A Clinical Report: Mental health, Self-esteem and Social Interaction in Adolescents with CL/P in the Context of Reconstructive Surgery

Birgitta Johansson Niemelä1, Valdemar Skoog2, Tor-Göran Henriksson2 and Viveka Sundelin Wahlsten1

1Department of Neuroscience, Child and Adolescent Psychiatry and Uppsala University Hospital, Uppsala, Sweden
2Department of Surgical Sciences, Plastic Surgery Clinic, Uppsala University Hospital, Uppsala, Sweden

Abstract

Background: Self-esteem in children and adolescents with deviations in function and appearance has been studied with diverse results. The effect of cleft lip/palate on mental health, self-esteem and social interaction were studied in the context of reconstructive surgery. Comparing parents’ and children’s self-esteem reports was also of interest. Exploring these differences could help the understanding of future mental health in patients with CL/P and their need for reconstructive surgery.

Methods: A descriptive study within an in-patient setting, Plastic Surgery Clinic, Uppsala University Hospital. Twenty-six CL/P patients between 13 and 19 years of age and their parents answered a specific condition questionnaire specially adapted for this study and Beck’s Youth Inventories the day before reconstructive surgery.

Results: Mental health was affected while self-esteem was on a median-high level for this CL/P group. Parents rated their children to have higher self-esteem as they grew older. However, females reported a diminished level from primary to secondary school age. Attention on CL/P was high. Twenty-three adolescents, or 85 % of respondents, wanted to change their appearance.

Conclusion: Mental health was affected by CL/P, especially for those children that had been bullied. Specifically, the wish to change appearance was associated with high level of anxiety and depression. The specific condition questionnaires proved to be more informative than the standardized measure regarding self-esteem under development for the sake of differentiating between parent-adolescent estimation of self-esteem.

Keywords: adolescents; self-esteem; social interaction, mental health, CL/P, reconstructive surgery

Introduction

In modern medicine it has become increasingly important to measure the psychological benefits of reconstructive intervention in terms of its impact on patients’ mental health, self-esteem and social interaction. Cleft lip and palate (CL/P) is one of the most common facial disfigurements, affecting 1.8/1000 newborn children.1,2. From a surgical perspective, the treatment of CLP provides good aesthetic and functional (speech, occlusion) results. However, the effect of this on psychological outcomes is not conclusive.

The effect on psychological outcomes such as behavioural, cognitive, family and emotional problems is questionable, while social adjustment and interaction ability to interact are demonstrated to be affected.3,4,5,6. Studies conducted on self-esteem in children present a complicated view on the developmental perspective, and results from clinical reports and measures of the notion of self-esteem in children with a cleft are often contrasting or even contradictory.7,8,9,10. However, the existence of adolescents with inhibited behaviour due to CLP makes it important to search for new ways to interpret and understand their troubled behaviour and also how to open up directions for new clinical management.11,12,13. In earlier studies by Niemelä et al.14,15, children’s self-esteem was evaluated according to the ITIA.16 After an interview with parents and children, a separate assessment with standardized test and questionnaires was conducted. According to ITIA children aged 7-16 undergoing reconstructive surgery have a median-high self-esteem before treatment, with no change being observed in their self-esteem one year afterwards. Otherwise, in interviews the children express satisfaction with the result of the surgery as well as a spontaneous expression of higher self-esteem. Parents evaluated their children as having improved mental health after leg lengthening and otoplasty surgery. However, the question of (self assessed) self-esteem remains unanswered, as it seems unaffected by reconstructive surgery.

The Current Study

The aim of the study was to continue the search for new ways of conceptualizing of self-esteem by asking adolescents to look back on changes in the levels of their self-esteem that can be meaningfully connected to age-related life experiences and context, such as, for instance reconstructive surgery.17,18,19

In this study we focused on young patients with cleft-lip and palate (CLP) during the final stages of reconstructive surgery. At this stage in the process, the initial steps of medically necessary interventions had been dealt with and now the more aesthetic part of the treatment was on the agenda. Plastic surgeons involved in this field often ask themselves why some adolescents ask for surgery while others do not. Is this a question of mental health or pressure from others?

A pilot study was performed with the aim of exploring important

*Corresponding author: Birgitta J. Niemelä, Department of Neuroscience, Child and Adolescent Psychiatry and Uppsala University Hospital, Uppsala, Sweden. Email: birgitta.johansson.niemela@akademiska.se

Received November 11, 2011; Accepted December 13, 2011; Published December 16, 2011


Copyright: © 2011 Niemelä BJ, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.
issues for the current study. The semi-structured interview was conducted by the plastic surgeon at the Plastic Surgery Clinic and the psychologist (BJN) outside the team, Uppsala University Hospital. Six adolescents with CL/P and their parents participated. After that interview study, two questionnaires were designed specifically for evaluation of the group in focus: Youth questionnaire (YQ-CLP) and Family Interaction (FI-CLP) [17].

Patients and Methods

Patients

A total of 33 adolescents between 13 and 19 years of age were referred to the Plastic Surgery Clinic, Uppsala University Hospital during the period 2005 to 2008 for secondary correction of nonsyndromic cleft lip with or without cleft palate. Four individuals refrained from undergoing a new operation and further 3 declined from participating in the study. Of the 26 participants (9 females/17 males, mean age 15.5 years), 10 had unilateral cleft-lip palate, 9 had bilateral cleft-lip palate, and 4 had unilateral cleft lip. Bilateral cleft lip palate, median cleft lip and bilateral cleft lip palate with palate cleft was each diagnosed for one child.

Learning disabilities (dyslexia, attention deficits or need for special teaching services) were identified in 7 boys, but IQs were within normal ranges. Six individuals were international adoptee. Thirty-three parents (21 mothers/12 fathers) representing all 26 children responded to a questionnaire.

The ratio of male/ female in this study sample (17 males and 9 females) was consistent with the increased incidence of cleft lip in boys. Informed consent was obtained from participants and their parents. The ethics committee approved the study.

Medical Procedure

Secondary procedures on the lip included excision of scar contractions, but also total lip reconstruction. Secondary nose correction procedures included adjustment of nasal wing and reconstruction of tip projection with elongation of the collumella.

Psychological Procedure

The families were initially informed about the study by written information, sent to their home, and complementary information was given in person at the ward. A psychologist, (BJN), who was not involved in the medical care, conducted the psychological assessment on the day before surgery. Accompanying parents were simultaneously involved in the medical care, conducted the psychological assessment, giving priority to changing looks/face (compared to other desired changes). The primary instruction was to estimate levels both at the time for the secondary correction and at the time when self-esteem was at its lowest.

Statistical Analysis

Differences in proportions were analyzed with Chi-2 test. Spearman’s correlations coefficient was used for testing the strength of association between variables. Pair wise differences were examined with Wilcoxon signed rank test and Friedman test. Repeated measure ANOVA was used for measuring interaction effects over time. A significance level of 5% was used. All analyses were performed with SPSS 13.0.

Results

Twenty-six adolescents with CL/P took part in the study by answering Beck’s Youth Inventories (BYI) and a condition specific questionnaire. A total of 33 parents answered the self-reports on self-esteem and social interaction. One patient refused to answer the BYI.

Mental Health BYI

Eleven adolescents did not report any problems on BYI scales. Eight adolescents of 25 had high scores on at least one BYI subscale. High scores were on the 95 percentile, which means that only 10% of
adolescents in the same age group had a worse self-reported mental health.

Seven adolescents had some kind of learning disabilities such as dyslexia or attention deficits. Five (20%) youngsters with learning disabilities also had heightened scores on 3-4 subscales of BYI and 2 had low self-esteem measures both on BYI and YQ-CLP. Anger was significantly associated with severe bullying and there was a trend of heightened Anxiety.

### Self-esteem BYI

According to the BYI scale the majority of the adolescents had self-esteem scores within median range (Table 1). However, there were 28% (n=7) who had somewhat low or very low self-esteem. Five of these also had problem scores on BYI (anxiety, depression, anger and anti-social behavior. Low self-esteem was seldom reported without other mental health problems seems rare. The adopted children (n=6) in this study reported median levels on the BYI self-esteem subscale.

### Self-esteem YQ-CLP:

In the condition specific questionnaire, self-esteem scores (on a scale 1-9) were on median level for both genders when the adolescent had to retrospectively estimate how good the global self-esteem was up to the age of 6 years, 8-10 years and 13-19 years. However, there was a significant interaction effect between males' and females' self-esteem from 8-10 years-of-age to 13-19 years-of-age. (F=4.4; p<0.05): that of females dropped while that of males grew (Table 2 and Figure 1).

The high self-esteem was related to parental support, family support and understanding friends. Factors that negatively affected self-esteem were being bullied and having "difficult people" around. The patients also reported that being nervous and having persistent negative thoughts had debilitating effects on their self-esteem. The factor that most negatively affected their self-esteem was meeting new peers and finding themselves in new social situations.

Parents were asked to estimate their child's lowest self-esteem and the highest. Both mothers and fathers reported a significant difference, with an increase in self-confidence being the predominant trend, mothers 5.3 to 6.8 and fathers 4.8 to 7.0 (Table 3).

There was a significant difference between the ratings of the parents and those of the adolescents (Figure 2).

### Social interaction YQ-CLP:

According to the answers in the specific condition questionnaire YQ-CL/P 8 of the adolescents with CL/P felt isolated. They could, for example, that they saw the home as "their castle", and claimed that: "I like being at home, but my CL/P made me like it even more" and "I enjoy staying at home. At home I don't have to talk/meet people who don't understand" (Table 4).

The adolescents with CL/P claimed that parental support was the most significant support factor when CLP could affect social interaction, with the next best support was being that of friends (Table 5).

Seventeen adolescents were bullied and 7 reported a severe form of bullying. During their first school years they were bullied in a physically or verbally direct way and at the time at which the survey was conducted they felt as if they were stared at.

### Attention to CLP

Attention to CLP was high. Twenty-four of 26 claimed to think frequently about CLP. They also felt observed by others because of their condition. Twenty-three adolescents (85%), wanted to change their appearance/facel.

The factors that followed in terms of desire for alteration were weight and social relations.

Twelve adolescents (48%) would like groups to be established for young patients in which they could get information and have open conversations about their condition and situation, or groups dedicated to developing their social ability. Six patients wanted individual consultation with a psychologist. Three wanted support for parents but no one desired family consultation. The desire for support was clearly related to self reported problems on BYI scales.

Adolescents and parents had few comments regarding experiences of past surgical intervention. They were either satisfied with the treatment or simply accepted the procedures. However, the adolescents thought they had been left out of the decision-making procedure until their teens.

### Table 5: Distribution of answers to social interaction: who or what has been the best support in relation to CLP?

<table>
<thead>
<tr>
<th>Parents</th>
<th>Health care</th>
<th>Friends</th>
<th>Sport</th>
<th>Church</th>
<th>Music</th>
</tr>
</thead>
<tbody>
<tr>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>N (%)</td>
<td>n (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>22 (88)</td>
<td>3 (12)</td>
<td>14 (56)</td>
<td>9 (36)</td>
<td>2 (8)</td>
<td>5 (20)</td>
</tr>
</tbody>
</table>

![Figure 1: Gender and self-esteem.](image1)

![Figure 2: Adolescents' and parents' estimation of self-esteem.](image2)
Discussion

Using the specially designed questionnaire, instead of data from a standardized measure of mental health, for this group of adolescents YQ-CL/P and their parents helped us appreciate how complicated life can be for these children. The information was a complement to Beck’s Youth Inventories (BYI) showing the clinical qualities of the questionnaires, such as, for instance, that parents are focusing on their children’s gradual improvement of function and appearance, as well as the importance of high quality information and reconstructive surgery as supportive for their ability to support their children’s self-esteem in spite of reported problems. In addition, the perspective of how self-esteem change over time was interesting and an important factor to be taken into account for future research.

The results indicated a subgroup of adolescents with CL/P who had been severely stressed by multiple factors such as learning disabilities, bullying, and female gender. Their mental health was affected according to BYI. The results of the standardized measures BYI demonstrated that 8 adolescents of 25 had high scores on at least one BYI subscale. Five adolescents reported high levels of anxiety and 5 high levels of depressive symptoms. Epidemiological studies in Sweden report mental health problems in 10-25 % of children and adolescents.[21] This comparison data indicates that, given the ratio of mental health problems in this group of adolescents with CL/P, they are clearly at a risk and in need for special attention. Hence, compared with a BYI standardized sample (2358 adolescents) and a sample of 149 psychiatric patients, the CL/P group in this study presented data more similar to the standardized group than to the psychiatric sample (Figure 3). [20] The research questions in YQ-CL/P provided much useful data. There were no items, dimensions or groups of factors that could explain BYI mental health ratings, but there were certain associations. Different cleft diagnoses were not found to be associated with any special type of response to study questions.

Physical problems were represented in this group by 7 male adolescents with learning disabilities, which could be associated with the social interaction and mental health problems reported. These findings are in accordance with the study by Person and colleagues on educational difficulties in adolescents with a cleft.[22] Apropos of this, Mueller et al. Point to the interplay of craniofacial and brain development, which might explain learning disabilities [23].

Bullying was the prominent problem reported to have affected them during childhood. It was significantly associated with self-reported psychiatric symptoms such as anger and there was also a trend of high scores on anxiety. This raised the question of what the affected child is likely to do with his/her anger and anxiety in the future.

Adolescents with CL/P and their parents rated self-esteem as median-high, while reports on social interaction problems during childhood were persistent and other problems such as encountering new situations and new peers continued to present difficulties.

We learned that the adolescent had decided that high self-esteem was good for social adjustment/interaction and also rated their self-esteem highly. In future studies, the pre-understanding of the self-esteem concept could be that the individual is pursuing self-esteem by attempting to satisfy standards of value and worth. [24] The immense importance of parents for their children in all respects - and not least in buffering their self-esteem during early life - has been demonstrated in previous research and confirmed in this study.[3,10] The parents considered their children’s self-esteem to have been, and to be continuing to be, improving. When parents saw new acceptance and behaviour in their children, they developed a higher estimation of their children’s self-esteem than did the adolescents themselves. The adolescent with CL/P has learned to have a high expectation regarding their self-esteem, supported by, at first hand, parental support and thereafter friends. [18] It would be interesting to explore if adolescents not affected by CLP also would put parental support first.

Females in this study had a diminishing trend in their self-esteem ratings compared to the males and there were mental health symptoms reported by 7 of the 9 females. This measure was performed before the secondary correction, so their self-esteem after surgery remains to be examined. However, the girls’ diminished self-esteem at the time of the survey was not fully anticipated by the parents. Girls can be more sensitive to people’s reaction to their appearance during the teenage years, according to Sinko et al.[25] The improvement of appearance can be of importance for self-perception in females according to Landsberger et al.[26] In this study, the adolescents did not feel as if low self-esteem related to the desire to change their appearance; rather, the trend was toward higher anxiety and depression symptom level. The improvement of appearance and function was often on the agenda when parent and child talked, while psychological well being, in terms of issues such as the child’s inner sufferings and interpersonal difficulties, were less discussed. This could be an explanation to the high level of self-esteem.

The different opinions reported by adolescents and parents are indeed important to notice and to further explore, since a deterioration of mental health and an elevated suicide rate are reported in studies of adult CLP patients. [27]. The adolescents in the study wanted the opportunity to talk either with other people in the same situation in a group setting arranged by the Plastic Surgery Clinic or with a psychologist on an individual basis. This might give them the opportunity to have reflective talks with others in the same situation and, thus, provide resilience and release from the acute sense of being different. However, the result of the self-esteem assessment by parents also demonstrates a need for support to young schoolchildren and their parents.[5]. The fact that the adolescents themselves reported bullying as harming them emotionally as well as physically provided information of a very serious nature that we need to act upon. [28]. Psychological assessments of mental health problems could also be informative when deciding the surgical interventions.
The limitations of the study were the small sample size and the fact of diverse CL/P diagnoses. The cognitive capacity of adolescents to retrospectively answer questions about self-esteem, such as, for instance, their self-esteem at different ages, needs further study, as does self-esteem in the same manner in a non-cleft population. Further limitations were the new untested questionnaires.

Conclusion

The results of this study offered new ideas for future research on self-esteem in adolescents with CL/P. Self-esteem reports were high, although experiences of social interaction had been difficult and even traumatic because of widespread experiences of bullying.

There was diminished self-esteem from primary to secondary school in female patients compared to the development of the male patients' self-esteem. However, parents considered their children’s self-esteem to increase as they grew older. The majority of the CL/P adolescents had been bullied through their earliest school years and their mental health was affected. However, the results from this study group more closely resembled the normal group than a psychiatric sample. Support groups and individual consultations with a psychologist were interventions suggested by those adolescents most affected by mental health problems.

Attention to CL/P was high. Twenty-four of 26 claimed to think on CL/P frequently. They also felt observed by others because of their condition. Twenty-three adolescents, or 85 % of the sample, wanted to change their appearance/face.

The results indicated a subgroup of adolescents with CL/P who had been severely stressed by multiple factors such as learning disabilities, bullying, and female gender. Psychological assessments of mental health problems could also be informative when deciding on appropriate surgical interventions.

The condition-specific questionnaires proved to be informative with regard to self-esteem under development, and also to differentiate between parent-adolescent estimation of self-esteem. Psychometric testing of the condition-specific questionnaire YQ-CLP would benefit the applicability of this instrument in work with the adolescents and parents in CLP care.

Adolescents and parents had few comments regarding experiences of past surgical intervention. They were satisfied or they simply accepted the procedures. However, the adolescents thought they had been left out of the decision-making procedure until their teens.

References