

Experiences of low mood in young people with cancer

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Abstract

Young people with cancer are at increased risk of psychological difficulty, given the physical, cognitive and psychosocial developmental changes that occur simultaneously. Despite this, literature reports low rates of depression or low mood in this group, and it is not well understood why, or whether this relates to their coping strategies. Psychological support for young people with cancer is also an unmet need, but there is limited knowledge on how young people would like this need to be met.

Using qualitative methodology, this study aimed to explore experiences and opinions of low mood in young people with cancer, consider how this relates to their unique developmental challenges, and the strategies used to cope. It also aimed to understand how young people thought services could improve coping and support for low mood.

Semi-structured interviews were conducted with 19 young people who had been diagnosed and treated for cancer. The framework approach, a form of thematic analysis, was used to systematically organise, code and interpret accounts, which were organised into three final domains: 'A harder time of life', 'Interpersonal impact of cancer', and 'Making sense of my emotions'.

Findings depict similarities and variations in young people's experiences of low mood in comparison to depression in young people without cancer. However, regardless of how this is defined or whether it merits a diagnosis, it is a challenging experience, and should not be ignored. Unique difficulties in young people significantly impact on low mood, and they used a variety of coping methods to try to manage, both individually, and

using support from their environments and support networks. Young people thought support for low mood could be improved by greater awareness of emotional difficulties in the context of cancer, and provision of effective, integrated, and accessible support. Clinical and research implications are discussed.

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Chapter 1: Introduction

Overview

Chronic physical health conditions such as cancer significantly increase the risk of mental health difficulties in young people, and there is increased initiative for provision of integrated physical and mental healthcare services (Das, Naylor & Majeed, 2016; Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Edwards & Titman, 2010, Department of Health (DoH), 2015). Historically, services separate age groups into ‘children’ and ‘adults’, and only in more recent years have those in the overlap of these groups been considered in more depth. ‘Young people’ have come to be considered a distinct group, and one which faces particular adversity through cancer, due to the developmental transitions they concurrently experience (National Institute for Health and Care Excellence (NICE), 2014; Teenage Cancer Trust (TCT), 2017; Zebrack & Isaacson, 2012). The emotional impact of cancer on young people and the way they cope, adjust and present with psychological difficulties such as low mood or depression, is a developing area of knowledge. While there is evidence of depression in a sub-set of young people with cancer, the experiences of low mood in this group have thus far been neglected. This thesis reports the findings from a qualitative study designed to address this gap in knowledge. The framework approach (a form of thematic analysis) was used to identify themes relating to the experience of low mood in cancer in young people, how their unique developmental challenges impacted on their emotional experience, and how they coped with low mood.

This chapter begins by outlining the presence of mental health difficulties in children and young people with physical health conditions, particularly considering young people with cancer. It describes and reviews the unique challenges of having cancer as a young person, and the impact on their psychological wellbeing. Depression or low mood in young people with cancer is discussed and the chapter then covers theories of coping in adult populations and young people without cancer. Links to coping in young people with cancer are drawn from these, due to the absence of theories specific to this population. The evidence base for interventions and support for psychological difficulties such as depression for young people with cancer is also discussed. Gaps in the literature are identified and considered, and the rationale for the study, for adopting a qualitative approach, and the research aims are outlined.

Mental health in the context of physical illness in children and young people

One in 10 children and young people experience mental health difficulties, and they have been highlighted as a priority group in promoting psychological wellbeing and preventing mental health difficulties in recent government documents, such as Future in Mind, and The Five Year Forward View for Mental Health (DoH, 2015; Mental Health Taskforce (MHT), 2016). The risk of developing mental health problems are increased by up to four times if children and young people also have a chronic physical illness (Edwards & Titman, 2010; Hysing et al., 2007; Mental Health Foundation, 2017; MHT, 2016; Pinguart & Shen, 2011; Young Minds, 2017). Mental health also has a significant impact and burden on psychological wellbeing and physical health (World Health

Organization (WHO), 2017; DiMatteo, Lepper & Croghan, 2000; Kennard et al., 2004; MHT, 2016; Moussavi et al., 2007; Piquart & Duberstein, 2010; Satin, Linden, & Phillips, 2009). Therefore, recognising, understanding and treating mental health difficulties in children and young people with physical health conditions, and providing integrated physical and mental health services have been highlighted as increasingly important and an NHS priority area (Das et al., 2016; DoH, 2015; Edwards & Titman, 2010; MHT, 2016; Naylor et al., 2016).

Cancer in young people. One such physical health condition is cancer, where cells abnormally grow and reproduce, forming a tumour in the body that invades and damages healthy cells around it, and often spreads (Macmillan Cancer Support, 2017; Oxford English Dictionary, 2017; NHS choices, 2017). Cancer is relatively common in children and young people, and in the United Kingdom (UK) an average of 1,800 children (aged 0-14 years), and 2,400 teenagers and young adults (aged 15-24) are diagnosed each year, children most often with leukaemia, and teenagers and young adults with lymphoma. Incidence rates have increased in both groups since the early 1990's, by 11% and 28% respectively, suggesting a growing problem (Cancer Research UK (CRUK), 2017). Due to advances in treatment, which predominantly includes one, or a combination of, surgery, chemotherapy, and radiotherapy (Macmillan Cancer Support, 2017; NHS choices, 2017), survival rates have also increased. Currently 82% of children and 84% of teenagers and young adults survive for five or more years after receiving a diagnosis, and cancer is now considered a chronic illness as opposed to life-threatening

(CRUK, 2017; Edwards & Titman, 2010). Thus, there is increased focus not just on survival as an outcome, but also the quality of survival, with reference not only to physical outcomes but also the emotional impact and outcomes of cancer (Brinkman et al., 2016; Jörngården, Mattson, & von Essen, 2007; Kaye, Brinkman, & Baker, 2017; NICE, 2014).

Cancer services in the UK consider young people to be those aged 13-24 years (NICE, 2005; NICE, 2014; TCT, 2017), and these individuals are considered a distinct group due to the unique challenges they face in relation to cancer and its' treatments, which affect the social, psychological, physical and sexual developmental processes that are concurrently occurring (Abrams et al., 2007; Evan, Kaufman, Cook, & Seltzer, 2006; Park & Rosenstein, 2015; Sansom-Daly & Wakefield, 2013). Mental health problems are most likely to originate at these ages regardless of ill physical health (Patel, Flisher, Hetrick, & McGarry, 2007), and young people with cancer are a group at elevated risk of psychological difficulty (Lang, David, & Giese-Davis, 2015). It is therefore important to understand more about mental health presentation and need in this population. This is supported by NICE guidelines for children and young people with cancer (2014), which recommend that the psychological and social needs of young people and their families are assessed and supported.

Unique challenges in young people with cancer

Although cancer has a significant emotional impact across the life-span, young people face additional unique challenges in relation to the age that they experience cancer. These include changes to their cognitive, physical, psychosocial and interpersonal development, and it is important to understand how these areas affect young people with cancer, and how they could further impact on psychological difficulty (Shama & Lucchetta, 2007; Zebrack, 2011; Zebrack & Isaacson, 2012). For example, Kaye et al. (2017) produced a conceptual framework considering the complex interactions between biological, individual, family, community and global factors across the lifespan. It posited that the many interactions and factors across these areas indirectly affect psychological difficulty such as depression in young people who survive cancer, and it would be beneficial to use this model to consider all possible impacting aspects, which could inform and develop holistic interventions.

Cognitive and physical development. Adolescence is a life stage involving a great deal of cognitive change. Individuals' brains continue to grow and develop into their mid-twenties (Arain et al., 2013; Johnson, Blum, & Giedd, 2009; Steinberg & Morris, 2001; Tanner & Arnett, 2009), and cognitive development is occurring, where thinking becomes more abstract, reflective, and flexible, and conceptual thinking and deductive reasoning develop (Piaget, 1964). In young people with cancer, their functional and cognitive developmental level directly affects their ability to appraise their cancer diagnosis, treatment and experience, and aptitude to integrate new information or

concepts into their existing knowledge base. This may mean that making sense of cancer and managing it, is impacted, resulting in greater risk of psychological difficulty (Sansom-Daly & Wakefield, 2013; Kaye et al., 2017).

In addition to cognitive and brain development, young people also progress through the stages of puberty, where their bodies transition and change as they move towards adulthood, and sexual characteristics develop (Steinberg & Morris, 2001). Cancer and treatment further impact on and interrupt the physical transformations taking place, and can result in stunted growth, weight gain, acne, endocrine deficiencies, thyroid difficulties, fatigue, and hair loss (Abrams et al., 2007; Albritton & Bleyer, 2003; Cavusoglu, 2000; Choquette, Rennick, & Lee, 2016; Evan et al., 2006; Evans, 1997). These physical changes can present as long term or late effects, and inevitably affect psychosocial and psychological development, and adjustment in young people, and increase the risk of mental health difficulties, both during cancer but also in survivorship (Abrams et al., 2007; Albritton & Bleyer, 2003; Choquette et al., 2016; Evan et al., 2006; Evans, 1997).

Psychosocial development. According to Erikson (1959), a young person progresses through two psychosocial development stages, the first of which is identity versus role confusion, in adolescence (12-18 years). This stage involves the search for values, identity and a concept of self, exploration of greater levels of independence, and a

desire to fit in, paving the way for adult roles. It is prominent in young people with cancer and impacted on significantly, due the struggle of retaining identity and a self-concept whilst going through cancer (Abrams et al., 2007; Albritton & Bleyer, 2003; Evans, 1997; Zebrack & Isaacson, 2012). After gradual distancing, a cancer diagnosis in young people results in an unexpected increase in dependence on parents and their involvement in caregiving and decisions about the future, at a point where their independence and new roles are still growing (Abrams et al., 2007; Albritton & Bleyer, 2003; Eiser, 1993; Evans, 1997; Zebrack & Isaacson, 2012). This poses challenges for the whole family and a struggle in the young person for independence and separation from their caregivers, to retain concepts of identity (Kyngäs et al., 2000). The experience of changes to a young person's physical self, due to cancer or treatment will also affect development of their identity and body image, which are especially difficult for young people to manage (Evans, 1997; Fan & Eiser, 2009). Body image and identity link closely together, and were found to associate with lower levels of self-esteem, adjustment to cancer, and reduced or altered social engagement in young people with cancer (Evans, 1997; Fan & Eiser, 2009; Larouche & Chin-Pouckert, 2006; Woodgate, 2005). Lasting difficulties with body image were found in adolescents who had completed cancer treatment, where 29% had a negative body image, and 26% still had significant anxiety about their physical health. The majority of this sample also qualitatively reported continued worries about their bodies (Fritz and Williams, 1988). Another study found that greater negative perceptions of self-worth, body image and social anxiety were associated with greater time since completing treatment (Pendley, Dahlquist, & Dreyer, 1996). Given that cancer in young people co-occurs with a time of physical change, and it

causes increased difficulty in the development of identity, in relation to body image, independence and self-concept, this increases the risk of challenge in proceeding through this psychosocial development stage. This could result in greater psychopathology and emotional difficulties in young people with cancer.

The other psychosocial stage young people progress through is intimacy versus isolation, in young adulthood (18-40 years), which involves exploration and development of sexual identity, and complex committed interpersonal relationships with people other than family (Erikson, 1959). Sexual identity difficulties may develop in young people with cancer, due to the impact of cancer treatment on body image, engagement in sexual activity, and affected fertility or reproductive abilities, which add an additional strain onto existing romantic relationships, or may cause reluctance to engage in these in the future (Abrams et al., 2007; Evans, 1997; Zebrack & Isaacson, 2012). Cancer changes the way young people can access information about sex and sexual health, as they miss out on the predominant sources from which this is usually gained, such as peers and education, and young people may have to prematurely face difficult decisions such as preservation of reproductive cells (Evan et al., 2006). Difficulties with sexual identity and the multiple stressors highlighted can also result in issues with self-esteem and reduced psychological wellbeing, which could increase risk, or contribute to development of psychological difficulty such as depression, both during cancer and afterwards (Evan et al., 2006; Evans, 1997; Fritz and Williams, 1988; Kent et al., 2012; Stinson et al., 2015).

Interpersonal and systemic factors. Given the impact of cancer on complex interpersonal relationships, and the fact that development does not occur independently of the environment, Bronfenbrenner's (1992) social ecological model (Figure 1) is described and considered in relation to young people with cancer. This model places the individual at the centre, and describes their microsystems as social interactions and activities with family, friends, healthcare and education services. The mesosystem links the multiple microsystems, and the exosystem represents interactions with wider family social networks, neighbours, the media, and social and legal systems. The macrosystem represents cultural and societal attitudes, which overarches and impacts on all preceding systems, and the chronosystem represents the passage of time, and life events, which may also be impacting on development, and on these systems.

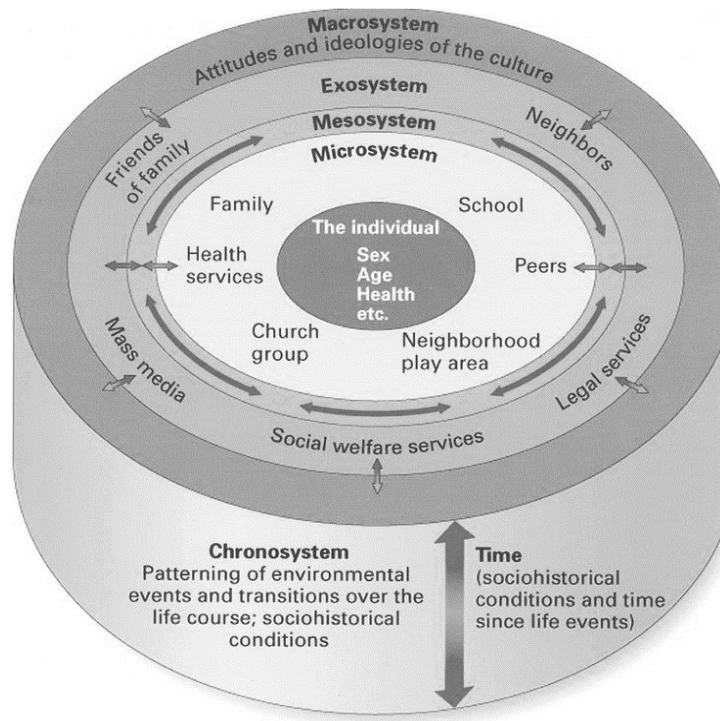


Figure 1. Social ecological model (Bronfenbrenner, 1992)

A young person's experience of and reaction to cancer, will affect and be affected by the surrounding systems highlighted in this model, especially within their microsystem (Mercer et al., 2015). There is a significant, and sometimes lasting impact on the young person's parents and family, and on communication and interactions, due to the unpredictable nature of cancer and the perceived lack of control that the young person and family have over the cancer and their lives (Allen, Newman, & Souhami, 1997; Gibbins et al., 2012; Keim et al., 2017; van't Hooft, Lindahl Norberg, Björkland, Lönnerblad, & Strömberg, 2016; Young, Dixon-Woods, Windridge, & Heney, 2003). While parents continue to be a young person's main form of care, their peer groups become increasingly important in provision of emotional support (Eiser, 1993; Kyngäs et al., 2000; Stanton-Salazar & Spina, 2005). Unfortunately, cancer disrupts young people's educational attendance and affects their existing social and romantic relationships, which inhibit opportunities for development and maintenance of relationships (Abrams et al., 2007; Çavusoglu, 2000; Kent et al., 2012). For example, as a result of being in hospital and unable to go out, young people found it difficult to maintain friendships (Gibson, Aldiss, Horstman, Kumpunen, & Richardson, 2010), and after cancer, they had to return to these interrupted contexts and rebuild friendships, which could be challenging (Choquette et al., 2016). Survivors reported that they suffered from social isolation either during cancer or in a delayed fashion, which associated with elevated psychological difficulty, such as depression (Howard et al., 2014; Kent et al., 2012). This highlights the challenges young people with cancer face in maintaining and continuing to develop interpersonal relationships, both while they experience cancer and after treatment, and the impact this has on their short- and long-term emotional wellbeing.

In summary, experiencing cancer as a young person can make this developmental stage particularly difficult, due to the cognitive, physical, psychosocial and interpersonal effects. These factors are likely to increase the risk of specific psychological difficulties, such as depression and anxiety in young people with cancer (Kaye et al., 2017; Lang et al., 2015), however few studies have directly explored these in relation to unique developmental challenges. It is important to address this gap as it would allow further understanding of the needs of this group, and how best to direct supportive services.

Low mood and depression in young people with cancer

Given the unique challenges young people diagnosed with cancer face, it is perhaps not surprising that the risk of psychological difficulty and burden is also high (Kaye et al., 2017; Lang et al., 2015; Zebrack, 2011). A range of emotional experiences have been described in young people with cancer, and are often incorporated within broader terms, such as distress, or health related quality of life (HRQoL) (Enskär & von Essen, 2007; Hedström Ljungman, & von Essen, 2005; Hedström, Haglund, Skolin, & von Essen, 2003; Kwak et al., 2013; Sansom-Daly & Wakefield, 2013; Vaudre et al., 2005; Wiener et al., 2006).

Depression or low mood in young people with cancer was selected as a specific psychological difficulty to explore further in the current research. This is because depression is the leading cause of disability worldwide (WHO, 2017), and has a

significant impact on physical health outcomes and quality of life, when comorbid with physical health problems in adults (Moussavi et al., 2007). Research shows depression predicts mortality in adults with cancer (Pinquart & Duberstein, 2010; Satin et al., 2009), and it significantly increases the risk of or is associated with non-adherence to treatment, in adults, children and young people with chronic physical illness such as cancer (DiMatteo et al., 2000; Kennard et al., 2004). Given the impact of depression on physical health and quality of life outcomes, it is therefore important to explore this specific difficulty further in young people with cancer.

Diagnostic factors in depression. Given that theories of depression and diagnosis have been predominantly developed in adult populations, this will first be reviewed, prior to consideration of this phenomenon in young people. Beck's (1976) cognitive model of depression describes the activation and dominance of three cognitive areas, resulting in negative views of self, experiences of interacting with the world, and the future. To meet diagnostic criteria of depression according to the Diagnostic and Statistical Manual of Mental Disorders, Version 5 (DSM-5) (American Psychiatric Association (APA), 2013), individuals must experience five or more of the following symptoms over a two-week period: depressed mood, reduced interest in doing things, weight or appetite changes, changes to sleep, restlessness or slowness, lack of energy, feeling worthless or guilty, problems concentrating, and suicidal ideation. Depression is not always detected or treated in adults with cancer, as the emotional reaction is considered normal, even though the symptoms of low mood significantly impact on quality of life, and are extremely difficult to experience (Chochinov, 2001; Moussavi et

al., 2007; Sharpe et al., 2004; Walker et al., 2014). It is also further complicated by the fact that physiological side effects of cancer and treatments are simultaneously diagnostic criteria for depression, such as changes in sleep, appetite, energy, and concentration (Dejong & Fombonne, 2006; Hedström et al., 2005). There is often the question of whether to adjust clinical cut-off scores in measures of depression to enable greater detection rates when occurring alongside physical illness, though this increases the risk of misclassification (Singer et al., 2009; Wang & Gorenstein, 2013). Given the overlap of symptoms and the challenge with measures, it is therefore recommended that clinical judgement is used when considering depression in the presence of a medical condition such as cancer (APA, 2013; Wang & Gorenstein, 2013), but uncertainty and lack of confidence can mean that detection of depression in the context of cancer is missed (Greenberg, 2004). These challenges may reflect why the presence of depression in adults with cancer is so variable, with a recent systematic review estimating 4-16% in inpatient and outpatient samples, and 7-49% in palliative care (Walker et al., 2013). Given the difficulty in diagnosis and varying prevalence rates in adults, it is key to explore depression and symptoms of low mood in young people with cancer, especially as this group faces additional challenges due to their developmental stage, affecting body image, identity, and interpersonal relationships (Sansom-Daly & Wakefield, 2013; Zebrack & Isaacson, 2012).

Presentation of depression in young people without cancer is more variable than in adults, and is described as persistent changes in the areas of mood, thinking, and activity levels, with an impact on day-to-day functioning (Masi, Favilla, & Mucci, 1998;

NICE, 2015). NICE guidelines (2015) recommend that sub-clinical symptoms of depression in young people should not be overlooked if they are relatively high or where there is risk of psychosocial difficulty, as they may develop into clinical levels of difficulty. This has been recognized in recent government policy, that has called for increased early intervention and quick access to mental health support services for young people (DoH, 2015; MHT, 2016). Due to the challenges in accurately detecting depression in young people without cancer, combined with the elevated risk of psychological difficulty in the context of cancer, there is a need to understand factors linked to the presentation of depression in young people with cancer, in order to accurately estimate prevalence rates.

Rates of depression in young people with cancer. Literature has demonstrated the significant effect of depression on physical health and quality of life outcomes, and variability in the way that it presents in adults with cancer. However, this has not been widely studied as an independent psychological difficulty in young people with cancer. Two recent reviews state depression is present in 5-42% of young people with cancer (Park & Rosenstein, 2015; Sansom-Daly & Wakefield, 2013), showing similar variability to adults. Variance might be associated with the number of different measures used across literature, and the timepoint at which depression was assessed. Clinical levels of depression have been observed in a distinct sub-set of young people with cancer shortly after diagnosis, during treatment, a number of years after completing treatment, and in long term survivorship (Allen et al., 1997; Compas et al., 2014; Fritz & Williams, 1988; Jörngården et al., 2007; Kwak et al., 2013; Muffly et al., 2016; Seitz et al., 2010; Von

Essen, Enskär, Kreuger, Larsson, & Sjöden, 2000; Zebrack et al., 2002; Zebrack et al., 2004). However, rates of depression often do not significantly differ when compared to published norms in the general population, or control groups (Allen et al., 1997; Eiser, Hill, & Vance, 2000; Kersun et al., 2009; Larsson, Mattson, & von Essen, 2010; Matziou, Perdikaris, Galanis, Dousis, & Tzoumakas, 2008; von Essen et al., 2000; Worchel et al., 1988). Of the minority of comparison studies where young people with cancer did present with significantly higher rates of depression, scores were still just below diagnostic cut-off (Li, Lopez, Joyce Chung, Ho, & Chiu, 2013), or all participants' scores were within normal ranges at all times (Jörngården et al., 2007).

Given the complex impact of a cancer diagnosis on young people, and greater risk factors, it is unclear how to make sense of the fact that the prevalence of depression is generally quite low. Methodological constraints within studies make it challenging to understand and delineate depression, due to diversity in sample age range, sample characteristics, inclusion of depression within wider concepts such as HRQoL or distress, assessment measures employed, and cultures being observed. There could be some hypothesized reasons for this presentation of depression in young people with cancer. Rates may be low because young people are resilient, they undergo post-traumatic growth, and depressive symptoms are not experienced (Castellano-Tejedor, Pérez-Campdepadrós, Capdevila, & Blasco-Blasco, 2016; Dejong & Fombonne, 2006; Zamora et al., 2017). Young people may experience depressive symptoms but are reluctant to or do not report these, due to concerns about stigma (Muffly et al., 2016; Taddeo, Egedy & Frappier, 2008). Self-report quantitative measures may not adequately detect symptoms,

despite being feasible to use for screening in this population (Kersun et al., 2009; Fritz and Williams, 1988; Recklitis, Blackmon, & Cheng, 2016). Alternatively, it may be that young people with cancer experience depression differently, and it is not recognized adequately by them, their families, or professionals, as it does not present in the way that would be expected for this age group. Due to the potential factors of stigma, difficulty with measurement, and variation in individual experience in young people with cancer, observing the concept of depression in this population may be too narrow, and may not capture experience. It may be more appropriate to broaden this, and instead consider symptoms of low mood in young people with cancer.

Parent and clinician reports of depression. Given the low rates of self-reported depression by young people with cancer, some studies have compared these to ratings from their parents or treating clinicians, and found consistently higher levels reported by these individuals (Hedström, Kreuger, Ljungman, Nygren, & von Essen, 2006; Kersun et al., 2009; Muffly et al., 2016; Worchel et al., 1988). Clinicians could successfully identify those with higher self-report depression scores, but also identified others who did not report depressive symptoms themselves. They were more proficient in detecting distress associated with physical aspects of cancer treatment, rather than psychosocial difficulties such as depression, which might be related to their medical training background, and less knowledge or confidence about mental health symptoms (Hedström et al., 2006; Kersun et al., 2009). It is unclear whether higher levels of depression from external reports are more accurate than young people's self-reports. It may be that they

are more accurate, and young people attempt to hide their feelings to protect their parents, in the same way that parents might attempt to hide emotions to protect their child (Young et al., 2003). Alternatively, it could be that these reports are less accurate, and parents and clinicians' own emotional appraisals or beliefs about cancer influence their perception of the young person's wellbeing (Balmer, Griffiths, & Dunn, 2014). Given this discrepancy, but without clarity on why it exists, it is especially important to better understand experiences of depression or low mood from the perspectives of young people with cancer, and to consider the way in which they experience and display symptoms of low mood.

Qualitative studies in young people with cancer. Qualitative studies have significant value in under-researched areas, and where a greater depth of knowledge would be beneficial to understand a phenomenon (Braun & Clarke, 2006; Campbell et al., 2007; Joffe, 2012; Smith & Osborne, 2008). Unfortunately, no qualitative investigations of the experience of depression or low mood in young people with cancer have yet been undertaken. However, they have been conducted to explore other areas, such as the overall experience in young people with cancer, or more specific areas such as HRQoL, major stressors, distress, and fear (Carlsson, Kihlgren, & Sørli, 2008; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Gibson et al., 2010; Hedström et al., 2005; Kameny & Bearison, 2002; Kuhlthau et al., 2015; McCaffrey, 2006; Olsson, Jarfelt, Pergert, & Enskär, 2015; Rechner, 1990; Wicks & Mitchell, 2010; Zebrack, Kent, Keegan, Kato, & Smith, 2014). These studies used focus groups, individual interviews, and surveys, with

variable forms of qualitative analysis which were not always specifically stated, and reported a variety of themes and domains. This included aspects of medical care or treatment and its effects, the effect on the individual, for example self-perceptions, developmental factors, control, and death, interpersonal factors with professionals, friends and family, and support and coping (Carlsson et al., 2008; Enskär et al., 1997; Hedström et al., 2005; Kameny & Bearison, 2002; McCaffrey, 2006; Olsson et al., 2015; Rechner, 1990; Wicks & Mitchell, 2010; Zebrack et al., 2014). Within some of these, feelings of depression were described (Enskär et al., 1997, Howard et al., 2014; Kuhlthau et al., 2015; McCaffrey, 2006). While it is useful to understand the broader experiences of young people with cancer, or aspects that cause distress or fear, and these studies provide promise that young people are willing to describe their experiences of cancer and emotional struggles, they do not provide clarification or detail on the experience of depression or low mood in this population.

To summarise, the literature suggests that routine measures of depression are used in young people with cancer, and they detect variable depression rates in small sub-groups of individuals, or at sub-clinical levels, at various time points throughout the cancer experience. To date, there is limited evidence about why young people present with depression or low mood, and whether this is associated with the unique developmental challenges they face as young people. Qualitative studies of low mood or depression in young people with cancer could help address this significant gap in the literature, by

providing greater understanding, which could aid detection of this difficulty, both by young people, and others around them.

Coping and adjustment in young people with cancer

The presence of psychological difficulties such as depression will also be affected and mediated by how young people adjust to and cope with having cancer, and it is therefore important to understand these processes, especially if they can shed additional light on why there is such variability regarding rates of depression in this group.

Coping. Coping can be broadly defined as the motivational and ever changing purposeful behaviours and cognitions produced to manage the internal or external demands of a harmful stressor. Coping is essentially a process of adaptation, where no one form of coping is considered the right type, it is more how effective that strategy is (Aldridge & Roesch, 2007; Cohen & Lazarus, 1973; Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). Coping is considered a precursor to adjustment, but both processes are iterative and ongoing, due to continuous re-appraisal and re-calibration to the situation (de Ridder, Geenen, Kuijer, & van Middendorp, 2008; Lazarus & Folkman, 1984; Walker, Jackson, & Littlejohn, 2004). It is important to understand coping, as struggling to cope and adjust to cancer in young people can increase the risk of, and result in presentation of, psychological difficulties, including low mood and depression (Aldridge & Roesch, 2007; Compas, Jaser, Dunn, & Rodriguez, 2012; Compas et al., 2014; Phipps & Srivistava, 1997).

There are no theories of coping specific to children and young people. Coping can be challenging to quantify and there are several different adult theories, all which generally divide into two areas. The first is an attempt to alter or control something individual or environmental, for example gathering information or problem solving, and the second is trying to reduce negative emotions, such as seeking social support, increasing positive cognitions, or acceptance (Compas et al., 2014; Eiser, 1993; Fields & Prinz, 1997; Folkman, 1997; Folkman & Greer, 2000; Lazarus, 1993). These two facets have been described in a variety of ways, for example problem-focused and emotion-focused (Lazarus & Folkman, 1984), primary control and secondary control (Rothbaum, Weisz, & Snyder, 1982), and approach and avoidance (Roth & Cohen, 1986).

When considering coping in young people with cancer, developmental processes need to also be considered. While most adolescents predominantly have the capacity to appraise the severity of their situation, cognitive skills are still developing, and young people have less experience in dealing with significant stressors, which could be applied to their cancer (Compas et al., 2001; Decker, 2006; Piaget, 1964; Zebrack & Isaacson, 2012). They may therefore initially be more reliant on unconscious behavioural forms of coping, such as seeking comfort from others, withdrawing, and attaching to objects for comfort, until their coping range can expand, and strategies become more conscious, abstract, varied, and can be selected or paired specifically with certain situations (Compas et al., 2001; Gunnar, 1994). However, as in adults, coping in young people is still viewed

as multifaceted, forming one component of a wider response set in self-regulation attempts when facing a challenging situation, and studies in young people with cancer have drawn on adult theories to assess and understand coping (Compas et al., 2001; Compas et al., 2012; Eiser, 1993).

Studies of coping in young people with cancer have produced inconsistent findings. A previous meta-analysis found greater problem-focused coping associated with less effective adjustment, and greater emotion-focused coping resulted in lower levels of depression, with time since diagnosis and particular treatment stressors as significant moderators (Aldridge & Roesch, 2007), whereas a more recent study found greater levels of secondary control coping and disengagement coping (which are equivalent to emotion-focused coping), were significantly associated with increased depression and anxiety (Compas et al., 2014). Opposing findings such as these makes it difficult to conclude what forms of coping are successful in promoting resilience or which result in greater levels of psychological difficulty. However, they do demonstrate that young people with cancer use a variety of coping forms, which can be captured with multiple adult coping theories.

Changes in coping. Studies of coping predominantly report strategies used by young people with cancer at one time point, though due to methodological difficulties it is not always possible to decipher the time since diagnosis when this was measured.

Given that coping has been established as a constantly changing process, and coping strategies may be time specific, this means both the phenomenon of coping and its measurement in young people with cancer could be more complex (Aldridge & Roesch, 2007; Cohen & Lazarus, 1973; Compas et al., 2001; Kyngäs et al., 2000). Coping strategies such as avoidance and denial may make the experience more bearable and reduce the emotional burden and symptoms of depression in young people, but applying this after cancer may have negative effects on psychological wellbeing, suggesting strategies should be monitored at multiple time points (Castellano-Tejedor et al., 2016; Dejong & Fombonne, 2006; Kyngäs et al., 2000; Phipps & Srivastava, 1997; Worchel et al., 1988). Given the potential use of avoidance strategies, and the fluctuation in coping and adjustment due to changing demands, levels of depression may also change over time, and this could be another complexity for clinical services (de Ridder et al., 2007; Dejong & Fombonne, 2006; Lazarus & Folkman, 1984). Given that coping as a process has not been explicitly examined, this needs to be addressed.

Qualitative studies of coping in young people with cancer. Several studies qualitatively explored strategies used within cognitive stress and coping models (Folkman, 1997; Folkman & Greer, 2000) by young people with cancer, at the onset of cancer or to manage concerns about physical and personal changes, alienation and anxieties. These found that all coping strategies within this model were used: problem-focused, emotion-focused, and meaning-based coping (moving away from an unattainable goal), and cognitive appraisals of the situation (Engvall, Mattson, von Essen,

& Hedström, 2011; Kyngäs et al., 2000). Specific strategies were most commonly having belief in recovery, and returning to normality quickly (Kyngäs et al., 2000). Other qualitative studies that did not use or report specific coping theories found that young people wanted to be more involved in discussions about treatment with healthcare professionals to cope with their lack of control, and retain some independence (Gibson et al., 2010). They experienced loss of confidence and rebuilding hope, with a fluctuation in the desire to move on from cancer, or give up entirely (Wu, Chin, Haase, & Chen, 2009).

Young people also coped by using sources of emotional support, particularly from family, friends, and healthcare professionals, and deemed these to be very important protective factors (Gibson et al., 2010; Ritchie, 2001; Kent et al., 2012; Woodgate, 2006; Zebrack, Mills, & Weitzman, 2007). Social support aided young people to manage difficulties with adjustment, body image, self-esteem, and transitioning back into school after treatment, and was a key resource in coping with cancer (Choquette et al., 2016; Fan & Eiser, 2003; Kyngäs et al., 2000). These studies confirm the variety of types of coping young people employ, some of which relate to their unique developmental challenges, or their experiences of psychological difficulties, such as depression or low mood. Some literature confirms that cognitive stress and coping models appear to be applicable to samples of young people with cancer, and that they had sufficient cognitive ability to use within their coping (Engvall et al., 2011; Kyngäs et al., 2000). Understanding the methods young people use to cope with cancer and low mood at different points of their cancer experience can help to inform services to better support this group. However, to

date there have been no qualitative studies which specifically address how young people cope with low mood in cancer.

Support for low mood and depression in young people with cancer

Although the picture of low mood or depression and coping in young people with cancer is unclear, research shows that at least a sub-set do experience depressive symptoms and struggle to cope with these, and there is a greater risk of their occurrence in this group (Lang et al., 2015). A wider group may also experience sub-clinical symptoms, which should not be ignored due to increased risk of psychosocial difficulty (NICE, 2015), and early detection of and intervention for difficulties such as low mood or depression may be especially relevant to young people with cancer (DoH, 2015; MHT, 2016). It is therefore important to understand provision of support for this population. Psychological care is a critical part of effective treatment in chronic physical health (Edwards & Titman, 2010), and NICE guidelines for cancer services for children and young people (2014) recommend assessment and support of psychological and social needs throughout the cancer care pathway. There is greater recognition that holistic, multidisciplinary support may help to improve outcomes of physical and psychological wellbeing (Kaye et al., 2015; Williams, 2012). The neglect of mental health needs, and the challenge in accessing support can have serious consequences for physical and psychological functioning, and HRQoL (Hedström et al., 2005; Smith et al., 2013, Zebrack, 2009).

While NHS England has commissioned cancer services specifically for young people (NHS England, 2015; Clic Sargent, 2017), not all are treated in such settings, as there are only 28 specialist units in NHS hospitals across the UK (Hollis & Morgan, 2001; Reynolds, Windebank, Leonard, & Wallace, 2005; TCT, 2017). Given this, and the variability in where young people with cancer might receive psychological support for depression or low mood, the overall evidence base for this population will be reviewed. Two recent systematic reviews have summarized the evidence base for psychological interventions for young people with cancer. One focused only on randomised controlled trials (RCTs) that measured outcomes of psychosocial interventions for children and young people with cancer (Coughtrey et al., 2017), and retrieved 12 published studies, four of which used a depression scale as an outcome (Lyon et al., 2014; Huang et al., 2014; van Dijk-Lokkart et al., 2016; Varni et al., 1993). The other reviewed interventions for both health promotion and psychological wellbeing in adolescent and young adult cancer survivors (Bradford & Chan, 2017), and retrieved 17 studies, two of which were psychological interventions that used a depression scale as an outcome, but neither of which were RCTs (Fisher, McNicol, Young, Smith, & Salmon, 2015; Seitz et al., 2014). Interventions in both reviews were variable: family therapy within palliative care to facilitate coping and advance care planning (Lyon et al., 2014), cognitive behavioural therapy (CBT) and problem solving for anxiety, assertiveness and social coping (Varni et al., 1993), therapist guided internet-based CBT for post-traumatic stress and anxiety (Seitz et al., 2014), metacognitive therapy for emotional distress (Fisher et al., 2015), telephone and web-based counselling for weight management (Huang et al., 2014;), and physical exercise and psychosocial training, including CBT, for social and emotional

functioning and coping with cancer effects (van Dijk-Lokkart et al., 2016). Ages of samples were variable and not always clearly stated, and only one sample was definitely within the classification of young people described in the UK, of 13-24 years (Lyon et al, 2014, TCT, 2017). Four studies found significant reductions of depression, two of which were RCTs, with a significant difference between experimental and control groups (Fisher et al., 2015; Huang et al., 2014; Lyon et al., 2014; Seitz et al., 2014). Retrieval of these studies suggests increasing interest and initiative to develop and test interventions to improve psychological wellbeing in young people with cancer, but also confirms this is still a developing area where there is currently a lack of good evidence of effective methods of support for this group (Bradford & Chan, 2017). The studies retrieved suggest that counselling, CBT, metacognitive therapy, and family therapy are the most commonly tested interventions so far in young people with cancer and psychological difficulty. However, none were specifically directed at reducing depressive symptoms, this was either secondary outcome, or was integrated within a broader measure of distress.

In spite of recommendations for its provision (Edwards & Titman, 2010; NICE, 2014), and the developing research in this area (Bradford & Chan, 2017; Coughtrey et al., 2017), support for mental health difficulties has been repeatedly highlighted as an unmet need by young people with cancer (Bennett, Shafran, Coughtrey, Walker, & Heyman, 2015; Dyson, Thompson, Palmer, Thomas, & Schofield, 2012; Keegan et al., 2012; Smith et al., 2013; Zebrack, 2009). In those who did seek or receive support, young people with cancer valued specialist psychological intervention, and often desired this

after treatment, however access could be difficult, and they thought that ongoing assessment of psychological needs through cancer was missing (Olsson et al., 2015; Tenniglo et al., 2017; Zebrack et al., 2007). Unmet needs were also found in the areas of information provision and communication, treatment processes, and survivorship after cancer (Palmer, Mitchell, Thompson & Sexton, 2007; Smith, Davies, Wright, Chapman, & Whiteson, 2007; Stinson et al., 2015; Thompson, Palmer & Dyson, 2007; van't Hooft et al., 2016).

There is clear variability in the evidence base for psychological intervention for young people with cancer, and little evidence or research into psychological support for depression or low mood. Psychological provision is still highlighted as an unmet need by young people with cancer, and it is therefore important to gather further understanding of how they think low mood should be treated in cancer, in order to inform future research and implementation of support services for this population.

Rationale for current study

To summarise, while it has been identified that young people with cancer face additional risk of clinical levels of symptoms such as depression (Lang et al., 2015), partly associated with increased psychosocial challenges at this life stage (Kaye et al., 2017; Muffly et al., 2016; Zebrack & Isaacson, 2012), prevalence reports vary, and at times they are similar to the general population or control groups without cancer (Allen et

al., 1997; Kersun et al., 2009; Larsson et al., 2010; Matziou et al., 2008; von Essen et al., 2000; Worchel et al., 1988). The experience of depression or low mood in young people with cancer is not well understood, and little is known about how young people's unique developmental difficulties impact on this emotional experience. To date, no qualitative investigations have been undertaken to understand low mood or depression in young people with cancer. The way that they cope with low mood is also unclear, and while previous studies have highlighted potential forms of coping that may increase or reduce depressive symptoms (Aldridge & Roesch, 2007; Corey, Haase, Azzouz, & Monahan, 2008; Compas et al., 2014), a qualitative study identifying helpful and unhelpful coping strategies in relation to low mood has not been conducted thus far. Additionally, while guidelines recommend psychological assessment and support throughout the cancer care pathway for young people, mental health in physical health settings continue to be a largely unmet need, which has very minimal funding levels, in spite of being so important (Bennett et al., 2015; Edwards & Titman, 2010; MHT, 2016). Recognising what young people with cancer use to help them cope, both with cancer and low mood, can also contribute to the coping literature in young people with cancer.

In light of this, the current study aimed to address these crucial gaps in the area. Specifically, the aim was to develop a more cohesive picture of the experience of depression or low mood in young people with cancer, given the lack of qualitative studies to understand this, the challenge of outcome measures for this group, and the fact that others around young people with cancer find it challenging to detect. Understanding more about the experience could not only aid detection of low mood in this vulnerable

population, but also understand causes or maintaining factors, and whether it associates with unique developmental challenges. Understanding what young people with cancer use to help them cope, both with cancer and low mood, can also contribute to the coping literature in young people with cancer. Gaining further understanding of what support for low mood they would like, in order to facilitate coping can also contribute towards recommendations for service provision.

Rationale for adopting a qualitative approach

These aims are most likely to be achieved by using qualitative interviews to gain perspectives of young people who have experienced cancer. A qualitative approach allows the gathering of meaning through comprehensive and multifaceted data, to gain a detailed understanding of experience, meaning and perspectives, that have not been previously defined (Braun & Clarke, 2006; Spencer, Ritchie, Lewis, & Dillon, 2003; Willig, 2008; Yardley, 2015). It was considered the most appropriate approach to capture and describe the exact essence of views and experiences about low mood in young people with cancer, coping, and support (Pistrang & Barker, 2012; Willig, 2008; Yardley, 2000). This is in line with the questions that qualitative studies wish to answer, which are contextual, diagnostic, evaluative and strategic (Ritchie & Spencer, 1994; Ritchie, Spencer & O'Connor, 2003b).

Qualitative research is recognised as increasingly valuable within health, social and public policy; it can explore change and outcome, positive or negative aspects, and aid understanding of complex behaviours and needs within systems (Campbell et al., 2007; Ritchie & Spencer, 1994). The exploration of deeper aspects of experiences that a qualitative approach can provide are well suited for use within healthcare, as they enhance understanding and working relationships between staff and patients (Yardley, 2000; Smith & Firth, 2011). They are also useful when there is little previous research in an area, as they can provide advanced knowledge (Campbell et al., 2007; Smith & Osborne, 2008; Strauss & Corbin, 1998). There has not been a great deal of research specifically on low mood in young people with cancer, and what has been done is mainly quantitative in nature, as previously described. These studies have been unable to capture potential underlying factors, experiences or opinions of the phenomenon of low mood in young people with cancer, and have focused more on the presentation of specific symptoms on measures in a snapshot of time. Qualitative interviews have greater sensitivity to detect aspects of experience or difficulties that cannot be measured by questionnaires (Eiser et al., 2000) and they provide idiosyncratic descriptive data, meeting a very different need from quantitative studies (Ritchie & Spencer, 1994). They facilitate complex articulation of experience without restriction, whereas quantitative approaches risk narrowing explanations, reducing experiences into predicted outcomes or quantities, and cannot offer the same level of insight (Barker, Pistrang, & Elliott, 2002; Lyons & Coyle, 2007). Quantitative strengths lie more with observation of particular variables and their correspondence to others (Yardley, 2000). It was therefore felt that using a qualitative approach would be more appropriate with this study.

Research questions

The current study aimed to investigate the following research questions by interviewing young people to gain their views and experiences:

- 1) What are the lived experiences of low mood and its presentation, in young people in the context of cancer?
- 2) How are the unique challenges facing young people with cancer considered to impact on the presence of low mood?
- 3) How do young people with cancer attempt to cope with low mood, and how could these types of coping strategies be further facilitated by services?

Chapter 2: Methodology

Participants

Inclusion criteria. Individuals were eligible to participate if they met the following criteria:

- Young people previously diagnosed and treated for cancer.

Diagnosed with cancer, such as leukemia, sarcoma, lymphoma, germ cell tumours and central nervous system (CNS) tumours, and subsequently received treatment. Due to potential variability in experiences, participants who were not in an active phase of cancer treatment at the time of interview were focused on.

- Young people diagnosed with cancer between the ages of 11 and 26.

UK young people's cancer services generally cover those aged 13-24 (NICE, 2014). However, due to follow-up trajectories and services' flexibility in accommodating individuals outside arbitrary age caps, the age criteria were relaxed during recruitment, to allow for two young people to participate, one who was diagnosed age 11, and one age 26.

- Ability to speak fluent English.

There was no funding for interpreters, and interviews were conducted in spoken English language, therefore this was a requirement for participation.

Exclusion criteria. Young people were excluded from participating in the circumstances of:

- Intellectual disability or acquired cognitive loss.

It was not appropriate to explore these within this research. Cognitive function and intellectual disability were not directly under study, and there is increased prevalence of psychological distress and mental health problems in these populations (Cooper et al., 2007; Young Minds, 2015).

- Current severe suicidal ideation or intent, or presence of current severe psychological disorder (e.g., active psychosis).

Young people with high levels of risk were excluded on ethical grounds. The researcher was trained to manage risk in the unlikely event that it arose, the interview would have been discontinued and the participant's GP informed, to facilitate referral to suitable services.

Sample size. The sample consisted of 19 participants. A criterion based non-probability sampling method was adopted, as participants had specific characteristics outlined in the inclusion and exclusion criteria (Ritchie, Lewis, & El am, 2003a). Specific guidelines for sample size when using the framework approach (a form of thematic analysis) do not exist, however it can be flexibly used with large and small samples (Ritchie & Spencer, 1994; Ritchie et al., 2003a). For example, in five studies that used

the framework approach within applied psychology care in mental and physical health, sample size *ranged* from 14-77 (Coughtrey, 2013; Leal et al., 2015; Parkinson, Eatough, Holmes, Stepley, & Midgley, 2016; Pistrang, Jay, Gessler, & Barker, 2012; Tighe, Pistrang, Casdagli, Baruch, & Butler, 2012). Thus, this study's sample size was suitable for the framework approach, to gain and synthesise a broad range of experiences, and was realistic in the time constraints.

Sample characteristics. Participant demographic details were collected, along with a subjective rating of mood state on that day and during the previous week, using the National Comprehensive Cancer Network (NCCN) Distress Thermometer, where 0 is no distress and 10 is extreme distress (2016) (Appendix 1; see Table 1). Ratings on the Distress Thermometer *ranged* from 0-6 (*mean* score 2.1).

Geographical location of participants was generally known: they represented a wide range of areas across the UK, but this is not reported, to maintain participant anonymity. Five participants were male and 14 were female. At the time of interview, ages *ranged* from 18-31 (*mean* 22.4 years). Sixteen participants identified as White British, one as British Bangladeshi, one as British Pakistani, and one as White European. Age at diagnosis *ranged* from 11-26 (*mean* 18.1 years). The time between receiving a diagnosis and participating *ranged* from 1-17 (*mean* 4.4 years). The overall types of cancer that participants had been diagnosed with were lymphoma ($n = 8$), leukaemia ($n = 6$), sarcoma

($n = 4$) and CNS tumour ($n = 1$). The majority of participants identified themselves as receiving follow-up checks for cancer ($n = 15$), one had been discharged from follow-up, one identified as being under late effects care but did not describe what they were receiving treatment for. Two participants were receiving maintenance treatment, which involves low doses of chemotherapy to prevent relapse, but where individuals can still go about their normal everyday lives (Macmillan Cancer Support, 2017).

Table 1. *Participant demographic details*

Pt no	Gender	Ethnicity	Age at interview	Age at diagnosis	Type of cancer	Current stage of cancer treatment:	Distress rating*	Interview type	Interview duration (minutes)
1	Female	White British	25	20	Hodgkin's Lymphoma	Annual follow-up	2	Face-to-face	39
2	Female	White British	31	14	Acute lymphoblastic leukaemia	Occasional follow-up	5	Telephone	49
3	Female	White British	21	18	Hodgkin's Lymphoma	3-month follow-up	3	Telephone	26
4	Male	British Bangladeshi	24	22	Burkitt's lymphoma	3-month follow-up	0	Face-to-face	33
5	Female	White British	22	18	Ewing's Sarcoma	6-month follow-up	0	Telephone	19
6	Female	White British	23	20	Non-Hodgkin's lymphoma	6-month follow-up	2	Telephone	23
7	Male	White British	24	18	Hodgkin's lymphoma	Discharged	0	Telephone	36
8	Female	White British	22	20	Acute pre-myeloid leukaemia	Remission, bone marrow every 3 months	0	Telephone	40
9	Female	White British	20	19	Acute lymphoblastic leukaemia	Maintenance treatment	2	Telephone	30
10	Female	White British	18	16	Acute myeloid leukaemia	2-month follow-up	2	Telephone	40
11	Female	British Pakistani	19	17	Hodgkin's lymphoma	4-month follow-up	0	Telephone	40
12	Female	White British	22	17	Acute lymphoblastic leukaemia	Remission, 4-month follow-up	3	Telephone	50
13	Female	White British	22	19	Craniopharyngioma	Clear at last MRI, in follow-up	5/6	Telephone	45
14	Female	White British	28	26	Hodgkin's lymphoma	2-month follow-up	3	Telephone	60

15	Male	White European	20	17	Osteosarcoma	3-month follow-up	3	Telephone	60
16	Male	White British	23	11	Ewing's Sarcoma	Late effects care	5	Telephone	70
17	Female	White British	24	18	Alveolar rhabdomyosarcoma	Remission, annual follow-up	6	Telephone	51
18	Male	White British	20	19	T-cell acute lymphoblastic leukaemia	Maintenance treatment	1	Telephone	55
19	Female	White British	18	14 Recurrence at 16	Hodgkin's lymphoma	3-month follow-up	2	Telephone	45

*Rated on the Distress Thermometer (NCCN, 2016) where 0 is no distress and 10 is extreme distress.

Recruitment. Over approximately six months, young people were recruited and self-selected to take part, through two main sources. The first was a London NHS children and young people's cancer service treating those aged 13-24, from which two participants were recruited. The researcher attended this service and approached young people who had been identified as potential participants by a member of their usual clinical care team. The researcher introduced young people to the study, provided them with a participant information sheet (PIS) (Appendix 2) and consent form (Appendix 3). The PIS detailed why the research was being conducted, what participating would involve, informed them of potential benefits and risks, of confidentiality and anonymity, and of the voluntary nature of participation and the right to withdraw. With agreement, the researcher took down details to contact potential participants regarding this further. The other source of recruitment was advertisements on the websites of several national cancer charities for children, teenagers, young people and adults, where interested individuals were requested to express interest by email or telephone. Seventeen young people were recruited through this method. Following expression of interest, they were contacted by the researcher to discuss participation in the study, eligibility was checked against the inclusion and exclusion criteria, they were sent out a PIS and consent form, and any questions regarding participation were answered.

All individuals were given time to consider participation. Where they agreed to take part, an interview was arranged at a mutually convenient time, and they provided written informed consent. They gave consent to be interviewed, for the interview to be audio-recorded, for access to relevant aspects of medical notes in case of risk issues emerging, and for use of their data up until the point of withdrawal, if

this were to occur. Consent provided by post or email where completion was not witnessed by the researcher was verbally confirmed at the start of the interview. Participants were given a copy of their consent form, and the researcher kept the original. Figure 2 shows a recruitment flow chart.

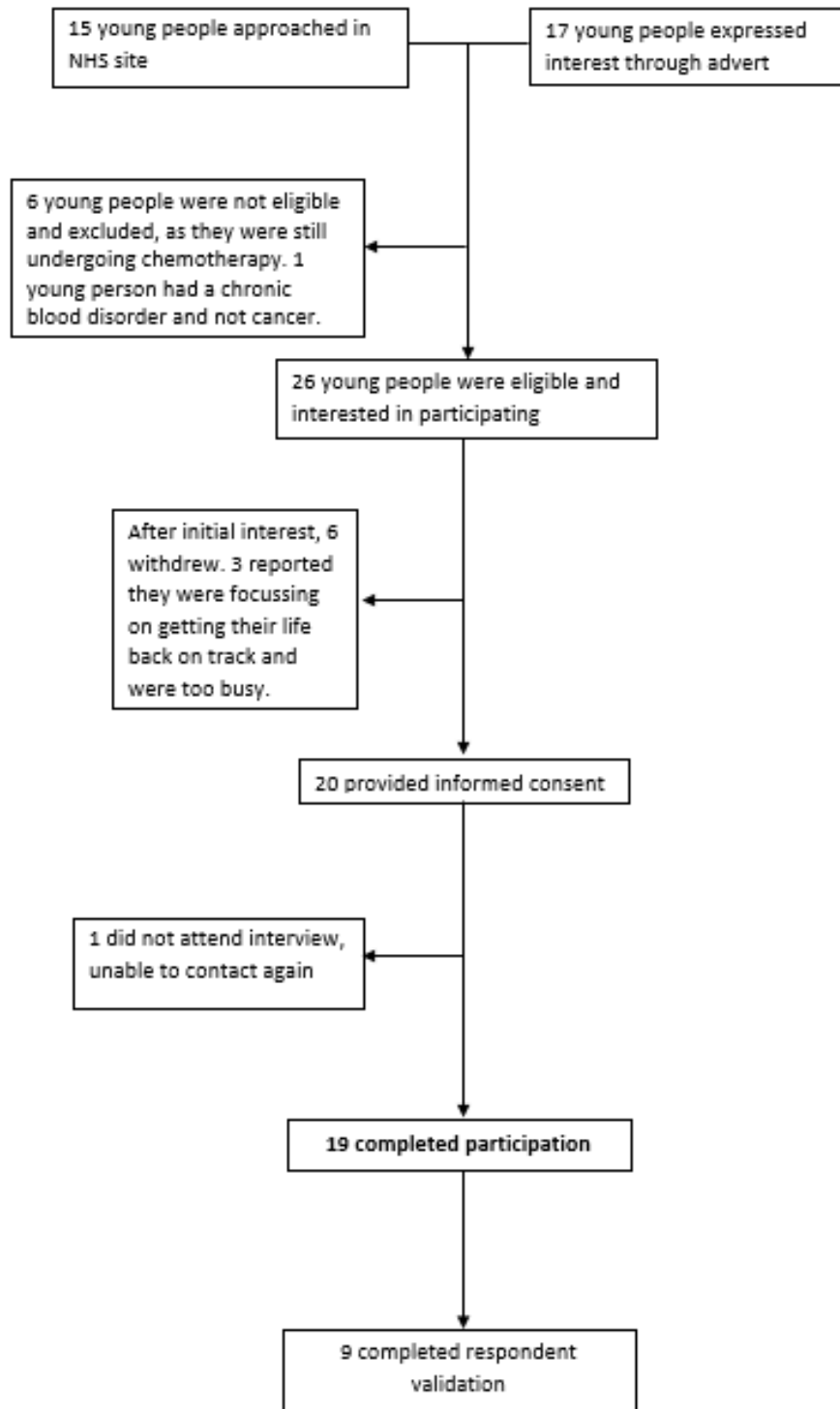


Figure 2. Recruitment flow diagram

Ethical considerations

Ethical approval. This study was part of wider research project, which received full ethical approval from the NHS Health Research Authority and London – Bloomsbury Research Ethics Committee (REC), allowing for combined NHS and local Research and Development approval (REC Reference 16/LO/0939; Appendix 4). This study also self-certified for ethical approval from Royal Holloway Research Ethics Department.

Informed consent. All participants were over 18 years at the time of interview and had capacity to decide to participate. They were given a PIS and time to consider participation, and if willing, they provided a written informed consent before an interview took place.

Risk. Due to the sensitive nature of the research topic, and the fact that participants were being asked to reflect on potentially difficult experiences, it was acknowledged that this may cause distress. However, participants were fully briefed beforehand about what participation would involve, they completed the Distress Thermometer (NCCN, 2016) prior to commencing the interview, and the researcher regularly checked in throughout the interview to ensure any distress was managed appropriately. If the researcher was concerned about anything said by participants, this was explored further, and if concerns were not resolved, or distress arose, participants were offered the opportunity to discontinue the interview, and if necessary were withdrawn.

As described in the exclusion criteria, young people presenting with severe levels of depression or risk to themselves or others were not considered appropriate for participation. Such concerns were not identified in any participants, however if they had been, the researcher possessed clinical skills that would have allowed management of this, and the interview would have been paused or terminated. If needed, individuals would have been withdrawn, signposted to sources of support, and their GP contacted, with the view to onward referral to a support service.

Access to support services. Participation was in addition to young people's usual care, and no participant was deprived of any aspect of usual care as a result of this study. Potential participants were informed of this through the PIS.

Confidentiality. Participants were informed of confidentiality as a research participant. They were informed that the interview would be transcribed anonymously with no identifiable information, but aspects of transcripts could be used as quotes within the write-up.

Reimbursement for participation. Travel expenses for participation were available for reimbursement through University project resources. However, this was never required. No other reimbursement took place.

Funding. The wider research project received funding from the Health Foundation, a charity aiming to improve healthcare provision for people in the UK. The smaller sub-section of the study that comprises this thesis did not receive any external funding.

Interview schedule development

Semi-structured interviews are the most frequent data source in thematic analysis and the framework approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Joffe, 2012). They allow for idiosyncratic development of questions to enable interview data specific to the research (Ritchie & Spencer, 1994). The semi-structured interview developed for this study (Appendix 5) was based on relevant literature on low mood and distress in young people with cancer, coping in both young people with and without cancer, and the study's research questions. It was developed collaboratively with the field supervisors. Broad main questions allowed flexible discussion with participants, and follow-up prompt questions were available for further exploration (Barker et al., 2002). The drafted interview schedule was shared with research representatives from two national cancer charities, and piloted with a TCT support coordinator at the local children and young people's cancer service. Adaptations were made based on feedback. Following completion of seven interviews and reflections in supervision, additional minor refinements were made to the interview schedule, to allow prominent areas to be explicitly discussed and explored.

Service user involvement

A regularly held young people's advisory group at a local NHS hospital was attended, to talk about the study, and discuss what language was most appropriate to discuss this difficulty. This was a key reason why the words 'depression' or 'low mood' were used more flexibly in interviews, to consider what was most fitting, accessible or least stigmatizing for young people, and to use their own language.

Interviewing procedure

Two interviews took place face-to-face, one in a room within the NHS site, and one within the field supervisors' affiliated University building. All remaining interviews were conducted over the telephone ($n = 17$), as recruitment took place nationally and there were often considerable distances between the interviewer and participant. Telephone interviews also enabled more flexibility, for example out of office hours.

At the start of the interview, participants were re-familiarised with the PIS and consent form, and they were asked if they had any further questions about taking part. They answered demographic questions to provide context, completed the Distress Thermometer (NCCN, 2016), and were then briefed about the interview, and asked the questions in the interview schedule (Appendix 5). Interviews *ranged* from 19-70 minutes (*mean* 41 minutes) and were audio recorded. They were transcribed verbatim by the researcher, with all identifiable data removed, and recordings and transcripts were securely stored.

Qualitative analytical approach

Introducing the framework approach. The framework approach is a form of thematic analysis that systematically and flexibly observes themes and identifies patterns of meaning in individuals' constructions of experience (Braun & Clarke, 2006; Gale et al., 2013; Joffe, 2012). The framework approach adds additional strength to thematic analysis, as it is more structured (Pope, Ziebland & Mays, 2000),

and provides an effective, practical and methodical slant (Ritchie & Spencer, 1994). The framework approach was first developed for use in large scale policy research (Gale et al., 2013; Ritchie & Spencer, 1994) and is an asset to the qualitative field given its flexible nature, applicability of use and explicit methodology (Ritchie & Spencer, 1994). It has several key features: it is grounded in participants' original accounts, remains dynamic and open to revision throughout the analytical process, and is inclusive of all material available (Ritchie & Spencer, 1994). It uniquely enables systematic organisation of data into themes, whilst also maintaining the context of experiences (Gale et al., 2013; Ritchie & Spencer, 1994). It does this by keeping individual accounts intact within a framework matrix, which allows comparison between, and across cases (Attride-Sterling, 2001; Gale et al., 2013; Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 1994; Ritchie et al., 2003b). This approach provides greater understanding of individual experience, whilst also increasing the ability to be rigorous and clear on data management and interpretation (Ritchie & Spencer, 1994; Ritchie et al., 2003b).

Adopting a jointly inductive and deductive approach. As in other forms of thematic analysis, the framework approach is flexible and allows for an inductive or deductive approach (Braun & Clarke, 2006). For this study, it was felt that adopting a jointly inductive and deductive approach was most appropriate; the semi-structured interview had questions and prompts guided by the research questions, but the interview style allowed flexibility of detailed discussions specifically related to each individual's account, and was adapted to ensure depth and breadth. Analysis and coding was inductively data-driven, as coding was not restricted to areas only relevant

to the research questions (Braun & Clarke, 2006), but it was also not entirely possible to ignore what information or experiences the interview was attempting to extract, to answer the research questions (Gale et al., 2013).

Rationale for choosing the framework approach

Thematic analyses, such as the framework approach, are especially suitable in less researched areas, and where views or experiences of a group are unknown (Braun & Clarke, 2006; Joffe, 2012). The framework approach originated from qualitative health research (Gale et al., 2013; Smith & Firth, 2011; Ward, Furber, Tierney, & Swallow, 2013), and as this research is situated in applied health, and there is limited qualitative research available in this area, the framework approach was thought to be most appropriate. Of published qualitative studies in similar health research areas, such as observing experiences of cancer care, or quality of life, forms of thematic analysis have been the approach of choice in the majority, though few have provided detailed accounts of the exact methods employed (Gibson et al., 2010; Kuhlthau et al., 2015; Mulhall, Kelly, & Pearce, 2004; Smith et al., 2007).

The framework approach was specifically selected over other thematic analyses because it allows experiences and accounts to be presented and interpreted whilst holding on to original individual accounts, promoting objectivity and reducing bias (Gale et al., 2013). It is suitable for homogenous data such as will be produced by this study, where a similar semi-structured interview was administered to all participants, allowing for differing perspectives or responses to questions (Gale et al., 2013). It provides strength through its' connections between analytical stages,

allowing a traceable path from which conclusions and interpretations are drawn, and improves transparency, which is so often criticised in qualitative research (Attride-Stirling, 2001; Pope et al., 2000; Ritchie & Spencer, 1994; Smith & Firth, 2001).

Framework analysis can also be used in conjunction with many of the recommendations in place for thematic analysis (Braun & Clarke, 2006), providing further methodological strength.

The framework approach compared to other qualitative methods

Prior to settling on the framework approach, other qualitative methodologies were considered, to ascertain which would be most able to answer the research questions.

Grounded theory. Grounded theory could have been valid in exploring perceptions of low mood in young people who experienced cancer, however the aim of this study was not to construct a situation-specific theory of low mood or coping with low mood (Charmaz, 2015; Pope et al., 2000; Smith & Firth, 2001). Given the lack of detailed research in this area, the aim was initially to generate themes that encapsulate experience (Joffe, 2012; Gale et al., 2013). Whether it would be useful to theoretically observe this and use it to inform a model in the future using grounded theory, could be subsequently considered.

Phenomenological analyses. Phenomenological analysis was considered, as it could be appropriate for this study, as individuals' experiences are of key interest. However, the present study aimed to observe patterns and themes across the larger

sample, and not become immersed in each participant's idiographic internal view of the world (Willig, 2008).

Interpretative phenomenological analysis (IPA) was also considered, however this approach emphasises interpretation, and considers how participants have made sense of experience (Smith, Flowers, & Larkin, 2009). Therefore, the aims are slightly discrepant from this study, which was designed to understand and analyse experiences themselves, by staying close to the data, and to remain as objective as possible, to aid robust and replicable results. IPA can run the risk of lacking clarity between the original account and the analyst's interpretations, and would have made results less transparent (Smith & Osborn, 2015).

Discourse analysis. Discourse analysis was not felt to be appropriate as this study did not aim to explore the patterns in participants' use and connotations of language in different discourses (Jørgensen & Phillips, 2002; Smith & Firth, 2001; Willig, 2008). Instead, from the critical realist epistemological stance in this research, there is the view that the language used by participants represents their reality. Language was only explored in one context in this study, and not interpreted further.

Narrative analysis. Although this research facilitated young people to construct narratives about their experiences of cancer and low mood, which they may not have done previously, this was not the direction that analysis took. Narrative analysis was not appropriate, as young people's narratives were directed by an

interview schedule, and did not explore open freely constructed stories of experience (Riessman, 1993).

Epistemological position

One's epistemological stance helps to direct the reporting of collected data, and how meaning is inferred (Braun & Clarke, 2006). It is therefore important to outline this, for interpretation to be understood. A critical realist approach has been adopted for this research, placing the stance between the opposing camps of realist and relativist (Willig, 2008). This approach aims to gain true information and realistic detail of experience, whilst also being aware that the data collected will not necessarily provide this directly, and some researcher input is required (Willig, 2008). It allows consideration within the data of individual experience and the broader social context, and how this impacts on meaning generated (Braun & Clarke, 2006). This position was most appropriate given that young people were interviewed about their subjective reality of experiences of cancer and low mood, at an age where they can verbally articulate this. However, the way they constructed meaning about experiences and themselves will have been impacted on by age, surrounding systems, and perceptions of, and interactions with, others.

Data analysis

Framework analysis involves separate but connected analytical stages, whereby the analyst derives meaning using a clear outlined process (Ritchie & Spencer, 1994). This process has been discussed by the original authors in five stages (Ritchie & Spencer, 1994; Ritchie et al., 2003b) and subsequently by Gale et al. (2013) in seven

stages, where the first original stage was expanded into three. The most recent outline of stages will be described, with detailed reference to the original description.

Transcription. All interviews were transcribed verbatim from the audio recordings, by the researcher undertaking this study, allowing for initial immersion in the data through this process.

Data familiarisation. Immersion and familiarisation with data began at the transcription stage and continued throughout analysis. The researcher became fully familiarised with the dataset by reviewing interview recordings, transcribing all data, re-reading transcripts, and looking through the reflective journal.

Initial Coding. Transcripts were read through line by line, and an initial code written in the margin, to describe or encapsulate what had been said. If the text itself represented a code, this was highlighted, and was noted as an in-vivo code, that used participants' own language (King, 2008; Spencer et al., 2003b). As this study was jointly inductive and deductive, open-coding was employed to highlight all potentially relevant data, but the overall research questions were held in mind to ensure these could be answered, as was the wider interview context. Five interview transcripts (26%) were coded independently by the researcher and an independent rater, to check for agreement from different perspectives and reduce bias.

Identifying and developing a coding index. Following initial coding, specific and concrete code names were developed, retaining in-vivo codes where possible (King, 2008; Spencer et al., 2003b). The codes were grouped together into categories, forming a coding index, which was constructed with the research aims,

and allowed data to be systematically labelled. An initial coding index was developed by the researcher and reviewed by the field supervisor. A consensus approach was taken to develop the final coding index (Appendix 6), whereby a sub-set of transcripts were jointly reviewed, allowing for codes to be newly introduced, moved or removed to ensure all relevant areas were captured. Discrepancies were reviewed and discussed and changes to the index were recorded to allow transparency.

Applying the index. The final coding index (Appendix 6) was then systematically applied to all transcripts, mapping out all data. Transcripts were annotated using the index; applying code labels in the margins (extract in Appendix 7). The independent rater applied the final coding index to five transcripts (different from the transcripts that were independently coded), to check for agreement, and discuss and agree on any discrepancies.

Charting data into the framework matrix. Having applied the coding index to all transcripts, data was placed into thematic charts, one for each code and its sub codes. Each respondent had their own line on the chart, ordered the same across all charts, so their whole experience was visible within the dataset. These charts formed the framework matrix (example chart in Appendix 8). The text within the chart was a refined summary of each participant's experience, preserving the context and language, with page references, indicating where this data was derived from in their account. It was key at this point to balance reductionist data strategies with retention of the true meaning and experience of participants. Efforts were made to engage in minimal levels of interpretation at this stage. Any data that did not appear to immediately fit was noted and retained, as this may still have been relevant.

Interpreting the data. The thematic charts within the framework matrix were then reviewed, to observe and infer patterns, explanations, and consider similarities and differences across the data. Key aspects were identified, to allow mapping and interpretation of the whole dataset. This process was conducted jointly with the field supervisor, to ensure a consensus approach was adopted, and maintain transparency in interpretation. This is how the final set of domains, themes and subthemes were developed.

Quality and validity in the framework approach

Despite the differences in qualitative and quantitative approaches, it is important to ensure where statistical analysis is not used, that the data, analysis and results produced are of good quality and validity (Yardley, 2015). General guidelines for good quality qualitative methodology (Elliott, Fischer, & Rennie, 1999; Mays & Pope, 2000; Yardley, 2015) are applicable to different forms of thematic analysis (Braun & Clarke, 2006). Yardley's (2015) criteria will be referenced as these are the most up to date guidelines. Braun and Clarke's (2006) 15-point checklist guidelines for good quality thematic analysis (Appendix 9) were also adhered to.

Sensitivity to context. Appropriate literature and research were reviewed, and research questions to be addressed were devised and stated. Sensitivity to participants' perspectives and positions was considered. Participants could choose how they wanted to take part, and a curious stance with open-ended questions was adopted in interviews, to allow the direction to be partially determined by participants, not purely the researcher's motivations. The researcher was not affiliated to a team providing

care to participants, which allowed open expression of experiences and opinions. Sensitivity to the data was upheld; the researcher made sure not to impose their own meanings on data, and remained open to detecting inconsistencies or alternative interpretations throughout analysis.

Commitment and rigour. The sample was purposive in nature as participants possessed specific characteristics, yet also self-selected to take part. Overall it is a group with a range of characteristics: diagnoses, age at diagnosis, ethnic group and gender, which can adequately answer the research questions. The researcher spent time becoming familiar with appropriate terminology in the clinical area, and the types of services that participants may have accessed, both for treatment of cancer and other support. This maximised engagement in the research topic and in interviews. Training, extensive reading and supervision in the framework approach were also undertaken to ensure competence in analysis.

Transparency and coherence. The framework approach has the strength of being transparent. The coding index and framework matrix allow a traceable path of analysis, with direct reference to the original location in the data. The process of analysis has been described in detail, and examples of different analytical steps are available in the appendices. Changes made during the process were recorded. Reflexivity is an important factor in transparency, which is discussed below. The research has been laid out in a coherent structure and transparency of data reporting and analysis also aids coherence.

Impact and importance. The anticipated impact of this research has been outlined in the introduction, and following the results, discussion will continue to formulate how it may be able to provide recommendations for improvement of service provision and future research paths.

Enhancing validity and reliability. In addition to the above areas, validity and reliability were enhanced in the following ways. Triangulation of codes was conducted, by checking codes with others, to ensure they were not limited only to the researcher's perspective (Yardley, 2015). This closely links with inter-rater reliability, which was employed, where 26% of the data was coded by an independent person (Pope, et al., 2000). Respondent validation was completed, where participants were sent a summary list of themes and illustrating quotes, and asked to complete a feedback form (Appendix 10) to ensure their views were adequately represented (Silverman, 2001). Participants were informed that if they did not respond, it would be assumed they were happy with their summary. Nine participants (47%) completed and returned the respondent validation feedback, and all were satisfied with themes suggested. No participants disagreed. Disconfirming case analysis was also used, where cases that did not corroborate with an identified theme or pattern were openly reported and discussed (Mays & Pope, 2000; Yardley, 2015).

Researcher as a person in context and personal reflexivity

There is importance within qualitative research of awareness of the researcher's own interpretations and perspectives (Elliott et al., 1999). This means it is necessary to consider my own characteristics that might impact on my involvement (Mays & Pope, 2000). I am a White British female in my late-twenties and have been

fortunate enough to be in good health and not personally experience cancer or significant health difficulties. However, whilst conducting this research, two extended family members were sequentially diagnosed with cancer, one terminally. This made me aware of the significant impact that cancer has, on the individual and family system, both emotionally, but also financially and practically. I was interested in conducting research with young people within paediatric settings based on previous research experience in this area, and was keen to continue to contribute to this area; to improve support for this client group, and ensure provision was appropriate and effective. I wanted the way I conducted this research and the representations the individuals I spoke with, to be both accurate and influential.

With the epistemological stance of a critical realist, I acknowledge my involvement in the joint construction of data, knowledge and meaning, whilst also aiming to remain objective and true to the accounts (Willig, 2008; Yardley, 2000). To protect from bias of my own perceptions, experiences and aspirations, a reflective journal was kept throughout the research process (extracts in Appendix 11). Entries were made before and after interviews, during coding, and when reflections or thoughts about the study or data arose. This journal ensured an adequate level of reflexivity was taking place, which is also important in maintaining quality of research (Braun & Clarke, 2006; Mays & Pope, 2000; Yardley, 2015).

Chapter 3: Results

Overall experience of participants

Young people described a variety of opinions and experiences with regards to low mood in the context of cancer. Despite receiving different diagnoses and being treated in a number of service settings in various locations, all participants were able to identify with, and describe the experience of low mood, though this was more prominent for some than for others. While young people articulated difficulties in relation to low mood, some also simultaneously identified ways of managing, highlighting both negative and positive aspects. Participants described strategies or external factors they used to help them cope, both with cancer, and low mood, and considered how services could improve support for low mood in young people with cancer.

Interpretation

Interpretation using the framework approach revealed eight themes, organised into three domains. These were: 1) A harder time of life, 2) Interpersonal impact of cancer, and 3) Making sense of my emotions, and are depicted in Table 2, with their themes and subthemes. Table 3 illustrates which participant accounts contributed to each subtheme.

Descriptions of domains and themes are presented in narrative form, with illustrative quotes selected to capture the relevance and meaning of the interpreted data (Braun & Clarke, 2006; Elliott et al., 1999). Where possible, exceptions to

themes have been highlighted, and both positive and negative aspects of cancer, low mood, and coping have been emphasised, in order to capture the full range of experiences. Where quotes have been edited, either to ensure anonymity by removing identifiable data, or to remove less relevant data, this is specified by "...", and any additional explanatory data added by the researcher is denoted using square brackets "[...]". Further supporting quotes for subthemes are shown in Appendix 12.

Table 2. *Domains, themes and subthemes*

Domain	Theme	Subtheme	Prevalence
1) Harder time of life	1.1 Not feeling normal	I'm all alone with cancer	19
		Isolating myself	15
		Lost shared experiences	17
		Looking visibly different	7
		Returning to normal afterwards	14
			17
	1.2 Life was just starting	Cancer took over	16
		Dragged away from independence	15
		Young people aren't meant to have cancer	4
	1.3 Losing your safety blanket after treatment		7
		Support and structure is gone	16
		You are left with your mood, and it doesn't stop	11
	2) Interpersonal impact of cancer	2.1 Cancer changed relationships	
Family and friends struggled to cope			18
Family and friends need support too			12
Their reactions made it worse			7
2.2 Being around other young people with cancer		No one understands what it's like	8
			14
		They understand and I'm not alone	16
		It's too sad	14
		Survivors' guilt is tough	8
			4
3) Making sense of my emotions	3.1 How do I even describe low mood?		19
		Low mood is there, like a niggle	9
		Cancer was the reason for feeling low	19
		Mood felt fragile	9
		So many emotions, it's a lot to go through	19
		It's difficult to name	15
	3.2 You just have to cope		19
		Keeping busy	17
		Acceptance and adjustment	12
		Positive coping and problem solving	18
		Not making it too real	11
		Long term perspectives on low mood and cancer	14
			14
	3.3 External factors in coping		19
		My support network got me through	19
Hospital support environment		14	
Talking therapy with a professional		16	
Improving support for coping		18	

Table 3. Themes and subthemes contributed to by participants

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16	P17	P18	P19
1) Harder time of life																			
1.1 Not feeling normal																			
<i>I'm all alone with cancer</i>	x	x	x	x		x	x			x	x	x	x	x	x	x	x	x	
<i>Isolating myself</i>	x	x	x	x	x	x	x	x			x	x	x	x	x	x	x	x	x
<i>Lost shared experiences</i>									x			x	x	x			x	x	x
<i>Looking visibly different</i>	x	x		x	x		x	x		x	x	x	x	x			x	x	x
<i>Returning to normal afterwards</i>	x	x			x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
1.2 Life was just starting																			
<i>Cancer took over</i>	x	x	x	x	x	x		x	x	x	x				x	x	x	x	x
<i>Dragged away from independence</i>					x			x					x				x		
<i>Young people aren't meant to have cancer</i>	x	x		x	x								x				x	x	
1.3 Losing your safety blanket after treatment																			
<i>Support and structure is gone</i>	x	x				x		x	x	x		x		x			x	x	x
<i>You are left with your mood, and it doesn't stop</i>	x	x	x	x		x						x	x	x	x	x	x	x	x
2) Interpersonal impact of cancer																			
2.1 Cancer changed relationships																			
<i>Family and friends struggled to cope</i>	x	x			x		x	x	x	x		x	x	x		x	x	x	x
<i>Family and friends need support too</i>	x				x			x	x				x				x		x
<i>Their reactions made it worse</i>				x			x				x		x	x			x	x	x
<i>No one understands what it's like</i>	x	x	x	x		x		x	x	x			x	x		x	x	x	x

2.2 Being around other young people with cancer

<i>They understand and I'm not alone</i>	x	x	x	x	x			x	x	x	x	x	x	x		x		x
<i>It's too sad</i>	x	x	x	x								x	x		x			x
<i>Survivors' guilt is tough</i>	x	x						x		x								

3) Making sense of my emotions

3.1 How do I even describe low mood?

<i>Low mood is there, like a niggle</i>	x	x	x	x						x				x			x	x	x
<i>Cancer was the reason for feeling low</i>	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
<i>Mood felt fragile</i>	x	x	x	x	x						x		x					x	x
<i>So many emotions, it's a lot to go through</i>	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
<i>It's difficult to name</i>	x	x	x	x	x			x	x	x	x		x			x	x	x	x

3.2 You just have to cope

<i>Keeping busy</i>	x	x	x	x		x	x	x		x	x	x	x	x	x	x	x	x	x
<i>Acceptance and adjustment</i>	x				x	x		x	x	x	x		x	x		x	x	x	x
<i>Positive coping and problem solving</i>	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x
<i>Not making it too real</i>		x	x			x	x	x	x		x	x		x	x			x	
<i>Long term perspectives on low mood and cancer</i>	x	x	x	x	x	x		x	x			x	x	x	x	x			x

3.3 External factors in coping

<i>My support network got me through</i>	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
<i>Hospital support environment</i>	x			x	x	x		x		x	x	x		x		x	x	x	x
<i>Talking therapy with a professional</i>	x	x		x	x			x	x	x	x		x	x	x	x	x	x	x
<i>Improving support for coping</i>	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x

Domain 1: A harder time of life

Young people's accounts of experiencing low mood resounded around it being more challenging to have cancer as a young person. This was because their life was just starting, and there was a sense of loss of adolescent or young adult experience, that could never be recovered. Cancer accentuated not feeling normal amongst their peers, and resulted in feelings of isolation and loneliness. The effects of low mood after treatment and in the long term were also discussed and were often especially difficult to experience, as it was hard to regain normality and independence, and to come to terms with the impact of cancer at a time of life when young people without cancer are typically focusing on forging independence and separating from their families of origin. This domain depicts "*a harder time of life*" (P13) to experience cancer, and attempts to encapsulate these areas in relation to low mood.

1.1 Not feeling normal. All young people's accounts indicated that not being normal impacted on low mood, they described how cancer created an abnormality and difference that distinguished them from their peers, and from how they were before cancer. *This* was especially challenging due to their age and stage of life where the emphasis is often on ensuring similarities with peers and fitting in.

Young people often felt very alone with their cancer, which highlighted the lack of normality they were experiencing, and resulted in feelings of low mood. They talked about experiences of physical loneliness due to isolation because of infections or compromised immunity, or being stuck at home or in hospital when friends and peers could carry on with their lives. Young people felt very lonely in the experience, which no one else they knew was going through or could relate to. This was especially prominent in those who were hospitalised on adult cancer wards, which they found very difficult and distressing. Some did not know whether their emotions of low mood were normal feelings to have in the situation.

“...you can have loneliness of...the physical isolation, and then there can be the loneliness from the fact that you are undergoing an experience that nobody else you really know or have related to up until that point has ever gone through.” P16

“...it all kind of adds to feeling quite, like you're the only one that's thinking that way...” P17

When describing low mood, young people mentioned isolation of themselves, withdrawal from others, not sharing their feelings, and behavioural inactivity in spite of the ability to do things. This happened at home or in hospital, during and after treatment, and was a noticeable change which emphasised that things were not normal, and they were feeling low in mood. Several young people noticed that while their low mood made

them want to be alone, self-isolation often made them feel worse, which highlighted the abnormality of experience, as this was usually a time where they would be more socially engaged with peers, and reliant on them for support.

“...someone kind of shutting themselves off from their family and friends. So not wanting to talk about things...not going to your friends and family as much as you would normally...I’m the kind of person that always would do that, like perfectly happy to talk about anything and I think that’s a very key thing that I stopped doing.” P1

“The not wanting to do anything...normally I’m very willing to sort of do things which you can do, the fact that you don’t want to do anything, you just kind of want to wallow.” P19

A small but significant number of young people described that their cancer caused them to miss out on shared experiences with their friends, and they had to witness others moving on to pursue exciting things without them. It was especially difficult to lose out on these at a developmental age when new and shared experiences with friends were so important, to strengthen the interpersonal relationships they were attempting to develop. This was perceived as a big loss, and highlighted the lack of normality in their situation.

“all my friends had gone to Uni, and obviously I had to stay and have treatment and stuff...it was seeing them, doing all the things that I wanted to do that I just couldn’t.” P12

“...the first one [cancer experience] was quite difficult, because of GCSEs and...friendship groups are very cemented at that point? So, feeling like by not being there I was losing friends and other friendships were being made. But then...when I relapsed the second time it was in between school and college so...it was like ‘well everyone else has moved on’, they’d made other friendships at their new schools and colleges...” P19

Changes to young people’s physical appearance significantly affected their mood. The effects of cancer treatment, such as chemotherapy and steroids made them look visibly different from before, giving them the “*look of cancer*” (P17). This highlighted the abnormal experience they were going through, and set them apart from others in a tangible way. Experiencing uncontrollable hair loss and weight changes were often described as very difficult, especially as these occurred at an age where they were already preoccupied by body image, and changes worsened previously existing appearance concerns. It was challenging to manage this, both practically and emotionally, especially as there were limited resources to help with this, and resulted in difficulties with low mood, confidence and self-esteem.

“...for me my low mood got reinforced by the fact that I’d lost my hair...not wanting to do anything and then picking myself up, and wanting to do something, looking in the mirror and then changing my mind...” P7

“...I mean as a teenager I was quite paranoid about the way I was looking, and then on top of that, having the hair loss...that was an issue for me personally...” P11

Some young people, but not all, were able to accept the effect that treatment had on their appearance, and tried not to let their negative feelings impact so much, which helped to reduce low mood and increase self-confidence.

“...initially my first thought was ‘oh my god, I’m going to lose my hair’ but actually when it started coming out, I thought ‘well I can’t be done with it, it doesn’t define me...’...but then...I wasn’t into my appearance as much as some other girls might be.” P5

The majority of young people found it difficult to return to normal even after treatment had finished. They described residual physical and emotional effects of treatment, which meant normality did not resume as fast as they wanted it to, and they could not force this to happen.

“...that’s when it really affected me, when I first finished my treatment...I had to jump straight back into work, back to reality, but it’s not normal reality, it’s the reality of living with cancer, having to work, still having side effects of chemo and fatigue...” P6

Some young people experienced late effects of cancer treatment, such as physical changes to the body and immune system, and experiences of pain, fatigue and hormonal

changes, such as hot flushes. These factors accentuated that life continued not to be normal, and served as reminders of cancer and the losses that young people had sustained as a result. This was especially difficult as a young person because of how much more of their life they had ahead of them, to have to deal with these effects.

“I feel because of...the ongoing, and probably...lifelong complications that I’ve now got to endure...it doesn’t really give way for any...relaxation shall we say...there’s no lapse of difficulty that I experience...” P18

One participant explained that they attempted to protect themselves from this by trying to keep life as normal as possible throughout treatment.

“...through my treatment I was very aware that it was going to be six months and then I was going to have to go back to normal life so I tried to, where I could to keep things as normal as possible, because I knew that it would be like difficult...But...she [another young person with cancer] was completely in a little bubble...her parents stayed in hospital every single night...that made her feel better at the time, that’s great, but I think she especially found it difficult to cope after because her life just changed so much, whereas I was quite aware of not letting mine change too much.” P14

Some could not remember what ‘normal’ had been like before, or could not find a normal to return to. Cancer had either integrated into their life story, or they had to find

themselves all over again, due to transitions that were happening at the time or that would have happened if they had not had cancer, and which in some cases affected their identity.

“...what if you’ve never even had a job and you’ve got to start out, and you don’t have a life to return to, it’s just like cut up your life and you’ve got to sort of...find yourself again, and you don’t really have an anchor about who you are?” P17

Some did not think they had been changed by their cancer, but were conscious that this was not a normal experience, and described feeling reluctant to tell new acquaintances about this, in case it was used to define them.

“going to Uni...I’d had this different experience that I didn’t particularly want to be defined by...I was a little bit older than everyone else, and I think I was worried about people asking ‘oh how come you’re a bit older?’ Or ‘what have you done in your gap year?’ and having to explain it all, ‘cause yeah I didn’t want to be defined by it.” P12

1.2 Life was just starting. Sixteen young people talked about the difficulty of having cancer when life was just beginning, because it came at a time when no one expected it and suddenly dominated when they were planning new life experiences.

Young people explained that having cancer at this point was especially difficult, and resulted in low mood.

Young people described how cancer took over their life, stopped the trajectory they were on, and meant they could not do things they were planning. The change from positive hopes and expectations of their future to enduring such a demanding situation was a significant loss that some struggled to come to terms with. The unpredictable nature of cancer onset, progression, and treatment also meant they had no control. This perpetuated the fact that life as they knew it, and the degree of control they had become used to as a young person were gone, and this was challenging to deal with, and had a strong impact on low mood.

“...they have to stop work and stop their tracks in life...it’s depressing...your life becomes hospital appointments, and doctor’s appointments, and blood tests, and scans. It’s like a never-ending whirlwind.” P6

“...I was incredibly fit and healthy, I was running half marathons, I was about to join the RAF and then all of a sudden...I gained a lot of weight, I don’t have any fitness anymore...all of my dreams and ambitions were just crushed.” P18

Young people described that cancer dragged them away from their independence. They lost this because they were so unwell and could hardly do anything for themselves, not even simple day-to-day tasks. Some young people had been living independently and could not continue to do so, and had to return to the family home, or had been about to transition towards greater levels of independence, which could not happen. There was a feeling of regression, with a requirement for greater dependence on others, which was both a difficult change and demeaning experience.

“...when your independence...is taken away from you, it’s hard...I couldn’t even feed myself I was that weak, I couldn’t pick up a knife and fork, someone else was having to do stuff...that’s what affected me most...” P8

“...that massively affected my relationship with my mum...it was about to be that moment where I...went off into the world, and it became that moment where she’d have to feed and clean and care for me and carry me, and like completely revert back...” P17

Young people talked about the difficulty of having cancer because they were not meant to, at their age. Neither they nor others expected them to be diagnosed, and some questioned what they had done to deserve it. So much was already happening, and cancer combined with and magnified the normal challenges they were facing at this stage of life. Some described being stuck between child and adult services, in hospital and other

support services, which made accessing information and support for physical and mental health more challenging.

“...I don’t drink, I don’t smoke, yet I’ve still ended up with cancer...you’re thinking ‘what have I done to deserve this?’” P5

“...we’re all meant to be fit healthy individuals, we’re not meant to have issues and problems with our bodies. So when it does happen, I think it’s as much as a shock to the people going through it as it is for the health care system itself and I think it still presents one of the largest gaps of employment support, of social care support, of financial support...” P18

1.3 Losing your safety blanket after treatment. Sixteen young people talked about the unexpected difficulty and low mood they experienced when treatment finished, which in some was a feeling that persisted for many months and in some cases, years. It felt like they lost aspects that had enabled them to feel safe. This was especially difficult to experience as a young person where they wanted to be able to manage things on their own, but found this challenging.

Young people talked about how after cancer treatment finished, all the structure and support from hospital, and friends and family was suddenly gone, but they still needed it and had not been prepared to lose it. They and others had built up to how

wonderful it would be when they finished, but these expectations were not always true, and for some this was an unexpectedly challenging time, where they experienced a lot of low mood. Young people might have become dependent on this support, and although it had been difficult to lose independence, it was scary to regain this, and face life after cancer alone. This may have been especially difficult for young people because they were in a transitional phase of developing their independence, and repeated changes to this throughout cancer may have affected their mood.

“...you kind of build up to this ‘oh I’m going to finish, it’s going to be amazing, I’m going to be so happy’ and then it just doesn’t happen. At the end you just flat-line, and it gets much worse because you don’t, you’re not going to hospital every day, you don’t have these links.” P1

“...the hardest thing for me is that once you finish your treatment you’re kind of let go from your hospital...you’re quilted in your blanket for so long, and then ‘oh you’re finished your treatment, you can go back into that big world’ and you haven’t got a clue!...when you’re in hospital you’re told ‘you can’t eat this, you can’t do that’...and then when you get out, you’re like ‘well, what can I do?’ put back in that...situation where you don’t...really know...” P8

Young people were left with their low mood once treatment had finished. The emotional experience of cancer came flooding back, and as the support and structure was

gone, there was no one to help them manage these. No longer being on treatment meant they had less to focus on, lost the ‘routine’ they had been in, and had nothing to aim for. The unstructured time spent recovering at home with no support to blanket them, meant there was more time to think about their experience and what they had been through. Some still experienced these feelings many years later, and thought they would never go away, suggesting that processing the experience was a chronic process. This was especially difficult to experience at such a young age, when they may not have had the cognitive and emotional structures in place to support emotional processing.

“...during treatment there’s still other things to focus on. Like you’ll feel low, for like an hour and then you’ll feel sick, and concentrate on feeling sick rather than on your mood as much, whereas once you’ve finished treatment, the physical side effects are gone, you are just left with your mood...” P19

“I think it can weigh on you...in a surprising way. I’m quite surprised how much I still think about it. And I also feel like I can’t tell people that because it just sounds a bit dramatic! To them it’s...years ago and everything’s fine and nothing’s visibly going on, but the amount that I still think about it is hard.” P17

Domain 2: Interpersonal impact of cancer

This domain depicts the complexities of cancer in relation to those around young people who underwent these experiences. Through the interviews, young people focused on the interpersonal aspects of cancer, particularly in reference to changes in close relationships, the effect on their family, friends, and partners, the effect of these people on them, and the resultant impact on presentation and management of low mood. They also discussed the interpersonal impact of being around other young people with cancer, and the benefits and difficulties of this.

2.1 Cancer changed relationships. All young people interviewed emphasised changes to their relationships due to their cancer. They talked about the effects that cancer had on their family, friends, and partners, how it changed the way that these people interacted with them, and the impact of these aspects on their low mood.

Young people described how in addition to their own struggles with cancer and low mood, their family, friends, and partners also sometimes struggled to cope, which resulted in changes to their relationships. Some young people noticed that these people avoided talking about low mood or cancer with them, or reacted in difficult ways because they did not know how to deal with this. They noticed reduced contact of the loss of friends entirely, which made it more difficult for them, as they had less people to turn to for support.

“I think a lot of my friends sort of panicked and disappeared, which felt...doubly horrible, that they weren't there and that they'd sort of made that decision, or couldn't feel like they could overcome it.” P17

“...I turned to my girlfriend...that was probably my worst decision...she had absolutely no idea how to handle it [suicidal feelings]...she started shouting at me for being selfish and thinking those ways...for actually talking to her about it...the one person I turned to and I thought I could turn to, turned out that she couldn't handle those sorts of emotions...” P18

They were also aware that those around them struggled psychologically because of their cancer; some said their parents had breakdowns or were signed off sick from work, or friends received counselling in relation to their cancer. Changes to the emotional wellbeing of others changed their relationships, and young people expressed a mixture of guilt about the impact of their cancer on friends and family, but also a struggle that some of the focus was removed from them.

“...one of actually the things that really bothers me still, is the damage I have done to my family...simply by...having to go through that and...the trauma which happened to them...” P16

Due to the knowledge that family, friends, and partners were struggling, a small number of participants thought that discussing low mood with these people was an additional burden. They therefore choose to conceal their low mood to protect others, and tried to

manage this on their own, and this resulted in changes to their relationships and interactions.

“...they were so freaked out by all the chemo and everything already you don't want to add another burden...that exacerbates it for the person...because then you kind of try to internally do everything yourself.” P1

Young people thought that support should be available for family and friends also, which could in turn improve their low mood as minimising changes in interpersonal relationships was a protective factor. This was discussed in three forms: support to help family and friends manage their own emotions, which would also mean the young person would not need to worry about them, to educate friends and family about low mood in young people during and after cancer, and inform them of helpful ways to behave and support the young person.

“...it would be good also for other people to have support, so I'd have really liked my friends to be able to like talk about it, or my little brothers, or my mum, instead of them being like 'we're the rocks...we can't let our guard down at all'.” P1

“...I guess just more awareness of it...especially young people and their friends, because those are the people that you have seen every day, but there's no reason why they'd be any good at helping you when

you're that ill, and if you're feeling low kind of making them aware of it...that could save so much unhappiness further down the line if everyone kind of sees it as a thing..." P17

Young people noticed that others' reactions towards them, while they experienced cancer and after treatment had finished resulted in altered relationships, and made them feel worse. It was particularly difficult when family or friends intended to help, but were in fact unhelpful. For example, if they made suggestions of ways to improve low mood that were not possible, provided unrealistic encouragement, were overly sympathetic, or put them in a sick role and told them not to do so much.

"...I always had people around me...saying 'oh don't worry about that...don't need to worry about doing so much...'...it just sort of reinforced the fact that I almost shouldn't be doing that stuff..." P7

"...people still say this to me now... 'you got through all of that, you can get through anything!' and I find that really hard when people say that because it's like, 'I got through all of that I'm not getting through this...I'm failing'...people think that you can get through something so you can do something else, but it doesn't really transfer like that..."

P17

Young people described the difficulty that friends and family did not understand what they were going through, and could not relate to the overall experience of cancer, or their low mood in this context. Some thought that unless others had had a similar experience themselves, they could not possibly understand. They also struggled with the fact that family and friends assumed they were better, and back to normal after treatment was over. This made it harder for young people to voice experiences of low mood, and thus changed the interactions and relationships with these people.

“...the not wanting to talk to people is exacerbated by the feeling that no one else understands it...it’s really tough because most people don’t relate to that at all.” P1

“I felt like people would almost be like ‘well, why are you feeling crap now? You’re fine!...you’re in remission’...I think probably people wouldn’t understand either.” P14

2.2 Being around other young people with cancer. Sixteen young people talked about the effect of being around or having contact with other young people who had cancer, which some perceived to have very positive aspects, but there were also difficulties with this, which impacted on low mood.

Many young people talked about the benefit and immense importance of communication with other young people with cancer who were going through the same experience, be this in person on a TCT ward, or using blogs or the internet. They could

Speak openly, and gain reassurance, advice and inspiration from each other. This generated a shared understanding of what they were going through, so they did not feel so alone, and was helpful in managing their cancer and low mood. They voiced the desire for services to help improve the connections and support that could be available between young people with cancer, as it was and continued to be so valuable.

“...I was really really lucky in the friends that I made...I met a lot of people my own age...they were the people who, if any of us were ever feeling low you would just text them, because they got it too...” P1

“...it just made it all much more manageable...knowing that you could talk to other people...in the same boat...four of us...we had all started our treatment like together so we were pretty much going through like the same thing, so that was...really good and really reassuring...that they were sort of feeling the same things...you could be like ‘ok, that’s fine then’, see how other people cope with things...” P14

This was not a universal experience however, and some young people also described challenges of being around others with cancer, in particular, the ways that it made them feel sad. Although there was an aspect of shared experience, it could be upsetting to see others going through an equally horrible or worse situation, or there was so much variety in treatment and prognosis, it was never exactly the same. Young people described odd dynamics or interactions if one person was more unwell than another, or

the envy they felt if others finished treatment when they had not. Some thought interactions could become too cancer focused, so did not find this helpful.

“...I wasn’t really interested in socialising with other kids with cancer...Particularly because we’re all in the same boat, but we’re all in different boats really...I was on a ward once with somebody with like two inoperable lung tumours, and he was about the same age as me, and I just found the whole thing really depressing, because I was just like ‘you’re going to die, and I’m not. How is that fair?’ and he looked fine, but it was just so sad. It was so tragic.” P2

“I think there’s...quite a lot of comparison there, and so when you talk to other people, there’s a lot of like ‘I did this and I did that’ and it does add pressure as well. Because some young people can still go to school when they’re on treatment, some just can’t. So...if one of your friends can still go to school, you feel like you should be able to too.”

P19

A small number of young people described the effect of witnessing the deaths of other young people due to their cancer, and described this grief, and survivors’ guilt impacting significantly on low mood. Experiencing this at their age was such an alien and unexpected experience, and they did not think services were set up to accommodate

support to help them manage. Some described the long-term effects of survivors' guilt, which stayed with them, sometimes beyond the rest of the cancer experience.

"...the main one is losing your friends...TCT was so amazing introducing me to these people, but...you're not really helped...you're really not given any support and actually...it's an unbelievable thing to go through...I lost like seven friends in a year...you never expect that to happen to you. And the amount of funerals you go to, when you're also really sick..." P1

"...friends that did pass away, not knowing why...they didn't survive. Survivors' guilt is a big, a big issue as well." P8

Domain 3: Making sense of my emotions

This domain encapsulates the process of young people making sense of their emotions through cancer and how these presented, having never witnessed anyone else go through this experience. Young people described times where they struggled to make sense of what was happening, both physically and emotionally. Their emotional experiences were so broad, and described many feelings and symptoms in relation to different times or situations, including the impact of cancer itself. They explained that it was difficult to even describe these experiences, or know what to call them. This domain also considers how they attempted to make sense of this, and found ways to cope or

manage, including external factors in making sense of emotions, and how coping or support for low mood could be improved.

3.1 How do I even describe low mood? All young people highlighted some difficulties in describing their mood through cancer, which was often related to the way their emotions presented, the interaction of cancer itself on low mood, and uncertainty about how to articulate and understand experiences.

For some, chronic feelings of low mood or sadness were present in the background of their life *“like a niggle”* (P14). These occurred in a constant, baseline form and could be difficult to manage or eradicate completely. Young people did not seem to find it easy to describe the ongoing nature of these feelings, and they were often not voiced until later in the interviews, when participants felt more comfortable.

“...it’s just a kind of constant, like the whole time it’s not going away...it’s continually happening but in a weird way it gets worse the longer you go on.” P1

“...for quite a while after it was just always there in the background...even if I was doing stuff...it would be there...like a niggle, just always feeling a bit shit all the time.” P14

In addition to other factors contributing to low mood described in previous domains, cancer was often the reason for low mood, and feelings were triggered or directly affected by it. The severity of low mood at different time points varied amongst individuals, and in relation to different situations, which is why it was difficult to describe. Some experienced low mood at diagnosis, and felt shocked, in denial, and overwhelmed. Then the reality of cancer hit them, often as treatment started, and they could not do things that they could before, and became bored and low in mood. It could be challenging to make sense of these emotions and understand what was low mood and what was the effects of cancer treatment. All young people described low mood in relation to the experience of adverse side effects in reaction to steroids and chemotherapy, such as pain, fatigue, nausea, infections, diarrhoea, and vomiting. This was so difficult for two participants that they became suicidal and did not wish to continue living. Being away from home for extended periods of time affected some young people's low mood, as did being in the context of cancer and surrounded by sickness, especially on adult cancer wards.

“...I don't know it's really hard to like describe...because physically you can't do anything anyway...you're so tired...I'm just trying to compare it in my mind to people I know with low mood who don't have cancer...they would kind of be more tired and lethargic...but if you have cancer and you're having treatment you're already like that...”

P1

“...I was very ill throughout it and...I did become suicidal at certain points. Basically because I was in continuous extreme pain...I was really very very ill...there was a patch where I’d probably basically just had enough.” P16

Some young people experienced fluctuation in their mood. They noticed mood could be knocked and shifted quite suddenly, by what could be viewed as small or trivial things, but that had a big emotional effect. These fluctuations could happen even in one day, and this pivot in emotion made it difficult to describe their emotions and make sense of them, because low mood was not necessarily a constant feeling as might be expected, in relation to depression or to the circumstances they were going through.

“I think that your mood sort of...it’s very very up and down. I’d say it’s very bipolar, in the way that I felt...it can just kick start a shift, very quickly into feeling very sad and angry very quickly. I think the...shift in mood for me was just very sudden...” P2

“When I’m good, I’m really good and I’m happy, but when I’m down I’m really really down.” P13

Young people experienced so many emotions and symptoms throughout cancer and afterwards, and they found it difficult to make sense of these, and to describe low mood. This included what could be considered hallmark symptoms of depression, such as

sadness, agitation, emotional outbursts, ruminative or negative thinking, suicidal ideation, and feeling devoid of emotion or having a flat affect.

“...when I was alone...I’d think about what I’d been through, and that’s what put me...in my low mood.” P8

“...if I have to be honest I was not low in mood...it was just more like, ‘I don’t want to think, I don’t want to feel anything’ ...it was just avoiding every kind of feeling that I felt in that moment.” P15

They also described changes to confidence and self-esteem, trauma responses such as flashbacks or memory blanks, anger, and worries or anxiety, and talked about the enormity of the experience of cancer as a young person. They thought all their emotions including those more specific to low mood, were tied together and not necessarily distinct, and it was a lot for them to go through. For example, some thought difficulties with self-esteem and confidence were part of low mood, or that anger was communicated through behaviour as a display of low mood. They also described that anxiety and low mood impacted on each other, where anxiety was related to uncertainty, existential fear of death, worries about family, procedural phobias, fear of cancer relapse, and social situations.

“...I remember one thing that really hurt me was when my mum would come...if she would do anything that would irritate me I would ‘switch’ at her, and...one or two minutes later...I wouldn’t know why I

did that and I would apologise to my mum and I would start crying...”

P4

“...while I was on treatment I was panicking about finishing...my friend would say ‘what if we get better, and then in five years’ time...we get cancer again and then we have a house and you can’t pay the mortgage?’ ...and then it would make you feel depressed. This kind of future scenario which does not even exist...future events that haven’t even happened make you really depressed, which is really bizarre...” P1

Young people found it difficult to name their emotional experience. They struggled to articulate their feelings both during cancer, and retrospectively. This was made more challenging because low mood was rarely openly discussed or named by professionals in hospital, or staff could not tolerate emotional reactions, which meant there was limited dialogue to attach their experience to.

“...it was just like the physical things [talked about in hospital] ...never...what if you’re actually feeling quite down, or what if you feel like this?” P10

Through the interviews, young people often identified with the words ‘low mood’. Some explicitly highlighted they had experienced low mood but not depression, some welcomed the term low mood because it was perceived as a less diagnostic label

compared to depression, and linked their emotional experience to cancer without pathologizing it. Others however thought that depression more appropriately described their emotional experience, or that low mood did not quite capture the severity of their feelings. Young people were of the opinion that there were individual differences in low mood in cancer and they were conscious not to overgeneralise the experience, so found it difficult to name for this reason also.

“...distress is a funny one...sometimes that sounds like there’s...something urgent going on that you’re distressed about, whereas low mood, is sort of more ongoing and doesn’t really have, there’s not like a fire that needs putting out, it’s just...it goes on, and that’s what makes it so miserable, that it goes on...I guess calling it depression...I think low mood is a good way of not like labelling it...it’s describing how you’re feeling, rather than giving someone a diagnosis...” P17

“I genuinely would just go one step and genuinely say depressive mood...I think it’s very true that a lot of what I have experienced has been depression....” P18

3.2 You just have to cope. All young people could identify some methods they used to understand their emotions in response to cancer and low mood, and ways they coped. There was the consensus among many that they “*just had to cope*” (P1) and had

to find ways to do this themselves as they often did not receive input or guidance at the time.

A coping strategy that many young people used, was that they kept busy and occupied. They found ways to focus on getting through treatment during this stage, and made themselves do things they enjoyed, both during and after treatment. This included spending time with friends and family, exploring creative outlets, and pursuing new interests. Doing these things gave them something to focus on and took their mind off the situation, or distracted them from negative feelings or thoughts.

“...just...keeping myself entertained. Not letting myself just sit there and dwell on the moment and all that was happening...keeping myself busy, with other things.” P11

“...I’m big into tennis, so...when I was feeling ok...I’d just go and help out...for an hour or so...energy was a problem, so...if I had a little bit of energy, I felt like using it positively would make me feel...mentally so much better. I might be physically tired and I knew I needed to take it easy, but mentally it was brilliant...” P12

Young people described times where they just had to accept and adjust to the situation or emotions they experienced, so they were more used to them. This helped them come to terms with their feelings, and cope with them. They described “*getting*

used to [treatment]” (P13), and developed a practical routine, or accepted what was happening so it integrated into their life at the time, and was more manageable. They also tried to let difficult feelings pass, and processed them over time, if they could.

“...becoming used to it and just get into a routine...taking all the medication, and going to hospital appointments, just getting used to it. That’s just my life now, and I’ve just got to deal with it really.” P13

“...you have to learn a lot of things, and you have to change your life. To adapt to your new situations and things...as time goes on...it’s good that you’ve adapted to it...” P9

Participants described positive coping and finding ways to solve problems that were causing their low mood. They had to find a way to take the positives from the situation, generated positive coping thoughts or reminders for themselves, and made nice plans to look forward to. They problem solved and rationalised difficulties to find manageable solutions, were motivated and determined to cope, set goals for themselves, and used humour. These were often not things anyone had told them to do, and they developed these on their own, to manage their low mood, when they noticed it was having an impact on them.

“...I know this sounds ridiculous, but going to the hospital to stay in for a few days, starts to feel just like a holiday, because you’re having a break from your life, and ...you have a change of scenery...after a

while, I started to take the positives out of the situation, to stop me feeling so shit, basically.” P2

“...whenever I was experiencing major difficulties mentally...I sort of took it upon myself to calmly think through things and realise...it wasn't going to go on forever and then I asked doctors different ways to go about treatments and that sort of thing...to make things manageable.” P18

Young people also described not wanting the cancer or their low mood to feel too real, as this made them feel worse. They engaged in avoidance, and described times when they did not want to see or hear the word ‘cancer’ everywhere, tell people when they were diagnosed, or talk too much about how they were feeling, as it was helpful not to focus on this all the time. They found it difficult to admit they needed help to cope with low mood, which may have been associated with the difficulty of admitting to themselves that they were struggling, as this made it too real. Avoiding understanding or addressing their feelings at the time was helpful, because they did not have the time, resources or support to cope in other ways.

“...I put it off [seeking support] for so long. Like, so long...I don't want cope with it, I didn't want to go through everything that I've been through and find out why I was so low...” P8

“...the more you talk about it...you might feel as though...you’re talking about it too much, causing more stress on top of that so it just sort of adds...” P9

Young people talked about looking back on how they coped with cancer, and their long-term perspectives of their experience. Some expressed wonder, amazement and pride at how they had navigated through such a difficult time, and again reflected that they just had to get through it. Some viewed their cancer experience as very separate from their current life, or highlighted that they looked at life differently, and cancer had allowed them to gain a broader perspective. Coming through the adversity of cancer allowed them to re-route their aspirations, such as wanting to go to University or move jobs, and made them feel more appreciative of life. This long-term view demonstrated coping processes had taken place, to enable young people to find a way of making sense of what had happened to them.

“...it amazes me that I’m done!...looking back on it now, I don’t know how...anyone does it.” P19

“I see life in a different perspective and I appreciate waking up every morning and not being sick, I appreciate eating properly...I appreciate everything more!...I would happily...go back...and carry on my life without having dealt with all this? Because it has ruined my life? But at the same time I am also still grateful for everything that I have experienced...” P18

Young people also thought that at times they had been unable to cope, as they were less equipped to endure cancer, could not use previous coping methods, and did not know how to manage. At these times, low mood was greater and they had just endured the feelings.

“I didn’t cope [with low mood] that well myself, I don’t feel like I did that well...” P4

3.3 External factors in coping. All young people talked about external agents in relation to making sense of their feelings, and coping with them, which included their support network, the hospital environment, and medical and psychological professionals, most of which were helpful. They also talked about how coping and low mood could be better supported by others in the future.

Young people focused on how hugely helpful their support network was, and the benefit this had on coping with cancer, and low mood. They talked about the value of family, friends, and partners, who stayed with them and supported them, reassured them, cheered them up, and treated them as they had before. Young people found it helpful to talk to people in their support network if they wanted to, or when their feelings became too much, enabling them to be open, and help others understand or make sense of them. They often talked to particular individuals about low mood, not everyone, so they could separate this from some interactions. These aspects were very helpful in coping with their

low mood. Close people in their support network also noticed when a young person's low mood was especially bad, and encouraged them to seek help for this, if this was needed.

"...my friends and family...just saw me as I was...before chemo. They didn't really let that change the way they behaved with me...that was really good for me." P11

"...my best friends would...be quite like 'you can tell us when you're not feeling ok...we know you're not, because you're not speaking to us very much'...when I had a really bad month...they'd be like '...it's fine to speak to us, we want you to speak to us'..." P1

Young people talked about hospital environments, staff and young people's cancer charities. They were considered very helpful by many young people in aiding coping with treatment and emotional wellbeing, whilst in hospital. This was due to a tailored environment for young people, available staff who discussed emotions and treatment, and where cancer was not the sole focus of interactions.

"...while I was in hospital, actual low mood support...was there. So while I was...I won't say incarcerated(!), while I was in hospital itself...the support definitely was there...the nurses were fantastic at their job..." P18

"Especially at the hospital I was at...they're really great there at treating cancer patients...they don't really treat them any

different...don't like tiptoe around or anything and...Teenage Cancer Trust ward is...I think one of my favourite wards in the whole world...makes you feel so comfortable and everything. They don't let them...really dwell, like be sad.” P11

Some young people received talking support or therapy from a professional to help them cope with low mood in cancer; during, or long after finishing treatment. As support is individually tailored, the content of this, or what was helpful to the young person often differed. However, many talked about how it facilitated them to process and make sense of their emotions, and of the benefit of having a specific space to talk about low mood, with someone separate, who was not emotionally attached to their situation. In those who received support after treatment, some said it would have been helpful to have this earlier on, whereas others thought this was provided at the right time, either because this was the point that they experienced the greatest amount of low mood, or as there were less conflicting demands for their time and attention.

“...they [professionals] helped you understand why...I was feeling a certain way...helped to understand a little bit more, and helped to work through it and digest...I mean that didn't help...until I was in maintenance actually, when I was thinking about it a bit more and had time to think about it...I didn't want to speak about it every week and all the time, so it was quite nice...you could talk about it when you wanted to?” P12

“...I had the support of the psychologist; that was useful...while I was an inpatient...someone else to talk to and sort of discuss things with...that doesn't know my parents, and that...wouldn't be talking to them...” P19

A selection of young people received psychology input but did not find this helpful, because they did not feel they were listened to or understood, or they were asked too many questions. Some did not receive any support, nor did they feel they needed it, as they could cope independently.

“...she [psychologist] was relating everything back to...my diagnosis, and she was saying 'oh well you've been through such a lot' and I was trying to say that it wasn't anything to do with my diagnosis, but she just, she didn't sort of understand...” P10

“...I didn't need people to help lighten my mood, I could do it myself, most of the time.” P2

Young people talked about how support from services could further facilitate coping with low mood in the context of cancer. A number of young people would have liked the experience of low mood to have been normalised, or to have been warned about its potential occurrence, as this would have better prepared them, or helped them feel less abnormal. They were also of the opinion that support for low mood and emotional difficulties should be openly on offer and available in a non-pressurised way at all stages of cancer treatment and at follow-up, in a similar way that physical health input is. They

wanted this to be accessible even when they were not at hospital, for example when they were recovering at home.

“...it’s a lot to take in...maybe having a counsellor or something, introduce them at an early stage of your diagnosis...that can follow you through with your journey...not just until the end of your treatment but follow-up, kind of like what we have our...follow ups of our physical health and what’s going on with our bodies, also follow up for our mental health and how we’re getting on...and our future, because...that’s what we’re really looking at isn’t it?!” P6

“...they [professionals] could have...approached it [psychological support] themselves first so...more people might could have come to them. But if you mentioned it to them then they help you....it’s not like they offer it on a plate sort of thing...I guess they don’t want to be like ‘oh just because you have cancer you’re going to have a low mood’...they could probably advertise in a subtle way of ‘ooh by the way, you could be going through this, so this is the help’...I wouldn’t say they should do it, but they could do...” P3

Chapter 4: Discussion

This study employed the framework approach of thematic analysis, to explore the experiences of low mood in 19 young people who had experienced cancer, and to address the following research questions:

- 1) What are the lived experiences of low mood and its presentation, in young people in the context of cancer?
- 2) How are the unique challenges facing young people with cancer considered to impact on the presence of low mood?
- 3) How do young people with cancer attempt to cope with low mood, and how could these types of coping strategies be further facilitated by services?

This final chapter reviews and summarises the results of this study, in relation to the research questions, and the current literature and understanding in this area. A critical review of this study is then discussed, considering strengths and limitations, and research and clinical implications. Finally, personal reflections and a conclusion are provided.

Overview of findings

Analysis revealed three domains from young people's accounts:

- A harder time of life
- Interpersonal impact of cancer
- Making sense of my emotions

As aspects of these domains and their themes relate to different research questions, each question is answered sequentially, drawing together relevant themes from the results, and considering corresponding psychological theory and literature.

Addressing the research questions

Research Question One: What are the lived experiences of low mood and its presentation, in young people in the context of cancer? The results show that young people's descriptions of their experiences of low mood in the context of cancer are multifaceted and broad, emphasised by the theme 'how do I even describe low mood?'. Aspects of the symptoms, triggers and maintaining factors described bear resemblance to diagnostic criteria, national guidelines, theoretical models of depression, and previous literature in this area, but other aspects appeared to present differently. Young people's reports of emotional experiences and interpretation of the symptoms also highlighted the challenge in detection and diagnosis of low mood in this population. Additionally, results from this study show that while young people did not necessarily know what to call their emotional experience, this did not matter too much to them, and they had greater interest in talking about the experience itself, and the impact of this, on them, and those around them.

The impact of cancer diagnosis and treatment on low mood. Young people identified that often a key trigger or maintaining factor for their low mood was directly

associated with cancer, and they described varying levels of low mood and other emotions, at different stages. Feelings most often described at diagnosis were shock, denial, and feeling overwhelmed by the situation, which mirrors findings of qualitative and quantitative studies in this area (Allen et al., 1997; Compas et al., 2014; Enskär et al., 1997; Jörngården et al., 2007). Young people's low mood was affected during treatment, by being in a context of sickness, both with others their own age, but more so with older adults, if they were hospitalised on an adult ward. Adverse physical side effects of cancer treatments such as chemotherapy and steroids also significantly affected young people's mood, as this often made them extremely unwell. A small minority experienced this to such an extent that they did not want to continue with treatment or became suicidal and did not want to continue living.

These findings support quantitative and qualitative literature, where depression has been observed in young people during cancer treatment (Kwak et al., 2013), or where treatment procedures and their effects were commonly referred to in overall cancer experience and sources of distress (Enskär et al., 1997; Hedström et al., 2005; McCaffrey, 2006; Wicks & Mitchell, 2010; Wu et al., 2009; Zebrack et al. 2014). They also corroborate research regarding risk of non-adherence to treatment when depressed mood was present, and elevated risk of suicide in young people with cancer (DiMatteo et al., 2000; Kennard et al., 2004; Park & Rosenstein, 2015; Taddeo et al., 2008). This study extends previous literature, by confirming the presence of low mood in young people in direct relation to cancer treatment effects, which has been previously inferred but not

explicitly explored. It provides greater in-depth knowledge about what specific aspects of cancer cause low mood, and provides the insight of the impact of environmental factors on low mood during treatment, such as being around others who were unwell. It is important for treating staff and family members around young people to be aware of this, so they can be better supported through this difficult time.

Long term effects of cancer on low mood. Young people experienced low mood after their cancer treatment, as highlighted in the themes ‘not feeling normal’ and ‘losing your safety blanket after treatment’. Young people found the time shortly after the end of their cancer treatment unexpectedly difficult, as they lost support they had grown used to, and were unpleasantly surprised when normality did not instantly resume. Residual effects of treatment maintained, and no longer having a treatment plan to focus on, work towards, or distract them meant young people felt lost and directionless, so emotions that they had previously avoided increased, and became more prominent. This is in line with findings in qualitative studies of young people in survivorship, where the end of treatment was difficult, due to the struggle of resuming normal life such as going to school, and the inability to maintain the same levels of pace due to altered energy levels (Choquette et al., 2016; Zebrack et al., 2014). In some, this prompted unexpected reactions, including depression, and unresolved emotional difficulties (Zebrack et al., 2014). The current study provides additional insight into why this time is so challenging; due to the loss of previous routines in getting through treatment, of support and structure from hospital, friends and family, and confirming the challenge of residual treatment

effects that prevented normality from resuming. Prevalence rates of depression in young people just after completing treatment have not been widely measured or reported in the literature, which suggests understanding of low mood at this point may have been missed, and efforts to repeatedly assess for signs of low mood throughout cancer should be made.

Results from this study also found long term difficulties with low mood, as a result of the physical and emotional experience of cancer. Other studies have described the long term emotional effects of cancer on young people (Fritz & Williams, 1988, Seitz et al., 2010; Von Essen et al., 2000; Zebrack et al., 2002; Zebrack et al., 2004), however this study provided a more detailed understanding of this, due to its qualitative nature and its specific focus on low mood. It has shown lasting difficulties with physical changes as a result of cancer, that served as reminders, and the long-term processing of the emotional experience, which meant that they could never truly escape their experience. It is vital to be aware and take notice of the persistent impact of cancer and low mood in young people, as this affects their wellbeing in survivorship, and psychological support could be provided to address this.

Low mood in young people with cancer in relation to theoretical literature and diagnostic criteria. Young people described constant and ongoing feelings of low mood, either through the whole cancer experience, or during a specific part of it (e.g., after completion of treatment), which could have a significant impact on their wellbeing, and was hard to manage. Noticeable symptoms of low mood included sadness, agitation, irritability, low motivation, fatigue, lack of energy, reduced activity, self-isolation,

withdrawal, out of character behaviours (such as emotional lability or regression), suicidal ideation, negative thinking, and rumination. Findings from this study support other qualitative studies that did not specifically explore low mood in young people with cancer, but interpreted similar themes. Enskär et al. (1997) described a main domain of ‘feelings and reactions’, within which depression and irritability were described, and Zebrack et al. (2014) found the experience of negative emotions, and difficulty managing these. McCaffrey (2006) also found that major stressors for young people with cancer resulted in emotional regression, which mirrors the reports from this research, of out of character or isolative behaviours. Considering Beck’s (1976) cognitive theory of depression, young people who experienced cancer described activation of negative views about themselves, about others around them or their interactions, (e.g., withdrawal or self-isolation), and about their future. Some struggled to find things to look forward to when they felt very low, or felt suicidal and did not want to continue living.

The symptoms described by young people in this study closely relate to indicators of depression in children and young people’s guidelines (NICE, 2015), and to diagnostic criteria for depression in adults (APA, 2013). Depression has been found in a proportion of young people with cancer, or in sub-clinical levels, by previous research that used questionnaires (Allen et al., 1997; Compas et al., 2014; Fritz & Williams, 1988; Hedström et al., 2005; Jörngården et al., 2007; Kwak et al., 2013; Muffly et al. 2016; Seitz et al., 2010; Von Essen et al., 2000; Zebrack et al., 2002; Zebrack et al., 2004). This study suggests that the experiences, symptoms and cognitive concepts described by young people with cancer have some similarities to depression in the general population.

It also demonstrates that regardless of whether symptoms present as sub-clinical on a measure of depression, they can still be negative and difficult to experience, and should not be ignored. Unaddressed problems persisted or deteriorated further for some young people, where they struggled more over time. Symptoms of low mood or depression in young people with cancer should therefore be recognised and addressed even if they are sub-clinical, as psychosocial areas are impacted, and early intervention should be available. This is in line with recommendations and guidelines for young people (MHT, 2016; NICE, 2015). These findings also suggest the benefits of developing a measure of low mood specifically for young people in cancer, to improve detection.

Detangling hallmark symptoms of depression from physical side effects.

Although not explored a great deal, this study found similarities and overlap of young people's experiences of low mood and physical effects of cancer treatment. Fatigue, lack of energy, and reduced activity levels could be experienced due to low mood or cancer, and symptoms in the DSM-5 criteria (APA, 2013) that were not mentioned in relation to low mood, such as changes to weight, sleep, cognition, and attention, were described with reference to the physiological effects of cancer treatment. This confirms a breadth of literature that describes the challenge in delineating physical and psychological symptoms which affects the ease of measurement, detection and diagnosis of low mood or depression in this group (Dejong & Fombonne, 2006; Hedström et al., 2005; Moussavi et al., 2007; Recklitis et al., 2016). While studies have found benefits of using the same depression measures in the presence of cancer, cut-off scores have often been adapted to

enable greater sensitivity to psychological difficulty, research has called for validation of measures within populations such as those with cancer, and clinical observation, judgement and interpretation is still required (Hann, Winter, & Jacobsen, 1999; Moussavi et al., 2007; Recklitis et al., 2016; Singer et al., 2009; Wang & Gorenstein, 2013).

In the absence of measures that effectively detect symptoms of low mood in young people with cancer, clinical judgement is even more important, which will be difficult if medical staff struggle to feel confident in detecting the reason for a symptom, and this may cause over- or under-report of observations (APA, 2013; Greenberg, 2004; Park & Rosenstein, 2015). However, given that this study has shown that young people have specifically attributed the experience of certain symptoms in relation to low mood and not to the physical effects of cancer, it is important for staff to be aware of these, and there could be benefits of training staff in this area. This also means that if it is too challenging to gauge the cause of symptoms through clinician observation, young people's reports could help to delineate this, if elicited appropriately. This could help to increase the detection of low mood in young people with cancer, and direct provision of support.

Detangling low mood from other emotions. In addition to the symptoms that correspond to low mood, young people experienced many other emotions, which felt tangled together, and were described in response to questions regarding low mood. This

suggests that the experience of low mood for young people with cancer is broad, and they identified with a number of different emotions. This wide range corresponds to literature in the area of young people with cancer, where many quantitative studies focused on measuring and producing prevalence rates for wider concepts such as distress (Enskär & von Essen, 2007; Hedström et al., 2005; Hedström et al., 2003; Kwak et al., 2013; Sansom-Daly & Wakefield, 2013; Wiener et al., 2006), HRQoL (Vaudre et al., 2005), or other psychological difficulties, such as post-traumatic stress, fear and anxiety (Aldridge & Roesch, 2007; Compas et al., 2012; Compas et al., 2014; Juth et al., 2015; Phipps & Srivistava, 1997). Qualitative studies have similarly done this, and the experiences of fear and anxiety in relation to death, cancer recurrence, threats to their body, social factors, and recovery, and anger and aggression, were identified both in this study and others (Carlsson et al. 2008; Enskär et al., 1997; Ferrari et al., 2017a; Hedström et al., 2005; McCaffrey, 2006; Zebrack et al., 2014). Depression can present comorbidly with anxiety in young people in the general population without cancer (Brady & Kendall, 1992; Garber & Weersing, 2010), so a similar occurrence may be observed in young people with cancer. While young people interviewed often thought that low mood was the predominant emotional difficulty in cancer, there were many other emotions present concurrently, and it is useful to have a greater understanding of this, as it could make low mood more challenging to independently measure, explore and support.

Fluctuations in mood. While low mood was described as a constant underlying feeling in cancer, some young people also described this as fragile, with fluctuations, and

good days amongst the difficult and low ones. This is a novel finding, as the nature and presentation of low mood has not been previously described. Although other studies have described the experience of mood swings in young people (Enskär et al.,1997; Wu et al., 2009), the quick shifts that young people in this research described were in addition to changes in low mood due to medication. These fluctuations may explain why quantitative reports of depression rates in this population are so low, as measures may have only been used at one time point, when young people did not experience symptoms. This means the overall picture of their emotional experience was not captured, and ongoing assessment of low mood could be vital. This could also elucidate why only sub-threshold levels of depression are found in young people, as diagnostic criteria require daily experience of five or more symptoms over a two-week period (APA, 2013), and fluctuations in low mood may happen too quickly to merit diagnosis. This furthers the understanding of the emotional experiences in young people with cancer, and leads on to the question of whether they experience depression or low mood, or if in fact this is something else. However, regardless of what it is called, defined or diagnosed as, it remains important to hold in mind that this emotional experience may fluctuate, but it does present on quite a severe level, and could benefit from support.

Young people self-identifying low mood and depression. Young people thought that the experience of low mood in cancer was individually different, and affected by many factors. This meant they did not want to make sweeping judgements about what to call the experience, as they only knew how they felt. This is in line with previous findings that young people thought despite illness experience being similar, everyone's experience

was unique (Rechner, 1990). The fact that low mood in cancer is considered to be heterogeneous by the individuals who experience it, may mean young people do not know how to identify with or report this experience, and could explain why rates of depression from quantitative measures are low.

Young people may have been additionally challenged in identifying low mood in themselves, as neither they nor medical treating staff knew what to call it, or how to discuss it, which is likely to have made it more difficult to talk about (Taddeo et al., 2008). It is also important to consider the cultural impact of mental health stigma, from the perspective of young people with regards to talking about it or seeking help, and from staff and support networks around young people, who may not want to over-pathologize the experience or over-diagnose depression. Stigma in mental health and reluctance to seek help is well researched in the general population, and exists in young people (Rickwood, Deane, Wilson, & Ciarrochi, 2005), and may also exist in young people with cancer. Young people with cancer may not disclose to others how they are feeling, because they want to avoid calling it depression or do not identify their experience with this word, and this finding may further the understanding of why reported rates are low. With this knowledge, creating an increased culture of openness about mental health challenges in the context of physical health, may help young people with cancer manage their emotions, and seek help for these if needed.

Research Question Two: How are the unique challenges facing young people with cancer considered to impact on the presence of low mood? Young people described a number of unique challenges that impacted on their low mood, and these were often closely related to their specific stage of life as highlighted in Domain 1: ‘A harder time of life’. This included difficulties in their feelings about themselves in relation to physical changes and their body image, and psychosocial developmental challenges such as the development of identity and independence in relation to life transitions. It also related to their peer groups and relationships with others, as depicted in Domain 2: ‘Interpersonal impact of cancer’. While it is acknowledged that people with cancer of all ages may experience some of these challenges, these areas have been identified in previous literature as especially difficult for young people.

Body image. Young people found it challenging to look visibly different from before and this made them stand out from others. Their experience of significant changes, especially hair loss and weight, affected low mood, confidence and self-esteem. Changes to physical self and appearance, and the time it took for this to return to normal after cancer, were described by some as a key trigger for low mood. This endorses previous research regarding the unique difficulties of altered body image in this population, both during and after cancer. Qualitative and quantitative studies in young people with cancer also highlighted feelings of not being normal, difficulties coming to terms with physical changes and adjustment to cancer, altered sense of self, and affected social interactions (Albritton & Bleyer, 2003; Abrams et al., 2007; Choquette et al., 2016; Enskär et al.,

1997; Evan et al., 2006; Evans, 1997; Fritz and Williams, 1988; Hedström et al., 2005; McCaffrey, 2006; Larouche & Chin-Pouckert, 2006; Pendley et al., 1997; Woodgate, 2005; Zebrack et al., 2014). While these studies found that changes to appearance and body image affected adjustment processes and coping, the current qualitative study strengthens the direct impact of altered body image on low mood in young people with cancer. It found that changes to appearance triggered low mood and were challenging to manage, and made young people reluctant to socialise with their peers. With this knowledge, resources or support to help young people manage this should be available, to address this challenge.

Identity. Young people were conflicted about whether cancer affected their identity and concept of self after cancer. Some felt that they had changed as result, or had lost part of themselves, which resulted in low mood and was difficult to accept and regain. Young people with cancer may have less opportunity for their concept of self to develop and become concrete prior to having cancer, so this could be more easily affected by the experience (Erikson, 1959). Other young people thought their identity had altered in a positive way, which is consistent with findings from Choquette et al. (2016), and post-traumatic growth which has been found in this population (Zamora et al., 2017).

Sexual identity was not described in detail by young people through this research, only that residual effects of treatment impacted on sexual activity, and long-term effects to hormone levels and uncertainty around disclosure of cancer in intimate relationships

were challenging to navigate. These are in line with previous literature (Abrams et al., 2007; Evan et al., 2006; Evans, 1997), but given the small amount of young people who described this, it may mean that the questions in this study were not directed sufficiently towards gathering accounts in this area, which can be a difficult and taboo topic to speak about. While it has been suggested that changes to identity and self-concept increase the risk of low mood in this group, this study found mixed results of the impact of cancer on identity, and its relationship to low mood. However, as changes to identity can result in low mood in some young people with cancer, there should be greater awareness and attention paid to their experiences of this, so it is detected earlier, as tailored support may be beneficial.

Interrupting life transitions and independence. Cancer interrupted young people's lives: school life, travels abroad, going to University, employment, and even future aspirations could not be pursued alongside peers as a result. This change, the losses suffered in relation to what they could have had, and the shock in receiving a diagnosis at that time in their life affected the level of control they had, and caused feelings of low mood and frustration. These aspects have been discussed in other qualitative experiences of cancer (Çavusoglu, 2000; Ferrari et al., 2017a; Kent et al., 2012; McCaffrey, 2006; Wicks & Mitchell, 2010; Wu et al., 2009; Zebrack et al., 2014), however this is the first time they have been explicitly associated to low mood. This therefore furthers the knowledge that they are a component in young people's experience of low mood, which is key when considering greater understanding of low mood, and to facilitate detection.

Young people found it very difficult when they lost their independence, and had to again become more dependent on their parents. They struggled with low mood internally, but also in interactions with others, in an attempt to retain identity and independence. These findings are supported by previous literature, which describes this as a unique difficulty associated with a young person's developmental stage (Abrams et al., 2007; Albritton & Bleyer, 2003; Eiser, 1993; Evans, 1997; Gibson et al., 2010; Kyngäs et al., 2000). Young people also found these aspects challenging after treatment, which is described in the theme 'losing your safety blanket after treatment'. They may have become reliant on the guidance and support received from hospital and their support network, and struggled to manage independently without it. This may have resulted in low mood because of the impact on their self-concept, and disruptions to their identity formation (Erikson, 1959). This suggests that struggles with life transitions and independence have an impact on low mood, and there is a need for recognition amongst staff and those close to young people, to support this specific challenge, or help them talk about it.

Abnormal experience, loneliness and isolation. The experience of cancer was very abnormal for young people, and this increased low mood. They reported that they felt lonely and isolated through their experience of cancer, both physically and emotionally, sometimes even if they were around other young people with cancer. These feelings also made them want to withdraw from others and isolate themselves, which are

hallmark symptoms of low mood or depression (APA, 2013; NICE, 2015). This associates with literature on young people's developmental processes; a great deal of this stage of life for young people is spent with peer groups, where they develop complex relationships and learn to function in a world generated by their peers (Erikson, 1959; Stanton-Salazar & Spina, 2005). When this could not happen, young people struggled with low mood. Other qualitative studies in young people with cancer also identified feelings of isolation when they were stuck at home or in hospital, missed out on activities, and could not go out like normal (Enskär et al., 1997; Gibson et al., 2010; Hedström et al., 2005; Howard et al., 2014; McCaffrey, 2006). Loneliness and social isolation are risk factors for increased low mood and depression in young people, adults and older adults without cancer, suggesting its importance in psychological wellbeing (Cacioppo, Hughes, Waite, Hawkey, & Thisted, 2006; Hall-Lande, Eisenberg, Christensen, & Neumark-Sztainer, 2007; Matthews et al., 2016). This study found that the abnormal experience and isolation of cancer directly impacts on low mood in young people, and may explain why young people are an age group at greater risk of developing psychological difficulties such as depression (Lang et al., 2015). Knowledge of this could help to inform support, from services and young people's support networks, to retain normality and reduce isolation as much as possible.

Impact of cancer on others. Interpersonal factors in relation to young people's family, friends, and partners, were frequently described in relation to low mood through cancer. At times, these individuals struggled to manage the young person having cancer

or experiencing low mood. Parents suffered from mental health difficulties, close people struggled to tolerate difficult conversations, and friends lost contact or left altogether, which resulted in feelings of low mood, guilt, sadness and anger in young people. These findings support previous research, which describes the significant psychological impact of cancer on those around young people (Gibbins et al., 2012; Mercer et al., 2015; van't Hooft et al., 2016), however this study found that this impacts in turn on the low mood young people experienced. Another qualitative study found young people struggled with the loss of friends (Zebrack et al., 2014), and given the importance of their peer groups in providing emotional support (Eiser, 1993; Kyngäs et al., 2000; Wu et al., 2009), this is especially challenging. Some young people concealed and internalised low mood, to avoid placing additional burden on friends, family, and partners who they knew were already struggling. This relates to previous research that found family members hide their feelings to protect one another (Eiser, 1993; Young et al., 2003). This may affect reported rates of depression and low mood in young people with cancer, as it is not shared or talked about, and may exacerbate the feelings of low mood in the young person. Therefore, support for those close to young people, both for their emotional wellbeing and to help them feel able to stay in young people's lives through cancer, may be key for all parties (Mercer et al., 2015).

Impact of others on the young person. Family, friends, and partners' reactions, assumptions, and lack of understanding made situations more difficult for young people to manage, and increased low mood. This highlights the impact of the beliefs and views

of others, about young peoples' cancer experiences, on their low mood and perception of their ability to manage (Mercer et al., 2015). Some assumptions fell in line with low mood being an expected reaction to cancer, and the view that the illness is acute in nature and not chronic, which has been found in other literature (Chochinov, 2001; Moussavi et al., 2007; Rechner, 1990; Sharpe et al., 2004; Walker et al., 2014). This may mean that wider societal views of cancer and talking about emotions, encapsulated within the social ecological model, are impacting on young people's low mood through cancer (Bronfenbrenner, 1992).

Cancer also altered relationships and interactions. Emotions were heightened, and maintaining or adapting relationships was challenging to manage in addition to cancer, which impacted on low mood. This is supportive of literature that describes the disruptive effect of cancer on existing family, social, and romantic relationships, and on the development of new ones (Abrams et al., 2007; Çavusoglu, 2000; Gibson et al., 2010; Howard et al., 2014; Keim et al., 2017; Kent et al., 2012; McCaffrey, 2006). These areas support that young people's experiences are affected by and affect their surrounding systems and this relates specifically to low mood (Bronfenbrenner, 1992; Mercer et al., 2015). This is important because relationships with family, friends, and partners are often protective factors and facilitate coping (Choquette et al., 2016; Corey et al., 2008; Eiser, 1993; Enskär et al., 1997; Fan & Eiser, 2003; Gibson et al., 2010; Kent et al., 2012; Kyngäs et al., 2000; Ritchie, 2001; Woodgate, 2006; Zebrack et al., 2007; Zebrack et al., 2014). If these are challenged by cancer, low mood may increase. Therefore, when

difficulties present amongst a young person's support network, this should be recognized, and could highlight where psychological support might be needed.

Being around other young people with cancer. Young people presented with varying views on the experience of being around other young people with cancer and the impact on low mood. Young people described the immense value of coming into contact and sharing the experience with other young people with cancer, to reduce feelings of loneliness, and gain advice and support from others who understood. The potential importance of encountering and connecting with other young people with cancer to aid coping with psychological difficulties such as low mood has recently been reported, based on its known value in other contexts (Reynolds et al., 2005; Shama & Lucchetta, 2007; Solomon, 2004; Wärnestål, Svedberg, Lindberg, & Nygren, 2017). It is surprising that literature in this area is so limited, given that this group lose shared experiences with peer groups at a time where closeness with friends is so key, and interventions such as peer support are recommended for young people without cancer (Eiser, 1993; Kent et al., 2012; Kyngäs et al., 2000; MHT, 2016; Smith et al., 2007). Being able to forge connections with others who can share experiences and provide support and understanding can be invaluable for coping, and it has been highlighted as an unmet need for this population, both by this study and in other literature (Smith et al., 2007; Zebrack, 2009; Zebrack & Isaacson, 2012). Group psychological and peer support have successfully been used with adults with cancer (Roberts, Piper, Denny, & Cuddeback, 1997; Klemm et al., 2003; Ussher, Kirsten, Butow, & Sandoval, 2006). Development of

this type of support is still in the preliminary stages for young people with cancer, with a recent study considering development of digital peer support services to increase accessibility (Wärnestål et al., 2017).

Some challenges of being around other young people with cancer were also described, that were uniquely difficult and created feelings of low mood, such as comparisons with others undergoing treatment, and seeing their distress and sickness. Survivors' guilt was also a particularly difficult experience, as in normal circumstances, this age group would rarely witness the deaths of several friends. Young people did not think there was a great deal of awareness about this issue, or psychological support to help them manage. There is very limited literature in this area, which is surprising given how significant an impact this is likely to have on low mood in young people with cancer. This suggests that the effects on low mood of connecting with other young people with cancer is mixed, and may individually vary. Therefore, while young people should be made aware of opportunities to interact with others, this should be optional, and up to them to decide if it would be helpful. Availability of psychological support for grief and survivors' guilt could also aid in reducing the burden of low mood in young people with cancer, as this significantly impacts on low mood.

Research Question Three: How do young people with cancer attempt to cope with low mood, and how could these types of coping strategies be further facilitated

by services? Young people described coping strategies they used to manage their cancer and low mood individually, and talked about what points they used these. They expressed opinions on how these varied over time, and spoke of the value and importance of their support network and environmental factors for coping. They also provided insight into how they thought services could improve support, to facilitate more effective coping with low mood.

Adaptive coping strategies. Young people described a broad range of coping strategies to manage their low mood through cancer, such as problem solving, maintaining normality, behavioural activation, positive coping and planning, acceptance, avoidance, and denial. These strategies can be placed into the different theories of coping. Problem solving, behavioural activation, and maintaining normality or attempting to keep the environment and interactions the same, are considered problem-focused, primary control, or approach coping, where the individual consciously alters something personal or environmental (Compas et al., 2014; Eiser, 1993; Fields & Prinz, 1997; Folkman, 1997; Folkman & Greer, 2000; Lazarus, 1993). Acceptance, positive coping and planning, avoidance, and denial are encapsulated within emotion-focused, secondary control and avoidance forms of coping, where the individual attempts to reduce negative emotions (Compas et al., 2014; Eiser, 1993; Fields & Prinz, 1997; Folkman, 1997; Folkman & Greer, 2000; Lazarus, 1993). Use of these strategies and consideration of the theories they fit within have been replicated in meta-analyses, quantitative, and qualitative studies of young people with cancer (Aldridge & Roesch, 2007; Castellano-

Tejedor et al., 2016; Compas et al., 2014; Enskär et al., 1997; Olsson et al., 2015; Rechner, 1990; Wu et al., 2009). This study further supports previous literature that young people with cancer use both forms of theoretical types of coping, to reduce low mood and the negative effects of cancer, in a way and at a time during their cancer that worked best for them.

Maintaining normality and independence were important in managing mood and to prevent low mood in young people in this study, and may be acting to counter the struggles of not being normal or independent. This form of coping has been noted in other qualitative literature in young people with cancer, though not specifically in relation to low mood (D'Agostino, Penney, & Zebrack, 2011; Gibson et al., 2010; Kyngäs et al., 2000; Olsson et al., 2015; McCaffrey, 2006; Rechner, 1990). Positive coping strategies were used both during treatment, after, and in the long term, where young people described a different view on life, or reflected on positive gains through cancer. This finding has also been drawn from other qualitative studies regarding the cancer experience in young people, but has not been directly associated to managing low mood (Enskär et al., 1997; Wu et al., 2009; Zebrack et al., 2014).

At times, young people in this study also coped with low mood by avoidance and denial of cancer or what was making them low, as this made it too real and worsened mood. This may be because young people found it difficult to think about this without

ruminating on it, or without a way to process this individually. This may also have been adopted in survivorship, as some young people felt detached or as if the experience had never happened. Illness perceptions, and severity or burden of disease (Weinman & Petrie, 1997) may also be associated with denial, as both young people and others around them appeared to view cancer as acute in duration, and once treatment was over, they thought normality would resume. These findings corroborate previous literature that states that coping strategies such as avoidance and denial made the cancer experience more bearable and reduced emotional burden, and symptoms of depression (Castellano-Tejedor et al., 2016; Dejong & Fombonne, 2006; Kyngäs et al., 2000; Phipps & Srivastava, 1997; Worchel et al., 1988). However, young people in this research also thought that if these strategies were engaged in for prolonged periods of time, this resulted in greater emotional upheaval, and greater incidence of low mood after cancer. This was because emotions caught up at a time when there were fewer aspects to focus on, so they could not engage in avoidance of emotions as easily. These findings improve knowledge about what strategies young people used to cope at different times, and could be used to direct support in clinical settings to facilitate coping.

Coping as an individual journey. Young people described coping as an individual process, and through their experience of cancer they found and used strategies that worked for them, some without professional input. These aspects are in line with literature that there is no right way to cope (Aldridge & Roesch, 2007). There were mixed views about the development of coping strategies that young people used through cancer.

A number of young people felt they had maintained aspects of coping from before cancer, others felt new strategies had developed during their cancer, and some felt coping strategies that they developed during their cancer were transferrable to everyday life, and they had continued to use these since. This suggests that provision of psychological support for coping could build on previously acquired strategies, but given the lack of experience young people may have in managing such adverse situations, these should not be relied upon in therapeutic work. New simple ways to cope could be introduced that match the young person's context and levels of physical ability.

Many young people felt their coping changed through cancer, sometimes consciously, because a previous attempt was not working. This links to the concept of meaning-based coping, within cognitive stress and coping models, which involves moving on from an unattainable goal, and finding another way to produce an outcome that feels more positive (Folkman, 1997; Folkman & Greer, 2000). This change in coping can only be confirmed in a longitudinal study, but findings support previous research that coping strategies and abilities fluctuate, with ongoing processes of adjustment and re-adjustment, to manage cancer and low mood (Aldridge & Roesch, 2007; Cohen & Lazarus, 1973; Compas et al., 2001; de Ridder et al., 2008; Lazarus & Folkman, 1984; Walker et al., 2004).

Within this changing picture, young people felt that sometimes they were able to cope, but other times they could not, which caused greater low mood and relates to the concept of relinquished coping, which denotes a lack of any attempt to cope with the situation. This concept is depicted within control coping theory (Rothbaum et al., 1982), which has been used to examine coping in young people with cancer (Compas et al., 2014), but relinquished coping has not been explicitly described in relation to low mood before. However, fluctuations between feelings of hope about change and the desire to give up entirely, were also found in Wu et al.'s (2009) qualitative study, and literature has concluded that struggles to cope resulted in greater levels of low mood (Aldridge & Roesch, 2007; Compas et al., 2012; Compas et al., 2014; Phipps & Srivistava, 1997). The findings of this study suggest that coping should be measured or assessed at multiple time points as, while young people may be able to cope well at one point, they may find another stage more challenging, and therefore psychological support may need to be available in a flexible way.

Support network, environmental factors, and formal psychological support.

Young people's support networks of family, friends, and partners, were clearly very valuable in helping them cope with their low mood, and with the overall experience of cancer. This finding is supported by other qualitative studies that found the importance of receiving social support from family and friends, both in coping with cancer and reducing symptoms such as depression (Choquette et al., 2016; Corey et al., 2008; Eiser, 1993;

Enskär et al., 1997; Fan & Eiser, 2003; Gibson et al., 2010; Kent et al., 2012; Kyngäs et al., 2000; Ritchie, 2001; Woodgate, 2006; Zebrack et al., 2007; Zebrack et al., 2014).

Young people valued the staff, support systems, and environment in hospital where they received their cancer treatment, and positive experiences of this facilitated coping and reduced low mood. Some young people talked about the value of TCT ward environments, which supports previous studies where tailored support and environmental factors, such as a happy and hopeful atmosphere, helped in young people's experience of cancer (Castellano-Tejedor et al., 2016; Enskär et al., 1997; Gibson et al., 2010; Hollis & Morgan, 2001; Olsson et al., 2015; Reynolds et al., 2005; Smith et al., 2007; Zebrack et al., 2007; Zebrack et al., 2014). The current study extends this knowledge, as these factors have not previously been related to low mood. However, not all young people in this study reported negative experiences of non-tailored support on adult or paediatric wards, which is consistent with a study that did not find significant differences in overall satisfaction between paediatric, adult and teenage wards (Reynolds et al., 2005). This mix of experiences shows that factors other than a tailored environment have a role in the influence of low mood, which is supported by the range of impacting factors found in this study, and previous research.

Some participants in this research received psychological support from a professional to help them cope with low mood, which was predominantly very helpful,

and this is confirmed by previous literature (Olsson et al., 2015; Tenniglo et al., 2017; Zebrack et al., 2007). The current study extends this literature however, as it gained knowledge on what aspects of psychological support young people valued, which could influence service provision. This was identified as having a separate person to speak with, who was not emotionally attached to their situation, within a safe space, to have someone to help process their emotional experience, and to provide strategies to help them cope with their low mood.

Improving support. Young people felt that cancer services could support coping with low mood more effectively in several ways. The occurrence of low mood during, after, and in long term survivorship of cancer could be more openly talked about and normalised amongst both medical and psychological professionals, which could make emotions easier to feel, articulate and manage. Those who did not receive support felt this would have been beneficial to them, though not everyone felt they needed it. Young people thought support for low mood should be available throughout cancer, either openly on offer or integrated into their care, and provided in a flexible and tailored way, accessible from home as well as hospital, with the potential to use technology to facilitate this. Others around young people should also have support options available, and should be educated to become more aware of how to support and promote young people to cope effectively. Age-appropriate materials should also be improved, as should the opportunity to connect with other young people with cancer. Some of these areas support the limited literature available in this area, where a previous study highlighted that support for

psychological difficulty in young people with cancer was helpful, especially after treatment (Olsson et al., 2015), and another emphasised the need for suitable, accessible and timely support (Tenniglo et al., 2017). While evidence-based interventions are developing in this area (Bradford & Chan, 2017; Coughtrey et al., 2017), many other studies emphasised that support for mental health difficulties in this population continues to be an unmet need (Bennett et al., 2015; Dyson et al., 2012; Keegan et al., 2012; Palmer et al., 2007; Smith et al., 2013; Thompson et al., 2007; Zebrack, 2009; Zebrack & Isaacson, 2012), and this is corroborated from the results of this study.

Critical Review

Strengths. A key strength in this study was that it addressed gaps in the literature. It is the first qualitative exploration of experiences of low mood in young people during and after cancer, and provides valuable insight into their experience, the impacting factors, and coping strategies used to manage. It is also the first qualitative investigation that directed questions towards how young people would like to receive psychological support to improve low mood in cancer.

This study used the framework approach for analysis, which provided a systematic and traceable analytic form: it enabled others to understand how interpretation and conclusions were drawn, and preserved individual participant accounts within and across themes (Gale et al., 2013; Pope et al., 2000; Ritchie & Spencer, 1994). An independent rater from a different professional field coded and applied the index to separate selections of transcripts, to ensure consistency and rigour, and reduce bias. The

researcher was also supervised in the framework approach, to ensure it was conducted correctly, and a consensus approach was used. Respondent validation checks were written and sent to all participants, and they were informed that no response would imply agreement. Responses were received from 47% of participants, all of whom confirmed that the summary accurately summarised and depicted the experiences they had shared.

The interview schedule used was developed following input from service users about appropriate use of language, and from two research representatives in national cancer charities. It was also piloted with a member of staff directly working in an NHS setting with young people with cancer, and adapted accordingly. An initial interview recording was also played to the field supervisor to reflect on interview style, and adjustments were made to follow-up prompt questions. This was done to ensure the interview environment created by the researcher was one where participants felt confident and comfortable to share experiences, so that in-depth and rich accounts were gathered.

The study sample included young people treated for cancer across the UK, both in young people's cancer services, and general paediatric or adult oncology wards. This prevented the risk of narrowing experience to only one geographical area, one treating centre, or one particular treatment experience, and therefore allowed a broad range of accounts to be encapsulated.

Limitations. Young people self-selected to participate, knowing that this study was exploring low mood during cancer, and therefore accounts of participants may not be representative of experiences of all young people with cancer. However, in an attempt to balance this, it was not an inclusion criteria that participants had to have experienced low mood themselves or that they were experiencing this at the time of interview.

The sample size within this study may be a limiting factor, as 19 young people were interviewed, which means generalisability of findings may not be possible. While response rate was good, with 73% of the originally eligible 26 participating, it could not be concluded whether those who participated were representative. A starting number of 26 eligible participants was also quite low, due to recruitment through online adverts, and the opportunistic nature of this in hospital. However, in relation to other published qualitative studies using interviews to explore experiences in young people with cancer, this number is fairly high. The majority interviewed 5-15 individuals, and only one exceeded the sample size of this study (Howard et al., 2014). A sample size of 19 was also appropriate for the use of the framework approach, based on previous studies that employed this method of analysis (Coughtrey, 2013; Leal et al., 2015; Parkinson et al., 2016; Pistrang et al., 2012; Tighe et al., 2012). Additionally, generalisability of results is not necessarily the aim of qualitative research, and it has been argued that the same criteria by which quantitative studies are judged is not applicable to qualitative studies, as they aim to provide a detailed narrative or perspective of individuals, about a specific situation (Mays & Pope, 2000; Schofield, 2002).

Seventeen of the interviews in this study were conducted over the telephone due to participant preference. This is a limiting factor, as it was not possible to pick up on non-verbal cues using this interview method, and previous research has suggested it is more challenging to develop rapport or explore subtleties within participants' accounts (Novick, 2008; Vogl, 2013). However, lengths were taken to ensure participants felt as comfortable as possible, for example the researcher provided more verbal feedback and cues than would have been provided if face-to-face. Participants also chose to be interviewed over the telephone as this was more flexible, and the drawbacks were felt to be outweighed by the benefit of increasing recruitment capacity, and the extension of the geographical areas this research could reach, by using this method. Additionally, research suggests that gathering data qualitatively over the telephone has similar levels of value and ability in sharing sensitive information, compared to face-to-face interviews (Sturges & Hanrahan, 2004; Vogl, 2013).

Given that all participants were no longer in active treatment for cancer and the majority were not experiencing symptoms of low mood at the time, recall bias may be a limiting factor in this study (Coughlin, 1990; Schwarz & Sudman, 2012). This study did not interview any participants who had terminal cancer or were not going survive their diagnosis, and thus their experience of low mood may not have been captured in these findings. The experience of low mood in young people with terminal cancer or in palliative care are likely to be different and potentially more significant, due to ongoing physical illness, existential issues, and family factors (Walker et al., 2013). It is noteworthy that a terminal cancer diagnosis was not an exclusion criteria for this study,

but the absence of these participants indicates that recruitment for future studies may need to specifically target this group.

This study extended the classification of ‘young people’ to 11-26 years at diagnosis, to accommodate two participants who were slightly older, and younger than the classification of young people in the UK, which is 13-24 years (TCT, 2017). However, all participants still identified as being young people, and some TCT services in the UK do in fact cover those as young as 11 and as old as 25 years (TCT, 2017). The experiences of low mood captured from those outside the original criteria also appropriately combined with those within. However, the broad age range may mean this research lost some nuanced experiences that those in early teenage-hood may struggle with more, compared to those in early adulthood for example. Age range was kept broad for recruitment purposes, and reflects the difficulty of consistency in this area, which other literature has also come up against (Lang et al., 2015).

This study used the words ‘low mood’ to describe the emotional experience young people with cancer may have gone through. It is acknowledged that these words risk adding confusion to an area where many different words are already used to describe the emotional experience. However, the term ‘low mood’ was used in place of depression, based on service user input from young people into the wording of the interview schedule, as they explained low mood would be more accessible and less stigmatising. The researcher agreed that this led to more open discussion about the broader emotional experience, and consideration of whether their experience does indeed fit into the concept of depression.

Research implications

There are several research implications highlighted by this study, which may benefit from further investigation.

It may be helpful to conduct further qualitative studies of low mood, such as a prospective longitudinal study of low mood in young people with cancer, interviewing them at various stages of cancer (e.g., diagnosis, treatment, post treatment, and long-term post treatment). This would enable the experience of low mood to be explored at different points, rather than the description of the whole experience retrospectively. This would provide increased understanding of the variance in low mood, or different trajectories that this experience may take, and how this was managed and supported over time.

Given that this study has identified that qualitative investigation of the experience of low mood in young people with cancer produces interesting and novel findings, a more in-depth qualitative study using a more homogenous sample could be carried out, using a methodology such as grounded theory or IPA, in order to develop a theory of low mood in young people with cancer, or to gain greater perspective and interpretation of how they made sense of their experience.

It might be beneficial to research and consider the development of a specific quantitative measure of low mood for young people with cancer, which could more sensitively detect and explore this difficulty. It could be helpful for this measure to consider the potential fluctuation in mood and therefore how to phrase questions, but also

the wider psychosocial and developmental factors that have been highlighted as specific issues for young people that contribute to low mood in cancer. It may also help to make this measure as minimally stigmatising as possible, to increase uptake and engagement.

This study highlights the opportunity for testing the efficacy of different forms of support for low mood in young people. For example, support provided or introduced by medical staff, or by clinical psychologists, using different psychological theories, such as systemic approaches with the young person and their surrounding systems, or cognitive behavioural approaches incorporating coping strategies. These interventions could also be tested for use with other psychological difficulties in young people with cancer, either specifically (such as anxiety), or in more broad measures of psychological wellbeing.

Different forms of support for young people with cancer could also be compared between different groups, for example within young people with cancer but between those where depression is diagnosed and those it is not, between young people with cancer and young people who do not have cancer, or even between young people and other age groups with cancer, such as children or adults.

Clinical implications

This study provides understanding of the experience of low mood in young people with cancer, and how their unique challenges impact on them. It also furthers knowledge on coping with low mood in cancer, and how services can facilitate coping. It therefore

has a number of clinical implications for services that treat, and charities that support, young people with cancer.

Clinical assessment. Given that clinical questionnaire-based measures may not appropriately detect low mood in young people with cancer, and the novel information about fluctuations in mood and potential under-reporting of difficulties by young people, care should be taken in the way this is assessed. It may not be appropriate for questionnaires to be the only measure of this (Recklitis et al., 2016), and it may be beneficial for staff to be aware of, or trained in the potential markers of low mood in young people with cancer, so there can be an observational measure of this also. This is supported by the government's Five Year Forward View for Mental Health paper, which described the need for investment in training to ensure staff working with young people can adequately detect mental health problems, and know how to act (MHT, 2016).

Assessment of low mood should also be an ongoing process, not time specific. This is due to the constantly changing demands and circumstances the young person may be experiencing, both during treatment and after completion, and with the knowledge that low mood might present at home as well as in hospital (Kyngäs et al., 2000). This recommendation is in line with NICE guidelines for children and young people's cancer services (2014), which suggests ongoing psychosocial assessment, at key points within the cancer pathway. However, it is interesting that young people have highlighted in their experiences that this did not happen within their experience of cancer. This might be associated with resource and funding levels of psychological provision within physical health contexts (MHT, 2016), and may mean that a screening measure could be used

initially. These areas emphasise the importance of evidence-based assessment of low mood in young people with cancer, where research and theory are both considered and used to deduce levels of difficulty that might be experienced. Effective detection of psychological difficulty such as low mood will mean that treatment can be more accurately delivered, and those who require support receive it.

Integrated psychological support. Training for medical staff working with young people with cancer could be beneficial. This could enable greater confidence in assessment of, and discussion about psychological difficulties in relation to the experience of cancer, and provide psychosocial support or appropriate referral for further input. This type of approach has been used and researched in adult cancer populations with both good and poor prognoses and comorbid depression, to excellent effect (Sharpe et al., 2014; Strong et al., 2008; Walker et al., 2014). Support should be integrated and multidisciplinary in nature both during and at follow-up of cancer (Tenniglo et al., 2017; van't Hooft et al., 2016). This was highlighted as important by young people interviewed in this research, and could be beneficial if applied to young people's cancer services. It is also in line with initiatives to better integrate physical and mental healthcare services, and to ensure parity of esteem (Das et al., 2016; Naylor et al., 2016; MHT, 2016).

Stepped care of psychological support. Care and treatment of depression in young people in mainstream mental health services follows a stepped-care approach,

where different levels of severity receive varying levels of support (NICE, 2015). Considering the applicability of this in young people's cancer settings, leaflets for young people, their family, and friends, to normalise low mood and provide psychoeducation may be a useful low-intensity intervention for mild symptoms of depression, with increased psychological support available if this is needed. A stepped care approach could also reduce stigma associated with mental health difficulties in a physical health context, and empower young people to self-refer or take more ownership of needing support for their feelings. These aspects also support a proactive or preventative form of psychological support, where information and resources about low mood and coping are provided to young people and those around them prior to difficulties presenting, but where further input is available if needed. This type of model, using proactive coping theory (Aspinwall & Taylor, 1997), has been used in adults with diabetes with positive effects (Kroese, Adriaanse, Vinkers, van de Schoot, & de Ridder, 2014), suggesting potential viability in young people with cancer. Such an approach is in keeping with recommendations in government policies with regards to the promotion of resilience, and preventative and early interventions, especially for young people (DoH, 2015; MHT, 2016).

Tailored interventions. Psychological support should be tailored to the young person and their cancer needs, and not be generic in nature, rather supporting a specialist personalised approach. Personal care planning has been successfully used in adults with cancer (Coulter et al., 2015), and future work is needed to explore whether this could be

implemented in young people with cancer. Specific consideration of their developmental stage would be needed, and the potential impact of this on cancer care and psychological wellbeing, including assisting with maintaining normality, retaining identity, and acknowledging the importance of peer relationships (D'Agostino et al., 2011; Zebrack, 2011). Peer support, and increased connections between young people with cancer should be established and accessible for young people, given the benefits of this form of intervention (Bradford & Chan, 2017; MHT, 2016; Shama & Lucchetta, 2007; Smith et al., 2007; Wärnestål et al., 2017), and youth projects to facilitate conversations about emotions in creative ways could be helpful (Ferrari et al., 2017a; Ferrari et al., 2017b).

Psychological support should also be flexible in terms of access, which could be facilitated using technology such as telephone and internet-based support, which is being explored and is showing promise (Bradford & Chan, 2017; Willems et al., 2017; Kanera et al., 2017). Other information and resources to help young people manage difficult aspects of cancer should also be tailored, both to cancer and to this age group (Zebrack & Isaacson, 2012). Access to psychological support for young people with cancer is variable at present, and improving this in the general young people population is a recent initiative and is in recommendations in guiding provision of mental health services (DoH, 2015; MHT, 2016).

Young people's cancer services. The majority of young people who experienced a TCT ward identified the benefits of being in a tailored environment for young people with cancer. Some young people who spent time on adult oncology ward environments found these very difficult and they significantly impacted on their mood. These interviews support the need for specialist young people's cancer wards, and demonstrate that not all young people access these services at present (Smith et al., 2007). Despite the TCT classification of young people as aged 13-24, the 28 TCT funded units across the UK have variability in the ages that they accommodate, including sub-groups of this, or even deviating outside of the range (TCT, 2017). This variation, combined with the geographical area a young person lives in, will vastly impact on their experience of cancer and consequently their low mood. This suggests the need for a unified definition of young people, that is operationalised and applied in cancer research and clinical services, and for continued expansion of young people's cancer wards and services, to further increase access and support for this group.

Personal reflections

Throughout the research process, I ensured awareness and consideration of my own perspectives and reflections (Elliott et al., 1999). Personal reflections here have been structured using Gibbs' (2013) reflective cycle, which considers the description, feelings, evaluation of experience, analysis, conclusion, and action plan.

My clinical experience as a trainee clinical psychologist, working with teenagers with chronic physical health conditions, and adults with depression, equipped me with

knowledge of the theories of depression and adjustment, how these present, and the skills to talk about these, and provide strategies to help, and motivated me and interested me in these young people's experiences. This could have affected the questions jointly developed and included in the interview schedule, and the way that I asked them and spoke to participants. I was conscious to maintain my position as a researcher and not a clinician through these interviews, and used my reflective journal, supervision and listening back to interviews, to ensure I continued to remain curious from a research perspective, and did not slip into a more clinical role of therapist.

Witnessing the impact of cancer in my own wider family system, how it complicated previous difficult relationships, and how an individual's previous values or ways of coping interacted with cancer, enabled me to better understand and notice the feelings evoked in me through the interviews and experiences. I made sense of this by considering that having a personal situation to attach these emotions to, brought to life what the participants I interviewed might have gone through, in a different context. It also led me to challenge my own beliefs about talking. Within my profession of choice, the value of talking is held quite dear, however considering my family experience and hearing accounts through this research in supervision, led me to understand that talking may not always be helpful, and some avoidance may in fact be protective. This meant that when young people in future interviews described some avoidance of feelings, I was more aware of this, and the possible constructive aspects of this form of coping.

I noticed that through my interviews, I spent much of the research process feeling in awe of the young people I interviewed, of their willingness to openly share their

experiences with me, to consider and reflect on the adversity they had been through, and their resilience and abilities to manage and find positives from it. This led me to want to be as true to these young people as possible, to do them justice, and to improve the experiences of future young people with cancer who experience low mood. I found myself thinking about the young people I interviewed, or about broader concepts of cancer and low mood, and used my reflective log to document and consider my thoughts. Having a space to note these down allowed me to remain objective for each new interview, without imposing information or ideas I had gained onto this participant. This also helped me to maintain my stance as critical realist and researcher.

Through analysis, I also noticed similarities in the themes or areas described in young people in relation to my own experiences. For example, whilst writing this thesis, I noticed feelings of loneliness, others' lack of understanding of the situation if they were not going through it themselves, and the value of shared understanding and experience with other trainees. I made sense of this by considering that in certain situations these feelings may emerge in many populations, but also that given the amount of immersion in my data through this process, I was more likely to notice similarities between this and my own life. I shared this with others in reflections, and remained aware of it, again to ensure that this did not affect interviews conducted, or the way I discussed my findings.

Conclusion

This study explored the experiences and opinions of low mood in young people with cancer, in relation to their unique challenges at this age, the way they coped with

this, and how services could better facilitate coping. Nineteen young people were interviewed, the transcripts from which were analysed using the framework approach.

In summary, young people with cancer who were interviewed articulated and described the presence of low mood. There were similarities and differences of their experience in relation to diagnostic criteria, and the findings corroborated challenges in diagnosis, associated with their identification of the experience themselves and the difficulty of overlap of physical and mental health symptoms. Regardless of how these experiences are constructed, as a diagnostic category of depression, as low mood, or otherwise, it is clear that they can be very challenging for young people to manage, and should not be ignored. Low mood appears to be a term that appropriately describes emotions and is acceptable to young people, to verbalise their experience. In addition to the significant problem of managing cancer, aspects of the challenge of low mood are also closely linked to the unique difficulties young people experienced through cancer, especially in relation to their stage of life, changes to their body image, identity, independence levels, and the interpersonal impact. This can make low mood more challenging to deal with and harder to voice.

Young people with cancer employ a number of coping strategies to manage low mood, and there is clearly a significant amount of resilience in this population. Many strategies young people used to cope were highly adaptive and constructive, and they

sought out and developed strategies that they found effective and helpful. However, services might be able to help ease the journey. This study suggests that young people may want something more proactive in terms of support, with normalisation of the possibility of low mood presenting during and after cancer, to reduce the feelings of this being abnormal, or something that should be hidden from others or not shared. Improving networks for young people with cancer as an additional form of support, but also to provide knowledge on how others have managed, could also improve the experience of low mood. Young people want support to feel available and accessible throughout their experience of cancer, which does not end when treatment ends. Future research, and service commissioners and developers should address these needs for this vulnerable population.

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Appendices

Appendix 1. Distress Thermometer (NCCN, 2016)

Removed for Copyright reasons.

Appendix 2. Participant information sheet

Information about the research

Project title: A qualitative investigation into the nature of low mood in young people

We work at the Institute of Child Health and Great Ormond Street Hospital. We would like to invite you to take part in a research project. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve for you.

Please read through the following information carefully and discuss it with others if you wish. Take your time to decide whether or not you wish to take part.

Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

We know that young people who have cancer are more likely to have other difficulties like anxiety or low mood. We want to understand why this is the case and how we can find the best way of treating these difficulties, which can affect the young person's overall health.

Why have I been invited?

We are inviting all young people aged between 13-24 years, who have a diagnosis of cancer to take part in this study.

Do I have to take part?

No, it is entirely your choice if you want to take part in the project. If you agree to take part, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive or how quickly you receive care.

What will happen to me if I take part?

If you are interested in taking part, you will be invited for an interview, where we ask you some questions about your experiences with low mood and/or distress. We will also show you the website with information and special worksheets to help with low mood and ask you what you think about them. Your parent is welcome to stay with you during the interview if you would like.

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

There are no specific risks from taking part in the project. We will not ask to take any blood, or give injections or anything like that. If we think that you need to meet with someone to discuss your wellbeing sooner (for example if your mood becomes lower during this time), then we will refer you to other services that can help.

The interview will be recorded with a voice recorder, and these are just for us – the researchers. No one else (for example, teachers or doctors) will hear your answers if you don't want them to.

It is possible that thinking about life and the effect of having cancer could be upsetting. If the interview questions do cause you any distress, please let us know at any time during or after the interview, so that we can offer support and think about what further help is needed.

Will taking part help me?

We cannot guarantee that the project will help you, but we hope that the information we get from this project will help improve the treatment of young people with low mood and cancer.

Will my taking part in the project be kept confidential?

If you agree to take part in the project, some parts of your medical records and the data collected for the project will be looked at by authorised persons from the research or clinical team. They may also be looked at by authorised individuals from the sponsor organisation, regulatory authorities or from the NHS Trust, where the research is taking place, to check that the project is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

We will also write a summary letter to you. Your parents will also receive a copy of this letter if you are under the age of 16.

What will happen if I don't want to carry on with the project?

You are free to withdraw from the project at any time. Your care will not be affected. If you do withdraw from the project, the interviews that you have given us up to that point will be used in the analysis of the project results. If you would prefer for this data not to be used, please let the researcher know.

What if there is a problem?

If you have a concern about any aspect of this project, you should ask to speak to the researchers, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service (PALS) at Great Ormond Street Hospital (020 7829 7862; pals@gosh.nhs.uk) or at UCL Hospital (020 3447 3042; PALS@uclh.nhs.uk).

What will happen to the results of the project?

We will write to you to let you know the overall findings of the project. We hope to publish the findings of the project. No names or other identifiable information will be used in any reports or publications.

Who has organised and approved the research?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This project has been reviewed and given favourable opinion by the London Bloomsbury Research Ethics Committee. The research is being sponsored by the UCL Institute of Child Health.

Who is funding the research?

This research has been funded by the Health Foundation.

Contact for further information

If you would like any further information, please contact:

Contact: Dr Anna ~~Coughtry~~ Coughtry

Address: Psychological Medicine Team, Great Ormond Street Hospital for Children
NHS Foundation Trust, Great Ormond Street, London, WC1N 3JH

Email: anna.coughtry.10@ucl.ac.uk

Telephone: 020 7905 2311 (internal extension 2196)

Appendix 3. Participant consent form



Participant Identification Number for this project:

CONSENT FORM

Project title: A qualitative investigation into the nature of low mood in young people

Name of Researcher: Prof. Roz Shafran & Dr Anna Coughtrey

Please initial all boxes

- 1. I confirm that I have read and understand the information sheet (dated 30/06/2016 version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, from the sponsor, 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.
- 4. I agree to the interview being voice recorded.
- 5. In the event that I decide to stop taking part in the study, I agree to the data up to that point being used in the analysis of the study results.
- 6. I agree to take part in phase 1 of the above study (completing an interview about my experiences).

Name of Participant

Date

Signature

Name of Person taking consent.

Date

Signature

Young person 16-24 Consent form date of issue: 30/06/2016
Young person 16-24 Consent form version number: 2
IRAS ID: 195812

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Appendix 4. HRA approval



Prof Roz Shafran
Professor of Translational Psychology and Honorary
Consultant Clinical Psychologist
UCL Institute of Child Health
30 Guilford Street
London
WC1N 1EH

Email: hra.approval@nhs.net

06 September 2016

Dear Prof Shafran

Letter of HRA Approval

Study title:	Understanding the nature of low mood in young people with cancer compared to young people without cancer: a qualitative investigation
IRAS project ID:	195812
REC reference:	16/LO/0939
Sponsor	Great Ormond Street Hospital for Children NHS foundation Trust & The UCL Institute of Child Health

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Appendix 5. Interview schedule

Interview schedule for young people

Introduction

I'm going to ask you some questions about your experience of having cancer and any low mood you experienced in relation to this. We know that dealing with a diagnosis of cancer can be really hard for you and your family to deal with and it's normal to find it hard to manage and take time to work out how it affects you. Our questions today will take about 20 to 40 minutes, to start with it might feel a little bit strange and one-sided – I'll ask questions now and again and give you time and space to talk through the answers. If you say something that I find interesting, I might ask you to talk a bit more about it to help me understand or I might come back to it later if that's ok, and you can do this too if you want to. Please let me know if you want to take a break or stop at any time. If there are any questions you don't want to answer, just tell me, that's absolutely fine, and we can move on to another one. Is that ok? Do you have any questions before we start?

Topics for discussion

Warm up question

**Either from your own experience or the experience of others,
what do you think low mood looks like or feels like for a young person with cancer?**

Prompts

Is this something you've experienced personally?

If not, do you know other young people who have had cancer who were low in mood?

How do you know/notice it's low mood?

How might others know or notice it?

Could you give me a specific example of what you mean?

(Is it easy to describe?)

When do you think low mood presents when somebody has cancer?

Do you think this is different for different people?

Do you think low mood is the right term for this? What would you call it?

Maintenance

What do you think keeps low mood going/maintained in young people with cancer?

Prompts

How do you know it's more than just a bad moment or a bad day?

Were/are there any particular situations that would make you feel down?

What do you think triggers those times of low mood?

What was going through your mind, what were you doing/not doing?

Are there things that made you feel worse?

Did it feel like a problem for you or did it feel manageable?

What do you think helped protect you from low mood?

What stopped low mood from getting worse?

How do you think young people with cancer, or you attempted to cope with low mood when it presented?

Prompts

Was there anything that made you feel better? Was there anything that helped?

Do you think this would be different from young people who have low mood but not cancer?

In what ways?

Do you think that this kind of coping works?

With the benefit of hindsight, was this coping helpful, in the long term?

Do you think coping styles might change, either from before cancer to when you have it, or during having cancer?

Is there anything that surprised you about the way you coped?

Did you feel like you could cope with it at the time, or that you just had to cope?

(something others have said)

In what ways do you think low mood/depression in young people with cancer is different from low mood/depression in young people who don't have cancer, or in adults who have cancer?

Prompts

How do you think it's the same/different?

How do you think other people view it?

Check covered differences in –presentation –maintenance -coping

Do you think it needs to be supported in a different way in young people with cancer? If you'd had help for low mood, would you have wanted it to be specific for young people with cancer?

Gaps in treatment

Was low mood talked about when you had cancer? (friends, family, people at hospital?)

Prompts

What kind of things did you talk about?

What was it like talking about your feelings?

How did you decide to talk about how you were feeling (or not)?

Would you have liked someone to talk to you about your low mood?

Is there anything more you think could be done to help with low mood/depression that isn't being done at the moment?

What kind of support do you think is needed or would you have liked to receive?

Prompts

If you felt you needed help, did you feel able to ask for it?

How could others help with this?

What do you think are the most important things to talk about?

When do you think during someone's cancer treatment this kind of help would be most useful?

Ending treatment seems to be a time where lots of young people have identified as an unexpectedly difficult time, what would have helped to make this easier?

How do you think services could help to improve your experiences of coping and managing low mood in the context of cancer?

Is there anything you think is missing?

Why would that have improved your experience?

We've talked a lot today about low mood but we are aware this isn't the only emotional difficulty that is experienced when young people have cancer.

Are there any other difficulties you experience/have experienced as a result of cancer?

Do you think these have more been or less of a problem than low mood?

Ending the interview

We've come to the end of our questions, thank you for talking with me and taking the time to think about and answer these questions.

Is there anything you'd like to add or is there anything important you think I missed out today?

How did you find talking about this today?

If there are any other questions later, please do get in touch at any point.

Check if happy to be sent themes for respondent validation check.

Appendix 6. Coding index

1) Experience of low mood

1.1 Knocked up and down

1.2 Chronic feelings

1.3 Individual differences

1.4 Difficulty naming emotional reactions

1.41 So many emotions

1.42 Not pathologizing emotions

1.43 Hospital didn't talk about it

1.5 Low mood during treatment

1.51 Shock of diagnosis

1.52 Effects of treatment

2) Ending treatment

2.1 Positive expectations were wrong

2.2 Support and structure is gone

2.3 Emotions catch up

2.4 Feelings stay long-term

3) Isolation

3.1 Isolating self

3.2 Lonely experience

4) Feeling different

4.1 Reduced activity

4.2 Missing out with friends

4.3 Looking different

4.4 Not 'normal' afterwards

4.5 I'm a different person

5) Unique difficulties for young people

5.1 Cancer takes over

5.2 Independence is gone

5.3 Too young for cancer

5.4 Awkward age

5.5 Normal life challenges exacerbated

6) Friends and family, cancer and low mood

6.1 Struggled to manage

6.2 Lost friends

6.3 Relationships changed

6.4 Assumptions made it worse

6.5 People didn't understand

6.6 Did unhelpful things

6.7 Sharing feelings is a burden

6.8 Educate them to support low mood

6.9 Support their emotions

7) Sharing with other young people with cancer

- 7.1 They understand
- 7.2 I'm not alone
- 7.3 Gained friends
- 7.4 Can talk openly
- 7.5 Get inspiration and reassurance
- 7.6 Never exactly the same
- 7.7 Others in the same horrible situation
- 7.8 Becomes too cancer focused
- 7.9 Survivors' guilt and grief
- 7.10 Increase connections and support between young people

8) *Individual coping*

- 8.1 Getting 'used to' treatment
- 8.2 Keeping a level of normality
- 8.3 Doing enjoyable things and keeping busy
- 8.4 Problem solving
- 8.5 Finding the positives
- 8.6 Accepting feelings and changes
- 8.7 Not focussing on feelings

8.8 Long term coping

- 8.81 Amazed and proud that coped
- 8.82 No choice but to cope
- 8.83 View life differently now
- 8.84 Cancer is separate from me

9) External input and coping

9.1 Support network

9.2 Hospital support environment

9.3 Talking therapy with a professional

10) Improving support for young people with cancer

10.1 Low mood should be normalised

10.2 Integrated and accessible throughout

10.3 Not overwhelming or compulsory

Appendix 7. Indexed transcript extract

P: Um...mine...mine were work. Work tended to put me in a, in a low mood because they were always bothering me...um thinking about friends that I'd lost, not necessarily passing away but friends that didn't know how to deal with me being diagnosed, that, the ones that didn't stick around, that kind of upset me, that I was still me. I hadn't changed. Um, yeah and that were it, that's mainly what it is...

I: Mmm. And would you say, I've kind of been using the words 'low mood', do you think that's the right term for it, is that, is that what you'd call it?

P: Yeah, definitely.

I: Ok, alright. And are there any things that you think keep low mood going, or kind of keep it maintained in young people with cancer, or in your experience?

P: Um...I think, I think that is isolating yourself, I think, especially me, I noticed that when I isolated myself, the low mood seemed to stay longer than what I wanted, The more I kept busy, the better I felt.

I: Ok. So, even though you wanted to, be on your own; that was something you wanted to do, you noticed that that was something that was keeping it going, is that right?

P: Yeah. I'd make myself get out and do something.

I: Ok, yep yep. And so you've mentioned some particular situations that kind of made you feel low, you mentioned thinking about losing friends and those kinds of things. Are there...would you, would you say there are things that kind of made you feel worse when you were thinking about things?

- Rosa Reed-Bere 5.5 Normal life challenges ▼
- Rosa Reed-Bere 6.1 Struggled to manage
- Rosa Reed-Bere 6.2 Lost friends
- Rosa Reed-Bere 8.84 Cancer is separate from me

- Rosa Reed-Bere 3.1 Isolating self
- Rosa Reed-Bere 8.3 Doing enjoyable things and▼

P: Um, I think it's the not knowing, and the not understanding... of, of why.. Like because we, us as a young person going through cancer, we can only ever see it from our side, we, we won't know what our friends and our families are thinking.. So not knowing why they chose not to stay.. Or.. And also like...with friends that did pass away, not knowing why were...why they didn't survive. Survivors' guilt is a big, a big issue as well.

I: Ok. And, would say survivors' guilt impacted on your low mood?

P: Yes, definitely.

I: Yeah, yeah. Ok. And, did low mood, did it feel like sort of a problem for you when you were going through cancer, or did it, did it feel like something that was manageable?

P: Uh *sighs* see, with me, when I was going through my treatment and everything, even though I was in low mood and I knew I had to get on with it, there was nothing that I could do, for me the low moods were after, after not being in hospital, not...not being around that community. Um...I found it a lot harder being at home 'cause when you're in hospital you're kind of in a place that's a blanket that quilts you.. You're with...you're with people that understand, the nurses understand, but when you get home, your friends and family don't understand what it's like and

Rosa Reed-Bere 1.4.1 So many emotions

Rosa Reed-Bere 5.3 Too young for cancer

Rosa Reed-Bere 6.2 Lost friends

Rosa Reed-Bere 7.9 Survivors guilt and grief

Rosa Reed-Bere 8.1 Getting 'used to' treatment

Rosa Reed-Bere 5.1 Cancer takes over life

Rosa Reed-Bere 2.2 Support and structure is gone

Rosa Reed-Bere 9.2 Hospital support

Rosa Reed-Bere 6.5 People didn't understand

Appendix 8. Example of thematic chart – code 4

Code 4: Feeling different					
Participant number	4.1 Reduced activity	4.2 Missing out with friends	4.3 Looking different	4.4 Not ‘normal’ afterwards	4.5 I’m a different person
1	Stuck at home and not able to get up, or be proactive, which is depressing. P1,6,9		You don’t feel like yourself at all, it’s difficult having to deal with hair loss, weight changes and physical signs of cancer and not knowing what to do about it. P3,4,9	You just think life is never going to be the same again. P7	
2	Not being able to go out because you’re too ill. P2,3,4		Real body issues in cancer, you look awful, you have no hair, you can’t control your weight, you just want to do normal things. P1, 2, 9	All of sudden you’re on your own, having to get back to normal and move on, and it’s really hard, don’t know what life is like now. P5, 6	I don’t know if I will ever have a normal life again. This is my life and my normal. P6
3	If you’re low you’re not motivated. P6 Nothing to do when you’re on treatment. P1,6				
4	Not getting up or doing anything; I couldn’t, I didn’t		My hair fell off and I wore a towel round my head to keep		

	want to or there was nothing to do. P1,2,6,7,8		warm, looked like a crazy person. P5		
5			Had really big hair and suddenly realised I was going to lose it. P2	Effects of cancer make sexual relationships difficult. P5	
6	Bored in hospital and unable to get out. P3			Expected to get back on with normal life, but it's not normal because you still have side effects. What is normal afterwards? P1, 3, 5	
7	Struggling with motivation; not wanting to go out or do anything. P1,2,5,6		Went straight back to school suddenly looking different, and thought everyone would notice. Lost confidence. P1 Low mood got reinforced by hair loss P1,2 Affected self-esteem. P8		Felt like a part of me had gone when they discharged me from follow-up. P3
8	Stuck in isolation with nothing to do. P4		Hair loss causes low mood, chemo side effects knocked confidence. P5, 10	You want to be normal, but you can't be completely normal. P7/8,10 It's like starting again afterwards. P11	You're not the same person, and you have go and find out who you are P2,11

9	So bored in hospital. P3 Can't do as much, your life is restricted. P7	Can't go out with friends like before diagnosis. P8		You've got to go back into the big world, but you can't live a normal life like before P7,8	
10	Bored at home doing nothing, wasn't well enough to go out. P6 Can't do a lot of things you normally do, can't do certain sports because of lines. P5, 7		Your body changes and you lose your hair. P4	Difficult transition from inpatient treatment to normal causes low mood, life is no longer on hold. P6, 8	
11	Couldn't go out, all cooped up at home. P1,8		Quite paranoid about looks as a teenager anyway, so gaining weight, and seeing hair come out and not knowing what to do was hard. P2, 3. I suddenly didn't look like before anymore. P4, 6	Unsure how to get back to your normal routine, forget what normal was P8.	You forget how you were before. P8
12	Not wanting to or being able to do much. P1, 3	All my friends had gone to uni, and did all the things I couldn't do, and I had to stay to have treatment. P1	Lost confidence because of treatment changes. P7, 8, 12	I felt like I'd lost things during treatment. P7	Different after treatment and didn't feel like myself, which affected confidence. P7, 8, 12
13	Not doing as much if	Everyone was leaving	Put on weight	Lasting effects of	

	feeling low, feeling low if not doing much. P3, 4, 8	school, getting jobs, going to uni and it was upsetting seeing what they were doing, I felt like I was missing out. P1, 5	because of medication which brings me down. P1,6	fatigue. P3	
14	Not being motivated. P1 Bored in hospital. P3	Missing out on things that friends are doing, not going to be a normal year. P1	Not having eyebrows or eyelashes changes your face and made me feel self-conscious. P2, 5, 17 My wig did look like real hair but I felt like I was covering something up. P14	Wanted to be normal straight away, but wasn't. P2, 3, 6 Going on dates afterwards was difficult. P18 Went back to work too soon after which made it difficult. P4 Should have been resting but instead pushed myself to do things. P17 Residual effects; tiredness, infections affected normality. P13,17 Still notice fatigue effects of treatment now. P2 Hormonal changes lasted a long time. P18	Feeling like a different person after cancer, but not sure how. P1 Don't know when I was last 'normal' and when I was ill. P7 Shaped me by going through it and coming out the other side. P19
15	Stuck in my room, unable to work,			Unsure about future. P7	Experience has changed me;

	exercise, or see people. P5, 7, 11			Trying to get back to my life, but physically couldn't straight away. P3, 11 Still experience pain due to treatment, and have to have more surgery P6, 8	before I was normal. P6
16	Spent a lot of time staying in my room and doing nothing, and stopped taking an interest. P3, 4, 8			Developed myalgic encephalomyelitis two years after finishing treatment. P11	Memories before cancer are not very good, and it's hard to know what was there before and what's there because of cancer. P9, 10 Cancer was forcibly maturing. P11
17	Couldn't get out of bed and didn't feel like doing things. P1, 2, 3, 4	Everyone was going to University and it set me apart; they were leading very different exciting lives. P1, 5, 6	I physically changed so much, you get the look of having cancer and battle with trying to pretend you're normal without being normal. P6, 12	Didn't know what next step was, there's nothing to return to. Your life has been cut up P4, 10 Fatigue and lower immune system, can't go out all night. P9 Physical effects remind me of what I can't do. P13	Got to find yourself again afterwards, with no anchor of who you are. Cancer can define you and provide new strengths in a positive way too. P10
18	Not wanting to get	Everyone had gone to	Gained a lot of	To move on you have	I'm trying to

	<p>out of bed or move. P1,2 Stuck inside P4</p>	<p>University. P1</p>	<p>weight and couldn't control appetite. Hated what I'd done to myself I tried to make myself throw up. P1, 3, 4</p>	<p>to pick up and start again, it's hard to go back to normal after. P2 Repeatedly hit with complications, treatment was not the end. I'll live with this for the rest of my life. P2,4,12</p>	<p>remake myself. P5</p>
19	<p>Not doing what you can do, because it's not what you want to do. P1 Physically cannot get out. P8</p>	<p>Wanting to be normal but realising you're not; you can't lead your life like they are. P1, 3, 6 Friendship groups cemented or more fluid at different stages, was missing out on forging these. P6</p>	<p>You can't maintain a sensible body weight. P7 Hair loss was hard, as it goes with who you are and you compare yourself to others. P7</p>	<p>Re-routing and adjusting even though still not strong enough to do everything. P2,11</p>	

Appendix 9. 15-point checklist for good thematic analysis (Braun & Clarke, 2006)

Process	Number	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'.

Appendix 10. Respondent validation letter

Dear [name]

In [month], you took part in a research interview about your experiences and opinions of low mood in young people with cancer. Thank you very much for taking the time to talk to me about your experiences.

Enclosed is a summary of what I think were the main themes of your interview. As we discussed at the end of the interview, I would like to invite you to provide feedback on this summary, including its accuracy and the extent to which it captures the things that were important for you to speak about. Please feel free to comment on any aspect of the summary, to point out anything you feel I have missed and to add any additional points that you have thought of since we spoke.

You do not have to provide any feedback if you do not want to. If you would like to, please write your comments on the feedback sheet enclosed and return it to me. Alternatively, I can post this out to you if you provide me with your address and you can return it in a stamped addressed envelope.

Thank you very much again for kindly contributing to our research.

Yours sincerely,

Rosa Reed-Berendt

Trainee Clinical Psychologist

Dr Anna Coughtrey

PI of GOSH-CANDI project

1. How accurate do you think the summary of your interview is? (Please circle)

Extremely Mostly Somewhat A little Not at all

2. To what extent does the summary capture the things that we spoke about with regards to experience of low mood in young people with cancer? (Please circle)

Extremely Mostly Somewhat A little Not at all

3. Is there anything missing from the summary that you think is important?

4. Have you thought of anything else since the interview that you would like to add?

5. Any other comments?

Appendix 11. Extracts from reflective journal

Interview 4: Pre-interview

Feeling more in the swing of the interviews. So far, I have only interviewed females of White British origin and given this participant is male with a name suggestive of a different ethnic origin, I am feeling mindful and interested in whether any different cultural stances might come out.

Interview 7: Post-interview

Interesting to have another male perspective, makes me think about men in relation to low mood. Both interviewed so far seemed to struggle a lot more with this, and were able to say this retrospectively. But could they have said this at the time? This participant seemed to find it hard to remember some aspects, is this just memory or had he blocked out some of his experience?

Interview 17: Post-interview

Went well. Talked more about being that in between age of child and adult and how that makes treatment hard. Talked about long term effects of cancer on emotional wellbeing and need for normalisation and feelings coming up. Have to be careful to remain in researcher role and not slip into providing too much reassurance to participants!!

Interview 18: Post-interview

Touching interview. People have lost so much through cancer- it really is a long-term condition in that way. Even if physical cause is no longer there, young people are often

left with so much. Will there be different groups of people and low mood with regards to severity of cancer?

Appendix 12. Additional subtheme quotes

Domain, theme and subtheme names	Quotes
<u>Domain 1: A Harder time of life</u>	
<u>Theme 1.1: Not feeling normal</u>	
Sub theme: I'm all alone with cancer	<i>"I'd had my surgery, I was having chemotherapy, I was alone in hospital. And I remember it was Eid...and I just spoke to my mum on the phone, and...I just broke down..."</i> P4
Sub theme: Isolating myself	<i>"...all my friends were still around, my parents and family were there and then as soon as they went off, that's kind of when the low mood started to strike?"</i> P18 <i>"...when I feel down I kind of just go to my room and want to be on my own..."</i> P13 <i>"...I noticed that when I isolated myself, the low mood seemed to stay longer than what I wanted."</i> P8 <i>"I...couldn't get of bed...feeling low rather than feeling ill."</i> P17
Sub theme: Lost shared experiences	<i>"all my friends are doing Uni and they're going out partying and things like that...I'd see them put things on Facebook and I'd feel really upset, because I can't do that...I just feel like I'm missing out."</i> P13 <i>"...[cancer] kind of separated me out from all people my age, like that, at that point everyone was going off to University and it kind of set me apart..."</i> P17
Sub theme: Looking visibly different	<i>"...the day your hair comes out...you've kind of shot so low and then there's nothing there to really help you get back up."</i> P1 <i>"...there's a lot more comparison when you're ill and the comparison seems a lot more obvious...your friends have got hair, you haven't, your friends can maintain a sensible body weight, you can't."</i> P19 <i>"...it did look like real hair but...I felt like I was covering something up? So then that was always on my mind and I was always conscious about that."</i> P14 <i>"...once you start accepting the way you look and you start going out like that, you do feel confident, as bad as it sounds but you know you can still be confident and have cancer..."</i> P11
Sub theme: Returning to normal afterwards	<i>"...after treatment you've got things that hold you back from being that normal person. So, like for me days out...you can't do it because you're so tired, because you're building...your body back up..."</i> P8 <i>"...all of a sudden you're back on your own, you have to put your trust in your body, to perform again, but you also</i>

have to get back to normal life again... You've just got to be normal now, got to go back to school, do your exams, be friends with everybody, go out like a normal person. And that adjust to normality is just so incredibly difficult. It's mind blowing to get your head around." **P2**

"I get tired easily and I get a cold really easily... I have to think about more things, and I can't like abuse my body in the way other people can, like I can't go out and party all night." **P17**

Theme 1.3: Life was just starting

Sub theme: Cancer took over

"...I had lots of things going on that were disrupted, and I think I still feel... even now, that part of my youth was taken away... that year was supposed to be really good and it was spent in hospital..." **P17**

"...you get to a point where you're feeling well and then all of a sudden you can't get off the loo and you're vomiting all night..." **P2**

"For me it [low mood] wasn't long after I was diagnosed, because that's when I was offered my dream job, so it was the sudden realisation of 'oh my life has literally just stopped and there's nothing I can do about that'." **P5**

Sub theme: Dragged away from independence

"...a lot of people when they've had tumours or cancers and things, a lot of 30 year olds, they might still be at home, with their parents like they haven't been able to get on and go to jobs and have children and stuff like a lot of 30 year olds..." **P13**

"...I was angry for a lot of it... I feel sorry for my mum from that point of view, but then that was because I was dragged away from my sort of independence..." **P5**

Sub theme: Young people aren't meant to have cancer

"...you have to force looking for things, rather than being like 'oh, here's all this information'... all the information we were presented with was for people in their 50's and 60's..." **P1**

"...young people that are going through cancer have it so much worse than other young people... anything that's considered low compared to someone who's going through cancer treatment..." **P4**

"...I feel like it's a harder stage to deal with, it's just a harder time of life, that's when everything is happening..." **P13**

Theme 1.4: Losing your safety blanket after treatment

Sub theme: Support and structure is gone

*"...family and friends, especially friends, are kind of excited that you've finished and they want to celebrate with you, and you're kind of like 'I don't really feel like celebrating, I still feel exactly the same as I have all along, but now there's nothing to work towards.'" **P17***

“...you don’t really think it’s going to be that different [after treatment], you imagine it’s going to be great: ‘Oh I don’t have to take twenty tablets a day anymore, oh that just sounds great!’ but you don’t realise the emotional impact of that is absolutely huge. You know, the hospital appointments are less, your house isn’t filled with sharps boxes anymore...you don’t have that, so what happens now? That’s the...question, what’s my life like now?” P2

“...when you’re going through treatment...you have so much support around you, and then once your treatment’s finished, you kind of get dropped, you have to get back on with normal life, and...it’s a lot..” P6

Sub theme: You are left with your mood and it doesn’t stop

“...because I haven’t really given myself enough time, I think my mood’s just been deteriorating because of it? I think that that’s starting to now show itself more and more.” P18

“...when I first came out of hospital I was ok, but kind of went downhill because I had to take medication and everything...to build me back up. I’d definitely say during the first year after...was a lot more down...” P13

“...it never stops...you’re battling with feelings for the rest of your life. I don’t think there was a day that went by that I didn’t think about it...” P2

Domain 2:
Interpersonal impact
of cancer

Theme 2.1: Cancer
changed relationships

Sub theme: Family and friends struggled to cope

“...I spoke to my dad about it a couple of times but...he’s probably not really that helpful for that kind of thing?...and I spoke to my mum about it a few times but a couple of times she got quite frustrated I think...I guess as much as I was going through it, she was as well?” P7

“...when I was in a group I’d always put on a brave face because I didn’t want to be a burden or anything...so I don’t think they noticed as much.” P12

“I knew that that was my fault, it made me pretty self-conscious of what I was talking about, what I was doing, how much I was complaining...I’d just try to get through and not talk to them about it...because I knew that I was bringing them down?” P18

Sub theme: Family and friends need support too

“...I wanted them to understand. And that’s a big part of what I want to do now...I want them to understand as much as we can understand, so they can be a part of it..” P8

“...I think the acknowledgement that low, like you’re not in a low mood all the time and there are going to be bits when you’re going to be in a really happy mood and everybody else around you must see? So I think awareness of like other people as well...” P19

Sub theme: Their reactions made it worse

"...they'll encourage you to do certain things that someone with depression...would do and it doesn't work the same way...I was bedbound I was too weak to do those certain things that they would tell me to do...to help..." P4

"...if they treat you like you're ill or... 'ooh, I have to be really careful around so-and-so' then it makes you feel like 'oh ok, well maybe I am really ill, if they need to treat me like this.'" P11

"...other people's views of me [affected low mood] as well...I might be having a good day, but then they'd still be like 'have a break now, sit down for a bit' and...so that was... it still was like a bad day." P19

Sub theme: No one understands what it's like

"...they don't know exactly what it's like. In terms of things like losing your taste...the lack of energy...the sickness...you can't really explain it." P9

"...your friends and family don't understand what it's like...for me that was the hardest thing. Because they just thought 'oh, she's not on treatment anymore, she's back to herself.', well I'm not." P8

"I think what people don't get is that recovery after, that takes longer than the treatment...some of those physical things are still there, as well as the mental issues...and...people don't totally understand that..." P14

Theme 2.2: Being around other young people with cancer

Sub theme: They understand and I'm not alone

"...it's going back to that comfort blanket, I was with people that had been through the same and kind of have an understanding of what you're going through, whereas friends that were at home I don't think I'd have talked the same to them, as I would to my friends who've been through what I've, what we've been through..." P8

"I know there were a couple of people who said 'I don't feel like I can talk to a psychologist...is it ok if I talk to you, you know what I've been through?' ...we used to all talk together, and even now, we've all got like group chats on social media...we all still talk...rather than like telling our consultants or something if we've got a problem..." P10

"...you have the ability to talk about anything and that if you do want to talk about cancer then everyone there understands, and will talk about it as openly, but if you don't want to talk about it then no one will bring it up?" P18

Sub theme: It's too sad

"...not with people of the same age...probably because I didn't like seeing other people in...horrible situations like myself and...I think sometimes that was all you ever sort of talked about..." P12

"...when I was going to the hospital...seeing those very young child's...it was very very upsetting me, and was

taking everything out from my mind...I was not crying when I was at home, I was crying when I was seeing those childrens and all the problems that they were going through...” P15

Sub theme: Survivors’
guilt is tough

“[social events with others with cancer]...can all just be centred around it and I didn’t like that like all the time, because it’s just...everyone’s talking about it the whole time, and I like don’t need to talk about it all the time” P3

“...I’d say I’m mostly completely fine now, but survivors guilt, I don’t think that will ever really go away...” P1

“...if people have like made friends during their treatment and...if anyone has like passed away...during their treatment so...there’s like someone who I was friends with, I know he passed away...I know that that was quite hard on me...” P10

Domain 3: Making sense of my emotions

Theme 3.1: How do I even describe low mood?

Sub theme: Low mood
is there, like a niggle

“...low mood, is sort of more ongoing...that’s what makes it so miserable, that it goes on.” P17

“...I was in a low mood throughout my whole treatment...” P4

“I genuinely would just go one step and genuinely say depressive mood...I think it’s very true that a lot of what I have experienced has been depression....” P18

Sub theme: Cancer was
the reason for low
mood

“...it’s always in the back of your mind and I think if you look sick and you feel sick... everything is a constant reminder, you’re in hospital constantly, you’re always seeing people who are sick...” P1

“...the steroids caused me to have intense pain... Which then led to my inability to walk for about two days...during that point I thought that that was it, I thought that was how I was going to lose my legs, I thought I wasn’t going to be able to...ever walk again, so...I had thoughts of...not wanting to continue, not wanting to carry on.” P18

“I was in an adult hospital at the time...seeing people like half dead...in front of me, they couldn’t speak, they couldn’t eat...it’s depressing.” P6

Sub theme: Mood felt
fragile

“...it just pushes you down so quickly, like...in the space of a day...” P1

“...it felt like if you were in a good mood, it was so easily moved by...letters or phone calls...mood were knocked by such little things...it felt fragile.” P19

“...that’s what it [cancer] does...just really affects your mood. Sometimes you’re happy, you go through mood swings really...you never live one day like in the same mood, you’d always go through at least a wave of

Sub theme: So many emotions, it's a lot to go through	<p><i>changes.</i>” P11</p> <p><i>“...I did some awful things, I threw things at my mother...I wouldn't throw things at my mother! But you just do things that you would never dream of ever doing as a reaction to the circumstances.”</i> P2</p> <p><i>“...more towards the end, getting back into social situations...that was to do to with my confidence I reckon, so I was anxious about...not being myself...not being...good in a social situation...”</i> P12</p> <p><i>“...you've got...the sense of existential dread about what's happened to you and what is going to happen to you...you've got the physical pain and trauma of what you are actually physically going through, and then obviously the emotional trauma of everything else that's going on.”</i></p>
Sub theme: It's difficult to name	<p>P16</p> <p><i>“...when I had a car...I kind of felt like I didn't know...how to show that I needed help so I can remember accidentally on purpose kind of driving it, just kind of denting the side of it...”</i> P7</p> <p><i>“...I don't feel like I was...depressed or anything, I don't think it was that severe, but it was...somewhere in between low mood and there...because you know some things happen now and I'm like 'oh, a bit of low mood' and you just have a day when you're...not happy about stuff but...if there's another word to describe it...it's more of a long term thing?...I can't really think of a word.”</i> P14</p> <p><i>“...I think everyone is so preoccupu..and rightly so... 'this is your treatment, this is going to make the cancer go away', or not, or...whatever...But it's never a 'this is likely to happen...FYI'...that's not really focussed on at all.”</i> P1</p>
<p><u>Theme 3.2: You just have to cope</u></p> <p>Sub theme: Keeping busy</p>	<p><i>“...I had to always occupy myself to keep going, so...as much as I really didn't like going, I had to get on the tube, and I had to get to the hospital...so I suppose I saw those little things as achievements, of doing something that day...”</i> P12</p> <p><i>“...I just try and pick myself up and get on with things I can enjoy. Like my dog...walking my dog and taking him to the beach and I actually do enjoy my work and I've got really nice friends there...I enjoy it and it motivates me.”</i> P13</p> <p><i>“...focus...on my school work, which just took my brain into a different place...I could just focus my mind on something completely different, I remember doing a big essay on Macbeth once, hooked up to a drip...”</i> P2</p>
Sub theme: Acceptance and adjustment	<p><i>“...this is going to sound really weird, in some ways the suffering became mundane and it was...just a thing that happened. It was more early on that I sort of gave up and had had it, but later on...it was just a thing I did.”</i> P16</p>

<p>Sub theme: Positive coping and problem solving</p>	<p><i>“...all the treatment that’s really hard, but you have a routine about how hard it is?” P17</i></p> <p><i>“...if you’re sort of fighting it...if you don’t accept what’s happening with you then you’re just going to be in denial.” P11</i></p> <p><i>“The idea of being out of treatment...and planning my future. That was very helpful.” P15</i></p>
<p>Sub theme: Not making it too real</p>	<p><i>“I always used to think... ‘well, my hair’s not getting shorter, this is the shortest it will ever be’ ...it sounds really weird but... ‘it’s only up from here!’ ...just trying to be positive...even if I did feel a bit self-conscious, just trying to like be confident...try to do that even if I didn’t totally feel it, at the time...” P14</i></p> <p><i>“...I’d probably write a list of what I wanted to achieve...some of them could be like long term goals of what I could achieve...by the time I finished my treatment, and some of them would be like daily goals...” P12</i></p> <p><i>“I didn’t say the word cancer for like two years I think, I couldn’t even say it, I couldn’t even bring myself to say ‘I’ve got cancer’, I couldn’t even do it. Sometimes you can’t, it’s just too hard.” P2</i></p> <p><i>“...when I was in my follow up I knew that there was support available, but I think sometimes especially me I think I was very reluctant to ask for it? I’d just be like, no I’ll just get through it myself...I didn’t want to make that initial step because I didn’t want to be like ‘oh can I make that appointment’...have to say that I was struggling a bit?” P14</i></p>
<p>Sub theme: Long term perspectives on coping</p>	<p><i>“...saying... ‘I’m ready to talk about it now’, I think it’s hard, that’s especially hard because either you don’t want to hear that you won’t feel good, you want to think that you’re going feel that life’s back, you want to be back to normal...” P19</i></p> <p><i>“...initially you do have to cope anyway when...you’re diagnosed with cancer...that’s just something that you have to...individually get on with...” P9</i></p> <p><i>“...it almost feels like...it didn’t happen now?...It feels like a really weird bad dream almost? It’s really strange, like, sort of thinking back to it.” P14</i></p>
<p><u>Theme: External factors in coping</u> Sub theme: Support network</p>	<p><i>“...once my cancer treatment’s finished I’ve gone back into retail and I know that my life has kind of been limited and shortened because of this cancer diagnosis, and I’ve decided I want to go to Uni, I want to progress, I want to get the best I can out of life?” P6</i></p> <p><i>“...my main thing was having my mum with me...she was my rock, my friend, good friend, we are good friends, my</i></p>

- family, they would come visit me... ” P4*
- “...my mum...she saw it as an external person and saw what it was doing and I think was very worried about it, so probably someone else picking it up with me, rather than myself.” P17*
- “...two of my best friends...even though they’re both in Uni, they did make an effort...they did manage to come to the hospital to see me and I meet them...when we go to the hospital I’ll meet for lunch as well, which is nice, so they’ve been great.” P13*
- Sub theme: Hospital support environment
- “...[TCT ward had] really nice TV’s on the walls...if my friends came over, we could just like sit and put a film on...my friends would all come in and they’d read or like make food together or like they’d bring stuff in that they’d made or get takeaways...and we could...still do that.” P14*
- “...when I was on the children’s ward, the people you’re surrounded by, like nurses...there were so many people trying to be happy, and they were achieving it very very well...that many nice people really helped, you kind of wanted to feel happy for them...?...I think when you’re surrounded by more happiness...” P17*
- “...all the nurses that I had on treatment were fortunately absolutely lovely to me, so having low mood during treatment was actually quite difficult!...they made it enjoyable for me, in a weird way.” P5*
- Sub theme: Talking to someone professional
- “...the counselling that I did, was the best thing that I did, related to low mood and cancer, it was the most helpful thing to me, but...I’m not sure I’d have been ready to do it when I was in my treatment...” P7*
- “...I think I needed to do that, to be able to understand and to work out why instead of just leaving it in a box in the back of my head. I needed to talk about it to kind of, make me feel better.” P8*
- “I think it probably would have been useful if I’d had access to a psychologist at the time, but I didn’t...” P16*
- Sub theme: Improving support for coping
- “...taking the time to think about looking after your emotional health, I just think could save so much time down the track as well? And time and money and resources just like, making it ok to feel that way and showing how you can get support and...I think...earlier on and then in the moment when it all finished as well...I think I would have felt differently...if I’d known all along that emotional health is part of it? Because when my doctor said to me ‘yes lots of people feel this way’, I just remember the relief and...if I’d known that earlier it probably wouldn’t have felt so horrible when I did feel it.” P17*
- “...just being able to talk to someone in a safe space regularly, I think it’s also very much...you have to say you want it. I think it would be better for it to be offered and*

assumed that you want it as part of your treatment. Like every two weeks... 'this is a slot you can come if you want to'. Or even, so I like lived quite far away from the hospital, and I drove, but just after chemo, like in that week after, you can't really leave, so having like the opportunity to just call someone..." P1

"...I think maybe if like hospital had made some kind of check in appointment with...some kind of psychologist...just for them to be like 'right well it's normal, you might feel like this'...not exactly forcing you but almost if that appointment had been made, I would have gone and that probably would have been better..." P14
