ORIGINAL ARTICLE

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Stigma experiences in youth with facial differences: a multi-site study of adolescents and their mothers*

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Structured Abstract

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Objectives – To describe stigma experiences of adolescents with congenital and acquired facial differences.

Design – Used baseline cross-sectional stigma-related responses from a four site (Seattle WA, Galveston TX, Chicago IL and Chapel Hill NC) US study enrolling 185 English speaking, US participants ages 11–18 years old with facial differences (60% male; 80% congenital conditions). Closed-ended, self-administered questions drawn from the Youth Quality of Life Instrument – Facial Differences Module (YQOL-FD) determined perceptions of stigmatization. Mothers (n = 153) were independently asked seven matching questions.

Results – Frequencies report combined responses of 'sometimes,' 'fairly often,' and 'very often.' Mother's responses are in parentheses.

- 35% (47%) noticed people staring at their face in the past week.
- 28% (43%) talked with others about how their face looks in the past month.
- 29% (31%) heard others say something about their face in the past month.
- 32% (32%) told peers about their facial difference in the past month.
- 12% (12%) felt left out of doing things with peers because of how their face looks in the past month.
- 11% (8%) got into a fight because of how their face looks in the past month.
- 20% (18%) were teased about how their face looks in the past month.

Conclusions – Stigma experiences were frequently reported by youth with facial differences and were correlated with independent parental report. This level of stigma suggests that media and public health interventions may be warranted to reduce discrimination, prejudice and negative adolescent social experiences related to facial difference.

Key words: adolescents; appearance; craniofacial; parents; social; stigma

Introduction

This paper examines stigma experience reported by adolescents with facial differences and their mothers. The expression of stigma experiences in this study were specifically related to facial difference, and thus comparisons cannot, and are not, made to unaffected control or comparison groups. This study seeks to profile the prevalence of stigma experiences associated with facial difference among youth and to determine whether mothers share the perceptions of their affected child.

Adolescence is a life stage in which self-awareness is strongly affected by peer feedback and social interaction. Appearance influences adolescent social life and stigmatization; teasing or bullying may be deeply damaging at this stage (1–13). This is also a developmental period in which social and media norms – film, magazine, TV, and advertising, frame self and peer expectations.

The appearance of the face, head, and oral area are immediately observable by others (14–16). Facial differences are quickly perceived in social discourse. There is much research to indicate that facial attractiveness has an important effect on psychological development and social relationships (5, 17–26).

While youth who do not have an apparent facial difference may experience stigma, especially associated with teasing, facial difference elicits special vulnerability for stigmatization. Unusual facial appearance has been associated with negative life experiences (27). Research indicates that appearance and facial difference affect quality of life, social experience, school performance, dating, employment success, and occupational attainment (27–37). It has been noted that many adults with facial difference thrive and achieve a high quality of life in spite of their stigma experiences (38).

Persons who have birth conditions that result in altered appearance or speech disabilities often report that their social experiences and roles are impacted by their appearance (39–48). Being visibly different implies being perceived by others as less than complete, or as disabled, limited, or otherwise reduced. The bodily signs of being different, known as stigma, carry a moral evaluation, usually a negative one. Goffman's (27) classic work *Stigma* provided a theory of stigmatization useful in understanding the social responses to human difference and health conditions. Goffman described how first impressions on meeting strangers, are based on observations of attributes like facial appearance that are 'transformed into normative expectations' and then into firmly held roles and responsibilities. Thus, individuals with a facial difference may suffer from stigmatization, either enacted or perceived.

Enacted stigma occurs when the individual directly experiences the damaging effects of stigma, such as discrimination, rejection, or physical abuse. It implies that others have treated an affected individual in a negative manner; the source of the negativity being from outside the person being stigmatized. Family members and persons working with those affected may also experience enacted stigma, sometimes termed courtesy stigma. The other form of stigmatization involves a process of self-discounting; perceived (or felt) stigma entails reduced self-perception. Perceived stigma often is the internalization of enacted stigma experiences. Examples may make this distinction apparent. A child who is teased about her face at school has experienced enacted stigma, whereas a child who feels unable to engage others in play all on his own, is experiencing perceived stigma. It is common that children who have negative enacted stigma experiences, will predictably internalize those and will manifest perceived stigma. Stigma may elicit shame and has the potential for eliciting severe social harm.

Methods

The purpose of this exploratory study was to profile the enacted stigma experiences of adolescents with congenital and acquired facial differences and to compare adolescent perceptions of stigma experiences with maternal perceptions. Given the specific nature of the questions developed to ascertain stigma experiences relative to facial appearance, it is not possible to compare the findings of youth with facial difference to other, non-affected youth.

The study employed self-administered questionnaires comprised of pre-tested closed ended questions administered to a cross sectional convenience sample at four sites. The questions used were drawn from a larger study of quality of life among youth with facial difference and methods, validity and reliability characteristics are described in detail in other publications (2, 7, 12, 49, 50). The Seattle Quality of Life Group (Seaqol Group) applied state-of-the-art development and analytic techniques to create a Quality of Life outcome module specific to facial differences for use in observational research, clinical trials, other intervention studies, and in clinical care (50). A large pool of perceptual items (n = 845) were initially evaluated to create a measure of aspects of quality of life known to the adolescent respondent. Through investigator judgment, this pool was reduced to 125 items which were presented to adolescents and professional experts for further evaluation. Finally, 30 perceptual items were retained and classified into five domains: negative consequences, negative self-image, stigma, positive consequences, and coping. The current study uses seven stigma items from the YQOL Facial Differences (YQOL-FD) module. This module was constructed to augment the generic Youth Quality of Life Instrument (YQOL) developed by Patrick and colleagues (2, 7) for use with youth ages 11–18 years. Methodology, scale construction, validity, and reliability are presented by Patrick *et al.* (51). The individual stigma experience questions were not developed to create a stigma scale and are not reported as a scale score. Univariate analyses are used.

Sample

This multi-site observational study was conducted by investigators at the University of Washington (Seattle), University of North Carolina (Chapel Hill), Northwestern University (Chicago), and the University of Texas Medical Branch at Galveston. The sites partnered with Shriner's Hospitals in Chicago and Galveston, Children's Hospital and Regional Medical Center in Seattle, the UNC Craniofacial Center at the University of North Carolina at Chapel Hill.

The recruitment goal was 185 youth and eligibility for participation in the study included having a visibly noticeable facial difference, the ability to speak and read English at the fifth grade level, and at least 2 years post-trauma for youth with acquired conditions. Youth were excluded if their primary caregiver indicated that they had a co-morbid mental or physical condition that had a greater impact on their life than their facial difference. All participants gave consent/assent to be in the study and all procedures were approved by the Institutional Review Board at each of the respective sites.

Participants were recruited through a treatment center (craniofacial or burn center) and clinicians identified potential participants who had an apparent facial difference and met the age requirement of the study. Project staff approached potential participants and their parents to elicit consent. This sample should be considered a convenience/clinic sample; population sampling was not employed. Data were collected as part of a self-administered questionnaire.

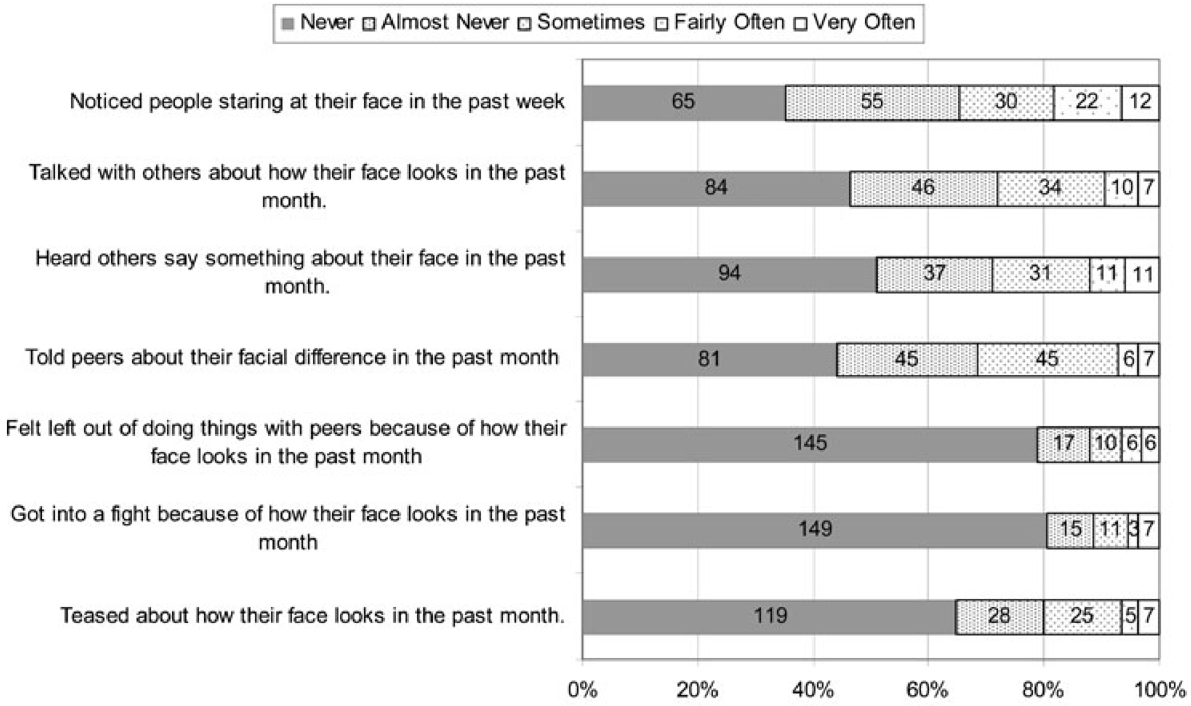
The sample (n = 185) was 60% male, English speaking, and age 11–18 years. All had facial differences, however 80% had congenital conditions. The adolescents were purposely recruited to represent a broad range of craniofacial conditions including: acquired conditions (burns, other trauma); and congenital conditions including: birth marks, brachial arch disorders, isolated or syndromic craniosynostosis, cleft lip, cleft palate, or both. Diagnosis was provided by the referring physician or dentist. The main objective of this sampling approach was to articulate a diverse set of perspectives regarding adolescents with facial difference, rather than to obtain a representative sample *per se*. Mothers (n = 152) were enrolled and independently were asked seven questions about their impressions of their child's stigma experiences (not necessarily directly observed). Maternal queries were modifications of the questions posed to their child.

Results

Responses to the stigma experience items were on a 5-point scale ranging from 'very often' to 'not at all.' Fig. 1 displays the frequency distribution of the adolescent responses to the stigma experience items. Given the frequency distribution of responses on the 5-point scale, the investigatory team decided to combine 'sometimes, fairly often, and very often' as indicative of ever experiencing stigma on Tables 1 and 2. For example, 35% (n = 64) of youth responded 'sometimes,' 'fairly often,' or 'very often' when asked 'Have you noticed people staring at your face in the past week?'

Among the study youth (in the past month), 28% talked with others about how their face looks, 29% heard others say something about their face; 32% told peers about their facial difference, and 12% felt left out of doing things with peers because of how their face looks. Furthermore in the past month, 11% got into a fight because of how their face looks, and 20% were teased about how their face looks.

Table 1 indicates that youth–mother agreement in the reporting of stigma experiences on an independent



YQOL-FD Wording of Stigma Queries:

Q1. During the past 7 days, how often did you notice other people staring at your face?

Q.2 During the past 4 weeks, how often did you talk with someone about how your face looks?

Q. 3 During the past 4 weeks, how often did you hear other people say something about how your face looks?

Q. 4 During the past 4 weeks, how often did you tell other people the same age as you about your facial difference?

Q. 5 During the past 4 weeks, how often were you left out from doing things that other people your age were doing because of how your face looks?

Q. 6 During the past 4 weeks, how often did you get into a fight with anyone because of how your face looks?

Q. 7 During the past 4 weeks, how often were you teased about how your face looks?

Fig. 1. Frequency distribution – adolescent responses.

basis was significant, though not necessarily high. For example there is a 0.36 correlation of mother and youth responses to the question regarding noticing people staring at your face in the past week, which resulted in a p-value <0.01. Thus, there is significant agreement between youth and mother ratings on this question.

The highest agreement ($p < 0.001$) between youths and mothers occurred in measuring teasing about how the face looks and in hearing others say something about the face. Moderate agreement ($p < 0.01$) was noted in noticing people staring at the face in the past week and in how often the youth talked with others about how their face looks. In general, youths and mothers revealed a significant level of agreement about the youth's experience of stigma on all variables.

Table 2 displays differences in male–female, and congenital-acquired condition ratings of stigma experiences. p-values were calculated associated with a z-score for difference in proportions tests. The tests are indicative of whether there is significant difference between stigma experience item responses in the two sub-groups being compared.

On all stigma experience variables, females report more stigma than do males. In the past week, fewer males than females noticed people staring at their face. Females were more than twice as likely as males to talk with others about how their face looks in the past month. Similarly, in the past month more than twice as many females than males heard others say something about their face or felt left out of doing things with

Table 1. **Do youth and mother agree? – correlations between youth and mother responses on stigma experience items**

Question	Youth (185)	Mother (152)	Mother/ youth correlations	*p*-value	r^2 variation shared in common
Noticed people staring at their face in the past week	35%	47%	0.36	<0.01**	0.13
Talked with others about how their face looks in the past month.	28%	43%	0.22	<0.01**	0.05
Heard others say something about their face in the past month.	29%	31%	0.35	<0.001***	0.12
Told peers about their facial difference in the past month	32%	32%	0.17	<0.05*	0.03
Felt left out of doing things with peers because of how their face looks in the past month.	12%	12%	0.20	<0.05*	0.04
Got into fights because of how their face looks in the past month	11%	8%	0.16	<0.05*	0.03
Teased about how their face looks in the past month.	20%	18%	0.45	<0.001***	0.20

Percent responding 'sometimes, fairly often and very often'
p values associated with significance of agreement.
ns, Not significant.
*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

Table 2. **Differences in stigma experience between males and females and between youth with congenital and with acquired conditions**

	Gender (n = 184)			Type of Condition (n = 185)		
Question	Male (110)	Female (74)	*p*-value	Congenital (149)	Acquired (36)	*p*-value
Noticed people staring at their face in the past week	26%	49%	<0.01**	29%	60%	<0.001**
Talked with others about how their face looks in the past month	19%	42%	<0.001***	25%	42%	<0.05*
Heard others say something about their face in the past month	19%	43%	<0.001***	27%	37%	>0.05 ns
Told peers about their facial difference in the past month	29%	35%	>0.05 ns	30%	37%	>0.05 ns
Felt left out of doing things with peers because of how their face looks in the past month	6%	20%	<0.01**	10%	20%	>0.05 ns
Got into fights because of how their face looks in the past month	7%	18%	<0.05*	11%	11%	>0.05 ns
Teased about how their face looks in the past month	15%	28%	<0.05*	20%	22%	>0.05 ns

Percent responding 'sometimes, fairly often and very often.'
p values associated with z-score for difference in proportions test–measure significant difference.
ns, Not significant.
*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

peers because of how their face looks. In the past month, 7% of males and 18% of females got into fights because of how their face looks and 15% of males and 28% of females were teased about how their face looks. In summary, males report less stigma experiences than females on seven out of eight indicators.

As shown in Table 2, a few significant differences were noted when persons with congenital and acquired facial differences were compared. Of the seven variables studied, five did not demonstrate significant differences between stigma experiences among those with congenital and acquired facial differences. Twenty-nine percent of persons with congenital conditions and 60% of persons with acquired conditions noticed people staring at their face in the past week. This resulted in a significant difference ($p < 0.001$) between those with congenital and those with acquired conditions. Twenty-five percent of persons with congenital conditions and 42% of persons with acquired conditions reported talking with others about how their face looks in the past month ($p < 0.05$). The ability to demonstrate significant differences between congenital and acquired conditions may be related to the small sample size of acquired facial differences (n = 36).

Discussion

This study, which is both limited and strengthened by being based on self-report, gives many clues as to how extensively adolescents with facial differences experience enacted stigma. It can be argued that stigma experiences tend to be under-reported and that the findings of this study represent an under-estimate of the occurrence of stigma. The hurtful nature of stigmatization and the social desirability of appearing positive may combine to produce a low level of self-reported stigma experience. It is striking then that enacted stigma experiences were reported by so many youth with facial differences and were often in agreement with independent parental report. The absence of a control or comparison group was determined by the specific nature of the stigma experience questions used which queried only about facial difference. Thus, no statements can be made about how much stigma affects non-facially different youth nor can youth with facial difference be demonstrated in this study to differ from unaffected youth.

The finding that mothers report very similar rates of stigma experiences as do youth, suggests agreement and validity to youth reports. It would seem likely that mothers and youths are exchanging information about stigma experiences, however this cannot be directly assessed with this data. Limitations to this study include the variation in the severity of facial differences within the sample. No attempt was made to adjust for the degree of severity, however this would be interesting to undertake in future studies. Additionally, future studies might examine the impact of stigma experiences on quality of life.

The finding that males were generally less likely than females to report stigma experiences raises questions about why this might occur. Do males receive fewer insults or have fewer comments or reactions to their appearance as compared with females? Do males just recall fewer incidents than females? There is some evidence to suggest the latter. In their meta-analysis examining the effects of facial attractiveness, Langlois *et al.* (20) found that children judged less attractive experienced more negative and fewer positive interactions than attractive children regardless of gender. Studies included in the meta-analysis were not self-reported; however, the findings indicated that gender did not play a role in how attractive or unattractive children were treated. Thus while males may have just as many negative social experiences related to their appearance as females, males may be less likely to acknowledge stigma experiences than females. This question cannot be answered in this study, but gender differences have been noted in other self-reports of emotional experiences related to appearance and social acceptance (52). Wiechman *et al.* (53) found increased depression among burn survivors was associated to gender (female) and degree of facial disfigurement.

Although few differences were noted between those with acquired and congenital conditions, one might consider that their life experiences differ in many ways. Persons with congenital facial differences have had all their lives to adapt and cope with their difference and never knew themselves as unaffected. However, youths with acquired facial differences have had to adapt to a change from what was at one time normative appearance. The age of onset for a facial difference may be worth exploring as a factor in adaptation as the skills and abilities available to cope as well as the impact of disfigurement may vary with developmental stage.

The high degree of reported stigma experience among adolescents with facial differences makes it worthwhile to consider when appearance becomes important as a life determinant. Studies show that by early school age, children make judgments about physical attractiveness in peers which bear resemblance to adult perspectives (29). This is when being attractive becomes a social 'good' and when children begin to differentiate based upon appearance; it is when stigma becomes enacted by peers.

The message that people with facial differences receive is that when appearance changes, so do other personal attributes and aspects of social life, including stigma. Thus, they are routinely encouraged to erase facial difference, to correct, to operate, to conceal or to change – but not to accept or celebrate difference. The medical impetus to normalization is forceful and fulfills a mission which is to change, alter, sanitize and clean up difference. It is worth considering what society loses when we seek to hide or erase difference.

For clinicians some simple steps may help in responding to potential stigmatization among patients. First, the clinician should be alert and recognize stigma in both the clinical setting and the community and be aware of the impacts of long-term stigma. It is helpful to give a family or patient an opportunity to talk about stigma experiences or to ask about teasing or bullying. It is important to identify the threshold when teasing becomes a damaging burden and to intervene with counseling or peer support. It is helpful to understand when patients want no further surgical or medical intervention and are ready to live with the face they currently have. Finally, clinicians can help reframe social values if they are willing to have a conversation with employers, schools, and insurers about enacted stigma and discrimination.

On a broad societal level, it is imperative to consider how public media could be used to re-build norms and expectations. How could new images of beauty or of success be promoted? Could facial differences be reframed as unique or interesting? Could advertising, film and theatre be a medium for creating norms of understanding and honoring difference? Can this be done without romanticizing those with a facial difference and without making them into super-heroes? Moving beyond stigma will promote positive, healthy and diverse contexts, within which acceptance and resilience are both enacted and felt by persons with facial differences. New research paradigms have emerged which focus on resilient responses, social policy, and quality of life in persons with facial difference (38, 44, 49, 54–61).

In this study, stigma experiences were found in as many as 35% of youth with a facial difference and youth reports were generally concordant with independent maternal reports. This level of stigma suggests that public health interventions may be warranted to reduce discrimination, prejudice, and negative adolescent social experiences related to facial differences.

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