

# An Assessment of Cleft Lip and Palate Treatment Satisfaction and Social Outcomes in Alabama

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*2024 Research Aid Awards (RAA)*

*Dr Tanner Godfrey*

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# FollowUp Form

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## *Award Information*

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*In an attempt to make things a little easier for the reviewer who will read this report, please consider these two questions before this is sent for review:*

- Is this an example of your very best work, in that it provides sufficient explanation and justification, and is something otherwise worthy of publication? (We do publish the Final Report on our website, so this does need to be complete and polished.)*
- Does this Final Report provide the level of detail, etc. that you would expect, if you were the reviewer?*

### **Title of Project:\***

An Assessment of Cleft Lip and Palate Treatment Satisfaction and Social Outcomes in Alabama

### **Award Type**

Research Aid Award (RAA)

### **Period of AAOF Support**

July 1, 2024 through June 30, 2025

### **Institution**

University of Alabama at Birmingham

### **Names of principal advisor(s) / mentor(s), co-investigator(s) and consultant(s)**

Chung How Kau

### **Amount of Funding**

\$6,000.00

## Abstract

(add specific directions for each type here)

Please see attachment

## *Respond to the following questions:*

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### **Detailed results and inferences:\***

If the work has been published, please attach a pdf of manuscript below by clicking "Upload a file".

OR

Use the text box below to describe in detail the results of your study. The intent is to share the knowledge you have generated with the AAOF and orthodontic community specifically and other who may benefit from your study. Table, Figures, Statistical Analysis, and interpretation of results should also be attached by clicking "Upload a file".

Assessment of Cleft Outcomes - Godfrey.pdf

Results to date are attached.

### **Were the original, specific aims of the proposal realized?\***

Our goals for the project were accomplished with the exception of the number of patients we aimed to enroll in the study. The CRS clinic was not able to release patient information for study recruitment, leaving us with only those CRS patients that received treatment at UAB Department of Orthodontics. However, the study continues with patients enrolled from Children's of Alabama database. Thus far, funds have not been dispersed to patients but will be soon, thus funds have not been utilized yet at this point.

### **Were the results published?\***

No

### **Have the results of this proposal been presented?\***

No

### **To what extent have you used, or how do you intend to use, AAOF funding to further your career?\***

This funding helped me to establish a basis in cleft lip and palate research and patient care. I intend to join/establish a cleft team in my area of practice; working on this project provided an excellent opportunity to work with a cleft team during residency providing needed training and exposure in this area.

## Accounting: Were there any leftover funds?\*

\$4,000.00

## *Not Published*

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### Are there plans to publish? If not, why not?\*

Yes. Once sufficient patient enrollment and questionnaire completion is completed in order to achieve the proper power level for statistical analysis, the result will be published.

*Comment: The AAOF PARC commends you on your study and encourages you/your department collaborators to continue toward completion as you remarked in your comments. We look forward to seeing the fruits of your labor as you pursue working with a craniofacial team in the future.*

## *Not Presented*

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### Are there plans to present? If not, why not?\*

Yes - as stated above, once adequate questionnaire completion is achieved for meaningful results, the results will be presented.

## *Internal Review*

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### Reviewer comments

*[Unanswered]*

*Comment: email sent to Dr. Godfrey confirming typo on remaining funds. The remaining funds are actually \$4,000.00 and he will work with his grants management office to process the refund to AAOF-GR 07/03/25*

### Reviewer Status\*

Approved

## File Attachment Summary

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### *Applicant File Uploads*

- Assessment of Cleft Outcomes - Godfrey.pdf

# **An Assessment of Cleft Lip and Palate Treatment Satisfaction and Social Outcomes in Alabama**

## **Abstract**

In the US, 1 in 600 individuals are born with a cleft lip and/or palate defect<sup>1</sup>. Cleft lip and palate has a significant impact on the function and appearance of the oral/facial region. Limited evidence suggests that adults and children with cleft lip and palate have increased social difficulties, increased psychosocial problems<sup>2</sup>. Specific examples include higher rates anxiety<sup>3</sup> and depression<sup>4</sup>, increased school drop-out rates and lower educational achievement<sup>5</sup>. Surgical and orthodontic treatment of cleft lip and palate aims to improve function and facial appearance, however, the extent to which these treatments improve social and psychosocial outcomes remains poorly studied. **Methods:** A study questionnaire containing an assessment of demographics, cleft treatment outcomes, oral health quality of life, social function, anxiety and depression was constructed utilizing validated sources. Questionnaires were delivered to patients over 18 having completed orthodontic and cleft surgical treatment from the Children's Rehabilitation Service of Alabama. **Results:** Responses collected totaled 14. Key findings include a general satisfaction for cleft treatment outcomes, with slightly higher than average levels of social disfunction, anxiety and depression. Oral Health Quality of Life was favorable for function, with less satisfaction with appearance. Finally, patients reported improvement in social function, levels of anxiety and levels of depression.

## **Introduction**

Cleft lip and/or palate (CL/P) is one of the most common birth defects, affecting 1 in 600 live births<sup>1</sup>. The physical and functional accompanying sequelae of CL/P are well documented and may include difficulties with feeding and speech. The severity varies considerably, but the physical appearance of the lip and/or nose is often significantly impacted, requiring various

surgeries to improve function and appearance. The altered appearance of the nose and lip in combination with speech difficulties during critical years of development have a documented impact on the psychosocial well-being and social skills of the individual<sup>2</sup>. Although some of the psychosocial impacts have previously been described, further clarification is needed to understand the long-term psychosocial function of individuals with CL/P. Furthermore, the psychosocial effect of CL/P corrective treatment remain largely unknown. Here, we aim to elucidate several key factors to begin to determine the extent of the psychosocial impact on individuals over time with CL/P as well as the effectiveness of CL/P corrective treatment in improving these outcomes.

Children and teens with CL/P commonly report teasing in relation to their speech and appearance.<sup>6</sup> Teasing has a strong association with development of anxiety, depression and loneliness.<sup>7</sup> These childhood experiences with teasing and bullying have been associated with an earlier onset of anxiety disorders and social-phobias in adulthood.<sup>8</sup> This raises several key questions: Do treated adults who have CL/P experience a higher rate of psychosocial and social difficulties? Does CL/P orthodontic and surgical treatment improve psychosocial outcomes? Does treatment satisfaction, appearance satisfaction and functional satisfaction correlate with improved social outcomes?

Treatment of CL/P is multidisciplinary in nature. Surgical care typically involves surgical lip repair, cleft palate soft tissue grafting, bone grafting of the palate and/or alveolar ridge and orthognathic jaw surgery. The timing and exact nature of surgical care is case and treatment center dependent. Orthodontic treatment typically begins prior to alveolar bone grafting around age 7 with different phases of treatment extending into early adulthood if orthognathic surgery is required. As case complexity and varied treatment approaches contribute to possible clinical outcomes and subsequent patient treatment satisfaction, we will analyze possible connections between patient perceived outcomes, treatment rendered and psychosocial outcomes.

## **Methods**

The selection criteria for this study included adult individuals (over 18 years old) with CL/P treated in the Children's Rehabilitation Services (CRS) program of Alabama. The CRS program renders comprehensive CL/P treatment funded through Alabama's Medicaid program.

Additionally, inclusion in this study requires the individual to have completed their final planned surgical and orthodontic care for at least 1 year, and must have completed at least 1 phase of orthodontic treatment. Those fitting these criteria were contacted and invited to complete the electronic informed consent, instructions, and study questionnaire. Participants were offered \$25 in compensation for completion and return of the study materials. Information collected includes general demographic information, basic social status information, cleft treatment outcome satisfaction assessment and social and psychosocial assessments.

### **Assessment of treatment satisfaction and oral health quality of life in patients with cleft lip and palate**

One of the key factors when assessing treatment outcomes is the patient's own perceived satisfaction with the treatment. Overall satisfaction was assessed utilizing an adjusted version of the Kiyak patient satisfaction questionnaire (Table 1).<sup>9</sup> This was accomplished using a 7-point Likert scale. Specific aspects of treatment outcomes were assessed using Noor and Musa's Cleft Evaluation Profile with a 7-point range Likert scale (Table 2).<sup>13</sup>

Table 1. Kiyak's Cleft Patient Satisfaction Questionnaire
If you had to make the decision again, how likely would you be to undergo the same treatment?
Considering everything, how satisfied are you with the results of your treatment?
How likely would you now be to recommend the same treatment to others?

Table 2. Noor and Musa's Cleft Evaluation Profile	
How satisfied are you with:	Very satisfied – Very Dissatisfied
Speech:	1 2 3 4 5 6 7
Hearing:	1 2 3 4 5 6 7
Appearance of the teeth:	1 2 3 4 5 6 7
Appearance of the lip:	1 2 3 4 5 6 7
Appearance of the nose:	1 2 3 4 5 6 7
Breathing through the nose	1 2 3 4 5 6 7
Profile of the nose:	1 2 3 4 5 6 7
Bite:	1 2 3 4 5 6 7

To assess patients' current oral health quality of life (OHQL), the validated and widely utilized Oral Health Impact Profile (OHIP5) will be used (Table 3). This will assess current levels of discomfort, oral function, appearance, and impact on daily life.

Table 3. Oral Health Impact - 5					
Rank Scale:	Never	Hardly Ever	Occasionally	Fairly Often	Very Often
Do you have difficulty <u>chewing</u> any foods because of problems with your teeth, mouth, dentures or jaw?					
Do you have painful aching in your mouth?					
Do you feel uncomfortable about the appearance of your teeth, mouth, dentures or jaws?					
Do you feel that there has been less flavor in your food because of problems with your teeth, mouth, dentures or jaws?					
Do you have difficulty doing your usual jobs because of problems with your teeth, mouth, dentures or jaws?					

**Assessment of social and psychosocial outcomes and improvements with treatment in cleft lip and palate patients**

Individuals with CL/P often experience teasing and/or bullying, accompanied by decreased self-esteem and increased negative appearance evaluation.<sup>14</sup> These factors have commonly been associated with negative impacts on psychosocial wellbeing.<sup>7,8,15</sup> Here, we analyzed the association between perceived treatment outcomes and levels of anxiety, depression and social function. For this study, participants were asked to complete the PHQ8 for assessment of depression<sup>12,16</sup> (Sup Fig 1). Scores range from 0-24 with ranges of 5, 10, 15, and 20 corresponding to mild, moderate, moderately severe, and severe respectively. For anxiety, the GAD7 assessment was used with scores ranging from 0-21, with severity ranges of 5, 10 and 15 corresponding to mild, moderate, and severe anxiety symptoms respectively<sup>17</sup> (Sup Fig 2). Social function was assessed using the Social Functioning Questionnaire (SFQ).<sup>11</sup> Scores for this assessment range from 0-24 points, with a score of 10 or more representing poor social function (Sup Fig 3).

## Results

The initial pool of patients for this study included 52 patients (CRS patients treated in the UAB Department of Orthodontics Faculty Practice). After screening for inclusion criteria – 25 met the criteria with 14 completing the questionnaire (response rate 56%).

Figure 1

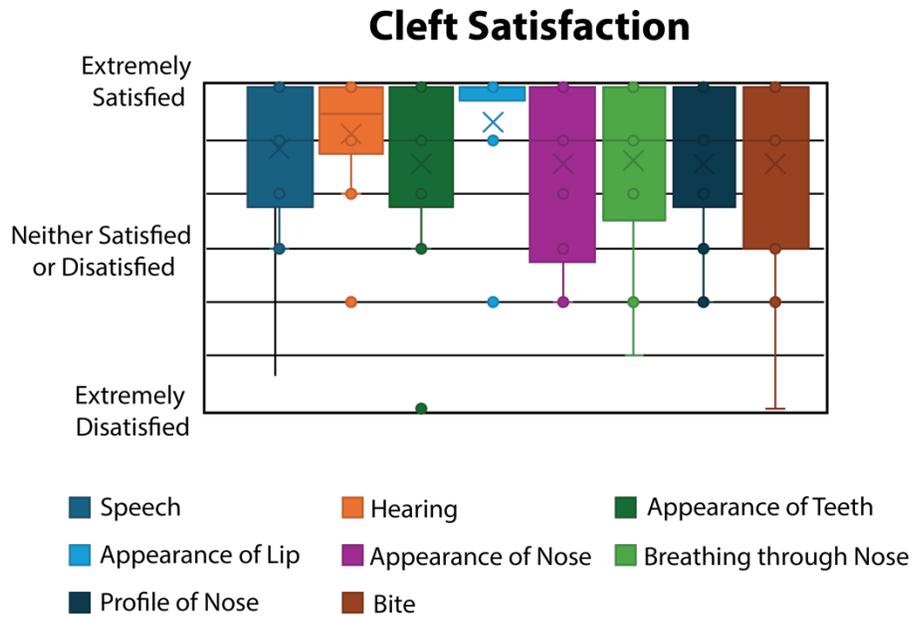
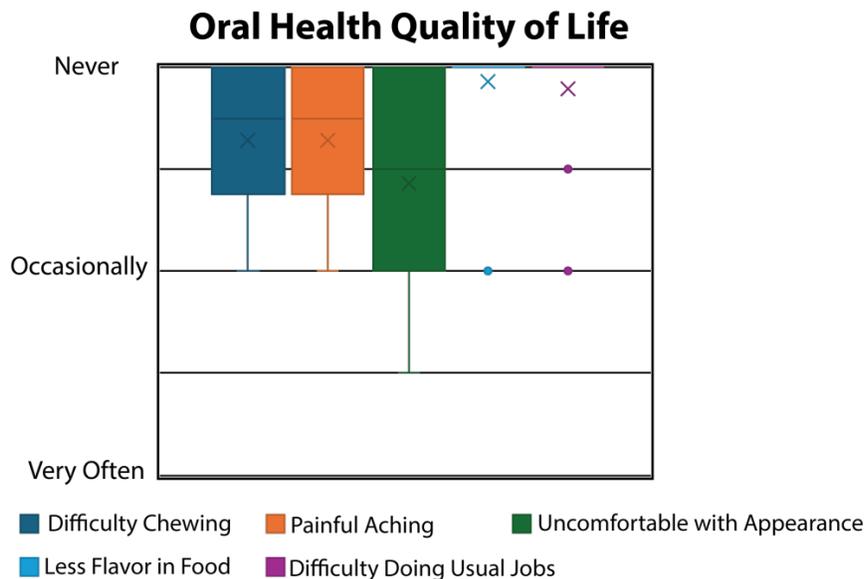
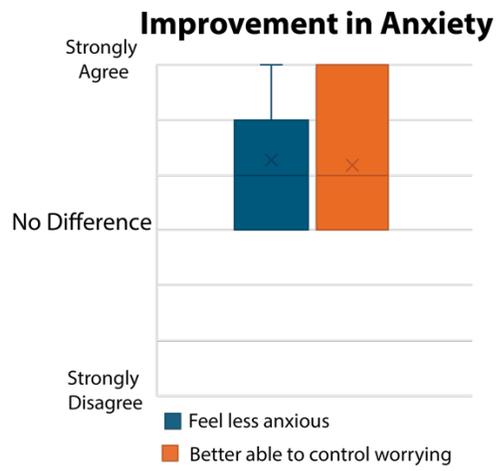


Figure 2







### Conclusions

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