

In Your Face: A Panel of Multisite Quality of Life Research on Youth With Facial Differences

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2:00-3:30 p.m.

Acknowledgement of Funding Support

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Goals

- To examine the impact of congenital and acquired craniofacial conditions on adolescent health and quality of life
- To develop a greater awareness of the frequency and nature of adolescent quality of life issues related to craniofacial conditions from base-line data obtained at 5 sites using the Youth Quality of Life (YQOL) Facial Differences Module

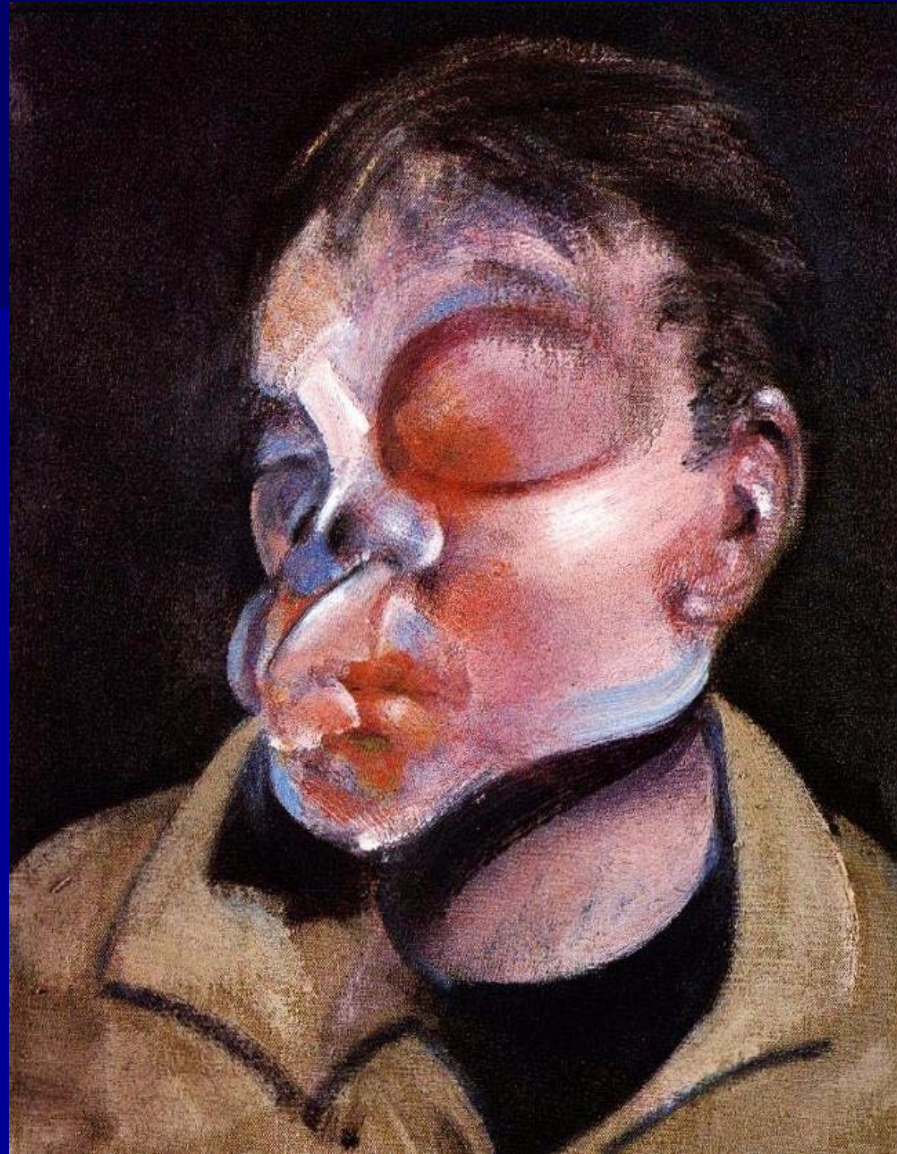
Panel Agenda

Note: To ensure equitable representation of the panel topics, please hold your questions until the end of the session. Thank you.

- Introduction
- Measuring the Quality of Life of Youth With Facial Differences
- Who Feels Bullied Most?
- Perceptions of Stigma Experiences
- Parent and Youth Perspectives on the Impact of Craniofacial Conditions
- Cross Cultural Aspects of Parental Perceptions and Expectations For Their Children
- Discussion & Questions



Girl Before a Mirror, 1932
Pablo Picasso



Self Portrait with Injured Eye, 1972
Francis Bacon

Appreciation for Wendy E. Mouradian, MD, MS



- Former Director of the Craniofacial Clinic at Children's Hospital and Regional Medical Center in Seattle
- Director, Regional Initiatives in Dental Education (RIDE)
- Associate Clinical Professor of Pediatrics, Pediatric Dentistry, Dental Public Health Sciences and Health Services (Public Health) at the University of Washington

Facial Differences Research Phases

- Phase I: Qualitative Development of Facial Differences Modules (NIDCR 2000-2002) – *Seattle site*
- Phase II: Cross-Sectional Testing of Facial Differences Modules (NIDCR 2002-2005) – *Seattle, Chicago, Galveston, Chapel Hill, Bristol*
- Phase III: Longitudinal Testing of Facial Differences Modules – *Under development*

Youth Quality of Life (YQOL) Modules and Domains

Generic YQOL – Research Version (41 Perceptual, 16 Contextual)

- Sense of Self
- Relationship
- Environment
- General

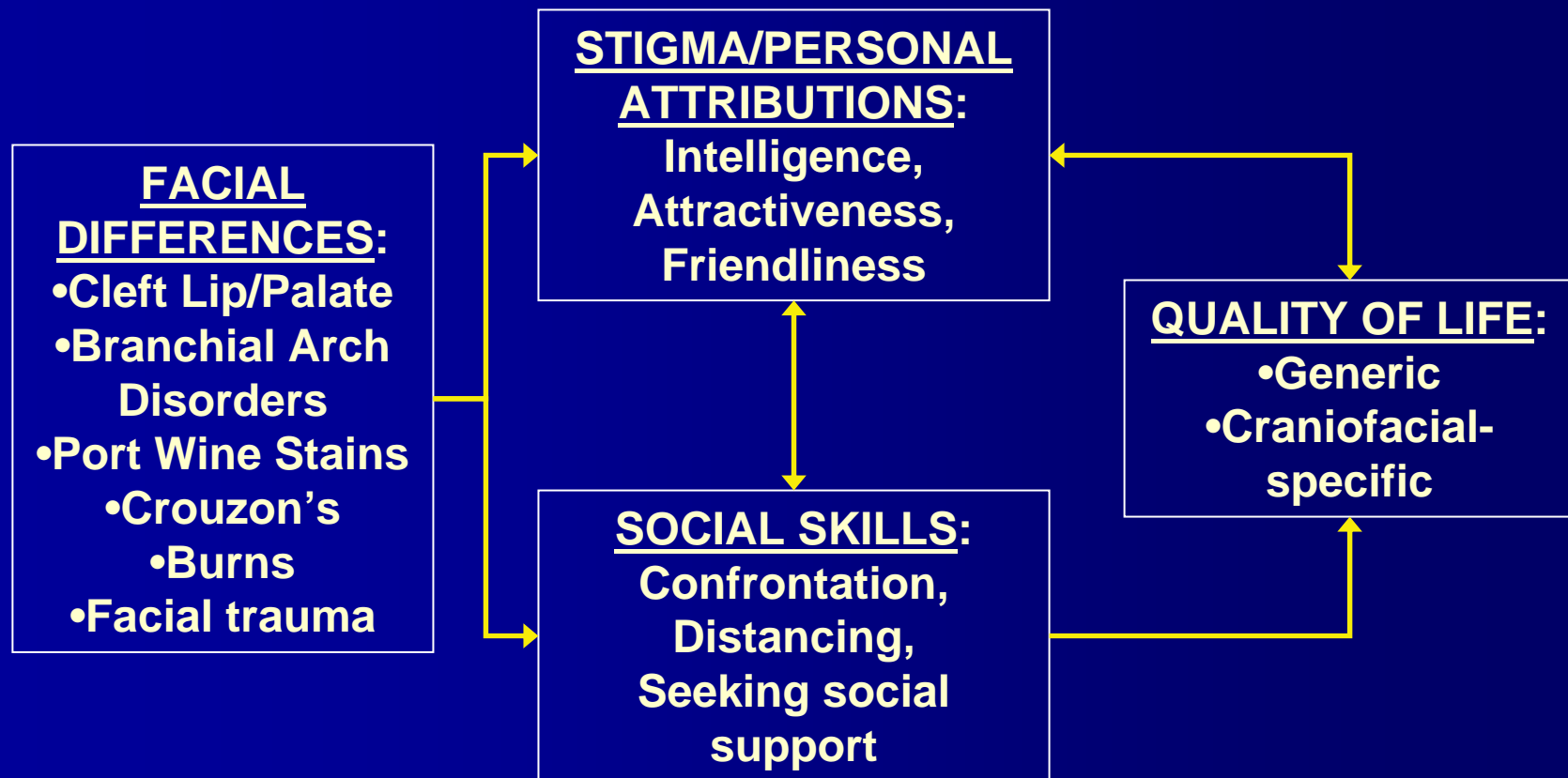
Facial Differences (30 perceptual, 18 Contextual)

- Negative consequences
- Negative self image
- Stigma
- Positive consequences
- Coping

Craniofacial Surgery (32 perceptual)

- Past surgeries
- Future surgeries

Conceptual Model for Facial Differences



Measuring the Quality of Life of Youth With Facial Differences

- **Donald Patrick**
 - University of Washington
- **Todd Edwards**
 - University of Washington
- **Tari Topolski**
 - University of Washington
- **Cassandra Aspinall**
 - Children's Hospital & Regional Medical Center
- **Kathleen Kapp-Simon**
 - Northwestern University
- **Nicola Rumsey**
 - University of the West of England
- **Ronald Strauss**
 - University of North Carolina, Chapel Hill
- **Christopher Thomas**
 - University of Texas, Galveston

Measuring the Quality of Life of Youth With Facial Differences

■ Objectives

- To describe the Facial Differences Module of the Youth Quality of Life Instrument (YQOL-FD)
- To evaluate the domain structure, internal consistency, reproducibility, validity, and respondent burden of the YQOL-FD

Sample Characteristics

	Total Sample (n=307) %	Acquired (n=104) %	Congenital (n=203) %
Age			
12-14	53	50	54
15-18	47	50	46
Sex			
Male	61	53	61
Ethnicity			
White	63	38	76
Hispanic/Latino	20	48	5
Other/Mixed	17	14	19

Youth QOL Facial Difference Module: Domains and Sample Items

YQOL-FD Domains	YQOL-FD Sample items
Negative consequences	<p>I avoid looking in the mirror because of how my face looks</p> <p>Having facial difference decreases chances of success in life</p>
Negative self-image	<p>I feel self-conscious because of how my face looks</p> <p>I feel frustrated about how my face looks</p>
Stigma	<p>Because of how my face looks, people have a hard time seeing who I really am</p> <p>People stare at me because of how my face looks</p>
Positive consequences	<p>Because of how my face looks, I am more accepting of other people</p> <p>I am a stronger person because of how face looks</p>
Coping	<p>I have gotten used to people making fun of how my face looks</p> <p>I try not to pay attention to other people when they say things about my face</p>

YQOL-FD Module: Questionnaire Sample

99. Because of how my face looks, I am in touch with other people's feelings *(please circle the number)*

Not At All

0

1

2

3

4

5

6

7

8

9

10

A Great Deal

100. People stare at me because of how my face looks *(please circle the number)*

Not At All

0

1

2

3

4

5

6

7

8

9

10

A Great Deal

101. Because of how my face looks, I have more anger inside me than most people know *(please circle the number)*

Not At All

0

1

2

3

4

5

6

7

8

9

10

A Great Deal

Reliability of the YQOL-Facial Differences Module (YQOL-FD)

YQOL-FD Domain	Number of Items	Cronbach's Alpha	ICC
Negative Consequences	6	.82	.80
Negative Self-image	5	.78	.80
Stigma	10	.90	.91
Positive Consequences	5	.81	.84
Coping	4	.71	.80

Note. N = 307. ICC N=47

Correlations Between YQOL-FD Domains

YQOL-FD Domain	Negative Self-image (-)	Stigma (-)	Positive Consequences (+)	Coping (+)
Negative Consequences (-)	.63**	.75**	.17**	.13*
Negative Self-image (-)		.71**	.37**	.29**
Stigma (-)			.33**	.31**
Positive Consequences (+)				.51**

Note. Lower scores on Negative self-image, Negative consequences, and Stigma are better. Higher scores on Positive consequences, and Coping are better. **Correlation significant at .01 level. *Correlation significant at .05 level.

Summary of YQOL-FD Domain Correlations

- Negative self-image, negative consequences, and stigma are highly correlated with each other in the expected direction.
- Positive consequences and coping are strongly related.
- Contrary to what one may think, higher positive consequences and coping are associated with higher levels of stigma.

Correlations Between YQOL-FD Domains and other Health Items

YQOL-FD Domain	Child Depression Inventory Total (-)	Self-rated Health (+)
Negative Consequences (-)	.53**	-.25**
Negative Self-image (-)	.39**	-.18**
Stigma (-)	.49**	-.18**
Positive Consequences (+)	-.04	.03
Coping (+)	-.05	.12*

Note. Lower scores on Child Depression Inventory (CDI) Total are better. Higher scores on Self-rated health are better.
 **Correlation significant at .01 level. *Correlation significant at .05 level.

Summary of YQOL-FD and other Health Item Correlations

- Self-rated health is a measure of function, and varies inversely with changes in negative domains, while it varies directly with coping.
- Depression increases or decreases in direct relation to negative domains.

Discrimination of YQOL-FD by Self-rated Severity

YQOL-FD Domain	Self-rated Severity Cut-point ^a			F ^b	Sig.
	Mildly Severe (n=250) Mean (SD)	Moderately Severe (n=23) Mean (SD)	Markedly Severe (n=20) Mean (SD)		
Negative Consequences	18.4 (20.1)	27.1 (21.7)	38.0 (25.0)	9.8	.00
Negative Self-image	37.3 (25.7)	53.3 (23.2)	53.9 (21.3)	7.7	.00
Stigma	27.3 (23.5)	37.9 (21.9)	45.6 (22.0)	7.4	.00
Positive Consequences	60.7 (24.9)	55.8 (21.0)	60.5 (26.2)	0.4	.66
Coping	60.1 (28.1)	62.2 (22.6)	57.1 (22.8)	0.2	.83

^aSeverity scores: Mildly severe - less than or equal to 3, moderately severe - equal to 4, markedly severe - greater than or equal to 5. ^bTest of between-subjects effects.

Note. Lower scores on Negative consequences, Negative self-image, and Stigma are better. Higher scores on Positive consequences, and Coping are better.

Discrimination of YQOL-FD by Origin of Facial Difference

YQOL-FD Domain	Facial Differences Group		F ^a	Sig.
	Acquired (n=99) Mean (SD)	Congenital (n=196) Mean (SD)		
Negative Consequences	24.4 (22.7)	18.3 (20.1)	5.6	.02
Negative Self-image	48.2 (23.4)	35.4 (25.8)	17.2	.00
Stigma	32.2 (21.1)	27.8 (24.9)	2.3	.14
Positive Consequences	61.1 (23.4)	59.8 (25.2)	0.2	.69
Coping	58.1 (26.7)	61.0 (27.7)	0.7	.39

^aTest of between-subjects effects.

Note. Lower scores on negative self-image, negative consequences, and stigma are better. Higher scores on positive consequences, and coping are better.

Predicting YQOL-R scores from YQOL-FD scores

- 20% of the variation in the General Quality of Life domain is predicted by the 4 scales of the YQOL-FD (negative self-image, coping, stigma, positive consequences) ($r=.45$)
- 38% of the variation in the Self domain is accounted for by negative self-image, positive consequences and stigma ($r=.62$)
- 21% of the variation in the Relationship and the Environmental domains is accounted for by negative self-image, positive consequences, stigma and coping ($r=.46$)

Conclusions

- YQOL- Facial Differences Module shows adequate reliability and validity
- Negative domains highly correlated with each other as expected
- Stigma and negative consequences positively correlated with coping suggesting more coping necessary as stigma increases
- Facial Differences Module correlates well with generic YQOL suggesting it augments generic quality of life
- QoL associated with facial differences lower for those with acquired conditions than those with congenital
- Respondent Burden: Facial Differences Module = 14 minutes, Craniofacial Surgery Module = 13 minutes, YQOL-R = 12 minutes

Use of the YQOL Modules

<http://www.seaqolgroup.org>

- Instruments (available in 4-6 weeks)
 - User Agreement
 - Order Form
- Copies of today's Session II presentations

Overall Conclusions

- Youth who are more stigmatized use more coping strategies, and also report more positive consequences
- Acquired report more negative consequences, less positive self-image, and more stigma experiences
- Mexican-Americans report worse future prospects and social competency than English-speaking
- Greater self-reported severity = lower generic QoL
- YQOL-FD augments information obtained on the generic YQOL-R