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## Fatigue in Pediatric Oncology Patients

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### 1. Introduction

Cancer-related fatigue in children is defined as a deliberate sense of being weak or having difficulty in moving extremities or even opening eyes. Fatigue may be resulted from environmental, individual/social or treatment-related factors and cause further problems such as playing with other children, lack of concentration or developing negative feelings (anger or sadness) (Hockenberry-Eaton&Hinds, 2000).

National Comprehensive Cancer Network also defines cancer-related fatigue as “a constant and subjective symptom of cancer treatment that affects general functions, perception of physical energy, mental state and psychosocial conditions, and cancer-related weariness” (Mock et al. 2000).

North American Nursing Diagnosis Association (NANDA), on the other hand, classifies fatigue as a self-reported diagnosis in an individual unrelieved by rest which manifests itself with a chronic and tiring exhaustion and a reduced physical and mental performance. In order to prevent adverse effects of fatigue, an effective management is attainable with a careful evaluation and designing individual-specific activities (Erdemir, 2005).

While cancer is now agreed to be a curable disease, especially with the rapid developments in medicine and technology, the prevalence and types of treatment-related side effects have been shown to correspondingly increase (Bal Yılmaz et al. 2010).

A literature analysis on the symptoms in children with cancer illustrated that early studies on pediatric cancer symptoms could be summoned in three main themes, which are treatment related pain; treatment related nausea-vomit and psychosocial symptoms associated with adaptation to being diagnosed with cancer (Allen et al. 1997; Bashore, 2004; Eiser et al. 1997). Enskar et al. (1997) added fatigue and feeling of sickness to these symptoms. Enskar et al. (1997) interviewed adolescents diagnosed with cancer and reported that they felt constantly weary and exhausted and they had occasional complaints of vomit, which eventually caused a feeling of sickness.

Fatigue is a universal symptom reported in cytotoxic chemotherapy, radiation therapy, and bone marrow transplant and with biological response modifiers. Despite being a common symptom among cancer patients, it has gradually increased to almost acute levels with the use of multidimensional treatment applications (Anderson et al. 2003; Mock et al. 2000). It has also been maintained that fatigue, unless supervised, adversely influences daily life

activities and quality of life (Taş&Bal Yılmaz, 2008). Fatigue seemingly lies at the core of the current debates since it proves to be a subjective condition with individually differing degrees of duration and characteristics (Yurtsever, 2000).

On account of its subjective nature and multifarious causes, defining and evaluating fatigue remain to be a challenge and it has been formulated within a wide array of medical disciplines. Physiologists understand fatigue as “reduced physical performance” while pathologists define it as “a physical and mental incapacity stemmed from neuromuscular and metabolic disorders”.

Nursing researchers commonly conceive fatigue as “a subjective symptom with overall effects ranging from slight exhaustion to unbearable weariness which impedes a person from accomplishing regular daily tasks and functions. Four different aspects of fatigue have been consistently focused on in medical and nursing literature and accordingly fatigue has been defined as:

- An experience affecting all bodily functions induced by emotional, cognitive and physical factors
- An unpleasant perception caused by distress
- A chronic and implacable phenomenon
- A subjective experience based on self-perception (Yurtsever 2000)

Considering that fatigue is primarily perceived by the patient, it is best defined with self-report besides physical examination, laboratory findings, reports from family members and health care professionals (HCPs) on patient's condition and behaviors as additional sources of information (De Nijs et al. 2008).

Fatigue can be observed in a variety of ways. Some of the determinant characteristics of fatigue are:

#### **Major characteristics**

- Constant verbal expression of the loss of energy
- Incapacity in sustaining routine activities

#### **Minor characteristics**

- A need for extra energy for fulfilling routine daily tasks
- Increase in physical complaints
- Being emotionally unsteady or sensitive
- Loss of concentration skills
- Reduced performance
- Lethargy or indisposition
- Indifference to environment
- Incapacity to fulfill social activities
- Inability to muster up enough energy despite having proper sleep (Yurtsever 2000).

## **2. Causes of fatigue**

Potential causes of fatigue are enlisted as follows:

## 2.1 Pathophysiological factors

- Infections:
- Acute infections; hepatitis
- Chronic infections; endocarditis
- Secondary to the situations below, associated with reduced tissue oxygenation; congestive heart failure, chronic obstructive pulmonary disease, anemia, peripheral vascular disease
- Secondary to the situations below, associated with biochemical alterations;
- Endocrine disorders; diabetes mellitus, Addison's disease, hypothyroidism, chronic diseases; kidney failure, cirrhosis
- Secondary to the situations below, associated with muscle weakness;
- Neuromuscular diseases; Parkinson, multiple sclerosis
- Secondary to the situations below, associated with the changes in food metabolism or nutritional deficiency; nausea, vomit, diarrhea, side effects of medicines...
- Obesity
- Electrolyte imbalance
- Eating disorders; Fe, B12 vitamin deficiency
- AIDS

## 2.2 Treatment related factors

- Associated with chemotherapy
- Associated with radiotherapy and immunotherapy
- Associated with side effects of certain medicines (long term use of corticosteroids, beta blockers...)
- Associated with surgical tissue damage and anesthesia

## 2.3 Situational factors

- Secondary to the situations below, associated with reduced activity and prolonged loss of condition
- Depression, anxiety, fever, diarrhea, pain, social isolation, nausea/vomit
- Associated with the intensity of role systems
- Associated with intense-excessive distress
- Associated with sleeping disorders (Yurtsever, 2000).

## 3. Factors that may increase or decrease the intensity of fatigue

Identifying fatigue in children also permitted children and parents to identify the factors that may increase or decrease the intensity of fatigue

### 3.1 Factors that may increase the intensity of fatigue

- Environmental factors; noise, hospitalization, hospital procedures, waiting at the hospital lounge, interpersonal relations, interrupted daily tasks

- Personal/behavioral factors; dynamism, sadness, changes in sleep patterns, waking up at night, having a bad sleep, changes in resting patterns
- Family and social factors, realizing family's anxiety
- Treatment/treatment related factors; onset of treatment, pain, lowering blood test results, stop eating, interventions, infection therapy

### 3.2 Factors that may decrease the intensity of fatigue

- Personal/behavioral factors; naps/lethargy, providing a comfortable sleep
- Personal/behavioral factors; encouraging participation in activities, supporting pastime activities, interacting with children
- Family and social factors; having visitors, participation in entertainment/pastime activities, ensuring comfort, changes in family life
- Treatment/treatment related factors; nutrition (Hinds et al. 1999A).

## 4. Cancer-related fatigue in children

Although adult oncology literature provides substantial data on fatigue and chronic fatigue, certain data still remain inadequate for the influences of cancer and cancer treatment on children (Langeveld et al. 2003). Studies on fatigue are narrow in scope in pediatric oncology literature which implies that health care researchers seemingly have underestimated cancer-related fatigue in children when compared to the studies of adult oncology. Cancer and chemotherapy related fatigue definitely possess different characteristics in children. The cancer treatment for children follows an intensive program in the first place in which the prime target is to ensure a high-dose therapy as much as possible. Curative approaches towards pediatric cancers achieved 70% rate of recovery in late 1990's. In contrast to adult treatment programs, fatigue hasn't been considered as a side effect in limiting dosages in pediatric programs because, first of all, fatigue is usually disregarded as a symptom that can possibly lead to dosage changes due to its diagnosis based on self-report. Secondly, unlike adults, children often fail to express their experiences with side effects of the treatment and they may be incapable of noticing the changes in their physical power and daily routines. Adolescents, on the other hand, may assume the loss of energy and fatigue as a natural consequence of having cancer. Thirdly, parents may not be well informed about fatigue as a side effect of the treatment and thus they may be unaware of the urgency for intervention. Most parents are inclined to oversee their children's changing patterns of activity so as not to discuss the matter with health care experts (Hockenberry-Eaton&Hinds, 2000).

Below is the report of a child experiencing fatigue:

Johny T. is a ten years old child with cell lymphoma taking chemotherapy. He remembers his agility before diagnosis. He frequently complains about weakness and fatigue and often wishes to lie down. As he can hardly run, he can't play baseball any more. He misses the school every so often because he needs help a lot and fatigue prevents him from concentrating on the lessons. Johny feels that resting all day may sometimes soothe the intense fatigue. Furthermore, he repeatedly experiences anger and sadness for being so tired as not to be able to play with his friends (Hockenberry-Eaton&Hinds, 2000).

Researches on the significance of fatigue in pediatric population have become prominent within the last 10 years. These studies mainly suggest that;

- Adolescents and children with cancer experience fatigue
- Developing a better insight into the function of fatigue in pediatric population ascertains a more accurate and thorough evaluation of the symptom
- Developmental levels of the children undertaking the treatment should be taken into consideration for an understanding of the symptom in pediatric population
- Understanding fatigue in pediatric population will certainly ensure a holistic approach by eliciting patients' and parents' perspective (Hockenberry et al. 1998; Hockenberry-Eaton&Hinds, 2000).

The analysis of fatigue primarily commenced with the definition of the symptom and its fundamental characteristics, which eventually facilitated establishing a model for understanding fatigue in children. Children with cancer suffer from symptoms of the illness as well as the side effects of chemotherapy. Moreover, they withstand physiological and psychological developmental changes characteristic of their age. They may be adversely affected by physiological and psychological side effects of chemotherapy during their daily routines and activities. These effects may further include nausea and vomit, loss or gain of weight, electrolyte imbalance, weakness and lethargy. These symptoms can be assessed in pediatric patients in a different manner with comparison to adult oncology patients. As a result, it is of utmost importance that fatigue be evaluated in children with cancer as a symptom in consideration of characterizing its outset, prevalence, severity and natural history (Hockenberry et al. 1998; Hockenberry-Eaton&Hinds, 2000).

Fatigue is a subjective experience and children and adults may differ in expressing a subjective experience. Accordingly, data gathered from adults and pediatric patients should be evaluated interdependently. Hinds and Hockenberry (2001) defined the characteristics of fatigue and factors that may increase or decrease the intensity of the symptom. They additionally reported that patients and parents tend to have different personal approaches and proposed that fatigue assessment should be conducted simultaneously for the multidimensional nature of the evaluation process and interventions (Hinds& Hockenberry-Eaton, 2001).

Mock (2000) stated that fatigue is widely regarded as a subjective experience in a majority of studies and that establishing a database for fatigue requires serious efforts to measure subjective experiences in an objective manner, which is to measure physical and cognitive variables. He also explained that a comprehensive definition of fatigue necessitates handling both subjective and objective indicators.

Children, parents or HCPs may have different ideas about the causes of the symptom, which urges an overall evaluation on the interventions to reduce fatigue. A number of scales have been developed to evaluate fatigue so far and some examples are Visual Analogue Scale Fatigue (VAS-F), Symptom Distress Scale, Yoshitake's Fatigue Scale, Rhoten Fatigue Scale and Pearson and Byar's Fatigue Scale (Hart, 1990). However, none of these scales have been peculiarly designed for children and adolescents, which surely hinder a proper evaluation. Linder (2005) reviewed the literature evaluating the measurements of physical symptoms and noted that fatigue was measured in only five different studies (Linder, 2005).



Hockenberry et al. (2003) developed the only scale particularly designed for measuring fatigue in children with cancer. Fatigue was commonly considered as an element of the quality of life. The first scales that measured cancer related fatigue in children were developed by Hockenberry et al. (2003). Theoretical guidelines of these scales were basically the results of their studies particularly focusing on cancer related fatigue in children and adolescents (Hinds et al. 1999B; Hockenberry et al. 1998). These studies defined fatigue as a subjective symptom referring to physical, emotional and mental perceptions and resulted in developing different scales for measuring cancer related fatigue in children, which are Children's Fatigue Scale, Childhood Cancer Fatigue Scale for Mothers and Fatigue Scale for 7-12 years old Pediatric Oncology Patients: Health Care Provider's Form. These scales were developed to determine the intensity, prevalence and causes of cancer related fatigue in children within the last week (Hockenberry et al. 2003). Evidently enough, the assessment of fatigue has been carried out by not only children themselves but also care provider family members and nurses in pediatric oncology literature (Bal Yılmaz et al. 2009; Bal Yılmaz et al. 2010; Baraud et al. 2003; Genç&Conk, 2008; Gibson et al. 2005; Gibson et al. 2006; Hindset al. 1999A; Hinds et al. 1999B; Hinds&Hockenberry-Eaton, 2001; Hinds et al. 2007A; Hinds et al. 2007B; Hinds et al. 2007C; Hinds et al. 2010; Hockenberry et al. 2003; Perdikaris et al. 2008; Perdikaris et al. 2009; Yeh et al. 2008).

Fatigue is a perceptive symptom and requires a multidimensional approach. Therefore, researchers are suggested to use other forms in combination while developing the scale and enable parents and HCPs to assess the symptom in addition to patient children (Hinds et al. 2007). It is considered to be imperative that perceptive symptoms should be evaluated by more than one single observer as in the design of the quality of life scales (Taş & Bal Yılmaz, 2008). Each individual may attribute different meanings to wellness in respect to physical, psychological, social and personal traits and consequently experiences the process of illness in a different way, which underscores the significance of an evaluation for both objective and subjective symptoms. Evaluation for objective symptoms entails the capabilities of children and adolescents, life conditions, functionality of environment and school and social relations while evaluation for subjective symptoms essentially comprises physical, emotional and social functionality of children and adolescents (Memik et al. 2007).

## 5. Management of fatigue

National Comprehensive Cancer Network maintained that fatigue should be rapidly defined, evaluated, controlled and treated with a multidisciplinary approach in each stage of the illness both during and after the treatment.

### 5.1 Care standards in fatigue management

- Fatigue is a subjective experience identified with self-reports of the patient and other sources of information
- Fatigue is an observable, diagnosable and curable symptom in line with the practice guidelines of clinics
- Fatigue can be characterized on first day of hospitalization and with regular visits later on

- Fatigue should be predominantly characterized, evaluated and reported during and after the treatment
- HCPs should request a timely consultation in evaluating and managing fatigue .
- Institution-specific standards should be developed by multidisciplinary committees for fatigue management
- HCPs should organize education programs to enhance professional knowledge and skills in defining and managing fatigue
- Families and patients should regard fatigue management as a part of holistic health care
- Health care outcomes should include data on cancer related fatigue
- A qualified fatigue care also reflects the institutional effort to enhance the quality of health care

Fatigue care must be contained in medical care expenses (Mock et al. 2000).

## 5.2 Role of nurses in fatigue management

Pediatric care services have deliberately reiterated the significance of supporting children's emotional and developmental needs for the last 30 years. In pediatric oncology, nurses undertake substantial responsibilities in assisting children and parents to adjust to the illness and the treatment procedures. Nurses can avert acute or delayed effects of the treatment and decrease the intensity of the symptoms by accomplishing considerable tasks such as monitoring, providing care, educating, consulting, conducting researches and pursuing patient's advocacy.

## 5.3 Nursing Interventions for fatigue

- Ensuring plenty of liquid intake
- Controlling the pain (medicines, relaxing, hot/cold application)
- Treating anemia (with the help of medical team)
- Controlling nausea and vomit (with medicine and relaxation)
- Controlling constipation (with medicines, diet and activities)
- Infection Control
  - *Regular bath*
  - *Regular mouth care*
  - *Washing hands before and after using toilet*
  - *Refraining from any contact with the crowds and people with contagious disease*
  - *Following asepsis-antisepsis principles in invasive interventions*
  - *Limiting visitors for neutropenic children*
- Planning Regular Diet
  - *Sharing the mealtimes with friends and family*
  - *Having nutritious snacks during the day.*
  - *Keeping food variety*
  - *Ensuring protein intake everyday*
  - *Resting before meals*
  - *Cooperating with the dietician*
- Ensuring Enough Sleep and Rest
  - *Planning activities and resting periods on a rotation basis*



- *Limiting naps with 20-30 minutes*
- *Avoiding activities or stimulants before sleep*
- *Maintaining regular sleep*
- *Doing relaxation exercises before sleep*
- *Assuring a quality night sleep*
- **Exercise**
  - *Wearing comfortable clothes and shoes*
  - *Jogging and exercises starting in a slow tempo and increasing gradually*
  - *Starting with 5-10 minute exercises and extending the sets 1-2 minutes every week.*
  - *Accentuating the significance of stopping exercises before getting exhausted*
- **Conservation of Energy**
  - *Designing activity programs as "work out-rest, work out-rest" sets*
  - *Ensuring having rest before getting exhausted*
  - *Avoiding hastiness as much as possible*
  - *Replacing hard exercises with soft exercises*
  - *Focusing on favorite exercises*
  - *Avoiding lifting heavy weights*
  - *Arranging play times with friends*
- **Maintaining interaction with family and friends**
  - *Informing patients and families about asking for help from family members, friends and HCPs (De Nijs et al. 2008).*

## 6. Conclusion

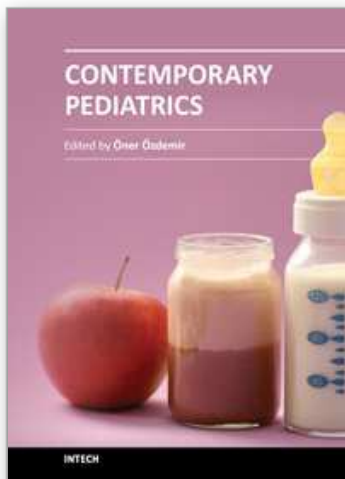
It was demonstrated that cancer-related fatigue in pediatric patients was perceived to be a significant problem by both parents and HCPs (Gibson et al., 2005; Bal Yilmaz et al. 2009; Bal Yilmaz et al. 2010). The studies mentioned above indicate that fatigue is an important clinical problem that is experienced by children undergoing cancer treatments. By better understanding the factors that cause fatigue, HCPs may be able to perform interventions that either reduce fatigue or make it easier for children with cancer to accept it (Magnusson et al., 1997). The effective diagnosis and treatment of fatigue not only enhances patients' quality of life, but it also improves the quality of care that HCPs are able to provide (Tiesinga et al. 2000). It is thought that to prevent fatigue from having a negative impact on children, all the factors contributing to their fatigue should be identified, then the signs of fatigue should be recognized, and finally, effective interventions should be planned to relieve their symptoms of fatigue (Knowles et al. 2000).

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