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RESEARCH

VALIDITY EVIDENCES OF THE BRAZILIAN VERSION OF THE DEMANDS OF ILLNESS INVENTORY

EVIDÊNCIAS DE VALIDADE DA VERSÃO BRASILEIRA DO DEMANDS OF ILLNESS INVENTORY

PRUEBAS DE VALIDEZ DE LA VERSIÓN BRASILEÑA DEL DEMANDS OF ILLNESS INVENTORY

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ABSTRACT

Objective: to translate and localize the Demands of Illness Inventory into Brazilian Portuguese, analyzing evidences for its validity and reliability. Method: methodological study carried out in six stages: translation, synthesis, back translation, specialist committee, pre-test, and evaluation of the author of the original instrument. The specialist committee was formed by eight professionals with different specialties. The agreement of these specialists was evaluated using the Content Validity Index and Kappa coefficient. The pre-test was carried out with 31 patients. The reliability was assessed using Cronbach's alpha. Results: all cultural adaptation stages showed adequate results. The Content Validity Index and the Kappa coefficient were above 0.83 and 0.81 respectively. The reliability was 0.95 for the instrument as a whole. Conclusion: this instrument is culturally adapted for cancer patients in the Brazilian context with satisfactory evidence of the psychometric properties evaluated, good acceptability and is acceptably easy to understand.

Keywords: Patients; Translating; Needs Assessment; Neoplasms; Validation Studies as Topic.

RESUMO

Objetivo: realizar a tradução, adaptação cultural, análise de evidências de validade e confiabilidade do Demands of Illness Inventory para o português brasileiro. Método: estudo metodológico realizado em seis etapas: tradução, síntese, retrotradução, comitê de especialistas, pré-teste e avaliação do autor do instrumento original. O comitê de especialistas foi formado por oito profissionais multidisciplinares. A concordância dos especialistas foi avaliada pelo Índice de Validade de Conteúdo e o coeficiente Kappa. O pré-teste foi realizado em 31 pacientes. A confiabilidade foi verificada mediante o alfa de cronbach. Resultados: todas as etapas de adaptação cultural foram realizadas satisfatoriamente. O Índice de Validade de Conteúdo e o coeficiente Kappa apresentaram valores acima de 0,83 e 0,81, respectivamente. A confiabilidade foi de 0,95 para o instrumento total. Conclusão: este instrumento se mostrou culturalmente adaptado para pacientes oncológicos no contexto brasileiro, com evidência satisfatória das propriedades psicométricas avaliadas, boa aceitabilidade e compreensão.

Palavras-chave: Pacientes; Tradução; Determinação de Necessidades de Cuidados de Saúde; Neoplasias; Estudos de Validação como Assunto.

RESUMEN

Objetivo: traducir, adaptar culturalmente y analizar las pruebas de validez y fiabilidad del Demands of Illness Inventory al portugués brasileño. Método: estudio metodológico realizado en seis etapas: traducción, síntesis, retro-traducción, comité de especialistas, pre-ensayo y evaluación del autor del instrumento original. El comité de expertos estaba compuesto por ocho profesionales multidisciplinares. El acuerdo de los expertos se evaluó mediante el índice de validez del contenido y el coeficiente Kappa. La prueba previa se realizó en 31 pacientes. La fiabilidad se comprobó mediante el alfa de Cronbach. Resultados: todas las etapas de la adaptación cultural se realizaron satisfactoriamente. El índice de validez del Contenido y el coeficiente Kappa mostraron valores superiores a 0,83 y 0,81, respectivamente. La fiabilidad fue de 0,95 para el instrumento total. Conclusión: este instrumento se ha adaptado culturalmente a los pacientes oncológicos en el contexto brasileño, con evidencia satisfactoria de las propiedades psicométricas evaluadas, buena aceptabilidad y comprensión.

Palabras clave: Pacientes; Traducción; Determinación de las necesidades de Atención Sanitaria; Neoplasias; Estudios de Validación como Asunto.

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INTRODUCTION

Cancer is the main public health issue in the world. In 2018, 18.1 million new cases were registered around the globe, with 9.6 million deaths from 46.8 million total cases.[1] A statistical projection from the World Health Organization (WHO)[2] estimates that, in 2040, there will be 29.5 million new cancer cases. In Brazil, estimates indicated there would be 625,000 new cases in 2021, not including nonmelanoma skin cancer cases.[3] Most recorded cases are in the Southeast (60%).

All cancer patients must be diagnosed correctly so they can receive adequate and efficient treatment. Whether the treatment aims for a cure or to prolong survival, its objective is to improve their quality of life.[4] The negative impact of the disease and of the cancer treatment itself, with its collateral effects, goes beyond the physical aspects of the individual and affects them psycho-emotionally and socially, while also affecting their family, work, and other aspects of their lives[5,6] An analysis of literature[5-8] shows a broad view about cancer patients, including their daily lifestyle, physical and psychological needs, and other necessities regarding information, rehabilitation, emotional support, communication, finances, spirituality, autonomy, sexuality, and nutrition.

Regarding their physical aspects, the most commonly reported issues were fatigue, pain, urinary incontinence caused by the treatment, and loss of sexual appetite. Regarding their daily lifestyle, the most relevant issue was the difficulty in carrying out daily activities (impossibility of caring for their home, touching cold objects, or ingesting cold beverages). In their psychological aspects, the most frequent need was related with the lack of psychological support when being affected by feelings of sadness, anger, anxiety, frustration, remorse, hopelessness, and uncertainty regarding the future. In the informational aspect, the most common issue was the lack of knowledge regarding the benefits and adverse effects of the treatment. Regarding health care, the most common issues were the lack of empathy from health professionals with the feelings and needs of the patient, and the loss of trust on the medical team to discuss treatments and life expectancy. Regarding emotional support, the most cited need was associated with the support from family and friends. In the spiritual aspect, the meaning of death was the most cited.

The above shows that identifying the needs and/or demands from the disease and its proper treatment is paramount to direct clinical care actions, as it facilitates the perception of all aspects involving care and aids the health teams in decision making. In this regard, the National Institute of Clinical Excellence, from the United Kingdom, recommends evaluating the physical, psychological, social, spiritual, and financial needs of patients. Furthermore, the Australian agency Cancer Australia recommends evaluating other needs, such as emotional, informational, and practical ones. They also suggest that identifying the needs of cancer patients earlier leads to good results, reducing distress levels, curbing the development of anxiety and depression, improving the quality of the care and the satisfaction of the patient, as well as the communication with the health team, while increasing adherence to cancer treatments and reducing the high-cost and use of the health system.

Nonetheless, in Brazil, there is no broad instrument regarding the demands of the patients that can make identifying their needs easier, such as the Demands of Illness.[9] This instrument, in addition to considering the physical aspect of the patient and the clinical aspect of the disease, also considers, for example, the meaning the patient gives to the situation they are in, the adaptation of family functioning, the care they receive from their partner, their situation at work, their social relationships, their self-image, and other elements. These aspects are important to formulate an intervention program, in addition to aiding the health team in their decision-making process.

Considering the above, this research aimed to translate and localize the Demands-of-Illness Inventory for Brazilian Portuguese, also analyzing the evidences for the validity and reliability of this instrument.

METHOD

This is an excerpt from a quantitative methodological agreement and reliability study based on the GRRAS tool[10]. The study was conducted in the chemotherapy outpatient clinic of a large public hospital in the state of São Paulo from January to July 2016. The main research was approved by the Research Ethics Committee from the Nursing school at the Universidade de São Paulo, under opinion 1.291.576, also being approved by the Center for Teaching and Research of the institution where data was collected, opinion 584/2015. Furthermore, the study was developed according with Resolution n. 466/2012, from the National Council of Health.

The original instrument was created in 1990, [9] in the United States, as the result of a research program involving 125 women with breast cancer, diabetes, or fibrocystic breasts. Its objective was to identify the demands of chronic disease patients. The content validity of the

instrument was conducted using a multidisciplinary panel formed by nurses who were researchers and specialists in oncology and family relations. Due to the little correlation between the dimensions, some items were replaced and/or added, as a product of a qualitative analysis of the interview with 115 patients. As a result, the instrument is formed by 125 items grouped in 7 dimensions and 10 subdimensions: physical symptoms, personal meaning, family functioning (adaptation, integration, partner caretaking, work or job situation, and decision making), social relationships, self-image, monitoring symptoms, and treatment issues (accommodation to regimen, relationship with providers, information, treatment evaluation, and direct effects). This is a self-applied Likert-type instrument, with the options NA = non-applicable; zero = "not at all", one = "rarely", two = "sometimes", three = "frequently", and four = "extremely". The assessment of the original instrument estimated its internal consistency, finding a 0.94 Cronbach's Alpha for all items. The values for each dimension varied from 0.69 to 0.87.

The process of adaptation of the instrument followed the directives proposed by Beaton, Bombardier, Guillemin, and Ferraz[11], and was formed by six stages: translation, synthesis, backtranslation, specialist committee, pre-test, and submission of the adapted instrument to the author of the original instrument. This adaptation process was carried out after approval of the author of the original instrument.

Stage 1 - Translation: The translation was carried out by two independent and experimented Brazilian translators, fluent in American English, which was the original language of the instrument, and native speakers of Brazilian Portuguese. These versions were named T1 and T1.

Stage 2 - Synthesis: The translations (T1 and T2) were synthesized by two Brazilian nurses, one of them specialized in clinical oncology, while the other had general clinical experience. Both were independent researchers and proficient in the English language.

Stage 3 - Back translation: The translators of this stage were native speakers of American English and proficient speakers of Brazilian Portuguese. Both translators lived in Brazil for more than 5 years, working as translators or English professors. They were not health professionals. These versions were named RT1 and RT2. These versions were sent to the author of the original instrument for evaluation.

Stage 4 - Specialist committee: From the 11 specialists invited to participate in the research, 8 accepted the invitation, while 3 did not respond. The committee was formed by two psychologists, three nurses specialized in oncology, one Brazilian Portuguese graduate, and two specialists in psychometry. The members of the committee had a mean of 17 years of experience. The committee evaluated all parts of the instrument, that is, the title, instructions, options of response, and items, according with semantic, linguistic, conceptual, and experimental equivalence. The version of the instrument generated by this stage was evaluated according with three criteria: a) degree of agreement between specialists; b) directives for the construction of Furr [12] and Furr and Bacharach measurement instruments;[13] and c) other adjustments, considering the objectivity and simplicity of the terms in the instrument.

a) The degree of agreement between specialists was evaluated considering the Content Validity Index (CVI) and Fleiss's Kappa coefficient. Values equal or above 0.83 for the CVI and 0.81 for Kappa were accepted, since these are considered to indicate a nearly perfect agreement.[14,15]

b) Directives for the construction of instrument, such as:

- The response options must be well-defined; no item can be classified in two or more categories simultaneously as this could lead to confusion.
- There can be only one question at a time.
- The wording must be clear; to this end, jargon must be avoided, as well as negative and/or double negative statements, as these difficult comprehension.
- Words such as "always", "never", "extremely", and "in no way" may impair the answer of the subject.

Stage 5 - Pre-test: 31 patients with cancer evaluated the adapted instrument. Each participant was consulted regarding the understanding and clarity of all parts of the instrument - title, instruction, and options of response of each item in the instrument. In case of any difficulty, the target population was asked for synonyms that could make the vocabulary clearer for them. These participants were addressed as they waited for attention in the waiting room of the outpatient chemotherapy clinic of a large hospital in the state of São Paulo, Brazil. The items in the instrument were changed if at least 20% of participants indicated to find some degree of difficulty, as proposed by Sousa et al.[16]

Stage 6 - The adapted version was sent to the author of the instrument for approval and potential considerations.

Figure 1 shows the flowchart of all stages of the research.

For the statistical analysis of the data, content validity was assessed using the quantitative evaluation of the agreement index, CVI, and Fleiss's Kappa coefficient. The CVI was calculated through the following formula: CVI = number of responses "1 = equivalent"/number of judges. The Kappa coefficient was calculated according with the formula: $k = \frac{\bar{P} - \bar{P}_e}{1 - \bar{P}_e}; \bar{P} = \frac{1}{N}\sum_{i=1}^{N} P_i; P_i = \frac{1}{n(n-1)}\sum_{j=1}^{n} n_{ij} * \bar{P}_e = \sum_{j=1}^{k} p_j^2$

For a preliminary analysis of the data, the internal consistency of the items was calculated according with the Cronbach's Alpha of the Inventory of Perceptions about the Disease - Patient Version, to assess the reliability of the instrument. The confidence level accepted was 95%, as calculated by the software SPSS v 23.0.0.0.

RESULTS

According with the total agreement indexes, nearly all elements of the instrument have high values, close to 1. Considering the value of agreement in regard with semantic, linguistic, conceptual, and experimental equivalence, 29 elements (28 plus the title) showed values equal or below 0.83 for CVI and equal or below 0.81 for Kappa in at least one of these equivalences. Only item 5 - "Nausea or upset stomach" - presented low values in all 4 comparisons made, with the lowest value being 0.63 for CVI and 0.52 for the Kappa. Furthermore, the experimental equivalence has the highest number of low agreement values. In turn, item 17 - "My own mortality" - presents the lowest value (0.50 CVI, 0.31 Kappa), as Table 1 shows.

Figure 2 shows the modifications carried out according with the criteria established. Therefore, the instrument adapted from the Inventory of Illness Perception started to include 129 items, because four items (30, 32, 34, and 41) evaluated two distinct aspects, "time" and "energy", and were, therefore, divided. The Likert-type responses varied from 1 to 5, where 1 = no; 2 = little; 3 = moderate; 4 = much; and 5 = very much. Also, the statements in 19 items were negative (items 30, 31, 32, 34, 41, 56, 58, 82, 89, 107, 108, 110, 111, 112, 118, 119, 120, 121, and 122). It should be mentioned that 55 items were not changed.

The adapted instrument was applied to the pre-test group, which was formed by 31 colorectal cancer

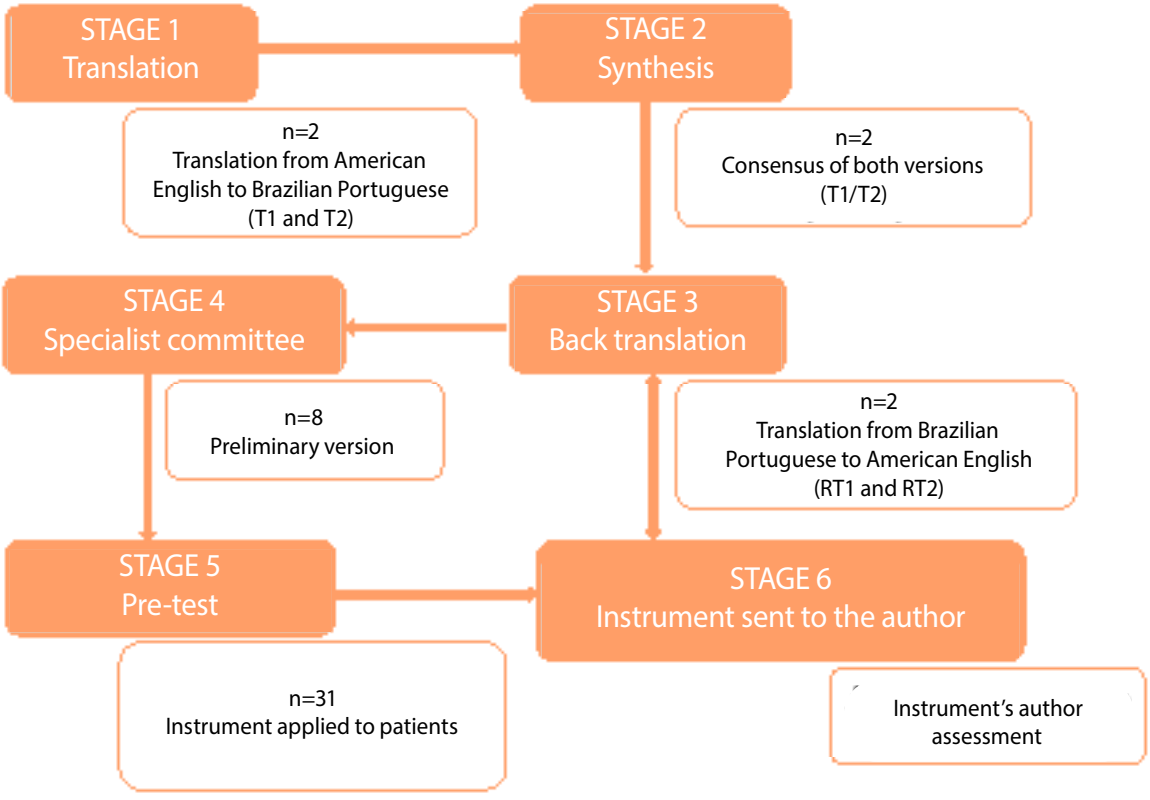

Figure 1 - Flowchart of the stages of translation and adaptation of the instrument Demands of Illness Inventory for use in Brazil

Table 1 - Content Validity Index and Kappa Coefficient of items whose agreement values for the instrument Inventory of Disease Perception are not acceptable

Brief Version		E. semantic		E. linguistic		E. conceptual		E. experimental		Total	
		CVI	K*	CVI	K*	CVI	K*	CVI	K*	CVI	K*
Demands-of-illness inventory		1.00	1.00	0.88	0.87	0.88	0.87	0.75	0.72	0.88	0.87
3.	**Pains in heart or chest**	1.00	1.00	1.00	1.00	1.00	1.00	0.75	0.72	0.94	0.94
5.	Nausea or upset stomach	0.63	0.52	0.75	0.72	0.75	0.72	0.63	0.52	0.69	0.65
10.	Heavy feelings in my arms or legs	1.00	1.00	1.00	1.00	1.00	1.00	0.75	0.72	0.94	0.94
15.	Not being able to achieve my goals in life	0.88	0.87	0.88	0.87	0.88	0.87	0.63	0.52	0.81	0.81
16.	How I might reorder the priorities in my life	0.88	0.87	0.75	0.72	0.88	0.87	0.75	0.72	0.81	0.81
17.	My own mortality	1.00	1.00	0.75	0.72	1.00	1.00	0.50	0.31	0.81	0.81
23.	Not having any past experience to relate this one to	1.00	1.00	1.00	1.00	1.00	1.00	0.75	0.72	0.94	0.94
29.	Income has gone down	0.88	0.87	1.00	1.00	1.00	1.00	0.75	0.72	0.91	0.90
33.	Doesn't have enough money for our health care bills	0.75	0.72	1.00	1.00	1.00	1.00	0.88	0.87	0.91	0.90
39.	The quality of my sexual activities has changed	1.00	1.00	1.00	1.00	0.88	0.87	0.63	0.52	0.88	0.87
41.	There is no time or energy for sexual activity	1.00	1.00	1.00	1.00	0.75	0.72	0.75	0.72	0.88	0.87
50	I need to be more sensitive to my partner's moods	1.00	1.00	1.00	1.00	1.00	1.00	0.63	0.52	0.91	0.90
52.	I need to protect my partner from stress	0.75	0.72	1.00	1.00	1.00	1.00	1.00	1.00	0.94	0.94
53.	I need my partner to be more sensitive to my moods	1.00	1.00	1.00	1.00	1.00	1.00	0.63	0.52	0.91	0.90
57.	I've had to miss more time at work than usual	0.88	0.87	0.88	0.87	1.00	1.00	0.63	0.52	0.84	0.84
58.	I'm not able to do my usual amount of work	1.00	1.00	0.88	0.87	1.00	1.00	0.63	0.52	0.88	0.87
66.	I often have to help others understand my illness	0.75	0.72	0.75	0.72	0.88	0.87	0.75	0.72	0.78	0.75
70.	I find that I need to help others accept my illness	0.75	0.72	0.88	0.87	0.88	0.87	0.88	0.87	0.84	0.84
77.	I feel I cannot always rely on my body	0.75	0.72	0.88	0.87	0.88	0.87	0.75	0.72	0.81	0.81
78.	I think more about my sexual appeal	0.88	0.87	0.75	0.72	0.88	0.87	0.75	0.72	0.81	0.81
79.	I think about the disfigurement caused by surgery/treatment	1.00	1.00	1.00	1.00	1.00	1.00	0.63	0.52	0.91	0.90
80.	I think about possibly needing to undergo surgery that would result in disfigurement	1.00	1.00	1.00	1.00	1.00	1.00	0.63	0.52	0.91	0.90
85.	I worry my illness may reoccur with its initial severity	1.00	1.00	0.88	0.87	0.88	0.87	0.75	0.72	0.88	0.87
96.	I sometimes think the adverse effects of treatment outweigh the possible benefits	0.88	0.87	1.00	1.00	1.00	1.00	0.75	0.72	0.91	0.90
103.	I'm considering the need to undergo more treatment	0.88	0.87	0.75	0.72	0.88	0.87	0.88	0.87	0.84	0.84
116.	I want to be more assertive about expressing the direction my treatment should take	0.88	0.87	0.88	0.87	0.88	0.87	0.75	0.72	0.84	0.84
117.	I want to be told the reason why, when asked to do something for treatment	0.88	0.87	0.88	0.87	0.88	0.87	0.75	0.72	0.84	0.84
125.	I often feel worse rather than better after treatment	088	087	063	052	088	087	088	087	081	081

patients, including 19 (61.3%) females and 12 (38.7%) males. Most participants were married (51.6%) with a mean time living together of 34 years (minimum 10, maximum 54), with a mean of 3 children (minimum 0, maximum 6). 8 participants (25.8%) had complete elementary education, 13 (14.9%) had finished high school, and 10 (32.3%) had higher education. Regarding their occupation, most patients were on leave or retired (32.3% in both cases). Most patients were responsible for supporting the livelihood of their homes (80.6%). Regarding the clinical characteristics of the disease, most participants are under palliative chemotherapy treatment (51.6%) who has been through surgery (71%).

Regarding the comprehension of the items, 7 (22.5%) patients mentioned having trouble understanding the term "finitude" in the item 17 - "My own finitude". After

Figure 2 - Description of the modifications the instrument Inventory of Illness Perception went through after the evaluation of the Specialist Committee

Reason for modification	Modification
Unacceptable values of agreement indexes	Title: The name "Demands-of-illness inventory" became "Inventory of Illness Perceptions" Item 3 - " Dores no coração ou no peito " became " Dor no peito ou no coração" In item 5, the expression "...de estômago" was removed Item 15 was reformulated "Não conseguir atingir ... metas de vida" into "Se vou conseguir atingir ... objetivos de vida" In item 16, the term "rever" was changed into "repensar" In item 17, the term "mortalidade" was changed into "finitude" In item 23, the expression "O fato de não ter nenhuma" was repllaced with "O fato de ter tido" In item 29, the term "queda" was replaced with "diminuição" In item 33, the preposition "de" was replaced with the preposition "para" In item 39 the expression "atividades sexuais" was replaced by "vida sexual" according with recommendations from a nurse specialized in women's health In the item 50, the expression "... estado de espírito do ..." was replaced with "... estado de ânimo do/da ..." In item 52, to the expression "... meu companheiro de ..." we added "... meu/minha companheiro/a do ..." In item 53, the terms "meu companheiro, sensível e estado de espírito" became "meu/minha companheiro(a)", "compreensivo(a)" and "estado de ânimo" In item 57, the expression "Eu tive que perder mais tempo ..." became "Eu passei menos tempo ..." In item 66, the term "sempre" became "geralmente" In item 70, the term "aceitar" was changed into "aceitarem" In item 77, the term "confiar" became "contar" In item 78, the expression ""meu apelo sexual" became "capacidade de atração sexual" In item 79 the term "desfiguração" became "transformação" In item 80 the term "desfigurar" became "mudar minha aparência" In item 85, the expression "gravidade inicial" was removed In item 96, "efeitos adversos" became "efeitos colaterais" In item 103, the expression "mais tratamento" became "mais tratamentos" In item 116, the expression "Quero ser mais firme" passou a ser "Quero ter mais clareza" In item 117, "Quero ... por que, quando me pedirem..." became "Quero que ... as razões quando soliciteds..." In item 125, the term "Sempre..." was replaced with "Geralmente..." and the expression "... e não melhor" was removed
Semantic analysis	Instructions: "eventos" was changed into "acontecimentos" and "indivíduos" to "pessoas" Item 4 - "Dores lombares" became "Dor nas costas" In item 20, the expression "vai voltar" became "voltará" In item 36, the term "adaptações" was changed into "mudanças" In item 41 the expression "atividades sexuais" was replaced by "relação sexual" according with recommendations from a nurse specialized in women's health In item 58, the preposition "de" was replaced with "para" In item 60, the expression "à administração da casa" became "ao cuidado da casa" In item 83, the term "suscetível" was changed into "vulnerável" In item 92, the expression "deteriore gradativamente" became "piore gradativamente" In item 95, "os tratamentos" was replaced with "o tratamento" In item 100 "Toda a minha vida é mais controlada" became "Minha vida está mais disciplinada" In item 101, the term "ajustei" became "mudei" In the item 106, the term "aguardar" was replaced with "esperar" In item 114, the expression "Tenho dúvidas..." was added In item 123, the expression "...físi In item 124 the expression. "... novos sintomas físicos ..." was replaced with "... novas complicações ..."

Continued...

...Continuation

Figure 2 - Description of the modifications the instrument Inventory of Illness Perception went through after the evaluation of the Specialist Committee

Reason for modification	Modification
Directives for the elaboration of the instrument	Response options: The option NA was removed The response scale changed from 0-4 to 1-5 The following items were separated and reformulated in affirmative sentences: Item 30, "Não tem tempo nem energia suficiente para atividades de lazer fora de casa" became "Tem falta de tempo para praticar atividades de lazer fora de casa" and "Tem falta de energia para praticar atividades de lazer fora de casa" Item 32, "Não tem tempo nem energia suficiente para receber os amigos em casa" became "Tem falta de tempo para receber os amigos em casa" and "Tem falta de energia para receber os amigos em casa" Item 34, "Não tem tempo nem energia suficiente para sair com os amigos" became "Tem falta de tempo para sair com os amigos ..." and "Tem falta de energia para sair com os amigos ..." Item 41 "Não tenho tempo nem energia para atividades sexuais" became "Me falta tempo para a vida sexual" and "Me falta energia para a vida sexual" The description of the following items was changed from a negative to na affirmative statement: Item 31, "Não tem ..." became "Tem falta ..." In items 56 and 58, "Não consigo ..." became "Tenho dificuldades ..." Item 82, "... possibilidade de não poder ..." became "... dificuldade de poder ..." In items 89 and 112, the word "não" was removed Item 107, "Não respeitam ..." became "Desconsideram ..." Item 108, "Não importassem" became "fossem pouco importantes" Item 110, "Não dizem a verdade ..." became "Escondem a verdade ..." Item 111, "Não demonstram preocupação" became "Pouco se importam" Item 118, "... não entendo ..." became "... tenho dúvidas ..." Item 119, "Não demonstram preocupação ..." became "Pouco se importam ..." Item 120, "Não estou satisfeito(a) ..." became "Estou insatisfeito(a)..." Item 121, "... não está sendo tratada corretamente" became "... está sendo tratada de forma incorreta" Item 122, "Não tenho confiança ..." became "Duvido ..."
Syntactic analysis	A comma was inserted in the writing before the items with: "Em consequência ..., eu tenho experimentado", "..., eu penso sobre", "..., nossa família:" and "..., eu"
Scope	The wording of the following items was adapted to make them refer to both genders, since there is no neutral gender in Brazilian Portuguese: In item 18 o termo "despreparada" became "despreparado(a)" In items 54 and 55, the terms "meu" and "companheiro" became "meu/minha" and "companheiro(a)" In item 74, from "insegura" to "inseguro(a)" In item 76, from "insatisfeita" to "insatisfeito(a)" In item 76, from "curada" to "curado(a)" In item 115, the term "pressionada" became "pressionado(a)"
Word simplicity	In item 24, the term "semelhante" was replaced with "parecida"

the meaning of this term was explained and synonyms for it were suggested, the term, participants suggested substituting the term "finitude" with the term "death", since it is better known by this population. As a result, this modification was carried out.

Regarding the application of the instrument, the mean time for patients to fill it in was 40 minutes. The internal consistency of the items was satisfactory: 0.95 for the total scale, varying from 0.66 to 0.94 for the dimensions, as Table 2 shows.

DISCUSSION

Table 2 - Internal consistency index of the items in the Inventory of Illness Perceptions

Factors	Cronbach's alpha coefficient
1. Physical symptoms	0.85
2. Personal meaning	0.84
3. Family functioning	0.93
a) Adaptation	0.85
b) Integration	0.77
c) Partner caretaking	0.94
d) Work or job situation	0.77
e) Decision making	0.75
4. Social relationships	0.66
5. Self-image	0.84
6. Monitoring symptoms	0.92
7. Treatment issues	0.92
a) Accomodation to regiment	0.76
b) Relationship with providers	0.78
c) Information	0.85
d) Treatment evaluation	0.86
e) Direct effects	0.74

This study is a pioneer attempt at translating and adapting the Demands of Illness Inventory between cultures. As a result, it is difficult to compare its results with those from other methodological studies. Therefore, to guarantee the quality of the original version, a rigorous methodology was used in regard to its directives for translation and cultural adaptation, following the six steps recommended by literature.[11] This method has been used by several authors in researches involving the translation and validation of assessment instruments in Brazil.[17-20]

The stages of translation, synthesis, and back translation were extremely valuable to guarantee that the version for the American context was equivalent to the version for the Brazilian one. The translation overcame the language barrier; the synthesis allowed the instrument to be made more adequate for the target population; and the back translation allowed for the author of the original instrument to evaluate the translation. The author did not make considerations, nor did he suggest any changes.

As a result, the multidisciplinary committee, after examining and comparing the synthesis version and the original in regard to semantic, linguistic, conceptual, and experimental equivalence,[14] sought to achieve an instrument that was closer to the language of the Brazilian cancer patient from an urban center, ensuring that the directives that regulated the creation of the measuring instrument were maintained. The results of a quantitative agreement analysis showed that all elements evaluated reached values above 0.83 for CVI and above 0.81 for total Kappa, with the exception of item 66 - "I always have to help others to understand my disease" -, whose result was 0.78 for the CVI and 0.75 for the Kappa. As a result, this item was modified into "I generally have to help others to understand my disease". Items whose CVI and Kappa levels were below 0.83 and 0.81, respectively, were modified. Examples are the title of the instrument itself - "Demands-of-illness inventory" -, which became "Inventory of Illnesses Perceptions", and the item 3 - "Heart or chest pain" -, which was modified into "Chest or heart pain", among others.

It should be mentioned that item 5 - "Nausea or upset stomach" - was the only one with low agreement values in all comparisons. This demonstrates the differences between American English and Brazilian Portuguese regarding grammar. This led to the exclusion of the expression "upset stomach". This shows the importance of the evaluation of the experts. Additionally, the results show that the lowest values were in experimental equivalence, when compared to the other comparisons. The experimental equivalence evaluated whether the items of the instrument were applicable to Brazilian culture. As a result, item 17 - "My own mortality" - had the lowest agreement value in this category. According with specialists, the term for "mortality" is not commonly used, which led it to be replaced by "finitude". However, the patients who participated in the pre-test had difficulties understanding this term, which led it to be replaced by the word "death" in the final version of the instrument. It is important for items and instructions in the instrument to be clear and simple, so participants understand them better, so they require little cognitive effort, thus increasing one's ability to answer and motivating a response.[12]

The Inventory of Illnesses Perceptions - patient's version also underwent changes regarding the construction of an assessment instrument, including the elimination of the answer "Non applicable" (NA), since it evaluated the same category as "No", which could confuse the participants.[16] Consequently, the response scale was altered, varying from 1 to 5. As instruments that evaluate attributes of human behavior, such as feelings, emotions, thoughts, and others, are evaluated, all individuals are considered to have these qualities to some degree. Therefore, for psychology, it is impossible to imagine an individual with no attributes. As a result, there are

recommendations according with which there should be no zero in the response scale.[12]

Following this criterion, the items 30, 32, 34, and 41 were also modified, being separated due to the fact they considered two different aspects: "time" and "energy". This meant that 4 extra items were added, increasing the total number of items in the instrument to 129. Scales that measure broad constructs usually require a greater number of items than those that measure specific constructs.[21] Considering this, evaluating the needs of patients requires a broad scope, involving many aspects of the life of the individual, from their physical to their financial aspect. This justifies the number of items in the Inventory of Illness Perceptions - patient version.

Other criteria, including a syntactic and a semantic analysis, and analysis of broadness and term simplicity, were also necessary. The specialist committee could change the instrument to be adapted, as in the case of this research, while varying the format of the instrument and changing or eliminating inadequate items, or even developing new items.[21] All these changes were accepted by the author of the original instrument and were, at the end, applied, as we believe that a good research depends on a good metric, which, in turn, depends on a good measuring instrument.

The Inventory of Illness Perceptions — patient version, when applied in the pre-test, underwent a minor change, as discussed above. Applying the instrument in this stage is essential to avoid costs or even mistakes during data collection.[22] On the other hand, the analysis of the internal consistency of the Inventory of Illness perceptions - patient version showed satisfactory correlations between the items, indicating that they are part of the same construct. The Cronbach's Alpha values found in this sample were similar to those in the original instrument[9] and in other studies.[23,24] Specifically, the original instrument had a total internal consistency of 0.94, with its dimensions varying from 0.69 to 0.87.[9] On the other hand. In turn, in a research carried out with colorectal cancer patients, the reliability coefficient was 0.96 for the entire instrument, varying from 0.78 to 0.95 in its dimensions.[23] In another instrument still, for diabetes patients, Cronbach's Alpha was 0.97 for all items, varying from 0.82 to 0.92 in its dimensions.[24] Finally, after the last stage, the process of translation and localization of the instrument was considered to be finished.

Thus, the final version of the Inventory of Illness Perceptions for spoken Brazilian Portuguese reached a good level of acceptability and understanding, being adequate for patients with chronic diseases, such as cancer. It stands out that making this instrument Available from will enable systematized evaluations to facilitate identifying the needs of patients in a more assertive manner.

Study limitations

Although the results showed a good agreement and internal inter-evaluator consistency, we suggest further research to be carried out about this topic, including patients with other types of chronic diseases, such as diabetes, breast cancer, multiple sclerosis, among others, so the same results can be confirmed in these populations.

It is important to indicate that translating and adapting are the first stages of the process of validating a psychological instrument for a new cultural context. Therefore, we recommend further studies to evaluate other validity evidence, such as the construct validity of the Inventory of Illness Perceptions - patient version in Brazil, using exploratory and confirmatory factor analyses, from the classical test theory. These analyses would enable an evaluation of the quality of the internal structure of the instrument associated with techniques of differential item functioning (DIF), from the item response theory (IRT), to evaluate the quality of its items.[25] Other validity evidences, based on the relationship with other variables, such as the converging, diverging, and face validity, among others, should be evaluated by correlating the Inventory of Illness Perceptions with other instruments recognized as the gold standard for these assessments.

This study makes Available from a useful tool that facilitates identifying the needs of patients with chronic diseases such as cancer. Using the results of this research, workers will be able to direct their actions to guarantee the formulation of intervention programs that attend to the real needs of cancer patients.

CONCLUSION

The Inventory of Illness Perceptions was translated and localized with the aid of cancer patients in the Brazilian cultural context, showing satisfactory evidence for its content validity through adequate equivalence in its semantic, linguistic, conceptual, and experimental aspects.

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