"The Elephant in the Room": Disclosing Facial Differences

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Abstract

Due to high visibility and low public awareness, people with facial differences (FD) frequently face decisions about whether to explain or disclose their FD. Although disclosure of concealable stigma has been frequently researched, little work has examined disclosure from the perspectives of people with FD, whose stigma is often not concealable. Thematic analysis was used to explore semi-structured interviews of adults ($n = 16$) with diverse FDs. Disclosure approaches varied dependent on the discloser, the disclosee, and context. Two themes illustrated participants' approaches to (non)disclosure: *agentic* and *autonomous*. Agentic described when participants felt they had no choice in explaining or not explaining their condition, which fell into subthemes of *forced disclosure, forced nondisclosure*, and *unauthorized disclosure*. Those who used autonomous approaches made the deliberate decision to disclose or not disclose their FD to others. Autonomous subthemes included *social avoidance, concealment, false disclosure, selective disclosure, indiscriminate disclosure,* and *broadcasting*. Three experiential themes — *misunderstanding*, *connection*, and *empowerment* — characterized antecedents, experiences with, and consequences of (non)disclosure. Agentic (non)disclosure and autonomous (non)disclosure were frequently associated with the misunderstanding theme, while autonomous disclosure involved themes of connection and empowerment and was thus experienced as more beneficial. Participants' advice was to allow people with FD disclosure autonomy. Improved social representation of people with FDs, public awareness, and stigma reduction will help remove the onus of disclosure from individuals with FD.

Keywords: facial difference, facial disfigurement, disclosure, stigma, visible difference

"The Elephant in the Room": Disclosing Facial Differences

Researchers have often studied the disclosure of concealable stigma — that is, revealing something that was previously hidden (Corrigan & Rao, 2012). But what if the difference is "plain as the nose on someone's face"? Facial differences or disfigurements (FD) are highly salient because they affect the face, a symbol of identity and focus of attention during social interaction (Bogart, Cole, et al., 2014; Clarke et al., 2013). People with FD routinely encounter others' stares and questions, prompting them to make decisions about whether or not to explain their appearance (Yaron et al., 2018). Yet people with FD have been left out of disclosure[1] research and frameworks. This research centers people with FD by qualitatively examining their experiences with disclosure in different life contexts.

FD can be broadly defined as a disorder, condition, mark, or injury[2] that is visible (at least sometimes) to others (Rumsey & Harcourt, 2004). FD can be congenital (i.e., present at birth, such as cleft lip/palate, birthmarks, and craniofacial syndromes), or acquired (i.e., as a result of facial injury, burns, cancer, or infectious or autoimmune conditions like Parry-Romberg syndrome). Some FD are common and may be more understood by the public, like clefts or burns, while others are rare and lack public awareness, such as Freeman Sheldon syndrome. Some FDs like birthmarks and mild to moderate burns can be *concealed* in some contexts (e.g., with hair, makeup, masks, etc.). Other FDs are typically *unconcealable*, including craniofacial syndromes that affect multiple facial structures or movements.

Stigma, according to Goffman (1963), is a deeply discrediting "mark" or attribute. Stigma

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[1] Due to a lack of research centering people with FD, there is no agreed upon term to describe the process of explaining a FD. We use the term "disclosure" in line with previous literature (Chaudoir & Fisher, 2010), as "what individuals verbally reveal about themselves to others" (Derlega et al., 1993). Others can see the FD, but disclosure is the process of informing others about the cause of the FD. Sometimes, the term "acknowledging" has been used to describe this process in visible disabilities or FD (Hebl & Kleck, 2002; Saal et al., 2014). Yet research makes it clear that more than an acknowledgement is expected; an explanation about the cause, nature, and accommodations is also demanded by others (Bogart & Tickle-Degnen, 2015; Calder-Dawe et al., 2020).

[2] There is significant, but not complete, overlap between the constructs of disability and FD. According to many disability frameworks, FD is considered to be a disability (Saunders, 2020; World Health Organization, 2001). However, some people with FD do not identify as disabled, perhaps because of a lack of FD representation in the disability community and attempts to avoid additional stigma (Swift & Bogart, 2021). In contrast, intentional FDs, such as facial tattooing or ritual scarring, are less related to disability and are outside the scope of this paper.

can be categorized into 1) *enacted stigma*, which is imposed by others (i.e., discrimination); 2) *internalized stigma*, when a stigmatized person internalizes and believes societal messages and enacted stigma to be true of themselves; or 3) *anticipated stigma*, in which a person comes to expect enacted stigma from others, which may lead them to conceal their stigma or to avoid situations in which their stigma may be salient (Mousley & Chaudoir, 2018). Stigma varies in the extent to which it is *concealable* or *unconcealable*. Those with concealable stigmas—such as chronic health conditions—may attempt to "pass" as not having a stigmatized identity, while those with more apparent stigma — as is the case with many FDs — often do not have that option. Having a novel or unexpected appearance denies people with FD of "civil inattention," the benign lack of regard afforded to people assumed to be non-stigmatized (Garland-Thomson, 2009; Goffman, 1963). Instead, people with FD and other visible differences experience enacted stigma by being avoided, ignored, bullied (Bogart, 2015; Bogart et al., 2012; Franzblau et al., 2015; Masnari et al., 2012), and/or beset by others' intrusive stares, questions, comments, and attempts to diagnose their difference (Calder-Dawe et al., 2020; Yaron et al., 2018). Enacted stigma and societal messages can also lead people with FD to internalize and anticipate stigma through low self-esteem and fear of negative evaluation (Masnari et al., 2012).

Much research has focused on disclosure experiences of people with invisible mental and physical health conditions and disabilities (Brohan et al., 2014; Corrigan & Rao, 2012; Grice et al., 2018; Romo et al., 2016; Toth & Dewa, 2014). In an expansion of early work by Herman (1993), Corrigan et al. (2013) describe a hierarchy of mental illness disclosure strategies. First, *social avoidance* involves telling no one and avoiding others and situations in which one's condition might be revealed. Next, those who engage in *secrecy* go out into the world, but do not disclose their condition. Third, *selective disclosure* involves disclosing to certain people who seem like they would understand but keeping the condition a secret from others. Fourth, *indiscriminate disclosure* abandons secrecy and concealment. Finally, *broadcasting* entails "coming out proud" and actively educating others about one's condition. Each approach involves

costs and benefits in various contexts (Corrigan et al., 2013). Social avoidance and secrecy deprive individuals the opportunity to meet supportive people but may reduce experiences of stigma. By abandoning secrecy, the latter disclosure categories help to reduce internalized stigma. However, these more open strategies may make a person a target for discrimination. Yet, this type of open and active disclosure may also engender feelings of personal empowerment, as people work to reduce enacted stigma toward both themselves and other people with their condition (Corrigan et al., 2013).

Although FD research has not focused directly on disclosure, a related literature describes how people with FD experience stigma and suggests that some of Corrigan et al. (2013)'s disclosure strategies may resonate (Rumsey & Harcourt, 2004). Research on Moebius syndrome, a rare congenital FD resulting in facial paralysis, finds it is visible yet unrecognized by the general public due to a lack of knowledge (Bogart & Tickle-Degnen, 2015). That is, although strangers notice an unusual appearance, they rarely understand its cause or nature, nor the accommodations that may be needed. Participants feared that discussing their FD would lead to further stigma. On the other hand, they felt disclosing could help advocate for those with FD, foster understanding and intimacy, and address preoccupation, mirroring the disclosure tradeoffs described by Corrigan et al., (2013). Some participants *broadcast* their disclosure by giving presentations at school or work, others *disclosed selectively* in some situations but not others, and one had never discussed their FD with a romantic partner of many years (Bogart et al., 2012).

In a study of people who lost parts of their faces (i.e. a nose or eye), Yaron et al., (2018) found that participants responded to stares, comments, and questioning in three ways: *ignoring*, *challenging*, or *explaining*. Ignoring may relate to Corrigan's avoidance strategy. Challenging involved responding confrontationally, actively staring back, or indicating that the person is being rude in order to take control of the situation. Some participants welcomed (polite) questions as an opportunity to explain and others engaged in anticipatory explanation in

order to preempt others' preoccupation or enacted stigma, relating to Corrigan's indiscriminate disclosure or broadcasting. Their responses were sometimes motivated by internalized stigma (feelings of shame and inferiority), and were other times used as a strategy to subvert stereotypes that people with disabilities are incompetent (Olney & Brockelman, 2003; Yaron et al., 2018).

The few modern studies on disclosure of visible differences have focused on concealable differences and disabilities (Sharratt et al., 2020), or upon a job interview context (Hebl & Kleck, 2002; Hebl & Skorinko, 2005; Lyons et al., 2018; Madera & Hebl, 2012). Sharratt et al., (2020) centered the disclosure experiences of those with visible differences such as burns, alopecia, and colostomy that were concealable (e.g., on parts of the body that were hidden by clothing. Thematic analysis of interviews indicated the disclosure scenario could be experienced as a challenging interaction and yielded five themes (Sharratt et al., 2020). 1) *Remaining invisible* involved concealing the difference, social isolation, and avoiding situations where a difference might be revealed (e.g., swimming). 2) *Agentic state disclosures* — named after Milgram's (1974) term describing individuals acting as agents of another (e.g., an authority figure) — referred to situations in which participants felt compelled by the demands of others or their context to disclose. 3) In contrast, *autonomous disclosures* — named after Milgram's term for greater self-determination — occurred when participants felt more in control of their disclosure experiences. Autonomous disclosure was motivated by goals to educate others, gain personal validation, and increase understanding. 4) *Preparing for and controlling disclosure* involved making practical preparations such as selecting the timing, location, and disclosure medium and preparing emotionally for reactions such as pity, shock, or acceptance. 5) *Moving beyond disclosure* included a revealed visible difference and a changed outlook for both the discloser and the disclosee. Though participants were sometimes compelled towards disclosure, the ability to remain invisible, avoid disclosure, to "pass" (Goffman, 1963), and control aspects of their disclosure experience (such as timing) may distinguish their experiences from those of

people with some FDs, which may be more difficult to conceal.

Studies of acknowledgement or disclosure of FD or visible disabilities in job interviews have primarily focused on the effects of these approaches on the *disclosee* (i.e., whether a participant posing in the role of job interviewer considers the visibly different person a good job candidate). Participant interviewers became preoccupied with the FD, resulting in working memory demands, divided attention, and self-regulation problems, leading to lower applicant ratings, which was somewhat ameliorated when the job applicant disclosed early in the interview (Madera & Hebl, 2012). Disclosure may be an effective technique for use in job interviews because it creates impressions of psychological adjustment and competence (Hebl & Skorinko, 2005), addressing perceivers' curiosity while reducing difference-related thought suppression (Hebl & Kleck, 2002).

The perspectives of *people with FD* regarding disclosure are lacking in the literature (Saal et al., 2014). The current study aimed to understand the disclosure experiences of people with FD in different life domains and to examine the applicability of existing disclosure frameworks to this population. This study was motivated by the goal to advance disclosure theory as well as to provide practical strategies for people with FD and those supporting them.

Method

Participants

Recruitment information instructing individuals to contact the researchers was shared by FD organizations including the American Cleft Palate-Craniofacial Association, Burn Survivors of New England, Children's Craniofacial Association, Facial Paralysis & Bell's Palsy Foundation, Moebius Syndrome Foundation, and MyFace via their websites, emails, newsletters, and social media. To be included, participants had to be 18 years or older, self-report having any FD, have the ability to communicate in English, and be currently living in the United States. Following Braun and Clarke's (2006) recommendations for interviews focusing on experiences to select a moderately sized sample, we aimed to recruit at least 15 participants,

and a total of 16 were ultimately interviewed. Ten participants identified as White, three were mixed race or other, two were Black, and one was Asian. Their education ranged from some college to PhD. Eleven were employed (eight full-time) and another was a full-time student. See Table 1 for further participant characteristics.

Procedure

This study was approved by the first author's Institutional Review Board. Participants were interviewed via phone or Zoom according to participant preferences between January 2021 and July 2021. Interviews were conducted by the first author, who disclosed having a FD, or third author, who disclosed having disabilities. Semi-structured interview questions were based on those used by Sharratt et al. (2020) and modified by our research team who has expertise and lived experience with FD and disability. We included questions about if, when, why, and/or in what domains (i.e., work, school, romantic interests, etc.) participants disclose and/or explain their FDs; the nature and content of the disclosure; outcomes of disclosure; and recommendations for others. (See supplemental material for interview questions.) Interviews lasted approximately 30 to 60 minutes. Participants received a $15 Amazon gift card. Following a Synthesized Member Checking approach (Birt et al., 2016), a summary of results with clarifying questions was sent to participants. Respondents generally agreed with the summary and provided feedback which we incorporated into our analysis.

Analysis

Interviews were transcribed verbatim by the second author. We conducted an inductive, semantic qualitative thematic analysis following the recommendations of Braun and Clarke (2006). These recommendations outline six phases of thematic analysis: data familiarization, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. The first and second author organized codes and themes using NVivo 12 Pro software. The first three phases were conducted inductively. At phase four, we recognized that our inductively generated themes overlapped with Corrigan et al.'s (2013)

and Sharratt et al.,'s (2020) disclosure frameworks. To maximize impact to disclosure theory, we noted when these frameworks fit our FD data, named themes and subthemes accordingly, and identified new subthemes that were not captured by existing frameworks. Using an iterative process, all authors brainstormed, suggested changes, and resolved disagreements via discussion.

We identified two overarching themes describing participants' perceptions of their disclosure as *agentic* or *autonomous;* see Table 2. Disclosure approaches were determined by the participants' subjective experience and interpretation. Additionally, we identified three experiential themes that described perceived reasons for, experiences with, and outcomes of disclosure: *misunderstanding, connection,* and *empowerment;* see Table 3. All themes were described according to their meaning rather than frequency, as thematic analysis does not equate frequency with importance (Braun & Clarke, 2022; Landrum & Garza, 2015). Following Braun and Clarke's (2006) guidelines, we illustrate how each disclosure approach related to experiential themes in Figure 1.

<div align="center">**Results**</div>

Experiential Themes

Experiential themes described antecedents, concurrent experiences, and consequences of disclosure. The misunderstanding theme involved enacted, anticipated, or internalized stigma, outsiders invalidating or failing to acknowledge issues related to FD, all of which were perpetuated by a lack of public awareness of FD. The connection theme included using humor and fun to cope with FD challenges, interpersonal sensitivity to "read the room" when making disclosure decisions, a sense of belonging and support, and viewing FD as an aspect of diversity and community. The empowerment theme involved independence, embracing one's unique identity as a person with FD, and finding a sense of purpose and meaning in FD. In the sections below, we describe the relationships between the experiential themes and disclosure approach themes. As can be seen in Figure 1, misunderstanding was widespread and related to all forms of

agentic (non)disclosure and autonomous nondisclosure. Connection co-occurred with all forms of autonomous disclosure, while empowerment was related to broadcasting and false disclosure.

Agentic (Non)Disclosure Theme

Agentic approaches included experiences where participants felt that external demands brought on by people or situations required them to disclose or not disclose. Individuals who reported agentic experiences felt they did not have a choice when it came to sharing or not sharing information about their FD. These experiences fell into three subthemes: *forced disclosure, unauthorized disclosure,* and *forced nondisclosure.*

Forced Disclosure Subtheme

In some situations, individuals felt forced to explain their FD. Some of these experiences co-occurred with the misunderstanding theme, as they felt pressured to disclose in order to avoid or clear up misunderstandings. While John preferred social avoidance, he felt forced to disclose in situations where not disclosing may affect his business.

I rent properties... Sometimes I have to explain, when I catch that someone's looking at the asynchronicity [of my face]... I'll explain, "I had an accident with my face." And, you know, if I smile I might not look like a smile so please disregard... I have to say it, because that could lose me a rental if somebody reads it wrong. (John)

In other situations, participants reported feeling trapped by intrusive questions. This usually occurred when the individual was unable to easily leave a situation. Maria shared an instance when this happened to her:

I was getting gas filled up...You have to have your window down to talk to the attendant...He had the tank thingy in my car, I couldn't just drive off, I was totally trapped while he told me his friend...was in a motorcycle accident and looked just like me...I couldn't leave the interaction... I really hate it. They feel like they can do that... they're in a position of power because they have to finish the transaction. (Maria)

Participants described feeling uncomfortable, stigmatized, or powerless when they were

forced to disclose. For example, Maria felt pressured to disclose so she could avoid the distressing misunderstandings others have about her FD.

> It makes me want to cry... It's like something bad must have happened to me... they think the worst of me like maybe I did it to myself. Like I was stupid and was in a motorcycle accident.... They're applying violence to me. And, if I did have an acquired facial difference through a traumatic event, that'd be very triggering. (Maria)

Forced Nondisclosure Subtheme

Some participants wanted to disclose, but others urged them not to. Friends, parents, and strangers advised participants to conceal or change their facial appearance. As Maria said, "I've been given lots of 'advice'... on how to 'fix' my face, like 'wear more make-up' and 'have you considered surgery? (when I have had many)'."

> I have been told to tell others I was in an accident because that is "easier" or more comfortable for other people to hear...I was asked what my tumor was at a party once and when I said it was a tumor and that I had stage three cancer, the room fell silent. I was then pulled aside and told that it was bold (and not in a good way) to be honest about what it was. As if lying about it, saying it was a really bad bee sting or something, was more socially acceptable - was better than being honest about something as "sad" as cancer. (Roman)

Advice to not disclose communicated to participants that their FD was not socially acceptable, relating to the misunderstanding theme.

Unauthorized Disclosure Subtheme

Unauthorized disclosure was characterized by experiences where others explained the individual's FD without their permission. This violation of personal autonomy restricted their ability to correct misunderstandings, which may have contributed to an uptick in others' stigmatizing responses (illustrating the relationship between these themes). In some cases, family members disclosed for their children against their wishes. Katie explained how it

bothered her when her mother shared her story with a group of women Katie didn't know. When one of these women later met Katie, her reaction was stigmatizing: "[The woman] met me and instantly started crying…The whole thing felt really weird and awkward… like, How bad is it? Somebody starts crying? You know, like, that's really bad."

Similarly, an acquaintance of John's had heard rumors about his FD and told a group of nearby strangers. John was distressed by this experience and reported drinking alcohol to cope. "I heard her say to someone across the room, 'Oh, it's true.' …they looked at my face… They heard about me through other people through the grapevine… And so, 'Oh my god, they know, everybody knows that now.'"

Autonomous (Non)Disclosure Theme

This theme was characterized by deliberate, independent decisions made by individuals with FDs to explain — or not explain — their condition to others. These experiences fit into six subthemes: *social avoidance, concealment, false disclosure*, *selective disclosure, indiscriminate disclosure*, and *broadcasting*. Inspired by overlap with Corrigan et al.'s (2013) disclosure costs and benefits framework, Table 4 summarizes costs and benefits of autonomous approaches as derived from our analysis.

Social Avoidance Subtheme

 Those engaging in social avoidance chose to actively avoid situations where their FD could be noticed. One of these individuals did so out of a fear of others misinterpreting his FD, highlighting an association with the misunderstanding theme: "I got character to my face. I mean everybody misreads my face so… for a while there… I stopped going places, stopped meeting people. I don't have any social life" (John).

Avoidance sometimes involved going to great lengths to avoid previous acquaintances. "I really didn't like how I looked. And so, I ended up going to community college in hopes that no one would recognize me, cause it was like an hour away" (Roman). Additionally, some interviewees described declining work or volunteer opportunities to avoid having to disclose

their FD. In all cases, individuals chose avoidance as a method of not disclosing their FD.

Concealment Subtheme

Unlike social avoidance, individuals who chose to conceal their FD did not avoid social environments. Instead, they attempted to conceal or minimize the noticeability of their FD using a variety of techniques (e.g., makeup, clothing, face masks, and hair styles). Participants concealed to reduce unwanted staring, questioning, and misunderstanding. "I sort of thought that a reason I was having a hard time making friends at this college was because...people only saw my birthmark, and they didn't see much beyond that...so yeah, I got really into covering it up" (Alex).

It was often difficult to conceal a FD. As Leo explained, "[Your FD] is literally on your face." However, all interviews took place during the COVID-19 pandemic, a time when mask use was prevalent. This afforded participants the opportunity to fully or partially conceal their previously unconcealable FD. Participants generally expressed positive feelings toward masks, reporting that they made them feel less self-conscious, reduced staring and questioning, and, essentially, described being afforded civil inattention:

> The pandemic for me, has been like a blessing in the sense that because I have my mask on, people don't ask me, what's that thing on my face? It's like lifting up an anxiety that I have felt my entire life. I was so used to people staring at me in the grocery store or the mall or the movie theater, and not having to deal with that now, it's awesome. (Alex)

> Others disliked or felt ambivalence about wearing masks. Some had functional issues

with masks, while Maria felt she was deceiving people about her FD by wearing one.

False Disclosure Subtheme

Participants sometimes gave false explanations of their FDs when they perceived others' direct questioning to be inappropriate. Katie and Tom enjoyed crafting humorous stories about the onset of their FD, including that a scar came from being in a knife fight or that they were "attacked by gorillas." Some participants also gave false explanations for their FD as a way to

protect themselves from situations they perceived as unsafe to disclose in. Conversely, Alex

primarily used false disclosure to make others uncomfortable and gain power over a situation:

> My friends and I were at a… café… and the server came up to us… and he asked, "Oh, my
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> God, what happened to your face?" And so I said, "Oh, it's from a fire that burned down
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> the orphanage that I grew up in." And then, everyone paused and I said, "I'm just
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> kidding. It's a birthmark, but, why do you ask?" And then he didn't say why he asked and
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> like, I seek to make the situation uncomfortable. So people can see or feel how
>
> uncomfortable it is for me.

These examples overlap with the empowerment theme, demonstrating how some

individuals used false disclosure to regain power over uncomfortable situations. Indeed, Alex

added that "when you've been dealing with this your whole life, [false disclosure] is sometimes

the only coping mechanism that works. It is something that gives you a little more power in the

situation."

Selective Disclosure Subtheme

Selective disclosure approaches included situations where participants made the

deliberate decision to only disclose to certain people but not to others. Participants explained

that whether they decided to disclose and the depth of information shared depended on the

nature of the inquiry, one's feelings toward the inquirer, and the context. As with other forms of

Autonomous (Non)disclosure, individuals felt they had a choice in their disclosure decision.

Selective disclosure often occurred in response to direct questioning. However, some

forms of selective disclosure were preemptive. Interviewees described starting meetings and

conversations by explaining their condition to prevent misunderstanding: "I told my boyfriend

before I met him. I said…. 'I just want to let you know that I do have a disability… So when I

meet you… you don't have any questions, concerns'" (Leo). Katie described doing several

"experiments" when interviewing for jobs. Once, she tried not acknowledging her FD, "and then

someone on staff was like, 'Were you in a fire? What happened?' You know, so the question was

still there." Due to these past experiences, and to avoid preoccupation with her FD, she later

tried disclosing via email prior to an interview, which she felt worked best:

> I feel what didn't work was where I would get called for the interview and then I would
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> come in and... just be like, "Before we start, let me just explain this to get it out of the
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> way." I think people didn't really process it very quickly. And so they were still thinking
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> about that when [interviewing about] other stuff. So, sending an email gave them a little
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> bit of time to kind of mentally prepare. (Katie)

As selective disclosure was characterized by only disclosing in some situations, there

were instances where individuals who had disclosed to some people decided *not* to explain their

FD to others. They felt it was irrelevant to share details about their FD in certain situations

and/or around specific individuals. For example, Maria felt it was unnecessary to tell people at

work: "People don't ask, and I don't feel the need to [explain] at work." Unlike decisions to

engage in social avoidance, concealment, or false disclosure, these individuals made deliberate

decisions to not disclose in certain situations rather than avoid the situation, alter their

appearance, or give false explanations about their FD.

While the misunderstanding experiential theme was mostly an antecedent to disclosure,

some participants described elements of misunderstanding — particularly stigmatizing

experiences — as an outcome of disclosure. When Maria was dating online, she didn't post

pictures and would wait to disclose her scar until she was asked to send a picture or to meet in

person. "One guy I was chatting online with, and it was a pretty good chat for a few

interchanges. And then... I sent him a picture. He's like, 'I don't think we're compatible'"

(Maria).

Overall, selective disclosure required a high degree of interpersonal sensitivity, linking

with the connection theme. Participants reported they had developed the ability to 'read' others

in social situations. When making selective choices about disclosure, individuals noted the levels

of comfort and interest of the disclosee, and the likelihood of a stigmatizing response. In turn,

assessing others' comfort prior to disclosing sometimes led to the individual with the FD feeling more comfortable.

Many found it easier to discuss their FD with those close to them or disclosed to build a connection. "It's a layer of myself that I open up to friends and family who I really trust… You're making an investment of trust with a friend or a loved one that is being paid in kind by more trust from that person" (Stephen). Others felt more comfortable selectively disclosing to others with FDs or other disabilities: "There was someone at the vaccination clinic and I could sort of tell like, over their mask [that they had a FD], so I pulled mine down to show solidarity." (Alex). As Alex illustrates, connection was both a reason for and a frequent outcome of selective disclosure. Following disclosure, many participants reported feeling more accepted, understood, and connected in their relationships.

Indiscriminate Disclosure Subtheme

Indiscriminate disclosure involved being open to telling anyone about one's FD. Unlike selective disclosure, these individuals did not mention any instances where they did not disclose to others. Participants employing this strategy did not withhold information about their FD from others. People usually asked Amy "what's going on with your face?" soon after meeting her, and she welcomed the opportunity to explain. As she was getting to know the man who would eventually become her husband, she was surprised that he didn't ask her, so she brought it up on her own to "get rid of the elephant in the room." Indiscriminate disclosure was also characterized by participants being okay with others — usually friends or family — disclosing their FD for them, a distinct deviation from our unauthorized disclosure subtheme where individuals were not okay with others disclosing for them.

A few participants posted information about their FD to websites, including dating sites. Some constructed their dating profiles to 'weed out' people who were intolerant of FDs: "I basically have a profile like, 'This is me,' you know, 'This is what you get.'… I don't want to be with someone who's freaked out by that anyway (Katie). Others shared FD information in their

web profiles to reduce questioning about their FD: "On my [dating] profile, I just wrote it out so that people wouldn't ask." (Alex).

As with selective disclosure experiences, indiscriminate disclosure experiences highlighted the high degree of interpersonal sensitivity these participants had developed, relating with the connection theme. Their highly attuned social skills allowed them to tailor the depth of their disclosure based on the behavior of others.

Connection was also an *outcome* of some indiscriminate disclosure experiences. Participants felt more accepted, understood, and connected following disclosure. Joe was able to better relate to his students through disclosure: "When kids hear [about my FD], and you kind of tear down that wall that like, 'Wow, they're just like me,' it makes it a lot easier for them."

Broadcasting Subtheme

Participants who used broadcasting openly shared information about their FD and sought to educate others by posting or speaking about their experiences or displaying awareness-raising items such as t-shirts. Some broadcast their experiences through connection with the broader FD community or people with disabilities, overlapping with the connection theme. Some individuals reached out to local and national support organizations to volunteer and share their story, while others shared their story in smaller settings, like a classroom.

While some participants planned their broadcasting experiences in advance, others made rapid decisions to openly disclose with little preparation:

> I was actually at a training on fundraising and how to create a story and how to really engage people emotionally into your fundraising story. They made us do an exercise where we had to tell, to our own discretion, a personal story... I wasn't really planning on that or anything... I was almost practicing. ...if I get up there and explain [my FD], how would this go? So I just kind of winged it. (Katie)

Aspects of the empowerment theme frequently overlapped with broadcasting experiences, in that broadcasting helped participants feel more confident, powerful, and in

charge of various situations. Some individuals felt their FD had an overall positive impact on their lives and noted how disclosing FDs can afford unique opportunities. "There are definitely some advantages" to having a FD when the music industry wants to highlight diversity (Leo).

Roman asked his doctor if there were any support groups or mental health workers that could help him with cope with his altered face due to facial cancer but was not given resources. He struggled to find language to search online, and eventually found the term "facial disfigurement," which ultimately imparted identity, community, and a means to explain his appearance. He since started support communities and advocacy efforts. "When you have language for who you are, it's empowering. And talking about it, it's empowering."

Others found meaning and purpose in raising awareness and educating others about FD. As Mary explained: "I feel like it's my job to educate the public that we still operate like, quote, 'normal people'." Some reasons for this outlook were rooted in religiosity, with some individuals feeling they were created to educate others about FD: "[God] made me this way as part of this mission, his own little part in helping with craniofacial awareness…to teach everyone about how diversity can be beautiful" (Cecelia).

Discussion

In one of the first studies to focus on experiences of disclosure among people with FD, we identified two disclosure themes, agentic and autonomous. Similar to Sharratt et al.'s (2020) findings, agentic disclosure was experienced as not under participants' control and was enacted by others without their permission or forced by unwanted questioning. Additionally, we identified a new agentic subtheme, forced nondisclosure, in which participants wanted to disclose but others told them not to. Autonomous approaches, as in Sharratt and colleagues' findings, were experienced as an intentional process to preempt questions or misunderstandings and/or to facilitate understanding, intimacy, and empowerment.

Many of Corrigan and colleagues' (2013) disclosure approaches map onto the autonomous approaches of our participants, including social avoidance, selective disclosure,

indiscriminate disclosure, and broadcasting. We also identified two new types of nondisclosure: concealment and false disclosure. Our participants did not engage in Corrigan et al's *secrecy* because it was not possible to keep their FDs completely secret. While secrecy involves avoiding telling others about an invisible stigma, concealment involves physically hiding the difference. False disclosure is another addition to Corrigan and colleagues' framework. This is likely due to the salience of FD compared to more concealable differences; this population is questioned by others with much greater frequency (Garland-Thomson, 2009; Yaron et al., 2018). For participants who were frustrated by intrusive questions, false disclosure was a means to take back control by making the other person feel uncomfortable, or to find humor in the situation, similar to Yaron et al., (2018)'s notion of responding to unwanted attention with "challenging."

Our findings provide additional nuance to the costs and benefits of disclosure approaches noted by Corrigan et al., (2013). The nondisclosure approaches social avoidance, concealment, and false disclosure were attempts to avoid enacted stigma, yet, as Corrigan and colleagues (2013) noted, they perpetuated misunderstanding via internalized and anticipated stigma and limited connection. However, false disclosure did have one perceived benefit— empowerment. Giving a false explanation for their FD sometimes made participants feel they had more power over the situation. In contrast, any type of disclosure comes with potential costs, including making the person a target for enacted stigma, such as bullying, discrimination, or invalidation. Participants sometimes felt it was unfair to be expected to violate their privacy by disclosing medical details (i.e. diagnosis) to others. Any disclosure may result in subsequent unauthorized disclosure (i.e., people telling others about a FD without explicit permission), which could be perceived as a cost for those who would like to keep their disclosure selective.

On the other hand, selective, indiscriminate, and broadcasting disclosure approaches were related to connection and reduced misunderstanding. For many participants employing these approaches, disclosing was perceived as an investment that could pay off with increased interpersonal closeness, trust, and commitment (as described by Rusbult, 1980). Disclosing was

also useful in stamping out misunderstanding and *disability spread*, in which others mistakenly believe an FD affects other areas of functioning (i.e. intellect; Bogart, 2015; Bogart et al., 2012). Building on the benefits of selective and indiscriminate disclosure, broadcasting was experienced as empowering and was motivated by a desire to raise awareness and reduce stigma for the FD community at large (Corrigan et al., 2013).

Compared to previous work on disclosing concealable visible differences (Sharratt et al., 2020), our sample more commonly described engaging in autonomous than agentic approaches. People with FD, in light of the heightened visibility of their conditions, may feel less ambiguity about whether others will notice their conditions, and may be more inclined to take control of (non)disclosure (Joachim & Acorn, 2000). Indeed, Maria felt it important to acknowledge that most autonomous disclosure was not completely under her control; she was making a personal choice to respond to social demands outside of her control. Such demands may require an individual to conform to a norm or understand the expectation that any deviation from a norm must be explained (Calder-Dawe et al., 2020). As such, any "choice" implied by autonomous disclosures may be understood to be situated in and bound to the broader context within which it is made.

Our analysis centered on participants' subjective experiences. Contextual factors like the tone and apparent intention of the person asking the question, as well as the participants' previous experiences, attributional style, and internalized and anticipated stigma, influenced whether the person with the FD disclosed, and whether they felt this was agentic or autonomous. For example, participants varied greatly in their feelings about FD-related questions. Alex felt that it was never appropriate to ask about a FD, so when asked, she engaged in autonomous false disclosure. On the other hand, participants like Amy welcomed interest, curiosity, and questions from others, seeing it as an opportunity to discuss the difference when it was otherwise hard to find a segue, and to address the "elephant in the room."

Reflexivity

The first author has a FD and the third author has disabilities. The insider status of members of the research team enhanced credibility of the research, allowing for a more authentic interview script, analysis, and ability to frame findings regarding the real-world issues at stake for people with FD. In combination with research team members without FD, our positionality allowed for multiple lenses of inquiry. The first author's FD was disclosed in recruitment materials. The two interviewers, the first author and third author, briefly disclosed at the beginning of interviews. Our team carefully considered costs and benefits in selecting this approach. Researchers with FDs and disabilities are underrepresented, and participants are acutely aware of this (Oliver, 1992; Partridge, 2020). We opted to disclose in order to maximize participant engagement, openness, and trust. It may be argued that by disclosing at the beginning of interviews, the researchers created an expectation to disclose. However, nearly all FD research involves recruiting individuals who disclose their FD in order to participate, so we did not expect our disclosures to alter participants' responses significantly. Our impression was that the interviews were open and honest, and ultimately, a large range of (non)disclosure approaches were discussed.

Implications

The taboo nature of FD creates competing social pressures. People with FD may feel compelled both to not discuss FD and to address curiosity and misunderstandings (Garland-Thomson, 2009). The level of interpersonal vigilance involved in impression management for people with FD can be draining and distracting (Cole & Spalding, 2008). Public awareness and stigma reduction must occur at the societal level, instead of placing the onus on individuals with FD. Participants felt that FD should be included in discussions about diversity in education and the workplace. Representation of FD in all areas of society — including education, media, policy, and art — is key. Several participants cited other current activism movements fighting for minority rights as an inspiration and called for increased activism for "face equality" as well (Partridge, 2012).

While social change is imperative, individuals must also be empowered to advocate for themselves and effectively manage social interactions. The most frequent advice offered by participants was to afford children and adults disclosure autonomy—that is, the choice of when and if to disclose. The more open forms of autonomous disclosure (i.e., selective, indiscriminate, and broadcasting) were associated with connection and empowerment, suggesting these may be experienced as most beneficial. These approaches align with approach coping, a strategy associated with positive health and well-being outcomes (Roth & Cohen, 1986). Those participants who described forced nondisclosure, even if it was intended as well-meaning advice from family or friends, experienced this as agentic and stigmatizing.

Clinicians and parents can model autonomous disclosure approaches by having open, frank conversations with the person with FD about if, how, and when to disclose. This could be achieved following guidance by Changing Faces to develop a few short phrases in advance to explain the FD so that people feel in control and prepared when disclosing (Blakeney et al., 2005; Michael et al., 2015). These discussions may help individuals cognitively and affectively process their FD and integrate it into their identity (Chaudoir & Fisher, 2010). Such discussions may also help individuals develop coping strategies that may help them when facing other people's curiosity and questions. Future work will examine the generalizability of disclosure approaches and outcomes to larger samples of those with FD and examine the roles of gender, age, concealability, rarity, and age of onset, with the goal of developing evidence-based disclosure guidance for people with FD, their families, and the public.

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Table 1

Participant Pseudonyms and Characteristics

Pseudonym	Age	Gender	Name of facial difference	Onset
Alex	31	Female	port wine stain	congenital
Alison	42	Female	Parry Romberg syndrome	adolescence
Amy	24	Female	Moebius syndrome	congenital
Cecilia	28	Female	Apert syndrome	congenital
Del	28	Female	Moebius syndrome	congenital
Joe	60	Male	Moebius syndrome	congential
John	66	Male	Bell's palsy	adulthood
Katie	43	Female	Freeman Sheldon syndrome	congenital
Leo	23	Male	Moebius syndrome	congenital
Maria	51	Female	congenital facial hemangioma and fatty facial tumors	congenital
Mary	64	Female	facial burns	adulthood
Roman	22	Male	facial cancer	adolescence
Sara	54	Femle	Moebius syndrome	congenital
Stephen	34	Male	Moebius syndrome	congenital
Tara	24	Female	hemifacial microsomia (including cleft lip and palate, micrognathia. bilateral microtia atresia)	congenital
Tom	43	Male	bilateral cleft lip and palate	congenital

Note. Additional demographics are presented in aggregate only in the text to maintain confidentiality.

Table 2

Disclosure Approach Themes and Subthemes

Disclosure Approaches		
Theme and Description	Subtheme	Description
Agentic (Non)disclosure: Characterized by external demands by others or contexts.	Forced Disclosure	Feeling forced to disclose by others or by the situation. Feeling forced to answer questions about the FD.
	Forced Nondisclosure	Others urging the person with FD not to disclose or to hide or minimize the FD.
	Unauthorized disclosure	Others disclosing for the person with the FD without their permission or against their wishes.
Autonomous (Non)disclosure: Characterized by deliberate, independent decision.	Social Avoidance	Avoiding social situations where the FD could be noticed.
	Concealment	Attempting to hide or reduce the noticeability of the FD.
	False Nondisclosure	Giving a false explanation about the cause of the FD.
	Selective Disclosure	Choosing to disclose to certain people but not others.
	Indiscriminate Disclosure	Being open to disclosing to anyone. Being willing to answer anyone's questions about the FD. Being okay with other people disclosing the FD.
	Broadcasting	Actively seeking to educate others by disclosing and sharing information about FD. Being involved in FD awareness efforts.

Table 3

Experiential Themes and Codes

| Theme	Description
Misunderstanding	Enacted, anticipated, or internalized stigma related to disclosure experiences. Invalidation of FD experiences. Outsiders misunderstanding FDs and associated experiences due to a lack of public awareness.
Connection	A sense of belonging and support related to disclosure. Includes using interpersonal sensitivity to determine appropriate disclosure approach.
Empowerment	Disclosure experiences related to feeling a sense of purpose due to their FD. Using disclosure to gain power over a situation.

Table 4

Potential Benefits and Costs to FD Autonomous (Non)disclosure Approaches

Autonomous (Non) Disclosure Approach	Potential Benefits	Potential Costs
Social avoidance	avoid enacted stigma	internalized and anticipated stigma; limits social participation; limits social support
Concealment	avoid enacted stigma; take advantage of civil inattention; can participate in society	internalized and anticipated stigma; may not be possible to completely conceal
False	take control; make people who are behaving inappropriately feel awkward	internalized and anticipated stigma; providing false information may confuse others
Selective	reduce misunderstanding; social support; intimacy; trust; address elephant in the room; find FD community	internalized and anticipated stigma; target for enacted stigma; others may engage in unauthorized disclosure; violates privacy
Indiscriminate	reduce misunderstanding; social support; intimacy; trust; address elephant in the room; find FD community	target for enacted stigma; others may engage in unauthorized disclosure; violates privacy
Broadcasting	reduce misunderstanding; social support; intimacy; trust; address elephant in the room; find FD community; empowerment; reduce stigma for the FD community	target for enacted stigma; others may engage in unauthorized disclosure; violates privacy; places onus on person with FD to destigmatize

Note. Bolded items are new additions to Corrigan and colleagues' (2013) disclosure approach framework.

Figure 1

Thematic Map of Disclosure Approaches
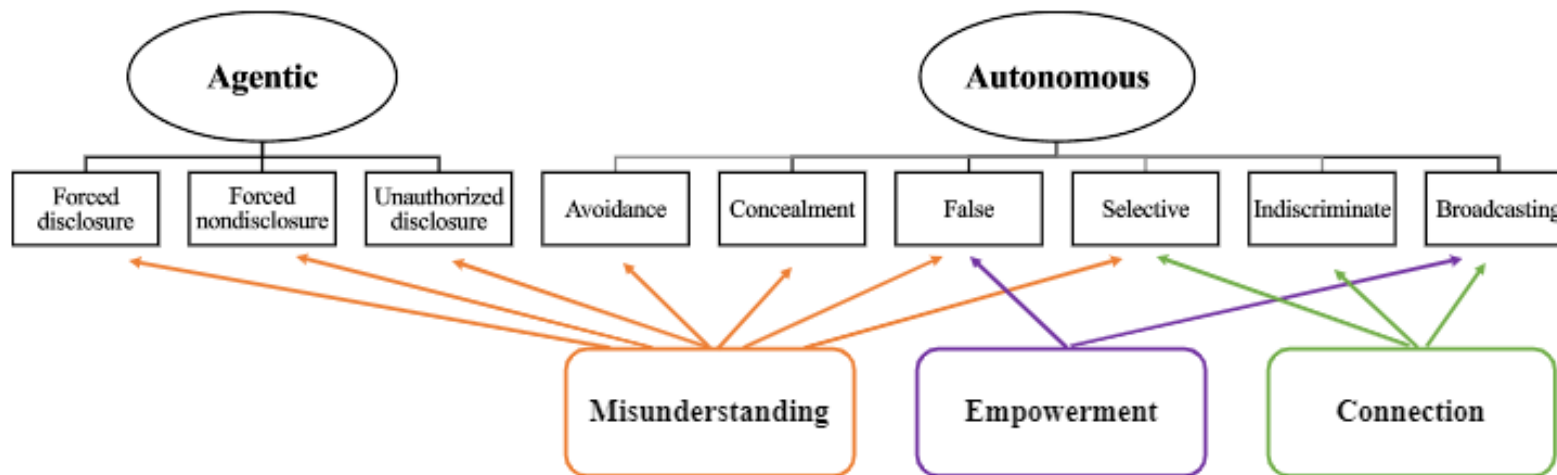
Note. Ovals represent disclosure approach themes, rounded rectangles denote experiential themes, and rectangles represent disclosure approach subthemes.