

TRANSLATION AND CROSS-CULTURAL ADAPTATION OF THE EDMONTON SYMPTOM ASSESSMENT SYSTEM FOR USE IN PALLIATIVE CARE^aDaiane da Rosa MONTEIRO^b, Miriam de Abreu ALMEIDA^c,
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ABSTRACT

The objective of the study was translation and cross-cultural adaptation into Brazilian Portuguese of the instrument Edmonton Symptom Assessment System (ESAS-r). The ESAS-r is a revised version of the instrument ESAS that assesses nine symptoms in Palliative Care. This is a methodological study based on a benchmark composed of six steps: translation, synthesis, backtranslation, expert committee, pre-test and submission of translated version for consideration of the authors. As a result, changes were made to the title, statements and certain terms to ensure adequacy of grammar and vocabulary. In the pre-test, the term 'nausea' raised doubts, and an additional explanation on this word was suggested. Standardization of instrument columns and the replacement of the term 'depression' for 'sadness' was also recommended. In this study, the ESAS-r instrument was translated and adapted to Brazilian Portuguese, and the next step will be testing the psychometric properties.

Descriptors: Palliative care. Scales. Nursing. Translating.

RESUMO

O objetivo do estudo foi realizar a tradução e adaptação transcultural, para o português do Brasil, do instrumento Edmonton Symptom Assessment System (ESAS-r). O ESAS-r é uma versão revisada da ESAS, que avalia nove sintomas em pacientes paliativos. Trata-se de um estudo metodológico que utilizou um referencial composto de seis etapas: tradução, síntese, retrotradução, comitê de especialistas, pré-teste e submissão da tradução para apreciação dos autores. Como resultado, para adequação da gramática e vocabulário, surgiram alterações no título, enunciado e em determinados termos. No pré-teste, o termo náusea trouxe dúvidas e sugeriu-se uma explicação sobre o significado da palavra. Recomendou-se a padronização das colunas do instrumento e a substituição de depressão por tristeza. Nesta pesquisa, o instrumento ESAS-r foi traduzido e adaptado para o português do Brasil, sendo o próximo passo a verificação das propriedades psicométricas.

Descritores: Cuidados paliativos. Escalas. Enfermagem. Tradução.

Título: Tradução e adaptação transcultural do instrumento Edmonton Symptom Assessment System para uso em cuidados paliativos.

RESUMEN

El objetivo del estudio fue la traducción y la adaptación intercultural para el portugués de Brasil, del instrumento Edmonton Symptom Assessment System (ESAS-r). ESAS-r es una versión revisada del instrumento ESAS y evalúa nueve síntomas en pacientes paliativos. Se trata de estudio metodológico que utiliza un marco compuesto de seis pasos: traducción, síntesis, retrotraducción, comité de expertos, previa a la prueba y la presentación de la versión traducida a los autores. Como resultado, para la adecuación de la gramática y el vocabulario, se realizaron cambios en el título y en ciertos términos. En la prueba preliminar la náusea trajo dudas y sugirió una explicación sobre el significado de la palabra. Se recomendó la normalización de las columnas del instrumento y la sustitución de depresión por tristeza. En esta investigación el instrumento ESAS-r fue traducido y adaptado para el portugués de Brasil, el siguiente paso es la verificación de las propiedades psicométricas.

Descriptores: Cuidados paliativos. Escalas. Enfermería. Traducción.

Título: Traducción e adaptación intercultural del instrumento Edmonton Symptom Assessment System para uso en Cuidados Paliativos.

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INTRODUCTION

Cancer is a disease that has been steadily increasing among the global population, and the World Health Organization (OMS) estimates around 27 million new cases by 2030⁽¹⁾. In Brazil, estimates for 2012 point to the occurrence of approximately 518,510 cases⁽¹⁾, and this disease is the second leading cause of death in the country⁽²⁾.

Many patients in the advanced stages of cancer also suffer from physical and psychological restrictions and they tend to die on hospital beds. In 1970, in England, a new assistance model for patients in the final stages of life was created, called Palliative Care. In this model of healthcare, pain is the symptom that receives most attention, although other symptoms are also common⁽²⁾. In general, these patients do not talk about what they are feeling and, when they do, conversations are usually not significantly relevant⁽³⁾. Consequently, it is important to count on an adequate instrument to control and monitor the needs of patients.

There are several scales of Palliative Care available to cancer patients, such as visual numbers, analogue, colour and questionnaires. The Karnofsky and Palliative performance scales are widely adopted examples in this type of care⁽²⁾, but neither comprehensively observes the symptoms presented by patients. In 1991, in Canada, an instrument was created to facilitate detection and monitor symptoms of cancer patients undergoing Palliative Care, called the Edmonton Symptom Assessment System (ESAS). This instrument was developed in a Palliative Care programme in the Edmonton General Hospital and its first version enabled evaluations by combining eight physical and psychological symptoms, namely: 'pain', 'activity', 'nausea', 'depression', 'anxiety', 'drowsiness', 'appetite' and 'well-being', with later addition of the term, 'shortness of breath'⁽⁴⁾. ESAS proved to be a user-friendly instrument for patients, even those who had some limitations⁽⁵⁾.

In 2010, the ESAS underwent changes to improve patient understanding of the system, and renamed ESAS-r. Some of the changes presented in the new system were term definitions, specified system assessment time, and order and structure of the scale⁽⁶⁾. In light of results, use of this version in Brazil improved assistance and allowed detection of frequency and intensity of symptoms, facilitat-

ing decision-making on behalf of teams for the provision of care. However, for the instrument to be used in Brazil, a detailed and accurate translation was required.

Translation and cross-cultural adaptation of instruments has been a widely adopted strategy, but certain recommended steps must be observed to ensure an adequate and effective process⁽⁷⁾.

This study can be very useful for healthcare professionals as there is no similar instrument in Portuguese to control and monitor symptoms, which currently hinders adequate assistance for patients of Palliative Care.

Consequently, the aim of this study is to present the translation and cross-cultural adaptation into Brazilian Portuguese of the instrument Edmonton Symptom Assessment System (ESAS-r) for use by patients undergoing Palliative Care.

METHODS

This is a methodological study conducted using a benchmark of six stages: translation, synthesis, backtranslation, expert committee, pre-test and submission of translated version for consideration of the authors⁽⁸⁾.

Stages of the translation and cross-cultural adaptation process

Translation: The translators were invited intentionally by e-mail. The instrument was sent by e-mail and translated by two independent translators who spoke Portuguese as their native language. As an inclusion criterion, translators had to have a degree in Letters/Linguistics with specialization in Portuguese/English; the exclusion criterion was lack of experience in translations. According to the benchmark, translator T1 was familiar with the study object and translator T2 received the instrument to translate as considered convenient.

Synthesis: The same translators attended a meeting with the researchers to synthesize results of the two translations. The new instrument was named T-12.

Backtranslation: Backtranslators were contacted at a specialized translation agency. The researchers contacted them by telephone to explain the desired profile. Inclusion criteria for translators was that they must speak English as a native language and have a degree in Letters/

Linguistics with specialization in English/Portuguese. The exclusion criteria was less than a year of experience in Portuguese translations. Instrument T-12 was sent by e-mail and translated again to the original language by the backtranslators. They were unaware of the object of this study. The backtranslations were returned by e-mail, and named BT1 and BT2.

Expert Committee: Members of the committee were intentionally invited by e-mail. Instruments T1, T2, T-12, BT1, BT2 and the original version were revised in a single meeting. Data were descriptively analysed, that is, notes were taken in relation to terms agreed by the committee until consensus was reached. Semantic, idiomatic, experimental and conceptual equivalencies were established between the original instrument and the new created version. The committee was formed by a teacher of nursing with thematic knowledge, a teacher of nursing, a nurse with knowledge on the methodological benchmark and a translator with thematic and linguistics knowledge.

Pre-test: The benchmark suggests 30 to 40 people for this stage. For this study, 10 patients, 10 family members and 10 nurses were selected. Sampling was based on convenience and personal invitation. The 30 participants were divided considering that the ESAS-r can either be completed by patients, family members or healthcare professionals. After signing a written informed consent (WIC), participants evaluated the Brazilian version of the instrument and answered a questionnaire to record their opinions in relation to the instrument. The objective of this stage was to gather information on understanding of the terms.

Submission of translation for consideration of the authors of the original instrument: The final version of ESAS-r in Portuguese and a copy of the reformulated English version was submitted to the main author of the instrument for evaluation of the translated version and possible suggestions or queries.

Ethical principles were observed, and permission was obtained from the main author of ESAS-r to translate the instrument in Brazil. The study was approved by the Research Ethic Committee of the institution and filed under protocol number 110251. Members of the Specialist Committee and participants of the pre-test signed a WIC, and anonymity was ensured.

RESULTS

In the first stage, translators maintained identical translations in relation to the terms 'pain', 'tiredness', 'nausea', 'appetite', 'shortness of breath', 'depression', and 'anxiety'. There were divergences with the terms 'System' and 'Revised' of the title. In the statements, there were grammatical changes in relation to the words 'how you feel now'. There were also differences in the terms 'drowsiness', 'well-being' and 'constipation', as shown in Chart 1.

In the synthesis, versions were analysed and, after reaching consensus, terms that could facilitate comprehension when filling in the instrument were preferred. In the backtranslation, data related to symptoms of pain, loss of appetite, shortness of breath and constipation were kept the same as the original instrument. Divergences are shown in Chart 2.

During the revision by the specialist committee, the title of the instrument was changed to *Escala de Avaliação de Sintomas de Edmonton (edição revisada)* (Edmonton Symptom Assessment Scale (revised edition)) (ESAS-r). The statement was defined as *Por favor, circule o número que melhor descreve como você está se sentindo agora* (Please, circle the number that best describes how you feel overall). Most of the terms were kept the same as those in the statements, with only two alterations. The term *Sem falta de apetite* (No loss of appetite) was changed to *Com apetite* (With appetite) and the expression *Melhor bem-estar* (Better well-being) was changed to *Com bem-estar* (With Well-being).

The new version of the instrument was applied to the pre-test stage. Data showed that most patients and family members were female, with average ages of 49.9 years for patients and 39.9 for family members. Sample characteristics are shown in Table 1.

Participants answered a form with the questions: Do you understand the terms used in this instrument?; Do you think that the ESAS-r is easy to use?; Do you have any doubts or suggestions?

Nine patients stated that they understood the terms, and that the only term that raised any doubts was the word 'nausea'. They all answered that the instrument was user-friendly, and the only suggestions were to add the meaning of 'nausea' and to standardize the word *Sem* (Without) in the left column of the ESAS-r.

Original ESAS-r	Translation T1	Translation T2
Edmonton Symptom Assessment System (revised version) (ESAS-r)	<i>Sistema de Avaliação de Sintomas de Edmonton (revised version) (ESAS-r)</i>	<i>Escala de Avaliação de Sintomas de Edmonton (revised version) (ESAS-r)</i>
Please, circle the number that best describes how you feel now	<i>Por favor, circule o número que melhor descreve como você se sente agora</i>	<i>Por favor, circule o número que melhor descreve como você está se sentindo agora</i>
No drowsiness Drowsiness=feeling sleepy Worst possible drowsiness	<i>Sem sonolência Sonolência = sentir-se sonolento Pior sonolência possível</i>	<i>Sem sonolência Sonolência = sentir-se com sono Pior sonolência possível</i>
Best well-being Well-being = how you feel overall Worst possible well-being	<i>Melhor bem-estar Bem-estar = como você se sente em geral Pior bem-estar possível</i>	<i>Melhor sensação de bem-estar Bem-estar/Mal-estar = como você se sente em geral Pior sensação de mal-estar possível</i>
No _____ Other problem (for example, constipation) Worst possible _____	<i>Sem _____ Outro problema (por exemplo, prisão de ventre) Pior _____ possível</i>	<i>Sem _____ Outro problema (por exemplo, constipação) Pior _____ possível</i>

Chart 1 – Divergences between T1 and T2. Porto Alegre, RS, Brazil 2011.

Synthesis T-12	Backtranslation BT1	Backtranslation BT2
<i>Escala de Avaliação de Sintomas de Edmonton</i>	Edmonton Symptom Assessment Scale	Edmonton Symptom Assessment Scale
<i>Por favor, circule o número que melhor descreve como você está se sentindo agora</i>	Please, circle the number that best describes how you feel now	Please, circle the number that best describes what you are feeling now
<i>Sem Cansaço Cansaço = falta de energia Pior Cansaço Possível</i>	No tiredness Tiredness = lack of energy Worst possible tiredness	Not tired Tiredness = Lack of energy Worst possible tiredness
<i>Sem Sonolência Sonolência = sentir-se com sono Pior Sonolência Possível</i>	No drowsiness Drowsiness=feeling sleepy Worst possible drowsiness	Not drowsy Drowsiness = feeling sleepy Worst possible drowsiness
<i>Sem nausea Pior nausea possível</i>	No nausea Worst possible nausea	Not nauseated Worst possible nausea
<i>Sem Depressão Depressão = sentir-se triste Pior Depressão Possível</i>	No depression Depression = feeling sad Worst possible depression	Not depressed Depression = feeling sad Worst possible depression
<i>Sem Ansiedade Ansiedade=sentir-se nervoso Pior Ansiedade Possível</i>	No anxiety Anxiety = feeling nervous Worst possible anxiety	Not anxious Anxiety = feeling nervous Worst possible anxiety
<i>Melhor Bem-Estar Bem-Estar/Mal-Estar = como você se sente em geral Pior Mal-Estar Possível</i>	Best well-being Well-being/ uneasiness = how you feel in general Worst possible uneasiness	Best well-being Well-being = how you feel in general Worst possible well-being

Chart 2 – Divergences between BT1 and BT2. Porto Alegre, RS, Brazil 2011.

Table 1 – Characteristics of the sample of patients and family members from November to December 2011. Porto Alegre, RS, Brazil 2011.

Characteristics	Patient n=10	Family members n=10
Sex		
Female	6	7
Age		
18 – 39 years	3	5
40 – 59 years	2	3
≥ 60 years	4	2
Education		
Primary School	4	4
Secondary School	5	3
Higher Education	1	3
Occupation		
Retired	5	2
Merchant	2	0
Teacher/Professor	0	2
Civil Servant	0	2
Other	4	4

All family members understood the terms, considered the instrument easy to use and did not make suggestions for the instrument.

In the sample of nurses, the average age was 33.2 years, as shown in Table 2.

The nurses understood the terms and thought the instrument was easy to use, but three suggested inclusion of the explanation 'Nausea = To feel sick/nauseated', changing the word 'depression' to 'sadness' and standardization of terms in the columns of the instrument.

The final version of the ESAS-r In Portuguese is shown in Chart 3.

DISCUSSION

The divergence presented by the translators in the first stage of the study refer to the term *sistema*, which in English, means system or method⁽⁹⁾. An ESAS validation study in Italian⁽¹⁰⁾ adopted the instrument title 'Edmonton Symptom Assessment Scale', considering that is known and referred to as a Scale. Consequently, in the synthesis stage, the word *Escala* (Scale) was selected for the title. In the statements, there was a slight change in the verb

form of the translations and adoption of a term that brought a colloquial manner of expressing words in Portuguese.

In some studies, the word 'tiredness', was replaced by the words 'fatigue'⁽¹¹⁾ and 'weakness'⁽¹²⁾, although it is translated as *cansaço*. A study indicated that certain words can be misinterpreted by those who use the instrument, and that some terms, such as *tiredness* should be better explained⁽¹³⁾. In other studies^(11,12) the words are changed without referring to the reason for this alteration. For use in Brazil, the word *cansaço* is thought to facilitate understanding.

In relation to the term 'drowsiness=feeling sleepy', the dictionary states that the adjective 'sleepy' is *sonolento*⁽⁹⁾. A study changed the term 'drowsiness' to 'sleep'⁽¹¹⁾. In the synthesis, all members approved the translation *Sentir-se com sono* (feeling sleepy), because it does not alter the meaning of the words, implying that if the person who completes the instrument does not understand the meaning of the word *sonolência* (sleepiness) and consults the definition, this person will evidently not understand the expression *Sentir-se sonolento* (feeling sleepy) either.

Table 2 – Characteristics of the sample of nurses, from November to December 2011. Porto Alegre, RS, Brazil 2011.

Characteristics	Nurses n=10
Sex	
Female	10
Age	
18 – 39 years	7
40 – 59 years	3
≥ 60 years	0
Graduate studies	
Specialization	5
Master's	5
Doctorate	0
Study duration	
1 – 5 year	5
6 – 10 years	1
11 – 15 years	1
16 – 20 years	2
21 – 25 years	1
Background in Palliative Care	
1 – 4 years	5
5 – 8 years	1
9 – 13 years	2
≥ 14 years	2

In the case of the 'well-being', the revisers decided to exclude the word *sensação* (sensation/feeling) and maintain all the other translations of T2. A study indicated that the meaning of *bem-estar* (well-being) is not understood by many patients, which hinders the selection of values from zero to 10 in the instrument⁽¹⁴⁾. To minimize any doubts, the ESAS-r was reformulated with explanations under each term that could lead to confusion⁽⁶⁾.

At the end of the instrument, a blank space was provided to insert a symptom. The ESAS-r has the indication 'other problem (for example, constipation)'. In the dictionary, 'constipation' is a noun that means *prisão de ventre*⁽⁹⁾ and, therefore, this term was selected to facilitate understanding.

The Specialist Committee did not consider the term *Sistema* as equivalent and the justification of this decision was that this instrument is known

in Brazil as *Escala* (Scale) and not as a *Sistema de Avaliação* (Assessment System). The instrument abbreviation was also discussed, as ESAS-r is an acronym created with the initials in English. A member of the Committee suggested insertion of the acronym EASE-r in the Brazilian Portuguese version. In translation and validation studies^(10,15), the ESAS maintained the same initials as the original instrument. If the initials were changed in Brazil, the instrument would probably not be identified as being the same, leading to the decision to use the same acronym as in the original version.

In terms of statements, the committee agreed to use the phrase suggested by T2. However, in some terms of the backtranslation, T2 inserted the word 'Not'. After revision, this same word was detected in previous versions of the ESAS, which does not occur in the version created in 2010⁽⁶⁾.

Escala de Avaliação de Sintomas de Edmonton (ESAS-r)		
Por favor, circule o número que melhor descreve como você está se sentindo agora		
Sem Dor	0 1 2 3 4 5 6 7 8 9 10	Pior Dor Possível
Sem Cansaço	0 1 2 3 4 5 6 7 8 9 10	Pior Cansaço Possível
Cansaço = falta de energia		
Sem Sonolência	0 1 2 3 4 5 6 7 8 9 10	Pior Sonolência Possível
Sonolência = sentir-se com sono		
Sem náusea	0 1 2 3 4 5 6 7 8 9 10	Pior náusea possível
Com apetite	0 1 2 3 4 5 6 7 8 9 10	Pior Falta de Apetite Possível
Sem Falta de Ar	0 1 2 3 4 5 6 7 8 9 10	Pior Falta de Ar Possível
Sem Depressão	0 1 2 3 4 5 6 7 8 9 10	Pior Depressão Possível
Depressão = sentir-se triste		
Sem Ansiedade	0 1 2 3 4 5 6 7 8 9 10	Pior Ansiedade Possível
Ansiedade = sentir-se nervoso		
Com Bem-Estar	0 1 2 3 4 5 6 7 8 9 10	Pior Mal-estar Possível
Bem-Estar/Mal-Estar = como você se sente em geral		
Sem _____	0 1 2 3 4 5 6 7 8 9 10	Pior _____ possível
Outro problema (por exemplo, prisão de ventre)		

Chart 3 – ESAS-r Brazilian Portuguese version. Porto Alegre, RS, Brazil, 2011.

Therefore, the committee considered that these expressions translated into Portuguese would not be clear enough to insert in the instrument, and chose to maintain the words in the version of the synthesis stage.

The item *Sem falta de apetite* (No lack of appetite) was re-evaluated, as the words *Sem* (No/Without) and *Falta* (Lack) have the same meaning. This form was therefore discarded because it could lead to misinterpretation of the person that completed the instrument. A study showed that patients who evaluated the ESAS stated that the term 'No lack' was a double negative and therefore led to confusion⁽⁶⁾. By consensus, the terms *Com apetite* (With appetite) and *Pior falta de apetite possível* (Worst possible lack of appetite) were inserted in the new version of the ESAS-r. Similarly, and for the same reasons, the preposition *Com* (With) was inserted to replace the adjective *Melhor* (Best) in relation to the item *Bem-estar* (Well-Being). Consequently, the scale contained the term *Com Bem-estar* (With Well-Being) in the left column.

In the pre-test, one of the patients suggested standardization of the term *Sem* (Without) on the

left of the ESAS-r. Patients frequently invert the grades of the terms 'appetite' and 'well-being' in the scale⁽¹⁰⁾ and, for this reasons, the items that patients suggested should be changed were *Com apetite* (With appetite) and *Com bem-estar* (With well-being). During the translation and cross-cultural adaptation stages, the terms *Sem falta de apetite* (Without lack of appetite) were replaced with *Com apetite* (With appetite). These changes are thought to facilitate understanding of the terms, considering that other patients in the study did not find them difficult to understand.

In relation to completing and understanding the instrument, all family members responded that they understood the meaning of the words, and considered the instrument easy to use and complete. None of the family members provided suggestions for improvement. A possible explanation for this absence of suggestions in relation to ESAS-r may be lack of knowledge on the instrument.

The sample consisting of nurses provided the highest number of suggestions for the Brazilian Portuguese version of the ESAS-r. One comment, which was also made in the group of patients, was

related to the symptom 'nausea'. Inclusion of the expression *náusea = sentir-se enjoado* (nausea – feeling sick) was suggested to facilitate understanding of patients who might be embarrassed to ask for the definition of this word.

Another suggestion, mentioned previously, was related to standardization of the expression *Sem* (Without) in the left column of the instrument. This alteration was suggested to improve visualization of the instrument. None of the studies on ESAS mention this specific detail. Consequently, this change was not thought necessary, considering that none of the patients expressed confusion when they graded the items.

A nurse suggested removal of the term 'depression' and use of the word 'sadness'. Generally, depression is used to describe a normal emotional state, such as sadness, and also to refer to a symptom or a disease⁽¹⁶⁾. Maybe this word should be re-evaluated, as patients relate depression to sadness because the instrument supports this similarity. The word should be taken into consideration in terms of intervention, as there is a difference in treatment for a patient who feels lack of joy and a patient who is, in fact, depressive⁽¹⁷⁾.

The terms 'well-being' and 'uneasiness', contrary to other publications^(5,13), did not raise doubts or suggestions in the pre-test stage. This may have occurred due to the statements included under the term. Prior to creation of the ESAS-r, literature did not provide information on the meanings of well-being and uneasiness attributed in the evaluation⁽¹⁴⁾, and it was noted that patient marked this symptom erroneously in the instrument⁽⁶⁾. Considering that it is the last item, patients may have been too tired or weak after completing the rest of the instrument and failed to pay attention when they had to select a grade for the symptom. This symptom is the last in the scale to reinforce use of the grading system as an overall evaluation of health in relation to other symptoms⁽⁶⁾.

Once all the alterations were made, the final version of the ESAS-r was submitted to the authors of the original instrument, who did not have doubts or suggestions on any of the changes.

CONCLUSION

The ESAS-r is an instrument that requires little effort to be completed, and is satisfactory

for use in Palliative Care. The aim of this study was achieved after conducting two important stages for use of this instrument in Brazil, namely translation and cross-cultural adaptations of the ESAS-r into Brazilian Portuguese. This study will evidently benefit clinical practices by helping healthcare professionals in the decision-making and critical judgement process based on the presented symptoms. Patients will also benefit from this new tool because it allows individualized and targeted attention to their feelings and problems.

The limitation of this study is difficulty in comparing obtained data with other studies, considering the high number of changes made to the ESAS in existing publications. According to information provided by the author of the ESAS-r, this new versions of the instrument is being validated in other countries, but there are no publications on this topic, which prevents comparison of new terms and changes inserted in this version.

In order to be implemented in healthcare instructions, the ESAS-r must also undergo a validation stage. Therefore, the next step of this study is verification of psychometric properties of the instrument.

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Received: 31.03.2013
Approved: 25.04.2013