Cross-cultural adaptation to portuguese...



# NOTE PREVIEW ARTICLE

# CROSS-CULTURAL ADAPTATION TO PORTUGUESE OF THE PATIENT DIGNITY INVENTORY INSTRUMENT

ADAPTAÇÃO TRANSCULTURAL PARA O PORTUGUÊS DO INSTRUMENTO PATIENT DIGNITY INVENTORY

ADAPTACIÓN TRANSCULTURAL AL PORTUGUÉS DEL INSTRUMENTO PATIENT DIGNITY INVENTORY Alessandra do Nascimento Cavalcanti<sup>1</sup>, Karina Danielly Cavalcanti Pinto<sup>2</sup>, Eulália Maria Chaves Maia<sup>3</sup>

Objective: to perform the cross-cultural adaptation to Portuguese (Brazil) of the Canadian instrument Patient Dignity Inventory. Method: this is a quantitative, cross-sectional and analytical study. The population of 125 participants is estimated in three different contexts (two hospitals and home care), and a sociodemographic questionnaire, a quality of life instrument (WHOQOL-Bref) and the inventory to be adapted transcultaneously from the Patient Dignity Inventory - PDI. Data resulting from the instruments used shall be evaluated using computerized software for statistical analysis. *Expected results*: it is expected, through the results obtained, that the inventory be adapted according to the scientific parameters of the literature, reaching confidence coefficients above 0.8, characterizing in an instrument of high efficacy that one intends to measure. Descriptors: Cross-Cultural Adaptation: Palliative Care: Hospitalization: Psyhcology: Translating: Validation Studies.

### **RESUMO**

Objetivo: realizar a adaptação transcultural, para o português (Brasil), do instrumento canadense Patient Dignity Inventory. Método: trata-se de um estudo quantitativo, transversal e analítico. Estima-se a população de 125 participantes, em três contextos diferentes (dois hospitais e atendimento domiciliar), e será realizada a aplicação de questionário sociodemográfico, de instrumento de qualidade de vida (WHOQOL-Bref) e do inventário a ser adaptado transculturalmente do Patient Dignity Inventory - PDI. Avaliar-se-ão os dados resultantes dos instrumentos utilizados com o auxílio de um software informatizado para a análise estatística. Resultados esperados: espera-se, por meio dos resultados obtidos, que o inventário seja adaptado de acordo com os parâmetros científicos da literatura, alcancando coeficientes de confiança acima de 0,8, caracterizando em um instrumento de alta eficácia ao que se pretende medir. Descritores: Adaptação Transcultural; Cuidados Paliativos; Hospitalização; Psicologia; Tradução; Estudos de validação.

Objetivo: realizar la adaptación transcultural, al portugués (Brasil), del instrumento canadiense Patient Dignity Inventory. Método: se trata de un estudio cuantitativo, transversal y analítico. Se estima la población de 125 participantes, en tres contextos diferentes (dos hospitales y atención domiciliaria), y se realizará la aplicación de cuestionario sociodemográfico, de instrumento de calidad de vida (WHOQOL-Bref) y del inventario a ser adaptado transculturalmente del Patient Dignity Inventory - PDI. Se evaluarán los datos resultantes de los instrumentos utilizados con la ayuda de un software informatizado para el análisis estadístico. Resultados esperados: se espera, por medio de los resultados obtenidos, que el inventario sea adaptado de acuerdo con los parámetros científicos de la literatura, alcanzando coeficientes de confianza por encima de 0,8, caracterizando en un instrumento de alta eficacia al que se pretende medir. Descritores: Adaptación Transcultural; Cuidados Paliativos; Hospitalización; Psicología; Traducción; Estudios de validación.

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Cross-cultural adaptation to portuguese...

# INTRODUTION

In the history of medicine and health care, have been created environment of dedication to sick people, without distinction of pathology or care, and have evolved into the structure known today, which are divided by degree of complexity, diseases, life stage (for example, childhood and adulthood), among others. 1 It is proposed that, currently, more than 70% of deaths worldwide occur in hospitals, specifically, in a more common in intensive care units. The reality of institutionalized death is thus associated with cultural and social aspects. It is noticed that, in the hospital environment, is the offer of technology and interventions that approach those who present difficulties to perform the care of a patient at the end of life in the home.<sup>2</sup>

It is noted that with the impossibility of treatment modifying the disease and the recognition that the patient is walking towards the end of life, does not mean that there is nothing to do. It is possible at this moment to establish a new perspective of work which prioritizes behaviors that aim at the care and quality of life of the subject, thus seeking the possibility for the dignity of life in the process of dying.<sup>3</sup>

Palliative care is conceptualized as an approach focused on promoting the quality of life of patients and their families in the face of diseases that threaten the continuity of life. It is therefore necessary to take care in the early identification, evaluation and effective treatment of pain and other physical, psychosocial and spiritual difficulties, aiming above all to prevent and alleviate suffering.4

By 2016, an estimated 58 million deaths worldwide have been recorded, of which 34 million are due to incapacitating and incurable chronic-degenerative diseases. It is also stressed that 86% of those in need of palliative care do not receive them due to scarce knowledge about the role of palliative care, existing cultural and social barriers, training and incipient competence of health professionals, and regulations excessively restrictive to opioid anesthesia, for example, are factors that act as obstacles to the implementation of measures in a way that is more coherent with the reality in which one lives.<sup>5</sup>

It was considered that, in the face of the context, the Patient Dignity Inventory (PDI) instrument was produced through a joint and extensive construction.<sup>6</sup> The aim of this inventory was to provide a measure of dignity-

related suffering and to serve as a screening tool to assess a wide range of issues that influence the sense of dignity. Thus, it is pointed out that dignity refers to an intrinsic moral value that presents itself in all individuals, relating to the freedom, responsibility and capacity of the subject. Thus, a way of helping health professionals to identify a range of problems that may cause distress between patients approaching death.

A theory was developed by Harvey Max Chochinov, in which the instrument is based on the model of dignity in the terminally ill, called Dignity Therapy. This model is addressed through a variety of themes and subtopics, such as the patient's physical conditions, psychosocial and spiritual aspects, which can influence the sense of dignity of a terminally ill patient. This approach is structured in the following therapeutic attitudes: attitude, behavior, compassion and dialogue (called ABCD of Dignity Therapy, just as there is the ABC of emergency in the area of health). It aims, therefore, to ensure the preservation of the dignity of the patient as an essential element in the treatment, independently of the clinical and demographic factors.8

It is understood that impairments to dignity diminish as these patients in end-of-life care are cared for in humanized contexts (welcoming environments, quality support, holistic care - effective symptomatic treatment whereas preservation of dignity is associated with care). Thus, the relationship between the humanized care of health professionals and caregivers is related to the preservation of the dignity.

# **OBJECTIVE**

• To carry out the cross-cultural adaptation to Portuguese (Brazil) of the Canadian instrument Patient Dignity Inventory.

### **METHOD**

This is a quantitative, cross-sectional and analytical study. It is explained that, in this way, the function of an epidemiological scientific research is to characterize the elements of the health-disease process and to reveal the interrelationships or associations existing in it using the appropriate methodology.

It is pointed out that the process of crosscultural adaptation will follow the step by step suggested by several authors, <sup>9</sup> which consists of the description of figure 1.

Cross-cultural adaptation to portuguese...

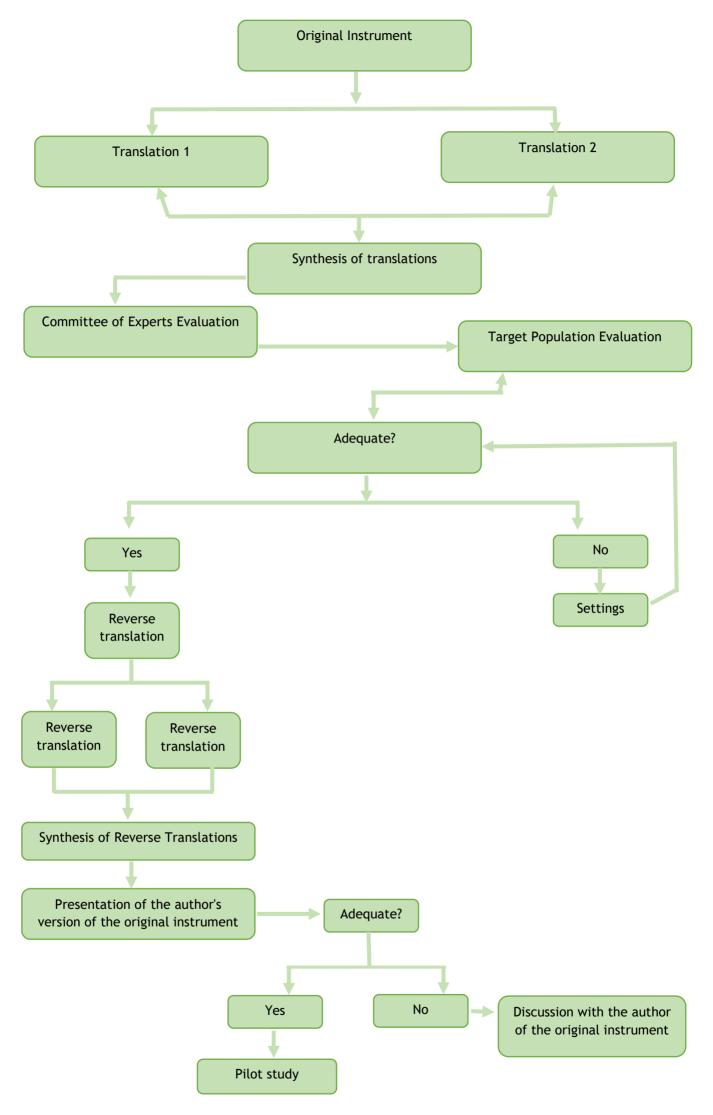


Figure 1. Cross-cultural adaptation of instruments. São Paulo (SP), Brazil, 2012.

step.

Cavalcanti AN, Pinto KDC, Maia EMC.

The calculation of the population sample is based on the proposal<sup>10</sup> which proposes the condition of five respondents per item of the instrument. It is added that thus, since the Patient Dignity Inventory (PDI) contains 25 items, 125 individuals will be required for the measurement equivalence

The selected individuals will be listed for the study by means of meeting the inclusion criteria established: a) patients between 20 and 59 years of age, regardless of race, class or social group; b) patients with preserved level of consciousness and self and alopsychic orientation; c) accept to participate in the research, by signing the Free and Informed Consent Term; d) patients who are protocolarily inserted in palliative care by the health team; e) patients linked to any of the research partner institutions.

Consideration should be given to exclusion criteria: a) patients in a state of mental confusion: b) patients who present neurological or psychological disorder that makes it impossible to participate in the research; c) patients taking medications that induce the sedative process or promote alteration of cognition processes; d) patients unable to respond to the proposed questionnaires due to some limitation related to the clinical condition. It is important to point out that items a, b and c, mentioned above, are information obtained through careful reading of the medical records available in the sector; in relation to item d, the criterion used to define the possible limitation of the patient will be through first contact, in which the patient's cognitive conditions will be evaluated after consulting the medical record.

The research will be carried out in the infirmary (adult) sectors of the Onofre Lopes University Hospital - HUOL and the Liga Contra Câncer Norte Riograndense, located in Natal / RN. Patients will be evaluated in a hospital environment, as well as research with patients followed by the Home Care Service.

The instruments will be applied for a period of one year, in which a battery of will be instruments used: Sociodemographic and Clinical Questionnaire; 2 - Patient Dignity Inventory (PDI); 3 WHOOOL-Bref. The instruments will be applied in the form of an interview, individually, based on a standard reading, by the researcher, in order to guarantee the homogeneous application to the chosen population.

The data collected by the PASW® Statistics program (*Predictive Analytics Software*, da

Cross-cultural adaptation to portuguese...

SPSS Inc., Chicago - USA) will be analyzed, by means of descriptive and inferential statistics. mainly in relation to the measures of frequency, percentages, analysis of internal consistency (Cronbach's alpha), tendency and dispersion, aiming the characterization of the participant sample and quantitative the other results. histograms, the Kolmogorov-Smirnov normality test and the Levene variance will be investigated after tabulation of the data to verify if there is a normal and homogeneous distribution of the data and thus help in the inferential statistical analyzes.

Approval was obtained by the Research Ethics Committee of the Federal University of Rio Grande do Norte under the CAEE: 01425318.9.0000.5537. All the ethical precepts of Resolution No. 510/16 of the National Health Council, which regulates research guidelines and norms involving the participation of human beings, shall be respected..

#### **EXPECTED RESULTS**

It is hoped that, given the above, it is possible to perceive the network multifaceted complexity that the palliative care theme in patients in the Unified Health System (UHS) can demonstrate. It can be understood that, on the one hand, there is the needs of a user that requires specific care, with a demand that no longer has to wait, and, on the other, there are the mishaps of the reality of a system that implements policies and who may perceive difficulties in the middle of this path, and sometimes the lack of tools and instruments may end up reducing the possibility of care that this user could receive.

It is believed, therefore, that the instrument in question, when adapted to the reality of this context, may help to improve care for these patients, promoting discussions, aiming to develop humanized actions and providing quality palliative care based on an instrumental understanding about the patient and the potential causes of his psychic suffering.

It seeks, therefore, to attend to the social aspects of health, allowing, from the results, to construct reflections and discussions. The search for psychosocial factors that may interfere in adherence is therefore promoted, in order to propose strategies that may contribute to the care of the subjects who need palliative care.

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Cross-cultural adaptation to portuguese...

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Submission: 2018/11/07 Accepted: 2018/02/06 Publishing: 2019/03/01

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