

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

Paymon Sanati-Mehrizy, BA; Nathaniel L Villanueva, MD; Jonatan Hernandez Rosa, MD; Rebecca Wu, MD; Donna Eckstein, MD; J Roscoe Wasserburg; Lester Silver, MD, MS; Peter J Taub, MD.

Abstract

Purpose: Outcomes-related studies in the treatment of cleft lip and palate traditionally feature a focus on objective measures, providing limited scope with regards to subjective indicators of quality of life in these patients^{1,2}. As previously described by Eckstein et. al, existing questionnaires contain uncertain validity or reliability, due to their ad hoc nature, or are not specific to the cleft community, making them unable to capture aspects unique to these patients². This study aims to identify the major themes implicated in the satisfaction of cleft lip and palate patients and their parents in order to create a comprehensive, valid, and reliable subjective questionnaire.

Methods: Patients who presented with a cleft of the lip and/or palate through the Mount Sinai Cleft and Craniofacial Center, parents of such patients, and care providers in multiple related specialties were invited to participate in 60-minute audio-recorded focus groups to discuss satisfaction. A total of five separate focus groups were conducted. These sessions featured a partially-structured discussion hosted by a moderator. De-identified transcriptions of these sessions were holistically evaluated for the participants' experience. Transcriptions were also coded with HyperRESEARCH software and analyzed for themes.

Results: Six major themes emerged through the analysis as factors affecting satisfaction of cleft lip and/or palate patients or their parents: (1) Communication & Navigation, (2) Cosmesis, (3) Financial Burden of Medical Care, (4) Oropharyngeal Functionality, (5) Patient Self-Esteem, and (6) Support Systems & Social Adjustment. Of note, patients tended to focus more on Theme 2 (Cosmesis) and Theme 6 (Support Systems & Social Adjustment), while parents tended to focus on Theme 1 (Communication & Navigation) and Theme 4 (Oropharyngeal Functionality).

Conclusions: We have identified important themes for assessing satisfaction and quality of life in patients with cleft lip and/or palate and their families. These themes will serve as the foundation for the development of a sound, patient-reported subjective questionnaire for cleft lip and/or palate.

References:

1. Cano SJ, Klassen A, Pusic AL: The science behind quality-of-life measurement: a primer for plastic surgeons; *Plast Reconstr Surg*; 123: 98e-106e, 2009.
2. Eckstein DA, Wu RL, Akinbiyi T, Silver L, Taub PJ: Measuring quality of life in cleft lip and palate patients: currently available patient-reported outcomes measures; *Plast Reconstr Surg*; 128: 518e-526e, 2011.

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