Measuring Quality of Life in Interstitial Lung Disease

To the Editor:

Chang et al (November 1999)1 studied the usefulness of four health-related quality of life (QOL) instruments, two generic and two respiratory-specific measures, in a group of interstitial lung disease patients (33 idiopathic pulmonary fibrosis [IPF], 10 sarcoidosis, and 7 miscellaneous), and concluded that the Medical Outcome Study Short Form 36 (SF-36) and the St. George’s Respiratory Questionnaire (SGRQ) are good tools for measuring health-related QOL or health status.

We would like to make a few comments. First, researchers should realize that there is a difference between health status or health-related QOL and QOL. Health status or health-related QOL assesses the influence of disease on physical, emotional, and social functioning. In contrast, the core of QOL is the person’s perception of his or her life. When QOL is studied using health status measures, one major problem is that lower levels of functioning are equated with lower QOL. This contrasts with empirical findings reflecting high perceived QOL in spite of low levels of functioning. Furthermore, QOL has a much wider scope than the physical, emotional, and social domains. For instance, the SGRQ measures 3 aspects (activity, symptoms, impact) and the SF-36 has 8 dimensions, whereas the World Health Organization Quality of Life assessment instrument (WHOQOL) measures 24 aspects of QOL. Moreover, QOL encompasses the respondents’ own perception of aspects of their life, while health status asks respondents about the presence or frequency of behavior and feelings.2 Second, in a number of studies that we conducted among sarcoidosis patients using the WHOQOL, it appeared that, among others, fatigue is a major problem for sarcoidosis patients.3-5 This aspect is not measured by the SGRQ nor the SF-36. Thus, when applying either or both of these measures recommended by Chang and colleagues,1 this important aspect is not assessed. Third, we have used focus groups with IPF patients to establish the feasibility of the SGRQ and the WHOQOL within this population. The focus group participants made substantial negative remarks about the SGRQ. In addition, the scales of the SGRQ were not mentioned as important aspects of life by the patients.2

Considering the above-mentioned remarks, we doubt whether the SF-36 and the SGRQ are good indicators of the problems that interstitial lung disease patients face. In previous studies, we established that the WHOQOL-100 has good validity and reliability within sarcoidosis patients. For example, the WHOQOL-100 distinguishes well between sarcoidosis patients with and without complaints.3,5 The WHOQOL-100 also appears to be useful in an IPF population.2

Jolanda De Vries, PhD
Tilburg University
Tilburg, The Netherlands

Marjolein Drent, MD, PhD
University Hospital Maastricht
Maastricht, The Netherlands

References


To the Editor:

We appreciate the concerns expressed by Drs. De Vries and Drent about our recent publication in CHEST.1 We agree whole-heartedly with the importance of distinguishing quality of life from health-related quality of life and health status. This is an important distinction and a distinction that one of us has written about extensively.2 Our article assesses health-related quality-of-life measures, and Drs. De Vries and Drent correctly point out that, in a few places in the article,1 we abbreviated the concept as quality of life when we should have used the abbreviation HRQOL (for health-related quality of life). Drs. De Vries and Drent cite some potentially exciting qualitative work comparing the Saint Georges Respiratory Questionnaire (SGRQ) and the World Health Organization Quality of Life (WHOQOL) instrument. We look forward to seeing this research in print. However, in choosing between the SGRQ, the Medical Outcomes Study Short Form-36, and the WHOQOL, it will be important that researchers decide what domains are most important in the particular study: quality of life or health-related quality of life and generic or disease-specific. Furthermore, for studies in which both domains are important, it will be important to have head-to-head comparisons of the instruments measuring the reliability, validity, and responsiveness of each. It will not be possible to make the blanket statement that WHQOL or SGRQ is a better measure for sarcoidosis or idiopathic pulmonary fibrosis based on a single qualitative study.

J. Randall Curtis, MD, MPH
Donald L. Patrick, PhD, MSPH
Jacqueline A. Chang, MD
Ganesh Raghu, MD, FCCP
University of Washington School of Medicine
and School of Public Health
Seattle, WA

References