



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

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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.

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1. 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 & Kiefer, 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 spectatoring and therefore permit greater sexual liberalism and more positive attitudes to unconventional sexual practices.

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1.1. 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 et al. \(2007\)](#), [Rumsey et al. \(2003\)](#), 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.

1.2. 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, Beuf, Lerner, and Nordlund \(1990\)](#) 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](#); [Loaring, Larkin, Shaw, & Flowers, 2015](#)), burn injuries ([Connell, Coates, & Wood, 2015](#)), psoriasis, acne, and eczema ([Magin, Heading, Adams, & Pond, 2010](#)), lymphedema ([2016, Winch et al., 2015](#)), 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

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