Fatigue in Adolescents With Cancer: A Review of the Literature

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Since the 1980s, fatigue has become recognized as one of the most commonly reported symptoms in patients receiving cancer treatments, with an incidence that approaches 100%. Research now shows that fatigue occurs in patients at all stages of the disease, during treatment and for years after treatment ends. Patients also report that fatigue is the symptom that often causes the most distress (Curt et al., 2000; Nail, 2002). Fatigue, therefore, deserves attention as a priority symptom that researchers and clinicians must address to achieve optimal outcomes in patients’ quantity and quality of survival.

Despite progress made in understanding fatigue, measuring its occurrence, and reducing its severity, the study of fatigue has not yet begun to extend beyond the adult population. Research programs recently have provided insight into fatigue in adolescents with cancer, an age group that requires specialized study because of their unique cancer epidemiology and developmental tasks. The purpose of this paper is to review the literature related to the symptom of fatigue in adolescents with cancer, discuss future research directions, and recommend clinical strategies for management of fatigue in this population.

Key Words: Fatigue, adolescent

Fatigue is a prevalent and distressing symptom in people with cancer, and adolescents with cancer are no exception. Research on fatigue in the context of age and development will help in the development of age-specific prevention and management guidelines. The developmental profile, cancer epidemiology, and research needs related to adolescents with cancer are unique. A number of descriptive studies now form the foundation of scientific knowledge about cancer-related fatigue in adolescents. From this research, a definition of fatigue has been constructed and age-specific instruments have been developed. In addition, several correlates and interventions have been proposed for future testing. This article reviews relevant literature related to the symptom of fatigue in adolescents with cancer, discusses future research directions, and recommends clinical strategies for management of fatigue in this population.

Cancer in Adolescents

Adolescents with cancer have not been studied as a distinct patient population until recent years (Barr, 2001; Bleyer, 2002a, 2002b; Lewis, 1996). Data about this population usually are merged with data from other age groups (usually children) or, worse yet, not recorded at all. Adolescent oncology, however, is now emerging as a new subspecialty in cancer control.

Although the World Health Organization suggests that the period of adolescence is between 10 and 20 years of age, many other definitions have been proposed (Lewis, 1996). The Surveillance, Epidemiology and End Results program of the National Cancer Institute reports cancer incidence in five-year brackets and has assigned adolescence to the quintile of 15-19 years of age. In the literature, including the Cumulative Index of Nursing and Allied Health Literature (CINAHL) database, adolescence is considered to span the teenage years. Thus, research varies because of the differences in how adolescence is defined.

In the 1990s, cancer incidence among people ages 15-19 was 203 new cases per million people in the United States (Bleyer, 2002a). This number is higher than in any of the younger age quintiles. From 1973 to 1995, the incidence of cancer in all younger age groups, including adolescents, showed annual increases approaching 1%. Fortunately, this trend of increasing incidence of cancer in adolescents now appears to have stabilized (Bleyer, 2002b). Reasons for this changing incidence are not known.

Adolescent cancers show a unique combination of cancer types not seen in any other age group (see Figure 1). Many cancers in this age group also are seen in younger children, such as acute lymphoblastic leukemia and central nervous system tumors. Other diagnoses in adolescents rarely are seen in children younger than 15, such as germ cell tumors and thyroid cancer. Similarly, common diagnoses in younger children, such as Wilm’s tumor, and the most common cancers in adults, such as breast, colon, and lung cancers, rarely are seen in adolescents (Bleyer, 2002a, 2002b).

Success in treating cancer in adolescents has not been as great as the success in treating cancer in children. In 1990, the overall...
In addition, adolescents do not frequently undergo treatment due to cancer, fewer than 3% of adolescents with cancer diagnoses, including sarcoma and acute leukemia, are lower in adolescents than in children. Only the diagnoses of thyroid cancer, melanoma, and germ cell tumors in adolescents show a better prognosis than in younger patients (Bleyer, 2000a).

Adolescents also are less studied than younger populations. Although more than 70% of children are enrolled in clinical trials, fewer than 3% of adolescents with cancer participate in clinical trials (Barr, 1999). In addition, adolescents do not frequently appear in the samples of adult or pediatric research studies related to nursing or symptom management. This lack of a concentrated focus on controlled and funded research may explain the smaller increments of treatment and outcome progress seen in the adolescent group.

A final consideration for the adolescent population with cancer is the unique challenge they present related to the critical developmental tasks at this time (Barr, 2001; Bleyer, 2002a; Lewis, 1996). These young people are physically maturing, assuming greater independence, exploring relationships with peers, making education and career decisions, and developing a sense of identity and self. A diagnosis of cancer accompanied by the demands of cancer treatment during this unique period challenges normal development and a successful transition into adulthood. Adolescents deserve age-specific support throughout all aspects of cancer therapy to help them achieve these developmental steps, maintain some semblance of normal teenage lifestyles, and resume meaningful and functional lives after cancer. This is especially true because the majority of adolescents with cancer will survive into adulthood.

Because of the unique cancer epidemiology as well as their juxtaposition between childhood and adulthood, extrapolating data from studies in younger children or older adults to this population of adolescents may be inappropriate. Efforts to study symptoms such as fatigue in the context of adolescent development are imperative. Strategies for dealing with this population should be based on scientific contributions that are derived from age-specific research.

**Literature Review**

An initial literature search of CINAHL, Medline, and PsychoInfo from 1980 to 2003, combining the search terms “cancer” or “neoplasm,” “fatigue,” and “adolescent,” yielded only a few research studies. The search then was expanded to look for fatigue included under “symptom,” combined with “cancer” and “adolescent.” This search yielded a number of studies in which fatigue was included in the overall symptom experience of adolescents with cancer.

Studies were included in this review if they
- Were published in English between 1980 and 2003
- Included any patients who were 12–19 years old

Note. Based on information from Bleyer, 2002a.

![Figure 1. Common Cancers Among Adolescents](image)

FIGURE 1. COMMON CANCERS AMONG ADOLESCENTS

- Lymphoma
- Sarcoma
- Acute leukemia
- Central nervous system tumor
- Testicular cancer
- Ovarian cancer
- Melanoma
- Thyroid
- Other

In conclusion, 15 articles are included in this literature review, which examines data from research studies to describe and explain the experience of fatigue in adolescents currently dealing with cancer or cancer therapy.

**Symptoms in Adolescents With Cancer**

Table 1 lists nine studies that provided information on fatigue as a component of the overall symptom experience of adolescents with cancer. The studies consistently showed that adolescents report fatigue as a common and distressing symptom during the cancer experience, with an incidence of up to 50% (Collins et al., 2000, 2002; Enskar, Carlsson, Golsater, & Hamrin, 1997; Hinds, Quargnenti, & Wentz, 1992; Novakovic et al., 1996). Fatigue was defined in these studies by indicators such as “feeling tired,” “feeling weak,” and “lack of energy.” Data were obtained through self-report questionnaires, open-ended questionnaires, interviews, and chart reviews. On questionnaires, fatigue usually was recorded as a single item on a scale of symptoms. Two studies (Collins et al., 2000, 2002) described use of the Memorial Symptom Assessment Scale and its psychometric properties in children 7–12 years of age and in older children and adolescents, 10–18 years of age. Both versions of the scale proved to be reliable and valid instruments to measure symptoms, including fatigue. Hinds et al. (1992) developed a Symptom Distress Scale for use with adolescents. Adapted from the adult version, this scale also proved to be useful, reliable, and valid.

Five studies were prospective in design (Collins, 2000, 2002; Enskar et al., 1997; Hinds et al., 1992; Hinds, Scholes,Gattuso, Riggins, & Heffner, 1990). Four were retrospective studies (Donaldson et al., 1981; Hockenberry et al., 2002; Novakovic et al., 1996; Wolfe et al., 2000).

The study samples ranged from 10 to 405 and consisted mainly of teens, al-
though younger patients also were included in several of the studies. The samples included adolescents with a variety of tumors who were receiving a variety of cancer therapies, including surgery, chemotherapy, and radiation therapy. One study was a report from parents of children who died with cancer, who listed fatigue as a common symptom at the end of life (Donaldson et al., 1981). Further information about the incidence of anemia in children and adolescents at time of diagnosis

<table>
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<tbody>
<tr>
<td>Donaldson et al., 1981</td>
<td>244 children under 21 years old, newly diagnosed with a variety of cancers</td>
<td>Investigate the relationship between nutritional status and other disease factors</td>
<td>Chart review</td>
<td>Fatigue correlated with anorexia (r = 0.40), weight loss (r = 0.27), fever (0.32), and early satiety (0.33) with p &lt; 0.01.</td>
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<td>Hinds et al., 1990</td>
<td>15 adolescents, 9–20 years old</td>
<td>Describe adaptation to cancer</td>
<td>Surveys (HAS, PHSCS, SDS)</td>
<td>Adaptation was lowest at 4 weeks after the start of chemotherapy and highest at 6 months; physiologic adaptation was not related to social adaptation or morale.</td>
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<tr>
<td>Hinds et al., 1992</td>
<td>33 adolescent patients with cancer</td>
<td>Describe symptom distress and its relevance and recommend measurement approach</td>
<td>Survey (revised SDS)</td>
<td>Of 10 commonly occurring symptoms, subjects reported “feeling tired” as one of the top three distressing symptoms.</td>
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<td>Novakovic et al., 1996</td>
<td>85 patients (mean age = 29) who recalled their cancer experience as a child (mean age = 15) with sarcoma</td>
<td>Describe the cancer experience and identify problems and benefits</td>
<td>Unstructured written interview</td>
<td>Subjects described “feeling weak” as one of the most frequent negative cancer experiences.</td>
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<td>Enskar et al., 1997</td>
<td>10 adolescents (15–20 years old) receiving cancer treatment</td>
<td>Identify adolescents’ experiences of areas affected by cancer</td>
<td>Qualitative interview</td>
<td>Fatigue was ranked in the top 5 of 92 problems that subjects reported.</td>
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<td>Collins et al., 2000</td>
<td>160 children 10–18 years old receiving treatment (mean age = 16)</td>
<td>Determine symptom prevalence and distress in children with cancer using MSAS</td>
<td>Survey (MSAS 10–18)</td>
<td>Nearly half of patients (49.5%) reported a lack of energy. Children receiving inpatient chemotherapy with solid tumors had a greater number of symptoms.</td>
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<td>Wolfe et al., 2000</td>
<td>103 parents of children deceased with cancer (mean age at diagnosis = 8.1 years ± 6.1 SD; mean age at death = 10.8 years ± 6.7 SD)</td>
<td>Describe the symptoms and suffering of children with cancer at the end of life</td>
<td>Interview</td>
<td>Parents reported that 89% of children suffered “a lot” at the end of life from at least one symptom, most commonly pain, fatigue, or dyspnea.</td>
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<tr>
<td>Collins et al., 2002</td>
<td>149 children 7–12 years old receiving cancer treatment</td>
<td>Evaluate reliability and validity of MSAS</td>
<td>Survey (MSAS 7–12)</td>
<td>One third of children experienced lethargy or insomnia; instrument was acceptable.</td>
</tr>
<tr>
<td>Hockenberry et al., 2002</td>
<td>405 children newly diagnosed with Hodgkin’s disease or a solid tumor, 1–18 years old</td>
<td>Determine the incidence of anemia in children and adolescents at time of diagnosis</td>
<td>Chart review</td>
<td>Incidence of anemia ranged from 51%–74% across ages and diagnoses.</td>
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</table>

In conclusion, a number of studies have confirmed that fatigue is a prevalent symptom in the adolescent cancer population. Although the generalizability of the studies is limited by small sample sizes, some retrospective designs, and samples that also included children, results showed that adolescents with a wide variety of cancers, at various stages of the disease, and receiving different treatments named fatigue as a common and troublesome symptom in their cancer experience. The studies most commonly used single items rather than a comprehensive instrument to measure fatigue. A few studies suggested variables that may relate to fatigue, such as nutrition, anemia, and type of cancer, but these variables need further testing.
Cancer-Related Fatigue in Adolescents

Six research studies specifically focused on fatigue in the population of children and adolescents with cancer (see Table 2). These qualitative, descriptive studies form the foundation for a growing body of scientific literature and the development of a conceptual model for cancer-related fatigue in adolescents.

Bottomley, Teegarden, and Hockenberry-Eaton (1996) published the first research abstract citing the symptom of fatigue in 75 school-age children with cancer. Although no demographic or methodologic information was available for this study, the sample is assumed to have included some adolescents. The abstract cited a fatigue incidence of more than 50% and suggested indicators of fatigue related to the physical and mental symptoms in these children.

Hockenberry-Eaton et al. (1998) were the first to describe the phenomenon of fatigue in children and adolescents with cancer. This descriptive study used focus group interviews with samples of children and adolescents at two children’s cancer centers. A nurse researcher led each session and followed the same format. Each session was audiotaped, transcribed, and coded into themes. Data from the adolescent sample revealed that adolescents described physical and mental symptoms of fatigue, which fell into 12 themes. The descriptions included not feeling normal, feeling sorry and mad, not wanting to be bothered, feeling sleepy, and wanting to lie around. The adolescents named 12 causes of fatigue, which included chemotherapy and its side effects, the hospital environment, sleep disruptions, too many activities, boredom, fear, and worry. Finally, adolescents identified eight strategies to help relieve fatigue, and these related to activity, rest, sleeping medication, distraction, socialization, and blood transfusions. Figure 2 lists the subjects’ responses that describe their fatigue experiences.

Hinds, Hockenberry-Eaton, Gilger, et al. (1999) compared patient, parent, and staff descriptions of fatigue in pediatric patients with cancer. Data generated by the focus groups of children and adolescents in the Hockenberry-Eaton et al. study (1998) and by the staff in the Hinds, Hockenberry-Eaton, Quargnenti, et al. study (1999) were compared to data generated by 31 parents of children with cancer who also participated in focus groups. The data showed that children and adolescents with cancer, their parents, and the staff agreed on many aspects of fatigue, but they also showed subtle differences. Although children emphasized the physical dimensions of fatigue, adolescents

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<tr>
<td>Bottomley et al., 1996</td>
<td>75 school-age children receiving cancer treatment</td>
<td>Evaluate the effects of cancer treatment</td>
<td>Not reported</td>
<td>More than half reported being tired, not sleeping well, and being unable to do normal activities.</td>
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<td>Hockenberry-Eaton et al., 1998</td>
<td>14 children 7–12 years old and 15 children 13–16 years old</td>
<td>Define and describe fatigue experienced by children receiving chemotherapy</td>
<td>Focus groups</td>
<td>Children described 8 physical and mental symptoms of fatigue, 6 contributing factors, and 3 helpful interventions. Adolescents described 12 codes, integrating physical, mental, and emotional factors; 6 causes; and 8 helpful strategies.</td>
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<td>Hinds, Hockenberry-Eaton, Quargnenti, et al., 1999</td>
<td>38 staff members who cared for patients with cancer 7–12 years old</td>
<td>Analyze perspectives of staff members about patients’ cancer-related fatigue</td>
<td>Focus groups</td>
<td>Staff reported fatigue as a distressing symptom, affected by environmental, disease-related, personal, cultural, and treatment factors.</td>
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<td>Hinds, Hockenberry-Eaton, Gilger, et al., 1999</td>
<td>29 children with cancer 7–16 years old, 38 staff members, and 31 parents</td>
<td>Compare patient, parent, and staff descriptions of fatigue</td>
<td>Focus groups</td>
<td>Children emphasized physical aspects, while adolescents merged physical and mental components. Parents and staff members focused on their roles to relieve fatigue, while patients cited rest and distraction as main sources of relief.</td>
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<tr>
<td>Davies et al., 2002</td>
<td>13 children with cancer 5–15 years old; 12 parents</td>
<td>Describe fatigue in children who have cancer</td>
<td>Interview</td>
<td>Energy was a key concept. Three types of fatigue were identified: typical tiredness, treatment fatigue, and shutdown fatigue. Three groups of strategies for relief were identified: replenishing activities, energy-conserving activities, and strategies to preserve low energy.</td>
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<td>Varni et al., 2002</td>
<td>220 children with cancer 2–18 years old (mean age = 10.9 years); 337 parents</td>
<td>Determine the measurement properties of the PedsQL MFS</td>
<td>Surveys (PedsQL Generic Core Scales, MFS, and Cancer Module)</td>
<td>Results demonstrated the reliability and validity of the fatigue scale.</td>
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MFS = Multidimensional Fatigue Scale; PedsQL = Pediatric Quality of Life Inventory
merged physical and mental components. Parents and staff viewed fatigue as a state of diminished energy. Patients cited rest and distraction as main sources of relief for fatigue and were more aware of what contributed to fatigue rather than what relieved it. Parents and staff focused on their role to relieve fatigue, citing interventions that may or may not have been recognized as helpful by the other groups.

From these data, Hinds, Hockenberry-Eaton, Gilger, et al. (1999) developed the following conceptual definition of fatigue in 13–18-year-old patients with cancer.

Fatigue is a complex, changing state of exhaustion that at times seems to be a physical condition, at other times a mental state, and still other times a combination of physical and mental tiredness. It is influenced by environmental, personal/behavioral, and treatment-related factors and results in the adolescent not being able to maintain usual involvement with friends, academics, or sports, experiencing negative emotions like anger, preferring not to be bothered by others, and a strong desire to lie down or rest. This changing state of exhaustion can be acute, episodic, or chronic and is relieved by changing the environment, rest, distraction, and medical/pharmacologic interventions (p. 282).

In 2002, Davies, Whitsett, Bruce, and McCarthy published results from a study that described fatigue in a sample of patients 5–15 years of age with cancer. The children and their parents participated in qualitative interviews to give a detailed description of fatigue. Findings suggested that energy is a key concept in the definition of fatigue and that these patients experienced three different types of cancer-related fatigue, managed by different strategies. The three types of fatigue were typical tiredness (normal ebb and flow of energy), treatment fatigue (energy loss greater than replenishment), and shutdown fatigue (profound, sustained loss of energy).

The patients used strategies that included replenishing activities, activities to conserve energy, and strategies that preserved what critical low energy remained. The study also identified factors that influenced the children’s use of fatigue-management strategies. These factors included the children’s temperament, previous lifestyle and environmental factors, and type of treatment.

A final study tested the psychometric properties of scales designed to measure health-related quality of life (HRQOL), fatigue, and cancer-specific HRQOL in children and adolescents with cancer (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales, Multidimensional Fatigue Scale (MFS), and Cancer Module were administered to children and adolescents with cancer and their parents as well as to a cohort of healthy children and their parents. The PedsQL MFS consisted of three subscales, addressing general fatigue, sleep or rest fatigue, and cognitive fatigue, with a total of 18 items using a Likert scale. The scales were comprised of parallel child self-report for ages 8–18 and parent proxy-report for ages 2–18, written in developmentally appropriate language for children and adolescents. The PedsQL MFS was feasible to administer as evidenced by no missing responses. The scale demonstrated acceptable reliability and validity, making it one of the first age-appropriate and multidimensional instruments to measure cancer-related fatigue in adolescents for clinical or research purposes.

In conclusion, this small number of research studies has provided a definition of fatigue in adolescents with cancer as well as a number of contributing and alleviating factors related to fatigue. Although generated from small numbers of patients, which also may include children, and limited by focus group methodology, these data provide the basis for construction of a conceptual model as well as development of quantitative instruments for further testing and refinement (Hinds & Hockenberry-Eaton, 2001; Hockenberry-Eaton & Hinds, 2000; Mock, 2001). In addition, this preliminary work sets the stage for future studies with correlational and experimental designs.

**Practice Implications**

Research into the fatigue experience for adolescents has begun only within the last five years, although earlier studies reported fatigue as a common and troublesome symptom in this population with cancer. Several small, qualitative studies have built a strong foundation of scientific knowledge and contributed to the development of the concept of fatigue in adolescents with cancer. Larger studies with more diverse subjects and settings now are needed to strengthen and refine the conceptual model (Mock, 2000).

The conceptual definition and model of fatigue provides direction to develop instruments to measure fatigue. The PedsQL MFS, developed by Varni et al. (2002), and the Pediatric Oncology Fatigue Instruments, cited by Hinds and Hockenberry-Eaton (2001) in their research, are new instruments that need further testing and integration in a variety of settings and studies. With accurate measurement tools, future studies can investigate the relationships between fatigue and other variables thought to contribute to fatigue in adolescents, such as anemia, nutrition, and sleep. Experimental research could test interventions that would prevent and manage fatigue in this younger population with cancer.

**Conclusions**

Exploratory research into cancer-related fatigue in adolescents provides clinicians with an operational definition of fatigue for use in the clinical setting. With an accurate and age-specific definition of fatigue, clinicians can more effectively assess this symptom in their adolescent patients and teach patients about its occurrence (White, 2001). Using the conceptual model already developed for fatigue, clinicians can assess for the presence of factors that may contribute to fatigue and make attempts to eliminate or minimize their effects. In addition, clinicians can teach about cancer-related fatigue and make efforts to emphasize or promote factors that adolescents have suggested may relieve fatigue (Davies et al., 2002; Hinds & Hockenberry-Eaton, 2001; White). Experimental research is needed to confirm which interventions are...
the most effective to prevent and manage fatigue, but, in the meantime, clinicians can base their interventions on the findings from the descriptive research completed to date and on individual trials and evaluation. Figure 3 presents clinical strategies for the management of fatigue based on the current research findings. Teamwork between researchers and clinicians can promote the most coordinated and efficient research to investigate related variables and test specific interventions for fatigue management. Most importantly, oncology clinicians can translate important findings from research into practice guidelines to better educate their patients about fatigue, provide the most effective symptom management, and help adolescents live as normal teenagers.

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References


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Rapid Recap

Fatigue in Adolescents With Cancer: A Review of the Literature

- During the adolescent period of development, adolescents are physically maturing, assuming greater independence, exploring relationships with peers, beginning to make education and career decisions, and developing a sense of identity and self.
- Success in treating cancer in adolescence has not been as great as the results in treating children with cancer. For example, sarcoma and acute leukemia survival rates are lower in adolescents than in children.
- Adolescents report fatigue as a common and distressing symptom during the cancer experience and describe fatigue as feeling tired, feeling weak, or lacking energy.
- Adolescents with cancer cite many sources of relief from fatigue, including rest and quiet time, distraction, exercise, and medical therapy.
- Interventions to relieve fatigue need to be individualized, and may include things such as negotiating times to sleep and awaken, encouraging use of items to facilitate rest and sleep (e.g. music, pillow from home), offering recreational and diversional activities, and setting limits on the number and duration of visits by friends and family when indicated.