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[Article]

Comparing patient, parent, and staff descriptions of fatigue in pediatric oncology patients

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Abstract

Fatigue in children and adolescents with cancer is a disruptive symptom meriting clinical intervention by nurses, but has eluded definition, measurement, and intervention. Fatigue in these patients exists within a greater context of illness, treatment, and child and family development. Any effort to define, measure, and intervene with fatigue needs to take into consideration the major components of these children and adolescents' treatment context. The purpose of this descriptive study was to learn from three perspectives (patient, parent, and staff) how fatigue is identified and defined in 7- to 12-year-old children and in 13- to 18-year-old adolescents with cancer, and what factors contribute to or alleviate this fatigue. To elicit this information, separate focus groups were conducted with patients, parents, and staff at two pediatric oncology centers. Resulting interview data were analyzed using pragmatic and semantic content analysis techniques and the Wilson concept analysis process. Findings clearly indicated that children, adolescents, parents, and staff define patient fatigue differently. The conceptual definition from the child data emphasizes the physical sensation of the fatigue; alternating and at times merging physical and mental tiredness are emphasized in the adolescent's definition. Parents and staff view themselves as responsible for alleviating patient fatigue; patients viewed rest and distraction as their primary sources of improving fatigue. The conceptual definitions of fatigue as rendered by our three groups of participants can assist pediatric oncology patients, their parents, and staff in identifying fatigue. Factors identified by these participants as contributing or alleviating fatigue could be the basis for future interventions designed to reduce fatigue in pediatric oncology patients.

An essential function of a nurse is to provide comfort to patients, even in situations in which the disruptive symptom is difficult to identify, define, and measure (1-5). Attempts to comfort are further complicated when such symptoms both defy words and vary in intensity, appearance, and behavior. The variations in and the elusive nature of the symptom can confuse patients, family members, and health care professionals, leading to disagreements over the basis of the symptom and how best to respond to it. One such disruptive symptom is fatigue in children and adolescents with cancer.

Fatigue in pediatric cancer patients is a symptom that has eluded definition in both children and adolescents (6,7). A definition would assist the child, adolescent, family member, and health care professional in identifying or diagnosing fatigue that might otherwise go unobserved and thus untreated, or be wrongly labeled and mistreated. Fatigue in children and adolescents diagnosed with cancer exists within a greater context of illness, treatment, and child and family development (8). This greater context can be used to gain both an understanding of fatigue as a symptom, including how and when it appears in pediatric oncology patients, and information regarding the treatment of fatigue. To gain such benefits, however, several components of the context must be studied. In the context of the pediatric oncology patient experiencing fatigue, components include the patient, the parent, and the staff.

BACKGROUND

Identifying, defining, and managing symptoms in children and adolescents with cancer frequently present challenges for health care providers. These major challenges include inadequate recognition of the symptom, because of a heavy focus on curing the disease, and distrust of the patient's reports of symptoms that are primarily private, subjective experiences (9). These two challenges contribute to a third challenge-the lack of reliable and sensitive measures to detect the symptom and its response to intervention. The understandably strong focus on cure in pediatric oncology necessarily relegated symptom control to a lesser focus. Life-threatening conditions such as infection or thrombocytopenia have gradually come to the forefront of supportive therapy in pediatric oncology (10). With advancing success in cure rates, the research and clinical focus has shifted to include symptoms such as pain or nausea and vomiting (11,12). Attention to these symptoms has led to new standards of care in pediatric oncology that include the evaluation of such symptoms as part of the patient's treatment (13,14). Fatigue in children with cancer, which is perhaps more subjective than pain or nausea and vomiting, has yet to receive the same level of research and clinical attention.

The subjective aspects of fatigue (i.e., lack of confirmed physiologic and laboratory indicators, as well as the general unfamiliarity with the symptom itself) contribute to a reluctance on the part of parents and staff to rely solely on the child's or adolescent's verbal report. Although in other age-groups, the patient's report is generally accepted as the most valid source on symptoms, a child's or adolescent's report is rarely the basis for intervention. More commonly, parent and staff observations are used in place of or to support the pediatric patient's report (14,15). This reluctance to consider the child's or adolescent's report sufficiently valid to prompt a change in care further highlights the need to include all of the principal components of the child's or adolescent's treatment context (patient, parent, staff) in developing symptom awareness; that awareness would include a common language or approach to describing and monitoring the symptom.

The challenges of symptom identification and management have created a lack of understanding of how fatigue shows itself in children and adolescents with cancer. Neither the biologic and behavioral dimensions of fatigue nor the patterns of fatigue (which include occurrence, intensity, frequency, and duration of fatigue) in these patients are known. Moreover, we do not know what constitutes a typical or average course of fatigue in pediatric oncology patients; outcomes of fatigue (pathophysiologic, developmental, or psychological) have not been considered. How fatigue affects other symptoms in these patients is also unknown. As a direct result of these unknowns, fatigue is not routinely anticipated or assessed in the child or adolescent being treated for cancer.

Defining and monitoring fatigue in patients has clear benefits, as evidenced by studies involving adults with cancer and children and adolescents with chronic fatigue syndrome (CFS). The dimensions and patterns of fatigue in adult oncology patients have been systematically documented (16-19), and the functional impairments that result have been measured (20-23). These studies have thus far yielded research and clinical assessment measures of fatigue in adult oncology patients (24-26), patterns of fatigue (27-30), and interventions (18,31).

Chronic fatigue syndrome (CFS) in children and adolescents has been described as a debilitating symptom complex that can have an abrupt onset and linger for months to years (32). Somatic complaints include unexplained tiredness, headaches, sleep disturbances, pain, dizziness, psychological changes, and abdominal symptoms (33-36). The Centers for Disease Control established diagnostic criteria based on the descriptive studies on CFS in children and adolescents. These criteria have provided a framework for assessing CFS. The same approach is needed on behalf of children and adolescents with cancer so that accurate assessments of their fatigue can be made and effective interventions implemented as needed.

PURPOSE

The purpose of this two-site, descriptive study was to learn from three perspectives (patient, parent, and staff) how fatigue in 7- to 12-year-old children and 13- to 18-year-old adolescents with cancer is identified and defined. The study also was designed to identify factors that contribute to or alleviate this fatigue.

METHODS

Study Setting and Population

Patients, parents, and staff from Texas Children's Hospital (TCH) in Houston, Texas, and St. Jude Children's Research Hospital (SJCRH) in Memphis, Tennessee, were invited through posted flyers, e-mail, and posted mail to participate in focus group discussions of fatigue in 7- to 12-year-old and 13- to 18-year-old oncology patients. TCH, a 49-bed inpatient unit that includes a nine-bed bone marrow transplant unit, admits approximately 200 new pediatric oncology patients each year. SCJRH is a 54-bed pediatric cancer center with a 12-bed bone marrow transplant unit and eight intensive care beds; it admits approximately 350 new patients each year.

The sampling frame for the study included (a) all 7-to 12-year-old and 13-to 18-year-old patients receiving care for cancer in both settings who were inpatients or outpatients on the 7 days when the focus groups were being held and who were able and willing to participate; (b) parents of eligible patients who consented to participate; and (c) all staff who provided direct care to patients in either age-group (i.e., nurses, physicians, social workers, respiratory therapists, etc.) A patient could participate even though his or her parent did not; similarly, a parent could participate even though his or her child did not. However, this occurred in only five families.

Parents of all eligible patients were approached directly by members of the research team and invited to participate. They were given information sheets about the study and directed to the focus group session. All eligible patients, with parent permission, were also directly invited to participate. In addition, flyers inviting parents and patients were posted at key locations throughout both settings. Clinical staff were invited by posted flyers, mailings, and announcements at staff meetings.

Focus Groups

Separate focus groups were used to solicit patient, parent, and staff perspectives because such groups are useful in generating detailed descriptive data about unexplained phenomena. The interaction among group participants encourages a synergistic effect as additional comments are offered in response to the comments of others. The group approach is also useful with individuals who are better able to express their feelings or experiences verbally rather than in written form (37-39). The focus groups were held in private meeting rooms in either the inpatient or outpatient areas at both sites. The groups ranged in size from three to six participants. The focus groups for 7- to 12-year-olds lasted from 25 to 45 minutes; for 13- to 18-year olds, from 30 to 45 minutes; and the parent and staff sessions lasted from 40 to 60 minutes. Two team members served as co-facilitators, and one served as the observer for each focus group meeting. The 10 members of the research teams at both sites were staff nurses, advance practice nurses, and nurse researchers.

The problem definition for the focus groups was to identify the essential attributes of fatigue in 7- to 12-year-old and 13-to 18- year-old patients being treated for cancer as well as the factors that contributed to or alleviated their fatigue. The research teams prepared for the study by completing a half-day workshop on focus groups and practicing the roles of facilitator and observer. Additional review sessions were completed by the research teams at two points equally spaced among the focus group sessions, which occurred over a 4-week period.

Instrument

Nine questions were developed to solicit the essential characteristics and contributory and alleviating factors of fatigue; these questions were pilot-tested with three to five individuals from each perspective group who met study eligibility criteria. Parallel forms of the questions were used for the patient, parent, and staff groups (Table 1 gives examples of the questions). In addition, an observational tool was developed for use during each focus group. An observer from the research team recorded the behavioral reactions of each participant to the interview questions. Each focus group was audiotaped and the tape transcribed by a medical transcriptionist at each site. One member of the team at each site validated the accuracy of the transcription before data analysis.

Child or adolescent group	Parent group	Staff group
We are going to spend some time today talking about how children feel during their treatment for cancer. One of the feelings some children have talked about is feeling tired, or having "fatigue."	All of the questions that I am going to ask you are about your child.	All of the questions that I am going to ask you are about the children with cancer who are 7 to 12 years old or adolescents with cancer who are 13 to 18 years old.
1. How would you describe what it's like to be very tired or fatigued?	1. How can you tell when your child is "very tired" or "fatigued?"	1. How would you describe fatigue, or "being very tired" in your patients?
2. Please describe the things you cannot do when you feel very tired.	2. What things are hard for your child when he or she is very tired?	2. What things are difficult for patients when they are "very tired?"
3. When you are very tired, or have low energy, what kinds of things help you feel better?	3. When you child is very tired, what kinds of things help him or her to have more energy?	3. When you are caring for a patient who is very tired, what kinds of things do you do to help him or her have more energy?

TABLE 1. Examples of parallel questions used in the child, parent, or staff focus groups

DATA ANALYSIS

Demographic data were analyzed by using descriptive statistics. Interview data were analyzed by using the pragmatic (classifying data for probable cause or effect) and semantic (classifying data for meaning) content analysis approaches described by Krippendorff (40). The sampling unit was the participant's response to the question posed by the group facilitator. The recording unit was the sentence in each sampling unit. More than 500 pages of transcribed discussion resulted from each of the four separate types of focus groups (7- to 12-year-old patient, 13- to 18-year-old patient, parent, and staff).

The two principal investigators (PI) from each site jointly coded the first two transcriptions and developed a coding dictionary for the interview data. Research team members then participated in a workshop on coding interview data. When a preestablished agreement level of 90% with the PI coding was achieved, members of the team were assigned a transcribed interview. Four team members independently coded the same interview. Training sessions for coding were repeated in verbal and written form during the 6-month coding period. A "percent agreement" was calculated by code, rater, and interview for each of the transcribed tapes. Agreement was signified by each coder assigning the same code to the same sentence or by leaving the same sentence without a code. The preestablished agreement criterion of 90% (number of agreements divided by the sum total of agreements and disagreements) (41) was maintained. Codes were subsequently categorized as follows: descriptors of fatigue, causes of fatigue, general alleviating factors, and staff-initiated actions in response to patient fatigue. The computer software program ETHNOGRAPH (SCOLARI, Sage Publications Software, Inc., Thousand Oaks, CA) was used to assist with data management and to generate tallies of the frequencies of each code by focus group type. The behaviors recorded on the observation forms were reviewed for agreement or disagreement with the verbal responses of participants. No disagreements were observed in any group.

Team members also completed a concept analysis of fatigue from each perspective using the focus group transcriptions. The Wilson method (42,43) was used. A conceptual model for each group (child, adolescent, parent, and staff) was generated to specify relationships between fatigue and contributory and alleviating factors. The model included categories of defined influencing factors. Trustworthiness of the content analysis and the concept analysis was supported by having multiple researchers and clinicians at both sites participate in data collection, analysis, and interpretation of findings. All of the participating researchers and clinicians have been involved in pediatric oncology for 1 to 23 years and thus have strong familiarity with the language and experience of the patient, family members, and staff. Four teleconferences were held between the participants of both sites during the periods of data collection, analysis, and interpretation, which facilitated discussion about and verification of the data and findings. In addition, findings were shared with and validated by individuals from each of the four perspectives.

SAMPLE

Fourteen 7- to 12-year-old patients participated in one of five focus groups. Most of the children were male (n = 8 or 57%) and white (n = 12 or 86%) (two were black). Approximately 57% (n = 8) of the participating children had diagnoses of leukemia or lymphoma; 43% (n = 6) had a solid tumor. The months since diagnosis ranged from 1 to 95 months.

Fifteen 13- to 18-year-old patients participated in one of five focus groups. Most of the adolescents were female (n = 10 or 67%) and white (n =9 or 60%). Diagnoses were divided somewhat evenly between leukemia or lymphoma (n = 8 or 53%) and solid tumor (n = 7 or 47%). Time since diagnosis ranged for the adolescents from 1 to 59 months.

Thirty-one parents participated in 1 of 10 focus groups. Of these, 28 were mothers and three were fathers. Most were white (n = 25 or 82%). Their children's diagnoses included leukemia (55%), lymphoma (23%), or solid tumor (22%).

Thirty-eight staff (8 advanced practice nurses, 23 staff nurses, 2 nurse managers, 3 nutritionists, 1 chaplain, and 1 physician) participated in 1 of 10 focus group sessions. The staff's experience in pediatric oncology ranged from 2 months to 23 years. Most were female (n = 35) and white (n = 33).

RESULTS

The content analysis of the focus group data generated 18 codes from the child data, 33 from the adolescent data, 35 from the parent data, and 55 from the staff data (Table 2). Codes from all four perspectives generally fell into one of two categories: descriptors of fatigue and causes of fatigue. Only the codes generated in each type of group (child, adolescent, parent, and staff) were used to identify the essential attributes of fatigue as perceived by that group. The resulting definitions of fatigue (Table 3) included the essential characteristics and outcomes of fatigue, as well as the contributory and alleviating factors. The number of essential characteristics, outcomes, and influencing factors constituting the conceptual definitions increased, with the lowest number occurring in the 7- to 12-year-old patients and the highest number in the staff-generated definition. The predominant essential attribute of fatigue in the 7- to 12-year-olds was a physical weakness; in the 13- to 18-year-olds, it was physical or mental exhaustion; and in the parent and staff perspectives, it was diminished to complete loss of energy.

	Focus Group			
Category of Codes	Child	Adolescent	Parent	Staff
1. Descriptors of fatigue	9	12	16	17
2. Causes of fatigue	6	13	11	16
3. General alleviating factors	3	7	8	15
4. Staff initiated alleviating factors	0	1	0	7

TABLE 2. Type and frequency of codes generated by the content analysis of data from the focus groups

Fatigue from the perspective of the 7- to 12-year-old pediatric oncology patient	Fatigue from the perspective of the 13- to 18-year-old pediatric oncology patient	Fatigue in the pediatric oncology patient from the perspective of the parent	Fatigue in the pediatric oncology patient from the perspective of the staff
Fatigue is a profound sense of being weak or tired, or of having difficulty with movement such as using arms or legs, or opening eyes, that is influenced by environmental, social, and treatment-related factors and can result in difficulties with play, concentration, and negative emotions (most typically anger and sadness). This profound sense of weakness or tiredness can be acute, episodic, or chronic and is relieved by rest and distraction.	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 to be 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.	Fatigue is a state of diminished-to-complete loss of energy that is influenced by disease state, nutritional, emotional, environmental, personal/behavioral, family, and treatment-related factors and that results in a decreased ability to participate in social, academic, physical, or self-care activities at the child's usual intensity or duration. This state may be acute, episodic, or chronic and can be accompanied by an emotional or mental withdrawal, mood change, physicial appearance change, decreased cooperation, and a desire to rest or lie down. The fatigue can be relieved by more flexible family schedules, encouraging the child to attempt usual activities, protecting the child from certain environmental stimuli, being sensitive to the child's emotional state, and providing physical or emotional comfort.	Fatigue is a state of diminished-to-complete loss of energy and/or will that is influenced by environmental, biochemical, personal, cultural, and treatment-related factors and results in reduced ability to participate in usual social, academic, physical, or self-care activities at the patient's typical intensity level or duration. This state, which may be acute, episodic, or chronic, can be accompanied by emotional or mental withdrawal, mood change (usually increased irritability), decreased cooperation, spiritual distress, and a desire to rest or lie down (all of which may differ by day, course of treatment, or diagnosis). This fatigue may be relieved by controlling the environment, being sensitive to the patient's emotional state and developmental status, providing support and guidance to the parents, and initiating pharmacologic/nutritional/blood product interventions.

TABLE 3. The conceptual definitions of fatigue derived from the content analysis of focus group data

In the Wilson concept analysis process, all codes by perspective were sorted for similarity and grouped into a possible total of eight categories of influencing factors, which were then conceptually defined. (Table 4 lists the categories from the staff perspective.) In the child model, no contributing factors were identified as fitting in the category of Cultural/Family/Others, and no alleviating factors were identified in the Environment or Treatment-Related categories. The seven contributing factors were most evenly distributed across the Environmental, Personal/Behavioral, and Treatment-Related categories. Thus, children do not perceive that their fatigue is caused by family or cultural influences but instead by their inability to get adequate sleep or to participate in exercise or other forms of activities, as well as by the negative impact of treatment and certain symptoms such as pain. In contrast, the three alleviating factors (napping,/sleeping, having visitors, fun activities) all fit conceptually in the categories of Personal/Behavioral and Cultural/Family/Others.

Category	Contributing factors	Alleviating factors
Environmental	Factors include the child reacting to a return or a continuing stay in the treatment setting, experiencing long waits involving prone positions or activities without physical movement, altered schedules or routines that do not reflect a defined beginning and ending of each day, and multiple situations of high cognitive demand such as information exchange and decision making.	Staff-initiated efforts such as protecting rest or sleep periods of the child by organizing care into concentrated blocks rather than as continuous and intermittent care efforts, implementing a schedule that reflects a defined waking time and bedtime, abbreviating a clinic visit to allow the child to leave as quickly as possible, and strong efforts to minimize noise levels and other forms of stimulation around the child.
Personal/Behavioral	Factors include the child's negative belief that he or she will be able to function in usual ways, or the experience of altered or interrupted sleep patterns (i.e., changing sleep locations, hours of sleep, depth of sleep), patient's age and lack of sufficient cognitive stimulation, leading to boredom or negative thoughts.	Staff-initiated efforts such as emphasizing what the child is capable of doing rather than what he cannot do, providing additional support for the child and encouraging him or her to voice concerns or fears, attempting to persuade the child to participate, allowing choices, being firm (at times) to involve the child in self-care activities, discovering ways to work with each child (such as slowly wakening the child), and encouraging the child to participate in exercise and other distracting activities as tolerated.
Cultural/Family/Other	Factors include the child's being adversely affected by the emotions, moods, concerns, and expectations of others, such as relatives or friends, and being urged by others to engage too vigorously in activities or to unnecessarily avoid participation in activities.	Factors observed by staff but initiated by families or friends include rearranging family schedules to do activities at times when the child is likely to have more energy or providing more quiet activities and rest periods, staff-initiated efforts with family members include encouraging them to examine their expectations of the child (whether too demanding or too minimal) and to not unnecessarily limit the child's activities or efforts so as to avoid dependency, and teaching parents relaxation strategies and emphasizing the importance of maintaining their own health.
Treatment-Related	Factors include the child's experiencing invasive examinations or procedures, repeated courses of treatment without sufficient days between to recover strength, inadequate nutrition or metabolic changes, adverse effects of therapy (such as inadequately functioning bone marrow), and diagnosis-related factors, such as stage of treatment.	Staff-initiated efforts include careful monitoring of the child's nutritional and hematologic status, administering ordered blood products, and evaluating nutritional, hematologic, and pharmacologic interventions to ensure that the child's needs are effectively met.

TABLE 4. Categories and definitions of factors that contribute to and alleviate fatigue in pediatric oncology patients from the perspective of staff

Similarly, no contributory or alleviating factors in the adolescent model were assigned to the category of Cultural/Family/Others. Five contributing factors were assigned to the Environmental category and six to the Personal/Behavioral category; only two were assigned to the category of Treatment-Related. In contrast, only two to three alleviating factors fit conceptually in those same three categories. Thus, adolescents perceive noise, inability to sleep, feeling upset or fearful or bored, and the effects of treatment as causing their fatigue. Being able to rest, leaving the hospital or clinic setting, being distracted, and receiving symptom relief or being involved in physical therapy were perceived as relieving their fatigue.

In the parent model, factors were assigned to all eight categories. Four to five contributory factors fit conceptually with all of the categories, with one exception-only one was assigned to the category of Cultural/Family/Other. Contributing factors were hospital sounds, interruptions, waiting, and needing to interact with too many other individuals. Other factors were related to worry, altered sleep, parental influences (e.g., "you are too tired to try to do that."), and the effects of treatment. Three alleviating factors were assigned to the categories of Personal/Behavioral and Cultural/Family/Other but only one each to the categories of Environmental and Treatment-Related. In general, parents perceived protected sleep time and their efforts to comfort and encourage their child, to be more patient with their child, changing the family schedule to better match their child's energy levels, and providing adequate nutrition as factors that improved their child's fatigue. In the staff model, all eight categories were also represented. Four to five contributing factors were assigned to all but one of the categories-Cultural/Family/Others-which had only two factors. Three to 10 alleviating factors were assigned to the four categories, but the category of Personal/Behavioral had twice as many factors as the other categories. Notable similarity between the parent and staff perceptions exists. Differences were primarily in staff perceptions of alleviating factors in that staff identified far more supportive behaviors that they could enact directly with patients plus additional strategies to help parents relax. A model depicting contributory and alleviating factors for each perspective (child, adolescent, parent, and staff) was then generated. (See Figs. 1, 2, 3, and 4.)

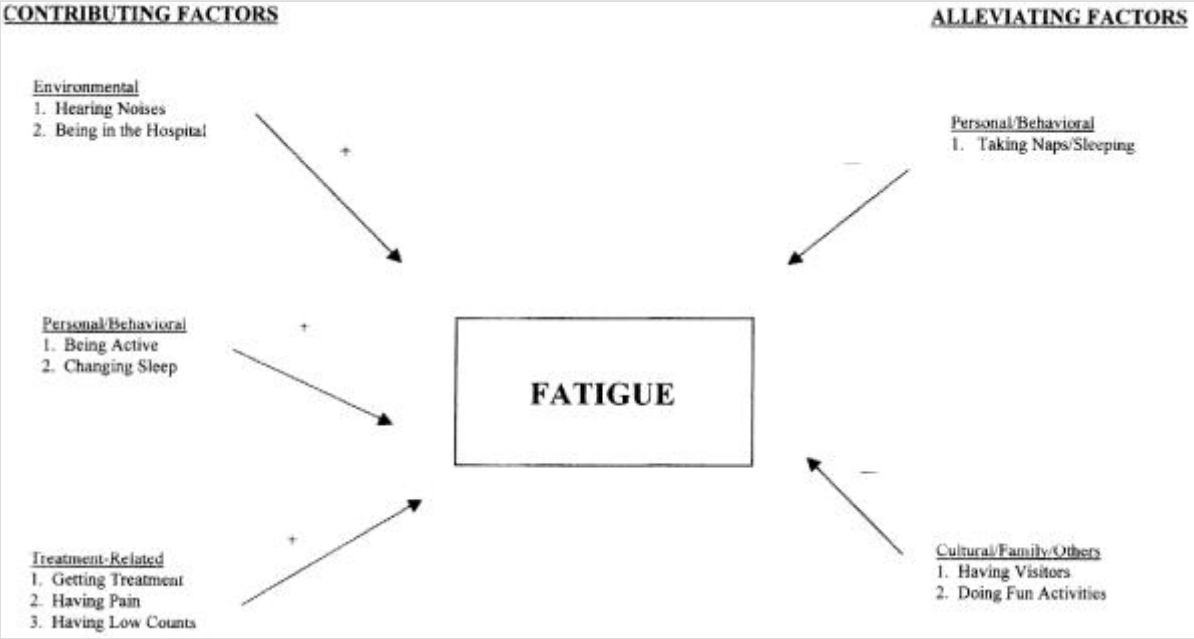

FIG. 1. Model depicting factors identified by 7- to 12-year-old patients that contribute to or alleviate their fatigue.

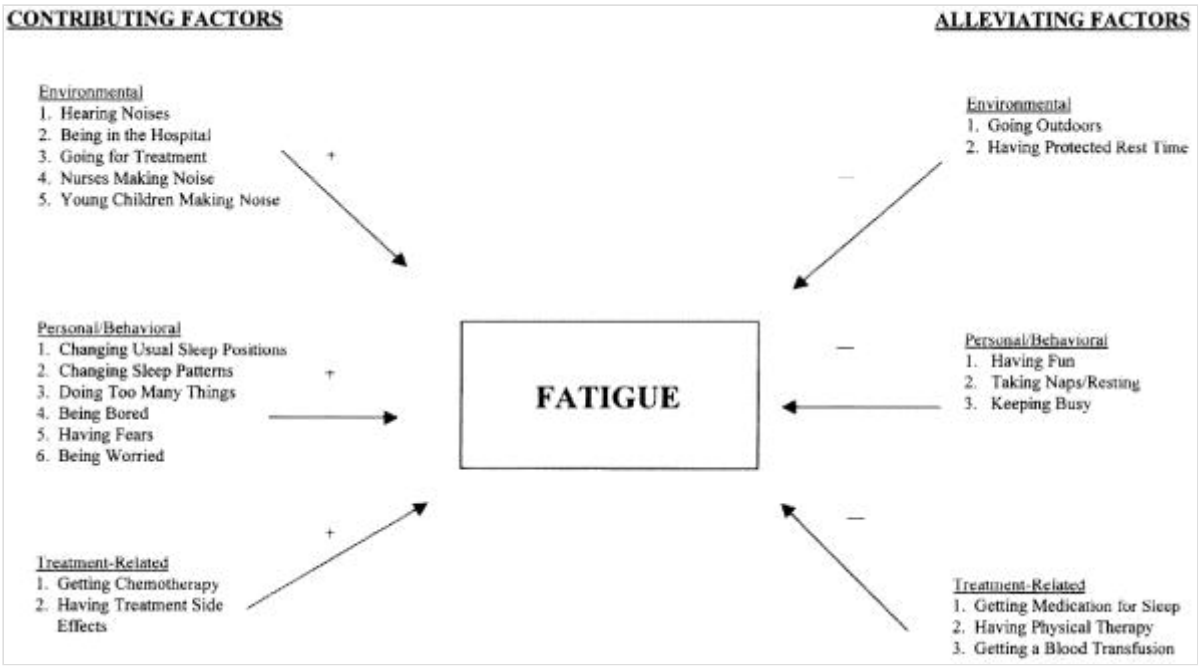

FIG. 2. Model depicting factors identified by 13- to 18-year-old patients that contribute to or alleviate their fatigue.

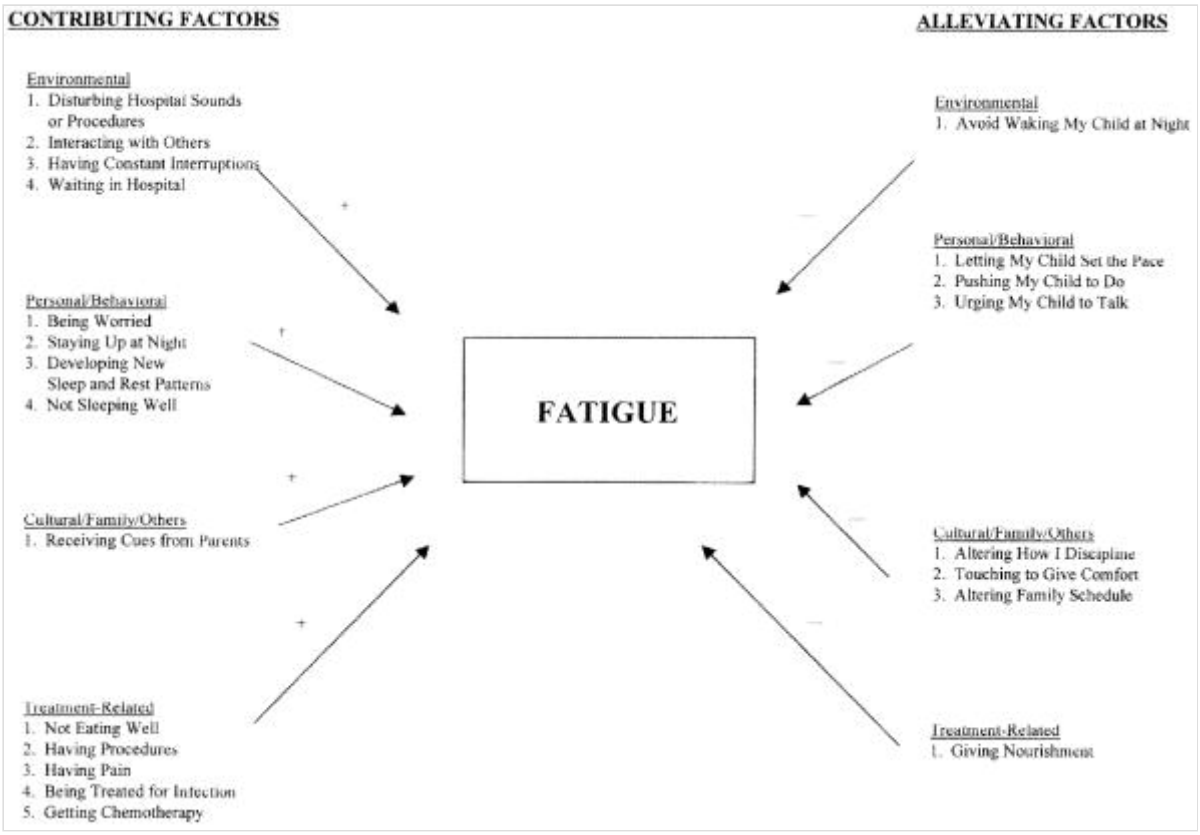

FIG. 3. Model depicting factors identified by parents as contributing to or alleviating fatigue in their child.

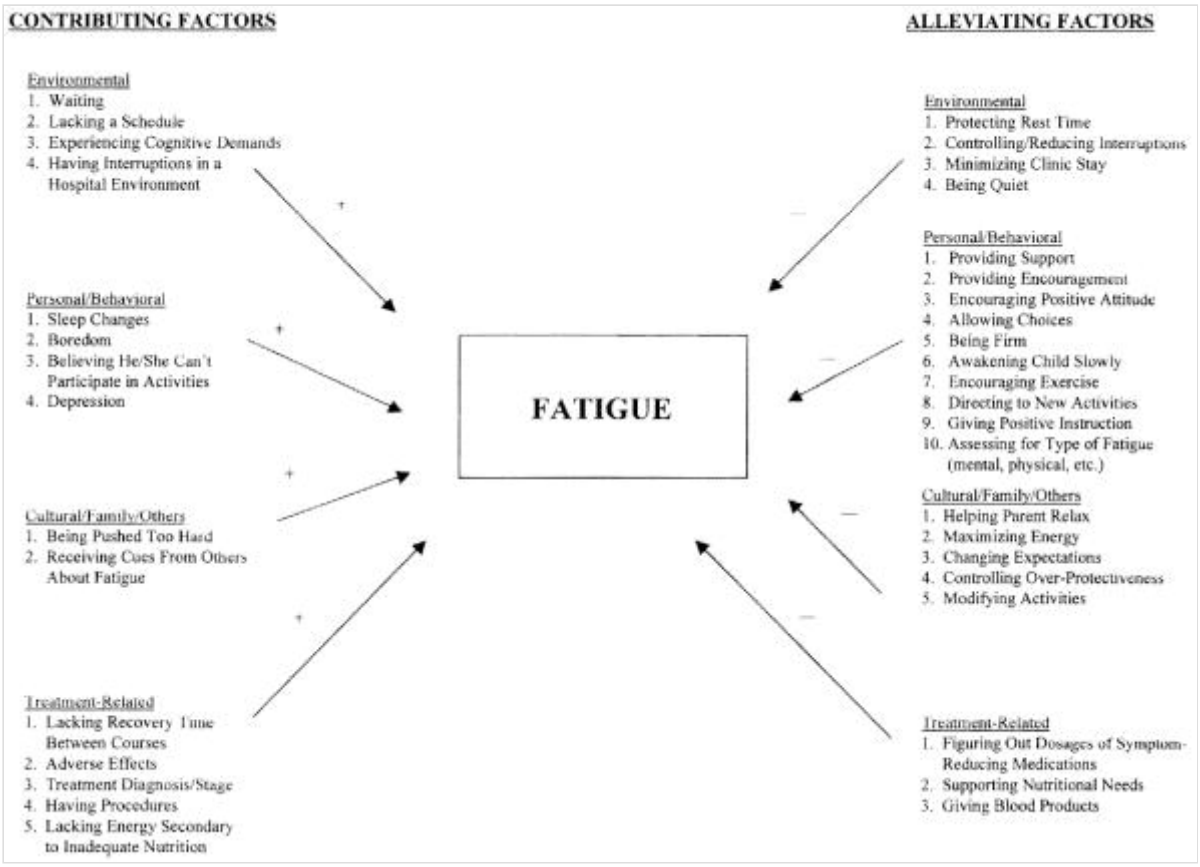

FIG. 4. Model depicting factors identified by staff as contributing to or alleviating fatigue in pediatric oncology patients.

DISCUSSION

The number of codes generated from the focus group data was age-related, with the fewest generated from the 7- to 12-year-old patient data and the highest from the parent and staff data. This trend was particularly apparent in the number of codes in the contributory and alleviating categories, indicating that younger children are more likely to perceive fewer factors as causes or alleviators of their fatigue. Adolescents, however, attribute their fatigue to a greater variety of sources and recognize a greater number of restorative interventions. Both patient groups identified more causes of their fatigue than alleviating factors, which suggests that they are more aware of what makes them feel fatigued than of what helps them to overcome fatigue. For children and adolescents to believe that parents and staff accept their reports of fatigue as valid and that they intend to assist them in reducing their fatigue, the interventions need to incorporate what the patients believe reduces their fatigue-rest and distraction.

The conceptual definitions of fatigue from the four studied perspectives share similarities and differences. The definitions all reflect changes in the patient's behavior (e.g., showing less than his or her usual abilities in social and academic areas) or emotional state (e.g., anger, sadness, or impatience). The definitions also share a recognition of the patient's desire to rest or lie down and the realization that fatigue can change in occurrence and intensity.

The child's perspective emphasizes a physical sensation (weakness), whereas the adolescent's definition emphasizes the dynamic sensation of physical or mental exhaustion. The parent's definition is broad (loss of energy) and encompassing (multiple causative factors), much like the staff definition; however, the staff definition also includes loss of will and spiritual distress. The parent and staff conceptual definitions contain the same essential characteristics for 7- to 12-year-old patients and 13- to 18-year-old patients. The difference between the two age-groups was in emphasis, with disruption of sleep and reduced energy more frequently mentioned by parents and staff of 7- to 12-year-old patients, and emotional withdrawal more frequently identified in 13- to 18-year-old patients. This finding suggests that the intensity of essential characteristics rather than type or number is what distinguishes fatigue in the two age-groups. The descriptions of fatigue from both patient groups differed from those contained in the literature about children and adolescents with CFS (32,33), because patients with cancer did not report as many somatic symptoms such as headaches or dizziness.

All four perspectives identified cancer treatment as a causative or contributory factor to fatigue in pediatric patients. Similarly, all four identified noisy, intrusive, or unfamiliar environments as contributing to patient fatigue. Children viewed distraction and rest as the greatest sources of relieving fatigue. They did not identify roles for staff in alleviating their fatigue. Adolescents identified rest, distraction, and medical/pharmacologic treatments as factors that diminish their fatigue. In contrast, parents viewed themselves as having the primary responsibility for diminishing their child's fatigue through creating more flexible family schedules, offering encouragement to their child, and protecting their child from intrusive sounds or interruptions that could disturb their child's rest or sleep. Staff viewed themselves as influencing fatigue in pediatric oncology patients both directly (initiating medical/supportive care interventions; providing words of encouragement to the patient) and indirectly (providing words of encouragement to the parents; planning less intrusive care.) These differing perspectives in terms of essential characteristics, and causative and alleviating factors, highlight the need to anticipate differences and to educate to diminish those. The differences regarding the role each perceives he or she has in influencing the child's or adolescent's fatigue also highlights the importance of involving all of the major components of the pediatric oncology patient's treatment context (patient, parent, and staff) in implementing a comfort approach. If this is not done, patients may feel their reports are being disregarded, and parents and staff may believe they did not do all that they could have done to provide comfort to the fatigued patient.

Study findings are descriptively elucidating of the diverse perspectives, and that is important with subjective phenomena such as fatigue. However, the findings also may indicate a limitation of relying only on self-report data because biologic and pathophysiologic correlates (such as those reported in the literature on adults with fatigue) are unlikely to be included yet may be helpful in explaining, predicting, or reducing fatigue in the child or adolescent with cancer. The strength of these findings is that they can assist nurses and other health care providers in educating patients, families, and staff about fatigue, and in completing accurate assessments that could prompt effective interventions being implemented.

CONCLUSION

Children, adolescents, parents, and staff use different words to describe fatigue, possibly because they each perceive fatigue somewhat differently. Our study findings may provide the basis of a shared language that could assist all four groups in identifying and labeling fatigue. Defining the symptom is the first step in providing comfort to the patient experiencing the symptom. Pediatric oncology patients, their parents, and staff share some beliefs about what causes and what alleviates fatigue. These study findings have identified those beliefs. Incorporating them into a care approach that includes assessing and monitoring fatigue in these patients will result in an improved understanding of their experience with fatigue and in providing them greater comfort.

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CE TEST: Fatigue in pediatric oncology patients

General Purpose

The general purpose of this continuing education offering is to provide the registered professional nurse with information on how fatigue in pediatric and adolescent oncology patients is perceived by patient, parents, and staff, and to identify factors that may influence fatigue development and relief.

Objectives

After reading this article and taking the test, you will be able to:

1. describe fatigue as a major disruptive symptom in children who have cancer;
2. summarize the results of focus groups' discussions about fatigue;
3. identify interventions helpful for relieving fatigue in pediatric oncology patients.

Test

1. Which of these symptoms in children who have cancer is described by the authors as being the most subjective?

a. pain

b. fatigue

c. nausea

d. vomiting

2. Which of these statements accurately describes the challenge associated with managing fatigue in children who have cancer?

a. There is a lack of reliable measures of the symptom.

b. Pain symptoms are best evaluated with objective evidence.

c. The greatest focus of care is on controlling symptoms.

d. Fatigue is routinely anticipated as an effect of treatment.

3. When compared to an adult, a child's report of fatigue is usually

a. accepted as the most valid source.

b. used as the basis for intervention.

c. considered secondary to staff observations.

d. validated by laboratory indicators.

4. Focus groups were used in the study to

a. generate descriptive data about fatigue.

b. develop a questionnaire.

c. create an observational tool.

d. validate the accuracy of the measurement instrument.

5. For which of these reasons was a conceptual model generated for each focus group?

a. to assist with data management and generate tallies of symptom frequency

b. to establish agreement or disagreement with verbal response of participants

c. to identify a concept analysis of fatigue for each focus group

d. to specify relationships between fatigue and contributory and alleviating factors

6. Which of these focus groups in the study identified the lowest number of essential characteristics of fatigue?

a. 7- to 12-year-old patients

b. 13- to 18-year-old patients

c. parents

d. staff members

7. This study identified that children perceived their fatigue as being caused by

a. family.

b. cultural influence.

c. lack of sleep.

d. having visitors.

8. Which of these statements accurately states the conceptual definition of fatigue from the perspective of the 7- to 12-year-old pediatric oncology patient?

a. a complex, changing state of exhaustion

b. a profound sense of being weak or tired

c. a state of diminished energy

d. a state of complete loss of energy

9. Which of these factors did the adolescent focus group identify as being effective for alleviating fatigue?

a. participating in physical therapy

b. having nutritious meals

c. receiving parental comfort

d. feeling accepted by the peer group

10. When compared to the parent group, the staff group identified

a. fatigue as a profound sense of being tired.

b. fewer categories of contributing factors.

c. strategies to help parents relax.

d. more supportive behaviors as alleviating factors.

11. Which of these factors is present in the conceptual definition of fatigue for all four focus groups in this study?

a. recognition of the patient's desire to rest

b. identification of staff roles for alleviating fatigue

c. recognition of need for pharmacologic intervention

d. identification of importance of maintaining regular schedule

12. "Awakening slowly" is an alleviating factor that was identified by which focus group in this study?

a. 7- to 12-year-old

b. 13- to 18-year-old

c. parent

d. staff

13. Nutritional support is an alleviating factor which was identified by which of the focus groups in this study?

a. child and adolescent

b. adolescent and parent

c. parent and child

d. parent and staff

14. Which of these conclusions can be drawn from this study?

a. Children, staff, and parents have the same perceptions of fatigue.

b. Pathophysiologic causes of fatigue are unlikely to be helpful in explaining fatigue.

c. Children, staff, and parents share some beliefs about what causes and alleviates fatigue.

d. Pharmacologic relief is essential for the treatment of fatigue.

15. Which of these approaches should a nurse take when caring for a hospitalized child who is experiencing fatigue related to oncology treatment?

a. Anticipate differences between the child and his parents' perspective of fatigue.

b. Set priorities based on the parents' perspective of the child's fatigue.

c. Expect the child to attribute his fatigue to family expectations.

d. Advise the parents to discourage other family members from visiting the child.

16. Which of these alleviating factors was identified only by the parent group in this study?

a. altering the family schedule

b. allowing the child to make choices

c. promoting the child's nutritional intake

d. being firm with the child

17. Which of these alleviating factors is identified by both the adolescent and staff focus groups in this study?

a. having physical therapy

b. allowing choices

c. providing blood transfusions

d. having visitors

18. Which of these approaches should a nurse take when caring for a pediatric oncology patient who is experiencing fatigue?

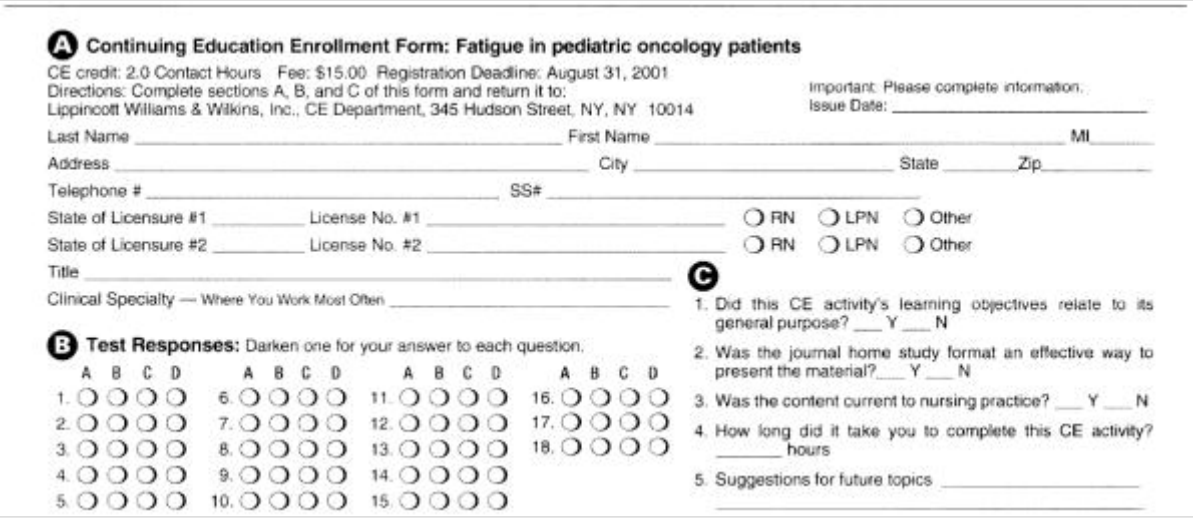
a. Incorporating the beliefs of the child and his parents into the care plan.

b. Focusing on the parent's interpretation of the child's experience.

c. Considering the professional staff viewpoint as the priority because it is the most objective perspective.

d. Recognizing that pharmacological intervention is essential for control of fatigue.

(Figure 5)



A Continuing Education Enrollment Form: Fatigue in pediatric oncology patients

CE credit: 2.0 Contact Hours Fee: $15.00 Registration Deadline: August 31, 2001
Directions: Complete sections A, B, and C of this form and return it to:
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Important: Please complete information.
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B Test Responses: Darken one for your answer to each question.

	A	B	C	D		A	B	C	D		A	B	C	D		A	B	C	D
1.	○	○	○	○	6.	○	○	○	○	11.	○	○	○	○	16.	○	○	○	○
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3.	○	○	○	○	8.	○	○	○	○	13.	○	○	○	○	18.	○	○	○	○
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5.	○	○	○	○	10.	○	○	○	○	15.	○	○	○	○					

C

1. Did this CE activity's learning objectives relate to its general purpose? ___ Y ___ N
2. Was the journal home study format an effective way to present the material?___ Y ___ N
3. Was the content current to nursing practice? ___ Y ___ N
4. How long did it take you to complete this CE activity? _____ hours
5. Suggestions for future topics _____

Figure 5. No caption available.

*In accordance with the Iowa Board of Nursing Administrative rules governing grievances, a copy of your evaluation of the CE offering (section C) may be submitted directly to the Iowa Board of Nursing. [Context Link]

Key Words: Children and adolescents; Fatigue; Parents and staff; Pediatric oncology

IMAGE GALLERY

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Table 1

Table 2

Table 3

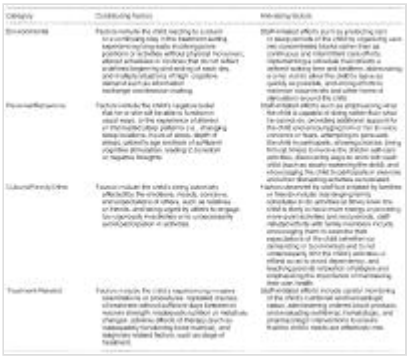

Table 4

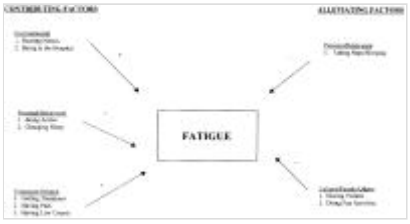

Fig. 1

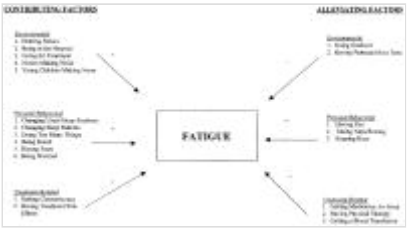

Fig. 2

Fig. 3

Fig. 4

Figure 5

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