

# Health Professionals' Perspectives on the Nature of Distress and Low Mood in Young People with Cancer

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**Running head:** Health Professionals' views of distress in young cancer patients

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## **Abstract**

**Purpose:** Young people with cancer are at increased risk of depression, yet evidence-based psychological interventions which are tailored to the specific needs of young people with cancer are scarce and depression in this group may be particularly challenging to recognise and treat. The aims of this study were to (1) explore the views of health professionals in recognising and treating low mood in young people with cancer and (2) identify the key components of an effective online treatment package for depression in this population.

**Methods:** Eighteen NHS health professionals with a range of professional backgrounds working directly with young people with cancer were interviewed using a semi-structured interview schedule. Responses were analysed using thematic analysis.

**Results:** Five themes emerged: (1) one size doesn't fit all – the nature of depression is complex and varied and symptoms fluctuate greatly in relation to physical health, (2) distress is completely understandable – it is important not to pathologise a normal reaction, (3) a stepping stone intervention – online interventions may promote engagement with face-to-face therapy, (4) connecting with others –the intervention should promote sharing experiences with others to reduce isolation , and (5) ownership and empowerment – lack of independence may be a cause of distress and young people should have control of the intervention .

**Conclusions:** The nature of depression in young people with cancer is complex and multifaceted. Online guided self-help may be useful when added as a component or first step of a treatment package including face-to-face talking therapies.

## Introduction

Around 2200 young people aged 15-24 years of age are diagnosed with cancer in the UK annually.<sup>1</sup> Living with, and beyond, cancer can have significant psychological impacts on the young person. Mental health disorders such as major depressive disorder, anxiety disorders and/or posttraumatic stress disorder have been reported in a quarter of young cancer patients.<sup>2,3</sup> As many as 50% of all patients experience significant symptoms of depression,<sup>4</sup> although rates of disorders vary by study.<sup>5</sup> The self-reported psychological distress reported among young people with cancer does not seem to vary with gender and age.<sup>6,7,8</sup> However, if left untreated, symptoms of depression are reported to persist after cancer diagnosis into adulthood.<sup>9,10</sup> This has serious consequences for physical and psychological functioning and leads to significantly reduced quality of life.<sup>11,12,13</sup> Psychological treatments including cognitive-behavioural therapy (CBT) delivered in a variety of formats including computerised interventions and guided self-help (GSH) are recommended treatments for young people with depression.<sup>14</sup> However, interventions developed for individuals with mental health difficulties without cancer may not be as effective for those with cancer and may require adaptation.<sup>15</sup> In order to deliver effective psychological interventions to treat mental health difficulties in young people with cancer, it is important to understand the potential physical and emotional aspects of distress caused by cancer and its treatment that go beyond traditional symptoms of depression. These may include feeling tired, nausea and pain from diagnostic procedures and treatment, concerns with appearance (e.g. hair loss, skin changes), lessened ability to get around, fear of death and feelings of alienation and isolation.<sup>16,17,18,19</sup> High levels of distress are not

caused by the same issues as those identified in standard depression manuals and include hair loss, missing leisure activities, worries about disease, missing school, mucositis, nausea and pain from procedures and treatment<sup>20</sup> which may lead to difficulties in accurately identifying psychosocial distress and depression in this population.<sup>18,21</sup> A further complication is that young people with cancer are a heterogeneous population whose psychological needs vary at different stages of cancer diagnosis and treatment.<sup>20,22</sup> Therefore, there is a need to provide interventions for depression that are personalised to account for the unique difficulties faced by young people with cancer and which are not addressed in standard depression manuals. However, evidence-based psychological treatments specifically tailored to support young people with cancer and depression are scarce<sup>23</sup>. Reviews of psychosocial interventions for young people with cancer have reported contrasting findings, with three reviews reporting potential benefits,<sup>23,24,25</sup> whilst a small meta-analysis reported small to non-significant effects.<sup>26</sup>

Young people with cancer have said that it is crucial that their mental health needs are recognised and addressed as part of routine care.<sup>27</sup> Therefore multidisciplinary oncology health professionals (including oncologists, haematologists, nursing staff, radiographers, play specialists, psychologists, psychiatrists and psychotherapists) play a key role in supporting young people with the multi-faceted symptoms of distress that they may experience as they go through treatment.<sup>28</sup> However, due to the particular characteristics of depression for this patient group, health professionals may experience challenges in identifying and treating low mood so it is essential to assess their views since they have significant contact with young people and are key to effective service delivery, particularly in the absence of empirically established interventions for depression and cancer.

Therefore, the primary aim of this study was to explore the views and perspectives of health professionals in recognising and treating low mood in young people with cancer.

Young people with cancer have expressed the need for psychological therapies for depression to be delivered in a way that maximises technology, e.g. online and computerised interventions, in order to allow them to manage their own care.<sup>29</sup> Computerised CBT has been found to be effective and acceptable for young people with cancer without depression<sup>30</sup> and could be particularly appropriate for young people with cancer as treatment is flexible and can be delivered at home or in hospital, reducing time spent away from school and peer groups. Similar integrated low-intensity interventions delivered by nurses in adult oncology services have been shown to be feasible, acceptable to patients, cost-effective and highly effective in reducing depressive symptoms in adults with cancer.<sup>15,31,32</sup> However, to date, computerised and online CBT packages have not been evaluated or adapted for use in young people with cancer. Therefore a secondary aim of this current study was to capture health professionals' views and opinions on the key components of an effective online treatment package for depression in this population.

## **Methods**

### *Participants*

Participants were recruited from a local NHS Teenage and Young Adult cancer service, selected for geographical convenience, providing treatment to patients aged 13-24 years old. Twenty three multidisciplinary health professionals who worked directly with young people with cancer on a regular basis were invited to

participate through emails sent to all staff members. Eighteen (78%) health professionals consented to participate. Participants were from a range of professional backgrounds including medicine, psychology, psychotherapy and psychiatry. Participants were members of the psych-oncology team (including psychologists, psychiatrists and psychotherapists;  $n = 10$ ), clinical nurse specialists ( $n = 3$ ), play therapists (who see young adolescents with cancer;  $n = 2$ ), radiographers ( $n = 1$ ), consultant haematologist ( $n = 1$ ) and activity coordinators (responsible for supporting young people and making being in hospital as positive experience as possible through providing informal activities and groups;  $n = 1$ ). Seventy-two percent of participants were female and the range of years spent working with young people with cancer was 1-28 years.

### *Procedure*

Ethical approval was granted by the Health Research Authority and local NHS Research Ethics Committee. This study took a qualitative approach in order to explore participants' complex experiences about working with young people with cancer in depth.<sup>33</sup> All participants provided written informed consent. Data were collected by semi-structured face-to-face voice recorded interviews lasting between 30-40 minutes. Interviews were conducted by four members of the research team: one trained graduate student, one PhD student, and two clinical psychologists, all of whom had experience conducting qualitative interviews. The research team was based at a separate institution to the participants and interviewers were therefore unknown to participants. All interviews were audio-recorded and transcribed verbatim by trained research assistants and all identifying information was removed.

### *Interview schedule*

A semi-structured interview schedule (Appendix A) was designed specifically for this study in order to elucidate a number of aspects of participants' experiences of working with young people with cancer and low mood. Topics included health professionals' views on the nature of low mood in young people with cancer, the differences with symptoms of depression in standard child and adolescent mental health services, and the characteristics of an effective treatment package for young people with cancer and low mood. In relation to the latter topic, participants were shown an early version of an online guided self-help intervention developed by the research team, based on the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma, or Conduct Problems (MATCH-ADTC).<sup>34</sup>

The interview schedule was used flexibly to ensure detailed information was obtained and included initial open questions with optional follow-up prompts.

### *Data analysis*

Thematic analysis was used to identify and categorise key themes in the data.<sup>35,36</sup> Analysis was based on an inductive approach, whereby the themes identified were grounded in the data.<sup>37</sup>

The six-phase approach to thematic analysis outlined by Braun and Clarke<sup>35</sup> was followed. (1) All interviews were transcribed verbatim and identifying information was removed to ensure anonymity. (2) Each transcript was then read several times to allow the research team to immerse themselves in the data. (3) Ideas that appeared significant or interesting were coded and noted against the transcript. (4) The codes and ideas were collated to form themes. (5) The identified themes were then reviewed against the raw data, and analysis continued until no

new themes emerged. (6) The refined themes were then named using a consensus approach.

The analysis was conducted by two qualitatively experienced members (AC & MS) of the research team to gain multiple perspectives on themes and enhance the credibility of the analysis. Each person analysed the data separately before discussing their analyses and agreeing the final themes. A subset of transcripts and the final set of themes were then reviewed by RS. The analysis was completed by hand without the use of qualitative analysis software.

## **Results**

Five themes and three sub-themes were identified and organised into two domains: (1) Challenges in defining depression and (2) features of an effective online intervention. There did not appear to be any pattern in the themes identified by participants from different professions. Each theme is presented in detail below and illustrated with quotations.

### *Domain One: Challenges in Defining Depression*

The first domain focused on the challenges that health professionals face in defining depression in young people with cancer. This included two themes relating to (1) the complex and varying nature of depression in this population and (2) that low mood, distress and depression symptoms were an understandable reaction to a life changing and life threatening diagnosis.

#### *One Size Doesn't Fit All*



Participants described the complex nature of distress in young people with cancer. They highlighted that the nature of depression differed from individual to individual and explained that *'one size doesn't fit all'* when identifying symptoms of depression in this population: *"Depression in young people with cancer is much more complex and it is difficult to operationalize those complexities."* Many participants explained that they did not find a depression diagnosis helpful because of these complexities e.g. *"Even though depression in a technical way may fit for this group of young people, actually that doesn't capture it, because actually it's much more complex than that...it's kind of one size doesn't fit all."*

#### *Fluctuating symptoms*

Participants explained that one of the complexities was that the symptoms of depression often fluctuated in response to changes in physical health and varied at different stages of treatment. For example, some young people reported increased symptoms of depression during active treatment whereas others reported worsening low mood following initial diagnosis or at the end of treatment: *"It's very variable and can change much more than you might see in depression [without cancer]. It can just be a bad few days of the week and then go bad again when they get some other bad news."* Similarly, participants explained that depression, symptoms often fluctuated rapidly with participants describing how a young person could present with severe low mood one day but be improved significantly the next (e.g. following positive test results): *"It is very variable and can change day-to-day much more than you might see in depression in young people without cancer."*

#### *Distress is Completely Understandable*

Almost all participants explained that low mood is a common and understandable reaction to cancer in young people e.g. *“young people go under the duvet, which is a very very common place...it’s like just shut your mind and just get through it and I think that is very appropriate. That seems to be completely understandable.”* Participants described how low mood was a normal and appropriate reaction to a cancer diagnosis and treatment: *“I think the majority of young people have low mood at some point, many points, throughout their whole journal. And lots of it is completely normal, they have enough reason to [feel that way]”* and *“We would very regularly see young people who would be very low in mood just because of what has just happened...so one would really feel that it would be very appropriate to be weeping and very upset...just think about the nature of chemotherapy and how many of us would just think ‘oh that’s ok, I’m fine with this”*

#### *Don’t pathologise distress*

Participants were clear that it is important that health professionals do not over-label a normal reaction to a difficult situation: *“Having a cancer diagnosis is one of the worst things that can happen to someone... everybody will have a catastrophic reaction to a catastrophic diagnosis.”*

Participants therefore thought it was important to validate young people’s emotional experiences and to normalise these e.g. *“normalise but don’t patronise.”* They said that it is vital that any intervention for depression *“allows young people to define their own emotions, rather than us defining it for them.”* They explained that it would be helpful for interventions to include information about depression in a way that validates young people’s experiences and allows them to make their own decision about what is a ‘normal’ emotional reaction, whilst also providing psychoeducation

about depression e.g. *“some sort of psychoeducation about depression, could be good, we know that the shock of cancer makes people feel like this, but if you start noticing these symptoms... for longer than, you know, a month, or whatever, then you know, do you talk to your GP, you don’t have to deal with this on your own.”*

#### *Domain Two: Features of an effective online intervention*

This domain comprised three themes focusing on the features of an effective online psychological intervention: (1) acting as a ‘stepping stone’ to promote engagement with face-to-face therapy; (2) enabling vulnerable young people to connect with others; and (3) promoting ownership and empowerment of young people with low mood and cancer.

#### *A Stepping Stone Intervention*

There was consensus among participants that online interventions could not replace the enormous therapeutic benefits of forming a therapeutic relationship through face-to-face psychological therapy: *“There is a huge amount of value in simply being with them [face-to-face] through the whole journey.”*

Participants suggested that GSH including online and computerised interventions for depression may have the most benefit for young people who do not or cannot currently engage with face-to-face services: *“The big issue with them when seeking help is that actually doing the talking, they don’t want to do that, whereas if you put them onto something online they are much more likely to engage in that, maybe at an earlier stage.”*

They described how there was a need for such interventions to act as a *“stepping stone”*, signposting young people to other resources and raising

awareness of face-to-face services, or having value in areas with long wait-lists for psychological therapies e.g. *“I think it could be useful as a stepping stone until they could get additional help”*. However, there was a consensus that such interventions should always be offered in addition to, not instead of, usual care.

### *Connecting with Others*

The majority of participants talked about relationships and the importance of engaging with others where possible, due to the isolating experience of having cancer during adolescence and the early adult years. Participants explained that *“we must keep human contact”* as young people with cancer often feel isolated and alone.

One concern raised by participants was that online interventions may increase isolation and they highlighted that it was important for treatment packages to encourage young people to *“get back into their lives”* when appropriate. Young people with cancer face various challenges in doing this, both practically and emotionally, and participants suggested that psychoeducation and support for managing these challenges were key areas for treatment packages to address, for example supporting young people to gradually increase social contact in a phased way: *“I think little behavioural things like this are really important. So I think something saying, you know, it might feel embarrassing or scary or difficult to talk about, but we know that talking to people is really helpful. How could you bring this up with your friends and family, you know... just... just something like that... could be really good.”*

### *Therapeutic benefits*

Participants explained that connecting with other young people with cancer could also have therapeutic benefits as it would highlight that they were not alone e.g. *“Low mood is definitely a mixture of feeling alone in the world and going through these experiences. And I think that sometimes it [interacting with others] does help...they can see that there are other kids who actually got through the same or similar.”* Connecting with others was also seen as therapeutic as it would help young people who were feeling ‘abnormal’ compared to their peers:

*“I think that what every teenage wants is to be normal, when you’ve got cancer you’re not normal. But you can find a little group so that you’re not alone. You’re not unique, you’re not the only person going through it, that kind of thing is probably the most beneficial for them.”*

The act of sharing experiences was also described as therapeutic by turning the young persons’ experience into something positive by helping other young people in the future: *“I think it would be really good as their experiences might help others in the future ...for some people I think that might be a way that they get something from this whole thing, that they feel they can give something back.”*

Participants described how they had seen how sharing experiences about cancer had resulted in young people taking a different perspective on their lives: *“Some say I wouldn’t change what has happened, which I always find is very remarkable, and somehow it’s the cancer that gives them the confidence to do A, B, C.”*

#### *Ownership and empowerment*

Participants highlighted that one challenge of being diagnosed with cancer as a young person was the sudden need to become dependent on others e.g. parents, during a time when they had been forging independence. One participant said: *“I think the things that cause the distress are the inability to be achieving the goals*

*that are part of adolescence*". Participants highlighted a need for interventions for depression to be flexible, personalised and modular rather than traditional linear manualised approaches so that young people could select topics that were relevant to them. Participants expressed the importance of empowerment in any psychological intervention and suggested that treatment was most effective when the young person had control over the intervention and could opt in and out of different treatment topics: *"Maybe something casual like an app [would be helpful], so they can pick up a module or two without having sessions in a particular order, or doing a certain number. Young people prefer that actually, they can make choices...it needs to be flexible."*

Some participants also talked about how identifying and recognising strengths was also important for empowering young people and ensuring that their identity went beyond having cancer: *"You start by thinking about your identity which is all of your strengths, and abilities and resources."*

## **Discussion**

This study explored the nature of low mood in young people with cancer from the perspective of health professionals working directly with this population. The themes that emerged from this analysis illustrate the challenges health professionals face when defining depression in young people with cancer. There was consensus that distress is an understandable reaction to a cancer diagnosis, and that care needs to be taken not to 'over label' what can be considered a normal reaction. Although cancer survival rates have significantly improved due to medical advances, many still view a cancer diagnosis as synonymous with death<sup>20</sup> and fear and low mood could therefore be considered a rational response. However, the fluctuating mood often

seen in this population may mean transient periods of low mood are difficult to identify as indicative of a mental health disorder and previous research has shown that health professionals can fail to accurately identify depression.<sup>18,21</sup> For example, physicians and nurses have been shown to overestimate levels of anxiety and depression in young people undergoing chemotherapy, yet underestimate symptoms of depression caused by the side effects of treatment.<sup>18</sup> Health professionals participating in this study described how normalising and validating emotions, and allowing the young person to define their own emotions, may help overcome some of these challenges. Further research is needed in order to understand how health professionals can avoid pathologising a normal emotional reaction whilst also ensuring that young people with depression are identified at an early stage so that appropriate support can be delivered. In line with a previous review,<sup>28</sup> health professionals discussed a wide range of factors related to low mood that young people with cancer might face, including the sudden loss of independence, the physical side effects of treatment (and subsequent impact on body image e.g. hair loss and weight changes) and the emotional and physical isolation from peers. It is likely that individual differences in emotional responses to these challenges will vary according to a range of risk factors including difficulties in parental coping, existing social or emotional problems prior to diagnosis, having a negative attributional style, and the type of cancer.<sup>38,39,40,41</sup> Therefore, it is important for interventions to be able to accommodate and support a heterogeneous group of young people.

Treatment for depression in young people without cancer is well established<sup>14</sup> however these treatments have not been systematically evaluated in young people with cancer.<sup>23</sup> The findings of this study indicate that health professionals thought it was likely that treatment adaptations would be needed to address the complex and

multifaceted aspects of low mood faced by the patients they saw. They highlighted that interventions needed to address the specific challenges faced by young people with cancer, such as the side effects of treatment and social isolation, which undoubtedly contribute to low mood. New, state-of-the-art modular psychological treatments based on CBT principles may lend themselves to personalisation for young people with cancer, as they combine fidelity to treatment protocols with flexibility to the individual presentation<sup>41</sup>. In this study, health professionals were shown an online intervention based on MATCH-ADTC<sup>34</sup>. Participants agreed that the modular design would empower young people to make choices about their own treatment and allow flexibility in addressing distress more broadly (rather than a sole focus on depression symptoms). It was suggested that other treatment approaches in addition to CBT (the psychological treatment recommended by NICE for mild depression) which are used in young people with cancer could also be incorporated as stand-alone modules. Narrative approaches may help the young person externalise both the depression and the cancer, e.g. using beads as prompts can help young people tell their own story of cancer and positions them as an expert in their own life.<sup>42</sup> Future research is needed to explore the effectiveness of flexible modular based interventions which would allow young people to select treatment topics that are most relevant to them.

Themes also emerged relevant to the usefulness of online GSH interventions for young people with cancer and depression. In young people without cancer, online CBT for depression is recommended and well established for mild-moderate low



mood.<sup>14</sup> Young people often favour such interventions over face-to-face therapy<sup>29</sup> and health professionals in this study highlighted that online GSH could add value to existing services as a first step in raising awareness of depression and signposting young people to other resources and services available to them, through a medium that they are comfortable and familiar with. Furthermore, health professionals highlighted the importance of relationships and engagement with others, which is often interrupted by cancer. For example, young people may miss school and other activities due to treatment appointments, or they may choose to withdraw socially due to the side effects of treatment.<sup>43</sup> Existing online GSH packages for depression tailored for use with young people with cancer could improve access to treatment and minimise further disruption to social and occupational functioning; however, further research is needed to ensure that such interventions do not increase a sense of isolation in young people with cancer. In addition, online interventions would empower young people to take control of their mental health,<sup>29</sup> which may be particularly important for this population as developmentally they are trying to forge independence and autonomy. Despite these advantages, health professionals in this study thought that online interventions should be provided as an adjunct to face-to-face talking therapies rather than as the sole provision of support. Therefore online interventions may be particularly helpful when integrated with existing services in the form of GSH.

This study has provided preliminary information regarding multidisciplinary health professionals' views of identifying and supporting young people with cancer

and low mood. However, the small sample size was recruited from a service which had a large multidisciplinary psychological services team to support young people, which may have influenced the findings and it is possible that the findings reported here are not representative of clinician views across the National Health Service. While it was felt that data saturation was reached with these 18 interviews, it is possible that further themes may have emerged were health professionals from different cancer services recruited. In addition, the views of other health professionals e.g. occupational therapists and physiotherapists were not represented in this research; future research should seek to capture the views of all health professionals involved in providing care to young people with cancer. Participants' views of the use of an online intervention for depression may in part have been influenced by their own age and attitudes towards technology; however, this was not measured in this study.

The findings of this study suggest that depression in young people with cancer is complex and multifaceted and can be challenging for health professionals to accurately identify. Online interventions may be a helpful adjunct to face-to-face therapy; however, future research is needed to evaluate existing online interventions for low mood to identify whether adaptations are required to effectively treat depression in young people with cancer.

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### **Author Disclosure Statement**

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## **Appendix A**

### **Drafted interview schedule for health professionals**

## Introduction

I'm going to ask you some questions about your experience of working with children and young people with cancer and associated low mood. It will take approximately 20 minutes, but please let me know if you would like to take a break or stop at any point. If there are any questions that you don't want to answer, please let me know, we can move on to the next one. Is that ok? Do you have any questions before we start?

## **Topics for discussion**

*Aetiology and maintenance of depression*

**What are your views on the nature of low mood in children and young people with cancer?**

### Prompts

How do you recognise it?

What does it look like?

When does it become a problem needing intervention as opposed to normal distress associated to a difficult diagnosis?

**How does low mood differ in this population compared to low mood in children and young people without cancer?**

### Prompts

What do you think are the different causal factors in those with cancer without depression, and those with depression?

*Treating depression in this population*

**What do you think an effective treatment package would involve to improve low mood in this population?**

Prompts

When would you use it?

What would it involve?

How would it differ from other treatment packages?

To what extent do you think techniques such as behavioural activation, methods to aid cognitive change and those to address other interpersonal challenges should be included?

**What do you think about the intervention being presented in an online guided self-help format?**

Prompts

How might this impact attrition/acceptability/access?

**Please have a look at existing treatment of online guided self-help for depression in children and young people. What adaptations, if any are needed?**

Prompts

Why is this needed/not needed?

**Ending the interview**

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

Is there anything you'd like to add?

Is there anything important you think I missed out today?

Do you have any questions or comments now we have finished the interview?

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