PARENT AND YOUTH PERSPECTIVES ON THE IMPACT OF CRANIOFACIAL CONDITIONS: A MULTI SITE STUDY

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IMPACT OF FACIAL DIFFERENCES ON QUALITY OF LIFE

- Poorer social skills and increased social problems
- Increased risk for negative feelings of self-worth
- Increased difficulties with psychological adjustment
- Perceived negatively in comparison to non-affected
- Report of lower overall quality of life
CRANIOFACIAL CONDITIONS & FAMILY FUNCTIONING

- Increased parental stress
- Affects family life
- Increased parental feelings of guilt
- Increase parental concerns about child
HYPOTHESES

- Those youth who attribute more positive personal consequences to their craniofacial condition will also report more positive overall quality of life.

- Youth who attribute more positive consequences to their craniofacial condition will have parents reporting better family functioning.

- Youth self report and parent report of more severe craniofacial condition will result in youth report of less positive overall quality of life.
PARTICIPANTS

- 180 youth
- From three sites: Chicago, Seattle and Chapel Hill
- Ages 11 to 18
- Congenital or acquired facial condition
- One parent per youth
MEASURES

- Youth Quality of Life – Research Version (YQOL-R)

- Positive Perception Measure (PPM)
  - (5 perceptual items from the Youth Quality of Life – Facial Difference Module (YQOL-FD) reflecting positive impact of facial difference)

- Youth and parent ratings of severity of the facial difference

YOUTH QUALITY OF LIFE RESEARCH VERSION (YQOL-R)

Domains

- General Quality of Life
- Sense of Self
- Relationships
- Environment
Because of how my face looks, I am in touch with other people’s feelings.

Because of how my face looks, I am more accepting of other people.

I am a stronger person because of how my face looks.

Because of how my face looks, I know more about life than other people my age do.

My facial difference has helped me to accept other people for who they are.
SEVERITY RATINGS

Rated on a 7-point scale from “Not at all severe” to “Extremely severe”

- Youth
  - “The medical problems currently affecting my face are:”

- Parent
  - “The medical problems currently affecting your daughter/son’s face are”
FAMILY IMPACT QUESTIONNAIRE

Domains
- Positive Parenting Impact
- Negative Parenting Impact
- Impact on Social Life
- Financial Impact
- Impact on Marital Relationship
- Impact on Siblings
SIGNIFICANT RESULTS

Regression analyses revealed two significant correlates of youth reported overall quality of life

- PPM was positively related to total YQOL-R
  \[ B = 0.342, \ t(180) = 3.84, \ p < .001 \]

- Youth reported severity of condition was negatively correlated with total YQOL-R
  \[ B = -4.6311, \ t(168) = 4.59, \ p < .001 \]
Self-reported Severity and Positive Perception (PPM) on QoL

Data condensed for clarity
## Quality of Life Domains

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<thead>
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<th>Domain</th>
<th>PPM</th>
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Regression analyses revealed that the predicted relationship between youth positive perceptions and family functioning was not supported.

Parents reporting greater severity were significantly more likely to report negative parenting feelings and greater negative impact on siblings.
DISCUSSION

- Youth who viewed their craniofacial difference more positively reported more positive quality of life.

- The more severe the youth perceived the craniofacial condition the lower was the reported quality of life.

- Positive perception of the impact of the craniofacial condition moderated the relationship between severity and quality of life.
This collaborative multi-site study was funded by grant number: R01 DE13546, from the National Institute of Dental and Craniofacial Research to the University of Washington.

We thank the children and families of Shriners Hospitals for Children, Chicago; Children's Hospital, University of Washington, Seattle; and the craniofacial center at the University of North Carolina, Chapel Hill.