

Evaluating COPD from the perspective of the patient

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In recent years, it has been standard practice to use multicenter studies to quantify the quality of life of patients with chronic obstructive pulmonary disease (COPD). There is a pragmatic side to this strategy since regulating agencies have been demanding that such studies include outcome variables related to symptoms in order to gain approval for new treatments. In contrast, the evolution of technology and available treatments has made it clear that, particularly regarding chronic diseases, the mere confirmation that a specific treatment modality has advantages in terms of individual outcomes, such as physiological variables or mortality rates, does not necessarily imply perceptible benefits for patients.

After two studies showed that prolonged home oxygen therapy reduced mortality,⁽¹⁻²⁾ we have been prescribing this therapy for patients with hypoxemia. However, despite such convincing evidence, it is difficult to persuade patients to use oxygen on a continuous basis. The negative impact of becoming aware of the severity of their illness, the annoyance of using the catheter and the equipment, as well as the perspective of social exclusion, are fundamental factors that influence their decision.⁽³⁾ Patients who agree to start treatment are likely to comply with the treatment if they are able to perceive immediate benefits, especially symptom relief. We prescribe bronchodilators even when an improvement in spirometric variables is not detected. This is another example showing that individual outcomes, such as mortality and physiological variables, although important, do not necessarily reflect the expectations of patients.

When we treat our patients, we make use of various data. We evaluate and quantify symptoms, the behavior of the disease over time and the impact on the activities of patients, as well as the frequency and intensity of exacerbations. We also make note of spirometric parameters. The summation of these data, together with an appropriate physician-patient relationship, allows the repercussions of the disease to be identified, the treatment to be determined and

the results to be evaluated. In a sense, health-related quality of life questionnaires have been developed in order to standardize responses in population-based studies, in which obtaining individualized information is not feasible.

For the past few years, various review articles have been published, in which the laborious methodology of constructing and validating such instruments has been detailed.⁽⁴⁻⁸⁾ Such questionnaires must be reliable, valid and responsive. They should provide similar results when the same phenomenon is evaluated under different circumstances (reliability), accurately measure what should be evaluated (validity) and be able to detect changes over time or those related to interventions (responsiveness). These questionnaires are classified as generic (those that can be used with different populations and diseases) or specific (those that are targeted at a specific disease).

The majority of the most commonly used instruments were constructed in English. Although a well translated version of such a document is adequate for local use, international publications will rarely accept the results of studies employing questionnaires that were not validated for a specific language. The study by Camelier et al.,⁽⁹⁾ published in the present issue, provides interesting reasons to intensify this discussion. In 2000, during the process of validating the Saint George's Respiratory Questionnaire (SGRQ),⁽¹⁰⁾ researchers from the same group translated the original questionnaire into Portuguese and then back-translated it into English. This document was then submitted to the author of the SGRQ, who approved it. As a consequence, this version was applied, validated and made available to researchers as an official version of the SGRQ in Brazil. A few years later, Camelier et al. detected interpretation problems caused by double-negative statements, some items were changed, and the new questionnaire was applied. Fortunately for those who had used the original version, and we count ourselves among that number,⁽³⁾ the authors showed that the change in

the formulation of the questions had not altered the measuring properties of the instrument.

The generic questionnaires most frequently used in studies with patients with COPD are the Medical Outcomes Study Short Form 36-item Questionnaire (SF-36), the Sickness Impact Profile, the Nottingham Health Profile (NHP) and the Quality of Well Being Scale. Among the specific questionnaires are the Chronic Respiratory Questionnaire, the SGRQ and the Seattle Obstructive Lung Disease Questionnaire.^(7,11) A recurring question when we design a study is which questionnaire we will choose. This choice is not simple since none is perfect, and none fulfills all the requirements. In addition, there have been few studies comparing the various instruments.⁽¹²⁾ Although there is no absolute rule, it is recommended that studies involving patients with COPD use a generic questionnaire in conjunction with a specific questionnaire.⁽¹³⁾ Until recently, these options for Brazilian researchers have had few options since, among the above-mentioned instruments, only the SF-36,⁽¹⁴⁾ the SGRQ⁽¹⁰⁾ and the less-often used Airways Questionnaire 20⁽¹⁵⁾ were validated for use in Portuguese. In 2004, the NHP⁽¹⁶⁾ was included in this list. In their study, Camelier et al.⁽⁹⁾ have contributed to broadening our alternatives when they modified the questions in the SGRQ, in which the evaluation period was reduced from a year to three months. Researchers now have the option of using either the original or alternative version of the instrument, depending on their objectives.

The increasing number of quality of life studies demonstrates that the Brazilian scientific community has now matched the international scientific community in terms of the importance given to this theme. It is essential that we use validated instruments in order to garner international acceptance for our studies. If a wider array of questionnaires is available, it will be easier for us to choose the best instrument for each study. New validations are welcome. Who will take up the challenge?

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