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## The Art of Coping with a Craniofacial Difference: Helping Others through “Positive Exposure”

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### Abstract

Finding ways to cope with social stigmatization is an important aspect of achieving adaptation for people living with visible genetic differences. This study describes the way individuals with craniofacial differences use an innovative photography and video experience with Positive Exposure (PE), a non-profit organization based in New York City, as a way to cope with their conditions. Thirty-five individuals between 12 and 61 years of age participated in this study. We administered surveys comprised of open-ended qualitative questions and quantitative measures designed to assess self-esteem, perceived stigma, and hopefulness. Data for this analysis was generated from the written questionnaires and interview transcripts.

Most participants reported high levels of self-esteem and hopefulness, suggesting that they were relatively well adapted to their condition. Almost all participants described experiences of stigmatization throughout their lives. However, participants demonstrated their ability to implement a variety of coping strategies to manage stigma. ‘Helping others’ emerged as a prominent strategy among participants, aiding in the often lifelong process of adapting to their genetic difference. PE was described as an avenue through which participants could reach out to individuals and society at large, helping them adapt further to their condition. ‘Helping others’ may also benefit individuals with craniofacial differences who do not consider themselves to be well adapted to their condition. Health care providers can collaborate with PE, advocacy groups and other community or support groups to identify additional ways individuals with craniofacial differences can help themselves by reaching out to others.

### Keywords

self-esteem; stigma; coping; positive exposure; craniofacial adaptation

## INTRODUCTION

Coping with stigma is an important aspect of achieving positive self-esteem for people living with visible genetic differences. Individuals with craniofacial differences are at particularly high risk for experiencing social stigmatization and discrimination [Topolski, et al., 2005; Strauss, et. al., 2007; Sarwer, et. al., 1999]. Human targets of stigmatization (individuals with craniofacial conditions being one such example) often are at risk for experiencing social and psychological stress, which can have a negative effect on their quality of life [Pruzinsky, 1992]. Consequently, individuals with visible facial differences need to find and implement effective coping strategies to sustain a positive psychological well-being [Puhl and Brownell, 2006]. This study explored the use of a unique photography and video experience as a vehicle for helping individuals with craniofacial conditions feel better about themselves as they continue to cope with the negative effects of social stigmatization.

Stigmatization describes the process by which a person is identified as being “different,” and subsequently devalued because of that difference. Stereotypes, often negative, ensue. Although research on the social stigmatization of individuals with visible genetic differences is only starting to emerge, there is already a substantial amount of literature about stigma related to more common conditions. For instance, stigma literature is abundant in research related to HIV/AIDS and other infectious diseases such as tuberculosis [Heijnders and Van Der Meij, 2006]. There is also a growing literature on the stigma of weight as obesity continues to become more prevalent [Puhl and Latner, 2007]. However, relatively little research has been conducted on the stigma, particularly perceived stigma, associated with living with a genetic condition. Research focusing on the quality of life of individuals living with several specific genetic conditions indicates that perceived stigma may be frequent. Findings from studies involving individuals affected with Marfan syndrome [Peters, et al., 2005], achondroplasia [Gollust, et al. 2003], Turner syndrome [Sutton, et al., 2005] and Proteus syndrome [Turner, et al., 2007] demonstrate the prevalence of stigma and its negative effects, suggesting a need for further investigation into ways in which individuals might identify effective coping mechanisms.

Within the craniofacial literature, a few research studies concluded that individuals with craniofacial differences are at particularly high risk of experiencing social stigma, especially during early adolescence when appearance is an important aspect of relating to others and forming peer relationships [Topolski, et al., 2005]. A study by Strauss and colleagues [2007] describes the stigma experiences of 185 adolescents with facial differences (both congenital and acquired) over a one month period. Participants were first asked to report stigma experiences that occurred within the week prior to participating in the survey: 35% reported that they noticed people staring at their face. When asked to comment on stigma occurrences over the past month, 29% of study participants reported overhearing people say something about their face, 12% felt excluded from peer activities on account of their appearance, and 31% either got into a fight or were teased about how their face looked. In another study, 38% of individuals with craniofacial differences reported stigmatization or discrimination in the workplace, and 71% reported discrimination in social situations [Sarwer, et. al. 1999]. Together, these studies suggest stigma experiences may be frequent among individuals with facial differences.

The frequency of social stigmatization alone does not reveal its effects on individual well-being. According to Crocker and Major [1989], the effect of social stigmatization on self-esteem is said to be a significant predictor of psychological well-being and mental health; but, “despite the strong theoretical support for such a prediction, empirical evidence that members of stigmatized groups have lower self-esteem than nonstigmatized individuals is

remarkably scarce” [Crocker and Major, 1989, p. 611]. These authors account for this theoretical and empirical dissonance by suggesting that individuals with craniofacial differences employ certain protective strategies to avoid internalizing the stigmatization: for example, an affected individual may attribute negative social attitudes and stigmatization to a general prejudice against their group as a whole rather than a prejudice against them specifically, thereby removing personal vulnerability. Another hypothesis put forth by Crocker and Major [1989] to explain the discordance between the theoretical literature and the empirical data is that stigmatized individuals may simply devalue the attributes upon which others base their criticisms and judgments. Similarly, Puhl and Brownell [2006], in their study on weight stigma, concluded that adopting successful coping strategies is crucial in a stigmatized individual’s quest to attain high self-esteem and sustain a positive self-image: “what contributes more strongly to psychological wellbeing is not the stigmatizing situations themselves, but the ways in which an individual copes with these experiences... [P]articular coping strategies are related to both higher self-esteem and lower depressive symptoms” [Puhl and Brownell, 2006, p. 1813]. In addition, possessing an arsenal of effective coping strategies that can help foster and sustain a positive self-image may also help individuals with rare genetic conditions identify positive attributes and life experiences generated by their unique differences [Eiserman, 2001]. Specifically, living with and adapting successfully to a visible facial difference may, according to Eiserman [2001], allow individuals to develop unique or enhanced skills, such as communication abilities, service to others, observational skills, inner strength, abilities to question society, and embrace new social circles.

The general literature on coping strategies is vast. Coping strategies used by stigmatized individuals may be emotion-focused (for example, avoidance or distancing) or task-focused (for example, journaling or joining a support group) [Lazerus and Folkman, 1984]. Within the literature on individuals living with craniofacial differences, one unexplored coping strategy is the act of helping others. This social phenomenon is considered a mutually beneficial relationship, especially when entered into by individuals living with challenging health circumstances or individuals struggling with their self-esteem [Roberts, et al., 1999]. The act of helping others can bring benefit to the “helper” by improving his or her sense of well-being through fostering “increased feelings of competence, equality, social usefulness, independence, and social value” [Roberts, et al. 1999: p. 843]. A study conducted by Schwartz and Sendor [1999] explored the benefits of being a peer supporter for individuals living with multiple sclerosis (MS). These scholars concluded that individuals living with MS, when put in a position to support others living with the same condition, not only changed the way they thought of themselves, but their perception of their own quality of life was also enhanced. This change occurred because of a shift in the supporters’ internal standards, values and conceptualization of their quality of life [Schwartz and Sendor, 1999]. The positive effects of this peer support study were lasting; after two years, the benefits to quality of life outcomes were still evident: “[B]y helping others, the patients were able to reframe their own suffering, derive a stronger sense of meaning in life, and feel a stronger awareness of the existence of a higher power” [Schwartz, et al., 2003: p. 779].

To our knowledge, no studies have explored the use of helping others as a coping strategy for individuals living with visible genetic differences. However, the findings of the two studies mentioned above support the unanticipated research finding of our study: namely, Positive Exposure (PE), a non-profit organization based in New York City that uses the photography and videography to challenge pervasive social stigmatization generated by the ignorance and fear of genetic difference, can benefit individuals living with craniofacial differences. PE provided a concrete and enjoyable vehicle through which individuals with visible genetic conditions felt they could help others, in effect helping them further their own adaptation and personal growth.

## MATERIALS AND METHODS

### Study Design

To explore the psychosocial effects of an experience with Positive Exposure on individuals with rare genetic conditions, PE partnered with the National Human Genome Research Institute (NHGRI) to conduct a transdisciplinary, qualitative, exploratory study. Individuals with craniofacial conditions were targeted for recruitment given that a number of studies reported that this population may experience low self-esteem, negative body image, social isolation, and stigmatization [Kapp-Simon, et al., 1992; Kapp-Simon, 1995; Pope and Ward, 1997b; Pope and Ward, 1997a; Sarwer, et al., 1999; Strauss, 2001; Topolski, et. al., 2005; Eiserman, 2001; Kelton, 2001]. Another motivation for engaging this population in our research stemmed from Eiserman [2001] and Strauss's [2001] articles, both of which underscored the relative lack of research evoking and emphasizing positive reflections and experiences pertaining to the lives of individuals living with craniofacial conditions.

To participate in this IRB approved study, volunteers needed to be 12 years of age or older, clinically diagnosed with a craniofacial condition, and able to speak and write in English. In addition, individuals were not eligible if they had ever participated in a professional photo-shoot before, either with Rick Guidotti or another photographer. Eligible volunteers gave written consent to engage in this multi-phase study. Participants agreed to complete a written survey comprised of quantitative measures and open-ended qualitative questions; participate in a photo-shoot and video interview; and complete a follow-up survey one month following the photo-session and interview.

Participants were recruited from a number of support groups for individuals with various craniofacial conditions including the Sturge-Weber Foundation, Forward Face & Inner Faces, CleftAdvocate, Moebius Syndrome Foundation, and the Treacher Collins Foundation. Recruitment flyers were distributed through organization list serves and posted on organization websites. Volunteers also learned about this study at conferences as well as through word of mouth.

### Phase I: The Written Survey & Questionnaire

At the outset of the study we administered a baseline survey which included questions inquiring after participants' sociodemographic information, their craniofacial diagnosis, their perceived severity of their condition, and their perceived control over their condition. Also incorporated in this survey were three quantitative scales used to assess self-esteem [Heatherton and Polivy, 1991], perceived social stigma [Rybarczyk et al., 1995], and hope [Snyder et al., 1996]. See Table I for more detailed descriptions of the scales.

Participants were also asked to write responses to a series of open-ended qualitative questions designed to mirror the primary issues targeted in the quantitative surveys, namely self-esteem, stigma, and hopefulness. In addition, we asked participants to share their interpretation of attractiveness as well as their experiences being photographed and their reactions to seeing themselves in photos.

### Phase II: The Photo-Shoot & Video Interview

After completing the first written survey and questionnaire, participants arranged a time and location for their photo-shoot and video interview. The location of the photo-shoots varied from support group conferences (N=12), to participants' homes and neighboring areas (N=13), to a photography studio in New York City (N=10).

Before beginning the photo-shoot, photographer Rick Guidotti engaged in a dialogue with each participant. Guidotti inquired after participants' interests, hobbies, and ambitions. Any concerns, worries, or fears participants may have had about being photographed were also discussed at this time. Guidotti also discussed the goal of Positive Exposure to reduce social stigma and fear. This conversation served to develop trust between the participant and the photographer—an essential ingredient for a successful photo session. Other factors that contribute to a safe and inviting shoot environment include respect, genuineness, compassion, and sensitivity.

Once rapport was established the photo-shoot began. The background of each photograph was variable depending on the venue of the session. Each session lasted approximately 30 minutes and hundreds of photographs were taken of each participant. (See Sutton, et al., 2006, p. 262 for additional information on PE photo-shoots).

Immediately following the photo-shoot, participants proceeded to the video interview portion of the study. Interviews were conducted by one member of the research team (JL, ES, or RG). Participants were asked to describe their experiences living with a craniofacial difference, as well as their relationships, support networks, how they manage the consequences of living with their condition, and their thoughts about the photo-shoot they had just completed. The interviews were semi-structured, which allowed participants to focus and elaborate on issues most relevant to their life circumstances. Video interviews lasted between 30 and 90 minutes. All interviews were video recorded and transcribed verbatim.

### **Phase III: The One Month Follow-Up Written Response**

One month after the photo-shoot and video interview, participants were mailed a second written response survey and questionnaire similar to the one received in phase one. The three quantitative scales were administered again, followed by a subset of the open-ended questions (See description of Phase I above). In the follow-up, however, participants were also asked to reflect and comment on their experiences with Positive Exposure, namely the photo-shoot and video interview. Once participants returned their completed survey and questionnaire they received copies of their written responses, a copy of their video interview, and several printed photographs.

### **Data Analysis**

The written responses and video interview transcripts were coded for themes related to our primary outcomes, according to standard qualitative research methods [Coffey and Atkinson (1996)]. All written responses and transcripts were coded by one coder (JL) and half were coded by a second coder (KS). Discrepancies in the coding were identified, discussed, and reconciled between the two coders. Codes were managed through NVIVO®, a qualitative data analysis software tool. Themes and frequencies in the data were identified and interpreted and illustrative quotations were culled to demonstrate our analysis and support our conclusions.

The quantitative measures were analyzed using SPSS statistical analysis software to arrive at descriptive statistics. Participants' scores were compared over time to determine whether any changes occurred following the intervention. The quantitative data was then analyzed in relation to the written qualitative responses and in-person interviews as a form of triangulation to corroborate the validity of our findings.

## RESULTS

### Sample Characteristics

The study was conducted between 2005 and 2007. Fifty-two eligible individuals completed phase one of the study, namely the written survey. Due to logistical barriers, usually the inability of either the participant or the photographer to travel to a common location on a given date, only 41 individuals were able to proceed to phase two: the photo-shoot and video interview. Of those 41 participants, 36 completed the one month follow-up written response survey (phase three). Of the 36 participants who completed the three phases of the study, one participant elected to withdraw from the study because of her expressed post-hoc discomfort with her interview. Consequently, our analysis is based on findings from the 35 individuals (aged 12-61 years) who completed all three phases.

Twenty-five women and 10 men between the ages of 12 and 61 participated in the study. Sturge-Weber syndrome was the most common diagnosis (N=13) followed by Treacher Collins syndrome (N=8) and Moebius syndrome (N=7). Other conditions included Noonan syndrome, amniotic band syndrome, cleft lip and palate, and other diagnoses. When asked about the perceived seriousness of their condition, most participants (N=29) deemed their condition mildly to moderately serious.

### Quantitative Scores

The mean scores of each quantitative measure (State Self Esteem, Perceived Stigma, and State Hope) were calculated two times: once at baseline and once at the one month follow-up after the photo-shoot and video interview. Possible scores for the State Self Esteem Scale range from 20 to 100. At baseline, our population's mean score was 73.4 (SD = 14.9), with an alpha coefficient score of 0.93. The Perceived Stigma Scale scores range from 24 to 96; our sample mean at baseline was 50.0 (SD = 11.5). The alpha coefficient for this scale was 0.89. The State Hope Scale scores range from 6 to 48. Our sample's mean score on the State Hope Scale was 37.2 (SD = 8.2). The alpha coefficient was 0.86. The mean scores of all three scales at the one-month follow-up were not significantly different from baseline averages; however, this study was not powered to detect differences. Rather, the quantitative data was collected as a means to corroborate the qualitative results. (See Table III)

### Qualitative Data

Social stigmatization, self-image, coping strategies, hope, and helping others were the prevailing topics and themes discussed by our participants. The results depicted below were generated from the data analysis of the qualitative written responses as well as the video interview transcripts:

**Stigma**—Almost all participants described experiencing stigmatization or discrimination at some point in their lives, especially during their childhood and adolescent years. They recalled feeling teased, singled out, and stared at. Many talked about school as a place where much of the rejection and discrimination occurred, usually by other students. One woman recalled being in second grade, trying to hide from the incessant teasing of one boy who would harass her in the hallways, as she moved from class to class. She hid in order to avoid his taunting, even if it meant being late for her class:

“And I remember he was teasing me, this little guy, I was just trying to hide away from him. Try to get away from him. And it didn't work because I went into the bathroom and tried to stay there, thinking that if the bell rings I know I'd be late for my second class...but I just, I guess I just didn't want to face being out there...” - 48 year-old woman



Another woman remembered an incident from when she was about 11 years old, when she was spending the summer at her grandparents' cottage and bathing at a public beach. Some boys, a bit older than she, left a lasting impression on her:

“I think one of the worst experiences that I can remember was when I was in a public bathing beach, swimming beach... and all of a sudden there were these boys... they started laughing at me and splashing. But the thing that bothered me the most was when one of them actually spat at me and so I thought, “Okay. I think I need to get home now.” - 61 year-old woman

Many of the participants affected with Treacher Collins syndrome also discussed the added social discrimination they endured as a result of their difficulty hearing, a consequence of middle and outer ear malformations. Many of them talked about how self-conscious they were, and still are, of their hearing aids and ears. One participant remembered that her that the kids in school used to make fun of her ears:

“They were all teasing me about my ears, again my ears, nothing else, just my ears, like how my ears are so small, they're so soft, and I try to fight back to tell the kids like, ‘Oh, you know, your ears are so big; they look like elephant's ears.’” – 32 year-old woman

Stigmatizing experiences also occurred for participants at grocery stores, jobs and other public venues. Some participants discussed difficulty dating, often feeling rejected because of the way they look. Dating was described by a number of our participants as a source of frustration. One man remembered having a crush on a girl in third grade, but when she found out about his crush, he was left feeling rejected:

“So she – she chased me around the yard and grabbed me and she told me, ‘Oh, I'm never going to go out with you. You're the ugliest person in the world.’ And I'm like, ‘Okay, thank you.’ That sticks with you throughout life, because I was, like, in third grade and I still remember that. – 29 year-old man

**Coping**—Participants in this study have employed a number of task-focused and/or emotion-focused coping strategies to help them endure the stigmatization. Some participants chose to avoid thinking about the stigmatization they experienced from strangers and classmates alike, having chosen instead to escape into reading, writing, or music. One woman described the ongoing challenge of coping with the stigmatization she felt, even coming from her sisters, who did not want to take her places because they said she would embarrass them. In the quotation below, she described her approach to handling the emotional toll associated with stigmatization at the end of each day:

“I try not to think about it. And, sometimes when I do, I'll go outside and I'll talk to my neighbor for awhile or I'll start listening to music.” – 24 year-old woman

The coping strategies that many of our participants used were generally healthy, such as journaling or compensating for their differences by doing well in school or getting involved in activities. Some of the coping strategies that participants used were not entirely healthy; a few talked about negative habits such as alcohol abuse. Two of our participants openly discussed their battles with anorexia. This participant discusses how she tried to use food to gain control of her life:

“I was very self-conscious. The only thing I felt like I could control was my weight. And because of that, I became anorexic and bulimic. And it was horrible. [In high school], I was so depressed and down in the dumps and just, you know, I didn't care at that point in my life, if I lived or died. And the only thing I had control of is, I'm not eating.” – 26 year-old woman

Many of our participants specifically mentioned that they felt better about themselves when they were helping others. A few individuals described volunteering to help people with disabilities. For example, one young woman volunteered with a horse riding program for kids with disabilities. Another helped out as a mentor when she was in college, living in a communal environment for college students with disabilities. Many participants expressed that their ability to reach out and empower others struggling with stigmatization and discrimination stemmed from their own personal struggle to overcome similar experiences of rejection. In the quotations below, one woman with Sturge-Weber syndrome and one boy with Noonan syndrome shared how living with a genetic difference enabled them to help and support other individuals ostracized by their communities:

“I was an advocate in high school because I saw that, you know, I’m not the only one that’s rejected. People who are fat are rejected. People who look plain or... perceived as not as pretty are rejected. So there are a lot of people who have the same cruelty or meanness even though they don’t have Sturge-Weber or whatever.”  
– 43 year-old woman

“[U]sually if I see someone who is being picked on as much as I was picked on—I know how it feels and I don’t care if they pick on me—I would stand up for him or her and just try to help cope with them. And if they say, ‘Oh, you never been like this,’ I would tell them my experiences, and they’ll just say, ‘Wow. How can you— how can you be living still? I would probably try to commit suicide.’ A lot of kids did say that to me...” - 15 year-old boy

**Self-Image**—Many participants discussed having a positive self-concept, although a very small minority of participants described having low self-esteem. One woman, a divorced mother of two, worked hard over the years to try and feel better about herself, but still struggled with her self-esteem:

“[I’m] just getting by and making sure I do what I can to look as best as I can which is pretty scary looking.” – 42 year-old woman

Most participants identified the ways in which their self-concept changed over time, feeling better about themselves as they got older. Some of them talked about feeling good about themselves in spite of their differences:

“Currently, I feel pretty positive about myself. Finally I am comfortable in my own skin. Yes, I recognize that I may be considered different from most people, but I’m okay with that.” – 27 year-old woman

“At the moment, I know I am cool. I’m special. And even though those nasty mean girls will try to bring me down I will always stay strong. I am proud of myself.” - 12 year-old girl

The words “Currently” and “At the moment” prefaced each woman’s description of how they felt about themselves on the day of the interview suggesting that there have been other times in recent memory when they have not felt as positive and confident about themselves. The use of these qualifiers serves to underscore the fact that one’s self-image is not necessarily fixed, but rather can change from day to day, month to month, or year to year, depending on the circumstances of their lives.

**Hope**—Almost all participants described feelings of hopefulness about their future. They generally had positive outlooks when they discussed or wrote about their career and future goals. Many participants described pursuing academic endeavors and professional careers in addition to building and supporting a family:



“My future plans include completing my education, going back to work and participating in my children’s activities. I hope to maintain my health in the process. Sometimes, I feel out of place with the other mothers involved in the kids’ activities, so I hope to one day feel comfortable in those settings.” – 26 year-old woman

Individuals also emphasized the importance of attaining short-term goals, like buying a house or finishing school:

“I hope to finish up my bachelor’s degree in community and human service. Then get my master’s in social work and eventually my social work license. I would like to work with children with cranial facial anomaly and their families.” - 37 year-old woman

Hope for a healthy future by means of improved medical treatments, better insurance coverage, and potential cures for their various craniofacial conditions was another common theme shared by many of our participants. In addition, many men and women in our study expressed the hope of living in a more accepting society—a society that one day can fully embrace rather than shun individual difference:

“I see my future as being very bright and fulfilling. My family and husband are wonderful and I have a lot of love in my life. I do hope for a long and healthy life together with my husband and the ability to have children. I also hope for my children to grow up in a world where they won’t be criticized for being who they are, or who their family might be.” – 25 year-old woman

**Positive Exposure Experience**—Every participant had at least one positive thing to say about their experience with Positive Exposure and most reported feeling uplifted following the photo shoot and video interview. Immediately following the photo shoot during the video interview, nearly every participant felt elated. Participants discussed feeling pleasantly surprised at how informal and natural the setting for their photo-shoot was and how well their photographs turned out. Some mentioned how they liked being the center of positive attention. They enjoyed hearing Rick tell them that they are “beautiful” and “amazing” and “gorgeous,” even if some of them said they did not completely believe it. By the end of the photo-shoot, participants talked about how good they felt:

“My Positive Exposure experience has been amazing. I think I’ve learned a lot about myself and have been reminded that I am a beautiful person and it is okay to be different.” – 25 year-old woman

“I had a wonderful time during the photo-shoot. At first, I was a little uncomfortable because [the photographer] was so complimentary and I kept thinking he couldn’t be referring to me. But gradually, I got into it and decided to enjoy the process.” – 27 year-old woman

Some participants discussed how their experience with Positive Exposure was important and valuable to them not only because they enjoyed the process but also because they supported the global mission of Positive Exposure, namely to educate society about individuals with rare genetic conditions in an effort to dissolve barriers that perpetuate ignorance and fear. Participants conveyed desires to serve as role models for individuals with similar craniofacial conditions in addition to educating the world at large—thus fostering PE’s notion that personal transformation generates community transformation, which can ultimately lead to broader social transformation.

**Helping Others through Positive Exposure**—Participants reflected favorably upon their opportunity to express their thoughts and feelings about living with a craniofacial

condition on videotape and hoped that their story might help someone else with a similar condition:

“The video interview, I believe, is a great idea for other (younger) SWS [Sturge-Weber syndrome] individuals and their families. I believe people learn well from other’s experiences. Also I came with a desire to help others.” – 43 year-old woman

In fact, approximately one-third of our study participants expressed the hope that Positive Exposure can create images and testimonials that might be used to help others with similar craniofacial conditions. Many participants hoped young children and parents of children with craniofacial differences would see their photographs and hear their stories and realize that living with a craniofacial difference is not as terrible as one might initially think.

Ultimately, participants wanted their images and stories to affect positively the way in which individuals with craniofacial differences are seen by society. Below are a few quotations that showcase the motivation behind many of our participants’ involvement in this research.

These participants reflected on their experience with Positive Exposure:

“I had a great time. I’ve come to notice that pictures or video of individuals with disabilities could be used as a tool to educate and to present them in a positive light to the world.” - 37 year-old woman

“By participating in this survey, I hope that other people with speech disabilities would gain more confidence and be encouraged to share their opinions with others.” – 21 year-old man

“This is a good project. I like that it helps everyone. The person who needs confidence in his or her mind will benefit from the photo shoot. The project also helps society to see differences differently.” - 35 year-old woman

“I enjoyed this and if I can, would love to do it again. I am happy I may change lives.” – 13 year-old boy

## DISCUSSION

The goal of this qualitative study was to explore whether Positive Exposure contributes to helping individuals with craniofacial differences improve self-esteem. Our sample demographic consisted primarily of adults who felt good about themselves, having worked toward adaptation to their condition over time. We discovered that our participants embraced PE as an avenue through which they could reach out to other individuals with similar genetic conditions, parents of children with genetic differences, and society at large in an effort to help shift the frequently negative attitudes directed at individuals with craniofacial differences.

Effecting social change is part of PE’s mission and the global objectives were made clear to individuals during their participation in this study. Interestingly, many participants spontaneously articulated the important role helping others played in their lives during the initial phase of the study before being introduced to the research team. In the questionnaires and video interviews, more than half of the participants talked about the various ways in which they incorporate helping others with disabilities and genetic differences into their lives. In reference to Positive Exposure specifically, some individuals discussed how they hoped their photos or video interview might help others (regardless of whether or not they are affected with a craniofacial difference) realize that people with craniofacial differences should be valued, considered “normal” and treated normally.

The extent to which affected individuals feel capable of helping others reflects, to a certain extent, their own state of adaptation to their difference. The participants’ ability to identify

their involvement in this study, and Positive Exposure more generally, as an opportunity to help others indicates their propensity and resolve to uncover new ways to improve their own self-esteem and further adapt to their condition. The literature on helping others suggests that participating in an experience such as PE may have promoted the ability of our participants to reframe their perceptions of themselves, part of the process of adaptation, especially if this was their first time reaching out to provide emotional support to others. For individuals who frequently engage in helping others, the ongoing nature of adaptation supports a continuous need for opportunities to find ways to further adapt to their conditions over time [Stanton, et al, 2001].

Participants identified PE as an opportunity to teach people about the experience of living with visible differences and were proud to be part of PE's efforts. By creating positive images and discussing on videotape how they dealt with being ostracized by others, our participants hoped to diminish fear and uncertainty and encourage others living with genetic conditions to have a positive attitude about themselves and their lives. Participants also hoped that their involvement with PE would send a message to society at large, one significant source of stigmatization and personal heartache, to improve social acceptance of those deemed "Other". Our participants hoped to demonstrate that in spite of, and because of, their visible differences they should be embraced by society as much as people without visible differences.

Many of our participants proved able to model positive self-esteem and hopefulness for others. With high self-esteem and hopefulness scores and moderate perceived stigmatization scores, our participants could meaningfully serve as peer leaders for other individuals with craniofacial differences challenged by the process of adapting to their condition. In addition to creating positive photographic images and testimonials, our participants poignantly discussed their experiences dealing with social stigmatization not only to validate their feelings, but also to suggest successful coping strategies to others. Through the act of reaching out to help others, individuals simultaneously continue to cope with their own feelings of perceived stigmatization.

Although our population presented themselves as well-adapted (perhaps a sample bias resulting from our older demographic and the fact that they were recruited primarily from support group foundations), the craniofacial literature underscores a wide range of psychological states within the population [Beaune, et al., 2004; Topolski, et al., 2005; Strauss, 2001; Eiserman, 2001; Sarwer, et al., 1999; Kapp-Simon, 1995]. If helping others can continue to shape positively the self-perception of individuals who are relatively well adapted, then similar benefits may occur for individuals with craniofacial differences who may struggle with low self-esteem, negative body image, and social awkwardness. According to a small body of literature that explores the phenomenon of helping others, engaging in such activities could actually serve to help improve psychological well-being for individuals, regardless of their level of adaptation. It is important to note, however, that helping others may not be appropriate for everyone; that feeling overwhelmed by the demands of others and giving beyond one's resources may have a negative effect [Schwartz, et al., 2003].

Our study results suggest a need for further research into the concept of helping others as a coping strategy for individuals with visible genetic differences. A deeper look into how helping others might shift perceptions of quality of life and promote finding new meaning in life would be a valuable contribution to the craniofacial literature and would help define the benefits of using such a coping strategy in this population. In the meantime, health care providers and support group organizations who work with individuals with visible facial differences might consider encouraging their patients/members to help other individuals

with conditions similar to theirs either in a volunteer or professional capacity. Helping others can be a mutually beneficial process, both for the person seeking help, and the person helping. This study brings to light the eagerness some individuals with craniofacial differences feel to reach out to others as they continue to work on their own lifelong process of adaptation and quest to sustain a positive self-image.

### Strengths and Limitations

The exploratory, qualitative design of this study, coupled with the innovative use of photography and videography, served as the primary strengths of this study. The multi-phase design of this project afforded us numerous opportunities to learn about our participants in greater depth, enabling us to gain insight into their life challenges, successes, and perceptions of their experience with PE. The qualitative nature of the inquiry enabled the discovery of helping others as a mutually beneficial engagement among individuals with craniofacial conditions.

The small and exploratory nature of the study could also be interpreted as a limitation, as our findings are neither generalizable to all individuals participating in Positive Exposure nor to individuals affected with craniofacial conditions. In addition, although we obtained self-esteem, perceived stigma, and hopefulness measures at several different time points throughout the study, the study was not longitudinal.

Further study is needed to determine whether and how PE may be accessible and beneficial for individuals living with craniofacial conditions challenged by low self-esteem. Based on our findings, future research should consider specifying inclusion criteria to recruit only those individuals found to have low self-esteem prior to participating in the study (perhaps assessed through a recruitment questionnaire). In addition, targeting a younger demographic might be more appropriate, as our participants consistently expressed that the time when they struggled most with issues of self-esteem and self-image occurred during their elementary and middle-school years. Future studies should also consider using broader concepts including a measure of self identity that includes self-image or self-concept. For it may be that self-esteem, a more stable measure of self worth, is relatively high among individuals raised in accepting home environments. However, these same individuals may feel negatively about their appearance and may suffer social consequences. Searching outside support organizations and foundations for recruitment will also contribute to a more accurate assessment of the potential benefit of PE on individuals with craniofacial conditions.

With respect to our unanticipated finding of helping others as a coping strategy for individuals with craniofacial differences, future studies should ideally target a diverse demographic with enough participants to answer the hypotheses raised by this exploratory study.

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TABLE I

## Scales

	<b>State Self Esteem Heatherton &amp; Polivy, 1991</b>	<b>Perceived Social Stigma Rybarczyk et al., 1992</b>	<b>State Hope Snyder et al., 1996</b>
Scale Questions	20	24*	6
Assessment	3 factors that affect self-esteem: daily performance, social interactions, and physical appearance	Adjectives depicting commonly used stereotypes to describe individuals with disabilities	Statements about life events, resourcefulness, and goal directed thinking
Response Range	1 ("not at all") to 5 ("extremely")	1 ("not at all true") to 4 ("very much true")	1 ("definitely false") to 8 ("definitely true")
Reliability	This scale has a coefficient alpha of 0.92.	This scale has a Cronbach alpha score of 0.91.	This scale has a Cronbach alpha score of 0.93

\* This scale was originally designed for a study involving individuals with leg amputations. We modified the scale slightly (with Dr. Rybarczyk's permission) to fit our study population by removing the adjective "clumsy," thus reducing the 22-item checklist to 21 items. We also added three adjectives to best fit our study population. These changes did not alter the psychometric properties of the scale.

**Table II**

## Sample Characteristics

	Number of Participants (N = 35)
<b>Age</b>	
12-15	8
16-22	4
23-35	13
36-50	7
51+	3
<b>Diagnosis</b>	
Sturge-Weber syndrome	13
Noonan syndrome	2
Moebius syndrome	7
Treacher Collins syndrome	8
Other/Unknown	5
<b>Gender</b>	
Male	10
Female	25
<b>Marital Status</b>	
Single, never married	24
Married	6
Divorced or separated	3
Widowed	1
Same-sex domestic partnership	1
<b>Has Children</b>	
Yes	5
No	29
No answer	1
<b>Education</b>	
< High School	11
High School Graduate	4
Some College	6
College Graduate	9
Post-Graduate	5
<b>Racial Background</b>	
White	32
Black or African American	0
American Indian or Alaska Native	0
Asian	2

	<b>Number of Participants (N = 35)</b>
Native Hawaiian or Other Pacific Islander	0
Other	0
No answer	1
<b>Ethnicity</b>	
Hispanic	5
Non-Hispanic	30
<b>Perceived Seriousness of Condition</b> <i>Scale of 1 -10: 1 = not serious; 10 = very serious</i>	
1 – 3	14
4 – 6	15
7-10	6
<b>Perceived Control Over Condition</b> <i>Scale 1-10: 1 = no control; 10 = complete control</i>	
1-3	14
4-6	14
7-10	6

**Table III**

## Quantitative Measure Scores at Baseline

Baseline Scores	State Self Esteem	Perceived Stigma	State Hope
Mean (SD)	73.4 (SD = 14.9)	50.0 (SD = 11.49)	37.2 (SD = 8.2)
Possible Range	20 - 100	24 - 96	6 - 48
Alpha Coefficient	0.93	0.89	0.86
Normative Data	428 college students Mean score (males): 72.0 (SD = 13.4) Mean score (females): 69.6 (SD = 13.1)	n/a	444 college students Mean score: 37.2 (SD = 6.3)