

THE EXAMINATION OF THE RELATIONSHIP BETWEEN POST-TRAUMATIC
GROWTH, PERCEIVED STIGMATIZATION, AND FACIAL APPEARANCE
SATISFACTION AMONG ADULTS WHO ARE BORN WITH
CLEFT LIP AND OR PALATE

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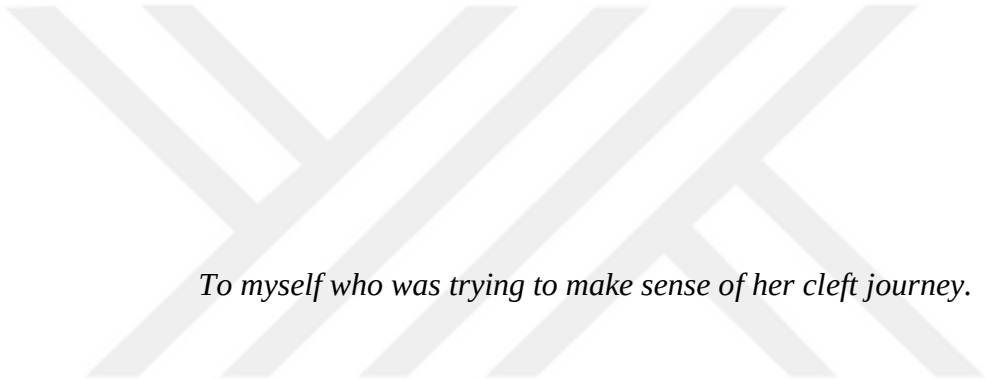
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To myself who was trying to make sense of her cleft journey.

ABSTRACT

Previous research shows a link between stigma and well-being; however, the addition of post-traumatic growth (PTG) remains unstudied in craniofacial literature. This study investigated the relationships between perceived stigmatization, the five dimensions of PTG, and facial appearance satisfaction in 146 adult people who were born with cleft lip and palate using decision trees to uncover the underlying cut-points and complexities. The sample was divided equally into training and test samples. The training sample accounted for 41% of the variance, and the replicated test sample accounted for a 36% percentage of variance in facial appearance satisfaction. As expected, in contrast to the negative relationship between perceived stigma and facial appearance satisfaction, the combined five dimensions of PTG had a positive relationship with facial appearance satisfaction. People with lower perceived stigmatization and higher PTG had the highest facial appearance satisfaction, whereas people with higher perceived stigmatization and lower PTG had the lowest facial appearance satisfaction. By utilizing tree algorithms, important thresholds were discovered, and while all PTG dimensions were able to enter the model, only average PTG emerged as an important predictor in both paths. In clinical practice, to promote PTG and decrease perceived stigmatization, age-appropriate support groups can provide a safe space for individuals to connect with others who have undergone similar experiences. Also, narrative therapy may be an effective tool for PTG.

ÖZET

Önceki araştırmalar damgalanma ile refah arasında bir bağlantı olduğunu gösteriyor ancak bunun travma sonrası büyümeyle ilişkisi henüz araştırılmamış. Bu çalışmada, karar ağaçları kullanılarak dudak damak yarığı ile doğmuş 146 yetişkin dikkate alınarak algılanan damgalanma ile yüz görünümü memnuniyeti arasındaki negatif ilişki ve travma sonrası gelişim ile pozitif ilişkisi araştırılmıştır. Eğitimde örnek, örnekte yüzde kırk birlik bir varyansı açıklarken, test örneği yüz görünümü memnuniyetinde yüzde otuz altı varyansı açıklamaktadır. Beklenildiği gibi algılanan damgalanma ile yüz görünümü memnuniyeti arasındaki negatif ilişkinin aksine, travma sonrası büyümenin yüz görünümü memnuniyeti ile pozitif bir ilişkiye sahip olduğu bulunmuştur. Algılanan damgalanma düzeyi düşük ve travma sonrası gelişimi yüksek olan kişiler en yüksek yüz görünümü memnuniyetine sahipken, algılanan damgalanma düzeyi yüksek ve travma sonrası gelişimi düşük kişiler en düşük yüz görünümü memnuniyetine sahiptir. Klinik uygulamada, travma sonrası büyümeyi teşvik etmek ve algılanan damgalanmayı azaltmak için yaşa uygun destek grupları, bireylerin benzer deneyimler yaşayan diğer kişilerle bağlantı kurması için güvenli bir alan sağlayabilir. Ayrıca öyküsel terapi travma sonrası büyümeyi teşvik etmede etkili bir araç olabilir.

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LIST OF ABBREVIATIONS

CL/P : Cleft Lip and Palate
PTG : Post-Traumatic Growth



CHAPTER 1

INTRODUCTION

The face is undeniably one of the most crucial factors in social interactions. It plays a vital role in communicating, expressing identity, and conveying emotions, making it an essential component of human interaction (Singh et al., 2020). Congenital facial conditions can significantly impact people's lives and lead to psychosocial challenges (De Sousa et al., 2009). One of the most prevalent craniofacial conditions is cleft lip and palate (CL/P), which can affect an individual's physical appearance and cause psychological distress (Chuo et al., 2008; Sinko et al., 2005; Stock et al., 2016). Worldwide, one in 600–700 babies are affected with CL/P (Moreira and Bernaola-Paredes, 2020). According to Berkowitz (2006) and Alansari et al. (2014), multidisciplinary treatment for craniofacial defects often starts in the first month of birth and lasts until late adolescence.

Throughout this phase, people with CL/P may encounter some difficulties that are either directly or indirectly related to their cleft (Ardouin et al, 2020; Zeytinoglu & Davey, 2012). Dealing with others' reactions is one of the most frequently mentioned difficulties for people with CL/P. According to studies by Chapados et al. (2000), Stock et al. (2016), and Faulkner et al. (2021), this can include gazing, comments, improper inquiries, or taunting. These actions can be overt, such as evident staring or teasing, or they can be covert, such as avoiding eye contact and these circumstances may stigmatize people with CL/P (Arias-Uruea et al., 2023; Bous et al., 2021; Kimotho & Macharia, 2020; Masnari et al., 2012). According to Hanzawa et al. (2012), stigmatization is the negative assessment of an individual or group based on traits like sickness, ethnicity, substance addiction, or physical

handicap. Perceived stigma refers to a situation where an individual feels marked or excluded negatively in the eyes of others (Mickelson, 2001). Individuals who experience stigma throughout their lives often internalize these experiences and tend to feel different or unaccepted. These negative experiences may also increase shame and lead to social withdrawal (Strauss et al., 2007). Additionally, many researchers report that individuals born with CL/P can experience a high level of dissatisfaction with their facial appearance (Cochrane and Slade, 1999; Rumsey et al., 2004; Rumsey and Stock, 2013). Since appearance is a crucial aspect of self-concept, negative social experiences like stigma can adversely affect subjective appearance evaluations and individual perceptions (Crerand et al., 2020; Stock and Feragen, 2016).

However, the conflicting results of studies suggest that the degree and direction of the impact of CL/P on a person's life are not definitively determined due to the multifaceted nature of the condition (Feragen & Stock, 2018; Havstam et al., 2011; Hunt et al., 2005; Rumsey & Stock, 2012; Straus, 2001). Some individuals can gain new perspectives when faced with their challenges. Those who have difficulties with aesthetics and appearance may begin to evaluate the concepts of beauty and uniqueness differently. They can potentially turn a negative situation into a positive one such as by increasing their empathy for others and strengthening their character, and coping skills (Cochrane and Slade, 1999; Oka et al., 2022).

Post-traumatic growth (PTG) is a concept that highlights the possibility of individuals experiencing a positive transformative process following negative and challenging experiences (Michael & Cooper, 2013). It is both a process and an outcome in the lives of individuals who can cope with challenges like the loss of a

loved one, chronic illness, accidents, or natural disasters (Tedeschi & Calhoun, 2004). More concretely, people can discover inner strengths, derive meaningful lessons, or transform these adverse experiences into new meaningful opportunities. Through this process and outcome, individuals develop stronger self-esteem, better stress management skills, deeper relationships, new perspectives, and more meaningful life goals to build a stronger psychological foundation (Calhoun & Tedeschi, 1999).

In this framework, individuals can enter the process of growth by accepting their biological characteristics, emotionally maturing, and drawing strength from their social support network. Individuals with CL/P may also enter the process of growth by learning to overcome their negative experiences in their childhood and developing adaptation skills (Eiserman, 2001; Searle et al., 2017). Anyone who has an appearance difference may find it easier to value their family and occupations over their appearance, which may lead to greater happiness (Strauss & Fenson, 2005; Thompson & Broom, 2009). Choosing challenging experiences as an opportunity for growth may contribute to a more positive relationship with their facial appearance, unlike the ones who adopt a negative view of their experiences such as stigma. It is reasonable to assume that PTG and perceived stigmatization have an opposite and significant relationship with facial appearance satisfaction.

This study aims to investigate the correlation between perceived stigma, PTG, and its various dimensions, such as new opportunities, improved relationships, personal resilience, spiritual development, and appreciation of life, on facial appearance satisfaction among adults with CL/P. Investigating this unstudied relationship may enhance our understanding of the role PTG plays in this

relationship, and the findings may guide future clinical practice and psychological interventions to better support this population.



CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. Cleft Lip and/or Palate (CL/P)

A CL/P is a birth defect characterized by an opening in the upper lip or roof of the mouth, resulting from when a newborn's facial structures do not fully close during development (Jugessur et al., 2009). CL/P is the second most prevalent congenital craniofacial defect in the world, occurring in roughly one in 600 babies (Chung et al., 2019). The most frequent diagnosis, according to Vlahovic et al. (2017), is CL/P, which is followed by isolated cleft palate and lip. Unilateral clefts appear to occur more frequently than bilateral clefts (Gómez & Puerto, 2018).

The complex etiology of CL/P is the result of a combination of genetic and environmental factors. Genetic research has connected various genetic origins to congenital malformations (Khan et al., 2020). According to Alois and Ruotolo (2020), CL/P can manifest as alone birth abnormalities or in conjunction with hereditary genetic diseases or syndromes. Furthermore, environmental factors such as vitamin deficiencies, maternal smoking, alcohol consumption, substance use, and exposure to chemicals have been linked to the onset of CL/P. CL/P is a condition whose development is influenced by the interaction of hereditary and environmental variables (Bezerra et al., 2015).

Factors such as geographical influence, ethnic elements, and gender affect the incidence of the anomaly. Oral and maxillofacial surgeons, plastic surgeons, orthodontists, dentists, speech pathologists, and several other professionals must work together to manage CL/P (Emam et al., 2021). Surgical interventions are a

prevalent course of action for CL/P and are usually undertaken at approximately six months of age (Alonso & Amundson, 2018).

CL/P exerts a substantial influence on multiple facets of a person's life, encompassing physical, emotional, and social aspects. CL/P can give rise to difficulties in speech, hearing, nutrition, and psychosocial domains (Alois & Ruotolo, 2020; Korkmaz et al., 2021). Among these difficulties, it is observed that individuals with CL/P frequently encounter social stigma (Strauss, 2007).

During childhood, most people can feel different due to cruel comments, and unwanted questions from peers (Oka et al., 2022; Nicholls et al., 2018; Alansari et al., 2014). The literature heavily focused on children's experience of being rejected or teased by their peers and having a problem with visible differences (Brunner et al., 2014; Chapados et al., 2000; Chetpakdeecheit et al., 2009; Havstam et al., 2011). Individuals who experience teasing or bullying mostly in their childhood may carry a negative self-perception throughout adulthood (Alansari et al., 2014; Oka et al., 2022).

2.2. Perceived Stigma

Stigmatization refers to the unfavorable assessment of a person or a group based on characteristics such as illness, ethnicity, substance abuse, or physical impairment (Hanzawa et al., 2012). Stigma is a social and powerful process characterized by prejudice, stereotyping, labeling, segregation, discrimination, and power loss. Stigma refers to the sociocultural process where non-conforming groups in society are labeled as abnormal, shameful, or undesirable, rather than referring to inherent moral flaws in individuals or groups. It is stressed as a result that stigma is

connected to the group of people that a person belongs to rather than the person themselves (Jones & Corrigan, 2014).

Fundamentally, stigmatization revolves around "differences," which are rooted in prejudices, biases, and exclusionary behaviors directed toward specific people or groups. These disparities include characteristics and actions that cause others to feel uneasy, repulsed, hostile, or afraid owing to things like physical appearance, age, gender, personality, sexual orientation, health, or disability. Mason et al. (2001) claim that the creation of a boundary that might divide people into a "us versus them" paradigm is the fundamental component of stigmatization. Once this idea is adopted, stigmatization takes place. Through the differentiation of people or social groups through the denigration of the individual, this process starts to highlight the "us versus them" paradigm. By rendering them into a damaged, tarnished, and worthless personality, stigmatization isolates the individual from their social surroundings (Thachuk, 2011). People who are subjected to stigmatization throughout their lives frequently internalize these experiences and believe they are stigmatized (Strauss et al., 2007).

On the other hand, the idea of perceived stigma includes a person's perceptions of the unfavorable attitudes that others may have about a particular conduct (Corrigan, 2000; Jacoby, 1994). Additionally, perceived stigma may be linked to social engagement restrictions (MacDonald, 1984; Devins et al., 1994) and unfavorable interactions within a community (Meyer, 2007). Vigilance and perceived stigma are positively correlated. In other words, the requirement for caution while interacting with members of the dominant group grows as the level of perceived stigma rises (Gardner, 1991). People who experience higher levels of stigma may

alter their behavior to prevent unfavorable responses from other members of society, frequently choosing to avoid public places (Hing et al., 2016; Lloyd, 2013).

Furthermore, stigmatized people or groups may decide not to be present in unwelcoming surroundings to avoid potential negative views from others (Fraser et al., 2020).

2.2.1. Perceived Stigma and CL/P

The phrase "perceived stigma" is associated with those who have CL/P or other congenital physical deformities. In particular, a CL/P can physically alter the face significantly (Stock & Feragen, 2016). As a result of this difference, individuals with CL/P may stand out in society and draw others' notice. People may feel different or isolated in society as a result, which can lead to feelings of perceived stigma (Hamlet & Harcourt, 2015). In addition, people with CL/P may come across negative social interactions including harsh looks, curious questions, or critical remarks. These events may exacerbate the stigmatization perception and cause people to feel anxious in public (Arias-Uruea et al., 2023).

Rumsey and Harcourt (2004) proposed that children who stand out physically are more likely to have negative social interactions and may be the target of negative social feedback. In this situation, people with CL/P frequently have to deal with other people's overt or covert reactions, such as looks, comments, inappropriate inquiries, or taunting (Feragen & Stock, 2018; Havstam et al., 2011; Roberts, 2014). People with CL/P may get stigmatized as a result of these encounters (Masnari et al., 2012; Noor & Musa, 2007; Strauss et al., 2007). Parents and children aged 11 to 18 with CL/P were regularly reported to experience stigmatization in Strauss et al.'s (2007) cross-cultural study. Negative encounters included individuals looking at their faces,

hearing others make comments around their faces, and feeling avoided (Strauss et al., 2007). In a study conducted by Sarwer et al. (1999) with 24 grown-ups with CL/P matched with a control group by age and sex, CL/P members detailed encountering a tall degree of separation in different social settings. A majority of participants (71%) declared that others stared at them or looked away from them in public settings. Reported problems included difficulty finding romantic partners, friends, employment, and experiencing negative comments about their cleft (Sarwer, 1999).

A study conducted by Masnari et al. (2012) found that children with different facial features were more likely to be stigmatized than their peers. According to Masnari et al., (2012), 25% of the participants revealed that they've been subjected to teasing about their looks and a majority of them revealed having staring and pity expressions from others. In another study, 75% of the participants reported being teased related to their cleft condition (Noor and Musa, 2007). In another study conducted with 93 Australian adults, a minority of the participants revealed that they encounter discrimination almost every day. Higher discrimination was related to low facial appearance satisfaction and lower levels of self-esteem (Roberts, 2014).

2.3. Facial Appearance Satisfaction among CL/P Adults

People with CL/P frequently experience low satisfaction with their facial appearance, which is one of the conditions' effects (Rumsey et al., 2004; Thompson & Kent, 2001). For instance, adults with CL/P expressed significantly greater dissatisfaction with their facial appearances, particularly with visible scars, nose, lips, mouth, and upper profile-related features, compared to a control group of 68 adults without CL/P (Marcusson et al., 2002).

Participants with CL/P reported less satisfaction with their facial appearance than those in the control group, in a different study by Sarwer et al. (1999). A significant percentage of participants in earlier studies reported not feeling satisfied with their facial appearance (Chuo et al., 2008; Rumsey et al., 2004; Thompson & Kent, 2001; Van Lierde et al., 2012). Therefore, it is evident that social stigmatization and unhappiness with facial appearance may be common among patients with CL/P.

Some studies look at the difficulties and psychosocial impacts of CL/P especially in childhood period, but it's important to remember that the results of these studies can vary and that there is no definitive way to say whether or not people with CL/P experience significant problems with stigma or are satisfied with their facial appearance. The severity of the problem, the cultural and social environment, an individual's resiliency, and the standard of medical care received are just a few of the variables that can affect how people with CL/P feel about their condition. For example, Hunt and colleagues (2005) looked into the opinions of dentists, parents, and kids with CL/P in their study. It turns out that kids with CL/P typically have good self-perceptions, and parents and experts tend to judge them more harshly than the kids do when it comes to looks. In another study, according to Starr (1978), people who did not view having CL/P as a problem had substantially higher levels of self-acceptance. Leonard et al. (1991) conducted a study with children and adolescents with CL/P. A self-concept scale, a few demographics, and several medical factors were used to examine the self-concept of 105 children and teenagers with CL/P. The majority of participants (98%) had self-concept scores that were average or above average, according to the results. Feragen et al. (2016) conducted a

study to understand how teenagers with CL/P perceive romantic attraction. The study found that self-reported happiness with facial features that were directly affected by CL/P had no impact on self-perceived romantic attraction. Similarly, self-reports of romantic attractiveness were unaffected by the 'objective' or self-perceived appearance of the fissure.

2.3.1. Perceived Stigma and Facial Appearance Satisfaction

It is noted that experiences of stigmatization have a significant relationship with the short-term and long-term psychosocial issues of individuals (Hunt et al., 2005). People may develop and carry these perceptions when they believe that they are the target of discrimination due to their physical characteristics, race, gender, age, sexual orientation, or another attribute (Cooney et al., 2006). Such impressions can have a negative effect on a person's emotional health (Moses, 2010), self-esteem (Crocker and Wolfe, 2001), and self-worth (Park and Crocker, 2008). People with CL/P have a physical difference in their faces from birth. Some people may act biased or stigmatizingly toward these persons as a result of their differences. These people might experience perceived stigma from society more frequently (Adeyemo et al., 2016; Masnari et al., 2012; Oka et al., 2022). Evaluations of individuals with CL/P regarding their satisfaction with their facial appearance depend not only on corrective surgeries but also on their experiences (Sarwer et al., 1999). Since appearance is an important aspect of self-concept, negative social experiences like stigmatization can negatively impact the subjective appearance evaluations of individuals with facial differences (Crerand et al., 2020; Feragen & Stock, 2016; Lovegrove & Rumsey, 2005).

In a study with 69 CL/P children aged 11 to 18 in Japan, it was discovered that experiences of stigmatization because of facial abnormalities may have a detrimental impact on one's perceptions of facial differences (Oka et al., 2022). As a result of poor self-evaluations brought on by perceived stigmatization, people with CL/P may be less satisfied with their facial appearance in this situation (Marcusson et al., 2002; Rumsey et al., 2004). Limited studies have demonstrated that perceived stigmatization is associated with lower facial appearance satisfaction in individuals with CL/P (Alansari et al., 2014; Hunt, 2005; Hunt et al., 2006; Hunt et al., 2007; Sarwer et al., 1999). For instance, 24 persons with CL/P and a control group that was age- and gender-matched were divided into two groups in research by Sarwer et al. (1999). In comparison to the control group, CL/P individuals reported feeling more stigmatized in a variety of social circumstances and being less satisfied with their facial appearance (Sarwer et al., 1999).

Hunt and colleagues conducted two studies in 2006 and 2007. The initial study encompassed 160 individuals aged 8 to 21 with CL/P, along with 113 individuals forming a control group. In this study, persons with CL/P expressed less satisfaction with their facial appearance and more frequent experiences of stigmatization compared to the control group (Hunt et al., 2006). Similar results were obtained from the second trial, which included parents of children with CL/P and parents of children without CL/P. In comparison to parents in the control group, parents of children with CL/P stated that their children experienced stigmatization more frequently and were less satisfied with their facial appearance (Hunt et al., 2006). Additionally, it was discovered in both research that stigmatization experiences

among CL/P individuals were a strong predictor of unhappiness with facial appearance (Hunt et al., 2006, Hunt et al., 2007).

Alansari et al.'s (2014) qualitative study in Canada included extensive semi-structured interviews with 11 persons with CL/P. Some participants reported feeling vulnerable to negative emotions such as feeling defective, demoralized, unworthy, different, and concerning how others perceive them which could be associated with perceived stigmatization as a result of past negative social experiences in their childhood. On the other hand, some participants also described their treatment process were a chance to build strong relationships with family members, and doctors. Moreover, some participants mentioned that going through the surgeries gave them a kind of personal strength and showed interest in other directions of their lives rather than their condition. All of them may be in line with personal growth (Alansari et al., 2014).

2.4. Post-Traumatic Growth

Individuals with CL/P can experience various challenges that may directly or indirectly relate to their clefts (Eisermann, 2001; Baker et al., 2009; Zeytinoğlu & Davey, 2012). However, while some individuals can adapt well and cope with the challenges of living with craniofacial conditions, others may face difficulties (Feragen & Stock, 2016; Ridley, 2020; Stock et al., 2016). Due to its multifaceted nature, the degree and direction of its impact on an individual's life are not definitive (Havstam et al., 2011; Hunt et al., 2005; Roberts, 2014; Rumsey & Stock, 2012; Strauss, 2001).

In this context, some studies with individuals with CL/P have yielded unexpected results. For instance, a study conducted by Bjornsson and Agustsdottir

(1987) found that CL/P had no impact on the psychosocial well-being of adolescents and adults and that they exhibited high psychosocial adaptation. Similar findings were made by Patel and Ross in their qualitative study from 2003, in which 16 out of 20 participants said that having CL/P at birth had little impact on their social lives. No statistically significant difference in satisfaction with appearance was detected between the two groups in a study by Crerand et al. (2017) that included 70 teenagers with CL/P and a control group of 42 participants. Shapiro et al. (2015) conducted a study with 74 children with craniofacial conditions and found that their levels of satisfaction with facial appearance and overall body satisfaction were equal. These findings suggest that children do not evaluate their appearances based solely on visible facial differences such as a noticeable facial scar. In this context, the study emphasizes the need to explore the interaction between satisfaction with appearance and psychological functioning (Shapiro et al., 2015).

The differing findings in these studies suggest that some individuals with facial differences may develop certain positive aspects of reevaluating their life experiences and coping with negative experiences more optimistically (Cochrane & Slade, 1999; Stock & Rumsey, 2015; Strauss, 2001). Indeed, it is possible for a traumatic event to lead to personal growth and resilience, making an individual stronger than they were before. Many studies in this area have indicated the presence of perceived positive outcomes following traumatic events (Ramos & Leal, 2013). The researches frequently uses terms like post-traumatic growth (PTG), stress-related growth, perceived benefits, positive psychological alterations, growth, positive adaptation, and more to describe these beneficial changes. The phrase "positive changes experienced as a result of psychological and cognitive efforts made to

overcome challenging conditions" is most frequently used to refer to PTG in particular (Ramos & Leal, 2013). According to Calhoun et al. (2000), posttraumatic development refers to a significant positive change that occurs as a result of handling a serious life catastrophe. PTG is defined as an improvement in functionality brought on by the effort to cope with a traumatic experience. It denotes a metamorphosis or improvement in functionality that transcends a person's capacity to endure extremely demanding situations (Tedeschi & Calhoun, 2004).

The perspective that results from the subjective experiences of a traumatic incident fundamentally affects the development of PTG when considering individual characteristics. The case being traumatic is related to shattering an individual's assumption world, disrupting the cognitive schemas they have to make sense of the world. Traumatic events disrupt all these assumptions, leading individuals to question their positive beliefs about the world and their invulnerability. Following this, individuals need to engage in a cognitive process to restructure a devastating experience, ultimately leading to PTG (Tedeschi & Calhoun, 2004).

2.4.1. The Domains of Post-Traumatic Growth

PTG does not refer to growth in a single dimension. PTG, according to Tedeschi and Calhoun (2004), entails changes in five domains: spiritual change, personal strength, new possibilities, interpersonal relationships, and appreciation of life. The first dimension of PTG, personal strength, includes the perception of greater personal strength, recognizing increased abilities to deal with future difficulties, and even the acknowledgment of being a more capable individual when compared to oneself before the trauma. The person clearly distinguishes that they possess more skills and power than they did before the traumatic event.

In the second PTG dimension, new possibilities, the person finds fresh alternatives in all facets of life when overcoming adversity. A fresh outlook on life and a change in core values and presumptions are necessary to forge a new route in life that leads to opportunities and possibilities that weren't there before the trauma.

The third PTG dimension is relating to others. After a crisis, individuals may need to seek help and support from their family and friends to understand the traumatic experience, cope with stress, and deal with loss. The person may feel a higher emotional connection, intimacy, and sense of authenticity in their relationships as a result of sharing personal negative experiences with others. Later, the person may become more receptive to accepting help from others and better utilizing existing social networks or investing in new relationships. This can lead to a more flexible way of thinking about relationships. Thus, some relationships may weaken or even end, and some relationships may become more meaningful for the individual.

The fourth PTG dimension is appreciation of life which involves encountering a traumatic event result in recognizing one's vulnerability and realizing that certain life events cannot be predicted or controlled. As a result, the individual starts to change the importance they place on certain events; they may begin to pay more attention to things they previously considered insignificant or worthless. For example, they may find greater enjoyment in everyday life experiences. As a result, one changes their priorities in life and develops a deeper appreciation for it.

Finally, the fifth PTG dimension of spiritual growth encompasses experiencing high levels of stress that may cause one to question religious or spiritual matters, or personal spiritual development. Increased belief in a higher spiritual entity may occur

after the trauma. Additionally, this notion might function as a coping mechanism in the mind. However, it's important to note that even non-religious individuals can experience some degree of spiritual growth in this context. The extent of spiritual growth may vary among trauma survivors and depends on their pre-existing religious or spiritual affiliations (Ramos & Leal, 2013).

2.4.2. Post-Traumatic Growth, Perceived Stigmatization, and Facial Difference Satisfaction

As previously mentioned, individuals with CL/P can face numerous challenging life experiences due to their congenital physical differences, and these difficulties may result in detrimental psychological effects like experiencing stigma and being dissatisfied with their facial appearance (Alansari et al., 2014; Marcusson et al., 2002; Masnari et al., 2012, 2013; Noor & Musa, 2007; Roberts, 2014; Strauss, 2001; Strauss et al., 2007; Thompson & Kent, 2001; Van Lierde et al., 2012).

Additionally, perceived stigma can create negative self-evaluations in individuals with CL/P, leading to less satisfaction with their facial appearance (Marcusson et al., 2002; Rumsey et al., 2004). Numerous studies have shown that among people with CL/P, perceived stigma is linked to reduced satisfaction with facial appearance (Alansari et al., 2014; Crerand et al. 2020; Hunt, 2005; Hunt et al., 2006; Hunt et al., 2007; Sarwer et al., 1999).

On the other hand, contrasting findings have emerged in some studies involving individuals with CL/P, where participants did not exhibit differences in perceived stigma or facial appearance satisfaction, or they did not report psychosocial problems (Crerand et al., 2017; Patel & Ross, 2003; Roberts, 2014; Rumsey et al., 2004; Shapiro et al., 2015). The conflicting results from research

highlight that the degree and direction of the impact of CL/P on an individual's life are not definitive due to the multifaceted nature of the condition (Havstam et al., 2011; Hunt et al., 2005; Roberts, 2014; Rumsey & Stock, 2012; Straus, 2001).

For example, a study conducted by Cochrane and Slade (1999) with 51 adults with CL/P revealed interesting insights. The study examined how individuals perceived both positive and negative experiences related to their condition. Twenty-seven participants reported experiencing negative experiences, such as stigma, due to their condition, and they indicated that these experiences influenced their views of their CL/P. On the other hand, 36 participants reported that CL/P had a significant positive impact on their lives, contributing to qualities such as resilience, character development, increased empathy towards others, and becoming more compassionate and understanding. Furthermore, nine participants claimed that their condition motivated them to change their perceptions regarding important values and relationships in life, aligning with the characteristics of PTG (Cochrane & Slade, 1999).

In conclusion, living with craniofacial conditions presents different challenges for individuals, with some adapting well and coping effectively, while others may struggle (Feragen & Stock, 2016; Ridley, 2020; Stock et al., 2016). PTG can be used to understand how individuals with CL/P cope with challenges and undergo a positive transformation process. Within the scope of PTG, accepting and embracing visible differences, making peace with one's own body, surrounding oneself with supportive individuals like family and friends, and gaining empowerment can contribute to a positive self-image (Egan et al., 2011). By learning to overcome traumatic experiences and developing adaptation skills, individuals with CL/P can

enter a process of growth (Eiserman, 2001; Havstam et al., 2011; Searle et al., 2017). People with facial differences can highlight some positive aspects as they reevaluate their life experiences and cope with negative experiences more optimistically (Cochrane & Slade, 1999; Stock & Rumsey, 2015; Strauss, 2001). Those who live with any kind of physical difference may find that they can place more value on aspects of their lives such as career and family rather than focusing on external appearances, which can lead to a greater sense of satisfaction (Strauss & Fenson, 2005; Thompson & Broom, 2009). In this context, PTG may lead to less focus on the physical differences and thus, even higher facial appearance satisfaction in individuals with CL/P. Furthermore, higher PTG levels may be even more beneficial for those who have perceived the most stigma and thus the lowest facial appearance satisfaction.

2.5. Current Research

As stated above, previous research by Crerand et al. (2020) shows a negative association between stigma experience and facial appearance satisfaction. Furthermore, PTG is known to be positively associated with positive self-image (Egan et al., 2011); however, the relationship with stigma and PTG on facial appearance satisfaction remains unstudied. Thus, the current study aims to investigate the relationships of perceived stigma and PTG, including its five dimensions, on facial appearance satisfaction in individuals with CL/P.

This study further aims to explore whether there is a clinically significant threshold for individuals with perceived stigma when considering facial appearance satisfaction. Thus, analytic techniques to group individuals based on these cut points and their differences in terms of facial appearance satisfaction are needed. Using

decision trees, specifically the CHAID algorithm, data can be split into as many distinct groups as statistically needed (Cite). Unlike analyses using mean/median or quartile splits, segmentation into two or more groups is not decided by looking at the descriptive statistics, instead the data drives the analysis. After the first splits and if the resultant groups are significantly different, total PTG and its five dimensions may enter the model. Here unlike regression, tolerance is not a problem to overcome with including multiple PTG dimensions and the total score. Additionally, each group of individuals varying in stigma may be further divided by any dimension of PTG or the total PTG score those results in increased significantly different groups based on facial appearance satisfaction. This allows the emergence of different PTG dimensions at varying levels of perceived stigma which may have subsequent clinical implications. For instance, those low in stigma may benefit from the PTG dimension of relating to others, while those high in perceived stigma may have higher satisfaction scores when they also show higher levels of appreciation for life.

Thus, for clinical purposes, the study aims to explore the statistically significant thresholds for perceived stigma and the five dimensions of PTG, as well as the total PTG score, as they relate to facial appearance satisfaction. While there are no specific hypotheses about cut points or which PTG variables will be significant, there are two expected main effects that increased perceived stigma will be related to lower levels of facial appearance satisfaction, and that if PTG or its dimensions enter the model, higher levels of those variables will be associated with higher levels of facial appearance satisfaction.

CHAPTER 3

METHODOLOGY

3.1. Participants

The participants were recruited with snowballing sampling via social media and cleft lip and palate-related online support groups. Participation was voluntary. The inclusion criteria for participation were having a cleft lip or cleft lip and palate without any other birth condition, being over 18 years old, and understanding English. The exclusion criteria were having any other chronic condition. In the sample of 146 adults born with cleft lip and/or cleft palate, 86 were identified as women, 55 as men, and 5 as nonbinary. The age range of the participant was between 18 to 40 ($M=26.15$, $SD=5.82$).

3.2. Procedure

Before data collection, the research received approval from the Özyeğin University Human Research Ethics Committee. Participants were contacted via email and WhatsApp. Before the survey administration, participants were provided with an informed consent form (Appendix A). The informed consent form included information about the purpose of the research and emphasized the voluntary nature of participation. Additionally, participants were informed that no personal identifying information would be collected, that anonymously gathered data would be kept strictly confidential and not shared with third parties, that the data would be used solely for scientific purposes, and that they could withdraw from the research at any time. Contact information for the researcher was also provided for any further inquiries from participants.

Following these explanations, participants provided voluntary consent to participate in the research. Research data was collected online using the researcher's Qualtrics account. The collected data was downloaded in XLS and sav formats and securely stored on the researcher's personal computer with password protection. IBM SPSS v26 software was utilized for the analysis of the obtained data.

3.3. Measures

In the research, primary data was collected using a four-section online survey form that included a demographic information form, a perceived stigmatization questionnaire, cleft-q – the appearance of the face, and the post-traumatic growth inventory. Information regarding the scales used in the research is provided below.

3.3.1. Demographic Information Form

The demographic information form prepared by the researcher includes two questions related to participants' ages and genders (Appendix B).

3.3.2. Perceived Stigmatization Questionnaire

Perceived stigmatization was measured using the perceived stigmatization scale developed by Lawrence et al. (2006). It includes 21 items, organized into three dimensions: absence of friendly behavior, confused/staring behavior, and hostile behavior. Participants respond to the items on a scale ranging from 1 (never) to 5 (always). A total of eight items (items 1, 5, 7, 9, 12, 15, 17, 20) are reverse-coded. A minimum of 1 and a maximum of 5 points can be obtained from the scale. The average score obtained from the scale reflects the level of perceived stigmatizing behaviors. In the original study, Cronbach's alpha coefficient for the scale was found to be .93 for the overall scale (Lawrence et al., 2006). In this study, internal consistency for the sample was found to be Cronbach's $\alpha = .79$.

3.3.3. The Post-Traumatic Growth Inventory

PTG was measured using the post-traumatic growth inventory developed by Tedeschi and Calhoun (1996). The scale includes a total of 21 items organized into five dimensions: personal strength, new possibilities, improved relationships, spiritual growth, and appreciation for life. Participants responded to the items on a scale ranging from 0 (not experienced) to 5 (very great degree). A minimum of 0 and a maximum of 5 points can be obtained from the scale. The average score obtained from the scale reflects the level of PTG.

In the original study, Cronbach's alpha reliability for the scale was found to be .90 for the overall scale (Tedeschi & Calhoun, 1996). For the five dimensions in the original study, the reliability coefficients for the scale were found to be .72 for the personal strength dimension, .84 for the new possibilities dimension, .85 for the improved relationships dimension, .85 for the spiritual growth dimension, and the appreciation for life dimension (Tedeschi & Calhoun, 1996). In this study, Cronbach's alpha reliability coefficients for the overall scale were found to be $\alpha = .91$, for the personal strength dimension $\alpha = .77$, for the new possibilities dimension $\alpha = .81$, for the improved relationships dimension $\alpha = .86$ for the spiritual growth dimension $\alpha = .85$, and for the appreciation for life dimension $\alpha = .72$.

3.3.4. CLEFT-Q – Appearance of the Face

Facial appearance satisfaction was measured using the facial appearance dimension of the CLEFT-Q scale developed by Klassen et al. (2018). The scale includes a total of 9 items, such as "*How much do you like how your face looks in photos?*" Participants respond to the items on a scale ranging from 1 (not at all) to 4 (very much). The sum of the responses is converted to a score between 0 and 100

using a conversion table, where higher scores indicate greater facial appearance satisfaction. In the original study, Cronbach's alpha reliability coefficients for the CLEFT-Q scale were found to range between .89 and .96 (Klassen et al., 2018). In this study, the Cronbach's alpha reliability coefficient for the scale was found to be $\alpha=.93$.

Table 1
Descriptive Statistics for Major Study Variables (N=146)

Scales	<i>M</i>	<i>SD</i>	Range (O)		Range (T)		Correlations	
			<i>Min</i>	<i>Max</i>	<i>Min</i>	<i>Max</i>	PTG	FAS
PS	2.31	0.66	1.05	4.14	1.00	5.00	-.176*	-.408**
PTG	67.54	17.77	0	100	0	105		.572**
FAS	44.45	20.68	0	100	0	100		

Note. PS = Perceived Stigmatization Scale, PTG = Post Traumatic Growth Scale, FAS = Facial Appearance Satisfaction. Range (O) = observed range, Range (T) = theoretical range

* Correlations significant at $p < .005$

** Correlations significant at $p < .001$

CHAPTER 4

RESULTS

4.1. Data Analysis

IBM SPSS 26 was utilized to conduct descriptive statistical calculations, correlations, and decision tree analysis on the dataset (IBM Corp, 2019). CHAID decision trees demonstrate complex variable relationships in a simple structure. Thanks to the CHAID decision tree algorithm, it was possible to group individuals with similar facial appearance satisfaction scores. The algorithm may either segment the sample using whichever factor yielded the highest F test value or the researcher can select the first variable manually. To increase validity, half of the participants were randomly assigned to the initial training group used to determine the tree structure, while the second half was assigned to test the replication of the initial design (Polat et al., 2008). To create a tree structure that is both concise and easily applicable to different scenarios, we applied the following partitioning rules: up to three levels were allowed, the parent nodes must contain at least 15 respondents, and child nodes had to contain at least 5 respondents. This study assessed the potential relationship between perceived stigmatization and PTG and its components on facial appearance satisfaction.

4.2. Descriptive Statistics

Participants reported a relatively low level of facial appearance satisfaction ($M=44.45$, $SD=20.69$ see Table 1 for descriptive statistics, theoretical and observed ranges). Furthermore, their average scores of perceived stigmas were relatively low to moderate ($M=2.31$, $SD=.66$). Overall, PTG scores were relatively moderate to high ($M=67.54$, $SD=17.77$).

4.3. Decision Tree

A CHAID decision tree was used to explore the relationship between perceived stigma, PTG and its five dimensions, and facial appearance satisfaction. As mentioned above, for replication purposes, the sample was randomly divided in two to create the training tree and the test tree (see Figure 1).

In the training tree, perceived stigma was chosen as the first variable, splitting the sample at the 2.48 level ($F[1,73] = 14.53, p < .005$), dividing participants into those with less than moderate levels of perceived stigma and those with moderate to high levels of perceived stigma. After this initial split according to perceived stigma level, the decision tree shows that those with low perceived stigma have 16 points higher facial appearance satisfaction than those with moderate to high perceived stigma. Participants with low levels of perceived stigma and scores less than or equal to 2.476 were further divided by degree of total PTG (split at 69.0; $F[1,43] = 11.45, p = .003$). Those with low levels of perceived stigma and high levels of total PTG had the highest facial appearance satisfaction score of 59.22 ($SD = 17.49$).

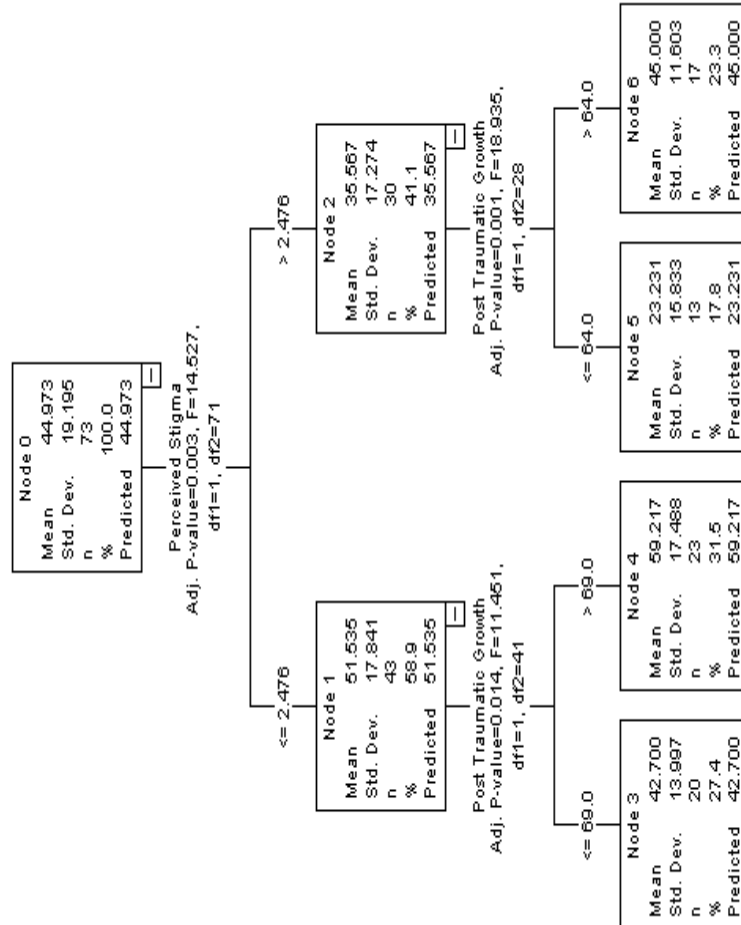
For the group with higher levels of perceived stigmatization, PTG was significant ($F[1,30] = 18.94, p = .001$). Those with higher levels of perceived stigmatization and lower levels of PTG had the lowest level of facial appearance satisfaction at 23.23 ($SD = 15.83$). This is 22 points lower than the group with higher levels of PTG and 36 points lower than those with low perceived stigma and high PTG. The training sample accounted for 41% of the variance in facial appearance satisfaction. It is important to note that, although they were allowed to enter the model, none of the five individual PTG factors emerged as important factors in the training model.

The anticipated facial appearance satisfaction scores in the replication using the second half of the data resembled the values in the training tree. Those with high perceived stigma and low levels of posttraumatic growth had the lowest facial appearance satisfaction, 22.21 ($SD = 24.99$). Those with similar levels of perceived stigma but high levels of posttraumatic growth had 28 points higher facial appearance satisfaction scores ($M = 50.21$, $SD = 17.10$).

Participants reporting lower perceived stigma and lower posttraumatic growth achieved a facial appearance satisfaction score of 39.75 ($SD = 15.18$). In the test tree, as in the training tree, participants with the lowest levels of perceived stigma and the highest levels of posttraumatic growth had the highest facial appearance satisfaction with a score of 59.12 ($SD = 15.83$). The test sample accounted for 36% of the variance in facial appearance satisfaction.

Test Sample

Facial Appearance Satisfaction



Training Sample

Facial Appearance Satisfaction

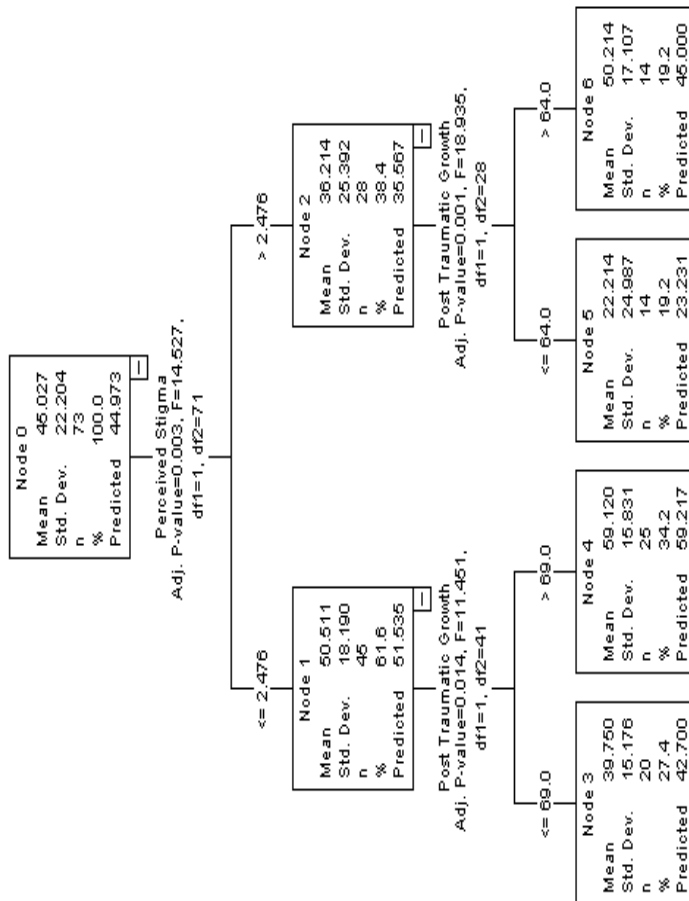


Figure 1
CHAID Decision Trees (N =14)

CHAPTER 5

DISCUSSION

5.1. Discussion of Findings

When the literature is examined; this study is the first study to examine the association between perceived stigmatization, PTG, and facial appearance satisfaction in individuals with CL/P. Furthermore, it is one of the few studies investigating clinical relationships using decision tree analyses. Overall the structure points to main effects, such that a high level of perceived stigmatization is related to low facial appearance satisfaction whereas high PTG is related to high facial appearance satisfaction. Furthermore, it uncovers significant thresholds of stigmatization and PTG associated with differences in facial appearance satisfaction.

Although no previous study examined the relationship between perceived stigma, PTG, and facial appearance satisfaction, one previous work (Cramer et al. 2020) found out negative relationship between perceived stigma and facial appearance satisfaction. Also, Roberts et al. (2014) established a negative relationship between perceived discrimination and facial appearance satisfaction. Thus, the existence of this negative relationship between perceived stigma and facial appearance satisfaction in this study is not surprising.

5.1.1. Perceived Stigma

Consistent with the study's hypothesis, individuals with high perceived stigmatization levels have lower facial appearance satisfaction levels. In the training sample, the low perceived stigma group has 16 points higher facial appearance satisfaction scores than the high perceived stigma group. In the test sample, the low stigma group has 14 points higher facial appearance satisfaction scores than the high

perceived stigma group. These results indicate that perceived stigma is an important indicator of satisfaction with their facial appearance. Perceived stigma can increase psychological distress, embarrassment, and shame which eventually result in negative self-evaluation of their facial appearance (Oka, 2022). Individuals also may compare themselves with society's beauty standards which leads to perceiving their flaws or differences more than it seems.

When the current situation of the sample is examined, it is observed that the mean perceived stigma score is 2.31 ($SD = 0.66$). This value is within one standard deviation of the original scale's mean value of 2.20 ($SD = 0.57$) (Lawrence et al., 2006). It is important to consider this when starting to examine the threshold of 2.48 chosen by the decision tree. Furthermore, the decision tree algorithm can optimally classify perceived stigma levels by selecting the cut-point and the number of cuts to categorize facial appearance satisfaction into groups. This suggests that the algorithm optimizes levels of facial appearance satisfaction by considering both the cut-point and number of cuts, instead of the researchers choosing these parameters (Fitzsimons, 2008). Although the relationship was in the expected direction, the threshold of 2.48 shows that, for those with CL/P, a higher than average score compared to both the original study's mean and the mean of the current study is associated with adverse facial appearance satisfaction. More research should be done with this sample to see if this is a clinically important threshold in the broad population of those with CL/P.

5.1.2. PTG

In this study, higher total PTG was related to high facial appearance satisfaction. In the craniofacial literature, this study is the first study to investigate

the relationship between PTG and facial appearance satisfaction. Considering the positive relationship between PTG and life satisfaction (Mostarac et al.,2021), and health-related quality of life (Senger et al.2023), in the current study PTG is positively correlated with facial appearance satisfaction. In the training sample, among the low perceived stigma group, people with high PTG have 17 points higher facial appearance satisfaction than people with low PTG. Among the high perceived stigma group, people with high PTG have 22 points higher facial appearance satisfaction than low PTG. In the test sample, among the low perceived stigma group there is 20 points difference in facial appearance satisfaction between low and high PTG. Among the high perceived stigma group, people with high PTG have 28 points higher facial appearance satisfaction than low PTG people. Thus across all groups, higher PTG levels were associated with elevated facial appearance satisfaction in different levels of perceived stigma. In the high perceived stigma group, total PTG makes the most difference in facial appearance satisfaction scores.

It is worth noting that only total PTG entered the model despite all dimensions being candidates for entry. Moreover, in the study, the different factors of PTG personal strength, new possibilities, improved relationships, spiritual growth, and appreciation of life have entered the model separately but the combination of dimensions of PTG as the average score was a better predictor in facial appearance satisfaction as the outcome variable. The reason for this finding may be that PTG manifests differently in different areas of life for each person.

It has been observed that individuals who have high perceived stigma and low PTG may develop negative feelings towards their facial appearance. Such individuals may require therapy to overcome these feelings. In clinical practice, clinicians should

strive to improve the overall PTG scores of their patients. This can be achieved by identifying the dimension of PTG with the lowest score and planning individual interventions based on those dimensions.

5.2. Limitations of the Study

The study is not without limitations, such as being cross-sectional and having a limited sample size. As all data were collected at the same time, causality cannot be inferred. Even though stigma experiences are mostly based on the 0-18 age period and facial appearance satisfaction increases over time (Hamlet and Harcourt, 2015) the current study focuses on how people with CL/P carry the stigma perceptions through the adulthood based on their experiences on earlier age. Thus, participants may be reflecting on past events. Longitudinal studies could measure stigma at an earlier point and assess facial appearance satisfaction in adults at a later time to aid with this directionality.

A further limitation lies in the fact that both stigma and PTG questions were not CL/P specific. However, during the informed consent it was noted that this study was only for participants with CL/P which was confirmed before they participation. Additionally, many participants were recruited through CL/P themed platforms. Directly measuring CL/P stigma and PTG growth could strengthen the current results. Another measure that could strengthen the study would be to include the surgery number of the participants and how satisfied they were with their results. This could serve as a control and would be important information to evaluate facial appearance satisfaction as the outcome variable.

Unfortunately in this study only 37% of the participants were male and slightly over 3% identified as non-binary. In the Crerand et al.(2020) study, it was

determined that women with craniofacial disorders experienced more body image disturbance and were less satisfied with their facial appearance. In this study, a more balanced gender distribution among participants will increase generalizability and provide stronger evidence of the relationship between gender and facial appearance satisfaction.

Finally, as participants were selected from the individuals identified through online channels and on a voluntary basis, the number of participants was 146 people. While the number may seem low, it is necessary to remember that one in 600 people are born with CL/P. Although this was the first study of its kind, future longitudinal studies with larger sample sizes, greater gender balance, and a few more CL/P specific features will contribute to the generalizability of the study.

5.3. Clinical Implications

Based on the study results, perceived stigmatization and PGT are two areas for clinical application. For those with cleft lip and/or cleft palate, growing up without knowing any other person with cleft lip and palate can be a common experience (Moi,2020). Since it is a rare health condition, people can feel lonely and different from their peers. To decrease perceived stigmatization and promote PTG, age-appropriate support groups can provide a safe space for individuals to connect with others who have undergone similar experiences. Collaborative understanding cultivates a feeling of togetherness and reciprocal assistance while it reduces feelings of isolation which is one of the premises of perceived stigmatization.

According to Ramos et al. (2017), psychosocial group interventions to enhance PTG among women with breast cancer gives a space for shared experiences and collaborative understanding which results in increased emotional disclosure,

challenges core beliefs and rumination, positive appraisals of negative events, cognitive processing, and social interaction. Encouraging emotional disclosure creates an environment where individuals feel safe expressing their feelings and experiences which can foster personal strength. Social interaction can increase improved relations and encourage individuals to recognize and celebrate their unique features apart from the cleft in their face can increase facial appearance satisfaction. Challenging negative core beliefs and positive appraisals of negative events can increase new possibilities and appreciation of life. In a supportive group setting, individuals may share positive affirmations about their facial features emphasize the diversity of appearances within the group and highlight the uniqueness of each individual's facial features as a valuable and integral part of their identity.

Additionally, Tedeschi and Calhoun (2012) suggest that individual therapies should adopt an existential-narrative framework which is a holistic understanding of an individual's experiences and challenges. Narrative therapy may be an effective tool for promoting PTG in various aspects. The idea behind narrative therapy is to explore individual stories and personal values. Individuals can separate their problems from their identity through externalization, which facilitates clearer recognition of their personal strengths. Reauthoring past experiences may help individuals reconstruct negative memories such as stigma experiences and interpret them in a new way. Also, finding moments in which they showed resilience can be used to overcome challenges in the present.

Reframing negative experiences, cherishing positive moments, and exploring alternative stories may create new possibilities and appreciation for life. Focusing on relational stories helps change the way they think about relationships, which

promotes and encourages healthier connections between people. Therapists can work collaboratively with individuals, using dynamic storytelling techniques to create narratives acknowledging growth and transformation over time. Although the authors suggest it, no intervention studies have been done. As overall PTG is important, such techniques and future studies can specifically target dimensions of PTG where the individual may have the least growth and could benefit the most from.

5.4. Conclusion

This study investigated the relationships between perceived stigmatization and PTG on facial appearance satisfaction using decision trees. Decision trees were used to find clinical thresholds for perceived stigma and PTG scores to group similar facial appearance satisfaction. They were also used to discover which PTG dimensions may be most associated with changes in facial appearance satisfaction for different levels of stigmatization. As expected, the overall relationship between perceived stigmatization and facial appearance satisfaction was negative. In contrast to the negative relationship between perceived stigma and facial appearance satisfaction, PTG was found to have a positive relationship with facial appearance satisfaction. People with low perceived stigmatization and high PTG have the highest facial appearance satisfaction whereas people with high perceived stigmatization and low PTG have the lowest facial appearance satisfaction. Although examined, overall PTG was a more important factor than any of its dimensions on their own. Hopefully future clinical interventions may utilize these novel findings to aid those with CL/P in increasing their facial appearance satisfaction and decreasing any subsequent factors associated with dissatisfaction.

APPENDICES

APPENDIX A

Ethics Board Application Form



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HUMAN RESEARCH ETHICS BOARD MEETING MINUTE

MEETING NO : 2023/12
MEETING DATE : 21.08.2023
APPROVAL CODE : 2023/12/02
MEETING ROOM : Özyeğin University
ATTENDEES : Prof. Dr. G. Canan Ergin
Dr. Öğr. Üyesi Ceren Hayran Şanlı
Dr. Öğr. Üyesi A. Nilay Şenol

HUMAN RESEARCH ETHICS BOARD APPLICATION FORM (FORM A)

Project Name	The Role of Positive Growth Between Perceived Stigma and Facial Appearance Satisfaction Among Adults with Cleft Lip/Palate
Project Manager	Kübra Kızıllırmak (Master's Thesis)
Project Manager's Contact Details	E-mail: Phone number:
Key Researchers	Thesis Advisors: Doç. Dr. Nilüfer Kafescioğlu & Dr. Senem Zeytinoğlu Saydam Contact Information:
Project Purpose and Summary	The study is carried out to investigate the aspect of living with a visible difference such as a CFA is repeated exposure to the social reactions of others, such as staring, comments, questions, or teasing (Rumsey & Harcourt, Citation2004). These can lead negative experiences with the condition including perceived stigma and decreased satisfaction with their facial appearance. (Crerand et al.,2020) Yet people can show growth while they are experiencing the negative experiences mentioned or later. According to the post-traumatic growth model, growth is both a result and a process (Tedeschi and Calhon,1999). How this growth will affect the relationship between perceived discrimination and facial appearance satisfaction is the focus of this study.

Research Methodology	Data will be collected with an online survey by Qualtrics. The questionnaire is in English. The survey contains questions regarding participant's age, gender as demographic information's. In the survey, 21-item Perceived Stigmatization (Lawrance et al.2006), 21-item Post Traumatic Growth scale (Tedeschi and Calhoun, 1999) 9 item Cleft-Q Appearance of the Face will be used. In total, the questionnaire has 53 items including gender and age questions. With the convenience sampling, researcher send survey to participants through social media platforms such as cleft lip and palate support groups, hospitals specializing in craniofacial care, online forums and social media groups dedicated to this community such as Cleft Proud which is largest support community. Participation in the study will be completely voluntary based. Information about voluntary participation, confidentiality, study purpose, will be shared with the participants at the beginning of the questionnaire. The participants don't have to sign any form or participate in the study. The consent information will be shared in the first page of online survey. They have the right to withdraw from the study at any time during the study without any penalty.
Ethics and Data Management Plan	No information about the identity of participant is requested in the survey except age and gender. The data will be kept confidential and only used for scientific purposes. The questionnaire will ask questions related to cleft lip/palate yet; if the participant feel uncomfortable for any reason during the answering the questions of survey, they can leave it. The collected data will be kept for the end of the study and then deleted. The results of our research will help individuals born with cleft lip/palate to better understand the difficulties they face in their lives and provide better support for their needs. Therefore, your participation is extremely valuable.
Participants	The inclusion criteria for participants to be eligible to participate in this study, having non- syndromic Cleft lip (CL), Cleft Palate

	(CP) or Cleft Lip and Palate (CL/P). Individuals who want to participate in the study should not be seen with any syndromic condition other than cleft lip and palate. In addition, to participate in the study, they must be at least 18 years old and have the ability to understand and communicate in English. Participants who do not meet these criteria will be excluded from the study.
Research Budget and Resources	No research budget or resources will be received for this study.

The Project “The Role of Positive Growth Between Perceived Stigma and Facial Appearance Satisfaction Among Adults with Cleft Lip/Palate” managed by Kübra Kızılırmak, a member of the Psychology Master’s Program, Couple and Family Therapy track at the Graduate School of Social Sciences at Özyeğin University has been reviewed.

- ☒ Ethical Approval is granted
☐ Amendment required
☐ Ethical Approval is declined

Signatures:

Prof. Dr. G. Canan Ergin
Chair

Dr. Öğr. Üyesi Ceren Hayran Şanlı
Member

Dr. Öğr. Üyesi A. Nilay Şenol
Member

APPENDIX B

Informed Consent Form

Dear Participant,

This research study is conducted by Kübra Kızılırmak, an M.A. student from Istanbul Özyeğin University Psychology Couple and Family Master Program under the supervision of Dr. Senem Zeytinoğlu Saydam.

The study is carried out within the scope of the master's thesis to investigate the role of positive growth between perceived stigmatization and facial appearance satisfaction among adults who are born with cleft lip, or cleft lip and palate. This online survey takes about 15 minutes. Your participation is entirely voluntary.

The inclusion criteria for participants to be eligible to participate in this study, are having non- syndromic Cleft lip (CL), or Cleft Lip and Palate (CL/P). Individuals who want to participate in the study should not be seen with any syndromic condition other than cleft lip and palate. In addition, to participate in the study, they must be at least 18 years old and have the ability to understand and communicate in English. Participants who do not meet these criteria will be excluded from the study.

No information about your identity (name, mail, etc.) is requested in the survey. The data will be kept confidential and only used for scientific purposes. This questionnaire will ask you to answer questions related to your cleft lip/palate yet; if you feel uncomfortable for any reason during the surveys requested to be filled during the research, you can leave it.

Thank you for your participation and contribution. The results of our research will help individuals born with cleft lip/palate to better understand the difficulties

they face in their lives and provide better support for their needs. Therefore, your participation is extremely valuable.

For more information about the study, you can contact the e-mail address:



APPENDIX C**Demographic Information Form**

1. Age: _____

2. Gender?

☐ Male

☐ Female

☐ Non-binary / third gender



APPENDIX D

Perceived Stigmatization Questionnaire

During your normal day, you probably see and talk to many different people.

We want to know how often people act in certain ways towards you. For each

question, rate how often people do certain things. Make your ratings about treated

you over the last year.

	1=Never	2=Almost never	3=Sometimes	4=Often	5=Always
1. People are friendly with me.	1	2	3	4	5
2. People call me names.	1	2	3	4	5
3. People avoid looking at me.	1	2	3	4	5
4. People I don't know act surprised or startled when they see me.	1	2	3	4	5
5. People are nice to me.	1	2	3	4	5
6. People don't know what to say to me.	1	2	3	4	5
7. People I don't know say "Hi" to me.	1	2	3	4	5
8. People laugh at me.	1	2	3	4	5
9. People are relaxed around me.	1	2	3	4	5
10. People feel sorry for me.	1	2	3	4	5
11. People pick on me.	1	2	3	4	5
12. People I don't know smile at me in a friendly way.	1	2	3	4	5
13. People don't know how to act around me.	1	2	3	4	5
14. People do "double takes" or turn around to look at me.	1	2	3	4	5
15. People are kind to me.	1	2	3	4	5
16. People bully me.	1	2	3	4	5
17. Strangers are polite to me.	1	2	3	4	5
18. People make fun of me.	1	2	3	4	5
19. People I don't know stare at me.	1	2	3	4	5
20. People treat me with respect.	1	2	3	4	5
21. People seem embarrassed by my looks.	1	2	3	4	5

APPENDIX E

Cleft-Q Appearance of the Face

How does your face look? Please answer thinking of how your face looks now.

How much do you like...	1= Not at all	2= A little bit	3= Quite a bit	4= Very much
1. ...how your face looks when you look your best?	1	2	3	4
2. ...how your face looks when you are ready to go out (like to a party)?	1	2	3	4
3. ...the shape of your face (e.g., round or oval)?	1	2	3	4
4. ...how your face looks in photos?	1	2	3	4
5. ...how well both sides of your face match?	1	2	3	4
6. ...how your face looks when you smile?	1	2	3	4
7. ...how your face looks when you laugh?	1	2	3	4
8. ...how your face looks from the side (your profile)?	1	2	3	4
9. ...how your face looks up closely?	1	2	3	4

APPENDIX F

The Post Traumatic Growth Inventory

Please indicate how much you experience the incidence.

	0=Not experienced	1=Very small degree	2=Small degree	3=Moderate degree	4=Great degree	5=Very great degree
1. I changed my priorities about what is important in life.	0	1	2	3	4	5
2. I have a greater appreciation for the value of my own life.	0	1	2	3	4	5
3. I have developed new interests.	0	1	2	3	4	5
4. I have a greater feeling of self-reliance.	0	1	2	3	4	5
5. I have a better understanding of spiritual matters.	0	1	2	3	4	5
6. I more clearly see that I can count on people in times of trouble.	0	1	2	3	4	5
7. I established a new path for my life.	0	1	2	3	4	5
8. I have a greater sense of closeness with others.	0	1	2	3	4	5
9. I am more willing to express my emotions.	0	1	2	3	4	5
10. I know that I can handle difficulties.	0	1	2	3	4	5
11. I can do better things with my life.	0	1	2	3	4	5
12. I am better able to accept the way things work out.	0	1	2	3	4	5
13. I can better appreciate each day.	0	1	2	3	4	5
14. New opportunities are available which wouldn't have been otherwise.	0	1	2	3	4	5
15. I have more compassion for others.	0	1	2	3	4	5
16. I put more effort into my relationships.	0	1	2	3	4	5
17. I am more likely to try to change things that need changing.	0	1	2	3	4	5
18. I have stronger religious faith.	0	1	2	3	4	5
19. I discovered that I'm stronger than I thought I was.	0	1	2	3	4	5
20. I learned a great deal about how wonderful people are.	0	1	2	3	4	5
21. I better accept needing others.	0	1	2	3	4	5

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