HHS Public Access

Author manuscript

Cleft Palate Craniofac J. Author manuscript; available in PMC 2018 January 01.

Published in final edited form as:

Cleft Palate Craniofac J. 2017 January ; 54(1): 2–12. doi:10.1597/15-167.

Body Image and Quality of Life in Adolescents With Craniofacial Conditions

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Abstract

Objective—To evaluate body image in adolescents with and without craniofacial conditions; and to examine relationships between body image and quality of life.

Design—Case-control design.

Setting—A pediatric hospital's craniofacial center and primary care practices.

Participants—70 adolescents with visible craniofacial conditions and a demographically-matched sample of 42 adolescents without craniofacial conditions.

Main Outcome Measure—Adolescents completed measures of quality of life and body image including satisfaction with weight, facial and overall appearance; investment in appearance (importance of appearance to self-worth); and body image disturbance (appearance-related distress and impairment in functioning).

Results—Adolescents with craniofacial conditions reported lower appearance investment ($p < 0.001$) and were more likely to report concerns about facial features ($p < 0.02$) compared to non-affected youth. Females in both groups reported greater investment in appearance, greater body image disturbance, and lower weight satisfaction compared to males ($p < 0.01$). Within both

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Portions of this study were originally presented at the 12th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies on May 9, 2013, Hilton Orlando Lake Buena Vista, Florida, USA

groups, greater body image disturbance was associated with lower quality of life (p <0.01). The two groups did not differ significantly on measures of quality of life, body image disturbance, or satisfaction with appearance.

Conclusions—Body image and quality of life in adolescents with craniofacial conditions are similar to non-affected youth. Relationships between body image and quality of life emphasize that appearance perceptions are important to adolescents' well-being regardless of whether they have a facial disfigurement. Investment in one's appearance may explain variations in body image satisfaction and serve as an intervention target particularly for females.

Keywords

body image; appearance investment; craniofacial conditions; adolescents; quality of life

Introduction

Craniofacial conditions such as cleft lip and palate are known to affect both the form and function of the face. While reconstructive surgical procedures can restore function, residual facial asymmetries and scarring can negatively affect appearance. Facial appearance differences often prompt misperceptions and undesirable judgments from others (Macgregor, 1990) which can be detrimental to body image. Body image is a multidimensional construct, typically defined as an individual's perception and evaluation of physical appearance and bodily functioning (Cash, 2011).

Body image has been widely studied in a range of individuals using a broad range of measures, many of which have focused on perceptions of weight and shape or satisfaction with overall physical appearance (Cash, 2012; Krawczyk, Menzel, & Thompson, 2012). In recent years, body image has received increasingly more attention in medical populations, particularly those which impact physical appearance (Fauerbach et al., 2000; Bowe et al., 2011; Clarke et al., 2014; Auerbach et al., 2014; Sarwer, et al. 2006). While condition-specific measures have been developed (e.g., Satisfaction with Appearance Scale; Emerson, et al., 2004), there is little consensus about which measures to use when assessing body image and psychosocial functioning among youth with visible differences (Feragen & Stock, in press; Roberts & Shute, 2011). Instruments developed for the general population may not be sensitive enough to identify specific concerns (e.g., concerns about facial features). In contrast, use of condition-specific instruments alone can make it difficult to evaluate similarities and differences with reference or control groups and potentially increase risks for over-pathologizing appearance and psychosocial problems. A combination of both general and condition-specific measures is likely indicated, although few studies have used this approach.

In the craniofacial literature, body image is often equated with "satisfaction or dissatisfaction with facial appearance." Some studies have found high rates of dissatisfaction with facial appearance (e.g., Hunt et al., 2005) while others have found evidence of fewer appearance concerns (Broder et al., 1992; Slifer et al., 2003). Satisfaction with appearance is associated with psychosocial resilience in youth with cleft lip and/or palate (Feragen et al.,

2009). However, little empirical attention has been paid to body image and its relationship to quality of life among youth with other craniofacial conditions.

Children and adolescents with craniofacial conditions, particularly older children with visible appearance differences (e.g., cleft lip and palate vs. cleft palate only), typically report reduced quality of life (Damiano et al., 2007; Broder et al., 2014) compared to both healthy adolescents and those with other chronic health conditions (Topolski et al., 2005). Unfortunately, these studies have not included thorough assessments of body image or appearance-related concerns. Measuring satisfaction with facial appearance is of limited explanatory value when critical aspects of body image, such as *investment in appearance* (the importance of appearance to self-worth; Cash et al., 2004a) and *body image disturbance*, defined as appearance-related distress (e.g., anxiety) or impairment in functioning (e.g., avoidance of social interactions) (Cash et al., 2004b) have yet to be evaluated. For example, individuals who are highly invested in appearance may experience more distress or worry about a facial scar and engage in more avoidance of social activities. In contrast, individuals who are less invested in appearance may not be as bothered by a facial disfigurement. Greater investment in appearance may also increase the likelihood of body image disturbance (Pruzinsky, 2002) which in turn may lead to greater risk for psychosocial problems and reduced quality of life.

A better understanding of body image dimensions is needed in order to predict which youth may be at greater risk for developing psychosocial problems and to identify targets for intervention and prevention. Furthermore, while adolescence is known to be an important time in body image development (Levine and Smolak, 2002), it is possible that youth with craniofacial conditions are at greater risk for body image and related psychosocial problems during this developmental stage due to facial appearance differences (Rumsey and Harcourt, 2007). Studies of body image in youth with craniofacial conditions and appropriately matched comparison groups would facilitate a better understanding of whether body image differs in this population compared to non-affected youth. Furthermore, given the well-developed literatures on body image dissatisfaction prevention and intervention strategies in healthy youth (e.g., Yager, Diedrichs, et al., 2013), this approach would enable exploration of the relevance of these initiatives for youth with craniofacial conditions.

This study addresses these gaps by 1) evaluating and comparing multiple dimensions of body image, specifically, investment in appearance, evaluations of appearance, and body image disturbance in adolescents with and without craniofacial conditions; and 2) examining associations between these dimensions and quality of life. Because there are known gender differences in body image (e.g., Cash, 2012), gender differences were also explored. Adolescents with craniofacial conditions were hypothesized to report greater body image disturbance and lower satisfaction with facial appearance compared to non-affected adolescents. Additionally, body image disturbance was predicted to be associated with lower perceptions of quality of life in both groups.

Method

Participants

Craniofacial group—Ninety-seven youth with craniofacial conditions from a large, urban, pediatric hospital's craniofacial center located in the Northeastern U.S. were approached to participate in the study. Seventeen (17.5%) did not return complete assessment packets, and another four (4%) were excluded due to incomplete data. Seventy-six adolescents (78%) provided usable data; of these, 70 were included in the data analysis as they were able to be matched to an appropriate comparison participant. There were no significant differences on any matching variables for those who did or did not complete the study.

Inclusion criteria for participation were: 1) Males or females ages 14–18 years; 2) Diagnosis of a craniofacial condition associated with visible appearance differences (e.g., unilateral or bilateral cleft lip and palate; facial clefts; hemifacial microsomia) that required surgical reconstruction; 3) Most recent major surgical procedure occurred at least three months prior to study enrollment (to account for temporary post-surgical appearance concerns which could impact responses to certain items). Exclusion criteria for the craniofacial and comparison groups included inability to read or understand English and diagnosis of intellectual or developmental disability.

Comparison group—Adolescents were recruited from the Pediatric Research Consortium (PeRC), the same pediatric hospital's practice-based research network. A list of potentially eligible participants (n = 4192) was generated using ambulatory electronic health record records from three regional primary care practices (one urban, two suburban) which were selected for their demographic similarities to the patients seen by the craniofacial center. Inclusion criteria for comparison group participants were: 1) Males or females ages 14–18 years; 2) No history of a craniofacial condition or other potentially disfiguring medical conditions or presence of physical anomalies.

A random sample of 652 adolescents was selected from the list of potentially eligible participants and contacted via letter about the study; 32 opted out via postcard. The remaining 620 participants were contacted by phone; 414 (67%) received a phone message about the study; 64 (10%) were unable to be reached due to full voicemail or wrong numbers; 48 (7%) expressed disinterest in the study; and 8 (1%) were ineligible upon further screening. Eighty-six adolescents were reached by phone and verbally expressed interest in participating. Of these, 56 returned completed packets (65%), and 42 were included in analyses as their demographic characteristics matched those of the adolescents in the craniofacial group. Adolescents in the comparison group were matched to adolescents with craniofacial conditions with respect to gender, age (within two years), race (white v. non-white) and BMI (underweight, normal weight, overweight/obese) prior to conducting between-group analyses.

Procedure

Institutional review board approval was granted for the study and informed consent was obtained from parents of youth under 18 years of age along with assent from the youth

themselves; participants 18 years of age or older provided informed consent. Adolescents with craniofacial conditions were recruited in person during an office visit and/or received a letter from the principal investigator and their treating surgeon with information about the study. Participants seen in the office were approached by a research assistant who reviewed eligibility, obtained informed consent, and distributed questionnaire packets. Stamped return envelopes were provided for those unable to finish the questionnaires in clinic.

Adolescents in the comparison group received a letter from the principal investigator and their pediatrician describing the study along with a post card that could be returned if the family was not interested. A member of the research team contacted potential participants by phone and conducted a screen for eligibility and reviewed study procedures. Eligible, interested participants received consents and packets of questionnaires in the mail along with a postage-paid, return envelope.

Follow-up reminder calls and letters were sent to participants in both groups if questionnaires were not returned within two weeks. Adolescents were compensated $25 for their participation. After completed packets were received, participants' medical charts were reviewed in order to collect information about the participants' medical and surgical histories. Data were collected over two years (2012–2013). Questionnaire packets took approximately 60 minutes to complete.

Measures

Given that the primary aim of this study was to evaluate and compare body image dimensions among youth with and without craniofacial conditions, a combination of both general and condition-sensitive measures was utilized. Because few studies in the general population have specifically examined satisfaction with facial appearance, an instrument developed for use with craniofacial populations (Satisfaction with Appearance Scale) was also administered to the comparison group.

Multidimensional Body-Self Relations Questionnaire-Appearance Scales (MBSRQ-AS)—This is a reliable and valid, 36-item measure developed for the general population that assesses attitudinal dispositions of body image (Cash et al., 1986; Brown et al., 1990). It has five subscales: *Appearance Orientation, Appearance Evaluation, Overweight Preoccupation, Self-Classified Weight, and Body Areas Satisfaction*. The *Appearance Orientation* subscale measures investment in appearance; higher scores reflect greater importance of appearance to self-worth. The other subscales assess evaluations of specific aspects of appearance; higher scores indicate greater satisfaction. Internal consistency was acceptable for all subscales in both groups (craniofacial and comparison groups respectively: Appearance Orientation: $\alpha = 0.86$ and $\alpha = 0.83$; Appearance Evaluation: $\alpha = 0.84$ and $\alpha = 0.88$; Body Areas Satisfaction: $\alpha = 0.85$ and $\alpha = 0.74$; Overweight Preoccupation: $\alpha = 0.75$ and $\alpha = 0.84$; Self-Classified Weight: $\alpha = 0.75$ and $\alpha = 0.89$).

Derriford Appearance Scale (DAS)—This is a reliable and valid 59-item measure of appearance-related distress and difficulties (e.g., avoidance of activities) that has been used in both the general population and among individuals with a variety of disfiguring conditions

(Carr et al., 2000; Harris et al., 2004). Higher scores reflect greater levels of distress and appearance-related dysfunction. Internal consistency for this measure was high for the craniofacial (α = 0.95) and comparison (α = 0.97) groups.

Body Image Disturbance Questionnaire (BIDQ)—This is a psychometrically sound, 7-item measure that measures symptoms of body image disturbance (e.g., preoccupation with appearance concerns, interference with daily activities) (Cash et al., 2004b; Cash and Grasso, 2005). Higher scores reflect greater body image disturbance. The BIDQ also includes qualitative questions so that specific concerns and their impact on daily functioning can be assessed. Internal consistency for this measure was acceptable for both the craniofacial (α = 0.85) and comparison (α = 0.87) groups.

Satisfaction With Appearance Scale (SWA)—This is a 20-item questionnaire developed by the UK Cleft Psychology Special Interest Group to assess satisfaction with facial features (Emerson et al., 2004). The first 12 items can be averaged to obtain a total score. Adolescents in the comparison group also completed this measure with the exception of one item that specifically referenced having a craniofacial condition. Internal consistency for this measure was high among both the craniofacial (α = 0.93) and comparison (α = 0.92) groups.

Youth Quality of Life Instrument (YQOL)—This 48-item measure assesses quality of life in adolescents. It has good psychometric properties (Patrick et al., 2007). Scores range from 0 to 100, with higher scores reflecting better quality of life. Internal consistency for the total score was high in both the craniofacial (α = 0.95) and comparison groups (α = 0.96).

Statistical Analyses

Study data were managed using REDCap (Research Electronic Data Capture) (Harris et al., 2009). Missing data was handled in accordance with guidelines for each instrument (e.g., imputation with mean score for missing item). Participants who had more missing data than could be addressed via these guidelines did not have total or mean scores calculated and were excluded from analyses for that particular measure. Descriptive statistics were calculated for demographic variables and measures (BIDQ and DAS total scores, MBSRQ subscale scores, SWA total score, YQOL total score). Assumptions of approximate normality and equality of group variances were verified, and non-parametric statistics were used if indicated.

Between-group comparisons were tested using the Student's t-test or the Wilcoxon Rank Sum test for continuous variables and the Chi-Square test or Fisher's exact test for categorical variables. Correlations of body image scores with psychosocial functioning measures, within cases and controls, were examined using a Spearman Correlation Coefficient. A p-value <0.05 was considered statistically significant; Bonferroni correction was used to adjust for type 1 errors.

Two multivariate MANCOVAs were conducted to examine differences between groups for appearance satisfaction (MBSRQ subscales and SWA) and body image disturbance (DAS and BIDQ), while adjusting for age, BMI, gender, and race. If an overall association was

identified, ANCOVA was then used to determine where specific differences occurred on the outcome measures. Bonferroni-Holm corrections were used to adjust for multiple comparisons. Between-group differences on the YQOL were evaluated via ANCOVA (with age, gender, BMI, and race entered as covariates). All statistical analyses were performed using SPSS version 21.

Results

Table 1 presents demographic characteristics for the sample. On average, adolescents in both groups were 15 years old, 55% were male, BMI was in the normal range for both groups, and the majority identified as non-Hispanic, Caucasian. There were no significant differences between groups on demographic variables. The majority of adolescents with craniofacial conditions had a diagnosis of cleft lip and palate (n = 52, 74%); fourteen (20%) were categorized as having congenital anomalies of the face and head; and four (6%) had congenital musculoskeletal deformities of skull, face, and jaw. Adolescents with craniofacial conditions had undergone a mean of 6.26 ± 3.31 surgeries; the average time since their last procedure was 61.08 ± 44.12 months. There were no significant differences between adolescents with cleft lip/palate versus other craniofacial conditions on any of the outcome measures. Thus, they were combined in all subsequent analyses.

Body Image Measures

Appearance Concerns—Sixty-five percent (n = 46) of the craniofacial group and 76.2% (n = 32) of comparison group reported at least one appearance concern on the BIDQ ($p = .24$). Adolescents with craniofacial conditions were significantly more likely to report concerns about facial features, most commonly about their nose and lips/mouth, compared to non-affected adolescents (65.2% vs. 37.5%; $\chi^2 = 5.83$, $p = .02$); non-affected adolescents were significantly more likely to report concerns about other body parts (71.9% vs. 41.3%, $\chi^2 = 7.10$, $p = .008$), most commonly about their weight and stomach size/shape.

Within the craniofacial group, females were more likely to report appearance concerns compared to males (87.1% vs. 48.7%, $\chi^2 = 11.29$, $p = .001$); they were also more likely to report concerns about facial appearance compared to males, although this difference did not reach statistical significance (54.8% vs. 33.3%, $\chi^2 = 3.26$, $p = .07$). No significant differences were noted for likelihood to report concerns about other body parts. In the comparison group, no significant gender differences were found regarding likelihood of reporting any appearance concerns (85.7% females vs. 66.7% males, $p = .15$) nor for likelihood of reporting facial or body concerns.

Appearance Orientation, Appearance Satisfaction, and Body Image Disturbance—Mean scores on the body image measures for both groups are presented in Table 2. Table 3 presents these results stratified by gender. Overall, scores for both groups on all measures fell within the normative range. In general, higher scores were observed for females versus males on the body image measures with the exception of males scoring higher on MBSRQ-AE and MBSRQ-BASS, all of which are consistent with gender differences in normative samples for the MBSRQ, BIDQ, and DAS (Cash et al., 1986; Brown et al., 1990; Cash et al., 2004b; Carr et al., 2000; Harris et al., 2004). As shown in

Table 2, adolescents with craniofacial conditions reported significantly lower levels of investment in appearance compared to adolescents without craniofacial conditions as assessed by the Appearance Orientation subscale of the MBSRQ-AS (3.24 ± .78 vs. 3.77 ± . 68, $p = .001$). However, the two groups did not differ with respect to the other subscales of this measure assessing more general appearance satisfaction, nor did the groups differ on the BIDQ or DAS (see Table 2). Adolescents in the comparison group reported greater preoccupation with being overweight (see Table 2) although the difference between groups was not significant.

In both groups, girls reported significantly ($p < 0.001$) greater investment in their appearance as compared to males (see Table 3). Females in both groups also reported less overall satisfaction with their appearance and more dissatisfaction with specific body areas compared to males (as measured by the MBSRQ Appearance Evaluation and Body Areas Satisfaction subscales), although this difference only reached significance within the comparison group. However, girls in both groups were significantly more preoccupied with being overweight compared to boys (see Table 3).

Females reported significantly higher levels of body image disturbance as measured by the BIDQ compared to males (see Table 3). On the DAS, females reported significantly greater levels of body image disturbance compared to males in the comparison group; there were no significant gender differences within the craniofacial group.

Multivariate Analyses—Multivariate analyses with adjustments for age, gender, race, and BMI yielded similar results to the descriptive group comparisons reported above (see Table 4). For the appearance satisfaction measures (MBSRQ subscales and SWA), MANCOVA revealed significant main effects for *group* (Wilks' Lambda = .75, $p < 0.001$, partial eta squared = .253) and *gender* (Wilks' lambda = .70, $p < 0.001$, partial eta squared = 0.30).

Follow-up univariate tests demonstrated significant group differences on the MBSRQ-Appearance Orientation subscale ($F(1,104) = 14.42$, $p < 0.001$, partial eta squared = 0.12), indicative of lower investment in appearance for the craniofacial group compared to non-affected adolescents (see Table 4). Similar main effects for group were found on the SWA ($F(1,104) = 3.93$, $p = 0.05$, partial eta squared = 0.04), with the craniofacial group reporting lower satisfaction with facial appearance than the comparison group, although this difference only approached significance after applying Bonferroni-Holm correction to account for multiple comparisons.

Follow-up univariate tests revealed significant differences by gender for the MBSRQ-AO ($F(1,104) = 26.79$, $p < 0.001$, partial eta squared = 0.21); MBRSQ-BASS ($F(1,104) = 5.27$, $p = 0.024$, partial eta squared = .05) and MBSRQ-OP subscales ($F(1,104) = 28.75$, $p < 0.001$, partial eta squared = .22) indicative of females reporting greater appearance investment and preoccupation with being overweight and lower satisfaction with specific body areas compared to males (see Table 4).

For the body image disturbance measures (DAS and BIDQ), MANCOVA yielded a significant main effect for *gender* (Wilks' lambda = 0.87, p = 0.001, partial eta squared =

0.13) but not for *group* (see Table 4) or their interaction. Follow-up univariate tests demonstrated that there were significant differences by gender on both the BIDQ ($F(1,106) = 14.60$, $p < 0.001$) and DAS ($F(1,106) = 7.53$, $p = 0.007$), with females reporting greater levels of body image disturbance compared to males (see Table 4).

Relationships between Body Image Dimensions and Quality of Life

As shown in Table 2, total quality of life scores did not differ significantly between groups, and there was no significant main effect for group on the YQOL total score while adjusting for age, gender, BMI, and race. There was a significant main effect for gender ($F(1, 106) = 3.96$, $p = 0.049$) with females reporting lower scores than males (78.48 vs. 83.92). Relationships between dimensions of body image (body image disturbance; satisfaction with facial appearance; overall satisfaction with appearance; and investment in appearance) and quality of life were also evaluated (see Tables 5 and 6). In both groups, greater body image disturbance was significantly associated with lower quality of life. Similarly, greater satisfaction with facial and overall appearance was associated with higher ratings of quality of life for both groups as well. Investment in appearance was unrelated to quality of life.

Discussion

Results of this study revealed some unanticipated observations regarding appearance and body image concerns among adolescents with and without craniofacial conditions. Adolescents with and without craniofacial conditions did not differ on satisfaction ratings for overall appearance, and differences in facial appearance satisfaction, while lower in the craniofacial group, were not significantly different between groups. However, adolescents with craniofacial conditions were significantly more likely to report concerns about facial features, whereas youth without craniofacial conditions were significantly more likely to report concerns about weight/shape or other bodily features. Over 65% of adolescents with a craniofacial condition had at least one appearance concern, most commonly about nasal and lip appearance. Hunt and colleagues (2005) previously found that adolescents with cleft lip/palate were most concerned about their noses, lips, teeth and scars; 68% were unhappy with a specific aspect of facial appearance. While facial concerns were most prominent within the craniofacial group, some adolescents reported concerns about other bodily features, consistent with the comparison group. Overall, these findings suggest that while facial concerns may be more common among adolescents with craniofacial conditions, they are otherwise similar to their non-affected peers in terms of their satisfaction with their facial or overall appearance.

Adolescents with craniofacial conditions reported significantly less investment in their appearance compared to non-affected adolescents. This suggests that as a group, appearance was less important to their sense of self-worth. A similar finding has been reported among adults who sought reconstructive procedures (Sarwer et al., 1998). Differences in appearance investment can be interpreted in several ways. High levels of investment are often seen in adolescents and young adults because of the role of physical appearance in the development of romantic relationships. At the same time, excessive investment can be seen as being symptomatic of forms of psychopathology with a body image component, such as eating

disorders or body dysmorphic disorder (Hrabosky et al., 2009). Lower levels of investment in appearance as observed in the craniofacial group could reflect efforts to build up other aspects of their self-concepts; it could also be indicative of an adaptive or protective strategy of minimizing the importance of appearance or adjusting standards for self-evaluation given that they were born with congenital facial differences (Thompson and Kent, 2001; Pinquart, 2013).

Females in both groups reported significantly higher levels of investment in appearance compared to males, a finding that is consistent with gender differences observed in adults (Cash et al., 2004a; Moss et al., 2014). Society places great emphasis on appearance for females, and these messages are often internalized, particularly by adolescents. Females may be more at risk for having concerns about appearance and psychosocial problems related to appearance if they are more heavily invested in appearance; greater investment has been linked to increased risk for both appearance-specific as well as more general psychosocial problems (Cash et al 2004; Pruzinsky, 2002). Investment has also been shown to moderate relationships between appearance evaluations and psychosocial functioning (Moss et al., 2014). Indeed, in this sample, females in both groups reported less satisfaction with specific body areas, greater preoccupation with being overweight, and greater levels of body image disturbance. These findings are consistent with their greater levels of investment compared to males. Adolescent girls with craniofacial conditions were significantly more likely to have any type of appearance concern and specifically, concerns about facial appearance. They also reported significantly higher levels of body image disturbance, as assessed by the BIDQ compared to males. Similar gender differences have also been found in studies of youth with CL/P and other differences requiring reconstructive surgery (Simis et al., 2001; Feragen and Borge, 2010).

As predicted, greater body image disturbance was significantly associated with lower quality of life in both groups. These results underscore the importance that appearance plays in adolescents' well-being regardless of whether they have a facial difference. They are also congruent with other studies of youth with craniofacial conditions that have found that dissatisfaction with appearance is associated with psychosocial problems and low quality of life (Millard and Richman, 2001; Topolski et al., 2005; Damiano et al., 2007; Feragen et al., 2009; Berger and Dalton, 2011) as well as studies in the broader body image literature (Simis et al., 2001).

Surprisingly, youth with and without craniofacial conditions did not differ on quality of life, with both groups reporting high quality of life overall. This is in contrast to other research which found lower overall quality of life in youth with facial differences compared to controls (Topolski et al 2005). Differences may be due in part to the fact that Topolski et al., 2005 included youth with acquired, traumatic facial differences (e.g., burns, gunshot wounds). Furthermore, the YQOL does not assess health-related quality of life or oral health-related quality of life; previous studies have noted that youth with craniofacial conditions are at greater risk for lower quality of life in these domains (Damiano et al. 2007; Broder et al 2014; Antonarkis, et al., 2013).

There were no differences between groups in overall levels of body image disturbance, satisfaction with facial appearance, or overall appearance satisfaction, although these findings are consistent with a recent study of 16 year old youth with cleft lip and/or palate (Feragen et al., 2015). Similarly, another large sample of adolescents presenting for plastic surgery (including some with cleft lip/palate) were equally satisfied with overall appearance compared to their peers, and body image was related to psychosocial functioning in both groups (Simis et al., 2001). Although past studies have reported risks for psychosocial problems including depression (Millard and Richman, 2001; Hunt et al., 2006), teasing and bullying (Feragen and Borge, 2010), and low self-esteem (Kapp-Simon, 1986; Broder and Strauss, 1989), the present study's findings are in line with recent studies that have found that adolescents with craniofacial conditions do not experience significantly more problems compared to the general population (Locker et al., 2005; Snyder et al., 2005; Berger and Dalton, 2009; Feragen et al., 2015). The lack of differences between groups observed in this study could also be due to high levels of body image concerns that are known to be present among youth in the general population (Smolak, 2012).

Discrepant findings regarding the prevalence and degree of body image and psychosocial problems in youth with craniofacial conditions may be due to several reasons. First, adolescents with craniofacial conditions may under-report difficulties or use self-protective strategies to maintain favorable self-views (e.g., denial; avoidance of activities that make them feel self-conscious) (Thompson and Kent, 2001; Berger and Dalton, 2009). When considered as a group, and not as individuals, they may be coping as well as their peers with the psychosocial challenges associated with adolescence or they are exhibiting positive outcomes despite living with a chronic stressor (Eiserman, 2001; Baker et al., 2009). There is also emerging evidence that the risk for psychosocial problems increases among youth with craniofacial conditions when comorbid medical and/or developmental problems are present (Feragen and Stock, 2014). This study specifically excluded youth who had significant cognitive and/or developmental delays which may explain in part the lack of evidence of psychosocial problems. These findings illustrate the importance of using appropriate comparison groups and using a combination of general and condition-sensitive measures when assessing psychosocial outcomes among youth with craniofacial conditions as these strategies ensure that findings are viewed in the context of what is developmentally normative. Further examination of processes that lead to healthy functioning and adaptation are also needed. For example, future studies should incorporate measures of resiliency and other factors (e.g., personality traits such as optimism; parent attitudes about appearance) that may contribute to positive body image development and coping.

Clinical Implications

Adolescence is an important time to assess and intervene with body image and psychosocial concerns given the number of normative developmental tasks (e.g., identity formation, establishing peer groups, dating) that occur during this stage (Levine and Smolak, 2002; Rumsey and Harcourt, 2007). Physical self-consciousness can derail attainment of these milestones, which can then leave individual at risk for social, emotional, occupational problems. Adolescence is also important with respect to treatment, as reconstructive procedures that can dramatically alter appearance (e.g., orthognathic surgery) are often

recommended as physical growth is completed. Adjustment to postoperative appearance changes can take time, and surgery can bring about fluctuations in body image and self-esteem (Lazaridou-Terzoudi, Asuman Kiyak, Athanasiou, & Melsen, 2003; Asuman Kiyak, Hohl, West, & McNeill, 1984). From a practical perspective, it is important to intervene while patients are still under the care of multidisciplinary teams since resources may still be readily accessible (e.g., referral to team psychologist). Given the prevalence of concerns about facial appearance in this sample, research and clinical assessments should utilize measures like the SWA and the BIDQ or DAS which permit the respondent to identify their specific concerns.

Understanding the specific types and impact of appearance concerns on daily functioning is also important when considering expectations for surgical outcomes. In some instances, there may be limits to what can be accomplished with reconstructive surgery, and continuing to pursue additional surgery in the context of unrealistic expectations may compromise the patient's psychosocial functioning and well-being. Psychological approaches, such as modifying appearance-related thoughts, behaviors, and investment may help improve outcomes in these circumstances. Given that adults with craniofacial conditions often struggle with body image, social anxiety, and stigmatization (Sarwer et al., 1999; Versnel et al., 2012; Roberts and Mathias, 2012; Stock et al., 2015), screening and interventions that target appearance concerns during adolescence could potentially improve psychosocial outcomes in adulthood.

Results of this study also support research and clinical approaches that consider similarities as well as differences between youth with and without craniofacial conditions. Such approaches may help limit past tendencies to pathologize youth with craniofacial conditions and also promote adaptation of body image prevention and intervention programs for use with craniofacial populations (e.g., Yager et al, 2013), particularly for adolescent girls. Clinically, it can be useful to educate patients and families about how common appearance concerns are during adolescence and that the experience of such concerns is not necessarily specific to having a cleft or craniofacial condition. Furthermore, the findings of this study suggest that youth with craniofacial conditions may be resilient to more common appearance concerns about weight and shape. Understanding factors that contribute to resilience (e.g., parental modeling of healthy appearance attitudes, de-emphasizing the importance of appearance when evaluating self-worth) may help inform care for youth with and without craniofacial conditions.

Limitations and Future Directions

Although this study represents one of the largest investigations of body image in youth with craniofacial conditions and is the first to examine dimensions of body image in this population, the data are cross-sectional. Longitudinal, controlled studies are needed to understand how body image and quality of life change over time and/or represent risk or protective factors for adjustment. Additionally, youth in this sample were at various stages of treatment. Future longitudinal studies are needed to assess how body image changes pre- and post-operatively among youth with craniofacial conditions and should incorporate multi-informant, multi-method approaches (e.g., combining qualitative and quantitative

assessment) to further assess body image and psychosocial functioning. Studies of factors that contribute to the development of body image satisfaction as well as disturbances and that evaluate the role that satisfaction with appearance plays in supporting adaptive functioning and resilience are also needed. Although youth in the sample were matched on age, gender, race, and BMI, socio-economic status was not assessed. However, the primary care practices used for comparison group recruitment were demographically similar to the catchment area for the craniofacial center and included both suburban and urban practices. A final limitation relates to selection bias. It is possible that participants in both groups had more concerns about body image (e.g., the study may have seemed more relevant to this group); alternately, youth with significant appearance concerns may have opted out due to shame or fear about disclosing concerns. As previously described, youth may have under-reported appearance or psychosocial problems because of the influence of social desirability. These data, however, suggest that youth in both groups presented with a range of appearance and psychosocial concerns. Adolescents in the craniofacial group were still being followed by multidisciplinary specialists. There may be important differences between youth who are still engaged in treatment versus those who opt out of treatment, either in terms of appearance perceptions or other factors (e.g., insurance coverage, family stressors) that may impact desire for and access to care.

Conclusions

Youth with craniofacial conditions do not report greater levels of body image disturbance or overall dissatisfaction with their facial or overall appearance compared to their peers. As a group, they report lower investment in appearance. However, females may be at greater risk for body image problems than males as a consequence of higher levels of appearance investment. These findings underscore the importance of evaluating self-perceptions of appearance and in particular, dimensions such as investment which can be a risk factor for body image and related psychosocial problems as these constructs can be helpful in identifying issues common to all adolescents, together with those more specifically associated with craniofacial conditions. Results of this study emphasize the need for screening as well as interventions to specifically target body image and appearance concerns in youth with craniofacial conditions. Future studies should examine factors that contribute to positive body image development in this population including how feedback from parents and peers may contribute to body image perceptions and how body image and quality of life change in response to surgical interventions.

Acknowledgments

We would like to express our appreciation and gratitude to the families who took part in this study as well as the Cleft Palate and Craniofacial Team at The Children's Hospital of Philadelphia. We also want to thank the network of primary care clinicians, their patients and families for their contribution to this project and clinical research facilitated through the Pediatric Research Consortium (PeRC) at The Children's Hospital of Philadelphia. We would like to recognize the efforts of Jacqueline Spitzer, MSEd, Jane Kovacs, Leanne Magee, Ph.D., Naeha Bahambra, Brian Misiti, and Jennifer Litteral who assisted with data collection and/or manuscript preparation.

This research was supported by the National Institutes of Health, National Institute of Dental and Craniofacial Research (Grant K23DE020854; C.E. Crerand, PI).

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Table 1

Demographic and Clinical Characteristics

Variable	Craniofacial	Comparison	
	M ± SD	**M ± SD**	***p***
Age (years)	15.40 ± 1.33	15.67 ± 1.28	.30
BMI (kg/m^2)	22.01 ± 5.10	22.97 ± 4.52	.32
	n,%	**n, %**	***p***
Grade			.43
8th	9 (13)	1 (2.4)	
9th	20 (29)	10 (23.8)	
10th	14 (20.3)	12 (28.6)	
11th	13 (18.8)	9 (21.4)	
12th	10 (14.5)	7 (16.7)	
College Freshman	3 (4.3)	3 (7.10)	
Gender			.56
Male	39 (55.7)	21 (50)	
Female	31 (44.3)	21 (50)	
Ethnicity			.34
Hispanic	7 (10)	2 (4.9)	
Not Hispanic	63 (90)	39 (95.1)	
Race			.67
Asian	4 (6.1)	1 (2.4)	
African American/Black	6 (9.1)	6 (14.3)	
Caucasian/White	52 (78.8)	32 (76.2)	
American Indian/Alaskan Native	1 (1.5)	0 (0)	
More than one race	3 (4.5)	3 (7.1)	
Participate in Extracurricular Activities?			.15
No	9 (13.2)	2 (4.8)	
Yes	59 (86.8)	40 (95.2)	

*For Categorical variables, Chi-Square or Fisher's Exact test was used

**For Continuous variables, 2-Sample t-test or Wilcoxon Rank Sum was used

Table 2

Body Image Dimensions and Quality of Life: Craniofacial vs. Comparison Group

Measure	Craniofacial Mean ± SD	Comparison Mean ± SD	*p*
BIDQ	1.70 ± .69	1.63 ± .68	.57
DAS Total	84.90 ± 29.35	84.21 ± 41.49	.94
SWA Total	7.03 ± 1.91	7.62 ± 1.64	.11
MBSRQ-AE	3.47 ± .79	3.55 ± .87	.59
MBSRQ-AO	3.24 ± .78	3.77 ± .68	.001
MBSRQ-BASS	3.66 ± .77	3.53 ± .64	.38
MBSRQ-OP	1.86 ± .85	2.18 ± 1.17	.22
MBSRQ-SCW	2.95 ± .69	3.02 ± .80	.45
YQOL	83.55 ± 12.01	79.61 ± 15.18	.23

BIDQ = Body Image Disturbance Questionnaire; DAS = Derriford Appearance Scale; SWA = Satisfaction with Appearance Scale; Multidimensional Body-Self Relations Questionnaire (MBSRQ): AE = Appearance Evaluation; AO = Appearance Orientation; BASS= Body Areas Satisfaction Scale; OP = Overweight Preoccupation; SCW = Self-Classified Weight; YQOL: Youth Quality of Life Inventory

Table 3

Body Image Scores by Gender and Group

	Craniofacial			Comparison		
	Male (n=39)	**Female (n = 31)**		**Male (n = 21)**	**Female (n = 21)**	
Measure	**M ± SD**	**M ± SD**	***p***	**M ± SD**	**M ± SD**	***p***
BIDQ	1.57 ± .66	1.86 ± .70	.03	1.34 ± .40	1.92 ± .78	.009
DAS Total	81.87 ± 28.53	88.71 ± 30.37	.22	66.67 ± 35.71	101.86 ± 39.99	.008
SWA Total	7.04 ± 1.89	6.91 ± 1.97	.74	8.13 ± 1.34	7.12 ± 1.78	.06
MBSRQ-AE	3.53 ± .76	3.39 ± .84	.46	3.84 ± .65	3.27 ± .98	.03
MBSRQ-AO	2.96 ± .80	3.60 ± .58	.001	3.43 ± .59	4.10 ± .59	.001
MBSRQ-BASS	3.74 ± .82	3.56 ± .70	.34	3.83 ± .50	3.23 ± .63	.001
MBSRQ-OP	1.56 ± .77	2.25 ± .81	.001	1.65 ± .59	2.71 ± 1.37	.003
MBSRQ-SCW	2.78 ± .67	3.16 ± .68	.04	2.83 ± .81	3.21 ± .77	.13

BIDQ = Body Image Disturbance Questionnaire; DAS = Derriford Appearance Scale; SWA = Satisfaction with Appearance Scale; Multidimensional Body-Self Relations Questionnaire (MBSRQ): AE = Appearance Evaluation; AO = Appearance Orientation; BASS= Body Areas Satisfaction Scale; OP = Overweight Preoccupation; SCW = Self-Classified Weight

Table 4

Multivariate ANCOVA Results for Appearance Satisfaction and Body Image Disturbance: Tests of Overall Model Significance[†] and Estimated Marginal Means for Group and Gender

		Model	Craniofacial M, 95% CI	Comparison M, 95% CI	*p*	Model	Male M, 95% CI	Female M, 95% CI	*p*
Appearance Satisfaction		Λ= .75 *p* <.001				Λ= .70 *p* < .001			
	MBSRQ-AE		3.46 [3.26,3.66]	3.57 [3.32, 3.83]	.50		3.67 [3.46,3.89]	3.31[3.07,3.54]	.03
	MBSRQ-AO		3.24 [3.08,3.40]	3.73 [3.53,3.93]	.001		3.12 [2.95,3.29]	3.79[3.61,3.98]	.001
	MBSRQ-BASS		3.63 [3.46,3.80]	3.57 [3.35,3.79]	.66		3.76 [3.57,3.94]	3.43[3.23,3.63]	.02
	MBSRQ-OP		1.90 [1.70,2.10]	2.10 [1.85,2.36]	.23		1.57 [1.35,1.79]	2.47[2.23,2.71]	.001
	MBSRQ- SCW		2.97 [2.84,3.10]	2.96 [2.80,3.13]	.94		2.86 [2.72,3.00]	3.10[2.94,3.25]	.03
	SWA Total		6.96 [6.53,7.39]	7.66 [7.11,8.21]	.05		7.58 [7.11,8.04]	6.80 [6.29,7.32]	.03
Body Image Disturbance		Λ= .39 *p* = .68				Λ= .90 *p* = .005			
	DAS		85.0 [77.05,92.96]	84.05[73.75,94.34]	.89		76.75[67.99,85.51]	93.75[84.30,103.19]	.01
	BIDQ		1.71[1.55,1.87]	1.61[1.41,1.81]	.45		1.47 [1.29,1.64]	1.91[1.72,2.10]	.001

[†]adjusted for BMI, race, age

BIDQ = Body Image Disturbance Questionnaire; DAS = Derriford Appearance Scale; SWA = Satisfaction with Appearance Scale; Multidimensional Body-Self Relations Questionnaire (MBSRQ): AE = Appearance Evaluation; AO = Appearance Orientation; BASS= Body Areas Satisfaction Scale; OP = Overweight Preoccupation; SCW = Self-Classified Weight

Table 5

Spearman Correlations of Body Image Dimensions and Quality of Life: Craniofacial Group

Variables	1	2	3	4	5	6
1. DAS	–					
2. BIDQ	**.60** *	–				
3. MBSRQ –AE	**−.65** *	**−.52** *	–			
4. MBSRQ –AO	.24**	**.38** *	−.17	–		
5. SWA	**−.65** *	**−.65** *	**.68** *	−.13	–	
6. YQOL	**−.65** *	**−.40** *	**.45** *	−.04	**.63** *	–

* $p < 0.01$, $p < 0.05$

1. DAS = Derriford Appearance Scale; 2. BIDQ = Body Image Disturbance Questionnaire; 3. MBSRQ - Multidimensional Body-Self Relations Questionnaire: AE = Appearance Evaluation; 4. MBSRQ AO = Appearance Orientation; 5. SWA = Satisfaction with Appearance Scale; 6. YQOL = Youth Quality of Life Inventory

Table 6

Spearman Correlations of Body Image Dimensions and Quality of Life: Comparison Group

Variables	1	2	3	4	5	6
1. DAS	–					
2. BIDQ	**.62** *	–				
3. MBSRQ -AE	**−.62** *	**−.67** *	–			
4. MBSRQ -AO	.22	**.46** *	−.26	–		
5. SWA	**−.74** *	**−.66** *	**.69** *	**−.30** **	–	
6. YQOL	**−.84** *	**−.53** *	**.62** *	−.17	**.76** *	–

* $p < .01$,

** $p < .05$

1. DAS = Derriford Appearance Scale; 2. BIDQ = Body Image Disturbance Questionnaire; 3. MBSRQ - Multidimensional Body-Self Relations Questionnaire: AE = Appearance Evaluation; 4. MBSRQ AO = Appearance Orientation; 5. SWA = Satisfaction with Appearance Scale; 6. YQOL = Youth Quality of Life Inventory