Health-related quality of life questionnaires in bronchiectasis: the simplest way to quantify complexity

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The human mind is probably the most complex machine in the known universe. Billions of neuronal interconnections lead each individual to respond differently to a specific stimulus, but this response can quickly alter, and it can also be modulated by interaction between the individual's environment and the genetic load that he or she has inherited. Any precise quantification of all this information is still beyond our capabilities, but a concerted effort is underway to increase the number of objective measurements that could provide us with data about the severity and activity of diseases and bring us closer, sooner or later, to what has become known as personalised medicine [1]. Nevertheless, none of the objective measurements currently available are ideal for analysing the overall impact of a disease. The key questions in this respect are: How does each individual experience the disease, not merely from a physical viewpoint but also in psychological, social and spiritual terms? What factors modulate this response? How do these vary over time? Severity, activity and impact are three different dimensions of a disease and therefore they should never be confused. At present, a disease's impact on an individual is evaluated by means of health-related quality of life questionnaires [2], which are the best tools available for gleaning the maximum information about the complexities of such an impact while simplifying it as far as possible. This has led most regulatory bodies to insist on the inclusion of health-related quality of life as one of the main outcomes of clinical trials evaluating different therapeutic measures [3, 4].

What is required of a good quality of life questionnaire for bronchiectasis? Basically, it should be specifically for use in bronchiectasis patients, suitably validated, applicable to different populations (external validity) and available in different languages. Further, it should be capable of changing to a clinically significant degree (*i.e.* a degree noticeable to the patient) after the administration of a specific therapy, or after relevant changes in the patient's circumstances [5]. Even the best questionnaire is useless, however, if nobody uses it, so another extremely important prerequisite is simplicity in terms of construction, handling and interpretation.

In an excellent article in the current issue of the *European Respiratory Journal* SPINOU *et al.* [6] report on the construction and validation of a new questionnaire specifically for use in bronchiectasis patients (the

second of its kind, after the Quality of Life-Bronchiectasis (QoL-B) [7, 8]) and on its translation into various languages. This new questionnaire, called the Bronchiectasis Health Questionnaire (BHQ), has one indisputable advantage: its simplicity. It has a mere 10 items and one single domain (whereas the QoL-B has 37 items and eight domains, and the St Georgés Respiratory Questionnaire [9] has 50 items and three domains), while its easy interpretation (it has one single overall health status score) undoubtedly enhances its clinical applicability. Furthermore, the authors conclude that, despite the questionnaire's simplicity, its validation is appropriate for most psychometric aspects (from item generation and item reduction to internal/external validation). They also show that the questionnaire works well in a population very different from that of the construction cohort (in this case, an Asian cohort). Finally, the authors also present a translation of the questionnaire into many of the world's most important languages. The publication of a questionnaire such as the BHQ for use in bronchiectasis patients must therefore be considered good news for the scientific community.

We must not, however, pass over the limitations evident in both the study and the questionnaire. Some of these may be solvable in the future, but others must be taken into account before using the questionnaire. One psychometric property is particularly worthy of note: the determination of the minimal clinically important difference (MCID), which is often overlooked. It is invaluable, however, as, over and above the statistical significance that can always be obtained by sufficiently increasing the number of patients, it is necessary to know the minimum change in the questionnaire's value that a patient is capable of detecting as clinically significant. This finding must therefore be considered clinically important after the application of a specific therapy. The questionnaire's simplicity, which is vital to its clinical applicability, could impede the calculation of the MCID, as it could be more difficult to achieve a significant change after a therapeutic intervention owing to the paucity of items [10, 11]. Another limitation of the questionnaire (as the authors themselves acknowledge) is its predominant focus on symptoms, at the expense of other extremely important aspects that affect the disease's overall impact and management in relation to patients' quality of life, such as psychological, emotional and personal factors. This means that it is not designed for an evaluation of the overall impact of bronchiectasis. Accordingly, when a more complete analysis of the impact of bronchiectasis is sought, this questionnaire must be used in conjunction with other questionnaires, preferably ones specific to bronchiectasis, such as the QoL-B, which analyses other important dimensions of the quality of life such as physical functioning, role functioning, vitality, emotional functioning, social functioning, treatment burden and health perceptions [8, 9]. Furthermore, although, as mentioned above, it is important to differentiate the severity, activity and impact of bronchiectasis, it is equally important to know the correlation and associations between these different dimensions of the disease. Future studies must therefore assess the correlation of this questionnaire with QoL-B in particular, as this could serve as a reference standard for the completion of the new questionnaire's validation. Finally, it would also be desirable to analyse the questionnaire's correlation with currently available measures of disease activity (biomarkers) [12] and severity (validated multidimensional scales) that are applicable to bronchiectasis, such as the FACED [13] and the Bronchiectasis Severity Index [14].

It is essential to find tools that provide complementary information about the overall effect of bronchiectasis, while being easy to use and interpret. In this respect, the future application of a questionnaire such as the one presented by these authors could become part of a simple score, along with other easily accessible measurements like the current multidimensional scoring systems and certain biomarkers. This could allow us to simply obtain (and quantify) a complete vision of the disease's effects on a patient in the three main dimensions mentioned above: impact, severity and activity.

Maybe the future will bring significant changes and a progressive understanding of the complex interaction of all the factors that determine the impact of disease on a patient. In the meantime, we have to manage with improvements in the capacity of these simple questionnaires, as they are the best tool at our disposal for obtaining information that no objective parameter is capable of providing.

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