

Cultural Validation of the Adolescent Pediatric Pain Tool (APPT) in portuguese children with cancer

Validação cultural do *Adolescent Pediatric Pain Tool* (APPT) em crianças portuguesas com cancro

Validación cultural del *Adolescent Pediatric Pain Tool* (APPT) en niños portugueses con cáncer

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Abstract

Theoretical framework: Pain assessment in children with chronic conditions requires the use of multidimensional tools, such as the Adolescent Pediatric Pain Tool (APPT), which identify the intensity, location and quality of pain.

Objectives: To validate the translation and cultural adaptation of the APPT for use in portuguese children and adolescents with cancer.

Methodology: The translation was validated through an independent process of translation and back-translation of the tool and its analysis was performed by a panel of reviewers until consensus was reached. The semantic validation of the descriptors of pain quality was performed by children with cancer aged 8-17 years, using the Q-sort method.

Results: A final version with conceptual, semantic, idiomatic and experiential equivalence to the original tool was obtained. Children revealed discriminative ability of the descriptors, being able to distinguish the words that they used to describe pain from those that they did not use.

Conclusion: The portuguese version of the APPT is a culturally adapted tool to assess the location, intensity and quality of pain in portuguese children with cancer.

Keywords: pain assessment; child; adolescent; cancer; nursing.

Resumo

Enquadramento: A avaliação da dor em crianças com doença crónica requer a utilização de instrumentos multidimensionais, como o *Adolescent Pediatric Pain Tool* (APPT), que identifiquem a intensidade, localização e qualidade da dor.

Objetivos: Validar a tradução e adaptação cultural do APPT, para uso de crianças e adolescentes portugueses com cancro.

Metodologia: Para validar a tradução foi utilizado um processo independente de tradução e retroversão do instrumento e a sua análise por um painel de revisores até obtenção de consenso. Os descritores da qualidade da dor foram submetidos a validação semântica por crianças com cancro dos 8-17 anos através do método Q-sort.

Resultados: Obtivemos uma versão final com equivalência concetual, semântica, idiomática e experiencial ao instrumento original. As crianças revelaram capacidade discriminativa relativamente aos descritores, diferenciando as palavras que utilizam para descrever a dor das palavras que não utilizam.

Conclusão: A versão Portuguesa do APPT é um instrumento culturalmente adaptado para a avaliação da localização, intensidade e qualidade da dor em crianças portuguesas com cancro.

Palavras-chave: avaliação da dor; criança; adolescente; cancro; enfermagem.

Resumen

Marco contextual: La evaluación del dolor en niños con enfermedades crónicas requiere la utilización de instrumentos multidimensionales, como el *Adolescent Pediatric Pain Tool* (APPT), que identifiquen la intensidad, la localización y las características del dolor.

Objetivos: Validar la traducción y adaptación cultural del APPT para utilizarlo con niños y adolescentes portugueses con cáncer.

Metodología: Para validar la traducción, un grupo de revisores realizó un proceso independiente de traducción y retroversión del instrumento y su análisis hasta obtener el consenso. Los descriptores de las características del dolor fueron sometidos a una validación semántica por niños con cáncer (de 8 a 17 años) a través del método Q-sort.

Resultados: Obtuvimos una versión final con equivalencia conceptual, semántica, idiomática y experiencial en relación al instrumento original. Los niños mostraron capacidad discriminativa en torno a los descriptores, diferenciando las palabras que utilizan para describir el dolor de las palabras que no utilizan.

Conclusión: La versión portuguesa del APPT es un instrumento culturalmente adaptado para evaluar la localización, la intensidad y las características del dolor en niños portugueses con cáncer.

Palabras clave: evaluación del dolor; niño; adolescente; cáncer; enfermería.

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Introduction

Pain is a subjective and multidimensional experience, which makes it difficult to be assessed, especially in children with chronic conditions, such as cancer. The quality of care includes pain management, which requires an accurate pain assessment. The assessment of pain intensity comprises only part of the experience of pain, while other important characteristics remain to be assessed. The *Adolescent Pediatric Pain Tool* (APPT) is an instrument that assesses not only the intensity of pain, but also its location and quality. The identification of the location and quality of pain enables making more accurate nursing diagnoses through the use of terms of the axes location and time.

The need to include an instrument with these characteristics in the study of pain experiences in children and adolescents with cancer encouraged its adaptation to the portuguese context.

The aim of this study was to validate the translation and cultural adaptation of the APPT for use in portuguese children and adolescents with cancer.

Background

Pain is one of the most prevalent symptoms (Dupuis et al., 2010) and also one of the most debilitating ones in the paediatric population with cancer (Wright, 2011). The main causes of pain are related to the procedures, the treatment and the disease process (Ljungman, Gordh, Sörensen, & Kreuger, 1999; Ljungman, Kreuger, Gordh, & Sörensen, 2006). Recent studies indicate that more than 80% of children with cancer have pain (Beretta et al., 2010), and that between 12.2% and 18.2% experience severe pain (Jacob, Hesselgrave, Sambuco, & Hockenberry, 2007; Jacob, Sambuco, McCarthy, & Hockenberry, 2008).

Although the negative impact of pain on children's quality of life is already known, pain has been underdiagnosed (Jacob et al., 2007). The Directorate-General for Health (DGS) has recently published a technical guidance on pain assessment in children, with recommendations on the need to collect data on pain characteristics, in particular location, intensity, quality, duration, frequency and associated symptoms (Ministério da Saúde. Direcção-Geral da Saúde, 2010).

The current scales aim at assessing pain intensity, but do not assess other important characteristics in the characterisation of pain in children with cancer, such as the location, quality and duration of pain. In fact, parents of children with cancer mention difficulties in determining the extent of pain using only pain intensity measurement scales, such as the visual analogue scale or a faces scale (Ljungman et al., 1999). The assessment of pain quality may provide information on its aetiology, particularly in the case of neuropathic pain. On the other hand, pain quality may indicate what the most significant dimensions of the painful experience are for patients (sensory, emotional, evaluative or temporal dimensions), thus guiding the selection of interventions. Finally, the reduction in the number of painful locations and the modification of pain quality may be indicators of the effectiveness of interventions, even if pain intensity is not significantly reduced.

However, in Portugal there is no instrument available that simultaneously identifies the intensity, location and quality of pain in both children and adolescents, as there is for adults (Figueiral, 2002).

A commonly used pain assessment tool in the US is the *Adolescent Pediatric Pain Tool* (APPT) (Savedra, Tesler, Holzemer, & Brokaw, 1995; Savedra, Tesler, Holzemer, Wilkie, & Ward, 1989; Tesler et al., 1991; Wilkie et al., 1990). This tool was inspired by the McGill Pain Questionnaire (Wilkie et al., 1990) and has been applied predominantly in hospitalized children aged 8 to 17 years old with cancer, sickle-cell disease and postoperatively, to assess the location, intensity and quality of their pain (Jacob, Mack, Savedra, van Cleve, & Wilkie, 2013; Fernandes, De Campos, Batalha, Perdigão, & Jacob, 2014).

The tool uses a body outline diagram with front and back views to locate pain, a 10-cm word graphic rating scale to assess pain intensity, a list of 67 descriptors of pain quality and an open space for children to add more words. The descriptors are grouped into four dimensions: sensory (37 descriptors), affective (11 descriptors), evaluative (8 descriptors) and temporal (11 descriptors). The psychometric properties of these descriptors show moderate correlation with pain intensity and the number of locations marked in the body outline diagram (Savedra, Holzemer, Tesler, & Wilkie, 1993; Wilkie et al., 1990). The evaluative descriptors are more strongly correlated with intensity ($r=0.44$; $p\leq 0.01$) than the affective ($r=0.38$; $p\leq 0.01$).

and sensory descriptors ($r=0.35$; $p\leq 0.01$) (Wilkie et al., 1990).

The use of the APPT in clinical practice has been advocated, since it is a useful method for children with chronic diseases to describe their pain experiences (Jacob et al., 2013).

Methodology

The methodological study was developed in two phases between November, 2010, and February, 2012. In the first phase, the APPT was translated and culturally adapted into portuguese (PT), following the methodology proposed by Beaton, Bombardier, Guillemin, and Ferraz (2000). In the second phase, the semantic and cultural validation of the tool was performed by children with cancer (Figure 1). Hence, the aim was to ensure the conceptual, semantic, idiomatic and operational equivalence of the original instrument.

The conceptual equivalence aims at ensuring that target concepts take on the same meaning as in their cultural context of origin. The semantic equivalence is the equivalence between the meanings of the words and it sometimes requires grammatical adjustments. The idiomatic equivalence concerns the idiomatic expressions and colloquialisms used in a given cultural context that cannot be literally translated without losing the meaning ascribed to them in the original context; they should, therefore, be replaced by expressions used in the target cultural context. Finally, the operational equivalence concerns the possibility of maintaining the same measurement systems as the original instrument (Beaton et al., 2000).

Permission was obtained from the author of the APPT for its translation and cultural adaptation. The study was approved by the Ethics Committees of the Health Sciences Research Unit – Nursing of the Nursing School of Coimbra, Coimbra Hospital Centre (CHC - *Centro Hospitalar de Coimbra*) and Portuguese Institute of Oncology (IPO - *Instituto Português de Oncologia*) of Porto, as well as the Boards of Directors of the CHC and IPO of Porto. The children's participation was voluntary after their assent and the parents' informed consent were obtained.

Participants and procedures

Phase I: translation and cultural adaptation

The original version of the APPT was simultaneously and independently translated in Portugal and Brazil, aiming at achieving a consensual version. As full consensus was not possible for cultural reasons, two versions were obtained: one adapted to Brazil and another adapted to Portugal. Their validation processes were performed separately.

The european portuguese version was reviewed by three portuguese native reviewers, fluent in english and experienced in contacting with children's vocabulary (a developmental psychologist, a physician and an english teacher), thus obtaining a first consensus version. This version was independently back-translated into english by two english native translators, who had no knowledge of the original version. Based on the two back-translated versions generated, a new consensus version was obtained, which was then sent to the author of the original instrument to check its agreement with the original version.

Phase II: semantic and cultural validation

The 67 portuguese descriptors of the APPT were *Q-sorted* (Wilkie et al., 1990) by portuguese children aged between 8 and 17 years, with a cancer diagnosis. Children were recruited at the Day Hospital and Haemato-Oncology Service of two central hospitals.

A group of 24 children was stratified according to age (8-12 and 13-17 years) and gender. The descriptors listed were printed on coloured cards (60x90mm), in font size 36. Each participant was approached individually and received a set of cards, all with the same colour. They were asked to recall their pain experiences and put the descriptors into three different categories: (1) words that *I know and use to describe pain*; (2) words that *I know but don't use to describe pain* and (3) words that *I don't know*. They were also asked to indicate other words that they would use to describe their pain experiences. One researcher was always present during the data collection process to clarify any doubts from the participants.

To be integrated into the APPT's final list, each descriptor would have to comply with the requirement of being known by more than 75% of

children (the sum of categories 1 and 2). Based on the results obtained, there was the need to perform

a second Q-sort with a group of children recruited in the same way as the previous group.

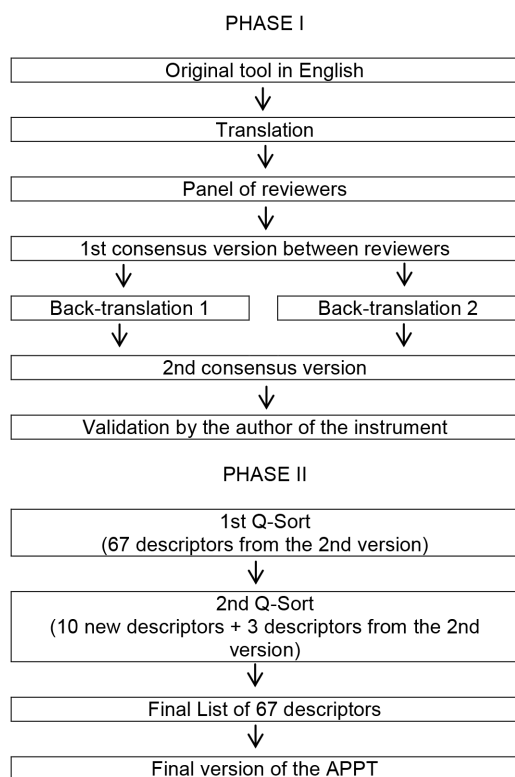


Figure 1. Phase I and phase II of the cultural validation process.

Results

Translation and cultural adaptation (Phase I)

In the back-translated versions into English, both translators agreed as to the instructions of the instrument, the pain intensity scale and 40 of the 67 descriptors. As for the other descriptors, 23 had semantic equivalence and only four seemed to have a different meaning from the original version. The second consensus version was achieved and sent to the author of the original instrument, who confirmed that the meaning of the original words had been preserved.

Semantic and cultural validation (Phase II)

Fourteen children in treatment and ten children out of treatment participated in the first Q-sort. The three most common diagnoses were: acute lymphoblastic leukaemia (n=13), osteosarcoma (n=3) and Ewing's sarcoma (n=3). The remaining children had other liquid or solid neoplasms (n=5).

Fifty-eight descriptors were known by more than 75% of children and were, therefore, retained for inclusion in the final list of descriptors. Seven descriptors did not reach this percentage, *i.e.* they were classified as *I don't know*: *moinha* (like an ache), *súbita* (comes all of a sudden), *latejante* (throbbing), *pulsa* (beating), *como uma ferroada* (like a sting), *racha* (splitting) and *rígida* (stiff). These were replaced by synonyms and submitted to a second Q-sort. Considering that two descriptors were at the cut-off point (75%), they were also submitted to a new Q-sort, along with a synonym for each of them to identify the children's preference for one or the other alternative. The children's only suggestion was the word *enjoa* (sickening), which was submitted to a Q-sort together with the descriptor *põe-me doente* (sickening) from the initial list, although this was known by the children, as the original descriptor - *sickening* - was suggestive of both translations.

All new suggestions complied with the requirement of being approved as pain descriptors (known by more than 75% of children). As for the descriptors that had already been submitted to semantic validation in

The list of descriptors resulting from both Q-sorts was added to the body outline diagram and intensity scale, thus obtaining the final version of the *Adolescent Pediatric Pain Tool* for portuguese children and adolescents (Figure 2).

ADOLESCENT PEDIATRIC PAIN TOOL

APPT – VERSÃO PORTUGUESA (PT)

INSTRUÇÕES

1. Pinta nestes desenhos as áreas que mostram onde tens dor.
Pinta as áreas grandes ou pequenas conforme a dor que tens nesse local.

Direita
Esquerda
Esquerda
Direita

10 cm 9 8 7 6 5 4 3 2 1 0

2. Faz um traço de cima para baixo nesta linha para mostrar quanta dor tens.

Sem dor
Dor pequena
Dor média
Dor grande
Pior dor possível

3. Indica ou faz um círculo nas palavras que descrevem a tua dor.

1 Aborrecida 10 Ma 11 Horrível 12 Inteniz 13 Terrível 14 Desconfortável 15 Dorida 16 Magoa 17 Fraca e continua 18 Como uma ferida 19 Sensível 20 Bate 21 Como uma cicatrizada 22 Como uma martelada 23 Como um muro 24 Palpita 25 Como uma mordida 26 Cortante 27 Como um alfinete 28 Como uma faca afiada 29 Como uma alfinetada 30 Afurada 31 Como um golpe	2 Como uma bolha 3 Arde 4 Quente 5 Como uma câlora 6 Esmaça 7 Como um beliscão 8 Belisca 9 Pressão 10 Faz comichão 11 Como um aranhão 12 Como uma picada 13 Arranha 14 Pica 15 Como um choque 16 Como um tiro 17 Corta 18 Dormente 19 Não deixa mexer 20 Inchada 21 Apertada	10 Muito desagradável 11 Mortal 12 Faz morrer 13 Mata 14 Faz chorar 15 Assustadora 16 Faz gritar 17 Aterradora 18 Causa torturas 19 Enjoa 20 Sufocante 21 Não passa 22 Incontrolável 23 Sempre presente 24 Vai e volta 25 Vem de repente 26 Constante 27 Continua 28 Dura sempre	15 Pára e recomeça 16 De vez em quando 17 Começa devagarinho 18 Às vezes 19 Sempre igual 20 Se quiseres, podes acrescentar outras palavras: _____ _____ _____ _____
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54 (3-4) ____ 57 = ____ %
 55 (10-12) ____ 11 = ____ %
 56 (1, 13) ____ 9 = ____ %
 57 (14, 15) ____ 11 = ____ %
 Total 67 = ____ %

Assessing the conceptual, semantic and idiomatic equivalence of the final version is of extreme importance, since some words and expressions may have different approaches, specificities and connotations inherent in every language and culture. In addition, each language carries with it a symbolic universe whose meaning is difficult to translate. The independent nature of both translations and back-translations, the selection of translators according to their mother tongue and the multidisciplinary of the panel of reviewers is an assurance of such equivalence. The results obtained from the discussions between reviewers show that, despite the difficulty of translating some descriptors, it is still possible to adapt instruments in other languages to the colloquialism of the portuguese language and make them comprehensible to children aged between 8 and 17 years.

This instrument in particular was previously adapted to spanish, in the United States, on a sample of 12 hispanic children aged between 7 and 17 years. A similar methodology was used regarding the process of translation and cultural validation of pain descriptors (van Cleve, Muñoz, Bossert, & Savedra, 2001). The authors did not report any difficulties in obtaining equivalence between both the original and translated versions. However, a descriptor was eliminated given its similarity to another descriptor that was already part of the list.

The descriptors of the APPT were also validated in Mandarin on a sample of 10 children aged between 6 and 18 years. The authors reported the need to eliminate some descriptors because they had no meaning in Chinese culture (Franck et al., 2004).

Similarly to Wilkie et al. (1990) regarding the construction of the original instrument and van Cleve et al. (2001) regarding the cultural adaptation of pain descriptors into the spanish language, we adopted the Q-sort methodology as it is an attractive and simple method, which allows obtaining the participants' individual perception on the task performed. Participants understood what was proposed and completed the task in less than ten minutes. Only a small number of descriptors was unknown to children. Although this group of words is commonly used by adults to describe pain, it does not seem to be part of the usual vocabulary of children aged between 8 and 17 years. The variability

in the number of words unknown to children may be related to their cognitive development, previous experiences and illness process.

The APPT has been used to explore pain experiences in children with different conditions, such as cancer and sickle-cell anaemia, thus allowing for a better understanding of the sensory, affective, evaluative and temporal dimensions of pain. Its use in daily clinical practice has been recommended, since it allows obtaining information on the aetiology, changing patterns and physical and psychosocial consequences of pain. Knowing the quality of pain may also enable the selection of therapeutic interventions which include not only analgesic drugs but also individualised psychosocial interventions (Jacob et al., 2013).

As limitations, we can mention the size of the sample, which, although small, was higher than those of similar studies (van Cleve et al., 2001). In addition, a large number of children was not experiencing pain when the Q-sort was performed, which may have influenced the classification of words.

Conclusion

The assessment of pain intensity has proved insufficient to understand the experiences of pain in children with persistent pain, as in the case of cancer. The clinical usefulness of a tool such as the APPT lies in the fact that it allows for a better characterisation of pain experiences, in particular with regard to the location and quality of pain.

This portuguese version of the APPT is conceptually, semantically, idiomatically and operationally equivalent to the original version. The study of its psychometric properties in children with cancer is underway. In the future, its validation in children of this age group with other conditions experiencing persistent pain may be considered.

The validation of the portuguese version of this tool contributes to the provision of culturally consistent health care, as it can be used in other countries, in children whose mother tongue is portuguese. In addition, the validation of an instrument in various languages promotes the development of multicentre studies, thus allowing for the joint analysis and comparison of results.

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