

Title:

Experiences of low mood in young people with cancer: a qualitative study

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DL has participated in speaker bureau for Bayer, Merck, Almirall, Execemed, TEVA, Roche, Novartis, Biogen, Sanofi; has had consultancy from Novartis, Bayer, Merck, Biogen, TEVA, Sanofi; has had research grants from Bayer, Merck, Novartis, Biogen. All are paid into DL's institution.

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Abstract

Young people with cancer are at increased risk of psychological difficulty, yet there is little research on their experiences of low mood or depressive symptoms to help inform treatment interventions. This qualitative study explored experiences and opinions of low mood or depression in young people with cancer, how their mood related to developmental challenges, strategies used to cope, and how services could improve support. Nineteen young people diagnosed and treated for cancer completed semi-structured interviews. Transcripts were thematically analysed using the framework approach, and analysis produced eight themes, organised into three domains: 'A harder time of life', 'Interpersonal impact of cancer', and 'Learning to understand and describe low mood'. Participants interviewed experienced low mood during cancer, and predominantly felt 'low mood' was a helpful term to describe their emotions. There were similarities and variations in their reported mood compared to clinical depression. The developmental challenges of being a young person with cancer negatively affected their mood. Participants used a variety of different coping strategies to manage these challenges. Young people were clear that they would like others to help them understand negative emotions experienced through cancer are normal to feel, and support for low mood to be accessible and available.

Keywords:

cancer, young people, low mood, depression.

Introduction

On average, 4,600 children, teenagers and young adults (aged 0-24 years) are diagnosed with cancer each year in the UK of whom around 83% survive for five or more years following diagnosis (Cancer Research UK, 2019). Given this, cancer and the long-term effects of therapy can be considered a chronic illness. As overall survival rates increase, there is greater focus on quality of survival, both physically and psychologically (Brinkman et al., 2016; National Institute for Health and Care Excellence (NICE), 2014). Young people with cancer (aged 13-24 years (NICE, 2014; Teenage Cancer Trust TCT), 2017)) are at elevated risk of psychological difficulty, due to the developmental challenges they face (Kaye, Brinkman, & Baker, 2017; Lang, David, & Giese-Davis, 2015; Park & Rosenstein, 2015). Brain growth and cognitive development are still occurring, affecting how they appraise and manage the cancer diagnosis and treatment (Arain et al., 2012; Piaget, 1964). Puberty co-occurs, and cancer and treatment interrupts the physical transformations taking place; causing stunted growth, weight gain, endocrine deficiencies, thyroid difficulties, fatigue, and hair loss (Abrams, Hazen, & Penson, 2007; Choquette, Rennick, & Lee, 2016). Cancer also affects psychosocial development: identity development, body image, and independence (Erikson, 1959; Fan & Eiser, 2009; Zebrack & Isaacson, 2012). Cancer can also disrupt young people's educational attendance, their ability to maintain existing social and romantic relationships, and impair development of new relationships (Choquette et al., 2016; Kent et al., 2012).

One of the potential psychological difficulties experienced during cancer and in survivorship is depression. Depression is the leading cause of disability worldwide (WHO, 2017). It reduces quality of life when co-existing with physical health problems (Moussavi et al., 2007). Depression is challenging to diagnose in the context of cancer, as a negative emotional reaction is normal, and physiological side effects overlap with diagnostic criteria e.g.,

changes in sleep, appetite, energy, and concentration (Moussavi et al., 2007; Walker et al., 2014). Quantitative studies of clinical depression in young people with cancer showed variable rates, from 5-42% (Park & Rosenstein, 2015; Sansom-Daly & Wakefield, 2013), presenting at various points during cancer: shortly after diagnosis, during treatment, years after treatment, and in long-term survivorship (Compas et al., 2014; Friend, Feltbower, Hughes, Dye, & Glaser, 2018; Kwak et al., 2013; Muffly et al., 2016). The variation in rates of depression is surprising, and it might be expected for rates to be higher in young people, given the complex effect of a cancer diagnosis and greater risk factors in this population.

Qualitative studies have significant value in under-researched areas and where greater depth of knowledge benefits understanding (Campbell et al., 2007; Joffe, 2012). While they have been conducted to understand young people's experiences of cancer, and specific areas such as health-related quality of life, distress, and fear (Kuhlthau et al., 2015; Olsson, Jarfelt, Pergert, & Enskär, 2015; Zebrack, Kent, Keegan, Kato, & Smith, 2014), none about the experience of depressive symptoms in young people with cancer have yet been undertaken. The presence of psychological difficulties, such as depression, are also affected by how young people adjust to and cope with cancer. Coping are motivational and purposeful behaviours and cognitions produced to manage internal and external demands of a stressor (Aldridge & Roesch, 2007; Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). While there are no coping theories specific to children and young people, research has shown that adult theories apply to young people with cancer. However, there are inconsistent findings regarding what aspects of coping are protective from or may exacerbate psychological difficulty (Aldridge & Roesch, 2007; Compas et al., 2014). Several studies have qualitatively explored coping strategies in young people, at the onset of cancer or when managing concerns about physical changes, alienation, and anxiety. In spite of this, the way

young people with cancer cope with symptoms of depression is unclear, and a qualitative study identifying helpful and unhelpful coping strategies in relation to depressive symptoms has not been conducted.

Psychological support has been repeatedly highlighted as an unmet need by young people with cancer, thus it is important to gain further understanding of how these individuals think depressive symptoms should be supported, to inform future research and support (Bennett, Shafran, Coughtrey, Walker, & Heyman, 2015; Friend et al., 2018; Smith et al., 2013). Given the gaps highlighted, this qualitative study aims to 1) explore the experiences of depressive symptoms and its presentation in young people in the context of cancer, 2) to understand how their developmental challenges affect the presence of depressive symptoms, and 3) to understand how they coped, and how these strategies could be further supported by clinical services.

Methods

This study was part of wider research project which received full ethical approval from the National Health Service (NHS) Health Research Authority (REC reference 16/LO/0939)

Participants and recruitment

Individuals were eligible to participate if they (1) had been diagnosed and treated for cancer; (2) were diagnosed between the age of 11 and 26 years; (3) self-identified as having experienced symptoms of low mood (defined as symptoms of negative emotion that may/may not reach diagnostic threshold for depression); (4) spoke fluent English. They were excluded if they had (1) pre-existing learning disability, as this would have made an interview exploring detailed concepts challenging (2) current severe suicidal ideation or intent; or (3) presence of current severe psychological disorder (e.g. psychosis, severe eating disorder).

Additionally, given the sensitive topic of discussion, there could have been concern about exacerbating such symptoms. If risk or distress had arisen during interviews, they would have been terminated and the young person signposted to appropriate services, however this did not need to happen.

Recruitment took place over 6 months. Research has shown that 6-12 participants is sufficient for data saturation to be reached in thematic analysis (Guest, Bunce, & Johnson, 2006), and other qualitative studies using the framework approach have had samples ranging from 24-37 (Leal, et al., 2015; Pistrang, Jay, Gessler, & Barker, 2012; Tighe, Pistrang, Casdagli, Baruch, & Butler, 2012). Thus it was decided a sample of at least 18 would be sufficient. Participants were recruited through two main sources (Figure 1). Two young people were recruited from a London NHS children and young people's cancer service. The researcher approached young people who were identified as potential participants by a member of their usual clinical team, introduced them to the study, and provided them with a participant information sheet (PIS) and consent form. With agreement, the researcher took contact details for potential participants. Seventeen young people were recruited through advertisements on the websites of CLIC Sergeant and Macmillan Cancer Support charities, where interested individuals expressed interest by email or telephone. Following expressed interest, they were contacted by the researcher to discuss participation and eligibility, were sent a PIS and consent form, and questions were answered. An interview was arranged at a mutually convenient time, and participants provided written informed consent.

The sample consisted of 19 participants from various geographical areas across the UK (Table 1). Five participants were male and 14 were female. They ranged in age at diagnosis from 11-26 (mean 18.1 years) and at the time of interview ranged in age from 18-31 years

(mean 22.4). Participants had been diagnosed with lymphoma (n=8), leukaemia (n=6), sarcoma 4 (n=4) and central nervous system tumour (n=1). Most participants were receiving cancer follow-up checks, one had been discharged from follow-up, one was under late effects care, and two were having maintenance treatment. One had experienced cancer relapse.

Participants were interviewed using a semi-structured interview schedule, which allows for idiosyncratic development of questions to enable data specific to the research to be collected (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Joffe, 2012). The semi-structured interview was based on relevant literature on depressive symptoms in young people with cancer, coping in young people with and without cancer, and the study's research questions. It was developed collaboratively by the authors and consisted of broad main questions, and follow-up prompts (Barker, Pistrang, & Elliot, 2002). Participants were asked broad questions such as "What do you think low mood looks like or feels like for a young person with cancer?" with probes such as "How do you know/notice it's low mood?", "How might others know or notice it?" or "Could you give me a specific example of what you mean?". The drafted interview was shared with research representatives from CLIC Sergeant and Macmillan Cancer Support charities as experts in research with this client group and a TCT support coordinator at the recruiting service, as a clinical expert with the client group. Adaptations were made to language and a question was added to ensure not only low mood, but other emotions young people might have experienced were acknowledged and validated (e.g. Were there any other emotional difficulties you experienced as a result of cancer?). An established NHS trust's young people's advisory group consisting of 12 individuals was then visited once to discuss the study, and explore the most appropriate and acceptable language to talk about this difficulty. This prompted the flexible use of the words 'low mood' in

interviews. Two interviews took place face-to-face, and 17 were conducted on the telephone. They were recorded using a digital voice recorder and lasted 41 minutes on average.

Analysis

The framework approach is a form of thematic analysis that systematically and flexibly observes themes and identifies meaning in constructions of experience (Braun & Clarke, 2006; Gale et al., 2013; Joffe, 2012). Thematic analyses are especially suitable in less researched areas, and the framework approach adds additional strength as it is structured, practical and methodical (Braun & Clarke, 2006; Joffe, 2012; Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 1994). It allows experiences and accounts to be interpreted whilst holding on to individual accounts, promoting objectivity and reducing bias (Gale et al., 2013).

Data were arranged into themes, whilst the context of experiences were maintained, by keeping individual accounts intact within a framework matrix, allowing comparison between and across cases (Gale et al., 2013; Ritchie, Spencer, & O'Connor, 2003). The seven stages of the framework approach were followed: interviews were transcribed, data familiarisation took place, initial codes were assigned, a coding index was developed, it was applied to all transcripts, all coded data was charted into a framework matrix, and data was interpreted, with development of a final set of domains, themes and subthemes (Gale et al., 2013). To ensure analysis was good quality and valid, general guidelines for good qualitative methodology were followed; Yardley's (2015) criteria to demonstrate validity in qualitative psychology, and Braun & Clarke's (2006) 15-point checklist guidelines for good quality thematic analysis (2006). Triangulation of codes was conducted, to ensure they were not limited only to the researcher's perspective (Yardley, 2015), and an independent rater conducted initial coding on five randomly selected interview transcripts (26%), and applied

the coding framework to five separate randomly selected transcripts (26%), to reduce bias. The coding framework allowed a traceable path of analysis, and while the lead researcher conducted analysis, a consensus approach was adopted with another author (AC), where codes and the framework were discussed throughout analysis. To protect from bias, a reflective journal was kept throughout the research process by the lead researcher to ensure an adequate level of reflexivity.

Results

Analysis and interpretation revealed eight themes, organised into three domains (Table 2).

Domain 1: A harder time of life

1.1 Not feeling normal.

Young people often felt very alone with their cancer, which highlighted the lack of normality. When low in mood, young people isolated themselves, withdrew, and were behaviourally inactive in spite of being able to do things. Some young people felt that cancer meant they missed out on shared experiences. It was especially difficult to lose out on these at a developmental age when new and shared experiences with friends were so important.

“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, diagnosed age 17.

Changes to young people's physical appearance significantly affected mood. Chemotherapy and steroids made them look visibly different (e.g., hair loss and weight changes) which were very difficult, especially at an age where preoccupation with body image is common. Some accepted the effects of treatment on appearance or tried not to let negative feelings dominate.

“...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, diagnosed age 18.

Most young people found it difficult to return to normal after treatment had finished. They described residual and late physical and emotional effects, which accentuated that life continued to be abnormal, and served as reminders of cancer. Some young people could not remember what ‘normal’ had been like before, or could not find a normal to return to.

“...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...find yourself again, and you don’t really have an anchor about who you are?” P17, diagnosed age 18.

1.2 Life was just starting...and then it stopped.

Young people described how cancer took over their life and stopped the trajectory they were on. The change from positive hopes and expectations of their future to such a demanding and uncontrollable situation was a significant loss. Cancer dragged young people away from their independence, and they were so unwell they could hardly do anything themselves. Some could not live independently, and felt like they regressed, with greater dependence on others, which was difficult and demeaning. The young people and others found it shocking they had cancer, as no one expected them to be diagnosed at their age. Some felt stuck between child and adult services, which made it challenging to access information and support.

“...I was incredibly fit and healthy, I was running half marathons...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, diagnosed age 19.

“...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...” P17, diagnosed age 18.

1.3 Losing your safety blanket after treatment.

After cancer treatment finished, the structure and support from hospital, friends and family was suddenly gone, but young people still needed it and were unprepared to lose it. Young people were left with their low mood once treatment finished. No longer being on treatment meant they had less to focus on and the emotional experience of cancer came flooding back. For some young people, the emotional effect of cancer was long lasting.

“...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...you’re not going to hospital every day, you don’t have these links.” P1, diagnosed age 20.

“...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, diagnosed age 20.

Domain 2: Interpersonal impact of cancer

2.1 Cancer changed relationships.

Young people’s family, friends, and partners also sometimes struggled to cope, which changed relationships, and some loved ones avoided talking about low mood or cancer with young people, or reacted in difficult ways because they did not know how to manage.

Reduced contact or loss of friends made it more difficult. Some young people concealed low mood to protect others and avoid adding what they perceived as another burden. Participants felt that friends and family did not always understand and could not relate to their experience.

Young people noticed that others’ reactions towards them altered relationships, and made them feel worse, particularly when family or friends intended to help, but were in fact unhelpful (e.g. suggestions of ways to improve low mood that were not possible or put them

in a sick role.) They also struggled with the fact that family and friends assumed they were better and back to normal after treatment, which made it harder to voice their feelings. Young people wanted support to be available for family and friends too. They thought this could also improve their own low mood, as loved ones would then know how to manage their own emotions, be more educated about low mood in young people during and after cancer, and be aware of helpful ways to behave and support the young person.

“...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...” P18, diagnosed age 19.

“...not wanting to talk to people is exacerbated by the feeling that no one understands it...”
P1, diagnosed age 20.

“...I always had people around me...saying ‘oh don’t worry about that...don’t need to worry about doing so much...’ ...it...reinforced the fact that I almost shouldn’t be doing that stuff...”
P7, diagnosed age 18.

2.2 Other young people with cancer.

Many participants talked about the benefit and importance of communication with other young people with cancer. They could speak openly, gain reassurance, advice and inspiration, and generate a shared understanding, so they did not feel so alone. They voiced the desire for services to help improve connections and support between young people with cancer.

“...it just made it all much more manageable...knowing that you could talk to other people...in the same boat... that was...really good and really reassuring...that they were sort of feeling the same things...” P14, diagnosed age 26.

Some young people described challenges of being around others with cancer. Although there was an aspect of shared experience, it could be upsetting to see others go through a similar or worse situation, and due to the variety in treatment and prognosis it was not the same.

“...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...” P2, diagnosed age 14.

A small number of young people described the effect of witnessing the deaths of other young people due to cancer, and the significant effect of grief and guilt on low mood. They expressed the need for support to cope with this experience of tremendous loss.

“...the main one is losing your friends...TCT was so amazing introducing me to these people, but...you’re really not given any support...it’s an unbelievable thing to go through...I lost like seven friends in a year...you never expect that to happen to you.” P1, diagnosed age 20.

Domain 3: Learning to understand and describe low mood

3.1 How do I even describe low mood?

For some young people, sadness through cancer was always present and difficult to manage or eradicate. Low mood was often triggered or directly affected by cancer, especially the adverse side effects of treatment, but the severity of low mood at different time points varied. It could be challenging for young people to make sense of their feelings and differentiate low mood from the effects of treatment. Being away from home affected some young people, as did being surrounded by sickness, especially on adult cancer wards.

“...I was very ill throughout it and...I did become suicidal at certain points. Basically because I was in continuous extreme pain...there was a patch where I’d...basically just had enough.” P16, diagnosed age 11.

Some young people experienced strong fluctuations in mood, sometimes in response to small, trivial events. Fluctuations made it difficult to describe emotions and make sense of them, because low mood was not a constant feeling.

“...mood...it’s very very up and down. I’d say it’s very bipolar...it can just kick start a shift, very quickly into feeling very sad and angry...the...shift in mood for me was just very sudden...” P2, diagnosed age 14.

Young people experienced so many emotions and symptoms throughout and after cancer, and it was difficult to make sense of these and describe low mood. They talked about the enormity of the experience and thought all their emotions were tied together and not distinct. This included hallmark symptoms of depression, and changes to confidence, self-esteem, trauma, and anxiety. Young people struggled to articulate how they felt during cancer. A contributing factor may have been that emotions were rarely openly discussed by professionals, or young people were concerned that others could not tolerate negative emotions. Most young people identified with the words ‘low mood’, as it described difficult feelings without pathologising them, though some felt the words were not strong enough and a term such as depression fitted better.

“...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, diagnosed age 18.

3.2 Finding ways to cope.

A coping strategy that many young people used was keeping busy and occupied. They found ways to focus on getting through treatment, and made themselves do things they enjoyed, such as spending time with friends and family, exploring creative outlets, and pursuing new interests. Young people described times where they just had to accept and adjust to emotions or the situation, which helped them come to terms and cope with their feelings. They described positive coping and problem solving that reduced low mood. They took positives from situations, generated coping thoughts or reminders, and made plans to look forward to. They also rationalised difficulties and used humour. They often did this on their own. Young people did not want cancer or low mood to feel too real, as this made them feel worse. They

engaged in some avoidance of understanding or addressing their feelings during cancer, which helped, because they did not have the time, resources or support to cope in other ways.

“...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, diagnosed age 17.

“...becoming used to it and just get into a routine...taking all the medication, and going to hospital appointments... That’s just my life now, and I’ve just got to deal with it really.” P13, diagnosed age 19.

“...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, diagnosed age 19.

Young people talked about their long-term retrospective view of their experience. Some expressed wonder, amazement and pride at how they had navigated through such a difficult time. Some did not feel they had coped well, and others viewed their cancer experience as very separate from their current life.

“I see life in a different perspective and I appreciate waking up every morning and not being sick...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, diagnosed age 19.

3.3 Needing others to cope.

Young people focused on how helpful their support network was, and the benefit of this on coping. They talked about the value of family, friends, and partners who supported, reassured, and treated them as they had before. They often talked to certain individuals about low mood, so they could separate this from some of their interactions.

“...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, diagnosed age 17.

Young people considered hospital environments, staff and young people's cancer charities as very helpful, and it aided their ability to cope with treatment and emotions. This was due to a tailored environment for young people, available staff who discussed emotions and treatment, and the reduction of a sole focus on cancer during interactions. Some young people received talking support or therapy from a professional during, or long after finishing treatment. Not all found this helpful, but many felt it facilitated them to process and make sense of their emotions. Some said it would have been helpful to receive earlier on, whereas others thought this was provided at the right time. Not all received support, nor did they feel they needed it. *"...they [professionals] helped you understand why...I was feeling a certain way...helped to work through it and digest...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, diagnosed age 17.

Young people talked about how support from services could further facilitate coping with low mood in cancer. A number of participants would have liked reassurance that the experience of low mood was normal through cancer, or to have been warned about its potential occurrence. Participants felt there should be an open offer to support throughout all phases of cancer treatment and follow up care.

"...it's not like they offer it on a plate sort of thing...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, diagnosed age 18.

Discussion

Young people's low mood was often triggered or maintained directly by cancer, but they described varying levels at different stages. Feelings most often associated with diagnosis were shock, denial, and feeling overwhelmed, which mirrors previous studies (Compas et al., 2014; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Jörngården et al., 2007). As also noted in previous research, young people's mood was negatively affected by the adverse side effects

of cancer treatment, and being in a wider context of sickness (Kwak et al., 2013; Wicks & Mitchell, 2010; Wu et al., 2009; Zebrack et al. 2014). This study provides greater knowledge about what specific aspects of cancer or environmental factors cause low mood. Young people also experienced low mood after their cancer treatment, both immediately and in the long term. This is in line with previous studies of young people in cancer survivorship (Choquette et al., 2016; Zebrack et al., 2014), but this research provides additional insight into why this time was so challenging; the loss of routine after treatment, the perceived lack of support from hospital, friends and family because they no longer had cancer, and coping with residual treatment effects. It also shows the lasting difficulties with physical changes, and the length of time it takes to process the emotional experience.

Young people described constant and ongoing low mood, either through the whole cancer experience, or during a specific part. Noticeable symptoms of low mood had some similarities to depression in the general population, but also overlapped with the physical effects of treatment. Previous questionnaire measurement of depression has detected this in a proportion of young people with cancer (Compas et al., 2014; Kwak et al., 2013; Muffly et al. 2016), but this study demonstrates that regardless of whether symptoms meet diagnostic criteria, they can still be negative and difficult to experience, and should not be ignored. It also confirms the challenge in delineating physical and psychological symptoms which affects the ease of measurement and diagnosis of low mood or depression in this population (Dejong & Fombonne, 2006; Recklitis, Blackmon, & Chang, 2016). In the absence of measures that effectively detect depressive symptoms in young people with cancer, clinical judgement is even more important, and staff need to be aware of symptoms that young people have specifically attributed to low mood and not the physical effects of cancer. Young people's verbal reports could also help delineate their symptoms and experiences.

Some young people also described a more novel finding, where mood felt fragile and fluctuated. These rapid changes may explain why quantitative reports of depression in this population are so low, as fluctuations happen too quickly to merit diagnosis or detect symptoms. This furthers the understanding of the emotional experiences in young people with cancer and leads to the question of whether they experience depression or low mood, or something else. It may be challenging for young people to acknowledge low mood in themselves, as neither they nor medical staff knew what to call it, or how to discuss it, and there could be additional effects of mental health stigma. 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. With this knowledge, increasing openness about mental health challenges in the context of physical health may help young people with cancer understand their emotions, and seek support.

Young people described challenges which were closely related to their specific stage of life and contributed to their low mood. These included difficulties in their feelings about themselves in relation to physical changes and body image; the abnormality, loneliness and isolation of the experience; and psychosocial challenges such as the development of identity and independence in relation to life transitions. This endorses previous research (Abrams et al., 2007; Choquette et al., 2016; Zebrack et al., 2014), however the current study strengthens the direct influence of these challenges on low mood in young people with cancer.

Cancer altered young people's relationships and interactions, and this was challenging to manage in addition to cancer. Interpersonal factors were frequently described in relation to low mood through cancer. Young people found it especially challenging when they noticed

others struggled to cope with their cancer, and it altered their relationships. This demonstrates the psychological effect of cancer on those around young people in turn affects the low mood of young people, and some young people concealed and internalised low mood, to avoid placing additional burden on others who were already struggling. This relates to previous research which explored negative psychological sequelae on those around the child or young person with cancer (Gibbins, Steinhardt, & Beinart, 2012; Long et al., 2018; Monti et al., 2017; Wilkman, Mattson, von Essen, & Hovén, 2018) and research which found that family members hide feelings to protect one another (Eiser, 1993; Goldman & Christie, 1993; Young et al., 2003). This may reduce reported rates of depression and low mood in young people with cancer. The reactions, assumptions, and lack of understanding that others sometimes showed to young people with cancer also made situations more difficult to manage, and increased low mood.

Participants had varying views about being around other young people with cancer and its impact on low mood. Some young people described the immense value of coming into contact and sharing the experience with other young people with cancer, to reduce loneliness, and gain advice and support. Challenges of being around other young people with cancer that were uniquely difficult and created low mood, such as comparisons with others undergoing treatment, witnessing others' distress and sickness, and experiencing survivors' guilt were also described. Literature regarding this in young people with cancer is limited, which is surprising given how significantly this can affect low mood, and given the importance of shared experiences has previously been highlighted as an unmet need (Zebrack, 2009; Zebrack & Isaacson, 2012). As there appears to be a mix of benefits and drawbacks of connecting with other young people, they should be made aware of optional opportunities to

interact with others, and support should be available if the experience of connecting with others negatively affects their emotions.

Young people described a range of coping strategies to manage low mood through cancer, which replicates findings in previous studies (Aldridge & Roesch, 2007; Castellano-Tejedor et al., 2016; Compas et al., 2014; Olsson et al., 2015). However, maintaining normality and independence, and positive coping strategies have not been specifically related to coping with low mood before. Additionally, avoidance and denial has been previously highlighted as making the cancer experience more bearable, reducing symptoms of depression (Castellano-Tejedor et al., 2016; Dejong & Fombonne, 2006), but young people in this research also thought that if these strategies were adopted for prolonged periods, they resulted in greater emotional upheaval, and more low mood after cancer. Young people described coping as an individual process, and through their cancer they found and used their own strategies, some without professional input. This reinforces the importance of considering coping individually, without a 'right way' to cope (Aldridge & Roesch, 2007). However, their ability to cope varied through cancer, and struggles to cope increased low mood. The findings of this study underscore individualised care and suggest that coping be assessed repeatedly, and psychological support be flexibly available.

Young people's support networks were very valuable in helping them cope with low mood and cancer, which supports other studies that found the importance of receiving social support from family and friends (Choquette et al., 2016; Kent et al., 2012; Zebrack et al., 2014). Young people valued the staff, support systems, and hospital environments, and positive experiences of these facilitated coping and reduced low mood. Some young people talked about the value of TCT ward environments, which supports previous studies of the

benefits of tailored support (Castellano-Tejedor et al., 2016; Olsson et al., 2015; Zebrack et al., 2014). Some received psychological support from a professional, which was predominantly helpful, and this is also confirmed by previous literature (Olsson et al., 2015; Tenniglo et al., 2017). The current study extends this and explicitly identifies the value of having a separate person to speak with, not emotionally attached to a young person, to have someone to help process their emotional experience, and help develop coping strategies.

Young people felt that cancer services could better support coping with low mood, by more openly talking about and normalising the occurrence of low mood during, after, and in long term survivorship. Some of those who did not receive support felt this would have been beneficial. They felt support should be integrated into care, individualized, and able to be accessed at home or in the hospital setting. Young people thought others around them should also have support options available and should be educated to be more aware of how to support and promote coping. There are commissioned cancer services specifically for young people, but not all young people with cancer are treated in these settings (NHS England, 2015; Teenage Cancer Trust (TCT), 2017). While evidence-based interventions are developing (Bradford & Chan, 2017; Coughtrey et al., 2017), there is variability amongst them, and studies have emphasised that support for mental health difficulties in this population remains an unmet need (Bennett et al., 2015; Keegan et al., 2012; Smith et al., 2013).

Limitations of this study include the fact that accounts may not be representative of the experiences of all young people with cancer. Given the age range classification of young people as 13-24 by TCT (2017), this sample was on the older side of the spectrum (mean age of diagnosis 18.1), perhaps because those who were older were more willing to talk about

their experience. Young people not interviewed or less willing to talk about their experiences may have felt low mood differently. No participants were undergoing active cancer treatment nor were many experiencing low mood at the time of interview, thus recall bias may be a limiting factor. Future research could explore the emotional experiences of young people who were in palliative cancer care, or of family or friends connected to young people with cancer.

In conclusion, this study reports young people's experiences of low mood during and after cancer, providing the first qualitative analysis and a valuable insight into this emotional experience. The findings corroborated challenges in detection of psychological difficulty when comorbid with cancer; young people sometimes struggled to identify emotional difficulty themselves, and they overlapped with physical symptoms. However, regardless of whether these experiences are constructed as a diagnostic category of depression, low mood, or otherwise, they were uniformly experienced as challenging to manage. Low mood was a term that appropriately described emotions and was acceptable to verbalise. In addition to managing cancer, low mood was closely linked to the difficulties young people experienced especially in relation to their stage of life and the interpersonal impact. Young people employed a range of coping strategies to manage, there is a great deal of resilience in this population and many strategies used were highly adaptive. However, services could help to further ease the journey. Young people wanted more proactive support, with normalisation of low mood to reduce the concerns of this being an abnormal reaction, or something that should be hidden. Improving networks for young people with cancer as an additional support and providing knowledge on how others have managed could also improve the experience. Young people wanted to feel that support was available and accessible throughout their experience of cancer, which does not end when treatment ceases. There is a need for future research and service provision to address these needs for this vulnerable population

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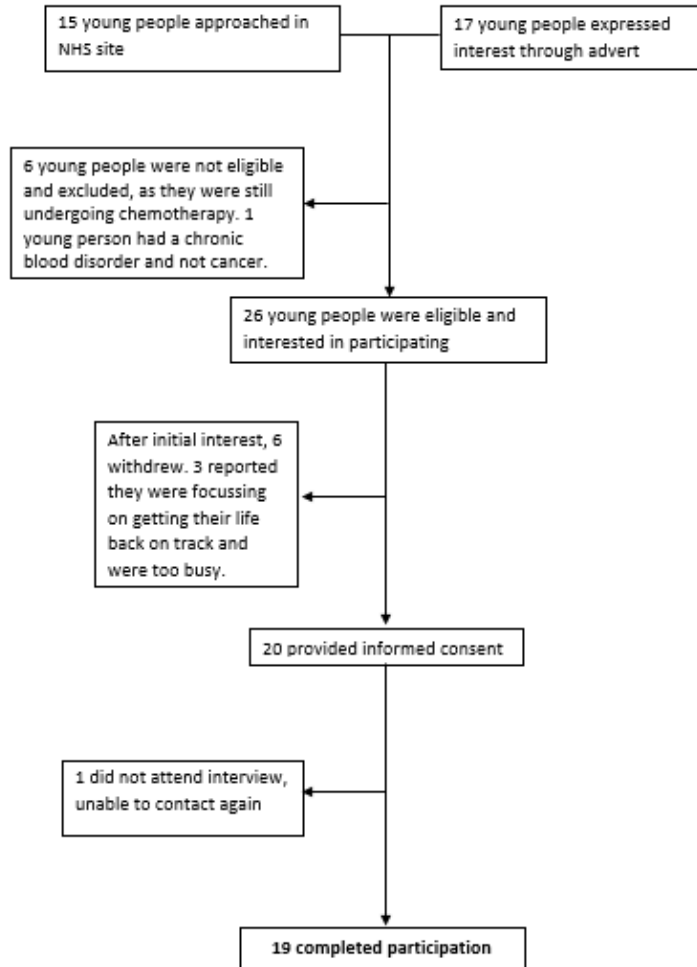


Figure 1. Recruitment flow diagram

Table 1. *Participant demographic details*

Characteristic	Mean or %
Female gender, %	74
Ethnicity, %	
White British	84
White European	5
British Bangladeshi	5
British Pakistani	5
Mean age (range) at interview, years	22.4 (18-31)
Mean age (range) at diagnosis, years	18.1 (11-26)
Cancer type, %	
Lymphoma	42
Leukaemia	32
Sarcoma	21
Craniopharyngioma	5

Table 2. *Domains and themes*

Domain	Theme	Prevalence
1) A harder time of life	1.1 Not feeling normal	19
	1.2 Life was just starting...and then it stopped	16
	1.3 Losing your safety blanket after treatment	16
2) Interpersonal impact of cancer	2.1 Cancer changed relationships	18
	2.2 Other young people with cancer	16
3) Learning to understand and describe low mood	3.1 How do I even describe low mood?	19
	3.2 Finding ways to cope	19
	3.3 Needing others to cope	19