

The lived experience of fatigue in children and adolescents with cancer: a systematic review

D. Tomlinson¹ · S. Zupanec² · H. Jones² · C. O’Sullivan¹ · T. Hesser¹ · L. Sung^{1,2}

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Abstract

Purpose Objectives of this systematic review were to summarize how fatigue has been described from the perspective of children and adolescents with cancer, the impact of fatigue on quality of life, and child reported contributing factors and potential alleviators of fatigue.

Methods We conducted electronic searches of Ovid Medline, EMBASE, PsycInfo, Science Citation, Social Science Citation (Web of Science), and CINAHL. We included studies of children and adolescents with cancer in which the experience of fatigue was described by the child/adolescent. The search was restricted to publications in English. Themes were summarized.

Results Eleven studies were represented in 18 publications. Ages of included children ranged from 6 to 19 years. Majority of studies used semi-structured interviews to elicit participant’s perceptions of fatigue. Terms used to describe fatigue included the following: tiredness, weary, loss of strength, dizziness, feeling drained, feeling drowsy, lacking motivation, exhaustion, and feeling emotional. Impact of fatigue related to not being able to participate in regular activities; needing to sleep or rest more; and impact on psychosocial

health. Perceived alleviators of fatigue included exercise, distraction, rest, eating, and drinking.

Conclusions Fatigue is impactful from the perspective of children and adolescents. Future research should focus on prospective exploration of the impact of fatigue on pediatric cancer patients and identifying approaches to reduce fatigue.

Keywords Child perspective · Fatigue · Lived-experience · Tiredness · Cancer

Introduction

Fatigue has been increasingly recognized as an important symptom in children and adolescents with cancer [1–3]. It affects children and adolescents with cancer at all stages of the disease trajectory from diagnosis to survivorship and the end-of-life period [4–15]. Fatigue has physical, mental, and emotional components and may be characterized by a lack of energy, decreased physical ability, and feelings of tiredness. [16–18] Fatigue is a subjective, multidimensional construct [3] that may occur acutely, episodically, or chronically [3, 17, 19] with multifactorial etiology [3, 20].

The literature of fatigue in children and adolescents with cancer has led to the development of a conceptual framework in an attempt to better understand this complex phenomenon [3, 17, 20–24]. Research into the measurement of incidence and severity of fatigue in children and adolescents with cancer is increasing with some early evaluation of interventions to reduce fatigue [25–28]. However, despite these efforts, there remains a lack of understanding as to how children and adolescents with cancer describe fatigue and the impact of fatigue from the child’s perspective. Their perspective is important as the meaning of fatigue is likely to differ between child self-report and proxy report from healthcare professionals and

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✉ D. Tomlinson
lillian.sung@sickkids.ca

¹ Child Health Evaluative Sciences, The Hospital for Sick Children, Toronto, ON, Canada

² Division of Haematology/Oncology, The Hospital for Sick Children, Toronto, ON M5G 1X8, Canada

parents [16, 29]. Further, little is known about children and adolescent perceptions of the factors that contribute to or alleviate fatigue. This knowledge is important as it may help to prioritize screening and treatment of fatigue and may inform future research related to approaches to prevent and treat fatigue in this population.

Several meta-analyses have been performed that investigate quantifiable fatigue in children with cancer [28, 30, 31]. However, the qualitative “lived-experience” of fatigue is under reported. With continued importance associated with fatigue in children with cancer, but limited progress in understanding its affects, we aimed to report on the child’s experience of fatigue, to report on the actual experience of how fatigue feels for these children. Therefore, the objectives of this systematic review were to summarize how fatigue has been described from the perspective of children and adolescents with cancer, the impact of fatigue on quality of life, and child/adolescent reported contributing factors and potential alleviators of fatigue.

Methods

Our systematic review was conducted following the PRISMA guidelines [32].

Search strategy

We performed electronic searches of the following databases: Ovid Medline (1946 to 20 July 2015), EMBASE (1947 to 20 July 2015), PsycInfo (1867 to 24 July 2015), Science Citation (Web of Science) 1900–2015, Social Science Citation (Web of Science) 1956–2015, and CINAHL (1990 to 20 July 2015). The search strategy used a combination of medical subject headings and text words to identify studies of fatigue in children with cancer. Electronic supplementary material 1 illustrates the complete search strategy. There was no restriction by trial type, but the search was restricted to publications in English.

Strategy for selection of publications for review

We defined inclusion and exclusion criteria a priori. We included studies in which children and/or adolescents with cancer self-reported on the qualitative experience of fatigue. A study did not have to have a main focus, or primary outcome, of fatigue measurement. Cancer symptom studies, including quantitative studies, were screened for the inclusion of any descriptors of fatigue, even if this was not a primary aim of the published study. Quantitative studies and mixed method studies were included in the review in order to screen for descriptors and reported quotes of fatigue. Quantitative studies may include quotes or comments from participants regarding

their fatigue, that we did not want miss, given the paucity of literature on this subject. Exclusion criteria were as follows: (1) Symptom of fatigue not discussed qualitatively; (2) only quantitative data reported; (3) participants over 19 years of age; (4) child’s fatigue only reported from parent/care giver or health care professional perspective; and (5) Publication not in English. We chose to exclude those studies not published in English due to the difficulty of translation, particularly when we wanted to report on descriptors and subjective opinions that may not be accurate when translated literally.

Two authors (DT, COS) independently reviewed the titles and abstracts of the studies identified by the search strategy. All potentially eligible studies were retrieved in full. The same authors independently reviewed the full text articles for eligibility. Consensus was reached on all studies included, with an inter-rater reliability of kappa = 1.00.

Data abstraction

Data were abstracted from included publications by two reviewers (DT, COS) using standardized data extraction forms. Data abstraction was performed by two reviewers independently. First author, year of publication, purpose of study, study design, and child age were abstracted. Information reported directly from the child related to fatigue descriptors, impact of fatigue on quality of life, perceived contributors, and potential alleviators were also extracted. Quotations were included where relevant.

Analysis

Data analysis involved coding of fatigue descriptors into themes that related to broader, overarching concepts using thematic analysis [33]. A theme was captured from children’s descriptors, if the data or quotes contained something important in relation to the lived experience of fatigue. Ideally, the theme may be apparent in several instances across the data, but this is not necessary to make a crucial point [33]. The two authors followed the phases of thematic analysis according to Braun and Clarke (2006), namely: (1) familiarization with the data (reading and re-reading), (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, (6) producing the results [33].

We aimed to provide a rich description of the entire data set, due to the subject of the lived-experience of fatigue being under-researched. To this end, we chose to use an inductive thematic approach, as there was no pre-existing code, or preconception. Our analytic process then involved a semantic level, that progressed from description, with data organized to show patterns in semantic content, and then summarized to interpretation, where we attempted to theorize their significance and implications [33].

Results

Figure 1 illustrates the flow diagram of trial identification and selection. [32] Of the 3,191 unique references identified by the search strategy, 86 were retrieved in full and assessed for eligibility. Of the retrieved full text publications, 68 were excluded, leaving a total of 18 publications which were included in this systematic review [10, 16, 17, 24, 34–46].

Table 1 illustrates the characteristics of the included publications. Eighteen publications resulted from 11 studies that have been reported over the last 15 years. There were 4 studies which reported results from the same cohort in multiple publications. In order to not overweight the same study, we chose to include each cohort only once in our review. All children and adolescents in the included studies were on active treatment during participation. The majority of the 11 studies ($n = 7$) used semi-structured interviews to elicit the perspective of fatigue from children and/or adolescents with cancer [10, 34, 35, 37, 43–45]. These interviews varied in length from 5 to 10 min to 1 h. One of these 7 studies supplemented the interviews with diaries. [44] One study solely used focus groups, [46] and one used diaries only [36]. One study used focus groups with the adolescent subsample participating in semi-structured interviews [18] and one study used questionnaire interview sheets [40].

Three studies focused only on adolescents greater than 12 years of age while 8 studies included children and

adolescents less than 12 years [35, 36, 44]. Only one study that included children and adolescents reported results from the children and adolescent groups separately. [16–18, 24, 41] The youngest child was 6 years of age and only nine 7 year olds were included across the studies. Six studies focused solely on fatigue [18, 34, 36, 40, 44, 46] while 5 studies reported on the spectrum of symptoms [10, 35, 37, 43, 45] with some containing minimal information about fatigue.

Table 1 summarizes descriptors of fatigue from the perspective of children and adolescents with cancer. The majority of direct quotes reported in all studies were cited by adolescents. However, differences between the small number of children's descriptors and those of adolescents were negligible. Where identified, the verbiage used by adolescents was more mature, but the themes were very similar as those for children. The terms used to describe fatigue included the following: tiredness, weary, loss of strength, dizziness, feeling drained, feeling drowsy, lacking motivation, exhaustion, and feeling emotional. During our review, we were aware that many of the quotes reported were concerned with the effect that tiredness or fatigue had on the children's or adolescents' lives, which we considered as impactful on the child's or adolescent's quality of life. Therefore, we illustrated this impact of fatigue on quality of life from the child or adolescent perspective in Table 1. Thematic analysis, of the direct quotes, resulted in the identification of themes related to: can't do the things they

Fig. 1 Flow diagram of publication identification and selection

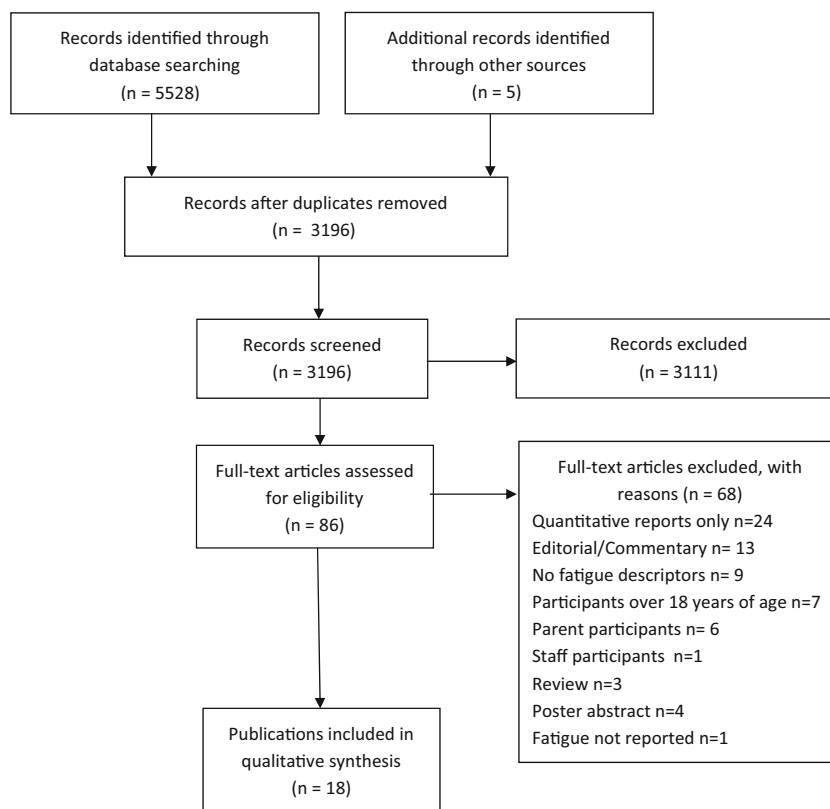


Table 1 Fatigue descriptors and impact on quality of life for children and adolescents with cancer

Author	Year	Purpose of study	Sample size	Mean age in years \pm SD or range	Methods to collect child perspective	Descriptors of fatigue	Impact of fatigue on quality of life
Hockenberry-Eaton [18] ^a	1998	Descriptions of fatigue	14	7–12	Focus groups	Emotional tiredness/feeling emotional: “sad or mad” “Sad, sad and hurt” “I can see tired in my eyes”	“When I am tired I can watch a movie, I can't read too well anymore because I can't keep my eyes open.” “I can't run fast or anything.” “It feels bad when you don't get to go home, it feels bad because when you don't get to go home you don't get to see your family and friends.” “If you're really tired you can't ride your bike” “I had to quit playing baseball, my counts were too low” “For me it's really hard to run and my legs feel like they're 100 pounds” “In the afternoon, I'll take a nap and before I was diagnosed with cancer I never did that.” “When I am in the hospital, I am just so drained when I get home” “...and you see this nice beautiful day and you're sitting there feeling ugly” “I get tired of being tired” “Sometimes all I can do is lay down. Can't even make it up the stairs.” “wasn't much I could do.”
Docherty [35]	2000	Patterns of symptom distress during initial treatment period	3	12–16	Semi-structured interviews	Emotional tiredness/feeling emotional: “it makes you so mad”	“Feeling tired all the time; get dizzy; mind was always tired; body feels like it's trying to sleep all the time; so emotional.”
Hedström ^b [8]	2003	Distressing events for children and adolescents	59	8–19	Semi-structured interviews	Reported that statements made about exhaustion related to disease. “I have no energy, I am so tired. I get blue. Blue and boring. Everything feels dull”	None specific to fatigue
Ream [44]	2006	Experience of fatigue in adolescents	22	14–20	Diaries and semi-structured interviews	Feeling “wiped out...and so tired” “exhausted, but it's like you haven't done anything...” “...I felt weak and that sort of thing” “I get tired all the time...”	“I had to lean on my mum and stuff, and my dad, and they would have to take me, walk me, to the bathroom 'cause I couldn't walk by myself” “If I walk from one side of the school to the other, when I get to the classroom I've got to sit down. It's like phew, I've made it” “By the end of the week it's really hard to get through the day” “I get tired quite a lot during the day” “I had some friends come over... I just didn't feel like talking or anything. I just felt too tired to like even notice that they were there. ““I was so tired. I would come home and just conk out and fall asleep and be missing dinner.” “My friends were all jumping around and having fun and I would just be sulking around. It was like I wasn't really there.”
Woodgate [45]	2008	Symptom experience	13	9–17	Semi-structured interviews	“Like, tired would be like, tired to do anything, even though you have the strength to do it, but you just don't want to.”	

Table 1 (continued)

Author	Year	Purpose of study	Sample size	Mean age in years \pm SD or range	Methods to collect child perspective	Descriptors of fatigue	Impact of fatigue on quality of life
Chiang [34]	2009	Experience of fatigue in Taiwanese children	17	12.1 \pm 3.3	Semi-structured interviews	Tired; weary; loss of strength; sleepiness; lack of motivation; feeling sluggish; difficulty thinking heavy eyelids; dizziness; exhaustion Felt "really drained"	Lying on bed, unable to play; unable to run and jump; refusal to interact with others; abnormal daily routines; unable to keep up in school; lack of patience. Fatigue causes a negative effect on mood: "Rotten; upset; irritable; annoyed; unhappy; "All I could do was lie down and sleep" "Slept all day... wasn't awake for my little brother's birthday." "I barely left my bedroom." Guilt when cancelling plans with friends due to fatigue. Less activity; less social interaction; negative mood. "I didn't even want to talk on the phone" "I wasn't able to go fishing with my friends." "I felt annoyed." "Cannot walk upstairs as before... mum or dad have to carry me upstairs... I have no strength of my own." "I had a big problem with my temper, then, I was in a very bad mood." "My memory got worse and worse." "I even found difficulty in getting out of bed"
Erickson [36] ^a	2010	Patterns of fatigue in adolescents	20	16.1 \pm 2.1	Qualitative diaries		
Wu [46]	2010	Cancer-related fatigue in Chinese children	14	7–18	Focus groups	"have no spirits"; "iredness" "weakness"; "lack of energy" "have no strength"; "exhaustion"; "awfully/ extremely/ fatally tired"	
Li [10]	2010	Impact of cancer	98	7–15	Semi-structured interviews	"I felt powerless after chemotherapy"	
Macartney [43] ^d	2013–2014	Symptom experience in brain tumor survivors	12	9–18	Semi-structured interviews	Feeling tired associated with low energy or drowsiness. Participants described having less energy or feeling drowsy particularly at the end of the school day	"I was not able to go to school because I had so little energy that I had a teacher come in for school. I only started off with going half days because I would get so tired I am trying to work up, I try to exercise more often and do sports. I'm trying different kinds of sports and outdoor stuff, so my energy is coming, it is better than it was before, a lot better but it (low energy) is still there." "When I am walking, like around a store for a long time, I have to sit down because I get tired."
Hesham [40]	2014	Perspective of cancer-related fatigue	125	6–18	Questionnaire interview sheet	A sense of physical tiredness; persistent tiredness; fatigue with rest.	Not reported

^a Aspects of study published in 5 publications, [16–18, 24, 41]^b Adolescent participants also reported in 2 publications, [8, 39]^c Original study reported in dissertation [38]^d Original study reported in dissertation [42]

like, inability to participate in regular activities, needing to sleep or rest more, and impact on psychosocial health such as sadness, guilt and annoyance (Table 2).

Table 3 illustrates contributing and alleviating factors from the perspective of children and adolescents; these were reported in 4 studies [18, 36, 43, 46]. Contributing

factors included the hospital environment and an assumed side-effect of diagnosis or treatment. Potential alleviating factors as perceived by children and adolescents included rest, exercise, distraction, eating, and drinking. Naps and rest were the most commonly cited factors, followed by increased physical activity.

Table 2 Themes emerging from thematic analysis from included studies ($n = 11$) and corresponding descriptor quotes

Themes	Quoted descriptors
Cannot do the things they like	<p>“When I am tired I can watch a movie, I can’t read too well anymore because I can’t keep my eyes open.”</p> <p>“I can’t run fast or anything.”</p> <p>“If you’re really tired you can’t ride your bike”</p> <p>“I had to quit playing baseball, my counts were too low”</p> <p>“For me it’s really hard to run and my legs feel like they’re 100 pounds”</p> <p>“I had some friends come over...I just didn’t feel like talking or anything. I just felt too tired to like even notice that they were there. “</p> <p>“My friends were all jumping around and having fun and I would just be sulking around. It was like I wasn’t really there.”</p> <p>“I didn’t even want to talk on the phone”</p> <p>“I wasn’t able to go fishing with my friends”</p>
Inability to participate in regular activities	<p>“In the afternoon, I’ll take a nap and before I was diagnosed with cancer I never did that.”</p> <p>“When I am in the hospital, I am just so drained when I get home”</p> <p>“...and you see this nice beautiful day and you’re sitting there feeling ugh”</p> <p>“It feels bad when you don’t get to go home, it feels bad because when you don’t get to go home you don’t get to see your family and friends.”</p> <p>“I had to lean on my mum and stuff, and my dad, and they would have to take me, walk me, to the bathroom ‘cause I couldn’t walk by myself;</p> <p>”If I walk from one side of the school to the other, when I get to the classroom I’ve got to sit down. It’s like phew, I’ve made it”</p> <p>“By the end of the week it’s really hard to get through the day”</p> <p>“I get tired quite a lot during the day”</p> <p>“I was so tired. I would come home and just conk out and fall asleep and be missing dinner.”</p> <p>“I even found difficulty in getting out of bed”</p> <p>“I was not able to go to school because I had so little energy that I had a teacher come in for school. I only started off with going half days because I would get so tired</p> <p>I am trying to work up, I try to exercise more often and do sports. I’m trying different kinds of sports and outdoor stuff, so my energy is coming, it is better than it was before, a lot better but it (low energy) is still there.”</p>
Needing to sleep or rest more	<p>“When I am walking, like around a store for a long time, I have to sit down because I get tired.”</p> <p>”Drowsy“</p> <p>“Feeling tired all the time; get dizzy; mind was always tired; body feels like it’s trying to sleep all the time”</p> <p>“I get tired of being tired”</p> <p>”Sometimes all I can do is lay down. Can’t even make it up the stairs.”</p> <p>“wasn’t much I could do.”</p> <p>“wiped out...and so tired”</p> <p>“exhausted, but it’s like you haven’t done anything...”</p> <p>“...I felt weak and that sort of thing”</p> <p>“I get tired all the time...”</p> <p>“really drained”</p> <p>“All I could do was lie down and sleep”</p> <p>“Slept all day...wasn’t awake for my little brother’s birthday.”</p> <p>“I barely left my bedroom.”</p> <p>“tiredness” “weakness” “lack of energy”</p> <p>“have no strength”; “exhaustion”; “awfully/extremely/fatally tired”</p>
Impact on psychosocial health such as sadness, guilt and annoyance	<p>“sad or mad”</p> <p>“Sad, sad and hurt.”</p> <p>“I can see tired in my eyes”</p> <p>“it makes you so mad”</p> <p>”So emotional”</p> <p>“I get blue. Blue and boring. Everything feels dull”</p> <p>“Rotten; upset; irritable; annoyed; unhappy”</p> <p>”I had a big problem with my temper, then, I was in a very bad mood.”</p> <p>“My memory got worse and worse.”</p> <p>“I felt powerless after chemotherapy”</p>

Table 3 Contributing and alleviating factors of fatigue in children and adolescents with cancer

Study	Contributing factors	Alleviating factors
Hockenberry-Eaton et al. (1998) [18]	Treatment; being active; pain; sleep pattern changes; low counts; hospital environment	<p><i>“I usually take two naps every day and that makes me feel better”</i></p> <p><i>“Having someone come visit you”</i></p> <p><i>“Reading a book”</i></p> <p><i>“Listening to music”</i></p> <p>A good night’s sleep.</p> <p>Being involved in physical therapy.</p> <p>Symptom relief.</p> <p>Leaving the hospital setting.</p>
Erickson et al. (2010) [36]	Nausea; pain; sleep disturbances; hospital environment; resuming usual activities or lifestyle; treatment-related symptoms e.g. anemia, increased intravenous fluids	<p><i>“After I had some lunch, I felt better.”</i>, <i>“One thing that boosted my energy was eating and drinking.”</i></p> <p><i>“I took a nap this afternoon and felt a little better afterwards.”</i>, <i>“I guess I needed a power nap.”</i> <i>“A nap helped a little.”</i></p> <p><i>“The transfusion made me feel slightly better.”</i></p> <p><i>“I went swimming and that woke me up big time.”</i></p> <p><i>“After basketball, my energy level went up.”</i></p> <p><i>“Feeling happy gave me more energy.”</i></p> <p><i>“My friend came over and that made me feel better.”</i> <i>“Talking to my friends made me feel better.”</i> <i>“My friends made me feel better and gave me more energy.”</i></p>
Wu et al. (2010) [46]	Diagnosis of cancer; noise in hospital environment	<p><i>“Taking a good sleep.”</i></p> <p><i>“Having a rest.”</i></p> <p><i>“Avoiding being interrupted by others.”</i></p> <p><i>“Exercise.”</i></p> <p><i>“Chatting with others.”</i></p>
Macartney (2014) [43]	Diagnosis of cancer	<i>“I just take breaks.”</i>

Interestingly, in the study by Wu et al. (2010) two quotes were reported by adolescents that alluded to an acceptance of fatigue as a symptom:

“Tiredness is normal....for sick patients, it is normal.”

“Generally I did not report tiredness....I would like to take this on myself. I think I can handle it” [46]

Discussion

In this systematic review, we identified 11 studies that included descriptions of fatigue from the child perspective. All 11 studies have been published in peer-reviewed journals; however, evaluation of the qualitative design in each of the included studies was not reported to have followed a standard guideline such as COREQ. [47] Despite this, the content in each of the studies was of high standard across the 3 domains of criteria for reporting qualitative studies, namely:

(1) research team and reflexivity, (2) study design, and (3) analysis and findings.

We found that very little is known about self-reported fatigue in children younger than 7 years of age. However, the limited data suggest that fatigue has an important impact on child/adolescents’ quality of life and that children and adolescents are able to report factors that contribute to fatigue and potentially reduce it.

Fatigue has been reported as one of the most prevalent symptoms experienced by children and adolescents with cancer [41, 48]. Nonetheless, others have suggested that fatigue in children and adolescents is under-recognized and under-reported [34]. Reasons for this discrepancy may include a poor understanding of how fatigue is experienced and the impact of fatigue in pediatric cancer. Children and adolescents themselves may not report fatigue as they may assume that it is an inevitable consequence of cancer treatments, and it is a symptom that must be endured with few treatment options [46]. Similarly, it is possible that parents and healthcare providers also believe that fatigue is an expected toxicity and do not emphasize approaches to reduce it.

We found that from a qualitative perspective, fatigue does appear to impact on child quality of life, particularly with respect to the ability to participate in regular activities. However, we were unable to quantify the magnitude of this impact for children or adolescents.

We also found that young children could verbalize factors that contribute to fatigue as well as factors that potentially may alleviate it. This information is important for two reasons. First, this type of data may provide new hypotheses about interventions which could be effective and could be formally studied. Second, it highlights the need for clinical practice guidelines focused on parents and children about approaches to prevent and treat fatigue.

With only nine 7-year olds being included in these studies, there is limited information about self-report fatigue in younger children. Although eliciting self-report symptoms in young children is challenging, self-reported pain scales and focus groups have been used with children as young as 4 years of age [49, 50]. However, proxy report by parent or health care provider is still the best measures we have for the very young child (less than 4 years of age). This age group presents a great challenge in characterizing the fatigue experience, while being at an important age to intervene with fatigue alleviators, given the complicated and rapid course of developmental skills, and early learning foundations during this time. Future research should focus on better understanding of fatigue in children and adolescents and, in particular, in younger children.

The strengths of our report are the systematic nature of the identification of studies and that a review of the child's perception of cancer-related fatigue has not previously been published. However, a limitation of this study is the restriction to English language publications. It is possible that additional descriptions of fatigue are present in other languages, and it is also possible that the experience of fatigue differs by culture.

Conclusion

There is a lack of descriptive data regarding fatigue in young children. More importantly, we know little about the impact of fatigue from the perspective of children. This information is important because severe symptoms, if not bothersome and without morbidity, merit less attention. Consequently, less severe symptoms that are highly bothersome require prioritization. Future research should focus on more detailed prospective exploration of the child's lived experience of fatigue, including description from children younger than 7 years of age. Focus on knowledge of interventions to prevent or treat fatigue could also be examined. A greater understanding of fatigue experienced by children with cancer will assist in improving care and subsequent improvement in health-related quality of life.

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Compliance with ethical standards

Conflict of interest The authors declared that they have no conflicts of interest.

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