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Patient-derived questionnaire items for patient-reported outcome measures in adults with strabismus

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Abstract

In a previous study we performed individual interviews of adults with strabismus and identified specific health-related quality of life concerns. In this present report we provide the entire list of specific questionnaire items that were created, one for each concern articulated in the interviews. Our aim in reporting this full list of 181 individual, patient-derived questionnaire items is to provide a resource to clinicians and researchers interested in developing patient-reported outcome measures for adults with strabismus.

Patient-reported outcome measures are important for the assessment of health, well-being, and treatment effectiveness. We have previously reported the development of the Adult Strabismus (AS)-20 questionnaire, a patient-reported outcome measure evaluating health-related quality of life (HRQOL) in adults with strabismus.^{1,2} In developing the AS-20 questionnaire, we created an initial list of all potential questionnaire items based on patient-derived concerns identified from individual patient interviews.^{1,3} We have not previously reported this entire list of potential questionnaire items, and we now see the value of making these items available as a resource to clinicians and researchers. In the present report we provide the full list of candidate questionnaire items originally identified from individual interviews of adults with strabismus.

Subjects and Methods

Approval for this study was obtained from the Mayo Clinic Institutional Review Board. All procedures and data collection were conducted in a manner compliant with the US Health Insurance Portability and Accountability Act of 1996, and all research procedures adhered to the tenets of the Declaration of Helsinki. Informed consent was obtained.

As described previously,^{1,3} 30 adults with strabismus (17 [57%] with diplopia and 13 [43%] without diplopia), across a range of diagnoses, were enrolled from a single strabismus practice (JMH). Each patient was interviewed using 11 open-ended questions in a

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Study conducted at: Department of Ophthalmology, Mayo Clinic, Rochester, Minnesota

semistructured format.³ Each interview was audiorecorded and transcribed, and transcripts were reviewed independently by three investigators.³

Each of the three investigators independently identified specific concerns in each interview. For each patient, the three lists of concerns (one from each investigator) were combined, and duplicates were removed.³ Concerns were then grouped by theme across all patients.

Two investigators reviewed the entire list of concerns, derived from all patient interviews and formulated a specific question for each specific concern. Questionnaire items were formulated as statements.

Results

Across all individual patient interviews a total of 1,301 specific concerns were extracted that pertained to HRQOL.³ From these concerns, after duplicates were removed, a total of 181 individual questionnaire items addressing specific HRQOL concerns were formulated.¹ This entire list of derived questionnaire items is provided in the eTable 1, grouped by theme.

Discussion

We have made available the entire list of questionnaire items derived from individual interviews of adults with strabismus. Making this complete list of items available provides a resource to other care providers and researchers interested in developing patient-reported outcome measures.

In the development of patient-reported outcome measures it is important to utilize the patient's perspective when establishing the content of items.^{4,5} This may be achieved using individual patient interviews or focus groups, and in the present study we elected to use individual patient interviews. By interviewing patients with a range of strabismus types and severities, and recording each specific concern we aimed to capture the full range of HRQOL issues affecting adults with strabismus.

The main purpose of making the complete list of potential questionnaire items publicly available is to provide other care providers and researchers with a resource to use in the development of other patient-reported outcome measures. One approach would be to use the statements as questions in an item bank,^{6,7} initially administering all the items to a large group of patients, performing factor analysis or principal component analysis to establish unidimensional domains, and performing Rasch analysis to Rasch-calibrate each item. This process could then lead to computer-adaptive testing,⁶ which would allow rapid administration of a few questions to provide a Rasch-calibrated score for each domain. Alternatively, short forms could be developed such as the AS-20 questionnaire.¹ The AS-20 has undergone Rasch analysis² and is now freely available online, with Rasch look-up scoring tables (www.pedig.org).

There are some limitations to our study. Although we interviewed a heterogeneous group of strabismus patients, it is possible we missed some concerns that may be specific to a

particular subpopulation of adults with strabismus, or may be present in other cultures. Nevertheless, we included each concern even if it was only mentioned once.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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