these methods. In this chapter the research questions are stated and followed by details

about ethical issues, recruitment, participants, procedure, interview schedule, measures and method of analysis.

6.1 Research questions

From the perspective of young people, what influences the impact that a cancer diagnosis has on their education?

- What are the main factors that hinder or facilitate education engagement for teenagers with cancer?
- To what extent do the education experiences of teenagers with cancer change over the first nine months of their diagnosis?
- What is the impact of education engagement on the overall coping and well-being of teenagers with cancer?
- Does cancer have an effect on teenagers' perceptions of themselves?
- Does cancer have an effect on teenagers' perceptions of school?
- Does education engagement affect the extent and nature of relations with pre-diagnosis peers?

6.2 Ethics

Participants for study three were recruited from the teenage oncology inpatient ward and outpatient clinic based at a large hospital trust in the north of England. This meant that the study fell under the remit of NHS ethics and local Trust Research and Development. An application was submitted using the Integrated Research Application System and ethical approval was granted on 20/09/2012. Subsequent research and development approval for this study was granted on 25/10/12 (Appendix 14b and 14c). The main ethical issues provoked by this study were; consent, recording images, and the risk, burden and benefits for participants. These issues and the resolutions of these issues will be detailed in the following section of this chapter.

6.2.1 Consent and right to withdraw

Because obtaining consent for participation in research studies from any young people under the age of sixteen is a difficult issue, the advice of the Quality Assurance Manager for Research and Development was sought at an early stage of research planning (21/04/2010). To obtain informed consent, participants must be able to understand the information about the aims and methodology of the study and what their involvement will entail. Regarding consent forms and signatures, the age of the participant is important. Those under sixteen years of age need to assent to participating, but also require the consent of a parent or legal guardian. Those sixteen years old and above are able to

consent themselves, but the assent of a parent or legal guardian is desirable. In both cases, the investigators signature is also required. These issues are relevant to written consent, but consent is an ongoing process and researchers should verbally re-visit aspects of the consent process to ensure that participants feel comfortable with what is happening and free to withdraw or pause as appropriate (Gibson, Richardson et al. 2005, Calman, Brunton et al. 2013). In practice in study three, the participant, parent/guardian and researcher all signed the same consent form at the end of a detailed discussion about the study. Both participants and parents/guardians were given the opportunity to ask questions prior to signing the consent form and informed that they could ask more questions and withdraw their consent at any time. At the outset of each interview, consent was verbally reiterated by the participant and checks were made so that they knew they were still free to withdraw at any time and they were reminded that they were not compelled to answer any questions if they did not feel comfortable. An opportunity was always taken to ask participants about consent issues when their parent/guardian was not present to attempt to minimise the risk of pressure being applied by parents/guardians for the young person to participate. Every effort was made to ensure participants felt comfortable in the study and no consent issues were experienced throughout the study. As far as it was possible to know, no participants remained in the study against their will or felt that they could not withdraw. The only minor issue was experienced when attempting to recruit young people who seemed very interested in the project themselves, but were persuaded not to participate by the parental view that they already had enough to contend with concerning their illness and treatment. This was an observation and not evidenced directly, but is an issue faced by researchers consenting young people who are under sixteen.

6.2.2 Production of photographs

Asking young people to be responsible for collecting visual data raised a number of ethical considerations (see Chapter four for a discussion of the literature around the ethics of taking photographs). The primary ethical concern was what the participants were allowed to visually record and how the content of these images could be governed whilst not overly restricting the freedom they had to control the content themselves. This was a particular concern regarding recording images of people and what were considered to be public places. It is not illegal or unethical to take photographs of people without their expressed consent if they are in a public place. However, in principle, participants may have wished to record images in private clinical areas of the hospital where other young people and families who were not involved in the research were present, or at school with other pupils and teachers in the background. In a previous study evaluating school-based outdoor education programmes with adolescents, participants were advised by the researchers to only record images of other people if they would be happy to be similarly photographed themselves (Smith, Gidlow et al. 2012). However, Mandleco (2013) recommended that participants engaging in photo-elicitation

interviewing should seek the consent of people that they wished to include in photographs to be used within the research. Taking these previous examples and recommendations into account, participants in study three of this research were given a booklet (Appendix 4) to provide guidance on what to record and what not to record. In line with the example from Smith, they were advised to be aware of what/who was in the background of their images, but in keeping with the example from Mandleco, they were advised that if they wanted to visually record particular people they should use a consent form, which was provided (Appendix 12). It was felt that the combination of these considerations would alleviate ethical concerns. Any recorded images that included non-consented people, could have had their features pixilated, so as to obscure their identity. In practice this never had to be implemented, although it may need to be considered in the future dissemination of the research. Any images that were recorded depicting anything that could be construed as indicating harm to the participant or others, or depicted any potentially illegal activity, would have been discussed with the research supervisors to decide how to proceed. Fortunately, in practice, this did not occur.

6.2.3 Anonymity

Another ethical concern was the potential for participants to be identified through publication or presentation of their images and subsequent interview data. This was addressed by committing to anonymise interview extracts or image labels used in any publications or presentations. Any images that contained people or personally identifiable images were pixilated so as to protect their identity and every effort was made to initially choose images as examples in presentations that contained no such identifiable data. Despite the ethical difficulties with including participant visual images in publications and presentations, Pyle (2013) highlights the importance of this data in communicating the participant voice to the audience and claims that the absence of this data produces only a partial representation of the research. This is especially important when the use of participant extracts verbal or visual, is needed to establish the context of the analysis and the authenticity of the outcomes (Pyle 2013).

The images that the participants produced were initiated by their participation in the research and therefore there was a potential ethical issue regarding ownership of the material. In practice the participants in this study all used their own devices to record their images and therefore to claim the images were anything except the property of the participant seemed unjustifiable. Participants were instead asked to provide the researcher with a copy of their images, which would be kept for the duration of the research and additional consent would be obtained from them if their images were desired for use in a publication or presentation. This approach was approved by the ethics committee assessing this research (Appendix 14b).

6.2.4 Risks, burdens and benefits

The participants in this research were young people as well as cancer patients and could therefore be classified as a vulnerable group on two counts. However, although cancer patients may already be experiencing the burden of symptoms, side-effects and illness, as well as all of the potential psychological and social disruptions, they still value the opportunity to participate in research and contribute their views (Terry, Olson et al. 2006, Murray, Kendall et al. 2009, Calman, Brunton et al. 2013). There was potential that during the course of their participation they may have discussed experiences and emotions that were difficult or upsetting. Teenagers only participated on the basis of fully informed consent and with the consent of a parent/guardian who indicated their judgment as to whether the individual was able to join the study without any foreseeable negative consequence. Before the young person was approached with information about the study, the TYA service supplied their judgement as to the suitability of potential participants based on their knowledge of the individual circumstances of young people and their professional experience of care in this area. Participants were given assurance that their personal details would be completely confidential, their interview data would be anonymous and that they would be free to withdraw from the research at any time. However, participants were advised that should they report anything within their interviews or peripheral conversations that indicated potential harm to themselves, or to others, or was suggestive of criminal activity, this would have to be disclosed to the relevant agencies. Fortunately, this did not occur during the study.

Participants in this research were all having their care managed by a TYA service, through which they were able to access support from staff that had been made aware of the research and agreed to provide this support if it was required. Therefore, if any issues did arise there was support available to the participant.

Participant burden was a concern for this research. Participants were asked to remain in the study for a minimum nine month period and during that time they were asked to complete a total of three interviews and twelve measures. This has been highlighted as a particular ongoing problem with longitudinal research with cancer patients, despite the need for and benefit of this type of research (Calman, Brunton et al. 2013). There was also the time taken to read the information sheets, consent to the study and record their experiences, which varied for individuals. An additional burden for participants was the process of being reminded about participating and the logistics of arranging interview times, which sometimes involved them remaining in outpatient clinics after their appointments. Ongoing consent to continue in the study was verbally sought at each time-point, so that participants had the opportunity to raise any concerns or withdraw from the study.

This burden was hopefully minimised by the fact that their participation was distributed across nine months of the study and they had long periods within that time where nothing was required of them regarding the study. Participants were given flexibility throughout the study about when they completed measures, recorded their experiences and engaged in the interviews. Any contact with me was arranged at a time when the participant was attending hospital, so that no extra journeys needed to be made. Participants were clearly informed about the potential for the research to help other teenagers with cancer in the future, and the wider context of the benefit of their participation was a motivating factor for the majority of them and worked to reduce any burden they may have experienced.

Contacting bereaved families was avoided by checking the status of participants with the TYA team before any reminders or documents were sent out to them. The TYA team were also asked to pass on any major changes to the care or health of any participants. Regular contact was made with the TYA team, as well as practitioners working in the inpatient and outpatient settings, so it was possible to keep up to date with the status of participants.

Participants were informed from the outset that if they had complaints about the study then they could take these to their key-worker (usually a Clinical Nurse Specialist) within the TYA service or wider clinical teams. If their participation in the study resulted in any complaints about the participant's school, then again they were advised to take these to their keyworker. If the participants revealed any concerns about the care they were receiving from the TYA service or clinical teams, then they could discuss these with me and I would advise them on the most appropriate course of action depending on the nature of their complaint.

Despite the risks and burdens involved, there were also potential benefits for participants. It was thought that participants in this research may have experienced some therapeutic benefit from taking part in the study and this could have come from the catharsis alluded to in the pilot study (see Chapter five) or from the satisfaction of contributing to research that could help others. They had the opportunity to discuss their experiences in confidence and have somebody show an active interest in their lives and cancer experiences. Participants also had the opportunity to be involved in research specific to their age group, which could lead to new developments for young people with cancer in the future. This was hopefully a motivating factor during the research and a source of satisfaction for participants once they had completed. The degree of ownership that participants had over the research process and the visual/media nature of the recordings hopefully made the research itself something enjoyable for the participants, rather than a burdensome task.

6.3 Recruitment

6.3.1 Sample Size

Sample size within qualitative research is a difficult issue that is affected by the subject matter of the research and the resources available to the researcher (Gaskell 2000). In comparison to quantitative sampling, qualitative research is not concerned with counting participants or data points, but instead is looking to address the complexities, details, meanings and relationships within information (Kuzel 1992). For qualitative research, an appropriate sample size is one that provides enough information to answer the research question(s) (Marshall 1996). When looking at a niche paediatric population, attrition is a critical issue because of the often low frequency of incidence in the population and must be considered when calculating an appropriate sample size (Holmbeck, Bruno et al. 2006).

Hefferon points out that there is often pressure for research students to include more participants than they actually need in I.P.A research and that there is caution about the merit of small sample sizes, stemming from a quantitative history in social sciences (Hefferon and Gil-Rodriguez 2011). Reid et al. (2005) claim that being able to provide a greater depth of insight into a smaller sample is more beneficial than broad statements about a wider sample in I.P.A research. Smith (2011) states that sample size is contextual depending on the nature of the project and difficult to prescribe for PhD students, but a loose recommended framework is four to ten participants for professional doctorates. The original aim of study three of this research was to recruit a sample of 10-15 teenagers with cancer. This sample size followed Smith's recommendations and was kept relatively small due to the in-depth qualitative interviewing that was to be conducted with each participant. In addition, qualitative research using I.P.A as the primary analytical method is regularly conducted using relatively small sample sizes and this is adequate for the rigour of I.P.A to produce interesting and detailed results (Smith 2011). The very thorough analysis of each individual transcript is very time consuming and has the aim of allowing detailed understanding of the experiences and perceptions of a particular group (Smith, Osborn et al. 2003).

The range in the sample size, 10-15, was to allow for potential attrition. It was thought that attrition could be a concern in a study population who had significant health difficulties and a range of factors competing for their attention when they were feeling well i.e. education, peers, family, and social activities. Because the sample size was 10-15 there would therefore be a total of 30-45 interviews conducted, as each participant would be interviewed over three time-points. The exact number of interviews was unknown at the planning stage as the rate of attrition was difficult to predict. As well as practical considerations, the sample size reflected the potential difficulty with recruiting participants from this vulnerable and limited target population. The TYA service in the recruiting centre received approximately 120 new referrals every year. This figure was inclusive of all young

people aged 13-25, with a wide range of oncology and haematology diagnoses. The exact number of young people referred to the TYA service in 2012 (the year preceding the start of recruitment) who would fit the inclusion criteria for this project was 20, but this figure has varied considerably over recent years.

Another factor which made it difficult to accurately predict the sample size at the outset of the research was data saturation. The concept of data saturation originally developed out of grounded theory (Guest, Bunce et al. 2006), but has since been commonly applied as thematic saturation to interview based qualitative psychology research, although some still claim it is only appropriate to grounded theory approaches (Shaw 2011). Thematic saturation has been defined as meaning that data should continue to be collected until novel themes are no longer generated (Green and Thorogood 2004). It is clearly unknown at the outset of a project at which stage novel themes will cease to be discovered. However, Francis et al. (2012) proposed that it is good practice in qualitative health research to define a-priori criteria for establishing data saturation. This paper highlighted two main principles for assessing data saturation; firstly, an initial minimum sample size should be specified, and secondly, it should be stated how many further interviews will be conducted where no new themes are identified (Francis, Johnston et al. 2012). Within study three of this research these principles were slightly more complicated to apply. As each participant was to be interviewed at three time-points, there could have been thematic saturation of overall education experiences at time-point one and the level of saturation at future time-points would be unknown. Therefore, the sample size for this project was set at a minimum of ten, with the rate of thematic saturation to be continually assessed throughout the process. The rate of saturation was assessed through observation of the content of the interviews with the participants, but also through the analysis process, which was ongoing throughout study three and regularly discussed within academic supervision. Recruitment was planned to be concluded when ten interviews were completed at time-point one and the final three of these interviews completed without identification of novel themes. Recruitment would have continued if novel themes were still being discovered at this stage. Recruitment may also have continued if the rate of attrition at the subsequent time-points was substantial.

In practice, twelve participants were recruited. The reasons for the recruitment of two additional participants were that one participant (Matt) completed only the first time-point and provided only a brief discussion of his experiences, and another participant (Faisal) was not able to continue beyond time-point one due to poor health. Therefore two additional participants were recruited to maintain the minimum sample of ten. It is acknowledged that another participant (Alanna) also only completed a single time-point, which was time-point three. However, her reflective account was so rich in detail that a further participant was not considered necessary. Also, at this stage of the study novel themes

had ceased to emerge and the recruitment of a new participant would have extended the study beyond its completion deadline.

6.3.2 Recruitment Procedure

Participants were recruited into this study from the referrals made to the TYA service. This service is based at a large hospital in the north of England and accepts referrals for teenagers and young adults with an oncology or haematology diagnosis from across a wide region. Clinical nurse specialists from the service and allied TYA practitioners identified potentially eligible teenagers using the inclusion and exclusion criteria (Tables 6.1 and 6.2). When potential participants were identified, the TYA service passed on the information about their next visit to hospital for an outpatient or inpatient appointment. A member of the clinical team known to the young person then asked if they would be happy to talk to me about the research and the possibility of them participating. If the young person agreed to be approached then a member of the service introduced me to them and their parent/guardian at an appropriate time, so that the research could be explained and any questions answered. The appropriate time was usually during an outpatient appointment or after an admission to the Teenage Cancer Trust unit for treatment. Teenagers and a parent/guardian were given study information and an opportunity to discuss the research. They were encouraged to take time to think about their potential participation, but they could also consent on the day if they wished. Once they had consented, discussions were held about the type of media they would like to use for recording their experiences. Participants were given the measures that they would need to complete and guidance on recording their images before each interview. A time and location was arranged for the first interview, which gave them a clear framework and timeline for completing the tasks. This interview date was clearly flexible if necessary to accommodate the rapidly changing world of teenagers with cancer.

6.3.3 Inclusion and Exclusion Criteria

Table 6.1 - Inclusion criteria

Young people were eligible to participate in this research if they:
<ul style="list-style-type: none">- had a leukaemia, lymphoma, soft tissue sarcoma or bone tumour diagnosis- were 13-16 years of age- were being treated with curative intent at the time of recruitment- were within 2 months of diagnosis- were referred to the TYA service

The most common teenage diagnosis groups were selected for inclusion within this sample to reduce the heterogeneity of the sample and allow for greater generalisability of the outcomes. The age range

for inclusion was selected for the same reason, as well as the homogeneity of the educational pathways experienced by the majority of this age group. Young people aged 13-16 years are predominantly engaged in regular education at a mainstream secondary or private secondary school. To extend the age range below 13 would include participants who were not teenagers and to extend upwards beyond 16 would allow for the inclusion of young people who had completed their education or were in further education, which can involve a wider variety of circumstances.

Table 6.2 - Exclusion Criteria

Young people would not be considered eligible if they:
<ul style="list-style-type: none"> - had a brain tumour or brain involvement - were receiving palliative care - had a mental health issue that would inhibit their ability to participate

Teenagers whose cancer involved the brain were excluded from participation because of the documented specific educational outcomes experienced by this group (Langeveld 2002, Koch 2004, Barrera 2005). As well as brain involvement, research has shown that teenagers receiving palliative care also have specialist needs and experiences relating to their changing life-span (Freyer 2004). However, if during the course of the research project a teenager moved into a palliative care or terminal phase of their treatment then they would have been given the option of continuing with the research and would not have been excluded at this stage for this reason. It did not seem appropriate to exclude them for this reason because disease progression and the experience of unsuccessful treatment is a valid experience that would be applicable to a proportion of teenagers with cancer as they tried to maintain engagement with their education. To be excluded from the research for becoming palliative or terminal would have been an unnecessary additional negative experience for participants who would already be faced with difficult circumstances. In practice, none of the participants in study three became palliative, although one participant (Faisal) did withdraw due to poor health.

If a teenager with mental health issues had wished to participate, advice would have been sought from the TYA service and/or clinical psychology team to assess the appropriateness of participation on an individual basis. The same would have been true for teenagers with learning difficulties who would also not have been excluded if they wished to take part. In both situations the advice of the research and development services would have been sought regarding ability to consent and participate in the research. Non-English speakers were also not excluded from participating in this research. If a teenager had wanted to participate and did not speak English then appropriate interpretation services would have been assessed for the interview stage and translations of the measures looked into. In practice, none of the above issues presented themselves during recruitment.

6.3.4 Retention of Participants

Stemming from the concerns regarding the attrition of participants in this research, several methods were used to encourage participants to complete all three time-points. The design of the methodology and procedure for study three was informed to some extent by the contributions of teenagers with cancer and practitioners from the TYA service, which was detailed in chapter four. A total of ten teenagers with cancer were approached individually to provide comments and feedback about the proposed design and procedure of the research, as well as the wording and format of the study documents. The TYA service was also given the opportunity to provide similar feedback and comments. It was hoped that involving appropriate people at this design stage of the research would increase the retention and cooperation of participants. The use of visual interviewing methods provided participants with a great deal of control over what they reported and how. It was hoped that this methodological approach would be more enjoyable and empowering to the participants and would therefore facilitate completion. To supplement the benefit of this approach, participants were offered vouchers from Amazon™, which would be issued on completion of the six month and nine month time-points. Throughout their entire nine month participation there was a high level of flexibility regarding all aspects of the research and the timings and methods involved. Every effort was made to retain participants by adapting the research to their individual needs and circumstances wherever possible.

6.4 Schedule of data collection time-points

Teenagers face a multitude of stressors throughout their cancer experiences and the prevalence and emphasis of these stressors will vary depending on their stage of treatment, disease progression, hospitalisation, symptoms and side-effects. All of these factors have the potential to influence the ability of teenagers to engage with their education and cope with their experiences. Therefore, it was important to this research to assess how these stressors and the subsequent responses of the teenagers changed over time.

Coinciding with recommendations made by Woodgate (1999) that future research in this area should use qualitative and longitudinal approaches, it was decided that participants would be interviewed and complete measures at three different time-points over a nine month period (Table 6.3). These time points were:

- within 2 months of diagnosis
- 6 months post diagnosis
- 9 months post diagnosis

These time-points were decided in collaboration with the TYA service to give the best opportunity to capture different stages of the cancer experiences of teenagers. After discussions with professionals in this area it was thought that the first two months after diagnosis was likely to be a distressing time for teenagers, where they would be uncertain about their future and how their lives would be affected by cancer and treatments. The cut-off time for recruiting participants after diagnosis was set at two months, as this allowed some flexibility of timing to avoid intruding on teenagers and their families too soon, but was thought to be early enough to capture the experience of being newly diagnosed. This also reflected the feedback given by young people in the consultation exercise (see Chapter four). To avoid any undue stress to teenagers and their families, the precise timing of this diagnosis time-point was decided on the advice of the TYA service and clinical staff working with the young person. As Calman et al. highlight (2013), sensitive recruitment so close to a life changing diagnosis is essential, and can affect the experience of the researcher and the participant within the research.

After six months, teenagers would have experienced many aspects of treatment for the first time, would have had some time to adjust to their illness and had an opportunity to see how this affected their education and everyday lives. For the majority of teenagers, the most intensive aspects of their treatment would have been completed after nine months and they would have been able to reflect to some extent on how they had coped with their cancer experience, assessed to what extent they had maintained engagement with their education and what factors had been important to them.

Table 6.3 - Schedule of data collection points and participant tasks

	Description / Activity
Pre-participation	Potential participants identified by TYA service
Within 2 months of diagnosis	Participants consented, completed measures and identified their choice of media. Then they had a two week period to record their experiences and at the end of which there was a visual interview.
6 months	Participants were sent a reminder two weeks before the six month interview along with the measures to complete. They brought their completed measures and recorded material to the visual interview.
9 months	Participants were contacted a month before this time-point to discuss arrangements for the visual interview or 'go along' interview and were sent the final measures to complete. If they chose to continue with the visual interviews they brought their completed measures and recorded material to the visual interview as before. If they opted for the 'go along' interview then individual arrangements were made.

6.5 Image creation

The qualitative data to assess the primary research question and contribute to the assessment of the secondary research questions was gathered using visual interviewing (see Chapter four for coverage of the literature on visual interviewing). This approach is based on using some form of visual stimuli as the starting point for an interview with a participant. Although most visual elicitation interviews use photographs, material can be generated using “virtually any visual image” [p13] (Harper 2002). Participants in this research were therefore given a degree of choice about the style of media they used to record their experiences. Although participants were given this choice, they all decided to use photographs as their visual medium.

The aim of using visual interviewing in this research was to give participants an increased sense of ownership of the interviews, research process and, more importantly, their experiences. Due to the limited presence in the literature of patient-centred teenage cancer education research, it was important for this research to facilitate a strong teenage voice. Participants in this research were asked to visually record any aspect of their experiences related to education and what had helped or hindered them to engage with their education during the two week period preceding their interviews. They were given instructions regarding the nature of images they could and could not record, but aside from this they had free choice over what they recorded and the reasons behind their choices. The instructions were in the form of a leaflet given to them when they consented to participate (Appendix 4). If a participant found it difficult to remember or articulate their education experiences then they were given suggestions to get them started e.g. to construct a ‘spider-diagram’ with ‘school’ at the centre and associated thoughts, feelings and experiences around the perimeter. This was identified as a potentially useful tool through pilot study two with a teenage participant (see Chapter five), but using this type of diagram as a stimulus has also been used successfully in previous research (Weller 2012). If a participant found it difficult to visually represent their education experiences in their chosen medium, then they were shown examples from pilot study one completed by the researcher, this was again a suggestion from the pilot study two.

It was important to this research not to restrict the freedom participants had to record any aspect of their experience of education engagement following a cancer diagnosis. Therefore, the guidance offered to participants about what they could and could not record to bring to the interviews was kept to a minimum. This open approach to the parameters in which participants can record images to reflect their experiences has been previously used in research with young people. Smith et al. (2012) used this open approach to try to ensure as far as possible that participants would be able to reflect their own experiences of a teenage camp through their photographs. Smith encouraged participants to ‘pace’ their photographs so as not miss out anything important occurring in the research timeframe.

They were told that they could record anything they wanted to, but to keep the research aims and interview in mind (Smith, Gidlow et al. 2012).

Participants in study three were told that their images would be discussed within an informal interview situation and that they had a two week period to record these images prior to the interview. Participants were made aware of the aims of the research and were advised to keep these aims in mind when recording their images. Therefore, although they had a lot of choice about the content of their images, they were advised to try to record images linked to their education experiences and anything that had helped or hindered their education engagement. They were encouraged to record things that they would be able to elaborate on in the interview and that it did not matter how many images they brought to the interviews, as long as there was something to discuss. Participants were advised to try not to take photographs of, or record anybody, who did not want their photograph taken, and to be aware of what or who was in the background of any images they recorded. However, if they did want to take photographs of, or record people, then to ask them to sign the short consent form provided to them. They were also advised not to record anything that could be seen as inappropriate or offend anybody. In terms of practicalities, it was established whether participants had the materials they needed to record their images and if not then materials would have been provided by the research team. It was also ensured that whatever medium was selected would be compatible with the research computers and equipment.

6.6 Interview schedule

The general approach taken in visual interviewing has been thoroughly detailed in Chapter four. The interviews in study three followed this approach by using photographs as the stimulus for discussion and as the scaffolding of the interview process and each participant's images provided a different structure and feel to the interview. Each interview therefore took a different course depending on the content of the images provided by the participant.

The interviews began with an initial short discussion about how the participant was feeling and how their education engagement had been in general. Following this, the photographs that they brought to the interview were discussed. These photographs were either printed hard copies or electronic images on smart phones or tablets. The participant was given control over the order in which the images were discussed. The direction of the interview from this point was significantly dictated by the content of the images, but the following general approach to questioning was taken:

- Can you tell me what is in this photo?
- Why have you chosen this particular image?

- What did you want to show me with this photo?
- What else could have been included in this photo?
- In what way is this photo linked to your education?

The photographs were discussed in turn until the participant appeared satisfied that they had shown everything they intended to show. The participant was able to direct the discussions around the photographs, however, themes and questions from the following interview schedule were explored where possible and appropriate to the photographs. If the photographs did not lead to the discussion of these issues then they were explored following the discussion of the photographs.

Not all of the participants wanted to engage in the visual image part of study three. Eight of the twelve participants provided visual images as part of their interviews. When the participants brought images with them, these provided the focus and structure for the interviews and the questions developed from these visual starting points. When participants did not provide images, the interviews commenced with some scene setting conversation about how they had been feeling since the previous interview, how much they had attended school and the questions forming the interview schedule were asked as far as possible in a way that flowed naturally from the participant's initial description of how they were feeling and what their education experiences had been like recently. The questions that appear in the interview schedule detailed below were therefore not implemented systematically, but were instead used where appropriate to the natural flow of the interviews that was led by the participants. This approach was participant-centred in either scenario and was adaptable to the flow of the individual interviews. This appeared to facilitate building rapport with the participants and enabled an individual flow and focus for each participant.

The themes and questions in the following schedule are derived from the findings in the previous phases of this research (see Chapters two and three). The majority of these areas were addressed at every time-point, however, questions relating to changes over time and overall reflections were only appropriate to time-points two and three.

All time-points:

What are their worries/concerns about education?

- *How do you feel about missing school?*
- *How soon after your diagnosis did you start to think about school?*
- *What are you most worried about?*
- *Is there anything you will enjoy about being away from school?*

What support have they received?

- *Can you think of anyone that has been helpful to you when you were trying to carry on with schoolwork?*
- *What times were they most helpful?*
- *Who has not been as helpful as you would have liked?*

What helps them and what hinders them with engaging with education?

- *Can you think of anything that has stopped you going to school?*
- *What is the most important thing that gets you to school?*
- *Do you ever not go to school when you are well enough to go?*
- *What do you wish someone had told you earlier that could have made things easier for you?*

How has time away from school affected their peer relationships?

- *How have your friends reacted since you've been ill?*
- *Have you seen more or less of your friends since you became ill?*
- *Have some friends been better than others at keeping in touch?*
- *Why do you think some of them are better at keeping in touch?*
- *In what way do you think missing school has affected your friendships?*

Time-point 2 (6 months) and 3 (9 months):

What has changed for them since the last time point?

- *Could you tell me about something that has changed since we last met?*
- *Could you tell me about the biggest thing that has happened to you since we last met?*
- *What do you hope we will be talking about next time we meet?*

What have they missed about school?

- *Could you tell me about a time when you missed being at school?*

What have they found positive about their cancer experience and education?

- *Could you tell me about a time when you felt good not to be at school?*

Time-point 3 (9 months):

How do they think their engagement with education during treatment has affected their overall coping and well-being?

- *Could you tell me about a time when school helped you cope with your cancer?*

- *Could you tell me about a time when things at school made it harder to cope with your cancer?*

What has their experience of the visual interview methods been?

- *How have you found recording your experiences in images?*
- *What have you enjoyed about recording your experiences in images?*
- *What have you found difficult about recording your experiences in images?*

This final set of questions was included as an evaluation of the visual interview method, as its use with this population is novel and therefore some evaluative and reflective comments from participants could have provided some useful insight into their experience of the method.

6.7 Measures

Psychometric measures were selected to contribute to the analysis of the primary research question and to assess some of the secondary research questions. These measures were given to participants at three time-points alongside the study and visual image information, and were completed in time to bring to the interviews. The measures covered four main areas of interest; coping, perceptions of school and self, well-being and education engagement. As discussed in chapter four, the measures offered a pragmatic and previously tested way of gathering additional data on participant's perceptions of themselves in these areas. The data from the measures was used in conjunction with the qualitative interview data to produce a more detailed understanding of the experiences of participants. Additionally, the results of the measures provided information on these areas regardless of whether they were explicitly discussed in the interviews, making the assessment of the secondary research questions possible in some cases and more complete in others.

A literature search was conducted in each of these four areas of interest to identify existing measures that would be appropriate to the research questions and the study population. Measures were selected for use in this research based on a number of factors:

- Previous research in this area has limited focus on patient reported outcomes completed directly by teenagers with cancer. Therefore, measures were only selected if they allowed for this type of data to be collected.
- As the measures would be completed by the teenagers themselves, they had to be appropriate for this age group. Measures were therefore only selected if they had been previously used in this age group, or specifically designed for this age group.

- To provide evidence to assist in pragmatically and reliably answering the research questions, only well validated measures were considered where available in the literature. The measures also had to focus on the areas addressed by the research questions.

6.7.1 Coping

Adolescent Coping Orientation for Problem Experiences (A-COPE) (Patterson 1987)

The A-COPE fulfilled all of the above requirements for use in this research. It is a patient reported outcome measure, appropriate for young people aged 11-18 and has been widely used to assess coping styles in adolescent health research. However, Sveinbjornsdottir et al. (2008) reported that the development of all of the most commonly used measures of adolescent coping, including A-COPE, did not conform to the ideal standards for the development of measures using exploratory factor analysis. Therefore there is some doubt about the exact validity of measures in this area and this is acknowledged in the interpretation of the data produced by this scale.

The A-COPE is a self-report questionnaire consisting of 54 specific coping behaviours that teenagers may use to manage and adapt to stressful situations (Appendix 7). Participants use a 5-point scale (1=never; 5=most of the time) to indicate how often they use each coping strategy when facing stressors. The A-COPE comprises twelve sub-scales. The sub-scales were developed using factor analysis and reduced the measure from an initial set of 95 items to the final set of 54 items. Each of the remaining 54 items had a factor loading of 0.40 or above onto one of the twelve sub-scales (Patterson 1987). The A-COPE was selected primarily to help address the research question “What is the impact of education engagement on the overall coping and well-being of teenagers with cancer?” As well as contributing to the assessment of this research question, the data gathered from the A-COPE contributed to the assessment of the primary research question and the question addressing changes over time.

6.7.2 Attitude to self and school

The Pupils Attitude to Self and School (<http://www.w3insights.pass-survey.com/pass.htm>)

The P.A.S.S fulfilled all of the above requirements for use in this research. It is a patient reported outcome measure and assess the attitudes of young people towards themselves and school. It is therefore the ideal tool for assessing the research questions “Does cancer have an effect on teenagers’ perceptions of themselves?” and “Does cancer have an effect on teenagers’ perceptions of school?” The P.A.S.S is a 50 item assessment tool used to assess 9 factors involved in young people's attitude towards themselves and their education (Appendix 9). Participants use a 4 point response scale to indicate to what degree statements apply to them. The P.A.S.S is a psychometrically validated instrument developed and piloted with large samples of young people in mainstream education. A

significant advantage of using this measure is in the ability to compare participants' results to thousands of normative data for pupils in this age group. This comparison will allow the assessment of the degree to which the way teenagers with cancer orientate themselves in education differs from the general population. As well as assessing how participant's attitude to self and school change over time, this research will be able to see to what extent the study population's scores as a group alter in comparison to the normative data during the first nine months after their diagnosis.

6.7.3 Well-being

The Warwick Edinburgh Well-Being scale short version (SWEMWBS) (Stewart-Brown 2009)

The SWEMWBS is also a patient reported outcome measure and therefore appropriate for the research. The SWEMWBS is a shortened version of the original WEMWBS and conforms to the expectations of RASCH analysis to a greater extent than the original 14 item scale (Appendix 8). Stewart-Brown also recommends the SWEMWBS where respondent burden is a concern. This is true for the current research sample, where participants completed several measures alongside the interviews. The SWEMWBS consists of seven items relating to the mental well-being of the participant. Teenagers respond to statements on a five-point scale ('none of the time' – 'all of the time'). The SWEMWBS has been selected to assess the research question "What is the impact of education engagement on the overall well-being of teenagers with cancer?", as well as to provide comparative data to the interviews to assess the overall education experiences of teenagers with cancer and assessing changes over time.

6.7.4 Education engagement

The literature review revealed that there are currently no measures available to assess the education engagement of teenagers with cancer. Therefore, a study-specific form was developed to collect information on; days of school missed/attended, extra-curricular activities missed/attended, contact with peers, support staying in contact with peers, hospital/home tutoring, independent learning, what support has been provided and who provided this support. This was a simple reporting form for gathering basic education engagement information. The data generated by this form provided some demographic information regarding the contact that a participant had with their place of education, used to place their experiences into context.

6.8 Analysis

6.8.1 What was analysed and how?

The interviews from study three were audio recorded and transcribed verbatim. The subsequent transcripts were analysed using I.P.A methods and this analytical work was closely supervised by the

academic supervision team to ensure rigour and grounding in the transcript data. In keeping with standard I.P.A. procedures, the first transcript was read and re-read thoroughly until the content was well known. Transcripts were annotated with anything that was felt to be interesting or significant. These annotations were usually descriptive notes referring to sections of the interview where the participant explicitly discussed aspects of their education (e.g. how often they attended school, or reintegration experiences/worries). Annotations at this stage also included anything that was interesting about their overall cancer experiences and anything that seemed to be having a level of positive or negative impact on them (e.g. the experience of telling family about their cancer, or the draining effects of treatment protocols). The first type of annotations clearly linked to the aims of the study, whereas the second type of annotations were made to represent what the participants had chosen to discuss, as well as providing context for their education experiences that could be used to more fully understand the complexities of these experiences. Each read of the transcript produced new insights and possible interpretations about the experiences of the participant and the meaning that they might have held (e.g. annotations made concerning 'continuity of education reputation' towards the end of a read through, provided additional depth to earlier annotations about the desire to sit exams on the subsequent read through). As well as straight forward annotations that highlighted and labelled extracts of interest within the transcript (e.g. "had home tuition in place very quickly, only core subjects. Reduced cognitive capacity."), more detailed annotations were made when possible underlying psychological factors were suggested or hypothesised (e.g. "infection concerns linked to a timeline of treatment. This timeline seems to be something he is focussing on and would be more important than the actual health consequences."). A third type of annotation was concerned with the dynamic of the interview and the way participants chose to present aspects of their experiences, and these type of annotations were made in case they could later be used to shed light on the framing of an experience (e.g. "very quickly moves from describing the operation to describing how it could be successful. Not giving me a chance to react negatively or worryingly before he adds something positive? How do teenagers cope with this kind of timeline for recovery?"). After several read-throughs, annotations sometimes began to cluster together in a logical fashion and tentative titles for these emergent themes were noted when they occurred (e.g. "explaining" was noted as a possible theme at an early stage of analysis). These themes were then assessed in more detail and discussed within supervision sessions to further elucidate the potential meaning (e.g. "explaining" became "telling and knowing" to better reflect the depth of meaning within this experience). Despite the level of abstraction implicit within theme-making, it was important to maintain a "thread back to what the participant actually said" (Smith, Osborn et al. 2003). Throughout this theme-making process, checks were made to ensure that the themes and clusters of themes were still traceable to the content of the interviews. This was supported by compiling tables of participant extracts to support each theme and then reading the content of these extracts to assess whether there was anything within them that was not well represented by the theme. The clusters were then given appropriate titles, which formed the

super-ordinate categories (e.g. “timelines”) and the example extracts for each theme were indexed and referenced to allow them to be easily found within the transcript.

Following the completion of I.P.A for the first transcript, the subsequent transcripts were analysed using the same method. There were two potential ways for this to progress: firstly, each transcript could have been treated individually with the I.P.A procedure described above proceeding from scratch with each new transcript; secondly, the emergent themes from the first transcript could be used as a guide for the interpretation of the subsequent transcripts. In keeping with best I.P.A practice, the first of these options was adopted, however, it was not possible to forget the analysis of previous transcripts. Therefore, it is acknowledged that the insights gained from the analysis of one transcript were carried through into subsequent transcripts on some level. Each of the transcripts was still treated individually and any emerging data was thoroughly scrutinised to ensure that it did fit with an existing theme or whether novel themes needed to be created. Every effort was made to ensure that participant accounts were not being treated inaccurately or for the sake of convenience. In many cases the analysis of a new transcript informed the current understanding of existing themes and this often resulted in alterations to the titles of themes, the way that themes were clustered together and the overall modelling of participant experiences. The modelling of the experiences of participants was continually changing with the addition of new analyses of transcripts and there were multiple iterations of conceptual models. There were also significant turning points within the analysis. For example, the analysis of Mario’s first and second transcripts produced the idea of timelines and timeline thinking. He very clearly articulated some of his experiences using these timeline metaphors and this provided a “gem” (Smith 2011), which resulted in a conceptual reshaping of the analysis that greatly enhanced the understanding of previous and subsequent transcripts.

The analytical process was ongoing and was conducted alongside the longitudinal interviews. Therefore, interviews were analysed before other interviews were conducted. There were two main advantages to using this approach. Firstly, ongoing analysis helped to provide increased understanding of participant experiences in the area of education engagement, which led to more informed questions in subsequent interviews. This was particularly useful within interviews with the same participant, where their previous descriptions of experiences could be reflected back to them to ask for extra detail or to highlight changes or similarities over time. Careful attention was paid to who was leading the interviews, and the aim was always for this to be the participant. The second advantage of ongoing analysis was the assessment of thematic saturation. Assessment of saturation was partly possible through conducting the interviews and noticing when a participant said something novel. This was significantly enhanced through attention to the details and underlying concepts of the transcripts involved in I.P.A. Through this process it was possible to assess whether the latest

interview had truly provided something new or added more depth and individual application of an existing theme.

The visual images that teenagers brought to the interviews were not in themselves analysed or part of the analytical process, they were simply used as stimuli and framework for the interviews. This was consistent with the current visual interview research in this area where photographs were sometimes used to increase contextual understanding of transcript analysis, but not as primary data (Wells, Ritchie et al. 2012, Mandleco 2013, Walton and Niblett 2013). It was the interview transcripts that provided the data for the I.P.A.

6.8.2 Measures

The measures used to assess coping, perceptions of school and well-being were analysed using SPSS to investigate descriptives, frequencies and associations in order to provide comparative data for the qualitative interviews and an assessment of the research questions. The assessment of the P.A.S.S involved the comparison of the data gathered from participants in study three to normative data previously collected from over 2,000 schools.

6.8.3 How qualitative and quantitative data were brought together

The qualitative and quantitative aspects of this mixed methods study were initially analysed discreetly. The qualitative data was analysed in an ongoing fashion, as described above. Whereas the quantitative data was analysed once all of the data had been collected. There would have been no benefit to a partial analysis of the measures as this information could not have been individually or practically used to improve the research process in the same way as the qualitative data. Following completion of the I.P.A, the analysis of the quantitative measures was compared with the qualitative analysis of the accounts of participants. This allowed an assessment of the compatibility between the descriptions offered by participants in their interviews and the picture of them that emerged through their completion of the measures.

Chapter 7 - Results of the Quantitative Measures from Study Three

Figure 7.1 shows the flow-chart developing the linkage between the chapters and shows that the methods developed in the previous chapter were used to collect the data, which will begin to be reported in the current chapter.

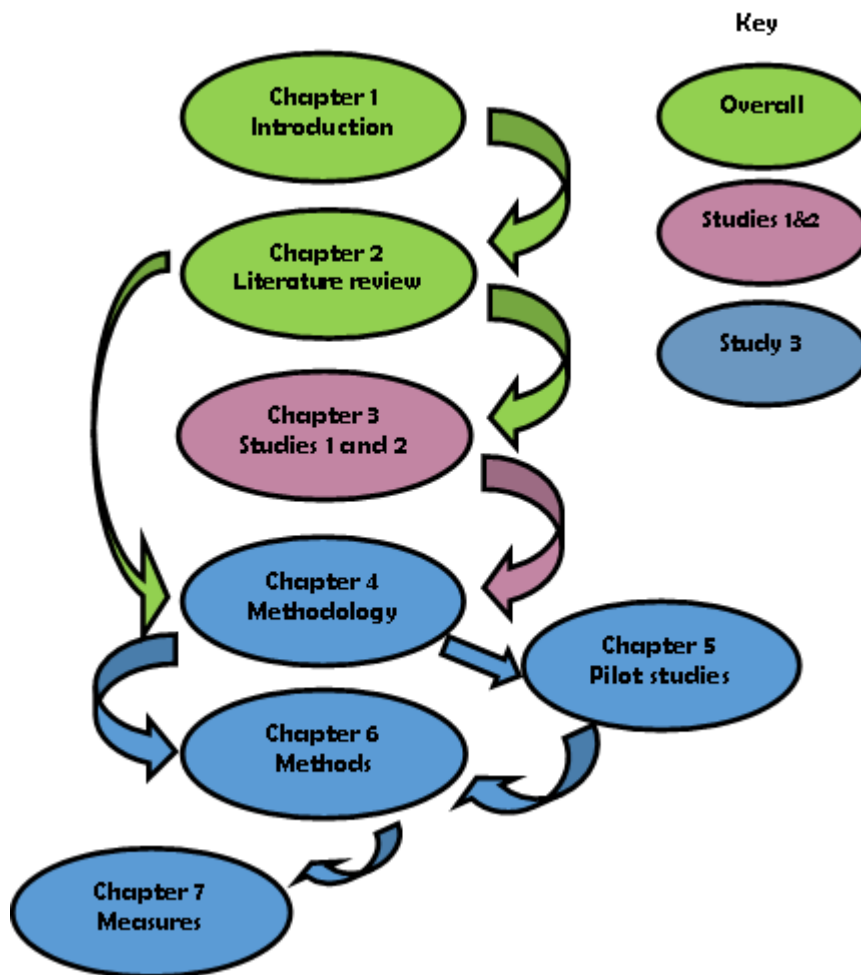


Figure 7.1 - Chapters flow-chart

This chapter presents the analysis of the standardised measures that were completed by participants at each of the three interview time-points (T1, T2 and T3). The demographic details of the participants in relation to age, diagnosis and gender are presented first, followed by self-reported details of education engagement and treatment history. The outcomes from the three standardised measures are then presented separately. As this study is a qualitatively-led mixed method approach, the sample size is very small for the inferential statistical analysis of the measures. Therefore, this chapter will primarily present descriptive statistics for each of the measures with the acknowledgement that the sample size is a limitation.

7.1 Recruitment Details

Table 7.1 shows details of the number of young people approached to participate in study three and the subsequent path that was taken by the sample as a whole. Details of individual participants and their path through the study are provided in the pen portraits in the next section.

Table 7.1 - Recruitment Details

Recruitment stage	N	Additional information
Approached	20	Young people were approached in an outpatient clinic having been introduced to the researcher by a member of the clinical team.
Consented	14	Young people all decided to consent at the time they were approached, rather than taking time to think about it.
Withdrew after consenting, but before participating	2	One of these participants decided before the interview that they did not want to have to think about the project in addition to their treatment and illness. The other was finding everything to do with their cancer frightening and we agreed, along with the TYA team, that the interviews would not be helpful at this stage.
Declined	6	Two young people declined because they felt their health was too poor to participate, and in both cases this was reinforced by the care team. One young person declined because they had already decided to defer their year of school and therefore did not feel they had anything to contribute. Another young person wanted to participate but was prevented from doing so by their parent. The final two young people declined without providing a reason.
Participated	12	These 12 participants all participated in at least one interview.
Participated in all 3 interviews	9	Two participants withdrew after the initial interview and another only completed the final interview. This is elaborated on in the pen portraits of Matt, Alanna and Faisal.
Completed all 3 sets of measures	8	Those that did not complete each time-point interview did not complete all measures. A further participant mislaid a set of measures and then did not want to complete them again.

7.2 Pen Portraits

It was important to the philosophy of I.P.A, and aim two of this PhD, that the analysis presented in the following two chapters chapter clearly represented the experiences reported by individual participants,

as well as assessing the convergence and divergence within the sample as a whole. Pen portraits have been argued as an effective way of highlighting the presence of participants within qualitative analysis (King and Horrocks 2010) and therefore a pen portrait of each participant has been presented below. The individual experiences of the participants were important, but care has been taken not to personally identify any participants through their pen portraits. Pseudonyms have been assigned to each participant and identifiable individual experiences have been omitted or edited to avoid identification. Participant pen portraits are presented below in alphabetical order.

7.2.1 Alanna

Alanna was 14 years old when she participated in her interview and was transitioning into Year 10 of high school. She had been diagnosed with a bone tumour in her leg. She was unique in the fact that she only participated in the final time-point interview and did not complete any of the quantitative measures. From the first time she was approached with information about the study Alanna consistently said that she wished to participate. This continued throughout the first nine months of her treatment, but it proved difficult to arrange a specific time for the interview and arrangements that were made were subsequently cancelled due to her feeling unwell or losing study documents. Through further discussion with her it became clear that recording images and completing measures were barriers to her participating. Once the need to record images was removed from the process Alanna was happy to take part in an interview and provided a valuable two hour account of her nine month cancer experience. Even when she technically became ineligible for the study because of too much time elapsing prior to her first interview, I maintained contact with Alanna because she genuinely seemed to want to participate, and because she informally told me about some of her education experiences when I saw her in outpatient clinics and inpatient wards. These experiences were interesting, well-articulated and were experiences that I felt would significantly add to study three. It did not seem pragmatic to exclude such potentially interesting experiences from the study because of issues of timing, when they could valuably contribute to a novel area of research.

Alanna reported that her education was very important to her, but she was unable to attend school during her treatment because of side-effects, especially related to pain and mobility. While she was absent from school she maintained her education via the hospital school service and with limited home tuition. She worked independently to maintain her school work and prepare for and sit some exams. Alanna experienced some difficulties in communications with her school while she was absent. On several occasions her and her father reported problems with receiving generic communications from school that did not reflect her health situation. Alanna was engaged in decision making during her treatment and discussed trying to understand the medical information she was surrounded by. She provided several examples of being confident in her physical appearance when

she lost her hair, but was not so comfortable with the adaptations she needed because of reduced mobility, such as a wheel-chair or crutches. Any reduction in her independence was difficult for her and these adaptations seemed to reflect this. Alanna appeared to feel responsible for the feelings of those around her, which included family, peers and other patients, and regularly discussed the impact her health could have on other people. I found Alanna a very engaging and inspiring young person, and enjoyed the interview that I conducted with her and her father. I was impressed with the way that she adapted to her cancer experiences and the confidence and self-awareness she exhibited when relaying challenging situations. I acknowledge that my positive view of Alanna could have affected the way that I present her experiences within this chapter. At the point of submitting this thesis Alanna had finished her treatment and had begun to reintegrate into school.

7.2.2 Annabella

Annabella participated in all three interviews, completed measures at all time-points, and provided some visual images at time-point one. Annabella was technically not a cancer patient as she was diagnosed with a haematological condition called A-plastic anaemia. However, she was included in the study because she was treated in the same clinics and wards as the cancer patients and had access to the same professional support and facilities. She turned 13 shortly before the first time-point interview, and was in Year 8 of high school. Annabella was interviewed alone at time-point one and talked about her experiences of diagnosis in a lively and engaging manner. She discussed the reaction of her peers to her diagnosis and all the work she had been doing recently at school. By the second time-point Annabella had experienced several months of intense treatment, including a bone marrow transplant, which she described as a very difficult time for her. In the second interview she had her mother present and was not as open in the discussion of her experiences. By time-point three Annabella was recovering well, but was still not able to attend school because of her compromised immune system. Annabella maintained her education through regular home tuition, but her increasing length of absence from school produced anxiety about her ability to reintegrate academically and socially, of which she provided several examples. Unfortunately, by the final time-point she reported increasing isolation from her peer group. This seemed to be caused by her absence from school and reduced ability to engage socially because of side-effects. Annabella was a young person with a variety of very challenging situations happening in her life and a participant I felt a tremendous amount of sympathy for. I felt that I built a good rapport with her and her mother, which I acknowledge could have resulted in a sympathetic analysis of her interviews. At the point of submitting this thesis Annabella was recovering well from her bone marrow transplant, but was still unable to attend school and by the time she is able to reintegrate she will have been absent for at least 18 months.

7.2.3 Faisal

Faisal was 16 when he consented to study three. He was attending school as well as a further education college. Faisal was willing and able to engage in the time-point one interview and completed the measures. Unfortunately, he became very unwell by time-point two and did not feel able to carry on with the study. During his interview Faisal discussed finding it very difficult to adjust to his diagnosis of leukaemia, especially because he felt very healthy and active only weeks beforehand. He talked at length about the impact that his diagnosis was having on his previously very structured approach to his path through education. He had set himself milestones and a timeline for progressing through college and onto university, which he perceived that his diagnosis would significantly alter. Faisal also described struggling with the inactivity imposed on him by his hospitalisation and felt that he would lose some of his cognitive abilities if he did not engage with his education. Faisal noticed the impact his diagnosis was having on other people and felt that they were wasting their time by visiting him in hospital. Unfortunately, it was not possible to see how this developed for him over time. At the point of submitting this thesis Faisal had recovered from his period of serious ill health and was successfully working his way through his treatment and back into education.

7.2.4 Georgie

Georgie was 13 years old when she was recruited to the study and was in Year 9 of high school. She was diagnosed with leukaemia and spent the first six weeks of her treatment in hospital. Georgie took part in all three time-point interviews and completed measures at time-points one and three. She had been taking photographs throughout her treatment regardless of participation in the study, and she selected photos to bring to interviews one and two. She was interviewed with her mother at time-points one and three and on her own at time-point two. Georgie did not attend school throughout her time in the study. She did not engage regularly with the hospital school, but did have a home tutor. She talked about not really enjoying the home tuition and that she missed the company of her peers from school. The overwhelming theme of the discussions with Georgie was her desire for everything to go back to normal. This was prevalent in her discussions about education, peers, health and family. Georgie also seemed to miss being stimulated and engaged, and highlighted this through her enthusiastic description of engaging with ward based activities and her desire to engage with people her own age on the ward. Georgie seemed to find it difficult to focus and engage in the interviews when we were discussing things that she might be worried about, or things that might happen in the future. She said that she only really focussed on the present and did not look too far into the future. I found Georgie quite a challenge to interview as it seemed that she found it difficult to remain focussed on any particular topic for any length of time. I also felt that she was a participant who would shut down or become upset when she was asked to elaborate on anything she had said that may have been

difficult for her. Therefore, although her interviews were interesting and a valuable part of the study, I felt that there might have been more to her experiences than I was able to discover. At the point of submitting this thesis Georgie had moved into the less intense phase of her treatment and had begun to think about returning to school.

7.2.5 Hayley

Hayley was 15 years old when she was recruited to the study and was in Year 11 of high school. She was diagnosed with Hodgkin's lymphoma and had the majority of her treatment in the outpatient clinic. She completed all parts of the study and provided photos at each of her interviews. Her mother was present at all three time-points and engaged in the interviews alongside Hayley. She maintained her education through independent study and home tuition, and was able to sit the majority of her G.C.S.Es. Despite being given assurances of her place in further education, her exam results were very important to her and she discussed still wanting to get good grades. She expressed a range of difficulties and anxieties related to reintegration, including body image, fitting into peer groups and being brought into the foreground because of her cancer. However, throughout the time-points she was able to adjust to these challenges and this was highlighted when she transitioned into further education and decided to keep her hair short as a mark of becoming a "new person". She regularly referred to new beginnings in her time-point three interview. This adaptation provided an interesting contrast with her mother who, although very supportive of Hayley, talked about wanting things to go back to how they were before. Hayley seemed confident and assured in her interviews, but when asked to reflect on the research process in her final time-point she revealed that she had been extremely nervous beforehand and almost did not attend at time-point two. There was an element to the interviews with Hayley and her mother that felt therapeutic. It seemed like their interviews for this study became their opportunity to discuss and reflect upon what had happened during Hayley's cancer experiences. I acknowledge that my perception of this dynamic may have altered my approach to the final two interviews with Hayley. At the point of submitting this thesis Hayley was attending her college full time and only attending the clinic for follow-up appointments.

7.2.6 Patricia

Patricia was 13 years old when she was recruited to the study and in Year 9 of high school. She was diagnosed with non-Hodgkin's lymphoma and spent extended periods of time in hospital during the first six months. Following this period of time she was treated in outpatient clinics. Patricia participated in all three time-point interviews, completed measures and provided photos in the first and second interviews. Patricia was interviewed with her mother at all three time-points and with her sister also for the second time-point. She was very quiet during the interviews and seemed to find it difficult or did not want to link her experiences to how she felt about them. Like Georgie, she was

very focussed on wanting everything to be normal, but unlike Georgie, she did not report feeling anxious about it. She did not attend school during the first six months of her treatment, but then began to reintegrate on a part-time basis. During her absence she did not talk about engaging in her education, with only infrequent home and hospital tuition and limited independent study. When Patricia transitioned into Year 10 she also moved to a new school. The reasons for this varied between her and her mother. Patricia cited new opportunities, but her mother felt like Patricia was not fitting back into her peer group and knew more people at the new school. Patricia said that she enjoyed being in the new school and felt like the new school, along with starting Year 10, gave her an opportunity for a fresh start. I found Patricia challenging to interview because I perceived that she did not really want to reflect on her experiences and was very reserved in her responses to questions. At times I felt that this may have resulted in me leading her in the interviews to a greater extent than with other participants, as I searched for questions and prompts that may have resulted in more detailed responses from her. At the point of submitting this thesis Patricia was attending school full time and attending her local hospital for follow-up appointments.

7.2.7 Mario

Mario was 15 years old when he joined the study and was in Year 11 of high school. He was diagnosed with a bone tumour in his leg and had to have intensive chemotherapy for approximately a year and had several operations, including an amputation. He engaged in all three time-points and provided photos at each interview. During his interviews he always seemed to try and be positive, often initially playing down serious issues until we discussed them further. He discussed his concern about infection risks, and how this impacted his education and peer interactions. Mario said his education was very important to him and he primarily maintained this through independent study and contact with his school teachers. He sat all of his G.C.S.Es at home or in hospital and regularly discussed wanting to get good grades despite his health difficulties and hospitalisation. Even in context of his health situation Mario was very upset when discussing his G.C.S.E results, which were lower than he expected. He transitioned into further education by time-point three and said he enjoyed the increased flexibility offered in his Sixth-Form. The analysis of Mario's interviews provided a key turning point in the conceptual understanding of the "timelines" element of the experiences of this study population. During his interviews I developed a respect for Mario in the mature and dignified way that he was able to discuss and reflect upon his experiences, which were often extremely difficult and upsetting for him. Similar to Hayley, Mario appeared to see the interviews as an opportunity to talk to somebody about what he was experiencing and feeling. I strongly sympathised with the struggles Mario was having and acknowledge that this may have influenced my analysis of his interviews. Unfortunately, at the point of submitting this thesis Mario was having further treatment because of the progression of his illness.

7.2.8 Matt

Matt was 14 when he was recruited to the study and was in Year 9 of high school. He engaged in the first time-point interview, provided photos and completed the measures. However, Matt found it very difficult or did not want to engage in his interview and to articulate his experiences. Both his mother and Grandmother wanted him to participate, which motivated him to consent, but I never felt that he was completely comfortable with the experience. When it came to the second time-point, he had returned to school, was attending the hospital infrequently and was more confident to say that he did not want to participate. His mother thought the reason for this was that he had moved on from the cancer part of his life and was focussed on getting back to normal and did not want to revisit or reflect upon his cancer experiences. The feedback that I received from the TYA service was that Matt had not engaged with any of the ward activities or with decision making within his treatment. Despite his only brief involvement in the study, Matt's approach to coping with his cancer experiences still provided a valuable contribution to the understanding of the way that participants adjusted to the presence of cancer in their lives. At the point of submitting this thesis Matt was attending school full time and attending his local hospital for follow-up appointments.

7.2.9 Nathaniel

Nathaniel was 13 years old when he entered the study and was in Year 9 of high school. He was diagnosed with a non-Hodgkin's lymphoma and spent regular time in hospital for the first four months of his treatment, but was then able to reintegrate into school after this time. He engaged in all three time-point interviews and completed all measures. He did not want to provide images as part of his interview process. Nathaniel acknowledged that he was not very comfortable talking about his experiences, but in the interview at time-point three he seemed to be more confident and in much better health. Initially he said he was overwhelmed by his diagnosis and all the extra attention it brought him from peers and from the increasing number of professionals around him. He struggled with side-effects of treatment, such as fatigue, and this limited his ability to engage in education in the early stages. He did engage with hospital teaching, but did not perceive this to be of much benefit to him. He had limited contact with his school until he began to reintegrate after six months. He said that reintegration was going smoothly for him. He regularly referred to the benefit of a visit to his school by a Liaison Nurse and how this had taken the pressure off him having to tell everyone about his cancer experiences, which was not something he wanted to engage in. At the point of submitting this thesis Nathaniel was attending school full time and attending his local hospital for follow-up appointments.

7.2.10 Nicola

Nicola was 16 years old when she entered the study and was just moving into the Sixth-Form of her school. She was diagnosed with a bone tumour in her leg and underwent long periods of intense chemotherapy and hospitalisation. She also had a major operation to amputate part of her leg. Nicola engaged in all interviews and completed the measures, but did not want to provide images for use in the interviews. Initially Nicola wanted to maintain her education through independent study, but found it too difficult within her treatment and deferred her study until the following school year. This was a decision she was happy with at the time and remained pleased with when she reintegrated back into Sixth-Form the following year. Nicola said she missed the routine of education and the purpose and structure it provided to her life. She was a very independent person capable of making her own decisions and gave many examples of when she had exercised this autonomy. One of the difficulties she expressed regularly was about the ownership of her cancer information and the frustration that arose when others had the wrong idea about what was happening to her or how she was coping. Nicola proactively adjusted to the changes imposed upon her and looked to positive adaptations and hope for the future. At the point of submitting this thesis Nicola had recently completed her treatment and was starting to reintegrate into her Sixth-Form. She was also in contact with a Paralympic organisation and had the opportunity to train for the Paralympic Games in 2016.

7.2.11 Robert

Robert was 15 when he was recruited to the study and was in Year 11 of high school. He was diagnosed with a Hodgkin's lymphoma and received chemotherapy treatment in the outpatient clinic. Robert engaged in all three time-point interviews, completed the measures and provided photos for each of his interviews. By time-point two Robert had completed his treatment and had returned to school on a part-time basis. He maintained engagement with his education through independent study and contact with his school, and managed to sit the majority of his G.C.S.Es. Robert was not intimidated by the idea of reintegrating into school after his diagnosis and took a confident approach to interactions with his peers and education staff, often talking about how he acknowledged his diagnosis himself as a means of humour or power. He was not affected by his hair loss and said he was proud to be bald, but did express some body image concerns about his weight loss. He was engaging within the interviews, but did express that he did not like to talk about his cancer experiences too much, preferring to tell people once and move on. Robert said that he did not like being bombarded with questions about his health by his peers or family members and often expressed a cumulative frustration even when he knew people were trying to be supportive. During his interviews I felt that Robert was keen to demonstrate that he was able to cope with his cancer experiences in a very confident and direct manner. Throughout the interviews I became aware that I was thinking this may be an image that he was putting forward in the interviews and may not reflect

the way he was feeling in the reality of the situations he discussed. It was difficult to explore this feeling further in the interviews, but I acknowledge that it may have influenced my interviews with him and the subsequent analysis. He successfully moved onto further education and was attending full time by time-point three.

7.2.12 William

William was 15 years old when first entering the study and was in Year 10 of a boarding school. He was diagnosed with Hodgkin's lymphoma and received chemotherapy treatment in the outpatient clinic. He engaged in all three time-point interviews, completed measures and provided photos for the first two interviews. William did not attend school until time-point three, at which point he went back full-time. In the time when he was absent William maintained his education through independent study and help from his school, but did not engage with hospital or home teaching services. Throughout his time in the study William had a very laid back approach to his cancer experiences and the impact they were having on his life. He said he was happy to go with the flow and wait until he was feeling better before returning to school. He did express boredom when absent from school and said that his attitude towards school had changed because of his time away, so that he was now more focussed. He worried about the possibility of having to take responsibility for medication at school, but this did not translate into a problem for him in reality. William missed his friends at school and said that this was exacerbated by the fact that he lived a long way from his school and therefore it was difficult to maintain contact with them. Throughout his interviews he stated that his school had been very supportive and accommodating, but, like Robert, he expressed a level of cumulative frustration at constant attention and questioning, even though he recognised it was positive. At the point of submitting this thesis William had completed his treatment and was back boarding at his school.

7.3 Demographics

Table 7.2 presents the demographic data for the participants, representing number and age of participants at each time-point, along with their diagnosis.

Table 7.2 - Participant gender, diagnosis and age at each data collection point

<u>Gender</u>	Male 6	Female 5	
	T1	T2	T3
Number of participants	11	8	9
<u>Age</u> Mean	M = 14.36 (13-16, SD 1.21)	M = 14.87 (13-16, SD 1.13)	M = 15.11 (13-17, SD 1.37)
<u>Diagnosis</u>			
Lymphoma	3	2	2
Hodgkin's Lymphoma	3	3	3
Leukaemia	2	0	1
Osteosarcoma	2	2	2
A-plastic anaemia	1	1	1
Time since diagnosis at T1 (weeks)	M = 6.9 (Range 1-12, SD 3.23)		
Time since diagnosis at T2 and T3 (months)	T2 M = 6 (Range 4-9, SD 1.41)	T3 M = 9.9 (Range 8-12, SD 1.05)	

The number of participants who completed the standardised measures varied across the time-points because one participant (Alanna) did not complete any of the measures despite completing an interview at T3, two participants (Matt and Faisal) withdrew from the study at T2 and a further participant (Georgie) misplaced her T2 documents and did not want to complete them a second time. There was an even distribution of gender, age and diagnosis across the participants. On average, participants completed their first measures 6.9 weeks after their diagnosis, which was within the specified two month recruitment time. The measures were completed at a mean time of six months after diagnosis at T2, which was in keeping with the planned method. However, measures were completed at nearly ten months after diagnosis at T3, which was a month longer than stated in the planned method. This extension to T3 was for two reasons. Firstly, there was a cumulative delay of three months across the time-points for Patricia because of delays caused by illness and logistics. Secondly, Nicola, Georgie, Annabella and Nathaniel were all due to participate in T3 during the summer holidays, so it seemed pragmatic to delay their T3 interviews for one month to allow them to experience the start of a new school year.

Table 7.3 shows the participant-reported information about the treatments they experienced, the amount of time for which they had attended school and the people who had helped them maintain engagement with their education. The education engagement and treatment questions were completed prior to the interviews at T2 and T3. Participants were asked to complete the questions in relation to

the period between their previous interview and their current interview. Therefore, the data collected at T2 relates to the period between T1 and T2.

Table 7.3 - Self-report treatment and education data

<u>Treatment</u>	T2	T3
Chemo as an inpatient	5	3
Chemo as an outpatient	4	3
Surgery	2	4
Radiotherapy	2	0
Bone marrow transplant	1	0
None	0	2
<u>School missed</u>		
I haven't been to school at all	2	2
Missed less than one month	1	4
Missed more than one month	5	3
I've been every day	0	0
<u>Other school activities attended</u>		
Yes	2	3
No	6	6
<u>Education Support</u>		
Home tutor	3	2
Hospital school	4	1
Learning mentor (hospital)	0	3
Learning mentor (school)	3	3
School tutor	1	1
School	0	1
Parents/carer	1	1

All participants had received treatment between T1 and T2, with some receiving more than one type of treatment during this time. Between T2 and T3, two of the participants received no treatment, but the remainder had continued to receive chemotherapy or have surgical procedures up until T3, which was at least nine months after their diagnosis.

Between T1 and T2, all participants, except one, had missed more than one month of school and two had not attended at all during this time. By T3 this figure had improved, four participants had missed less than one month, but none had attended every day. As well as not attending school, there was limited engagement in extracurricular activities, with six of the participants at each time-point having no engagement with these activities.

It seemed that the majority of education support between T1 and T2 came from home or hospital teaching. The involvement of the hospital school had reduced by T3, presumably because of reduced hospitalisation of the participants. School learning mentors provided support to three participants, but

overall participants did not indicate that their own schools provided much of their education support, although the data does not show whether the participants asked for or wanted this support.

7.4 Standardised Measures

Three standardised measures were administered (see Chapter six for details):

- The Warwick Edinburgh Well-Being scale short version (SWEMWBS) (Stewart-Brown 2009)
- Adolescent Coping Orientation (A-COPE) (Patterson 1987)
- The Pupils Attitude to Self and School (<http://www.w3insights.pass-survey.com/pass.htm>)

7.4.1 SWEMWBS

The SWEMWBS is a seven item measure that uses a five point Likert scale ranging from one (none of the time) to five (all of the time). Higher scores indicate higher levels of well-being and mean scores for individual items could range from 1-5, with total scores ranging from 7-35. This measure has no sub-scales and therefore the results are presented in Table 7.4 as a total mean score for well-being, alongside means for the seven individual items. The individual items have been presented in the order that participants reported well-being in these areas.

Table 7.4 - Descriptive statistics for the SWEMWBS

	T1	T2	T3
Number of participants	11	8	9
Mean per item	3.81	3.98	3.98
Range for mean per item	3.29 – 4.71	3 – 4.86	3 – 5
Total mean for all 7 items	26.73	27.89	27.86
<u>Mean for individual items</u>			
<u>Item 1</u> I've been able to make up my own mind about things.	4.73	4.25	4.00
<u>Item 2</u> I've been dealing with problems well.	4.18	4.25	4.00
<u>Item 3</u> I've been feeling optimistic about the future.	4.09	4.00	4.33
<u>Item 4</u> I've been feeling close to other people.	3.82	4.38	4.22
<u>Item 5</u> I've been thinking clearly.	3.91	3.88	4.00
<u>Item 6</u> I've been feeling relaxed.	3.27	3.88	4.00
<u>Item 7</u> I've been feeling useful.	2.73	3.25	3.33

The first point that was interesting to note, considering the health status of the participants, was that the scores for all of the measure of well-being were relatively high at each time-point. The SWEMWBS has not been used in an equivalent age sample with health difficulties, however, in a recent study using the SWEMWBS to assess the feasibility of an online psychology programme in a normative population of Australian students (n=154, 12-18 years old) the total mean scores for the two study groups were M=24.8 and M=23.8 (Manicavasagar, Horswood et al. 2014). The “Understanding Society” longitudinal U.K. population study, showed a mean SWEMWBS score of M=25.3 for the general population in a sample of over 34,000 participants with an age-range of 16-80+ (Booker and Sacker 2011). Both of these normative populations reported lower levels of well-being than the participants in study three, who showed total mean scores of M=26.73 (T1), M=27.89 (T2) and M=27.86 (T3). As well as overall scores, each individual item at every time-point had a mean score above the mid-point of the scale, which meant that participants reported experiencing each of these factors of well-being at least some of the time. The majority of these means were over or approaching 4.0, which indicated that these feelings of well-being were experienced “often”. The only exception to this was “feeling useful” at T1, which fell slightly below this figure, and likely reflected the difficulties of the diagnosis period and the often increased periods of hospitalisation during this time.

The area in which participants most frequently reported high levels of well-being was the item “I’ve been able to make up my own mind about things”. At T1 participants almost unanimously felt that they could make up their own mind all of the time. Although this figure remained high, it did seem to reduce slightly during the course of their treatment, which could indicate a reduced capacity or opportunity to make their own decisions within the medical world.

Despite the uncertainties that could have been a part of their cancer diagnosis experiences, participants consistently reported feeling optimistic about the future. The fact that this figure increased slightly by the final time-point is interesting given the variety of situations that the participants were experiencing regarding the stage of their treatment. This did not seem as straightforward as participants finishing treatment and therefore not being as worried about the future. For those that had finished treatment, there was sometimes a great deal of uncertainty about survivorship issues such as reintegrating into school and peer groups, which could have led to pessimism about the future. Also, for those that had not finished treatment, there was sometimes ongoing uncertainty and worry about the success of this treatment. It seemed that in either situation the participants wanted to report their optimism.

One-way ANOVAs were conducted to assess whether age, gender or diagnosis could be potential contributing factors to the overall well-being of participants. Again, this is with the acknowledgement

of the limiting nature of the sample size. The effect of age on overall feelings of well-being approached significance for T3 ($F(2, 6) = 5.268, p = 0.046$), despite being strongly non-significant at the previous two time-points (T1 $F(3, 7) = 0.475, p = 0.709$ and T2 $F(2, 5) = 0.809, p = 0.496$). This demonstrated that older participants were more likely to report higher feelings of well-being at T3. Neither gender nor diagnosis were indicated as potentially significant factors on self-reported well-being at any time-point.

7.4.2 A-COPE

The A-COPE presented participants with 54 potential coping strategies to be rated on a five point Likert scale depending on frequency of use, ranging from 1 (never) to 5 (most of the time). In Table 7.5, the sub-scales are presented in the order in which they were endorsed by the participants.

Table 7.5 - Descriptive statistics for the A-COPE sub-scales

	T1	T2	T3
N	11	8	9
<u>Scores for sub-scales (mean, range and standard deviation)</u>			
Being humorous	M = 3.73 (2.00-5.00, SD 0.88)	M = 3.93 (2.00-5.00, SD 1.10)	M = 4.06 (3.00-5.00, SD 0.85)
Developing self-reliance	M = 3.11 (2.33-3.83, SD 0.53)	M = 3.04 (2.00-3.83, SD 0.65)	M = 3.19 (2.50-4.50, SD 0.61)
Seeking diversions	M = 3.10 (2.75-3.63, SD 0.34)	M = 3.04 (2.13-3.50, SD 0.53)	M = 3.15 (2.63-4.25, SD 0.57)
Developing social support	M = 3.05 (2.17-4.17, SD 0.54)	M = 2.81 (1.67-3.67, SD 0.77)	M = 3.06 (2.50-3.83, SD 0.45)
Solving family problems	M = 3.20 (2.67-4.00, SD 0.33)	M = 2.75 (2.17-3.33, SD 0.53)	M = 2.91 (1.67-4.17, SD 0.83)
Relaxing	M = 3.00 (1.50-4.25, SD 0.91)	M = 2.61 (1.25-4.00, SD 1.14)	M = 2.97 (1.50-4.00, SD 0.79)
Investing in close friends	M = 2.90 (2.00-5.00, SD 0.84)	M = 2.75 (2.00-4.00, SD 0.69)	M = 2.50 (1.50-3.50, SD 0.71)
Engaging in demanding activity	M = 2.80 (1.50-4.00, SD 0.82)	M = 2.61 (2.00-3.25, SD 0.48)	M = 2.64 (2.00-3.50, SD 0.59)
Ventilating feelings	M = 2.15 (1.50-3.00, SD 0.50)	M = 2.67 (1.00-3.83, SD 0.96)	M = 2.37 (1.17-3.33, SD 0.77)
Avoiding problems	M = 1.67 (1.40-2.40, SD 0.36)	M = 1.60 (1.20-2.80, SD 0.52)	M = 1.62 (1.00-1.80, SD 0.27)
Seeking professional support	M = 1.27 (1.00-2.00, SD 0.34)	M = 1.75 (1.00-3.50, SD 1.00)	M = 1.22 (1.00-1.50, SD 0.26)
Seeking spiritual support	M = 1.21 (1.00-1.67, SD 0.31)	M = 1.38 (1.00-2.33, SD 0.65)	M = 1.26 (1.00-1.67, SD 0.32)

“Being humorous” was the most regularly reported coping style and trended towards a slight increase over the three time-points. “Seeking spiritual support”, along with “seeking professional support”, were seldom reported coping strategies, with the vast majority of participants reporting that they never accessed either of these two avenues of support. It seemed that coping strategies that were focussed on the efforts of the individual were preferred by this population. The top three coping strategies were all

concerned with the participants doing something themselves, rather than looking to external sources for support.

There seemed to be only a very limited effect of time on the coping strategies employed by participants. As can be seen in Table 7.5, the means for each of the coping sub-scales remained stable across the time-points. This seemed to indicate that participants retained the same approach to coping throughout their treatment and raises the possibility that these coping strategies may have existed pre-diagnosis. The only possible exceptions were the slight rise in seeking professional support at T2 and the trend towards decline over time in the amount that participants invested in close friends. It is possible that participants wanted to seek professional help more often during the time when they were having the most intensive periods of treatment, or that this help was more prevalent during times of hospitalisation. It is also possible that the close peer relationships of participants were gradually affected during their time away from school and other peer interactions. However, because of the limited sample size, both of these interpretations could be easily affected by the experience of one participant.

One-way ANOVAs were conducted to assess whether age, gender or diagnosis were contributing factors to the likelihood of a participant having a preference for a certain coping style at a certain time. No significant effects were seen for gender or diagnosis, but several of the coping sub-scales were affected by age to a significant degree. “Being humorous” at T3 showed a significant effect of age ($F(2, 6) = 16.619, p = 0.004$), meaning that older participants were more likely to use humour as a coping strategy. Other significant factors for age were “avoiding problems” at T1 ($F(3, 7) = 10.323, p = 0.006$) and “being humorous” at T1 ($F(3, 7) = 8.697, p = 0.009$), meaning that older participants were more like to use humour and to avoid problems at T1. However, some of the individual items that comprise the avoiding problems sub-scale did seem to be more applicable to the older participants e.g. using drugs, drinking alcohol or smoking.

7.4.3 Pupil Attitude to Self and School (P.A.S.S)

The P.A.S.S presented participants with 50 self-report items about their perception of themselves as a learner and their attitude towards school. Participants endorsed items on a four point Likert scale ranging from (1) “no, not at all” to (4) “yes, a lot”. The 50 individual items contributed to the formation of nine sub-scales. Scores on the nine sub-scales have been assessed against normative data previously collected using the P.A.S.S. This normative data is comprised of approximately 600,000 surveys across 2,000 schools. The tables below show which percentile of the normative data the participants are within. The normative data groups the education key-stages three and four together, with key-stage five represented separately. Tables 17 and 18 present the P.A.S.S data from study three

in these two groups of key-stages. Table 19 shows the scores for the individual participants at the three time-points. The colour coding system represents the cut-off scores for the level of satisfaction within a certain factor; green = high satisfaction (31-100), yellow = moderate (21-30), orange = moderate-low (6-20) and red = low (0-5). Education establishments using the P.A.S.S apply this coding system to indicate areas of concern requiring attention or intervention.

7.4.3.1 Overall group P.A.S.S scores

Table 7.6 - Overall P.A.S.S scores for key-stage 3 and 4 participants

Time-point	T1	T2	T3	T1	T2	T3	T1	T2	T3
Category	Overall	Overall	Overall	Boys	Boys	Boys	Girls	Girls	Girls
Frequency	9	7	5	4	4	2	5	3	3
1. Feelings about school	78.5	84.2	64.3	85.2	93.6	85.2	70.3	62.4	40.6
2. Perceived learning capability	61.2	69.8	61.2	74.5	74.5	81.2	53.9	63.8	53.9
3. Self-regard as a learner	74.1	74.1	47.3	82.1	89.1	82.1	63	48.1	33.7
4. Preparedness for learning	77.1	77.1	60.5	85.9	91.5	85.9	66.4	57.6	38.3
5. Attitudes to teachers	73.7	73.7	57.4	84.5	84.5	84.5	74.8	58.4	36.8
6. General work ethic	81	81	60.1	92.7	92.7	92.7	61.4	37.2	37.2
7. Confidence in learning	66.4	81.6	66.4	55.3	89.5	89.5	69.1	51.4	51.4
8. Attitudes to attendance	78.7	65.9	65.9	88.7	80.5	88.7	76.9	47.1	33
9. Response to curriculum demands	79.4	79.4	63.7	89.8	95.9	89.8	62.3	43.2	43.2

Table 7.6 shows the results for the participants when they were in key-stages three or four. The first point to note is that, as a cohort, the participants in study three did not highlight any particular areas of concern in their responses to the P.A.S.S at any of the time-points, and this was true for males and females. As a group, it appeared that their scores on all sub-scales reduced over time, indicating that there may be a reduction in satisfaction with themselves as learners and their perception of school as their engagement with education was compromised by their cancer and treatments. It also appeared that male participants scored higher on all sub-scales than female participants. However, because of the small sample size the data could have been skewed significantly by the absence of data when an individual participant moved into key-stage five or did not complete the measure at a particular time-point. The impact of individual data within the small sample size also made it difficult to assess the influence of gender. As can be seen in Table 7.8, one female participant in particular provided low

scores on a variety of sub-scales and was therefore skewing the overall influence of gender considering there were only three or five female participants at any time-point.

Table 7.7 - Overall P.A.S.S scores for key-stage 5 participants

Time point	T1	T2	T3	T1	T2	T3	T1	T2	T3
Category	Overall	Overall	Overall	Boys	Boys	Boys	Girls	Girls	Girls
Frequency	2	1	4	1	0	2	1	1	2
1. Feelings about school	86.4	100	95.6	73.8		95.2	96	100	96
2. Perceived learning capability	82.7	99.1	82.7	72.6		85.7	85.1	99.2	85.1
3. Self-regard as a learner	59.5	94.8	74.4	39.7		81.2	77.9	94.9	77.9
4. Preparedness for learning	75.4	98.6	83.9	69.1		77.2	83.4	98.6	91
5. Attitudes to teachers	71.5	100	83.7	27.1		84.1	92.5	100	83.4
6. General work ethic	43.6	96.6	96.6	0.7		95.4	97.6	96.4	97.6
7. Confidence in learning	70.8	97.2	86	44.5		83.3	82.6	97.4	88.2
8. Attitudes to attendance	72.6	72.6	83	54.9		90.1	82.8	73.5	82.8
9. Response to curriculum demands	77.7	98	77.7	38.1		76.1	95.2	98.1	79

Table 7.7 shows the overall scores for those participants in key-stage five. The problem of sample size is even more acute in this sub-set of data. However, again there were no areas of less than high satisfaction for the group, as the two areas highlighted as yellow and red are representative of only a single male participant at that time-point. The final time-point for the whole group showed very high satisfaction scores when compared to the final time-point of the key-stage three sample. All scores for key-stage five were above the 74th percentile, whereas the key-stage three-four group had no scores above the 66th percentile. This could represent the potential increase in independence and flexibility offered in further education, however, this is an area of potential interest for the future and cannot be relied upon within this small sample size.

7.4.3.2 Individual P.A.S.S scores

Table 7.8 - Individual P.A.S.S scores for all participants

Time-point	Name	1. Feelings about school	2. Perceived learning capability	3. Self-regard as a learner	4. Preparedness for learning	5. Attitudes to teachers	6. General work ethic	7. Confidence in learning	8. Attitudes to attendance	9. Response to curriculum demands
1	Annabella	72.1	18.3	47.2	50.5	94.8	15.9	49.7	79.2	63.5
2	Annabella	63.9	76.3	33.7	68.7	73.0	33.7	81.2	50.8	45.2
3	Annabella	84.6	72.2	47.8	57.3	64.0	7.1	83.8	82.9	81.1
1	Patricia	62.2	43.3	47.8	46.8	42.1	62.2	32.3	54.8	29.3
2	Patricia	65.9	45.4	49.2	50.3	44.8	42.9	12.0	57.0	17.3
3	Patricia	15.2	19.6	34.5	19.2	29.8	67.8	4.8	13.7	17.3
1	Matt	78.7	79.2	90.8	82.2	79.5	83.3	23.9	90.4	96.2
2										
3										
1	Nathaniel	49.3	54.1	62.6	74.8	64.0	94.6	41.9	40.0	81.1
2	Nathaniel	71.5	54.1	62.6	74.8	64.0	83.3	76.9	28.6	65.3
3	Nathaniel	74.9	66.8	64.3	78.1	82.9	67.8	86.3	57.0	66.7
1	Georgie	71.5	63.8	62.6	66.5	64.0	83.3	68.8	70.6	65.3
2										
3	Georgie	65.9	75.1	22.7	78.1	67.8	67.8	71.9	57.0	47.1
1	Mario	89.7	73.3	91.4	94.3	67.0	96.7	98.0	90.6	96.7
2	Mario	95.7	80.3	85.6	84.2	67.0	88.1	95.2	70.7	96.7
3	Mario	95.6	97.9	85.0	91.1	72.6	88.0	98.4	71.7	88.8
1	William	100.0	94.0	85.6	94.3	100.0	96.7	89.7	97.8	83.0
2	William	100.0	86.0	95.3	97.1	100.0	99.3	93.0	97.8	98.9
3	William	95.7	94.0	91.4	97.1	96.3	99.3	95.2	97.8	96.7
1	Robert	97.8	80.3	76.6	90.0	90.6	96.7	85.0	94.7	83.0
2	Robert	100.0	80.3	98.0	98.8	100.0	96.7	96.8	97.8	98.9
3	Robert	95.6	58.1	85.0	55.6	93.0	99.2	41.3	96.1	60.1
1	Hayley	85.4	80.3	49.4	90.0	82.1	88.1	77.8	90.6	67.7
2	Hayley	79.9	64.5	76.6	68.7	82.1	69.7	68.9	54.5	83.0
3	Hayley	95.6	93.2	59.8	95.4	84.3	69.8	86.6	82.7	60.1
1	Nicola	95.6	83.9	74.7	83.9	93.0	96.8	80.6	82.7	95.1
2	Nicola	100.0	99.1	94.8	98.5	100.0	96.8	97.2	71.7	98.2
3	Nicola	91.5	69.1	74.7	83.9	84.3	99.2	86.6	71.7	88.8
1	Faisal	73.9	77.1	43.8	65.9	28.5	0.5	51.0	53.7	39.0
2										
3										

Table 7.8 provides a more beneficial use of the P.A.S.S data within study three, by showing how the individual participants scored across the three time-points. Patricia demonstrated the most areas of low satisfaction across the sub-scales and there appeared to be a downward trend in her scores across the time-points. By T3 her scores were all areas of concern except for the factors related to “self-

regard as a learner” and “general work ethic”. Several of these scores had reduced substantially from T1; for example, her “feelings about school” had reduced by 47%. At T3 her “confidence in learning” had also reduced significantly to the 4th percentile having been in the 32nd percentile at T1, which represented a change from high to low satisfaction and would be an area of serious concern to her school.

Annabella, Matt, Nathaniel and Georgie all reported some areas of less than high satisfaction at one or more time-points. These participants were all from the younger section of the sample having entered the study in Year 8 or 9. Matt reported only moderate satisfaction with his “confidence in learning”, but unfortunately there was no opportunity to assess any change over time for Matt as he withdrew after T1. Nathaniel only reported moderate satisfaction with his “attitude to attendance” at T2, which was understandable as this was a time when he was out of hospital and trying to reintegrate gradually into school, but his lack of satisfaction did show that he wanted to attend more than he was able to, which hints at a positive attitude towards reintegration (discussed further in the next chapter). All of Nathaniel’s scores were higher at T3 than T1, which seemed reflective of his recovered health and reintegration into school. The only two factors that were lower at T3 than T1 were “general work ethic” and “response to curriculum demands”, which could have been reflective of ongoing problems with fatigue and the difficulties he had when trying to catch up with work that he had missed. Georgie showed one factor with significant reduction at T3, which was her “self-regard as a learner”. This factor reduced to only moderate satisfaction and was in the 22nd percentile having been in the 62nd at T1. This could have been reflective of the difficulties she experienced with attending school alongside her negative perception of the benefit and quality of hospital and home teaching, which resulted in her not engaging in education to a great extent during her time as a cancer patient. Annabella showed two areas of low-moderate satisfaction, which were “perceived learning capability” at T1 and “general work ethic” at T1 and T3. Interestingly, her “perceived capability” started as low-moderate, but increased to high by T2 and remained high at T3. Annabella had similar increases in “confidence in learning” and “response to curriculum demands”. This was perhaps reflective of her successful engagement with home tuition services and the benefit she reported of the one-to-one work with the tutor.

Mario, Hayley, William, Robert and Nicola all maintained a high level of satisfaction across all nine sub-scales at all three time-points. These were all participants who were in the older two years of the sample having entered the study in Year 11 or 12. Despite remaining highly satisfied according to the cut off scoring system, Robert did demonstrate a reduction in his scores in four factors at T3, which were: “perceived learning capability”, “preparedness for learning”, “confidence in learning” and “response to curriculum demands”. This could have been a reflection of his cancer experiences, but seemed more likely to be connected to his transition into further education and the adjustment to a

new curriculum. Hayley also remained highly satisfied with herself as a learner and with her school throughout the time-points, but demonstrated a trend towards her scores reducing at T2 and increasing again at T3. This was true for six out of the nine factors and could be a reflection of coinciding events at T2, which included the most intensive parts of her treatment and her G.C.S.Es. In contrast, Nicola's most consistently high scores were at T2, when she had recently experienced her leg amputation, was still having intense chemotherapy and had deferred her Year 12 study until the following academic year. It is possible that her decision to defer her education had relieved the academic pressure on her and allowed her to be free of any negative education experiences that might have impacted her P.A.S.S reporting. It is also possible that at T1 she was experiencing the combined pressure of a new cancer diagnosis and maintaining her education, and at T3 she was reintegrating into her school, but at T2 she was free from any of these difficulties and was experiencing successful, albeit challenging, treatment.

Faisal was the remaining participant who was part of the older half of the sample, having entered the study in Year 12. Unfortunately, change over time could not be assessed for him as he had to withdraw after T1. He reported moderate satisfaction with his "attitude towards teachers" and very low satisfaction with "general work ethic", which was below the 1st percentile. This extremely low rating of work ethic could have been a result of his withdrawal from his education at this time due to hospitalisation and the high levels of fatigued he was experiencing, which would have made it difficult for him to work. Faisal also discussed feelings of despair about the impact his cancer would have on his educational plans and therefore his low self-reported work ethic could reflect apathy created by that despair.

7.5 Discussion

Despite the limiting effect of the sample size, several important findings emerged from the data collected via standardised measures. Overall, through the SWEMWBS and the P.A.S.S, participants reported reasonably good levels of psychological and educational well-being. Both of these measures indicated limited cause for concern for this sample as a whole compared to normative data. The P.A.S.S showed that some participants had shown difficulties in some areas of their perception of themselves and their school, most notably Patricia's reduction in scores across multiple sub-scales during her time in the study, which seemed to reflect her lack of engagement with her education. Also, when looking at the individual scores for the P.A.S.S it seemed that there may well have been an influence of age on the scores of participants, even though this could not be reliably shown in the overall sample, with younger participants seemingly more likely to report lower levels of satisfaction in some areas, especially in those sub-scales related to perception of themselves. The A-COPE seemed to show that participants preferred to use humour or rely on themselves as a means of coping,

rather than seeking external support from professionals or spiritual sources. It also showed that coping strategies remained stable over time, although these are self-report measures and say nothing certain about the coping behaviours that were employed in practice and the responses of participants may have reflected a version of themselves that they wanted to project or believed to be true. There did not seem to be patterns of change over time for the sample as a whole in any of the measures, although again, this could be seen in some factors for individual participants and could be better understood in context of their individual circumstance.

The number of self-report items that were completed by participants in study three was a consideration when deciding how many and what specific measures to use. Therefore, the inclusion of additional measures may have added unnecessary burden to the time and effort of participants. However, having now completed the study, there could have been different choices made regarding which measures to use. The SWEMWBS reported a very positive overall picture of the well-being of participants, but this measure tends towards a positive conceptualisation of well-being by asking for the presence of positive events and feelings and has been shown to be more prone to self-deception than other scales (Tennant, Hiller et al. 2007). The data from study three could have been different if a measure like the Hospital Anxiety and Depression Scale (Carroll, Kathol et al. 1993) was used that assesses the presence of negative events and feelings. Therefore, it may have been beneficial to the more comprehensive assessment of well-being to have included this measure alongside the SWEMWBS. A further assessment of the appropriateness of the measures is presented in Chapter Nine and includes feedback from the participants.

In the following chapter the results of the I.P.A of the interview data will be presented. The findings from the measures presented in the current chapter will be referred to in the next chapter, where they can be placed in context and provide depth and contrast to the qualitative accounts.

Chapter 8 – Results of the Interpretative Phenomenological Analysis of the Interviews from Study Three

Figure 8.1 shows the flow-chart developing the linkage between the chapters and shows that the methods developed in chapter six were used to collect the data that was reported in the previous chapter and will be elaborated upon in the current chapter.

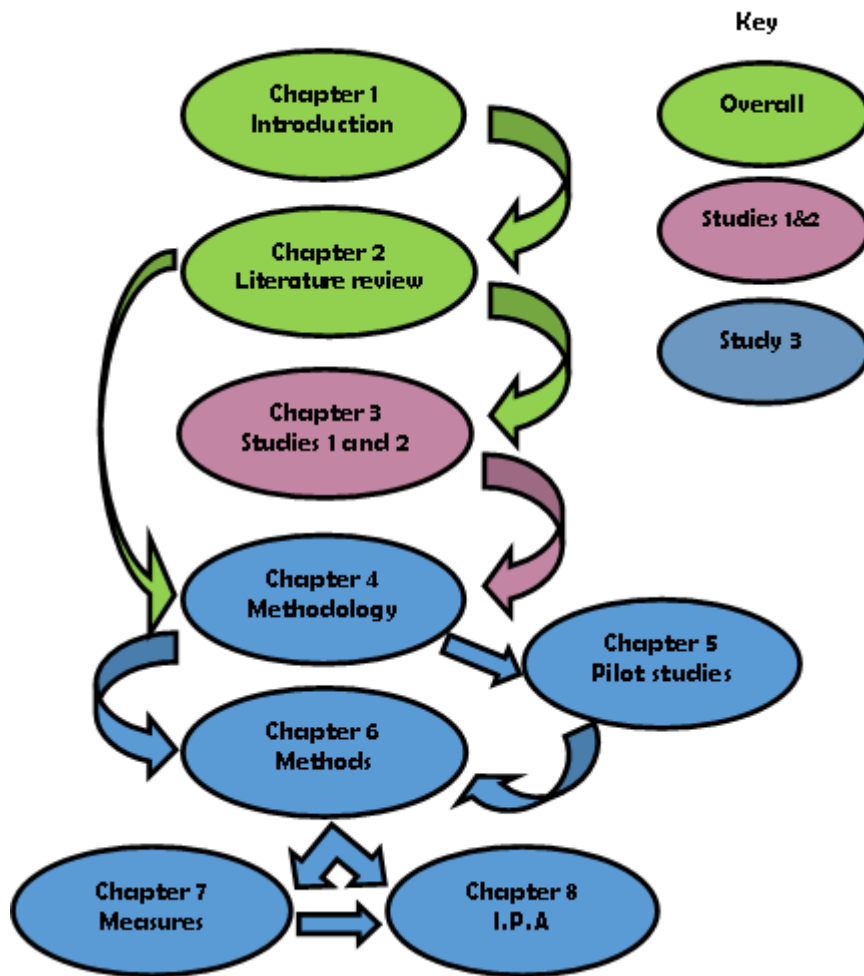


Figure 8.1 - Chapters flow-chart

The primary aim of this chapter is to present the interpretative phenomenological analysis of the qualitative accounts given by participants in study three. Details of the participants are provided, followed by a description and elaboration of a conceptual map used to visually represent the I.P.A themes and connections within the data. Findings from the quantitative measures, presented in the previous chapter, will be included in the context of the themes within the map where they provide support, contradiction or depth to the qualitative analysis. Interview extracts from the participants will be provided throughout the chapter to exemplify the points that are made and to show how the general claims are represented at an individual level. Interview extracts presented in this chapter show three

different types of speaker: P represents the participant; P1 represents the parent; and S represents the interviewer. Each extract will be followed by the participant's study name, the time-point the extract was from and the line number for reference. Examples of the photos taken by participants can be seen in Appendix 16.

8.1 Participant Details

Table 7 - Participant details from study three

Participant	Age at time-points			Diagnosis	Interviews completed	Visual images	Parent present
	T1	T2	T3				
Patricia	13	14	14	Lymphoma	3	Yes	Yes
Matt	14	n/a	n/a	Lymphoma	1 (T1)	Yes	Yes
Hayley	15	15	16	Hodgkin's Lymphoma	3	Yes	Yes
Mario	15	16	16	Osteosarcoma	3	Yes	No
Alanna	n/a	n/a	14	Osteosarcoma	1 (T3)	No	Yes
Robert	15	16	16	Hodgkin's Lymphoma	3	Yes	No
William	15	15	16	Hodgkin's Lymphoma	3	Yes	Yes (T3)
Nathaniel	13	14	14	Lymphoma	3	No	Yes
Annabella	13	13	13	A-plastic Anaemia	3	Yes	Yes (T2)
Nicola	16	16	17	Osteosarcoma	3	No	No
Faisal	16	n/a	n/a	Acute Lymphoblastic Leukaemia	1 (T1)	No	No
Georgie	13	14	14	Acute Lymphoblastic Leukaemia	3	Yes	Yes (T1)

Based on the suggestions from young people in the consultation exercise reported in 4.2.1, participants were given the option of having a parent present in their interviews. As you will see from Table 8.1, five participants had a parent present at every interview, three had a parent present at a single time-point and four did not have a parent present at any time-point. It is undeniable that having a parent present in the interview had the potential to influence the extent and content of the dialogue with the participant. For the participants the presence of a parent seemed to have positive and/or negative influences on the interviews. For some participants, most noticeably Matt, Patricia and Nathaniel, there seemed to be the temptation to pause and wait for their parent to answer when they were struggling with a question. In this case every effort was made to redirect the parental perspective back to the participant to assess the extent that they agreed or wanted to comment. It may have been difficult for some participants to disagree with a parent in this situation, but this was difficult to assess. The presence of a parent also seemed to inhibit the expressiveness of some participants, most noticeably Annabella who was very animated in the two interviews without her parent present and very subdued in the interview with her parent. However, the opposite also seemed to occur for others, where the presence of a parent appeared to give them more confidence to express themselves, and this was seen in Georgie and William. On a basic level, parents often acted as a memory aid for

participants by providing them with names, dates and sequences of events when participants faltered, or by reminding them of events and examples related to the question being asked. For other participants, most noticeably Hayley and Alanna, the presence of their parent created an account of their experiences which appeared to be deepened by the interaction of the young person and their parent. Hayley and her mother used the interviews to discuss Hayley's experiences in a way that they had not done outside of the research. They reflected on the experiences of the other and this reflection seemed to result in more in depth discussions and richer data.

The analysis of the interview data presented in this chapter is primarily focussed on the experiences of the participants that they directly offered during the research. However, occasional extracts from parents will be used when they offered particularly relevant insight into the experiences of the participants, and only when they reflected what was being discussed by the participant during their interview.

8.2 Conceptual map of the experiences reported by participants

In this section, a conceptual map (Figure 8.2) created out of the analysis of the participant interviews is described. The production of a model or map as part of the analysis is not a standard component of I.P.A, however in this case it seemed that a standard production of themes and clusters did not represent all of the conceptual elements of the analysis. The development of this map was driven by close analysis of the accounts of experience provided by participants and aimed to be grounded in those experiences and not informed by any a-priori assumptions, theoretical or otherwise. Instead, the map sets out a proposition for the hierarchical and inter-relationship of master themes, themes and sub-themes. The aim of the map is to show how the emergent themes from the I.P.A appeared to interact and cluster, although the extent to which this was applicable to each individual participant was variable. The themes within the map provided headings under which to discuss the convergence and divergence of the experiences described by the participants. The contribution of each participant to the development of each theme is detailed in Table 8.2.

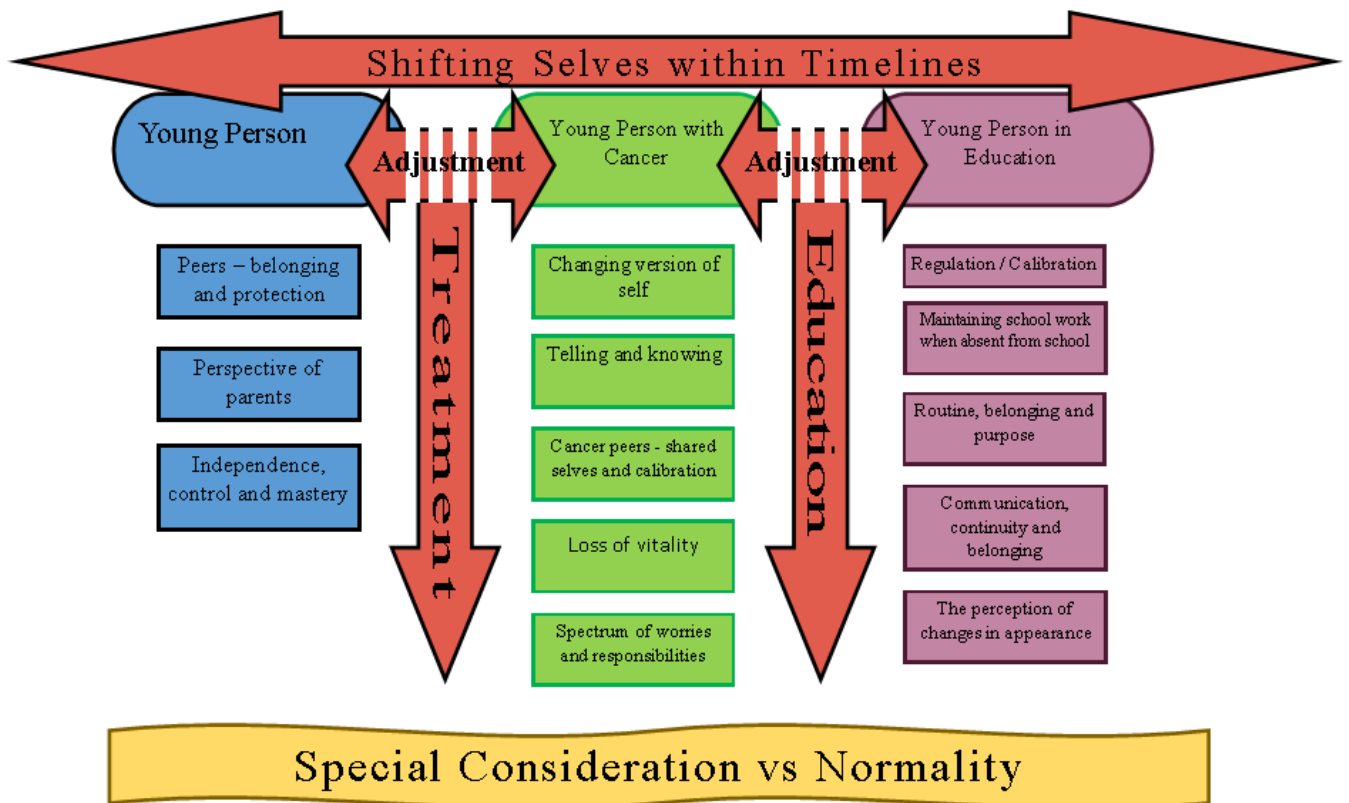


Figure 8.2- Conceptual map based on the I.P.A of participant transcripts

Table 8.2 - Thematic contribution made by each participant

	Patricia	Matt	Hayley	Mario	Alanna	Robert	William	Annabella	Nathaniel	Nicola	Faisal	Georgie
Education timeline	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Treatment timeline	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Adjustment timeline	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Changing version of self	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Telling and knowing	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Cancer peers			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Loss of vitality	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Spectrum of worries			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	
Peers	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Parental perspective	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Independence			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Regulation and calibration			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						<input checked="" type="checkbox"/>
Maintaining school work	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Routine, belonging and purpose	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Communication		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Changes in appearance			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Special consideration vs Normality	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>

The map proposes that young people explained their experiences across three dimensions of self: the self as a young person, the self as a young person with cancer and the self as a young person in education. The map theorises that particular experiences can be understood in terms of these three versions of self. Furthermore, the versions of the self that participants discussed, and the experiences most closely connected to them, appeared to be heavily structured by the concept of time. This was typically in the form of future orientated thinking, but also incorporated reflections on what was past. There appeared to be three timelines identifiable in the data and these related to education, treatment and adjustment. These timelines are presented in the map alongside or in-between the versions of self to which they are most applicable. The role of timelines in the map is explained further in the next section. Finally, an underlying psychological experience described by participants, across versions of the self and timelines, was the tension between the desire for normality and the need for special consideration. This experience intersected the different versions of self and permeated many of the experiences described by the participants. The remainder of this chapter will discuss the analysis of the accounts of participants under the I.P.A themes, timelines and underlying principles present within the map.

8.3 Shifting selves within timelines

Participants talked about themselves, implicitly and explicitly, with reference to three different aspects of their 'self'; themselves as a young person; themselves as a young person in education; and themselves as a young person with cancer. These three versions of self had unique defining experiences, timelines and tensions. However, they did not exist in isolation, and the conflict and resolutions between the competing needs of these three versions of self provided some of the more interesting and challenging aspects of the experiences of participants. The extent to which these three selves were in conflict altered depending on the environment (hospital, school, home, community) and the point on the various timelines at which participants found themselves. Alongside these three versions of self, participants described moving through different timelines. Participants described experiences running along three timelines that fitted with the different versions of self: 1) Education; 2) Treatment; and 3) Adjustment. This timeline structure has not been artificially imposed upon the data, but was derived from the way that participants often structured their experiences and the metaphors that they used when describing them. The timelines ran parallel to each other, but also interacted and intersected, with structure, progress and consequences occurring in one timeline often making it more or less difficult to progress in another timeline. These three timelines are described below.

8.3.1 Education timeline

Prior to their cancer diagnosis the most pertinent timeline participants were moving through in their lives was education. The education timeline progressed in a linear fashion for participants and had milestones and markers of progress. This structure had a normalising effect on young people by providing them with a previously unquestioned and largely unchanging framework for their present and future lives. That the education timeline continued regardless of their involvement, taking their peers along with it, gave some participants a sense that something important was carrying on without them. Their ability to maintain progress through this timeline was often used as a marker of the impact their treatment was having.

As early as diagnosis, participants were concerned about the potential for their cancer to affect their education timeline through reduced school attendance and missed school work. At time-point one, some participants were very focussed on the things they were going to miss in their immediate future, like examinations, careers appointments or completing ongoing work. Here, Faisal described the frustration of having to miss an exam that he had prepared for during the previous six months.

P: I booked [my assessment for] nine o'clock on the 10th of January and when the gentleman said six weeks I was thinking, oh this six months that I have had in [school] and I'm just missing that exam now and I've passed all the theory exams and the practical exam the P.E exam I can't even do because I'm not going to be there – Faisal T1 157-161

The use of the phrase “I can't *even*” conveys a sense that something like taking an exam should be, and is usually, straightforward for him, but is now frustratingly unattainable. In context of his very recent diagnosis of leukaemia, missing this exam was still a major concern for him and was something he discussed far more than the potential health impact of his illness. Below, Annabella described similar disappointment about not being able to see a section of her education timeline through to its conclusion because of not being able to complete a textiles project, which she had also intended as a gift:

P: I've started my [textiles] project but I haven't... obviously haven't been able to finish it and it was meant to be a Christmas present for my brother's dog! Because he's got a new dog, and I was going to do a coat - Annabella T1 75-77

As Alanna explained below, frequent periods of hospitalisation, alongside dealing with side-effects, sometimes made it too difficult for her to simply attend school.

P: ...seven to ten days is when you normally get ill so it's like your seventh day is Sunday so you normally get ill Monday, Tuesday, Wednesday. So there's no point going anywhere...- Alanna T3 889-890

Therefore, the intersection of her medical and education timelines provided a set of timeline barriers that frustrated and demotivated her efforts to engage with education. This was something that many participants reported, especially during more intensive periods of treatment, but also due to the frequent need for blood tests, scans and appointments.

As well as the ongoing impact of regular appointments, the timing of specific coinciding events in the education and treatment timelines made it difficult to engage in education. For example, in the extract below, Hayley described how her radiotherapy treatment occurred during her G.C.S.E period and that the side-effects of radiotherapy were the most significant she had experienced throughout her treatment timeline. Hayley was a participant that made significant efforts to maintain her education and was only thwarted when side-effects became overwhelming.

S: And that was right in the middle of all your GCSEs?

P: It was...

P1: Proper poorly with it as well weren't you?

P: Yeah, I wasn't like... I don't think I was too bad to begin with but like the further it got on the worse I got and I ended up missing my last exam because I just wouldn't have been able to go in. – Hayley and Hayley's mother T2 26-31

Participants seemed to be aware that the education timeline was moving on regardless of their ability to move with it. Several participants made reference to their peers moving through their education timelines as normal and that this had an impact on the ability of participants to interact with their peers socially and academically. Here, Nicola described the practical problems this caused her socially:

P: Yeah, but it's harder now, because obviously, they've got their exams coming up [laughs] so every time I'm free, they're like, "Oh, I've got to revise", [laughs]. – Nicola T2 348-351

Nicola would normally have been moving through the same timeline as her peers, which would have meant they had shared time within education settings, but would also have had the same periods of free time outside of education. The importance of sameness of experience and context was expressed by several participants when they realised they were no longer having the same experiences at the same pace as their peers. For example, throughout her interviews, Georgie regularly referenced the

importance of “normal” to her and her comparison of her new situation to the normality being experienced by others.

S: So just, so why would you rather do your own work rather than the work that they set?

P: Because then I know where I’m up to and then I can do it the same as everybody else, kept like on the same lines and then when I go back I know I’m doing the same thing - Georgie T1 216-219

In this extract she clearly expressed timeline thinking through language such as “kept on the same lines”, but also the importance of sharing the same education experiences as her peers in the present as a preparation for reintegrating into school in the future. Below, William expressed the problems he faced when he reintegrated into education and the impact that missing time from school had on his ability to maintain the same academic progress as his peers. He used the timeline metaphor “catching up”, which suggested that he conceptualised his education timeline moving forward at the same pace regardless of his involvement with it, and that it was now his task to make up this lost time. The alternative to this way of thinking would have been for him to think about his absence from school as halting the progress of his timeline and that his return to education was a return to this point.

P: Some of the subjects yeah I still haven’t... they’d moved on but it was too hard catching up then other subjects like... I found maths, I’m finding it quite difficult to catch up because I missed quite a large section of maths – William T2 86-88

Within the education timeline there were several significant transition points described by participants. Because of the age of the sample these were either: moving between years 9 and 10 and thinking about G.C.S.Es; moving from high school into further education; or moving to a new school. It was interesting to see how these education transitions were planned in light of their competing treatment timeline and how this was experienced by the participants.

Several participants making the transition from Year 9 to Year 10 found that selecting the subjects they wanted to study for G.C.S.Es was a way of focussing their efforts in the short term i.e. just focussing on the subjects they would study in the future. This appeared to be a positive aspect of timeline thinking because participants could minimise the perception of wasted effort in the present and instead work towards a future point when they would be able to engage in education with fewer health related barriers. However, choosing G.C.S.E options was not always straight forward for participants who were absent from school and in some cases it was not even possible. The extract below demonstrated how Alanna, who had to spend a considerable amount of time in hospital around this transition period, was not able to select the options that she wanted and “was left” with options that were not her choice. During her interview she discussed this in detail and it seemed that the

restriction of her options was difficult for her as it reduced her free-choice, but it also removed a subject from her curriculum which she perceived as an area of mastery and success for her. This was a time in her life when both her autonomy and mastery were already being compromised by the physical side-effects of her treatment.

P: I wanted to do ICT again so I can better my grade but when we've got to the task of filling in my things....

P1: By the time we got the paperwork we were in hospital.

P: Yeah, and then when we rang them up to say they'd gone, all the places in ICT had gone and then I was left with two groups with things like dance, drama, PE...! – Alanna and her father T3 742-748

For other participants who were diagnosed during Year 11, their primary education timeline concern tended to be how their diagnosis would affect them sitting their G.C.S.Es, the grades they would achieve and how this in turn would impact their transition into further education. Without exception, these participants were given reassurance by their schools that they would be allowed to commence further education regardless of the outcome of their G.C.S.Es and that they would not be expected to sit any of their exams unless they felt able to. Here, Hayley describes the “leeway” that she has been given regarding her place in Sixth-Form.

P: Yeah. They say I'm pretty much on the road to get in, I think they just having a bit of leeway with me because you know... yeah so... hopefully I'm going to go for that and be OK! " - Hayley T1 52-53

Hayley does not explain the “because”, but seems to be referencing her status as a young person with cancer and the shared understanding that this will or should result in special consideration. Throughout her interviews, which spanned the period before, during and after her G.C.S.Es, this leeway was important to her and gave her the flexibility to decide how she wished to approach her exam period. She approached it, as many participants did, by remaining as involved in the process as possible.

Following completion of G.C.S.Es several participants made the next transition into further education. Some participants discussed aspects of this transition in terms of being able to make a fresh start alongside existing and new peers who were all experiencing a new beginning at Sixth-Form. This seemed to have a normalising effect on participants and was helpful in their transition from being a young person with cancer to a normal young person in education. However, several participants reported difficulties with this transition and this was present in the accounts of participants who were still experiencing treatment, as well as those who had completed. In the extract below, Mario discussed feeling unprepared for the step up in work because of the time he had missed during Year 11 and felt that he had been “dropped straight into” the A-level standard of work. In line with this, his

responses to the P.A.S.S sub-scale “response to curriculum” decreased at this final time-point, from the 96th to the 88th percentile. Although it did seem that good support from the education staff helped him to adjust to this new education environment and to move past the initial feelings of being out of his depth. Similar to William, the use of the metaphors “dropped straight into it” and “got back into that” seemed to conceptualise education as an ongoing flowing process that he joined, rather than something that stopped and started based on individual circumstances.

P: Physics feels like a big difference, and like being dropped straight into it is quite tough but maths my teacher helped me so that's... I have kind of got back into that easy. And computing, it's not too bad, I've always found it quite easy so...- Mario T3 256-258

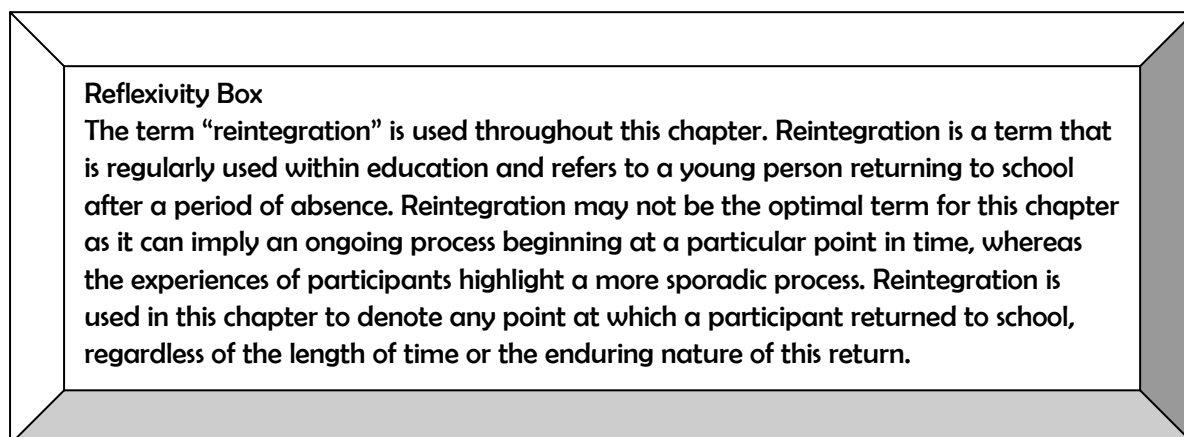
Hayley described similar difficulties when making this transition. In the extract below, she described her experiences in her A-level classes and the expectation from teachers that she would have a certain level of knowledge about the subjects from previous study at high school. For Hayley this seemed to expose the void in her education timeline created by her cancer experiences and implied a sense of incompleteness. She described the “basic stuff” that she had missed, which seemed to imply that it was knowledge that she should have had and was self-conscious about not having. Hayley also showed reduced responses to the P.A.S.S sub-scale “response to curriculum” from the 83rd percentile at time-point two, to the 60th at time-point three. Hayley had finished her treatment by several months at this point and it was an indication of the ongoing impact that missed time could have on education experiences further through the timeline.

P: Like basically biology and geography where you like take your GCSE stuff and then you like go on to it more in A level and like I've missed a year of it so I've missed quite a lot of the basic stuff that is needed like they're saying to me 'well you should know about this, you did it in GCSE' and it's like 'yeah well I wasn't there for a year so you probably did it in that year because I don't remember it!' because I kept... well I kept one of the biology books and I've looked through it and there's nothing about it in there so... it's like 'Oh God!' - Hayley T3 917-922

Robert also made the transition into Sixth-Form and was pleased to remain in his same school so that he did not have to explain his cancer experiences or justify any lower grades he had received. Maintaining this continuity in the education timeline seemed to be important for Robert and implied an associated continuity of self, which was facilitated by familiar surroundings and people that had known him before his diagnosis. Although he too demonstrated a reduction in P.A.S.S sub-scales related to confidence and preparedness for learning at the final time-point.

P: I felt okay like ‘cos it’s the same school that they helped me with the GCSEs so they knew what I’d been through and what they could help me with...but I just thought it was like another year basically, not like a totally different experience, just another year at the same school and that just seems to have worked fine for me. – Robert T3 208-212

In her time-point three interview, Patricia said she had transferred to a new school for the beginning of Year 10 and this was also her first reintegration into school following completion of her treatment.



Reflexivity Box
The term “reintegration” is used throughout this chapter. Reintegration is a term that is regularly used within education and refers to a young person returning to school after a period of absence. Reintegration may not be the optimal term for this chapter as it can imply an ongoing process beginning at a particular point in time, whereas the experiences of participants highlight a more sporadic process. Reintegration is used in this chapter to denote any point at which a participant returned to school, regardless of the length of time or the enduring nature of this return.

When discussing this transition with her, she reported that it was her own decision to change schools and that she had wanted to move because there were more opportunities for her at the new school. Later in the interview when her mother contributed to the discussion, she reported that Patricia was not fitting back into her peer group successfully and wanted to move to the new school because her brother and her peer group from her local community were pupils there. Patricia showed a significant reduction in scores for the P.A.S.S at the final time-point, with seven out of the nine sub-scales indicating areas of concern. This demonstrated a different timeline void to the academic void experienced by Hayley and Mario in the earlier extracts. Patricia seemed to experience a void in the continuity of her peer interactions that would have been facilitated by attendance at school. It was possible that Patricia may have wanted to be with her community peers and her brother in the new school regardless of this timeline void, but she was denied the opportunity to adjust to her previous school and to integrate with the peer group there through a shared experience of moving through the education timeline together. In the extract below, Patricia’s mother explained that the friends that Patricia had made at school had developed new friendships while Patricia was absent and that she “wasn’t fitting in”, so it was easier to move to a new school where she had existing friendships.

P1: Like I said it was her choice, it was she moved schools, you know, because after the treatments she came back to school and she just felt she wasn’t fitting in and everything, her new friends, her friends had new friends and didn’t fit, so she decided to, in the school where she’s moved to that’s where her brother goes to and other friends, you know, from [the local area] people that we know, generally socialise with, their children go to that school as well, yeah, so you know, people that she knows, yeah, friends. – Patricia’s mother T3 353-358

When participants moved into further education it seemed that they had more flexibility to alter the way their education timeline was structured. Two of the participants that had moved into post-16 education earlier in the research process described this flexibility. Both participants opted to defer their impending exams due to periods of hospitalisation and side-effects of treatments. They experienced this alteration in their timelines very differently. Nicola accepted this timeline alteration as an inevitable consequence of her circumstances and a decision that gave her more freedom to deal with her present reality as a young person with cancer. She continued to engage with the first term of her A-levels as far as possible and this was not primarily to maintain her work, but was to make her reintegration easier the following year. Nicola reflected in time-point three that because she had covered some of the work the previous year she had given herself more leeway now that she was reintegrating. This demonstrated a clear timeline approach to maintaining her education in context of her treatment.

S: Yeah, so because that was something, yeah, the first time I spoke to you you said you were going to do that, try and make this time easier, so is that, how is that working?

P: Yeah, no it's good 'cos like one of my teachers came up to me and she was like, "There's literally no point in you coming to my lessons 'cos I'm using the same PowerPoints and the same work as last year," so I was like, "Oh okay," so that gave me like a bit of leeway like if I'm, like my leg's aching or something, I don't have to go kind of thing. But like if it's just drama that I have to go to 'cos I haven't done that one before. But yeah. – Nicola T3 181-188

Nicola seemed to be able to positively reshape her education timeline to suit the needs of her new situation. Faisal did not have the same perspective of control over his timeline adjustment and was very frustrated by the impact the decision to defer a year would have on his educational plans, as demonstrated in the extract below.

P: I was doing A Levels, I was doing BTEC sport, BTEC ICT and biology and this has sort of completely like messed everything up because I wanted to kind of, I sort of had like a plan in my head so like I'll finish like when I'm eighteen and then I'll go to university and that'll be delayed now because the school's saying they're not going to pressure me to come back like because I'm not allowed to go to any public space for about three or four months because of risk of infection...

S: Yeah, okay.

P: I'll be like left behind a bit because the school said like you're welcome to come again in September and the work I've done from this year, the files, I can still use next year so the school have been very understanding as I said before, it's just the time though. - Faisal T1 95-100

He had a clear perception of his education timeline and the milestones that he needed to achieve. For Faisal, the impact on his timeline was the dominant concern and the primary way that he

conceptualised the impact of his cancer on his life. He did acknowledge the flexible approach of his school, but still felt that he would be “left behind” and would not be moving forward as he would have liked. His response to the P.A.S.S sub-scale “general work ethic” was lower than the 1st percentile and perhaps indicated his resignation to his situation. Unfortunately there was not an opportunity to see how this changed for him over time as he was not well enough to participate in further time-points.

In summary, the education timeline seemed to represent the conceptualisation of the education experiences described by participants. They used timeline thinking to gauge the impact that their diagnoses had on their progress through education, with reference to their previously held plans and the relative progress of their peers. Continuity of the timeline seemed positive, with the opposite negative impact that gaps within the timeline caused for academic and social progress. It seemed interesting that the timeline framework for education remained so strongly present given the cancer diagnoses experienced by the participants. It is conceivable that a diagnosis of cancer would have reduced the desire for these young people to progress through education in this structured fashion. However, it seemed that the framework imposed by the education system and the way they perceived forward motion in their lives was powerful and not easily removed or reduced. It is possible that this is particularly relevant for young people compared to older adults. The regular milestones present in the education of young people and the comparative progress alongside same age peers is not as present for older adults and therefore the enduring strength of timeline thinking may be a trait that is particular to this population.

8.3.2 Treatment timeline

A second timeline appeared to frame, both implicitly and explicitly, the experience of treatment. Participants regularly used timeline metaphors as a way of describing and shaping the idea and experience of treatment and these metaphors were present more regularly and explicitly in this timeline than any other. The metaphors used to describe treatment imply movement backwards and forwards on a timeline that seemed to have diagnosis at the beginning and a future recovery point at the end. The text in bold provided some examples in the extracts below:

P: Yeah I wanted to go home as well so it kind of **pushed me forward**. – Mario T2 40

P: the only things that's **setting me back** is this next lung operation, that's the only thing that will **set me back** and then once I get my new leg then I'll be able to like concentrate more and do more activities and stuff...- Mario T3 98-101

P: my treatment didn't have to be **pushed back** because my platelets were never low and my bloods were OK so every time I came to get the infusion it didn't have to be **pushed back** so I could just start it straight on that day. – Robert T2 12-14

The treatment timeline was described as both structured and unstructured, with associated certainty and uncertainty. When diagnosed, participants were presented with a sudden protocolising of their lives, through a regimented system of appointments and a treatment plan to be worked through. The treatment timeline was imposed on them very soon after diagnosis and presented them with a range of treatment options that were previously unknown or only vaguely known to them. It seemed as though participants bought into this timeline conceptualisation very heavily and this conveyor-belt approach to treatment and recovery significantly shaped their experiences.

Participants, even at time-point one, often described this treatment timeline in a very matter of fact and chronological manner. In the extract below, Nicola described her treatment plan, which involved some very intense periods of chemotherapy and a serious operation with unknown and potentially very challenging rehabilitation to follow. The way she described this plan as a timeline seemed to remove some of the impact of the individual events within the timeline and gave it the feeling of something just to be worked through. This seemed like an acceptance and regurgitation of the timeline presented by the medical practitioners, rather than her own shaping of the timeline, and the emotional and psychological impact these experiences may have on her.

P: so I've got ten weeks of chemo, this is my last week now, and then I've got surgery like next week hopefully to completely replace the femur with titanium from hip ball and sockets, and then I'll be in a wheelchair for like six weeks or so and like it'll be intense physio to get my legs on the go.

S: And then is it more, have you to get some chemo...

P: More chemo after that, yeah. – Nicola T1 18-25

Timeline thinking appeared to take a surprisingly high priority for a lot of participants. A good example of this was from participants who talked about the risks of contracting infections if they returned to school, went to public places or saw others who were ill. Interestingly, this infection risk was never discussed in terms of the health ramifications and the feeling of being ill, but instead was talked about in terms of setting them back and delaying their progress through the timeline, as described here by Mario and Annabella:

P: I still feel like quite strongly about like having people around the house who have got like coughs or colds or anything like that, like I just want to try not to catch anything so it doesn't set me back like any time. - Mario T2 135-137

P: Just so that I don't pick anything up. Otherwise it's more hospital – Annabella T1 100

A good example of the potential for timelines to provide a helpful focus for participants came at the start of Mario's time-point two interview, where he said everything had gone "smoothly". He seemed to be referring to his successful progress through his timeline, because during the time in question he had an amputation of his leg, some very intensive chemotherapy and considerable periods of hospitalisation, which would not normally be considered as things going "smoothly", but in terms of moving through his treatment timeline this period of time had involved no delays. His references to not being able to attend school or being able to walk properly seem to be softened by the success of his timeline progress.

P: Yeah I think you saw me just before the first picture and everything's been going pretty well and smoothly. I've not been able to go to school or anything because of... I can't walk yet properly but besides that everything is going well with chemo and everything. – Mario T2 3-5

Within the treatment timeline there were set routines and patterns of behaviour that participants were instructed to observe. These new routines provided an artificial structure to the day-to-day lives of participants that was outside of their personal wishes. Several participants brought photographs of piles of tablets to the interviews (Figure 8.3) and discussed having to regularly take a wide range of medications at set intervals. This medication regimen could be very draining for participants in combination with other strict behaviour demands governing diet, activities and exercise. The extract below from Robert gave a feeling for the regimented nature of pill taking and William highlights how difficult it was to remember everything that was expected from him.



P: every morning I have to have something to eat, then get my pills and then at lunch time I have to take my pills, it's just a constant.. it's tiring, it's very tiring! - Robert T1 306-308

P: The first picture is all my pills. There's quite a lot of them, there's quite a lot to remember. – William T1 39

Figure 8.3 - Robert's pills T1

Despite the day-to-day structure of participant behaviour, treatment timelines also provided a degree of uncertainty about the success of the treatment and the possibility of setbacks and alterations. Even when the inevitable milestone of finishing treatment was reached, there was often further ongoing uncertainty regarding recovery, rehabilitation, long-term side-effects and fear of potential relapsed disease. Appointments also continued after treatment was completed, further extending the treatment

timeline. Those participants that completed treatment during the research period described a range of closure activities including; “all-clear” conversations, parties, holidays, presents and returning to school full time, but there was sometimes tension between the closure of completing treatment and the continuing impact of appointments, side-effects and adaptations. The extract below showed Robert with a clear sense that completing treatment was the end of the journey for him and the end of himself as a ‘young person with cancer’. This was a consistent theme in Robert’s final interview and he seemed to be willing and able to leave that ‘self’ behind and move on with the rest of his life.

P: Yeah because on Saturday 20th I had an end of chemo party, because I had a pre-chemo one, so it was at this club and my mum organised this cake and on it said ‘thank ‘F’ it’s over!’ so like everyone saw it and goes ‘that’s about right!’ - Robert T2 122-114

In contrast, William highlighted the ongoing nature of follow-up care, which was experienced by some participants as a barrier to their movement away from themselves as a young person with cancer.

P: Well I have sort of X-rays and scans every two months for the next year or so and then just like being followed up I guess for the next... I think its five years – William T2 111-112

The treatment timeline, as described by participants in this section, imposed a new structure on their lives, routines and behaviours. Despite being linear, the duration of the treatment timeline was not predictable and the path through it was subject to delays and changes. However, the concept of treatment as a timeline did give participants the potential to view very difficult individual events in the context of progression through a timeline, which could diminish or obscure the emotional and psychological impact of these events.

8.3.3 Adjustment timeline

The adjustment timeline appeared to be multifaceted. It incorporated the adjustment of the participants to the version of themselves as a young person with cancer, but also the adjustments they had to make to the effects of cancer and treatment upon their lives. This timeline was not always linear and participants moved back and forth along this line throughout their experiences depending on the issue in question. There was also a wide degree of variety in the extent to which participants were able and willing to engage with the issue of adjustment, which affected their position on the timeline.

For some participants the adjustment to the presence of cancer in their lives began with some relief. Several participants reported periods of absence from school due to symptoms prior to their cancer

being diagnosed and this had sometimes lasted several months. Participants often reported difficulties during this pre-diagnosis phase that involved pain, ill-health, great uncertainty and self-doubt. For some participants, being diagnosed removed some of the uncertainty and allowed them to start coping with what was already a changing reality. So, the adjustment to a new version of themselves as a young person with cancer actually clarified previous uncertainty by providing an explanation for what they had been experiencing. Before she was diagnosed with leukaemia Georgie had begun to think that she was “skiving” from school and was doubting the reality of her need to be away from school.

P: like the last month but I thought, well I seemed to be having a lot of days off school and after that...I started to think maybe I'm skiving now- Georgie T1 307-309

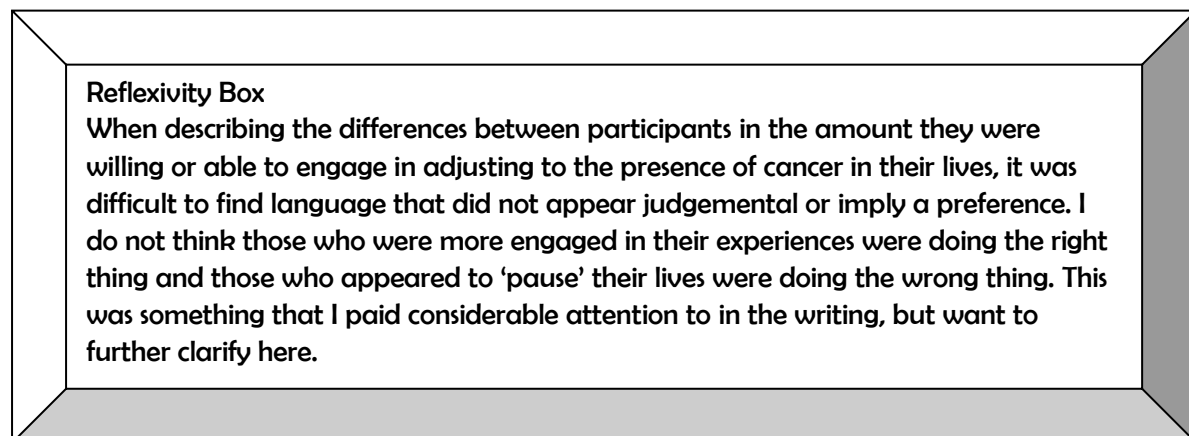
All of the elements that participants described having to adjust to seemed to hinge on their underlying acceptance of the presence of cancer in their lives. Some participants saw opportunities for their cancer experiences to bring something new and, in some cases, positive into their lives alongside the obvious difficulties. This manifested itself in a variety of ways even within the same issue. For example, in the extracts below, Nicola and Hayley both discuss getting new hair after losing it as a side-effect of treatment. In these extracts, Nicola's hope for a different hair style seemed to be for the sake of variety, whereas Hayley's use of new hair was more of an important and outwardly visible component of becoming a “new person”. It seemed that throughout her interviews Hayley had grown in confidence because of the difficulties she had been overcoming and the fact that she was able to attend school with a new appearance was a sign of her increasing confidence. She could have worn wigs or hats until her hair had regrown to her previous style, but instead she used her new shorter hair as a symbol of her new and recovered self. It also seemed that she had grown used to the idea that cancer had brought her into the foreground at school, and instead of shying away from this, as she had done initially, she decided to take ownership of this experience in the new environment of Sixth-Form.

P: I'm hoping the same because I had like mousy brown hair and it was curly, I hope it's curly, I don't want it to be straight. – Nicola T1 46-47

P: Yeah I do because it's like new people so they're not going to remember me as being like long ginger hair and they're just going to think 'yep, new person, short ginger hair!' – Hayley T2 388-389

There appeared to be a continuum ranging from participants who incorporated their cancer experiences into their lives moving forward and those that wanted to keep the different versions of themselves separate. Some participants seemed to ‘pause’ their lives as a normal young person when they were diagnosed with cancer and then ‘restart’ again once treatment was completed, with a void in-between in which they were a young person with cancer. Therefore there seemed to be no need for

them to actively engage with adjusting to their cancer experiences, as they were going to return to their normal lives afterwards. Other participants seemed to engage more with adjusting to their cancer experiences and incorporated the experiences of themselves as a young person with cancer into a new version of themselves as a normal young person. There was no ideal place for a participant to be on this continuum, nor is this continuum prescribed as something that a participant should have worked through, moving from negative to positive. Instead there seemed to be advantages and disadvantages for each participant depending on where they were on the continuum between pausing their lives and fully incorporating their cancer experiences.



For those participants who seemed to have paused their lives when they were diagnosed, they had the advantage of being able to return to their 'previous life' and self without seeming to carry any immediate burden from their cancer experiences. For example, throughout her interviews, Patricia found it difficult to, or chose not to, reflect on her cancer experiences and more specifically how those experiences interacted with her 'normal life' and her school life. When describing her return to her peer group in the extract below, Patricia said that she never thought about her cancer experiences when treatment was completed. She appeared to want to keep the versions of herself separate and that seemed to facilitate aspects of her return to her previous normal life.

S: And do you think, I mean do you talk to any of your other friends about sort of what's happened over the last year or so, do you talk about it very much with anybody?

P: No, not much, no, it never comes to my mind.

S: It never comes to your mind, no.

P: No – Patricia T3 91-95

Patricia went on to say that the physical effects of her treatment, such as hair loss, were not factors that affected her to a great extent. For her, it seemed that not incorporating her cancer experiences into the rest of her life provided her with a degree of protection from some of the potential emotional and

psychological impact of cancer that were experienced by other participants who were more actively involved in adjusting to these new experiences. This was not something that she discussed explicitly, but was a common underlying theme in her responses to questions and description of experiences.

S: Does your hair, I don't know if you've lost all your hair because you have a hat on, but is that something you think about when you're thinking about going into school?

P: I'd wear my hat in school.

S: And how do you feel about wearing the hat in school?

P: It doesn't bother me. – Patricia T1 238-242

Other participants reported difficulties more intensely at the time they were happening. Although more difficult at the time, this subsequently seemed to develop into an advantage for these participants because of the satisfaction they often expressed when they had adjusted to and overcome these difficulties. In her time-point one interview, Hayley had described in detail the difficulties she had with the idea of returning to school and in particular the extra attention she may draw because of her status as a young person with cancer and the changes to her physical appearance. The extract below showed Hayley describing “a good point” in her adjustment timeline, where she had moved passed these difficulties and had started to accept cancer related changes.

P: And I just thought ‘right, just forget it, I’m just going to go in a hat instead of like having all that hair’ because there’s no point like wearing the wig and then people thinking it’s actually real hair and then like a few months down the line just whipping it off one day and like ‘oh you’ve got really short ginger hair! It’s not long brown hair!’ so yeah. That point was like, that was a good point for me because I had the confidence to actually go to school without my wig on. – Hayley T2 359-364

Participants adopted different perspectives to guide them through the adjustment timeline and find their place between a paused life and a life that realigns throughout the experience of cancer. Some participants talked about their status as a young person with cancer as something they had no choice but to adjust to. In the extract below, Robert described his perspective to combat worry about the future.

P: some people were like some people would say ‘are you not like worried about it not getting better?’ and I went ‘well if it doesn’t then I can’t do anything about it so I might as well just live for the now and just do stuff’ – Robert T2 194-196

This extract conveyed a sense that he did not have any perceived control over what was happening to him and therefore should not worry about the future and concentrate on making the most out of what was happening in the present. Like Robert, many participants, especially in the earlier time-points,

seemed to benefit from an orientation in the present and a “day-by-day” approach to moving through the adjustment timeline, where they did not reflect to any great extent on the longer term implications of what was happening to them. This was a way for them to cope with the challenges of the immediate present, which seemed to be more difficult when orientated across more of the timeline and in a longer term context that was uncertain and unpredictable. The extracts below from William, Annabella and Georgie, all point towards a focus on where they were at the time, rather than a worry about the future. William seemed to be happy to relinquish some control over his experiences and “just go with it” in a calm and relaxed way. William always appeared confident that he would progress through his treatment successfully and this approach was a way of him passing this time with the minimum of stress.

P: Because I think I would have been, I don't know, I think everyone, everything would have been a lot worse, would have seemed a lot worse if you think about it. But if you just let, if you just go with it and let it happen it's not, yeah it's not, yeah, it goes quicker and it's not too bad – William T3 1008-1011

Annabella had a very long and potentially complicated treatment timeline, involving a bone marrow transplant and long periods of time in hospital and away from school, so breaking this timeline down into smaller sections helped her to adjust in stages to the enormity of the treatment timeline she was faced with.

P: I had a kind of weekly plan, that's about it...Just taking it day-by-day at the minute. – Annabella T2 476-485

In Georgie's case, this was a perspective that she was recommended by staff as a way to combat her anxiety about the future.

P: Yeah. And everybody, well people just think stick where I am now instead of thinking about, worrying about the future or anything. – Georgie T1 1417-1418

Regardless of the perspective they had on their adjustment, the majority of participants reported some degree of withdrawal from their cancer experiences at some stages of their treatment. This seemed to be a way for some of them to fortify themselves for future treatment or hospitalisation, but also gave them time and space to engage in being a normal young person. It seemed important for the different versions of self to each have an opportunity to be the central focus. If participants allowed themselves to always be a young person with cancer, then the extent they were a normal young person or a young person in education was reduced. Also, as Annabella says in the extract below, constantly thinking and talking about difficult things can be a burden. Annabella's extract below is in relation to her interaction with other young people on the inpatient ward and showed that, even in an environment

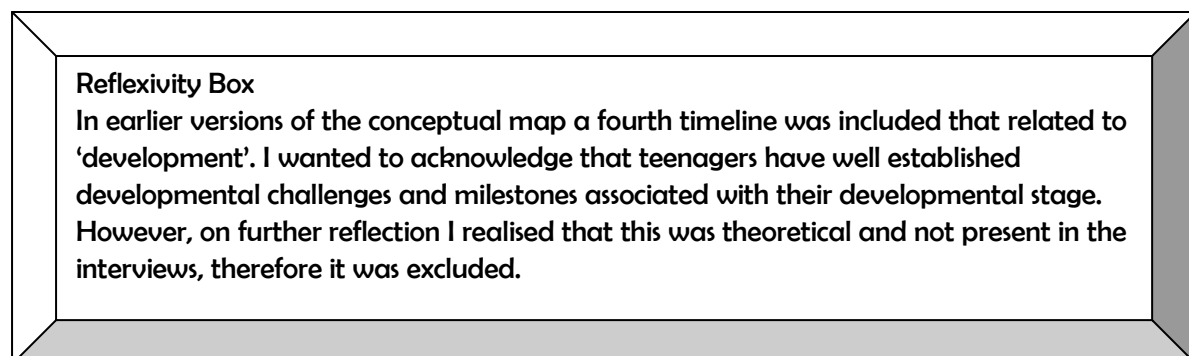
where the focus is on being a young person with cancer, there was still the need to be a normal young person.

P: It was alright, we just sort of just... we'd laugh about stuff rather than thinking about bad stuff. Because if you are thinking about like sad, rubbish stuff then it just makes you feel rubbish! – Annabella T1 484-486

The extract below from Mario showed his need to be a normal young person at home and then build himself back up to being a young person with cancer when returning to hospital.

P: Well when I'm ill I usually see how long it is until the end, even if it's like another week. But I just... I try not to think about it like at all, I try to leave it out of my mind and then just on the last day...
S: So you try and... when you're at home you try and just put it out of your head and then just sort of start thinking about it when it gets close to coming to hospital?
P: Yeah, a bit closer. – Mario T2 179-181

This section has shown that adjustment was thought of in terms of a timeline, but not necessarily a timeline to be worked through in a linear fashion, as with the education and treatment timelines. Participants had to make adjustments between the needs of different versions of themselves, and the extent to which they wanted, needed or were able to do this varied. The experience of adjustment between different selves over time was an individual experience.



8.4 Being a young person with cancer

There were three distinct versions of self presented in the map at the beginning of this chapter. Becoming a young person with cancer was the new version of self that was thrust into the lives of participants after their diagnosis. There was very limited preparation for some of them and the acceleration into this version of self appeared incompatible with the other versions of self, normal young person and young person in education, which grow and develop over much longer periods of time and involve known developmental milestones that are culturally enacted and rehearsed. This

point is illustrated by the extract from Faisal presented below. During his interview Faisal referred back many times to feelings of disbelief at his diagnosis, saying it was “like a dream”. It seemed that this was complicated for him by the sudden nature of his diagnosis and his perception of the incompatibility between his enforced situation as a young person with cancer and the feelings of wellness he experienced only a few days beforehand.

P: I couldn't believe it, I felt like I'm a dream or something, this is not happening, like I feel like... I felt completely fine, like a couple of days before I was here I was in the gym working out and like people, how are you feeling, I was like, like the forms and stuff here and stuff and at the moment where my body's aching but before I was like no because I was completely fine and it was like, I just couldn't believe it- Faisal T1 222-227

The effect on participants of the emergence of this new version of self were experienced in many aspects of their experience of engagement with education, but also with their experiences of being a normal young person. The following sections describe the experiences of participants becoming a young person with cancer and how this affected their idea about themselves, how their idea of themselves changed over time, telling others about their cancer, new peer groups, their experience of changing vitality and the increase in worries compared to the previous version of themselves.

8.4.1 Changing version of self

Becoming a young person with cancer led participants to express three further versions of self that were situated in time: present-self; past-self; and future-self. Participants talked about the past version of themselves before they had cancer and how they may or may not be able to get back to that version again. They talked about the present version of themselves with cancer undergoing treatments and how difficult that was, or how well they were coping with that experience. They also imagined a future-self where they were disease free, back to normal or adapting to their new reality. These versions of self were not experiences that the participants discussed, but were ways in which they shaped how they made sense of what was happening to them, or might happen in the future. Similar to the adjustment timeline, although these three versions of self were situated in time, participants did not progress in a linear fashion from one to the other. Instead they moved their focus back and forth between these selves depending on the requirements of different situations, which will be elaborated below.

Two of the participants unfortunately had to have leg amputations as part of their treatment. Interestingly, both of them approached this by orientation to present and future selves. After hearing the news of the impending amputation and immediately after the operation, both participants described thinking about and researching possible Paralympic activities that they might have been

able to participate in. It seemed that imagining a future version of themselves participating in positive activities was a way of coping through projecting themselves into the future where they could escape from their immediate difficulties, but also construct their own timeline for the experience, which had the potential to end positively and with achievement. In the extract below, Mario described some of his research into the Paralympic classification that he would belong to, and even though he acknowledged some of the steps he would need to take, the extract showed his excitement about the possibility of moving towards a positive future in an area where his physical change would open up new opportunities rather than being an obstacle. It also showed the immediate positive action of research and information gathering.

P: I'm not sure... usually when I'm watching like what my class would be I'm just kind of thinking like 'what's the record to beat?!'

S: Right OK! So do you imagine yourself sort of trying to do that kind of thing?

P: Yeah, definitely. I'm going to try it and get a running leg and everything so... but I'm not sure when because I think you've got to prove that you can't run with the leg that you've got at the moment before you can start looking into getting running ones.

S: Right, OK. So you've obviously... it sounds like you've done a little bit of research into that?

P: Yeah, definitely! I've just been looking on the internet and YouTube at videos and stuff. – Mario T2 199-207

In contrast to the use of future selves to provide positive context to the present-self, some participants wanted to maintain traits from their pre-diagnosis selves as a way of maintaining continuity of character and showing that they were still the same person they had always been. Alanna discussed on several occasions feeling like she had always been “the strong one” amongst her peers and family. This sense of her own strength appeared to provide her with motivation and confidence to adjust to the difficulties imposed upon her by cancer. The extract below showed that this continuity of character led to her feeling aware of and protective over the feelings of her peers when returning to school. Feeling like she was still the same person and showing others she was still the same person, appeared very important to her reintegration into school and her peer group.

P: I'd never say 'I'm in pain' with my friends, because I'm sort of... basically I'm sort of the strong one, they talk to me, I'm a really good friend like that so I'd never say if I'm in pain, I've never cried in front of them, I never ever... they're my friends and that's it, I'm really strong like that in front of them- Alanna T3 1266-1269

The idea of continuity of self throughout and beyond the cancer experience was strongly present in the interviews with Robert. However, Alanna seemed to use her continuity of self to help her with adjustment to cancer and her positioning within peer and family groups, whereas, Robert was keen for

other people to remember him as he was before his cancer diagnosis and not to see him as the ‘Robert with cancer’. It seemed that Robert thought others might perceive the ‘Robert with cancer’ to be a different person to the ‘Robert prior to cancer’ and this was not how he felt about himself. In the extract below it seemed that his past-self was the self that he wanted to define him and not his present-self as a young person with cancer. Although his desire to be seen as his past-self seemed clearly stated in the extract below, Robert was not ashamed of being a young person with cancer and in other sections of his interviews he discussed being “proud to be bald” for example. To Robert it seemed that cancer was an experience he was having, rather than something that defined him.

P: Yeah, it’s like I don’t want people to pick me out for being... for what I’ve got, I just want to be seen as me being normal and remember me with hair and stuff like that because I don’t want to be... ‘oh be careful with him because he’s got that...’ – Robert T1 122-124

The idea of continuity of self was compromised for some participants because of the physical and psychological impact of their cancer and treatment. The extract below from Nicola showed an emotional and psychological unreliability of herself. Not being able to rely on a consistent version of herself and how she would interact with others on a given day, led her to feel that interacting with her might be a “waste of time” for others and that it was difficult for her to plan social activities in advance.

P: I guess I’m just tired because of like the chemo and the anti-sickness drugs, so then like I don’t know what mood I’ll be in, like I might be really moody, so that I don’t like to arrange it and then they come all the way here and then me being like not talking to them kind of thing, so I think it’s better to like just to do it like last minute and just come and visit me at home if they want to kind of thing.
S: So is that to do with like how, like what their experience will be or what your experience will be or is it like...?
P: I don’t know, I just, I always think it might be a waste of time if I’m like not very talkative, you know, and like because we live relatively far away it’s like, I think it would be a waste of money if I’m not very talkative when they come. – Nicola T2 556-565

The final time-point interviews gave participants the chance to reflect upon their changing versions of themselves throughout their time in the study. In her final time-point interview Hayley looked back over her photographs from time-points one and two. In the extract below it seemed that she was having difficulty reconciling how she *felt* at those times with how she *appeared* in her photographs, but also that she felt a degree of sympathy for the past-version of herself. Looking back on the photographs provided her with an opportunity to timeline and to compare her present-self, where she had finished treatment, was attending Sixth-Form and described herself as a “new person”, with her past-self where she looked unwell and could remember the difficulties she had been through. The

extract below showed the positive and negative effect of this timelining as a reminder of difficult times, but also a calibration of her present-self and a reflection on survival.

P: Like I never felt properly ill, like I never felt as though like I looked like a cancer patient but looking at those photos like I do look pretty rough in some of them! Like with the ill face...

S: How do you feel about those ones where you think you weren't looking maybe so well as now?

P: It is quite depressing, I had a bit of a cry about it when I was sort of in bed! But yeah, it's just in the past so I'm just not trying not to think about it. Don't start mum...! It is just a bit, it is strange looking back at them.

S: Yeah I bet it is, yeah.

P: I just think positively, like I look at them pictures and then I look in the mirror and it's like 'well, you don't look like that anymore do you?!' so it's all good.

S: And that sounds like that's been your approach the whole way through so...

P: Yeah. – Hayley T3 811-825

It seemed that being diagnosed with cancer led to challenges to the continuity of self in the experiences of participants. Orientating their view of themselves in the past, present or future gave them the opportunity to shape this view to some extent and could be beneficial to the way they were coping with a particular experience. However, it was difficult for some participants to maintain continuity of self amongst the turbulence of their cancer experiences. Part of this turbulence related to the participants telling others about their cancer experiences. The following section discusses the way in which being diagnosed gave participants important information and how they proceeded to decide who could know this information, how to tell others and what the implications were.

8.4.2 Telling and knowing

Becoming a young person with cancer did not happen in an isolated environment and participants discussed at great lengths the intricacies of telling others about their cancer experiences and deciding who had rights to this information. The dynamics of telling and knowing were a key part of the experiences of participants and exemplify how we make sense of ourselves and our experiences in relation to others. Participants were aware of the impact this information might have on others and the subsequent responsibility they felt for this impact. Telling others information of this magnitude and of such a personal nature was often a new situation for participants and one for which they did not always feel prepared or equipped. Leading up to their diagnosis of cancer, participants were aware that family, peers and other people in their lives had been worrying about their health and the outcome of medical tests and scans. Following their diagnosis participants found themselves in possession of sensitive information which other people in their lives wanted to know. This situation gave participants a certain amount of responsibility for deciding who to tell and how to proceed with this.

Without an existing approach in place it was interesting to see how participants approached the process of telling others. Participants varied in their method of telling, but the majority of them engaged in the process of telling to some extent. There was often guidance from parents, and parents usually took some of the responsibility for telling family members. Education and health professionals helped some participants tell peers and staff at school, but participants seemed to take this responsibility for themselves with friends and peers, and this situation was heightened in the education environment where they encountered the majority of their peers in one place. Many participants, like Nicola, decided to tell close family and close friends first and the information tended to spread from this point with participants involved to varying degrees. It is interesting that Nicola described wanting to keep the experience “low key”, and this seemed to imply that telling wider networks of peers would be a more intense experience.

P: Well at first we kept it like low key but, and I just told my close friends - Nicola T1 201

One of the approaches often described by participants was of systematically working through a hierarchical list of people to tell. This was more difficult for participants who were attending school, as the peers tended to all be present in one place at one time, making it more difficult to be systematic. Alanna, in the extract below, describes telling small groups of peers in turn and clearly showed that she wanted to reinforce the idea that she was maintaining a positive outlook.

P: So telling them I'd just say... I wouldn't tell them in front of everybody else, I'd tell them sort of like two or three people at a time and things and just say 'look I've got cancer and I will tell you everything that I could' and they were like 'oh right... are you going to beat it?', 'yeah, of course I am! What do you think?!' - Alanna T3 236-239

Others, like Robert, wanted to tell as many peers as possible at school in one go and then did not want to discuss it with them afterwards. Telling a large group of peers in one place at one time gave Robert control over the story and avoided repetition of the story, which unlike Alanna, he found frustrating rather than seemingly beneficial.

P: I made a decision with my head of year and form tutor to go to my form room, just my form room, not assembly or something like that, and I went in and I said 'right, I haven't been to school for the past couple of days because I noticed a lump on my neck' and everyone went like 'oh!' and I said 'and basically what it is it's a cancer' - Robert T1 275-278

Interestingly, Robert still had a hierarchy of telling and felt the responsibility to tell his cousin personally and individually. It seemed that he wanted to contain the experience for his cousin as he expected it to have a significant impact on him and be able to personally attend to his reaction. It also

seemed as though he valued the reaction of his cousin and therefore thought that it warranted his extra attention.

P: I took a picture of my mum and dad because like family has been really really useful in this, because when we found out, when I was diagnosed, we called them all up and said 'right we need to tell you something and it's going to be a bit hard for your to take in but don't worry, it's treatable, blah, blah, blah'. They were all obviously shocked at first and my cousin, he took it quite hard, I didn't want his dad... I didn't want his mum and dad to tell him, I wanted to tell him personally and like I knew straight away as soon as I told him it hit him because he went from like 'you alright?' to like being blank and straight so...- Robert T1 232-238

The spread of information about their cancer mainly happened through their peer groups. Both Hayley and William, in the extracts below, were concerned about their peers "wondering" about what had happened to them and why their appearance had changed. They both felt that the way to address this concern was through their peers having the right information, and that this information would stop them wondering what their peers were thinking about them. In context of other parts of Hayley's interviews, it seemed that this was something she thought "people have got to know", but was complicated by her desire to not be brought into the foreground when reintegrating into school.

P: Yeah, so, but people have got to know haven't they really, it's like better... like when I've got this [Hickman line] like hanging out and stuff they're not going to be like asking me 'why have you got that? Why are you wearing a wig?' and all that so... It is better that they know. - Hayley T1 78-80

P: No, I think it's alright. It's better that kind of they know what's going on than just wondering what's happened. – William T3 562-563

The idea that people might have the wrong story seemed to be connected to having the wrong idea about them and that the story about their cancer equated to the formation of themselves as a young person with cancer. Their own story of their cancer experiences helped to build a version of themselves, and through telling and retelling an 'accurate' version of this story participants could have some control over how this self was created and moulded. For some participants, as demonstrated by the extract from Alanna below, having ownership over their story was a way for them to reinforce their own beliefs about this story and about themselves as a young person with cancer. Alanna repeats that she is "not going to die" as a reassurance to her peer group within school when telling them about her diagnosis, but this repetition of a version of the story that she owned and was comfortable with also seemed as though it reinforced her conviction in this belief.

P: then they'd all come and say 'so why've you been off? What's wrong? What's wrong?' and I'd go 'they're 95% sure I've got cancer, but I'm not going to die' and they'd go 'are you sure? Are you sure?' and I'd go 'yeah, I'm not going to die'. – Alanna T3 208-211

Sometimes owning the story meant being able to shape it in the way they wanted others to perceive it, rather than necessarily reflecting what was really happening. Alanna thought that if others perceived she was coping well then it would be easier for them to support her. For her, telling her story became a cycle of reinforcing a positive attitude in herself and in others.

P: I didn't say there's a chance I could, I just said 'no I'm going to beat it' so they didn't worry about it.

S: Oh OK, so did you want to give off that impression to them so that they'd feel better about it or was that how you were feeling?

P: Both. It's how I felt about it and... because if everybody else thinks that I'm going to beat it then they're all going to support me to help me beat it, if everybody thinks that I could die from it then they're going to be... they're minds would be all over the place about what to do and everything so...

Alanna T3 153-160

In the extract below, Nicola seemed very annoyed that somebody she had never spoken to did not have the “proper” version of her story. As this person was not known to her she could have been unaffected by this inaccuracy, but the impact of this was intensified through the combination of her life becoming public property and a lack of control over the shaping of this process.

P: I'm alright, really, because I prefer people to ask questions rather than to like talk about me behind my back and like enquire through word of mouth. Like this guy who I went to primary school with, he messaged me the other week, and he was, like, "Oh, I heard that you had to have your leg amputated", and like so I was explaining it to him, and I was like "So who did you hear it off?", and it was this guy that I'd never heard of, and I was like "Well, how does he know, like the proper story if I've never spoken to him", and it really annoys me. So I'd rather people ask me personally so I can like tell them, like the actual story - Nicola T2 355-361

The idea of their lives becoming public property extended beyond the stories they told and into the reactions of others. It seemed that participants had lost a degree of privacy and that a very personal experience was to some degree public property, especially within the school environment. In the extract below, Georgie was worried about reintegrating into school because of the extra attention she might receive from school peers with whom she had no relationship. She felt that this situation would make her feel “awkward” and in the context of her repeated statements about wanting to feel normal,

having the attention of many distant peers would have been a challenge to her desire for normality and a change to her previous peer group dynamic.

P: Everybody might come and ask me, everybody, it might be a bit awkward maybe.

S: What kind of things do you think they might ask you?

P: I'm not sure. They might just like come and talk to me even if I don't know them. - Georgie T2 846-858

Hayley also experienced this extra attention from peers when she reintegrated into school and was surprised by the emotional response from peers who would not normally speak to her. It seemed that Hayley was annoyed with their reaction to her and that it reflected a false intimacy between these peers and her personal experiences. It appeared that perceived 'overreactions' from peers created the idea that they were identifying too much with the experience of the participant and making it their own. This highlights the two-way difficulty with the reintegration dynamics for participants and their peers. The young person with cancer does not have the experience of how to disseminate the information about their cancer and how to deal with the consequences, but neither do their peers know how to react, or how to put into practice their perceptions of how they are 'supposed' to react.

P: So... yeah that first day back... people that I didn't even talk to normally they just started crying, and it was like 'what are you crying for? I don't even know you- Hayley T2 541-542

Participants regularly reported receiving a flurry of questions and comments from peers when visiting or reintegrating into school after their diagnosis. Participants sometimes felt bombarded with this flurry of questioning. It was more difficult for participants to maintain a sense of normality in the context of school, because their previous absence provided a before and after that allowed peers to compare two versions of the participant in relation to their appearance, mobility and abilities, which clearly propelled them into the foreground in a way that was more glaring than in the hospital, at home or in the community. Fielding questions from other people was a challenge for those participants who were trying to just be a normal young person in education and did not want to talk about cancer. Sometimes for these participants it highlighted the limitations of their knowledge about their cancer experiences and led to vulnerability when answering questions from peers. Robert found this flurry of attention and questioning had a cumulative frustration and draining effect on him.

P: I just go 'I'm fine, it's a little bit bad but don't worry, it's... I'm fine, I will get better' and then they'll just go 'oh, good, good, good' and then another person will come up and ask the same question and like 'I'm fine!' – Robert T1 106-108

Nathaniel described this cumulative effect of questioning from peers had already begun before his diagnosis and in subsequent interviews he continued to struggle during times of questioning from peers, preferring not to talk about it.

P: Yeah, because it just gets a bit annoying. Like when I had the operation just on the massive lump I had, it went really big and they all just asked, everybody asked me, what's that, what is it and I didn't know so I just said, I don't know but everybody asked me it, virtually everybody and it just got really irritating and annoying, you know. – Nathaniel T1 159-162

There was often a sense from participants that neither they nor their peers really knew how to deal with the idea of talking about cancer experiences. This seemed to be a problem of the mismatch between participants' version of themselves as a young person with cancer and the previous version of themselves as a normal young person or young person in education that they shared with their peers. It seemed that when there was a shared self in common between peers, that a gradual understanding of the rules of interaction built up over time and that this dynamic was altered when participants introduced a new self into the situation. After the initial flurry of concern and questions, participants and their peers often reverted back to previous dynamics, and in most cases this seemed desirable to participants. Peers often did not know how or when to ask questions, as well as if it was acceptable to broach the subject. This led to participants and peers taking cues from each other when none of them really knew the right way to proceed. The extract below from Mario demonstrated the confusion within the dynamic of his peer group. They shared activities and time together, but he perceived them to be scared to ask him about his health. He did not say that he knew this to be true, which implied they had not openly talked about it. He said that he was happy for them to ask him questions and it appeared that if somebody had broached the subject they would all have been able and happy to discuss it.

P: No, we don't usually talk about it, it's usually just playing on games or watching TV or whatever, just chilling really.

S: And have you spoken to any of them or have they asked you questions about your operation and things like that?

P: Not really, I don't know, I think they must be quite like... a bit scared to ask. But I'm not bothered if they did ask.

S: So do you not sort of tell them anything about it unless they ask?

P: No, yeah.- Mario T2 246-253

In the extract below from Nicola, it seemed that some of her peers avoided this issue by addressing their questions to her friends rather than directly to her. She did not explain the "don't want" in this extract, but it seemed that she was referring to her perception that peers did not want to upset her or

say the wrong thing, and that it was safer and more diffused when talking to her friends instead. With Nicola's desire to control her story, this had the potential to cause her difficulties.

P: I guess some people like they don't want to ask questions because they don't want, so then they ask like closer friends kind of thing so they're go around me, - Nicola T1 217-218

The above extracts are from participants who were happy to discuss their health with their peers. However, some participants, like Patricia, did not really want to talk to friends about their experiences. This seemed to be linked to wanting to keep herself as a young person with cancer separate to herself as a normal young person, which fits with her more 'paused life' approach to adjustment. This approach seemed to help her with her desire to maintain normality when reintegrating into school, but risked a lack of understanding from her peer group as to what she had experienced as a young person with cancer. As has been shown with other participants, an increase in information to peers can help with their understanding of what might have changed for participants whilst moving through their cancer experiences and lead to appropriate adjustments.

S: They ask you lots. What kind of questions do they ask you?

P: Like 'are you alright?' 'are you fit?' 'how are you doing?' things like that.

S: Yeah, and what do you say to them?

P: I just say 'I'm OK, what about you?'

S: Right so you're still worried about whether they're OK as well! So you said they treat you just as normal really?

P: Yeah.

S: And do you talk to your friends at home about things that happen?

P: Not much." – Patricia T1 101-113

Being a young person with cancer, could alter the power balance in relationships within the school environment. This was not expressed by all participants and most did not want or recognise this particular change in dynamic. For others, as well as telling peers and staff about their cancer experiences to inform them, some participants embraced the new power that their 'status' gave them. Robert for example, articulated several different episodes where he had 'used' this 'power'. Robert mainly used his status as a young person with cancer to attempt to put his peers at ease, by using humour, as in the extract below where he jokes that they cannot deny him anything. Robert also reported this as a frequently used coping style in the A-COPE.

P: myself making fun of this bad situation, putting a light twist on it, so like I'd go to school and Wayne, one of my friends, would like... I'd trick my friend by saying 'oh can I have your dessert?' and

he'd say 'no' and I'd say 'you can't say no to a cancer patient!' or I'd just try and get out of everything by saying 'I'm a cancer patient, you can't do that!' – Robert T2 183-188

In relation to the education staff, Robert realised that his unique status as a young person with cancer gave him a different relationship with staff, often putting them in an awkward position. In the extracts below, Robert described being able to say “no” to education staff and explicitly said that he enjoyed this change in dynamic.

P: I was told they were all told but obviously because everyone is not wearing a hat it's just instinct for them to go 'take that hat off' and like when you get your substitute teachers they'll be more thorough about it and go 'don't talk to me like that!' you know, 'get outside!' which hasn't happened yet, but I want it to so I can say 'actually, no, you can't tell me that!' – Robert T1 155-158

P: I like to have the power to say no to a teacher and they can't do anything about it, [both laugh], that gives me the power. - Robert T3 380-381

These extracts showed that the timing and manner in which he conveyed his status as a young person with cancer within school altered the dynamic of his relationships within education. It seemed that asserting power was important to Robert as he reintegrated into school because he wanted to feel some ownership of his status as a young person with cancer and show that his cancer was not dictating to him as a victim and that he was still in control of himself.

8.4.3 Cancer Peers – Shared selves and calibration

As shown in the previous section, becoming a young person with cancer brought new information and a new version of the self that altered some peer group dynamics. However, becoming a young person with cancer also introduced a new peer group made up of other young people with cancer. This new peer group shared the self that was not shared with healthy peers and this provided opportunities for positive interactions, as well as potentially negative calibration of experiences. There is no template on how to be a young person with cancer and it seemed that interactions and observations of other young people with cancer contributed to the ongoing construction of this version of themselves. Some of the participants discussed the relative importance of new peers in helping or hindering their adjustment to cancer.

The main positive expressed by participants was that other young people with cancer could relate to what they were experiencing and presented them with an opportunity to discuss experiences with people who could relate to them as both a young person with cancer and a normal young person. In

the extract below, Nicola talked about the importance of being known, and how it was easier to talk to other young people with cancer because of this shared knowing.

P: Yeah, I think so, because like I guess people at school don't understand it whereas it's nice talking to people here about it because they know what you're talking about – Nicola T1 883-884

For Alanna, this shared knowing also contained an element of being believed about the extent of her pain, which her previous peers were not likely to have experienced and would therefore not be able to gauge or accurately understand.

P: They don't know what it's like and they don't know what pain you go through. I used to hop around school and they just thought 'oh she's got a bit of an ache' but I was in agony – Alanna T3 1264-1265

The ability to share understanding and knowledge with other young people with cancer produced a new sense of normal, which was different to and independent from the sense of normal experienced by their other peers, but also by their past-selves. In the extract below, Hayley described her relationship with another young person with cancer and referred to that person as somebody else who was "normal". It seemed possible that each version of self that the participants were living with had its own associated sense of normality that could be shared with comparable individuals.

P: Not many, I speak to [patient name], like I've got her on Facebook so I keep talking to her which is nice, it's just nice to know someone else who is normal!- Hayley T3 204-205

Other young people with cancer also provided participants with a degree of calibration of their experiences and adjustment. This could result in positive or negative reshaping of experiences. Perceiving that other young people with cancer were in worse situations than they were could be used as a way to adjust their own perspective and maintain a positive outlook. However, other young people with cancer who were perceived to be coping better than they were, especially if their situation was perceived as worse than the participant's own, could be a source of guilt or anxiety. In the extract below, Hayley described having another pupil with cancer in her school and the guilt she felt when she perceived his determination to attend despite his external signs of difficulty.

P: Or... yeah he's younger than me and he looks ill. He's got cancer and he's got... he's had to walk round on crutches, he's drip white, he's obviously bald, he's got a massive yellow bandage and he goes to school like every day and I feel so guilty for not having gone in. It's just... I...

S: OK, so because of seeing him and seeing him going in and that sort of thing?

P: Yeah, I just feel like every time I see him I'm just like 'o God! Why are you at school? Just go home

and relax it's not good for you!' It can't be... because every day, there's not been a day when he hasn't gone in.

S: Wow OK, yeah that's quite impressive.

P: I just do feel really guilty for not going in – Hayley T3 634-643

Alanna's perception of other young people with cancer wanting to retain their hair when it began to fall out, made her feel that the approach she had taken to shave it all off before it began to thin, was the correct one for her.

P: That's a lot easier than... because you see a lot of them who don't shave it or anything and it's all wispy and.... just to have some hair...- Alanna T3 361-362

Robert calibrated the success of his progress through his treatment timeline against the difficulties other young people with cancer had experienced and concluded that he had been fortunate not to have more set-backs.

P: A bit yeah because like every time I came in like I saw a couple of teenagers who had to like go home and then come back a week later for the bloods to be level again. But luckily I was able to get in there and just start it – Robert T2 19-21

As well as the less direct calibration described above, participants also looked to this new peer group for guidance and inspiration about how to cope with and adjust to being a young person with cancer. Georgie said that she “chatted about lines” (T1, 86-92) with other young people with cancer in reference to central lines and later she described selecting her own type of line based on experiences of others. Nicola found Alanna's confident approach to wigs and hair loss inspiring and this helped her to feel confident about her own appearance and to model how to be a young person with cancer.

P: Yeah, it helps like, I guess it helps with like friendship and like self-esteem, because like [Alanna] especially, she, we were talking about like wigs and hats and stuff and she was like, “oh no, I don't care, like I'll just walk around”, and I find that really good and like really inspiring - Nicola T1 895-898

Ongoing calibration and construction of themselves was often reduced with their peers at school because of the change in dynamic imposed by cancer and the new experiences cancer gave them. Calibration with the behaviours, attitudes and experiences of other young people with cancer provided participants with a peer group that they shared experiences with and could interact with to construct their ideas of how to be a young person with cancer.

8.4.4 Loss of vitality

Participants regularly referred to the impact that cancer, and more particularly the treatments for it, had on their energy. The compromising effects of treatment on their energy levels were felt as a direct physical side-effect, but also as a more fundamental loss of vitality needed to engage in their lives and their education. The extracts below from Annabella and Hayley showed how this loss of vitality was used to compare their past-self to their present-self and calibrate the way that cancer had changed their abilities. In fact, Hayley described running up the stairs as something that she missed, and it appeared that a lot of participants missed this simple feeling of vitality.

P: there was this big road, this big hill, it took us 15 minutes just to walk up that!

S: Right OK, so that's longer than it would normally take you then is it?

P: Yeah! Before we would run it! - Annabella T1 142-144

P: Like I was always tired and to begin with I couldn't even get up stairs without needing an hour's rest at the top, but now I can like... one thing I miss is running up the stairs because I've never just walked, I'd run up the stairs every time and I'm getting there now, I can sort of jog! – Hayley T2 171-174

Loss of vitality seemed to be exasperated by the lethargy that could ensue from periods of hospitalisation and bed rest, as shown by the extract below from Mario, where he described being “just sat in bed” for days at a time, suggesting that this was all he could manage or all that he wanted to do.

P: Yeah, when I'm actually in hospital I'm just sat in this bed for two days straight or five days straight or whatever! But when I'm at home I'm moving around and doing everything so. – Mario T2 161-163

In the extract from Mario he explained that his loss of vitality was more acute when in hospital, but loss of vitality for other participants infiltrated many aspects of their lives, reducing their ability to engage in social and educational activities. Cancer and treatments had a serious impact on the energy that participants had to engage in education and the physical side-effects of treatment were regularly cited as a reason for participants being absent from school. Fatigue, reduced concentration, reduced immune system function and sleep problems were the most common specific physical effects associated with loss of vitality. As the extract below from William shows, reduced ability to concentrate was not only a barrier to engagement with education, but an associated source of anxiety for participants when reintegrating into school. The time spent away from education and the periods of inactivity associated with hospitalisation increased the “challenge” of summoning back a sense of vitality and energy to reengage with themselves as a young person in education.

P: I think maybe like the concentration side of things... I'm a bit nervous about that actually, sort of sitting in a classroom listening for... working... it's going to be quite... I think it could be quite... not difficult, but a challenge – William T1 150-152

During periods of absence from school many participants reported engaging with home and hospital tuition services. The aim of these services was to fill the void in the education timeline caused by cancer and to address the potential for young people to disengage from education activities during these gaps. Many participants who engaged with these services reported that the one-to-one nature of home and hospital teaching and the immediate access to feedback and guidance helped them to stay engaged with education and keep them active. In some cases, participants said that they felt they were able to achieve more and progress quicker with their work than their peers in school. In the extract below Alanna says that she was motivated to engage in education, but still needed support because of the reduced concentration she was experiencing.

P: I wanted to do my school work and everything, but I needed someone there with me for my concentration – Alanna T3 585-586

Annabella, who experienced home tuition for a long period of time due to an 18-month enforced absence from her school following her bone marrow transplant, nicely described the immediacy of the support available through her home tutor and the benefit of a lack of other distractions. For Annabella, the relationship with her home tutor seemed to also provide her with a sense of continuity and stability that she was no longer able to get from attending school and progressing normally through her education timeline.

P: Just if you get stuck on something you don't really have to wait for your teachers, you know, to see someone else, you can just ask and plus there's not really much distraction, so also if you get... if you're not quite sure on something you can kind of get her to explain it to you – Annabella T2 553-556

8.4.5 Spectrum of Worries and Responsibilities

Becoming a young person with cancer brought with it a new spectrum of worries and responsibilities compared to being a normal young person. Participants now had to think about the fine details of specific pieces of school work whilst also dealing with new issues around pain, mortality and coping with often severe and life altering treatments. They also described how they were thrust into an environment that was usually unknown to them and were faced with new images, vocabulary and people that would not normally be part of their lives. For example, Alanna found it “real tough” to be exposed to the previously unseen world of children with cancer and imagined that this would have been the same for her friends if they had visited her there.

P: like sometimes I'll stay and I'll go on ward 31, which is all the kiddies, and I don't want them to go on there because that's real tough, seeing little kids having cancer – Alanna T3 838-840

Participants often discussed the impact their lives were now having on other people, primarily family members and peers. The lives of a lot of people now centred on their needs and the unpredictable world of being a young person with cancer. Participants described the difficulty they had knowing that their cancer diagnosis and the effects of treatment would potentially have an upsetting and distressing effect on other people. There was a sense that they were suddenly more responsible for the feelings of others. In the extracts below, Alanna and Robert both described the impact specific aspects of their experience as a young person with cancer had on their peers at school. Alanna, who was very comfortable with her adjustment to hair loss, described very carefully preparing her friends to see her without hair. Despite the care she had taken, the sight of her without hair was still upsetting for some of her friends. It appeared that this type of situation was difficult for participants because, as well as adjusting and coping with the impact of cancer on themselves, they were also responsible for the impact it was having on others. This was particularly difficult for participants in situations like Alanna's, where there was a disconnection between the reactions of others and their own experiences. Alanna was attempting to control the presentation and framing of her own experiences, but seemed to feel that this was undermined by the reactions of others.

P: Yeah, I told them all, I went 'I'm going to take my hat off, if you want me to put it back on... if it... if you *really* want me to put it back on, I will, don't worry, it doesn't bother me but I just need to take it off' so I took it off and I saw some of my friends crying, kind of like [Name], who I was talking about, she was crying and I saw them crying and I went 'why are you crying? It's not you, it's my hair, I'm not bothered, it's just hair – Alanna T3 1135-1139

Following Robert's announcement of his cancer diagnosis to his peers at school, he was informed how the news had affected the mood of the entire year group and had resulted in lessons being rearranged due to the upset of some students. To hear of this was difficult for Robert, especially in light of the approach he had taken to telling, which was to do it in one go and then leave it behind. He did not know that he would affect so many people with the news of his cancer. It must have been difficult for Robert to know that his news had caused such a widespread reaction and it seemed that he felt some level of responsibility for this. It also suggests that it is complicated for a school community to process these types of serious issues, especially in context of the difficulty some peers have on an individual level with knowing how to react and behave in these situations.

P: when I told the whole school it spread like wildfire, it went around the whole school like so quickly, mostly the whole school or my whole year just like was so depressed and so quiet, I wasn't there, but I heard it was very bad place to be. – Robert T3 447-450

The effect of their cancer diagnosis on other people was also felt on a more practical level. Faisal described, in the extract below, feeling like his girlfriend and family were just “wasting” their time when they came to see him in hospital and this was also said previously by Nicola. He seemed to feel responsible for the “pointless” time they were spending together just sitting in the hospital. This was almost an extension to the loss of vitality felt personally by some participants and Faisal could see this loss of vitality in the people around him and felt responsible for it.

P: Um, like, like she comes every day, I feel she's like wasting [her] time or something but because like all that, like all that we normally, my dad and my girlfriend do, is sit here or and sit here or it's like we'll walk to the reception and walk back and it's just like a bit pointless – Faisal T1 349-351

Robert provided a photograph of a wallet to represent the “big effect” that he perceived his cancer situation had on the finances of his family. He recognised, as other participants had done, that parents often had to take long periods of time off work and had transport him to and from appointments.



P: And then the last photo is like a picture of a wallet because with me coming here like driving and everything it's obviously having a big impact on like financial and stuff like that for my mum and petrol and stuff like that. And obviously I've been treated to stuff, which I'm not complaining about! But it is obviously having a big effect – Robert T1 416-419

Figure 8.4 - Robert's photo of a wallet T1

8.5 Being a young person

When participants were diagnosed with cancer they did not cease to want to be normal young people. Participants in this study wanted to be seen as a normal young person amidst the new experiences brought about by having cancer. Normative issues that are important to this age group, such as peer and family relationships, social activities, mastery and emerging independence were all discussed by participants in light of the impact of their cancer diagnosis.

8.5.1 Peers - belonging and protection

The normative issue that was most often discussed by participants was the impact that cancer had on their peer groups and the role that peer groups played in their education engagement. Peer groups and sometimes an identified best friend, were often important factors in the confidence participants had regarding their reintegration into school. Belonging to a strong peer group seemed to provide participants with a protective environment, where they could feel safe, welcome and normal when returning to school. However, when this was not available it could have a detrimental effect on participants, as seen in the extract below from Hayley. The absence from school of her best friend on the day that she had planned to return to school was a strong enough factor that she felt, not only less confident in returning to school, but that it was not possible for her to return on that day. It seemed that the presence of her best friend would have offered Hayley a degree of certainty in amongst the uncertainty she felt about her reintegration, the certainty that at least one person there would know how she was feeling and provide her with protection and security. It also seemed that Hayley viewed her reintegration as a shared experience between her and her best friend, and something that they would go through together.

P: Well I was going to go in about two weeks after but [Name] said... my best mate [Name], she was ill that day, it just like... oh I was so upset because I was going to... I'd properly prepared myself that I was going to go in, I was going to wear my wig, I was going to be there with [Name], you know 'it's going to be fine', and then she said she wasn't going in and it was like 'oh, right OK, I can't go in' because yeah, I just needed her there! To be able to give me that confidence, because she's in a lot of my lessons as well so she's just... she's the strong one really! But I couldn't have gone in without her so I think I just stressed myself out so much, I didn't sleep or anything, I just felt so ill... I think I was making myself ill just thinking about having to go in on my own. But yeah, so I ended up not going in.
- Hayley T1 388-396

Almost unanimously participants reported that seeing friends was the main factor that they were looking forward to when reintegrating into school. They often felt like they were missing out on the gossip and everyday interactions of their peer group that they would usually have engaged in at school. It was also highlighted by participants that there were significant sections of their peers groups that they "don't see as much because I'd normally see them through school" (Alanna - T3 276). Maintaining relationships outside of the school environment was difficult for participants. Peers often found it difficult to visit participants in hospital because of time commitments, travel and the wishes of participants to not be seen in hospital. When participants were at home and therefore not in the school or hospital environments, the presence of their self as a young person with cancer sometimes encroached on their attempts to engage with their peers as a normal young person. This is exemplified by the extract below from Hayley, where she describes feeling "like a cripple" when her friends came

to visit her and she could not stay awake. There was frustration and embarrassment in this extract and this was described by several participants as a barrier to their interaction with their peers.

P: I don't know, like it would have been nice to see my friends more because obviously they're busy they can't come over every day, but...

P1: It's not the same when they see you at home anyway is it?

P: No I just feel like a cripple or something, just like sat on the sofa and like I couldn't stay awake for very long so like they're talking to me and I'm sort of like nodding off and it's awful! – Hayley and her mother T3 671-676

Participants regularly reported trying to carry on with peer relationships as normal young people. However, the needs they had as a young person with cancer often provided a new framework within which these interactions had to occur. For example, infection concerns experienced by participants who had lowered immune systems altered the dynamic of their peer interactions. The extracts below from Mario and Alanna showed the extent to which this issue affected these interactions. Mario and his mother described how limiting his concerns about infection were for his interactions with his peers and for social activities in general. His mother explains how his friends have become very cautious of this issue as well as the concerns Mario had himself. It would have been difficult for this heightened concern on both sides not to have affected the dynamic between them.

S: Yeah, and does it stop you going to other places like I don't know, like friends or family or visiting other people?

P: Usually not because I just try and like keep away from the person who is ill but if they're like ill I wouldn't go and visit them so...

P1: I'd say you are kept away from people an awful lot. I'd say it has affected you in that way. Because like round our house, to be honest he's maybe two friends and you know kept his friends like some of them have come back to the house or he goes to his friends... normally his friends are really really cautious of his... I know you've turned people down saying not to come and visit because he's really really cautious of that. So I think... you haven't... even going to the bank the other week, we went to the bank and somebody came out who'd got a cold and he didn't want to go back in that room because they were drifting in colds so we just went straight home then really.

S: Yeah... so would you say that's true?

P: Yeah, it is.- Mario and his mother T1 120-133

The extract from Alanna showed that there was also a divide between her and her peers in terms of knowing the rules to this new framework for interaction. Alanna was confident enough to take charge of this divide, but other young people might not have been so comfortable.

P: No because it's like, I'll say to them, 'if you've got a cold just sit a little bit away from me' or I'll say 'don't be offended, but I've still got a low immune system remember' – Alanna T3 1368-1369

Participants regularly described using social media as a way to keep in contact with their peers that did not involve attending school, or peers visiting them at home or in hospital. However, it seemed that the type of peer interaction that was possible at school was not really achievable through interactions over social media and that the face to face contact with peers was still a void in their lives.

P: I still talk on Facebook and text and Whatsapp and all that. It's not the same as seeing them and talking to them properly. – Alanna T3 802-804

When there were prolonged periods of absence from school and from their peers, participants often worried about how they would reintegrate back into their peer group. This was a complex concern, but often stemmed from a realisation that their experiences as a young person with cancer had changed their perspective on the normative priorities and worries involved in being a normal young person. This change in perspective was not something that they perceived had happened for their peers, so there was often anxiety about how this would manifest itself on their reintegration. In the extract below, Annabella realised that her attitude towards challenges has changed since her diagnosis and she discussed this change in comparison to what she had previously known and now expected from her peers.

P: I don't know, I think I've just got a different attitude now towards challenges and things. - Annabella T2 305

Hayley described an argument between her friends about which restaurant to go to and how she felt like this was not something to argue or fall out over and that her attitude towards this type of issue had changed during her experiences as a young person with cancer. It seemed that for these two participants, and for several others, the reintegration into their peer group was complicated by trying to return to a previously shared concept of what was normal, but with new experiences that made it more difficult to readjust back to this shared concept.

P: The last thing they said to each other was 'I never want to speak to you again' and I was like 'there's bigger things to worry about than Nando's, you don't have to make like a lifelong feud between yourselves'.

S: Do you think you think differently about that kind of thing now having been through the things you've been through in the last year?

P: Oh yeah. – Hayley T3 734-739

Although some of the issues about peer relationships were complicated, for some participants the problem with being isolated from their peer group was as simple as missing their friends and feeling lonely without them. This was exacerbated by education situations like home tuition, which although helpful and often necessary, were in themselves isolating.

P: Yeah, it's okay. There's no-one to talk to... Like it can just be a bit boring sometimes but that's it really – Georgie T2 561-577

As well as the difficulties, simple or complicated, experienced by participants in their relationships, there were also positive impacts that cancer could make on relationships with family and friends. Some participants reported that their cancer experiences had brought them closer to friends and/or family members. This was often because friends and family had made more effort to see them due to their health situation and the support they required, and that this extra time spent together had improved their relationships. As well as extra time, participants often talked about feeling cared about and the positive impact that had on their ongoing relationships. It also seemed that peers, through having to consider the new difficulties experienced by their peer with cancer, had become more empathetic and this had improved some relationships.

P: my sister's been like coming up more to see me and like make sure I'm okay and that, she gives mum a break kind of thing, like she can go home and she'll stay here for a night or so, and she like, she's been a lot more, because we always used to argue and she's been like weirdly friendly with me kind of thing...

[Laughter]

P: ...but it's kind of nice, like we do things as a family more now - Nicola T1 696-707

P: not just family as well, it's also my friends from like my swimming club. They're always like 'will you come out and catch up?' so it's really brought loads of friendships and family together – Robert T1 250-252

P: It was, some of them it made it stronger...

S: Okay.

P: ...friendships, yeah. And then the others just kind of stayed the same. – William T3 558-564

Pre-diagnosis peer groups also provided an environment where some participants felt more comfortable using humour to make light of their cancer experiences and to laugh at something that was otherwise very serious. It seemed that it was difficult for them to do this with parents, education staff or some medical staff, but with peers it felt more appropriate. Humour surrounding cancer seemed to provide a way that some of them could integrate the two versions of themselves as a young

person with cancer and a normal young person, which made their experiences more accessible to their peers. Being humorous was also the most commonly reported coping style in the A-COPE data.

P: And it's like I'll put funny stuff on Facebook like... the other day... we put.... 'look at my hair... my hair is a state and don't even get me started on my eyebrows because they're out of control!' and everyone was laughing at me through that! - Alanna T3 288-292

8.5.2 Different perspectives between participants and parents

Some participants reported differences in perspectives on their cancer experiences between them and their parents. This dynamic could be difficult for participants as they tried to cope with being a young person with cancer whilst calibrating their experiences against the perspective of their parents and families.

The dynamic between Hayley and her mother, who was present at all three interviews, was interesting. Their relationship seemed very good and her mother was clearly very supportive of Hayley, but it was clear that they had different approaches to coping. Hayley was generally very positive despite having times when she said she felt anxious or upset, whereas her mum was a lot more anxious about the potential for things to go wrong. Alongside this difference in outlook, Hayley, especially as she moved through the time-points, became increasingly focussed on the future and looking to incorporate her cancer experiences into her life and move forward for a fresh start, whereas her mum regularly referred to how things used to be and getting back to that previous version of normal. This difference in perspective was something they became increasingly aware of throughout the interviews and they acknowledged the benefit that Hayley's attitude had on them both.

P: Yeah, mum was like 'oh my God, she's going to just fade away, it's all going to be doom and gloom from now on' but I was just like 'I'm going to get better, it's fine'. Because when I first got diagnosed...

P1: I think she's kept us all as positive as we can be, if she had been really... if she'd felt like I felt we would just be a shrivelled up mass in the corner somewhere! But yeah, thank God she's been so strong really. – Hayley and her mother T3 332-337

In the extract above it seemed that Hayley's mother was benefiting from the positive outlook that Hayley developed during her treatment. However, the transference of perspectives could go both ways. Mario discussed at length his concern about the potential to contract infections when returning to school and that this was a major factor preventing him attending school and reducing his interaction with his peers. In the extract below he presents a photo of his mother and immediately describes her

concern about infection risks. Although this concern was clearly protective from his mother, it appeared that he had internalised her concerns and this developed into a serious concern of his own.

P: I think we've got one more, just my mum doesn't want me to go to school.

S: Oh OK, this is a picture of your mum.

P: Yeah, just risk of infection.

S: OK, so is she... she doesn't want you to go into school?

P: Just because... I think she doesn't want anything to get set back and she wanted to get... to make sure I get over it as quick as I can.

S: Do you agree with her or...?

P: Yeah, I think I do... I know that I've like seen friends, like seeing them outside of school quite a bit, but I just don't want to get like an infection. That's the last thing I want. – Mario and his mother T1

289-297

This difference in perspectives continued into post-treatment life for Robert and his mother. After completion of his treatment Robert was happy to quickly put his experiences as a young person with cancer behind him and move forward into Sixth-Form for a new beginning. However, his mother needed more substantial closure to these experiences. This was highlighted by their differing attitudes towards attending a MacMillan survivorship talk. Robert did not feel any need to attend, but his mother felt it would be important for both of them. Robert did attend, but only to support his mother. It seemed that there was a difference in the timelines for adjustment experienced by Robert and his mother.

P: I think she wanted closure but I thought I was alright with it 'cos I thought, done it, let's just forget about it and move on but she wanted closure for it, understandable really. - Robert T3 14-16

Nathaniel and his mother also expressed differences in their timelines for adjustment that continued after the completion of treatment. Nathaniel wanted to forget about his experiences as a young person with cancer and go back to normal, which fitted with the 'paused-life' approach to adjusting to his cancer experiences that he demonstrated throughout his interviews. In contrast, his mother wanted to reflect upon what had happened in hospital, especially when they returned to the hospital for the second time-point interview having not been there since completion of his treatment.

P: I'm not the same as you, I always want to forget it more than you. – Nathaniel T2 289

The presence of cancer in the lives of participants clearly had an impact of their relationships with peers and parents. The interactions and dynamics between their various peer groups and family

formed part of an ongoing calibration and construction of how participants viewed themselves and their changing circumstances.

8.5.3 Independence, control and mastery

Participants were in a difficult position regarding their ability to be independent and autonomous whilst facing an increased degree of fragility and reliance on others. The physical effects of cancer and treatments meant that they often had to rely on family, friends and a wide range of professionals for assistance in their everyday lives. Participants were less able to attend school or to socialise independently with their peers and therefore missed out on these areas to be young people away from the presence of adults. The independence of participants was further affected by a change in the way they perceived everyday events like eating and drinking, and where they would go to spend time. This seemed to add a degree of constriction to their lives and, as shown in the extract below, it was difficult for them to remain independent and spontaneous.

P: Yeah. And then like when we go out to a restaurant like I've got to say 'oh is it a reputable place? Like, is it a good standard?'...It's really difficult, I have to check them or wash them and really be hygienic about food and where it comes from, if I can have it, if it is safe for me to have it, stuff like that. – Robert T1 347-352

Some participants seemed happy to relinquish the majority of their independence and let other people help and guide them through their cancer experiences. This tended to be an approach that was more prevalent in the younger participants and in those who adopted a more 'paused-life' approach. As one of the participants that seemed to express herself in terms of this approach Patricia said "I don't think I thought much" (T3 240) when responding to questions about what sort of things she thought about when she was in hospital. Patricia said that some of this was because she was "too tired to think" (T3 236), but a passive approach was a consistent theme of her hospital experiences. Relinquishing independence because of hospitalisation was not always an acceptable part of the experience for participants. The extract below from Faisal showed that his experience of hospitalisation limited his independence of movement and altered the way he could interact with others.

P: Yeah, because like I know we used to, like in hospital...argument here but whenever he does, he always like, like runs off before we've finished arguing, before we can resolve the matter he just like sort of wanders off and I can't wander off because I'm stuck in hospital and everything – Faisal T1 370-373

For all participants there were periods during their experiences when they had no option but to become more dependent on other people. This was often linked to reduced mobility and physical

capacity to do things for themselves. For those participants that wanted to be actively independent and maintain an active approach towards their adjustment, this enforced dependency could result in real frustration. Alanna was very active in her approach to her illness and wanted to engage in every aspect of herself as a young person with cancer and the adjustments that were needed between the other versions of herself. Therefore the enforced reduction in her independence lessened her ability to do this and was reported as some of the most difficult times she experienced.

P: Pushing myself and being in it because you... you sort of at the beginning feel like... sometimes you go all... and crying and you start feeling helpless because you can't walk, just like 'yeah I've got to sit in a wheelchair and I've got to get pushed' so it does... you just feel sad because you can't do anything yourself but... like I can't bend my leg at the moment, I can't dress myself, I can't put my pants on and things so my mum and dad have to help me, that keeps getting to me a lot that I can't dress myself and I have to have someone with me all the time in case I slip, so it's stuff like that you've got to have somebody all the time, that's hard. – Alanna T3 903-910

Participants often maintained a desire for mastery and control in their lives despite the difficulties imposed by their diagnosis. The degree to which they could control their lives had diminished with their diagnosis of cancer and the influx of protocols and professionals, which provided a structure to their lives that they did not generate themselves. Alongside this reduced control, participants were less able to engage in areas where they had previously experienced mastery, such as education, sporting activities and social interactions. Participants who talked about being more actively engaged in adapting to their cancer experiences tended to seek new areas where they could regain some control and experience some mastery. Participants often expressed losing some degree of control over their bodies due to the effects of treatment and illness. Altered mobility, hair loss, skin rashes and weight changes all affected the way that participants viewed themselves and perceived other people to view them. In the extract below Robert expressed his desire to have his “body how I want it to be”. Robert showed a desire for control over his own body, but also to maintain this control despite the input from family and friends, who regularly told him not to worry about it while he had his treatment.

P: I just... I don't know, I've always had this thing that I don't... I just like my body how I want it to be so like if someone goes 'oh..', I know when I put weight on I can tell, I'm like 'no, I need to lose it' so I'm always like trying to eat more fruit or I try to do more exercise and stuff like that. – Robert T1 209-212

Some participants seemed to counter this reduction in control over their body by taking on their own body as a project and working at repairing themselves and rehabilitating incrementally. Part of this process for some participants involved acquiring a degree of mastery through understanding their illness, as well as the functions and outcomes of their various treatments. This seemed to help them

gain some control over the experience, but also the improved mastery gave them the confidence to talk about what was happening to them and to feel that they could contribute to decision making.

P: And they give you this pack, I read through it and I read through it again and again and then I got my head round it, because I helped everyone else didn't I? Because they'd go 'well what is it?' and I'd go 'it's an osteosarcoma, it's in the bone' and I explained what operation I'd have if I was having it and what they needed to do and everything – Alanna T3 146-149

In the extract above, Alanna demonstrated this desire for mastery. This process seemed to give her a sense of power and pride in feeling that she had managed to achieve a level of mastery within the complicated medical environment and with complex medical information. In the extract below, she described using this feeling of mastery to make decisions about the level of drugs she was receiving.

P: Yeah. if I took control of it and knocked myself down I'd be fine, if someone said 'right you're down now' they don't know how I feel, I could be in absolute agony and they'd say 'right we're going to knock that down because you don't seem too bad', 'well no, it's under control'. – Alanna T3 1026-1030

It was not always easy for participants to remain central to their own experiences, as information and decisions sometimes appeared to be happening around them rather than directly including them. It seemed that this was acceptable to participants when they did not believe they could have useful input or it was not an important issue to them, but was very frustrating for them when they wanted to be included or felt that they were being overlooked. In the extract below, Nicola described being given different information to other people about the potential for her to have an amputation. In the context of a timeline with reduced engagement in education and limited opportunities for potential mastery, being excluded from decision making processes about her own body seemed to be even more unacceptable.

P: No, because when I first went for my consultation, like when I first got diagnosed, it was before my biopsy, I went to one of the doctors, my consultant who was going to be doing the surgery, and one of the first things he said was, "You won't lose your leg", and apparently, to everyone else that I'd spoken to he said, "There's like a chance you could". So my mum was like really, really annoyed about it. – Nicola T2 43-47

However, not all participants talked about seeking mastery and control over their medical experiences and there was sometimes a sense that taking on responsibility for self-managing aspects of their care was a responsibility that they were not all ready for. In the extract below, William showed that he felt the responsibility for managing his medications when returning to school. This was amplified for him

because he attended a boarding school and would therefore be responsible for his medications for more extended periods of time.

P: Well if... when I go back to school I have to probably do that all myself, like sort it out myself which is quite a big responsibility – William T1 53-54

8.6 Being a young person in education

8.6.1 Regulation and calibration

Based on the interviews with the participants, school was an important environment to develop and maintain an idea about themselves and a sense of their value. Seeing themselves reflected back in the reactions of peers and teachers to their behaviour, opinions, appearance and achievements provided an ongoing gauge through which they could adjust their developing ideas about themselves. This was present in the interviews with participants post-diagnosis and would seem to also have been a part of their pre-diagnosis school lives. The regulation and calibration possible within the school environment developed their version of themselves as a young person in education through school work, exams and school routine, and themselves as a normal young person through interaction with peers and the school community. Missing time from school because of illness and treatments meant that participants were not as immersed in this ongoing regulation and calibration. The following sections will detail the experiences of participants as they tried to maintain engagement with their education and the regulation provided by this area of their lives.

8.6.2 Maintaining school work when absent from school

When participants were not attending hospital or attending school they had two primary options for maintaining their education; home tuition and independent learning. The idea and experience of having a tutor working with them at home was viewed in a variety of ways across participants. Some participants clearly did not like the idea of being taught at home and this sometimes resulted in a lack of engagement with this service. These participants felt uncomfortable with a stranger coming into their home and working so intimately with them in a one-to-one capacity. In the extract below Hayley described that the problem with home tuition was not knowing the person and that her focus then shifted from the work itself to the dynamic between them.

P: I think I get worse when it's somebody that I don't know. Like I get really nervous and I don't... I'm more conscious about what I'm doing and stuff than actually learning the stuff. – Hayley T2 117-118

Home tuition and independent learning could not replace all of the work covered in lessons. Missing time from classes meant that a lot of participants were missing out on the more fluid parts of their

lessons and the ability to interpret the lessons in their own way. In the extract below, Alanna described having to prepare for an exam without all of the information because she had been absent for lessons and the content of these lessons was not represented in the textbook.

P: All I had was a book to read and my memory from a month, two months, before to do an exam and there was stuff in there that she'd never taught me and I had to work it out for myself because they taught it in the lesson but it wasn't in the book or anything – Alanna T3 470-472

Robert described the fluidity of understanding that was present in his lessons, and how both the students and teachers would constantly adjust the way that information was presented and shaped in order to facilitate understanding. It was difficult for participants to replicate this fluidity of learning.

P: it helps to like jot down notes which they think will benefit us or like if there is something on the board that the teacher gets but we don't we change it to like how we understand it, or write it how we understand it – Robert T1 186-188

For some participants the idea of doing school work at home or in hospital was difficult, which prevented their progress when they were not able to attend school. It seemed that this represented a blurring of boundaries between themselves as a young person, a young person with cancer and a young person in education. This blurring of boundaries seemed to stem from identifying each self as belonging to a different environment, i.e. school is for schoolwork, home is for normal life and hospital is for treatment. Patricia was one of the participants who did not like working at home and this seemed to pre-date her cancer diagnosis. This perspective made it more difficult for her to maintain progress through her education timeline as she had long periods where she did not attend school or access home tuition services.

S: No, ok. So, do you think you'd like to have a tutor at home? How do you feel about someone coming round and doing some work?

P: Probably not at home, but in the hospital.

S: So, does it feel strange the idea of someone coming to your house and doing some work?

P: No, I just don't like doing work at home. - Patricia T1 186-190

Many participants, like William, found that they struggled with their motivation to engage with school work when at home, and this was often attributed to fatigue and reduced concentration, rather than the inappropriateness of working at home.

P: I tried to but I just couldn't, couldn't be, no I just couldn't do it, I don't know.

S: Okay.

P: Yeah, didn't feel like it – William T3 195-199

8.6.3 The regulatory importance of exams

Exams, coursework and grades placed an arbitrary yet tangible value on the abilities of participants. Participants often talked about their grades and reports in a way that suggested these external verifications were important to their idea of themselves as a normal young person and to their ideas about how others perceived them. In the extract below, the idea of continuity of reputation for herself as a young person in education seemed very important to Alanna. A mistake had been made and she had received lower grades than she was expecting, but she worried about the impact this would have on her reputation in the future.

P: my grades, they're really important to me because obviously I was starting my GCSEs that year, I started with GCSEs a year earlier, and I did my GCSEs this year so...

S: So yeah, I mean that doesn't make you...

P: Because if they look back on that and then saw that [bad report] and not knowing what had gone on that year thinking in year 9 'oh she messed about, she got messy, she was predicted an F and now a U in history' it wouldn't have been very fair on me. – Alanna T3 513-519

All of the participants that were due to sit G.C.S.Es managed to sit the majority of these exams, only missing exams that were in subjects they perceived as a lower priority. These participants managed to sit exams in school for the most part, but they usually had the option to sit exams at home or in hospital if they needed to. Participants had not always received their exam results during the period that they were in the research, but the overall feeling was that they had not achieved the same level that they would have done without their cancer experience. Missing their exams would have been a situation that was understandable in the context of their cancer diagnosis and treatment. One reason described by participants for sitting their G.C.S.Es was the importance to the education timeline. Sitting exams in the present reduced the amount that they would need to re-sit in further education and therefore enabled them to more easily move through their education timeline with their peers. Mario had this timeline factor in mind when sitting his G.C.S.Es and had clearly thought about the impact of his present actions on his future self.

P: The only thing I've got to catch up on is the bit that I missed at the beginning of Sixth-Form so I'm just going straight on to A levels really, and just carrying on with everything because I caught up on my GCSEs as much as I could. So now it's just made it like a lot easier. – Mario T3 244-246

Beyond just the timeline impact, the importance of exam results and achieving grades was shown in several participants who sat their exams despite significant health obstacles. As well as the health difficulties, participants were all given guarantees that they would be able to continue in their education timelines regardless of having sat these exams. Therefore, they were presented with a framework of circumstances that removed the pressure to sit their exams. However, participants in this situation often expressed frustration at the potential of having to repeat exams in further education and the feeling that they would have wasted the previous work they had completed and the time they had invested. It appeared difficult for participants to let go of the well-established idea that they needed to do well in their exams. This need to still do well in exams seemed to be due to the regulatory aspect of receiving grades, especially for participants who were used to a high level of achievement, and the importance this level of achievement had for their idea of themselves. Even with the removal of most of the external pressure from professionals and parents to sit exams, even less to do well in exams, participants often retained a sense of internal pressure. The two extracts below from Mario and Robert, clearly showed that they were both aware of the removal of external pressure to sit exams, but still felt the desire to “get a good mark”. Robert echoed Alanna’s earlier concerns about ongoing reputation, but also felt that missing his exams would be taking “the easy option”. This fitted with Robert’s general outlook of not letting his illness dictate to him.

S: No, no. Well that’s not a bad thing really at all! OK, well that’s... so does that make you feel slightly better about your exams?

P: Yeah. It makes me feel like I don’t need to get the grades to like get into the Sixth-Form or anything.

S: Yeah. So does that affect the amount that you revise knowing that you don’t necessarily need the grades to get into the Sixth-Form?

P: I’m not too sure because I’m sort of like... not too like... I don’t know much of the subjects because I’ve been out for such a while, it just goes, and I still need to revise quite a bit because I still want to get a good mark. But obviously in the back of my head I know that I have a place in Sixth-Form. –
Mario T1 278-287

P: I remember because I said this to my mum, I said ‘even though I’ve got a place I still want to get good GCSEs’ so I still revised and still tried to get at least my target grades or all passes, so above C or... C and above at least.

S: So... this might sound like a strange question but given the fact that you’d already got your place in college, what was your motivation for still wanting to do well in your exams? Why did you still want to sort of push yourself to do well in those?

P: I didn’t want to like take the easy option and just say ‘oh I’m not going to bother with my GCSEs because I’ve already got a place’, and some jobs do look back at your GCSEs whereas most people say ‘oh GCSEs don’t count for anything, it’s A levels other stuff’, but then there are some jobs that do go

back to your GCSEs to see what you did and how you went on so I thought I might as well still try at least. – Robert T2 409-419

A clear example of the continued importance of exams and exam results for participants came from Mario. During the final time-point interview, when he was able to reflect on taking his exams and getting his results, it was clear that the grades meant a great deal to him. Despite the fact that he did not need the grades to move forward in his education timeline and despite the obvious obstacles that he was able to overcome just to be able to sit the exams including intensive chemotherapy, long periods of hospitalisation and an amputation of his leg, and despite the fact that he achieved some very good grades, he was still very upset at achieving lower than his predicted grades. In his interviews he had very openly discussed his amputation and other sensitive issues, but the following two extracts are the only times he became upset during any of the three interviews and demonstrated the impact that his G.C.S.E results had on him. He seemed to think that the results reflected a lack of effort on his part and it appeared that his perceived failure to reach the standards he set for himself was not tempered by the reality of his health situation.

P: Well the head of the school said I had a spot whatever, but in my actually GCSEs I got A*, A and the rest were Bs.

S: OK, so how did you feel about those grades then?

P: They were quite good, I always thought I'd do better.

S: Yeah. Do you think it would have been... how different were they then you were sort of expecting?

P: Quite...

S: Quite... take some time.

P: They were quite...

S: Quite a bit different were they? OK. So do you want some tissues?

P: It's fine.

S: You just take a minute. Sorry, do you mind me asking you about these kind of things?

P: No it's fine. – Mario T3 213-225

S: Yeah, OK. I was going to ask you as well, do you think there has been any sort of turning points in the last like nine months or a year, any times where you kind of suddenly felt different about maybe school or education or even just like things you have been going through in the hospital? Do you think there's any time where you sort of you know, you've felt bad about it and something good has happened or the other way round?

P: Just my GCSEs really, I obviously didn't put too much work in.

S: Yeah, OK, so that's something that was a difficult time for you then.

P: Yeah (very upset). – Mario T3 337-344

It was difficult to explore the reasons behind this in much detail due to the upsetting nature of the conversation, but it appeared that he had always considered himself a high achieving student and was used to receiving high grades, so the reality of receiving lower grades was seen as a reflection on him and not just as a result in context of his cancer experiences. It could also have been an objective symbol for how his diagnosis had impacted his life and how he was no longer the same young person he had been before his diagnosis.

8.6.4 Routine, belonging and purpose

Some participants missed the structure that the school routine brought to their lives and how the need to attend school motivated them to be active. This regulating routine was something that participants had rarely been without before being diagnosed with cancer and without it there seemed to be a loss of normality and shape to their lives.

P: Besides work, probably just friends, but they have been to see me quite a bit so I'm not too sure what the biggest thing that I've actually missed out on is. Probably just routine of like getting into school and everything.- Mario T3 275-277

Mario described actively missing the routine of education and this was something that was presented by numerous participants, who felt that the school routine “felt more normal” (T2 10-11) as William put it. Nicola noticed the benefit of routine in her life when she had been without it for a period of time following her diagnosis and then was able to get it back later in her treatment. This seemed to help her structure her life and provided her with more purpose to her actions.

P: Yeah, but I prefer it more structured because I feel like maybe I was making excuses before like, and I wasn't pushing myself to like get into school, and I preferred sleeping in in the morning and then going in later, but I think it's better if I get up and like start, if I get up and start getting on with it then I feel better, and like maybe if I'm tired I can have a nap in the afternoon kind of thing, whereas before it was just kind of like, “oh, I'll just sleep all day” – Nicola T1 667-671

Reintegrating into school during treatment provided some participants with something positive that could distract them from their cancer experiences. It also provided them with something positive that they could actively engage with to relieve the monotony and boredom they often expressed related to their treatment and inactivity. It seemed that for some participants, like Nathaniel, having the monotony of hospitalisation and the lethargy that could come with illness and treatment, heightened the appeal of engaging with school.

P: Alright because I'm getting a bit bored at home, I'm getting bored here and I just want summat else to do, like I'd much rather be at school than in hospital- Nathaniel T1 252-253

8.6.5 Communication, continuity and belonging

Participants appeared to want to maintain their school work, sit exams and remain part of the school community wherever possible. Whilst they were unable to attend school to achieve this they relied to some extent on communication with school to facilitate these aims. Participants reported that their communication with school was successful primarily when there was one person assigned from the school to oversee the liaison with them. This single point of contact meant that the participant and their family knew who to go to for information and with questions, which was important in a world that was now increasingly saturated with professionals, appointments and information.

P: Yeah, he's been very supportive like every time he sees me he's like 'are you alright Robert?' just like most of my friends and he's always checking up and he's always saying... say if I had like a coursework deadline he'd arrange something with the teacher and me that would obviously extend the deadline or shorten... cut something out of it to make it more appropriate for me or easier for me to complete. – Robert T1 164-168

In the extract above, Robert described how his main point of contact within school had helped him to arrange his continued education, but also provided a sense care and concern.

P: Well there's some Social Workers and there's loads of people, there's like [Liaison Nurse] and [Nurse] and Social Workers and CLIC Sargent and all sorts.

P2: Yeah. I'm not quite sure...

S: And these are all people from the hospital are they who come and help?

P: There's loads of different people.

P2: I'm not quite sure how they're informed, how much the school's been informed yet. – Georgie and Georgie's mother T1 1025-1034

In this extract from Georgie and her mother, they demonstrated the amount of professionals that entered their world and how they were not sure if any of these professionals had made contact with Georgie's school. In many cases schools were unsure of who had responsibility for the care and communication with the participant and when it was appropriate to make this contact, which resulted in gaps in the education timeline. It often appeared that individual members of education staff took it upon themselves to contact or not contact the participant and that this was not always a systematic approach. It was sometimes difficult for schools to judge when it was appropriate for the participant to attend school. There were often different states of readiness between the participant, the family, the healthcare team and the school, which could lead to frustrating and seemingly unnecessary

precautions and delays in attendance from the perspective of the participants like Hayley for whom “just that one day” in school was very important. This seemed to link back to issues of reduced independence and a lack of ability to be spontaneous.

P: I don't know really, I don't know if they were just... I don't know... like keep treading round it so it's not... making sure it's not too early or something but I don't know really... they just... I think it was more annoying because we just wanted it to be on that day, just that one day to have a few hours at school. – Hayley T1 546-549

Participants were very sensitive to the quality of communication from schools and the extent to which they felt the school cared about what was happening to them. It was not enough for the schools to have communications in place to facilitate their ongoing education engagement, the participants wanted to feel cared about and feel that they were still part of the school community. As Annabella pointed out below, it was not enough to simply get in contact, but the quality of communication that was important.

P: Well the sheet that I've been given has always got a contact list on. Which doesn't really mean that they're very helpful, it just means that they've got in contact! – Annabella T1 547-548

Nicola, as many participants did, was keen to talk about the nice things that her school had done to show they cared about her.

P: And the teachers are really, really good as well, especially my senior tutor, because it's actually the first time he's, like been a senior tutor, it's only his second year in the school, and he's had to like deal with me [laughs]. So, but he's been really good, like he keeps ringing up and stuff, and like the school sent me flowers after my operation, so that was nice, and my old school sent me flowers as well [laughs]. – Nicola T2 434-438

Whereas for Georgie, the perceived lack of care from her school when she was diagnosed had an ongoing effect on her view of support from them.

P: I don't suppose they really care and Mr [NAME] the Head Teacher, I've never met him and I've been there for years.

S: Okay. Would you like it if they got in touch with you more like just to see how things were going?

P: Not really because they weren't very interested in the first place so. – Georgie T1 1356-1370

This feeling of being cared about was also discussed by participants as an important factor in relation to the warmth of welcome back into school. Amongst all the educational practicalities and cancer

related concerns and adjustments, this basic warmth of welcome was an important factor when it was present and damaging when it was absent.

P: she came running down the class going ‘oh Alanna, Alanna, Alanna!’ and she gave me hug... and she didn’t even teach me that much that year – Alanna T3 688-689

8.6.6 The perception of changes in appearance

Alterations to the physical appearance of participants were regularly cited as a cause for concern when reintegrating into school. School was an environment where physical appearance seemed to be in much sharper focus than in the environments of home, hospital or community. This sharp focus heightened the difficulties and anxiety experienced by participants when calibrating their appearances with the reactions they received from peers and professionals. Hair loss, weight change and skin rashes, were all felt more acutely in the school environment by the majority of participants and this seemed to be a combination of what they thought about their appearance themselves and what they imagined others would be thinking. In the extract below, Georgie seemed to think it would be inevitable that others would wonder if she was wearing a wig. This perception was not based on any previous experiences or comments and seemed more like a projection of her own anxiety about how authentic and convincing her wig appeared.

P: people obviously are going to say “oh I wonder if she’s got a wig on” because everybody would do that, I’d do that, just wonder.

S: Yeah, so you think people would be wondering if you’ve got a wig on?

P: They’d wonder, wonder, I would wonder – Georgie T1 1015-1020

Robert had a similar perception that it would be “obvious” that somebody would say something to him about his hat, but this only seemed to be a concern for him within school when he was not protected by his friends or people who knew about his health situation. Similar to his issues with receiving questions from peers, there appeared to be a cumulative element to his concern about the attention his hat might draw within school.

P: At home I don’t wear a hat because obviously I don’t feel the need to but in school... sometimes in lessons I’ll take it off because I’m surrounded by my friends and like people who know about it, but I won’t walk around the corridor with no hat on because I know that someone will obviously say something and if they did yeah, I’d be like ‘fine, whatever’ but if it carried on I think it would eventually start bothering me. – Robert T1 136-140

In the final extract below, Mario tried to play down his concern about his skin rash, but did acknowledge that he would have been “really conscious about it”. Physical appearance was a clear intrusion of the young person with cancer into the normal and education lives of participants, which was challenging for them to mask if they wanted to and difficult not to project their anxiety onto what others might be thinking of them.

S: So that kind of having a rash all over you and thinking about the way that you look, does that make a difference for going into school?

P: Yeah it would... it's not too much of like a big deal but it obviously would yeah. I'd obviously be like really conscious about it and everything – Mario T1 89-90

The issue of wearing wigs and/or hats when reintegrating was difficult for some participants, who were often concerned about how realistic wigs appeared and whether teachers and pupils would draw attention to them or try to remove these items. Participants again varied in how they coped with these physical changes, with some wanting to avoid reintegrating into school at all until issues had resolved and others seeing it as a challenge and an opportunity to demonstrate their confidence and positive coping. This was demonstrated in the extract below from Robert who, despite his initial concerns about the reactions of peers at time-point one, embraced his status as a young person with cancer and was “proud to be bald” by time-point three.

P: Not really 'cos all the way through when I had it in main school I like, I were proud to be bald, I didn't really care about that – Robert T3 373-374

It also seemed that participants were more worried about their appearance at school than in other environments because of the potential attention and reactions of peers who were not their close friends. This was reminiscent of the attention described in the earlier telling and knowing section regarding reintegration.

P: Because I think maybe they [close friends] understand it [hair loss] a bit more, because you probably talk to them more about it or yeah... and then your sort of friends but not as close friends, they don't really understand it as much because you know you haven't talked to them as much about it all – William T2 146-148

William explained in the extract above, that the anxiety surrounding the wider circle of peers was due to the perception that they did not understand his treatment and why he had lost his hair. Following on from her extract above, Georgie compounded her concern about what others might have thought of her wig with her fear that “somebody might try to grab it” (T1 1014).

Outside of the issue of hair loss, participants had interesting perspectives on the adaptations they needed to use as they reintegrated into school life. They often worried about how others would perceive these adaptations, not simply in how they looked, but also in whether they were justified. This concern was primarily related to adaptations for mobility issues. In the extract below, Nicola worried that her intermittent need for the support of crutches would be perceived by her peers as attention seeking behaviour because there was no externally obvious need for them.

P: the crutches I guess because like I don't have my leg in a pot or anything, and it doesn't look like I've broken it and like I'm still walking on it but I'm taking weight off it but then like sometimes I can just dump my crutches down and I'll walk, so then I think people are like, "what an attention seeker!" kind of thing.- Nicola T1 273-276

Mario had taken a photograph of his walking stick, but in the extract below, clearly was playing down his need for the use of it. This was an interesting contrast between feeling it was an important enough issue in his life to record it and bring it to the interview, but then playing down the need for it.

P: This is just obviously this... I don't really need it but I just use it for safety.
S: So that's a walking stick.
P: Yeah, it's my walking stick, I just take it to school just for safety just in case I was to trip or anything like that.- Mario T3 89-92

In contrast to the others, there was one participant, William, who said that he was more self-conscious in the community, because in the school environment everybody knew him and knew his situation, but in the community people did not. The amount that people knew about and understood his situation was very important to William and something he referred to regularly. William was a participant who consistently reported his school as a very supportive environment and this sense of support may have been enhanced by the fact that he attended a boarding school and therefore pupils were living in a school community all of the time.

P: I don't know. I think because when you're out and about in town no-one knows what's happened, they just, but in school people know what's going on, they just know you like, yeah. – William T3 538-540

Nicola raised an interesting point about her observations of the generational differences in perception of amputations and changes in appearance. She believed that because of the positive coverage in the media of the Paralympic Games and the difficulties faced by returning soldiers, her generation was better prepared for coping with the sight of amputations. Her experiences seemed to support her views

and she noticed that it was younger children and adults who tended to stare at her after her amputation, but that her same age peers were more accepting.

P: I think it's, like the generation I've grown up with, like, rather than like what my mum had, because, obviously, like in her day it's like, it was like people with diabetes and, like smokers that had, because they had such bad blood circulation they had to have the amputations, whereas, like I've grown up with the Paralympics and like young people and like soldiers and all of that, so, like, all along I've been, "Well, now I can be a Paralympian, I can get my blade, I can go running, I could be rowing or whatever" – Nicola T2 58-64

P: Yeah. Like, it tends to be, when I go out, like, obviously, you can see that I've got a backwards foot, kind of thing, and, like the young kids, they stare a lot because, obviously, they don't know any different, and then it's like older people that stare, but, like my generation don't tend to stare. – Nicola T2 67-70

8.7 Special consideration vs normality

A fundamental concept that appeared to underpin the interaction between the different forms of self experienced by participants and their location on the various timelines and in different environments was the tension between the desire to be treated normally as a young person or a young person in education and to have special consideration as a young person with cancer. Participants in this study often expressed wanting to be treated normally when returning to school, but then found it difficult and upsetting when their cancer experiences were not taken into account and adjustments were not made in the way they were treated. However, the participants often contradicted themselves in this area, moving between the two ends of this scale at different times, with different people and in different environments, sometimes simultaneously wanting to be treated as a normal young person and considerately as a young person with cancer. The fluidity of the positioning of young people on this scale seemed to be connected to which version of themselves they perceived to be dominant at the time. The extracts below from Alanna and Nicola typified the desire not to be treated differently, but at the same time to be treated with consideration.

P: I wanted them to not be exactly the same with me, I wanted them to sort of... sort of be responsible, normally they're quite crazy and weird. Like not feel sorry for me or anything but be more thoughtful but still be their normal selves. – Alanna T3 254-256

P: I don't want people to treat me differently but I'd rather them know so they're not like aggressive with me kind of thing and they don't knock me. - Nicola T1 204-206

Participants regularly expressed the desire for their peers in particular to treat them as a normal young person and not as a young person with cancer. This appeared to reflect the interaction that they had with their peers where they shared what it was like to be a normal young person. These interactions were complicated by the presence of the self as a young person with cancer that was not shared with their peers. The extracts below all demonstrated the desire to be treated normally and not differently because of their diagnosis.

S: Do you... I mean how does that make you feel? If they're treating you just as normal? Because I know that some people can treat people differently when they're not feeling very well, and how does that make you feel that they treat you like normal?

P: Good because they're not just being quiet and that

S: So you said you liked seeing your friends when you went into school. Do you worry at all about what your friends will react when you go into school or how other students will react when you go into school?

P: No, because nobody has treated me any differently at school – Patricia T1 212-217

P: they just saw me as I was before I got diagnosed so I was happy about that, because I didn't want anybody treating me differently because of what I'd got. So I'd said that, I said 'don't treat me differently because I don't want to be treated any different' – Robert T2 197-200

As in her previous extracts, Georgie focussed on “doing normal things”, and her search for normality within the context of her cancer experiences was present throughout her interviews.

P: My friends will all be there and we'll be just like doing normal things – Georgie T1 979

When reintegrating into school, participants seemed to find it difficult when education staff did anything to highlight them as different from other young people in education in front of their peers. For example, when Hayley was learning about cancer in a science lesson, the teacher was unsure how to cope with this in relation to her status as a young person with cancer and this was difficult for both of them. The teacher tried to acknowledge the situation by asking her for help with the subject matter, probably in an attempt to acknowledge and make light of the potential tension, but this brought Hayley's status as a young person with cancer into the foreground in an area where she wanted it be in the background or not present at all.

P: Yeah, it's like 'if there's anything that I'm saying wrong just tell me and I can like adjust it' and I was like 'oh OK, I don't really know what...!'

P1: I think he's finding it harder than anybody isn't he? Because he's... I think he's scared of saying something that's going to hit a nerve and maybe upset her.

P: Like he'll say stuff and then he'll like go really quiet or like start stuttering, it's awful! 'Please don't you are making it worse! Just stop it!'

S: So you think that he's nervous about saying the wrong thing.

P: Yeah.

P1: He's very aware of your presence isn't he?

P: Yeah (inaudible) 'stop it's getting worse!'

P1: And you sit right at the front of the class with him and it's like...!

– Hayley and Hayley's mother T3 249-259

Despite the desire of participants to be treated as a young person in education, their situations often necessitated some form of practical special considerations, like being allowed to work in different areas of the school, having classes moved to new locations or being able to wear different clothing. This type of practical special treatment rarely resulted in any problems for participants when it was addressed in private and planned in advance. In some cases it was seen as a privilege or an appropriate and welcomed consideration. In the extracts below, Nicola and Robert both reported examples of these practical allowances. Nicola seemed to appreciate having a separate area to work in that she had some control over. Robert realised that the allowances made for him were different from those of fellow students.

P: My senior tutor has also offered me like his room that I can like just go in there and I can work in the corner because there's like this corner bit and it's like away from the classroom and he says I can work in there... I can bring friends in there as well – Nicola T1 471-475

P: on some occasions I was allowed to wear jacket over if I did feel cold whereas other students couldn't do that – Robert T2 251-252

Those participants that sat exams during this period of research were often allocated a level of special consideration in the form of adjustments to their grades, extra time, separate areas to take exams and having somebody to scribe for them. Having a separate area to sit exams was often helpful for participants because it gave them more flexibility to take extra time and to access help that they might need, without the embarrassment of drawing attention in a busier exam room. However, it was often the case that these areas were also used for other students with a variety of health, educational and behavioural difficulties, and participants did not always feel comfortable in this environment. In the extract below, Hayley described being grouped with nervous students and "people that caused trouble". It was unclear exactly how she felt about this experience. She was pleased to not be in the main exam room, but might have felt that her health situation did not fit with the problems of the other students she was now grouped with.

P: Oh yeah, yeah. Like instead of being in like that main study hall, where there's like loads and loads of kids, I just got put off to one side. I was put in like a room with like the fidgeters, and people that cause trouble

P1: All the nervous students and things...

P: All the ones that cry all the time! So but... it was alright... they didn't seem to...

P1: You felt quite normal in that room didn't you! You are the one going through treatment and cancer and everything and they're just crying because they're dreading their exam! It's like 'get a grip!'

– Hayley and her mother T2 502-509

The majority of participants cited mobility around school as a concern for reintegration. This seemed to fall into two categories of experience; practical concerns about access, and concerns about special treatment and appearance. Participants often had mobility issues because of temporary fatigue or pain, and in some cases because of more permanent surgical procedures like amputations. Access around schools was often difficult because of stairs and the distances that young people had to cover when moving between lessons in crowded and hectic corridors. The adaptations that participants had to make were usually more of a concern than the access itself. Participants had to make use of crutches, wheelchairs and lifts, which highlighted them as a young person with difficulties and brought with it increased and unwanted attention. Special consideration that related to the physical abilities of participants and their altered needs related to health sometimes highlighted participants as physically changed. This made some participants feel that their status as a young person with cancer was being brought too much into the foreground. There appeared to be a very fine line between successfully accommodating the changing needs of participants and doing too much to draw attention to these changes. The extract below from Nicola, showed how the school had made every effort to accommodate her mobility difficulties, but this was not something that she wanted to take advantage of because she wanted to appear as she had previously been and was not ready to be treated as “disabled”.

P: But like they've registered my card to the lift and also at the side gate, so mum can get, like drive round the back, but I just think that, like, because I don't want to be treated any differently. Like I hate it when people like, like treat me like I am disabled kind of thing, so I'd rather like use the steps than the lift.

S: So you don't want to be treated in that way when you go back to school.

P: Yeah, which is why I don't want to go in much without my prosthesis, because it's not that I like don't want people seeing me with this, it's because I like want to use the steps- Nicola T2 609-615

Communication with school was highlighted as another area where special consideration of participants as a young person with cancer was needed and not always present. When communication with school was inaccurate, badly timed or absent, the impact on participants could be acute. It

seemed as if schools struggled to always inform all of their staff about the health situations of participants, which sometimes led to them being treated unfairly or without due consideration within school. In the extract below, Nicola described an incident when her unique status as a young person with cancer within school was not understood and therefore she was answerable to the same rules and boundaries as other students. She attributed this to a lack of knowledge of her individual circumstances.

P: I was signing in three minutes early and...he was having a go at me for signing in early because like I went to my registration room and no one was there and I hadn't been there the day before and I was like, "oh, I don't know where anyone is, I'll just go and sign in at the office", so I went up there and it was three minutes until the buzzer was going, so he was like having a go at me for that but I think like if he knew who I actually was I think he'd understand more. - Nicola T1 402-408

A major problem with communication, which manifested itself in a variety of forms across participants, was examples of participants and families receiving communications from the school that were generic and untailored to the specific situations of the participants as young people with cancer. Hayley received a letter saying that she needed five G.C.S.Es to achieve her place in college and this contradicted her previous understanding of the situation. This letter from school was unsettling for her and seemed to reapply pressure for her to sit her exams that had previously been removed. In an already turbulent time, this type of inconsistency was not helpful for her.

P1: We got that random letter didn't we, saying that you needed five GCSEs...

P: Yeah that was a bit scary!

P1: So that put a lot of pressure on her because she was thinking 'I don't even know if I can do one, let alone five!'

P: Yeah of C and above." – Hayley and Hayley's mother T2 54-58

Alanna had received several phone calls, letters and texts asking her and her parents to justify her repeated absence from school. The school had been informed of her cancer diagnosis and it seemed as if these were automated communications that had not been deactivated for her. Unfortunately the school had also not contacted her to show their concern for her, which was a situation that was upsetting and frustrating for her and her family, and was exacerbated by the generic communications.

P1: No I got the text that basically said 'for the parent of Alanna, could you please contact us and let us know why Alanna's not in school and when you expect her to be returning' and I thought we've been through all this with the school I was so mad, you know, so I actually phoned the school and I said 'I want to speak to someone, I want to speak to the headmaster....I said 'from January to now which is

end of March/April', I said 'not once have you been in touch, to say 'how is she doing?'' – Alanna's
Father T3 435-450

Alanna also received a school report that did not show special consideration for her status as a young person with cancer and was a real source of upset and anger for her and her family. In her interview she described this situation in considerable detail and regularly used the word "hurt" to describe the effect this report had on her. In the extract below it was clear that the comments she reported from her teachers were not reflective of her special circumstances or the efforts she had put in to continue engaging in her education. It also seemed that where comment sections were left blank reflected the void in her education timeline to an unnecessary extent. This extract also reiterated the importance to participants of a feeling of care coming from the school. In context of the previously discussed importance of continuity of reputation expressed by Alanna, the effects of this school report were even more damaging to her and her feelings towards school.

P: But just before the meeting we got my report didn't we? And that hurt me.

S: Yeah, so tell me about it, I know you've told me before but just tell me about that again, about the report.

P: Well some of the teachers, about two or three of them acknowledged that I'd been off school due to an illness, one of them put 'Alanna's not been in school due to an illness' the other one put that I hadn't been in so she can't make realistic comment on my work, but then a couple of teachers didn't put anything, they just left it blank, not even put... one of them put 'I hope you are getting better' not one of them... some have them had put nothing. One of them just put blankly, 'Alanna has not attended school'. And then I'd been... in ICT I think it was, I'd been working at a... I did my exam, I did it in January, all through my chemo, I did it in hospital and I got a C, well they put on an expected grade for the end of the year an F! – Alanna T3 455-465

Robert was another participant who received warnings for missing lessons because of hospital appointments, and this occurred after he had completed his treatment and was in Sixth-Form. This showed that communication still needed to be considerably tailored to their special circumstances when participants were in the follow-up stage of care. A similar experience occurred for Hayley and in both the extracts below there was a sense of unfairness that came through. Robert felt that it was unfair that he was sanctioned for missing lessons because of a hospital appointment and a lesson clash, whereas, it appeared that Hayley felt that it was unfair that she had not been given enough time to readjust to being a young person in education and to build up her knowledge and skills in college before being told that she might not be good enough.

P: they automatically put me into like a category where they expected me to be there all the time, like a normal student but 'cos I think in that, in my Sixth-Form they insisted like if you miss a lesson you get

a stage one referral and if you miss it again it's stage two and due to drama I had to miss a biology lesson and then like the next day I had to miss 'cos of a hospital appointment and I came back and they said, "Oh you've got a stage two," and I'm like, "Okay, why?" my mum comes in about that 'cos she thought it's not really fair that you had to miss drama and also hospital, like it's not my fault that I had to miss it. – Robert T3 289-296

P1: I think you found that biology blip quite upsetting originally didn't you?

P: Yeah I was like 'I've done rubbish at biology' yeah and like a few of my... they were just like mini tests and there was this... I did bad in half of them and I got like A's in the other half so I was just like 'well what am I doing wrong?!' like in psychology I got a D in one of them but I got an A* in the other one and I was like 'how have I done that?!' and they were like... they were saying to like the whole class, not just to me, like 'if you've got below a certain grade', and I was below it on some of them, like 'why are you in college? Why are you in Sixth-Form? What are you doing with yourself?' basically saying stuff like this, 'this is the only like...'

P1: Which was horrid.

P: 'This is only like a few weeks into the college and if you're doing bad now what are you going to be like later?' and I was sitting there thinking 'oh my God!' and then you cried and then I cried!

P1: Yes going back, that was like 'yeah, new start now let's go' and then within two weeks of being told 'well why are you here? You are not getting the grades' and you were just like thinking 'well I haven't been at school for like eight months, I've done my GCSEs and...' – Hayley and Hayley's mother T3 901-916

There was variability in the extent to which the extra attention received as a young person with cancer was a positive or negative experience. The previous sections detailed some of the negative aspects and anxieties associated with special consideration. It was true that some participants found being brought into the foreground embarrassing and difficult to cope with, whereas, others seemed to thrive in the increased attention. Alanna seemed to thrive in the extra attention received from peers, and most of this attention was positive. The extract below showed that her peers enhanced her belief that she was "strong" and was coping successfully with her situation. It also seemed that the awareness of her strength from more distant peers was something that she enjoyed and possibly linked to the importance of her reputation.

P: A lot of people from my school are like... I wouldn't know them, well I'd know who they were because I've talked to them a few times, but they'd like... they'd message me on Facebook saying 'you are really strong and courageous doing this and you are a role model' and everything like that.

S: And these were kind of people your age at school?

P: Yeah, people my age at school that...

P1: Not sort of friends.

P: Not my friends, no, not people that I'd talk to most of the time, just people that I'd, you know, met once or twice and talked to them and knew who they were, and they just messaged me saying 'you are really... you make us proud' and things like that, I mean really nice.

S: So how did that make you feel then? Getting that kind of contact from people?

P: It was really... I... it was really nice, it... for people that you don't know, so they don't know how you are and they're saying that 'you are really strong doing this' it makes you really... it makes you smile a lot! – Alanna T3 165-178

Even when special consideration was positive, several participants expressed a level of cumulative fatigue in this area, regardless of how well they understood the reasons and positive intent behind it. Robert had previously expressed this in relation to receiving questions from peers and telling them about his diagnosis, and this was a consistent feeling for him. Even William, who had been very laid back about his cancer experiences in relation to school, expressed this sense of cumulative fatigue with people making sure he was ok.

P: Like when the first person had said it I'd said, "Look," I understood 'cos it's the first time I'd ever seen them so they said, "Are you okay?" and I said, "Yeah, fine," but like in that day 20 other people would ask, "Are you okay, are you okay?" and I'm like, "Yeah, I'm fine, yes I'm fine," it just dragged on me saying the same thing over and over again – Robert T3 431-434

P: It was quite, not annoying but, I don't know, you just kind of wanted to be left alone sometimes and they were always asking, I don't know, like yeah, always like making sure you're okay, which is a good thing but it just, after a while it kind of gets a bit, I don't know, like the everyday thing
– William T3 418-421

This chapter has demonstrated the complexity of the experiences described by participants in their interviews. Instead of offering straightforward descriptions of the practicalities involved in attending school and maintain school work, participants relayed the inter-relation of different versions of themselves across time and environments. The conceptual map and the analysis of the interviews presented in this chapter have offered some insight into these experiences. The following chapter will situate these insights into the existing literature, the findings of the studies one and two, and will discuss implications for future research and practice.

Chapter 9 – Discussion

Figure 9.1 shows the final flow-chart of the linkage between the chapters and shows that the background and literature presented in chapters one and two, along with the data collected and presented in chapters three, seven and eight have all contributed to the final findings and claims of this thesis.

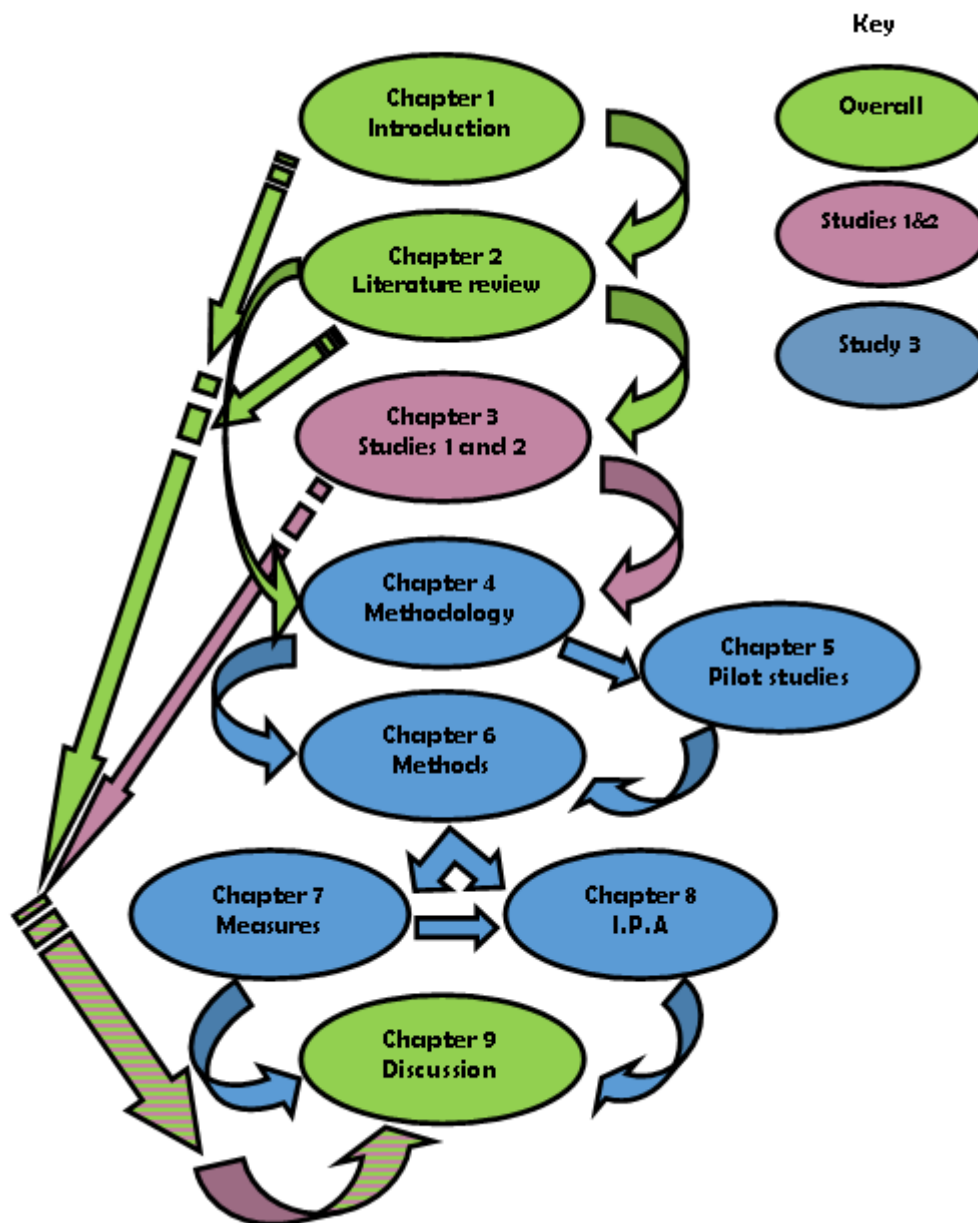


Figure 9.1 - Chapters flow-chart

In the concluding chapter of this thesis there is an exploration of the important and novel contribution that the findings from all three studies have made in relation to existing relevant literature. The discussion develops through an assessment of the research questions that drove study three and how

these questions were answered by the findings of all three studies when compared to the literature presented in chapter two. This is followed by an evaluation of the suitability of the methods to the sample, a quality assessment of the qualitative analytic method and a discussion of the limitations of the research. The findings of this thesis have opened interesting avenues to be investigated further and suggestions for the direction of future research are discussed. The chapter concludes by re-visiting the three initial aims of the thesis outlined in chapter one, which includes a list of practical recommendations for the provision of services. This list of recommendations could be applied to current practice and the development of new services so that they can be informed by the experiences of young people and lead to an improvement in the way we support teenagers with their education after being diagnosed with cancer.

9.1 Study three: Research questions

The findings from study three will be interrogated to see the extent to which they can answer the research questions that were set at the end of chapter four. These ‘answers’ will also be examined in the light of existing work, exploring how they extend or challenge current knowledge.

9.1.1 From the perspective of young people, what influences the impact that a cancer diagnosis has on their education?

To answer this question the following section will discuss the findings of the studies in relation to academic aspects of education presented in the literature review in chapter two; absences, reintegration and academic achievement. Following this, the novel contribution that the studies make in answer to this question will be discussed in relation to the conceptual map presented in chapter eight.

The methodology for study three invited participants to discuss any aspect of their experiences with continuing education after a diagnosis of cancer. Given this openly exploratory approach, it was interesting to see what aspects of their experiences they chose to focus on. Based on the findings of previous studies into the education of young people with cancer, it is conceivable that the data presented in the previous chapter could have been comprised of predominantly academic factors, such as rates of attendance (Bonneau 2011), the achievement of grades for coursework or exams (Nagarajan 2003), home and hospital teaching (Searle 2003) and the practicalities of reintegration and communication (Moore 2009). The participants did discuss elements of these academic experiences. It was clearly shown that participants in studies one and three experienced significant absences from school and that these absences were still a problem approaching a year after diagnosis for the majority of participants. The accounts of participants in study three showed that school absence was often a concern immediately following their diagnosis, which was in keeping with the findings of studies

such as the interviews with young people newly diagnosed with cancer conducted by Hedstrom et al. (2005).

The extent to which absences affected actual, rather than perceived, academic performance was not specifically quantitatively assessed in this thesis. The P.A.S.S showed that responses to the factor 'response to curriculum demands' given by participants reduced over time from the 79th percentile for the group at time-points one and two, to the 63rd percentile at time-point three. There was a comparable reduction in the factor 'attitude to attendance', which dropped from the 78th percentile at time-point one, to the 65th at time-point three. This would indicate that there was potential association between attitudes to attendance and ability to respond to the demands of the curriculum. The reflections of participants in the interviews who had received their G.C.S.E results would also suggest that their academic performance, as indicated by their grades, had been adversely affected by their absence from school. For example, both Hayley and Mario discussed their disappointment with G.C.S.E grades and significant periods of absence from school, which they also reported in the education data gathered alongside the interviews. However, despite the appearance of a reduction in academic achievement, the conceptual map discussed in chapter eight would suggest that, if a correlation between absences and a reduction in academic performance could be established and consistently demonstrated, it would need to be assessed in relation to a wide variety of other potentially influencing factors including; the extent a young person felt part of their school community, the intensity and frequency of coinciding medical events, the experience of changing peer group dynamics, the quality of communication with school and their perspective on the educational options available to them when absent from school. The findings of this research would suggest that a quantitative assessment of the impact of absence from school on academic performance for this population is excluding the nuances necessary to fully understand the complex nature of the education experiences of teenagers with cancer. The individual context is key to understanding the impact that school absence has on young people with cancer. When looking at this in relation to the experiences discussed by Hayley and Mario, both of whom were disappointed with their academic achievement and experienced significant school absence, it becomes clear that this context is important. To say that their increased absence from school correlated with their reduction in academic achievement would simplify and marginalise the transformative effect of Hayley's turbulent experiences when developing the confidence to reintegrate into school. Mario overcame significant challenges to be able to sit his G.C.S.Es and managed to achieve a high level of academic performance. However, overcoming these challenges to be able to get good grades did not dampen the disappointment he felt at his perception of his objectively marginal reduction in academic achievement. In a quantitative assessment of Mario the likely conclusion would have been that, despite his low attendance, he did not experience a significant reduction in his academic achievement, which would have been a poor reflection of his individual experience.

In answer to the specific research question – ‘what influences the impact that cancer has on education engagement?’ – the conceptual map provides a good starting point. This map was developed with close attention to the accounts of experience put forward by participants and clearly demonstrates that these accounts were not confined to the academic experience of education alone. Participants’ accounts positioned the competing needs of different versions of themselves within different environments, moving within linear and nonlinear timelines, as the dominant force by which their relationship with education was shaped by the complexity of their concurrent experiences. What was normal for them as a young person or a young person in education was often in conflict or compromised by the needs they faced as a young person with cancer. The conflict and compromise of these three different aspects of themselves was heightened in the school environment, where their previous norms were reflected back to them through their contact with peers and by comparing present and past functioning. Underpinning the competing needs of different experiences of self, timelines and environments was the tension between the desire for normality and the need for special consideration.

The construction and elaboration of the conceptual map, presented in detail in chapter eight, contributes a new level of detailed understanding and focus on the intricacies of the experiences of teenagers as they engage with their education after a diagnosis of cancer. This is not currently present in the literature in this area. Specific themes and interactions within the map will be used throughout the remainder of this chapter to answer the secondary research questions in relation to the literature described in chapter two. The findings discussed in relation to the secondary research questions all contribute to the overall understanding of the primary research question.

9.1.2 What are the main factors that hinder or facilitate education engagement for teenagers with cancer?

The conceptual map defined the underlying interactions of self and time, but there were more specific themes within this map and experiences within these themes that contribute answers to the secondary research question - What are the main factors that hinder or facilitate education engagement for teenagers with cancer? The remainder of this section will discuss the perception of hospital and home teaching services, reintegration, telling about cancer, being brought into the foreground and belonging to the school community, as important factors that hinder or facilitate engagement with education. There appeared to be a relationship in the factors that facilitated or hindered education engagement, in that when the experience of participants within these areas was positive they became a facilitating agent, but when they were experienced negatively they were a hindrance.

Perception of hospital and home teaching

To continue with school work when absent from school, the relationship and perception that participants had with the home and hospital teaching services seemed important. Participants like Annabella described the positive relationships that could develop between young people and home tutors, and that the benefits of one-to-one tutoring could result in young people improving academically. Annabella demonstrated improvements on her P.A.S.S scores in the sub-scales of “perceived learning capability” and “confidence in learning”, which reinforced her description of the benefits on home tutoring. Searle et al. (2003) reported that some of their participants demonstrated similar benefits of home tuition, but that this was only limited to the short-term, whereas Annabella seemed to develop an increasingly positive relationship with her home tutor over time that appeared to facilitate her engagement with her school work. It has to be said that, despite this facilitation of school work, Annabella did suffer from the effects of being absent from school on other areas of her school life, most notably her relationship with her peer group and feeling part of her school community. In their assessment of homebound schooling Searle et al. (2003) described more negative than positive experiences of this form of education, including; limited instruction time, perception of inconsistent quality of teaching, and the sadness over separation from peers and school. Several participants in study three, most notably Georgie, expressed these concerns about home tuition. What is not clear in the study by Searle et al. is the extent to which these negative experiences affected the ongoing engagement of young people with their education. Georgie clearly expressed her perception that the home and hospital teaching service were not as credible to provide teaching to her as her regular school, and this appeared to be a major hindrance to her education during her time away from school. Another hindrance, described particularly by Hayley, which was not present in the study by Searle et al., was the awkwardness of the dynamic of spending one-to-one time with a stranger in their own home. Hayley described how her focus was on this dynamic and not the school work. Her difficulties with the experience of this awkward dynamic ended her relationship with the home tuition service.

Reintegration

In keeping with the TYA education literature discussed in chapter two (Manne and Miller 1998, Palmer 2000, Searle 2003, Hokkanen 2004, Koch 2004, Duffey-Lind 2006, Mitchell 2006, Grinyer 2007) studies one, two and three found that reintegration was a major challenge for teenagers with cancer. Study three participants reported being concerned about this from a very early stage, which was again in keeping with findings of studies such as Hedstrom et al. (2005) and Decker (2004). Study three also agreed with the findings of Palmer (2000) and Hokkanen (2004) that concerns about reintegration could stem from fears about being teased because of altered body image. Participants in study three also discussed concerns about falling behind academically, which was highlighted in the study by Searle et al. (2003) and peer acceptance, which is discussed further in section 9.1.7. However, the findings of study three added to the existing literature by demonstrating that young

people were not only concerned about being teased about changes in appearance, but were experiencing anxiety about the adaptations that they might need because of changes to their body, such as crutches, wheelchairs, lifts and special passes. Participants regularly discussed not wanting to attend school because of not being able to climb stairs or move around the building, but they also did not always want to use lifts, wheel-chairs or crutches. Some participants, like Nicola, were also aware of feeling like they had to justify these adaptations to others and to themselves. The factors described in the remaining sections of this research question, also affected reintegration, but are worthy of separate discussion.

Telling

The development of a conceptual model of the experiences of TYAs with cancer has shown that peers of teenagers with cancer find it difficult to find out about the cancer diagnosis (Taylor, Pearce et al. 2013). Study three increases the understanding of the need for young people to tell peers and members of the education staff within school about their cancer experiences and how they go about doing this. The majority of participants had not had the opportunity to tell people within their schools about their diagnosis before beginning their treatment. 'Telling' was a major source of anxiety when thinking about reintegration and an issue that was in the forefront of the minds of participants when practically reintegrating into school. The issue of telling about cancer has previously been examined in a sample of 37 young adults (18-34 years old) (Hilton, Emslie et al. 2009). This study found that young adults were very open about their diagnosis and protective of the feelings of their relatives, but that there were significant gender differences. Hilton et al (2009) found that young men comprised most of the minority cases where they were more likely to be worried about how they were perceived by peers, be secretive about their diagnosis and use humour to pre-empt sympathy. This sample was slightly older than the participants in study three and there seem to be differences in the experiences of telling. Participants in study three did not appear to differ by gender; for example, both Robert and Alanna discussed using humour to facilitate the experience of telling, and Hayley and Nathaniel told of times when they did not want to discuss their cancer experiences with peers.

Being brought into the foreground

An issue that was not explicitly discussed in the literature presented in chapter two is that changing appearance, the need for adaptations and issues surrounding telling, all brought participants into the foreground of their school environments. This was an area where the tension between their desire for normality and their need for special consideration was evident. Being brought into the foreground because of the special consideration they needed as a young person with cancer and the attention their return would draw was a source of great anxiety for some participants when reintegrating. All participants seemed to experience this to a greater or lesser extent. For some, like Hayley, Nathaniel and Georgie, the anxiety about being brought into the foreground of school was present long before

the reality of reintegration. Georgie had not returned to school by the end of the study and the attention she expected to draw upon her return appeared to be a significant factor in keeping her away from school. Nathaniel's anxiety did not turn into practical problems and he appeared to reintegrate with only minor difficulties relating to this issue. Hayley described several examples of problems that she had with her cancer experiences or changes in her appearance being highlighted within her Sixth-Form and this remained a concern for her despite her mainly positive experience of adjustment to survivorship and her new education environment.

Normality is a concept that is regularly discussed as essential in relation to the psychosocial care of teenagers with cancer (Lewis 1996, Grinyer 2007) and Sharma described "the primary goal for adolescents with cancer is to be as normal as possible" (p. 103) (Shama, Lucchetta et al. 2007). For participants in study three, especially in relation to their experiences with education and reintegration, it seemed that the desire to be as normal as possible fluctuated significantly and was not always the primary goal. At different times, with different people and in different contexts participants described desiring normality and wanting to be treated with special consideration, sometimes simultaneously and often changing their position over short periods of time even within the same context. As presented in chapter eight, this extract from Alanna typifies the presence of contradictory messages about normality:

P: I wanted them to not be exactly the same with me, I wanted them to sort of... sort of be responsible, normally they're quite crazy and weird. Like not feel sorry for me or anything but be more thoughtful but still be their normal selves. - Alanna T3 254-256

In context of this fluctuating desire for normality and special consideration, knowing how to treat participants when reintegrating into the school environment was sometimes very difficult for members of school staff, parents and peers to get right.

Belonging to the school community

The sense that a participant had about the amount they were cared for by their school and how much they felt they still belonged to, and were wanted by, their school seemed to be an important factor in their successful ongoing engagement with education. This is in keeping with aspects of the well-being and education literature presented in chapter two, which showed that the school community could be very important to the well-being and school outcomes of young people (Ahmavaara and Houston 2007). Study three added to the understanding of the relationship between school community and well-being for young people with cancer by showing that the feeling of school community seemed to be predominantly influenced by the quality, content and frequency of communication from school during periods of absence. Many studies have shown the moderating effect on reintegration of good

communication between schools, medical practitioners and young people and their families (Searle 2003, Mitchell 2006, Moore 2009). However, findings from study three suggest that clear and appropriate communication from school about academic issues, alongside caring communication about the health situation of participants, was a combination that seemed to facilitate continuing education engagement through making the young person feel wanted by the school community. The interviews in study three presented several examples where communication that was not tailored to the needs of the individual could be very distressing and a barrier to reintegration e.g. the school report given to Alanna or the unadjusted exam results given to Hayley. Findings from study three suggested that the underlying factor was that these kinds of miscommunications made the participants feel uncared for and, along with their absences, further reduced their sense of belonging to the school community. The article by Moore (2009) and my own article (2009) suggested that a specialist education worker could facilitate these communication, but the experiences of participants in study three, who all had access to the support of a specialist learning mentor, suggest that this is only part of the solution. It seemed that where the school identified one member of staff to be the main source of communication, and who already had a good relationship with the young person and their family, then participants had a better experience of communicating with their school, which facilitated their reintegration and made them feel a more valued part of the school community, which in turn facilitated their feelings of well-being. It also seemed that the support from the specialist learning mentor was not necessarily covering all the aspects of education engagement with which participants were struggling. Study three did agree with the study by Moore (2009), which showed that education staff were not always clear about what support they should offer young people and the best timing of this support. However, more understanding was given to this issue through the discussion of the ever-shifting dynamic between normality and special consideration that made delivering the right support, at the right time, very complicated, especially when there was not regular communication between school and home. This issue is further complicated by the findings presented by Koch (2004), who identified that teachers had lower expectations of teenagers with cancer compared to healthy controls. Lower academic expectations from teachers was not something that was explicitly discussed by participants in study three, however, a low frequency of communication from school was seen by some participants as an indication that the school were not interested in their progress, medically or academically. For participants in study three it seemed that attempting ongoing progress through their perceived education timeline had an important implicit message; that planning for the future remained important and appropriate.

9.1.3 To what extent do the education experiences of teenagers with cancer change over the first nine months of their diagnosis?

The conceptual map presented in chapter eight showed that the perception of time and moving through timelines was an important fundamental concept that helped to shape the experiences of participants. However, this was more connected to their adjustment to the presence of cancer in their lives and their orientation to reality, which will be discussed in more detail in section 9.1.4.

In relation to specific education experiences, all participants showed changes in attendance, with some increasing their attendance as they moved through their treatment and others being forced into longer periods of absence as treatment effects built up. Drew (2007) described the ongoing narrative wreckage that could occur in young people with cancer and affect their education and vocational plans. Study one showed that 74% of participants had changed their educational and vocational plans following their diagnosis. Some participants in study three also discussed reshaping their education timelines because of the impact of their cancer. This often involved short term adjustments to timetables and reduction in the number of subjects they were involved in, but also longer term changes to education plans, such as Nicola and Faisal deferring a year of study or Alanna having to study different subjects at G.C.S.E level. In his interview Faisal appeared to acutely perceive the narrative wreckage caused by his cancer diagnosis and was finding it difficult to imagine how he would piece his education timeline back together.

Barrera (2005) and Searle (2003) both reported finding that periods of extended absence from school could result in young people feeling socially isolated. This certainly appeared to be the case with Annabella who was forced to spend the entire study period away from school because of the immune compromising effects of her bone marrow transplant. In the final time-point interview she described several examples of isolation from her peer group, including peers not attending a social event she had organised and friends initiating contact with her less frequently. Annabella described being absent from school and extended periods of hospitalisation as concurrent factors that resulted in her social isolation.

Some participants reported a change in attitude towards education, such as William now being more focussed in classes or the periods of absence experienced by Nathaniel making him realise the positive part that school played in his life. However, other participants like Patricia who did not maintain engagement with her education, or like Georgie who did not feel part of her school community throughout her treatment, seemed to develop an apathy or anxiety about returning to school. As well as expressing this through her interviews, Patricia demonstrated this through her declining responses to the P.A.S.S from a total mean score of 46.75 at time-point one, to a total mean

score of 24.65 at time-point three. This reduction moved scores below the cut-off for concern in seven out of nine sub-scales at time-point three, compared to one out of nine at time-point one.

The long-term impact on education and employment was difficult to assess within study three because participants were only in the study for approximately nine months. However, there were signs of changing plans and experiences that could potentially result in longer term difficulties. Several participants, including Alanna and Mario, discussed being interested in changing their vocational plans to work in areas related to their cancer experiences, for example, hospital teaching or prosthetics. Other participants, including Robert, Hayley and William, experienced difficulties when they returned to school because of the academic time they had missed during their treatment. It is conceivable that this void in their education timelines could result in longer term consequences for their academic attainment.

9.1.4 What is the impact of education engagement on the overall coping and well-being of teenagers with cancer?

It would have been ideal to be able to answer this question by saying that those participants who engaged more regularly with education in school, hospital and home were significantly more likely to report higher levels of well-being and cope more successfully with the impact of cancer. However, the answer to this question was more complicated to assess and comprised complex intersecting experiences. Based on the data gathered from the SWEMWBS, it would appear that the mental well-being of the teenagers in study three did not significantly change over time, and therefore it would be difficult to conclude that the varying levels of engagement with education experienced by participants affected their well-being. There appeared to be a similar consistency with the data gathered from the A-COPE, which would indicate that their coping strategies did not significantly alter over time. However, the A-COPE only measured generic coping strategies and not the extent to which participants were able to adjust to their cancer experiences over time and how this affected distress or anxiety. The literature review by Gil (2005) reported several studies that showed that young people with cancer were more likely than healthy controls to engage in repression and avoidance coping styles (Canning, Canning et al. 1992, Phipps and Srivastava 1997). The findings of the A-COPE would suggest that this was not the case within this sample of young people. The sub-scale for avoiding problems was only the tenth most reported coping style out of twelve. However, some of the individual items comprising this sub-scale were not always very relevant avoidance options for participants (e.g. taking drugs, smoking or drinking alcohol). A further problem for the A-COPE and SWEMWBS scales was that the literature showed that repressors are less likely to report problems in self-report measures, which makes them a difficult group to identify or assess using self-report measures (Canning, Canning et al. 1992, Phipps and Srivastava 1997, Gil 2005). It did seem that

Patricia was a participant who may have been using a repression style of coping, which could have been as a quick fix to alleviate the impact of her cancer experiences, and in this regard she seemed successful. However, Baylis (in Huppert, 2005), would argue that this could perhaps influence her relationship with reality and have longer-term consequences for her well-being.

The interviews provided more data to answer this question and a more in-depth assessment of the experiences involved. It seemed that education provided participants with an environment where they could engage with fundamental aspects of their developmental stage, such as; peer relationships, mastery, independence, belonging, and developing a sense of self through regulation and calibration. All of these factors were described by different participants at different times as having an effect on their ability to cope with stressors in their lives related to their engagement with education and their overall coping and feelings of well-being. The perceived success felt by participants in dealing with these stressors within school seemed to be generalisable to other areas of their lives at home, in hospital or in the community. Many examples of this were reported in the analysis in chapter eight. Mario appeared to use his exam results and his ability to attend school as a benchmark for how significantly his cancer had affected his life. Through interactions with his peers and teachers, Robert used his school as an environment where he could demonstrate his confidence and his ability to successfully cope with his cancer experiences. Hayley talked about how positive she felt when she had developed the confidence to attend school with short hair, having previously been very anxious about reintegrating into school. Alanna discussed several examples of how frustrations and difficulties related to her education resulted in feelings of distress and periods of uncertainty. Patricia did not engage with her education throughout her time in the study and, despite the limited amount of distress discussed by her in the interviews, she did report worsening scores on several factors within the P.A.S.S over time and discussed difficulties with her peer group and returning to school. Annabella could not engage with her school during her treatment and she also discussed increasing difficulties with isolation from her peer group over time. These examples, and many more, from the interviews with participants in study three demonstrated that engagement with education could be an important part of the calibration of how much their cancer experiences were having an impact on their well-being and their pre-diagnosis perception of themselves. As well as being a factor in its own right, the school environment was the hub for a vast number of components that made up the well-being of these young people; peers, belonging, independence, mastery, body image, social norms and an established understanding of who they are. When trying to cope with, and adjust to, the presence of cancer in their lives, the school environment provided many of them with significant milestones and opportunities to demonstrate how successfully they had adjusted, or to recognise and worry about how difficult it was.

The review by Decker (2005) showed that older teenagers with cancer used a greater variety of coping strategies compared to younger teenagers. Although age was not a significant factor in the analysis of the A-COPE, it appeared that in their interviews the older participants described more detail and variety in the way they coped with difficult situations. The interviews with Mario, Robert, Nicola and Hayley were far richer in detailed descriptions of how they coped with and adapted to stressors, than the interviews with Patricia, Annabella, Nathaniel and Georgie. It was difficult to assess within this study the extent to which this was a reflection of normal development, or whether young people with cancer experienced a degree of acceleration in their coping maturity.

The idea of the adjustment timeline presented in chapter eight, could be related to the idea of congruency between coping strategies and perceptions of control presented in the study by Sorgen et al (2002). The idea presented in chapter eight of a continuum between a “paused-life” orientation to adjustment to cancer and continuing adjustment and incorporation of cancer experiences could be linked to perceptions of control. It seemed from the interviews in study three that those participants who had appeared to ‘pause’ their lives were also those who demonstrated a reduced involvement in decision making and planning related to their education and health. This reduced involvement could be linked to a perceived lack of control over decisions and events in these areas of their lives and would therefore be a coping orientation that was linked to their perception of control. The two participants that seemed to exemplify either end of this continuum were Patricia and Alanna. Patricia did not discuss involvement with any aspect of decision making and progression through any of her timelines; she did not discuss wanting or being able to assert any control over her experiences. Alanna, however, regularly discussed wanting, and feeling able, to make decisions about, and influence, her experiences regarding her health and education. I would argue that both participants demonstrated an orientation to coping that was appropriately linked to their perception of control.

In contrast to the findings of Wu et al (2009), it did not seem that most participants in study three had abandoned the idea of academic achievement in favour of focussing on the effects of losing their health. Instead, it seemed that participants were aware of their education timelines moving forward and were keen to be able to re-join them when they were able to, or re-shape them to accommodate their new reality. However, the experiences discussed by participants in study three did overlap to some extent with the four themes identified by Palmer (2000) in her study of adolescent cancer support groups. The first theme of the “challenge of improving family support”, was discussed by participants in study three with regard to the impact they could see their diagnosis was having on their family emotionally, financially and practically, but also in the way the participants were coping differently and adjusting at a different pace to their parents. However, in contrast to the findings of Palmer, participants more regularly discussed the positive way that their cancer had changed their relationships, through increased caring, contact and closeness, rather than the negative impact on

family relationships which was only rarely hinted at. As has already been discussed, participants regularly talked about experiences in relation to the second theme of “the challenge of others’ discomfort with discussing cancer”. However, in addition to the findings of Palmer, which discussed communication with relatives, participants in study three discussed the heightened difficulty with this issue in the school environment with peers and members of education staff. The third theme of “gaining peer support” was a constant presence in all aspects of this thesis and is discussed in more detail in section 9.1.7. The final theme of the “challenge of feeling betrayed by one’s body”, was also present in the interviews with participants, and was regularly related to losing independence because of physical limitations and the challenges presented by altering appearance. There was no evidence of the “nothing to lose” (p. 51) attitude discussed by Palmer; in fact the young people in study three often took on their own body as a project and in a way this became something constructive they could work on.

Throughout the coping and well-being literature it seemed that the way that young people orientated themselves in time was important. The timelines aspect of the analysis presented in chapter eight was mainly an implicit feature of the way that participants shaped and made sense of their experiences. However, there were examples where participants appeared to use timelines to structure their view of education, health and adjustment, as well as referring to and comparing between past, present and future versions of themselves. A reinterpretation of the past or imagining the future to impact upon the present is consistent with the ideas described by Tucker (2012) in his analysis of the experiences of a mental health service user. Tucker’s paper highlighted how past, present and future were not discreet structures acting independently on a continuum, but instead had a transformative dynamic relationship with each other, whereby, a reimagining of the past or the anticipation of a future could help to reshape the present and this could be beneficial or potentially damaging. There were several examples of this within study three. Mario and Nicola both used the idea of future Paralympic competition to help them adjust to their leg amputations, whereas, Georgie stated that she had consciously stopped thinking too far ahead as it was causing her significant anxiety to imagine the uncertainty of her future, and this was an approach adopted by a number of participants at different times.

In the introduction the question was posed “Does education matter to young people after being diagnosed with a life threatening illness like cancer?” The paper by McCullough et al. (2000) showed that everyday difficulties and major life events provided distinct categories of experience for young people and that both had the ability to affect well-being in distinct ways, and therefore both should be attended to when addressing the well-being of young people. This is very important for the implications of the current thesis. Cancer is undoubtedly a major life event, but the experiences discussed by participants in study three show that a cancer diagnosis and ongoing engagement with

education are distinct but intersecting experiences that influence each other and both contribute to the well-being of teenagers.

9.1.5 Does cancer have an effect on teenagers' perceptions of themselves?

Based on the data gathered from the P.A.S.S (see chapter seven) it would seem that cancer did not have an effect on the participants' perception of themselves as learners. The scores for the overall group indicated no areas of concern compared to normative data, although some individuals did show some reduction over time on certain factors. However, as well as the competing needs of different versions of themselves that were discussed in the previous chapter, the interview data from study three showed that most participants changed the way they viewed themselves in relation to their changing physical, academic, cognitive and social abilities. Most participants viewed themselves differently as their body image changed over time, regardless of whether this was a source of anxiety or an area they were coping with successfully. The fluctuation in their ability to concentrate because of fatigue, pain, discomfort and periods of absence from education, affected the way that they were able to engage in their education and perform academically. Linked to the idea of orientation in time discussed in the previous section, Alanna discussed the importance of continuity in her perception of herself from past to present, and this seemed to re-shape her experience of the present in two ways. Firstly, her previous idea of herself as somebody "strong" seemed to propel her to remain strong in the face of cancer related stressors. However, secondly, her previous idea of herself as independent seemed to increase the negative impact of the reduction of independence brought about by physical limitations on her. The idea of continuity of self was also difficult for participants because they often could not rely on a consistent version of themselves, day-to-day, hour-to-hour. This was demonstrated by Nicola in her feelings of not wanting people to visit her because she would not know how she would feel on the day, not just physically, but emotionally, socially and psychologically. It seemed that not being able to rely on a consistent version of herself in the present diminished her desire and confidence to engage in areas of her life.

Adolescence is a time of change and ongoing development of an idea about oneself. In terms of how participants in study three perceived themselves, there seemed to be a difference between experiences that had an impact on them in the short term and those that changed their fundamental view of themselves. There was considerable variation between participants in terms of the extent that cancer related experiences were able to alter their fundamental self. Taking three participants of the same age as examples, Robert, Hayley and William all demonstrated different dimensions of this experience. Robert regularly discussed the impact that his cancer experiences were having on him and his education, but there seemed to be a clear divide between his acknowledgement of the surface impact of events like hair loss, short term changes to peer interactions and behaviour restrictions, and the

fundamental core of his self that remained constant and intact. William discussed going through his cancer experiences in a very relaxed fashion with very limited impact of his cancer experiences on his life and his perception of himself, whereas, Hayley demonstrated that her experiences of cancer had a gradual transformative effect on her perception of herself as a member of school, as a friend, as a daughter, in relation to her self-confidence and ultimately made her a “new person”.

It is interesting to think about the level of control that young people might have over the ability of cancer to change their fundamental self. Can young people open themselves up or close themselves off from the potentially positive or negative transformative effects of cancer? It would appear that participants in study three attempted this consciously or unconsciously. Robert seemed to take an active stand against cancer - that it could disrupt him temporarily, but would not ultimately change him - and he always seemed like he thought this was within his control. At the completion of the study I believe he was successful in this approach. Patricia did not appear to demonstrate any perception of control over how cancer affected her and her conscious or unconscious approach seemed to be to ‘pause’ her life and let the experience of cancer run its course. Patricia did seem to suffer some ill effects of her cancer experiences in relation to her peer group at school and her scores on the P.A.S.S indicated that cancer did have a negative impact on her perception of herself. The example of Hayley seemed to show her initially fighting against the impact that cancer was having on her, but by the final time-point seeming to embrace the changes to herself as positive. The extent that Hayley felt in control of this experience was not as clear as for Robert and Patricia, but I think she developed an increasing sense of control over time.

9.1.6 Does cancer have an effect on teenagers’ perceptions of school?

Again, according to the P.A.S.S data, the participants in study three did not show any signs of cancer significantly affecting their perception of school compared to the normative data. In fact, the subscales that related to their perceptions of school showed more consistently high scores than those related to perceptions of themselves as learners. However, the interview data clearly showed that cancer and the subsequent communication with school could significantly affect how participants perceived their relationship to their school, as discussed in sections 9.1.1 and 9.1.2.

9.1.7 Does education engagement affect the extent and nature of relations with pre-diagnosis peers?

In agreement with the literature presented in chapter two (Manne and Miller 1998, Palmer 2000, Searle, Askins et al. 2003, Decker 2004, Hokkanen 2004, Meltzer 2005, Duffey-Lind 2006, Mitchell 2006, Woodgate 2006, Grinyer 2007, Mattsson, Ringner et al. 2007, Cassano, Nagel et al. 2008), studies one, two and three showed that peer relationships were important in the ongoing education

engagement of teenagers with cancer and that time away from school reduced the amount that young people could engage with their peers. The majority of participants in study three discussed changes in their peer group dynamics that were brought about by their diagnosis of cancer. These were not always specific to school, but school was an environment where these changes in dynamics and the difficulties surrounding these changes were brought into sharper focus. Issues surrounding talking about cancer and having different experiences from their peer group could be significant factors in altering peer group dynamics. Previous studies have shown that this fear of peers moving on without them can be a major concern (Gibson, Mulhall et al. 2005, Grinyer 2007).

The amount that participants were able to attend school directly affected the frequency with which they could interact with their peer group. This was particularly apparent in those peers that were not necessarily close friends and where school provided the main opportunity for interaction with them. Even closer friends often found it difficult to visit participants in hospital because of distance, travel and appropriateness. Issues surrounding visiting in hospital often still applied when the participant was at home, alongside other issues such as infection risks. It therefore seemed that there were multiple barriers to continued engagement with peer groups and that reduction in education engagement was a significant part of this.

It seemed that each version of self that the participants were living with had its own associated sense of normality that could only be easily shared with comparable individuals. Several participants discussed feeling different from their peers over time because of their changing priorities and perspectives provided by their cancer experiences, and that this altered their peer dynamics. For some participants in study three, like Annabella, Patricia and Georgie, their absence from school, and change in attitude and experiences, seemed to be responsible for ongoing negative changes in their peer relationships. Study one showed that successful maintenance of peer groups was a significant factor in successful reintegration and reduced the impact of body image. Study three showed several examples of participants who reported feeling different from, and not understood by, their pre-diagnosis peer groups because of their cancer experiences, although this was not the case for all. In fact, for some participants like Alanna and Robert, being different from their peer group was not necessarily a negative experience for them and could result in opportunities to positively influence others or experience different levels of power within their relationships. Manne et al (1998) showed that teenagers with cancer had smaller social networks than healthy controls, but the participants in studies one and three showed that this was not always the case. Participants in study one showed a mixed response to the question of how many friends they had lost during their cancer experiences and study three showed that the size of social networks could increase or decrease depending on the individual circumstances. Many participants like Robert, Georgie, Mario, Hayley, Nathaniel, William and Nicola reported no losses of friendships and in fact discussed an increase in the number of peers

wanting contact with them, although this was not without resulting difficulties such as being bombarded with questions and over-attention. These participants also often reported an increase in the quality of relationships with friends and family members, which demonstrates the need to assess quality as well as quantity of social networks. However, there was also evidence of participants intentionally reducing the amount that they interacted with their peers because of concerns about infection risks, not wanting friends to visit them in hospital, difficulties with being able to rely on a consistent version of themselves and the perception that they were not fun to be with.

It seems clear, from the findings of the studies in this thesis and the assessment of the literature in this area, that peers are a vital component in the education and wider health and social experiences of young people with cancer. The maintenance of peer groups appears to be a facilitating factor in successful engagement with education, but also an outcome of successful ongoing education engagement. Peer groups and education engagement seem to be so tightly linked that it is difficult to assess a clear cause and effect i.e. do peer groups help maintain education or does education help maintain peer groups? The evidence gathered in this thesis would lead to the conclusion that it appears to be a perpetual cycle of mutual reinforcement, which can be easily disrupted by a significant event like a diagnosis of cancer and the change in dynamic that cancer brings to both peer groups and education engagement.

9.2 Summary of contribution to the literature

In summary, the main contributions that this thesis has made to the literature are as follows:

- Education engagement is a complex experience for teenagers with cancer, which involves intersecting timelines, competing needs of different versions of self and a range of psychosocial issues.
- The extent to which teenagers want to be treated normally or with special consideration fluctuates over time and between environments, and therefore needs to be attended to closely. It is not as simple as just treating them normally.
- The intricacies of telling people in school about their cancer experiences are a major concern for young people when reintegrating into school.
- Appropriate individually tailored and caring communication from the school is essential for teenagers with cancer to feel part of the school community and this is important for their well-being as well as their engagement with education.
- Peer groups and education engagement appear to be a perpetual cycle of mutual reinforcement and therefore maintaining one will facilitate the maintenance of the other.
- There appears to be a continuum of orientation to adjustment to cancer, which ranges from young people pausing their lives, to incorporating cancer experiences into a new version of themselves.
- A quantitative investigation of education engagement is not well suited to the complexity of the experiences of teenagers with cancer.

9.3 Examining the fit of the methods to the sample and the research questions

In the concluding part of the final time-point interviews, participants were asked what they thought about being involved in the study. For most of the participants, this was their first time being a participant in research, although some did say they were part of clinical drug trials, which required significantly less input from them. The following sections evaluate the methodology of study three from the perspective of participants as well as my own. All extracts are taken from their interviews at the final time-point.

9.3.1 Overall feelings about participation

Those who completed all three time-points appeared to be happy that they had participated in the research. It seemed that some participants derived some direct benefit from the interviews and others, like Nathaniel and Georgie in the extracts below, were simply happy to be doing something that would help other young people in the future.

P: But it isn't really like for my benefit, it's for other peoples' really. – Nathaniel

P: It's alright to do it because it doesn't really take up much time if this can help somebody else out really. – Georgie

Those participants who felt like they had directly benefitted from the study mainly discussed the positive effect of talking to somebody about their experiences. As demonstrated by the extract below from William, it seemed that some participants were not provided with other situations in which they were able to do this in a safe environment with somebody who was not an immediate part of their lives, or were not taking advantage of other opportunities.

P: And it's good to talk to someone about it, about, yeah, stuff, yeah definitely stuff about school and, because you don't, you wouldn't normally talk about that, you wouldn't normally think about what's stopping you going to school or things like that, yeah.

S: So it has been useful for you then, has it been, or...?

P: Yeah. Just been, yeah, just been good to think about it, yeah. - William

In the extract below, Hayley described how she felt very anxious before participating in the interviews. When she revealed this, it was a surprise to me, because she had appeared so composed and confident in discussing her experiences during the interviews. The idea that it was good “just

spilling everything out” really captured the cathartic effect that a number of the participants discussed from having the opportunity to talk about what was happening in their lives.

P: Well like the day before I’ll get really agitated and I’ll just stress out a lot. Like it got to the point once where I was crying because I thought ‘oh no I’m going to have to do it again and I’m so scared and I don’t know what I’m going to say, I’m going to run out of things to say!’ but then once I get here I really enjoy it because it’s just a really nice way of just spilling everything out that’s happened. – Hayley

Participants also reported that the ease of the practicalities of conducting the research was something that they appreciated and facilitated their participation. Nicola valued the fact that “it doesn’t really take up my time” because the interviews were arranged at a time when she was already in hospital. Nathaniel also appreciated the interviews being at good times for him, but also seemed to value clear communication and punctuality:

P: And you’ve got it at good times to being good with us, you’ve told us when stuff is going to be and you’ve come on time so it’s been alright really. - Nathaniel

9.3.2 Reflection on the overall research process

From my perspective, one difficulty with recruitment and scheduling the subsequent interviews was working to the time kept by the teenagers and TYA oncology services that have adapted to flexibly accommodate the needs of teenage patients. Variation in the cycle of their symptoms, side effects, treatments and appointments could occur very quickly and therefore disrupt the research process. This was an inevitable part of research in this area, but one that still caused logistical challenges for the study, especially in context of having limited time week by week that I could dedicate to the study. For example, it was difficult when an interview was arranged for a specific time when both the participant and I were available, for it to then be cancelled due to illness, changing appointment times or newly scheduled procedures. Additionally, there were challenges presented by the developmentally typical daily rhythms and lifestyles of some participants. For example, I arrived for an interview on several occasions to find that the participant was asleep, had decided to meet with friends, or had simply forgotten the appointment. All of these issues caused delays, but were of course understandable in context of the variety of demands on their time and the side effects of treatment.

When conducting this kind of psychosocial research with a sample of teenage cancer patients in a clinical environment, it was difficult to avoid feeling that what I was doing was sometimes an understandably low priority for the young people, their families and some of the clinical practitioners. The primary aim of these clinical areas is to deliver care and treatment to the patients and the main

reason for the young people to be in that area is to receive this care and treatment. It was therefore a challenge of communication and relationship building to be able to find time and space to speak to young people about the research, or conduct the interviews, without interfering with their care needs. This is an area where I believe my previous experience helped me to negotiate the challenges of working in these environments.

Another challenge of conducting research with this population has been spending time with young people who are going through difficult experiences that they may not survive. Interviewing participants over a nine month period gave me the opportunity to discuss their experiences and build a rapport with them and feel some level of investment in their lives. This was further enhanced by the detailed attention given to their interviews through I.P.A, where I felt that I grew to know and empathise with them and their challenges to an even greater extent. My experience in this area has again been helpful to me here, as well as having the opportunity to talk about these challenges with supervisors and members of the TYA support and clinical teams.

As well as the emotionally difficult issues of working with this population there were several challenges to my professional boundaries and maintaining the role of a researcher. Throughout study three, my integrity as a researcher was challenged by the pull of several other roles including; counsellor/therapist, education advisor, TYA professional, friend and empathiser. When interviewing and getting to know participants over three time-points, it was a challenge not to provide them with advice and reflections about their approach to themselves, their family/friends and their education. This challenge continued in the analysis of their transcripts, where great efforts were made to ensure that the analysis was based on what participants had said rather than what I had thought about them or had observed during my time with them. It was an inevitable reaction to sympathise with their struggles and how they were treated in some situations, but it was important to try to ensure that this sympathy did not undermine the aims of the research, as this would have been detrimental to the research and to the participation of the young people.

9.3.3 Visual methods and the interviews

The use of the visual element of the interview method within study three had varied success across the participants. As discussed in chapter four, initially this seemed like a method that would suit this particular population of young people, but during recruitment it became clear that this was not always the case. For some young people, the idea of visually representing their experiences for use in the interviews was a barrier to their participation, as was the case with Alanna as discussed in her pen portrait in chapter eight. This was something that I adapted throughout recruitment and over time the visual element of the study became a suggestion rather than a compulsory component.

For those participants that did participate in the visual element of the study there seemed to be some positive experiences.

P: Once I remember to take them they were good because it gives like something to talk about which I'd probably forget if I was just talking like this so... it was like a reminder to tell you whatever it was. - Mario

As Mario describes above, the photos gave him a memory aid during the interviews and allowed him to cover all of the issues that he wanted to discuss. In the extract below, Robert describes how the photos provided him with some control over the flow of the interview and allowed him to talk about what he thought was important, rather than having to fit his experiences to a set of questions.

P: It's been a good idea, like it's been a good idea 'cos I can say like what's helped me and like what's been a big part of my life just going through it, rather like asking questions which can like lead off to other things of what I haven't done or what hasn't helped me.

S: So you think that sort of you taking photos of what you, what you're interested in.

P: Yeah, good idea. - Robert

Some of the participants who did not use visual methods still provided some feedback about elements of the interview process. Annabella said that she didn't "feel pressurised into talking about things" during the interviews and this seemed to be an important factor for her. Nathaniel was a participant that did not find it easy to talk about his feelings or his hospital experiences:

P: Yeah, well you don't talk about the hospital, you talk more about like how it's been after the hospital.

S: Yeah, yeah. So has that been...

P: So that's been okay. - Nathaniel

For him, the ability within the interviews to focus on moving on from his hospital experiences, rather than dwelling on what had happened, was a positive part of his participation.

9.3.4 Longitudinal

The longitudinal aspect of the methodology allowed for flexibility and adaptation within the study, which was an important part of the successful recruitment and participation of young people in this population. As mentioned above, components within the method, like the optional use of visual methods, changed over time, which would not have been possible with a single time-point. The longitudinal method allowed adaptation to the needs of individual participants over time as I got to

know their preferences. For example, in his first interview Nathaniel and his mother said that he was not comfortable talking about his feelings, so I was aware of that during subsequent interviews, whereas, throughout the interviews with Mario, Nicola and Hayley, it seemed that they were more comfortable with me delving deeper into difficult and emotional aspects of their experiences. Through adapting to the individual participants, I felt that I was able to more sensitively discuss their experiences, which facilitated their ongoing participation and resulted in a better interview experience for both parties. This kind of adaptation to individuals was possible during the course of a single interview, but was made easier through interviewing over several time-points.

The extract below from Hayley, showed another element of longitudinal interviewing. Her participation in a longitudinal study of this type provided her with a structure that implicitly and explicitly encouraged her to reflect on how she may have changed over time. In this way the study design to some extent shaped its own outcomes in relation to timelines and reflections on changing perceptions of self.

P: Like I never felt properly ill, like I never felt as though like I looked like a cancer patient but looking at those photos like I do look pretty rough in some of them! Like with the ill face...

S: How do you feel about those ones where you think you weren't looking maybe so well as now?

P: It is quite depressing, I had a bit of a cry about it when I was sort of in bed! But yeah, it's just in the past so I'm just not trying not to think about it. Don't start mum...! It is just a bit, it is strange looking back at them.

S: Yeah I bet it is, yeah. – Hayley

It seems that any difficulties caused by this aspect of longitudinal methods were outweighed by the increased level of detail and understanding of the experience of participants that came from being able to situate them in distinct places in time and assess what changed and what remained constant.

9.3.5 Mixed-methods

The majority of the data that has contributed to the assessment of the research questions came from the interviews and I.P.A. The detailed assessment of the individual experiences of participants described in their interviews provided a rich source of data. The understanding of this data was only partially enhanced by the inclusion of the quantitative measures. It also seemed that participants derived more positive experiences from engaging with completing the interviews than the measures. The interviews gave participants the opportunity to have ownership of the way they shaped and discussed their experiences, whereas the measures offered them a framework within which they had to fit their experiences. Some participants found that this framework did not always suit them. In the

extract below, Nathaniel describes how some of the options in the A-COPE were amusing to him, and it seemed that this was because they were not coping strategies that were relevant to his life.

P1: Some of the questions have been quite funny haven't they?

S: I know, which one? I mean I don't want to pre-empt it but I'm guessing that some of the coping questions were funny were they on that?

P: Yeah, "Do you smoke?!" "Do you take drugs?!" – Nathaniel and his mother

However, the completion of the quantitative measures did not appear to be a barrier to participation and only Georgie missed providing measures at a time-point, which was because of losing completed documents, rather than refusing to complete them. The analysis of the measures was compromised by the limited sample size, but the data did show that cancer did not significantly affect the well-being, perception of themselves or their school in this sample of teenagers. Some individuals, such as Patricia, did show variation in these measures over time, and this added depth to the understanding of her experiences, especially in light of her reserved nature in expressing herself in the interviews. It was interesting to see that preferences for certain coping styles, such as being humorous, were consistent across the sample and did not significantly change over time.

This study presented a good opportunity to collect data from this population in a longitudinal design and the incorporation of quantitative measures alongside the interviews was a worthwhile method to pursue for potentially interesting and useful data. Overall it seems that the majority of the main findings could have been achieved through the qualitative methods alone, but the data provided via the measures has added some additional detail to the qualitative data and highlighted areas for future research using more substantial sample sizes.

9.3.6 Reflection on "go-along" interviews

In chapter four there was a discussion of go-along interviewing and in chapter six this was referred to as an option for the final time-point interview. Go-along interviews were unanimously refused by the participants in study three, all of whom opted for their previous method of interview, whether that was visual or not. It became clear that participants would have been uncomfortable with me being any part of their school day, and this was a feeling that I increasingly shared with them. All interviews were conducted either in a room in the outpatient clinic or in the inpatient ward. These could be said to be settings that situated the young people in an environment where they had previously had experiences related to their cancer, but this was not an explicit part of the interview and was more of a practical limitation of the research. The only example that approached being a go-along, was the final interview with Nathaniel. Despite not wanting a go-along interview, I agreed to meet Nathaniel and his mother at their local hospital where he was attending a follow up appointment for the extra convenience of

not having to travel to the main cancer centre. The room that we had intended to use in the outpatient clinic was unavailable and there were no other rooms available. On Nathaniel's suggestion, we went into the hospital grounds and conducted the interview outside on a bench in a quiet area. This interview was conducted with Nathaniel and his mother and was the most engaged and animated Nathaniel had been in all three time-points. We used elements of the environment to reflect on his experiences in the main cancer centre and how they differed from his current reality. Overall I felt this interview was a success and that being in this environment, although far from planned, facilitated Nathaniel's engagement and comfort within the interview.

9.3.7 Reflection on “gems”

As discussed in chapter four, Smith (2011) describes three distinct categories of gems that can illuminate the analysis of interviews in I.P.A; shining, suggestive and secret.

There were several examples of gems within the I.P.A in study three. The analysis of the interviews with Mario initiated the idea of timelines and timeline thinking. I would describe this as a secret gem, as I do not believe that Mario was conscious of the seemingly influential effect that his timeline conceptualisation was having on his understanding of his experiences.

In the first interview with Hayley she described the idea of reflection. Initially she said that she did not like to see her reflection in the mirror as it reminded her of how ill she looked. From this starting point we discussed how her appearance was also reflected back to her from friends and adults in her life. This had a large influence over the ideas of reflection and calibration that are present in the analysis in chapter eight. This seemed like a suggestive gem, as it was partly understood by Hayley herself, but needed more analytical work before it became part of the overall understanding of the experiences of the sample.

Hayley also provided another suggestive gem when she described herself as a “new person” when entering Sixth-Form. When used in comparison with the experiences of other participants like Matt and Patricia, this idea of becoming a “new person” resulted in the development of the adjustment timeline and the associated idea of “pausing” life or incorporating cancer experiences.

A good example of a shining gem was given by Alanna when she talked at various points in her interview about the importance of her ongoing reflection on her past qualities and her reputation with friends and education staff, and how this could be damaged by cancer. This was an important point in the development of the idea about continuity of self, which illuminated the understanding of the experiences of several other participants.

9.5 Quality Assessment

As discussed in chapter four, the quality of study three was assessed using the guidelines proposed by Smith (2011) for assessing the quality of published I.P.A research. Although study three is presented in a thesis and not in a peer reviewed journal publication, the standards expected of published research provided the best benchmark for assessing the quality of this research and could speak to the potential for publishable contributions to the literature. Although study three had a mixed-methods design, the majority of the interesting findings were drawn from the qualitative interviews and subsequent I.P.A. Therefore, it seemed that assessing the quality of the I.P.A would be the most relevant and useful approach. The following section presents discussion of the quality of study three under the headings of the I.P.A quality assessment proposed by Smith. For a description, taken from Smith, of how quality should be assessed in these areas please see Appendix 15.

9.5.1 The paper should have a clear focus

Despite the exploratory nature of the research aims, questions and methods, this thesis had a clear focus, which was to investigate the education experiences of teenagers with cancer. The nature of the participant led methodology meant that the interviews were intentionally open to being shaped by each participant. This resulted in the discussion of a wide range of experiences that were related to a greater or lesser extent to the overall area of interest, which was education engagement. Due to the limited literature base in this area, as shown in chapter two, having a broad framework within which participants could discuss the experiences that were important to them, provided the best opportunity to construct meaningful accounts of their experiences. Having a narrower focus on education would have potentially missed some of the more interesting parts of the experiences of participants and the relative interactions of psychological and emotional factors.

However, despite the broad framework within which the study began, during the analysis presented in chapter eight, the conceptual map and the thematic structure discussed within it, provided a focus to the variety of experiences discussed within the interviews. The accounts given by participants were often complex and this complexity was deepened when assessed across the entire sample. The I.P.A presented in chapter eight aimed to retain a sense of this complexity of interacting and concurrent medical, psychosocial and emotional experiences, whilst assessing the importance of education engagement, which remained the focus of the study. In future publications the restriction of word limits imposed by journals will further encourage and develop the focus on specific aspects of this work.

9.5.2 The paper will have strong data

The data generated for the I.P.A in study three came from the interviews and for Smith “getting good data requires doing good interviewing” (p. 24) (Smith 2011). As discussed in chapter one, I believe my experience of working with teenagers with cancer helped me to be sensitive to their needs and conduct good quality interviews. Using a longitudinal approach allowed me to build a rapport with each participant through an increasing awareness of their individual situations and experiences, which enabled me to be more sensitive in the interviewing of each participant. Throughout the time-points the interviews were adapted to the needs of each individual participant and I believe that this also contributed to good quality interviews that produced strong data. Participants were allowed choice in several aspects of the interview method including; whether and how to provide visual images, when and to some extent where the interviews happened, and they were predominately allowed to direct the course of the interviews through their images and/or their descriptions of experiences.

9.5.3 The paper should be rigorous

The rigorous nature of the I.P.A method was adhered to throughout the analysis, through attentively examining the transcripts of each participant and developing analytical interpretations that were reassessed frequently. The rigour of I.P.A in study three is also represented by the extracts from participants and Table 8.2 showing the themes that each participant contributed to. Smith recommends that when conducting I.P.A in samples with over eight participants, each theme should be represented by at least three of these participants. Table 21 shows that this was the case for study three, regardless of whether extracts were presented from each participant in the analysis presented in chapter eight. The aim of using extracts was to clarify the theme under discussion and anchor the analysis in the experiences of the participants. Therefore, some participants were more frequently represented in the extracts than others and this was because extracts were selected that best exemplified the issue under discussion, rather than ensuring that an equal number of extracts were presented from each participant.

As well as demonstrating that the I.P.A was indeed derived from the individual experiences of the participants, rigour was encouraged through regular analysis meetings with the supervisory team, where emerging themes and maps were examined to assess their representation of the data. This also encouraged ongoing assessment of the extent of researcher influence and external judgement of participants rather than a focus on the experiences they described.

9.5.4 Sufficient space must be given to the elaboration of each theme

This is an area of quality assessment in which a thesis has a significant advantage over a published paper. The I.P.A presented in chapter eight was extensive, covering the conceptual map and I.P.A themes in thorough detail spanning over seventy pages.

9.5.5 The analysis should be interpretative not just descriptive

The initial approach that was taken to ensure that the analysis of the interview data was interpretative and not merely descriptive was to closely follow the method of I.P.A as described in chapter six. Through a close examination of each individual transcript, the analysis developed from the factual and descriptive elements of their accounts, to the meanings these experiences might hold for participants. The interpretation of experiences was further enhanced through the development of themes and the conceptual map presented in chapter eight. The conceptual map was comprised of overarching and interacting interpretative psychological concepts and constructs, which remained grounded in the interview data, but were more than descriptions of their experiences. Extracts were presented for each section of the analysis and interpretation was offered for the extent to which these extracts contributed to the theme under discussion. Throughout the interpretation of the experiences of participants, alternative interpretations were discussed in supervision meetings and presented at points of the analysis. These alternative interpretations were then rejected or used to further enhance or replace an initial interpretation. The assessment of alternative interpretations provided an important part of the ongoing interpretation of the data and was a further step away from more straightforward descriptions.

9.5.6 The analysis should be pointing to both convergence and divergence

The assessment of convergence and divergence was carefully attended to in the construction of the I.P.A themes and conceptual map. Each theme and subtheme was presented with attention to the different ways they were expressed by participants and the meaning that themes seemed to have for individuals. Contrasting examples were presented through extracts and interpretation, so as to provide a construction of the analysis that was representative of all participants. A good example of this was the adjustment timeline that was presented within the timelines theme. There appeared to be a significant variety of ways that participants presented their experience of adjustment to cancer and cancer related experiences. Close attention was paid to giving a representative and non-judgemental portrayal of the divergence present within this timeline, whilst maintain a sense that this divergence was within a convergent theme of adjustment.

9.5.7 The paper needs to be carefully written

The work throughout this thesis has been through several stages of drafting before the final version presented here. Chapter eight underwent the most numerous and substantial re-drafting, as the clarity

and consistency of the I.P.A was to provide the most important content of the thesis. Careful attention was paid to the way that the I.P.A was conducted and explained, so that the analysis was always grounded in the experiences of the participants and not the judgement of the author.

9.6 Limitations of the research

The main limitation of study three of the research was the small sample size for the analysis of the quantitative measures. This limited the statistical analysis that could be applied to the data and therefore a reliable assessment of interrelationship of variables was not possible. However, the small sample size was an inevitable consequence of the mixed methods approach, which was qualitatively-led and therefore tied to the needs of the interviews. Conducting and analysing a significantly greater number of interviews to allow for the generation of enough quantitative data to reliably analyse the measures would not have been practically possible.

It would have been interesting to have taken a different approach to sampling whereby young people could have been screened to assess their existing engagement with education and then two groups, “engagers” and “non-engagers”, could have been interviewed. The sampling approach, and potentially the methods, may have favoured those young people that were able and/or willing to engage with the research and their education.

It would have been good to have had a neutral research space to conduct the interviews. The majority of the interviews were conducted in consultation rooms or “quiet rooms” within outpatient clinics, or on the inpatient ward at the young person’s bed or side room. All of these interview spaces may have had connotations for the young person of clinical and medical experiences, which may have influenced their behaviour or feeling within the interviews.

The potential influence of the researcher in shaping the design, implementation and analysis of the research is a common criticism of qualitative research and one that can be applied here. It is hoped that the reflexive sections throughout the thesis have made this potential influence as transparent as possible. It is also hoped that this influence has ultimately been a strength of this piece of research rather than a limitation.

9.7 Implications for future research

The research presented in this thesis has provided the first in-depth qualitative investigation of education experiences for teenagers with cancer. Through this research the complexity of the experiences of this population has begun to be uncovered and this has opened many potential avenues requiring further exploration in future research. I believe that this thesis has also shown the benefit of

a qualitative approach when investigating the complicated lives of young people with cancer, and that future research should strongly consider using qualitative methods to understand the needs of this population. The difficulty that previous research has had in establishing consistent quantitative findings within TYA psychosocial oncology research, presented in chapter two, is perhaps reflective of the problem quantitative methods have in capturing the full complexity of the intersecting timelines and experiences involved in the lives of teenagers with cancer.

It would be interesting to focus on the further investigation of specific aspects of the findings of this thesis. Further research into the intricacies of telling and knowing across the TYA population has the potential to yield interesting findings that could inform support and information provided to young people with cancer. It may be worth assessing this in narrow age brackets within the TYA spectrum to investigate age differences in the experience of telling.

Timeline thinking shaped aspects of the analysis of study three, but it was a result rather than a focus of the research. The extent to which the timeline approach to conceptualising treatment shapes the experience of cancer for young people would be an interesting area to investigate further. It seemed that participants were often regurgitating the treatment timeline given to them by clinicians in a very matter of fact and often impersonal way. It would be interesting to look at different approaches to viewing this timeline that include the fluctuating impact of treatment and cancer on the mind and emotions of young people. There may be potential here to help some teenagers reconceptualise their timelines so that they seem less like a series of steps to be worked through.

The sample of study three was limited to 13-16 year olds and therefore the investigation of older teenagers and young adults would illuminate the extent to which the findings are applicable to a different section of the TYA population. It would also be interesting to assess to what extent the findings would be consistent across other TYA populations with health related difficulties such as; cystic fibrosis, diabetes, asthma, chronic pain and mental health.

Although a primary purpose of this research was to give teenagers the opportunity to discuss their experiences in their own words, future research may benefit from comparing analysis of the experiences of maintaining education for teenagers with cancer from the perspective of teenagers, parents, education practitioners and members of the healthcare team. It may be possible to use this approach to comprehensively identify where the barriers are to the successful maintenance of education for young people.

9.8 Revisiting the aims of the thesis

Aim 1 - To investigate the experiences of teenagers as they try to maintain engagement with their education following a diagnosis of cancer.

This aim has been the driving force behind every aspect of this thesis. The literature reviews and the three studies have all contributed valuable information to the assessment of the education experiences of this population.

Aim 2 - To produce an evidence base for the area of education engagement that was centred on the perspective and experiences of teenagers with cancer.

The realisation of this aim is twofold and ongoing. Firstly, this research has begun to add to the literature through two journal publications, which cover the SRR and the findings of studies one and two. However, out of the information in these publications, only study one was generated from the perspective and experiences of teenagers with cancer. The findings of study three provide a far greater depth of analysis and insight into the experiences of teenagers with cancer and the dissemination of this work has begun through presentations at conferences and research meetings. This dissemination is planned to continue through presentations, but also through peer-reviewed publication(s). The education experiences of teenagers with cancer have not been assessed in this much detail using qualitative methods and with education as the main focus. Therefore, the publication of the findings from study three will be an important addition to the literature, which will have the voices of the teenagers themselves at the centre.

Aim 3 - To provide evidence and recommendations for the future development of services to appropriately support teenagers with their education following a diagnosis of cancer.

The literature reviews and the three studies provide evidence that can be used to inform the development of services to support teenagers with their education after a diagnosis of cancer. Since commencing this research I have provided consultation to professionals developing TYA professional roles to support education engagement, as well as a group of researchers designing a research project to develop an assessment tool for educational and vocational satisfaction in this population. I aim to work further with professionals and organisations in this area to convert the following recommendations into future research, guidelines for practice or, ideally, job descriptions for

specialist education support workers. The key recommendations for the development of future services and support that have emerged from this thesis are as follows:

- Education issues should be addressed as close to diagnosis as is reasonable in the individual circumstances.
- It should not be assumed by anybody involved that education is no longer an important or relevant issue to a young person after a diagnosis of cancer.
- Young people should be given the option to be involved in every decision made about their education, health and social life, and be guided as to how they could exert influence i.e. give them examples.
- The maintenance of peer groups should be encouraged and facilitated by schools, parents and hospital staff, who need to work with the young person to break down logistical, social, health and personal barriers to peer interactions.
- Young people should be advised and supported about how and when to share their cancer diagnosis and experiences with others and how to cope with the ramifications of this telling.
- Schools need to be flexible in reorganising the young person's education timeline to allow them to progress with their peers, if this is what they want. In fact, in reference to a young person with cancer, schools are presented with circumstance that give them the opportunity to be more flexible than normal in the way education is delivered and conceptualised, which is an opportunity that should be taken.
- Schools should be aware of the individual and fluctuating nature of the young person's need for special consideration and normality, and should work closely with the young person, parents and healthcare staff to monitor this shifting balance and achieve the best situation possible.
- Immediately after diagnosis, schools should be advised to nominate a single member of staff with an existing good relationship with the young person and family to be their main contact for all communication, questions and logistics. All communication from the school to the young person should go through this member of staff to minimise the risk and potentially damaging effect of miscommunications.
- Schools should value, encourage and facilitate the young person's ongoing involvement in school work and exams through regular communication with the hospital school and home tuition services, but also with the young person and their family.
- Schools should be advised to demonstrate ongoing care and concern for the young person regardless of their ability to attend school and be encouraged to involve the young person in as many aspects of the school as they are able to participate in, so that they can still feel part of the school community.

- A specialist education worker should be available to all young people with cancer and this person should have a job description that allows them to support the wide range of psychosocial issues outlined in this thesis, as well as attending to the practicalities of education.
- The intersecting experiences of education, cancer and adolescent development are complicated and individual and therefore schools, healthcare professionals, parents and peers should be advised to be as flexible as possible in addressing the individual and changing needs of the young person.

9.9 What next?

Following the completion of this thesis there are several plans to engage further with the participants and disseminate the findings to the appropriate clinical and care communities. In the final interviews participants were asked if they would like to receive a summary of the findings, which all of them were interested in. A summary of the findings will therefore be prepared in language appropriate to the population and distributed to them. Care will be taken to ensure that the families of the participants have not been bereaved in the period between the completion of the study and the dissemination of the findings. Participants will be encouraged to comment on these findings if they are willing and able to.

In addition to the published SRR and questionnaire studies featured in chapters two and three, a minimum of one and maximum of three further peer reviewed publications will be pursued. The findings from study three will be condensed and focussed into an article that will aim to be published in a journal appropriate to the field of TYA oncology. It is possible that an article which practically outlines an approach to education support for young people with cancer will also be pursued, which would be based on the list of recommendations in 9.8. Regardless of whether a practical article is pursued, the practical application of the work in this thesis will be explored with appropriate organisations within TYA care. The third potential publication would be a discussion of the methods used in the main study and the appropriateness of their implementation with this population.

Conference presentations and research meetings will also be used to disseminate this work. It is planned to ask the participants from study three if they would be willing to be part of the dissemination of the findings and to discuss some of their education experiences.

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List of Appendices

1. Find Your Sense of Tumour Questionnaire for Study One
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15. I.P.A quality assessment guide

Appendix 1 - FYSOT Questionnaire

When you were diagnosed were you.....

1. At school
2. At college
3. At University
4. Working
5. Not working (full time mothers/carers/disability allowance)
6. Unemployed

How much of a priority is it for you to continue with your education at the moment?

1. Very important
2. Quite important
3. Not that important
4. Not important at all

How much education did you miss during treatment?

1. I didn't missed any
2. Not that much
3. About half
4. Most of it
5. All of it
6. I'd already left education when I was diagnosed

Have you managed to go back to full time education?

1. Yes
2. No
3. I haven't finished treatment
4. I'd already left education when I was diagnosed

Has missing time from education affected your friendships?

1. No not at all
2. Not that much
3. Quite a bit
4. Yes a lot
5. I haven't missed any education
6. I'd already left education when I was diagnosed

What was it like for you when you first went back into school, college or university?

1. Very hard
2. Quite hard
3. Not that bad
4. Easy
5. I haven't gone back to education

Does your appearance ever affect your willingness to go to school, college or university?

1. Yes a lot
2. Yes quite a bit
3. No not that much
4. No not at all
5. I'd already left education when I was diagnosed

Do you think the education support you had during your treatment was....

1. Non-existent
2. Not good enough
3. Okay
4. Very good
5. I'd already left education when I was diagnosed

Who has helped you the most with your education during your treatment?

1. Teachers at school, college or university
2. Other staff at school, college or university
3. Education staff at hospital
4. Health staff at hospital
5. Parents
6. Home tutor
7. Other
8. I was left to sort it out myself

Have your education plans changed since you were diagnosed?

1. Yes a lot
2. Yes quite a bit
3. No not that much
4. No not at all
5. I'd already left education when I was diagnosed

Do you feel you have a strong say in how much time you spend at school, college or university?

1. A lot
2. Quite a bit
3. Not that much
4. Not at all
5. I'd already left education when I was diagnosed

Appendix 2 - Practitioner Questionnaire

Initial Email:

Dear All

Please find attached a link to complete an online questionnaire:

The purpose of this questionnaire is to assess the current feeling amongst professionals regarding the effect a cancer diagnosis has on the education of teenagers. By completing this questionnaire you will be providing important data, which will contribute to a wider study in this area. The questionnaire should take no longer than 15 minutes to complete.

If you have any questions before completing the questionnaire please contact Simon Pini on s.pini@leeds.ac.uk

Please click on the following link:

www.psych.leeds.ac.uk/q/teenagecancer

Many thanks

Sue Morgan MBE

Questionnaire:

What is your role within TYA oncology services?

How long have you worked with TYA oncology patients?

Which Teenage Cancer Trust unit(s) do you work with?

In general, how much of a priority do you think it is for patients to continue with their education during their treatment?

1. Very important
2. Quite important
3. Not that important
4. Not important at all

In your experience how important do you think the following issues are in relation to a teenage cancer patient's satisfaction with education? (Please rank from 1- the most important to 10 - the least important)

- | | |
|--|--------------------------|
| School attendance | <input type="checkbox"/> |
| Future education/career plans | <input type="checkbox"/> |
| Reintegration during treatment | <input type="checkbox"/> |
| Self-esteem | <input type="checkbox"/> |
| Reintegration after treatment completion | <input type="checkbox"/> |
| Independence | <input type="checkbox"/> |
| Relationships with peers at school | <input type="checkbox"/> |
| Body image in relation to school | <input type="checkbox"/> |
| Academic achievement | <input type="checkbox"/> |
| Behaviour | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> |

Could you please comment on your selection?

What are the main barriers you see patients facing when continuing their education during treatment?

What do you see going well for patients when continuing their education during treatment?

Who do you think provides the most education support to patients during treatment?

What do you think of the standard of education support available to patients during their treatment?

1. Non-existent
2. Not good enough
3. Satisfactory
4. Good
5. Excellent

What do you think would be the most important change that could be made in order to minimise the impact of a cancer diagnosis on a teenager's education and why do you think this is the case?

Any further comments.....

Appendix 3 - Information Leaflet

The Emma Mallby Memorial Fund
University of Leeds and Computer

UNIVERSITY OF LEEDS

<http://emmf.org/>

What now?

Take some time to think about whether you would like to take part and talk it through with anybody you would like to. Think of any questions you have for the researcher or anything you are not sure about. Once you have decided then contact the researcher or ask somebody to contact them for you and we can get started.

UNIVERSITY OF LEEDS

www.leeds.ac.uk

Would you like to be involved in research aimed at improving care for teenage cancer patients?

The Leeds Teaching Hospitals **NHS**
NHS Trust

www.leedsteachinghospitals.com

Simon Pini
tel: 07980 551929
e-mail: s.pini@leeds.ac.uk

The Emma Mallby Memorial Fund
University of Leeds and Computer

What is the aim of the study?

At the moment there is not very much information about how cancer affects the education and school life of teenagers. By understanding more about this we will be able to give good advice to people who set up services to support teenagers with their education all across the country.

When would I take part?

You can take some time to decide whether or not to take part, but you will need to decide within two months of your diagnosis. As it says above, you will then be asked to be involved at two other times; 6 months after diagnosis, and 12 months after diagnosis. The interviews will be arranged at a time that suits you and you can take the photos/recordings at any time you have one of the study cameras.

Why should I take part?

Teenagers all over the country can have problems with school and their education because of cancer. At the moment not all teenagers get help with their education when they have cancer and sometimes the help they do get is not as good as it could be. With your help in this study we can help improve this situation for teenagers with cancer in the future. You might also enjoy it!

What is involved?

If you decide to take part then this is what would happen:

You will be asked to complete a short consent form and three questionnaires

You will then be loaned a digital camera, digital recorder or asked to complete a scrap book for a couple of weeks and asked to record anything in those two weeks that has helped you or stopped you carrying on with your education (more details on another sheet)

An interview will then be arranged when you will come and talk about the photos you have taken with the researcher (Simon Pini) This will then be repeated after 6 months and 12 months, so the amount that you have to do will be spread out over 12 months.

Will anybody know I am taking part?

Your personal details (age, name etc) will be confidential. All of the data (questionnaire results, interview recordings and study forms) will only be looked at by the research team (Simon Pini, Siobhan Hugh-Jones and Peter Gardner) and your name will not be used (you will be given a number instead). All of the data will be stored securely in locked filing cabinets or on secure University of Leeds computer systems. Any reports, presentations or publication of results will not name anybody taking part.

Is there a downside to taking part?

If you do decide to take part then we will be asking for some of your time, but it will be spread over 12 months. There is the possibility that during the interviews we may talk about some things that you find difficult or upsetting, but you will never be forced to talk about anything you do not want to. If at any point during the study you would like to talk to anybody about your feelings and experiences of cancer, please let the researcher know and we can sort something out for you. If you do decide to take part you will always have the option of withdrawing at any time you want to.

Appendix 4 - Image Instructions

The Emma Malby Memorial Fund
University of Leeds

<http://emmf.org/>

UNIVERSITY OF LEEDS

www.leeds.ac.uk

The Leeds Teaching Hospitals NHS
NHS Trust

www.leedsteachinghospitals.com

Simon Pini
tel: 07980 551929
e-mail: s.pini@leeds.ac.uk

Photo and image recording instructions

What happens to the images after the interview?

When the interview is completed the photos you have taken will be kept securely by the research team. Any photos that show people's faces will have to be blurred or pixilated. If we want to use any of your images in any of our reports we will ask you first.

Why am I taking photos/images?

We will have a look at the photos you have taken or what you have recorded when you come to the interview. In the interview we will talk about what you have recorded and why you have recorded it.

What do I take photos/images of?

You will have a lot of free choice about what to take photos of or record, but we would like you to stick to things that are linked to this project. So, we would like you to record anything that you think has helped you or stopped you carrying on with your education. Try to record things that you will be able to talk a little bit about in the interview. You can record something just as a reminder of something you would like to talk about in the interview.

How many photos/images should I bring?

It does not really matter how many photos you take or things you record. Do not worry about bringing too much to the interview, but try and bring enough so that we have something to talk about. Aim for at least 5 things that have helped you or stopped you carrying on with your education.

When do I take photos/images?

You will be asked to take photos or record images in the two weeks before each interview and we will send you a reminder of when this is.

What can't I take photos/images of?

Try not to take photos of or record anybody who doesn't want their photo taken. Be aware of what or who is in the background. So, if you take photos on the ward, then try not to get other patients or families in the background unless they are meant to be part of it. If you would like to take photos of or record people then ask them to sign the short consent form we will give you. Do not record anything that could be seen as inappropriate or offend anybody.

Can I use my own camera?

You can use your own camera or camera-phone if that will make things easier for you. You will be able to borrow one from the research team if you would like to. If you are using your own camera then we will need to check that we can get the images from your camera onto the research computer before we start.

Appendix 5 - Parent information sheet

The Education and School Life of Teenagers with Cancer

Your child or a young person in your care has been approached to be involved in research aimed at improving care for teenage cancer patients?

What is the aim of the study?

At the moment there is not very much information about how cancer affects the education and school life of teenagers. By understanding more about this we will be able to give good advice to people who set up services to support teenagers with their education all across the country.

What is involved?

Participants will be asked to complete a short consent form and three questionnaires. They will then be loaned a digital camera, digital recorder or asked to complete a scrap book for a couple of weeks. They will be asked to record anything in those two weeks that has helped or stopped them carrying on with their education (more details on another sheet).

An interview will then be arranged when they will come and talk about the photos they have taken with the researcher (Simon Pini). This will then be repeated after 6 months and 12 months, so the amount that they have to do will be spread out over 12 months.

When would they take part?

They can take some time to decide whether or not to take part, but will need to decide within two months of their diagnosis. As it says above, they will then be asked to be involved at two other times; 6 months after diagnosis, and 12 months after diagnosis. The interviews will be arranged at a time that suits them and they can take the photos/recordings at any time they have one of the study cameras.

Will anybody know they are taking part?

Their personal details (age, name etc) will be confidential. All of the data (questionnaire results, interview recordings and study forms) will only be looked at by the research team (Simon Pini, Siobhan Hugh-Jones and Peter Gardner) and their name will not be used (they will be given a number instead). All of the data will be stored securely in locked filing cabinets or on secure University of Leeds computer systems. Any reports, presentations or publication of results will not name anybody taking part.

If they tell me something during the project, or take a picture of something, that makes me believe that they are at risk of harm, or may harm someone else, then I am required to tell

someone else so that harm can be prevented. So, confidentiality only holds until this point. If this situation did occur then I would need to tell the appropriate person within the care team, but I would discuss this with the participant first so they understood what would happen next.

What is the benefit of taking part?

Teenagers all over the country can have problems with school and their education because of cancer. At the moment not all teenagers get help with their education when they have cancer and sometimes the help they do get is not as good as it could be. With their help in this study we can help improve this situation for teenagers with cancer in the future.

What are the possible downsides of taking part?

If they do decide to take part then we will be asking for some of their time, but it will be spread over 12 months. There is the possibility that during the interviews we may talk about some things that they could find difficult or upsetting, but they will never be forced to talk about anything they do not want to. If at any point during the study they would like to talk to anybody about their feelings and experiences of cancer, they can ask the researcher or a member of the teenage and young adult service to arrange this for them. If they do decide to take part they will always have the option of withdrawing at any time.

What now?

Take some time to think about whether you would be happy for the young person to take part and talk it through with anybody you would like to. Please feel free to ask the researcher or teenage and young adult service any questions you may have. Once you are happy for the young person to take part then please talk to the researcher about signing a consent form.

Researcher: Simon Pini

Telephone: 07980 551929

E-mail: s.pini@leeds.ac.uk

Appendix 6 - Patient Consent Form

Patient Consent Form

The Education and School Life of Teenagers with Cancer

Study ID:

- 1. I confirm that I have read and understand the information sheet dated (version _____) for the above study, and have had the opportunity to ask questions.
- 2. I have read and understood the instructions for taking photos, making videos or scrap books.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.
- 4. I understand that my identity will remain anonymous throughout the study, including any reports or articles that might be written using the results of the study.
- 5. I agree that my interviews can be recorded so that the researchers can analyse the data.
- 6. I agree that the recording of my interviews and the results of my questionnaires can be stored in secure files by the research team.
- 7. I understand that even if I withdraw from the study, the data collected from me will still be used in analysing the results of the study, unless I specifically withdraw consent for this.
- 8. 'I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [*company name*], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.'
- 9. I agree to take part in the study.

Name of patient..... Date.....Signature.....

Name of parent/guardian..... Date.....Signature.....

Name of researcher..... Date..... Signature.....

Appendix 7 - Adolescent Coping Orientation for Problem Experiences

(ACOPE)Scale items:

When you face difficulties or feel tense, how often do you...

1. Go along with parent's requests and rules
2. Read
3. Try to be funny and make light of it all
4. Apologize to people
5. Listen to music-stereo, radio
6. Talk to a teacher or counsellor at school about what bothers you
7. Eat food
8. Try to stay away from home as much as possible
9. Use drugs prescribed by doctor
10. Get more involved in activities in school
11. Go shopping, buy things you like
12. Try to reason with parents and talk things out, compromise
13. Try to improve yourself (get body in shape, get better grades, etc.)
14. Cry
15. Try to think of the good things in your life
16. Be with a boyfriend or girlfriend
17. Ride around in the car
18. Say nice things to others
19. Get angry and yell at people
20. Joke and keep a sense of humour
21. Talk to a minister/priest/rabbi
22. Let off steam by complaining to family members
23. Go to church
24. Use drugs (not necessarily prescribed by a doctor)
25. Organize your life and what you have to do
26. Swear
27. Work hard on school work or school projects
28. Blame others for what's going on
29. Be close with someone you care about
30. Try to help other people solve their problems
31. Talk to your mother about what bothers you
32. Try, on your own, to figure out how to deal with your problems or tension
33. Work on a hobby you have (sewing, biking, etc.)
34. Get professional counselling (not a school teacher or school counsellor)
35. Try to keep up friendships or make new friends
36. Tell yourself the problem(s) is not important
37. Go to a movie
38. Daydream about how you would like things to be
39. Talk to a brother or sister about how you feel
40. Get a job or work harder at one
41. Do things with your family
42. Smoke
43. Watch T. V.
44. Pray
45. Try to see the good things in a difficult situation
46. Drink beer, wine, liquor
47. Try to make your own decisions
48. Sleep
49. Say mean things to people, be sarcastic
50. Talk to your father about what bothers you
51. Let off steam by complaining to your friends
52. Talk to a friend about how you feel
53. Play video games (Space Invaders, Pac-Man), pool, pinball, etc.
54. Do a strenuous physical activity (jogging, biking, etc.)

USE THE FOLLOWING RESPONSE CATEGORIES

- a. Never
- b. Hardly
- c. Sometimes
- d. Often
- e. Most of the time

Appendix 8 - SWEMWBS

The Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of
each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

"Short Warwick Edinburgh Mental Well-being Scale (SWEMWBS)
© NHS Health Scotland, University of Warwick and University of Edinburgh, 2007,
all rights reserved."

Appendix 9 - P.A.S.S items

P.A.S.S. Items	
Q1: "I think carefully about my work"	Q26. "I find school work too difficult for me"
Q2. "I worry about getting my work right"	Q27. "I am bored at school"
Q3. "I can ask my teacher when I am stuck with my work"	Q28. "My teacher notices when I have worked hard"
Q4. "I enjoy doing hard school work"	Q29. "I am happy when I am in school"
Q5. "I can concentrate on my work in class"	Q30. "I am on time for lessons"
Q6. "I know how to solve the problems in my school work"	Q31. "I like being at school"
Q7. "I like doing school work at home"	Q32. "When I get stuck with my work, I can work out what to do next"
Q8. "This school is a friendly place"	Q33. "I like having problems to solve"
Q9. "Teachers explain things well"	Q34. "I need more help with my work"
Q10. "My attendance at school is good"	Q35. "My teachers tell me when I have done something well"
Q11. "I think that problem solving is fun"	Q36. "I feel safe when I am in school"
Q12. "I'd rather be somewhere else than in school"	Q37. "I get into trouble during breaks or lunchtimes"
Q13. "I think the rules in school are fair"	Q38. "Learning new things is easy for me"
Q14. "I can read well"	Q39. "I know the meaning of a lot of words"
Q15. "I think this is a good school"	Q40. "I like my teachers"
Q16. "I like doing tests"	Q41. "I feel I belong to this school"
Q17. "I am lonely at school"	Q42. "I am clever"
Q18. "My teachers expect me to work hard"	Q43. "I make mistakes with my work"
Q19. "I behave well in class"	Q44. "Working hard in school will help me in the future"
Q20. "I like having difficult school work to do"	Q45. "The work I have to do in class is too easy"
Q21. "I like discussing things"	Q46. "Thinking carefully about your work helps you do it better"
Q22. "I like using my brain"	Q47. "I get anxious when I have to do new work"
Q23. "I know how to be a good learner"	Q48. "I try to do my best in lessons"
Q24. "Learning is difficult"	Q49. "I can do my homework easily"
Q25. "I'm not good at solving problems"	Q50. "When I'm given new work to do, I feel confident I can do it"

USE THE FOLLOWING RESPONSE CATEGORIES

No, not at all
No, not much
Yes, a bit
Yes, a lot

Appendix 10 - Patient Data Sheet - Baseline

Study Number:

How old are you?

Where do you live?

Which school do you go to?

What school year are you in?

What type of cancer do you have?

How long has it been since you found out you had cancer?

Who is your main hospital contact person? (usually a nurse specialist)

Appendix 11 - Patient Data Sheet – 6 and 9 months

Study Number:

How old are you?

What type of cancer do you have?

What treatment have you had since the last interview? (you can tick more than one box)

Chemotherapy as an inpatient Radiotherapy

Chemotherapy as an outpatient Surgery

How much school have you missed since the last interview? (tick the one box the is closest to your answer)

I haven't been to school at all I've been every day

I've missed less than one month I've missed more than one month

What after school activities have you been to since the last interview? (e.g. school trips, sports activities)

Who have you had education support from since the last interview? (you can tick more than one box)

Home tutor Hospital school Parents/Carer
Learning Mentor (hospital) Learning Mentor (school) Other

Other.....

Photography Consent Form

To be completed by individual(s) (parents/guardians if subject is less than 18 years of age) before photographs are taken.

The person taking these photographs is participating in a research project in association with researcher **Simon Pini** at **University of Leeds** and will only be used in a later interview with that person in order to help the discussion.

Person(s) in photograph

I hereby grant permission for the photographs to be used in this way.

Name & Address (please print)
.....
.....

Signature.....Date.....

If the photographs are to be used in any other way further permission will be obtained from you.

Photography Release Form

I hereby agree that the researcher **Simon Pini** undertaking a project at **University of Leeds** has the right to use the photograph shown below in a report on the associated research project and possible publication in scientific journals.

Person(s) in the photograph

I hereby grant permission for the photographs to be used in this way.
To be completed by individual(s) (parents/guardians if subject is less than 18 years of age).

(please tick) I confirm that all identifying features have been disguised/removed.

Name & Address (please print)
.....
.....

Person who took the photograph

I hereby grant permission for the photographs to be used in this way.

Name & Address (please print)
.....
.....

Signature.....Date.....

Actual image to be used shown here

Appendix 14 - Ethical and R&D Approvals

Appendix 14a - University of Leeds ethical approval for studies one and two



Appendix 14b - NHS ethical approval letter for Study Three



Health Research Authority NRES Committee Yorkshire & The Humber - Leeds Central

Yorkshire and Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS8 4RA

Telephone: 0113 30 50188
Facsimile: 0113 85 56191

20 September 2012

Mr Simon Pini
Research Assistant/PhD student
University of Leeds
Psychosocial Research Group
Level 3, Bexley Wing
St. James' Hospital, Leeds
LS9 7TF

Dear Mr Pini

Study title: Education Experiences of Teenage Cancer Patients
REC reference: 12/YH/0387

Thank you for your letter of 07 September 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

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

Management permission or approval must be obtained from each host organisation prior to

Appendix 14c - Local R&D approval for Study Three

The Leeds Teaching Hospitals NHS Trust

Ref: Michael Wood

25/10/2012

Mr Simon Pini

Psychosocial Research Group
Level 3, Bexley Wing
St. James' Hospital, Leeds
Leeds
LS9 7TF

Research & Development

Leeds Teaching Hospitals NHS Trust
34 Hyde Terrace
Leeds
LS2 9LN

Tel: 0113 392 2878
Fax: 0113 392 6397

r@d@leedsth.nhs.uk
www.leedsth.nhs.uk

Dear Mr Simon Pini

Re: NHS Permission at LTHT for: Education Experiences of Teenage Cancer Patients
LTHT R&D Number: UI12/10356
REC: 12/NS/0082

I confirm that *NHS Permission for research* has been granted for this project at The Leeds Teaching Hospitals NHS Trust (LTHT). NHS Permission is granted based on the information provided in the documents listed below. All amendments (including changes to the research team) must be submitted in accordance with guidance in IRAS. Any change to the status of the project must be notified to the R&D Department.

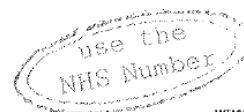
Permission is granted on the understanding that the study is conducted in accordance with the *Research Governance Framework for Health and Social Care*, ICH GCP (if applicable) and NHS Trust policies and procedures available at http://www.leedsth.nhs.uk/sites/research_and_development/.

This permission is granted only on the understanding that you comply with the requirements of the *Framework* as listed in the attached sheet "Conditions of Approval".

If you have any queries about this approval please do not hesitate to contact the R&D Department on telephone 0113 392 2878.

Chairman Mike Collier CBE Chief Executive Maggie Boyle

The Leeds Teaching Hospitals incorporating:
Chapel Allerton Hospital Leeds Dental Institute Seacroft Hospital
St James's University Hospital The General Infirmary at Leeds Wharfedale Hospital



W1A285

Appendix 15 - I.P.A Quality Assessment Guide

Table 10. What makes a good IPA paper?

The paper should have a clear focus. Papers providing detail of a particular aspect rather than a broad reconnaissance are more likely to be of high quality. This focus may be determined at the outset or emerge during analysis. This focus is apparent in many of the good IPA papers illustrated, for example, Chapman et al. (2007) examine the impact of one particular technology in heart disease. Turner et al. (2002) sample one specific group of ex-professional sports players.

The paper will have strong data. Most IPA is derived from interviews and this means that, for the most part, getting good data requires doing good interviewing. This is a particular skill that must not be underestimated. The quality of the interview data obtained sets a cap on how good a paper can subsequently be. Examples of good data are given in many of the summaries of good papers presented earlier. High-quality data is integral to the success of these papers.

The paper should be rigorous. One should aim to give some measure of prevalence for a theme and the corpus should be well represented in the analysis. Extracts should be selected to give some indication of convergence and divergence, representativeness and variability. This way the reader gets to see the breadth and depth of the theme. For papers with small sample sizes (1_3), each theme should be supported with extracts from each participant. For papers with sample sizes of 4_8, in general, extracts from half the participants should be provided as evidence. For larger sample sizes, researchers should give illustrations from at least three or four participants per theme and also provide some indication of how prevalence of a theme is determined. The two papers on chronic fatigue syndrome by Dickson et al. (2007, 2008) have, for IPA, a relatively large sample size. Their persuasiveness is enhanced by careful articulation of measures of prevalence. The overall corpus should also be proportionately sampled. In other words, the evidence base, when assessed in the round, should not be drawn from just a small proportion of participants.

Sufficient space must be given to the elaboration of each theme. In certain circumstances it may well be better to present a subset of the emergent themes so there is room to do justice to each, rather than presenting all themes but doing so superficially. The French et al. (2005) paper on patient explanations for heart attack is enhanced by having an extended and elaborate account of one of the emergent themes.

The analysis should be interpretative not just descriptive. An interpretative commentary should follow each of the extracts presented. The author is thereby showing the particular ways extracts are contributing to the unfolding theme. In order to do this the researcher is engaging in the double hermeneutic: trying to make sense of the participant and trying to making sense of their experience. For further discussion on pushing interpretation deeper, see Smith (2004).

The analysis should be pointing to both convergence and divergence. Where an IPA study reports data from more than one participant, there should be a skilful demonstration of both patterns of

similarity among participants as well as the uniqueness of the individual experience. The unfolding narrative for a theme thus provides a careful interpretative analysis of how participants manifest the same theme in particular and different ways. This nuanced capturing of similarity and difference, convergence and divergence is the hallmark of good IPA work.

The paper needs to be carefully written. Good qualitative work always requires good writing. The reader will feel engaged by a well-wrought, sustained narrative. As a result, he/she will consider they have learned in detail about the participants' experience of the phenomenon under investigation. Have a look at some of the papers rated good in this review to see what good writing looks like.

Appendix 16 – Examples of the Photos taken by Participants

Matt



Hayley



Mario



Robert



Annabella



Georgie

