ORIGINAL ARTICLE

Validation of the Portuguese Severe Respiratory Insufficiency Questionnaire for home mechanically ventilated patients

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Questionnaire; Portuguese; Home mechanical ventilation; Quality of life

Abstract The aim of this study was to develop and validate the professional translation and cultural adaptation of the Portuguese Severe Respiratory Insufficiency (SRI) Questionnaire. The sample was composed of 93 patients (50 male patients, 53.8%) with a mean age of 66.3 years. The most frequent diagnostic groups were chronic obstructive pulmonary disease, obesity hypoventilation syndrome and restrictive chest wall disorders. The patients were asked to fill in both the SRI and SF-36 questionnaires. Factor analysis of the SRI questionnaire was performed leading to an explained variance of 73%, and resulted in 13 components. When analyzing the reliability, we obtained values for Cronbach’s alpha above 0.70 for most subscales with the reliability of the summary scale being even higher (0.84).

This professional translation and cultural adaptation of the Portuguese SRI Questionnaire has good psychometric properties which are similar, not only to the original, but also to other translations. These characteristics make this questionnaire applicable to the Portuguese population receiving home mechanical ventilation for severe respiratory insufficiency.

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Introduction

Non-invasive ventilation (NIV) is indicated in patients with chronic severe respiratory insufficiency of different causes.
Not only the underlying disease, but also the intervention can have a deep impact on the patients’ quality of life.

Health-related quality of life (HRQL) questionnaires are multidimensional tools that explore aspects of patients’ lives that are not covered by other diagnostic tools. Even though it is a complex task, they are an invaluable source of information on how disease affects a patient’s life, and they should be sensitive to changes related to progression of disease or treatment interventions. HRQL questionnaires have gained increasing importance in recent years in both research and clinical settings. In general, specific HRQL questionnaires are designed and validated for specific and highly prevalent diseases such as asthma or chronic obstructive pulmonary disease. Until recently, there was no questionnaire for patients with severe respiratory insufficiency requiring home mechanical ventilation (HMV), regardless of the underlying disorder.

The Severe Respiratory Insufficiency (SRI) Questionnaire is a multidimensional instrument with high psychometric properties designed to measure specific HRQL in patients with respiratory insufficiency receiving HMV. It was originally developed in German, but has recently been professionally translated into several languages such as Spanish, English, Danish, Dutch, French, Japanese, Norwegian, Polish and Swedish and most of these translations have already been validated or are currently being validated. Moreover, it has also been validated and used in many recent studies on NIV.

It is the aim of the international SRI project to stimulate research activities in the field of HRQL and home mechanical ventilation. For that purpose both the original version and the translated versions of the SRI are provided on the website of the German Respiratory Society free of charge for non-profit research activities.

The objective of this study was to produce and validate the professional translation and cultural adaptation of the SRI into Portuguese. The results obtained were also compared with the Portuguese version of the SF-36 questionnaire. The SF-36 is a widely used and validated questionnaire to evaluate HRQL. Contrary to SRI questionnaire, which has been specifically developed for respiratory patients, SF-36 is a general HRQL measure that applies to the general population, as well as to patients suffering from different pathologies. Therefore, we found it useful, not only to compare both questionnaires in our sample population, but also to compare our results with reference values for SF-36 for the general Portuguese population.

Methods

Questionnaires

The SRI Questionnaire is a self-administered questionnaire containing 49 items that patients score on a 5-point Likert-scale (1: completely false; 2: quite false; 3: partly true/partly false; 4: quite true; 5: completely true) according to how true each statement has been for them in the preceding week. The questionnaire contains 7 HRQL domains, or subscales, and is designed in such a way that each item belongs to just 1 subscale. The 7 subscales are: respiratory complaints (SRI-RC) – 8 items, physical functioning (SRI-PF) – 6 items, attendant symptoms and sleep (SRI-AS) – 7 items, social relationships (SRI-SR) – 6 items, anxiety (SRI-Ax) – 5 items, psychological well-being (SRI-WB) – 9 items and social functioning (SRI-SF) – 8 items. The final score for each subscale is calculated, after recording certain items, by the corresponding percentage. The summary score (SRI-S) is obtained by calculating the arithmetic mean of the subscale scores, in such a way that this calculation would not be possible if any of the scores were missing. A high overall score indicates a good HRQL, while a low overall score indicates a poor HRQL.

The SF-36 consists of eight subscales (0–100) measuring different aspects of health status with lower scores indicating poorer health or higher disability: SF-36-PF (physical functioning); SF-36-RE (role-physical); SF-36-BP (bodily pain); SF-36-GH (general health); SF-36-VT (vitality); SF-36-SS (social functioning); SF-36-MH (mental health).

Portuguese translation and cultural adaptation

The Portuguese translation was obtained from the original German questionnaire, using the translation-back translation process by two independent professional translators.

The equivalence of the back-translated items to the original items was evaluated and grouped into 3 categories according to previous recommendations: category A: items that were fully equivalent; category B: items that were not fully equivalent or that contained different wording, but the content is similar; and category C: items that were not equivalent or that needed to be checked. Items rated A and B were left as they were and items rated C were reevaluated and rephrased accordingly with both of the independent translators being involved and the original questionnaire creator. The final version was written according to the New Portuguese Spelling Reform.

Validation

This study was conducted in the Pneumology Department at Centro Hospitalar de Vila Nova de Gaia/Espinho (Portugal), a tertiary care teaching hospital. Ethical approval was obtained from the hospital Ethics Committee.

Patients with chronic hypercapnic respiratory failure, from a wide variety of causes, established on HMV for at least 30 days were eligible for the study. Exclusion criteria were refusal to participate and an exacerbation in the preceding 3 months.

The patients were asked to fill in both the SRI and SF-36 questionnaires. Patients were also asked to take home another SRI Questionnaire, to complete it 15 days later and to mail it back to the corresponding author.

Patients were categorized into six categories: chronic obstructive pulmonary disease (COPD), restrictive chest wall disorders (RCW), obesity hypoventilation syndrome (OHS), combined COPD and obstructive sleep apnea (COPD + OSA), neuromuscular disorders (NMD), and other pathologies (miscellaneous).
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