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Psychological and Social Factors in Undergoing Reconstructive Surgery Among Individuals With Craniofacial Conditions: An Exploratory Study

Ms. Heather Bemmels, M.S. [Doctoral student],

Department of Educational Psychology, University of Minnesota, Minneapolis, Minnesota

Dr. Barbara Biesecker, Ph.D., M.S. [Director],

Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program, and Associate Investigator, Social and Behavioral Research Branch, National Human Genome Research Institute/National Institutes of Health, Bethesda, Maryland

Ms. Johanna L. Schmidt, M.P.H., M.G.C. [Genetic Counselor],

Children's National Medical Center, Washington, DC

Ms. Alyson Krokosky, M.S. [Assistant Director],

Genetics Resources and Services, Genetic Alliance, Washington, DC

Mr. Rick Guidotti, B.F.A. [Founder and Director], and

Positive Exposure, New York, New York

Ms. Erica J. Sutton, M.A. [Doctoral candidate]

Dalla Lana School of Public Health and the Joint Centre for Bioethics, University of Toronto, Ontario, Canada

Abstract

Objective—Reconstructive surgery to improve psychological well-being is commonly offered to children with craniofacial conditions. Few studies have explored the challenges of reconstructive surgery beyond the physical risks: poor treatment outcomes, infection, brain damage, and death. This qualitative study aims to understand the psychological and social implications such interventions can have for individuals with craniofacial conditions.

Design—A total of 38 individuals between the ages of 12 and 61 with such craniofacial conditions as Sturge-Weber syndrome, Treacher Collins syndrome, Möbius syndrome, cleft lip and palate, Noonan syndrome, Crouzon syndrome, and amniotic band syndrome participated in semistructured video-recorded interviews. Participants were recruited at conferences, through study flyers, and by word of mouth. Descriptive, thematic analysis was used to identify themes related to reconstructive surgery.

Results—Dominant themes included undergoing surgery to reduce stigmatization, the psychological and social implications of the interventions, outcome satisfaction, parental involvement in decision making about surgery, and recommendations for parents considering surgery for their children with craniofacial conditions. Experiences with reconstructive surgery varied, with some participants expressing surgical benefits and others, disillusionment.

Conclusions—The range of participant attitudes and experiences reflect the complexity of reconstructive surgery. Pediatric health care teams involved in the care of children with

craniofacial conditions play an important role in advising patients (and their parents) about existing treatment options. The psychological and social implications of reconstructive surgery should be relayed to help families weigh the risks and benefits of surgery in an informed and meaningful way.

Keywords

craniofacial conditions; decision making; parental role; pediatrics; psychological and social implications; reconstructive surgery

Offering reconstructive surgery for children born with craniofacial conditions (CFCs) such as Sturge-Weber syndrome, Treacher Collins syndrome, Möbius syndrome, and cleft lip and/or palate is considered part of the standard of care (see Table 1) (American Cleft Palate–Craniofacial Association, 2009). Children with these conditions often undergo multiple surgeries (MacGregor, 1980; Marsh, 2006). Health care providers (HCPs) recommend surgical intervention to parents of children with CFCs to improve physical function and/or psychological well-being (Marsh, 2006; Mouradian et al., 2006). Although surgery for the former is accepted, surgery for the latter elicits debate among scholars and professionals in the field.

Contradictory empirical evidence challenges the assumption that reconstructive surgery can improve psychological well-being in individuals with CFCs by increasing their self-esteem and reducing their experience with stigmatization and marginalization in the community (Edwards et al., 2005; Asch, 2006; Marsh, 2006; Aspinall, 2010). Some research supports the theory that reconstructive treatments for CFCs can result in increased self-esteem (Lefebvre et al., 1986; Arndt et al., 1987; Kay et al., 2005), perceived improvement in appearance (Lefebvre et al., 1986; Hansen et al., 2003), and enhanced social engagement (Arndt et al., 1987; Troilius et al., 1998). However, a handful of studies have found that although individuals who opt for surgical intervention might be extremely pleased with the outcome promptly following surgery, their satisfaction often dissipates over time, leaving them susceptible to future psychosocial challenges (Lefebvre et al., 1986; Arndt et al., 1987; Sarwer et al., 1999; Bruce, 2009).

Given the relative lack of long-term studies measuring sustained satisfaction and psychosocial benefits following reconstructive surgery (Arndt et al., 1987; Edwards et al., 2005; Marsh, 2006; Mouradian et al., 2006), some scholars encourage health care professionals, parents, and children to reflect critically on whether surgical intervention to prevent anticipated psychological and social challenges—an unsubstantiated promise—is the most effective avenue to pursue when weighed against the known and unknown risks that accompany surgery (Edwards et al., 2005; Asch, 2006; Aspinall, 2006, 2010; Marsh, 2006; Mouradian et al., 2006). As Mouradian et al. (2006) noted, “in the surgical setting there is always ‘something to lose’” (p. 143). More specifically, with every surgery a child assumes certain physical risks—however infrequent—including adverse reactions to the anesthesia, infection, blood and/or tissue loss, poor treatment outcomes, brain damage, or death (Lefebvre and Barclay, 1982; Aspinall, 2006, 2010; Marsh, 2006; Mouradian, 2006; Mouradian et al., 2006). Whereas the physical risks of reconstructive surgery are well established, little is documented about the potential psychological and social aftermath of these procedures (Edwards et al., 2005; Asch, 2006; Mouradian et al., 2006). Our research addresses this gap in scholarship from the retrospective view of adolescents and adults who elected to undergo reconstructive surgery for their CFCs and the minority within our sample demographics who did not.

This is a secondary data analysis from a study entitled Photographic and Video Experience (PAVE) that sought to explore the impact of Positive Exposure (PE)—a nonprofit organization that uses photography and videography to challenge social prejudices around genetic variation—on individuals with CFCs (Sutton et al., 2006; Loewenstein et al., 2008). PAVE interviews revealed that participants consistently initiated discussions about their experiences—positive and negative—with reconstructive surgery. In this analysis we sought to explore the diversity of reconstructive surgery experiences; to understand the psychological and social outcomes resulting from these procedures; to highlight the range of parental influence in decision making around childhood surgery for CFCs; and to share participant recommendations for parents of children with CFCs considering surgery.

Methods

The National Human Genome Research Institute (NHGRI) and PE collaborated in the design and execution of this study. The institutional review board at the NHGRI approved this study.

Participants

Eligible participants were at least 12 years of age, had a clinical diagnosis of a craniofacial disorder, and demonstrated oral and written proficiency with the English language. Individuals who had previously taken part in a professional photo shoot with any photographer were considered ineligible. Participants were recruited in three ways: (1) at conferences for organizations that support individuals with craniofacial disorders, (2) by flyers distributed electronically to support groups and organizations for individuals with CFCs, and (3) by word of mouth. The participating support groups and organizations included The Sturge-Weber Foundation, Forward Face & Inner Faces, Cleft Advocate, Moebius Syndrome Foundation, and the Treacher Collins Foundation. Individuals interested in participating in the study contacted the research team. A total of 28 adults and 11 children and their parents provided written consent (or written assent in the case of children) to participate in the study.

In addition, we obtained written consent from the seven participants whose photographs are featured in this article. Participants reviewed both the manuscript and the photograph prior to giving their consent. We included these photographs as part of PE's larger mission to reframe how individuals with CFCs—and rare genetic disorders more broadly—are typically presented and featured in medical journals and textbooks by capturing the whole individual, not just the specific features caused by the genetic difference. In addition, we included these photographs to underscore that many of our participants view themselves differently than individuals without CFCs view them.

Procedure

Participation in PAVE involved completing a self-administered baseline survey, a photo shoot, a video interview, and a follow-up survey 1 month after the photo shoot. Each photo shoot lasted approximately 30 minutes. Participants then engaged in an in-person, video-recorded interview that ranged in length from 30 to 90 minutes. (The interviewers were members of the PAVE study team. Each interview was conducted by one of two research fellows, a psychiatrist, or a photographer. Interviewers were trained in open-ended interviewing techniques.) The interview guide was semistructured, consisting of a list of topics (i.e., adolescence, high school, family, friendships, work/profession, challenges with condition, extracurricular activities) to explore participants' experiences living with a CFC, including their relationships, sources of support, and coping strategies. The first 12 interviews revealed that participants introduced discussions around their experiences with

craniofacial surgery. Consequently, a topic item about surgical interventions was added to the interview guide (i.e., Surgeries).

A total of 39 participants completed the baseline survey and engaged in a PE photo shoot and video interview. Of these, 36 participants completed the follow-up survey. One participant withdrew from the study following the interview. Data for this analysis was derived from the 38 video interviews.

Data Analysis

Interviews were transcribed verbatim by professional services. The first author watched all videos and read a sample of the transcripts to gain familiarity with the data and to verify the accuracy of the transcriptions. Codes were identified after watching the interviews and the coding scheme evolved through the systematic, line-by-line analysis of each transcript (Strauss and Corbin, 1998; Sandelowski, 2000). After one author (H.B.) coded all transcripts, a research fellow independently coded a random sample of eight transcripts, using a descriptive codebook, to confirm coding accuracy. Coders discussed all discrepancies until consensus was reached on all codes. Codes were entered into NVivo™ software to aid in data management. Reconstructive treatments emerged as a dominant theme with five subthemes: surgery to reduce stigmatization, psychological and social effects of treatment, satisfaction with surgical outcome, parental involvement in decision making, and recommendations for parents considering surgery for their children with CFCs.

Results

Participant Demographics

A total of 38 participants between 12 and 61 years of age (mean, 30 ± 13 years) participated in the video interview. Nearly two thirds of these participants were female ($n = 26$), and most participants self-identified as white ($n = 34$). Education levels varied among our participants, as did marital and parental status (see Table 2). Diagnoses were self-reported to include Sturge-Weber syndrome (Figs. 1 and 5) ($n = 15$), Treacher Collins syndrome (Fig. 2) ($n = 8$), Möbius syndrome ($n = 7$), Noonan syndrome ($n = 2$), cleft lip with or without cleft palate and associated anomalies (Fig. 4) ($n = 2$), unknown causes ($n = 2$), Crouzon syndrome (Fig. 3) ($n = 1$), and amniotic band syndrome (Fig. 6) ($n = 1$). In the baseline survey, two interview participants reported not having CFC-related surgeries.

Reconstructive Surgeries and Treatments

Participants described three distinct motivations for undergoing craniofacial surgery, yet acknowledged that surgeries can have multiple purposes: (1) for physical health or comfort; (2) for improvement in function (e.g., speech, hearing); and/or (3) for aesthetic purposes. For some participants the motivations for surgery were self-derived; whereas, others felt external pressure, particularly from their parents. Participants predominantly discussed their experiences with surgical interventions to improve function and aesthetics because both affected how they were perceived and/or treated by others.

Surgery to Reduce Stigmatization

Participants disclosed that often their primary goal for undergoing reconstructive treatments was to improve their overall quality of life by reducing stigma. For some participants, this meant embarking on a surgical quest to look “normal”: “They reconstructed my ears. Now they are as close as possible to normal. I mean, you can’t really replicate normal, but it’s as close as possible” (Megan, age 32). Some participants discussed undergoing reconstructive treatments to reduce questioning, staring, or teasing: “Before I was 18 years old, my lip was bigger than it is, because I didn’t have ... I was 18 when I had the surgery for my lip. And,

yeah, I got teased. I got teased: I was always called ‘fat lip’ and everything and there wasn’t really much I could do” (Rita, age 48).

Psychological and Social Effects of Treatment

Our participants described a variety of experiences related to the process of undergoing surgery. Although the most common descriptions revolved around where, when, and how frequently participants had treatments, some participants provided more intimate details about how it felt to have the procedures and the limitations they encountered postsurgery. The most detailed descriptions focused on the negative effects and challenges of the process including the overall number of surgeries, amount of school missed, changes in appearance, and even, paradoxically, increased stigmatization.

Many participants talked about the sheer number of surgeries endured throughout their youth: “It was hard [growing up with Treacher Collins]. I had 20 operations ... So I was in and out of the hospital a lot” (Nicole, age 22). The frequency of surgery consequently led to increased hospitalization stays and school absences that, in some cases, led to being held back a grade: “I had to repeat second and fifth grade because of my surgeries ... I’ve had pretty much a hard life with school and surgeries in the way” (Isabella, age 14). As a result of undergoing numerous surgeries, some participants struggled with their ever-changing appearance. Rachel (age 34) talked about how her countless facial transformations only added to the teenage stresses she experienced and subsequently caused her to become more withdrawn:

I think I became more self-aware in high school because I was just going through a lot of typical high school things on top of having a constantly changing image. Every summer you have surgery and you just don’t know what you’re going to look like after it. Usually, you look like you’ve lost a fight with Muhammad Ali. I think I retreated more into myself and I was very frustrated and bitter.

For some participants the time immediately following their surgeries was the most difficult because they perceived an increase in social stigmatization. Participants explained that their peers would comment on their absences from school and/or the drastic change in their appearance. Jessica (age 25) recounted a scenario where the principal made an announcement over the school’s public address system:

If you see Jessica walking, she has whatever and to be careful. The moment I get out in the hallway for first period everyone is just staring and backing up. And, I’m like “Oh, my god. I’m not diseased or something.” That was the worst. That was the worst thing. It was the worst problem I had with having the surgeries and everything.

Finally, reconstructive treatment meant that individuals with more subtle manifestations found themselves needing to disclose their condition to friends and/or colleagues. The health implications of their condition were invisible and, but for the surgery, did not need to be divulged. Surgery generated questions and ultimately led to unintended disclosures as a result of altered appearances and long absences from school or work:

Through high school I always thought all my friends didn’t know that I’m hearing-impaired ... So I was having my major jaw surgery that summer. My mom said, “You have to tell your friends.” And I just said, “No, not this time. We’re all going to college anyway and they don’t need to know.” She said, “You can’t come back at Christmas break and have a new jaw.” So I had to explain everything. (Mia, age 27)

Satisfaction With Surgical Outcome

In describing their attitudes toward the outcomes of their reconstructive surgeries, participants focused specifically on surgical outcomes related to their appearance. One third of our participants talked about how the degree of perceived improvement in their appearance affected their feelings about surgery and whether they would have additional surgeries in the future. One positive effect of surgery noted by participants was improved self-esteem. One participant (Nathan, age 29) was very open about his struggles with self-esteem, particularly in the context of relationships. Although he feels that his self-confidence has improved through surgery (“It’s better, because, like I’ve had—through surgery I think like, ‘Okay, I look better now, I feel better.’”), he still feels on the periphery when it comes to dating.

Julia (age 24) commented that despite the difficulties of undergoing jaw surgery, she appreciated the benefits of the surgery due to the considerable difference that she and others were able to see in her appearance: “The biggest surgery I did have in high school was when they finally did this huge jaw surgery ... My mouth [was] wired shut for 9 months ... I was still able to talk and I still went to school and everybody just saw this huge difference in looks and everything.”

Several participants stated that as a result of their satisfaction with past reconstructive treatments, they planned to have further elective treatments. However, whereas some participants felt in control of the number and frequency of their reconstructive treatments, others described an addiction to the surgical quest for the perfect face: “I guess living with it now is a lot easier but also a lot harder because I’m, like, ‘I want this done. I want that done.’ I’m more, like, I want to be, you know, normal. The older I get, the more I see what’s wrong with me” (Nicole, age 22).

Not all participants, however, spoke favorably of their reconstructive treatments; some participants felt that the outcome of surgery did not justify the difficulties associated with the intervention. A major disappointment cited by some participants was that they did not notice a significant change in their appearance after the surgeries. A woman with Treacher Collins syndrome talked about how she had been told that one surgery would lead to a significant change. After a series of interventions she reported feeling disheartened because she never saw the transformation:

No amount of surgery is going to make me look any better. It might help a little bit, but to what extent? And I know now that I don’t want any more surgery. I can’t go down that route because every time I had surgery, I thought, “Oh. I’m going to look better this time. I’m going to look all better. It’s going to be all fixed.” And I had just had that mentality for so many years. That’s what had been told to me when I was little. Eight, 9 years old, one surgery, that’s all it’s going to take. I was like, “Okay. I’ll do it. No problem.” But year after year, I mean I had a surgery every summer from when I was 8 to 18. You know what? It’s just like, “Wait, it’s not getting better. Nothing has happened. No, I’m not really seeing any significant progress.” But, everyone else would tell me, “Oh. You look so much better.” But I don’t feel better. I don’t feel better about myself. I don’t think I look any better when looking in the mirror. (Marissa, age 28)

Parental Involvement in Decision Making

Some participants reported the influence their parents had on their decision to undergo reconstructive treatments. Although a few participants recalled wanting reconstructive treatments when they were younger, others disclosed feeling pressured by their parents. Some participants did not mind that their parents wanted them to have surgery; whereas,

others resented the intimation that there was something about their appearance that needed changing.

Sometimes participants talked about why they needed surgery through the perspective of their parents. One participant, for example, recounted how her parents would get comments from strangers after her surgeries, and when she had not had a surgery for a while she noted that “my [her] mom might want to do it again.” When asked whether she wanted the surgery, Ashley (age 24) said, “I think it’s mostly my parents. I don’t want it done. I ... I think I look fine, but they think it’s too dark ... I’m pretty sure they want it for cosmetic issues.”

Another participant with Sturge-Weber syndrome talked about how she did not want to have more laser treatments even though her parents were strongly encouraging it:

Katelyn (age 14): “I don’t want any more surgeries but my parents want me to get another surgery.”

Interviewer: “Really? How come?”

Katelyn: “I don’t know. I think they still want to go by my eye ... and on my lip, but I don’t want any more surgeries. I’m just sick of them.”

Interviewer: “Is the experience uncomfortable or you just don’t feel that there is any need for them?”

Katelyn: “Well, it’s kind of both. Because I don’t feel that I need them – cuz nobody asks me anyway. And then, I’m just tired of them.”

Conversely, one participant with Treacher Collins syndrome talked about how her parents always included her in reconstructive treatment decisions: “You know, my mom always taught me—she’s like, you know, ‘if you want to get your ears done it’s up to you. It’s not up to me. It’s not up to how I feel, what the public thinks, you know, it’s up to you’” (Nicole, age 22).

Difficulties can arise when a patient’s point of view regarding reconstructive treatment is at odds with what a parent or a HCP would prescribe. Understanding these tensions is important prior to undergoing surgery. One participant with Möbius syndrome acknowledged current controversies around the “smile surgery” and the difficulties parents face in terms of how best to help their child living with a CFC; yet, she defended her decision not to undergo the surgery by underscoring that there was nothing about herself that needed to be corrected or reconstructed:

Shannon (age 35): “Well, I know there’s a controversy right now about the smile surgery, and a lot of parents are wanting their children to have it. And, I have mixed feelings, personally. I understand the part of why they want to have it. On the other hand, I’ve thought about having it, but I realize that if people can’t see my smile, then there’s something wrong with them, not me.”

Interviewer: “If we offered you ... smile surgery today, would you do it?”

Shannon: “No. I wouldn’t do that. It just doesn’t really faze me to have it [Möbius syndrome].”

Participant Recommendations for Parents

Finally, participants offered advice to parents of children born with CFCs. A number of participants provided advice related to reconstructive treatments ranging from intervening early to encouraging waiting until children are older to make decisions for themselves. Some participants suggested that parents seek out good doctors (“[Do] research and interviews [on] different physicians before making any surgical decisions. There are lots of good craniofacial centers around the country. Don’t just go to the first doctor you see and say, ‘Okay, fine.’” [Beverly, age 61]) and introduce reconstructive surgery early:

Definitely ... start when they’re young ... when they’re a baby ... as far as surgeries ... As young as 3 or like 3, 4, or 5. Regarding surgeries, tell the child that everything should be up to them and for—for themselves, not for anybody else ... So I think the parents should have a one-on-one, let them know that this is for your confidence and nobody else’s. Make them aware how surgeries can help them. (Nicole, age 22)

Others maintained that parents should wait until their child is older before considering surgery, not only so the child can be part of the decision-making process, but also because they believe that if a child has surgery too young it will only necessitate the need for future surgeries once they have finished growing:

I think that one day [parents] should talk to the kids ... about surgeries and everything, but I think they should wait until the kids are like 12, 13, or whatever. They will be more aware, and they would certainly know better what they want to do with their face—what they want to have done. And at least that way they wouldn’t have to have repeated surgeries over and over and over, because they’re still growing. (Megan, age 32)

Some participants cautioned parents of children with CFCs against projecting their own issues regarding their child’s diagnosis onto their children. For example, Julia (age 24) describes dry skin as a manifestation of her condition. She was upset that her mother’s reaction to her skin condition included repeated efforts to take her to a spa as well as encouraging laser surgery:

So if they’re younger I would try to teach them to take the best care of themselves, but I would never try to push them [into surgery] ... because no matter what, we look at it differently and see it differently and don’t understand it the way that everybody else does. It’s very different. I saw how the one mom, she was like “Yeah, but her skin is so dark. I’m just trying to get her to scrub it and scrub it and scrub it.” I was like you want my advice, get some medicine that will help you out ... Other than that I would stop agitating cuz truthfully ... I felt that my mom was starting to make fun of me for my looks, you know.

Similarly, Beverly (age 61) stressed the importance of dealing with emergent health and surgical issues, but explained that overemphasizing the CFC can take an emotional toll on the child:

Yes, you have to deal with whatever the physical manifestations are. If the child has the hearing aid or has to have surgeries ... I do know some people who unfortunately focus way too much on their Treacher Collins or the child’s Treacher Collins to the point where I think it can be—it has a very serious emotional impact on the child later. Definitely, just raise the child as normally as you can, and deal with whatever needs to be done.

Discussion

Reconstructive surgery for children with CFCs has implications that extend beyond the sought-after psychological benefits of improved well-being and reduced social stigmatization. Although some participants in this study enjoyed the surgical benefits of increased self-esteem and reduced stigmatization, others were explicit about the emotional and social toll that surgical intervention introduced into their lives as a result of missing school, spending considerable amounts of time in hospitals, adjusting to an evolving appearance, wondering whether the next surgery would be their last, and/or dealing with the unforeseen social stigma that often accompanied such eventualities. Satisfaction with the surgical outcome also contributed to participants' post-op psychological self-assessment. Some participants were elated with the difference surgery made in their physical appearance; others expressed sustained dissatisfaction after each surgical procedure failed—by their estimation—to deliver the promised aesthetic improvements. Finally, the pattern of contrasting experiences extended to parental influence in the decision to undergo surgery and the extent to which parents included their children in such decision making.

Given the spectrum of participant experiences and advice they offered for parents around surgery, decisions to undergo elective surgical interventions are personal and unique to each child and his or her family: There cannot be a “one size fits all” approach to such decision making. Although not all surgeries can be delayed until a child is old enough to participate in decision making, our data support child involvement whenever possible. Pediatric HCPs engaged in the care and treatment of youth with CFCs are in a position to advocate for patients considering surgery by presenting a balanced appreciation of the psychological and social benefits and challenges of surgery. Specifically, providers can help patients identify their hopes and expectations and/or fears and concerns around surgery; explore alternatives to surgery with their patients; and work with parents to ensure that children are part of the discussions and decision making around surgery.

Pediatric HCPs can help attenuate the emotional and social challenges inherent in the reconstructive surgery process by candidly discussing the possibility of such repercussions with patients and their parents prior to surgery and collaboratively devising coping strategies to deal with such difficulties should they arise. For instance, adolescents often experience the challenges associated with surgical recovery at their schools. Therefore, pediatric HCPs can encourage and prepare parents to be their child's advocate and educate teachers and students in advance of the scheduled surgery to minimize psychological distress following a procedure.

That patients may find themselves dissatisfied with the surgical outcome is not inconsequential given that improvement to one's appearance is often among the primary motivations for undergoing reconstructive surgery (Marcusson, 2002; Sinko et al., 2005). As adolescents consider surgical interventions, HCPs should present reconstructive treatment plans in a manner that will encourage realistic expectations following surgery. Realistic surgical goals may not only serve to minimize post-op dissatisfaction, but also might lead patients to reassess whether they even want the intervention in question. Some scholars, for example, have proposed a way of thinking about disability that questions the therapeutic imperative, which is defined as the medical culture's goal to provide a cure for all conditions and ailments (Scully, 2008). Specifically, scholars who object to the therapeutic imperative argue that some of the challenges that arise from disabilities are social in nature and the use of extensive resources and medical technologies and treatments to reduce social difficulties is only one course of action—and in some instances an inappropriate one (Asch, 2006; Dreger, 2006; Scully, 2008). Within the context of CFCs, patients and their families may consider nonsurgical approaches to managing stigma associated with CFCs (Asch, 2006).

Moreover, as explicated in the literature (Asch, 2006; Aspinall, 2006, 2010; Mouradian et al., 2006) and reiterated by a number of our participants, individuals with CFCs often experience their condition differently from those around them, and, therefore, they may not see the need for “therapy” at all. By recognizing that the therapeutic imperative may drive some surgical practices (Bruce, 2009), pediatric HCPs can broaden the options available to their patients by helping patients and their parents consider whether noninvasive approaches to increasing self-esteem and coping with stigma (e.g., support groups, community advocacy) may be more beneficial (Asch, 2006; Marsh, 2006; Mouradian, 2006; Mouradian et al., 2006; XX, 2008; Aspinall, 2010). In addition, cognitive and behavioral therapy and social skills training also have been found to effect positive outcomes among individuals with CFCs (Kapp-Simon et al., 2005; Maddern et al., 2006; Edwards et al., 2011).

Finally, our participants underscored the significant role that parents often play in deciding whether their children will have elective reconstructive surgery. Some participants encouraged parents to take a proactive approach to surgery to ensure that their children have the best doctors and the best treatments as early as possible. Others felt that surgical intervention to improve psychological well-being should be a measure considered only once the child can engage fully in the decision-making process. Some participants expressed having surgeries foisted upon them; whereas, others were given complete control over the decision. A growing body of scholarship advocates vehemently for the inclusion of children in such decision-making processes (Alderson et al., 2006; Aspinall, 2006, 2010; Mouradian, 2006; Mouradian et al., 2006).

Our data offer empirical support in favor of improved communication among patients, their parents, and HCPs. Caregivers should listen to children and adolescents with CFCs and try to understand how the CFC affects the patient. Given that individuals with CFCs often perceive their condition differently than their parents do, HCPs should make certain that children are undergoing reconstructive surgeries because *they* want them and not due to the potential therapeutic effects such interventions might have on their parents. That children undergo surgery to make others feel better is a sentiment that has been raised by a handful of scholars (Alderson et al., 2006; Asch, 2006), reinforcing our finding as a genuine concern to be taken seriously.

Ultimately, the factors involved in decision making around craniofacial surgery are complex. Circumstances may arise whereby a child does not want a surgery that his or her parents and treating team feel is warranted. In such cases, the treating physician should include a genetic counselor and/or a bioethicist as part of the health care team to help understand and negotiate competing interests. In addition, a suitably qualified HCP should be involved to assess the child’s decision-making competency.

This study design involved a recruitment strategy of convenience. Thus, our sample is not representative of the full spectrum of CFCs. As an exploratory study, it was not designed to represent all individuals affected with CFCs. Moreover, given that participants self-selected to participate in this study, their views on surgery may be different from those of individuals with CFCs who chose not to participate in the study. In addition, we only interviewed individuals at one point in time: Participants were reflecting on past surgical experiences as well as discussing the surgeries that lay ahead. Individuals may perceive their surgeries differently at different times in their lives. Finally, our study sample included individuals with varied CFCs and was too small to make comparisons of findings across conditions. As a result, our findings may not apply to all types of surgeries for all types of CFCs. However, that individuals with distinct diagnoses shared similar stories with respect to emotional and social challenges following their surgeries suggests that such risks are, to some extent, common across CFCs and should be factored into decision making around surgery.

Conclusion

Reconstructive surgery for individuals with CFCs remains the standard of care. Although our findings confirm existing research promoting surgery as a mechanism for increasing self-esteem, reducing stigmatization, and improving function and physical health, we also discovered that such interventions brought unintended and unanticipated emotional and social challenges. Exploring the effects of surgery was not the initial purpose of PAVE, but rather an emergent theme. Additional research on this topic is needed. For instance, the concept of acting in “a child’s best interest” is commonly reflected in medicine. Specifically, what does “the child’s best interest” actually mean in this context and from whose perspective? In addition, further research should aim to identify children’s cognitive capacity to make decisions that have longitudinal implications. Our findings have implications for the design of prospective longitudinal studies to explore the implications of surgical intervention over time; qualitative inquiries that seek to understand parent perspectives towards craniofacial surgery for their children with CFCs; and explorations of how surgical decision making for individuals with CFCs, children specifically, is negotiated.

In addition to illuminating new directions for research in the area of craniofacial surgery for individuals with CFCs, our findings generated concrete advice to health care teams and parents. For example, pediatric HCPs should consider incorporating holistic depictions of risk when discussing reconstructive surgery options with their young patients and their parents. Arming patients and their parents with insight into the possible negative psychosocial outcomes that could result from surgery—and decision making around surgery—affords parents an opportunity to reflect critically on their own motivations behind wanting their children to have surgery; to explore a range of treatment options not only with the pediatric health care team but also with their children; and to help their children develop effective coping strategies to mitigate any unwanted side effects should their children decide to undergo reconstructive surgery.

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FIGURE 1.
Animal lover with a heart of gold living with Sturge-Weber syndrome.

FIGURE 2.
Billing analyst living with Treacher Collins syndrome.

FIGURE 3.
Artist and member of AmeriFace and Operation Smile living with Crouzon syndrome.

FIGURE 4.
Health care quality data analyst/online education system administrator and emergency medical technician living with cleft lip and palate.

FIGURE 5.
Student living with Sturge-Weber syndrome.

FIGURE 6.
Actor living with amniotic band syndrome.

TABLE 1

Condition Descriptions and Possible Craniofacial Surgical Interventions

Condition	Common Characteristics	Surgeries Used
Sturge-Weber syndrome	Vascular malformations of the skin (port-wine stain), eyes (congenital glaucoma), and brain (leptomenigeal angiomas). Seizures and other neurological manifestations are common.	Laser surgeries are performed to lighten the birthmark and decrease potential hardening of the area that can develop over time (Troilius et al., 1998; Hansen et al., 2003).
Treacher Collins syndrome	Malar and maxillary hypoplasia, downslating palpebral fissures and lower eyelid colobomas, microtia and other ear malformations, and hearing loss.	Surgeries to correct micrognathia, underdevelopment of the cheekbones, ear malformations, and other facial differences (Posnick and Ruiz, 2000).
Möbius syndrome	Complete or partial facial paralysis. Some individuals with Möbius syndrome have hand and lower limb deformities.	Facial animation surgery performed that involves the transplant of new muscle tissue into paralyzed region of the face (Zucker et al., 2000).
Cleft lip and palate	Lip and/or palate do not fuse <i>in utero</i> .	Children might undergo surgeries to improve speech, reduce ear infections, and facilitate chewing (Mouradian et al., 2006). Secondary cleft surgeries are offered to improve aesthetics and psychological function (Mouradian 2006; Mouradian et al., 2006).
Noonan syndrome	Short stature, congenital heart defects, broad or webbed neck, cryptorchidism, pectus deformity, lymphatic anomalies, coagulation defects, and other features. Typical facial features include low-set posteriorly rotated ears, wide-spaced eyes, ptosis or heavy eyelids, tall forehead, and short up-turned nose.	Facial features among individuals with Noonan syndrome tend to become less prominent over time (Romano, 2010) and there are little data available about the frequency with which patients choose to undergo craniofacial cosmetic surgeries. However, craniofacial surgeries may be done to correct orbital manifestations of Noonan syndrome in some cases (Randolph, 2011).
Crouzon syndrome	Premature fusion of the coronal sutures leads to proptosis, external strabismus, mandibular prognathism, and midface hypoplasia. Crouzonodermoskeletal syndrome (OMIM #612247) has associated acanthosis nigricans.	Remodeling of skull structures to restore normal anatomy of the skull to allow normal growth of the brain (Renier et al., 2000). Laser surgery may be used to treat acanthosis nigricans in some cases (Kapoor, 2010).
Amniotic band syndrome	Amniotic rupture results in constriction of growth <i>in utero</i> and development of soft tissue deformations affecting the limbs and facial structures.	Craniofacial surgeries to repair rare facial clefts, cleft lip and/or palate, and other craniofacial anomalies. Other surgeries may include rhinoplasty, frontal bone remodeling, and corrective surgery for micrognathia (Morovic et al., 2004).

TABLE 2Demographics for Participants >18 Years of Age^{*}

Variables	n = 28
Education level	
Less than high school	2
Completed high school	4
Some college	7
College graduate	9
Graduate-level education	6
Marital status	
Never married	16
Married	7
Separated or divorced	3
Long-term relationship	1
Widowed	1
Parental status	
Not parent	22
Parent	6

^{*} All participants > 18 years of age ($n = 10$) had not graduated from high school, were not parents, and were never married.