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Review

Health-related quality of life measurement in patients with chronic respiratory failure

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ABSTRACT

The improvement of health-related quality of life (HRQL) is an important goal in managing patients with chronic respiratory failure (CRF) receiving long-term oxygen therapy (LTOT) and/or domiciliary noninvasive ventilation (NIV). Two condition-specific HRQL questionnaires have been developed to specifically assess these patients: the Maugeri Respiratory Failure Questionnaire (MRF) and the Severe Respiratory Insufficiency Questionnaire (SRI). The MRF is more advantageous in its ease of completion; conversely, the SRI measures diversified health impairments more multi-dimensionally and discriminatively with greater balance, especially in patients receiving NIV. The SRI is available in many different languages as a result of back-translation and validation processes, and is widely validated for various disorders such as chronic obstructive pulmonary disease, restrictive thoracic disorders, neuromuscular disorders, and obesity hypoventilation syndrome, among others. Dyspnea and psychological status were the main determinants for both questionnaires, while the MRF tended to place more emphasis on activity limitations than SRI. In comparison to existing generic questionnaires such as the Medical Outcomes Study 36-item short form (SF-36) and disease-specific questionnaires such as the St. George's Respiratory Questionnaire (SGRQ) and the Chronic Respiratory Disease Questionnaire (CRQ), both the MRF and the SRI have been shown to be valid and reliable, and have

Abbreviations: BMI, body mass index; COPD, chronic obstructive pulmonary disease; CRF, chronic respiratory failure; CRQ, Chronic Respiratory Disease Questionnaire; HRQL, health-related quality of life; LTOT, long-term oxygen therapy; MRF, Maugeri Respiratory Failure Questionnaire; NIV, noninvasive ventilation; OHS, obesity hypoventilation syndrome; SF-36, Medical Outcomes Study 36-item short form; SGRQ, St. George's Respiratory Questionnaire; SRI, Severe Respiratory Insufficiency Questionnaire

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better discriminatory, evaluative, and predictive features than other questionnaires. Thus, in assessing the HRQL of patients with CRF using LTOT and/or NIV, we might consider avoiding the use of the SF-36 or even the SGRQ or CRQ alone and consider using the CRF-specific SRI and MRF in addition to existing generic and/or disease-specific questionnaires.

Contents

1. Introduction

Various pulmonary or extrapulmonary diseases can cause chronic respiratory failure (CRF). Most of these diseases are usually advanced, incurable, and progressive, damaging patients' health physically, psychologically, and socially. Long-term oxygen therapy (LTOT) and/or domiciliary non-invasive ventilation (NIV) are often prescribed to improve symptoms and health-related quality of life (HRQL). Under these conditions, there may be a need to measure HRQL using questionnaires specifically for those receiving such treatments, apart from disease-specific questionnaires that focus on a specific disease and treatment.

Disease-specific questionnaires are preferred, especially in clinical trials, due to their better responsiveness to medical interventions, rather than generic questionnaires [1] such as the Medical Outcomes Study 36-item short form (SF-36) [2], which is the most frequently used generic questionnaire in clinical trials associated with NIV [3]. The St. George's Respiratory Questionnaire (SGRQ) [4] and the Chronic Respiratory Disease Questionnaire (CRQ) [5] are the main disease-specific HRQL questionnaires, and were originally developed for patients with chronic obstructive pulmonary disease (COPD). Although they are also used for patients with other respiratory diseases, they were validated in patients with mild to severe diseases, and not in patients with CRF. In addition, these instruments may include items not specific to patients with CRF who are usually treated with LTOT and/or NIV. Although the HRQL of CRF patients could be measured as a worst-case scoring indicator, these types of instruments may prevent the detection of deterioration in HRQL over time. Thus, a condition-specific questionnaire for patients with CRF irrespective of underlying diseases, the Maugeri Respiratory Failure Questionnaire (MRF) [6], was developed. Later, a more specific questionnaire for patients with CRF receiving NIV, the Severe Respiratory Insufficiency Questionnaire (SRI) [7], was developed.

HRQL measurements have three properties [8]: (1) to differentiate people with better HRQL from those with worse HRQL (discriminative property); (2) to measure the degree of HRQL changes after medical intervention or over time (responsive property); and (3) to predict future outcomes, such as mortality (predictive property). By assessing these properties, we reviewed HRQL measurements in patients with CRF, with a particular focus on the condition-specific MRF and SRI questionnaires.

2. CRF-specific HRQL questionnaires

The MRF and SRI are the two main CRF-specific questionnaires in use (Table 1). One disadvantage of disease- or condition-specific questionnaires is that the more specific the questionnaire, the less broad its area of application. Namely, the MRF and SRI are only valid for those with CRF, and not for those without. The MRF was first developed as the MRF-28 [6] for use in patients with CRF. Its 28 items are grouped into three subscales: daily activity, cognitive function, and invalidity. The total score was then calculated from the subscales. The scores ranged from 0 (best HRQL) to 100 (worst HRQL). The MRF-28 was modified to the MRF-26 by reducing the 28 items to 26 items [9]. The MRF-26 has two subscales, activity and perceived invalidity, and the total score is calculated from the subscales. Unfortunately, it does not have a psychological domain, such as anxiety or depression, which is an important determinant of HRQL.

The SRI was specifically validated as a multidimensional instrument with high psychometric properties for patients receiving long-term NIV [7,10]. Recently, it was further validated in patients with COPD receiving LTOT [11]. It was originally developed in German, and has since been translated into several languages [12]. Its international adaptation is summarized in Table 2. The SRI consists of 49 items divided into seven subscales: Respiratory Complaints, Physical Functioning, Attendant Symptoms and Sleep, Social Relationships,

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