

# Developing a sophisticated instrument to measure the coping strategies of people with hereditary retinal diseases

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## Footnotes

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## Abstract

**Purpose :** Our understanding of the coping strategies used by people with visual impairment to manage stress related to visual loss is limited. There are several coping questionnaires developed for medical conditions but none for eye diseases. This study aims to develop a sophisticated coping instrument in the form of an item bank implemented via computerized adaptive testing (CAT) for hereditary retinal diseases. As CAT system iteratively presents items based on a patient's response to previous items, we hypothesize that fewer items will be required to gain a precise measurement of the coping compared to the full item bank.

**Methods :** Items on coping were extracted from qualitative interviews with patients with hereditary retinal diseases which were supplemented by items from a literature review. A systematic multi-stage process of item refinement was carried out followed by expert panel discussion and cognitive interviews with patients with hereditary retinal diseases. The final coping item bank had 30 items. Rasch analysis was used to assess the psychometric properties of the coping item bank. A CAT simulation was carried out to estimate an average number of items required to gain precise measurement of hereditary retinal diseases-related coping.

**Results :** The coping item bank was answered by 189 participants (median age = 58 years; range = 19 to 87 years; retinitis pigmentosa; 77%, females, 55%). The coping scale demonstrated good precision and targeting. The standardized residual loadings for items revealed that six items related to active coping grouped together. Removal of the six items reduced the precision of the main coping scale and worsened the variance explained by the measure. Therefore, the six items were retained within the main coping scale. Our CAT simulation indicated that, on average, less than 10 items are required to gain a precise measurement of coping.

**Conclusions :** This is the first study to develop a psychometrically robust coping instrument for hereditary retinal diseases. Our CAT simulation indicated that on an average, only 4 and 9 items were required to gain measurement at moderate and high precision, respectively. The coping item bank can be used by clinicians and researchers to better understand the coping responses of people with hereditary retinal diseases.

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