Becoming Known: Disclosure and Exposure of (In)Visible Difference

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Abstract

Bodily or physical differences constitute one class of potentially stigmatized characteristics. The existing literature confirms that those with appearance altering or disfiguring conditions ('visible differences') may experience both felt and enacted stigma and seek to conceal their difference. Furthermore, issues relating to the disclosure or revelation of visible difference are frequently cited. The present study used qualitative methods to explore participants' experiences of having disclosed otherwise unknown or hidden visible differences to others, and considered these experiences within the context of existing theories on the disclosure of stigmatized characteristics. Semi-structured interviews were conducted with 15 participants who had a variety of visible differences. The data were analyzed through inductive thematic analysis with the resultant themes indicating participants concerns and anxieties related to disclosing their differences, variable levels of agency within, preparation for, and control over the disclosure scenario, the importance of their difference being seen by others, and the personal and inter-personal changes that disclosure could facilitate. In consideration of participants' experiences of the disclosure of visible difference and the applicability of existing models of disclosure to this scenario, a working framework that incorporates the specific issues relevant to the disclosure of visible differences is proposed.

Keywords: visible difference; appearance; stigma; disclosure; thematic analysis

Disclosure and Exposure: Informing Others of (In)Visible Difference

Goffman (1990) defined stigma as “an attribute that is deeply discrediting” (pg.13) the result of which is that the bearer is “reduced in our minds from a whole and usual person to a tainted, discounted one” (pg.12). Goffman (1990) also presents the etymology of ‘stigma,’ with the Greeks originally using the term to refer to physical indications of dubious moral status via visible scars from cuts or burns deliberately inflicted on slaves, criminals, or traitors. These physical signs are included within the modern usage of the term, with the primary types of stigma introduced by Goffman (1990) including bodily or physical differences. For those whose differences are not immediately visible, they may, like others with stigmatized characteristics, be ‘discredited’ to those who are aware of their difference, and ‘discreditable’ to those who remain yet unaware (Goffman, 1990).

While an individual remains ‘discreditable’ (Goffman, 1990) and has a ‘concealable stigmatized identity,’ which includes hidden appearance-altering conditions (Quinn & Earnshaw, 2011), it follows that they may make attempts to ‘pass’ for one not possessing the characteristic. This is achieved through managing and controlling the personal information made available to others (Goffman, 1990). The consequences of failing to ‘pass’ in public spaces may include the denial of the brief but unintrusive and non-threatening acknowledgement, the ‘civil inattention’ (Goffman, 1963), that individuals routinely afford to and expect from one another. For example, the presence of an unusual, novel, or unexpected physical appearance may cause others to stare and thus facilitate an interpersonal exchange which can be imbued with meaning and stigmatize those who do not conform to the visual status-quo (Garland-Thomson, 2009). This can act to deny the recipient of this attention their right to be treated equally and respectfully by others, and thereby repudiate their humanity (Yaron, Meershoek, Widdershoven, & Slatman, 2018).

Stigmatized characteristics or features may be made known to specific others through voluntary disclosure, forced disclosure (e.g. where disclosure may be required to explain absences from work), or via a confident sharing the information entrusted to them (Quinn & Earnshaw, 2011). Others obtaining this knowledge may lead to experiences of both 'felt' and 'enacted' stigma (Scambler & Hopkins, 1986). This conceptualization accounts for overt discrimination ('enacted' stigma) in addition to the fear of enacted stigma and associated feelings of shame ('felt' stigma) (Scambler & Hopkins, 1986).

While research has focused upon stigma and psychological conditions, the stigmatization of physical disabilities remains an emerging field (Kowalski & Peipert, 2019). In this nascent research area, everyday ableism has been shown to manifest in interactions between those who are disabled and those who are not via intrusive, diagnostic practices including staring at one's difference, invasively questioning one about difference, judging or pronouncing upon one's difference (Calder-Dawe, Witten, & Carroll, 2019; Zitzelsberger, 2005), and ignoring, avoiding or shunning (Lourens & Swartz, 2016) those that are observed to be different. Individuals with physical disabilities and differences may strategically use avoidance and concealment to reduce social visibility and stigmatization (Zitzelsberger, 2005). Conversely, individuals with marginally perceptible disabilities can be misperceived as able-bodied (Calder-Dawe et al., 2019). This can minimize visual scrutiny and offer a degree of control over disclosure, though such individuals may be required to disclose, explain, and even prove their disability to others in order to gain their understanding and access appropriate accommodations and support (Calder-Dawe et al., 2019).

The literature on the psycho-social consequences of living with another form of physical difference, a disfiguring condition ('visible difference'), demonstrates that the association between difference and stigma remains familiar and relevant. Visible difference has been defined as “potentially noticeable differences in appearance that are not culturally sanctioned” (Kent & Thompson, 2002, p.103). Like disability, visible difference may not always be readily apparent to others and so may form the basis of disclosure interactions, and/or involve intentional concealment from others.

The desire to conceal a visible difference to escape negative evaluation, minimize anxiety, reduce felt stigma, avoid situations and interactions which may render a visible difference salient and circumvent enacted stigma, intrusive stares, comments and questions (the denial of ‘civil inattention’), is a recurring feature of the visible difference literature (Kent & Thompson, 2002; Rumsey & Harcourt, 2004). Such phenomena have been identified in empirical studies of those with vitiligo (Kent, 2000), alopecia (Wiggins, Moore-Millar, & Thomson, 2014), facial difference (Yaron et al., 2018), young people with psoriasis (Fox, Rumsey, & Morris, 2007), those with limb absence in a sexual context (Batty, McGrath, & Reavey, 2014), and individuals with a range of appearance-altering conditions (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2019; Thompson & Broom, 2009).

Similar concerns are evident in work that has elucidated the act of disclosing one’s visible difference to specific others. This may be experienced within a romantic context, where the disclosure of visible difference can induce anxiety, apprehension, and uncertainty (the ‘disclosure dilemma’) (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2018). Similar patterns emerged among adolescents/young adults with a range of visible differences (Griffiths, Williamson, & Rumsey, 2012) and prosthesis users (Mathias & Harcourt, 2014; Murray, 2009).

The visible difference literature has referred to these disclosure experiences, but they have not been the dedicated object of research. Equally, the literature has not examined the applicability of existing theories of disclosure. As Chaudoir and Fisher (2010) argue, such theories primarily focus upon the decision-making process rather than upon the interaction between the discloser and the recipient, the outcomes of disclosure, and the connections between these elements (e.g. see Afifi & Steuber, 2009; Joachim & Acorn, 2000; Omarzu, 2000; Ragins, 2008).

Furthermore, not all such theories are concerned specifically with stigmatized characteristics (Greene, 2009; Greene, Derlega, & Mathews, 2006) but may address related concepts such as ‘secrets’ (Afifi & Steuber, 2009), or ‘shameful secrets’ (DeLong & Kahn, 2014). Others focus on a specific context, such as the workplace (Clair, Beatty, & MacLean, 2005; Toth & Dewa, 2014), a particular stigmatized characteristic, such as one’s HIV status (Kimberly, Serovich, & Greene, 1995), or a combination of these factors, such as the disclosure of a mental health condition at work (Toth & Dewa, 2014).

Arguably, the disclosure processes model (DPM) (Chaudoir & Fisher, 2010) (Figure 1) offers the most complete theoretical model of the disclosure of concealable stigmatized identities. The DPM accounts for decision-making and outcome processes, crucially arguing that disclosures motivated by positive, approach-focused goals (e.g. strengthening a relationship) are more likely to facilitate a beneficial disclosure experience, desirable outcomes (e.g. increased intimacy, trust), and encourage future disclosures via a positive feedback loop, than those underscored by avoidance-focused goals (e.g. attempting to minimize the likelihood of social rejection). The DPM (Chaudoir & Fisher, 2010) does not focus as intently upon the cost-benefit analysis that characterizes the disclosure decision-making process in other models, such as that of Ragins (2008). The DPM is also concerned only with verbal, interpersonal disclosures and so does not capture non-verbal strategies and methods of disclosure. The latter receive attention within the revelation risk model (RRM) of Afifi and Steuber (2009).

In research investigating which stigmatized characteristics people disclose and therefore indicating where the relevance of these models lies, Chaudoir & Quinn (2010) found that weight/appearance concerns constituted the second most commonly disclosed characteristic (behind mental health conditions). Furthermore, these were associated with the greatest fear of disclosure and the lowest levels of self-esteem. The weight/appearance category included eating disorders but, when these findings are considered alongside the visible difference literature, they suggest that the disclosure of physical difference is an important domain, worthy of further investigation.

The current research therefore aimed to address the lack of research dedicated to the disclosure of the stigmatized characteristic of having a visible difference, by exploring the disclosure experiences of adults with concealable visible differences. It aimed to utilize those experiences to consider the applicability of the DPM (Chaudoir & Fisher, 2010), the RRM (Afifi & Steuber, 2009), and the work of Ragins (2008) to such disclosures.

Methods

Design

Semi-structured interviews were conducted for the purpose of generating qualitative data relating to participants' experiences of informing other people of their difference. These interviews took place in late 2018 and early 2019.

Participants

Participants were recruited in response to adverts sent to the email addresses of individuals who had registered an interest in the work of the Centre for Appearance Research, and adverts placed on the social media and/or newsletters of the Centre for Appearance Research and approximately 15 charities and support groups who represent those with appearance-altering conditions. A total of 15 participants were interviewed. Participants confirmed that they were aged at least 18-years-old, were based in the UK or Ireland, and all but one had experience of informing other people of their visible difference. Participants were aged 21 to 70-years-old (mean = 45). Table 1 contains demographic characteristics, with real names replaced by pseudonyms, and indicates how each participant described their difference in terms of its nature and location(s) upon their body.

All participants described possessing a visible difference that they typically concealed from others or concealed, or had concealed, within specific social contexts (e.g. using make-up, clothing, or a hair-piece). For a small number of participants, the every-day noticeability of their difference could fluctuate (e.g. dermatological conditions can flare up and recede). The visible differences participants discussed are detailed in Table 1.

Procedure

Ethical approval for this research was granted by the University of the West of England Faculty of Health and Applied Sciences Research Ethics Committee. The study adverts contained a link to Qualtrics© webpages hosting the participant information sheet. Interested participants had the option of contacting the research team or leaving their contact details, in which case the first author contacted them.

Once participants had indicated their interest in the research and been fully informed about the study, arrangements were made for the interview to take place. Participants were offered the choice of being interviewed over the phone, or via an online video/voice service. One participant requested to be interviewed in person. Their interview was conducted face-to-face.

Following consent, participants were interviewed by the first author, using the interview guide shown in Table 2. This was developed by the first author, drawing upon the DPM (Chaudoir & Fisher, 2010) and components of the RRM (Afifi & Steuber, 2009), and Ragins (2008) to help inform its content. Draft items were reviewed, and input provided by the second and fourth authors. The draft guide was reviewed by a UK-based Alopecia charity, which indicated the guide was appropriate and acceptable. It was therefore adopted for use.

In the interviews, the first author deployed the guide flexibly and responsively to give priority to participants' accounts while maintaining focus on the topic under discussion. The guide was structured to afford each participant the opportunity to talk more generally about themselves and their appearance before moving on to specific disclosure scenarios.

One participant (Amber) was not able to discuss actual disclosure experiences but spoke about the debilitating fear and anxiety that such a scenario would incite, and the restrictions she placed upon herself in order to avoid others knowing about or seeing her difference. The average (mean) duration of all 15 interviews was 75 minutes.

Data Analysis

Interviews were recorded and transcribed verbatim by the first author. This transcription ensured familiarity with the data and constituted part of the first phase of an inductive, data driven, thematic analysis (Braun & Clarke, 2006). The process detailed within the subsequent phases of the six-step process described by Braun and Clarke (2006) was followed. The analysis was primarily semantic in nature, though this necessarily involves interpretative and theoretical elements (Braun & Clarke, 2006). The analysis was conducted within Nvivo$^{©}$ 12 Pro software.

Once the first author completed the first three phases of the analysis (data familiarization, generation of initial codes, and searching for themes) the second and third authors reviewed a total of seven of the transcripts and provided input into stages four and five (reviewing themes, defining and naming themes). The second, third, and fourth authors contributed to the final phase, the production of this report.

The first, second and third authors met to discuss the provisional analysis. Subsequent iterations were communicated via e-mail. The themes presented here were agreed by those three authors based on their individual reading and interpretation of the data. The adopted process of analysis does not require a measure of inter-rater reliability (Braun & Clarke, 2013, 2014; Terry & Braun, 2016), though the co-authors’ contribution provided additional ideas connected to the substance and ordering of the thematic structure and helped ensure that the analysis remained firmly grounded in and founded upon, the data. In addition, a summary of the findings was sent to all participants. Those that responded expressed their interest in, and agreement with, the findings.

Epistemological Position

This research was conducted from the paradigm of Pragmatism (Morgan, 2007, 2014). This emphasizes the temporal and context-dependent nature of knowledge (Hall, 2013) and avoids the dualisms described as dividing realist and interpretative paradigms (Doyle, Brady, & Byrne, 2016; Morgan, 2007). In addition to acknowledging the co-creation of knowledge and the intersubjectivity of research, the ‘abduction’ (Morgan, 2007) inherent within Pragmatism considers that existing knowledge, theory, and data all influence one another in a multidirectional way, and thus refutes the proposition that knowledge may be entirely inductively or deductively generated. Similarly, Pragmatism (Morgan, 2007) requires that the transferability of knowledge and research beyond the immediate context be considered, rather than assume it is either entirely and uniquely context-bound or capable of generalization to all historical, cultural, and social settings.

Results

The analysis resulted in the generation of four themes. These are illustrated in Table 3 along with their associated sub-themes and example codes. Each theme featured in the accounts of an overwhelming majority of the participants, though some aspects of these accounts were contradictory and conflicting.

Remaining Invisible

This first theme pertained to participants' desire to avoid their difference being known to or seen by others. Within the context of participants describing how they believed their difference to have contributed to feelings of anxiety, self-consciousness, shame, embarrassment, vulnerability, reduced self-esteem, and reduced self-confidence (although in some instances more positive personal consequences were also acknowledged), their accounts described how they would take deliberate action to render their difference invisible to others. A small number of participants described doing so to protect those close to them (partners, parents, and children) from embarrassment. This action included the often inconvenient concealment of difference (via clothes, make-up, hairpieces, and behaviours) to exert control over who had knowledge of their stigmatized identity, to blend in, and to foster a sense of physical normalcy:

> You try and look as normal as possible. You don't want to draw attention to yourself because you're already aware that you look very different… I did a lot of keeping my head down and trying to fade into the background (Isabella, Pityriasis Rubra Pilaris)

This extended into appearance being experienced as a barrier that could prevent engagement in beneficial and desired activities, social engagements, and relationships. Self-consciousness, the fear of negative evaluation and scrutiny, and the wish to render their difference invisible to others, resulted in avoidance:

> I just basically don't put myself in a position which is a shame because there's lots of things that I'd like to do. I'd like to go swimming. I'd like to go to the spa and things like that but I wouldn't do it with anybody I knew (Amber, Vascular malformation)

Just over half the participants explained how this had impacted their social lives and led to periods of relative isolation and/or loneliness:

> I would isolate myself and I think now that's impacted on my social interaction… I have made a conscious effort to challenge that and go out but it's difficult. Isolation has been kind of the way of coping (George, X&Y chromosome variation)

Participants described the intrusive comments, questions, and assumptions that others made about or of them when their difference was known about or visible. These experiences contributed to a fear of disclosure and the enacted stigma that could flow from others being aware of their difference:

> I know other people who've got alopecia that is visible, so like they've literally got no hair on their head or it's in really visible areas, and they've had such a horrible, nasty comments. And I think it's that, having that sort of fear of somebody making a comment like that to me… I don't know how I'd react. (Sofia, Alopecia Areata)

It was also apparent that anticipating a disclosure scenario excited concern about its consequences. These included increased attention being drawn to the individual and their appearance, awkward social interaction, exclusion from a group, and rejection. Rejection was of particular concern to those contemplating disclosure to a romantic partner, a scenario that featured heavily in the accounts of many participants:

> I thought about going to [city's] gay village... I just couldn't do it. I just thought, what's the point?... Should it go any further then I need to tell them about the stuff that they can't see and, you know, who's going to be interested in me then (Noah, Colectomy and Colostomy)

In a minority of cases these fears severely restricted participants' self-efficacy for romantic relationships and scenarios (real and hypothetical) that would involve their difference being known and/or seen by another:

> In the end I had to break off the relationship because I was too frightened to let him see me with no clothes on. So, we couldn't go any further (Julia, Vitiligo*)*

Enacting Agentic and Autonomous Disclosures

Despite their desire to keep their difference invisible and unknown, all but one of the participants had experience of disclosing their difference to another. Their testimonies portrayed the initiation of a disclosure scenario as involving varying levels of choice, and indicated many disclosures were not the result of a conscious, deliberate decision-making process. Some disclosures were more responsive or externally motivated. These are described within the first sub-theme, 'Agentic State Disclosures.' This term is used to refer to an idea broadly similar to the 'agentic state' described by Milgram (1974), in which individuals were interpreted as acting as the agents of another (an authority figure). In the present research, participants may be considered to be agents of, and driven by, the authority and demands of the immediate context. Disclosures in which greater choice and individual agency were described form the second sub-theme, 'Autonomous Disclosures.' This alludes to the greater levels of self-determination described in the 'autonomous state' of Milgram (1974)

Agentic State Disclosures. Many disclosure episodes were not initiated by participants, did not arise from deliberation and the exercise of individual autonomy, or were otherwise unplanned. Instead they were directed or dictated by another, by circumstance, or by necessity, and so were 'agentic' in nature. This also included examples of inadvertent or incidental disclosure resulting from being overheard. Similarly, participants described onward disclosures made, in breach of trust, by those they had previously told, in which cases those making the onward disclosure may be conceptualized as unauthorized agents of the participants. The most common experience of agentic state disclosure was, however, disclosure undertaken in response to a direct question regarding their appearance and behaviours for which another requested an explanation:

> We came back from holiday and he said "do you mind me asking what, what, what's on your hand or what's" - I think he pointed to his chest and he didn't want to say it… I just said it and that was it (Sienna, Birthmark)

In other instances, circumstances conspired to coerce disclosure or participants made a spontaneous disclosure without having given this prior thought. These agentic disclosures were often with new or potential romantic partners. Disclosure to such persons was, at times, presented as being necessary to avoid the potentially awkward consequences of physical intimacy, namely accidental discovery:

> I knew I had to tell him or somebody at some stage because [the] last thing I wanted was to start getting intimate with somebody and then they find my wig falling off, you know? Or they find I've only got one boob. (Millie, Alopecia and Mastectomy)

As is evident from the language within this extract, participants' autonomy was compromised by the nature of the relationship with these new or potential partners, the implied expectation that such relationships must progress towards physical intimacy, and the possibility of such discovery. While a choice may have subsisted in the sense that participants could terminate such relationships before this point, participants indicated that they felt they had no choice but to disclose. They were therefore devoid of choice, disclosing instead out of necessity.

The role of the other person and the nature of their relationship with the participant were understood to impact not only upon participants' ability to make decisions about disclosure, but also upon disclosure itself. The accounts suggested romantic partners were particularly liable to ask questions, were likely to be in a (real or anticipated) situation that necessitated disclosure, and were therefore often the recipient of agentic state disclosures.

Autonomous Disclosures. Other disclosure experiences, including some disclosures to romantic partners, were presented as being the result of more conscious deliberation and the exercise of participants' autonomy. Participants reflected upon numerous goals that motivated these disclosures. These included personal, interpersonal, and practical goals. Practical goals included securing administrative and logistical support from employers and other institutions (e.g. because appearance-related anxieties were preventing attendance). Personal motivations referred to a desire to increase others' awareness, educate them, gain personal validation through disclosure, and being 'honest' with another person. The desire to be honest was connected to a sense of personal relief from something that could be perceived as a lie:

> Partly I wanted to unburden myself because I feel like I'm partly living a lie and I didn't want to be accused of being fake or lying or, I, I just want to be kind of honest so I've got it out there so to speak (Lily, Alopecia Universalis)

These goals may be distinguished from those more explicitly concerned with the interpersonal relationship between participants and their recipients. These included the aspiration of sharing something personal with the recipient and becoming more understood by them.

The decision to disclose, and the act of disclosure itself, were presented as being difficult domains for participants to navigate. High levels of emotional investment in a given relationship exacerbated this challenge. For a minority of participants (approximately one-third) the decision was made after assessing the likely risks and rewards that disclosure may entail:

> I think you've really got to sort of look at like how you, by telling this person, or deciding to tell this person what, what will be the outcomes if it's good or bad and you know, if, which ways it could go and whether if the good outcome isn't really that great then what's the point in telling them? (Sofia, Alopecia Areata)

Preparing For and Controlling Disclosure

Participants spoke about ways in which they had prepared for and exerted control over some elements of the disclosure process. They also acknowledged that there was a central component of this experience over which they had little influence, namely how the recipient responded.

Making Practical Preparations. Participants discussed various ways in which they had prepared for and affected control over the disclosure scenario. This included deliberately selecting the timing, location, level of privacy, and medium through which disclosure was enacted. Remote disclosures were discussed by over half of the participants and had been conducted over the phone and electronically (including via dating applications):

> The way I told him was... I text him to tell him. I did that for a couple of reasons. It was easier for me. I didn't have to sit, have that embarrassing conversation to his face. But

> also I kind of wanted to make it easier for him if he wasn't going to be interested because of that… I thought actually if he was going to let me down, he might find it a little bit easier to do it by a text message (Mia, Alopecia Universalis)

More commonly recounted were face-to-face disclosures. Some participants reported incorporating a visual revelation of their difference into this situation or using a prepared script:

> [I] just went through my normal thing "oh yeah, it's vitiligo, it's a skin condition. It's when your body is attacking itself and melanin underneath your skin… my body thinks the melanin is an alien and attacks it and that's what causes it to disappear…" just the normal spiel I give to most people (Julia, Vitiligo)

However disclosure was enacted, approximately half the participants reported having engaged in advanced planning for the scenario. This ranged from thinking about where and how to broach the topic, to the preparation of a picture book to give to future adoptive children.

Participants described exerting some control over how open they were with the other person and the level of depth of the interaction. Sometimes relatively brief, even superficial, conversations ensued. Participants did not necessarily consider this problematic nor associate it with poor disclosure experiences or outcomes.

Preparing Yourself Emotionally. Participants described receiving a varied range of, sometimes unpredictable, responses to disclosure. These included undesirable reactions, reported by all but one participant, such as overtly negative comments, reactions that demonstrated a distinct lack of support and empathy, unwanted sympathy or pity, embarrassment, and shock:

> He [potential romantic partner] was just sort of in a state of shock… and I think he just thought I was lying, and what was I wearing a wig for, and why was I covering it up? And there I was being honest. So it was all just all about him and his reaction really. I

> don’t think there was any comprehension of what it’s like to live with it. (Lily, Alopecia Universalis)

A smaller number of participants reported reactions characterized by ambivalence, with little indication of an overtly negative response nor the provision of explicit emotional support, acceptance, and empathy. All but two participants discussed positive and supportive reactions, indicative of the recipient’s acceptance of their visible difference:

> We were going to go away and it was going to be our first time in that sort of [romantic] situation… so I made a bit of light of it and most of them would just turn round and say “oh really, well I’ve got this and I’ve got that” and it was sort of like trying to compare apples with pears and it just took away the whole tension and embarrassment (Ruby, Klippel Trenaunay Syndrome)

As alluded to by Ruby, a little under half of the participants reported a disclosure episode as having facilitated the recipient sharing something personal in return. This included, but was not limited to, the mutual disclosure of visible difference:

> She went upstairs, she come downstairs, and she had a packet of face wipes. And she took all her make-up off and she’s got, you know, discoloration, skin patches… I’d never seen her without makeup on so I didn’t know. And I was like ‘wow!’ So we sort of revealed all to each other and it was like ‘wow!’ (Sofia, Alopecia Areata)

Many participants had experience of varied reactions and the overwhelming sense was that the reaction of another was not something that was within their control:

> I choose to tell someone and how they react to it is up to them. That’s the bit I can’t control. And that took a long time to realize. I think in the early days I was trying to

> control how they react to it because… I did not know how to deal with their reactions and that was the bit I was scared of. (Ivy, Alopecia Universalis)

Participants therefore implicitly distinguished factors that were potentially within their control and which could be the subject of preparation and planning, such as the form of disclosure, from those that were not, primarily the reaction of the other. It was thus inherent within the accounts that those making disclosures should accept this lack of control and prepare themselves emotionally for a range of potential reactions. Participants also felt it was important that those making disclosures did not assume that a recipient would necessarily react negatively as, oftentimes, participants' experiences were more positive than anticipated, and the fear of disclosure was disproportionate to its actuality.

Moving Beyond Disclosure

Participants understood being seen by another person as a major component of the disclosure process and as presenting additional challenges. Furthermore, disclosure was considered an impactful interaction with a variety of potential consequences, addressed within the second sub-theme.

Being Seen. Participants unanimously considered the physical revelation of their visible difference as central to the disclosure process. On occasion and in some contexts this was presented as being the preferred disclosure mechanism:

> I felt the need to be seen to be healthy to try to stay in work, I made the choice to go playing sports again. And after the sports game on a Saturday, I would take my clothes off and go to the showers like everyone else (Charlie, Burn scarring)

It was more common, however, for participants to describe the act of letting others see their difference as provoking anxiety, making them feel exposed and vulnerable, and being the most difficult constituent of disclosure:

> (Amelia's Mother) hadn't actually seen my face raw. And this was something I almost kind of never intended for her to see. I think the shame was just so bad I just felt I couldn't. (Amelia, Cystic Acne)

Participants' accounts indicated that the disclosure process was progressive in nature. Telling another person could be followed by the more difficult step of showing them. The final and most intimate stage was allowing them to touch their body in the area of its difference:

> If it's an intimate relationship, the first time actually showing or exposing your scalp is petrifying and then if someone wants to touch your head as well, aww, it, it's it makes me feel sick thinking about it now. It, it's the concern that they'd be repulsed and especially if it's an intimate situation as well. If you're about to have sex or you've just had sex or whatever it's like "oh no" that's, that's sort of [a] really scary situation. (Ivy, Alopecia Universalis)

A Changed Outlook. Participants spoke about their belief that these disclosure experiences had resulted in fundamental change to the recipient's attitudes, outlook, openness and empathetic ability. Some participants described the recipient becoming more protective of them following disclosure. It was not, however, just the recipient that could be changed by these episodes, with positive reactions leading to increased confidence for future disclosure:

> They just saw me that day, warts and all… it made me feel a little bit less worried, then, about the next time. I thought well they, they've not, they've accepted me for this, so actually what is the problem? (Ruby, Klippel Trenaunay Syndrome)

Disclosure was also conceptualized as a scenario that could facilitate inter-personal changes and depending on the reaction, test, break, or, strengthen a relationship. This could provide an indication of its potential viability and even help move it towards realizing this:

> Telling somebody about something that is hidden will not necessarily be negative for the relationship and most likely will make the relationship stronger and, if it doesn't, then probably it wasn't worth it in any case as a relationship... If that's going to really bother you then I don't think the relationship would have gone any further in any case. (Noah, Colectomy and Colostomy)

Discussion

The findings indicate that the disclosure of visible difference can be a challenging and anxiety-inducing interaction and constitute an important facet of the experience of living with a difference that is not readily apparent to others. Felt and enacted stigma (Scambler & Hopkins, 1986) were both evident, with the "Remaining Invisible" theme including participants' accounts of engaging in 'passing'(Goffman, 1990) to render their visible difference irrelevant and evade enacted stigma and the negative evaluations of others. In 'passing,' participants may be understood as avoiding discovery (Yaron et al., 2018) by availing themselves of a cultural assumption that any given individual does not have a visible difference, just as those with marginally visible disabilities may be assumed to be able-bodied (Calder-Dawe et al., 2019).

'Passing' may carry immediate, culturally mediated benefits but may also serve to reinforce conceptions of normality, emphasize the 'otherness' of visible difference, and prevent one from being fully seen, and accepted in their entirety, by others (Lourens & Swartz, 2016). In addition to covering their difference, participants avoided activities and relationships in which their difference could be exposed. It was therefore apparent that the reduction in participants' enjoyment of their humanity could extend beyond the specific acts and reactions of others into their own actions and beliefs.

It is important to acknowledge that the desire to remain invisible, avoid experiences of felt and enacted stigma, and the behavioral avoidance that have been described, all subsisted within the prevailing cultural context. This is captured within sociocultural models of body image and appearance which may, broadly, be understood as contending that societies generate and endorse social ideals of beauty. These are transmitted to individuals via numerous sociocultural channels, with individuals internalizing these ideals and their appearance dis/satisfaction being largely a function of a self-comparison against these ideals (Tiggemann, 2011). The result is therefore that individuals feel pressure to conform to unattainable social appearance ideals (Gill, 2007) and narrowly construed conceptions of normative appearances (Zitzelsberger, 2005). These cultural ideals do not sanction visible difference and may contribute to experiences of, and reactions to, stigmatization, both felt and enacted.

In the present research, participants' responded to these circumstances with both 'passing'(Goffman, 1990) and avoidance, though these were not sustainable in all situations, with the immediate context sometimes necessitating disclosure. This may be considered somewhat similar to the 'forced disclosures' identified by Quinn & Earnshaw (2011), though they do not develop the concept beyond giving the example of having to disclose criminal convictions when applying for a job. The current research suggests that less explicit, more subtle situational and relational influences may also act to compel disclosure. These were addressed within the "Agentic State Disclosures" sub-theme. This indicated that, contrary to the RRM of Afifi and Steuber (2009), participants' disclosure experiences were often not the culmination of a complex decision-making process and an assessment of the positive and negative consequences of doing so.

The RRM does distinguish disclosures that are initiated by the affected person from those involving their response to a question and suggests different strategies may be employed in either case, but all disclosures are considered to be the result of a risk assessment. The sense of spontaneity recounted by some participants in the current research remains understated within the RRM (Afifi & Steuber, 2009) and DPM (Chaudoir & Fisher, 2010), which, like other models of disclosure, may overstate the agency with which individuals act, and assume disclosure results from the autonomous choices of rational, self-regulating, and calculating actors (Gill, 2007). Choices are theorized as being individual in nature with the importance of structural and societal forces underplayed (Braun, 2009), and the immediate situational imperative, discussed by participants in this research, overlooked.

In instances where disclosure was situationally or relationally necessitated, the process was fluid and responsive to, and dependent upon, external stimuli. It was often spontaneous. This may be partially attributable to the nature of the stigmatized characteristics being disclosed. For example, unpredictable and variable appearance-altering conditions and the ability of participants to ‘pass,’ may render some differences neither invisible nor visible but result in fluctuations between these two states. These differences therefore oscillate between both arms of the model of disclosure of visible and invisible chronic conditions proposed by Joachim and Acorn (2000). In addition to the arguments made above, the characteristics of the individual and the immediate context may therefore dictate that disclosure does not always involve the same level of autonomy proposed by the DPM (Chaudoir & Fisher, 2010), RRM (Afifi & Steuber, 2009) and other theoretical models.

The lack of autonomy seemed particularly pertinent within the romantic context where, much like physical indications of having had breast cancer (Shaw, Sherman, Fitness, & Breast Cancer Network Australia, 2016), differences may become apparent as relationships progress toward physical intimacy. Indeed, some of these disclosures (e.g. disclosing to avoid physical embarrassment) overlapped with the avoidance-focused goals of the DPM (Chaudoir & Fisher, 2010). There was sometimes little sense of a true decision being made, however, as participants spoke of disclosure as a necessity. This may reflect their understanding that in order to progress such relationships, physical intimacy and full bodily revelation would be required. Non-disclosure would require they disengage from intimacy and thus actualize a feared outcome of a poor disclosure experience, the breakdown of the relationship. This perceived lack of choice reflects, to an extent, the participants of Stutterheim et al. (2016) who sometimes felt compelled to disclose their HIV status in response to physical symptoms and the questions of others.

Where more autonomy was understood to have been exerted (“Autonomous Disclosures”) or disclosure was considered more ‘voluntary’ (Quinn & Earnshaw, 2011) there was evidence that the decision to disclose could be motivated by approach-focused goals (Chaudoir & Fisher, 2010). It was noticeable, however, that only approximately one-third of the participants described undertaking the risk-reward or cost-benefit analysis anticipated by Ragins (2008). While the accounts indicated that participants understood these disclosures involved a greater level of self-determination, it will be important to conduct further research to examine and understand more fully the cultural and social forces that may influence this decision-making process. For example, some disclosures were rationalized and presented in terms of the desire to obtain specific practical, personal, or interpersonal outcomes. The potential consequences of disclosure and/or non-disclosure together with the prevailing social climate, which may include levels of public interest, awareness, and understanding, may act to constrain these choices to a greater extent than was reflected within the participants' accounts.

Participants' accounts gave little indication that they understood the goal of specific disclosures to have influenced how they were enacted, the response of the recipient, nor the long-term consequences of disclosure. In this regard, the DPM (Chaudoir & Fisher, 2010) did not seem applicable to participants' understandings of their disclosure experiences. Chaudoir and Fisher (2010) acknowledge that varying levels of cultural stigma associated with different stigmatized characteristics may impact upon the likelihood of rejection and other negative outcomes. It is thus conceivable that visible difference may induce such vulnerability, particularly within the domain of romantic relationships where appearance may be especially salient.

This is portrayed in "Preparing Yourself Emotionally," where the reactions of others were considered somewhat removed from the process of disclosure. Instead, they were attributed primarily to the recipient's characteristics. This indicates participants felt this fundamental aspect of the disclosure experience was outside of their control, and reinforced the idea that those disclosing visible difference should not consider themselves responsible for the reaction of the recipient (Sharratt et al., 2018). The accounts suggested it was important to be comfortable with the practical choices that disclosure can evoke and to be confident and calm in delivering the disclosure message, but also to try to appreciate that one cannot be responsible for, nor control, the reaction of others. Participants wished to impart this message to those who may encounter a disclosure scenario in the future, though the emotional demands and challenges contained within their accounts indicated that this perspective was not always easy to adopt at the point when disclosure is enacted. This understanding tended only to be possible as participants learned from experience and seemed, with regards to some relationships, some disclosure contexts, and some participants, to remain at least partially unrealized.

The ability of participants to learn from their experiences and the impact of one disclosure upon future episodes was evident in the “Preparing For and Controlling Disclosure” theme and was reminiscent of the feedback loop of the DPM (Chaudoir & Fisher, 2010). Participants spoke, however, more of how their experiences informed their sense of self-efficacy and emotional preparedness for disclosure than their tendency towards deciding whether to disclose. The ability to assign responsibility for negative responses to the recipient may be considered one element of this preparedness, and may engender resilience to undesirable disclosure reactions and outcomes.

The disclosure message was communicated in several ways, including several media (“Making Practical Preparations”). This highlighted how the exclusive focus of the DPM (Chaudoir & Fisher, 2010) upon verbal disclosures is a major limitation when considering its applicability to participants’ experiences. While the RRM (Afifi & Steuber, 2009) encompasses verbal strategies along with written forms of communication (e.g. email, text), it classifies the latter as an indirect strategy: a strategy that does not involve directly telling the recipient and which eliminates immediate feedback. It is unclear whether this distinction and definition remains sustainable. It is important that models of disclosure account for the variety of mechanisms, including non-verbal behaviours (Masur, 2018) and social media (Andalibi & Forte, 2018), through which disclosure communications can occur.

The “Being Seen” sub-theme introduced an additional aspect of participant’s disclosure experiences, the physical revelation of their difference. In some cases disclosure was conducted through this visual medium. In others it was considered part of a process that was imbued with greater emotional vulnerability than verbal disclosure alone. This echoed the sentiments of some participants with facial differences, who described how their face being seen was akin to public nudity (Yaron et al., 2018). In the same research, participants considered that that permitting intimates to see their un-covered face acted as a marker of acceptance and intimacy. Models such as the DPM (Chaudoir & Fisher, 2010) are concerned with verbal disclosure and originated from researching concealable stigmatized identities, many of which may not have a hidden visible component. Consequently, this aspect of the disclosure experience, along with less prominent but also relevant concerns about being touched, are not accounted for.

In light of the etymology of stigma (Goffman, 1990), recognition that potentially visible characteristics can be stigmatizing (Chaudoir & Quinn, 2010; Kowalski & Peipert, 2019), and the limitations inherent within existing models of disclosure, a provisional framework of the disclosure of visible difference is presented in Figure 2. This draws upon the main features of this scenario that were discussed by participants and incorporates facets of the disclosure of visible difference that are otherwise uncaptured by existing models. Figure 2 is, however, based on qualitative data from 15 individuals and so will require refinement in the future as more data on this topic is generated.

Furthermore, the provisional framework included in Figure 2 is subject to limitations that may be considered inherent within any model, theory, or framework that focuses primarily upon the individual as the object of interest. It is hoped this orientation has produced a framework that will prove useful in future research and to those contemplating disclosure along with those that may provide care or support to them. While the importance of the immediate disclosure situation or scenario is captured, in its current form the framework does not afford priority to the social, cultural, contextual, and relational influences and forces that may be relevant to the disclosure scenario.

It will also be necessary to explore these factors further in considering the transferability of the provisional framework and the findings of this research. Naturally, these limitations and considerations dictate that Figure 2 remains provisional, conditional, and should be developed further in future research concerned with this phenomenon.

Reflexive Analysis

The researcher did not communicate whether they had a visible difference to participants and was not asked about this by participants. It was therefore not clear what participants believed or felt about the researcher in terms of their appearance or other demographic characteristics, nor how these attributes may have impacted the research interactions. Despite these uncertainties, the researcher's impression was that the interviews were full, open, and honest. The nature and depth of the data generated together with the post-interview interactions with participants acted to strengthen this belief, although these discussions did not elucidate upon the ways in which the researcher's identity may have been salient to the participants.

Most of the interviews were conducted over the telephone. Of the two conducted over the internet, one was 'voice only.' As with previous visible difference research (Egan, Harcourt, & Rumsey, 2011; Sharratt et al., 2018), this medium produced rich and detailed data. The researcher believes that this allowed his focus to rest upon the expression, tone, and content of the participants' accounts, removing the saliency and immediacy of appearance (Fox et al., 2007) and the possibility of participants feeling their appearance was being scrutinized. One participant, however, requested they be interviewed in person. This could be accommodated and so the interview proceeded in this manner. Participants were not asked to explain their reasons for preferring any particular medium of communication but, given this request and assuming sufficient resources are available, it may be preferable to explicitly offer participants this option in future research. Where a choice is offered in future appearance-centered work, a small portion of each interview could be dedicated to investigate participants' choice of medium.

Strengths and Weaknesses

To the authors' knowledge, this is the first dedicated study of the disclosure of visible difference. Some limitations, however, must be acknowledged. There was a lack of ethnic and racial diversity amongst the participants with all participants identifying themselves as white British, white, or other white, and the accounts of men are underrepresented. Given the relevance of the romantic context, it is also noteworthy that all but one of the participants identified as heterosexual.

Given that the focus of this research was upon the disclosure of a stigmatized characteristic, it is especially important that further research seeks to examine the experiences of those who may also experience prejudice, discrimination, and stigmatization because of other features of their identity. For example, visible difference may be imbued with specific cultural meanings amongst those with racial and ethnic identities that are not represented in this research (Thompson, Clarke, Newell, Gawkrodger, & the Appearance Research Collaboration, 2010). The intersection of visible difference, other marginalized identities, and disclosure should be considered further.

This research has elucidated the understandings and disclosure experiences of participants with visible difference, and has considered the applicability of the disclosure processes model (DPM; Chaudoir & Fisher, 2010). The nature of the qualitative design means that it was not feasible to empirically test the tenets of the DPM, such as the proposition that disclosure and its long-term outcomes are influenced by whether it is motivated by approach or avoidance goals.

Future Research

Further research should empirically evaluate models of disclosure and incorporate a longitudinal design in order to capture unfolding disclosure experiences. The prominence of the disclosure scenario, specifically within romantic relationships, suggests that research dedicated to the development of an intervention to assist in the navigation of this scenario, is warranted.

Conclusion

This research has examined the varied disclosure experiences of those with, and who have disclosed, visible difference. The applicability of models of disclosure have been considered and a working framework that incorporates the specific challenges connected with the disclosure of visible difference has been proposed.

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Table 1

Participant Demographic Details

Pseudonym	Gender	Age	Visible difference (and affected area(s) of body)	Relationship status	Interview method	Interview duration (minutes)
Amber	Female	56	Vascular malformation (stomach)	Married	Phone	21
Amelia	Female	22	Cystic Acne (face)	Single	Phone	114
Ava	Female	21	Alopecia Universalis (whole body)	Single	Phone	76
Charlie	Male	55	Burn scarring (torso, limbs)	Married	Phone	57
George	Male	48	X&Y chromosome variation (physique, hips)	Single	Skype© (voice)	77
Isabella	Female	57	Pityriasis Rubra Pilaris (whole body)	Divorced	Phone	69
Ivy	Female	43	Alopecia Universalis (whole body)	Married	Phone	71
Julia	Female	61	Vitiligo (lower legs, lower arms, face)	Divorced	Phone	84
Lily	Female	50	Alopecia Universalis (whole body)	Single	Phone	91
Mia	Female	29	Alopecia Universalis (whole body)	Engaged	Phone	59
Millie	Female	70	Alopecia (whole body, except: eyebrows, eyelashes, legs) and mastectomy (breast)	Partnered	Phone	65
Noah	Male	53	Colectomy and colostomy (rectum, pelvis)	Separated	Skype© (video)	104
Ruby	Female	53	Klippel Trenaunay Syndrome (leg)	Separated	Phone	58

Sienna	Female	27	Birthmark (whole body, except: one hand, face)	Single	Phone	68
Sofia	Female	35	Alopecia Areata (head; scalp only)	Married	In person	115

All participants identified their ethnicity as white British, other white or white.

All but one of the participants identified their sexual orientation as heterosexual, one identified as gay

Table 2

Semi Structured Interview Guide

General questions

- Please could you tell me a little about yourself, perhaps imagining you've been asked to describe or summarise your life in a paragraph or two?
- How would you describe your visible difference to someone that does not know you?
- How do you feel about your visible difference, what does it mean to you?
- How do you think other people interpret your visible difference?
- What, if any, has been the impact for you of having a visible difference?

Participants were then asked to describe in their own words an incident when they had told someone that they had a visible difference before being asked specific questions focused on that event (or series of events)

- Why did you decide to tell this person about your visible difference?
- What outcome(s) or changes were you hoping for once you had told the other person about your visible difference?
- Was there anything that you were anxious or fearful about in advance of telling them?
- Overall, how were you feeling about telling the other person in advance of doing so?
- How did you prepare for disclosing to the other person?
- Can you describe how you went about telling them that you had a visible difference?
- To what extent were you able to share your most private thoughts, feelings, and experiences connected to your visible difference?
- How did you feel during this discussion?
- How did the other person react to you telling them about your visible difference?
- How did the process of disclosing your visible difference compare to your hopes and expectations?
- In what ways did things change immediately following the disclosure?
- Would you do (or have you done) anything differently in the future as a result of this experience?
- How would you summarise your feelings about the process of telling this person about your difference?
- Is there anything we've not discussed that you'd like to speak about?

Do you have any other experience of telling someone about your visible difference that you would like to talk about?

- With [this/all these] experience[s] of sharing your visible difference with someone else in mind, what would be your advice to someone doing so for the first time?

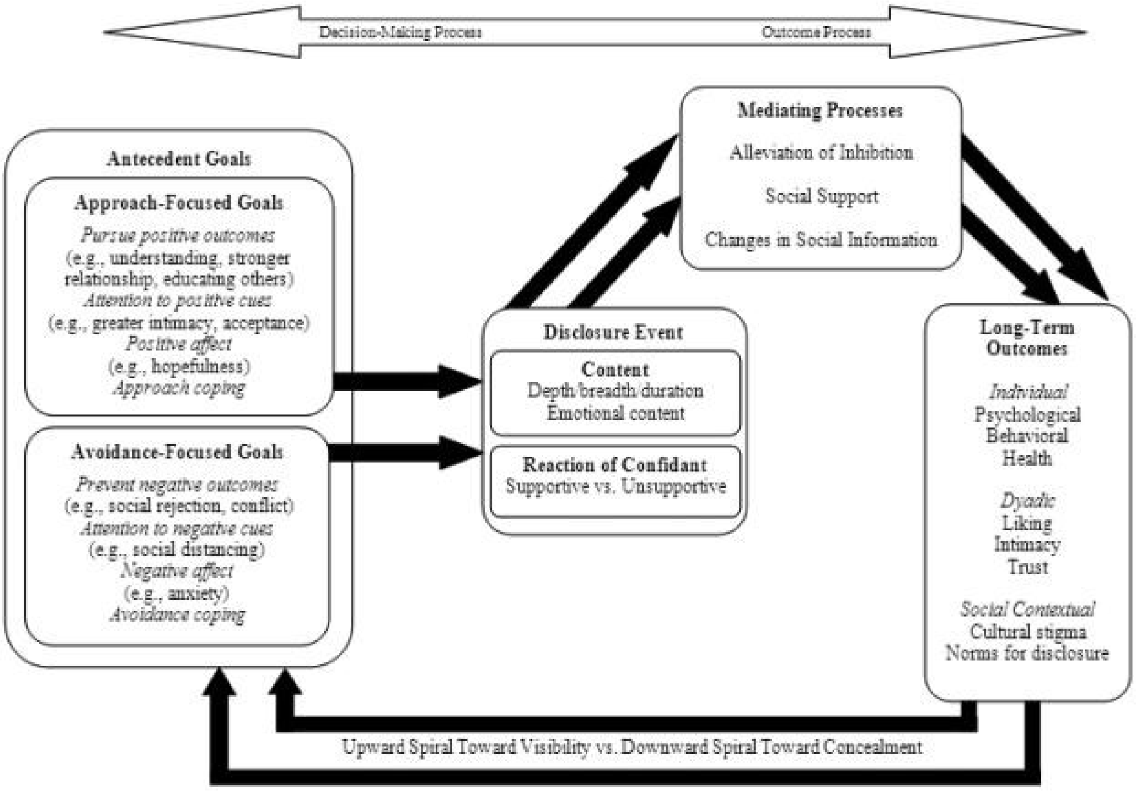
Table 3

Themes, Sub-themes, and Example Codes

Theme	*Sub-theme*	*Example Code*
Remaining invisible	-	Seek normalcy
Enacting agentic and autonomous disclosures	Agentic state disclosures	Responsive disclosure
	Autonomous disclosures	Educate the other
Preparing for and controlling disclosure	Making Practical Preparations	Dating applications
	Preparing Yourself Emotionally	Shocked response
Moving beyond disclosure	Being seen	Feeling exposed
	A changed outlook	Changed recipient

Figure 1

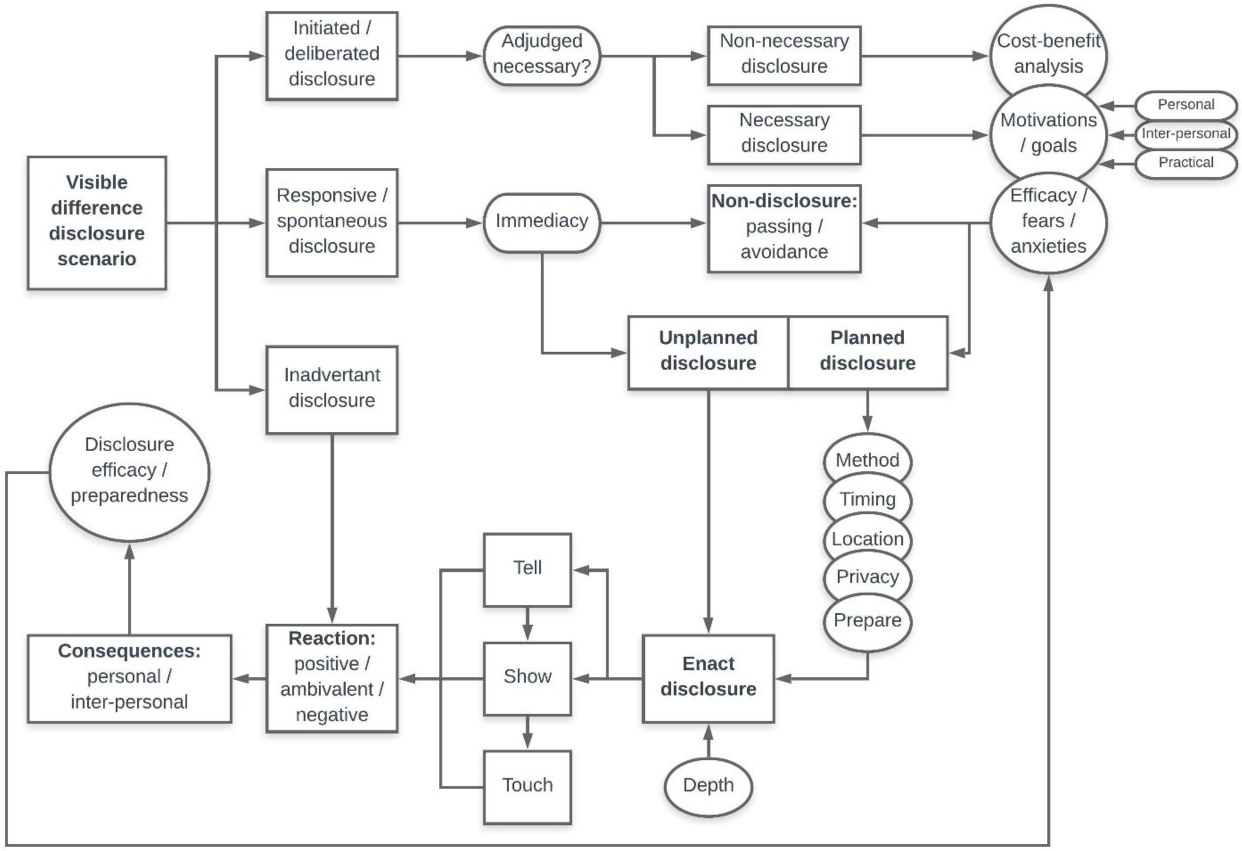
The Disclosure Processes Model



Chaudoir, S. R., & Fisher, J. D, the disclosure processes model: understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity, Psychological Bulletin, 136(2), 236, (2010), APA as publisher, reprinted with permission

Figure 2

Working Framework of the Disclosure of Hidden Visible Difference



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