Health-Related Quality of Life Assessment: An Inexpensive Tool for Cystic Fibrosis Care

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Cystic fibrosis (CF) is a rare disorder among non-Caucasians and there is great disparity in provision of care across regions and countries. Underdiagnosis and lack of basic treatment are the challenges faced by many countries in southern Asia. Development of sustainable, cost-effective strategies that will improve diagnosis, clinical care protocols, and treatment of CF in these countries is important. Various patient-reported outcome measures are routinely used to study effectiveness of interventions, assess clinical status, and monitor progression of the disease [1].

The article published in this issue of the Journal by Modaresi et al. [2] reports findings from a cross-sectional study done on school-aged CF patients to investigate the correlation between severity of CF lung disease with health-related quality of life (HRQoL) scores. Two objective measures were used to quantify severity of lung involvement, CT imaging to document structural damage and 6-min walk test (6MWT) to measure functional impairment. Main observation made by the authors was that there is a positive correlation between severe lung involvement assessed by CT scores and QoL assessed by a generic tool. In addition, 6MWT performance (distance walked) correlated with certain non-physical domains in the HRQoL.

HRQoL tools assess patients' perception of their wellbeing in a structured manner. There are several tools available for use in the pediatric age group, and disease-specific QoL questionnaires have certain advantages. McLeod et al. pointed out that there can be wide variability in the application and interpretation of these tools [1].

Ability of CT scans to detect early CF lung changes and to track disease progression is well established [3]. Major drawback of this modality is radiation exposure. Validation of noninvasive and inexpensive tests or tools which will

correlate with CT imaging is useful. Tepper et al. reported good correlation of CT findings, specifically bronchiectasis and air trapping with HRQoL at two different time points 2 y apart, but noted that QoL scores did not fully capture the progression in CT changes over the study period [4].

Six-minute walk test, a simple noninvasive test, has emerged as an important tool for monitoring clinical status of children with CF [5]. In resource-limited settings this can have an exceptional value, as the test can be done with practically negligible investment. However, standardization of methodology is very important. The authors have previously reported that 6MWT results did not correlate with CT findings in the same cohort [6]. However, in this article, they only demonstrated how this test correlates with QoL. An extension of this concept could be to study a combination of 6MWT and QoL tools in monitoring progression of CF lung disease. Another area of future research is to study the utility of QoL surveys during teleconsultations and shared care clinics. Fine tuning of QoL tools to make them culturally acceptable and user-friendly will further improve their acceptability.

In conclusion, the efforts made by the authors to correlate HRQoL scores to structural and functional effects of CF lung disease in school-aged children are appreciated. Further work on this will be beneficial, especially in resource poor settings.

Declarations

Conflict of Interest None.

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