



*Citation for published version:*

Loades, M, James, V, Baker, L, Jordan, A & Sharma, A 2020, 'Parental experiences of adolescent cancer-related fatigue: A qualitative study', *Journal of Pediatric Psychology*, vol. 45, no. 10, pp. 1093-1102. <https://doi.org/10.1093/jpepsy/jsaa080>

*DOI:*

[10.1093/jpepsy/jsaa080](https://doi.org/10.1093/jpepsy/jsaa080)

*Publication date:*

2020

*Document Version*

Peer reviewed version

[Link to publication](#)

This is a pre-copyedited, author-produced version of an article accepted for publication in *Journal of Pediatric Psychology* following peer review. The version of record Maria E Loades, DClinPsy, Venessa James, MSc, Laura Baker, DClinPsy, Abbie Jordan, PhD, Aditi Sharma, MSc, Parental Experiences of Adolescent Cancer-Related Fatigue: A Qualitative Study, *Journal of Pediatric Psychology*, Volume 45, Issue 10, November-December 2020, Pages 1093–1102 is available online at: <https://doi.org/10.1093/jpepsy/jsaa080>

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**Parental experiences of adolescent cancer-related fatigue: A qualitative study**

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We have no known conflict of interest to disclose.

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**Acknowledgements**

The authors would like to thank the participating parents for their altruism and openness in sharing their experiences for this research study. The authors would also like to thank the Bristol Royal Hospital for Children – Oncology and Haematology Team and the University Hospitals Bristol Adolescent and Young Adult (TYA) Cancer Service who supported recruitment to this study. Dr Loades is funded by the National Institute for Health Research (NIHR Doctoral Research Fellowship, DRF-2016-09-021). This report is independent research. The views expressed in this publication are those of the authors(s) and not necessarily those of the NHS, NIHR or the Department of Health and Social Care.

### Abstract

**Objective:** Cancer-related fatigue is common, disabling, and chronic, but professional help is not necessarily sought. Parents can support symptom management and facilitate help-seeking. This study explored parental experiences of their adolescent's cancer-related fatigue and what they do to help.

**Method:** Qualitative semi-structured interviews were conducted with 21 parents of 17 adolescents aged 12-18 who were previously diagnosed with cancer. Reflexive thematic analysis was used to analyse the data.

**Results:** Three high-order themes were generated. Firstly, "fatigue is inevitable and unpredictable". This encompassed parental perceptions of fatigue as variable, distinct from normal tiredness, and linked to sleep and mood. Fatigue was seen as arising from cancer, which rendered parents helpless. Secondly, "fatigue is disruptive to normal life" beyond cancer treatment, which is contrary to expectations. Thirdly, parents managed fatigue by trying to balance the adolescent's desires for normality and their own perception of what is realistic with encouraging activities, and by seeking support from others.

**Conclusions:** Parents see adolescent cancer-related fatigue as multi-faceted and experience it as unpredictable and attributed to cancer. They struggle to distinguish normal adolescent behaviour from problematic fatigue, and to balance supporting and empowering the adolescent to live life to the fullest whilst also being realistic about the limitations imposed by fatigue and the benefits of activity. Parents try to manage fatigue practically but want more information about adolescent cancer-related fatigue to help establish their own and their adolescent's expectations.

## Introduction

Fatigue is described as a changing state of exhaustion, including physical, mental and emotional tiredness (Hockenberry-Eaton et al., 1998) and is one of the most common and distressing symptoms for individuals with cancer. Depending on how fatigue is assessed and whether it is assessed during or after active cancer treatment, as many as 100% of adolescents report that it is a prominent and problematic symptom (Spathis et al., 2015). The causes of fatigue are not fully understood, but evidence suggests that normal neuronal function is disrupted by inflammation, autonomic imbalance, HPA-axis dysfunction, and/or mitochondrial damage, which may subsequently cause fatigue (LaVoy, Fagundes, & Dantzer, 2016). Fatigue has a detrimental impact for both the affected adolescent and their family, causing significant disruption. This can be experienced as distressing and impacts on daily life, particularly physical and social activities, as well as attending school (Spathis et al., 2015). Importantly, for some adolescents, the effects of fatigue on functioning can be long-term, persisting over many years and well beyond cancer itself (Langeveld, Ubbink, & Smets, 2000).

Encouragingly, there is emerging evidence for graded exercise treatment for cancer-related fatigue in adults (van Vulpen et al., 2019) and some indications that exercise and activity management, psychoeducation, and peer support can alleviate cancer-related fatigue in adolescents (Nowe et al., 2017; Spathis et al., 2015). Guidelines recommend both exercise and psychosocial interventions (e.g. Cognitive Behavioural Therapy [CBT]) for cancer patients and their families (NCCN, 2019). Although cancer-related fatigue is likely to be biological in causation, cognitive and behavioural responses to the fatigue will contribute to its maintenance (Loades & Chalder, 2020), and it is these patterns that exercise and CBT-based interventions seek to address.

Despite the high prevalence and deleterious impact of fatigue on adolescents with cancer, and the availability of potentially effective treatments, fatigue is often accepted by adolescents and parents as an inevitable consequence of cancer and cancer treatment (Gibson, Garnett, Richardson, Edwards, & Sepion, 2005) and is therefore not necessarily discussed with medical professionals. Thus, fatigue is under-diagnosed, under-reported and under-treated (Berger, Mitchell, Jacobsen, & Pirl, 2015), giving rise to unnecessary suffering (Kestler & LoBiondo-Wood, 2012). Additionally, little is known regarding maintaining factors of fatigue in adolescents with cancer and which interventions might best manage such fatigue (Erickson et al., 2013).

Adolescents often require parental help to enable them to seek and access healthcare; for example, parents may facilitate or support symptom recognition and may help manage the practicalities of help-seeking (Sayal et al., 2010). This is likely to be true of adolescents with cancer too. Furthermore, adolescence is a developmental period in which individuation from the family of origin begins, and independence grows (Drew, Kable, & van der Riet, 2019). Ongoing fatigue and resultant disability may interrupt this normative process, necessitating ongoing dependence on parents (Gibson et al., 2005). Parents of children with cancer have been found to respond to cancer-related fatigue by restricting the amount of activity the child does (Chiang, Yeh, Wang, & Yang, 2009). Therefore, exploring how parents of this population understand the most common CRF symptoms experienced by their adolescents and what they do to try to help, is important to improve the recognition and management of these symptoms. This includes cancer-related fatigue.

Whilst parents play a critical role in supporting adolescent's experience of cancer-related fatigue and in facilitating help-seeking, little is known regarding the parental experience of their adolescent child's fatigue. Gibson et al. (2005) used a questionnaire survey method with 95 parents of children and adolescents, and although fatigue was reported

to be prevalent and troublesome, it was perceived by parents as something to be tolerated, with few believing it could be managed or treated. However, this particular study did not address questions about how parents may experience adolescent cancer-related fatigue in a more comprehensive way because it did not gather rich, in-depth detail about lived experience and was therefore unable to probe for reasons why fatigue was troublesome. Spathis (2019) explored parental experiences of cancer-related fatigue more extensively, but in a predominantly young adult population ranging from age 16 to 27 with a mean age at cancer diagnosis of 19 and a mean age at the time of participation of 22, rather than in adolescents. Given the normative emergence of independence and autonomy at the adolescent life stage, further exploring parental perceptions of adolescent cancer-related fatigue would make an important contribution to the existing literature. In this study, adopting an idiopathic rather than a nomothetic approach enables a more detailed focus on the particular and the ability to understand parental experiences of their adolescent's fatigue in detail. Therefore, this study sought to specifically explore how parents experience adolescent cancer-related fatigue post-treatment, and how parents try to support the management of their adolescent's fatigue.

## **Method**

### *Participants*

Parents and carers (henceforth referred to as 'parents') were eligible to participate if they had a child aged 12-18 years previously diagnosed with cancer who was either on active or maintenance treatment, or up to 12 months post-treatment. This is the period during which specialist oncology services are most heavily involved, and therefore would be the most opportune time to provide fatigue-related support. Potentially eligible families from the larger population of paediatric and young adult haematology and oncology patient families in the South West of England were approached directly by a member of the cancer specialist staff (typically a nurse, social worker or psychologist) from the Bristol Royal Hospital for Children

Oncology and Haematology Team and the University Hospitals Bristol Adolescent and Young Adult (TYA) Cancer Service. They were given information about the study and its aims and were invited to contact the research team directly if they were interested in taking part. It was anticipated that between 15-25 participants (including some parental dyads) would be recruited based on the sample size required to reach data saturation in previous related qualitative research studies (Hinds et al., 1999; Spathis, 2019).

During the recruitment period (February – August 2019), 26 parents (from 21 families) provided their contact details to the research team. Of these, 17 families agreed to participate ( $n = 21$  parents, including 4 dyads, who were interviewed separately to one another). Of the 5 families who did not take part, 1 was ineligible, 1 was not contactable, and 3 opted not to take part due to competing commitments). The characteristics of the parent sample ( $n = 21$ ) and their children with cancer ( $n = 17$ ) are presented in Table 1.

#### *Ethical considerations*

Ethical approval was granted by an NHS Research Ethics Committee (18/SW/0222), and by the relevant university departmental Research Ethics Committee (18-303). Participants were provided with information about the study and informed that they could withdraw at any time without prejudice. They gave informed written consent prior to interview, which included consent to publish anonymised quotations.

#### *Procedure*

Data was collected via individual semi-structured interviews. Prior to being interviewed, each participant had the opportunity to read the study information sheet, pose questions and seek clarification from the research team about the study. At the start of the interview, participants were reminded about the aims of the study, and their right to withdraw, as well as confidentiality. Participants then completed a consent form and a brief demographic form. The interview was guided by a topic guide, comprised of open-ended questions, 5 each

pertaining to fatigue, pain, and distress (see table 2), which were piloted on three adolescent cancer ‘experts by experience’ prior to the start of data collection. Fatigue questions were posed first. Parents’ answers regarding their adolescent’s pain and distress will be reported elsewhere. Participants’ answers were probed in more detail by the interviewer where appropriate to through use of open-ended prompts such as ‘Can you tell me more about that?’. We did not explicitly ask about differences between current fatigue levels and fatigue during treatment. The topic guide was adapted and developed during the study to enable further exploration of developing themes.

Two Masters in Health Psychology students (VJ and AS) conducted the interviews under supervision (LB, MEL, AJ). Interviews were audio-recorded and interview duration ranged from 18-80 minutes ( $M= 39$ ,  $SD= 15$ ). Interview data was transcribed verbatim using Microsoft Word and all information was anonymized at the point of transcription. This included assigning pseudonyms for participants and any individuals they mentioned in the interviews. All transcripts were checked for accuracy against the audio recording by another member of the research team.

### *Data analysis*

Data was analysed using inductive reflexive thematic analysis (TA). Inductive reflexive TA is a well-established and popular method for analyzing qualitative data, particularly interview type data (Braun & Clarke, 2006; Braun & Clarke, 2019). A critical realist perspective was taken (Vincent & O'Mahoney, 2018), assuming that truths exist independently of human cognition (ontological realism), and that we construct our knowledge of them through our own subjective experiences (epistemic relativism). For example, according to a critical realist position, unobservable experience like fatigue cause observable events like being unable to complete schoolwork, and they can be understood only if people understand the experiences (fatigue) that generate events (being unable to complete



schoolwork). We therefore assume that our analysis is at best an approximation of reality, and that our task as researchers was to try to understand, as accurately as possible, the perspectives of the participants regarding the experience of interest (cancer-related fatigue) through their accounts and interpretations of observable events.

Data collection and analysis occurred concurrently. Recruitment stopped when the data collected had sufficient information power to address our research question (Malterud, Siersma, & Guassora, 2016) and data saturation had been reached. Analysis was undertaken by VJ and MEL using NVivo 12 and manual coding. The analytic process was iterative and increasingly interpretative as the researchers derived latent meaning from the data. The first stage involved familiarisation with the data, which was achieved through actively reading and re-reading the transcripts. During this stage, existing ideas and understandings about cancer and cancer-related fatigue, and the developmental context of adolescence, were being held in mind, whilst also remaining open to novel ideas and unique understandings. In the second stage, VJ manually generated initial codes in NVivo based on patterns in the data. In the third stage, the long list of initial codes was collated by hand into a draft thematic map of candidate themes and sub-themes. These were reviewed and refined with input from all authors, particularly MEL, who independently carried out the first 3 stages for the first 3 transcripts. MEL and VJ met to discuss initial themes. In stage 4, VJ worked through the remaining transcripts, iteratively shaping themes until they worked with the dataset to provide a summation of meanings which addressed the research questions. MEL reviewed several further transcripts independently. In the fifth stage, MEL and VJ worked together to describe the intrinsic nature of each theme, the inter-theme relationships were defined, and to name the themes. Stage six involved writing the thematic account (VJ and MEL). Given the heterogeneity of the sample and our aim to explore experience broadly, we opted not to

provide frequency counts to quantify how many participants' narratives contributed to each theme and subtheme.

As authors, we were mindful of our own backgrounds and the possible impact of these on our interpretation of the data. Among the solely female research team, we acknowledge experience as mothers (VJ, MEL, AJ), with experience in the field of paediatric and adolescent fatigue (MEL), experience in the field of cancer in adolescents and young adults (LB), experience in the field of paediatric and adolescent pain (AJ) and interest and experience of working in the area of long-term complex care within an NHS setting (VJ, AS). Our own assumptions and perspectives were discussed and reflected on in research supervision meetings, and reflective notes were kept by VJ and MEL during the data analysis process.

## **Results**

Three high order themes with concomitant subthemes pertaining to the parental experience of adolescent cancer-related fatigue were generated from the interview narratives. Themes comprised: (1) "Fatigue is unpredictable and inevitable", which included descriptions of the varied ways in which fatigue can manifest and its links with other symptoms, and the explanations parents gave for fatigue; (2) "Fatigue is disruptive to normal life", which encompassed the process of adjustment to fatigue and (3) "How do we manage?", including balancing fatigue and functioning and seeking support from others.

### ***Theme 1. Fatigue is unpredictable and inevitable***

Fatigue was seen as unpredictable, which was apparent in different ways (subtheme 1: 'The many faces of fatigue'), and inevitable, as it was attributed to being a consequence of cancer and/or treatment (subtheme 2: "Making sense of fatigue").

#### *The many faces of fatigue*

This subtheme encompasses how fatigue was seen as unpredictable and interwoven with other cancer-related symptoms.

For parents, the extent of their adolescent's fatigue developed over time and manifested itself both physically and cognitively. Physical fatigue was unpredictable; *“some days she'll [adolescent with cancer] be up at the crack of dawn all bright 'n breezy...um 'n then literally she can just be sat 'n go “I'm tired 'n I'm going to bed”* (P13, mother of a 17 year old female with Hodgkin's Lymphoma). In contrast, some parents described adolescent fatigue as more cognitive in nature. For example, one mother reports how her daughter *“was only about 2 weeks finished with the chemotherapy 'n y'know...her brain just wasn't functioning properly 'n she had y'know exams 'n coursework to do”* (P10, mother of a 16 year old female with a germ cell tumour). Regardless of its manifestation, parents clearly distinguished adolescent fatigue from normal tiredness. For example, a mother described how *“you (adolescent) can get a wave of tiredness that just hits you during the day for no actual reason and it's a completely different feeling apparently to a normal being tired, I need to go to bed early”* (P08, mother of a 16 year old male with a brain tumour and pineal tumour).

Parents talked about how fatigue was linked to other symptoms, which made it difficult to disentangle fatigue from their adolescent's sleep and mood. One participant described how she experienced difficulties *“trying to tease out as well what's real physical 'unable to manage' fatigue and what's psychological 'this is too difficult for me to cope with' fatigue”* (P21, mother of a 12 year old female with a lymphoma). Whilst sleep could be helpful to adolescent mood, it was not helpful in alleviating fatigue; *“she'll wake up I think feeling better but sometimes it's better in mood as opposed to better in energy levels”* (P07, mother of an 18 year old female with thyroid cancer). It was notable that adolescent sleep was perceived to be unrefreshing; *medical fatigue doesn't make any sense because the more you*

*sleep ... you still feel rubbish ... you're not refreshed by sleep* (P02, mother of a 17 year old female with osteoblastic sarcoma).

### *Making sense of fatigue*

Fatigue was described as being inevitable and seen to arise from cancer and/or its treatment. Parents attempted retrospectively to make sense of their adolescent's fatigue in the context of cancer, with the benefit of hindsight, but at the time the fatigue appeared, they had attributed it to other causes such as normal teenage behaviour; *"she kinda stopped doing virtually everything 'n got fairly what we thought was lazy 'n teenagerish 'n ... saying she was tired but y'know you don't really attribute it to anything when there's no other symptoms so I think probably the fatigue was from the tumour"* (P10, mother of a 16 year old female with a germ cell tumour).

In the here and now, parents continued to attribute the fatigue to biological causes that were the result of cancer. For example, some parents rationalised fatigue as an adaptive biological function; *"that's because her body's...it's probably...y'know, not shut down, but it's kinda preserving itself"* (P01, mother of a 16 year old female with acute lymphoblastic lymphoma). Other parents thought fatigue was inevitable as a biological effect of cancer; *"there's no ifs and buts - you will have all the side-effects [of adolescent cancer] ...you will have fatigue"* (P20, father of a 12 year old male with an optic glioma). Whilst such explanations seemed to help some parents understand their adolescent's behavior in response to fatigue, some continued to struggle to distinguish between normative adolescent behaviour and fatigue-driven behaviour. This is demonstrated by a father who described how in relation to his daughter, it was hard to tell *"how much it still affects her is difficult to tell 'cuz she's 18 now and 18 year olds do spend vast amounts of time lying in bed doing very little"* (P09, father of an 18 year old girl with a germ cell tumour).

There was a sense of resigned acceptance both for parents and, by their accounts, for the adolescents themselves, with one parent describing how her daughter had “*almost been at the point of a resignation like, ‘This is how it is’*” (P06, father of an 18 year old female with thyroid cancer). The perceived inevitability made parents feel helpless, with one parent describing how “*there’s no helpful way...just got to get on with it [fatigue]*” (P18, mother of an 18 year old male with a germ cell tumour). This sense of helplessness was disempowering and distressing, placing strain on parents; one parent described how “*we don’t deal with it very well...I don’t, I cry a lot*” (P17, mother of an 18 year old female with acute lymphoblastic leukaemia). This helplessness meant that some parents set very high expectations for themselves; “*you’re totally helpless...you feel you can just...be an uber-parent...that’s all you can be*” (P02, mother of a 17 year old female with osteoblastic sarcoma). The contradiction here between doing all you can and yet an implied limitation of this is an illustration of the paradox between feeling helpless and yet striving to be the ultimate parent.

### ***Theme 2. Fatigue is disruptive to normal life***

Due to fatigue, maintaining or resuming a normal life felt elusive for parents and they perceived it to be similar for their adolescents. They described having to adjust to a new normality which was different from what they had expected, which had a systemic impact too. As a mother describes, her daughter “*really did try hard to get back to normal life when the treatment had finished but she has struggled with the tiredness*” (P10, mother of an 18 year old female with a germ cell tumour).

Fatigue extending into the future beyond cancer and active cancer treatment was poorly understood, contending against normative expectations about life beyond cancer. This was possibly due to the opposing causal attributions parents made about fatigue. Notably, a mother described how “*a lot of people think treatment’s finished therefore everything’s*

*finished ... they don't understand that actually the treatment was the bit that was all very controlled 'n everything but afterwards they still get the tiredness still get the fatigue"*(P05, mother of an 18 year old female with Ewing's sarcoma). These general misperceptions about returning to normal life after cancer treatment were compounded by messages about the adolescent regaining 'normality', perceived to originate from healthcare professionals. For example, a father described how *"the consultant we met with last time seems very happy that in 12 months' time she'll [adolescent with cancer] be back on her feet"* (P06, father of an 18 year old female with thyroid cancer). However, such expected regains in 'normality' were unobtainable due to the long-lasting effects of adolescent fatigue.

Parents described how the impact of adolescent fatigue extends beyond the adolescent and parent to affect the wider family, with families themselves needing to adjust to their 'new' situation. One mother described how *"we used to be quite an active family, we were out Saturday and Sunday...from 9 till whenever y'know...but now we can manage about 2 hours out and about which has become the new norm"* (P19, mother of a 12 year old male with an optic glioma).

### ***Theme 3. How do we manage?***

Parents described practical ways in which they had managed the challenges arising from cancer-related fatigue. These included 2 subthemes: 'it's a balancing act', and 'seeking support from others'.

#### *It's a balancing act*

For parents, a critical issue was how to respond to their adolescent's cancer-related fatigue and this was experienced as a balancing act. Notably, many parents believed that encouraging the adolescent to rest was a useful response. This is expressed by a mother who described how she *"let them [adolescent with cancer] have the rest, take them up a drink if they don't get up, don't say "You've got your chores, you've got to do your studying, you've*

*got to catch up!”...you have to let them rest ‘n just let them know it’s OK...to just take a break”* (P05, mother of an 18 year old female with Ewing’s sarcoma). However, parents reported challenges with balancing their adolescent’s need for rest with enabling the adolescent to do what they want to do. Specifically, one parent described this conscious balance as

*“trying to make sure that she’s still doing the things she wants to and can but that we’re not pushing her beyond what she can manage, and it’s also been a bit of a learning curve trying to work out what she can manage”* (P21, mother of a 12 year old female with a lymphoma).

This meant that parents needed to alter their expectations and to accept the limitations imposed by their adolescent’s fatigue; *“lower your expectations ‘n get organised”* (P10, mother of an 18 year old female with a germ cell tumour).

In addition to balancing their paradoxical desire to protect their adolescent whilst also facilitating adolescent functioning, parents also experienced conflict between what they wanted for their adolescent and the adolescent’s desire to *“carry on as normal the best I can”* (P03, father of a 15 year old boy with acute myeloid leukaemia). One mother describes how *“there have been times when I’ve sorta like, said to her [adolescent with cancer], ‘No, you’re not doing that ‘cuz, y’know, you are tired blah, blah, blah.’ and she’s like, ‘You’ve ruined my life, rah-rah-rah. All I wanna do is go out with my friends!’ and’ I’m like, ‘Go’”* (P04, mother of a 13 year old female with acute myeloid leukaemia). Adolescents reportedly maintained high expectations of what they could achieve; *“I think that why she’s been so determined to do her GCSEs and go to prom is because she wants to be as normal as possible”* (P14, father of a 16 year old female with Hodgkin’s lymphoma). Despite parental guidance, adolescents tended to deny when the demands of carrying on as normal were getting too much, until the

tipping point was reached; “...then she knew when she'd pushed herself too far 'cuz that's when she'd drop” (P04, mother of a 13 year old female with acute myeloid leukaemia).

Marshalling their resources to meet the challenge of cancer-related fatigue involved pragmatic acceptance; “I think it's just learning to pace yourself and accept the limitations and trying to work around that” (P21, mother of a 12 year old female with a lymphoma).

Parents tried to find what is practicable and achievable. Shifting the focus from fatigue to helping their child achieve a small aspect of daily routine was beneficial; “sometimes it was an effort to get her to go out of the room for half an hour a day...she got to the point where she learned that...that helped...that leaving the room helped” (P02, mother of a 17 year old female with osteoblastic sarcoma). This shift required parental proactivity and preparedness; “...however competent 'n capable your child is generally they're gonna need a bit of support” (P10, mother of a 16 year old female with a germ cell tumour).

It also required parental perspective taking; “although it feels horrible being firm with your child it helps them eventually, because it helps them to manage their own fear 'n their own anxieties” (P02, mother of a 17 year old female with osteoblastic sarcoma).

#### *Seeking support from others*

Parents sought both emotional and instrumental social support. Emotional support came from interactions with other parents in similar circumstances; “Non-judgmental...a complete empathy...it helps you to help other people whilst you're in that situation, it's normalising 'n you still feel like a human being with skills” (P02, mother of a 17 year old female with osteoblastic sarcoma).

Parents expected professionals in health, social care and education to provide instrumental social support, particularly in the form of information about fatigue. Some parents felt adequately informed; “I was prepared for the tiredness quite well through either the literature or through um the specialist nurses” (P11, mother of a 15 year old female with



acute lymphoblastic leukaemia), suggesting that being provided with information helped to shape realistic expectations. Other parents felt ill-informed; *“we had no idea that the fatigue would be such an issue”* (P06, father of an 18 year old female with thyroid cancer). This meant that their expectations did not match the subsequent reality of cancer-related fatigue. *I think it would’ve been helpful to have some information to start with to know what to expect b’cuz y’know when we were talking with the consultants they said ‘Yes she will be tired’ but I’m not sure you really grasp the level of tiredness that it’s gonna entail* (P10, mother of an 18 year old female with a germ cell tumour). Parents emphasised a need for adolescent cancer-related fatigue-specific information; *“I definitely think there needs to be something that is very much adolescent age specific...they’re not children...they’ve got very different needs”* (P05, mother of an 18 year old female with Ewing’s sarcoma). Parents valued help from professionals in securing support for their adolescent at school; *“[cancer nurse specialist] has been helpful all the way through...(she) did speak to school at the beginning”* (P20, father of a 12 year old male with an optic glioma). However, some parents found themselves battling a lack of understanding about their child’s post-treatment needs; *“schools ‘n colleges need to understand that treatment’s one thing, ‘n it’s very obvious, but actually post-treatment it still takes a long time for the young person to recover”* (P05, mother of an 18 year old female with Ewing’s sarcoma).

### **Discussion**

This qualitative study explored parental experiences of adolescent cancer-related fatigue and found that parents perceived fatigue as unpredictable, inevitable, and disruptive to normal life. Adolescent cancer-related fatigue was described as both physical and/or cognitive, and as variable, being overwhelming at times and imperceptible to others. Parents perceived adolescent cancer-related fatigue as an inevitable side effect of cancer, rendering them helpless in the face of it. Parents found it hard to distinguish normal adolescent

behaviour from fatigue, making it difficult to know when fatigue was a problem. Fatigue was perceived to continue to thwart the return to normal life beyond cancer for the adolescent, parent and family. There was a conflict between parents' expectations and reality, and between parents' expectations and those of the adolescent themselves, necessitating a balancing act by parents to support and enable the adolescent. Looking to the future, parents talked about adjusting to a new normal within the bounds of adolescent cancer-related fatigue. Whilst they used practical strategies such as maintaining but also relaxing rules and norms, trying to find what is realistic and achievable, and seeking social support, some wanted more information about fatigue, particularly developmentally appropriate information for the adolescents themselves to help with setting realistic expectations of fatigue.

The perceived inevitability of cancer-related fatigue is consistent with the narrative accounts of Chinese children with leukaemia (Wu et al., 2010) and with the accounts of teenage and young adult cancer patients and their parents (Spathis, 2019). Whilst fatigue is a commonly experienced symptom (McCulloch, Hemsley, & Kelly, 2018; Spathis et al., 2015; Walter et al., 2015), this perceived inevitability, combined with the perceived biological causation, is likely to impact on expectations about the availability of treatments to remediate it and therefore, on their propensity to seek help. This may go some way to explaining previous findings of under-reporting and under-treatment of fatigue in adolescents who experience cancer (Berger et al., 2015). Whilst fatigue is highly prevalent during and after cancer treatment, treatments such as graded exercise programmes and CBT may help to remediate and overcome it (Chang, Mu, Jou, Wong, & Chen, 2013; Lopes-Junior et al., 2016; Nowe et al., 2017; Walter et al., 2015).

Study findings identified that parents tried to make sense of adolescent cancer-related fatigue in relation to other aspects of cancer, including the biological impact of cancer on the body and treatment side-effects, and the impact of these, for example, on mood. Whilst

biological factors are likely to cause fatigue to arise, the cognitive behavioural model of fatigue includes cognitive and behavioural factors in the maintenance of fatigue (Loades & Chalder, 2020). Consistent with the link which parents perceived between fatigue and mood, children and adolescents with cancer-related fatigue have highlighted how fatigue impacts on quality of life, including by limiting their ability to do enjoyable activities, which may impact on mood, and by impacting on mood directly (Spathis, 2019; Tomlinson et al., 2016). Furthermore, fatigue in other adolescent long-term health conditions (e.g. multiple sclerosis) has been linked to mood (Carroll, Chalder, Hemingway, Heyman, & Moss-Morris, 2015) and conceptualising fatigue as related to mood is also consistent with symptom clusters in adolescents with cancer (Erickson et al., 2013; McCulloch et al., 2018). There was an implicit understanding of the links between fatigue, mood and behaviour (for example, moderate activity as beneficial) in parents' narratives, and further explicit psychoeducation for parents about the cognitive behavioural model could build upon this.

Although parents described fatigue as distinct from normal tiredness, they also talked about how difficult it was to distinguish normative adolescent behaviour, such as a propensity to sleep in, and a reticence to engage in activities, from fatigue-driven behaviour. This is likely to be particularly unique to this life stage, and it is consistent with the findings from a sample of parents of young adults post-cancer treatment (Spathis, 2019).

For parents, (re-)establishing a normal life beyond cancer was also complicated by the unpredictability and variability of adolescence as a life stage. Adolescent cancer-related fatigue was described as interfering with the return to normality and other studies have found that it interferes with normative adolescent independence processes (Spathis, 2019). This is common in the illness context and has been described as the two-fold burden of developing into adulthood whilst also adapting to life with and beyond illness (Nowe et al., 2017). The lack of knowledge about what a normal trajectory looks like within paediatric cancer may

exacerbate this problem (Kosir, 2019). Given that parents wanted more information about what to expect, a priority for future research should be to examine and establish trajectories of fatigue over time.

#### *Study limitations*

Given the dearth of research into parental perspectives on adolescent cancer-related fatigue, we focused on parents and did not interview the adolescents themselves. Therefore, we were unable to compare the narratives of parents to the adolescents' own experiences. Fathers were also under-represented, which meant that we were unable to compare maternal and paternal experiences of adolescents' fatigue as data saturation is unlikely to have been reached within the paternal subgroup.

#### *Research and clinical implications*

One of the top three research priorities for adolescents who have had cancer is developing interventions to reduce short- and long-term effects post-treatment (Aldiss et al., 2019), including for fatigue. Our research has highlighted that a potentially important component to understanding how the adolescent cancer-related fatigue experience is constructed and what help is sought is parental perceptions of fatigue. Future research could extend the current study by focusing on longer-term effects post-treatment by including those who are further into remission, and those who are survivors of childhood cancer (i.e. early age at initial cancer diagnosis), for instance. Longitudinal, prospective studies will be important to establish expected trajectories for fatigue post-cancer.

We have highlighted that a complication for parents is in distinguishing normal adolescent behaviour (e.g. a propensity to sleep in) from fatigue-driven behaviour. Furthermore, and importantly, parents wanted more information about adolescent cancer-related fatigue, both for themselves and developmentally appropriate information for their affected adolescent. There is evidence that promising treatments are available for fatigue in adolescents with

cancer (Chang et al., 2013; Lopes-Junior et al., 2016; Nowe et al., 2017; Walter et al., 2015). Providing information about this evidence base could help to address the resignation to it as inevitable and empower them to view it as a challenge, enabling them to take small, concrete steps towards adapting to it or overcoming it. It may also encourage them to seek help for it. Therapeutic support delivered online has been found to develop adaptive coping skills after cancer (Maurice-Stam et al., 2014). Including a focus on fatigue within such programmes and developing guided online or mobile application-based self-help specifically focused on fatigue may overcome the potential barriers posed by fatigue in accessing face-to-face treatments and peer support groups.

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Table 1. Participant and adolescent demographics and clinical characteristics

	<b>Father/mother</b>	<b>Adolescent's age (years)</b>	<b>Adolescent's gender</b>	<b>Adolescent's cancer type</b>	<b>On/off treatment</b>
P1	Mother	16	Female	Acute lymphoblastic leukaemia	On
P2	Mother	17	Female	Osteoblastic sarcoma	Off
P3	Father	15	Male	Acute myeloid leukaemia	Off
P4	Mother	13	Female	Acute myeloid leukaemia	On
P5	Mother	18	Female	Ewing's sarcoma	Off
P6	Father	18	Female	Thyroid cancer	On
P7	Mother				
P8	Mother	16	Male	Brain tumour / Germ cell tumour pineal tumour	On
P9	Father	18	Female	Germ cell tumour	Off
P10	Mother				
P11	Mother	15	Female	Acute lymphoblastic leukaemia	Off
P12	Mother	15	Female	Osteosarcoma	Off
P13	Mother	17	Female	Hodgkin's lymphoma	On
P14	Father	16	Female	Hodgkin's lymphoma	On
P15	Mother	14	Female	Osteosarcoma	On
P16	Father				
P17	Mother	18	Female	Acute lymphoblastic leukaemia	On
P18	Mother	18	Male	Germ cell cancer	Not reported
P19	Mother	12	Male	Brain tumour - Optic glioma	On
P20	Father				
P21	Mother	12	Female	Multifocal cutaneous anaplastic large cell lymphoma	On

**Table 2.** Topic guide which was used flexibly to guide the interviews (fatigue-relevant questions only, pain and distress questions available from the corresponding author on request)

<i>Fatigue</i>
Some parents have told us that fatigue is a problem for their child,
<ul style="list-style-type: none"> <li>• Can you tell me about your son's/daughter's experience of fatigue?</li> <li>• How well do you feel you understand your son's/daughter's fatigue?</li> <li>• What have you found to be the most helpful ways of managing your child's fatigue?</li> <li>• Can you tell me about any resources or support that you have found beneficial or would have liked to have been offered?</li> <li>• What advice would you give to other parents of children with cancer about managing their children's fatigue?</li> </ul>