A Phenomenologic Study of Fatigue in Adolescents Receiving Treatment for Cancer

Faith Gibson, MSc (Cancer Nursing), PhD, RSCN, RGN, ONC, Cert Ed RNT, Anne B. Mulhall, BSc, MSc, PhD, Alison Richardson, BN (Hons), MSc, PhD, PGDE, RNT, Jacqueline L. Edwards, BSc (Hons), MSc (Palliative Care), RGN, RSCN, Dip Cancer Nursing, Emma Ream, BSc (Hons), MSc, PhD, RGN, and Beth J. Sepion, B Ed (Hons), MSc (Child Health Nursing), RSCN, RGN, SCM

Key Points . . .

➤ Cancer threatens the life and personhood of adolescents.
➤ Fatigue has been shown to be prevalent in children and adolescents with cancer.
➤ A cyclical relationship exists between fatigue and other factors, such as busy lives, study, and work pressures.

Fatigue

Fatigue has been defined as a “subjective, unpleasant symptom that incorporates total body feelings ranging from tiredness to exhaustion creating an unrelenting overall condition functional aspects of their lives. But this realignment of life occurs alongside their struggle to meet normal developmental milestones. The overall aim of this exploratory study was to describe fatigue as a phenomenon and to identify whether and how it affects well-being and the ability to maintain normal activities in adolescents undergoing cancer treatment.

Background

In the United Kingdom, the annual total incidence of cancer in adolescents aged 13–19 is nearly 150–200 per million (Stiller, 2002). Adolescents have been identified as a distinct and particularly vulnerable group with specific and complex needs (Hollis & Morgan, 2001; Kelly, Mulhall, & Pearce, 2003; Lewis, 1996; Souhami, Whelan, McCarthy, & Kilby, 1996). Developmental theory suggests that adolescence is a crucial stage in the process of building self-esteem, establishing autonomy, forming self-image, and preparing for adulthood (Erikson, 1968). Chronic illness is yet another challenge faced by adolescents. Treatment is known to have physical effects on adolescents (Rechner, 1990), and “being tired” and “unable to get around” causes them significant distress (Hinds, Quargnetin, & Wentz, 1992). Adolescents consider the physical side effects of treatment as the worst aspect of cancer, significantly affecting their quality of life (Enskar, Carlsson, Golsater, & Hamrin, 1997), and “getting on with life” is a primary goal for them (Rechner). Thus, they develop strategies to help manage changes in the social and

Purpose/Objectives: To generate a detailed description of how adolescents with cancer manage their daily lives and the way in which fatigue affects this.

Design: Phenomenologic.

Setting: A pediatric oncology unit at a regional cancer center in the United Kingdom.

Sample: A convenience sample of adolescents (N=8), aged 16–19 years and with hematologic or solid tumors, who currently were undergoing primary treatment.

Methods: Semistructured interviews were conducted using 11 open-ended questions.

Main Research Variables: Adolescents’ perceptions of fatigue, well-being, and ability to maintain normal activities.

Findings: Adolescents reported fatigue as overwhelming and embedded in a syndrome of symptoms and emotions associated with the illness itself and with treatment. Fatigue had a significant effect on physical, psychological, and social well-being, placing an extra burden on adolescents who were striving for normality.

Conclusions: Equipped with a rich description of fatigue, clinicians will be better prepared to initiate strategies congruent with their own work settings and particular patients.

Implications for Nursing: The findings should enable healthcare professionals to construct a more accurate and perceptive picture of the needs of particular individuals, highlighting those that may be amenable to intervention.

Faith Gibson, MSc (Cancer Nursing), PhD, RSCN, RGN, ONC, Cert Ed RNT, is a lecturer in the Children’s Nursing Research Institute of Child Health at Great Ormond Street Hospital for Children in London, United Kingdom; Anne B. Mulhall, BSc, MSc, PhD, is an independent training and research consultant at the Coach House in Ashmanhaugh, Norfolk, United Kingdom; Alison Richardson, BN (Hons), MSc, PhD, PGDE, RNT, is a professor of cancer and palliative nursing care at the Florence Nightingale School of Nursing and Midwifery at King’s College in London; Jacqueline L. Edwards, BSc (Hons), MSc (Palliative Care), RGN, RSCN, Dip Cancer Nursing, is a clinical nurse specialist in pediatric oncology outreach on the Children’s Unit at the John Radcliffe Hospitals in Headington, Oxford, United Kingdom; Emma Ream, BSc (Hons), MSc, PhD, RGN, is a senior lecturer at the Florence Nightingale School of Nursing and Midwifery at King’s College; and Beth J. Sepion, B Ed (Hons), MSc (Child Health Nursing), RSCN, RGN, SCM, is a lecturer in pediatric oncology at the School of Nursing and Midwifery in the University of Southampton, United Kingdom. This study was supported by the Lisa Thaxter Trust. (Submitted March 2004. Accepted for publication September 12, 2004.)

Digital Object Identifier: 10.1188/05.ONF.651-660
that interferes with individuals' ability to function" (Ream & Richardson, 1996, p. 527). In adults, fatigue has been identified as a highly prevalent and distressing symptom of cancer and its treatment (Richardson, 1995; Stone et al., 2003; Stone, Richards, A’Hern, & Hardy, 2000; Winningham et al., 1994). In addition to the fatigue experienced during treatment, support is mounting that patients who are in remission (Servaes, Verhagen, & Bleijenberg, 2002) or who have advanced cancer and palliative care needs also experience fatigue (Krishnasamy, 1997; Ream & Richardson). An evidence base is accumulating for practice in adult cancer care concerning the prevalence (according to tumor site, stage of disease, and treatment administered) (Hotopf, 2004), mechanisms (Andrews & Morrow, 2001), assessment (Ahlberg, Ekman, Gaston-Johansson, & Mock, 2003), and management (Mock, 2001) of fatigue.

Evidence suggests that fatigue is prevalent in cancer, with most studies indicating this to be more than 30% (Hotopf, 2004). The main factor inducing fatigue appears to be the therapy itself (Richardson, 2004). Several models for the etiology of cancer-related fatigue have been generated, such as altered muscle metabolism, vagal afferent activation, exercise physiology, and hypothalamic-pituitary axis dysfunction (Andrews, Morrow, Hickok, Roscoe, & Stone, 2004). The extent to which other conditions, such as anemia (Bron, 2001), cognitive and mood disturbances (Valentine & Meyers, 2001), and circadian sleep disruption (Lavidor, Weller, & Bakoff, 2003), predispose individuals to fatigue, are consequences of it, or are concomitant has yet to be fully revealed (Richardson, 2004). Irrespective of this incomplete knowledge base, sufficient evidence is available to shape clinical practice. Assessment is key to recognizing and managing this distressing symptom, and a wide range of screening and more comprehensive assessment instruments are available for use (Wu & McSweeney, 2004). However, a gold standard is not yet available, and further psychometric testing is required to gain confidence in the belief that measures are consistent with definitions and specific characteristics of the cancer population, such as age (Varricchio, 2000). Nonetheless, the instruments available are helpful in identifying symptoms amenable to immediate management rather than waiting for fatigue to interfere significantly with daily activities (Richardson & Ream, 1997). General management has been outlined in clinical guidelines drawn from a review of the literature and professional consensus (National Comprehensive Cancer Network, 2004). In children’s cancer, the body of knowledge on fatigue is at a much earlier stage.

Clinical observation reveals that fatigue or tiredness is experienced in adolescents during and after treatment for cancer. Empirical evidence also is available from programs of research focusing on children and adolescents. The seminal work of Hockenberry-Eaton et al. (1998, 1999) clearly demonstrated that fatigue was prevalent in children and adolescents with cancer. Fatigue existed within a complex context of illness, treatment, and cognitive development. A major finding was how children of differing chronologic ages perceived fatigue in different ways. For example, 7- to 12-year-olds viewed their experiences within a physical framework, highlighted in one description, “I see tired in my eyes, and I have a dull face” (Hockenberry-Eaton et al., 1998, p. 176). In comparison, the 12- to 19-year-olds viewed fatigue with a more global perspective such as being “physically tired and mentally challenged” (Hockenberry-Eaton et al., 1998, p. 177). Fatigue since has been reported in childhood cancer survivors (aged 18–38) (Langeveld, Grotenhuis, Voute, de Haan, & van den Bos, 2003; Langeveld, Ubink, & Smets, 2000) who described its negative effect on their daily lives. Preliminary data from the current study with adolescents (aged 16–19) who were more than five years off treatment revealed a cyclical relationship between fatigue and other factors such as having busy social lives, study, and work pressures (Edwards, Gibson, Richardson, Sepion, & Ream, 2003). In summary, fatigue has been identified as a near-universal experience that adversely affects the quality of life of patients and their families (Davies, Whitsett, Bruce, & McCarthy, 2002; Hinds et al., 1999).

Early evidence provides descriptions of fatigue from the perspectives of children and adolescents, parents, and healthcare professionals. These descriptors have been incorporated into three instruments to assess fatigue that currently are undergoing testing for reliability and validity (Hockenberry-Eaton et al., 2003). From the evidence that already exists, discerning the specific experiences of adolescents is difficult because, rather than being viewed as a distinct cohort, they have been included or excluded in research involving children or adults (Lewis, 1996). Thus, the effect of fatigue on physical, psychological, and social well-being has not been examined solely from the perspective of adolescents.

Adolescent Growth and Development and Chronic Disease

Adolescents with cancer face not only the challenges of the disease, but also the challenges of adolescence (Hanna, 1993). Adolescence is a pivotal period that greatly influences later emotional development (Heaven, 1996). During this time, adolescents develop an integrated image of themselves as unique individuals, synthesized from the values of their parents, teachers, and peers (Pelms, 1981). At this stage, they are passing crucial developmental milestones, creating their own individual identity, and beginning to establish independence from their parents and other figures of authority (Schave & Schave, 1989). In addition, their personal value system is evolving, and they are seeking new and meaningful relationships with like-minded peers (Schave & Schave). Thus, adolescence is a time of immense psychological and physiologic transformation, characterized by transitions and decisions (Kelly, 1991). It often is perceived as a difficult stage in relationships with parents.

McKinney, Fitzgerald, and Stommen (1977) listed the developmental tasks that adolescents have to achieve to reach maturity as
• Achieving independence from parents
• Acquiring the social skills required of an adult
• Achieving a sense of oneself as a worthwhile person
• Developing the necessary academic and vocational skills
• Adjusting to a rapidly changing physique and sexual development
• Achieving an internalized set of guiding norms and values.

When the diagnosis of cancer is superimposed on this process, difficulties in coping may arise at any point on the treatment continuum (Ettinger & Heiney, 1993). Adolescents with a
chronic illness such as cancer face great challenges in achieving developmental tasks as a result of social isolation, changes in body image, and the physical effects of their treatment (Ritchie, 1992, 2001; Weekes & Kagan, 1994). Thus, care of adolescents with cancer requires an understanding of how the cancer experience can threaten the continuing achievement of developmental tasks. This will facilitate strategies to support chronically ill adolescents in their continuing development (Ritchie, 2001).

**Research Approaches**

Fatigue is a subjective, complex, and multifactorial symptom that is suited to explication through qualitative research methods. Yet no studies have used qualitative methods with adolescents alone to generate a detailed description of their experience of fatigue while receiving treatment for cancer. This study used one particular qualitative methodology—phenomenology—to address this.

Several schools of phenomenology exist, but the one adopted here is based on transcendental phenomenology (Husserl, 1970) as modified by Moustakas (1994). This approach attempts to describe phenomena as they manifest to the consciousness. It seeks to avoid all presuppositions placed on experiences in advance, whether sociocultural or scientific. The aim is to go back to the experience itself—the essence of the experience before it has been filtered through a person’s perceptions of it. Phenomenology is about capturing life as it is lived, but it is not a study of the attitudes or feelings of people about a particular topic. Rather it is the object of their experience that is sought. Thus, although Husserlian phenomenology produces qualitative data, they are obtained through an essentially objective approach.

The aims of this exploratory study of adolescents undergoing primary treatment for hematologic cancer or solid tumors were to

1. Describe the concept of “fatigue” and determine whether it exists in adolescent patients aged 13–19.
2. Explore perceived well-being and the ability to maintain normal activities in this group.
3. Explore the physical, cognitive, affective, and emotional feelings associated with fatigue in adolescents undergoing primary treatment, and determine any impact of fatigue on their well-being and ability to maintain normal activities.
4. Ascertain mechanisms used by adolescents to cope with fatigue.

**Methods**

**Sample and Setting**

A convenience sample of adolescents aged 13–19 with hematologic or solid tumors, who currently were undergoing primary treatment at a regional cancer center in the United Kingdom, were approached a minimum of six weeks following commencement of treatment. Researchers thought that approaching potential participants earlier in their disease and treatment trajectory was inappropriate for ethical reasons. Adolescents were excluded if they, their family, or the healthcare, social, or teaching professionals considered them to be too physically or psychologically distressed to participate.

The clinical nurse specialist identified potential participants. A member of the research team made contact with families either by letter (if adolescents were receiving outpatient care) or face to face (if adolescents were receiving inpatient care). Potential participants and their parents were given verbal and written information and consent forms. Confirmation or refusal to participate was established via either the telephone or a face-to-face visit in the hospital. Where appropriate, completed consent forms were obtained and dates for interviews were arranged.

**Pilot Process**

Research with adolescents may require particular strategies for recruitment and data collection (Dashiff, 2001). A pilot process indicated that a written invitation to participate with a follow-up telephone call was time consuming and ineffective. Personal contact by the researcher proved to be a more successful recruitment strategy and therefore was used throughout the main study. Pilot work also demonstrated the time needed to put participants at ease before interviewing; thus, an ice-breaker activity that included questions about favorite music, television shows, or food was introduced (Dowswell & Vandestienne, 1996). Providing information that was comprehensible for the age range and yet not oversimplified was challenging. Pretesting of information sheets confirmed that they were clear and informative.

**Main Data Collection**

Semistructured interviews were conducted in a venue of participants’ choosing, usually their own homes. Prior to interview, some time was spent establishing rapport between researchers and adolescents. The questions reflected those asked in a previous study on fatigue (Hockenberry-Eaton et al., 1998). They were open ended and covered aspects of life during treatment but focused on fatigue (see Figure 1). Interviews lasted one to two hours, were tape-recorded, and were transcribed verbatim. Demographic details also were collected.

**Ethical Issues**

Ethical approval was granted prior to commencement of the study. Written information regarding the study was provided for the adolescents and their parents. Written informed consent, or consent and assent in the case of participants younger than 18 years old, were obtained.

- Fatigue...Doctors and nurses call this overwhelming tiredness fatigue. What do you think? How would you describe it? How is it for you? Tell me more about it.
- Do you think there are different types of feeling tired? Being tired in your body or your mind?
- In the last week were there certain activities that were easy or difficult for you to do?
- Tell me more about the things you cannot do when you feel tired.
- How long does feeling tired last?
- Have your school, college, or work activities changed? If so, how?
- Have you ever had trouble falling asleep at night? Why do you think that happens?
- Does sleep help you feel less tired?
- How tired are you feeling today? Why do you think you are feeling this way?
- What have you been able to do (friends, watch television, sports, study or work, eat)?
- When you are feeling tired or have low energy, what things help you feel better?
- How do you feel compared to your friends? Is anything different between what they can do and what you can do?

Figure 1. Interview Prompts
than 16, was obtained. Participants were assured of their right to withdraw from the study at any time.

Data Analysis

Data were analyzed according to Moustakas’ (1994) modification of the Stevick-Colaizzi method. Researchers following this approach must set aside prejudgments regarding the phenomenon in a disciplined and systematic way. This process (the epoche) was achieved by reviewing thoughts, beliefs, and knowledge. This reflective meditation was repeated until preconceptions were identified clearly and written down. As the researcher returned to each participant’s interview transcript, these preconceptions were reviewed so that the object of the participant’s experience was observed naively.

Each tape-recorded interview was listened to and read by the researcher taking each statement in the data as being of equal value. The researcher then listed all nonrepetitive significant statements from the transcripts; these are referred to as the invariant horizons. Statements irrelevant to the topic or those that overlapped were discarded, leaving only the invariant horizons or “meaning units” of the experience. The invariant horizons were clustered into themes that were used to identify the unique qualities of the phenomenon that stood out—the textural description. Imaginative variation then was used to develop a structural description. This depicted the underlying factors that account for what is being experienced—how the experience of the phenomenon came to be what it is. Imaginative variation involves the researcher thinking about how the phenomenon might vary for different people, in different places, and at different times to try to understand how the phenomenon came to be experienced in the way that it did (Moustakas, 1994). The individual textural and structural descriptions then were integrated into the composite textural and structural description.

Study Rigor

In accordance with the principles for qualitative research, the study was assessed for credibility, auditability, and transferability (Sandelowski, 1986). Credibility (i.e., the presentation of a faithful description, which would be immediately recognized by those undergoing the experience) was confirmed by sending the individual and composite textural and structural descriptions to the participants and requesting that they carefully examine them and make any additions and corrections. No changes or queries were raised. Credibility also was ascertained by carefully following the process of epoche and returning to the identified preconceptions as each individual transcript was analyzed. Auditability was addressed by providing sufficient information of the decision trail taken by the researchers. Transferability (i.e., the results of the study are found to be meaningful and applicable) will be best judged by the recipients of the study.

Findings

Eight adolescents were recruited to the study. Data were collected over the course of a year. Table 1 outlines participants’ demographic characteristics, diagnoses, and treatment modalities. Figure 2 provides the clustered invariant horizons. What follows is a description of the adolescents’ accounts, conflated using imaginative variation to propose possible meanings of the phenomenon fatigue (Moustakas, 1994).

The Composite Textural and Structural Description

Fatigue as a phenomenon: Fatigue was ever present in varying degrees, depending on the stage and intensity of treatments. For these adolescents, fatigue was the absolute and complete exhaustion experienced after therapy. The word fatigue seldom was used; instead they describe it as being “knackered,” “knocked out,” or “shattered.” This type of fatigue prevented all normal activity and left them weak, inactive, and unmotivated with aching and painful limbs. These were times when they were “whacked” and stayed in bed most of the day. This utter physical tiredness could last for days on end.

The end of a cycle of therapy did not bring complete resolution, although several spoke of how they felt less fatigued between treatments. “I am a lot more perky in myself. I am happy now, as now I am having a week off of stuff, waiting to pick up and start my next block of treatment, so I am more myself” (16-year-old male with leukemia). However, episodes of fatigue were unpredictable and varied in their intensity and duration. Fatigue might have been expected or unexpected, but either way it was accepted as part of the process, leaving one participant feeling that nothing more could have been done to help her. “No, no, I just thought, ‘Oh well, get on with it.’ ‘Sleep it off’ type of thing” (19-year-old female with leukemia).

Fatigue also was experienced in different ways in different places. “I was] tired when I was in the hospital but more awake when I would go out or something, when I got out of the hospital. I don’t know, it just seemed different, and I felt a lot more, like this—‘Yeah the world is welcoming me’” (17-year-old female with a brain tumor).

Tiredness was recognized to occur in both body and mind. “Different types of tiredness really, you felt wiped out with

---

Table 1. Demographics of Study Participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>Range = 16–19</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Ethnic group</td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>5</td>
</tr>
<tr>
<td>African</td>
<td>1</td>
</tr>
<tr>
<td>Indian</td>
<td>1</td>
</tr>
<tr>
<td>Pakistani</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>4</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>1</td>
</tr>
<tr>
<td>Brain tumor</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Treatment received</td>
<td></td>
</tr>
<tr>
<td>Chemotherapy alone</td>
<td>3</td>
</tr>
<tr>
<td>Chemotherapy, radiotherapy, and surgery</td>
<td>3</td>
</tr>
<tr>
<td>Chemotherapy and radiotherapy</td>
<td>1</td>
</tr>
<tr>
<td>Chemotherapy, radiotherapy, and bone marrow transplantation</td>
<td>1</td>
</tr>
<tr>
<td>Educational status</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>7</td>
</tr>
<tr>
<td>College</td>
<td>1</td>
</tr>
</tbody>
</table>

N = 8
Fatigue
- What is fatigue?
- Being fatigued
- Timing and duration of fatigue
- Inactivity and fatigue
- Effects of fatigue
- Sleeping patterns
- Strategies for dealing with fatigue
- Fatigue in context
- Fatigue as unexpected

Psychological effects
- Effect on psyche
- Frustration—knowing you could do more
- Loss of concentration
- Guilt
- Acceptance
- The hospital stuff—scary stuff
- The stress of treatment
- Treatment as pointless

Trying to regain normality
- Fearful to engage in life again
- Venturing into the world
- Being careful
- Strategies that help with illness
- Seeing an improvement
- Being determined

How is life affected?
- Overwhelming effects of chemotherapy
- Dependence
- Effect on practical aspects of life or lifestyle
- Loss of normal routine
- Changing family relationships
- Effect on social life—social exclusion
- Reaction of others

What has changed?
- Changed personality
- Changed body or changed mind
- Positive changes
- Being different, comparisons—falling behind
- The effort for normal activities—having to think before you do
- Missing out on crucial points in life
- Thwarted ambitions—the end of dreams

Altered life perspectives
- Life as unpredictable
- Apprehension about the future
- Experiences too deep to be forgotten

Figure 2. Themes and Subthemes Derived From Invariant Horizons

actually physically being able to move around and because of the chemotherapy, and you feel so tired because you’ve done things which, um, makes your brains hurt even more” (17-year-old female with sarcoma).

Disrupted sleeping patterns were common. Participants had problems falling asleep, precipitated by worry about their predicament, and discomfort or the need to urinate also accounted for fitful sleeping. Even after a good night’s sleep, some woke still tired and did not “pick up” until lunchtime. Whereas bodily fatigue usually was related to chemotherapy and trying to become more active again, mental fatigue was related to three main areas: trying to concentrate, being in some social situations, and coping with the enormity of diagnosis. Mental fatigue was very prominent for one participant who had multiple health problems, including diabetes, tuberculosis, and cancer. A 17-year-old female with leukemia said a body massage would be nice but “I won’t be thinking of the relaxation and you know the relaxation techniques and stuff like that. I know I’ll be thinking about the stuff.” Lying around all day, being inactive, also contributed to fatigue. Thus, physical inactivity and a lack of mental stimulation contrived together to cause fatigue. This was a mental type of tiredness—the tiredness of being bored—but it also mediated physical tiredness. A tension existed between needing to rest the physical body when doing so may have engendered more mental fatigue.

A number of strategies were used to relieve fatigue. Sleep can be beneficial, refreshing mind and body and enabling worries to be obliterated. But the quality of sleep often had deteriorated. “Before I go to sleep and wake in the morning refreshed and ready for the day, and now I wake up and think, ‘Oh, I have got to get up and go and do the stuff’” (19-year-old male with brain tumor). Herbal baths, aromatherapy, and high-energy drinks provided some relief, but this was restricted to bodily fatigue, and the effect was temporary. Physical remedies provided physical relief. However, eating may have been instrumental in relieving fatigue in more complicated ways. The pleasurable, rather than the nutritional, aspect of eating was emphasized—eating nice things made them feel normal again. Normality was not just a physical or psychological state, but it held importance beyond this in setting the experience of illness against past events and current cultural norms. Physical fatigue also was combated by social activity. The constant chatting involved in such situations was felt to boost energy levels. Thus, a physical symptom could be ameliorated through social action or inaction. Although physical treatments such as blood transfusions, mentioned specifically by some of the adolescents, were important, social healing also was needed.

Talking to friends and family relieved mental fatigue and distracted the worrying mind. Yet normal social interaction could produce physical and mental fatigue. Thus, trying to deal with fatigue involved refreshing the body through rest and sleep and distracting or calming the mind. A balance needed to be struck between the remedy and its outcome.

Clearly, fatigue is a complex conflation of physical and mental effects. One may precipitate the other but in no particular order. Overwhelming fatigue such as that experienced through the treatment of cancer is embedded in a syndrome of symptoms and feelings associated with the illness itself and with treatment. Furthermore, the fatigue described by these adolescents was not recognized as normal—normal tiredness was the type experienced before illness when you had done too much. Normal tiredness came from doing normal things; it was different from the fatigue that came from things such as chemotherapy and radiotherapy and living with a diagnosis of cancer.

How life is affected: The unpleasantness and daunting nature of therapy seeped through in these accounts. This involved sleeping, vomiting, feeling nauseated and “down,” walking rather than running, a killing of the desire to eat, mood swings, and a loss of motivation. During treatment, and particularly during intensification, the practicalities of life became almost insurmountable. The simplest of activities became challenges.

It’s just that, I mean, getting in and out of the bath is not really too much of a problem with the line, it’s just er,
sort of after that, then you are actually quite tired. And then you sort of dry yourself and sit on the toilet sort of things, and then you just sort of have to rest for a while. So you are only half dressed, and you still have to rest (17-year-old male with leukemia).

Psychological well-being was precarious. The gravity of their situation was not lost. Hospital visits, although routine and boring, could cause physical and emotional pain. Nightmares about treatment and stressful visions pierce any sense of rest and tranquillity. Fatigue made everything seem worse. A vicious circle of stress related to a scary illness and scary treatment generated fatigue that, in its turn, could worsen problems and symptoms. In the shadow of an extraordinary life, ordinary life became scary as self-confidence was lost.

I was thinking, I am gonna be such, like, like, ah, ah, you know, like, such a, maybe, scared of everything? Like, when somebody shouts loudly, I suddenly get so scared I just shake, and our phone is really loud, and, all of a sudden, it just rings, and it just gets really, you know, I just really jump” (17-year-old female with leukemia).

Everyday life was a struggle. This created an unwelcome dependence on others. Family members had to assist with aspects of daily life and intimate activities. Adolescents who were beginning to separate from their family were abruptly returned to their childhood ties. Illness, treatment, and associated fatigue caused a well of frustration. Before they were ill, many of these adolescents led a very active life, playing sports, dancing, and socializing. All that changed. This brought frustration because of not being able to do more and guilt because of not fulfilling normal obligations, giving others more work, spoiling family outings, and getting angry with family members. Thus, the guilt of bringing pain to loved ones fashioned the experience of diagnosis and treatment.

The aftermath: All of the adolescents were receiving active treatment, but therapy protocols usually included less intensive maintenance periods. As the immediate effects of radiotherapy, chemotherapy, and surgery subsided, life improved but was far from normal. Four categories marked this phase—the loss of routine and comparisons with the past, acceptance, trying to attain normality, and altered life perspectives.

The sense of a normal lifestyle was still absent. The routine of school, homework, and going out during the weekends still was not regained, and the adolescents had fears that it never would be. Normal activities required considerable planning. The adolescents needed to rest before going out and to wake up in time to “get with it.” Going out with friends required determination and effort. Thus, experiences that previously were enjoyable became a test of endurance. Life for all of these adolescents changed fundamentally and often in stark contrast to the past. Strenuous physical sport was not possible, and ordinary social life was curtailed. Motivation might have been present, but the adolescents did not have physical stamina. Illness, treatment, and associated fatigue engendered a sense of frustration.

In contrast, for some the aftermath of immediate treatment heralded a phase of acceptance, an understanding that slowing up may be necessary and beneficial. Life was tailored to what was possible. “Relaxing” subjects were chosen at school, and activities such as reading gave way to less taxing pursuits such as watching television. Life took on a slower pace; they became used to doing less. Many activities just seemed too much bother.

When I, like, first started treatment, um, it didn’t feel too good because I am quite an active person, and, like, I have got a horse that I used to go on and muck out, but, um, so it didn’t really feel very good because I was usually outside doing things, and I would get really bored easily as well. But now I have kind of got used to it because you kind of get into a routine and so it’s not, when I sit down I just think, “Well, I am just sitting down watching TV.” I am not thinking about what I could be doing (19-year-old female, diagnosis not disclosed).

The progression toward normality depended on the type of cancer and its treatment. For some, as they neared the end of protocols or when they were on maintenance therapy, going to school for short periods became possible. However, ability to attend was variable and unpredictable, often dictated by how ill they felt in the mornings. Some regained the strength for physical activities such as sports and socializing outside of the home. However, others still were relatively inactive and confined to home.

Social exclusion became a reality, and considerable effort was required to avoid it. School is important for passing examinations, but it was construed more often in terms of its social aspect. The adolescents had a fear of friends moving on and being left behind because they needed to be able to go out to see their friends. “Even though I have got double vision sometimes, we go to the cinema . . . just so I can see my friends” (19-year-old male with brain tumor). Life for these adolescents then became a series of accommodations and compromises. Social exclusion became constructed through a sense of desertion, a loss of confidence in past relationships, and trust. Recovery was experienced through the social sanctions of others. Whether at school or at play, re-engaging life engendered fear. This may have been the fear of being away from the support of parents and family, the fear of infection, or the fear of facing everyone who knows or half knows about their illness. A tension existed then between wanting to be normal, knowing the comfort this brings, and yet being fearful to engage in normal activities in case they upset them or made them ill again.

Finally, the experience of illness and its treatment changed not only the physical and social dimensions of these adolescents’ lives, but it also altered their perspective on life itself. Along with this came apprehension and confusion. Life was unpredictable and treatment protocols seemed to change without explanation. “So I never know what’s happening with me; I just have to talk to my consultant” (17-year-old female with leukemia). They always had an apprehension for the future. “It does get to me. I try, I think, I think, I think a lot more about the future. I am more apprehensive, scared of what’s going to happen and what has happened” (17-year-old female with leukemia). Immediate treatment was surrounded by immediate fears about future treatments, a normal life, and life itself. They spoke with desperation: “I don’t know; it’s all sort of gone out of the window. It’s come to a halt, finished” (19-year-old male with brain tumor, who played hockey and basketball for the town team and hoped to be a sports instructor). On the very brink of adult life, dreams were thwarted and cut off.
Discussion

At a time in life when adolescents are making new peer relationships, renegotiating relationships with their parents, and making life plans, cancer threatens life and personhood. The adolescents in this study reported that fatigue was overwhelming, embedded in a syndrome of symptoms and emotions associated with the illness itself and with treatment. Fatigue was accepted as a consequence of having cancer. The symptom was perceived to have a significant effect on physical, psychological, and social well-being, placing an extra burden on adolescents who were striving to achieve “normal” and usual growth and developmental patterns. Uncertainty and anxiety were featured in many of the adolescents’ accounts alongside strategies used to manage symptoms and their cancer experience.

This study supports previous research indicating that fatigue is experienced by adolescents receiving treatment for cancer (Davies et al., 2002; Hockenberry-Eaton et al., 1998, 1999; Hockenberry-Eaton & Hinds, 2000). The current study’s findings reinforce the view that fatigue is a complex phenomenon that is unpredictable and bothersome. It is associated with exhaustion of energy resources and requires strategies to manage fluctuations in energy levels (Davies et al.). The distinction among typical tiredness, treatment fatigue, and shutdown fatigue reported by Davies et al. was evident in the adolescents’ accounts. What was most striking was the difficulty adolescents had in separating the symptom from the overall experience of cancer. Qualitative approaches, such as phenomenology, are able to capture such experiences. This reinforces the view that understanding cancer is not always best achieved through quantitative research because this type of research is prone to reduce the cancer experience to discrete events (Woodgate & Denger, 2003a). Further research is required to capture the meanings and feelings adolescents assign to symptoms they experience throughout the whole cancer trajectory.

The current study corroborates previous work indicating that understanding the “whole” cancer experience is important because symptoms cannot be viewed in isolation (Woodgate & Denger, 2003b). Although individual symptoms are important in shaping the overall experience, each symptom is connected and related to others (Woodgate & Denger, 2003b). For the adolescents in this study, fatigue was overwhelming, affecting them physically and mentally. Furthermore, fatigue was persistent not only through the diagnostic period, hospitalization, and treatment but also into the recovery period. Developing a symptom profile that reveals the relationship between clusters of symptoms is worthy of further study.

A universal experience of adolescents in the study was their attempt to lead normal lives and to reach developmental milestones despite their diagnoses. This is consistent with previous research that stressed the importance of maintaining a sense of normality (Clarke-Steffen, 1993) and resilience (Woodgate, 1999b) to develop into a well-adjusted individual. Similar to previous work, the current study reveals that a chronic illness such as cancer determines, in part, how adolescents choose to live their lives, integrating their illness experience into their everyday lives (Woodgate, 1998) and coping in the face of significant adversity (Woodgate, 1999a). Whether this finding would be consistent through all stages of adolescence needs to be confirmed by exploring the experience of cancer through all three stages of adolescence: early, middle, and late.

When this study is considered alongside published work describing fatigue in children and adolescents, an evidence base for practice is emerging. When preparing adolescents at the time of diagnosis, fatigue as a symptom experienced during and after treatment needs to be included. Verbal and written information about fatigue is important and could include the strategies that adolescents in this study described as being helpful. Moreover, healthcare professionals need to be aware of the effect of fatigue to ensure that adolescents are prepared for it, in the same way that they are prepared for other symptoms. Encouraging healthcare professionals to assess and record the experience of fatigue would help to build a more comprehensive picture of this symptom and how adolescents choose to manage it. Further work using evidence from research and clinical experience is required to develop strategies and treatments for fatigue that then might be tested for their effectiveness in clinical trials.

Implications for Practice

A central strategy that healthcare providers can use to help adolescents with cancer achieve normalcy is to provide care that preserves and fosters their continuing achievement of developmental tasks and provides emotional protection from threats posed by the experience of cancer (Ritchie, 2001). Care underpinned by an understanding of normal development assists adolescents to develop strategies to continue with school, maintain relationships with friends, and keep their existing support systems active and strong (Weekes, 1991). This approach necessitates knowledge of adolescents’ psychosocial resources, current goals, and future personal expectations. The challenge for healthcare professionals is to develop strategies that help adolescents with cancer to get on with life.

Strategies will need to account for the fact that fatigue is embedded in the total experience of having cancer, where meaning, perception, and actual experience are interconnected. Adolescents in this study were able to suggest what helps and described strategies they used to relieve fatigue. Previous studies indicate that adolescents coped more effectively when they were able to use what they perceived worked best (Weekes & Savedra, 1988). Evaluating the effectiveness of such strategies in clinical practice is important.

For adolescents with cancer, minimizing the tension between their life trajectory and treatment trajectory is important (Gryner, 2002). To achieve this, understanding of individual needs must be elicited so that they may be matched to appropriate services (Department of Health, 2003). This study will increase healthcare professionals’ understanding of what it is really like for adolescents to have treatment for cancer. This should enable healthcare professionals to construct a more accurate and perceptive picture of the needs of particular individuals, highlighting those that may be amenable to intervention. From the researchers’ knowledge about fatigue, some initial implications for practice can be distilled from the adolescents’ accounts (see Table 2).

Limitations

This was a small, in-depth study of the experience of eight adolescents receiving treatment for cancer. Although the adolescents had a number of features in common, such as having cancer and receiving chemotherapy, in other respects
Table 2. Themes From Participant Accounts and Implications for Practice

<table>
<thead>
<tr>
<th>Key Themes</th>
<th>Supporting Quotation</th>
<th>Implications for Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>In the afternoon, and I just sort of sit down and sort of dozed with the TV on, and just sort of sit there, not really watching it and not really listening (male with brain tumor, 19 years).</td>
<td>• Prepare adolescents and families to anticipate fatigue and altered sleeping patterns.</td>
</tr>
<tr>
<td></td>
<td>I can’t really control it, and it gets, like, a bit worrying and emotional, like, I get all moody, and that’s not normally me, most of the time (male with leukemia, 16 years).</td>
<td>• Adjust education material to include information about fatigue.</td>
</tr>
<tr>
<td>Psychological effects</td>
<td>Even though I have got double vision, sometimes we go to the cinema... just so I can see my friends (male with brain tumor, 19 years).</td>
<td>• Plan time-limited activities.</td>
</tr>
<tr>
<td>Trying to regain normality</td>
<td>Then Mum picks me up so I don’t... and she drops me off as well so I don’t have to catch a train (female, 19 years, diagnosis not disclosed).</td>
<td>• Encourage maintenance of social contacts (e.g., e-mail, Internet).</td>
</tr>
<tr>
<td>How is life affected?</td>
<td>The weekly chemo, I used to get very tired; I wouldn’t do anything. If anything, I would sleep all day (female with brain tumor, 17 years).</td>
<td>• Educate family members to maintain normality and facilitate contact with friends.</td>
</tr>
<tr>
<td>What has changed?</td>
<td>It does get to me, I try, I think, I think, I think a lot more about the future. I am more apprehensive, scared of what’s going to happen and what has happened (female with leukemia, 17 years).</td>
<td>• Identify strategies to support reintegration to normal life.</td>
</tr>
<tr>
<td>Altered life perspectives</td>
<td>• Provide opportunities to talk and express feelings.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Acknowledge feelings associated with the cancer and its treatment.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Respond to nonverbal expressions of emotional fatigue.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Refer to other healthcare professionals as appropriate.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Encourage liaison with school and employers to prepare for alterations in activity and concentration.</td>
<td></td>
</tr>
</tbody>
</table>

they were very different. Age, gender, and diagnosis varied in this population. How much these variables affect fatigue cannot be commented on at this point. The findings therefore cannot be generalized to all adolescents receiving treatment for cancer. However, the universal picture that emerged from the data may be used by healthcare professionals to guide them when developing relevant plans of care.

The concept of fatigue in adolescents who have not had cancer has been described (Tomoda et al., 2000; Wright & Beverley, 1998). Characteristics include persistent fatigue associated with fever, pharyngitis, headache, excessive sleepiness, low energy, decreased appetite, loss of interest or pleasure in usual activities, loneliness, social isolation, and feelings of unhappiness, some of which were mentioned by adolescents in the current study. How far the fatigue described by them is unique to the cancer experience requires further study. Future studies exploring cancer-related fatigue should include adolescents who have not had cancer.

Conclusion

This was a small-scale exploratory study, but it does provide rich primary evidence for improving the quality of life for many adolescents living with cancer. Healthcare providers need to appreciate the importance of how difficult life can be for adolescents who have a chronic illness (Woodgate, 1998). They need to identify ways to help adolescents adjust to a cancer diagnosis, gain control of their symptoms, and be successful in reaching their developmental milestones. This will best enable them to lead a fulfilling life, despite the short- or long-term physical, psychological, and social effects of cancer.

The authors wish to thank the adolescents who participated in this study.

Author Contact: Faith Gibson, MSc (Cancer Nursing), PhD, RSCN, RGN, ONC, Cert Ed RNT, can be reached at gibsof@gosh.nhs.uk, with copy to editor at rose_mary@earthlink.net.

References


