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CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

Cystic Fibrosis Research News

Citation:

Bernstein RM, Riekert KA, Quittner AL. Measuring Knowledge of Disease Management in Adolescents with Cystic Fibrosis: Initial Psychometric Evaluation. Pediatr Allergy Immunol Pulmonol. 2018;31(2):56-65.

What was your research question? (50 words maximum)

How well does the adolescent version of a test called the Knowledge of Disease Management-CF (KDM-CF-A) measure what a young adult knows about cystic fibrosis (CF) symptoms and treatments?

Why is this important? (100 words maximum)

Knowledge about symptoms and treatments is an essential step in sustaining daily care according to individual treatment plans for young adults with CF. Accurate tests are needed to correctly assess knowledge and identify places where there are knowledge gaps, especially for young adults.

What did you do? (100 words maximum)

Participants between the ages of 11-20 completed the KDM-CF-A. Among those participants, half of them were female. All eligible participants attended a CF care center, spoke English, and had a CF diagnosis. Each item was checked in order to finalize the tests, including different ways it could be answered and how often it was answered correctly.

What did you find? (100 words maximum)

Several original items were deleted for being too easy or too hard or because they didn’t work well with other sections. The final result had three sections: the Total Knowledge Scale, Self-Management subscale, (12 items) and Treatment Information subscale (11 items). The KDM-CF-A worked well to study young adults’ knowledge of CF. The average Total Knowledge Scale score was 67%. We expected to see that older participants and those with private health insurance would have more CF knowledge, and this was true. Knowledge was not associated with patients' lung function or height and weight (body mass index percentile).

What does this mean and reasons for caution? (100 words maximum)

The KDM-CF-A had good reliability (was consistent) and validity (measured what it was supposed to). It may be useful for understanding the gaps in knowledge for young adults with CF and improving these through interventions for each person. The KDM-CF-A was not compared with other self-reported measures of knowledge, which is a core strategy for evaluating validity. When this study started, few young adults were on CFTR modulators due to timing of approvals.

What's next? (50 words maximum)

Knowledge related to CFTR modulators will need to be added to an updated measure. Translating the KDM-CF-A into Spanish will need to be done. Once these changes are made, the KDM-CF-A will need to be studied again. Future studies should use this measure along with the parent version to examine associations between parent and young adult knowledge.