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## Original Article

# Individuals with Cleft Lip and/or Palate Demonstrated Improved Self-Reported Psychosocial Functioning Following the Onset of the COVID-19 Pandemic

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## ABSTRACT

**Objective:** To evaluate the impact of the COVID-19 pandemic on the psychosocial functioning of individuals with cleft lip and/or palate (CL/P).

**Methods:** Patients with CL/P  $\geq 6$  years old were prospectively recruited from the Cleft and Craniofacial Clinic of a tertiary children's hospital. From July–October 2021, eligible patients (or their parent/guardian) were sent a survey regarding their psychosocial functioning before and after the start of the pandemic.

**Main Outcome Measure:** The difference between prepandemic and intrapandemic patient-reported outcome scores.

**Results:** Thirty-six patients (20 female, age:  $15.9 \pm 9.8$  years) responded. Most had cleft lip and palate (77.8%), responded online (69.4%), interacted remotely via both voice- and video-conferencing (62.9%), and wore masks routinely (77.1%). Similar numbers of patients responded independently (27.8%), responded with the help of a parent/guardian (36.1%), or had a parent/guardian respond on their behalf (36.1%). General social-emotional well-being ( $p = 0.004$ ,  $r_{tb} = 0.659$ ) and satisfaction with facial appearance ( $p = 0.044$ ,  $r_{tb} = 0.610$ ) significantly improved after the start of the pandemic. Compared to their general intrapandemic social-

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emotional well-being scores, patients reported higher scores while wearing a mask ( $r_{rb} = 0.827$ ) and lower scores while interacting remotely ( $r_{rb} = 0.605$ ), although all were still significantly improved compared to their prepandemic scores ( $p \leq 0.010$ ). Patients also reported significant improvement in social functioning while wearing a mask ( $p = 0.036$ ,  $r_{rb} = 0.519$ ), whereas they did not when considering their general intrapandemic feelings/experiences ( $p = 0.269$ ,  $r_{rb} = 0.211$ ).

**Conclusion:** Patients with CL/P demonstrated significant improvement in overall social-emotional well-being, satisfaction with facial appearance, and social functioning after the start of the COVID-19 pandemic, particularly when wearing a mask.

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## Introduction

Cleft lip and/or palate (CL/P) is the second most common birth defect in the United States, with an incidence of 1 in 940 live births.<sup>1</sup> Treatment for CL/P begins at birth and continues through early adulthood, with functional and aesthetic problems often persisting. Feeding, speech, hearing, and dental issues; bone and soft tissue deformities; facial asymmetries; and scarring may be present from surgeries.<sup>2–5</sup>

Investigations of the psychosocial consequences of CL/P have reported increased risk for depression, anxiety, social and learning difficulties, poor quality of life, and low self-esteem<sup>2–6</sup>; however, other studies found no significant differences in these rates.<sup>3,5,6</sup> The facial appearance and symmetry of patients with CL/P are commonly rated more negatively than those of nonaffected individuals. In addition, CL/P patients are perceived to display negative-quality facial expressions. Observers routinely report high levels of “social distance,” or emotional disconnect, when observing CL/P photographs. Beyond appearance, CL/P patients with hypernasal speech are more likely to encounter additional social barriers. Bullying and social stigmatization are significantly higher among CL/P patients than participants in the control group, with reported rates of 20% to 95%. Bullying typically occurs at school and is mostly related to appearance and/or speech.<sup>2–6</sup>

Studies identified differences in the psychosocial impacts of CL/P based on cleft type, sex, and reporter (e.g., parent vs. self-report). Children with cleft palate only (CPO) experience more cognitive difficulties than nonaffected children or children with cleft lip only (CLO) or cleft lip and palate (CLP). Children with visible clefts (i.e., CLO or CLP) report greater dissatisfaction with appearance than those with CPO. Similarly, girls report more emotional and appearance-related concerns with their CL/P, whereas boys report more behavioral, attentional, and peer interaction-related problems.<sup>2–5</sup>

Widespread disease outbreaks can have profound psychosocial consequences. Disease outbreaks—such as SARS, H1N1, and AIDS—have been associated with acute stress disorder, posttraumatic stress disorder, anxiety disorders, and depression. Analogous effects have been demonstrated since the onset of the coronavirus disease 2019 (COVID-19) pandemic.<sup>6–14</sup> While increased social isolation, limited access to medical care, and stress displayed by family and friends may have been traumatic for the general population, these changes may have had unexpected benefits for CL/P patients. Social distancing may have decreased negative peer interactions, and disruptions in medical care may have provided a break from its attendant psychological burdens.<sup>6,7,15–18</sup> Wearing masks in public may have hidden facial asymmetries and scarring, and shifting from in-person activities to voice- and video-conferencing may have allowed unparalleled control over the presentation of CL/P individuals in social interactions.

Prior studies examined the influence of the COVID-19 pandemic on psychosocial functioning in patients with craniofacial abnormalities,<sup>6</sup> but none have specifically studied patients with CL/P. The purpose of this study was to evaluate the impact of the COVID-19 pandemic—and the social and behavioral changes it precipitated—on the psychosocial functioning of individuals with CL/P. The authors hypothesized there would be a significant difference between CL/P patients' psychosocial functioning before versus after the onset of the pandemic.

## Methods

### *Patient recruitment*

Institutional Review Board approval was obtained to prospectively recruit patients from the Cleft and Craniofacial Clinic of a large tertiary referral children's hospital. Patients were required to be at least school age (at least 6 years old, with no upper limit) and diagnosed with CL/P. The clinic follows patients into adulthood, so surveyed patients included children and adults. The patient-reported outcome (PRO) measures used in the study were only available in English, thus patients under the age of 18 needed to have an English-speaking guardian, and those 18 years or older needed to be English-speaking. Eligible patients (or guardians) were emailed a survey link in July 2021 asking about their psychosocial functioning before and after the start of the COVID-19 pandemic. Another email was sent the following month to patients and families who did not respond or who began but did not complete the survey. In September and October 2021, patients were mailed a paper survey and a return-addressed, prestamped envelope if they had not responded to either email or had started but not completed the survey. Responses were gathered through December 2021.

### *Survey design*

The survey was composed of select portions of 2 previously validated oral health-related quality of life (OHRQoL) PRO instruments: the 19-question Child Oral Health Impact Profile short-form (COHIP) and the CLEFT-Q.<sup>19–26</sup> Both instruments have discrete scales that can be used independently without affecting their psychometric properties. This study's survey utilized a single scale from the COHIP (social-emotional well-being) and 4 scales from the CLEFT-Q: social function, school function, psychological function, and facial appearance. Participants filled out these 5 scales based on their feelings and experiences in 2 scenarios: before and after the onset of the pandemic. Participants also filled out the COHIP social-emotional well-being scale and the CLEFT-Q social function scale based on their feelings and experiences in 2 additional scenarios: while voice- and/or video-conferencing and while wearing a mask in public. The COHIP social-emotional well-being and the CLEFT-Q social function scales were repeated 2 additional times because they were most likely to reflect the direct impact of obscurement of facial differences caused by remote interaction or mask-wearing.

Demographic information was collected, including age, sex, cleft diagnosis (lip, palate, or both), medical diagnoses, survey format (online or mailed), typical method of remote interaction (voice, video, or both), routine mask-wearing (yes or no), and level of assistance with the survey. Guardians were allowed to fill out the survey on behalf of patients who were too young or could not fill it out themselves, and patients who were old enough could fill out the survey independently or with a guardian's help.

### *Statistical analyses*

Continuous variables are reported as mean  $\pm$  standard deviation. Categorical variables are reported as percentages. Before analysis, scores for the COHIP social-emotional well-being scale were reversed by subtracting each item-level score from 6—transforming scores of 1 and 2 into 5 and 4, respectively—due to negative wording.<sup>20–22</sup> The CLEFT-Q scale scores were converted to a score from 0–100 using proprietary conversion tables provided by McMaster University. Normality was assessed with the Shapiro-Wilk test. Based on the results, patients' pre-COVID scores were compared to their intra-COVID scores as well as their remote interaction and mask-wearing scores using the Wilcoxon

**Table 1**  
Demographic characteristics.

Sex	
Male	16 (44.4%)
Female	20 (55.6%)
Age (y)	15.9 ± 9.8 (7 to 51)
Cleft	
Lip	6 (16.7%)
Palate	2 (5.6%)
Lip and palate	28 (77.8%)
Respondent	
Patient	10 (27.8%)
Patient with parent/guardian	13 (36.1%)
Parent/guardian	13 (36.1%)
Format	
Online	25 (69.4%)
By mail	11 (30.6%)
Remote interaction	
Voice	3 (8.6%)
Video	10 (28.6%)
Voice and video	22 (62.9%)
Routine mask wearing	
Yes	27 (77.1%)
No	8 (22.9%)

Values are number followed by percent of respondents or mean ± standard deviation followed by range.

**Table 2**  
Comparison between OHRQoL PRO scores before versus during the COVID-19 pandemic.

	Before	During	Difference	p-Value	$r_{tb}$
Social-Emotional (CH)	23.0 ± 6.1 (10 to 30)	25.0 ± 5.3 (12 to 30)	2.2 ± 4.3 (−4 to 14)	0.004*	0.659
Social (CQ)	76.5 ± 21.7 (32 to 100)	78.6 ± 21.1 (43 to 100)	3.3 ± 14.3 (−30 to 44)	0.269	0.304
School (CQ)	82.8 ± 19.1 (50 to 100)	84.0 ± 18.7 (50 to 100)	1.7 ± 6.9 (−7 to 33)	0.279	0.418
Psychological (CQ)	80.5 ± 23.0 (26 to 100)	80.6 ± 21.3 (32 to 100)	0.7 ± 13.3 (−32 to 50)	0.951	0.022
Face (CQ)	63.5 ± 26.0 (0 to 100)	64.9 ± 26.2 (0 to 100)	2.8 ± 8.4 (−14 to 24)	0.044*	0.610

Values are mean ± standard deviation followed by range.

OHRQoL: Oral Health-Related Quality of Life; PRO: patient-reported outcome; COVID-19: coronavirus disease 2019; CH: Child Oral Health Impact Profile (COHIP); CQ: CLEFT-Q questionnaire;  $r_{tb}$ : rank-biserial correlation coefficient.

\* Indicates significance at  $p < 0.05$ .  $r_{tb} \geq 0.1$  indicates a small effect,  $\geq 0.3$  indicates a medium effect, and  $\geq 0.5$  indicates a large effect.

signed-rank test. Effect size was assessed with the rank-biserial correlation coefficient ( $r_{tb}$ ),<sup>27–29</sup> with values  $\geq 0.1$  indicating a small effect,  $\geq 0.3$  indicating a medium effect, and  $\geq 0.5$  indicating a large effect.<sup>30</sup> All analyses were performed using R Statistical Software version 4.2.2 (R Core Team).<sup>31</sup>

## Results

The survey was sent to 176 patients. Forty patients responded (22.7% of total); however, 4 responses were incomplete, leading to 36 total participants (20.5% of total). Patients who were no longer in school at the onset of the pandemic ( $n = 4$ ) were removed from the school function scale assessment. Demographic characteristics are reported in Table 1. Two patients had diagnoses in addition to CL/P: one with agenesis of the corpus callosum and the other with Van der Woude syndrome.

Overall social-emotional well-being and satisfaction with facial appearance had significant improvement ( $p \leq 0.044$ ) and large effect sizes ( $r_{tb} \geq 0.610$ ) when comparing pre-COVID OHRQoL scores to intra-COVID scores. In contrast, social, school, and psychological functioning were not significantly affected ( $p \geq 0.269$ ), despite moderate effect sizes for both the social function scale ( $r_{tb} = 0.304$ ) and the school function scale ( $r_{tb} = 0.418$ , Table 2).

**Table 3**

Comparison between OHRQoL PRO scores before the start of the COVID-19 pandemic and while interacting remotely and wearing a mask during the pandemic.

	Before	During	Difference	p-Value	$r_{rb}$
<b>Interacting remotely</b>					
Social-emotional (CH)	23.0 ± 6.1 (10 to 30)	24.6 ± 5.6 (10 to 30)	1.5 ± 3.5 (–8 to 10)	0.010*	0.605
Social (CQ)	76.5 ± 21.7 (32 to 100)	78.1 ± 21.7 (43 to 100)	1.7 ± 10.3 (–24 to 44)	0.448	0.211
<b>Wearing mask</b>					
Social-emotional (CH)	23.0 ± 6.1 (10 to 30)	27.0 ± 4.3 (16 to 30)	3.9 ± 5.6 (–6 to 18)	<0.001*	0.827
Social (CQ)	76.5 ± 21.7 (32 to 100)	81.0 ± 19.9 (43 to 100)	4.6 ± 12.0 (–14 to 44)	0.036*	0.519

Values are mean ± standard deviation followed by range.

OHRQoL: Oral Health-Related Quality of Life; PRO: patient-reported outcome; COVID-19: coronavirus disease 2019; CH: Child Oral Health Impact Profile (COHIP); CQ: CLEFT-Q questionnaire;  $r_{rb}$ : rank-biserial correlation coefficient.

\* Indicates significance at  $p < 0.05$ .  $r_{rb} \geq 0.1$  indicates a small effect,  $\geq 0.3$  indicates a medium effect, and  $\geq 0.5$  indicates a large effect.

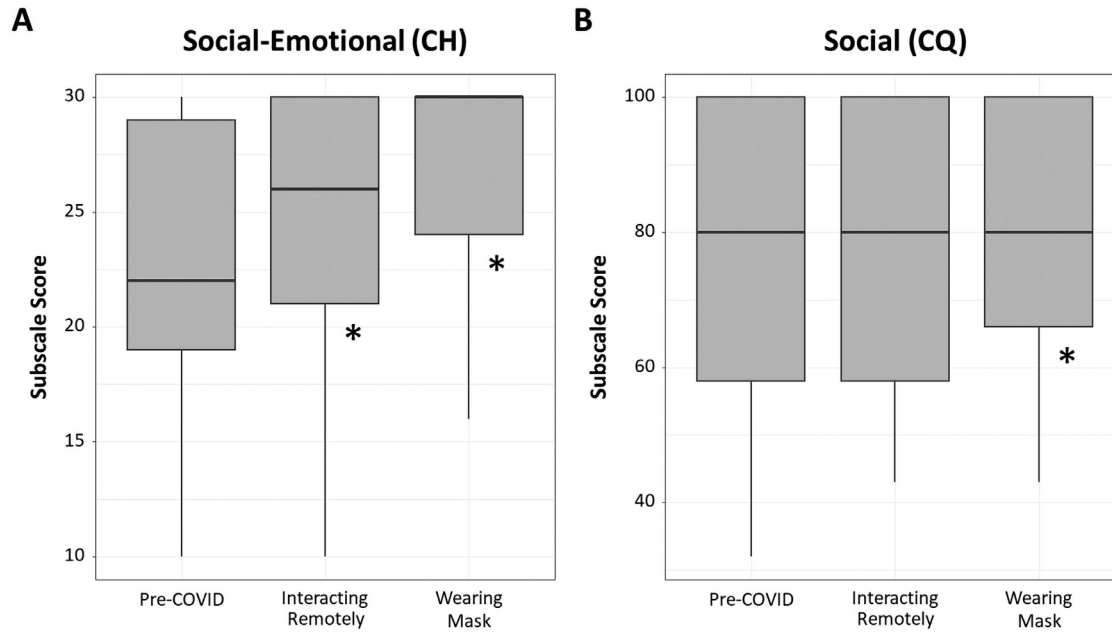
For the scales with significant improvement (COHIP social-emotional well-being and CLEFT-Q appearance of the face scales), the items with the largest relative score increase were “felt that you looked different because of your teeth, mouth, or face” and “been teased, bullied, or called names [ . . . ] because of your teeth, mouth, or face” from the COHIP, which increased by 0.51 and 0.39 standard deviations, respectively. From the CLEFT-Q, satisfaction with facial symmetry demonstrated the largest relative score increase (0.36 standard deviations), followed by satisfaction with facial appearance in photos (0.31 standard deviations).

Similar to their intra-COVID responses, patients reported significant improvement in overall social-emotional well-being when asked to consider their feelings and experiences while interacting remotely and mask-wearing in public ( $p \leq 0.010$ ), with large effect sizes in both. However, patients reported less social-emotional improvement with remote interaction ( $r_{rb} = 0.605$ ) versus their general feelings and experiences during the pandemic ( $r_{rb} = 0.659$ ), whereas they reported even greater improvement in mask-wearing ( $r_{rb} = 0.827$ ). While patients had not reported significant improvement in social functioning (per the CLEFT-Q social function scale) when asked more generally about their intrapandemic feelings and experiences, they reported significant improvement in social functioning when asked to consider just their feelings and experiences while wearing a mask ( $p = 0.036$ ,  $r_{rb} = 0.519$ , Table 3, Figure 1).

Feelings of looking different and frequency of bullying or name-calling showed the greatest relative increases in score (0.65 standard deviations for each in the context of public mask-wearing). From the CLEFT-Q social function scale, patients feeling like they fit in demonstrated the most relative improvement (0.46 standard deviations), followed by patients’ comfort with people looking at their face (0.39 standard deviations).

## Discussion

To our knowledge, this study is the first to examine changes in psychosocial functioning following the onset of the COVID-19 pandemic among patients with CL/P utilizing cleft-specific PRO measures. In contrast to the general population, patients with CL/P demonstrated a significant increase in psychosocial wellness following the pandemic’s onset. There was significant improvement in social-emotional well-being, appearance of the face, and social function. Patients reported the greatest improvement with interpersonal interactions, such as feelings of looking different or fitting in and frequency of bullying or name-calling. Compared to their general feelings and experiences during the pandemic, patients reported less improvement in social-emotional well-being while interacting remotely with others via voice- and/or video-conferencing but more improvement while wearing a mask in public. Patients only reported significant improvement in social functioning when asked to consider their feelings and experiences while wearing a mask and not when considering their feelings and experiences generally during the pandemic or while interacting remotely. These findings suggest that



**Figure 1.** Comparison between Oral Health-Related Quality of Life (OHRQoL) scores before the start of the coronavirus disease 2019 (COVID-19) pandemic and while interacting remotely and wearing a mask during the pandemic. Scales included the Child Oral Health Impact Profile (CH) social-emotional well-being scale and the CLEFT-Q (CQ) social function scale. The top and bottom of each box represent the 75<sup>th</sup> and 25<sup>th</sup> percentiles, respectively, and the thick line within each rectangle represents the median. The terminal points of the lines extending from the top (when present) and bottom of each rectangle represent the maximum and minimum values, respectively.

improvements in psychosocial well-being in patients with CL/P following the onset of the COVID-19 pandemic may be due in large part to routine mask-wearing, decreasing the ability of peers and the general public to differentiate their facial appearance from population norms. These results suggest that despite ongoing innovations and interventions for patients with facial differences, these individuals continue to lack improvement in their confidence. This indicates a need for stronger support and advocacy for patients with facial differences.

Huang et al. examined PROs before and after the onset of the COVID-19 pandemic among patients with congenital craniofacial diagnoses; however, CL/P patients were not assessed separately from the overall cohort, making it impossible to identify CL/P-specific effects. Huang et al. used general pediatric PRO measures that did not assess several parameters including self-image, self-confidence, teasing, bullying, and the impact of patients' orofacial appearance on their psychosocial functioning. They found that patients with congenital craniofacial diagnoses demonstrated increased depressive symptoms during the COVID-19 pandemic.<sup>6</sup> In contrast, the current study found that CL/P patients did not experience any increase in depressive symptoms following the pandemic's onset but demonstrated substantial improvement in their psychosocial well-being. This finding highlights the importance of specificity in the independent analysis of craniofacial disease processes.

Most studies exploring the impact of the COVID-19 pandemic on the mental health of children, adolescents, and the general population have found increased rates of depression, anxiety, stress, loneliness, and decreased life satisfaction.<sup>8–14</sup> Evidence suggests reductions in psychological well-being are related to decreased outdoor activities and social connectivity.<sup>8–13</sup> In contrast, the present study discovered increases in social-emotional well-being, satisfaction with facial appearance, and social functioning, for CL/P individuals in the context of public mask-wearing following the COVID-19 pandemic onset. Patients reported substantially decreased rates of bullying and name-calling during the pandemic, which have been shown to be sources of psychological distress in the CL/P population.<sup>2–6</sup> Improvement in CL/P patients' psychosocial functioning may have been related to their facial differences hidden by masks, causing decreased routine bullying. While COVID-19 lockdowns and social distancing may have negatively impacted the mental health of the general population, the psychosocial well-being of CL/P patients may have improved by removing the frequent stress of social interactions.

CL/P patients reported increased feelings of social compatibility, self-confidence, and comfort with their facial appearance, in both their own and others' assessment, after the start of the pandemic. These improvements, as well as decreases in teasing and bullying, were most pronounced while patients were wearing masks, suggesting that visible perioral differences that persist after CL/P repair may cause continued appearance-related stigma in patients with CL/P. Prior studies have shown that the faces of patients with CL/P are rated more negatively than those of control participants and are perceived to demonstrate more negative facial expressions.<sup>2–6</sup> With masks covering facial differences, CL/P patients may have avoided this stigma, potentially leading to the improvements in social-emotional well-being, self-image, and social functioning seen in the current study. While masking may have been beneficial, this benefit may have been lost with remote interaction via video-conferencing, as it would have been unusual or inappropriate to wear a mask in these instances. Video-conferencing may have increased attention toward CL/P patients' faces, causing increased awareness of their facial differences in this setting. This increased awareness of facial differences may have caused the smaller increase in patients' social-emotional well-being while interacting remotely versus generally during the pandemic or while wearing a mask.

While CL/P patients in this study and previous studies demonstrated social stigmatization due to facial differences, published evidence highlights this trend among patients with any facial differences. Meyer-Marcotty et al. evaluated facial perception in patients with unilateral CL/P and severe class III malocclusions compared with that of a control group.<sup>32</sup> The study found that patients with unilateral CL/P and orthognathic patients had lower attractiveness ratings than those of control groups, with the unilateral CL/P patients being rated the least attractive group.<sup>32</sup> The study also found that male unilateral CL/P patients had lower attractiveness ratings than female unilateral CL/P patients.<sup>32</sup> This study highlights the negative perception of facial differences. Although our study did not subjectively assess patients with CL/P, the existing literature demonstrates there has been a negative connotation toward individuals with any facial features different from societal norms.

Along with negative connotations, the era of social media causes increased pressure on children and young adults to conform to societal perfection. Jankauskiene et al. evaluated the effect of social media on appearance ideals, body appreciation, and disordered eating in adolescents.<sup>33</sup> The study found all positive correlations were stronger in girls than boys.<sup>33</sup> These included mean browsing hours per day, internalization of thin and low body fat ideals, lower body appreciation, and disordered eating.<sup>33</sup> Sanzari et al. evaluated the impact of social media on eating disorders and body image.<sup>34</sup> The study found lower body appreciation, negative perception of body appearance, and increased likelihood of seeking weight loss and body positivity content in women than men.<sup>34</sup> Both studies demonstrate the strong impact social media can have on an individual's self-perception, specifically that of adolescents. This pressure can translate to individuals with facial differences and may be reflected in our study results. This indicates that outside of facial differences and CL/P patients, societal stigmatization and social media can have strong influences on an individual's self-perception.

### *Limitations & future directions*

This study's findings must be understood in the context of its limitations. As a retrospective, subjective assessment, there is possibility of recall bias, given that participants were asked to report their feelings and experiences before and during the COVID-19 pandemic. Our study also had the potential for sample bias due to low sample size. Approximately two-thirds of surveys were filled out either with the help of a parent or guardian or by a parent or guardian on behalf of their child, so parental bias may have influenced the results. Prior studies show that there can be significant discrepancies in OHRQoL scores reported by patients versus their parents.<sup>2,3,5,35,36</sup> Selection bias may have impacted the study's findings, as the response rate was approximately 20%. Despite these potential sources of bias, the results of the present study are commensurate with established norms. In a sample of 110 patients with craniofacial diagnoses, Broder et al. reported a mean COHIP social-emotional well-being score of  $21.6 \pm 1.2$ .<sup>20</sup> Klassen et al. sampled over 2,400 children and young adults with CL/P and found mean scores for the CLEFT-Q social function, school function, psychological function, and appearance of the face scales to be 72–76, 75–80, 72–77, and 60–71, respectively.<sup>26</sup> The current study found mean pre-COVID scores for these same scales to be  $76.5 \pm 21.7$ ,  $82.8 \pm 19.1$ ,  $80.5 \pm 23.0$ , and  $63.5 \pm 26.0$ , respectively, and a mean COHIP social-emotional well-being score of  $23.0 \pm 6.1$ .

The population from which the study sample was drawn may not have been representative of the greater CL/P population, potentially limiting generalizability. Finally, the small sample size prevented comparisons between demographic groups and may have impaired its ability to detect significant changes.

The results of this study and the published literature demonstrate that our society has yet to evolve past the stigma of facial differences, especially in those of younger age. Although there is budding research on this topic, further emphasis should be put on the importance of changing how the general population perceives patients with facial differences. Future research and patient care should focus on educating the general population about facial differences and the psychosocial implications societal actions may have on the younger generation.

### **Conclusions**

This study found that patients with CL/P demonstrated significant improvement in overall social-emotional well-being, satisfaction with facial appearance, and social functioning after the start of the COVID-19 pandemic, in the context of wearing a mask in public. As many of the social and behavioral changes brought on by COVID-19, such as mask-wearing and social distancing, are returning to prepandemic norms, there is a need to raise public awareness of the condition and of the harms that teasing and bullying can cause.

### **Conflict of Interest Declaration**

The authors declare that there is no conflict of interest.



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None.

## Ethical Approval

IRB Exempt Approval from Advocate Children's Hospital.

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Christine Provenzano, BSN, RN, CPN.

## Author Contributions

**Jordan Larson:** Conceptualization, Methodology, Formal Analysis, Writing - Original Draft, Writing-Reviewing and Editing. **Kelly Ho:** Writing- Original Draft, Writing- Reviewing and Editing. **Hillary Lai:** Writing- Original Draft, Writing- Reviewing and Editing. **Vick Shaholli:** Writing- Reviewing and Editing. **John Smetona:** Supervision, Writing- Reviewing and Editing. **Frank Vicari:** Supervision, Writing-Reviewing and Editing. **Sanjay Naran:** Supervision, Conceptualization, Methodology, Writing- Reviewing and Editing.

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