Review Article

Psychometric Properties of Instruments Used to Measure Fatigue in Children and Adolescents With Cancer: A Systematic Review

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Abstract

Context. Despite the recognized distressing symptom of fatigue in children with cancer, little information is available to assist in the selection of an instrument to be used to measure fatigue.

Objectives. The objectives of this study were to 1) describe the instruments that have been used to measure cancer-related fatigue in children and adolescents and 2) summarize the psychometric properties of the most commonly used instruments used to measure fatigue in children and adolescents with cancer.

Methods. Five major electronic databases were systematically searched for studies using a fatigue measurement scale in a population of children or adolescents with cancer. Fatigue scales used in those studies were included in the review.

Results. From a total of 1753 articles, 25 were included. We identified two main fatigue measurement instruments used in a pediatric oncology population: 1) the Fatigue Scale-Child/Fatigue Scale-Adolescent and the proxy report versions for parents and staff and 2) the PedsQL™ Multidimensional Fatigue Scale. These two scales show similar attributes with reasonably good internal consistency and responsiveness.

Conclusion. Either the Fatigue Scale or PedsQL Multidimensional Fatigue Scale can be incorporated into clinical research. Future research should focus on identifying specific fatigue measures more suited to different purposes such as comparative trials or identification of high-risk groups. J Pain Symptom Manage 2013;45:83–91.

Key Words
Cancer-related fatigue, scales, measurement, psychometric properties, children, adolescents

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Introduction

Fatigue has been increasingly recognized as an important symptom during and after treatment of cancer in children and adolescents[1–3] and may be defined as having physical, mental, and emotional components characterized by a lack of energy, decreased physical ability, and feelings of tiredness.[4–6] Cancer-related fatigue (CRF) is a subjective multidimensional construct[3] that may be acute, episodic, or chronic in nature.[3,5,7] The etiology of CRF is frequently multifactorial.[3,8] Fatigue is apparent in children and adolescents with cancer at all stages of the disease trajectory.[9–15]

Recent publications about fatigue in children and adolescents with cancer have provided theoretical background knowledge and developed a conceptual framework in an attempt to better understand this complex phenomenon.[3,8,16–18] This information also has enabled the development of instruments that can measure CRF in children and adolescents.[19–21]

Fatigue measures for children and adolescents are important because they allow the burden of fatigue to be described, high-risk groups to be identified, and treatments to be evaluated and compared. There are two main approaches to the measurement of fatigue in children, namely self-report and proxy report by parents, other caregivers, or health care professionals. As studies that focus on fatigue are developed, it is important to ensure that reliable and valid fatigue measures are being used. It also would be useful to understand how existing instruments differ so that the best instrument could be selected for a specific trial. However, little information is available to guide in the selection of an instrument to be used to measure fatigue in pediatric oncology trials.

Consequently, the objectives of this study were to 1) describe the instruments that have been used to measure CRF in children and adolescents and 2) summarize the psychometric properties of the most commonly used instruments that measure fatigue in children and adolescents with cancer.

Methods

Search Strategy for Identification of Studies

We conducted literature searches using the Ovid search platform and included the following databases: MEDLINE, Embase, PsycINFO, and Controlled Trial Register. We also used EBSCOhost to search the CINAHL database. Databases were queried from inception to April 11, 2011. The search strategy used the following subject headings and text words: "asthenia or fatigue or sleep deprivation," "neoplasms," and "scale or measurement." The search was limited to studies including children age zero to 18 years. This included proxy report for the younger age groups of children.

Strategy for Selection of Articles for Review

One author (D. T.) evaluated articles identified by the search strategy and applied the eligibility criteria. Articles were included if they were clinical research studies that reported on the use of a fatigue measurement tool in children or adolescents with cancer and reported at least one psychometric property. Articles also were included if they described a study that used a fatigue measurement scale as an outcome measure in such a manner that the psychometric properties of the selected instrument could be secondarily evaluated. Studies were excluded if they 1) were not research studies, 2) did not include a cancer population, 3) did not include children, 4) did not quantify fatigue, and 5) did not evaluate or report any psychometric properties of a fatigue instrument.

Review of Psychometric Properties of Fatigue Instruments Examined

We reported the following psychometric properties: reliability (internal consistency $[0.9 > \alpha \geq 0.8]$), test-retest ($r > 0.5$) and interrater ($r < 0.04$) reliability, construct validity, and responsiveness. For construct validation, we examined convergent construct validity in studies that used another self-report scale (correlation coefficient ≥ 0.7).[22] Another aspect of validation, known group validity, was derived by examining studies, often intervention studies, that showed a statistically significant difference in scores between groups hypothesized to have differing amounts of fatigue ($P < 0.05$). We evaluated responsiveness by examining statistically significant increases in scores to fatigue-increasing events or stimuli such as a medication and significant decreases in scores to fatigue-decreasing events such as passage of time after treatment ($P < 0.05$). We also noted if any studies evaluated newer approaches to

instrumentation, namely Rasch analysis and item response theory (IRT).

Results

Fig. 1 illustrates the flow of article selection. A total of 1753 articles were identified by the search strategy. Abstracts and titles were initially screened for duplicates and eligibility. Among the 1753 articles, 276 (15.6%) were duplicates and 1329 (76%) did not meet eligibility criteria. After initial screening, 148 articles were retrieved for full text review. Full text review resulted in 20 articles that were not research studies, 36 articles that included populations other than children, 52 articles in which fatigue was not quantified, and 15 studies in which psychometrics were not evaluated, leaving a total of 25 studies included in the review.[20,21,23–46]

Characteristics of the 25 articles included in this review are summarized in Table 1. The most commonly used instruments were 1) the Fatigue Scale-Child (FS-C)/Fatigue Scale-Adolescent (FS-A) and the proxy report versions for parents (Fatigue Scale-Parent) and staff (Fatigue Scale-Staff) ($n = 13$)[20,21,24,25,27,30–32,36–39,43,46] and 2) PedsQL™ Multidimensional Fatigue Scale (MFS) ($n = 8$)[29,33–35,40,41,44,45] self-report and parent proxy version. Four other CRF instruments also had psychometric properties reported: 1) Pediatric Functional Assessment of Chronic Illness Therapy-Fatigue, 2) Memorial Symptom Assessment Scale (MSAS), 3) Daily Fatigue Report Scale, and 4) McCorkle Symptom Distress Scale (SDS).

The FS-C, developed by Hockenberry et al.,[21] was the most commonly evaluated instrument. This instrument measures self-reported CRF and provides a fatigue intensity score.

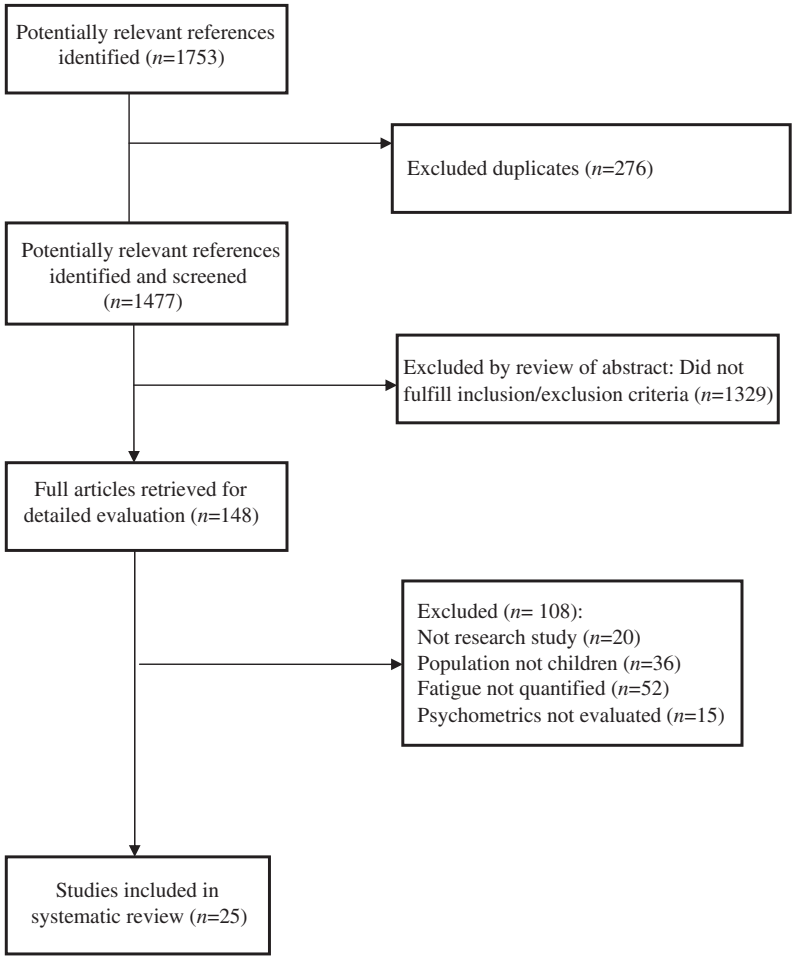

Fig. 1. Flow diagram of study identification and selection.

Table 1

Measures of Fatigue in Studies of Children and Adolescents With Cancer ($n = 25$)

Study	Participants	Fatigue Scales Used	Psychometric Properties Examined
Fatigue Scale (Child, adolescent, and parent)			
Psychometric testing of 10-item reduced version of the FS-C[20]	221 children aged seven to 17 years across three studies: 1. 53 children and their parents ($n = 51$) 2. 150 children and their parents ($n = 148$) 3. 18 children and their parents	FS-C FS-P Produced a 10-item FS-C	Internal consistency reliability: $\alpha = 0.81$ FS-C; 0.76 FS-C (10-item) Correlation between FS-C and FS-P: $r = 0.441$, $P < 0.0001$ Used Rasch to reduce FS-C from a 14- to 10-item version. Used receiver operating curve to demonstrate sensitivity and specificity of threshold for delineating high cancer-related fatigue
Sleep habits and fatigue of children with ALL receiving maintenance chemotherapy[46]	Nine adolescents aged 14–18 years 53 parents of children aged four to 13 years	FS-A FS-P	Known group validity across some groups but not all: $P < 0.0007$ (four- to seven-year-olds who have sleep problems vs. without sleep problems) to *$P = 0.71$ (13+-year-olds who have different sleep patterns)*
Changes in fatigue during cancer treatment in children: adolescent and parent report[36,37]	40 children aged seven to 12 years 29 adolescents aged 13–15 years 69 parents of above children and adolescents	FS-C FS-A FS-P	Responsiveness over time: children: $P = 0.003$; adolescents: $P = 0.03$; and parents: $P = 0.02$
Carnitine plasma levels and fatigue[32]	67 children aged seven to 18 years	FS-C FS-A	Correlation with free carnitine plasma levels $P = 0.016$ and total carnitine plasma levels $P = 0.043$
Impact of nursing interventions on fatigue in children receiving chemotherapy[27]	60 children aged seven to 12 years and their mothers; 30 in intervention group and 30 in control group	FS-C FS-P	Known group validity for comparison between intervention and control groups: mean 27.23 vs. 42.13, $t = 5.25$, $P < 0.001$
Chemotherapy-related fatigue in childhood cancer[43]	12 children with cancer aged seven to 17 years and their parents	FS-C FS-A FS-P	Correlation between self-report and parent proxy report: $r = 0.247$, $P < 0.01$
Gender differences in sleep, fatigue, and activity in children with ALL receiving dexamethasone[39]	65 children aged five to 17 years 84 parents	FS-C FS-A FS-P	*Known group validity not apparent for comparison between genders: mean ± SD pre-dexamethasone children, boys 9.78 ± 8.53 vs. girls 8.24 ± 6.33; adolescents, boys 20.50 ± 5.74 vs. girls 30.00 ± 9.07; parent proxy, boys 32.24 ± 10.41 and girls 34.52 ± 10.18. On-dexamethasone results also not significant; P-values not reported*
Massage therapy for children with cancer[38]	17 children aged one to 18 years	FS-C	*Known group validity not shown for comparison between massage and control groups; P-value not reported*
Development and testing of the Chinese version of the FS-C[24,a]	108 children aged seven to 12 years	FS-C-Chinese PedsQL MFS	Internal consistency reliability: $\alpha = 0.89$ Convergent validity with PedsQL MFS: $r = -0.36$ to -0.62 *Known group validity not shown between anemic and not anemic groups or on-treatment and off-treatment: $z = -0.35$ to -1.69, $P > 0.05$*
Reliability and validity of the Chinese version of the FS-A[25]	51 adolescents aged 13–18 years	FS-A-C	Internal consistency reliability: $\alpha = 0.89$ Known group validity between anemic and non-anemic adolescents: $z = -1.68$, $P = 0.048$
Enhanced-activity intervention in children with cancer[30]	29 children aged seven to 18 years Parents and HCPs of above children	FS-C FS-A FS-P FS-S	*Known group validity not shown for comparison between intervention and control groups: patient report $P = 0.91$; parent report $P = 0.37$; staff report $P = 0.67$*

Dexamethasone alters sleep and fatigue in children with ALL[31]	100 children aged five to 18 years (four treatment groups on and off dexamethasone)	FS-C FS-A FS-P	Responsiveness over time across all four groups: $P < 0.0001$ Known group validity in patient report for comparison between off and on dexamethasone in five- to 12-year-olds, $r = 6.70$, $P < 0.0001$, and in 13- to 18-year-olds, $r = 6.45$, $P = 0.0074$. Parent report also showed higher fatigue in on-dexamethasone groups, $r = 10.11$, $P < 0.0001$
Three instruments to assess fatigue[21]	149 children aged seven to 12 years 147 parents 124 HCPs	FS-C FS-P FS-S	Internal consistency reliability: FS-C $\alpha = 0.84$; FS-P $\alpha = 0.88$; FS-S $\alpha = 0.88$ Construct validity: correlation between scales, FS-C with FS-P $r = 0.35$, $P < 0.001$; FS-C with FS-S $r = 0.16$, $P = 0.05$; FS-P with FS-S $r = 0.43$, $P < 0.001$ Responsiveness over time: frequency of fatigue $P = 0.018$; fatigue intensity $P = 0.069$
PedsQL™ MFS			
Effects of aerobic program on reducing fatigue in children with ALL[45]	22 children aged seven to 17 years; 12 in intervention group and 10 in control group	PedsQL™ MFS (Chinese version)	*Known group validity not apparent between control and intervention groups across all time intervals: general fatigue P = 0.07–0.9; sleep/rest fatigue P = 0.41–0.9; and cognitive fatigue P = 0.20–0.86*
Parent report of QoL for children with cancer and no realistic chance of cure[40]	73 parents of children aged two to 18 years: two groups of 30 and 43	PedsQL™ MFS (parent proxy)	Known group validity for comparison between those who died six months or less vs. those who died more than six months from the interview: general fatigue mean difference 15.8 (95% CI 2.4–29.1), $P = 0.021$; sleep rest fatigue mean difference 16.0 (95% CI 3.5–28.5), $P = 0.013$; *cognitive fatigue mean difference 6.9 (95% CI −4.2 to 17.9), P = 0.221*
Fatigue, sleep, and QoL in adolescents receiving chemotherapy[29]	20 adolescents aged 12–19 years	PedsQL™ MFS	*Responsiveness over time not statistically significant: P = 0.82*
Physical activity program with adolescents[33]	10 adolescents aged 14–18 years	PedsQL™ MFS	Responsiveness over time from baseline to three months: general fatigue $P = 0.02$; sleep/rest fatigue and total fatigue $P = 0.01$; and *cognitive fatigue P = 0.38* Baseline to one year: sleep/rest fatigue $P = 0.02$; total fatigue $P = 0.05$; *general fatigue P = 0.10; and cognitive fatigue P = 0.33*
Measuring fatigue for children with cancer[34]	159 children aged eight to 18 years	PedsQL™ MFS pedsFACIT-F	Convergent construct validity: correlation with PedsQL MFS $r = 0.86$, 0.71, and 0.57 for general fatigue, sleep fatigue, and cognitive fatigue, respectively, $P < 0.001$
Clinical factors associated with fatigue over time in children with cancer[44,a]	48 children aged seven to 17 years 48 parents of above children	PedsQL™ MFS FS-P	PedsQL MFS: self-report responsiveness over time when subscales were treated as multi-domain constructs, $P < 0.001$. Parent proxy fatigue scores for all domains changed over time, $P < 0.001$ FS-P: known group validity for cumulative corticosteroid use and decreased hemoglobin, $P < 0.001$
Parent proxy report of fatigue in children with brain tumors and ALL[35]	256 parents of children aged two to 18 years; 86 children with brain tumor and 170 with ALL	PedsQL™ MFS PedsQL™ MFS (parent proxy)	Known group validity between brain tumor and ALL groups: total fatigue mean difference −6.0, $P = 0.02$; general fatigue mean difference −7.2, $P = 0.006$; cognitive fatigue mean difference −11.6, $P = 0.0003$
PedsQL in pediatric cancer[41]	220 children aged five to 18 years 337 parents of children aged two to 18 years	PedsQL™ MFS PedsQL™ MFS (parent proxy)	Internal consistency reliability in all subscales and across all age groups: $\alpha = 0.77$–0.89 child; 0.85–0.93 parent proxy report Known group validity between on- and off-treatment groups: $P = 0.024$–0.001 across subscales

(*Continued*)

Table 1
Continued

Study	Participants	Fatigue Scales Used	Psychometric Properties Examined
Others			
Symptom assessment in adolescents after chemotherapy[42]	51 adolescents aged 10–19 years	MSAS 7-12	Responsiveness over time for tiredness: frequency $P = 0.03$ and intensity $P = 0.02$
Changes in children's reports of symptoms during chemotherapy[25]	66 children aged 10–18 years	MSAS 10-18	Responsiveness over time: $P < 0.05$
Patterns of fatigue in adolescents receiving chemotherapy[28]	20 adolescents aged 12–19 years receiving chemotherapy	Daily Fatigue Report Scale	Correlation with PedsQL MFS: $r = 0.72$, $P < 0.01$ Responsiveness over time suggested but not shown
Social support and symptom distress in AYA with cancer[26]	Study 1: 127 AYA aged 11–26 years Study 2: 72 AYA aged 10–21 years	SDS	Age at diagnosis predictor of fatigue: $P < 0.009$ Responsiveness (time since diagnosis): $P = 0.012$–0.032

FS-P = Fatigue Scale-Parent; r = regression coefficient; ALL = acute lymphoblastic leukemia; PedsQL™ = Pediatric Quality of Life Inventory; MFS = Multidimensional Fatigue Scale; HCP = health care professional; FS-S = Fatigue Scale-Staff; QoL = quality of life; pedsFACIT-F = Pediatric Functional Assessment of Chronic Illness Therapy-Fatigue; MSAS = Memorial Symptom Assessment Scale; AYA = adolescents/young adults; SDS = McCorkle Symptom Distress Scale.
Note: Non-significant statistical reports of psychometrics are italicized.
[a]Studies using two fatigue scales.

Recommended for children aged seven to 12 years, this 14-item, two-part measure asks for "yes" or "no" responses for each item regarding the child's experience of fatigue-related symptoms during the last week. A "yes" answer directs the responder to complete an additional five-point Likert item quantifying the intensity of the symptom. Frequency scores range from 0 to 14, and intensity scores range from 0 to 70; higher scores correspond to greater fatigue. However, the 14-item version of the FS-C has been replaced with a 10-item version.[20] The 10-item version has been developed using IRT. An adolescent version (FS-A) is specified for 13- to 18-year-olds. The parent proxy version (Fatigue Scale-Parent) includes 18 items, with scores ranging from 18 to 90. The staff proxy version (Fatigue Scale-Staff) includes nine items, with a total score range from 9 to 36. Table 1 illustrates that this scale generally has good internal consistency, inter-rater reliability, and responsiveness. Known group validity is more variable.

Similarly, Table 1 illustrates the psychometric properties of the second most commonly evaluated measure, the PedsQL MFS,[41] designed to measure child and parent perceptions of fatigue. This 18-item scale includes three subscales: 1) general fatigue (six items), 2) sleep/rest fatigue (six items), and 3) cognitive fatigue (six items). Each item has a Likert-type response scale, with higher scores indicating fewer fatigue symptoms. The child report version includes three age ranges (five to seven years, eight to 12 years, and 13–18 years), whereas the parent proxy version includes a fourth age range of two to four years. In general, this instrument has good internal consistency and responsiveness. Similar to the Fatigue Scale, known group validity is inconsistent.

There were no reports that directly compared the two instruments or that evaluated whether participants preferred one scale over another. Only one study used Rasch analysis for instrument development or evaluation; Rasch analysis was used to reduce FS-C from a 14- to a 10-item version.[20]

The other scales that include measurement of fatigue, which have been used less often in pediatric studies, are the MSAS, the Daily Fatigue Report Scale, and the SDS.

The MSAS contains 32 items and was developed to provide multidimensional information about a diverse group of common symptoms.[47]

With the MSAS, if fatigue is present, then frequency and intensity are measured. The MSAS was modified for use in children, resulting in the 30-item MSAS 10-18.[47] When it was noted that very young children had difficulty with the MSAS 10-18, the eight-item MSAS 7-12 was developed.[48]

The Daily Fatigue Report Scale[28] was developed to allow adolescents to describe the effects of fatigue on daily life. Fatigue severity, fatigue bother, and fatigue interference are rated on a numerical scale from 0 to 10.

The SDS is an 11-item scale measuring symptoms, including fatigue, during the past week. Items are scored using a five-point Likert-type scale, with responses ranging from 1 = no problems to 5 = maximum amount of problems. This instrument was developed specifically to identify the concerns of patients receiving active cancer treatments.[49]

Discussion

This systematic review identified two instruments to measure CRF in children and adolescents that have acceptable psychometric properties, the Fatigue Scale and the PedsQL MFS. In general, these instruments have similar attributes, with reasonably good internal consistency and responsiveness. Both measures have inconsistent reports in terms of known group validity. Although this finding could be related to actual lack of validity, it is more likely that either the previous studies have not measured well-defined groups where differences should be apparent or the previous sample sizes are inadequate and do not provide sufficient power to demonstrate differences between two groups.

Although the Fatigue Scale shows good interrater reliability, this issue is always problematic, as perceptions of parents and children can genuinely differ because fatigue is primarily a subjective experience; child self-report should be the primary source of information for fatigue intensity where possible, based on age, cognitive and communicative abilities, and situational factors. There is general agreement that information should be obtained from both parents and children wherever possible and that both provide meaningful although possibly different evaluations of fatigue.[50–52]

Although these two instruments have received a moderate amount of attention, we do not have any information to guide the choice of which instrument should be used for what purpose. Furthermore, an additional four instruments have received some psychometric evaluation. Future research should continue to identify other reliable and valid measures of fatigue in pediatric cancer. In addition, future research could begin to determine which measures are more suitable to a specific purpose. For example, on the one hand, some measures are likely more sensitive to change and may be more appropriate for use in comparative trials. On the other hand, some measures may be less burdensome and may be appropriate for large studies of heterogeneous groups of children with a goal of identifying high-risk populations. Identification of optimal tools to measure fatigue will facilitate research focused on identifying patterns of fatigue and study of interventions to reduce CRF in children.

We found that only one study used more modern approaches to instrumentation such as Rasch analysis or IRT.[20] Given that Rasch analysis and IRT may be considered superior to classical test theory,[53] use of these approaches to develop or refine instruments measuring fatigue in pediatric oncology is an important future goal.

Limitations of our review include a focus on pediatric cancer patients. It is possible that there are good measures of fatigue that have been used outside of the cancer population. However, it also is possible that CRF is a specific phenomenon and that an instrument with good psychometrics outside of the cancer population may not have good psychometric properties within the pediatric cancer population.

In conclusion, our findings demonstrate that either the Fatigue Scale or the PedsQL MFS can be incorporated into clinical trials as endpoints when the intention of the study is to evaluate fatigue or the effects of an intervention on fatigue in a population of children or adolescents with cancer. Preference of these scales has not been investigated. Future research should focus on identifying specific fatigue measures more suited to different purposes.

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