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Face, Normalcy, Identity:

Systems of support for individuals with clefts of lip and palate.

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Systems of support for individuals with clefts of lip and palate

Introduction

The social stigma of facial anomalies, while clearly present in society is rarely openly discussed. As with many forms of disability people seem to prefer to avoid the issue as though doing so makes it disappear. This tactic, however is complicated by the fact that facial anomalies cannot be ignored and must be faced in daily social interaction, even in such ordinary aspects as casual conversation. I cannot truly say when my interest in pursuing this topic began, but it caught my attention early on and has only grown throughout my life, inspired both by my personal experiences and the effects of this stigma I have witnessed. Several key moments stand out sharply, perhaps the strongest of which occurred when I was seventeen years old, when I became fully aware of just how important our faces are to social interaction. This realization happened during a high school project designed to make students examine the varying forms of prejudice that they come across in daily life and then speak about one we had personally experienced. I, born with a complete cleft of lip and palate, spoke about this feature that had been present from the moment of my birth, which I have carried around for all to see because I can never hide it. I spoke about my face and the scars it still bears. For the first time in my life I publically addressed the malformation of my face from such a personal perspective. And I cried. This discovery of how much the difference in my facial appearance had influenced and continued to affect my life has inspired my interest in understanding the greater social impact of facial anomalies.

In his book on *Stigma*, Goffman (1963) shows how humans ascribe a social identity to the people we meet in order to categorize them. He then proceeds to divide social identity into two categories: the virtual social identity, which is assigned merely by visual characteristics, and the actual social identity, which is formed through longer acquaintance with a person and constructed from more than just superficial appearance, (Goffman 1963: 2). Because of the prominence of the face in social interactions, facial anomalies are among the most conspicuous types of physical differences and they often cause negative first impressions. As a result, people with facial deformities suffer severe stigma. Stigma, as Goffman defines it, is the negative associations with a trait or characteristic considered undesirable. As he puts it, “[A person] is thus reduced in our minds from a whole and usual person to a tainted, discounted one,” (Goffman 1963: 3). The visibility of facial deformities prevents them from being hidden and so those who have a facial deformity are constantly subject to social marginalization and isolation. They endure exclusion from normal social relations and often have to deal with reactions ranging from discomfort to disgust. People with these deformities often experience low self esteem, struggles with social interaction, discrimination in the workforce, and an increased unconscious negative bias from others, (De Sousa, Devare, and Ghanshani 2009). These are all consequences of the stigma associated with perceived negative deviations from the norm, especially those as visible as a facial deformity. Facial deformities are not something that can be ignored.

This stigma is a particularly important one to address because of the large number of people it effects. Clefts of lip and palate alone affect approximately one in every 700 children¹. Not only are they the second most common birth defect in the world, but they are

¹ This statistic is for developed countries. In developing countries clefts occur in approximately one in every 350 children.

also the most common facial birth defect. (Parker et al. 2010). The group of people affected by facial deformities forms a substantial part of society and one whose plight has been ignored for too long.

There are two general categories of facial anomalies. The first is congenital facial anomalies. The ones that individuals are born with include: Treacher Collins syndrome,² Microtia,³ Down Syndrome,⁴ Stickler syndrome and Clefts of lip and palate.⁵ The second category is facial anomalies acquired later in life. These often come from accidents, cancer, burns or other physical trauma. Many individuals who grow up looking “normal” struggle to adjust to their new face and the stigma that comes with it. For this paper however, I am focusing on individuals who are born with facial anomalies since they, through growing up with a facial anomaly are, for better or worse, more likely to be shaped by the experience.

The fact that individuals with facial anomalies often have no choice in whether or not to display a physical attribute that distinguishes them from the majority of society sets this issue of stigma apart from others. People often try to present what they consider to be the best aspects of themselves however individuals with facial anomalies do not have this

² “Treacher Collins Syndrome is a rare, genetic condition affecting the way the face develops – especially the cheekbones, jaws, ears, and eyelids. These differences often cause problems with breathing, swallowing, chewing, hearing and speech.” (Seattle Children’s Hospital Research Foundation)

³ “Microtia is the incomplete development and growth of the outer ear. This can lead to a small, abnormally shaped or absent ear. It usually involves one ear although both ears may be affected in some children.” (Seattle Children’s Hospital Research Foundation)

“Microtia and Atresia usually occur together[...] Atresia means no ear canal.” (Microtia: Congenital Ear Deformity Institute)

⁴ “Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome. A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single crease across the center of the palm – although each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all.” (National Down syndrome Society)

⁵ “A cleft lip is an opening in the lip. A cleft palate is an opening in the roof of the mouth. Clefts happen because of incomplete development of the lip or palate while the baby is forming before birth.” (American Cleft Palate-Craniofacial Association). A person can be born with just a cleft or cleft palate, or a combination of the two.

option and must always challenge stigmas during social encounters. A study examining facial deformities and plastic surgery emphasized this point:

Once the standards of normality and abnormality are determined- in this case what constitutes an attractive face or an ugly one- we must recognize the important role of visibility as it functions in the interactional processes between the disfigured individual and those with whom he comes in contact. One of the basic difficulties associated with facial deformity evolves from the social perception, that is, what a person appears to be to others, and the impression he gives because of his looks. (MacGregor et al., 1953, p.63)

There is a common perception of an association between physical deviations from what is considered to be a normal appearance, and intellectual, emotional or other shortcomings; one is often seen as a sign of the other even when there is no evidence in a particular case. This association is related to the idea that there is an average or normal person, or in this case a set of physical characteristics and that this “norm” is considered desirable.

The concept of a norm... implies that the majority of the population must or should somehow be part of the norm [...] So, with the concept of the norm comes the concept of deviations of extremes. When we think of [difference] in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants. (Davis, 2010, p.6)

Since the normal distribution is arranged on a bell curve it is implied that these deviations from the norm can be either positive or negative. Most individuals fit inside the curve but a small portion reside in the tails, above or below the main cluster. The people in the main cluster are generally seen as healthy, reasonably intelligent, functioning members of society. Those who fall above the norm are usually people whose deviations are considered positive; for example: geniuses, musical or artistic talents, professional athletes, and physically attractive individuals. Paradoxically, although these people technically fall above

the general distribution of the normal curve, they often are held up as a standard of an ideal normalcy that the rest of humanity should strive to achieve, (Connell 1995, p.70). Negative deviations are seen as those that fall below the main curve. "By contrast, the *grotesque* as a visual form was inversely related to the concept of the ideal..." (Davis 2010, p.6) and represents the discomfort which anomalies, especially those as visible as facial anomalies, arouse. When compared to the idealized norm they become even more severely inferior. Examples of the association with these negative deviations are, lower than average intelligence, physical deformities, and mental disabilities. These characteristics often shape how the individual is perceived, beyond the characteristic itself, "We tend to impute a wide range of imperfections on the basis of the original one," (Goffman 1963: 5). Because of this many people with physical disabilities are viewed as meaner and less intelligent than those without physical anomalies, and, in turn, mental disabilities are often associated with ugliness.

Physical differences such as facial anomalies, however, are almost uniformly perceived as belonging to the negative end of the spectrum. There are multiple labels that are used to describe these differences or scars with deformity, malformation, and disfigurement being just a few. Many of these, even simply using the word "difference" have a negative connotation because they imply a deviation from the norm. I have chosen to use the term facial anomaly, not because it is perfect, but first because it was recommended to me by some of the healthcare professionals I interviewed, and second because it can be applied to all of the varying physical differences. In the quotes taken from interviews they are described both as anomalies and deformities since the decision to use the word anomaly instead of deformity was made during the course of the research. I also refer to

individuals with facial anomalies both as individuals when I am speaking generally, and as patients when I am describing them in relation to something said by healthcare professionals since their relationship is that of caregiver and patient.

This study is an inquiry into the types of stigma experienced by individuals with facial anomalies, most specifically, clefts of lip and palate. In addition, this study examines the types of support available to these individuals to help them deal with the stigma and what additional kinds of supports healthcare professionals believe could be helpful. I chose to research this topic because I believe that a better understanding of the stigma associated with facial anomalies can improve our ability to counteract it.

Methods

This study explored the significance of congenital facial anomalies by seeking information from healthcare professionals who cared for children and adolescents with such anomalies. A semi-structured interview was developed to focus on three topics: the stigma of facial anomalies, the systems of support for individuals with facial anomalies, and what forms of social support are still needed. I chose to focus, in particular, on these three topics because I believe that together they describe the problem, what is currently being done about it and what should be the focus of further efforts. Because this project involved human participants IRB approval was obtained prior to the start of the study.

Overall I conducted eleven interviews both with people that I had known in the past and new contacts made during my research. I used snowball-sampling beginning with individuals that I knew from my own years as a patient, or knew to have worked with these individuals and through them reaching out to others who had also worked with these

individuals and could speak to their experiences. I tried to speak with a diverse group of medical professionals in order to gain a broader understanding of the issues. Out of my eleven interview participants, five were physicians: two surgeons, two pediatricians, and one psychiatrist; the rest were allied healthcare professionals who regularly participate in cleft panels or in the care of children with facial anomalies: one a genetic counselor, two speech pathologists, an audiologist, a social worker, and an orthodontist. Six of the individuals I spoke to worked on craniofacial panels and all had experience working with patients with some form of facial anomaly, most commonly clefts of lip and palate. Though I did not specifically seek them out two of the interview participants themselves had facial anomalies. Both chose to speak from personal as well as professional experience when talking to me and I made sure to gain specific consent to record and use their personal experiences in my research. For convenience, the interview participants came predominantly from the Sacramento California area.

I created an interview guide (see Appendix B) which I used to help direct the interviews. The interviews were conducted individually, in person or by telephone or Skype. At the beginning of each interview I read the consent form to the participant and obtained clear verbal consent. The complete structured prompt included follow up questions which I used as necessary to elicit information but omitted if the topics were covered in the natural flow of conversation. When the participants raised relevant topics on their own I followed their lead rather than impose a structure that might interrupt their train of thought. Many of the participants seemed knowledgeable about the social ramifications of facial anomalies and seemed eager to discuss their perspectives. Each

interview was recorded using both audio and written methods and the audio recordings were later transcribed.

Results

The Stigma of Facial Anomalies

All of the individuals I spoke to agreed that stigma is an issue for individuals with facial anomalies, though there were varying opinions as to how much it affected the individuals. The stigmas they described were: the negative judgments that are caused by the visibility of facial anomalies, the self-consciousness and lack of confidence that can arise as a result of awareness of those judgments, the perceived connection between cognitive function and physical appearance, and the social exclusion that can come from difficulties with communication due to verbal articulation errors common to individuals with facial anomalies. Finally, while the professionals I spoke to clearly acknowledged the stigma that these individuals are subjected to they were also quick to assert that this stigma does not dominate the lives of these individuals and that many of them choose for themselves how much to allow it to impact their lives.

Visibility

The visibility of facial anomalies is one of their most significant characteristics (Goffman 1963: 5) felt that humans are inclined to take one perceived negative characteristic as evidence of the existence of others. Since facial anomalies are so visible they are an easy characteristic for this type of association. Three of the professionals I interviewed spoke specifically about this association and the impact that it has on

individuals with facial anomalies. The psychiatrist, for example explained why and how those anomalies matter:

Yeah. I do. I absolutely do think that and you know the thing is there's been lots of studies that have backed up the notion that people who are considered classically beautiful or people that have facial symmetry tend to be thought of as more intelligent, more capable. They definitely have a bias in terms of people responding to them in a more positive way, so I think having something on your face- humans are biologically oriented since birth to first look at the center of the face- so I definitely think having a deformity on the face is more impactful in terms of how people respond to you than if it were say a limb or another part of the body. (Psychiatrist)

Many of those I interviewed told me that the patients they worked with felt that people judged them based on that one aspect of their physical appearance. In particular the two people I spoke to who not only worked with these individuals but also had facial anomalies themselves, spoke strongly about the impact it had on their everyday interactions with friends, colleagues and strangers. They spoke of a constant awareness of the stares they and the patients they work with get on a regular basis:

Even just walking down the hall to show the child where to pick up their medicine we got so many stares and I'm just like- we're inside a Kaiser facility. Imagine if we were outside at Target or something? (Social Worker)

It is well known that people make quick judgments about others based on physical appearance such as skin color, dress style and obvious disabilities, because of this the stigma of facial anomalies is amplified by their conspicuousness during social interaction. This visibility of facial anomalies can lead to individuals being self-conscious of their differences to the point that they are uncomfortable when engaging in social interactions.

Self-consciousness and social interaction

More than half of the professionals I interviewed spoke of how this self-consciousness about their physical appearance affected the patients with whom they interacted. Although some individuals did fine, others clearly showed signs that it was difficult for them to deal with the attention their anomaly received. These individuals were described as more shy and more introverted and one of the surgeons I spoke to gave examples of concerns he had heard patients voice: “This affects my confidence, what can we do to make it better? I don’t like it. Other people see it and I see it,” (example of patient concerns from my interview with the First Surgeon). It is also worth noting that the patient’s concerns seem to be less focused on the anomaly itself and more on societal reactions to it.

There was some disagreement about the age at which individuals began to raise concerns, or as many of the healthcare professionals told me, their parents began to raise concerns that they had mentioned at home. Typically, it seems that individuals become conscious of their facial anomaly around the age of five or six however the majority of the people I spoke to said that it isn’t until the twelve to fourteen age range, right about the age at which individuals begin attending junior high, that they truly begin to voice concerns about their appearance:

Its usually junior high age when they’re- I think the kids both boys and girls become a little bit more self-aware at that age. Probably how they look becomes more important. They’re probably more picky and potentially they start to like boys and girls then it becomes a little bit more of an issue of how they look. (Second Surgeon)

This issue of being concerned over appearance is particularly impactful for individuals with facial anomalies as adolescence is a time when many individuals are focused on realizing an

ideal of normalcy. Because of their conspicuous difference and deviation from this prized concept of a norm they can feel an even greater sense of self-consciousness:

A longing to just fit in and seem normal and there's always this thing that is literally right on your face that it seems like people always want to ask you about or it seems that people don't stop looking at. And I don't need to tell you that during adolescence especially 11 to 13 or 14 that's a time developmentally when everyone dresses the same, tries to be the same and you don't want anything that makes you stick out... (Psychiatrist)

Over half of the healthcare professionals spoke of seeing this self-consciousness and lack of confidence in some of their patients and it seems likely that the struggle to fit the established concept of normal is a major part of why adolescents seem to be the ones most often raising concerns about their facial anomalies.

An interesting comparison can be made between the descriptions of patients and stigma from the United States of America and the descriptions of patients and stigma seen by the healthcare professionals who have worked on missions abroad. The members of craniofacial missions to countries where surgical repairs are not as easily accessible described more extreme cases of stigma and its effect on individuals. There they described children being unable to attend school and adults unable to get a job because of their facial appearance. They also described how these individuals constantly tried to cover their mouth and nose with hands, hair or clothing in an attempt to hide the malformation. These unrepaired clefts of lip and palate are much more obvious than the scars that remain from the surgical repair that are readily available in countries such as the United States, western Europe, and Japan. From their perspective the more extreme the deviation from "normal" the more extreme the social reaction. While the stigma is much more obvious in these

examples it is by no means less pervasive here in the United States simply because repaired anomalies are not as visible.

The perceived association between cognitive function and facial anomalies

When I asked about specific stigmas during the interviews the one that was mentioned most frequently was the perceived connection between intelligence and the symmetry of a person's face:

It would be like people thinking they were not as smart because they had a cleft or their speech articulation being poor and so they can't be understood. Or they feel they can't get a job because of their cleft. And I'm not saying that's true but that's what they relay back to me. (Genetic Counselor)

Intelligence is one of the most common associations and likely one of the most impactful on a person's life. As mentioned above, it makes it difficult for someone to get a job if the interviewer's bias is to assume that they are not as smart as other "normal" looking applicants. All the healthcare professionals who I spoke to made it clear that no such connection actually exists. The association between facial anomalies and intelligence is likely related to the prominence of the face in interpersonal communication. When people talk to each other it is socially correct to look at the other person's face, which makes it harder for someone to attempt to ignore that which they may perceive as a deviation. In reply to a question about whether she thought that the stigma was worse because it was a facial anomaly, a speech pathologist with extensive experience in the education system said this:

Yes...[facial anomalies] make it worse because I think anything associated with the head the neck the face- I think [people] directly relate that to the brain as opposed to someone who only has one arm or is in a wheelchair. If someone is in a

wheelchair I don't think people jump straight to the idea that it could be related to brain injury or some kind of a brain defect. I'd say yes, definitely- if there is going to be a stigma it is going to come more from the face. (Second Speech Pathologist)

For individuals with facial anomalies it can have a huge impact both on the way they are perceived by society and on the way they perceive themselves as a result. The Second Speech Pathologist also pointed out that people rise to meet expectations. In a society in which expectations for success for individuals with perceived negative deviances are often very low, individuals with facial anomalies are not encouraged to strive for success. Thus I believe that this stigma created by the lack of expectation for the intellectual capabilities of individuals with facial anomalies would be particularly detrimental to these individuals.

The speech connection

Before conducting this project I had been focused solely on the visual aspect of the social perception of individuals with facial anomalies. My interviews with speech pathologists, in particular raised the issue of another type of stigma that I discussed primarily with the speech pathologists, though it also occurred in some of the other interviews is the relationship between facial anomalies and difficulty with speech. Facial anomalies not only have a physical component but they also often have an oral or auditory one as well. As I was told many times in my childhood "It's all connected." Many individuals with facial anomalies struggle to learn to produce sounds in ways that their "normal" peers do not. Unlike the common articulation errors that many children make, these effects are unlikely to disappear with age and thus require intervention by speech pathologists to help the individual learn to pronounce certain sounds. Though not related to appearance, speech plays an important role in how an individual is perceived by those around them.

The first speech pathologist I spoke to described how this barrier to communication could have a profound effect on a child's early socialization. Parents can be apprehensive about enrolling their kids in pre-school programs or other activities for fear that they will be ostracized because of their early difficulties with communication. This fear does not seem unfounded; many of the people I interviewed expressed the sentiment that "kids can be cruel" as one of the main problems faced by children with craniofacial anomalies.

Although not universally agreed upon, the vast majority of the individuals I interviewed agreed that the stigma of facial anomalies remains a part of the experience of having one. These stigmas, and reactions to stigmas, show that facial anomalies can have a profound effect on the individuals who bear them.

Resilience and Empathy

While it is rarely explicitly stated, this idea that facial anomalies have solely negative effects on a person's life is not uncommon. The majority of the people I interviewed argued against that belief. It is easy to hear about these struggles and assume that having a facial anomaly is the defining force that shapes these individuals lives, however the healthcare professionals I spoke to made it clear that while certainly not trivial, the majority of their patients did not feel that the effect on their lives was so overwhelming. Though this information is primarily collected from individuals with an outsider's perspective these doctors and specialists have extensive experience with patients with facial anomalies and in some cases have been present for most of the repair process. They spoke of how these individuals made it clear that they did not solely want to be judged on this one characteristic because it alone does not encompass all of their identity. While many people

spoke to the issues that are faced by individuals with clefts, they made it clear that the impact these issues had on an individual was strongly dependent on how the individual chose to confront them.

My personal experience is that it poses a challenge for the patient and certainly can make the social aspects of life and things like that a little more difficult but I find that most people can compensate and overcome these challenges and they can do it very well, actually. A lot of it is just the confidence a person has in themselves. (First Surgeon)

This assertion is especially important because it contradicts the assumption that individuals with facial anomalies are victims of their deformity or malformation. The healthcare professionals described how these individuals became more empathetic towards other people because of understanding gained through their experiences with clefts of lip and palate. They also described individuals with facial anomalies as more likely to be aware of what others around them might be struggling with:

I think this is something that for younger kids and, of course, middle schoolers is really hard to wrap your head around but as you age a little- I think older teenagers can get this- is that we develop compassion in so much as we struggle with something. So what you struggle with becomes a point of connection with other people and they may not have had the same thing you had and that's the thing with a facial deformity... but that having something that you struggled with is a source of compassion. "Hey, I struggled with this. I understand maybe your struggle- you're a kid that has diabetes-" or you know "depression or you've lost a parent. We all have things that have made our life harder" and that can be a point of connection rather than alienation. (Psychiatrist)

Additionally, several of the healthcare professionals I interviewed spoke about the resilience displayed by individuals with facial anomalies. The visible scars and the long, often painful, medical treatment and repairs are for many people just more challenges to overcome. This is not meant to imply that the facial anomaly disappears in any sense,

however, it seems that especially when given support, individuals with facial anomalies can make that difference something that they can learn from rather than a burden that weighs them down.

Systems of Support

Nearly all of the healthcare professionals I interviewed agreed that social support is fundamentally important to an individual's success. I chose to focus on social support because it is one of the areas of this field that has not seen as much research. Medical has historically been prioritized and continues to be so today with social support often treated as a component of the medical support. The amount and type of social support an individual receives is often dictated by the structure of the medical care they are simultaneously receiving. This system of medical prioritization can lead to a lack of effective social support, in many cases because the healthcare professionals simply don't have the time or resources. A range of types of social support were described, the ones most frequently referenced were: prenatal testing, the online blogs that connect parents and individuals with facial anomalies, and the support provided by the parents and family of the individual with a facial anomaly.

Types of Support

My interviews led me to conclude that there are two main forms of support for individuals with facial anomalies, medical and social, which are becoming increasingly interconnected. Medical support involves the craniofacial teams and other medical professionals who work on the physical repair of the facial anomalies. The social support is

provided by the therapists and social workers as well as family, friends, teachers and even strangers. I include strangers because many of the people I talked to, in particular the ones who had facial anomalies themselves, spoke of how the stares of strangers on the street could be a constant negative reminder of their difference. A greater social awareness of what it actually means to have a facial anomaly could be enormously helpful to mitigating the current stigmas. There is a bit of overlap between these two types of support as therapists and social workers are still part of the support provided by the medical field yet they are also one of the principal forms of social support and for some individuals they are the only one.

Craniofacial panels are one of the most important aspects of the medical support. They are multidisciplinary panels composed of physicians, speech pathologists, audiologists, social workers, genetic counselors, orthodontists and others who meet with individuals with facial anomalies and evaluate the repair process. The frequency of these meetings varies from patient to patient, usually between once a year and once every few years. These meetings function both to check in on the individual as well as plan further treatment. Some of the people on craniofacial panels that I spoke to suggested that more frequent meetings might be useful to help make sure that the individuals are not suffering from stigma because of their facial anomalies. While at first primarily focused strictly on the physical repair process they have grown to accommodate the social aspects of patient support as well. However, the focus remains on the physical anomaly and medical treatments.

Social support for individuals with facial anomalies still comes mostly from family and friends. While social workers and therapists are important parts of the craniofacial

panels and do monitor the progress of patients with facial anomalies, they only see the individuals for infrequent evaluations and therefore support during day to day social interaction mostly comes from less formal sources.

Prenatal testing

One of the most commonly mentioned forms of support for individuals with facial anomalies is not actually directed at the individuals themselves but instead their parents. Prenatal testing which allows doctors to detect the probability of facial anomalies prior to birth has apparently been an important change that has evidently been very effective for helping parents support children's facial anomalies, particularly clefts of lip and palate. One physician explained that by better preparing the parent they can help ensure that the child has people ready and willing to be supportive from the moment of their birth:

I think the psychosocial stuff is not just for the patients but for the parents as well and I think by having the pre-natal diagnosis it really starts the process and I think we can get the shock value and the problems that they're going to face out right away. We talk to them about what's going to happen. We talk about surgery, I show them before and after photos and I talk to them about what's going to happen and when the baby is born its not a surprise and the parents can enjoy the delivery and not be surprised and scared and they can know what to look for and know that everything is going to be okay. (Second Surgeon)

Not only does this make the parents less scared during the delivery but it can also help parents move past the anomaly itself and understand what a cleft is and how it will affect the lives of their children. This also gives them a chance to connect with other parents of children with facial anomalies prior to the birth of their child.

Online parent support groups

I was at first surprised to find that the majority of the online support groups are not geared toward helping connect individuals with facial anomalies, but rather the parents of these individuals. However, as one professional explained it to me, in many cases they are the first ones to need social support:

Physician: The surgeries when you're a new born, three months old, five months old... You had a cleft palate right?

Interviewer: Yeah. Lip and palate. The whole deal.

Physician: You don't remember those things right. I mean you don't remember any of it. But your parents do. I bet your mom has specific- very specific, very vivid memories. So I think this kind of a thing can be hard on the parents and I think that's probably where that stems from. (First Surgeon)

While parents are often the ones in charge of providing emotional and social support for individuals with facial anomalies they rarely actually get any kind of instruction in how to do this. While there are websites that provide materials on subjects such as stopping bullying, these online support groups seem to be one of the main places that parents can ask questions and talk with people who have or are going through the same experience. Because of this these groups appear to be an important and effective resource for helping parents provide support for their children:

It's a very difficult role for parents as you probably know because they still have to be the parent but they also have to be an advocate as you probably know. They take on a very challenging role in my opinion where they have to play so many different roles in educating themselves on what needs to happen and then advocating for that, working with insurance companies which is always a nightmare and then working with all these different doctors and all these different panels and all these different panels or specialists who all have their own opinion whether its surgery or ENT or orthodontists- it covers so much that just managing that is, I think, a massive

undertaking as a parent. Plus- you're emotionally involved in this as a parent. (Orthodontist)

The importance of a parent's role as the primary advocate for children with facial anomalies is often overlooked. Through connecting parents and giving them a place both to ask questions, and sometimes ask for help, these support groups play an important role in ensuring that parents can, in turn, support their children with facial anomalies. These support groups, are of course, not specific to parents and often include individuals with facial anomalies as well. However, in general, parents appear to be more active contributors and beneficiaries of these groups.

Family Support

The idea that how much of an impact the facial anomaly has on an individual's life is related to the support they are given is one that came up strongly in about half of the interviews I conducted. The healthcare professionals that I interviewed emphasized the importance of strong support systems for individuals with facial anomalies, often connecting an individual's wellbeing to the social support provided by their family and friends.

Some teasing can happen because of it, but ultimately it's really in the hands of the person in the end. I find that patients who are well grounded, who have confidence and good support can overcome that and really just move on with their lives and be very successful in whatever they're doing. I find that patients who don't have those things can become more affected by the fact that they have a little bit of asymmetry to their nose or a scar on their lip. (First Surgeon)

These healthcare professionals focused in particular on how the individuals who did have strong support systems seemed in general to be happier, more confident and less affected

overall by having a stigmatizing facial anomaly. When asked specifically about whom he believed provided this support for individuals with facial anomalies one of the physicians I interviewed said:

I think the family all together. Parents, brothers, sisters, aunts, uncles cousins. The most successful ones I see are the ones that have a very strong family situation. (First Surgeon)

Parents are often the most important role models in a child's life and the way they handle the child's facial anomaly can influence the way the child does. The healthcare professionals I interviewed told me that parents who are open to the challenges, yet still treat their children as capable and intelligent, often raise children who do not feel severely impacted by their facial appearance.

On the other hand, parents who focus too much on the scarring or asymmetry often reinforce the individual's own concerns. During my conversation with the social worker she described a patient who has had multiple surgeries, which have left her face virtually without a mark. She feels comfortable with her appearance and her doctors are satisfied with her repairs but her mother continues to push her to have more surgeries saying that she can still see the scars. The social worker described how this lack of support from the patient's mother hurt her self-esteem and even, at times, reduced her to tears. They often described individuals who did not have strong support systems as quieter and less comfortable with their appearance. They are the ones that try to cover their faces and state that they dislike the stares they get. While even individuals that seem more comfortable with their facial asymmetry make it clear that they are aware of the way strangers look at them, it seems that the people who do not have as much social support struggle to deal

with the sense of stigma that results from the attention paid to the asymmetry of their features.

What is Still Needed

One question that I was particularly interested in answering was what systems of support the healthcare professionals believed were still needed for the patients with whom they worked. The ones most often repeated were: increased connection and communication between individuals with facial anomalies, better communication between the patients and their doctors, and education for parents and in schools. The second point was particularly emphasized by an audiologist who spent part of her career working in a school and therefore was able to observe the interaction between individuals with facial anomalies and their peers in a school environment.

Increased Connections and Communication Between Individuals with Facial Anomalies

Healthcare professionals across the board emphasized the importance of networks for individuals with facial anomalies. As explained earlier, there are a number of these that exist but many of them focus more on supporting parents than on the individuals themselves. This is understandable since much of the repair process happens during a person's early childhood when it is the parents who can benefit most from this type of support system. The parents involved in these kinds of groups share stories, recommend specialists and even bring food to new parents or to help out when a child is having a surgery. The role that these groups play in supporting parents, and through them the individual with the facial anomaly, is clearly important, yet they are limited in that they are

not official parts of the craniofacial teams and are therefore dependent on the involvement of parents in a given area. Also, despite the progress they've made connecting the parents with each other, they do not seem to have been as effective at connecting the individuals themselves with their peers. A number of the healthcare professionals I interviewed spoke of how their patients felt lonely, that they did not have someone who truly understood what they were going through (both medically and socially). For these reasons many of the healthcare professionals I spoke to recommended online groups that focus on connecting individuals with facial anomalies with each other to give more of them the opportunity to share support with others who have been through the same experiences.

Increased Communication Between Patients and Doctors

Although not specifically mentioned as something that needs to be worked on, many of the healthcare professionals I interviewed described sometimes having difficulty talking to the patients themselves rather than the parents or other adults in the room. This is not surprising, as the repair process for many facial anomalies that are present at birth, begins during the patient's childhood. Obviously, at this time the child is not capable of making decisions themselves about their treatment but the healthcare professionals I spoke to, in particular the pediatricians, surgeons, and orthodontist, spoke about how they often struggled to engage with the patient. The parents often act as intermediaries, between the patients and doctors communicating with the healthcare professionals what their children have told them previously. One of the surgeons described worrying that the younger kids felt intimidated in his presence and the orthodontist with whom I spoke described how

many of the children with facial anomalies that he sees seem to be “burnt out on doctors” by the time they reach him.

But it's difficult for patients. One of the challenges for patients who have been through the whole cleft lip and palate experience even by the time I see them they've already been to so many doctors and they are so tired of it and they are so sick of all the different things that have happened and that they know will happen and it's hard because they are already burned out on it. Sometimes by age 7 they're already sick of the whole doctor thing. (Orthodontist)

While this attitude is completely understandable and from my own personal experience with the repair process I can say that I certainly felt that way, it is concerning how common it seems that people with facial anomalies struggle so much to communicate with the professionals who are reshaping their faces.

Better Education for Parents and in Schools

Many people said that education aimed at informing people and therefore reducing stigma was one of the most important forms of support still needed. Various forms of education were suggested, from educating the parents or caregivers about the implications, both medical and social, of having a facial anomaly to educating the school systems and through them the greater public. The medical education for parents is improving with clear guidelines for aspects of care such as how to feed infants with facial anomalies, the social guidelines are less clear, particularly because they are often so dependent on each individual situation. While there are websites such as the one created by the Cleft Palate Foundation that provide links to information about preventing bullying and guides to help improve self-esteem, they often do not have the same kind of in-person support as the medical aspects. This leaves the parents or guardians, particularly those with fewer

resources to begin with, learning how to provide social support when they themselves are still struggling to come to terms with caring for a child who, at least early on, requires greater care. Furthermore, in addition to being caregivers for the children they are also required to be advocates in the school system:

And those other ones that don't have that support- the grandparents or the aunts don't know how to go to the school and talk to the teachers so I have to step in because they are telling me "I feel so alone." And some of them have had suicidal thoughts so I have to bring it up to the people they're living with, say "You have to be more aware of what's going on with her. She's not happy at school. The school doesn't know about certain things and people are making fun of her speech."
(Social Worker)

Unlike with the medical aspects of patient care, advocating for an individual's fair treatment in the school system falls predominantly to the parents or guardians. This means, that while some people receive extraordinary levels of advocacy and support, others do not. Further, the social worker I spoke to said that the socio-economic status of the family could have an effect on how well an individual dealt with the stigma of facial anomalies. In particular she said that children from impoverished families were more at risk since they did not have access to the same resources. This makes it more difficult for both children and their parents to cope with the extensive repair process of a facial anomaly. To ensure that this unequal advocacy does not affect children as strongly several of the individuals I spoke to suggested increasing the awareness of teachers and school systems about the challenges faced by individuals with facial anomalies.

Because of the greater visibility during childhood before the repairs are complete one of the most important places to focus diversity education is in schools. This was a particular focus for the social worker and the speech pathologist that had worked in the

school system since they heard the most from the children about the stigma they faced in classrooms:

But a lot of the patients when they're younger you know little kids are more open to talking and its also, you know the severity of their cleft lip or if they have any other facial anomalies its depends too how the parents raise them- what kind of school they go to. But some people when they raise them they still face whatever – the teachers looking shocked, not coming near them. A lot of them say, "They don't think we notice that they're staring at us" and the kids are like "We can tell by the corner of our eyes that they're staring at us" but they choose to ignore it and move on. But some of them even try to educate their school. They say "It's better if you come and ask me questions I can try to educate you, you don't have to stare." And it's also up to the school to educate, I think too. (Social Worker)

While it is admirable that these individuals are often advocating for themselves, this is undeniably not something that they should be required to do. They cannot devote the same focus and energy to succeeding in school and extracurricular activities if they are simultaneously challenging stigmas. The speech pathologists, in particular, advocated the importance of widespread and continuing diversity education in school systems:

I think, unfortunately, a lot of day in our schools there's a lot of teasing and even though we've done a whole lot to educate kids about diversity I don't know that we've done a good enough job ... Well I probably- I'm not going to say "failed" I think it needs to be continually present because every few years we have a new crop of kindergarteners and first graders and second graders. I have a 4 year old grandson and I think even at that age that its really important we talk about differences, that some people were given this gift and some people were given that gift and you know this is how we need to approach our interactions with them. Because I think sometimes we fail to talk about it. It's so obvious and then that sometimes makes people think that there is something wrong with them because no one is bringing that up. (Second Speech Pathologist)

Improving the education within school systems would not only likely have a profound impact on the reduction of bullying but it would also help create a more aware and understanding and supportive society. Simply reducing the negative stigma associated with facial anomalies would relieve a large amount of the social challenges faced by individuals with facial anomalies.

Discussion

I began with a question regarding the presence of stigma in the lives of individuals with facial anomalies, the support they currently receive to help deal with that stigma and what support might still be needed in order to help these individuals thrive in a society that values the ideal of normalcy. Through that research I've confirmed that facial anomalies are associated with significant stigma and that this stigma has considerable impacts on the lives of individuals with facial anomalies. I have learned that many of the current systems of support are focused on the parents of individuals with facial anomalies as they are the primary source of support for the individuals themselves. I was also informed that the main ways types of support still needed are: more communication between individuals with facial anomalies so that they can help support each other; better communication between healthcare professionals and patients since they are the ones who can for the most part, best communicate their needs; and increased education for parents and school systems so that they can be supportive and work towards reducing the general stigmas surrounding facial anomalies.

Future Research

In continuing research I would be interested in speaking with parents of individuals with facial anomalies as well as focusing on the lived experiences of the people themselves. It will be particularly interesting to see how the perspectives of healthcare professionals relate to personal experiences. While the healthcare professionals had the advantages of having seen many patients with facial anomalies as well as expertise gained by years of working with these individuals, they cannot provide as clear an understanding of what it is like to grow up with a facial anomaly and the stigma that is associated with one. Although two professionals I spoke to did have facial anomalies themselves, my research was not focused on their personal experiences and so the discussion focused more on their patients, though their own experiences certainly influenced their responses and led to some interesting discussions.

In a future research project I would continue to conduct ethnographic interviews focusing on the experiences of individuals with facial anomalies. In particular looking at what types of stigma they have experienced, how they feel that they experience this stigma and how it has impacted their lives, and the kinds of support that have been accessible to them as well as how that support has affected them. I would also be interested in examining how these individuals perceive their own facial anomalies. I would conduct these interviews with individuals over the age of eighteen since they could talk about their experiences growing up as well as how they feel now. Overall my focus would be on the personal experience with facial anomalies and the associated stigma.

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Appendix A

Verbal Informed Consent Script

Hello, my name is Ariane Farris. I am a student at the University of Puget Sound and I am conducting a project studying the normalcy and stigma tied to the identity of facial deformities, specifically that of cleft lip and palate. I am interviewing members of craniofacial panels, as they are the ones who work most closely with individuals born with cleft of lip and palate. I would like to talk to you about your interactions with individuals with clefts of lip and palate, the standard treatment guidelines, and the systems of support that already exist as well as what is still needed. I will use the information gathered to produce a paper that will be published in Sound Ideas and my findings will be presented at the University of Puget Sound Fall Arts, Humanities, and Social Sciences Symposium.

I would appreciate it if you would take the time to participate in this interview. With your permission I will make an audio recording of the interview. I am the only one who will hear the audio recording. I will delete it as soon as I have transcribed the conversation. Pseudonyms will be used on the transcription and identifying information will be changed for the sake of confidentiality. Although the interview may touch on personal topics you are not obligated to answer any questions that make you feel uncomfortable. If you want to stop at any point, please let me know. We can take a break or stop the interview completely. That's fine with me, so don't worry about it. There will be no compensation for this interview or for other participation in this project. The interview should take approximately 30 minutes.

Do you have any questions? Are you willing to participate in my study?

Unique interviewer ID# _____

Interviewer's Signature _____ Date _____

Appendix B

Interview Guide

1. Personal experience with patients with facial deformities/clefts of lip and palate.
 - a. How long have you been doing this work?
 - b. In what capacity?
 - c. What is usually the duration of your work with a single patient?
 - d. What, if any, kind of additional contact following termination of treatment do you have with the patient?

2. Perspectives on the social impacts of facial deformity.
 - a. Do you perceive having a cleft to have an impact on your patients' identity or sense of themselves? If so how?
 - b. Do you believe that the process of cleft treatment including surgical repair, dental, speech therapy and others, have an impact on the patient's sense of identity?
 - c. What kinds of impacts?
 - d. What kinds of things do your patient's do or say that give you this sense?
 - e. Are those impacts negative? Positive?
 - f. What forces seem to shape patient expectations of the outcome of their treatment?
 - i. What do you notice about social (particularly media) portrayals of facial deformity? How do you see your patients respond to media representations of facial deformity. Is this something that comes up as part of your conversations about treatment outcomes?

3. Perspectives on the concerns of the patients
 - a. What concerns do the patients or their family's raise about the patient's appearance before, during and after treatment?
 - b. Do your patients mention concerns about their physical appearance and how it is viewed by others?
 - i. If yes, what can you tell me about the kinds of concerns they mention? For example do you hear reports of people being or worrying about being teased, bullied, or excluded?
 - c. Do your patients mention concerns about the social disruptions caused by treatment; for example times out of school for surgeries, speech therapy, etc. Do they mention concerns about how this is seen by peers?

4. Do you think children with clefts need some kind of support because of the social consequences of having a cleft?
 - a. If yes, what kinds of support?
 - b. If not, why?

5. Existing support systems. (Specific types of support)
 - a. What types of support systems are available to children and adolescents with clefts?

- b. How are they effective
 - c. How are they ineffective?
- 6. The support systems that are still needed. (Specific types that are still needed)
 - a. What is needed to make them more effective? Why?
- 7. Have you ever worked with children with facial deformities in other countries?
 - a. How are the social experiences of children with clefts different for patients in those countries as opposed to patients you treat here?
- 8. Is there anything else that you think I should know?
- 9. Is there anyone else that you know who might be interested in being interviewed for this project?