



## “You feel different in your body”: Experiences of fatigue among children undergoing radiotherapy for cancer treatment



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### ARTICLE INFO

#### Article history:

Received 21 December 2021

Revised 27 June 2022

Accepted 9 July 2022

#### Keywords:

Rest

Sleep

Mood

Pediatric cancer

patient's perspective

### ABSTRACT

**Purpose:** The aim of this research is to examine the experience and impact of radiotherapy related fatigue in children diagnosed with solid tumours.

**Design and methods:** Children ( $n = 25$ ) and parents ( $n = 19$ ) participated in a semi-structured interview on the last week of radiotherapy treatment. The study sample included children who were 6 to 14 years of age, diagnosed with brain or solid tumour, and received radiotherapy as part of their treatment protocol over the period of 6 weeks. Interpretation of data was undertaken through the adoption of thematic analysis approach.

**Results:** Data revealed children's experience and response to fatigue while undergoing radiotherapy. Several recurring themes arose about their experience of fatigue/tiredness while undergoing radiotherapy. Two themes and eight sub themes, namely 'Experience of Fatigue' ("You feel Different in your body", Mood and Feeling, Activity and Occurrence) and 'Response to Fatigue' (Rest and Sleep, Activity, Mood and Concentration and Eating Habit) were identified.

**Conclusions:** The findings illustrated significant fatigue on activity sleep, rest and mood of children undergoing radiotherapy.

**Practice implications:** Monitoring and addressing fatigue and its consequences during radiotherapy treatment are essential to improve well-being of children with cancer.

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### Introduction

Cancer represents a leading cause of disease-related death and treatment-associated morbidity in children, with an increasing trend in recent decades worldwide. Nevertheless, the 5-year survival of childhood cancer patients has been raised impressively to >80% during the past decades, primarily attributed to improved diagnostic technologies and multi-agent cytotoxic regimens (Stiller, 2019). This strong benefit of more efficient tumour control and prolonged survival is compromised by an increased risk of adverse and fatal late sequelae (Zahnreich & Schmidberger, 2021). Cancer diagnosis is a major life stressor to the child and the family as it can affect the physical, psychological and quality of life of the child and the psychological and emotional state of the family.

Fatigue is the most common symptom experienced by adults and children with cancer; it can be associated with the cancer itself, cancer treatment, and/or other symptoms such as depression or poor sleep (Barsevick et al., 2013). Hockenberry-Eaton et al. (1998) were among the first to report the experiences of fatigue in children and adolescents with cancer. Pediatric cancer patients reported fatigue to be one of the most prevalent, intense treatment and illness related effects experienced during therapy (Hockenberry et al., 2003; Hockenberry-Eaton et al., 1998). Over the past decades, some scientific progress has been made in understanding and treating cancer-related fatigue, however three major problems have limited further progress: lack of agreement about measurement, inadequate understanding of the underlying biology, and problems in the conduct of clinical trials for cancer-related fatigue in children (Barsevick et al., 2013). Fatigue is a particularly common and troubling symptom for cancer patients that has a negative impact on quality of life throughout all phases of treatment and stages of the illness (Al Maqbali, 2021). The most common symptoms (prevalence >34%) were nausea, fatigue, decreased appetite, pain and feeling drowsy in hospitalized children with cancer (Miller et al., 2011).

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Children and parents reported pain, fatigue, nausea and sleeping difficulties as the most frequently occurring symptoms (Montgomery et al., 2021). Cancer-related fatigue is a disabling symptom that often continues after cessation of treatment (Nap-van der Vliet et al., 2019). It impairs school functioning and reduces the ability to participate in social roles and activities (Knight et al., 2018; Salter et al., 2019). Studies about cancer-related fatigue have been performed in children undergoing chemotherapy but very few studies were conducted in children undergoing radiotherapy. Since the 1960s, pediatric oncologists have gradually become better organised in large study groups and participation in clinical trials is today considered as the standard of care, with most children with cancer in Europe and North America being enrolled on available treatment protocols (Erdmann et al., 2021). Chemotherapy is nowadays the main element of therapy, but irradiation is still required for some patients. With the advent of multimodality therapy and supportive care, five-year cancer survival exceeds 80% in most European and North American countries today (Erdmann et al., 2021). Knowledge of fatigue among pediatric cancer patients is extremely important in the process of assessment, treatment and management. Hence, a better understanding is needed regarding the child perspective of the problem of fatigue. This study aimed to understand the phenomenon of fatigue from the child's perspective, and how it impacts on the child's quality of life.

## Methods

A qualitative study was used to understand the response and experience of fatigue from a child perspective while undergoing radiotherapy using a semi structured interview guide. The recruitment of pediatric cancer patients occurred at a large tertiary cancer hospital in Melbourne, Australia (the Peter MacCallum Cancer Centre – referred to as Peter Mac) from October 2016 until March 2019. Consecutive patients referred for radiotherapy were ascertained.

Peter Mac is one of the few centres of excellence in Australia that treat children with solid tumours and provides a multi-disciplinary approach to diagnosis, management and supportive care. Peter Mac accepts referral of children from Royal Children's Hospital, Parkville and Monash Medical Centre, Clayton to deliver radiotherapy as an adjuvant treatment for cancer. At the time the study was conducted, Peter Mac delivered radiotherapy to approximately 100 to 120 pediatric patients each year; radiotherapy was delivered primarily in an outpatient setting.

The researcher who conducted the interviews was a pediatric nurse consultant who also coordinated and provided clinical care to the children while receiving hospital treatment. The interviews were held in the treatment waiting area at the hospital. These were private interview rooms that were familiar to the family and the child as the researcher uses the rooms during regular assessments and to deliver nursing care while on treatment. To maintain privacy, the researcher, along with the parents were the only persons present in the room while the child was being interviewed. The interview room was child-friendly to maintain a happy and safe environment during the interview. The researcher was mindful to keep this interview as a two-way communication, and helping the child and parents feel comfortable and relaxed during the interview. Parents were present during the interview to support their child emotionally and ensuring that the child feels safe and confident to answer the questions. There is more emphasis on listening by health researchers in interviews, it's important therefore that there is a two way communication to remain focused on the topic or question at all times during an interview (Mitchell, 2015).

Ethics approval was obtained from the Royal Children's Hospital Human Research Ethics Committee (Aug 2016), Peter MacCallum Cancer Centre's Governance team (Sept 2016) and Charles Darwin University (July 2016). Families interested in participating in the study were screened to confirm that they met the study inclusive criteria. Written informed consent was obtained from all parents of the participants.

**Table 1**  
Semi-structured interview guide.

Semi-structured questions
How will you describe tiredness?
Which part of the day do you feel tired the most?
What do you like to do when you are tired?
Does tiredness change your daily routine?
How do you manage tiredness?

The parents and children were informed that they were allowed to withdraw from the study if they wish to at any time, and that this would not affect the nursing care or cancer treatment of their child.

Children who were between 6 and 14 years of age, diagnosed with brain or solid tumour, and received radiotherapy at Peter Mac as part of their treatment protocol (alone or having combined therapy such as chemotherapy and/or surgery) over the period of 6 weeks were eligible to be included in the study. The age range was decided upon careful consideration to cover the wide range of experiences of children, and it was decided to include parents in the interviews to provide emotional support as needed. Children and families who have difficulty in communicating in English, those who do not wish to participate in the study, and those who received radiotherapy under anaesthesia were excluded. Semi-structured interviews were conducted on the last week of radiotherapy treatment on a day and time that best suited the child and parents. Interviews were audio recorded and written notes were documented simultaneously on the interview guide sheet. Informed by the research literature in this topic, a senior qualitative researcher and a pediatric nurse consultant designed an interview guide (see Table 1). The interviews utilised open-ended questions, thereby allowing for participants to reflect on their experiences of fatigue and tiredness while undergoing radiotherapy. Interviews were de-identified, and the recorded audio of interviews were then transcribed verbatim. The transcribed data were first reviewed and coded by one researcher, then data and codes were reviewed by two other researchers. Interpretation of data was undertaken through the adoption of thematic analysis approach, whereby the qualitative data is organised to explore the experience and response to fatigue while undergoing radiotherapy (Moser & Korstjens, 2018). All analysis were completed on the combined patient responses and parent responses from the semi-structured interviews. Arbuckle and Abetz-Webb (2013) noted that parent's interviews may be helpful in assessing the child's awareness of their condition and terminology used to reference of symptoms. Researchers considered data saturation was reached when no new codes were coming out of the interviews.

## Results

During the study period, 149 children were referred to Peter Mac for radiotherapy. Of those, 124 children were not eligible to be included in the study (i.e. planned to have <5 weeks of treatment; required general anaesthetic for treatment; <6 years or >15 years of age) and 25 eligible children were interviewed. The study sample included children who were between 6 and 14 years of age, diagnosed with brain or solid tumour, and received radiotherapy at Peter Mac as part of their treatment protocol over the period of 6 weeks.

All 25 children and 19 parents participated in the interview. The interviews lasted for approximately 15–20 min for every patient. Reasons for parent participation in the interview included the children where shy, not able to explain, or parents filled in with scenarios happening at home daily. Table 2 describes the demographic characteristics of the children included in this study. There were slightly more boys (60%) compared to girls (40%). The children received 45–70 Grey (median 54.0 Grey) of radiation as part of their treatment based on their diagnosis and radiotherapy protocol they were following. The children

**Table 2**  
Characteristics of patients interviewed.

Characteristics		N = 25 (%)
Age (mean, SD)		10.4 (2.1)
Age group	7–10 years	15 (60%)
	11–14 years	10 (40%)
Gender	Female	10 (40%)
	Male	15 (60%)
Parents also took part of the interview		19 (76%)
Diagnosis – cancer type	Astrocytoma	1 (4%)
	Craniopharingioma	5 (20%)
	Diffuse Intrinsic Pontine Glioma	1 (4%)
	Ependymoma	2 (8%)
	Germinoma	1 (4%)
	Glioma/Glioblastoma	5 (16%)
	Liposarcoma	1 (4%)
	Medulloblastoma	4 (16%)
	Melanoma	1 (4%)
	Nasopharyngioma	1 (4%)
	Osteosarcoma	1 (4%)
	Rhabdomyosarcoma	1 (4%)
	Synovial Sarcoma	2 (8%)
Anatomical site	Brain	15 (60%)
	Brain and Spine	4 (16%)
	Head and Neck	3 (12%)
	Lungs	1 (4%)
	Hand	1 (4%)
	Abdomen/Pelvis	1 (4%)
Radiotherapy total dose (median, range)	45–54 Gy	17 (68%)
	50–70 Gy	8 (32%)

were mainly diagnosed with brain and solid tumours, 60% of the participant received radiotherapy to their brain.

The direction of the interviews was determined by the participants and their parents. Through analysis of transcripts, several recurring themes arose about their experience of fatigue and tiredness while undergoing radiotherapy. The interviews were centred on two themes and eight sub themes, namely ‘Experience of Fatigue’ (“You feel different in your body”, Mood and Feeling, Activity and Occurrence) and ‘Response to Fatigue’ (Rest and Sleep, Activity, Mood and Concentration and Eating Habit). The themes and sub themes were summarised in Table 3 and described in more detail below.

*Theme 1: Experience of fatigue*

*“You feel different in your body”*

Children experienced fatigue in many different ways. Some children described the phenomenon of fatigue related to their muscles, physical aches and pains, and how they felt different in their body:

*That I feel different in my body* [(#C23)]

One child described very specifically:

*Tiredness for me is like when my body feels like it’s a big un-stretched muscle. Through the day I just feel like every single muscle was really stretched* [(#A20)]

Other children related fatigue to a struggle to keep their eyes open and expressing:

*It’s like when your eyelids start falling down-you can’t keep them open* [(#C16)]

When discussing about activities, several children verbalised that they were not able to perform physical activity, exercises, or do much. This was voiced by a parent’s perspective of what they heard the child verbalise at home:

*Well sometimes I feel sick- -cannot be bothered to do things* [(#P23)]

Participants, children and parents, expressed that it’s just not the physic that was affected, at times they were feeling low:

*You can’t think - like I’m a zombie -like your brain is just empty-like you don’t have any imagination or anything like that* [(#C22)]

*I find him tired easily doing something mental - If you ask him something to decide to choose over something will take forever to choose simple things. You can tell when he is tired, he is very down in energy and will tell me* [(#P8)]

A few children related fatigue to feeling lazy and not wanting to get out of bed:

*Sort of feeling sleepy, sort of just like I’m just lazy sort of tired* [(#C7)]

*Like lounging around like having afternoon naps, Out of energy, don’t want to do anything, I can’t really get out bed and even if you have a good sleep, you still struggle to wake up in the morning* [(#C12)]

However, a number of the participants experienced fatigue, but were unable to define or describe fatigue.

*Mood and feeling*

In addition to the physical effects of fatigue, the children discussed fatigue as a changing state in mood, concentration, nutrition, and how they felt hard to move or do anything:

*I want to like not do much, Just don’t feel like up to anything* [(#A6)]

*I would describe tiredness as she would be a little bit more -Just sit in the care and zone out* [(#P24)]

*I sleep well during the night but when I wake up I still feel tired* [(#C17)]

A small number of parents contributed to how their child felt when they were tired: my child would say:

*I feel a bit not right, feel drained all my energy from earlier of the day* [(#A4)]

*In the morning if we don’t wake him up he doesn’t want to wake up-he says” why do we have to go to Peter Mac so early* [(#P4)]

Quite a few children realised they were grumpy, annoyed, frustrated, and not motivated to do anything:

*More of you’re not motivated.* [(#C12)]

**Table 3**  
Supporting quotes for major categories.

Theme 1: Experience of fatigue	
"You feel different in your body"	"My eyes get really tired: like heavy, I want to shut my eyes like really bad and cannot be bothered doing much" (#A3) "Incapability of doing physical work and exercises like running or walking" (#A4) "It's like when you cannot do anything or keep your mind on" (#C19) "When I feel restless, Feel like I want to sleep all day" (#A6) "He cannot handle any noise" (#P5)
Mood and Feeling	"He gets frustrated, he probably has a short temper- especially with sisters and he is annoyed easily in the afternoon" (#P11) "She has her moments, everything tastes different – change of taste. it's just trying to find bits and pieces –often at the moment nothing is working" (#P9) "I definitely think that its accumulated-He has got more tired as time has passed for sure - But only in the afternoon he is normal" (#P16) "Probably a sleepy feeling-sometimes I feel a bit exhausted" (#C21)
Activity	"Well, my concentration has been a bit down, when someone interrupts when I am talking then I forget, lost concentration too" (#C16). "It does not change the normal routine but it just probably is a little bit harder to concentrate on doing the routine things. I used to do crochet so it's a little bit annoying sometimes when I cannot concentrate to do it. -I actually do random things-Because sometimes I do one thing and sometimes do the other-sometimes I look at it and other times I don't" (#C21) "Sometimes he cannot do simple activities -he cannot do it – example: play with siblings, read a book, go outside, he cannot do things when he is tired- he just cannot move, he's just stationary in one spot" (#P5) "Yes my routine is affected sometimes, cannot go to school" (#C9) "Went for a school fete during the week end-stayed there only for 2 h and said 'I want to go home' and became teary" (#P23) "I talk to friends via social media- but I prefer to see them in real life" (#A13)
Occurrence	"Morning (#P10) waking up is difficult" (#C10) "Some days are different than the others-Mostly in the afternoon" (#C19) "Probably when I wake up, when I come home from school which is about three thirty" (#C7) "I usually feel a bit tired when I wake up-Morning tea time -like 11:30 am- evening tea time – like 5 pm-probably the tired feeling in the morning is just a feeling like I have not been rested properly" (#C21) "I think definitely he is a little bit brighter at the beginning of the week and the end of the week there's more fatigue" (#P17)
Theme 2: Response to Fatigue	
Rest and Sleep	"Just like lay down shut my eyes for a few minutes then get back up and then I feel better" (#C7). "If I do much during the day, I can sometimes make me more tired" (#A6) "I like to rest -Sometimes put the technology devices down and close my eyes" (#C25) "I feel well after I sleep but just really tired mentally and physically" (#A20)
Activity	"Just wants to curl up in the couch not to be annoyed" (#P3) "Lying around on the couch, like you do not want to do anything, just tired to sit down, I just sort of relax, like sit down and sort of just do nothing and just watch a movie on TV" (#C7) "Watch Television, go on to technology, you do not really listen to the words or anything-really watch it that's all, Enjoy cooking" (#C12) "Just sit down-play video games-watch Netflix-sit down and relax" (#A20) "Sit on the couch and watch like a movie or something" (#C24) "I feel like going back to bed or sit and watch movies" (#C25) "Trying to overcome fatigue by exercise. My aunt is a Radiation therapist, who discussed the need for exercises for fatigue, followed instructions" (#A4) "Interact with friends on social media, Friends come over sometimes" (#A3)
Mood and Concentration	"My routine for the day depends on my mood" (#A4) "He coped okay but a little bit grumpy" (#P1) "He is more disappointed because he does not want to miss out on things" (#P5) "Keep his manner – very little words" (#P23)
Eating Habit	"Never too tired to eat" (#P5) "When I'm tired, I'm just sitting around which means I'm bored, which means I eat out of bored hunger and it makes me hungry" (#A6). "I also eat a little bit more to try and get my energy levels back" (#C2) "For dinner we really have to help to get out of bed to eat dinner" (#P3)

<p>Cannot be bothered doing much</p> <p>[(#A3)]</p>	<p>when I'm trying to think about walking or staying out of the way of people</p> <p>[(#C21)]</p>
<p>I might feel little bit annoyed and frustrated</p> <p>[(#C21)]</p>	<p>Whereas a few parents also identified that concentration had been affected while their children experienced fatigue:</p>
<p>Parents also observed the mood swings in their children:</p> <p>He gets frustrated, he probably has a short temper- especially with sisters &amp; he is annoyed easily in the afternoon</p> <p>[(#P11)]</p>	<p>Not concentrating at all even conversations in the car</p> <p>[(#P3)]</p> <p>He is very easily distracted more than normal</p> <p>[(#P16)]</p>
<p>So she goes to the bed because she is tired and wants to watch the siblings play and then gets upset because she wants to play</p> <p>[(#P14)]</p>	<p>He cannot process things when he is tired (#P5).</p>
<p>A small number of children realised that they find it hard to concentrate:</p> <p>I kind of find it a bit hard to concentrate –It's probably just thinking its quiet hard to just try and think about something else-You know</p>	<p>Sometimes I cannot be bothered to eat-I'm just you know don't feel hungry at all</p> <p>[(#C22)]</p> <p>Children who were aware that their nutrition was affected during the treatment said:</p>

*I found myself losing a bit of weight but I am not able to eat when I am tired*

[(#C7)]

Some parents observed that their child preferred a soft diet compared to a regular diet when tired. A parent expressed that they understood their child and tried to work effectively around his/her need and tiredness. However, that led to the concern about their child:

*Realizing that he couldn't do all the things he would do - We sort of have to think right if we want to go somewhere we have to go another way - example instead of walking in the after go by wheel chair*

[(#P1)]

*He is shy looking at the audio recorder and hence not answering*

[(#P17)]

#### Activity

Children have described the changes in their body have impacted their routine activities while they were on treatment:

*I wouldn't be able to do as much, I just rest more like I'm not doing much during the day*

[(#A6)]

*Shower myself but I used to shower twice a day, now I shower once a day*

[(#C13)]

*I can't play board and that was one of my favourite things*

[(#C14)]

*Daily routine has changed, because when I went walking and I had to stop for a drink or something or sit down for a minute*

[(#C24)]

Some parents have expressed their observations towards daily activities when the child is at home and coming to the hospital for daily treatment:

*He takes a long time to get out of bed, thinking and decision making has slowed down. If you ask him something to decide to choose over something will take for ever to choose simple things, even to decide what he is going to eat for lunch takes a long time. He meets all basic needs*

[(#P8)]

*Go to bed a bit earlier now-Friday nights we used to have late nights of 9:30 pm to 10 pm but you're going to be bed earlier now. After the last few weeks after walking up the stairs he is tired- so I bring his clothes down and goes up to brush his teeth*

[(#P17)]

*After the last few weeks after walking up the stairs he is tired- so I bring his clothes down and goes up to brush his teeth*

[(#P17)]

*Not much on his bike but playing continuous with siblings and cousins - takes a break and goes back*

[(#P18)]

Regarding sports, few children verbalised that they stopped playing sports:

*Haven't played sport-was in the league but had to step down, it was like putting an eight-year-old kid against a five year old it's not fair*

[(#A20)]

School being a major part in the growth and development of the child's life, some of the children have spoken about how their school life and routine had changed:

*Not able to go to school, but I don't want to go to school when I'm sick*

[(#C11)]

*I went to school every day and now, I'm going for few hours & few times a week as my class is really loud and I get a big headache*

[(#C12)]

*Occasionally I'm a bit annoyed not being able to go to school*

[(#C16)]

A few of the parents discussed how their child goes to school only for a couple of hours during the day because they were tired. Children expressed that they missed on socialising and meeting friends even though they tried to connect via social media:

*I miss face to face social interactions with friends*

[(#A3)]

*If I'm outside during weekends with friends or family, we have to leave early, I used to go out a lot with friends before*

[(#C5)]

*It's annoying because I like to go out with my friends a lot*

[(#A6)]

*Imagine I want to go out at one o'clock imagine this but I will start feeling tired at 11 am or 12 noon and I can't do it*

[(#C16)]

However, other children expressed contrasting feelings about socialising with friends:

*I don't really like being nagged when I'm tired because that's when I'm not in the brightest of moods- so when I'm in a very angry mood, lazy mood and if anyone annoys me, I will complain about it-get annoyed depending on who is talking and what they are talking about*

[(#A20)]

*I can't really be bothered to talk as much and be social*

[(#C22)]

#### Occurrence of fatigue

Fatigue and tiredness were experienced by all children. When asked about which part of the day they were more tired, some children experienced tiredness in the morning, with parents verbalising the same:

*Mainly in the morning-because that's when I just wake up-I that's when I'm at my most lazy peak*

[(#A20)]

A small number of children, and their parents, verbalised that children were more tired in the afternoon:

*Mostly in the afternoon and when I do all my work and that's when I start to loose energy*

[(#C2)]

*Normally after like 1 pm–2 pm she will say: I need to close my eyes-middle of the day seems to hit her quiet hard*

[(#P14)]

Other children were tired at different times of the day; morning and late afternoon said a couple of children, afternoon and night said some parents, and only night said a small number of the children:

*Probably more at night, I feel like I have gone through the whole day & depending on what I did I'm tired more at night*

[(#A6)]

Whole day on and off said a few of the participants.

A small group of parents observed that their child was a little bit brighter at the beginning of the week when they started the radiotherapy sessions on Mondays, when compared to the end of the week (Friday). Children did not have radiotherapy on the weekend.

*I think definitely he is a little bit more bright at the beginning of the week and the end of the week there's more fatigue*

[(#P17)]

## Theme 2: Response to fatigue

### Rest and sleep

When children were tired, most of them rested lying on the couch or on their bed, out of which only a few watched movies or played on their gadgets (e.g. tablet). Some shut their eyes and laid down which made them feel better. Some parents expressed that their children took short naps or had a lazy break.

*Just like to lay down shut my eyes for a few minutes then get back up and then I feel better*

[(#C7)]

Many of the children verbalised that they preferred to sleep when they experienced fatigue and few of the parents acknowledged the same. A small number of the children preferred to both sleep and rest when they experience fatigue.

*Just wants to curl up in the couch not to be annoyed*

[(#P3)]

### Activity

Several of the children opted to reduce the physical activity and watch television, movies or just lie down and day-dream:

*I don't really feel like jumping, I just like sitting down, I sort of just listen to conversations and I would just sit down and just daydream sometimes*

[(#C7)]

*Just sit on the couch, watch TV & do something that doesn't involve doing actual things*

[(#A3)]

*Most of the time I just listen to a video or watch one. Lie on a couch-doing whatever is closer for me to do – like if I had a Slime great then I would do that and I would play with that for a little bit, if I had my iPad out play on that you know, basically whatever was available and I liked*

[(#C22)]

Only one participant was actively going out shopping, reading and doing school activities and explained how he tried to overcome fatigue

by exercise as his relative had given this information to him prior to commencing radiotherapy. Many parents observed that their child did a lot less walking and activity and preferred to just relax on the couch or bed watching television or playing video games.

A few of the participants expressed how they only watched friends play soccer as they couldn't play. One child verbalised how they went to school and when they felt fatigued would put their head down on the desk and take rest. A small number of the participants enjoyed friends coming over and playing with siblings but one participant expressed the concern:

*People coming and talking keeps me awake -it's like I need to stay awake*

[(#C16)]

A couple of parents however had concerns:

*Friends come to see her depending how she feels*

[(#P9)]

*I tell him to-just tell the visitors or someone and just go to sleep*

[(#P16)]

However, there was one parent who said that his/her child was:

*Happy to sit and play with one of his friends-I see a big change in his demeanour when he has someone there to visit him. He just suddenly is more alert, more awake and more available to have a conversation and then after they leave he is generally gets very tired*

[(#P22)]

### Mood and concentration

Some children verbalised their response to fatigue based on their mood:

*I am very grumpy, I don't really want people talking to, I like to be alone, because I'm bored and anxious*

[(#A6)]

Children would also choose their activities based on their mood:

*I do something that I enjoy-because I usually don't get tired from something that enjoy doing probably wouldn't do things that I don't like to do unless I have to*

[(#C12)]

Some of the parents expressed how their child spoke very few words and became a bit grumpy as a result of experiencing fatigue while on treatment. One parent was even concerned about concentration of her child:

*Mum asked: Have I said anything that wasn't true and he replied 'I didn't listen to what you said*

[(#C11)]

### Eating habit

Eating habits changed for some of the children:

*When I'm tired, I'm just sitting around which means I'm bored, which means I eat out of bored hunger and it makes me hungry*

[(#A6)]

*I also eat a little bit more to try and get my energy levels back*

[(#C2)]

One parent expressed how concerned they were to support their child during dinner time:

*For dinner we really have to help to get out of bed to eat dinner*  
 [(#P3)]

## Discussion

The purpose of this study was to understand, from the child's perspective, how they experience and respond to fatigue while undergoing radiotherapy for cancer. The findings of the current study are consistent with previous reports on cancer-related fatigue in children - all children included in the study experienced fatigue while on cancer treatment (Hinds et al., 2010).

Fatigue is one of the most common, distressing, and persistent symptoms in patients with cancer (Berger et al., 2010; Mooney-Doyle, 2006). Moreover, this subjective sense of tiredness or exhaustion related to cancer or cancer treatments, often not proportional to recent activity, can interfere with usual functions (Berger et al., 2010; Mooney-Doyle, 2006). Our findings are in line with the description of fatigue in mostly adult studies. Children included in this study described fatigue as a state of "feeling tired" mentally and physically that affected many aspects of their lives such as daily activities, mood, feeling, and social interaction.

In this study, children reported experiencing fatigue mostly when they wake up in the morning and later in the afternoon when they were not motivated to do any activity. Some parents interviewed also mentioned that their children were more fatigued at the end of the week and increased feeling fatigued in the later weeks of radiotherapy when compared to the earlier weeks of treatment. Among adults diagnosed with cancer, they commonly reported a peak in fatigue in the days following chemotherapy (Berger et al., 2010; Prue et al., 2006). In adult cancer patients undergoing radiotherapy, fatigue followed a gradually increasing pattern until the end of treatment with a gradual decline after completion (Dhruva et al., 2010; Purcell et al., 2010).

A decrease in exercise and physical activity was reported by most children included in this study. Earlier studies of fatigue in children with cancer reported that children undergoing chemotherapy were found to have poorer health-related quality of life, physical functioning and school functioning when compared to healthy children (Baggot et al., 2010). Crawley et al. (2009) reported that fatigue in children and adolescents with cancer was associated with significant functional disability and this had a considerable impact on emotional, physical and social functioning (Crawley et al., 2009). Our findings are also consistent with a qualitative study on childhood cancer related fatigue (Antill Keener, 2019) where parents reported that their child's energy level prohibited everyday functioning and led to changes in the child's usual activities. One exception was a participant included in this study who was active, exercised everyday while on treatment, and did not experience fatigue. This latter finding is consistent with some studies on the effect of exercise on cancer related fatigue (Tomlinson et al., 2014; Van Dijk-Lokkart et al., 2019) that showed a moderate effect of exercise on the reduction of fatigue, depression and sleep disturbance. An update of the review performed on six studies investigating the effects of a physical exercise training intervention in children with cancer (Braam et al., 2016) provides evidence of modest positive effects of physical exercise training interventions for children with cancer.

Earlier studies of sleep disruption and fatigue among children receiving chemotherapy for acute lymphoblastic leukaemia showed that sleep disturbance was common even after the end of treatment. (Gordijn et al., 2013; Warris et al., 2016; Zupanec et al., 2010). Sleep disturbance possibly contributed to increased fatigue (Zupanec et al., 2010) and children with hypersensitive response to dexamethasone demonstrated more troubled sleep (Warris et al., 2016). In this study, children diagnosed with solid cancer undergoing radiotherapy also had their sleep habits changed, but none reported having problems getting to sleep at night. In fact, most children slept well at night but they also slept or rested often during day time. What is new about our findings is that children slept or rested during the day because they were

not motivated to do anything. This finding is consistent with the results in a study that evaluated the support for the need for symptom assessment in the clinical setting as the patients self-report symptoms of pain, sleep/rest, fatigue area disruptive presence in the lives of children and their families as they interfere with the child's ability to participate in age appropriate activities and negatively influence their quality of life (Linder & Hooke, 2019).

A parent in the current study revealed how her child was happy and his mood changed when he received a visitor. This finding is supported by a study in children and adolescents with cancer that examined the different dimensions of fatigue and health-related quality of life, where participants showed greater problems in the physical emotional and school functioning but less problems in social functioning (Nunes et al., 2017). The current study findings revealed that fatigue altered the children's mood, and as consequence they preferred to be alone and not interact with others. This finding is consistent with a longitudinal study of adult cancer patients where more than half of the patients were reported to have mental stress, worry or mood changes while on treatment (Butt et al., 2008). In a qualitative study (Reed-Berendt et al., 2019) involving young people with cancer, low mood was often triggered or maintained directly by cancer. Patients described varying levels of mood at different stages, and sometimes they struggled to differentiate mood changes from physical symptoms. The study further explained how young people described constant and ongoing low mood, either through the whole cancer experience or during a specific part of the treatment, and it persisted after cancer treatment, both immediately and in the long term.

## Practice implications

Monitoring and addressing fatigue and its consequences during radiotherapy treatment is essential to improve well-being of children with cancer. Pediatric oncology nurses are highly motivated to follow best practice guidelines to improve patient care. Nurses need to identify the presence of physical, social and mental components related to fatigue in their patients to address fatigue. Acknowledgement of the signs and symptoms of fatigue will enable them to support the children and families while undergoing radiotherapy.

## Strengths and limitations

The qualitative design facilitated the research objective to obtain the children's perspectives of fatigue and how they coped with it. This study was conducted in a single setting. Additional research is warranted in different settings and different cancer diagnosis to fully understand the experience and response of fatigue among children undergoing radiotherapy for cancer. The interviews were relatively short in duration and some parents were involved in the interview process. As Patel et al. (2016) states, when employing qualitative methods in the pediatric setting, interview guides, methods and length of the interview require careful tailoring to ensure the child's perspective are captured and to allow children a comfortable way to communicate about their experience, including interview breaks to provide them the opportunity to talk about non-interview topics. Moreover, having parents involved in the interview may be helpful in assessing the child's awareness of their condition and terminology used to reference of symptoms (Arbuckle & Abetz-Webb, 2013). That was particularly important for younger children in the study. Cancer diagnosis and treatment protocols varied greatly, this may have affected the reported levels of fatigue. It was not possible to compare fatigue by diagnosis and treatment protocols due to the small number of participants. Nevertheless, our findings could lead to improve knowledge about fatigue in children with cancer and promote better assessment of fatigue by health professionals. Tailored strategies for fatigue management could lead to improvement in quality of life in children and adolescents with cancer. This is an area of research that hold much potential.

## Conclusions

Pediatric oncology nurses should be encouraged to conduct a comprehensive approach to symptom assessment, including the frequency and severity of fatigue among children undergoing radiotherapy for their cancer. Understanding the effect of fatigue on physical and psychological symptoms while taking care of their patients is paramount. Future research on better ways to improve fatigue management strategies in pediatric oncology are needed.

## Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Credit statement

JT, MNK and NW contributed to the conception and design of the study. JT conducted all interviews and did the initial data analysis, then data and codes were reviewed by PCV and NW. The final data analysis was discussed and consented by all authors. All authors contributed to the interpretation of data, revising the draft critically for important intellectual content, and approved the final version.

## Declaration of Competing Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## Acknowledgments

We thank the children and their parents for their assistance and cooperation in participating the current study.

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