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Fatigue in adolescents with and following a cancer diagnosis: developing an evidence base for practice

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Abstract

Although fatigue has been a focus for research in adult cancer care for some time, the same cannot be said for adolescent oncology practice. This paper summarises the literature concerning fatigue in adolescents with, and following, cancer diagnoses, drawing on data from four empirical studies. Fatigue is multidimensional, multifactorial and highly subjective, but can be managed to enhance self-caring and coping strategies. All of the studies reviewed within indicate that fatigue is a troublesome symptom, which impacts on quality of life. From this review, we set up a research study. This paper provides a brief report of preliminary data from this study drawn from a group of adolescents in late remission from childhood cancer. These data are used to evaluate the utility of focus groups as a method of data collection in exploring the concept of fatigue in adolescents. Concurring with the studies we reviewed, findings from the preliminary data suggest that fatigue is a highly subjective and 'abnormal' phenomenon that holds a variety of implied meanings and associated metaphors connected with past experiences of childhood cancer. The focus group proved to be a viable research method to facilitate mutual disclosure and provoke discussion. Recognition of the research challenges with adolescents, where there is the potential for a range of meanings for the experience of fatigue, is an important finding for future studies.

Keywords: Fatigue; Cancer; Adolescents; Focus group; Case study

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1. Introduction

Clinicians and researchers cannot underestimate the impact of fatigue. It has been recognised to be a significant part of the patient's experience of cancer. Patients rank fatigue as the most prevalent, burdensome symptom and believe that it is an inevitable consequence of having treatment for cancer. Hence, they do not report their experiences to healthcare professionals and, as a result, they suffer in silence [1,2].

Research with adults suggests that fatigue features at various time points in the disease trajectory: as a consequence of cancer treatments, in patients who are in 'remission' [3] and in patients with advanced cancer who have palliative care needs [4–6]. Important similarities and differences between the experiences of adults who have cancer and the experiences of children or adolescents cannot be assumed at this time. Little is known about the occurrence, causes, conceptual and operational definitions of fatigue in children and adolescents. In addition, it can be difficult to discern the specific experiences of adolescents as they are often not viewed as a distinct cohort, and have tended to be included or excluded in research involving children or adults [7]. This has meant that current knowledge with regard to

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fatigue in adolescents is based on clinical experiences rather than on empirical evidence. Mark, an adolescent with Hodgkin's disease, illustrates what practitioners perceive to be some of the problems:

Mark is 16 years old and is presently receiving chemotherapy. Before he became ill, he reports that he was very active playing tennis for the school team. He was taking nine GCSE educational examinations and he was planning to undertake further studies: but he has had to put this on hold. Just before his diagnosis, he had become more and more listless. This was the main reason for him visiting his General Practitioner. Following the start of chemotherapy, he reports overwhelming tiredness, which is getting worse with each cycle of chemotherapy, to the point he cannot concentrate on playing his beloved computer games. He describes his body as heavy and his mind as a blur. His parents state that he has become distant and does not wish to socialise with his friends. They feel this is because of his hair loss and the fact he cannot do the things with them that he wants. He has not told anybody at school that he has cancer.

In this paper, we report on evidence from four empirical studies and then describe a study that is underway in the United Kingdom (UK) that seeks to focus specifically on adolescents' experience of fatigue, during and following treatment. Preliminary data from this study are included as evidence of early findings that compliment and extend studies previously conducted in the field.

2. Review strategy

A literature search was carried out using Medline, Pubmed, Culminative Index Nursing and Allied health literature (CINAHL) and PsycINFO for the period of 1966–July 2003. The search strategy was divided into the components of population—adolescents (aged 13–19 years), setting—cancer and/or neoplasm, study factor—fatigue. Using the key words, FATIGUE, and ADOLESCENT and CANCER or NEOPLASMS resulted in 56 articles being identified. From these 56 articles, five were selected based upon four studies. Forty-nine articles were excluded due to the following four factors:

1. No reference to adolescents, based solely upon either adults or children (aged below 12 years).
2. Not a cancer population
3. No reference to fatigue as a symptom
4. They were editorials or case reviews.

The papers retrieved were empirical studies adopting qualitative methods, with one paper employing measurement scales. An evidence table detailing the papers reviewed is set out in Table 1.

Discussion of this review is divided into three sections. As there were so few papers to review, we begin by providing a brief description of the studies. Using the main themes revealed in the studies, we examine the nature of fatigue. The final section of our paper examines the coping strategies developed by adolescents to help manage this symptom.

3. Description of studies

All four studies have been carried out within the last 5 years. They emanate from programmes of research in The United States of America, Canada and The Netherlands. Similarities between the research questions can be found. They share the overall aim of defining and /or describing fatigue in a given population under study. Two studies had an additional aim of documenting perspectives of parents and/or healthcare professionals [8,9]. Three adopted a qualitative research methodology together with one-to-one interviews and focus groups [9–11]. The fourth [12] used a triangulated methodology that encompassed both qualitative and quantitative strategies in the form of a questionnaire that incorporated a structured assessment tool: the Multidimensional Fatigue Inventory (MFI 20) [13]. The scale consists of a five-point rating scale: general fatigue, physical fatigue, mental fatigue, reduced activity and reduced motivation. It has not been validated within an adult cancer population nor in an adolescent population.

Two studies focused their investigation on fatigue occurring during treatment [9,10] and two concentrated on symptoms experienced during the long-term follow-up [11,12]. No study was found that had been carried out specifically with an adolescent population. However, all four studies had included adolescents in their sample, alongside either children or young adults. Two studies selected participants aged between 5 and 20 years [9,10]. Two studies included a sample of young adults with an age range of 16–49 years (mean age at diagnosis of 8 years) [11,12]. It was not clear from the demographic data presented, the number of participants who fell between the ages of 16–19 years. This is problematic, as the uniqueness of patients' needs will not be highlighted and hence service delivery and treatment could be ineffective where participants in a study have a wide age range [14].

4. Findings

4.1. Fatigue is highly subjective

Although common terms and themes were found within the findings of the four studies, they also

Table 1
Evidence table for the 4 papers selected

Author [Ref.]	Research aim(s)	Study sample	Method	Key findings
Study 1 Hockenberry-Eaton and colleagues, 1998 [10] Hinds and colleagues 1999 [8]	1. To define and describe fatigue experienced by children and adolescents receiving cancer treatment 2. To document HCPs perspectives of fatigue in children and adolescents 3. To compare paediatric oncology patients, parents and HCPs' descriptions of fatigue 4. To identify contributing factors and methods to alleviate fatigue	$n=14$ children aged 7–12 years $n=15$ adolescents aged 13–16 years $n=38$ HCP's (31 nurses, 2 nurse managers, 3 nutritionists, 1 chaplain, 1 doctor) $n=31$ parents (28 mothers, 3 fathers)	Focus groups	Fatigue was described as a total loss of energy, influenced by environmental, biochemical, personal and treatment factors. A state = acute, episodic or chronic. Descriptors of fatigue varied according to the stage of child/adolescent developmental maturity. Similarity between parent and HCPs' descriptors found.
Study 2 Davies and colleagues, 2002 [9]	Describe fatigue in children with cancer	$n=13$ children/adolescents aged between 5–15 years $n=12$ parents	One-to-one interviews	Fatigue was described by the impact it had upon energy levels Fatigue was viewed as multifactorial—physical, mental and emotional. Three types of fatigue described—typical fatigue, treatment-related fatigue and shutdown fatigue.
Study 3 Langeveld and colleagues, 2000 [11]	To explore the concept of fatigue in long-term survivors of childhood cancer	$n=35$ survivors aged 18–38 years. Age range at diagnosis of childhood cancer 1–19 years Time since treatment (range 8–25 years)	One-to-one interviews	Half of the group reported experiencing fatigue most of the time. Fatigue present despite 9 h sleep each night Significant impact upon quality of life; employment and relationship with spouse. Described as exerting oneself to the utmost, both physically and mentally.
Study 4 Langeveld and colleagues, 2003 [12]	Assess the level of fatigue in young adult cancer survivors of childhood cancer	$n=416$ young adult childhood cancer survivors, age range 16–49 years Completed treatment range of 5–33 years ago Comparison group, $n=1026$ young adults age range 16–53 years	Questionnaire Multidimensional fatigue inventory (MFI-20)	No difference overall in the levels of fatigue reported between survivor and comparison groups. Survivor group reported a higher level of mental fatigue compared with physical fatigue. A relationship between fatigue and depression proposed.

HCP, Healthcare professional.

illustrated a degree of diversity in the manner in which participants expressed their experiences. This is similar to findings from adult studies, where various definitions relating to the subjective perspective of fatigue have been proposed [15–19]. A variety of pseudonyms for fatigue have been proposed. In the 4 studies reviewed, the researchers tended to use the terms, 'fatigue' or 'a lack of energy'. In contrast, participants used a large repertoire of phrases such as 'exhausted', 'wrung out', 'wearing away your body', 'apathetic', 'tired', 'absent-mindedness', 'lazy', 'sleepy', 'mentally tired' and 'overwhelmingly tired'. These words represent a broad view of the varying degrees of intensity and the impact it has on functional ability. Such descriptors highlight fatigue as idiosyncratic and highly personal. It is notable that 'fatigue' was not a term used by young people. This raised two issues for our study to consider:

1. The problem of semantics. Unless professionals are able to interpret the many meanings and metaphors communicated and expressed by the young person, research findings will be inconsistent and interventions potentially ineffective.
2. The features that characterise adolescence are the building of self-esteem, establishing autonomy, and forming self-image: known to be seriously interrupted by the impact of cancer [20,21]. The way a young person will make sense of their experience will be situated within the stage of development. Unless researchers consider the stage of development, research findings will be jeopardised and will be inappropriate when applied to clinical practice.

Both issues imply that any study attempting to explore the symptom of distress would first need to explore the beliefs, values and practices of the adolescent with cancer who is fatigued.

4.2. Fatigue in young people is multidimensional

Similar to theories developed from studies in adult cancer populations [15,22–25], fatigue in adolescents can be described as a multidimensional phenomenon. It has been found to vary in its presence and characteristics. It also remains unknown whether fatigue varies according to the stage of disease, differs between a healthy population and a cancer population, and whether it differs across the different ages of adolescence, according to gender or tumour groups.

Findings from the four studies with participants 'on treatment' suggest that fatigue is a dynamic experience with distinct phases. Two studies distinguished between the three phases of the fatigue experience described by young people. The first study categorised the experience as acute, episodic or chronic [8]. Similarly, but using different terminology, the second study described it as, a typical tiredness, treatment-related fatigue and shut-down fatigue [9]. The various quotes given by participants relate to the impact upon energy levels, both physically and mentally, and are judged in terms of the impact upon the individual's ability to perform tasks such as studying, ability to sleep and participate in family and social activities. What is not known is whether fatigue levels fluctuate in intensity or distress, as these types of measurement strategies were not adopted in any of the studies.

The prevalence of fatigue posttreatment was also not examined. One study reports that approximately half of the participants ($n = 17/35$) reported fatigue to be present most of the time [11]. Further points of note were that the group also reported fatigue to be present most or all of the time since their diagnosis and/or treatment and present upon awakening, despite 9 h of sleep every night. These factors had a negative effect on daily and social activities. Similar to findings from the two studies with participants 'on-treatment', the course of fatigue in the 'long-term follow-up' group also appeared to fluctuate. However, some individuals also experienced fatigue on awakening, whilst others said it was worse at the end of the afternoon or evening. The severity and associated distress with the presence of fatigue were not recorded.

Whether fatigue is more or less prevalent in cancer populations compared with the general population is unanswerable at this time. A comparison group was included in one study, which reported no statistical difference between a group of young adults who had cancer ($n = 416$), and those who did not have cancer ($n = 1026$) [12]. A theoretical reason for this finding was proposed, whereby a response shift may have occurred. Over time, participants learn to live with their level of fatigue to a point where they do not recognise it as important. Another reason may also relate to the stage of psychosocial functioning of adolescents and young adults at the time of interview. It is well known that young people seek normality as a coping strategy during cancer treatment [26] alongside mechanisms such as keeping busy, adopting a philosophical stance and the use of selective forgetfulness [27]. It is not known whether these strategies are adopted in the management of fatigue. As such, fatigue may be a symptom that is hidden from the view of researchers or healthcare professionals unless appropriate assessment strategies are adopted.

4.3. Fatigue in young people is multifactorial

There is much speculation within the scientific world over the mechanisms responsible for fatigue associated with cancer. Exploratory laboratory studies, in both animals and humans, suggest a biological response to cancer and its treatment [28], while clinical studies, in both adults and children, suggest multiple factors [10,17,18,22,24,25,29,30]. The combination of factors proposed are presented in Table 2.

Findings from all four studies gave varied and multiple reasons for fatigue. Those participants who were 'on treatment' gave reasons related to treatment or environmental factors such as noise levels at night affecting sleep patterns, chemotherapy, boredom, pain, low counts, fear, anxiety and a lack of appetite. These were not surprising, as they had been interviewed in a hospital setting, either as inpatients or outpatients, where these factors would have been uppermost in their minds. Had participants been interviewed in their own home, it is not known whether similar factors would have been cited. A lack of reference to the cancer diagnosis as a contributing factor in the cause of fatigue was found within all of the studies reviewed. No reference was given in the two studies focused on childhood cancer survivors to the contributing factors, highlighting the need to investigate this area further.

4.4. *Fatigue can be managed with coping strategies*

Common strategies used by participants on treatment were identified. These measures included both medical interventions, such as blood product support, and self-care strategies, such as controlling the environment so that naps and sleep could be gained, distraction techniques, adequate nutrition and relaxation. The overall benefit of these strategies was not measured in any of the studies. Similarities between these findings and those of adult studies can be seen. Adopting passive self-care behaviours such as sleep enhancement, distraction, relaxation and light exercise are common strategies used by adult patients during treatment [31–33]. The impact of fatigue on functional tasks was not reviewed. Functional tasks such as educational studies, attending school/college, part- or full-time employment are common features of adolescent life that need to be assessed with respect to their impact on fatigue.

Unlike the on-treatment group of adolescents, adopting coping strategies for individuals posttreatment did not appear to be a common behaviour. In one study that asked what helped with fatigue, a third of the participants could not think of any activity that would help. The remainder gave sleep, rest and recreational activities as common strategies adopted [11]. This does suggest that following completion of cancer treatment the participants felt a sense of hopelessness and inevitability in living with the symptom. However, it is not clear the amount of information or support that was given to individuals posttreatment regarding the presence and management of the symptom, as this was not a question asked within the studies. To date, no controlled intervention studies have been found.

5. Summary

Research into fatigue in adolescents is insubstantial at this time. This is evident from the dearth of studies to date and lack of direct focus within studies on adolescents. The results demonstrate that fatigue is a troublesome symptom. They suggest that the concept of fatigue is highly subjective. Fatigue is an abnormal phenomenon that holds a variety of implied meanings and associated metaphors, compounded by a developmental stage that may affect perception, meaning, mechanisms and management strategies. All the studies have broken new ground by developing a theoretical background to understand a phenomenon that is witnessed in practice. From the results we have studied and reflections from our clinical experience we conclude that:

Table 2
A summary of the factors associated with the experience of fatigue in adults and children

Adults	Children aged 7–12 years
• Metabolites • Activity/rest patterns • Energy patterns • Sleep/wake patterns • Disease, cytokines • Treatment (e.g. chemo-, radiotherapy, immunotherapy, surgery, diagnostic tests) • Disease symptoms (e.g. pain, fever, dyspnoea, nausea, vomiting, cachexia, weight loss, haematological, endocrine and biochemical abnormalities) • Intercurrant diseases (e.g. arthritis, asthma, cardiac disease) • Psychological patterns (e.g. depression, anxiety, personality type, stress) • Miscellaneous factors (e.g. time spent travelling to the hospital, amount of support from family and friends, age, lifestyle, environment)	• Treatment (e.g. chemotherapy) • Treatment-related side-effect (e.g. pain, low blood counts, poor appetite, infection) • Being active • Sleep pattern/changes • Hospital environment (e.g. noise from other children and nurses) • Psychological patterns (e.g. boredom, fear, worry) • Miscellaneous (e.g. being pushed too hard by treatment, a lack of a schedule, waiting times for treatment, lack of an adequate time for recovery between treatments)

1. Fatigue is a prominent symptom for adolescents with and possibly following cancer.
2. Fatigue is a complex area for investigation in this group because of the all-encompassing multi-dimensional nature of its characteristics.
3. The experience of fatigue is compounded by the stage of cognitive development, a classic feature of adolescence.

6. The study

Our study is a collaborative project between paediatric nurses and adult cancer nurse researchers and is the first of its kind. The focus of our research was to explore and describe the experience of fatigue from the adolescent's perspective. Six aims guided the research:

1. To explore the perceived well-being and ability to maintain 'normal' activities in adolescent patients (13–19 years) undergoing primary treatment for cancer, adolescents (13–19 years) who have not had treatment for cancer for 1–2 years, adolescents (13–19 years) who have not had treatment for cancer for over 5 years and adolescents (13–19 years) who have not had cancer.
2. To explore the concept of 'fatigue' and whether it exists in adolescents undergoing primary treatment, adolescents in remission and adolescents who have not had cancer.
3. To explore the physical, cognitive, affective and emotional feelings associated with 'fatigue' in adolescents undergoing primary treatment, adolescents in remission and adolescents who have not had cancer and determine any impact of fatigue on their well-being and ability to maintain 'normal' activities.
4. To ascertain mechanisms utilised by adolescents undergoing primary treatment, adolescents in remission and adolescents who have not had cancer, to cope with 'fatigue'.
5. To compare subjective self-assessment of 'fatigue' obtained via the FACT-Fatigue [FACT-F] Scale [34], Health and Fatigue Questionnaire, interviews and Focus Groups.
6. To evaluate the feasibility of a computerised longitudinal data collection method for use in the adolescent population.

Three research methods were employed: one-to-one interviews using a semi-structured interview guide, focus groups using previously validated questions [10] and a structured diary (paper or electronic version).

The literature we reviewed was crucial in developing our study. A number of methodological decisions were made early on in the planning stage to ensure that the research would make a valuable contribution to the evidence already available and, where possible, would replicate and extend elements of previous studies. The methods of data collection were chosen to enable the researchers to explore further the four main themes highlighted earlier. Meaning, perception, causes and characteristics of fatigue were examined. Additionally, the nature of the coping strategies used were explored. The uniqueness of this research is that it focuses on adolescents as a single entity, includes a healthy group for comparison and evaluates the use of a structured diary that may be useful for clinical practice.

At the time of writing this paper, the research is still underway. However, it has been possible to obtain preliminary data reported below as evidence of the usefulness of the approach taken and the richness of the data that is being revealed.

7. Preliminary data

One focus group was set up including adolescents who had finished their treatment more than 5 years ago.

8. Data collection

A focus group is defined as "...a carefully planned discussion, designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment..." [35]. This technique aims to facilitate self-disclosure and animated discussion [36]. The purpose is to encourage adolescents within a group setting to discuss their experiences of fatigue in an environment that is similar to the situation of having a conversation with friends.

9. Sample

Following ethical approval, a sample of participants aged 13–19 years was sought from those attending the long-term follow-up clinic in a regional children's oncology unit. Age-appropriate information was provided to potential recruits through the use of an information sheet and a poster displayed within the waiting area of the out-patient department. 14 teenagers, 5 males and 9 females, between the ages of 13 and 15 years were approached, but all declined participation. 13 teenagers, 9 males and 4 females, were approached between the ages of 16 and 19 years. Out of the 9 males, 5 did not respond and 4 declined. All 4 females agreed to participate.

Table 3
Focus group questions

1. How would you describe fatigue or feeling tired?
2. Are there different types of feeling tired? Like being tired in your body or mind?
4. Please describe the things that you can't do when you feel tired?
5. How long does feeling tired last?
6. Have your school activities changed? If so how?
7. Do you ever have trouble falling asleep at night? Why do you think that happens?
8. Does sleep make you feel less tired?
How tired are you feeling today? Why do you think you are feeling this way?
9. When you are tired, or have low energy, what things help you feel better? [10]

Table 4
Step-by-step process for data analysis of the focus group

Step 1. With the aid of a computer, from the electronic version of the transcript from the interview, each statement that was considered relevant to the concept of fatigue was highlighted.
Step 2. All highlighted statements given by each participant were removed from the transcript and saved into a new document.
Step 3. All non-repetitive, non-overlapping statements highlighted above were listed and saved with quotes linked to each participant who gave them.
Step 4. The non-repetitive, non-overlapping statements were clustered into core themes.
Step 5. From the core themes, a textural structural description of the experience of fatigue for each participant (case studies) was compiled.
Step 6. From each participant's case study, the key statements were compiled into a universal description that represented the group as a whole. [37]

10. Procedure

An introductory statement was read out to the group before beginning the audio-taped discussion using a series of questions and prompts (Table 3). The group session lasted approximately 90 min. At the end of the session, the assistant moderator offered a summary of the discussion. This provided an opportunity for the participants to add any final comments or to clarify any points made, prior to confirming that the summary was complete.

11. Data analysis

A phenomenological method of analysis was used [37]. Two concepts are important within this method when extrapolating data: identifying statements that refer to the 'meaning' of the phenomena (textural descriptions) and identifying statements referring to the physical expression of the phenomena (structural descriptions). In other words, highlighting what is experienced, and the way the 'what' is experienced. The risk of reporter/researcher bias within the analysis was minimised by the use of a technique within phenomenology known as bracketing [38]. During this process, the researcher reflects and acknowledges suppositions regarding the phenomena under study at the start, which are put to one side.

Data were organised and analysed in a step-by-step approach (Table 4). Two researchers undertook validation of data findings independently. Case studies were formulated as they have been found to assist in the identification of potential relationships between findings and provide a basis for generating stable hypotheses for further research [36]. Postal distribution to each participant of their own case study to clarify and confirm acceptance of findings was carried out. Verification by the participants was one of the systematic procedures introduced to improve the data analysis.

12. Results

Four female participants aged between 16 and 19 years, who gave their ethnic status as White British, were recruited into the focus group. Two had received treatment for a diagnosis of leukaemia and two for solid tumours. The length of time from the completion of treatment (period of remission) ranged from 5 to 13 years.

Nine core themes were identified. These were further subdivided into (a) textural themes (1–4), that is the experience of fatigue, and (b) structural themes (5–9), the structures that affect function or are used as coping mechanisms for the fatigue experienced.

12.1. Textural descriptions of fatigue

12.1.1. Theme 1—making sense of fatigue

All four participants found it difficult to articulate their understanding and experience of fatigue, leaving them with a sense of confusion that in turn left them with a need to make sense of their experience. For example, Adele stated: "*it [tiredness] doesn't make sense in a way because I am really active ...I never sit in, but* *when I get home that's it, I am out for the count and before I go [out to socialise], I have to sleep, I don't think that its normal.*"

12.1.2. Theme 2—finding a cause for fatigue

In exploring a meaning for their experiences of fatigue, participants attempted to find a cause for their fatigue, providing an explanation that could be given to others. The origins were multifactorial and were viewed as having both a psychological and social component. Six major sub-themes emerged: a busy social life, work and college, inactivity resulting in boredom and low mood, habit-forming behaviours such as alcohol, smoking and poor diet, personality, having had childhood cancer resulting in hospitalisation, immobility and stress. For example Rebecca stated: "*I think stress plays a part in tiredness. I mean 'A' Levels and that is very stressful ...I smoke which probably doesn't help-...Concentrating in class, I do sometimes feel like I could just fall asleep, but I don't think that's fatigue, I just think that's just from boredom to be honest.*"

12.1.3. Theme 3—the emotional side of fatigue

Linked to the confusion felt at articulating fatigue, three members of the group were left with powerful feelings of anger and frustration that on occasions resulted in them having outbursts of emotion. For example, Lucy stated that: "*I get so emotional, I just want to cry. I think that I should be in bed, I have missed an hour now and I get so upset about it because I know that I need that sleep and I say [Name of boyfriend] give us a call tomorrow, just get out the car, I just want to go home to bed, I just want to go now please and I think I am getting so angry because I need to be, I am just craving to go home just to get into bed I just think, how can I tell you to go away because I need to sleep.*"

12.1.4. Theme 4—type of fatigue

All four members believed fatigue to be due to their behaviour. For example, Rebecca stated: "*Its almost like a lazy tiredness, its like I oh I can't be bothered to do that so I am tired...I think that a lot of it is mental, if I tell myself to do it then I can switch off.*"

12.2. Structural descriptions of fatigue

12.2.1. Theme 5—you controlling fatigue

The fact that fatigue was believed to have psychological origins left the participants with a belief that fatigue could be controlled. For example, Rebecca and then Adele stated: "*I will be inside, I will want to collapse and sleep for a week, but I won't let myself and I will go out.*" "*I have like energy spurts and that's a lot to do with it, I don't know how to use my time so, I will go out and have a crazy hour when I am absolutely buzzing and then dead and I have to sort of recharge and I am like that, like a battery and I go off and I am hyper and then I have to recharge...*"

12.2.2. Theme 6—fatigue controlling you

There were times in day-to-day life when the energy used in controlling the symptom resulted in personal costs and a sense that fatigue could not be conquered. For example, Rebecca felt that: "*If I had a late night, I am probably better off the next day not sleeping ...but then later, I just go out bing that was great, but I am now out for the count.*"

12.2.3. Theme 7—bed as a haven

From the daily focus on fatigue, an overwhelming drive for sleep emerged. Sleeping an adequate time or having what was seen as good quality sleep appeared to leave participants with a sense of satisfaction, sleep was viewed as meaningful, a comfort, providing space and a sense of freedom. Fatigue was seen as positive in that it granted permission to sleep. Quotes from Adele and Lucy illustrate this: "*I could sleep anywhere anytime...I so enjoy sleep ...my favourite place in the world is bed, I get under my covers and this is bliss, I sleep all day on times, I just need to catch up.*"

12.2.4. Theme 8—fatigue as a metaphor for past childhood cancer experiences

One participant reported fatigue as a negative experience. She attributed the sensations of fatigue that was experienced as a reminder of her previous cancer treatment. Associated with this memory was a fear that being tired and having to sleep was a signal that she had spent a significant amount of her life in hospital, being ill which had been traumatic. Chloe stated: "*I was a fighter, I couldn't go to bed...I was scarred, I was agonised...I never once recall sleeping... I do feel tired, but I don't, I think through all the years you know since I was about nine I never once recall sleeping.*"

12.2.5. Theme 9—the management of fatigue

Multiple creative activities were given by all four members to manage their fatigue. These ranged from sports activities to rest and relaxation. Although these mechanisms were viewed as helpful, not all the participants used them.

12.3. Case studies and composite description of fatigue

Case studies were constructed; one of the case studies is given in Table 5. From an analysis of all four case studies, a composite description of fatigue was compiled. This is provided in Table 6.

13. Discussion

Findings from this preliminary data illustrate that fatigue in this population is a complex phenomenon for

Table 5
Case study of an adolescent girl with fatigue from a preliminary study

Fatigue has been a symptom that Lucy had experienced over the years, with varying degrees of intensity. She described a picture whereby fatigue has a changing face. She attributed this to the different phases and activities she had been involved in. Lucy had cancer treatment in infancy. She described the changing nature of fatigue over the years as a result of changes in her lifestyle and enjoyment in work-related activities. The presence of fatigue was constant and could be all encompassing for Lucy, evoking feelings of desperation. As a result, Lucy had reduced her social activities. Sleep for Lucy was seen as luxurious and a comfort. Although the frustration Lucy encountered as part of her experience of fatigue is viewed as a negative trait, this was due to the fact fatigue was overwhelming her and she was not able to sleep. Lucy described her experiences of fatigue as a positive element to her life-style, in that sleep is used as a coping mechanism. Lucy also found methods of relaxation such as aromatherapy beneficial.

Table 6
The composite description of fatigue in adolescent girls from preliminary study

The symptom of fatigue as experienced by teenage girls who were in long-term remission from childhood cancer was highly subjective, with varying degrees of intensity and meanings applied. The range in the nature of the experience was one of an overwhelming, all encompassing, abnormal, negative feelings, to one of being natural, normal and positive. This left individuals with an inner personal struggle to make sense of their experience. For some, the presence of fatigue was a constant associate from which there can be daily concern, evoking feelings of agitation, frustration and anger—a battle—from which sleep is used as the day-to-day companion, tempering levels of fatigue, but never conquering it. This led to a state whereby there was an irresistible drive for either an increase in the amount of sleep or an improvement in the quality of sleep achieved. Overall fatigue was described in terms of the impact it had on psychological well-being and functioning rather than physical well-being and functioning. An uncertainty of its origins is given, but the stress of teenage life is a factor that emerged as a key attribute rather than past consequences of childhood cancer treatment. Fatigue was viewed as the result of having busy social lives, maintaining a balance with employment and academic studies. However, what was felt to be a compounding cause in the experience was the psychological impact of living with the knowledge that you have had a life-threatening illness that you have overcome.

Fatigue was not a symptom that had ever been discussed with the teenagers by HCPs. However, it had been an issue that the teenagers had discussed with friends and family. It was felt that prior knowledge and awareness of the potential to be more tired than they believed acceptable would have been beneficial. Such information would not alter how to live life, or leave a sense of regret at having had cancer treatment, but would have provided permission to sleep more than what was deemed 'normal' for teenagers.

HCP, healthcare professional.

investigation. Recognition of the research challenges that can be encountered when working with a group of adolescents alongside the potential for participants to provide a wide range of subjective meanings is essential for any programme of research or any future qualitative research study involving adolescents. Qualitative research techniques, such as the focus group, proved to be a useful strategy in exploring the experience of fatigue. However, it is difficult to state whether a different method, such as one-to-one interviews or case studies, would have been more acceptable to adolescents. The preliminary data supported the use of this research method in that it showed it could provide insight into teenagers' inner worlds and perspectives on a subtle, yet significant, problem for them.

A potential cyclical relationship is present between fatigue and other factors, such as having busy social lives, study and work pressures. The effect of these factors was the need to use sleep as a coping strategy. A strong link between the perception of the symptom and its physical expression also appeared to be significant with participants believing that they could control the expression of fatigue if the situation required. Furthermore, there appeared to be a cyclical relationship between the perception, thinking and feeling of fatigue, and the physical expression of fatigue. These links could relate to pressures within adolescent life, e.g. academic study balanced against socialising. This may be a specific feature in the expression of the symptom experienced by young people who are entering change in their developmental processes, and is an area for further investigation. The distinct lack of reference to the physical components of fatigue, such as muscle tiredness or fatigue affecting eating habits was also of interest. This early finding appears to be different from individuals receiving cancer treatments where the physical manifestations of fatigue are described as key characteristics within conceptual models [15,39]. In the struggle to make sense of the experience of fatigue alongside having had a life-threatening illness, the participants questioned whether the presence of fatigue was associated with past cancer treatments. This is not to say fatigue was not physical in its nature for the participants; instead, it was not an aspect that was high on the agenda within the group discussion. It also raises an important question for the study as a whole as to whether the fatigue experienced by adolescents with cancer on treatment is a different phenomenon to fatigue experienced by adolescents postcancer treatment?

14. Conclusion

The review and preliminary data illustrate that fatigue in this population is a complex phenomenon for investigation. The importance of exploring the impact of cancer and fatigue experienced by young people cannot be overestimated. Recognition of the research challenges with a group of adolescents, where there is the potential for a wide range of meanings, is essential for future research studies. Research is now in progress that will assist in the development of a theory of fatigue in this age group. Anticipated is a programme of research that will look at the prevalence, characteristics and correlates of fatigue. The findings should further inform evidence-based practice with respect to assessment, self-care strategies and the education of staff.

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