Identification of Key Themes Related to Quality of Life in Cleft Lip and Palate Patients

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Disclosures

Nothing to disclose
Introduction

- Most outcome measures in CLP are objective assessments
- Limited subjective indicators of QoL in CLP

Goal: Identify major themes implicated in the satisfaction of CLP patients and parents

Generate: Comprehensive, valid subjective questionnaire
Staged Development

Stage 1: Themes → Preliminary Questionnaire + Pilot Testing

Stage 2: Field Testing → Revision and Finalization of Questionnaire

Stage 3: Evaluation for Validity and Strength
Methods: conducting focus groups

- Patients and their parents with cleft lip and/or palate invited to discuss satisfaction/QoL
- Moderator-conducted focus groups
  - 60 minutes
  - Audio-recorded
  - Partially-structured
- Audio recordings transcribed verbatim and de-identified
Methods: data analysis $^{2,3,4}$

- Team-based reading to understanding themes
- Independent articulation of interviewee’s story
- Team-based creation of generalized concepts
- Transcript reading and verification of concepts
- Identification of preliminary codes
- Identification of trends of themes $^5$
Results

**Five** focus groups were conducted
- 2 patient groups
- 2 parent groups
- 1 provider group

**Six** major themes (codes)
1. Communication & Navigation of Care
2. Cosmesis
3. Financial Burden of Medical Care
4. Functionality
5. Self-Esteem
6. Support Systems & Social Adjustment
Results: frequency of themes

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## Results: co-occurrence within text

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“I was five, and these little kids were saying they didn’t want to play with me because I had this big red line on my face. And I was like ‘I can’t help it!’ They really didn’t understand, and they kept on calling me ugly and just really bad names.”
Discussion

- Support System and Social Adjustment
- Cosmesis
- Functionality
- Self-Esteem
- Communication & Navigation
- Financial Burden of Medical Care

Quality of Life
Future Directions

- Creation of a preliminary questionnaire based on themes identified
- Additional recruitment of patients and parents for more focus groups
- Focus groups with providers for possible areas of discordance
- Focus groups with non-native English speakers
References


5. Dedoose by SocioCultural Research Consultants, LLC. Manhattan Beach California