Evaluation and Adaptation of the FACE-Q | CRANIOFACIAL Patient-Reported Outcome Measure for Ophthalmology Patients

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1. Study Objectives
   1. To assess the content validity of 7 FACE-Q sections in Corneal Anesthesia, Retinoblastoma, and Strabismus; patients/survivors, and their parents/guardians.
   2. To adapt the FACE-Q to develop a PROM specific to Corneal Anesthesia, Retinoblastoma, and Strabismus, and a corresponding parent-proxy version.

2. Background
   Patient-reported outcome measures (PROMs): Tools that assess patient perceptions of health outcomes via standardized and validated questionnaires.

   According to prior research, PROMs specifically tailored for patients who have been treated for corneal anesthesia via corneal neurotization surgery (unpublished) and retinoblastoma survivors are vital.

3. Methods
   1. Cognitive Debriefing Approach Overview
      - Round 1 of Cognitive Debriefing Interviews
      - FACE-Q Modifications
      - Round 2 of Cognitive Debriefing Interviews

      To ascertain the relevance of, identify problems with, and solicit modifications to the FACE-Q.
      Made in collaboration with patient partners, & scientific & clinical stakeholders.
      To evaluate the acceptability and relevance of modified FACE-Q questions.

   2. Sampling
      Following COSMIN* Guidelines
      Per Round: n = 42
      Per Condition: n = 14
      Per Participant Type (Parent or Patient/Survivor): n = 7

   3. Inclusion Criteria
      - Corneal Anesthesia, Retinoblastoma, or Strabismus patients/survivors ≥ 8 years old
      - Parents/Legal Guardians of patients/survivors who are either: < 8 years old, Developmentally delayed, OR Hard of hearing

   4. Data Collection
      During each interview, participants assessed FACE-Q’s comprehensibility, relevance, and comprehensiveness by reviewing:
      1. Instructions
      2. Each question
      3. Response options
      4. Overall section

   5. Data Analysis
      Interviews were transcribed & coded to identify feedback/new concepts/suggestions for modifications
      Tallied # of participants offering each specific feedback or suggestion

4. Preliminary Results
   Interviews Completed to Date:
   - 7/7 Retinoblastoma Survivors
   - 6/7 Parents of Retinoblastoma Survivors
   - 4/7 Corneal Anesthesia Patients

   All 7 FACE-Q sections deemed to be relevant to the Retinoblastoma and Corneal Anesthesia experience

   To improve FACE-Q Relevance and Comprehensiveness:
   - Prosthetic Eyes
   - Visual Impairment
   - Accommodations at School
   - Interpersonal Relationships
   - School
   - Psychological Function
   - Pain/Acute Pain

   To Improve FACE-Q Comprehensibility (Common Consensus):
   - Preference for 5-point Likert scale
   - Preference for consistent response options
   - Preference for recall period to be extended from “past week” to “past month”

   Overall:
   - Comments made regarding redundancy
   - Rewording suggested for clarity and appropriateness

5. Discussion
   The study results suggest key modifications to be made to the FACE-Q to make it comprehensible, comprehensive, and relevant to the 3 target patient populations. More suggestions and feedback are to be uncovered as the study progresses.