Fatigue Pictogram: an option for assessing fatigue severity and impact

PICTOGRAMA DE FADIGA: UMA ALTERNATIVA PARA AVALIAÇÃO
DA INTENSIDADE E IMPACTO DA FADIGA

PICTOGRAMA DE FATIGA: UNA OPCIÓN PARA LA EVALUACIÓN
DE LA SEVERIDAD E DEL IMPACTO DE LA FATIGA

Dálete Delalibera Corrêa de Faria Mota[1], Cibele Andrucioli de Mattos Pimenta[2], Margaret Isabel Fitch[3]

ABSTRACT

The purpose of this paper was to validate the Fatigue Pictogram for use in Brazil. Data was collected at four oncology ambulatory clinics in Sao Paulo (Brazil) and at the Nursing School of Sao Paulo University. A convenience sample of 584 cancer patients, 184 caregivers and 189 undergraduate nursing students completed the Karnofsky Scale, Fatigue Pictogram-Brazilian Version, and the Beck Depression Inventory (BDI). Validity and reliability tests were performed. Test-retest showed that the instrument has good stability. The first item of the Fatigue Pictogram discriminated students from caregivers and patients but not patients from caregivers. The second item discriminated all groups. Adequate convergent (fatigue and depression) and divergent (fatigue and Karnofsky Scale) validity was observed. The Fatigue Pictogram is a valid, reliable, and easy-to-use tool for assessment of cancer-related fatigue but needs adjustments for use among healthy individuals.

KEY WORDS
Fatigue.
Neoplasms.
Reproducibility of results.
Validation studies.

RESUMO

O objetivo foi validar o Fatigue Pictogram para uso no Brasil. Os dados foram coletados em quatro ambulatórios de oncologia de São Paulo (SP) e na Escola de Enfermagem da USP. A amostra de conveniência envolveu 584 pacientes com câncer, 184 acompanhantes e 189 estudantes de graduação enfermagem, que responderam ao Picto-grama de Fadiga, ao Inventário de Depressão de Beck (IDB) e Escala de Karnofsky (KPS). Foram feitos testes de validade e confiabilidade. O Teste-reteste mostrou que o instrumento tem boa estabilidade.O primeiro item do Pictograma de Fadiga discriminou estudantes de cuidadores de pacientes, mas não pacientes de cuidadores. O segundo item discriminou todos os grupos. Observou-se adequada validade convergente (fadiga e depressão) e divergente (fadiga e Karnofsky). O Pictograma de Fadiga é valido, confiável e fácil de usar para avaliar fadiga em câncer, mas necessita ajustes para uso em pessoas saudáveis.

DESCRITORES
Fadiga.
Neoplasias.
Reprodutibilidade dos testes.
Estudos de validação.

RESUMEN

El objetivo fue validar el Pictograma de Fatiga para su uso en Brasil. Los datos fueron recolectados en cuatro clínicas de oncología ambulatoria de São Paulo (SP) y la Escuela de Enfermería de la USP. La muestra de conveniencia incluyen 584 pacientes con cáncer, 184 acompañantes y 189 estudiantes de posgrado en enfermería, que respondió a la Pictograma de Fatiga, del Inventario de Depresión de Beck (BDI) y la escala de Karnofsky (KPS). Realizado pruebas de validez y fiabilidad. Test-retest mostró que el instrumento tiene una buena estabilidad. El primer item del Pictograma de Fatiga discriminó a estudiantes de los cuidadores de los pacientes, pero no los pacientes de los cuidadores. El segun item discriminó todos los grupos. Hubo suficiente validez convergente (fatiga y depresión) y divergente (Karnofsky y Fatiga).Pictograma de Fatiga es válida, fiable y fácil de utilizar para evaluar la fatiga en el cáncer, pero necesita ajustes para el uso en personas sanas.

DESCRIPTORES
Fatiga.
Neoplasias.
Reproducibilidad de resultados.
Estúdios de validación.

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[1] BScN, MScN, PhD. Research Coordinator of the Instituto do Câncer de São Paulo. São Paulo, SP, Brazil. dalete.mota@globo.com   [2] PhD, Associated Professor of the Nursing School of the University of São Paulo. São Paulo, SP, Brazil. parpca@usp.br [3] RN, PhD, Head, Oncology Nursing and Supportive Care, Toronto Sunnybrook Regional Cancer Centre, Toronto, Canada.
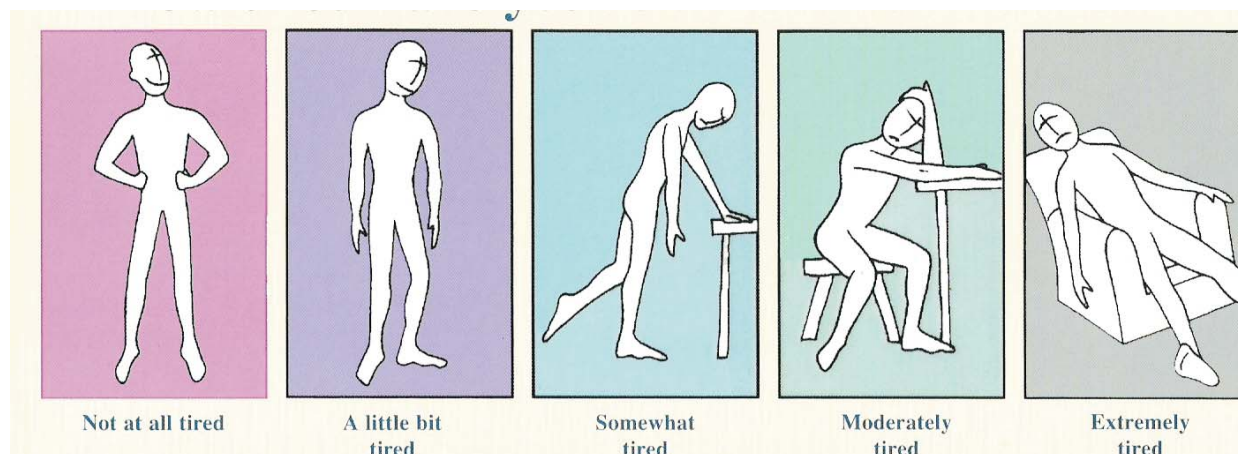
INTRODUCTION

Fatigue is an unpleasant physical, cognitive and emotional symptom described as a sense of tiredness not relieved by common strategies that normally restore energy. It varies in duration and intensity and reduces, to different degrees, the ability to perform the usual daily activities[1]. In Brazil there is a lack of instrumentation for fatigue assessment and that may lead to difficulty diagnosing and managing this symptom among cancer patients.

Dozens of instruments for assessment of subjective concepts, for example fatigue, are available in the literature[1], but many are criticized because of their extensive length and complex language. Pictographic scales are measurement tools that use simple and easily understood illustrations and seem to have good applicability in clinical practice. The Pain Faces Scale is one of the best known pictograms used to assess the symptom of pain, and it has been proven to be adequate for usage among children, adults and elders with different illnesses such as cancer or post-surgery pain[2-5]. Pictograms are also used to teach patients how to self-administer medications by different means, such as insulin or vaginal creams[6-7].

The Fatigue Pictogram[8] is an illustrated instrument for fatigue assessment (Figure 1). It has two questions with five figures representing each response option. The items assess the intensity of fatigue and the impact of fatigue on daily activities. Since it is very short, simple and easy-to-use, it seems useful for both practical nursing and research. Considering the interest in making comparisons between populations around the world or populations with different illnesses, and the recommendation to make cultural adaptations to existing instruments instead of creating new ones[9], this study aimed at assessing the fatigue of Brazilian cancer patients and testing the psychometric properties of the Fatigue Pictogram - Brazilian Version (BV).

How tired have you felt over the last week?

Not at all tired   A little bit tired   Somewhat tired   Moderately tired   Extremely tired

How much does feeling tired prevent you from doing what you want to do?

I can do everything I normally do   I can do almost everything I normally do   I can do some of the things I normally do   I do what I have to do   I can do very little
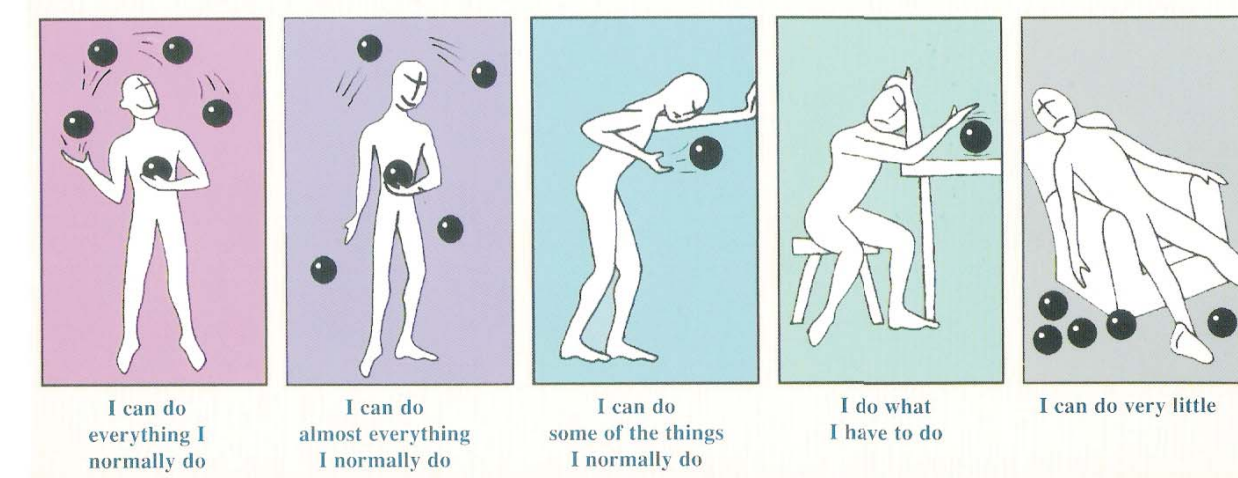
Figure 1 - Fatigue Pictogram

METHOD

Population and sample

Three groups participated in the study. Convenience samples of patients and caregivers, age 18 or over, with adequate abilities of comprehension and communication were gathered from four oncology clinics. Patients (n=584) from a cross-section of tumor sites and stages, who were either receiving active cancer treatment (chemo and/or radiotherapy) or were not receiving treatment at the present time, participated. The inclusion of patients with different tumor sites and stages served the purpose of testing the Pictogram validity over a greater range of cancer patients than had previously been achieved. Caregivers (n=184) with no history of cancer formed a group of healthy individuals. All nursing students (n=314) from the Nursing School of the University of Sao Paulo, age 18 or over, with no history of cancer, were invited to participate in the study, and 189 (60.2%) participated. These students formed a group of young healthy individuals. The caregiver and nursing student groups were constructed as healthy groups to test the discriminant validity of the Fatigue Pictogram.

Location and time period

Patients and their caregivers were recruited from four oncology clinics in Sao Paulo, Brazil, from July/2006 until July/2007. The nursing students were recruited from the Nursing School of the University of São Paulo, from March until May/2006. The research was approved by the Ethics Committees from all institutions involved and all participants signed the Informed Consent.

Instruments and procedures for data collection

Patients and caregivers were invited to participate in the research after their scheduled medical appointment. Those who accepted were instructed to answer the instruments on two different occasions. The first assessment was at the same time as the clinic appointment. The second assessment was 12 to 15 days following the first and occurred at home. The participants received a sealed envelope in which to return the answered instruments. At the Nursing School, the students were invited to participate in their classrooms, and those who accepted answered the instruments on one occasion.

At the first assessment, patients, caregivers and students answered an Identification Profile (age, gender, marital status and education level), the Fatigue Pictogram-BV and the Beck Depression Inventory. Only patients and caregivers were assessed for performance status (Karnofsky Performance Scale), and information regarding tumor site and cancer treatment was obtained for the patients. At the second assessment, patients and caregivers answered the Fatigue Pictogram - BV.

The Karnofsky Performance Scale[10] was used to test the divergent validity of the Fatigue Pictogram-BV. It is composed of phrases which reflect performance status scaled from 100% to 0%, with 100% representing a person with no sign of illness and 0% representing death. It does not have a cut-of-score. It is frequently used in oncology research and clinics around the world.

The Fatigue Pictogram is an ordinal scale[8]; it has two questions graded by 5 illustrations, with subheadings that assess intensity (not at all tired, a little bit tired, somewhat tired, moderately tired and extremely tired), and its impact (I can do everything I normally do, I can do almost everything I normally do, I can do some of the things I normally do, I do what I have to do, and I can do very little). It does not have a cut-of-score to diagnose fatigue or to determine the intensity of the symptom.

The Fatigue Pictogram was submitted to the translation and back-translation process. For its translation, two native-speaking Portuguese individuals translated the instrument from English to Portuguese. Two separate Portuguese versions were developed and they were presented in a pilot test to ill and healthy individuals in order to verify if the terms used in the instruments were clear. A Portuguese version was created using the most comprehensible terms. The back-translation was done by a native English-speaking individual. The back-translated version was approved by one of the Pictogram authors (Fitch).

The Beck Depression Inventory was used to test the convergent validity of the Fatigue Pictogram. It has 21 items, graded from 0 to 3; the minimal score is 0 and maximum score is 63. Higher scores suggest greater risk for depression. In Brazil, the cut-of-scores for individuals without a previous depression diagnosis are: 0-15, no depression; 16-20, dysphoria ; 21-63, depression. The Beck Depression Inventory has been validated in the Brazilian population[11].

Data analysis

Each item of the Fatigue Pictogram was tested separately for its psychometric properties (reliability and validity) because it does not have an overall score. The software SPSS (Statistical Package for the Social Sciences, Version 15.0) was used for statistical testing. $P<0.05$ was considered statistically significant.

Rest-retest reliability (interval between initial administration and second administration of 12 to 15 days) was assessed using the Kappa agreement coefficient, Spearman correlation coefficient, and Wilcoxon signed-ranks test. The hypothesis tested was that fatigue would be stable among cancer patients who were not receiving cancer treatment (chemo and/or radiotherapy) and caregivers during the interval of 2 weeks.

The Spearman correlation coefficient was also used to verify the correlation between the two items of the Fatigue Pictogram. The answers given by the patients, caregivers

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and students to the first and second items were compared. Discriminant validity was analyzed by comparing the fatigue among the cancer patients, caregivers and nursing students, using the Kruskal-Wallis test. Convergent validity was tested, with the expectation of a positive correlation between the scores on the Fatigue Pictogram and those of the Beck Depression Inventory (Spearman correlation coefficient). Divergent validity was tested, expecting to find a negative correlation between the Fatigue Pictogram and the Karnofsky Performance Status Scale (Spearman correlation coefficient).

RESULTS

A total of 957 subjects participated in the study: 584 cancer patients, 184 caregivers and 189 nursing students (Table 1). The frequency of answers given in the Fatigue Pictogram are presented in Table 2.

Table 1 - Demographic characteristics, performance status and depression scores of patients, caregivers, and nursing students - São Paulo, 2007

		Patients N= 584	Caregivers N= 184	Students N= 184
Socio-Demographic Characteristics				
Gender	Female - n(%)	358 (61,3)	121 (65,8)	182 (96,2)
Marital Status	Living w/partner - n(%)	366 (63,1)	134 (72,8)	5 (2,6)
	Living w/o partner - n(%)	215 (36,9)	50 (27,2)	184 (97,4)
Age	Mean (SD)	57,0 (13,0)	50,0 (12,7)	21,6 (2,8)
	Median (min-max)	57 (20-88)	50,0 (18-8)	21 (16-39)
Education (years)	Mean (SD)	10,4(5,4)	12,3 (4,6)	15,7 (2,8)
	Median (min-max)	11 (0-26)	ll,0 (1-28)	15 (11-32)
Depression and Performance Status				
Depression	Mean (SD)	11,0 (9,1)	8,6 (7,6)	10,9 (7,5)
	Median (min-max)	9,0 (0-53)	6,13(0-34)	9,5 (0-41)
Karnofsky* *Performance* Status	100%-80% - n(%)	461 (78,9)	137 (74,5)	
	70%-60% - n(%)	108 (18,5)	5 (2,7)	
	50% ou menos - n(%)	12 (2,1)	1 (0,5)	
Disease and treatment characteristics - n(%)				
Primary Tumor site	Breast	177 (30,3)		
	Colo-rectal	154 (26,4)		
	Prostate	70 (12,0)		
	Lung	41 (7,0)		
	Hematological	33 (5,7)		
	Other	109 (18,6)		
Tratamento para o câncer	W/o chemo or radiotherapy	231 (39,6)		
	W/ chemo or radiotherapy	278 (47,6)		
	Other treatments (hormone or immunotherapy)	75 (12,8)		

*100%-80% - patients totally independent for daily activities;
70%-60% - patients partially dependent for daily activities;
< 50% - patients totally dependent for daily activities.

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Table 2 - Distribution of the Fatigue Pictogram answers given by patients, caregivers and students - São Paulo - 2007

Item A Fatigue Intensity	Pacientes (N=584) (1st. assessment) n (%)	Caregivers (N=184) (1st. assessment) n (%)	Students (N=189) n (%)
Not at all tired	118 (20,2)	25 (13,6)	2 (1,1)
A little bit tired	222 (38,0)	65 (35,3)	29 (15,3)
Somewhat tired	158 (27,1)	56 (30,4)	84 (44,5)
Moderately tired	60 (10,3)	31 (16,8)	60 (31,7)
Extremely tired	26 (4,4)	6 (3,4)	14 (7,4)
No answer	0 (0,0)	1 (0,5)	0 (0,0)

Item B Impact of Fatigue	Pacientes (N=584) (1st. assessment) n (%)	Caregivers (N=184) (1st. assessment) n (%)	Students (N=189) n (%)
I can do everything I normally do	192 (32,9)	64 (34,8)	11 (5,8)
I can do almost everything I normally do	168 (28,8)	67 (36,4)	65 (34,4)
I can do some of the things I normally do	122 (20,9)	28 (15,2)	65 (34,4)
I do what I have to do	63 (10,8)	20 (10,9)	43 (22,8)
I can do very little	39 (6,6)	4 (2,2)	5 (2,6)
No answer	0 (0,0)	1 (0,5)	0 (0,0)

Among the patients, 41.8% reported extreme tiredness, while 38.3% reported a moderate to extreme impact on their usual daily activities. Among caregivers, 50.6% reported a moderate to extreme tiredness and only 28.3% reported a moderate to extreme impact; 83.6% of the students reported moderate to extreme tiredness, and 59.8% reported a moderate to extreme impact on usual activities.

In all groups there was a statistically significant correlation between answers given on the first and the second items of the Fatigue Pictogram (Table 3). For the patients and caregivers, the Spearman correlation coefficients were high and the percentage of variance was approximately 30%, (i.e. fatigue impact related 30% to the intensity of tiredness). Among the students, the correlation was 0.321 and the variance was 0.103, indicating that the impact of fatigue had low capacity to explain the intensity of tiredness.

Table 3 - Correlation between the items of the Fatigue Pictogram - São Paulo - 2007

	Patients	Caregivers	Students
Correlation between Item A and Item B	r= 0,532*	r= 0,551*	r= 0,321*
Explained variance (r^2)	r^2= 0,283 28,3	r^2= 0,304 30,4	r^2= 0,103 10,3

*p<0.05

Table 4 -Test-retest using data from first and second assessment (mean interval = 14 days) - São Paulo - 2007

Group	Kappa agreement 1st. x 2nd. assessment		Spearman r correlation 1st. x 2nd. assessment		Wilcoxon Signed rank 1st. x 2nd. assessment	
	Item A	Item B	Item A	Item B	Item A	Item B
Patients not receiving chemo or radiotherapy (n1=306; n2=39)	0,210*	0,350*	0,543*	0,588*	12,25-11,73	9,71-10,17
Caregivers (n1=184; n2=39)	0,505*	†	0,630*	0,546*	7,30-6,00	8,50-7,56

* p<0.05
† Not calculated because of empty cells

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The test-retest results are presented in Table 4. Thirty-nine patients (12.7%) who were not receiving active cancer treatment, and 39 (21.2%) caregivers answered the Fatigue Pictogram twice (mean interval= 14 ± 2.6 days).

For both the patients not receiving cancer treatment and for the caregivers, we expected to see high agreement on both items between Time1 and Time2, moderate positive correlation, and no significant differences in the ranks. We observed a moderate agreement for caregivers (Item A) and a weak agreement for patients, although both were statistically significant (Table 4). The correlation between T1 and T2 assessment for both times was good in both the patient and caregiver groups and there was no difference in ranks (Wilcoxon's Test).

It was anticipated the Fatigue Pictogram would be able to discriminate cancer patients from caregivers and nursing students. Item A discriminated the students from both patients and caregivers (Kruskal-Wallis p<0.01), but was not able to discriminate the patients from the caregivers (p=0.560). For Item B, significant differences were observed among the three groups (patients, caregivers and students). The hypothesis, that the cancer patients would have the most severe fatigue, was not supported as the students reported the highest fatigue scores and impact (Table 2).

The correlation between the Fatigue Pictogram scores and Beck Depression Inventory scores provided a test of convergent validity, while the correlation between the Fatigue Pictogram scores and the Karnofsky Performance Status Scale provided a test of divergent validity (see Table 5). A positive correlation between fatigue and depression was expected, as was a negative correlation between fatigue and performance status.

Table 5 - Correlations between fatigue, depression and performance status - São Paulo - 2007

Groups	Fatigue Pictogram	Karnofsky	Beck Depression Inventory
Patients	Item A	-0,261 (p=0,000)	0,418 (p=0,000)
	Item B	-0,513 (p=0,000)	0,425 (p=0,000)
Caregivers	Item A	0,202 (p=0,006)	0,020 (p=0,792)
	Item B	0,227 (p=0,002)	0,034 (p=0,650)
Students	Item A	†	-0,184 (p=0,025)*
	Item B	†	-0,094 (p=0,250)

‡ The Karnofsky Performance Status Scale was not used during the students' assessment.
* negative but not statistically significant

The correlation between fatigue and depression was positive and statistically significant for cancer patients, while no correlation was evident for either the caregivers or the nursing students (Table 5). The correlation between fatigue and performance status was negative and statistically significant for the patient group. For the caregiver group, the correlation was positive and statistically significant.

DISCUSSION

Fatigue assessment for cancer patients in the clinical setting should be brief, simple, reliable and valid. However, not many instruments have all of these characteristics. The Fatigue Pictogram is a short and easy-to-use tool that was designed for both assessment and research with cancer patients. Because it uses figures or pictures, there can be advantages for individuals with a low scholarly level[6], or for extremely disabled patients. This study evaluated psychometric properties of the Fatigue Pictogram in the Portuguese language. The results of this study demonstrate that the psychometric properties of the Fatigue Pictogram are satisfactory for the assessment of fatigue of cancer patients, but the results were not satisfactory for caregivers and nursing students.

A higher number of students reported greater intensity of tiredness (Item A) and impact of the fatigue (Item B) than what was reported by the patients and caregivers (Table 2). This was surprising, as it was expected that the cancer patients would be the group with the most severe fatigue. It is necessary to highlight that the students, in comparison to the patients and caregivers, were younger, female, did not live with partners, and possessed a higher level of education. Perhaps because of these characteristics they may have a different meaning or conceptualization of fatigue, inducing different expectations regarding the symptom. Acknowledging fatigue as a subjective phenomena, with physical, social, and emotional components, it is possible that life experiences, age, gender and education level, among other factors, may contribute to the process of symbolization of the concept. Regardless of this, the Fatigue Pictogram was developed and tested in cancer patients and it is therefore important to test its validity in other populations.

Although these two dimensions (intensity and impact) are considered in concept of fatigue, little is known about the strength of this relationship. This study found there was good correlation between Items A and B of the Pictogram for patients and caregivers (r=0.532 e r=0.551, respectively). In addition, fatigue intensity accounted for about 30% of the impact on daily life activities (Table 3). This interesting datum is not frequently discussed in the literature, because it supports the understanding that behavior is multidimensional. For students, the correlation and percentage of vari-

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ance between intensity and fatigue and detriment to daily life activities were smaller, i.e., fatigue intensity had a smaller effect (10.3%), as shown on Table 3.

The correlation between the Items A and B for patients and caregivers was good (r=0.532 and r=0.551, respectively) and approximately 30% of the impact of fatigue on usual daily activities was explained by the intensity of fatigue (Table 3). This type of data is rarely discussed in the literature, although it is very interesting and reinforces the knowledge that behavior is factorial/multidimensional. With the group of students, the correlation was low and the percentage of variance between intensity and impact of fatigue was smaller. In other words, the impact on activities was less influenced by tiredness (10.3%), as presented on Table 3.

The results of the test-retest for the patients not receiving treatment and for caregivers were satisfactory, indicating that the reliability or stability of the Fatigue Pictogram was adequate for these populations. It would be interesting to assess test-retest using data from patients undergoing treatment to determine if the Pictogram is sensitive to the change in fatigue.

The results of the convergent and divergent validities were diverse among the three sample groups. The correlations were statistically significant and considered good for cancer patients (w/ or w/o cancer treatment), indicating that the instrument is valid for this group (Table 5). The correlation between fatigue and depression, and fatigue and performance status were also observed in other studies with cancer patients[13-18]. However, for caregivers and students, the correlations had unexpected results. It is possible that fatigue among healthy individuals is different than that among patients.

The Fatigue Pictogram presented good validity and stability for cancer patients. The Fatigue Pictogram was considered inadequate for healthy individuals (not valid). There is a need to evaluate modifications to the Fatigue Pictogram. Two suggestions are made: substitution of the term *tiredness* for the term *fatigue*; and change the verbs in Item B to the past tense, since Item A refers to the past week. In addition , a study to identify the meaning of the figures for patients and healthy individuals, and the distance between each picture (ordinal scale) should be done. The Fatigue Pictogram is a promising instrument and its improvement should be very useful.

CONCLUSIONS

The Fatigue Pictogram is a short and simple instrument, with great potential for usage in clinical practice and research. The results demonstrate that the Pictogram, in the Portuguese language, may be used for cancer patients in punctual assessments (non-sequential) and may not be used at the moment for healthy individuals.

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Correspondence Addressed to: Dálete Delalibera Corrêa de Faria Mota
Rua Três de Maio, 130 - Ap. 82 - Vila Clementino
CEP 04044-020 - São Paulo, SP, Brazil