

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

**Claudia Crilly Bellucci, Kathleen Kapp-Simon,  
Donald Patrick, Todd Edwards, Tari Topolski,  
Michael Barr, Ronald Strauss, Christopher Thomas**

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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
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# CRANIOFACIAL CONDITIONS & FAMILY FUNCTIONING

- Increased parental stress
  - Affects family life
  - Increased parental feelings of guilt
  - Increase parental concerns about child
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# 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.
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# PARTICIPANTS

- ❑ 180 youth
  - ❑ From three sites: Chicago, Seattle and Chapel Hill
  - ❑ Ages 11 to 18
  - ❑ Congenital or acquired facial condition
  - ❑ One parent per youth
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# 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
  - Family Impact Questionnaire (FIQ) Donenberg & Baker(1993)
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# YOUTH QUALITY OF LIFE RESEARCH VERSION (YQOL-R)

## Domains

- General Quality of Life
  - Sense of Self
  - Relationships
  - Environment
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# PPM ITEMS

- 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.
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# 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”
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# FAMILY IMPACT QUESTIONNAIRE

## Domains

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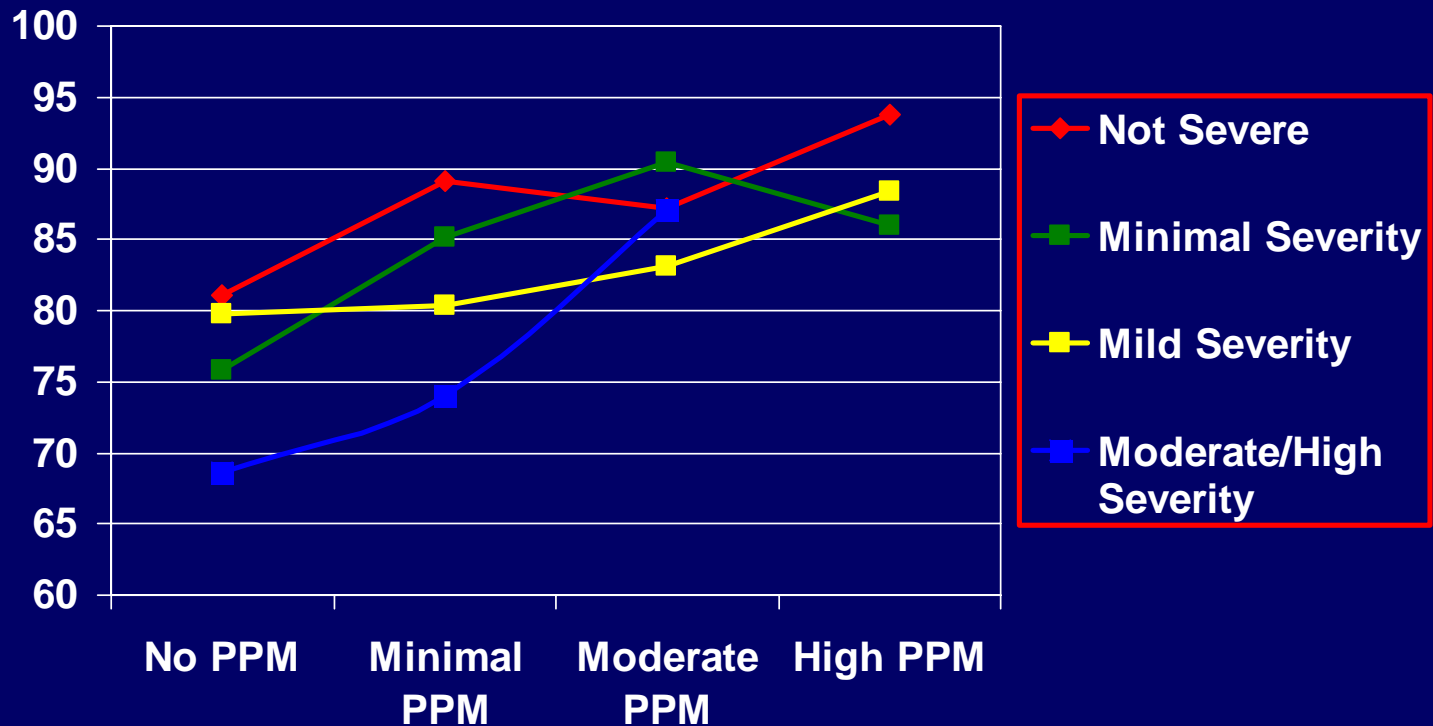
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# SIGNIFICANT RESULTS

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

- PPM was positively related to total YQOL-R  
[B = .342,  $t(180) = 3.84$ ,  $p < .001$ ]
  - Youth reported severity of condition was negatively correlated with total YQOL-R  
[B = -4.6311,  $t(168) = 4.59$ ,  $p < .001$ ]
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# Self-reported Severity and Positive Perception (PPM) on QoL



Data condensed for clarity



# Quality of Life Domains

## Predictors for Quality of Life Domains

Domain	PPM	Severity	Gender
General	.001	.001	
Self	.002	.001	.009
Relationship	.001	.001	
Environment	.001	.001	

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# FURTHER RESULTS

- 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
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# 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.
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