PERCEPTIONS OF STIGMA EXPERIENCES: MULTISITE STUDY OF MOTHERS AND CHILDREN WITH FACIAL DIFFERENCES

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Funded by NIDCR R01 DE13546
Issues

- The impact of appearance on adolescent social life
- Stigmatization
- Social, and media norms
- How much does appearance function as a determinant of life experiences?
- Does appearance affect quality of life and social experience?
Bodily signs of being different carry a moral evaluation, usually a negative one.

Theory of stigmatization.

First impressions are transformed into normative expectations, and then into firmly held roles and responsibilities.
The Face

- Immediately observable
- Principal target of attention in interpersonal interaction
- “everyday after I brush my teeth, I’ll stare in the mirror and see something I never like about me.” – 14 y.o. male
Purpose of this study

- Profile the stigma experiences of adolescents with congenital and acquired facial differences.
- Compare adolescent perceptions of stigma experiences with parental perceptions.
Methods

- Self-administered questionnaires
- Closed ended questions; 8 stigma items
- Baseline, cross-sectional data
- 4 sites: Seattle, Chicago, Galveston, & Chapel Hill
- N=185
- 60% male
- English Speaking
- 11 – 18 years old
- All had facial differences – 80% congenital
- Mothers (n=152); asked 8 matching questions also asked of their child
# Feel Unwelcome

**Q:** During the past 4 weeks, how often have people your age made you feel unwelcome because of how you look?  
*(Child wording)*

**Q:** During the past 4 weeks, how often have people your daughter/son’s age made her/him feel unwelcome because of how she/he looks? *(Parent wording)*

<table>
<thead>
<tr>
<th>YOUTH</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>61%</td>
</tr>
<tr>
<td>Almost Never</td>
<td>16%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12%</td>
</tr>
<tr>
<td>Fairly Often</td>
<td>4%</td>
</tr>
<tr>
<td>Very often</td>
<td>7%</td>
</tr>
</tbody>
</table>

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Sometimes, Fairly Often, Very Often 23%
Youth Responses
“Sometimes, Fairly Often and Very Often”

- 23% Made to feel unwelcome by peers in past month.
- 35% Noticed people staring at their face in the past week.
- 28% Talked with others about how their face looks in the past month.
- 29% Heard others say something about their face in the past month.
- 32% Told peers about their facial difference in the past month.
- 12% Felt left out of doing things with peers because of how their face looks in the past month.
- 11% Got into fights because of how their face looks in the past month.
- 20% Were teased about how their face looks in the past month.
## Youth/Mother Responses

“Sometimes, Fairly Often and Very Often”

<table>
<thead>
<tr>
<th>Response</th>
<th>Youth</th>
<th>Mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made to feel unwelcome by peers in past month.</td>
<td>23%</td>
<td>24%</td>
</tr>
<tr>
<td>Noticed people staring at their face in the past week.</td>
<td>35%</td>
<td>47%</td>
</tr>
<tr>
<td>Talked with others about how their face looks in the past month.</td>
<td>28%</td>
<td>43%</td>
</tr>
<tr>
<td>Heard others say something about their face in the past month.</td>
<td>29%</td>
<td>31%</td>
</tr>
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<td>32%</td>
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<td>12%</td>
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</tr>
<tr>
<td>Got into fights because of how their face looks in the past month.</td>
<td>11%</td>
<td>8%</td>
</tr>
<tr>
<td>Were teased about how their face looks in the past month.</td>
<td>20%</td>
<td>18%</td>
</tr>
<tr>
<td>Percentage</td>
<td>Percentage</td>
<td>Response Description</td>
</tr>
<tr>
<td>------------</td>
<td>------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>17%</td>
<td>31%</td>
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</tr>
<tr>
<td>26%</td>
<td>49%</td>
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</tr>
<tr>
<td>19%</td>
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Male / Female Trend

- Males report less stigma experiences than females.
Congenital/Acquired Responses

“Sometimes, Fairly Often and Very Often”

<table>
<thead>
<tr>
<th>Percentage 1</th>
<th>Percentage 2</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>20%</td>
<td>33%</td>
<td>Made to feel unwelcome by peers in past month.</td>
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A trend noted that acquired conditions appeared to initiate more stigma experiences than did congenital conditions.
Summary of Stigma Experiences

- Reported by up to 35% of youth with facial differences.
- Youth and mother generally shared perceptions
- Females tended to elicit more
- Acquired conditions tended to elicit more
Q: When Does Appearance Become Important?

- By age 7, children make judgments about physical attractiveness in peers which bear close resemblance to adult perspectives.
- Being attractive becomes a social “good”
- When stigma becomes enacted by peers.
In America we’d like to believe that we make our own opportunity … that environment, not genetics or appearance makes us who we are.
• When appearance changes so do other personal attributes and aspects of social life … including stigma.
• Medical impetus to normalization is forceful.
For Clinicians

- Recognize stigma
- Be aware of its impact
- Give an opportunity to talk about stigma
- Intervene with counseling or peer support
- Understand when no further treatment is desired
- Talk to employers, schools, insurers about stigma and discrimination
Could public media be used to re-build norms and expectations?

- Advertising
- Film
- Theatre
We have an opportunity to move beyond stigma, and to promote positive healthy and diverse contexts, within which acceptance and resilience are both enacted and felt.