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Abstract

Many studies show that cancer-related fatigue is one of the most common symptoms experienced by children as a side effect of cancer therapy. This problem has grown considerably in recent years; the exact mechanisms underlying fatigue remain unclear. Therefore, assessing and managing this symptom can be problematic. This article describes the findings from a survey evaluating how health professionals (n = 56) at the Pediatric Oncology Centers in Izmir currently define and assess cancer-related fatigue. The results demonstrate that while the problems associated with fatigue are acknowledged, assessment tools are not widely used, and the majority of health professionals report that they would benefit from further education on the subject to assist in the care of patients.

Keywords

cancer, children, fatigue

Whereas medical progress and technological advances have led to treatments that have lengthened the life expectancy of children with cancer, these same treatments can also cause several side effects (Eddy & Cruz, 2007; Enskär, Carlsson, Golsäter, & Hamrin, 1997; Hockenberry, 2004; Whitsett, Gudmundsdottir, Davies, McCarthy, & Friedman, 2008). When fatigue, which is one of the most serious of these side effects, is not well controlled, patients' quality of life and social life are negatively affected. Patients are also less able to cope with their disease and its side effects. Many patients therefore experience great distress as a result of fatigue (Anderson et al., 2003; Ellen, Ros, & Grijpdonck, 2008; Magnusson, Karlsson, Palmblad, Leitner, & Paulson, 1997; Mock, 2001; Piredda et al., 2007; Yurtsever, 2007; Zebrack & Chesler, 2002).

In children, cancer-related fatigue is known to result from environmental, personal/social, and treatment-related factors. It has been shown to cause physical problems such as a decrease in the inclination to play games or even an unwillingness to do so, as well as the feeling that it is difficult to move one's extremities and open one's eyes. It has also been shown to cause mental problems, such as an inability to concentrate, irritability, and depression (Davies, Whitsett, Bruce, & McCarthy, 2002; Hinds et al., 1999; Hockenberry-Eaton & Hinds, 2000).

Until recently, cancer-related fatigue has received limited clinical attention in pediatric oncology. During the past

decade, however, fatigue has become better recognized and understood by health care professionals (Barsevick et al., 2004; Genc & Conk, 2008; Hockenberry-Eaton & Hinds, 2000; Mooney-Doyle, 2006; Perdikaris et al., 2008). The accurate assessment and effective treatment of cancer-related fatigue may improve not only the quality of care that patients receive, which is clearly important, but also the quality of life of patients, which should be the main goal of health care providers (HCPs) (Eddy & Cruz, 2007; Genc & Conk, 2008).

Although clinicians have observed cancer-related fatigue in children receiving treatment for childhood cancers for many years (Hockenberry-Eaton & Hinds, 2000), it has only recently become a popular research topic (Whitsett et al., 2008). The first study to recognize cancer-related fatigue as a symptom that is often experienced by pediatric cancer patients was a study of adolescents with cancer that was performed by Enskär et al. (1997). In another study, fatigue was observed to be a common symptom in children and adolescents with leukemia and was found to have a

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negative impact on their quality of life (Perdikaris et al., 2008). In the pediatric oncology literature, Hockenberry-Eaton and colleagues (1998-2004) have carried out many of the important studies on related fatigue as a symptom experienced by children and adolescents suffering from cancer. These studies resulted in the development of the conceptual model of fatigue as well as instruments to evaluate cancer-related fatigue in pediatric patients (Hinds et al., 1999; Hockenberry, 2004; Hockenberry-Eaton et al., 1998; Hockenberry et al., 2003; Hockenberry-Eaton & Hinds, 2000).

Wolf et al. (2000) reported that fatigue was one of the 3 most common end-of-life symptoms experienced by children with cancer (Wolf et al., 2000). Davies et al. (2002) identified 3 types of cancer-related fatigue in children: (1) typical tiredness, (2) cancer treatment fatigue, and (3) shutdown fatigue. They also suggested specific interventions that were dependent on the type of fatigue patients were experiencing (Davies et al., 2002).

In a longitudinal study that listed and evaluated 10 treatment-related symptoms in pediatric cancer patients, fatigue was found to be the most stressful symptom, thereby, drawing attention to the importance of fatigue in pediatric oncology patients (Hinds et al., 2000). In 2003, Hockenberry et al. demonstrated the reliability and validity of the Childhood Fatigue Scale and Parent Fatigue Scale (Hockenberry et al., 2003). Moreover, Hedstrom, Haglund, Skolin, and von Essen (2003) studied the symptoms that children and adolescents suffered from during their cancer treatments and found that pains from medical procedures, nausea, and fatigue were the most common physical symptoms that young patients reported (Hedstrom et al., 2003).

In a literature review, Edwards et al. (2003) concluded that fatigue was a complicated symptom of great importance and that future studies were needed to improve physicians' understanding of it (Edwards et al., 2003). In another literature review, Erickson (2004) analyzed studies that had examined fatigue in adolescents with cancer and discussed future research directions in the field. The author also recommended clinical strategies for management of fatigue in this population (Erickson, 2004). Hockenberry (2004) reviewed the studies related to the side effects experienced by pediatric cancer patients that had been published between 2000 and 2004, and she found that in addition to pain, nausea, vomiting, malnutrition, and mucositis, many young patients also suffered from fatigue (Hockenberry, 2004). Gibson, Garnett, Richardson, Edwards, and Sepion (2005) demonstrated that cancer-related fatigue in pediatric patients was perceived to be a significant problem by both parents and health care professionals (Gibson et al., 2005).

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, Dijkstra, Dassen, Halfens, & Van Den Heuvel, 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, Borthwick, McNamara, Miller, & Leggot, 2000). The lack of availability of scales that can be used to assess fatigue makes it difficult for clinicians and researchers to accurately assess and describe this symptom in oncology patients (Gibson, Edwards, Sepion, & Richardson, 2006; Knowles et al., 2000; Magnusson et al., 1997; McCabe, 2009; Piredda et al., 2007). We undertook this study because, to our knowledge, no prior studies have been carried out in Turkey that have measured fatigue among children who are receiving treatments for cancer, have reported on the causes of cancer-related fatigue in pediatric cancer patients, or have discussed potential measures to reduce this symptom. The goal of the study was to assess HCPs' knowledge regarding cancer-related fatigue in children.

The specific research questions we asked were the following:

- How do HCPs rank the cancer-related symptoms experienced by patients?
- Do HCPs perceive fatigue as a problem in their patients?
- How do HCPs assess fatigue in their patients?
- Are HCPs aware of the signs of fatigue in their patients?
- Are HCPs aware of the causes of fatigue in their patients?
- What measures do HCPs take to reduce or minimize patients' fatigue?
- What teaching preparation have HCPs received regarding cancer-related fatigue?

Methods

Setting and Patient Population

The study participants were recruited from the 4 pediatric oncology clinics (Ege University Hospital, Eylül University Hospital, Behçet Uz Children's State Hospital, and the Tepecik State Hospital) that are located in Izmir, Turkey, between February 2008 and March 2008. All doctors and nurses who worked in the pediatric oncology clinics were

considered for inclusion in the study. There were 64 nurses and 18 doctors working in the clinics at the time the survey was conducted; 44 nurses and 12 doctors participated in the study.

Research Design

Our research questions required a method that would provide an overall description of the approach that HCPs working in the 4 included pediatric oncology clinics take with regard to cancer-related fatigue. We wanted to focus specifically on HCPs' impressions of the prevalence of fatigue, their awareness of the signs of fatigue, and the approaches they used to assess fatigue, as well as the interventions they used to treat it. We also wanted to examine the educational backgrounds of HCPs with regard to cancer-related fatigue in pediatric patients. Therefore, a descriptive study design was chosen that would be based on the results of a structured survey questionnaire. After careful and critical appraisal of the literature, we were only able to identify 3 previous studies on this topic that had used a survey (Gibson et al., 2006; Knowles et al., 2000; Magnusson et al., 1997). We based the design of our questionnaire on those that were used in the previous studies. Necessary modifications were made to the questionnaire to account for language and cultural differences. In total, the questionnaire contained 15 items, which generally took the form of closed-ended questions. However, open-ended questions were also included to allow the respondents to provide their own views on a specific issue (eg, "What are the interventions that you might consider to reduce fatigue?"). The responses to the open-ended questions were classified and/or categorized so that they could be further analyzed.

The content validity of the survey questionnaire was assessed by a doctor and 2 nurses who worked in the field of pediatric oncology. A pilot study that included 3 doctors and 3 nurses working in the pediatric oncology clinic of Ege University was conducted prior to this study (the results are not included in this study) to assess the relevance and wording of the survey questions as well as the general appearance and acceptability of the overall questionnaire. No changes were made based on the results of this pilot study.

After the HCPs at the 4 previously mentioned pediatric oncology clinics were asked if they wanted to participate in the study, questionnaire forms were given to willing participants. The forms were collected back the same day.

Data Analysis

Statistical analysis was carried out using the SPSS 11.0 statistical software package (SPSS Inc, Chicago, IL). Data were analyzed descriptively and are presented as summary statistics (percentages and total number of respondents).

Ethics

Before the study was initiated, written consent was obtained from the Ege University Nursing School Ethics Committee and from the hospitals at which the research was conducted. Verbal consent was also obtained from the doctors and nurses who participated prior to survey administration.

Results

The research population comprised doctors and nurses who worked in the pediatric oncology clinics that were mentioned above. The majority of respondents were nurses (78.6%, $n = 44$). Typical respondents were between 25 and 34 years of age (66%, $n = 37$). A total of 20 of the HCPs (35.7%) had completed their training 1 to 2 years prior to the study (19.6%), 11 had completed their training 3 to 7 years prior to the study (19.6%), 11 had completed their training 8 to 12 years prior to the study (19.6%), 7 had completed their training 13 to 17 years (12.5%) prior to the study, and 7 had completed their training more than 18 years (12.5%) prior to the study. The majority of HCPs had worked in an oncology setting for either 1 to 2 years (48.2%, $n = 27$) or 3 to 7 years (28.6%, $n = 16$).

Questions

How do you rank the cancer-related symptoms experienced by patients? Each respondent ranked the frequency of occurrence of 9 different symptoms in their patients on a scale of 1 to 5 (1 = most rare to 5 = most frequent). The 9 symptoms that were listed were the following: anxiety, lack of appetite, hair loss, tiredness, constipation/diarrhea, pain, nausea, trouble sleeping, and breathlessness. An additional line was included for HCPs to note down optional symptoms. A total of 75% of HCPs ranked hair loss as the most frequently occurring symptom, whereas 55% ranked nausea, 38% ranked tiredness, 34% ranked lack of appetite, 21% ranked pain, 16% ranked constipation/diarrhea, and 16% ranked anxiety as the most frequently occurring symptom.

Is fatigue a problem for your patients? The replies, which ranked on a 5-point scale that ranged from not at all to very much, revealed that many of the HCPs believed that fatigue was a major problem for their patients. A total of 38% of HCPs replied *very much*, 33% replied *much*, and 0% replied *not at all*.

How do you assess patient fatigue? All participants replied that the patient stated that he/she felt tired, 29.2% replied that they had checked the patient's hemoglobin value, and 21.4% replied that the patient showed symptoms of anemia, such as breathlessness. All the HCPs who cared for pediatric cancer patients stated that they did not use any tools to assess patient fatigue.

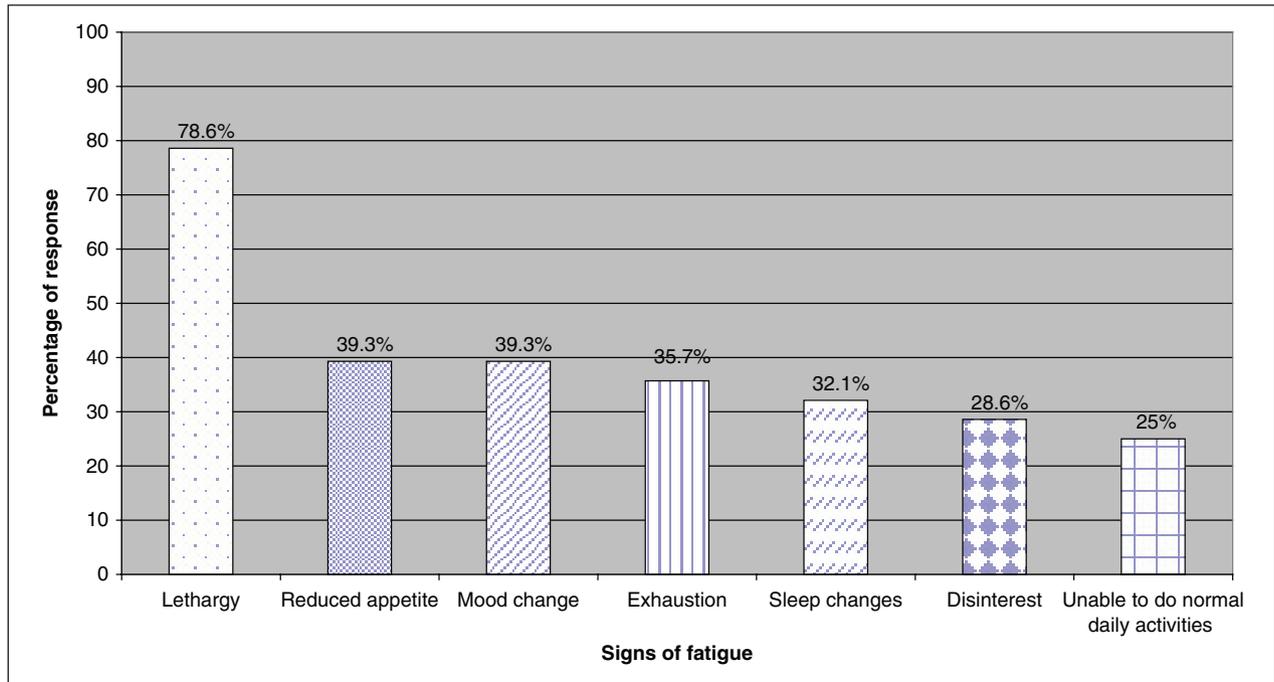


Figure 1. Most frequently reported signs of fatigue in children

What signs of fatigue do you most often observe in your patients? The signs of fatigue (Figure 1) that HCPs reported as occurring most frequently were lethargy (78.6%, $n = 44$), reduced appetite (39.3%, $n = 22$), mood changes (39.3%, $n = 22$), exhaustion (35.7%, $n = 20$), sleep changes (32.1%, $n = 18$), and disinterest (28.6%, $n = 16$). Other signs of fatigue reported by HCPs included disinterest (42.6%, $n = 20$), insomnia (38.3%, $n = 18$), and inability to perform normal daily activities (25.0%, $n = 8$).

What do you think causes patients' fatigue? The respondents were asked to list factors that they thought contributed to cancer-related fatigue. The 5 most frequent factors that the HCPs felt contributed to cancer-related fatigue in pediatric patients are summarized in Figure 2. A large number of the HCPs attributed patient fatigue to chemotherapy (92.9%, $n = 52$), psychological factors (73.2%, $n = 41$), and anemia (55.4%, $n = 31$). Other factors that were reported by respondents included malnutrition (30.4%, $n = 17$), the disease process itself (30.4%, $n = 17$), changes in sleep habits (12.5%, $n = 7$), and radiotherapy (7.1%, $n = 4$).

How do you think patient fatigue can be reduced? Most of the responses implied that fatigue could be reduced in various ways (Figure 3), including looking more closely for the signs of fatigue (57.9%, $n = 32$), using pharmacological interventions (57.9%, $n = 32$), having conversations/presenting patients with information regarding fatigue (42.1%, $n = 24$), using nutritional support (42.1%, $n = 24$), and with rest and relaxation (7.9%, $n = 5$).

Did you receive instruction about cancer-related fatigue during your professional training? The majority of the health care professionals (73%, $n = 41$) reported that they had not received any education regarding cancer-related fatigue during their career. Of those who had received education, 17.0% ($n = 9$) had only received 1 to 2 hours of training in the form of a seminar. The overwhelming majority of the participants (75.0%, $n = 42$) reported that they would benefit from further education about cancer-related fatigue in pediatric patients to improve patient care.

Discussion

In this study, we surveyed HCPs at 4 pediatric oncology clinics about the approach that they took to cancer-related fatigue. The respondents were asked to estimate the percentage of patients in their clinic who experienced fatigue.

At the time of the survey, the HCPs stated that fatigue, much like hair loss and nausea, was a major problem experienced by their pediatric cancer patients. This finding is similar to those of other studies, in which the prevalence of cancer-related fatigue was reported to be between 65% and 100% (Gibson et al., 2005; Knowles et al., 2000; Magnusson et al., 1997). Generally, health professionals in our clinics tend to pay more attention to other cancer-related symptoms, such as nausea, vomiting, pain, and hair loss, than they do to fatigue. Fatigue is not a new concept in pediatric oncology; it is just a new concept in Turkey.

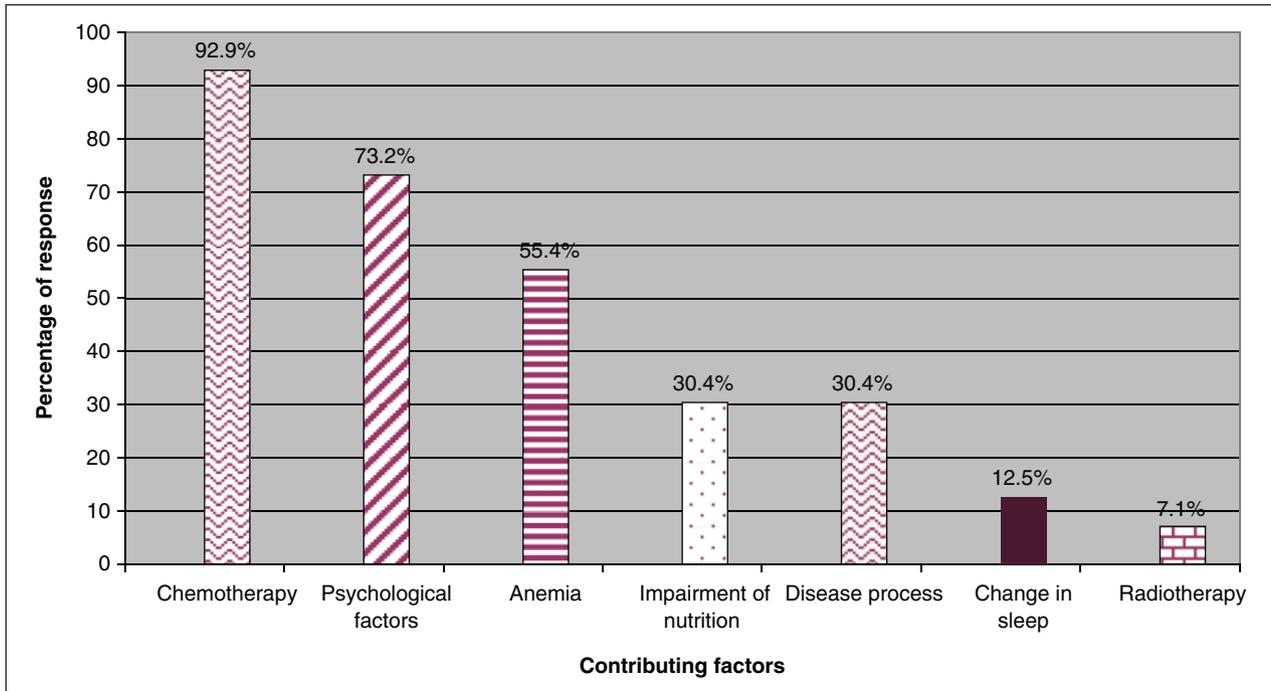


Figure 2. Most frequently reported factors thought to contribute to fatigue

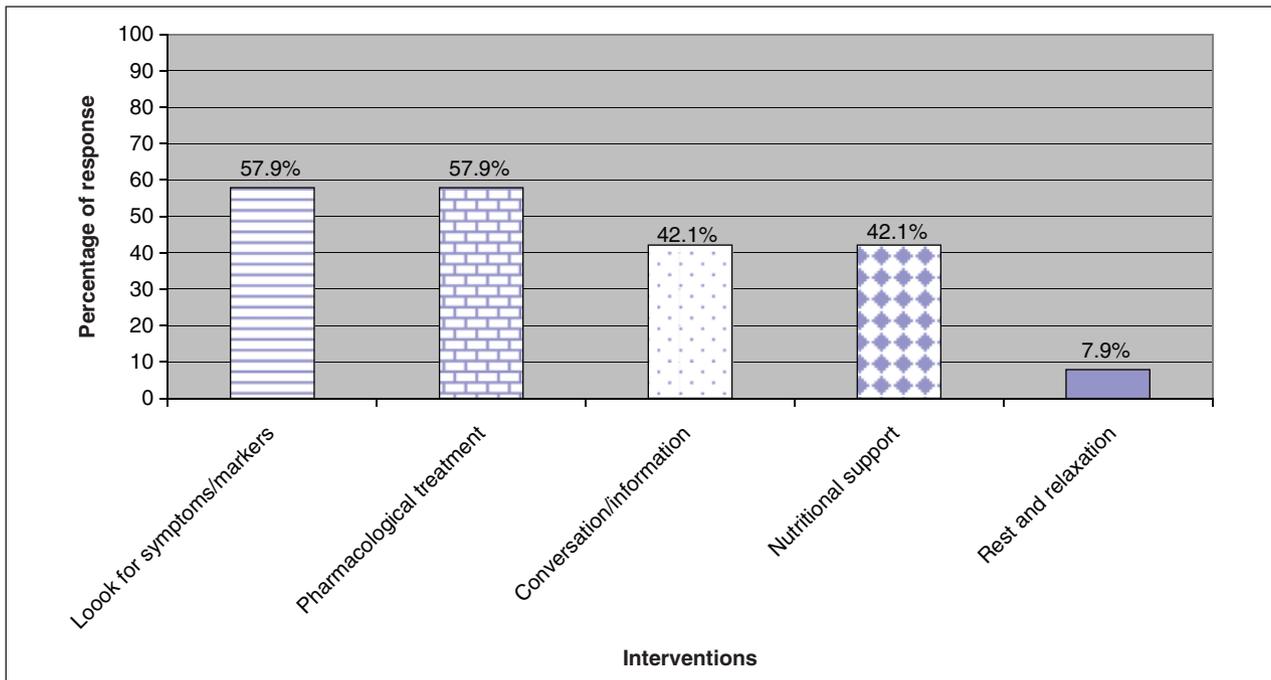


Figure 3. Interventions considered useful in helping reduce fatigue

It should also be mentioned that even though fatigue is a very common symptom that is experienced by patients, health professionals may not be well enough informed about the signs and symptoms that are related to fatigue.

When we asked how HCPs recognized that a patient was suffering from fatigue, 21% replied that the patient was exhibiting symptoms of anemia, and 29% replied that they checked the patient's hemoglobin value. At the time

at which this study was performed, all the HCPs stated that they did not use any tools to assess fatigue in their pediatric oncology clinics.

Health care professionals regard lethargy, reduced appetite, mood changes, exhaustion, sleep changes, and disinterest as signs of fatigue in their patients. In a study in which nurses' knowledge and attitudes about cancer-related symptoms were investigated, lethargy, reduced appetite, and tiredness were the symptoms that the included nurses most often identified as signs of fatigue (Knowles et al., 2000). Because fatigue is a subjective concept, different people have different definitions of it. These findings emphasize the importance of considering objective, as well as subjective, data when assessing patients for the presence of signs of fatigue.

In our study, the respondents stated that chemotherapy, psychological factors, and anemia were the most common causes of fatigue in their patients. However, it is important to acknowledge that both the nature and treatment of cancer cause fatigue. Although cancer-related fatigue in pediatric patients is a relatively newly debated issue in our country, it is clear that health professionals are aware of the causes of fatigue.

We also examined the interventions used by the health professionals to reduce cancer-related fatigue. The respondents stated that they used different strategies to reduce fatigue in their patients, such as looking for the signs of fatigue, pharmacological interventions, having conversations/presenting patients with information regarding fatigue, nutritional support, and rest and relaxation. Interventions used by HCPs, which have been mentioned in other studies, to reduce fatigue include rest, symptom control, informing the patient and the family of the signs and symptoms of fatigue, nutritional support, exercise (Gibson et al., 2006; Knowles et al., 2000; Magnusson et al., 1997), and blood transfusion (Magnusson et al., 1997). Although there are multiple studies that have examined the prevalence of fatigue in patients with cancer (Erickson, 2004; Yurtsever, 2007), there have been very few studies that have assessed the effectiveness of particular interventions to reduce the severity of the condition (Ellen et al., 2008). The literature does, however, suggest that individual and planned interventions to eliminate fatigue, for example, exercise, providing distractions, relaxation, and sleep promotion may be effective at reducing fatigue (Ellen et al., 2008).

Most of the study participants reported that they had not received any education regarding cancer-related fatigue during their professional training, but they felt that they would benefit from further education about the condition to improve their care of patients. This finding is similar to those of Magnusson et al. (1997) and Knowles et al. (2000) who found that 77% and 80% of HCPs, respectively, felt that they would benefit from further education about cancer-related fatigue. Most of the health professionals in our study reported that they felt inadequately informed about how to deal with cancer-related fatigue. On the basis of

this finding, we feel that systematic education regarding cancer-related fatigue will not only increase health professionals' confidence in dealing with the condition but also help increase the quality of life of patients with cancer.

Study Limitations

At the time of the study, few oncology HCPs in Turkey were familiar with interventions for cancer-related fatigue. Also, all the HCPs stated that they did not use any tools to assess for the presence of fatigue in their clinics. This shows that fatigue was a low priority for HCPs in Turkey and was not included as part of a standard patient assessment. However, fatigue is a complex phenomenon, and further research on the topic is required. The next step in this research should be the introduction and evaluation of an assessment tool that can be used in the clinical setting.

Conclusions

To our knowledge, no prior studies have been performed that have investigated the knowledge and attitudes of health professionals regarding cancer-related fatigue in children and adults in Turkey. Health care professionals from all the pediatric oncology clinics in Izmir, one of the major cities of Turkey, were included in the study. The results represent Izmir, but they cannot be generalized to the country as a whole. We found that health professionals regard cancer-related fatigue as a problem and that they are aware of the causes of fatigue. Also, health professionals reported that they use a variety of interventions to reduce fatigue. Many of those surveyed felt that they would benefit from further education regarding cancer-related fatigue in pediatric patients.

Based on our findings, we recommend that additional studies be carried out to further define and evaluate both the subjective and multidimensional signs of fatigue, to find the most effective interventions, and to determine the types of education that would be most useful to health professionals who deal with cancer-related fatigue as part of their clinical duties. We feel that such initiatives would improve the quality of care of patients suffering from cancer-related fatigue.

Declaration of Conflicting Interests

The author(s) declared no conflicts of interest with respect to the authorship and/or publication of this article.

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