

**Understandings and experiences of visible difference and romantic relationships: A
qualitative exploration**

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Declaration of Competing Interests

Declarations of interest: none

Acknowledgements

Funding: the preparation of this manuscript was supported by a donation to the Centre for Appearance Research from the Vocational Training Charitable Trust (VTCT) Foundation.

Abstract

The association between disfigurement ('visible difference') and romantic relationships has received relatively little consideration in the research literature. This qualitative research, conducted in the United Kingdom, explored participants' accounts of their visible difference and romantic life. Semi-structured interviews were conducted with 22 participants who had a variety of visible differences. Inductive thematic analysis demonstrated that participants understood their difference as having a pervasive and enduring impact. These encompassed challenges that must be negotiated in the formation of romantic relationships, including feeling unattractive to others and feeling personally devalued. Relevant physical and sexual sequelae were comprised of anxieties regarding informing partners of a difference, impacted sexual activity, and concerns about heritability. Finally, the potential for partner support and acceptance to positively impact romantic relationships was recognised. This research highlighted the need to extend our understanding of visible difference and intimate relationships and to develop effective interventions to ameliorate appearance-related concern.

Keywords: Visible difference; Disfigurement; Romantic relationships; Intimacy

Introduction

The study of body image and sexuality has featured in the research literature, with much of this work devoted to the association between negative body image and sexual function in women (Woertman & van den Brink, 2012). This association includes lower sexual desire (Koch, Mansfield, Thureau, & Carey (2005), arousal (Sanchez & Kiefer, 2007), satisfaction (Calogero & Thompson, 2009), sexual esteem and sexual assertiveness, as well as higher sexual anxiety and sexual problems (Weaver & Byers, 2006) and increased sexual avoidance (La Rocque & Cioe, 2011) in those with negative body image. These relationships have been linked with cognitive self-absorption, which is an intense fixation upon, and monitoring of, an individual's own bodily parts or *spectatoring* (Masters & Johnson, 1970) during sexual activity (Woertman & van den Brink, 2012). Similarly, Woertman and van den Brink (2012) proposed that the application of the model of sexual functioning proposed by Barlow (1986) posits that anxious self-evaluation and self-focus during sexual activity may cause cognitive distraction and adversely impact sexual function.

The contention that negative body image contributes to cognitive distraction during sex is consistent with the findings of Meana and Nunnink (2006) who demonstrated that negative body image predicted appearance-based sexual distraction in both college men and college women. Measures of sexually contextualised body image, including self-focus, self-consciousness, and avoidance of bodily exposure during sexual activity, have been shown to better predict disrupted sexual functioning than general measures of body image (Cash, Maikkula, & Yamamiya, 2004; Woertman & van den Brink, 2012; Yamamiya, Cash, & Thompson, 2006) and to mediate the association between body image and sexual functioning (Sanchez & Keifer, 2007).

Conversely the literature also indicates that positive body image may contribute to increased sexual desire and improved sexual function. This has been found in studies that have shown a positive association between body esteem and sexual desire (Seal, Bradford, & Meston, 2009) and between body appreciation and sexual function (Satinsky, Reece, Dennis, Sanders, & Bardzell, 2012). Furthermore, Swami, Weis, Barron, and Furnham (2017) suggested that positive body image may protect the individual from spectating and therefore permit greater sexual liberalism and more positive attitudes to unconventional sexual practices.

Visible Difference

Whilst the research discussed so far has centred upon body image and sexuality, it is also apparent that those with appearance-altering conditions or an altered appearance may believe their sexual and romantic lives to have been impacted by their appearance. Such differences in appearance may be understood as constituting “visible difference” and have been defined by Kent and Thompson (2002, p.103) as “potentially noticeable differences in appearance that are not culturally sanctioned.” These authors also assert that visible difference may result from congenital conditions, traumatic events, disease processes, and medical treatment.

The challenges to psychosocial well-being that visible difference can present have been summarised by Rumsey and Harcourt (2004). These included challenges identified in academic commentaries discussing social and cultural adversities, such as discrimination, the negative judgements and reactions of others (Kent & Thompson, 2002), and stigmatisation (Goffman, 2000; Kent, 2000). Furthermore, they encompassed individual, psychological difficulties including low self-esteem, high levels of anxiety, depression, social anxiety, social avoidance, and reduced quality of life, as indicated by mixed-methods empirical

research (Rumsey, Clarke, & Musa, 2002; Rumsey, Clarke, & White, 2003) and via the review of Thompson and Kent (2001). Individual adjustment and appearance anxiety is, however, not well predicted by the nature of the difference nor linearly related to or predicted by objective measures of size or severity, as demonstrated empirically by Moss (2005), Ong and colleagues (2007), Rumsey and colleagues (2003), and Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004).

It is, however, important to acknowledge that many individuals with a visible difference do not report psychosocial difficulties and that qualitative analyses have explored the possibility of visible difference exerting a positive influence upon the lives of those affected. Eiserman (2001) interviewed 11 adults with craniofacial conditions about their experiences of living with a visible difference. The themes identified captured how those living with craniofacial difference attributed a sense of meaning and coherence in life to looking different, as well as a plethora of positive attributes, such as enhanced communication skills, inner strength, and a valuable social circle to the presence of their difference. Egan, Harcourt, and Rumsey (2011) conducted individual and group interviews with adults with a range of visible differences who identified as adapting positively to their condition. Participants considered their visible differences to have facilitated personal growth by developing their resilience, resourcefulness, and calmness, and to have improved their relationships with, and understanding of, others. The consideration, support, and acceptance of partners was identified as being especially valuable in this respect and provided an indication of the importance of the intersection of romantic relationships and visible difference.

Visible Difference and Romantic Relationships

Whilst adjustment to visible difference has received attention in the research literature, the specific sphere of visible difference and romantic relationships has remained on the periphery of this body of work. Quantitative research has indicated that adult attendees of a plastic surgery outpatient clinic considered their intimate behaviours to be greatly affected by their appearance (Appearance Research Collaboration, 2014). Similarly, studies of those with a specific appearance-altering condition consistently report an impact upon sexuality and romantic relationships.

Porter and colleagues (1990) reported that 25% percent of 158 participants with vitiligo believed their condition to have impacted negatively upon their sexual relationships. In a larger study of 936 patients with psoriasis, between 35.5% and 71.3% of participants reported encountering sexual difficulties as a result of their psoriasis (Sampogna, Gisondi, Tabolli, & Abeni, 2007). The authors attributed the wide range in responses to the nature of the items to which participants were required to respond. Items that were more specific in nature and restricted to defined periods of time, such as the last week or the last four weeks, were endorsed so as to indicate lower levels of sexual difficulty than those which were more general and were not restricted in this way. Amongst those that had received treatment for head and neck cancer, one-third of respondents reported substantial problems with sexual interest and enjoyment, and one-quarter problems with intimacy (Low et al., 2009). Longitudinal research with patients with burn injuries indicated that burn injuries negatively impacted sexuality, body image, and relationship aspects of quality of life and that this effect subsisted regardless of good physical and functional recovery (Connell, Coates, & Wood, 2013; Connell, Phillips, Coates, Doherty-Poirier, & Wood, 2014)

Despite these quantitative studies indicating that visible difference may impact upon romantic and sexual life, there exists a paucity of qualitative research elucidating experiences and understandings of visible difference and romantic relationships and exploring the nature

of these reported impacts. That which does exist has focussed upon the experiences of adolescents. The qualitative data provided by adolescent participants in the work of Griffiths, Williamson, and Rumsey (2012) demonstrated that they believed appearance to be important in securing a relationship but felt unattractive, feared negative evaluation, found it difficult to talk with the other sex, attempted to conceal their difference, and feared revealing it to a new partner. Similar cognitions and behaviours were identified in an online qualitative study of eight adolescents with psoriasis, who reported avoiding intimate behaviours as a result of reduced self-confidence (Fox, Rumsey, & Morris, 2007), but explorations of this subject matter in adult populations have yet to be reported.

Whilst no previous qualitative research has specifically examined romantic relationships and visible difference amongst an adult population, qualitative research concentrated upon a particular condition or group of conditions has been reported. This has focussed upon those living with a broad range of appearance-altering conditions including below-the-knee amputations (Mathias & Harcourt, 2014), alterations in appearance associated with breast cancer (Ginter & Braun, 2017; Loring, Larkin, Shaw, & Flowers, 2015), burn injuries (Connell, Coates, & Wood, 2015), psoriasis, acne, and eczema (Magin, Heading, Adams, & Pond, 2010), lymphedema (Winch et al., 2015, 2016), testicular cancer (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011), and vitiligo (Thompson, Clarke, Newell, Gawkrödger, & The Appearance Research Collaboration, 2010). Participants in these studies experienced low self-confidence, low self-esteem, self-doubt, emotional and relational concerns, and internal fears of being judged, negatively evaluated, and rejected. Similarly, participants reported having experienced sexual difficulties, feelings of being physically unattractive, and being unable to meet a new partner. To the knowledge of the authors there exists, however, no previous reported research dedicated to exploring experiences of visible

difference and intimate, romantic relationships. It is this deficit that the current research sought to address.

In light of quantitative research demonstrating that visible difference and appearance-altering conditions may impact negatively upon sexuality and romantic relationships, the confirmation from a disparate body of qualitative work that this may be so, and the absence of qualitative research specifically dedicated to understanding and exploring the impact of visible difference upon romantic relationships in adults, the current research aimed to address the following research question: do participants with a visible difference understand their appearance to have impacted upon their intimate, romantic relationships? In order to then elucidate any such impact a second research question was adopted: how do participants with a visible difference understand, and how have they experienced, their appearance as impacting upon their intimate, romantic relationships?

Method

Participants

Semi-structured interviews were conducted with 22 participants living in the United Kingdom who were over the age of 18 years and who considered themselves to have a visible difference. This included 16 women and six men. Participants were aged between 25 and 64 with an average age of 43 years. Sixteen participants were married or in a relationship whilst six were single. All participants expressed heterosexual romantic preferences and spoke exclusively of heterosexual romantic experiences.

When considering the visibility of their difference in daily life, 12 participants stated that their difference was ordinarily visible to others and 10 believed their difference was not visible in this way. Eight participants had a condition they described as congenital or genetic, whilst the remaining 14 had acquired their difference through injury, illness, or disease. The

participants' visible differences were: alopecia (five participants), ankylosing spondylitis (one), breast cancer-related scarring (two), cleft lip and/or palate ('cleft') (six), facial birthmark (one), facial palsy (one), facial palsy and breast cancer-related scarring (one), facial scarring (one), ichthyosis (one), and psoriasis (three).

Materials

In addition to audio-recording equipment and computer hardware and software (including Nvivo 11), an interview guide was developed for use in this research. The first author drew upon the existing literature to devise draft questions that were reviewed and revised with input from each of the co-authors, who drew upon their extensive research and clinical experience. These were reviewed by and pre-tested with other researchers in the research centre in which the first author is based but were not pilot tested with potential participants as they were to be deployed flexibly, in a responsive manner. There also existed a desire not to lose data and potential participants to the study as concerns relating to the number of participants that may volunteer to discuss this sensitive subject persisted. The questions that related to romantic relationships are included in Table 1. These questions were utilised flexibly within the context of each interview and follow-up questions were asked in response to each participant's account in order to afford primacy to their voice.

Procedures

Semi-structured interviews were employed to explore participants' understandings and experiences of visible difference and romantic relationships, giving them freedom to express themselves whilst retaining a focus on the object of the research. In an attempt to empower participants (Trier-Bieniek, 2012) and in recognition of the possibility that those taking part may have been anxious about meeting with, and being visually scrutinised by, a researcher, each participant was offered a choice between three forms of synchronous verbal

communication. These were an interview conducted in person, over the telephone, or via an internet-mediated video service (Skype).

Having obtained ethical approval for this research from the University of the West of England faculty research ethics committee, the study was advertised by a university press release, on the social media accounts of the authors' research centre, and by 17 support groups and charitable organisations for those affected by visible difference. These organisations used a variety of methods, including social media, websites, and newsletters, in order to make their members and subscribers aware of the research. Potential participants contacted the researcher in response to these adverts. The researcher answered any questions they had, ensured they had access to full information about the study, and made practical arrangements for conducting the interviews. Each participant provided verbal or written fully informed consent before their interview was conducted. The first author conducted all the interviews. The first author had conducted qualitative focus groups and interviews (including interviews with staff and patients of the United Kingdom's National Health Service) in two previous research projects, had attended training sessions and benefited from the informal advice and guidance of supervisors and colleagues at three universities (including the one at which this research was conducted), and had extensive experience of providing a confidential listening and emotional support service to those in distress. The research team therefore considered the first researcher competent and prepared for this task. In support of this assessment and to help ensure the quality of the data, the first and last authors conducted regular debriefing sessions in which the content of each interview and the first author's experience of conducting it were discussed and reflected upon.

Of the 22 participants, 15 chose to be interviewed over the telephone, five face-to-face, and two via Skype. The interviews lasted for an average of 65 minutes. The number of participants interviewed accords with guidance given by Braun and Clarke (2013, p. 48) that

20 interviews constitute a large sample for interview studies employing thematic analysis. Recruitment ceased when data saturation was adjudged to have occurred. This was assessed on the basis of the ongoing review and analysis of interview notes, reflection on the data, and when the generation of emerging codes indicated that the data were comprehensive in scope, rich in nature, and the accounts of multiple participants demonstrated common essential characteristics (Morse, 1995, 2015). Participants were not offered and did not receive any remuneration or compensation in connection with their participation in this study. In order to protect participants' anonymity, pseudonyms have been used in this report.

Data Analysis

The interview data were audio recorded and transcribed verbatim by an independent party before being thoroughly checked at least twice by the first author on a word-for-word basis for errors and misinterpretation of the dialogue. This confirmed the accuracy of the transcripts as well as ensuring the first author was thoroughly immersed in and familiar with the data, having also conducted all 22 interviews.

This familiarisation with the data constituted the first phase of the inductive approach to thematic analysis advocated by Braun and Clarke (2006, 2012, 2013) for exploratory studies. The inductive, data driven analysis gave priority to the accounts of the participants and explored semantic features of the data in addition to its latent meanings.

The first author manually coded hardcopies of the entire data-set, deriving codes that described interesting features of the data. Example codes are provided in Table 2. The codes were collated and clustered into candidate themes and sub-themes. In line with the guidance of Braun and Clarke (2006), and as is consistent with the methodological approach adopted (Braun & Clarke, 2013, p.279, 2014; Terry & Braun, 2016), this process of coding the data was performed by the first author rather than by multiple, independent coders.

Throughout this process, however, the first author worked closely with the last author, a professor of appearance psychology with over 20 years' experience of conducting, collaborating in and supervising qualitative research. The first and last author met regularly to discuss coding, candidate themes, and candidate sub-themes. Such discussion included reference and referral to the transcribed interviews in order to ensure the analysis remained grounded in, and justified by, the data and was therefore credible, meaning that it was trustworthy, verisimilar, and plausible (Tracy, 2010). Decisions relating to the content and organisation of themes and sub-themes were taken jointly by the first and last author. The analysis was further reviewed, refined, and confirmed in two meetings between the first author, the second author, a senior lecturer in health psychology, and the third author, an associate professor in appearance psychology. The second and the third author each have over 10 years' experience of relevant qualitative research. A further review of the analysis was conducted separately in one meeting between the first author and fourth author, an experienced research active clinical psychologist. Furthermore, the second author independently coded one transcript and discussions between the first and second author revealed a strong consensus with all pertinent issues and potential codes identified by the second author forming part of the analysis.

As part of this review process and in order to maintain an accessible record of the data, the first researcher utilised the Nvivo 11 software, coding the data set at the level of themes and sub-themes within this programme. The review process resulted in five candidate themes connected to romantic relationships and intimacy being collapsed into the three detailed below. "The Disclosure Dilemma" had been a candidate theme but was subsumed into "Looking Different: Physicality and Physical Reality" as a sub-theme. Components of a fifth candidate theme focussing upon the impact of appearance upon participants' romantic identity were distributed amongst the final three. These are defined in the Results section

below. In order to further ensure the credibility of the analysis (Tracy, 2010), a provisional summary of the findings was sent to the 21 participants that indicated they wished to receive this document. Five participants responded. All comments supported the analysis.

Results

A total of five themes arose from the final analysis. Two themes were principally concerned with the participants' thoughts, feelings, and experiences of visible difference in their daily life, whilst three related specifically to their intimate and romantic lives. In line with the focus of this paper, the three themes focussing on intimacy and romantic relationships are presented in Table 2 and presented within this report. This table also illustrates the organisation of these themes, their subthemes, and provides some example codes.

Appearance Attracts and Detracts

This theme reflected participants' understanding that appearance is of fundamental importance to attraction and attractiveness to others and also that participants considered themselves to be personally devalued by their difference.

Appearances are central to attraction. This sub-theme was discussed by 19 of the 22 participants who, in espousing the centrality of appearance to attraction, suggested that a positive appraisal of their physical appearance and being perceived as being physically attractive was important to the formation of romantic relationships. The presence of a visible difference was characterised as negating the attractiveness of participants to others and was thus represented as an obstacle to potential relationships of this type:

You get somebody that's saying all the right things: "It doesn't matter" and "bloody hell, I'm going bald anyway" and then, to totally ignore you. Don't tell me it's not an issue when it obviously is. But I do understand because, honestly, and I'm not just saying it for

you, I do understand. I do understand because we do, as much as you like to say “I love the person inside,” it’s a physical attraction that first makes you go over to that person and talk to them. It’s a physical attraction that will make me or any man on a dating website scroll through pictures and go “Oh God, no, no, next one! Oh he’s a bit of alright” You know? It’s, that’s what we do. It’s what we do, isn’t it? So I do understand and I try, I try really hard not to let it bother me. (Michelle, alopecia)

In some cases this was presented as the greatest challenge associated with visible difference:

The worst period for me was during the periods when I was a young person and wanted to be courting or should have been courting. That was the very worst period. And, again, perhaps I was out of the people insulting me time but I was then into the period of how do I make myself presentable to the opposite sex? (David, cleft)

Attractiveness was considered to be contextualised and dictated by societal appearance ideals, ideals to which visible difference did not conform:

I think a lot of it’s the media and magazines and television as to what in Western society is deemed as attractive, whereas if you were in Hawaii or somewhere it might be big is beautiful or whatever, or Africa a long neck or whatever but, yeah, I think in Britain it’s, or Western society it’s, yeah, certain things are deemed to be more attractive than others and hair, particularly as a woman, is I suppose the crowning glory or the, I mean, it’s just a sign of, of desirability, attractiveness, fitness, the whole shebang really. Youth. So I suppose, yeah, losing my hair I felt old or unattractive, yes. (Elaine, alopecia)

Appearance ideals and the importance assigned to judgements of attractiveness were believed to be applied more rigorously and felt more acutely by women than by men. Half the participants explicitly discussed the idea that women are subjected to relatively more

appearance pressure, or were more liable to be assessed on the basis of how they look, than men:

My husband's got no hair, it's never really bothered him, I don't think. I don't know, perhaps I'm wrong but I do feel that women do seem to have more pressure on them. But then you hear a lot, don't you, of guys now having anorexia and dysmorphic and all that stuff so, yeah, maybe. Maybe I'm wrong about that but it does seem more of a female thing." (Karen, breast cancer)

In light of the perceived negative reactions and judgements of others, participants occasionally communicated concerns about whether another person could ever find them attractive. Such feelings were particularly pertinent to those who were single at the time of the interview. The sense of diminished attractiveness to others was described by several participants and characterised as limiting their romantic opportunities. These participants believed that their difference made them a less attractive proposition as a partner and dictated that they could enter into a new romantic relationship only with an existing friend or someone with whom they had already developed a sense of trust and understanding:

It would be a lot harder to meet someone, to spend time with them in the first place, it would have to be either a friend-of-a-friend or someone that for some reason you've got to spend a bit of time with someone at work or something like that. (Ryan, facial palsy)

Despite the perceived disadvantages associated with appearance-based judgements, there was acknowledgment from seven participants that these judgements were natural, involuntary, and that they themselves may also evaluate others on a similar basis:

I'm probably the world's worst for judging people on looks as well. I look at people and think "Oh, I don't want to look like that!" You know you do, you know, I look at people

who are bigger than me and think “Oh if I stop going on my bike I’m going to be that big” so I think it’s kind of programmed into you. (Beth, facial scarring)

Finally, it is important to acknowledge that the accounts of three participants were not consistent with these ideas and indicated that their difference had not impacted their romantic lives, nor diminished their romantic prospects. Speaking about an ex-boyfriend who had told Vanessa he did not remember her psoriasis, Vanessa said:

He said ‘Some guys don’t even care about that as long as they can get the girl. So, psoriasis really? Who cares?’ And apparently, he’s right. (Vanessa, psoriasis)

The discounted self. Whilst the previous sub-theme addressed concerns about how visible difference diminishes attractiveness to others, this second sub-theme addressed feelings of personal deficiency expressed by 19 of the 22 participants. These respondents deemed themselves to be devalued by their appearance, making them a less viable romantic partner:

I’ve got this one breast, if you like, and the other one was done but it’s an implant but there’s no nipple there, it’s like I’m deformed and there’s lots of scars... and I think it looks ugly... in my eyes already I’ve finished myself off because I think intimacy is out of the question now. (Valerie, facial palsy and breast cancer)

Such concerns were especially salient in the accounts of participants who were single at the time of their interview and for those in relationships when contemplating being single. Participants described adopting compensatory strategies as they sought to promote other socially- and culturally-desirable characteristics, which were more directly within their control. These included the sculpting of the body through physical exercise:

I couldn’t control my face but I could control myself from the shoulders down. So I did what I could with that and I still do with that. (Luke, cleft)

Participants thus conceptualised relationship formation as being akin to a negotiated exchange in which the relative worth of each partner is scrutinised by the parties involved. Deficiencies in appearance may be compensated for by other desirable characteristics, abilities, or status. Other qualities that were expressly mentioned included cultivating a gregarious personality, obtaining a good education, job status, wealth, and possessing the currency of relative youth:

I've always thought that I'm not good enough sometimes, you know, why would someone good looking want to be with me? And then so, in that respect I've gone for older men who haven't been as youthful. Then, when I was 27, I ended up with a 44-year-old and he just turned out to be the biggest idiot ever. But I kind of latched onto him because I was thinking "It's safer. He's not going to leave me" and "He should be grateful he's with someone so young, you know, regardless of what I look like, you know." (Beth, facial scarring)

Ten of the participants who were either enjoying or could envision a healthy relationship attributed this situation to luck, good fortune, or the rarefied and special qualities of their partners who accepted them despite their difference. An additional participant speculated that other people with a visible difference may feel this way but did not personally subscribe to this notion. In several instances, this combination of feeling devalued but also lucky or grateful had contributed to a tendency to accept unrewarding relationships. Three participants maintained that they got married to someone precisely because of such feelings:

I ended up marrying the wrong person... he, you know, was being a moral support and I thought uhm, no-one else will ever want me again, no-one else will ever find me attractive, he wants me, I'd best just settle for this then, you know? So I think in

hindsight if I hadn't have lost my hair, I would never have settled with him and, you know, got married. (Elaine, alopecia)

Looking Different: Physicality and Physical Reality

This second theme is devoted to the physical consequences of living with a visible difference and how these impact upon romantic relationships.

The disclosure dilemma. This sub-theme was discussed by 13 participants. This included 9 of the 10 participants who considered that their difference was not immediately visible or was ordinarily concealed. In addition, this theme included contributions from participants who said that the visibility of their condition fluctuated, from those whose difference could be concealed but who routinely chose not to hide it, and from one participant with multiple differences (some normally visible, some not).

For these participants, the moment of disclosure of their difference assumed central importance in their experiences of visible difference and romantic life. Those in established relationships could recall the concern they had felt as this moment approached, whilst for single participants the anxiety was ongoing. This moment of disclosure represented an extra hurdle to overcome in forming a relationship. One participant considered this insurmountable:

I've got to explain, well actually, you know, I'm deformed as well on the chest. I couldn't see myself right now or the near future explaining that to anybody because at least I can hide that. At least no-one can see that but me. (Valerie, facial palsy and breast cancer)

Elaine explained why this revelation of a physical difference was so problematic:

I'm presenting one image to the world but the reality is something else, so they've got to then get their head around the fact that I'm not this woman with long hair and whatever and I'm actually bald. So they meet one woman but if they go to bed with me it's a totally different woman and they think "Oh, who's this?" (Elaine, alopecia)

As alluded to by Valerie and Elaine, physical intimacy was viewed as the defining point before which this disclosure was required. Contributing participants were unanimous in considering it necessary to tell a partner about their difference rather than have them discover it. This approach was related to a conviction that if they were to avoid telling a new partner about their difference this would be interpreted by the partner as being deceitful, deceptive, or dishonest. Yet, despite the conviction that telling a partner was of great importance, the act itself was characterised by uncertainty and anxiety regarding how, where, and when to do so and how that other person would react. Speaking about Internet dating sites, Michelle said:

(I) had various different thoughts off people as to what I should do with regards to my alopecia, from "No, make sure all your photos on there you have got wigs on," "You shouldn't have to tell anybody anything about it," "Let them get to know you as a person first." But then I feel I'm being quite deceitful in that regard so, after lots of trials we have now settled on my page with photos of me with wigs and a couple of daft ones of me polishing my head with a can of Brasso [laughs]. (Michelle, alopecia)

The pictures were then integrated into a deliberate disclosure strategy in an attempt to overcome this uncertainty and anxiety. Michelle described how she would turn the conversation to these photos which could be (and had been) mistaken for pictures of her engaging in charity fundraising activity. Other participants spoke about strategies used to minimise the chances of a hurtful response, such as disclosing at the end of a date, doing so on neutral territory, and disclosing remotely by messaging or phoning potential dates before

meeting. Such strategies did not guarantee positive reactions but helped participants exert control over the disclosure scenario and to some extent, limited their exposure to hurtful responses. The discomfort associated with uncertainty about the nature of the reactions of others appeared to drive participants' anxiety. This was reflected in descriptions of the variety of reactions experienced in the past, ranging from palpable shock and rejection to acceptance and understanding:

With my current boyfriend, again, I would, I always feel a bit nervous. I remember showing him and him just saying he liked it so, it was very positive. (Chloe, facial birthmark)

Invading physical intimacy. This sub-theme conveys the impact of their visible difference upon physical intimacy and sex and was drawn from the accounts of 17 of the 22 participants. These participants described three discrete effects. The first was a reduction in the desire for sexual contact, attributed to feeling deeply unattractive. For participants who did not have a partner this could manifest itself through the avoidance of situations that may lead to sex:

When I've got it at its height, it still does rather worry me. It almost makes it as if there's a sort of a "hunting season," although, not the word I want "mating season" as it were, outside of the time when my condition has got particularly bad. I know it's a bit pathetic and all the rest of it, especially knowing what I know objectively but, yes, I do think it will have an effect on my confidence in that respect. (Austin, psoriasis)

Some participants in relationships rejected the advances of their partner because of such feelings. This represented a physical manifestation of participants' anxiety about their attractiveness to others and their low physical or sexual self-esteem. Some female

participants whose difference affected feminised and sexualised areas of the body ascribed this to a reduced sense of femininity:

Our sex life has been completely interrupted during all this... and I kind of know when we're going to do it because I leave a bra on... (it has) just has taken away every idea of femininity completely... you're just like an alien. No eyebrows, no eyelashes, nails, things that kind of you see as feminine, lovely long painted nails, lovely mascara eyelashes. (Jodie, breast cancer)

The second, less pervasive effect was that some participants felt discomfiture at being seen naked by their partner and would conceal their difference during physically intimate moments. Jodie's extract has already illustrated this "shrouding." In describing the use of towels and wraps to cover up and how it felt to be seen naked by her loving and supportive partner, Sian alludes to the powerful way in which this could diminish intimacy within a relationship:

(I) feel like I could be standing naked in front of a stranger, or a stranger walks in the room when I'm naked. (Sian, ankylosing spondylitis)

The final component of this sub-theme refers to the perceived tendency of visible difference to detract from participants' ability to enjoy sexual contact with a partner. Visible difference was therefore understood as having the ability to 'steal the moment:'

It just stops you being in the moment, I guess sometimes. If you're moving your head on the pillow and you then remember you haven't got any hair. (Florence, alopecia)

This was not necessarily the result of a partner noticing the difference or behaving in a way that made participants feel uneasy. Charlotte explained that during sex she felt compelled to alter position to make her difference less visible, even though she acknowledged that this was more of an issue for her than for her partner:

He's not looking at it, or my ex-boyfriend wasn't looking, obviously busy doing what else, but... for some reason it will pop in and I'll be like "Ah... I've got... I don't want. Um..." I've got to move because I don't want him to look at me. (Charlotte, cleft)

Concerns over the heritability of appearance-altering conditions. Nine participants with conditions that may include a genetic component, including all six participants with cleft, two with dermatological conditions, and the participant with ankylosing spondylitis, contributed to this sub-theme. They spoke about the possibility of their children acquiring the condition and the impact this may have upon their child's life:

If it was a girl I, well, like I said, if, I would've been really, really heartbroken. Not for me but for them and the impact it would have on their lives. (Pete, cleft)

Participants relayed their distress at these thoughts, their relief at finding this was not a reality and, in one case, the considerable distress and guilt they associated with their child having the same condition. One participant spoke of making a decision not to have children because of heritability and another recounted a level of uncertainty about whether they would have continued with the pregnancy had their child been found to share their condition. Most participants, however, discounted this possibility:

We did quite a bit of making sure that it was checked during the scans and when the girls were born, just so we were prepared and we were aware of it and it was checked out so that we could be kind of prepared and plan for it rather than we would necessarily have done anything different. (Anthony, cleft)

These comments imply that some participants understood the termination of pregnancy as one potential course of action that needed to be considered, even if immediately dismissed. This may speak to the "sort of unspoken eugenics" (Pauline, ichthyosis) that one participant felt society encouraged.

Looks Help Delineate and Define Relationships

This final theme encapsulated understandings that participants' romantic relationships and visible difference could positively interact, with visible difference carrying the potential to improve romantic relationships.

Assessing romantic partners by their reactions. Just over half the participants (13 of 22) spoke about the reaction of a romantic partner to their visible difference functioning as a test or acting as a barometer of that person's character. This was often but not exclusively contemplated in connection with a disclosure scenario. This process was perceived as enabling participants to make a judgement about the likelihood of a relationship progressing based upon the reaction and response to their difference:

Part of me would think more of them as a person if, if they didn't have an issue with it, if they were still willing to try and get to know me as a person... I would think that that would make me have a much more positive attitude toward them so hopefully, even if I wasn't thinking that physically that they were my cup of tea, I would hope that that, in itself, that their attitude would change the way that I would be thinking about them.

(Michelle, alopecia)

Where partners or potential partners did not provide an accepting and supportive response, or when an overtly negative reaction was anticipated or experienced, the reaction was seen as reflecting negatively on that other person:

Obviously if anyone did react negatively you'd know that they were an idiot so you wouldn't give them the time of day after that anyway! (Chloe, facial birthmark)

Although many participants had spoken about visible difference reducing their own self-worth, self-confidence, and value as a partner and had acknowledged that prevailing appearance ideals worked to their disadvantage, they expected potential partners to react with

compassion and understanding to their difference. Adverse reactions were considered unreasonable and as a sign of superficiality, detracting from the other person's worth.

Enriching and fortifying relationships. This sub-theme featured in 18 of the 22 accounts. Building on ideas introduced in the previous theme, participants argued that when their relationships progressed beyond the early stages, they became deeply rewarding and personally enriching as participants could:

Know that you're, that you have been taken as the whole package, warts and all, is, is a very wholesome feeling. To know that... somebody that has asked you to spend the rest of your life with them... it is quite something. And it is nice to know that they see through the outer crust of you and right into your heart and soul and mind. (Eleanor, psoriasis)

This sense of acceptance encouraged participants' belief in the legitimate, enduring, and robust nature of their relationships. Furthermore, the challenges an appearance-altering condition could present were considered adversities that could be overcome together, strengthening intimate interpersonal bonds. Visible difference was thus understood to offer some opportunity to develop durable, resilient, and sincere relationships. This was directly contrasted with relationships founded upon physical attraction:

At the end of the day, looks don't matter. It's what the person's like inside... When you get old and crumbly all you've got left is friendship and the people who would look beautiful and haven't developed a friendship with their partners, I think are the ones who split up. (Pauline, ichthyosis)

Participants also offered recognition of an indirect mechanism through which their appearance positively impacted their relationships. This was a perceived effect upon their

own personal characteristics, which included increased independence, strength, resilience, and openness. In turn, this influenced their ability to engage in rewarding relationships:

Being born with a cleft has certainly had an influence on how I am now as an adult. I do think it's had an influence on who I am and that's probably been to an extent fairly positive in that colours the way I approach things and stuff. I think my cleft has made me who I am and that led to us having our relationship. (Anthony, cleft)

Receiving treasured support. This sub-theme was discussed by every participant. Whilst participants suggested that anybody without a visible difference cannot truly comprehend their experience, they valued the emotional support, companionship, security, protection, and encouragement towards engagement in activities that a romantic partner could offer:

To me, once you're in a relationship, and you know it was a reasonably meaningful relationship, then you know, you can forget that issue because you've got that person, the person's with you and you've been supported... so, to my mind once that's got the relationship then the disfigurement more or less disappeared. (David, cleft)

Participants spoke about their partners not seeing or caring about their difference. This was generally considered positive, to have assisted the development of the relationship and helped the participant to fully engage with the wider world. It could, however, hinder communication within a relationship, as it made it more difficult to acknowledge the impact of visible difference upon that relationship. In examining the prolonged sexual abstinence in her relationship, Karen described how she had not discussed this with her partner despite her evident concern and uncertainty regarding whether her partner continued to find her sexually attractive:

I suppose it was me thinking “Oh he must see me differently, he’s never going to want me again” and then maybe he didn’t or maybe he did think that... I don’t know if he sees me in the same way but I’ve never spoken to him about it, which is quite bad really. I think I should. (Karen, breast cancer)

This was compounded by participants’ experiences with the healthcare profession. Their interactions with medical professionals were presented as being characterised by a lack of support and understanding regarding the experience of living with a visible difference:

In terms of what’s offered it’s been entirely physical and medical. When I revisited the doctor, a month or two ago now, she actually asked me a couple of questions. “Has it affected me?” “Do I, has it affected my confidence or anything?” So that was the extent that it was only a couple of questions and there was no “OK, if you wanted to talk to someone here’s the number,” or something. It was very clinical. (Ryan, facial palsy)

This extended into the realm of romantic relationships and participants’ intimate lives:

Just be a bit more sympathetic, you know. I was 37 and I still had hopes of getting married and having a family and he [the Doctor] basically told me that “You’ve got no hair, it’s not going to come back so deal with it.” (Ruth, alopecia)

The three female participants who had mastectomies and breast reconstructions as part of their treatment all reported dissatisfaction with the approach of the healthcare profession. Their testimonies suggested that they were unhappy with the level of professional support available. Furthermore, healthcare staff failed to fully appreciate the psychosocial impact of their altered appearance and the potential for their romantic relationships and sexual lives to be adversely affected:

I think the thing was that they would make you look ok in a bra and that’s kind of always stuck with me. When I thought they were just going to scoop all the gubbins out and put

an implant in and stitch you back up and when they say “No, we will just make you look OK in a bra.” I don’t want to just look OK in a bra, you know? (Jodie, breast cancer)

In light of the difficulty experienced in discussing such issues within a relationship, the perceived lack of professional support, and the belief that others may not fully comprehend how it feels to live with a difference, participants identified peer-to-peer and expert-patient led interactions as the most preferable mechanism for delivering and receiving effective structured support:

If they did like a, you know, they had a self-help group going on, if you like, and, you know, you could talk to them people too because they’re all probably going through the same thing but, as I say, you can’t really talk about the intimacy too much to your friends because they could get embarrassed as well. (Valerie, facial palsy and breast cancer)

Discussion

This study represents the first qualitative exploration of romantic relationships for adults with a visible difference that is not limited to a specific condition or group of medically or physically similar conditions. Drawing on qualitative data from 22 participants with a variety of conditions the findings demonstrated that participants understood their appearance and their romantic lives to be inexorably connected and that this association could endure through the lifespan of a relationship.

Participants’ accounts of the formation and early stages of romantic relationships were characterised by concerns regarding the negative evaluation and judgments of others. These arose in connection with the initial judgments of potential partners and the moment of revelation or disclosure of a difference. The supposition that visible difference set participants apart from others indicated that, for this study population, a visible difference constituted a stigmatising characteristic. Participants had experienced both felt and enacted

stigma (Scambler & Hopkins, 1986) in connection with their appearance. This took the form of feelings of being negatively judged and assessed as a potential partner, anticipatory anxiety prior to disclosure, and the actual negative reactions of others. The considerable anxiety induced by the disclosure scenario can be conceptualised as resulting from participants' contemplation of the voluntary but necessary transition from being discreditable by their existing-but-unknown stigmatised characteristic to potentially being discredited by a known stigmatised trait (Goffman, 2000).

Anxieties subsisting in anticipation of the moment of disclosure may be attributed to the negative consequences of concealment. These include the threat of the stigmatised condition being discovered, and the fear of revelation to a significant other (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014). Such anxieties may arise as a result of the intrusive thoughts predicted by the preoccupational model of secrecy (Lane & Wegner, 1995). This model posits that secrecy promotes thought suppression and that such suppression leads to intrusive thoughts before renewed efforts at suppression and a cyclic repetition of intrusion and suppression. This model that has been shown to be relevant to other stigmatised conditions (Smart & Wegner, 1999) and its applicability to those with visible difference should be further explored.

The analysis indicated that participants internalised appearance expectations and ideals together with the negative connotations associated with visible difference. Internalised appearance standards may have contributed to the perception of stigma and to experiences of it, in both its felt and enacted form (Scambler & Hopkins, 1986). Kent and Thompson (2002) described a process in which social signals regarding the distinctive and defective nature of one's appearance help form internal and external shame schemas in which the individual appraises themselves as inadequate and believes that others will reject them or discriminate against them. This can lead to feelings of shame and anxiety as well as cognitive distortions

and automatic negative thoughts. These cognitive distortions may include hypervigilance to the reactions of others and interpretative biases (Kent, 2000; Thompson, Kent, & Smith, 2002). It is thus conceivable that the internalisation of social standards of appearance may have contributed to experiences of felt stigma and to cognitive biases in which incidences of enacted stigma are more readily interpreted.

The devaluation and discounting of the self by the participants was consistent with the internal shame schema proposed by Kent and Thompson (2002). This provided evidence of negative self-concept and echoed the accounts of young men with testicular cancer who considered themselves “damaged goods” as a result of the physical sequela of their cancer (Carpentier et al., 2011). The explicit possibility of compensating for this perceived deficiency evidenced an intuitive knowledge of the “mating market” in which an individual’s characteristics and qualities may strengthen or weaken their bargaining power and dictate how their own demands and preferences may need to be adjusted as romantic and physical partnerships are formed (Swami, 2016). Whilst the most obvious consequence of participants devaluing themselves in this way related to the formation of relationships, it was apparent that this had the potential to help sustain unrewarding and even damaging relationships as some participants felt that their opportunities to negotiate alternative options were curtailed by their appearance.

In common with the findings of Mathias and Harcourt (2014), the initial reaction of a partner to participants’ below-the-knee amputations was considered a screening mechanism or filter of potential partners and relationships. Such responses were typically, but not uniquely, contemplated within the context of a disclosure scenario. Crucially, participants conceptualised the real and imagined negative responses of potential partners as being indicative of the character of that other person rather than reflective of participants’ innate value as a romantic partner and so, within this context, were able to detach themselves from

the internal shame schemas proposed by Kent and Thompson (2002). Thompson and Broom (2009) identified a similar tendency as they found that participants with visible differences attributed the negative behaviours of others to the negative attributes of those other persons. The authors interpreted this as a self-protective strategy, utilised to decrease the emotional discontent experienced as a result of negative reactions by making external rather than internal attributions. Their work was not, however, concerned with the reactions of potential partners and the current research suggests that some participants in this study also employed this protective strategy within the romantic domain.

Evidence of these external attributions was drawn primarily from the participants' contemplation of the specific reactions (real or imagined) of new or potential partners to their difference, contained within the sub-theme "Assessing Romantic Partners by their Reactions." The sub-theme "Appearances are Central to Attraction" demonstrated that participants understood others, more broadly, to appraise them and their attractiveness based upon their appearance. Furthermore the related sub-theme "The Discounted Self" suggested these value judgements had been internalised and participants considered themselves personally devalued by their visible difference. Further research should examine whether external attributions may protect against experiencing appearance distress in connection with romantic relationships, feelings of attractiveness, and one's value as a partner.

The ongoing impact of visible difference upon established relationships was evident from participants' anxiety about their partners perceiving their difference during sexual activity, the avoidance of such activity, and the concealment of their difference from their partners during intimate moments. This supports the contention of Batty, McGrath, and Reavey (2014) that failing to live up to normative notions of health and beauty can be disruptive to sexual encounters and that such strategies represent attempts at removing the salience and immediate visibility of the perceived deficiency. Furthermore, this indicates the

potential relevance of the spectating phenomena (Masters & Johnson, 1970) to those with visible difference. As with that phenomena, participants spoke of being overtly conscious of the affected part of their body and this awareness impacting upon their sexual activity, implying some overlap between the study of body image and visible difference within the domain of appearance and sexuality.

Moving away from sexual activity, the suggestion that the presence of a visible difference could help strengthen established romantic relationships reinforces the propositions of Egan and colleagues (2011) in two ways. First, the belief that romantic relationships can benefit indirectly from the positive personal growth facilitated by a visible difference adds specificity to their claim that such growth can extend into improved relationships with others. Furthermore, Egan and colleagues (2011) identified the support, understanding, and acceptance of partners as being particularly important to their participants' sense of having adjusted positively to their difference. Participants in the current study evidenced this when they expressed belief in the legitimacy, sincerity, and durability of their romantic relationships with such beliefs being engendered by caring and compassionate partners. Their testimony solidified ideas expressed by single women with breast cancer, who anticipated experiencing a sense of confidence that a new partner would be interested in them as a person and not just because of how they look (Ginter & Braun, 2017). This resembles the unconditional acceptance of one's body by family, partners, and friends that has been cited as a characteristic that helps promote and maintain positive body image (Tylka, 2012; Tylka & Wood-Barcalow, 2015).

The existing visible difference literature demonstrates that the nature, severity, and size of a difference are not strong predictors of adjustment (Moss, 2005; Ong et al., 2007, Rumsey et al., 2003, 2004). The present research, however, indicated that the experiences of those with visible differences that are not immediately obvious to others may vary in some

respect from those that are more evident. “The Disclosure Dilemma” presented a unique challenge to those whose difference was not immediately apparent or could be concealed. The data also signalled that appearance, romantic relationships, and physical intimacy were understood as particularly salient issues for those affected in more highly sexualised areas of the body (such as the breasts) or those strongly associated with femininity (such as the hair). As this research does not permit conclusive comparisons to be made between sub-groups of the participants, further research could investigate the impact of visibility, sex, and the area of the body affected by a difference upon experiences of romantic relationships and sexual activity.

Limitations

Whilst this research provided novel insights into experiences of visible difference and romantic relationships, its limitations must be acknowledged. The participants were heterosexual and spoke primarily about traditional monogamous relationships. Other sexualities and relationships are therefore not represented in the data. This was not by design but a function of those responding to the advertisements for the study. Participants were primarily drawn from those that have some connection with support groups and charities that exist for those with an altered appearance. It is possible that respondents with these connections, or who, at a minimum, monitor the media of support groups and charities, may differ as a group from those that do not. For example, such individuals may experience their difference as more personally salient than others.

Participants were aware of the focus of this research and this awareness may have influenced potential participants’ decisions concerning whether they wished to participate. Those who considered their difference to have exerted a significant impact upon their romantic lives may have been more likely to volunteer to be interviewed, with those who do

not understand their difference as having exerted this impact potentially being underrepresented in the data. Similarly, only individuals who self-identified as having a visible difference were interviewed. Whilst this is consistent with the subjective nature of visible difference, it does mean that those with an appearance-altering condition or an altered appearance who do not self-identify in this way remain unrepresented.

The research project attracted a greater number of women than men. Whilst the experiences of men were captured, it is plausible that the relative lack of male representation influenced the nature of the analysis. It is also conceivable that having a male researcher conduct the interviews could have impacted potential participants' decisions about whether to engage with the research. Furthermore, participants' willingness to discuss issues of gender, sex, and sexual activity together with the researcher's receptiveness to such topics may have been partially shaped by dynamics of gender. Whilst six participants (five women and one man) spontaneously informed the researcher that they had never told anyone else about some of the experiences and thoughts that they discussed in the interviews or that they had not spoken about them with their partners or with family members, it is not possible to be certain that all participants were so candid nor to know what else participants may have disclosed to another researcher. Future research concerning related topics may benefit from offering participants a choice between researchers of different sexes and with different gender identities.

The interviewer did not consider himself to have a noticeable visible difference and did not indicate otherwise to the participants. It is possible that, like his sex, this aspect of the researcher's identity had a salient impact upon the nature and content of his interactions with participants. Indeed, a number of participants expressly stated that it is very difficult for someone without a visible difference to fully empathise and understand the experience of someone with a visible difference. This may have been especially relevant to the five face-to-

face interviews and the two conducted via Skype where the researcher's visible identity may have been more prominent. There is value in reiterating, however, that the participants interviewed via these more visual mediums of communication explicitly chose to interact with the researcher in these ways and had the option for their interviews to be conducted via the telephone.

The data were collected, coded, and analysed by the first author. This process was undertaken in line with guidance relating to the active and reflexive nature of the chosen analytic strategy. The analysis was the subject of on-going review, discussion, and agreement with the co-authors and a summary of the analysis was provided to the participants for comment. The chosen approach does not, however, include any formal metric to confirm the reliability of the analysis and so it is not possible to provide Cohen's kappa in order to gauge and evidence inter-rater reliability.

Conclusion

This work focussed upon the under-researched intersection of visible difference and romantic relationships. Whilst participants considered visible difference to have positively impacted and strengthened some aspects of their relationships, appearance related concern and distress were evident. These were manifest as concerns relating to the judgements and perceptions of others, in participants' assessment of their own value as a partner, and in their descriptions of the disclosure of a visible difference to a romantic partner. Furthermore, anxieties related to sexual activity and physical intimacy, apprehensions connected to the heritability of some appearance-altering conditions, and dissatisfaction with the unavailability of effective support mechanisms, were all expressed. The identification of these negative consequences implicates engagement in romantic relationships as an area of activity which should be addressed by future psychosocial interventions designed for adults with visible

difference. Furthermore, work to raise awareness amongst healthcare professionals and to promote skills and resources to facilitate effective support may also prove beneficial.

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Table 1

Semi-Structured Interview Guide Questions

Questions

Could you say something about any experiences you have of very close, intimate relationships?

Are there any ways in which appearance is important to intimate/romantic relationships?

Would you be able to describe any ways in which your appearance has impacted upon these relationships or this aspect of your life?

What do you think are the important factors in explaining why your appearance has affected you in this way?

What would it take to reduce or remove (or, if positive impact, sustain) this impact?

Could you say anything about whether you have engaged in any specific behaviours or taken any action to reduce or alter any such impact upon your intimate life?

Could you describe the behaviour of your partners or potential partners in connection with your appearance?

How do you feel your partners or potential partners feel or felt about your appearance?

How do you imagine your intimate life would be different if you did not have your visible difference?

How do you feel about the future of your intimate relationships?

Table 2

Romantic Relationships and Intimacy Themes, Subthemes, and Example Codes

Theme	Subtheme	Example codes
Appearance Attracts and Detracts	Appearances are central to attraction	Assessed on looks Women’s appearance crucial
	The discounted self	Personal deficiency Compensate for appearance
Looking Different: Physicality and Physical Reality	The disclosure dilemma	Uncertainty over revelation Partner reaction to reveal
	Invading physical intimacy	Avoidance of sex Sexual preoccupation
	Concerns over the heritability of appearance-altering conditions	Pass appearance on Impact my child
Looks Help Delineate and Define Relationships	Assessing romantic partners by their reactions	Response sends message Judge partner on response
	Enriching and fortifying relationships	Appearance is shallow Galvanised me

Receiving treasured support

Partner protective

Lack support
