Exploring and Measuring the Perceived Impact of Visible Difference upon Romantic Relationships

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Volume ii. Appendices (listed and contained therein)

i. Abstract

Appearance altering or disfiguring conditions can lead to a variety of ‘visible differences.’ The presence of a visible difference may impact negatively upon an individual’s well-being and be associated with psychosocial difficulties, including social anxiety, anxiety, depression, reduced quality of life, unfavourable self-perceptions, and challenging interpersonal interactions. One domain that may be impacted is that of visible difference, appearance concern, and intimate, romantic relationships. This topic has, however, received relatively little attention in the literature.

This thesis aimed to address this gap in the literature. This was done via the adoption of a pragmatic, mixed-methods approach, and the execution of three empirical research studies. First, a qualitative exploration was undertaken, involving semi-structured interviews with 22 participants with a variety of visible differences. Three intimacy-specific themes were generated through thematic analysis. These revealed a multitude of impacts, understandings, and experiences connected to this topic. As no measure of these existed, the themes were utilised in the development of draft items in order to create a research scale (named ‘CARRIS’) measuring appearance distress within a romantic context. Data were collected from participants with visible difference and a final sample of *n*=253 contributed to the second study, an exploratory factor analysis. This helped refine the scale into a parsimonious, three-factor, form, begin the validation process, and indicated some between-group differences. The final study involved the administration of the refined scale and the collection of fresh data from a final sample of *n*=144 participants in order to confirm the structure of the scale via confirmatory factor analysis. CARRIS’ four-week test-retest reliability (*n*=49) was also assessed.

This thesis explored visible difference and intimate and romantic life. It indicated this as an important component of participants’ experiences of and adjustment to visible difference. It generated, evaluated, and began the validation of a new measure of appearance distress within a romantic context, and introduced the theoretical and clinical implications of such work.

ii. Acknowledgements and Dedications

Please indulge me, it is here that I must try to express my gratitude to some of the people who have contributed to this thesis and offered me their support and encouragement.

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Martin Persson: from colleague, to friend and mentor. Thank you for the belief you have in me, the opportunities you provide me with, and the odd triple hopped IPA!

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iii. Abbreviations

AC	Dr Alexandra Clarke, research active Clinical Psychologist
ARC	the Appearance Research Collaboration
Bartlett's	Bartlett's Test of Sphericity
CAR	the Centre for Appearance Research
CARRIS	the Centre for Appearance research Romantic Relationships and Intimacy Scale (the scale developed through the research presented in this thesis)
CCEI-H	the Crown Crisp Experiential Index: Hysteria Sub-scale (Crown & Crisp, 1979)
CFA	confirmatory factor analysis
DAS	the Derriford Appearance Scale (Carr, Harris, & James, 2000; Carr, Moss, & Harris, 2005)
EFA	exploratory factor analysis
F1	CARRIS factor one: sexual anxiety and self-consciousness
F2	CARRIS factor two: negative evaluation and being judged as unattractive
F3	CARRIS factor three: benefiting from partner empathy
FA	factor analysis
FIS	the Fear of Intimacy Scale (Descutner & Thelen, 1991)
FNE-B	the Fear of Negative Evaluation – Brief (Leary, 1983)
IPAF	iterated principal axis factor analysis
LJ	Dr Elizabeth (Liz) Jenkinson, Senior Lecturer in Health Psychology
KMO	the Kaiser-Meyer-Olkin Measure of Sampling Adequacy
Levene's test	Levene's test for equality of variances
ML	maximum likelihood factor analysis
MBISCDPIS	the Male Body Image Self-Consciousness During Physical Intimacy Scale (McDonagh, Morrison, & McGuire, 2009)
MSIS	the Miller Social Intimacy Scale (Miller & Lefcourt, 1982)
NR	Professor Nichola Rumsey OBE, Professor Emerita of Appearance Psychology
ONS	The Office for National Statistics
PAF	principal axis factor analysis
PCA	Principal Components Analysis

Prolific	the Prolific research platform https://www.prolific.ac/ (previously branded as Prolific Academic)
SMC	squared multiple correlations
TM	Dr Tim Moss, Associate Professor in Health Psychology
WBISCDPIWPS	The Women’s Body Image Self-Consciousness During Physical Intimacy With a Partner Scale (Wiederman, 2000)

1. Introduction

1.1. Introduction to this Thesis

This thesis focusses upon the intersection of visible difference and intimate, romantic relationships. Its primary goals were, first, to conduct an exploratory qualitative study in order to gain an understanding of the experience of those with a visible difference within the romantic sphere. Secondly, if warranted by the exploratory work and in response to the need identified by Dr Alexandra Clarke (AC), to develop a novel research measurement instrument that could be used to assess any perceived impact of visible difference upon romantic relationships. This thesis adopted an approach rooted in pragmatism and utilised a sequential mixed-methods design. This thesis encompasses an exploratory qualitative study, an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA).

1.2. Overview of this Chapter

This chapter defines the concepts of intimacy and romantic relationships for the purposes of this thesis and considers their importance to and in our lives. It then goes on to introduce the term 'visible difference,' essentially referring to a changed or altered appearance that differs from the 'norm,' before presenting the psychosocial effects that visible difference may entail. I argue that the existing research indicates an individual's intimate and romantic life is one domain which, for some, we may expect visible difference to impact. The subsequent chapter then goes on to introduce and consider existing research relevant to the intersection of visible difference and intimate, romantic relationships.

1.3. Intimacy and Romantic Relationships

1.3.1. Intimacy and Romantic Relationships

Literature relating to intimacy defines it as the sharing of what is innermost with others, close familiarity, and/or friendship, and states that it may include sexual activity and/or love (Popovic, 2005). Manne & Badr (2008, pg.2546) adopt the interpersonal process model of intimacy (Reis & Shaver, 1988) and define it as "the process whereby an individual expresses important self-relevant feelings and information to another and, as a result of the other's response, comes to believe that they are understood, validated, and cared for."

They adopt this definition as the interpersonal process model of intimacy (Reis & Shaver, 1988) conceptualises intimacy as a psychological need (Manne et al., 2004) fulfilled via an interactive process in which self-disclosure and partner responsiveness are the critical components. The development of intimacy is considered to be a dynamic, transactional process encompassing verbal and non-verbal actions and during which one person communicates personal, salient, meaningful information to another, and the other responds, potentially also disclosing information in return (which I will call a response-disclosure). The information shared by each partner may include their thoughts, emotional disclosures, and factual content. The original speaker interprets the response and may, if the response coveys understanding, acceptance, validation, care, sensitivity, or positivity towards the speaker, adjudge it to be responsive, resulting in the development of intimacy within and between the dyad. In turn the recipient forms their own interpretation. Furthermore, individual characteristics, qualities, needs, goals and motivations will be influential in determining each partner's actions and interpretations. Whilst the model is centred upon specific interactions, intimacy is acknowledged as being a quality that accrues and develops over time and through repeated interpersonal transactions (Laurenceau, Barrett, & Pietromonaco, 1998; Manne et al., 2004; Reis & Patrick, 1996; Reis & Shaver, 1988).

It is clear that emotional disclosures are associated with greater perceived intimacy than factual information (Laurenceau et al., 1998). This is attributable to the opportunity afforded to the recipient to provide support and confirm the speakers' core understanding and view of their self that emotional disclosures offer (Laurenceau et al., 1998). Where this is not done and concerns are not shared, romantic couples' intimacy can be negatively impacted and they may experience greater distress along with lower well-being and relationship satisfaction (Manne et al., 2015).

The significance to intimacy of both key components, self-disclosure and partner responsiveness have been demonstrated empirically, with both components contributing significantly and uniquely to daily intimacy and this being associated with global marital satisfaction and relationship intimacy (Laurenceau et al., 1998; Laurenceau, Barrett, & Rovine, 2005). Laurenceau et al. (1998) also offered support for another contention of Reis & Shaver (1988), that the perceived quality and nature of the self-disclosure may be more strongly associated with feelings of intimacy in newer relationships but that as people grow closer together, the responsiveness of the other party is more critical in determining the original speaker's perception of intimacy.

Interestingly, whilst partner responsiveness was important to perceptions of intimacy and closeness for women with breast cancer and for their partners (overwhelmingly men) making response-disclosures, self-disclosure by the patient did not to play a significant role in their assessment of intimacy, whereas self-disclosure by the partners (via response-disclosures) were associated with the partner's perception of intimacy (Manne et al., 2004). The authors argued this may be because, within the context of breast cancer, patients are liable to be relatively uniformly comfortable making them and so the response-disclosure they receive from their partner assumes relatively more importance. Their results, however, were similar for both cancer based disclosures and more general topics of discussion and so they also posited the possibility of a difference between women and men. They suggested that women felt closer to their partners when their partner responded with their own disclosure in a caring, accepting, understanding fashion but were less concerned by their own, initial, disclosure. The (male) partners' perceptions of intimacy, which were more consistent with the model, depended on the nature of their response-disclosure and the patient's disclosure.

This gendered interpretation received support from further work with prostate cancer patients (men) disclosing to partners (women). Both self-disclosure and partner responsiveness were associated with greater intimacy for the patients and for their partners (Manne et al., 2018). Such results are highly consistent with the interpersonal process model of intimacy (Reis & Shaver, 1988). These studies indicate the value of that model and may be interpreted to suggest that when a woman partner makes the initial disclosure (to a man), her perception of intimacy is somewhat independent of her own initial disclosure. This is different when a man makes the initial disclosure, when a man responds, and also when a woman responds. In each of those cases the disclosure/response-disclosure are all important in developing intimacy. As a respondent, the nature of a woman partner's own response-disclosure was important to her in developing her sense of intimacy, more so than her initial disclosure when initiating discussion (Manne et al., 2018, 2004).

Whilst the interpersonal process model of intimacy (Reis & Shaver, 1988) is largely applicable to romantic unions and whilst some differences between women and men may subsist within that context, commentators such as Miller (2012) characterises intimate relationships as those that feature knowledge, caring, interdependence, mutuality, trust, and commitment, noting that close friendships, family, and partner relationships as all being capable of satisfying these criteria. This illustrates that it is possible to conceive of intimate relationships that do not include a sexual or romantic element. Parks & Floyd (1996), however, established that intimacy is sometimes understood to include a romantic or sexual dimension and is thus distinguished from related concepts, such as 'closeness,' on that basis.

Whilst a number and variety of relationships may be considered intimate, Miller (2012) specifically discusses the importance of intimate partners and his text focusses primarily upon these romantic relationships. Indeed, he argues that the close ties of knowledge, care, and interdependence lead couples towards mutuality, considering themselves as a couple instead of two separate individuals. For the purposes of this thesis it is therefore relationships and interactions between romantic partners and potential romantic partners that will be referred to as intimate, romantic relationships (and herein ‘intimacy’ and ‘romantic relationships’ should be understood in this context). Such relationships may encompass emotional intimacy, feelings of closeness, being listened to and understood, free expression, and sexual intimacy (Schaefer & Olson, 1981 cited in Popovic, 2005).

1.3.2. The Benefits of Intimate, Romantic Relationships

In addition to evidence indicating the benefits to existing romantic relationships of intimacy (Laurenceau et al., 2005), the enjoyment of intimacy has long been considered a vital need for human mental health and psychological adjustment (Descutner & Thelen, 1991). Furthermore, for those who desire them, a satisfying, close relationship may be considered essential to a healthy, well adapted, happy, meaningful adult life. Realised closeness needs being associated with greater happiness, functioning, and health whereas the lack of a close relationship is associated with powerlessness, loneliness, and depression (Popovic, 2005).

Empirical evidence for such claims can be found in the work of Rudberg, Nilsson, and Wikblad (2000). Amongst survivors of testicular cancer, living with a partner was one of the primary predictors of having high levels of health-related quality of life. Other such predictors of high health related quality of life were perceived attractiveness, being fertile, and having children. This suggests that, amongst those with visible difference, living with a partner can contribute to a broad range of beneficial psychosocial and physical outcomes.

Moving away from literature concerned with visible difference and appearance altering conditions, the benefits to health of intimate relationships and marriage are well established and are consistently demonstrated in research (Keenan, Ploubidis, Silverwood, & Grundy, 2017; Ross, 1995; Ross, Mirowsky, & Goldsteen, 1990; Wood, Goesling, & Avellar, 2007). This conclusion stands when confounding variables such as education levels, socio-economic status, age, and race are controlled for (Carr & Springer, 2010; Ross & Mirowsky, 2013), has been replicated in different geographical territories and in different time periods (Ploubidis, Silverwood, DeStavola, & Grundy, 2015), and across large samples drawn from the British National Child Development Study (Keenan et al., 2017; Ploubidis et al., 2015) and the National Health Interview Study in the USA (Denney, Gorman, & Barrera, 2013; Liu, Reczek, & Brown, 2013).

Smith (2019) concluded that the benefits of marriage and similar intimate relationships represent a central component of the evidence linking social connection and health status and that *'relationships matter.'* The benefits include lower levels of depression, psychological distress, both chronic and acute physical conditions including cancers, suicide, and overall mortality in those that are married. Marriage is associated with greater health and well-being as those within a marriage tend to benefit from the greater social integration, emotional support, and economic security offered by this economic unit bound by emotional ties (Ross, 1995; Ross & Mirowsky, 2013; Ross et al., 1990). They benefit financially from economies of scale and the division of domestic labour (Ross & Mirowsky, 2013), and from instrumental support (Carr & Springer, 2010).

The social and emotional support provided by this relationship may benefit an individual's emotional health, reduce a number of risky health behaviours such as heavy alcohol consumption and smoking, encourage beneficial health behaviours, aid in processes connected to the detection and treatment of, and recovery from, disease and illness (Ross et al., 1990), and may protect against immune-mediated inflammatory processes (Holt-Lunstad, Smith, & Layton, 2010; Robles, Slatcher, Trombello, & McGinn, 2014; Uchino, 2006). The beneficial effect of these health behaviours (Carr & Springer, 2010; Keenan et al., 2017) and the negative association between health and never having co-habited (Ploubidis et al., 2015) tends to be greater amongst men than women.

Research has also acted to refine and confirm the assertion of (Ross, 1995) that being married *per-se* is not uniquely beneficial, rather the presence of significant social attachments and relationships is. Whilst marriage does generally appear to offer the greatest benefit, above and beyond cohabitation and other relationship structures and irrespective of whether those co-habiting are in same-sex or different-sex relationships (Carr & Springer, 2010; Denney et al., 2013; Liu et al., 2013), cohabitation has been shown to offer many of the health benefits of marriage and even to be associated with greater happiness and self-esteem than marriage (Musick & Bumpass, 2006, 2012).

Increasing attention has therefore been paid to the quality of relationships in explaining these findings, with Carr and Springer (2010) arguing that cohabitation brings many marriage like benefits but, typically, may involve poorer quality relationships, greater instability, and also that healthier individuals may be more likely to marry (social selection), thus contributing to the ongoing disparity. Indeed, measures of social integration, or social support, have been shown to function as strong predictors of survival in a meta-analysis of studies exploring the connection between survival and social relationships (Holt-Lunstad et al., 2010).

It is also important to acknowledge that research has indicated that the health benefits of a given marital status may vary. For example, amongst those that are married, greater marital relationship quality is related to better health (Robles et al., 2014). Within romantic relationships more broadly, factors such as a match or mismatch in the partner's anger coping styles (Bourassa, Sbarra, Ruiz, Karciroti, & Harburg, 2019), spontaneous behavioural expressions of intimacy when subjected to stress (Ditzen et al., 2019), and perceived partner responsiveness (Stanton, Selcuk, Farrell, Slatcher, & Ong, 2019) (how well individuals feel their romantic partners understand, care for, and appreciate them), a core component of intimacy within the interpersonal process model of intimacy (Reis & Shaver, 1988), all carry significant health implications. It is possible to suggest that within the health and well-being context, not only that '*relationships matter'* (Smith, 2019) but that the nature and quality of those relationships also matter. It is clear that factors which operate as a barrier to the existence and enjoyment of romantic relationships may therefore impact physical and psychological health and well-being.

1.3.3. Attraction and Attractiveness

Whilst being married and the presence of intimate, romantic relationships are, generally, beneficial, there is evidence to suggest that physical attractiveness is important within this context, may impact initial attraction processes and, in turn, may influence an individual's ability to develop these relationships. Miller (2012) concludes that people are attracted primarily to those whose presence is in some way rewarding. Those who are considered beautiful provide a direct reward to those with whom they interact in the form of their physical appearance. As is consistent with this, attractive individuals are considered more socially desirable as friends, are considered to carry greater potential as dating partners, and experience greater intimacy in social interactions (Davison, 2012).

The advantage of being adjudged physically attractive, however, may go beyond social desirability based solely upon physical characteristics. A review of the evidence provided by Swami and Furnham (2008) demonstrated that physical attractiveness and appearance have an important and predictable effect on judgements that people make about others. Miller (2012) agrees and explains that humans make immediate judgements about the appearance of others and assume that attractive people also possess a variety of other desirable traits and are positively evaluated by others.

This phenomenon has been labelled 'what-is-beautiful-is-good' (Dion, Berscheid, & Walster, 1972). Their research found that those depicted in stimulus photos as being physically unattractive were judged to be less socially desirable, less likely to obtain higher occupational status, lower in marital competence, lower in social and professional happiness and in total happiness, and less likely to marry than those depicted as more attractive. Whilst the sample was relatively small and comprised of college students in the USA, similar findings have been replicated and reproduced (e.g. Brewer & Archer, 2007) to the extent that both Miller (2012) and (Swami & Furnham, 2008) conclude that the effect has been substantiated. Indeed Miller (2012) concludes, within the context of heterosexual romantic attraction, attractiveness and appearance are valued as the second most important quality by men and the third by women.

The valued placed on appearance is important as humans seek romantic relationships in what has been called the 'mating market' (Swami, 2016; Swami & Furnham, 2008). In this competitive domain, individuals must compromise on their ideal partner in recognition of the preferences of potential partners and their ability to negotiate a romantic match, being a function of their own relative desirability. Physical attractiveness is considered one of the characteristics or properties important to mate choice demands and preferences and which will influence an individual's relative bargaining position. Women and men seem unwilling to compromise on physical attractiveness within the context of short-term, sexual partners, and focussed on their partner's interpersonal responsiveness and attractiveness when considering a longer term relationship (Regan, 1998). In negotiating the 'mating market,' being perceived as physically unattractive may therefore reduce an individual's liability to be considered for short-term and, consequently, longer-term relationships. It may act to delimit an individual's choices and opportunities through a reduction in their relative bargaining strength and necessitate they adjust their own preferences and demands accordingly.

Conceptions of this 'marketplace' can be subsumed into 'filter theories' of attraction and relationship formation (Feingold, 1988; Kerckhoff & Davis, 1962). These specify that social demographics and social stratification operate to influence who a given individual is likely to meet and socialise with and thus define and skew the 'pool' of potential partners. From that 'pool,' those that are less desirable, who are assessed to have a lower market value, are screened out in an active decision making process (Feingold, 1988) akin to that described within the 'mating market' (Swami, 2016; Swami & Furnham, 2008). Those that are desirable and have similar and shared beliefs and attitudes are retained as potential partners. (Kerckhoff & Davis, 1962). Finally, complementarity of personality needs is assessed, with partners forming longer term relationships with those who are compatible across constructs such as inclusion, control, and affection (Kerckhoff & Davis, 1962) and romantic dyads are formed (Feingold, 1988).

During the filtering process and in attraction and relationship formation, it has been presumed that the 'matching' of Walster, Aronson, Abrahams, and Rottman (1966) dictates that people seek out partners whose social desirability, including their physical attractiveness, is similar to their own. This requires that individuals assess their own value and select potential partners based their value and the likelihood of reciprocation, leading to unions of people with similar levels of social desirability, who are 'in their league' (Shaw Taylor, Fiore, Mendelsohn, & Cheshire, 2011).

Whilst some empirical support exists for 'matching' (Berscheid, Dion, Walster, & Walster, 1971) and an early meta-analysis indicated that the correlation between romantic partner attractiveness levels was stronger and more consistently found that the same correlation amongst friends (where it only existed at all amongst men) (Feingold, 1988), Shaw Taylor et al. (2011) argue that robust empirical evidence in support of 'matching' is rather limited. In four studies of on-line dating behaviours, using experimental, observational, and survey methods they provided qualified support for the occurrence of 'matching,' but with evidence that desirable partners are preferred by all participants regardless of their own self-worth, but that those who have greater self-worth reported being more likely to contact more desirable potential partners.

The work of Shaw Taylor et al. (2011) also indicated that physical attractiveness based 'matching' did not drive decisions to contact potential partners. Those who did contact persons of similar physical attractiveness were, however, more likely to receive a reply and therefore the authors argued that 'matching' may not be attributable to abstract preferences or even initiation behaviours but to reciprocity in responding to that first contact. That is, in the on-line environment at least, physical 'matching' may occur at a later stage than previously contended, at the stage of mutual interest being expressed. Attractiveness 'matching' may therefore be less critical at the initiation stage but become increasingly important as couples progress through successive stages of dating initiation.'

1.3.3.1. Attraction and Visible Difference

Taken together, it is clear that 'what-is-beautiful-is-good', filter theories, and 'matching' all carry significant implications for those with a visible difference, which may impact upon how they are assessed by others and their conception of their own value or worth. Evidence of this may be found in a small study Halioua, Williams, Murray, Skalko, and Vogelsong (2011) have examined the 'what-is-beautiful-is-good' effect using photographic stimuli depicting individuals with and without an altered facial appearance (a visible difference). They found that photos which included a visible difference were stared at for longer than those that did not and those they depicted were rated as less intelligent, trustworthy, attractive, optimistic, and capable. In similar but also small-scale work, Stone and Potton (2019) showed structural manipulations to the expressive features of photographs of two faces invoked a range of stronger negative emotional reactions than a skin blemish on the forehead, which in turn invoked more negative emotion than control versions of the pictures. Furthermore, stronger emotions were associated with a greater period of fixation.

Such work is consistent with the earlier work of Bull and David (1986) in which faces that were manipulated so that they appeared scarred were rated as significantly less confident, less attractive, less sociable, and more dishonest than when they appeared without such manipulation. Similarly, photos of faces with a visible difference (scarring) were rated as less attractive than those without in work conducted by Phelan and Edlund (2016) and this effect subsisted regardless of whether the scarring was to central or peripheral areas of the face. Studies, such as these, that rely on using ratings of photographs and photo-manipulation, however, have been criticised for lacking ecological validity (Rumsey & Harcourt, 2005), in particular because they do not permit any interaction between the participant and the person depicted (Bull & Rumsey, 1988).

Research which may carry more ecological validity, but which provides insight into the experiences of only one individual, is the case study of Tevik and Feragen (2015). This research followed a young woman in Norway who, at age 17, had orthographic cleft surgery which left her without a visible difference and as being adjudged as very attractive by family, friends, and health professionals. Using clinical notes from 10 therapist sessions over a one-and-a-half year period and one in-depth interview, her experiences are elucidated in considerable detail. What is striking is that 'Sarah' reports that the response she aroused in others, especially heterosexual men, fundamentally altered with her appearance. She palpably experienced the sexual desire of others and was approached for romantic contact, a new type of attention that she found difficult, provoked anxiety, heightened alertness and hyper-arousal in her, and even seemed to trigger unexpected and disturbing childhood memories. Whilst it is possible her appearance and behaviour altered in other ways during this period, the researchers argued that Sarah's visible difference had protected her from being an object of others' sexual desire. Surgery altered this and her case provides a compelling illustration of how the reactions of others may be dependent upon one's physical appearance and be influenced by the presence of visible difference.

1.3.3.2. Under Represented and Minority Groups

Before proceeding with the presentation of this thesis, I should acknowledge that appearance ideals and the meaning ascribed to having a visible difference can vary from and within cultures and sub-cultures. Consequently, conceptions of attractiveness may also be differentially affected. Whilst a small portion of the literature referred to in this thesis does acknowledge this, or at least situate its findings very specifically, the thesis does not focus on Black, Asian, and Minority Ethnic (BAME) groups nor lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ+) communities.

Within these communities, and within other communities such as particular religious communities, alternative or particular standards of beauty and resultant beauty practices and forms of attractiveness can be relevant as socially defined norms and ideals are contextually situated and operate differently according to race, ethnicity, and culture (Naqvi & Saul, 2012) Indeed Naqvi and Saul (2012) highlight the work of Chiu and Babcock (2002) which describes how, within workplaces in China, external appearance may be valued less than in Western societies and not carry the same implicit connotations regarding to the possession of superior social skills by those adjudged physically attractive. Instead the Confucian value of internal goodness assumes cultural importance and significance, with conscientiousness and good-naturedness being more critical to assessments of the individual. Similarly, the response to and meanings of visible difference within the romantic domain can be culturally specific (Das, Khondokar, Quamruzzaman, Ahmed, & Peck, 2013; Thompson, Clarke, Newell, Gawkrodger, & Appearance Research Collaboration, 2010).

In addition to BAME communities, LGBTQ+ communities may also operate within their own appearance norms, ideals, and standards. Huxley and Hayfield (2012) build the case that appearance may be especially important to those who want to appeal to men as sexual partners. Accordingly, heterosexual women (Rothblum, 1994) and gay men (Jankowski, Fawkner, Slater, & Tiggemann, 2014; Morgan & Arcelus, 2009) place particular value upon their appearance. Lesbians though, who may be less concerned with the male gaze are more resistant to traditional Western beauty ideals (Atkins, 1998). As such, the male preference for both thinness and attractiveness (Legenbauer et al., 2009) may generate appearance expectations, ideals, and greater pressure for those who wish to appear attractive to men. This explanation neatly explains the findings of Hayfield, Halliwell, and Clarke, (2017), that heterosexual women were more likely to remove body hair than lesbian and bisexual women and engaged in more cosmetics use, which was lowest amongst lesbians. As with BAME groups, differing understandings of attractiveness can influence individual responses to visible difference with lesbian women suffering fewer body image concerns after breast cancer (Fobair et al., 2001) and sexual and gender minority women being less likely to seek reconstructive surety after a bilateral mastectomy than heterosexual women (Brown & McElroy, 2017).

With these caveats in place, the preceding literature indicates that those who are judged as less physically attractive and those that have a visible difference may be more harshly adjudged by others. This may curtail their ability to form romantic relationships. It also indicates that visible difference and intimate, romantic relationships may be a topic that warrants research attention. Before considering this topic in more detail and introducing the concept of 'visible difference,' I introduce theories applicable to close interpersonal and romantic relationships.

1.3.4. Relationship Theory

In addition to the interpersonal process model of intimacy (Reis & Patrick, 1996; Reis & Shaver, 1988), which explains the development of intimacy within a relationship, and theories of attraction, a number theoretical explanation of romantic relationships have been proposed. Whilst the focus of this thesis was upon experiences of visible difference and romantic relationships and then the development of a tool to assess the perceived impact in this domain, the underlying mechanisms from two dominant theories of romantic relationships are introduced here for context and completeness.

First, the infant attachment theory of Bowlby (1997, 1998b, 1998a) postulates that children develop emotional bonds with significant others, are motivated to maintain these bonds, and seek proximity to their primary attachment figure (Finkel, Simpson, & Eastwick, 2017). This has been applied to adult relationships by Hazan and Shaver (1987, 1994). Hazan and Shaver (1987) identified similarities between infants and their attachment figures and adult romantic relationships. Both relationships involve a degree of preoccupation with and vigilance of the attachment figure's responsiveness. Both involve a close emotional connection or bond and emotive dependency on the other's behaviour. In both cases this bond is formed in part through close physical contact and these relationships are typically adjudged to be the closest relationships. Finally, whilst physical attraction and passion are important to romantic relationships, especially in the early stages, comfort and emotional support (replicating the 'safe haven' of infant attachment) increase in importance over time (Hazan & Shaver, 1994). They provided empirical evidence (Hazan & Shaver, 1987) for the applicability of the typology of infant attachment introduced by Ainsworth, Blehar, Waters, & Wall (2015), and in broadly similar proportions to those evident amongst infants. This delineated infant attachment as being characterised by secure (characterised by a level of distress when the other leaves, comfort upon their return, and the ability to use the other as a secure base from which to explore and engage with the world), anxious/ambivalent (characterised by anger, anxiety and preoccupation with the other), and avoidant (characterised by indifference at separation, the avoidance of contact, and the direction of minimal attention toward the other) attachment styles (Hazan & Shaver, 1994).

Hazan and Shaver (1987) were able to characterise the romantic experiences of secure adults as being friendly, happy, trusting, avoidant participants as fearing closeness, and found the relationships of those categorised as anxious/ambivalent as being defined by jealousy, emotional highs and lows, and the desire for reciprocation. Furthermore, they presented evidence that participants' romantic attachment style may be associated with their mental models of relationships (an adaptation of Bowlby's working models, which he saw as being a core and consistent component of personality) and memories of their childhood experiences. Those with secure attachment reported warmer parental relationships and a positive or optimistic view of the intensity and duration of romantic relationships. Avoidant participants saw their mothers as cold and rejecting and believed typical media depictions of romantic relationships were unrealistic, and anxious /ambivalent participants viewed their fathers as unfair and said they rarely find real love. The results suggested a life-course trajectory of attachment style. Despite this the authors expressly acknowledged a degree of fluidity within specific relationships and that an individual may demonstrate different styles in different contexts as attachment style are products of an interaction between the individual, their attachment style, and the situation, which would include the behaviour and attachment style of their partner.

Subsequently, the avoidant category of adult attachment has been divided into two: preoccupied-avoidant, and fearful-avoidant (Bartholomew & Horowitz, 1991). As described by Buren and Cooley (2002) this results in a four category model of secure, dismissive, preoccupied, and fearful attachment styles. Secure individuals see themselves favourably and believe others will respond well to them. Dismissive persons view themselves positively but others negatively and may not value relationships. Those with a fearful attachment style consider themselves un-loveable and believe others to be rejecting and untrustworthy. Finally, preoccupied people view others positively but have a negative view of the self and may find self- worth primarily via the value others place in them.

The categorisation of individuals into those with particular and distinctive attachment types was, however, fundamentally challenged and altered by the work of Brennan, Clark, and

Shaver (1998) and Fraley, Waller, and Brennan (2000). They introduced, evidenced, and refined the idea that adult attachment patterns are formed by an individual's position across two dimensions; attachment-related anxiety and attachment related avoidance. High attachment-related anxiety is typified by concerns about the availability and responsiveness of the partner. High attachment-related avoidance individuals avoid becoming dependent upon, close to, and opening up to others. Furthermore although attachment profiles are considered to be dimensional, extremes of: high avoidance – high anxiety would correspond to a fearful attachment style; high avoidance – high anxiety to dismissive; low avoidance – high anxiety to preoccupied; and low avoidance – low anxiety to a secure style.

In common with those original comments, regarding contextual fluidity, of Hazan and Shaver (1987), the potential vulnerabilities and highly avoidant and anxious behaviours of individuals with corresponding dimensional profiles, are now understood to emerge and become evident when elicited by the distress of internal stressors, external relational stressors, and/or negative external events. These are all capable of evoking prototypic responses, as per the attachment diathesis-stress process model (Simpson & Rholes, 2012, 2017). Involvement in a committed relationship (Tran & Simpson, 2009) and attachment tailored emotional and behavioural buffering by partners (Overall, Simpson, & Struthers, 2013; Simpson & Overall, 2014) can protect against and reduce the manifestation of these prototypic responses.

Finally, for the purposes of this thesis, it is important to reflect that appearance related concerns and experiences may be capable of evoking the distress that would predict regression to these prototypical behaviours in those that are highly anxious and/or highly avoidant. Furthermore, whilst attachment theory as applied to adult romantic relationships tends to focus upon the nature of relationships, Hazan and Shaver (1994) argue that attachment needs, a desire to protect or offer comfort (caregiving), and sexual needs may all motivate interpersonal attraction. Attraction can therefore depend upon the relative importance of the function of the relationship that is sought. Where sexual needs are relevant, an attractive physical appearance, sexual availability, and sexual value can be extremely important to the process of attraction. In common with the 'filter theories' introduced previously, this is considered to be a primary instigator for seeking proximity of others, the first step towards the development of specific attachments and romantic relationships. This may represent a challenge for those with an appearance that is not considered attractive or to indicate high sexual value.

Social exchange theory, originating in the work of Thibaut & Kelley (1959) represents another dominant theory of romantic relationships, essentially likening a relationship to an economic exchange in which each party seeks to maximise the benefits received from the relationship and minimise their associated costs, the ‘minimax’ principle. It thus shares its core conceptual territory with the ‘mating market’ idea that has previously been introduced, but whilst that idea was discussed primarily within the context of attraction, the implications of social exchange theory for ongoing relationships will be addressed.

Fundamentally, social exchange theory presumes that relationships are formed of four distinct stages. These are; sampling, in which the individual makes a prior assessment of the potential costs and benefits of the potential relationships that may be available. This is followed by bargaining. At the outset and during the early stages of a relationship the partners may be considered to be testing the decision they have made and assessing the reality of their analysis, calculating whether the relationship should be pursued. Where the bargaining phase is assessed positively, the relationship progresses towards commitment, broadly understood as the long term orientation and intention to remain in a relationship with a partner, maintaining a psychological attachment to them (Tran, Judge, & Kashima, 2019). Here, intimacy and commitment to the relationship increase whilst engagement in sampling and bargaining may decrease or become more predictable, potentially lowering the associated costs of maintaining the relationship. Finally, institutionalisation implies the establishment and embedment of relational norms, values, and equity.

The decision to maintain a relationship is considered a function of its comparison level, a measure of ‘profit.’ Whether the outcome is acceptable to the individual is influenced by internal (e.g. self-esteem) and external factors (e.g. prior experiences, social, representations and messaging). Likewise, the comparison level is set against the comparison level for alternatives. This concerns whether an individual’s existing relationship is more or less rewarding than viable alternatives and is strongly associated with commitment to relationships as well as being predictive of satisfaction (Sprecher, 2001). It is also apparent that those in relationships are inclined to rate other people as being less physically attractive than those who are not, indicating that the presence of an existing relationship may impact upon the assessment of the value of an alternative (Simpson, Gangestad, & Lerma, 1990).

An underlying principal of social exchange theory, that individuals are motivated to seek maximum gain at minimum cost, has been questioned by equity theory (Walster, Walster, & Berscheid, 1978). This adaptation instead prefers the pursuit of equity. That is equity between what one contributes to a partner and relationship and what one receives. Inequity is considered distressing, regardless of the direction in which it subsists. Dissatisfaction created by inequity may lead to realignment, achieved through the restoration of equity or by adjusting perceptions of costs and benefits, potentially normalising behaviour or consequences that were previously considered costly. Though not as strongly associated with relationship satisfaction as the comparison of alternatives, Sprecher (2001) concluded that it is at least modestly associated with both satisfaction and commitment but does not predict relationship stability or quality.

A further adaptation of social exchange theory, and one that carries significant traction, is the investment model of Rusbult (Rusbult, Agnew, & Arriaga, 2011; Rusbult, 1980). The primary contention and main contribution of the investment model is that relationship commitment is considered to depend upon outcomes, such as the 'profit' of social exchange theory, an assessment of the best alternative, the comparison level for alternatives, and one's investment into the relationship. This investment is comprised of resources that are intrinsic, such as time and emotional effort, and extrinsic (or were extrinsic) to the relationship, such as one's existing home. The potential for the loss of the investment to date increases dependency upon the relationship and reduces the likelihood of the relationship being terminated (Rusbult et al., 2011). Accordingly, commitment increases as investment increases, when 'profit' is high, and when there are no alternatives perceived as offering better outcomes relative to costs. The investment model may also be supplemented by the addition of planned, but as yet unrealised, investments (Goodfriend & Agnew, 2008) or 'valued' linkages, the loss of which may be considered akin to lost opportunity. Likewise, subjective norms may be influential in the relative assessment of a relationship, thus recognising the importance of what others may think about a relationship (Agnew, Arriaga, & Wilson, 2008).

The investment model has found support in meta-analyses, with Le and Agnew (2003) identifying satisfaction followed by comparison with alternatives and investment as the strongest predictors of commitment to a relationship, noting that this applies across cultures, genders, and same-sex relationships. Very similar results arose from the systematic review and meta-analysis of Tran, Judge, and Kashima (2019), with relationship satisfaction, investment, then quality of alternatives enjoying the strongest association with commitment. Their work extended beyond interpersonal and romantic relationships but within that domain investment was relatively more important (as compared to non-interpersonal and more transactional relationships, such as professional relationships), although the association was reduced in lesbian and gay relationships.

The material introduced, concerned with attractiveness and the value and connotations placed upon appearance, the indication that stressors may contribute to the demonstration of underlying typographical attachment styles, the importance of a satisfactory, negotiated bargain position, and comparisons with alternatives, suggests that romantic relationships and appearance, and specifically visible difference, may be topics worthy of investigation. Before eventually doing so, this thesis will now consider more carefully what is meant by the 'visible difference' and what visible difference may mean to those whose live with an altered appearance.

1.4. Visible Difference

1.4.1. Defining Visible Difference

The term 'visible difference' refers to any disfiguring condition that results in an individual having an altered or non-normal appearance. Such conditions may be congenital or acquired after birth, with acquired difference resulting from a traumatic incident, or as a consequence of disease or illness and/or its treatment (Kent & Thompson, 2002). Examples of visible differences include dermatological conditions, burns, scarring and craniofacial abnormalities (Bessell & Moss, 2007). Visible differences may also be conceptualised as being either normally visible or normally non-visible (Moss, 2005), depending upon whether they are apparent and observable during everyday life and interactions. This thesis incorporates all such differences, distinguishing only where it is salient to do so.

This broad definition and conceptualisation of visible difference has been adopted in order to ensure the greatest applicability and utility of the outputs of this thesis. Visible difference and the appearance element of many health conditions, benefits from relatively little funding and receives relatively little research attention, consequently I wanted to maximise the applicability, the transferability, of the research outputs this work generated. As Rumsey and Harcourt (2004) have argued, there is 'remarkable consensus' in the difficulties and challenges reported by those with different appearance altering conditions and the existing research literature suggests that the type of visible difference an individual has does not predict adjustment. Where these claims have been examined empirically, condition specific effects have been small and somewhat sporadic, being characterised by considerable within group (condition) variance (Rumsey, Clarke, & White, 2003; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). As the authors of the research conducted by the Appearance Research Collaboration (reported in Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014) concluded, their data indicated a pattern of similarities in adjustment and distress profiles between those attending different clinics (e.g. plastics, dermatology, burns), rather than differences.

Furthermore, it has been reported by those that work clinically with this population that their clinical experience indicate that the type of visible difference an individual has is not a good predictor of adjustment (Clarke et al., 2014). Likewise, the one NHS service dedicated specifically to people with a different, unusual or changed appearance, the Outlook Service within North Bristol NHS Trust, caters to individuals with any visible difference. Whilst the patients of that service receive individualised care, its existence points to the commonality of social experiences indicated by the work of Rumsey, Clarke, and White (2003). This commonality further justifies the focus resting on visible difference rather than a specific condition. It is important to acknowledge from the outset that that this may have resulted in some condition specific nuance escaping detection. I would not argue that no such nuance exists. I considered that the benefit of conducting work focussed on a broad population, work that future research can refine if necessary, outweighed this issue.

This thesis attempts to avoid framing visible difference negatively. It is for this reason that the term ‘visible difference’ is used, rather than ‘disfigurement.’ Rumsey and Harcourt (2004) argue that negative terminology is at best unhelpful but at worst it can exacerbate the difficulties experienced. Examples of terms they consider too negative include ‘disfigurement,’ ‘deformity,’ ‘abnormality’ and ‘defect.’ They argue, however, that it is important to ensure that terminology used is clear and provides access to the shared understanding that a word such as ‘disfigurement’ may evoke. During this thesis the term ‘visible difference’ or ‘difference’ will primarily be used although alternatives such as ‘appearance altering condition’ may occasionally be employed.

1.4.2. The Psychosocial Impact of Visible Difference

It is well established that living with a visible difference carries the potential to impact negatively upon an individual’s psychosocial well-being. Rumsey, Clarke, and White (2003) demonstrated that a considerable proportion (13-93% depending on the measure utilised) of 220 persons attending burns, dermatology, general plastics, hands and head, neck, and maxillofacial out-patient clinics reported psychosocial difficulties. These included raised anxiety levels, depression, social anxiety, social avoidance, and a reduced quality of life. Whilst the study included no control or comparison group, it indicated that these may be considered significant challenges for some with visible differences. Rumsey and Harcourt (2004) describe how visible differences may contribute to lowered self-perceptions and difficult social interactions via a spiral of negative emotions, maladaptive thought processes, unfavourable self-perceptions and negative behavioural patterns.

It is, however, important to acknowledge that many people do not report problematic adjustment or difficulties associated with their visible difference and may consider that positive consequences have flowed from their appearance (Egan, Harcourt, & Rumsey, 2011; Eiserman, 2001). This thesis therefore remains alert to the possibility of positive adjustment and attempts to avoid the potentially unethical negative focus and pathologising of visible difference of which Egan et al. (2011) warn.

1.4.3. Predicting Psychological Distress

Contrary to assumptions that may pervade even amongst the medical profession, the psychosocial impact of visible difference is not strongly predicted by, nor linearly related to, external or objective measures of the severity of a condition, such as clinician ratings of severity and noticeability (Moss, 2005; Rumsey et al., 2003, 2004), a physical measure of the extent of facial lipoatrophy experienced by HIV-positive patients (Ong et al., 2007), or scores on a validated scar severity rating scale (Brown, Moss, McGrouther, & Bayat, 2010). Whilst clinician ratings involve their own subjectivity, this subjectivity is externally located. It is not the participants' subjectivity but eh subjectivity of clinicians well versed in treating patients with the conditions under consideration. Indeed, it is this, participant, subjectivity, their evaluation and understanding of their condition, that better predicts psychological adjustment and psychosocial distress (Brown et al., 2010; Moss, 2005; Ong et al., 2007).

The importance of subjective interpretations does not, however, entirely eliminate the contribution that a more objective or externally sourced measure of severity may make to adjustment. The contribution of both the objective nature of a condition and the individual's subjective assessment was quantified by Moss (2005). Using a sample of four-hundred plastic surgery outpatients, Moss illustrated a linear relationship between participants' subjective assessment of the severity of their condition and adjustment amongst those with normally visible and normally non-visible differences alike. This subjective assessment accounted for some 20% of the variance. In respect of normally visible conditions only, a weaker relationship accounting for 7% of the variation was demonstrated between an objective assessment of severity and problematic adjustment.

This relationship was, however, non-linear and followed an inverted 'U' shape with adjustment being more problematic amongst those with objectively moderate severity then those with severe or mild severity (Moss, 2005). The implication that the impact of objective severity may be different for normally visible and non-visible conditions is interesting. This distinction offers some support for the claims of Clarke (1999) and Williamson and Wallace (2012), who have argued that the extent to which visible difference interrupts everyday communication processes is relevant to adjustment, with greater interruption being more challenging. Further support for this view garnered from the findings from and the nature of difficulties experienced by participants with thyroid-associated ophthalmopathy (Jensen & Harder 2011) and Moebius syndrome (Bogart, Tickle-Degnen, & Joffe, 2012).

Moss (2005) accounted for this non-linear relationship (between the objective severity of visible conditions and adjustment) with two possible explanations. One such explanation was that the likelihood of pain or functional limitations may be greater amongst those individuals who have an, objectively, more severe visible difference and so appearance concerns assume relatively less importance. Similarly, those with, objectively, less severe visible differences may have been more likely to have co-morbid personality characteristics or psychopathology that led to them seeking surgical intervention (and thus their participation in that research). The rationale preferred by Moss (2005) for the finding, however, was that the social reactions of others may be predictable and consistent towards those with mild and severe conditions but less predictable and more ambiguous for those with moderate differences. He proffers the varying levels of predictability as a potential explanation for the non-linear effect with unpredictable and inconsistent reactions to visible differences.

Further research by Lawrence, Fauerbach, and Thombs (2006) focussed upon the importance participants ascribed to their overall appearance. This may be referred to as investment in appearance. They identified an interaction effect amongst 346 burn survivors, reporting that amongst participants that assigned little importance to their appearance, scar severity did not predict body esteem. When, however, the importance of appearance was high, there was a strong predictive relationship between burn scar severity and body esteem with more severe scars predicting lower body esteem scores. Objective factors, such as severity, may therefore impact well-being and adjustment within certain contexts, such as where appearance investment is high or where the difference is normally visible.

Despite the evidence that objective severity may explain some of the variance in adjustment in some contexts, the relative predictive power of subjective and objective assessments suggests that subjective assessments are more powerful. This means that the psychological and social conditions and factors related to visible difference should be given priority in the research and clinically, as physical treatments in the form of plastic surgery or other appearance altering procedures cannot offer a panacea for the psychosocial impact of visible difference (Rumsey & Harcourt, 2004). Such treatments may reduce the objective severity of a condition, but are unlikely to eliminate it and may not address the individual’s powerful subjective evaluation of their difference. It is therefore important to understand some of the theoretical explanations offered for the impact of and individual adjustment to, visible difference.

1.4.4. Theories of Visible Difference

The study of the psychosocial impact of visible difference remains somewhat devoid of an integrated, unifying theory of adjustment (Kent, 2000). Kent highlights four theoretical models: the social anxiety model of Leary and Kowalski (1995) in which the level of anxiety one experiences is dependent upon their confidence that they can manage the impression they make upon others in social situations; the theory of stigma proposed by Goffman (1974) under which socially devalued characteristics can lead to avoidance and rejection by others; the social skills model of Rumsey, Bull, and Gahagan (1986) and Partridge (1998) in which a preoccupation with appearance can contribute to the demonstrations of poor social skills; and the body image disturbance model of Cash and Grant (1996) in which socially mediated messages about attractiveness can result in a negative body image and that negative schema maybe activated by triggering events. Each was relevant to the experiences of participants with vitiligo. Whilst Kent (2000) saw a degree of overlap between these approaches and argues that each provides some unique insight, none offers a fully comprehensive theory, and an integrated approach drawing on each would be required to effectively support those experiencing distress.

In addition to the four theories highlighted by Kent (2000), and focussing on the concept of avoidance, which features heavily in Kent's analysis and the theories he refers to, Newell and Clarke (2000) and Newell (1999) adopt the fear-avoidance model of exaggerated pain (Lethem, Slade, Troup, & Bentley, 1983; Slade, Troup, Lethem, & Bentley, 1983). They apply it to the distress that an altered body image may cause, with facial disfigurement used as the most salient exemplar. Newell (1999) argues that the model applies equally to all visible differences, both congenital and acquired. The model postulates that the fear experienced as a result of a visible difference, including fear concerning the reaction of others, interacts with the individual's life events, personality, history of bodily changes and body image coping strategies to produce the psycho-social context within which the individual will either confront the fear or avoid it.

Confrontation is conceptualised as the adaptive response and may lead to habituation, improved social skills, predictions of future success, increased self-efficacy, increased confidence, and eventually social integration or re-integration (Newell, 1999). Avoidance, however, is deemed maladaptive, does not facilitate increased social skills and leads to further isolation, generalised anxiety, predictions of failures to cope, generalised avoidance and social isolation. It is thus inherent within the model that treating only an individual's physical appearance should not be expected to automatically lead to concordant psychological and psychosocial gains.

The work of Newell and Clarke (2000) and Newell (1999) has proven influential and fear avoidance is often referred to explicitly in literature examining appearance altering conditions (Bessell & Moss, 2007; Connell, Phillips, Coates, Doherty-Poirier, & Wood, 2014; Griffiths, Williamson, & Rumsey, 2012; Rumsey et al., 2004). In other cases, research refers to social avoidance (Clarke, 1999; Rumsey et al., 2003) and avoidance or avoidant behaviours (Connell, Coates, & Wood, 2015; Fox, Rumsey, & Morris, 2007). In these latter cases, the fear-avoidance model may be applied as explaining the mechanism through which avoidance may contribute to sub-optimal outcomes and inhibited adjustment. Rumsey, Clarke, and Musa (2002) illustrate this when they elegantly describe social avoidance as a 'tempting but highly destructive coping strategy' (p.565) before explaining how such a strategy removes the opportunity for the person with a visible difference to habituate to the curiosity of other people and to practice coping responses.

Components of the fear-avoidance model can be detected within the ARC's 'bio-psycho-socio-cultural' framework, as reported by Clarke et al. (2014) and adapted by Thompson (2012). This is the most complete response yet provided to Kent (2000) and was developed in order to elucidate the constructs and factors that may contribute to appearance well-being and formulates this outcome as an interaction between:

- predisposing personal, social and historic factors (including demographic factors, early experiences, sociocultural factors and physical appearance factors);
- appearance related beliefs and cognitive processes (including: appearance schemas (salience, valence and any self-ideal appearance discrepancy); appearance processing (social comparisons, fear of negative evaluation, selective attention and social and bodily monitoring); and general dispositional style);
- current social and cultural influences; and
- appearance specific reactions and well-being (including: behavioural engagement style (which may be engaging with or avoiding social interaction), safety behaviours such as concealment or pro-social behaviours; and positive and negative emotional reactions)

The framework is consistent with the cognitive-behavioural approach that Newell and Clarke (2000) and Newell (1999) advocated but goes beyond this, or any of the four theories described by Kent (2000) to suggest demographic, experiential, social, cultural, physical, emotional and cognitive elements that may also contribute to appearance well-being. The ARC framework is a heuristic device designed to inform research and practice. It therefore lacks some specificity as to how the various components interact and is acknowledged by the authors to be informed by clinical experience as well as previous research (Clarke et al., 2014). Designed as it was, to offer a consensus framework for a large group of researchers undertaking a collaborative quantitative study, it was also constrained by the measures available at the time. Furthermore, it has been reported in several different iterations (Thompson, 2012; in two different forms in (Clarke et al., 2014), thus some disagreement remains amongst the authors regarding its optimum form.

The broad 'bio-psycho-social' orientation of the ARC framework has parallels with the dominant approach that exists within the realm of health psychology. The 'biopsychosocial' approach (Engel, 1980; Engel, 1977) asserts that social, psychological and biological systems and processes interact to determine health status. This approach has, for example, been modelled by Lutgendorf and Costanzo (2003) with specific reference to the biological, psychological and social processes through which stress may be implicated in health outcomes. Indeed, Rumsey (2008) has argued that appearance and health psychology are related disciplines as appearance and health behaviours can be closely associated with one another. Consequently, the psychology of appearance should be an area that health psychologists dedicate attention to. More broadly, healthcare professionals should be aware of the psychosocial impact of appearance concerns upon patients with visible differences (Rumsey, 2008). It is argued that this 'biopsychosocial' approach to health psychology and of the ARC framework require that some emphasis is placed upon an individual's cognitive processes and emotional condition, but that these are always situated within a broader social and cultural context. It is important that any attempt to understand the impact of appearance upon an individual should acknowledge the broader factors and the socially situated nature of a given individual and their reaction to and understanding of their appearance. These issues will remain relevant to this thesis and inform the qualitative study in particular.

1.4.5. Visible Difference and Functionality

One consideration which impacts upon some individual's experience of visible difference is any accompanying functional impairment. By their very nature some visible differences are more likely to be connected with physical, functional limitations and challenges. For example, individuals who have experienced limb amputations or forms of cancer (such as head and neck cancer) may also experience physical and functional impairment alongside their altered appearance.

Naturally, it is important to briefly acknowledge that the experiences of those with such impairments are compounded by a society which operates in a way that fails to accommodate individual needs and differences, turning physical impairment into disability. This is the essence of the social model of disability, developed largely from the work of Oliver (1983, 2009, 2013). In common with theories of visible difference, such as the stigma of Goffman (1974) and the body image disturbance model of Cash and Grant (1996), the social model of disability contends that social systems, structures, and processes create and perpetuate negative experiences, discrimination, and the exclusion of individuals with physical and functional impairments.

Visible difference and functional impairment may therefore be considered to occupy a somewhat similar or closely aligned space. They may impact, affect, and interact with one another. We have already met the contention that the non-linear relationship between the objective severity of visible difference and individual adjustment may be attributed to pain or functional limitations experienced by those who have more severe visible differences, meaning appearance assumes relatively less importance (Moss, 2005). Other evidence, however, has indicated that functional impairment and adjustment (measured across sexuality; body image; affect; and relationships) may be somewhat independent, with the negative impact of burn injuries continuing irrespective of functional recovery (Connell et al., 2014).

Whilst this thesis remained centred upon experiences of visible difference, it is appropriate to recognise the potential for functional impairment to impact individual’s romantic lives. In some ways this may correspond with the impact of visible difference (which will be addressed shortly). As Taleporos and McCabe (2001) have highlighted, sexual activity may be impacted by functional impairments. Some sexual activity or variations of sexual activity may not be feasible for some, although Taleporos and McCabe (2001) have indicated that this can require increased creativity and carries the potential to be perceived positively as a result.

Reviewing research concerned with those who have had limb amputations, Geertzen, Van Es, and Dijkstra (2009) cited pain, erectile dysfunction, reduced mobility, and decreased libido as potential difficulties in this respect. In addition, Geertzen et al. (2009) also refer to the negative self-image that those with amputations may hold whilst Taleporos and McCabe (2002b, 2002a) have indicated sexual-esteem, body-esteem, and self-esteem can be closely associated. Hormonal treatment for cancers such as breast cancer can interrupt sexual functioning and also impact body image (Hungr & Bober, 2020). Those with Peyronie's disease (characterised by penile curvature) may experience pain, psychological concern, and sexual dysfunction (Ziegelmann, Trost, Russo, & Levine, 2020). A qualitative meta-synthesis of research focussed upon that those with dermatological conditions illustrates that those with such conditions can also experience affected sexual function (Barisone et al., 2020).

In concordance with the social model of disability, those with functional impairments are also liable to experience negative reactions from others, centred upon their impairment (Geertzen et al., 2009), as impairment is not included within the social conception of attractiveness and sexuality. They may believe that they are undesirable to others (Taleporos & McCabe, 2001), and can be perceived as asexual, unsuitable as romantic partners (Milligan & Neufeldt, 2001), rendering them more likely to be single than those without functional impairments (Taleporos & McCabe, 2003; Verschuren, Enzlin, Geertzen, Dijkstra, & Dekker, 2013). Functional impairment may also result in other disadvantage, for example in terms of employment or social opportunities (O'Brien, Roe, Low, Deyn, & Rogers, 2012), which may act to limit or impact romantic opportunities. Whilst it is not feasible to introduce and examine these issues here, it is important to acknowledge that functional impairment can be relevant to those with visible difference and that this is not explored within this thesis.

It is also important to reiterate, however, that not all visible difference is associated with functional impairment. The work in this thesis is centred upon appearance and the psycho-social impact of visible difference within the romantic context. Whilst functional impairments would be recognised as relevant to the experience of some of those with visible difference, they are not the focus of the thesis. In the future, studies of romantic relationships, appearance, embodiment, and functional impairment may draw these issues more closely together in a holistic, integrated fashion. The under-explored topic of visible difference and romantic relationships remained at the nucleus of this thesis and it is hoped that this may, in time, help facilitate that integration.

Having introduced the areas of intimate, romantic relationships, and visible difference in this chapter, the next chapter of this thesis will go on to consider research that has examined the intersection of these two areas.

2. Visible Difference and Romantic Relationships: Literature Review

The preceding chapter introduced the relevance of appearance and attractiveness to attraction and the judgements that may be made by others about a given individual. It also detailed some of the psychosocial impacts that visible difference may entail. Writing within the body image literature, Shaban (2010) argued that intimacy requires confidence, trust, positive self-worth, and openness and that these are the opposite characteristics associated with poor body image. Given that a similar argument may be made in respect of visible difference, these ideas indicate that the impact of visible difference upon intimate, romantic relationships is a legitimate research topic.

Early research supports this proposition. Koster and Bergsma (1990) reviewed the literature relevant to adjustment and coping amongst those with facial cancers. They highlighted the importance of appearance to interpersonal interactions and concluded that disfiguring conditions were prejudicial to social interactions at the two extremes of the intimacy spectrum, the very superficial and the very intimate. It is therefore to a body of research, albeit a rather disparate one, examining the intersection of visible differences and romantic relationships that this thesis now turns via a review of the existing literature. This will include a consideration of the impact, challenges faced, risk and protective factors, and examples of positive adjustment. It was also intended to use this review to interrogate the availability of a research measure concentrated upon the impact of appearance concerns amongst those with visible difference upon their experiences of intimacy and romantic relationships. Broad search terms were therefore employed in order to capture any such measures.

It is necessary to acknowledge, however, that aside from the research of Griffiths et al. (2012) focussing on adolescent romantic relationships and the ARC study published in (Clarke et al., 2014) there existed very little prior research examining visible difference and romantic relationships. Consequently, much of the work that is discussed herein relates to specific conditions or groups of conditions rather than to visible difference *per se*. Similarly, intimacy and romantic relationships are often referred to but are not the primary focus of the research. The argument is thus made that dedicated research is required in order to explore, define, and measure the perceived impact of visible difference upon romantic relationships.

2.1. Literature Search Method

As the literature is disparate and includes primarily condition specific studies which, in most cases do not focus primarily on intimacy and romantic relationships, a systematic review of the literature relevant to visible difference, appearance altering and romantic relationships was not appropriate. In addition, the available literature spans many different research methodologies, methods, and measures. A 'traditional' literature review was therefore performed.

In order to provide some structure to this traditional review, as advocated by Aveyard (2014), an EBSCO search of seven relevant databases was searched for appropriately truncated forms of the following search terms: (1) visible difference or disfigurement or altered appearance and (2) intimacy or intimate relationship or interpersonal relationships or romance or romantic or relationships or dating or partners. This resulted in one hundred and thirty-seven hits. The title and abstract of these were screened on an inclusive basis and relevant articles read. Pertinent references within these articles were followed up and were combined with my initial reading on the topic. This was an ongoing process and was supplemented with subsequently published work. The literature that was identified is discussed in the remainder of this chapter.

2.2. Visible Difference and Romantic Relationships: The Literature

Before introducing this literature, some preliminary issues should be addressed. First, whilst various studies identify, quantify and/or describe some kind of impact of visible difference upon romantic relationships, few explanations are offered. Much of the literature does not refer to any kind of theoretical underpinning of the phenomena they identify or make an attempt at situating their findings within a theoretical background. As such, the emphasis has been towards description rather than explanation and a theoretical synthesis has not been attempted at this stage.

Secondly, much of the work examined has been drawn from literature that is concerned with the effect of a specific condition upon people's lives and well-being. Whilst appearance is often implicated, it may be that other condition or disease processes are evident. The existing work rarely attempts to tease these apart and, where the focus of the research was not specifically upon appearance, it was not always entirely apparent that appearance was the dominant concern.

Finally, the different methods, methodologies, and measures used mean that it is difficult to offer a comprehensive and consistent picture of the research findings. Those that have been identified have been collated and synthesised to the best of my ability in order to present a representation of the current state of knowledge. As this relates to an under-researched area, this has required complementary, conflicting, and different research to be drawn together in order to comment on what the literature says about the impact of visible difference on romantic relationships, who may be at risk or susceptible to these impacts, the nature of the challenges experienced, and the possibility of positive adjustment.

2.2.1. The Impact of Visible Difference upon Romantic Relationships

Notwithstanding the caveats mentioned above, several quantitative studies lend support to the contention that appearance altering conditions impact negatively upon intimate, romantic relationships. The research indicates that participants believe that both the quality and quantity of their relationships have been affected by their appearance altering conditions. In particular, the impact of dermatological conditions has received some attention. This is especially interesting as the impact of dermatological conditions upon an individual's physical health status, or upon their functionality, may in many instances be less severe than other appearance altering conditions such as, for example, many forms of cancer. Whilst it remains something of a speculative assertion, it may be reasonable to argue that the appearance altering effect of dermatological conditions may therefore be relatively important.

Working with patients of vitiligo clinics in the United States of America; Porter, Beuf, Lerner, and Nordlund (1990) generated a questionnaire to assess 158 people, finding that 25% reported their condition to have impacted negatively upon their sexual relationships and 10-15% believed it to have limited their sociability with the opposite sex and the number, or frequency of potential or actual sexual relationships. Their findings also highlighted the importance of appearance to participants as being one of four predictors of sexual adjustment to vitiligo. In another, larger, study of a dermatological condition and also using unvalidated questionnaires, Long, Funnell, Collard, and Finlay (1993) surveyed over 3,000 members of the National Eczema Society by post. Of their adult sample of just under 2,000, 14% felt that the development of their personal relationships had been affected by their condition. Similarly, 19% reported a negative impact upon their sex lives.

In a study of 936 psoriasis patients 35-71% of participants reported encountering sexual difficulties as a result of their psoriasis. These difficulties correlated positively with other quality of life areas related to social relationships (Sampogna, Gisondi, Tabolli, & Abeni, 2007). For example, a question asking about feelings of being physically unattractive or sexually undesirable at times when their psoriasis was bad correlated strongly with questions concerning more general embarrassment, uneasiness, and impaired social activities. For Sampogna et al. (2007) the disfiguring nature of the condition explains, at least in part, its impact on all aspects of quality of life. These conclusions were drawn, however, from a measure that consisted of an amalgamation of items concerning sexual life drawn from a four different dermatology quality of life scales, meaning that the measure was therefore once again unvalidated.

Taken together, these studies of participants with skin conditions indicate that, as with other psychosocial challenges, a sizeable minority of those that have such conditions report experiencing some problematic aspects of intimacy. Like much of the visible difference research, however, these studies did not include a control group and so comparisons with those who were not affected were impossible. Magin, Pond, Smith, Watson, and Goode (2008) did, however, compare those with acne, psoriasis and atopic dermatitis to a normative control group. They found that those with these dermatological conditions were more likely to be single than those without. These patients were also younger and less likely to be in paid employment and so there may have existed other systematic differences between the groups.

It is not only skin conditions that have been studied within this context. Low et al. (2009) combined two items from a health and neck cancer quality of life questionnaire, a self-designed intimacy questionnaire, and a quality of life measure. They reported that amongst those that have received treatment for head and neck cancer one-third report substantial problems with sexual interest and enjoyment and one-quarter problems with intimacy. The earlier work of Gamba et al. (1992) in a similar population and using responses to closed interview questions, reported that amongst those with extensive visible difference (as assessed by a physician) 74% reported reduced sexuality and 27% a worsened relationship with their partner. Those with minor differences fared better and did not experience a worsened relationship but 39% did report reduced sexuality.

The work of Connell, Coates, and Wood (2013) and Connell et al. (2014) focussed on burns patients. In each study patients responded at discharge and one, three, six, and twelve months post injury. Their earlier study (Connell et al., 2013) used two sub-domains from a burns specific health scale (Kildal, Andersson, Fugl-Meyer, Lannerstam, & Gerdin, 2001) to demonstrate that participants reported a significant negative impact upon the sexuality and body image satisfaction sub-domains. In 17.2-21.8% of cases (depending on the specific item) sexual arousal and interest was impacted at a year post burn and 27.9-43.7% of participants indicated body image concerns at the same time (again, varying by item). At one-year follow-up the researchers received only 87 responses and the composition of the sample appeared to prevent the data from being analysed longitudinally.

The larger study of Connell et al. (2014) utilised the same burns specific health scale but specifically utilised four (of the nine) sub-domains: sexuality; body image; affect; and relationships. The analyses demonstrated that the negative impact of a burn injury subsisted over the follow up period in respect of all domains and regardless of physical functional recovery. Whilst pre-injury baseline data was not available, Connell et al. (2014) argued that the results suggest that the emphasis society places on appearance, youthfulness and athleticism coupled with the disfiguring nature of burns dictates that many individuals suffering burns may experience negative and enduring changes in all four domains.

Drawing on the condition specific literature one final time in this section (and whilst acknowledging the focus of this thesis is upon adults and adult experiences) Feragen, Stock, Sharratt, and Kvalem (2016) identified that significantly fewer adolescents with a cleft lip and/or palate reported being in a romantic relationship at age 16 and a significantly greater proportion reported never having had a romantic relationship as compared to reference data. When participants with a visible cleft lip were compared to those with a cleft palate, however, there were no significant differences between those groups. Whilst some of the between-cleft group comparisons relied on relatively small sample sizes, this does cast some doubt upon the relevance of appearance to the findings.

Whilst the literature referred to in this section has focussed on specific conditions, initial research conducted by the ARC (reported in Clarke et al., 2014) spanned a broad range of conditions resulting in visible differences. This group highlighted the need for a short research scale focussed on intimate behaviours, having concluded that no such measure existed. Their preliminary findings, using a self-generated measure, showed attendees at a plastic surgery out-patient clinic experienced many more appearance concerns within this context than adults without a visible difference and led them to undertake the early steps of constructing such a scale. Whilst this research did not progress further and the scale was never completed, their findings highlighted the potential for visible difference to impact upon the intimate, romantic domain as well as the residual need for such a measure to be developed.

The possibility of this impact and the need for a specific scale also draws support from the work of Clarke, Hansen, White, and Butler (2012). Working with over 500 patients referred for NHS cosmetic surgery and utilising standardised measures alongside a structured clinical interview, the authors report that many participants reported the belief that a new relationship would be impossible because of their ‘abnormal’ appearance and that the avoidance of potential partners often preceded more generalised social avoidance. Also adding weight to this argument is the research of Moss, Lawson, and White (2015). They examined the factor structure of the 24 item version of the Derriford Appearance Scale (DAS) (Carr et al., 2005), a shortened version of the original 59 item DAS designed to measure appearance distress amongst those with a visible difference (Carr et al., 2000). Moss et al.

(2015) identified a two-factor structure general self-consciousness; and sexual and bodily self-consciousness. The second factor suggests these concerns may be central to the experience of visible difference. The DAS24 sub-construct has, however, only two (of six) items that relate to sexual behaviour and whilst the work thus suggests intimacy and sex are legitimate areas for measurement and are closely bound with feelings about one's visible difference the scale is not sufficient to identify the specific areas of concern and challenges that may arise.

2.2.2. Who is Susceptible?

The existing literature indicates that there may be several characteristics that could indicate which individuals may be most at risk from experiencing challenges in their romantic life in connection with appearance altering conditions. Before moving on to those that factors for which there is more evidence, the potential influence of cultural background and ethnicity should be acknowledged. Examples of research where the specific cultural context has featured prominently include the qualitative, stigma oriented and feminist couched study of the victims of domestic assault with fire in India (Furr, 2014) and the examination of experiences of stigmatisation amongst British South Asian women with vitiligo (Thompson et al., 2010). There is, however, limited work in this field. Combined with the cultural nuances that the limited research has identified, this makes the broad between group comparisons that follow difficult to make with regards to ethnicity and cultural background. One factor, however, that can be examined and is implicated in this way is relationship status.

2.2.2.1. Relationship status.

Relationship status has been identified as being associated with embarrassment and a greater impact upon sexual relationships amongst those with vitiligo. The authors argued that embarrassment was problematic in non-sexual interpersonal encounters, this may hinder the development of potentially sexual relationships, and that appearance is an important resource in initiating sexual relationships. They concluded that dermatological conditions may be particularly stressful to those that are single (Porter et al., 1990).

Similar findings arose from a systematic review of eleven studies looking at sexuality in amputees. Geertzen, Van Es, and Dijkstra (2009) summarise that reduced mobility may combine with the reactions of others, who discount the person with the amputation romantically, to limit potential sexual partners and that unmarried amputees report a greater impact of the amputation on concerns about sexual functioning. The authors suggested this may be because it is more difficult to start a sexual relationship as an amputee than to experience an amputation within the context of an existing relationship. There also exists evidence from a postal questionnaire developed for the purposes of understanding men's satisfaction with a and rationale for accepting or refusing a testicular implant after undergoing an orchiectomy for testicular cancer that those in steady relationship were less likely to want to have a prosthesis than those who were not in such a relationship (Adshead, Khoubehi, Wood, & Rustin, 2001). This may have indicated that those who were not in established relationships felt a greater need to reduce the noticeability of their difference.

Interestingly, the existence of an intimate relationship has also been demonstrated to function as a protective factor amongst burns victims. Participants in relationships prior to their burn were less likely to suffer negative outcomes as measured by the affect and the relationship domains of the burns specific health scale used by Connell et al. (2014). These findings thus signal that not only may those who are not in established relationships experience more concern about their sexual relationships, and that that they may not benefit from the insulation that a relationship may offer against the emotive impact of suffering an appearance altering event.

2.2.2.2. Sex.

Sex is another factor that the literature highlights as of potential relevance. The research is, however, somewhat inconsistent and conflicting. The review of Geertzen et al. (2009) identified amputation as being associated with more sexual problems in men than in women. These findings resonate with the study of vitiligo's effect on sexual relationships conducted by Porter et al. (1990), who note that women experience more adjustment issues overall, but that men experience more problematic adjustment within the sexual domain. They assign their sexual domain specific finding to the greater likelihood of men initiating sexual contacts and their hesitancy to use cosmetics to hide or camouflage the condition. Low et al. (2009) also identified intimacy as being more problematic for men than women when surveying by post those who had received treatment for head and neck cancer. Their explanation was twofold: women have greater access to social support; and that sex remains more salient to men over the lifespan.

Whilst the research presented so far suggests that visible differences may impact more severely on men's intimate experiences than women's, other studies support the opposite contention. In analysing the factor structure of DAS24, Moss et al. (2015) found that women scored more highly, and thus experienced more distress, on both factors. The effect size was small in respect of the general self-consciousness factor but medium-large in respect of sexual and body self-consciousness factor. Whilst this points towards women experiencing greater levels of sexual appearance distress, it must be noted that the six items constituting the second factor contain only two items relevant to sexual and romantic activities (pertaining to undressing with a partner and an adverse effect on sex life).

The review of Connell, Coates, Doherty-Poirier, and Wood (2013) as well as the research of Connell et al. (2014) also suggest women may be more affected than men. Interestingly, Connell et al. (2014) found an interaction between sex and the location of the burn site. Amongst men the burn site was not correlated to a negative impact upon sexual function and satisfaction. Burns in normally visible areas of the upper limb, lower limb and face were correlated with a greater impact in this sexuality domain amongst female participants.

2.2.2.3. Location and severity of visible difference.

The research related to the sex of an individual makes it difficult to draw any firm, or even preliminary, conclusions regarding the relative impact of visible difference on intimacy and romantic relationships amongst women and men. The interaction with burn site location found by Connell et al. (2014) does, however, hint at the potential relevance of the location on the body of a difference.

There exists some additional evidence that corroborates this finding. Ramsay and O'Reagan (1988) have shown a relationship between the severity of psoriasis and inhibition of sexual relationships in psoriasis patients who responded to a questionnaire but also that those with plaques in the genital area were twice as likely as those without such plaques to report such inhibition. Gonçalves et al. (2014) reviewed twenty-two papers examining sexuality in burns victims. Amongst their findings were the conclusions that greater sexual dysfunction was related to a total burn surface area of over 20% of the body's total surface area and to burns on the genital region and/or exposed areas such as the face and hands. These studies lend weight to the argument of Clarke (1999), made in relation to severity, that the extent to which visible differences interrupt communication processes is critical. They also expand upon this visibility hypothesis by reference to the potential impact upon the sexual domain of the genital area being affected.

The indication that the location of a difference may predict adjustment perhaps sits a little uncomfortably with the established understanding within the field of visible difference that subjective rather than objective factors function as the most reliable predictors. It is therefore interesting to note that other work has found an effect of the severity of a condition. Greater levels of sexual impairment have been associated with more clinically severe cases of psoriasis (Sampogna et al., 2007). Physicians' severity ratings for patients with a variety of dermatological conditions have been found to correlate negatively with the sexual life sub-domain in validation work for a quality of life for Turkish people with skin diseases (Gurel, Yanik, Simsek, Kati, & Karaman, 2005) and, when using such rating to categorise participants into ‘severe’ and ‘minor’ groups, also to be associated with a negative impact on self-esteem, a worsened relationship with a partner, reduced sexuality, and greater social isolation in those adjudged to have a severe difference.

As a consequence of these research findings, in the quantitative work presented within this thesis I provide a preliminary exploration into these issues by examining for group differences according to relationship status, sex, location and type of visible difference, and participants’ subjective ratings of visibility and the extent of their difference.

2.2.3. The Nature of the Romantic and Intimate Challenges Experienced

Whilst the focus so far has been on quantitative research, this reveals little about the nature of the challenges and difficulties experienced in the romantic domain by those with visible difference. Existing qualitative work, drawn primarily from condition specific studies, provides some indication of how this intersection is experienced although, again, there is little research focusing specifically upon visible difference, intimacy, and romantic life.

The powerful, individual, experiential accounts of Tindle, Denver, and Lilley (2009) offer rich and personal insight into the experiences of the three authors, each of whom had a form of cancer. Divided into three sections each written by one of the co-authors, the impact of visible difference upon the intimate lives of the first and third author is clearly documented whilst the second author was not left with any visible difference as a result of her disease. The first author considers that not feeling attractive was one of the most damaging aspects of her treatment and reiterates that the threat to her health should not have rendered her appearance or sexuality irrelevant. She describes almost feeling obligated to tell people she meets about her condition and that the illness ‘baggage’ combined with her altered appearance pervades social interactions well into her survivorship. As the author recovers her health and moves forward with her life, she describes herself as becoming more concerned with her alopecia and its impact upon her ability to form a new romantic relationship which she perceives as a very important element of her life.

The third author directly raises post-surgical scarring as a major concern that led her to believe no man would ever find her attractive again. Indeed, the prospect of scarring was her most salient concern at the time of her post-operative cancer diagnosis, upon unexpectedly learning that a tumour rather than a blood clot had been removed (Tindle et al., 2009). These individual accounts introduce some of the ideas that are commonly referred to in the existing literature. The challenges that are detailed most consistently comprise concern about one's level of attractiveness to others, fear and avoidance, concealment, and stigma.

2.2.3.1. Attractiveness as a partner.

Whilst adopting a predominantly heterosexist position and focussing upon monogamous relationships, the literature provides a clear indication that, like two of the three authors of Tindle et al. (2009), participants with appearance altering conditions have reported feeling that their appearance makes them unattractive to others and reduces the perceived likelihood of establishing a relationship. Whilst the work was concerned with an adolescent population, using an on-line survey developed for the study Griffiths et al. (2012) found almost half of their 40 participants harboured concerns relating to their future romantic life and understood visible differences as causing them to feel unattractive, leading to teasing and bullying, and to difficulties in talking to the other sex.

Several qualitative studies, drawing upon semi-structured interviews and the analysis of naturally occurring on-line data and focussed upon the experiences of those with congenital or acquired limb absences illustrate this point (Batty, McGrath, & Reavey, 2014; Mathias & Harcourt, 2014; Murray, 2005). These concerns have been reported as being especially pertinent amongst single participants and those in short term relationships (Batty et al., 2014; Murray, 2005), with concerns being expressed about their ability to find a partner that would be accepting of their altered body. Indeed, participants in the work of Mathias and Harcourt (2014) described how their internal fears and self-doubts resurfaced within the context of initiating new relationships, despite feeling generally well adjusted to their condition and their appearance.

The potential importance of the immediate cultural context is considered by Thompson, Clarke, Newell, Gawkrodger, and ARC (2010). In their qualitative study of the impact of vitiligo upon British South Asian women it is evident that the condition was experienced as breaching cultural beauty ideals and led to family members expressing concern about participants' prospects for marriage. The authors described the cultural context as meaning that vitiligo was constructed as an impediment to social acceptance and marriage. Dermatological conditions have also been experienced as challenging outside of this specific cultural group. The case study of one individual with psoriasis offered by Chrissopoulos and Cleaver (1996) explicitly identified the impairment of heterosexual relationships as a major challenge. The participant felt unattractive, uncomfortable and that this inhibited contact with the other sex as she withdrew from this sphere to avoid the rejection she feared. Whilst this powerful account thus offers an illustration of how difficulties in intimate relationships may be experienced it is not clear how or why this one particular individual account was selected by the authors from a series of six interviews to form the basis of their publication.

The online qualitative survey of 95 UK participants (or which 84 were women) with alopecia areata conducted by Davey, Clarke, and Jenkinson (2019) highlighted how some participants were not able to be bald at home as they feared their partner would find their appearance disturbing or unattractive, expressed doubt that anyone would want to be with them, and suggested that it is not possible for them to feel 'sexy.' An association between the cultural significance of hair and its connection to femininity was drawn with such strength that some participants felt intense shame and believed they would never have an intimate relationship because of their alopecia.

Amongst qualitative work centred on conditions which often carry severe connotations regarding ill health, such as a thematic analysis of interviews with those who had treatment for head and neck cancer (O'Brien et al., 2012), an interpretative phenomenological analysis of interviews with heterosexual women with breast cancer and their partners (Loaring, Larkin, Shaw, & Flowers, 2015) and grounded theory research also examining the experiences of women who had had breast cancer (Laura-Kate Shaw, Sherman, Fitness, & Breast Cancer Network Australia, 2016), a thematic analysis of accounts provided in interview by adolescent and young adult men who had survived testicular cancer (Carpentier, Fortenberry, Ott, Brames, & Einhorn, 2011), and a thematic analysis following interviews with women with lower limb lymphedema (Winch et al., 2016), the resulting visible difference has been described as one of several factors that can make relationships difficult for those impacted.

It is clear that this carries the potential to make the formation of new relationships challenging. O'Brien et al. (2012) described how changes to participants' role, their physical functionality, and their appearance combined to affect their personal identity, reduce their confidence and self-esteem and their desire to socialise and so limited their opportunities to meet people of the opposite sex. Equally, however, qualitative data from an on-line survey of 128 women who had undergone mastectomy and/or breast reconstruction following a breast cancer diagnosis, illustrates that these fear can pervade well established relationships. Whilst single participants feared a negative reaction from potential partners, other participants were fearful of their partners' and husbands' responses, feeling unattractive and being uncertain whether they remained desirable to their partner (Herring, Paraskeva, Tollow, & Harcourt, 2019). The participants of Loaring et al. (2015) described similar concern, despite explicit reassurances to the contrary being received from their partners.

The young men who Carpentier et al. (2011) spoke with explained that the feeling of difference inspired by testicular cancer had recast them as ‘damaged goods’, with the physical consequences of their disease making them feel incomplete and emasculated. It was not only those who were single that felt like this, with those who had a partner at the time of diagnosis and treatment reporting a delay in the resumption of sexual relations and experiencing feelings of uncertainty once they were resumed. Ballard et al. (2019) identified similar concern through conducting interviews, analysed via thematic analysis, with those with Silver-Russell Syndrome, a condition associated with short stature. Men and women felt they lacked romantic appeal, did not conform to appearance ideals, and were liable to be treated only as friends by potential partners. The authors report, however, that this was particularly pronounced amongst the male participants, who felt that that their lack of height and muscle mass had made them feel less masculine and ‘sub-standard.’

2.2.3.2. Concealment.

Kent (2000) argues that, amongst those with disfigurements, concealment is one of the most common strategies adopted to deal with appearance concerns and to avoid stigmatisation. Concealment may be considered to be emotionally trying as, like with chronic illness (Joachim & Acorn, 2000) deliberate concealment puts the individual in the position of being ‘discreditable’ (Goffman, 1974). An accidental or inadvertent disclosure may discredit them and their assumed persona. Having acted to conceal a difference, young women participants with transversal upper limb reduction deficiency identified concerns over the difficulty of revealing their condition to someone who they were dating, as demonstrated in the grounded theory study of strategies for coping with stigma conducted by Krantz, Bolin, and Persson (2008) and as those with below the knee amputations resorted back to using concealment as a strategy at times of high anxiety (Mathias & Harcourt, 2014).

Participants in an on-line survey of those with alopecia areata described engaging in concealment from others and expressing concern about the revelation of their alopecia, both generally and to new partners (Davey et al., 2019). The findings of Griffiths et al. (2012) neatly capture the impact of this predicament. Their adolescent participants who all identified as having a visible difference, viewed concealment as helpful in the short term, such as when attracting a partner. The participants feared rejection if they revealed their difference immediately or early in the relationship. In the longer term, however, concealment was understood as increasing anxiety precisely because they felt compelled to reveal their condition once the relationship had developed and become more intimate. They feared such revelation may end their relationships, felt guilty or deceitful for concealing the difference, and were wary of their partner appraising them as such. Comparable findings are also evident from the study of 12 women with microtia (Hamlet & Harcourt, 2020). The participants habitually concealed their condition but experienced considerable anxieties and uncertainties when establishing a new relationship and contemplated the revelation of their microtia to new partner, not knowing when and how to do so, and also at the potential for more organic discovery by their partner.

For this reason, concealment may be considered as carrying the potential to be especially problematic with regards to intimate relationships as it is unlikely to be sustainable in the long term. Kelly (1992) argued from interviews with individuals who had surgery for ulcerative colitis, that revealing difference within or in anticipation of intimate relationships serves to potentially transform a condition from being part of the individual's private self to forming part of their public identity. Any resulting rejection is conceptualised as the semi-public denial of their right to be treated as a normal person and so the changed body can contribute towards a psychological barrier to sexual relationships, increased anxiety and, for some, virtual paralysis in intimate relationships.

It is also interesting to see an indication within the literature that healthcare professionals can be acutely aware of this difficulty and that it has relevance within clinical consultations. Guest, Griffiths, and Harcourt (2018) interviewed eight psychosocial specialists working within a burns care service. Thee practitioner participants reported romantic relationships as being a concern for young people and adults, explaining how some individuals wished to conceal their scars from existing or potential partners.

2.2.3.3. Fear and avoidance.

One theoretical explanation for those with visible differences feeling compelled to conceal their difference where possible is that they may fear the negative reactions of others, the associated stigma, and the confirmation of their lack of attractiveness that revealing a difference to a potential romantic partner may entail. Indeed, Thompson, Kent, and Smith (2002) refer to sexual intimacy as one example of a behaviour that those with vitiligo avoid in order to protect themselves from the reactions of others. Likewise, Fox et al. (2007) describe how young people with psoriasis manifest their reduced self-confidence by avoiding social activities and intimate relationships.

The thematic analysis of Magin, Heading, Adams, and Pond (2010) focussing on the impact of acne, psoriasis, and atopic eczema as well as work with adolescents with visible difference by Griffiths et al. (2012), together with the research of Connell et al. (2015) with those who have suffered burns all indicate that a fear of rejection can underpin intimacy concerns. These can include a fear of revealing a concealed difference and in some instances can also result in avoidant behaviours. This is discussed explicitly by Loaring et al. (2015) within the context of women who have had breast cancer and who feared rejection from their partners and so felt compelled to cover the affected parts of their body. This occurred despite the reassurances of their partners. Similarly, the interpretative phenomenological analysis of Ward Khan, O'Keeffe, Nolan, Stow, & Davenport (2019) describes reduced sexual desire and activity, impacted self-esteem and a tendency towards the avoidance of physical intimacy as a result of appearance anxieties amongst their participants; women with lower limb amputations.

The identification of fear and its associated avoidant behaviours is consistent with the fear avoidance model (Newell & Clarke, 2000; Newell, 1999) as anticipated, feared negative reactions are avoided through minimising exposure to risk. This work cannot establish whether such fear arises as a consequence of the presence or acquisition of a difference, from other life events, or occurs randomly or naturally, and this is not the focus of this thesis. Despite this limitation, it appears clear that the intimate sphere can provide an opportunity for the expression of the fear of rejection and that this carries the potential to impact the romantic life and experiences of some of those with visible difference.

2.2.3.4. Positive Adjustment

Despite the research presented above, there has been some recognition in the literature that positive consequences may also be associated with visible difference and that these can extend into the romantic domain. Whilst our understanding may remain limited and the possibility continues to be under researched (Clarke, 1999), aspects of positive adjustment to visible difference were also evident in this literature review. For example, Kelly (1992) proposes that physical scars resulting from radical surgery may be incorporated within an individual's self-concept and symbolise survival of the threat posed by the ill health. Moving towards intimate relationships and participants with a variety of visible differences, the thematic analysis of Egan et al. (2011) identified relationships with others as a sphere that carried the potential to facilitate positive adjustment via the provision of support or encouraging self-reliance. Participants recognised the role of a partner, family, and friends in providing consideration, support, and acceptance, suggesting that supportive relationships may encourage or permit positive adjustment and acceptance.

Whilst supportive relationships may encourage positive adjustment to visible difference, visible differences may, themselves, also contribute to the development of supportive relationships. Participants have spoken of using their status as amputees and potential partners' reactions to this fact as a tool to help distinguish those with whom a relationship may be worth pursuing (Mathias & Harcourt, 2014). In an interpretative phenomenological study of how those with visible difference manage intrusive reactions, the scarring of one of the four participants not only provided a way of assessing the viability of potential relationships and eliminating those that may be too shallow to accept him, but also provided a certain kudus within a particular community to which he belonged (Thompson & Broom, 2009). Within the biking community he believed scarring could be interpreted as representing a level of masculinity. This may serve to enhance the participant's standing within a masculine hegemony, potentially impacting positively upon intimate relationships.

2.3. Summary

Whilst the literature is rather disparate, and it has been necessary to consider findings from quantitative and qualitative studies focussing on a variety of issues with participants drawn from a wide range of specific conditions or group of conditions, this review has highlighted the clear potential for visible difference to impact upon romantic relationships. The focus has primarily been on negative impacts; however, the possibility of more positive effects has been raised, and the contention that intimate relationships may offer some protection from challenges associated with visible difference, introduced.

The piecemeal nature of the literature and the lack of a dedicated, defining, comprehensive study focussing on experiences of visible difference and romantic relationships in adults highlights that further research is required in order to explore these areas more thoroughly. More specifically the perceived impact, challenges and positive experiences experienced in connection with the intimate, romantic life of those who have a visible difference should be explored in more detail and with more focus. Such research should focus on the challenges that arise, how these are experienced and managed, how they impact upon the individual and their relationships and would suit qualitative enquiry.

It was also striking from the literature that was reviewed, that there was no reported research measurement tool that specifically examines the impact of appearance concerns and visible difference upon romantic relationships and intimacy. This is despite the description of the second factor within DAS24 (Carr et al., 2005) being labelled 'sexual and bodily self-conscious,' though it includes only two items pertaining to intimacy and sexual activity. Whilst measures such as scales designed to assess women's (Wiederman, 2000) and men's (McDonagh et al., 2009) body image self-consciousness during physical intimacy, or physical disability, sexual and body esteem (Taleporos & McCabe, 2002a) were identified, there was none specifically focussed upon the impact of visible difference on individuals' ability to engage in and enjoy romantic relationships.

Similarly, much of the work that has been introduced was experiential in nature or has looked for associations between individual variables or small groups of variables, often measured or assessed using measures that were generated or adapted specifically for the study in question. The disparate nature of this literature reviewed meant that it gave no sense of a dominant theoretical thread or orientation. As such, it is difficult to argue clearly ascertain underlying constructs which contribute to the difficulties and challenges experienced by some participants within the sphere of intimacy. The exploration of this area and the development of a measurement tool examining adjustment to visible difference and appearance concern within the context of intimate situations amongst those with a visible difference is thus a legitimate research goal, one that may follow from and build upon a dedicated qualitative enquiry.

3. Mixed Methods in this Thesis

3.1. Introduction to this Section

As a result of the review of the existing literature, I decided to focus the initial phase of this thesis on an in-depth exploration of experiences of visible difference and intimate, romantic relationships. A strong priority was also to produce research outputs that would have research and potentially clinical utility, hence a provisional plan (subsequently confirmed by the findings of the first phase of research) was formed to use the initial qualitative exploration to inform the development of a mechanism to assess and measure any associated impacts. Validating this mechanism would involve quantitative research.

The research programme thus involved asking different research questions at different stages of the work. It was clear that these aims would be addressed by very different methods and produce very different forms of data, with the exploratory element being suited to inductive, qualitative forms of enquiry and those concerned with quantifying and measuring suited to hypothetic-deductive, quantitative research (Dures, Rumsey, Morris, & Gleeson, 2011). Crucially, it was anticipated that the research programme would use the initial qualitative findings to inform the subsequent quantitative stages and to generate draft scale items largely derived from those qualitative findings. The overall design of the research programme was therefore framed as ‘mixed methods,’ in that qualitative and quantitative approaches were both to be utilised within an overall project (Johnson, Onwuegbuzie, & Turner, 2007).

Whilst such an approach may be useful and common (Doyle, Brady, & Byrne, 2016; Johnson et al., 2007) and allows the research to draw on the strengths of both approaches (Johnson & Onwuegbuzie, 2004), it is not entirely free of controversy. Indeed, as Willig (2013) reports the research methods to be employed should be chosen in light of the research question and the epistemological position of the researcher. Social sciences have traditionally adopted a realist, positivist epistemology when conducting quantitative work and an interpretative, constructivist epistemology when performing qualitative research. These epistemologies have long been considered incommensurate (Morgan, 2007) or incompatible. This ‘incompatibility thesis’ (Johnson & Onwuegbuzie, 2004), means it is important to establish a consistent and coherent philosophy when conducting mixed methods research. The remainder of this chapter will consider this issue before justifying the adoption of the pragmatism advocated by Morgan (2007, 2014) and discussing the use of mixed methods within this thesis.

3.2. Paradigms and Epistemologies

The incompatibility thesis stems from the very different ontologies and epistemologies traditionally associated with qualitative and quantitative work (Bishop, 2015), the idea that they are mutually exclusive, and the belief that one is superior, held by ‘purists’ connected to each paradigm (Johnson & Onwuegbuzie, 2004). Quantitative methods have long been associated with a realist or positivist ontology which is predicated on the belief that there exists a stable, ‘real’ world independent of human thought and perception and that the purpose of research is to acquire objective, error-free knowledge (Yardley & Bishop, 2015). Such knowledge may lead to uncovering causal relationships and universal truths that are capable of general application beyond the immediate time and context within which they were discovered (Johnson & Onwuegbuzie, 2004).

Qualitative methods, however, have been accompanied by an interpretative or relativist (phenomenological, constructivist, or constructionist) ontology (Yardley & Bishop, 2015) that views reality as being socially constructed (Dures et al., 2011). This presupposes that the world can only be known through our individual conceptual frameworks and therefore all knowledge is subjective, and contextually and culturally embedded (Bishop, 2015). It is not possible to separate the knower and the known (Johnson & Onwuegbuzie, 2004).

As relayed by Doyle et al. (2016) these two broad ontologies and epistemologies were not just considered incompatible but were contested in the ‘paradigm wars’ that posited them as being diametrically opposed. They add that this precluded the mixing of methods, as to do so would require the researcher subscribe to two opposing, mutually exclusive philosophies underpinned by completely different ontological, epistemological and methodological assumptions.

The resultant barrier to mixed methods research may be understood as being limiting for researchers. Each approach may provide different insights and respond to different questions. Any single approach may therefore be considered to be partial and our understanding may be improved by combining and drawing on the strengths of each (Dures et al., 2011). This view necessarily considers that neither approach is superior to the other but recognises them as serving different purposes.

Despite these difficulties, mixed methods has become recognised as the third major approach, standing alongside qualitative and quantitative research (Johnson et al., 2007). The most commonly adopted philosophy or paradigm within mixed methods research is that of pragmatism (Bishop, 2015; Doyle et al., 2016; Dures et al., 2011; Feilzer, 2010) which has contributed to a relative subdual of the ‘paradigm wars’ in recent years (Bryman, 2006b). It is to the pragmatism advocated by Morgan (2007, 2014) and its ability to counter the incompatibility thesis that this discussion will now turn.

3.3. Pragmatism

Pragmatism avoids ontological and epistemological dualisms, refocuses researchers’ attention on what works at the time, for the required purpose, and has great utility (Biesta, 2010; Dures et al., 2011). It acts to free researchers to select the methods, techniques, and procedures that most closely complement the needs and purposes of the research (Creswell & Creswell, 2017). This approach permits the marrying of quantitative and qualitative methods in order to provide the best understanding available (Dures et al., 2011), supports the utilisation of the realist and interpretative paradigms and offers a philosophy within which mixed methods can subsist (Johnson et al., 2007). The reduction of pragmatism to ‘what works’ is, however, a trivialisation (Hall, 2013) and an oversimplification (Morgan, 2014). It is therefore important to introduce the underlying philosophy of pragmatism.

3.3.1. The Philosophy of Pragmatism

Morgan (2007, 2013, 2014) draws upon the pragmatism of John Dewey in explaining the philosophical orientation of pragmatism. This envisages that the mind and the world are constantly transacting with one another. Morgan (2007) explains that Dewey’s focus is on ‘*the experience of actions in the world, rather than the existence of either a world outside those experiences or experiences outside such a world*.’ Pragmatism argues that all knowledge is based on experience but does not emphasise the concept of ‘truth’ (Morgan, 2013). The emphasis is therefore different to the debates with which the metaphysical paradigm (including realist and interpretative approaches) is primarily concerned: the nature of reality, the ability to access and the existence of ‘objective truth.’

Pragmatism requires that one no longer affords primacy to such questions and instead concentrates upon the nature of human experience. The consequence is not the integration of the realist and interpretative paradigms within the metaphysical approach but the adoption of an alternative approach, constituted along different lines, within which dualisms and the incompatibility thesis are avoided (Feilzer, 2010; Morgan, 2007), and experience is central.

The primacy of experience is explained by Morgan (2014) who highlights that experiences are understood to involve a cyclical interpretative process. Beliefs are interpreted to generate emotive and embodied actions and such actions interpreted to generate beliefs. This leads to habit, where existing beliefs satisfactorily encompass the present context, and enquiry, involving conscious, thoughtful, directive, decision making and reflection. These experiential transactions are conducted within a constantly changing environment and the process of enquiry is necessary in order to manage the resultant uncertainty such surroundings engender (Hall, 2013). This means knowledge is temporal, context dependent, must be continuously reassessed, revised, and its transferability to other situations asserted via further action before 'warranted assertions' may be made (Hall, 2013; Johnson & Onwuegbuzie, 2004).

This 'fallibilism' acts to acknowledge that knowledge is imperfect, incomplete, uncertain, and conditional and that scientific enquiry is one, structured, facet of natural human enquiry (Johnson & Onwuegbuzie, 2004). It also introduces the goal of pragmatism as being to employ the most appropriate research methods to explore the research question at hand (Feilzer, 2010). As each method may offer a different version of knowledge and may add to understandings provided by other means.

3.3.2. Reconfiguring Epistemological Dualisms

The mention in the previous section of the potential transferability of knowledge by Hall (2013) alludes to the work of Morgan (2007) who argues that pragmatism offers alternative positions to some of the key dualism inherent in the traditional realist (quantitative) and interpretative (qualitative) paradigm. Instead of prioritising induction (qualitative) or (deduction) (quantitative), pragmatism acknowledges that existing knowledge, theory and data influence one another in a multidirectional manner. No research is completely value free or exclusively data or theory driven and so the movement between induction and deduction may be called abduction (Morgan, 2007).

The subjective (qualitative) and objective (quantitative) dualism is also considered artificial. Morgan (2007) argues that no research is entirely objective, no research is entirely subjective, and that much knowledge is co-created through joint action. Therefore, 'intersubjectivity' is preferred. Morgan (2007) also considers this to reflect the belief that the object of investigation is a real world, but one that is and can only be accessed via an individual's unique interpretation. Finally, Morgan (2007) argues that no research can be so unique so as to have no applicability beyond its immediate context or setting nor can be capable of generalisation to all historical, cultural, and social settings. Considering the transferability of research and knowledge from the immediate context to other settings and scenarios bridges the context-generality dualism.

The approach to these issues advocated by pragmatism is consistent with the goals and methods employed within this thesis, so far as is achievable to understand the experiences of others through qualitative work and utilise this understanding in developing a quantitative measure. Furthermore, the goal of pragmatic research is to facilitate positive change in the world (Bishop, 2015). This was also coherent with these goals as it was hoped some change would flow from the increased understanding facilitated by the qualitative study and the scale produced by the quantitative work. Pragmatism was therefore adopted as the paradigm within which this research was conducted. The fundamental approach of using qualitative work to inform the development of a new research measure is, in nature, consistent with pragmatism.

3.3.3. Pragmatism and this Thesis

The exploratory, qualitative work was analysed using a data-driven form of thematic analysis that is commonly referred to as being inductive (Braun & Clarke, 2006) and was, naturally, impacted upon or generated through my own subjectivity. The draft interview schedule, the analysis performed, and my own subjectivity were each undoubtedly influenced by my prior knowledge of existing literature. It is therefore impossible to argue that this did not represent an abductive process.

Furthermore, the qualitative work was produced in collaboration with my supervisors and the research participants. It involved the joint and subjective creation and interpretation of data, but the analysis remained rooted in and grounded upon the data. It involved examining participants' subjective thoughts and feelings relating to incidents that they had experienced. Again, the intersubjectivity of pragmatism describes this more accurately than describing the work as 'subjective' or 'objective.'

Finally, whilst few researchers would claim that their qualitative work is capable of being generalised, some may argue the accounts are so individual as to be entirely context dependent. This, however, would be somewhat inconsistent with using the testimony of individuals to help construct and inform a quantitative measure. Furthermore, the concept of data saturation would be difficult to establish and perhaps have little meaning if the findings were not capable of any application beyond the immediate data. Similarly, the search for common meaning that thematic analysis entails (Braun & Clarke, 2006) may be rather purposeless if all accounts are entirely individual and completely context dependent, as no two individuals occupy the same world or share the same experiences. Whilst the transferability of findings must not be overstated, discussion about the extent of their transferability are more rational and consistent than a claim that they have no application beyond the immediate data. This concept forms part of the 'resonance' criteria of Tracy (2010) in assessing the quality of qualitative work. Whilst this is hard to assess, Tracy (2010) asks whether a reader feels the research overlaps with their on situation and action, the feedback I have received from those with whom I have shared this work, both professionals in the field and those with visible difference, has indicated that some measure of transferability and resonance were achieved.

The quantitative work aligned closely with pragmatism. At the EFA stage the items were generated through a subjective process that involved interpreting the qualitative findings and related literature. They were then assessed and selected using relatively objective (statistical) criteria, albeit criteria that I selected, and a degree of subjective interpretation. Despite having a hypothesised factor structure, the final structure was inductively produced as EFA is an exploratory method. The CFA represented the further use of statistical assessment methods which, although more deductive in nature, remained open to revision where adjudged necessary. The development and assessment of the items and the scale thus involved abduction and intersubjectivity. Whilst it is hoped that the resultant scale has relatively broad utility, it is fully acknowledged that further research may suggest scenarios and contexts within which it is more or less useful than others. It is thus not entirely context specific, nor likely to be fully generalizable. The concept of transferability describes its potential use more realistically.

As pragmatism is functional and focussed upon the consequence of action (Dures et al., 2011) and permits methods to follow and flow from research questions (Johnson & Onwuegbuzie, 2004) rather than be dictated by a specific metaphysical epistemological position (Creswell & Creswell, 2017), the adoption of pragmatism underpinned the use of mixed methods within this thesis.

3.4. Mixed Methods Research in this Thesis

Having introduced the appropriateness of employing mixed methods for the research contained within this thesis and considered the underlying philosophy of pragmatism, this section will now discuss mixed methods and consider their place in this thesis.

Leech and Onwuegbuzie (2009) highlight that most published mixed methods research employs a variety of methods in order to answer questions that neither the quantitative or qualitative paradigms can answer alone. It is important, however, to understand what is meant by mixed methods research and having examined many of the leading definitions, Johnson et al. (2007) offer this:

> *the type of research in which a researcher… combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purpose of breadth and depth of understanding and corroboration (p.123)*

They also distinguish between an individual mixed methods study and a programme of research where methods may be mixed across a related set of studies. This thesis used both qualitative and quantitative data collection methods, data, and techniques of analysis and therefore represents a mixed methods programme. Whilst the qualitative stage informed the quantitative stage, the stages were conducted independently from one another.

The reference to the qualitative stage informing the quantitative stage also hints at the sequential nature of this project. The classification of the project as involving sequential rather than concurrent mixed methods forms part of the categorisation system of Leech and Onwuegbuzie (2009). They also refer to the fully-partially mixed distinction. The current project would be considered fully mixed as the qualitative analysis was instrumental in determining the substance of the quantitative items and so the mixing occurred prior to the interpretation stage, the defining feature of 'fully mixed methods' research.

In considering the emphasis of the research, I consider that each stage has equal importance and so this would be expressed as QUAL→QUANT (Johnson & Onwuegbuzie, 2004). The qualitative and the quantitative stages addressed different goals of the thesis, both equally important, and the quantitative work was predicated upon the qualitative analysis. I did not consider the development of the scale to be any more, nor any less, important than the exploration of the intersection of visible difference and romantic relationships.

In addition, I am more personally inclined towards qualitative enquiry and always believe that the novelty of the qualitative work means that it was of at least equal worth to the quantitative stage. It is therefore difficult, in this case, to subscribe to the status quo reported by Doyle et al. (2016) that where an exploratory, sequential design is used to develop an instrument the quantitative phase usually takes priority. The mixed methods employed were thus exploratory (Doyle et al., 2016) and represent a fully mixed, sequential, equal status design (Leech & Onwuegbuzie, 2009).

As Doyle et al. (2016) intimate, the literature reports that mixed methods are often deployed in developing an instrument (Bishop, 2015; Dures et al., 2011; Johnson et al., 2007) and explicitly falls within the 'development' purpose of the framework proposed by Greene, Caracelli, and Graham (1989). This was also one of the 16 explicit reasons for combining methods identified in the review of (Bryman, 2006a). Dures et al. (2011) argued that a sequential exploratory research programme, with qualitative work preceding quantitative research, is well suited to the investigation of new phenomena.

Whilst the phenomena under consideration here may not be new, the limited dedicated research that existed in the area makes this design particularly appropriate. In the absence of a strong body of existing research the qualitative findings drawn from participants who have visible difference provided a stronger and more appropriate foundation for the quantitative items than could be obtained from other sources. The use of mixed methods in this way and for these purposes is neither uncommon nor unprecedented and is advocated in the creation of health measurement scales by Streiner, Norman, and Cairney (2015).

3.4.1. The Dimensions of Mixed Methods Research in This Thesis

Bryman (2006a) identified five dimensions out of which typologies of mixed methods research are constructed and related these to five main questions. Answering these can provide additional clarity on the use of mixed methods in this thesis. Bryman's five questions, together with these answers are:

> *Are the quantitative and qualitative data collected simultaneously or sequentially?* This has been addressed above. Sequential data collection was the primary mechanism. There was, however, at the EFA stage, the opportunity for participants to comment and feedback upon the draft items and so, to lesser extent, the EFA also involved the simultaneous collection of qualitative responses.
>
> *Which has priority – the quantitative or the qualitative data?* Again, this has been addressed already. The qualitative research carried priority in addressing the exploratory part of the research project, the quantitative work had priority in refining the scale. Overall, I consider that neither was more important than the other.
>
> *What is the function of the integration?* The function of the integration was to allow the exploratory qualitative findings to inform the content and development of the quantitative measure. This may be classified as 'development' (Greene et al., 1989) or 'instrument development' (Bryman, 2006a).
>
> *At what stage in the research process does the multi-strategy research occur?* The findings of the qualitative work informed the content of the quantitative items and therefore impacted all subsequent data collection, analysis, and interpretation.

Is there more than one data strand? The current research was multi-strand in that there were multiple research methods, multiple sources of data.

3.5. Summary

Having introduced and discussed both pragmatism and mixed methods research and considered the place of each in this thesis, the next section will move forward to dealing with the first research study, the exploratory, qualitative investigation. Before doing so, however, one final comment on mixed methods work will be offered. Feilzer (2010) argued that mixed methods work can require a researcher fulfil multiple roles and analyse different types of data in different ways. In light of the variety of approaches that are used within appearance and health psychology and the function of a PhD to act as a training and learning opportunity, the appropriateness of and personal benefits to me of having an opportunity to work with and in different methods should also be acknowledged.

4. A Qualitative Exploration of Visible Difference and Intimate, Romantic Relationships: Methodology

4.1. Introduction

The first stage of original research reported in this thesis is a qualitative exploration into the ways in which adults with a visible difference understood and had experienced their difference within the context of their intimate, romantic relationships. The literature review had identified this gap in existing research and a qualitative study was therefore undertaken to examine the following research question: how do adult participants with a visible difference understand, and how have they experienced, their appearance as impacting upon their intimate, romantic relationships?

4.2. Participants

4.2.1. Inclusion and Exclusion Criteria

To explore the experiences of visible difference and intimate relationships, participants were asked to confirm that they have or have had a visible difference, which was described as an altered appearance or disfiguring condition. As is consistent with the literature in this field and as introduced in Chapter 2, the focus was upon individual and subjective experience of visible difference. Consequently, no medical confirmation was sought and the participant's interpretation of their condition was afforded priority.

Participants were also asked to confirm that they were at least 18 years of age. Due to the available resources it was necessary for participants to communicate verbally in the English language. It was also important to ensure the safety and emotional well-being of the participants and the researcher. Any persons with a diagnosed mental health condition that was untreated or untreatable and which impacted upon their ability to engage in everyday activities were also excluded. Participant self-report was the only reasonable and feasible way to confirm eligibility. This confirmation was sought through the inclusion of relevant information in the Participant Information Sheet (Appendix A1), dedicated items within the consent form (Appendix A2), the researcher's interactions with potential participants (which confirmed the ability to communicate in the English language), and through the researcher verbally detailing the eligibility criteria to each participants and seeking verbal verification that they were at least 18 years of age and did not have a diagnosed mental health condition that was untreated or untreatable and which impacted upon their ability to engage in everyday activities. Each participant’s self-reported eligibility was thus ascertained prior to conducting their interview.

4.2.2. Methods of Recruitment

In order to capture a broad range of experiences participants with a diverse array of visible differences were recruited. In order to achieve this goal and in recognition that recruitment of those with a visible difference may be challenging, the primary method of recruitment was via support groups and charities. Twenty-six individual organisations were approached, some with a generic focus on visible difference and providing information, support, and advocacy to and for those with visible difference and some that are concerned with a specific condition.

Of these 26 organisations, three refused to advertise the study to their members, their reasons being that publicising research was outside of their activities. Another six agreed to consider the request, but did not provide a decision and failed to respond to further contact. The remaining seventeen organisations agreed to provide their members with details of the study and this was done through a variety of means, including their websites, social media (primarily Twitter and Facebook), in e-mail updates, and hard copy newsletters. In addition and in an attempt to reach potential participants who did not have contact with these organisations, the research was also featured in a press release issued by the University of the West of England.

The material advertised for both those with a visible difference and their partners or ex-partners to be interviewed. Partners were requested as despite this not being the focus of the thesis, it was thought this would make an enlightening sister study to run alongside the primary study of those with visible difference. Unfortunately, the response from partners was extremely limited with only two participants identified and this aspect of the study was discontinued after discussions with NR.

4.2.3. Process

The advertising material provided my contact details and a link to a website (Qualtrics) where potential participants could access full information about the study, see my contact details, and leave their own if they wished for me to contact them. When potential participants provided their contact details or contacted me by phone or by email, I responded and communicated in kind, providing a brief description of the research and information in the form of the Participant Information Sheet (Appendix A) together with details about the consent process (consent form at Appendix A1). Where participants wished to proceed, appropriate arrangements were made.

4.2.4. Response Rates

A total of 196 people moved beyond the initial page of the Qualtrics site which provided some preliminary information, the eligibility criteria and a prompt asking whether they wished to continue. Some potential participants were filtered out by questions pertaining to the eligibility criteria, and more lost to natural attrition. In total 149 persons progressed to seeing the Participant Information Sheet. Of these 68 indicated they were interested in participating in the study, six were not, the remaining 75 provided no response. Of the 68, 12 indicated they would want to contact me, 47 that they would like me to contact them. Contact details were left by 40 individuals whilst nine provided no response.

I attempted to communicate with all these 40 persons and with the 12 who contacted me directly. This led to communications with 52 individuals who had a visible difference. This communication was discontinued by 22 persons who did not progress to interview; five made arrangements for an interview or provided consent, but subsequently asked to rearrange or failed to attend the interview and did not respond to further communications; the phone number left by one person did not work; one person was not based in the UK/Ireland; and one person contacted me after the decision had been taken to close recruitment. The remaining 22 participants were interviewed. Throughout this recruitment process I made efforts to be attentive and communicative but deliberately avoided exerting undue pressure on any person to participate, so did not send numerous emails or leave numerous messages when any individual became non-responsive.

4.2.5. Characteristics of Participants

Of the 22 participants, 16 were female and six male. Sixteen were partnered or in relationships whilst six were single. Twelve participants had a difference that they considered to be ordinarily visible to others, whilst ten believed their difference to not normally be visible to others. Eight participants had a congenital condition whilst the other fourteen had acquired their difference after birth. Participants were aged 25 to 64 and had an average age of 43 years. All participants expressed heterosexual preferences, one participant also discussed homosexual feelings that they had not acted upon.

The participants’ visible differences can be described in the following broad terms: Alopecia (5 participants); Ankylosing Spondylitis (1); Breast Cancer (2): Cleft Lip and/or Palate (Cleft) (6); Facial Birthmark (1); Facial Palsy (1); Facial Palsy and Breast Cancer (1); Facial Scarring (1); Ichthyosis (1); Psoriasis (3).

4.3. Data Generation

4.3.1. Semi-structured interviews

In order to explore participants' thoughts, feelings, and experiences without constraining their accounts unduly, a qualitative methodology was adopted. This ensured that the participants' voices were given priority whilst studying this under-researched area. Within this qualitative methodology semi-structured individual interviews were employed. Semi-structured interviews allow the researcher to ensure a balance is achieved between providing participants with the opportunity to express themselves and the need to ensure the focus of the research is not obscured (Kelly, 2010). This balance between flexibility and focus is one of the strengths of semi-structured interviews. I had prior experience at conducting qualitative interviews in connection with a sensitive topic and so was confident that this balance could be achieved.

An interview guide (Appendix A3) that had been generated by me with input and comments from the supervisory team (NR, TM, EJ) and a research active clinical psychologist (AC) was used in conducting the interviews. The input of the supervisory team ensured the guide was appropriate for the topic and was unlikely to cause participants concern or distress. The guide envisioned contextualising the account of each participant and establishing rapport, trust, and confidence via a discussion of the nature of their visible difference, their feelings about whether appearance is important, their feelings about their appearance, and whether this and impacted upon their lives. The interview would then progress to consider intimate, romantic relationships. The interviews generally followed this structure and produced rich data throughout. The guide was not followed slavishly, as I attempted to flexibly respond to each participant. The guide originally contained prompts or areas of likely discussion drawn from existing literature for me to refer to if necessary but in practice these were not relied upon. The substantive body of the interviews varied in length from just over one-hour fifty minutes to just over twenty-six minutes. Of the remaining twenty interviews thirteen were between one-hour and one-hour twenty-three minutes and seven were between forty-two minutes and one hour.

4.3.2. Interviews or Focus Groups?

Individual interviews constitute the primary (Aborisade, 2013) and dominant (Braun & Clarke, 2013) technique for qualitative data collection but focus groups, typically run by recruiting three to eight participants (Braun & Clarke, 2013) to take part in a collective, moderated discussion were also considered as a method of data collection.

Aborisade (2013) contends that individual interviews are used to conduct detailed explorations of individual experiences, choices and biographies, and to explore sensitive issues whilst group interviews (or focus groups) consider topics of public interest or common concern. Braun and Clarke (2013) agree, recognising that individual interviews are often considered ideal for sensitive issues but, at the same time, some participants may prefer a group setting. They conclude, however, that generally interviews are most suitable for examining individual experiences, understandings and perceptions in relation to issues in which participants hold a personal stake.

Others argue that focus groups may be a suitable method to deploy in researching sensitive topics (Wilkinson, 2015), and can lead to enhanced disclosure within a secure environment where one participant's disclosure can facilitate that of another (Frith, 2000). Frith (2000) also argues that participants in a focus group can agree, elaborate, contradict, challenge, and disagree with one another which can potentially increase the depth and quality of the resultant data.

These arguments are, however, countered by claims that the social context of a focus group may inhibit some and lead to personal censorship (McParland & Flowers, 2012), even creating an environment in which undue influence, censorship and conformity can occur (Wooten & Reed, 2000). Frith (2000) and Hollander (2004), respectively, raise the concern that research concerned with sex and focus groups may lead to participants providing socially desirable responses. Frith (2000) also highlights that there may be a risk of over-disclosure if the research environment and intimate group dynamic encourages participants to say more than they intended. It therefore seemed ethically dubious to subject participants to this social environment. I consider this risk to have been controlled in the two-way interactions that ensued as I was bound by ethical obligations, professional codes of practice, and was alert to these possibilities.

Barbour (2010) introduces another ethical complication, maintaining that focus groups should be carefully composed in order avoid participant distress, for example through unfavourable self-comparisons being made between participants. Given the potential, suggested by the existing research, for visible difference to negatively influence participants' intimate lives and feelings about themselves, this was considered a substantive risk. The adoption of individual interviews allowed me to minimise this risk through carefully controlling any self-disclosure and ensuring that the focus of the interaction remained on the participant. I did not systematically disclose whether I have a visible difference of any kind nor provide details of my own relationships.

Before moving on from this issue it is worth noting that a third solution was considered. Offering participants a choice of an individual interview and a focus group may have represented an ethical solution and these methods have previously been combined within the field of appearance research (Egan et al., 2011). Concerns relating to the argument that focus group data represent collective and negotiated rather than individual understandings (Hollander, 2004; Lehoux, Poland, & Daudelin, 2006) and are subject to group processes, but are often used and analysed as a tool for collecting individual level data (Hollander, 2004) meant this option was discounted.

Finally, literature introduced in Chapter 2 suggested that it was reasonable to anticipate that some participants would have experiences of a level of difficulty in their psychosocial adjustment, may suffer from some level of social anxiety (Rumsey et al., 2003) and adopt avoidant behaviours (Newell & Clarke, 2000; Newell, 1999). Exposing such individuals to a focus group scenario and asking that they discuss the intersection of visible difference and intimacy carried the potential to lead to distress, embarrassment, self-presentational concerns, and social anxiety. Individual interviews were thus considered most appropriate for this research.

4.3.3. The Medium of Participation

The decision to engage with participants through individual semi-structured interviews led to consideration of another issue, what medium or media to use to facilitate that engagement. The means through which qualitative interviews may be conducted include traditional face-to-face interviews, telephone interviews, and those conducted via electronic mediums such as e-mail or (instantaneous) messenger services (Opdenakker, 2006). Coulson (2012) highlights how methods other than face-to-face interviews can be convenient for researchers and participants alike and increase access to and for otherwise hard to reach participants. I decided to offer face-to-face interviews, telephone interviews, and Skype interviews to participants but not e-mail or instant messenger based options. Each is discussed below.

4.3.3.1. Face-to-face interviews.

As these are considered the ‘gold standard’ (Novick, 2008) of qualitative data collection, participants were offered the choice of participating through this medium. I offered to travel to a location convenient to participants or to meet them at the premises of UWE.

4.3.3.2. Telephone interviews.

Despite the claim that remote interviews may be shorter and less detailed than those conducted in person (McCoyd & Kerson, 2006), there is burgeoning recognition that remote methods can produce high quality data. Claims such as those of McCoyd and Kerson (2006) lack a substantive empirical basis and there is no evidence that phone interviews lead to impoverished data or data that are more difficult to interpret (Novick, 2008). Indeed, data generated through phone interviews may not differ from that generated in face-to-face interviews (Sturges & Hanrahan, 2004).

Phone interviews have previously been successfully employed in connection with sensitive issues (Trier-Bieniek, 2012) and visible differences (Egan et al., 2011). Novick (2008) argues that phone interviews may be particularly appropriate for sensitive topics as the medium allows participants to relax and facilitates the calm disclosure of sensitive information. Such claims are mirrored by Braun and Clarke (2013) who list the benefits of virtual interviews as including their potential suitability for sensitive topics arising from the that fact they are more anonymous and less likely to lead to participants feeling judged or under social pressure.

This point was relevant to this study as not only is the focus a sensitive topic but informal discussions with charities in the sector revealed people with a visible difference can be reluctant to meet in person. Providing participants with the opportunity to converse through a medium which excluded the visual sense and dictated that I could not judge or examine participants' physical appearance was considered beneficial. This may have also acted to render my own appearance irrelevant.

One concern over the use of the telephone interviews is the potential loss of rapport between the interviewer and participant (Evans, Elford, & Wiggins, 2008; Mealer & Jones, 2014; Novick, 2008). There exists no empirical demonstration that this issue is problematic or impacts upon the quality of data produced but it must be acknowledged that this would be a very difficult phenomenon to evidence. Of course, conducting face-to-face interviews is not a guarantee of rapport (Trier-Bieniek, 2012) and I would argue that behaving in a way that may generate rapport, by being respectful, empathetic, listening attentively to participants, responding appropriately to what is said, and giving primacy to their account should therefore be a hallmark of any qualitative interview.

The importance of establishing good rapport with participants is emphasised by Karnieli-Miller, Strier, and Pessach (2009) who stress that the researcher is seeking access to the participant's private and intimate experiences and so it is critical to build good rapport rooted in a considerate and sympathetic relationship and a mutual sense of trust. I therefore made efforts to adopt the conversational style advocated by Burke and Miller (2001) being friendly, courteous, and conversational during the discussion and ensured the interview did not rush straight to a discussion of very private topics. I also attempted to build rapport through polite and interested pre-interview contact (Trier-Bieniek, 2012). By way of example, a participant who mentioned in pre-interview contact that they had recently started a new job was thanked for taking the time to take part in the research during a period of change in their life, asked how the job was going, and wished well with this venture.

I was also flexible and accommodating with requests for the timing and (where appropriate) location of interviews so that participants' personal and work commitments would be affected as little as possible. Consequently, some interviews were conducted at weekends and in the evening and requests to rearrange or postpone were always responded to in a friendly manner that demonstrated my gratefulness for the participant's continued interest in the research.

4.3.3.3. Skype

I also made the decision to offer Skype (or similar) voice-over-internet video calls to participants. These were considered somewhat analogous to telephone and face-to-face interviews. They provide the instantaneous verbal communication common to both mediums but also a limited and two-dimensional visual depiction. Hay-Gibson (2009) sees these voice-over-internet protocol methods as offering great potential. In considering their utility she argues that the added 'human element' of video calls (in comparison to voice only calls) could be a good thing and improve the quality of the interaction or could lead to embarrassment or nerves if the participant is not used to being on camera. As the intention was always to offer participants the choice about how to engage with the research process and so empower them (Trier-Bieniek, 2012), this potential disadvantage was avoided.

4.3.3.4. E-mail and messenger

Whilst these various mediums of communication were offered through which the semi-structured interviews could be conducted, they all involved the production of synchronous, verbal data. Methods that would not share these characteristics were not offered. As such, there was no opportunity offered to participants to conduct the interviews through e-mail or an instant messenger service. The rationale for excluding these forms of data collection was primarily that whilst they may have some advantages such as flexibility and convenience (McKenna, Green, & Gleason, 2002), the written data produced by instant messenger services were considered quite distinct from verbal data produced by spoken interviews, with the asynchronous and written data produced by e-mail exchanges a further step change from spoken interviews.

Evans et al. (2008) also highlight a number of potential problems with utilising these methods: participants may feel rushed, this medium places a greater burden on those engaged in interaction as they have to translate their thoughts into typed content; the questions may be experienced as being formulaic and 'cut-and-paste' in nature, and participants may multi-task and therefore only devote a portion of their attention to the conversation. They argue that participants may enjoy the discursive nature of a verbal conversation and employing this medium left the participants in no doubt as to what was required; an in depth and personal discussion. Their conclusion, arrived at in the context of research interested in a sensitive topic relating to sexual activity, was that online synchronous methods of communication may not be well suited to the emotional and intellectual demands of an in-depth interview. Additionally, Opdenakker (2006) warns that participants in an e-mail exchange are more likely to forget to reply or lose interest in the interview, prematurely terminating the discussion. These concerns all contributed to the decision to discount those methods in the present research.

Given that one method employed (the telephone) in particular allowed participants to retain some of the anonymity that other remote methods would have granted and obviated the need for them to physically appear before a researcher, I did not feel there was sufficient justification to extend the methods employed to conduct the interviews by email or instant messenger.

4.3.4. Data Generation Summary

Individual interviews were considered most appropriate for exploration of a sensitive topic. The lack of any established negative impact upon the data arising from the use of phone interviews coupled with the benefit that some participants may experience and the desire to empower them within the research process justified offering participants the choice about the medium through which they would engage with the research. Due to concerns about the differing nature of written and verbal data and asynchronous/synchronous communications, this choice was restricted to traditional face-to-face interviews, telephone interviews and skype interviews. Of the twenty-two interviews, fifteen participants chose to be interviewed over the telephone, five on a face-to-face basis, and two via skype.

4.4. Ethics

This research received ethical approval from the University of the West of England: University Research Ethics Committee: Faculty of Health and Applied Sciences pursuant to the application for ethical approval I submitted (Appendix A4). The approval is contained within Appendix A5 and the associated Risk Assessment at Appendix A6. The more pertinent ethical issues associated with this research will now be introduced.

4.4.1. Medium of Participation

The decision to offer participants a choice as to whether the interviews were conducted in person or remotely via phone or Skype was motivated in part by ethical considerations. It was offered to ensure participants were as comfortable as possible (Elmir, Schmied, Jackson, & Wilkes, 2011), had the option of participating from a familiar location (McCoyd & Kerson, 2006) and were able to exercise some autonomy in deciding how to participate. This acted to empower participants within the research process (Trier-Bieniek, 2012).

Offering this choice was considered especially important within the context of the specific research study and the characteristics that some of the participants may display. Fox et al. (2007) argued that hosting their on-line focus groups in an ‘appearance-less’ environment may have encouraged the contribution of their young participants with psoriasis who may have had concerns about the appearance of their skin. These comments are consistent with both Elmir et al. (2011) and Egan et al. (2011) who highlight that the use of phone interviews may help researchers access hard to reach populations. It is possible that the impact of visible differences renders some potential participants ‘difficult to reach,’ especially those who may react to their status in an avoidant manner and may find the prospect of speaking to someone in person intimidating or potentially upsetting. Offering a choice about the medium of participation, the level of physical and (perceived) visible scrutiny to which participants may subjected was intended to minimise the likelihood of causing harm or distress to participants.

4.4.2. Informed Consent

All participants provided their full informed consent to participate in the study. They received a copy of the information sheet (Appendix A1) and provided consent in accordance with the detailed consent form (Appendix A2).

4.4.3. The Nature of Participation

The participant information sheet explicitly stated that the interviews were for the purposes of research and did not constitute any kind of therapeutic intervention or treatment and that the researcher was not a therapist or a counsellor. This was done to ensure that participants were not accidentally misled and their expectations of the potential benefits of participating were realistic.

4.4.4. Anonymity

To ensure the anonymity of participants each participant was allocated a pseudonym that was used when transcribing, analysing, and reporting the research data. All place names and the names of other persons were altered or omitted at the transcription stage. As such, the data were anonymised as close to the point at which they were collected as was possible.

In addition to the information included in the consent form, I made a specific point of reiterating verbally to every participant that quotations and summary information may be published and that this would be attributed to the participant via a pseudonym, but that certain of their demographic details may be attributed to that pseudonym. This explanation was provided as the subject matter of this research made it possible that specific experiences and incidents may be referred to by participants. As these occasions may involve another person it was considered possible that other persons who may conceivably see or hear resultant publications and presentations may recognise or consider themselves able to identify the participants from the quotations used and the information provided. To guard against this possibility participants were asked to inform me if they would rather that any particular incident or event was not directly referred to in presenting the research. I repeated this at the end of each interview and specifically asked whether the participant had mentioned anything that they would not want published.

4.4.5. The Consent Process

The consent form was provided to participants in advance of the time arranged for interview and consent was provided in one of three ways, being:

i. in person. Where interviews were conducted on a face-to-face basis, consent was confirmed by the participant signing and dating the consent form, which was also signed and dated by me;

ii. in writing in advance. Participants who chose to participate remotely were asked to sign, date and scan or post the consent form to me or to indicate their consent in the body of an email. In either instance immediately prior to the interview commencing I confirmed verbally with the participant that the participant had provided consent and that the consent remained valid;

iii. verbally prior to interview. For interviews conducted remotely where the participant had not already provided written consent, then immediately prior to the interview I asked the participant to confirm that they have read and understood the participant information sheet and consent form. I read the consent information to the participant and asked for verbal confirmation of their consent. I indicated that this has been done on the consent form. Participants providing consent in this way were also asked to confirm their consent at the start of the interview.

4.4.6. Participant Distress

Some mild distress was noted during some of the interviews. Where this happened, I offered participants appropriate contact details (appearance and mental health support organisations, NR, the Outlook service) but all declined. The participants seemed to consider the distress to be a natural consequence of talking about a difficult subject that is often not discussed openly and that their distress was within normal or everyday parameters. Some participants expressed the feeling that the interview was a cathartic experience as the topic is often neglected and opportunities to speak and be listened to rather limited.

One instance of mild distress did result from a hypothetical question the interviewer asked of an early participant that was in a relationship. For the purposes of this question the participant was asked to imagine they were not in the relationship and how they might feel about their intimate life. The participant concerned expressed some discomfort at this and said that they had not thought about this possibility. Whilst the distress was not severe, was contained and short lived, I did not continue with this question in subsequent interviews as I felt less comfortable with the possibility of inducing mild distress via a novel, hypothetical situation as opposed to discussing pre-existing experiences, thoughts or beliefs.

4.5. Saturation and Sample Size

Whilst it is not possible to conclusively predetermine a sample size for qualitative work, Braun and Clarke (2013) advise that a small (6-10 participants) to moderate (10-20) sample size is often used for interview studies examining the experiences of those being interviewed. I anticipated that the sample size for the study would be towards the greater end of this spectrum. Visible difference occurs in many forms and I considered this desirable in order to capture a broad a range of experiences and understandings from a relatively heterogeneous sample of participants. This desire for heterogeneity justifies going beyond the sample size of 12 that Guest, Bunce, and Johnson (2006) recommend for studies of homogenous groups that are focussed upon a narrow sphere of activity.

In order to ensure that the study did not over-recruit, I monitored the data on an ongoing basis as it was collected. Recruitment was suspended once I believed that data saturation had been realised. Data saturation, however, and as distinct from the theoretical saturation of grounded theory (Francis et al., 2010), remains poorly defined and operationalised (Guest et al., 2006; O'reilly & Parker, 2013). Definitions of data saturation share common characteristics and include references to the point at which no new themes, findings, concepts or problems emerge (Francis et al., 2010) and at which additional data does not generate new information (Braun & Clarke, 2013; O'reilly & Parker, 2013).

These broad definitions are consistently applied but the way in which the point of saturation is judged, assessed or decided is rarely reported (Francis et al., 2010). Both Fusch and Ness (2015) and Bowen (2008) concur, stating that pragmatic guidelines for determining saturation are almost non-existent in the qualitative literature. The recent work of Hennink, Kaiser, and Marconi (2017) may have at least partially redressed this situation and offers researchers a mechanism through which saturation may be judged more precisely during the process of analysis, however, this was published too late to be of assistance in this analysis.

Data saturation was therefore informally assessed on the basis of my ongoing review of interview notes, reflection on and preliminary analysis of the data. It was achieved once I believed the data were comprehensive, rich, and the accounts of participants demonstrated common essential characteristics and began to feel familiar (Morse, 1995, 2015b).

Despite these efforts to judge data saturation and the knowledge that this may be a common occurrence, I therefore feel a little exposed in making this claim. My judgement may have been influenced by the broad recommendations as to sample size that have been introduced above as well as by the availability of willing participants. In the absence of a pre-defined process for determining saturation, it is conceivable that such influences may have impacted my consideration of this issue and swayed me towards an assessment that saturation had been reached.

It is also interesting that Wray, Markovic, and Manderson (2007) discuss their process of data collection as being somewhat traumatic, wearing, and wearying on the research team. Whilst I did not experience the physical symptoms and emotional stress or burnout that these authors describe, they introduce the concept of researcher saturation. This could be interpreted as providing a novel way of looking at saturation where it is not the data that is saturated, but the researcher that is saturated by the data, perhaps unable to absorb any more or conceive of more themes or new data.

Were this researcher saturation to occur then the criteria of Guest et al. (2006) may apparently be fulfilled as it is possible that new information would be ignored by a saturated researcher and considered unimportant, interpreted in light of the existing themes or incorporated into them in a deductive manner. I was not conscious of this but given the possibility of innumerable interpretations and analysis of potentially unlimited data, it is perhaps a concept that warrants further consideration especially considering the poorly operationalised notion of data saturation.

O’reilly and Parker (2013) prefer to discuss the appropriateness and adequacy of a sample to address the research question and the richness and depth of the data and analysis produced. In this case the sample was both appropriate and adequate as it encompassed those with a range of conditions, experiences, relationship histories and situations, of both genders and through a broad range of ages. It was, however, limited to heterosexual experience. The richness and depth of data are aspects that perhaps escape measurement but are best evidenced through, and in, a considered analysis. I believe the interviews to be detailed, personal, full, and open. These factors combined led me to consider that the number and nature of participants interviewed, and the nature of the data produced are all indications that the study and its sample was appropriate, adequate, rich, and deep. My residual concerns related to data saturation were therefore appeased by reference to the criteria of O’reilly and Parker (2013).

4.6. Data Analysis

4.6.1. Thematic Analysis

The data generated in this study were analysed using thematic analysis as described by Braun and Clarke (2006, 2013, 2014). This method of analysis was considered the most appropriate as it is useful for applied work (Braun & Clarke, 2014) and allows the researcher to systematically organise and identify commonalities of meaning and experience across the data-set (Braun & Clarke, 2013). Conducting thematic analysis therefore ensured the analysis proceeded in manner which acknowledged and respected the voices of individual participants and the richness of the data, but which primarily enabled these commonalities to be identified and themes generated around them. As the intention was to use the findings in order to develop a measurement scale, it was important to attempt to capture the common, shared elements of the participants' accounts to help ensure their transferability (Morgan, 2007) from these particular accounts to the experiences of those with visible difference more generally.

Whilst not every participant's experiences contributed to every theme, working with the data-set as a whole and drawing on ideas and meanings that were common amongst participants helped ensure this transferability was achieved and that that 'warranted assertions' (Hall, 2013; Johnson & Onwuegbuzie, 2004) could be claimed, albeit on a necessarily tentative and provisional basis, as the findings were used to inform the future work. The ability of thematic analysis to function in this manner illustrates that it offers a qualitative method rather than a methodology and is characterised by theoretical flexibility meaning that its use is compatible with the adoption of different epistemologies (Braun & Clarke, 2006), here pragmatism.

This theoretical flexibility and focus upon commonality of meaning and experience justified the use of thematic analysis in preference to idiographic methods, such as interpretative phenomenological analysis (Smith, 1996; Smith, Flowers, & Larkin, 2009; Smith, Flowers, & Osborn, 1997; Smith & Osborn, 2003). Interpretative phenomenological analysis is concerned with lived experiences, the meaning individuals ascribe to their experiences, acknowledges the importance of understanding the person in their context, that their verbal reports, cognitions, and the physical world are connected but uses interpretative analysis to bridge the gap between verbal accounts and underlying cognitions (Smith, 1996). It thus employs the 'double hermeneutic' (Costello & Osborne, 2005) of the researcher interpreting the participant's own interpretation, and recognises the researcher's own inherent subjectivity.

Interpretative phenomenological analysis is, however, not theoretically flexible in the same way as thematic analysis. Its idiographic focus dictates that it would be appropriate if conducting a detailed exploration of the experiences of a small number of homogenous participants (Braun & Clarke, 2013). This is reflected in the analysis process whereby each account is fully analysed before any attempt is made to draw the accounts and the analysis together and in the relatively small sample sizes that are employed. As a consequence, commonality of meaning and experience is not afforded the same priority and the transferability of Morgan's (2007) pragmatism could not be asserted, even on a provisional basis, as was intended in abstracting the qualitative findings for the process of scale development. To do so would be to create an epistemological dilemma or clash. In addition, the desire to establish knowledge and develop a scale with applicability to and for individuals with a broad range of visible differences and other demographic characteristics was incompatible with the homogeneity that interpretative phenomenological analysis demands of its participants and would have made the performance of applied research across this range of individuals somewhat problematic. These problems were avoided by the adoption of thematic analysis.

Other methods of qualitative analysis were unsuitable for the aims of this thesis. methods of discourse analysis, such as those propagated by Potter and Wetherell (1987) and Wetherell and Potter (1988), examine the construction of meaning in and through language and discourse and the creation, adoption, use, and effect of the tools and resources employed within social interactions, these being ‘interpretative repertoires.’ This would be appropriate if, for example, the focus was upon examining appearance and power or group dynamics within naturally occurring conversation. The approach is less suitable for the performance of applied research and the examination of participants’ experience, as link between verbal accounts, cognitions, and experiences is considered less secure and less reliable. Methods of discourse analysis would therefore fail to provide an understanding of experience or an understanding that could then be translated into a measurement scale and, as they exist within constructionist epistemologies, are inconsistent with the transferability of pragmatism.

Finally, the grounded theory of Charmaz (2006) and Strauss and Glaser (2017) could have offered a viable methodology, if the aim of this thesis had been to build theory. Such theory may have, in time, been capable of application but it was always my desire to attempt to create a useable tool, capable of immediate practical application. Whilst the adoption of thematic analysis permitted this to happen, employing grounded theory would have required several iterations of the qualitative study as a provisional theory was developed, refined, and tested. This iterative process would have demanded theoretical sampling and consumed the whole of this thesis. As such, the specific aims of this thesis would not have been served by deploying grounded theory. Grounded theory also tends to suit a focus upon sociological structures and processes rather than individual experience (Braun & Clarke, 2013). Of course, this could have been a legitimate goal but the desire was always to elucidate experience before developing a scale. Thematic analysis permitted this in a way that would have been difficult to achieve through grounded theory.

4.6.2. Process of Analysis

Having established the appropriateness of thematic analysis and as the topic has not been researched extensively and remains relatively lightly theorised, the analysis was inductive in nature. This meant that the data were coded and themes generated without attempting to fit a pre-existing coding framework, pre-defined codes, the researcher's own analytic preconceptions (Braun & Clarke, 2006) or prior theory and research (Boyatzis, 1998). This data-driven or 'bottom up' approach permitted a rich description of the whole data-set rather than an early focus or concentration upon a particular aspect of the data (Braun & Clarke, 2006). The entire data-set was coded, and candidate codes and themes related to general thoughts and experiences connected with visible difference and those pertinent to intimate relationships were identified. My intention was, so far as is possible, to let the data direct the analysis. Such an approach was therefore consistent with the broad nature of the research questions and with the stated aim of this research, namely to investigating a variety of experiences, thoughts, feelings and phenomena related to the intersection of intimacy and visible difference.

The themes identified were primarily semantic in nature (See Chapter 5). This means that they explicitly represent what was said by participants (Braun & Clarke, 2006) and are thus manifest or directly observable in the data (Boyatzis, 1998). As is evident in the analysis, however, an attempt has been made to consider underlying ideas, assumptions and conceptualisations and so some themes contain a more latent dimension (Braun & Clarke, 2006). The analysis specifies where this more interpretative element has been applied and where the boundaries of the semantic content of participants' accounts lie.

The primarily semantic nature of the analysis and the focus of the research upon individual psychology and personal accounts, dictated that the analysis presented an experiential account. Again, this is consistent with pragmatism, as individual meaning and experience is central, but the broader social context within which such meaning is generated and situated is also acknowledged, particularly in connection with the more latent aspects of the analysis (Braun & Clarke, 2006).

The process of analysis itself was conducted in accordance with the six steps detailed by Braun and Clarke (2006) and the following paragraphs briefly describe the procedure followed. References to phases (or steps) are to the phases that those authors have documented.

The first phase of the analysis was familiarisation with the data. This was an active, ongoing process that only ceased upon completion of the analysis, this thesis, and the publication associated with this analysis (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2018). It began with me conducting each of the interviews and listening to the recordings. During this phase (and at all subsequent times) listening was active in nature and I began to think analytically about the data, make connections, and notice commonalities and familiarities in the accounts of participants.

The interview data were transcribed verbatim. Whilst I was fortunate to be able to engage another party to transcribe the data (having ensured the participants were aware of and consented to this), I was conscious that transcription can be viewed as a key phase of data analysis and an integral part of its interpretation (Bird, 2005). Similarly, Downs (2010) considers it a responsibility inherent upon a researcher to transcribe the data they have been gifted by participants and eventually helps the analysis as the researcher knows the data more thoroughly.

In the present research I carefully listened to each recording with the transcript in hand and methodically checked the accuracy of the transcript. This process was time consuming, though perhaps not quite as time consuming as performing the transcription personally, and was given great attention. The content, form and formatting of the transcripts were thus meticulously verified and the transcripts came to resemble the form which they would have taken had I personally conducted the transcription. I believe I became as familiar with the data as if I had conducted the transcription. When comparing this process to transcription I have performed myself, I may even suggest that the careful checking of transcripts whilst listening to audio-recordings allows greater attention to the content of the recording than the act of transcribing itself, which carries its own demands on attention, accuracy, and focus, especially for typists such as myself of only average skill.

I would thus argue that the process of listening and editing without being so distracted by my own rather cumbersome typing skills or the dread (Bird, 2005) that can accompany large amounts of transcription, may even have kept me closer to the data and alleviated a possible sense of frustration that may otherwise have been evident. The process of listening and editing was more relaxed and less fraught than my other experiences of transcription. This may therefore have helped with data familiarisation and the crystallisation of preliminary thoughts concerning the analysis. It is contended that the process followed did stimulate thought, involve data familiarisation and understanding, and did inform the early stages of the analysis, even though it was the simultaneous re-listening and editing of the data that facilitated this rather than transcription.

The second phase of the thematic analysis involved me producing an initial list of ideas about the data, its commonalities, and connections and using this to produce an initial set of codes and features that were interesting and pertinent to the research question. This process was completed using hard copies of the transcripts and writing notes on and highlighting the manuscripts on an inclusive basis. These codes were then organised into themes during the third stage of the analysis so that all codes were included within a theme. The themes were thus clusters of codes that seemed to share common underlying ideas, experiences and thoughts.

These candidate themes were reviewed during the fourth phase of the analysis, which involved ensuring the themes had a central, organising principle and that the codes fitted into them. The process also involved an ongoing restructuring process. The draft thematic structure was constantly altered and revised to comprehensively represent the data (or my interpretation of it).

A major revision made during this process was the treatment of “The Disclosure Dilemma”. Initially a candidate theme, I subsequently felt it could be incorporated into “Looking Different: Physicality and Physical Reality” as a sub-theme. Not only was it very much concerned with the physical consequence of visible difference, but it was applicable to only a particular sub-set of the participants. I also distributed components of a fifth candidate theme focussing upon participants’ romantic identity (provisionally entitled ‘Impacting Identity’) amongst the final three themes rather than have it constitute its own theme. For example the idea of being personally deficient or defective as a partner was originally contained within this fifth candidate theme but was conceptually linked to the idea that appearance is central to attractiveness, a visible difference may render one less attractive, and that it requires a special partner or a great deal of luck to enjoy a successful relationship and so was incorporated into the ‘Appearance Attracts and Detracts’ theme.

At this stage of the process and in a slight departure from that detailed by Braun and Clarke (2006), I loaded the transcripts into the qualitative data management programme Nvivo. I then went through each transcript applying the relevant themes and sub-themes using that software so that I had a full electronic version of the analysis. The software was utilised at this relatively late stage as I did not want to let the technology dominate the process and was familiar with pen and paper coding. It is also a quirk of the Nvivo software itself that it functions very well for deductive coding but has, in my opinion, less utility for inductive coding. I therefore felt it was more appropriate to use Nvivo as a tool for organising the data.

The data were therefore organised and coded in Nvivo but only following and subsequent to the process of developing the themes and thematic structure 'ex-vivo.'

The themes and sub-themes were then named and further refined in the fifth phase of analysis with the final thematic structure being represented in Chapter 5 of this thesis. The essence of each of these was detailed in a short narrative and the relationship between overarching and subordinate or sub-themes defined. Relationships and areas of overlap between the themes were noted so that they could be included within the final report. Producing the report (contained within this thesis) was the sixth and final phase. It should be acknowledged that the process of analysis was ongoing and overlapping so that whenever the data were referred to (including during the coding process on Nvivo) the themes and thematic structure were re-examined and, sometimes, revised. Using Nvivo promoted this process as the software enables codes to be fully examined and altered and extracts coded and un-coded in a flexible and intuitive manner.

Throughout the process of analysis, I met regularly and consulted with NR. In these meetings we discussed coding, candidate themes, and candidate sub-themes. Such discussion included reference and referral to the transcribed interviews to ensure the analysis remained grounded in the data and was credible (Tracy, 2010). The analysis was also reviewed in two meetings between me, TM and LJ, and in one meeting with AC. LJ also independently coded one transcript and our discussions revealed a strong consensus regarding the issues and codes identified by LJ and myself.

4.6.3. Member-checking

In addition to the involvement of NR, TM, LJ, and AC, and in an attempt to further ensure the analysis was grounded in the data and credible, the participants were offered the opportunity to receive and comment upon a provisional summary of the findings (Appendix A7a). Of the 22 participants, 21 chose to receive this summary and the summary was e-mailed to each of these 21 participants. This email explained that the summary was drawn from all the interviews that had been conducted and stated that:

If you feel that there is anything that is of importance to you and it does not fit within these themes or if you disagree with anything in this document, please do contact me and we can discuss this – I would of course be very grateful and interested to hear your thoughts.

Five participants responded, and all the comments they made on the analysis were supportive (e.g. describing it as 'interesting'). No negative comments or suggestions for changes were received.

Whilst this may be interpreted as something that supports the veracity of analysis, and I subscribe to this interpretation at least partially, I was a little disappointed that a greater number of participants did not respond. Equally, as the comments provided were positive, the eventual findings did not benefit from being re-examined in light of detailed comments made by participants in response to these provisional findings.

I am somewhat culpable in facilitating this circumstance as, upon reflection, the form and format of the summary that was provided may be considered somewhat text heavy and therefore inaccessible (Birt, Scott, Cavers, Campbell, & Walter, 2016). Furthermore, the synthesised, aggregated findings that were presented may make it rather difficult for meaningful comments to be provided by an individual participant and then interpreted by the researcher (Morse, 2015a). Yet, as Birt et al. (2016) argue, the method of analysis employed meant that, generally, participants should still have been able to recognise their experiences within the findings and engaging with participants in this manner carries the potential to challenge, encourage reflection upon, and even add meaningful data that can form part of the analysis. This, however, did not transpire.

Where member checking is employed in future research, the synthesised member checking procedure detailed by (Birt et al., 2016) could be employed in order to attempt to maximise utility of this process. This is particularly appropriate where, like with the present research, the epistemological position adopted by researchers asserts that an external reality can only be known through individual thoughts, feelings, meanings and interpretations (Birt et al., 2016). This mirrors the ‘intersubjectivity’ of Pragmatism (Morgan, 2007) and so whilst member checking was appropriate given the epistemology adopted, there may be room for improvements in its execution in future research.

4.7. Summary

This chapter has introduced the method by which a qualitative exploration was conducted and has articulated the detail of this process. The following chapters will introduce the three themes resulting from the analysis that were concerned with intimacy and romantic relationships.

5. Qualitative Study: Analysis

5.1. Introduction

The analysis of the qualitative data resulted in the generation of five main themes. These themes, their corresponding sub-themes, and second order subthemes are depicted in Table 5.1. Of these themes, the first two: 'Personal Reflections on Looking Different' and 'Our Socially Situated Appearance' were not specific to intimacy and romantic relationships but pertained to appearance more generally. These are presented in the form in which they have been published (Sharratt, Jenkinson, Moss, Clarke, & Rumsey, 2019) in Appendix A7b but are not included within the body of this thesis. The remaining three themes: 'Appearance Attracts and Detracts,' 'Physicality and Physical Reality,' and 'Appearance Delineates and Defines Relationships' related specifically to romantic relationships and intimate situations. Over the course of the following chapter, each of these and their constituent sub-themes shall be introduced and examined in turn.

Table 5.1

Qualitative Analysis: Themes, Subthemes and Second Order Subthemes: Non-intimacy and Intimacy

Theme	Subtheme	Second order subtheme
Non-intimacy themes		
Personal Reflections on Looking Different	Becoming one with difference	I look different, I feel different, am I different?
		Growing into myself
	Hiding away	Covering up to conform
		Staying safe
	This lonely planet	-
Our Socially Situated Appearance	Appearance as a projection…	…of being a woman
		…of media influence
		…that me and mine reject
		…that you must learn to see through
	Being public property	-
	Searching for comparative normality	-

Intimacy specific themes		
Appearance Attracts and detracts	Looking to love	-
	The discounted self	Deficient me
		Lucky in love
Looking Different: Physicality and Physical Reality	The disclosure dilemma	-
	Invading physical Intimacy	Corporeal disinclination
		The shrouding
		Stealing the moment
	Selfish genes	
Looks Help Delineate and Define Relationships	The Litmus test	-
	Enriching and fortifying us	-
	Treasured Support	-

5.2. Appearance Attracts and Detracts

This theme reflects the belief, expressed explicitly by some participants and inherent within the accounts of others, that seeking, maintaining and enjoying all facets of a rewarding relationship is one of the biggest challenges they have experienced in connection with their difference. Appearance was understood as fundamental importance to attraction, the initiation, and initial stages of a relationship. These initial stages were considered the most difficult period to negotiate. Once this early barrier is overcome the challenges were understood to subside, but not disappear.

Within this theme sits the sub-theme ‘Looking to Love,’ capturing the importance that was assigned to appearance within the attraction process. Participants understood appearance to be fundamental to this and visible differences to impact negatively, meaning that an altered appearance represented a considerable obstacle. The second sub-theme ‘The Discounted Self’ refers to the reduction in personal and social capital that participants believed to stem from visible difference and how this reduced their value or worth as a viable intimate partner, leading them to discount themselves as such. These feelings are discussed within the ‘Deficient Me’ second order sub-theme. Its sister second order sub-theme ‘Lucky in Love’ introduces the sense of gratitude or good fortune, expressed in connection with and by a number of participants who enjoyed healthy and rewarding relationships.

5.2.1. Looking To Love

All participants spoke to this theme, highlighting the perceived importance of physical appearance and initial impressions to attraction. Appearance was understood as facilitating relationships and interpersonal attraction and influencing judgments of attractiveness and desirability. Visible difference acted as a barrier to finding a partner and entering into a fulfilling relationship. An examination of the accounts revealed evidence that participants themselves were susceptible to making these value laden judgments and attributions, with a minority acknowledging this expressly.

The potential impact on participants' intimate lives was amplified by feelings of low self-confidence, and self-esteem, the doubt and uncertainty expressed in connection with the more positive and with the neutral reactions of others, and the gendered effect of appearance ideals. In considering the possibility of overcoming such obstacles and initiating a relationship, several participants spoke about the most viable way into a relationship being affected by their visible difference. The accounts of a small number of participants, however, were not consistent with the ideas expressed within this theme and are offered in recognition of the multiplicity and diversity of experience expressed within the interviews.

Participants felt that their attractiveness to others was, largely, a function of their physical appearance and was diminished by their difference. This was apparent in Luke's account, a participant that described an active and healthy intimate life and who generally felt his visible difference had not hindered his romantic life. Speaking about his brother showing him and others a picture of a sexual partner he recounted:

> *I said to them, joking, pretending I was upset… "I will never have a bird like that for all my life." And they laughed, obviously that was why I said it [inaudible] then it occurred to me and I thought "No actually, that's probably quite accurate"… I would put it down to cleft lip and palate because I've not had my final operation so I will always wonder what my capabilities would have been beyond that (Luke, Cleft)*

This demonstrates how participants felt that judgements made by others in connection with their appearance and about their level of attractiveness are important and can be limiting. Whilst Luke did talk about other people who do not have a visible difference being in a similar position, he felt that in his experience and with regards to his own attractiveness to others, his cleft was negatively assessed by others, dictating that some potential partners were beyond his reach. This idea will feature heavily in the sub-theme 'The Discounted Self.'

Before progressing this discussion, it is important to recognise the implicit assumption within Luke's account. This is that the person depicted in the photo was beyond his reach because she was physically attractive. In Luke's words:

> *she was absolutely spot-on, she was gorgeous (Luke, Cleft)*

Whilst Luke did not explicitly say that he would have felt differently if she had been less attractive, he did not recount feeling this way when approaching other women. In addition to the assumption that the person depicted would have strict appearance-based criteria for a partner, Luke presupposed that he would fail to meet them. This is despite his successful romantic life and his descriptions of himself as sporting, active, and physically fit. Luke was therefore making judgements about someone, about how desirable they are as a partner, and about how receptive they would be to him based entirely upon how the other person looked. It is not clear that Luke was aware of how his own judgement of another mirrors those he feared would be made about himself, but this does demonstrate how appearance was considered central to attractiveness and that some participants may, perhaps without being entirely conscious of doing so, assess other people in this way.

Whilst rare, Luke was not the only participant to verbalise such ideas. Beth recounted making similar attributions about her current partner and enjoying the thought that other people would be impressed by how her previous partner, a model, looked:

> *[partner's name] came along and the first thing I saw was how good looking he was on his picture, thinking he either won't be like that or he won't be interested in me kind of thing (Beth, Facial Scarring)*

Whilst the attractiveness of the other was only discussed in isolated instances, participants often spoke of being conscious of the appraisals of potential partners. This assessment was important, even essential, to the process of two people coming together romantically:

> *I think you've got to have that, otherwise (.) I mean all the other things follow, don't they, over the years? But that initial attraction has to be there (Karen, Breast Cancer)*

Visible difference was presented as an obstacle that undermined the ability of some participants to enter into a relationship which transcended physical attraction:

> *it does make it a lot harder because as much as you want to get to that stage... the first instinct, it is a physical thing, it is… can you live with that person and are you attracted to them? (Ryan, Facial Palsy)*

Potential partners were perceived as considering visible difference to be unattractive and undesirable, therefore making initiation of a relationship more difficult:

> *I do think there are… if you were to say to a population of men "Would you go out with this woman who's got alopecia?" I think some of them would say no (Florence, Alopecia)*

These feelings had been borne of the reception from potential partners, as Michelle demonstrated when talking about a dating site where her friends chose the pictures of her:

> *all the photos that my friends put on there were ones that they think are lovely photos of me but, needless to say, they're all bald-headed photos and I think I was probably on that website for coming up to about a year and I got no interest at all (Michelle, Alopecia)*

As Michelle had used other dating websites where her difference was not so immediately apparent and had received more interest, she felt able to make this attribution. Whilst several participants spoke of the attention of potential partners waning once they were aware of the difference there was an example of a participant being unsure whether his acquisition of a difference contributed to the breakdown of his relationship:

> *when we first broke up one of my friends who'd had a few to drink and he said to my ex "Oh did you break up because of his face, his Bell's Palsy" and obviously she said "no" and took offence to that but it did make me think would there be… whether she says it or not, on a sub-conscious level would there be an element of that? (Ryan, Facial Palsy)*

The doubt and uncertainty in Ryan's mind may reduce feelings of self-esteem, self-confidence, and self-efficacy for intimate situations and represented an unwelcome and worrying distraction. These ideas will feature again in more detail, but here it is sufficient to specify that participants spoke about feeling less attractive to others as a result of their difference, even where concrete evidence of others' feelings was not available:

> *I was only discussing it with my friend the other night. I said "Well now I'm never going to meet anyone because imagine you know I, now if you were to undress now and 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 (Valerie, Facial Palsy and Breast Cancer)*

Several participants described the initiation of a romantic relationship as the greatest challenge that they had faced in connection with their visible difference. These comments came from those that were single when interviewed:

> *in terms of every day talking, you see I'm a relatively open, extrovert person, but I am quite shy when it comes to the opposite sex and therefore it does, (.) it does increase the inhibition considerably because you've got rejection squared, rejection potential squared, I guess (Austin, Psoriasis)*

> *I think this is the hardest bit that I find with having alopecia is dating. I think that's the hardest, the hardest thing (Anna, Alopecia)*

Such sentiments were echoed by those who were in a relationship but able to reflect on their life beforehand:

> *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… 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)*

The significance of these concerns was apparent when Charlotte was asked to contemplate how her life might be had she not been with her partner. This question caused some discomfort. Consequently, the line of questioning was discontinued with Charlotte and subsequent interviewees. Charlotte described feeling panicked and sweating at the thought and said:

> *I'd probably be alone for the rest of my life! I laugh, but I wouldn't have… (Charlotte, Cleft)*

Her description of experiencing a strong physical reaction to envisaging a situation in which she may be seeking a new relationship and the suggestion that she would feel unable to achieve this, spoke to how problematic the presence of a visible difference seemed in that scenario.

The importance of visible difference to attraction was portrayed as something that was more important to judgements made of women than of men:

> *I think we're, you know, judged by how we look and particularly I'd say primarily women, you know, how attractive we are and yes it is very appearance driven. (Elaine, Alopecia)*

Despite these thoughts and despite participants' feelings that they were liable to being unfavourably evaluated or disadvantaged because of their difference, several participants expressed the sentiment that this was both natural and understandable. Speaking about the negative reactions of potential partners to her alopecia, Michelle said:

> *my friends and my family get all cross on my behalf really and it's me trying to be logical and diplomatic about it all and saying "but I do understand" because, honestly, and I'm not just saying it for you Nick, 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)*

Other participants spoke about their own tendency to assess others based upon their physical attractiveness:

> *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)*

A small minority of participants pondered whether partners were aware of the judgements of others and experienced stigma by association: Pauline spoke of meeting a friend of her husband for the first time:

> *I met this guy, was on my wedding day, and unfortunately he was on our table and he obviously found me quite a surprise and he said to me "Oh [husband] never mentioned you" and you know, I'm not quite sure what he meant by that but, you know, it was like "He must be ashamed of you, he never mentioned you." That's how I take it (Pauline, Ichthyosis)*

Pauline believes his subsequent actions confirmed her interpretation:

> *we don't hear much from him now. We didn't hear much from him before but we hear even less from him now so I feel quite stigmatised and I feel [husband] has been quite stigmatised for being with me (Pauline, Ichthyosis)*

Speaking about the earlier stages of a relationship, Michelle discussed how a potential partner may worry about the social consequences of dating her:

> *I can't think who it was that asked me other day and I did say "I do honestly think they're probably worried sick about 'Oh God, what will my mates… what if I take her in the pub? What are my mates going to think?'" sort of thing (Michelle, Alopecia)*

Perhaps in part due to these uncertainties and perceived stigma, participants reported feeling that their confidence and self-esteem had been impacted by their difference, with participants expressing the view that they felt unable to fully engage in and enjoy their own intimate lives as a result. Here it is specifically participants' confidence in their ability to initiate and maintain relationships that was understood as being diminished and interactions with a significant other or potential partner that provided the context in which these concerns would manifest themselves. Examples of this include Pete's description of how his low self-esteem meant that it took perseverance on the part of his (now) wife to convince him that it was him, not his friend, whom she was interested in:

> *I thought oh well she didn't fancy me I just thought she fancied my mate. That was a self-esteem thing again. I would never have ever looked at anybody. I'd have thought she'd never ever like me (Pete, Cleft)*

Whilst Pete and others in his situation recounted historic concerns, for those seeking relationships these prevailed and were experienced as significant obstacles in exploring relationships:

> *I can't take that next step because my stomach goes, everything goes, my confidence just goes and I think I can't do it because… and then I always say to my friends, 'no because he'll see me in the daylight.' I think it was dark when they see me (Valerie, Facial Palsy and Breast Cancer)*

It was, however, not only those seeking a relationship who expressed that their confidence and self-esteem had been affected by their appearance. Sian described how her confidence had disappeared since the onset of her condition despite her partner's support and reassurance:

> *He always says that I'm beautiful and I'm perfect and so, but I still don't feel comfortable with myself. I know that's one person that I shouldn't feel like that around. He's never said anything to me to make me feel like that (Sian, Ankylosing Spondylitis)*

The final substantive point to be introduced in connection with this sub-theme involved a potential route into a new relationship that some participants found protective. Several participants argued that a relationship would be more feasible if they were friends with a new partner before developing a romantic attachment.

> *I'm not that confident to sort of go up to someone and be like 'here's me' I have to wear them down as a friend first really, so hoping they would look past the looks really and like, you know, me for who I am (Beth, Facial Scarring)*

The hypothetical existence of a pre-partnership relationship was therefore seen as obviating the negative judgement and assessment of Beth's attractiveness and value as a partner that might be formed without this prior acquaintance. It is important to highlight that this did not necessarily imply that a potential partner's prior knowledge of the difference would circumvent 'the Disclosure Dilemma' (see below - contained within 'Physicality and Physical Reality'). Ruth described how she had not explicitly told her current partner about her Alopecia but was still able to conceive of him as a partner:

> *the last five years, I haven't had that desire to get close to somebody who I didn't already know. And with the guy that I'm sort of seeing at the moment, again, I've known him for such a long time that I feel comfortable with him, not comfortable enough to tell him, but it's not the same as meeting a stranger and worrying about it (Ruth, Alopecia)*

Ryan considered this prior relationship a prerequisite and disregarded the possibility that a new partner could be anyone other than someone he already knew:

> *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 so at work or something like that (Ryan, Facial Palsy)*

The implication inherent within these comments was that these participants felt more able to countenance a future romantic relationship where there already existed a level of trust, understanding, and acceptance. These feelings were connected to a fear of rejection by some, with Beth speaking expressly about the existence of a friendship making her believe more confidently that she would not be rejected, and Ryan said that he would find it 'strange' if someone he did not know was 'happy just to get with me.'

Before progressing, it is pertinent to acknowledge that a minority of participants (specifically Anthony, Lisa, Luke, and Vanessa) did not subscribe to the ideas contained within this theme and explicitly claimed that their difference had not impacted upon their romantic or intimate life nor made them feel less attractive to others. Recounting a discussion with a former partner, Vanessa reported 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)*

Anthony described his long-term relationship and could only recall his Cleft having been an issue in any way within the context of having children. Luke argued that his Cleft had:

> *never really, never really held me back like that to be honest (Luke, Cleft)*

There is some inconsistency in Luke's account however, as he had also commented on the photo of the woman his brother had sex with as 'being out of reach' for him (see above). Despite this, it was clear that some participants did not believe their difference to have affected their experiences of attraction and intimate relationships in a meaningful way.

5.2.2. The Discounted Self

The ideas expressed within 'Looking to Love,' focussed primarily on participants' concerns regarding how others judge them but may have contributed to participants discounting themselves as viable and/or valuable intimate partners. This stemmed from a sense of personal deficiency and being undeserving of the romantic attention of another. This may have resulted from internalised societal ideals, the negative reactions and comments of others (including some potential partners and some ex-partners), and participants feelings about themselves. These ideas are explored in depth within the second-order sub-theme 'Deficient Me.'

This discounting of the self was also apparent in participants expressing their gratitude, or luck, at having a caring partner or having romantic interest expressed in them. This suggests that these circumstances were sometimes attributed to good fortune or chance rather than being deserved. These feelings are presented within the second-order sub-theme 'Lucky in Love.'

5.2.2.1. Deficient me

In light of the perceived importance of appearance in, and to, attraction, participants expressed the view that their difference rendered them as being in some way deficient, less attractive, and less desirable as a partner

> *no-one's going to look at someone and go "Oh, they've got Bell's Palsy that's the kind of thing I like." So I don't think that it would be in someone else's mind that they would like me, if that makes sense (Ryan, Facial Palsy)*

> *it's something that I'm just kind of resigned to now. I don't know, unless I met somebody who I felt [was] 100% comfortable with and that was totally accepting, but even then I think in the back of my mind I would still think "You don't really fancy me looking like this". I think it's always going to be in the back of my mind that I'll worry about it (Ruth, Alopecia)*

This belief in how others may assess difference seemed, in some instances, to be so strong and so pervasive that participants entirely discounted themselves as potential partners and considered a romantic relationship to be impossible. This discounting of the self was demonstrated vividly when Valerie recounted a conversation with a friend about the possibility of entering another relationship:

> *I said to her 'I don't think anybody…' she went 'don't think like that. You get this all over and you don't know what for the future' and I said 'I think I do. I think I've already made my mind up. I don't think I'll ever let anybody in ever again.' And she was like 'well you can't say that, you just see what happens.' I know I can't say that, what happens in the future, but 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)*

Participants who were in a relationship recounted previously feeling that they were devalued by their appearance and that this impacted their belief in the possibility of beginning a relationship:

> *I know you perhaps might say you meet a certain kind of girl in a disco but, you know, they're not, or they're going there to pick up the best they can do for themselves so I felt right at the back of the queue (David, Cleft)*

Similarly, Karen, who was in a relationship, contemplated how she would feel if she was single and believed that at some points (specifically after a mastectomy but before reconstructive surgery was complete) she would have been unable to envisage a new relationship:

> *I just couldn't imagine meeting a guy when you've had a mastectomy, I couldn't. Now I'd be fine, but during that time I just, no it's, and I think it's a lot to expect a man to take on, I feel. I don't know, maybe I'm wrong but…* (continuing very shortly afterwards)*… I'm just thinking of one friend in particular, and she's said that there's*

> *no way she would contemplate meeting a man until she's had all her surgeries and stuff and yeah, I think I would feel the same. I wouldn't even be dating I don't think (Karen, Breast Cancer)*

Karen's words suggest a sense of incompleteness, not being whole or being somehow less than other people until her reconstructive surgery is complete. This may be interpreted as including feelings of being considered less than fully human and therefore stigmatised, disempowered, and debarred from some of the human experience. It is, of course, necessary to acknowledge that other health related influences and concerns may have been at play here. Even so, Karen was focussing upon appearance and her words suggest that the reconstructive surgeries and her resulting appearance may serve something of a symbolic purpose within the context of her journey through cancer.

The sense of being somehow less than human is augmented by Ryan's account. He described adopting a passive role in his recent experiences of dating, because he felt that his appearance now dictated that the other person would need to decide whether he was acceptable to them and whether they would consider him as a partner. As such, his autonomy, humanity, and empowerment seemed to have been diminished. Speaking about a friend's attempt to match him with one of their friends:

> *it's not my decision if that gets taken further or not. No I'm very much leaving that to my friend. If they think that, you know, if they can talk to this person and speak to them a bit more give them a bit more information, gauge what their reaction is and things and then it is very much… I would go along with whatever they think in many respects. It's not something I'm going to push myself as I don't think it's my call to make (Ryan, Facial Palsy)*

Participants' conceptualisation of themselves as being deficient was evident from the level of disbelief that some described upon realising that others were attracted to them. Pete's comments about believing his (now) wife was attracted to his friend (presented within 'Looking to Love') typified this, as did Luke who was one of the participants to disavow any fundamental impact of his appearance upon his romantic life:

> *I remember one girl in particular really was attractive and it took me a while to do anything about it because I struggled to believe that she actually liked me beyond being a friend, although the signs were quite loud clearly and were obvious to other people, I struggled to believe it (Luke, Cleft)*

These doubts were also expressed from within supportive and healthy relationships:

> *with me, it's always been about the way I look. Yeah, I need to be healthy, I understand that, but it was a big thing for me the way I looked because obviously if I didn't look a particular way then why would he want to be with me? Why would, you know, I suppose stuff like that. The 'look' was more me I think (Jodie, Breast Cancer)*

In addition to alluding to the importance ascribed to appearance, even within the context of treatment for and recovery from cancer, demonstrating how interlinked Jodie considered appearance and attraction to be. This illustrates how devalued participants could feel. Jodie felt unable to escape the thought that she had or would become unattractive and her partner would cease to value and her and their relationship. Likewise, Beth's thoughts about the attractiveness of her partner and how this may reflect upon her (discussed in 'Looking to Love') were coupled with self-critical thoughts:

> *I think that was part of me thinking 'oh why would they like me?' But I'm a bit like that in my current relationship, that I do think like if you could tick all your boxes of your ideal man in looks-wise [partner] fits that thing, the dark hair, dark eyes, dark skin, it's kind of the look that I've gone for throughout. And then I do think, he's not had a proper relationship for four years and I'm thinking 'Oh has he just lowered his standards because he was desperate?' (Beth, Facial Scarring)*

The idea that her partner must have lowered their standards evidences Beth's understanding that she is lessened by her appearance and that this would diminish her romantic appeal and potential for intimate relationships with certain (attractive) others. Similarly, some participants spoke about avoiding particular situations because of how they felt about how they looked. This is addressed specifically in relation to physical intimacy within 'Corporeal Disinclination' (in 'Physicality and Physical Reality') but is also relevant here. A small number of participants spoke about regulating their intimate life depending upon appearance fluctuations so that they did not have to negotiate sex whilst their condition was most prominent:

> *when it comes to the opposite sex, you know I'm heterosexual, and sometimes I put off until I… if I've got treatment coming I may put things off for a while (Austin, Psoriasis)*

Perhaps the strongest example of this was provided by Valerie who believed that such concerns precluded her from having a romantic relationship. She described being so shocked that a man she did not know asked for her number that she '*obviously'* said no, as if providing it was not an option. She had also given false numbers to potential suitors as she feared that they would quickly realise they had made a mistake if they saw her in the light. Her sense of being of little worth as a partner was evident in this passage:

> *(I) just think there's no, there's no happy ending, I'm not going to be able to say yes to anyone because I'd have to end up, well I'd tell them about this. And I think, oh, and also, if anyone approached me say, as you say, tomorrow, I'd have a wig on, I'd have this facial paralysis, this operation on my breast and I think no, I'm just a wreck. I'm not normal and I think, so just right away that'd come in my head and I'd go 'oh no, no thank you' or I'd start explaining, going 'well actually you wouldn't want to go out with me because I've got this and I've got that' (Valerie, Facial Palsy and Breast Cancer)*

As an alternative to an avoidant response to feelings of being devalued by their appearance, participants also spoke of another, compensation. This strategy involved participants developing or offering other socially and culturally desirable traits to compensate for an altered appearance. Participants spoke about achieving this through adopting a gregarious personality, obtaining a good education or job status, wealth, and possessing 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 (Beth, Facial Scarring)*

Speaking about a specific partner, Beth continued:

> *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' (Beth, facial Scarring)*

It was also achieved through sporting prowess and fitness, which acted as a means by which to sculpt the body and increase its attractiveness. Luke spoke about his focus on sport and fitness offering him the chance to wrest back control over his appearance:

> *I think that was massively due to cleft lip as well because obviously I was uncontrol…. 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)*

The conceptualisation of appearance as being compensated for by developing and improving other aspects of one's life, or by the possession of relatively (to their partner) desirable qualities, suggests that participants considered a relationship to represent a bargained or negotiated position. This negotiation involves considering one's advantages and disadvantages against those of the partner or potential partner. The perceived deficiency and the attempts to overcome it suggests an economic-type exchange in which any particular characteristic, trait, ability, or status may have a value or worth and one's global appeal may be surmised from the combined value of individual components. This is consistent with the way that those considered to be especially attractive were assumed to immediately discount those with a visible difference as the perceived imbalance may be too great.

This perceived imbalance and participants' sense of being diminished by their difference carried the potential to influence relationships beyond their formation. Several participants recounted how their appearance had been used as a '*weapon*' (Eleanor, Psoriasis) against them by others, primarily ex-partners. Eleanor presented this as being one component of an arsenal that could be deployed against her. Her difference was thus conceptualised as a potential weakness that could be utilised by a partner as and when they desired to wound her. This echoed other participants' accounts:

> *we broke up and the first thing he said to me was 'I wouldn't want kids anyway in case they looked like you' and that's always stuck. So, yeah, I'm pretty sure that was said out of spite to hurt me (Charlotte, Cleft)*

Speaking about her unfaithful ex-husband, who would bring people she did not know home from work, Valerie explained how she had felt these episodes represented her appearance being used against her within a relationship that was characterised by unequal power:

> *I'd say hello to them and then I'd leave the room because I was thinking 'he's making me feel little' because I can't sit and have a conversation because I know that person's looking at me going 'well I don't really blame him having affairs. Look at the way she is.' I felt like that conversation was going on, might have all been in my head but I felt that's what the conversation was (Valerie, Facial Palsy and Breast Cancer)*

This second-order sub-theme has therefore introduced participants' sense of being diminished and devalued by their appearance, and illustrated that it is not only others' judgments but also participants' evaluation of themselves that appears connected to their difference. The ability to compensate for having an undesirable appearance has also been examined. The possibility of ex-partners utilising participants' appearance against them links closely to the sister second-order sub-theme, examined next.

5.2.2.2. Lucky in love

Participants who were in relationships tended to describe themselves as being lucky or fortunate. The accounts suggested that a number of participants still felt, to an extent, like Charlotte's younger self:

> *as a teenager any attention that a male or boy gave me, I kind of jumped on as such, as in 'oh my God, he thinks I'm alright' do you know what I mean? 'He's paying me attention' and that kind of thing' (Charlotte, Cleft)*

This was mirrored with references to participant's luck:

> *he's just not very easily the marrying sort and it's quite a coup that I've even got him. I'm an incredibly lucky woman. Incredibly lucky (Pauline, Ichthyosis)*

This sentiment was spoken about while describing their partner and their qualities, but it was apparent that participants considered their luck to include having obtained or retained their partners despite their visible difference:

> *I was quite lucky really with [wife] because we've been together, I met her when she was 17 so we've been together ever since… so it hasn't really had that much of an impact. Not to me (Pete, Cleft)*

Pete viewed his good fortune in meeting his wife at a young age as protecting him from the negative effects that he believed his difference could otherwise have had. It is noteworthy that there is a willingness to ascribe this to luck and to implicitly assume that another hypothetical path would be less beneficial. In a passage in which she spoke about rejecting her partner's physical advances because of how she felt about herself, Eleanor expressed her gratitude at having her partner and commented on his supportive and accepting nature, describing the impact upon their physical relationship:

> *If he can love me why can't I love me? So, yeah, it just it does become all a bit circular really. Because, yeah, I just feel overwhelmed with gratitude that I've got such an amazing husband who can be like that so why can't I embrace his advances? (Eleanor, Psoriasis)*

These expressions relate to two corresponding ideas. The first is that participants' enjoyment of a relationship depended to some extent upon chance. Secondly, participants in relationships were almost universally complimentary about their partners and how their partners coped with, responded to, or accepted their difference and this was seen to reflect their rarefied qualities and engender a corresponding sense of gratitude towards them:

> *It was almost like 'am I going to find someone that is accepting of this?' and then also, it's going to have to be someone really special that's going to want to take this on. I don't know whether that's the right way to think but that's how I thought at the time (Florence, Alopecia)*

Whilst this appreciation of partners may be positive in many ways, the combination of feeling devalued or discounted and feeling lucky and grateful towards a partner, contributed to a level of vulnerability expressed by some participants. This was explicitly acknowledged by Eleanor:

> *I was quite young, he was a fair bit older than me and I didn't see that he formed relationships with people who were vulnerable, and by vulnerability in my case I'd refer to, yes, I had psoriasis, I had confidence issues and I was quite a lot younger than him. But he liked people like that because they made him feel strong and I saw that in the relationship he went on to have and the one prior to ours (Eleanor, Psoriasis)*

Similarly, there was limited recognition that participants' feelings about a potential partner may be particularly influenced by that person's acceptance of their difference. Just as Charlotte spoke about reacting strongly to any attention she had as a younger person, Michelle pondered how this would influence current appraisals of prospective partners:

> *would that make my thoughts on them totally different, even I was a little bit dubious at first and thought 'oh I don't know if quite we're compatible, I don't know if you're really my type?' But then, who knows? If I had a response from them where they genuinely didn't seem to have an issue with my alopecia would that change my viewpoint on them? I wonder (Michelle, Alopecia)*

The potential consequences of such a response were expressly contemplated by Luke who, despite not feeling that he had done so, wondered whether some people with a visible difference may feel compelled to accept a sub-optimal relationship because of concerns about their viability as a partner:

> *I feel some people in the same boat as me may 'settle', if you like, for lack of a better word, whereas I think it has helped me because I've never gone out with a woman who, as far as I'm aware, cheated on me or anything like that or anyone who's too bothered about what people think about them and stuff like this (Luke)*

Luke's deliberation proved prescient as there were examples of participants attributing poor relationships to the presence of their difference. Whilst this comprised only a minority of participants, the feelings expressed are so powerful and important that they must be afforded recognition:

> *I ended up marrying the wrong person and I, I, looking back now, I mean I've had five years to think about this since we split up, and I think it was because I felt at that time that he was there for me, he wanted me and he was wanting to support me. I don't mean financially because I was still working, but he, you know, was being a moral support and I thought 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)*

> *I didn't have a girlfriend of any real meaning of the sense of the word until I was in my early 20's and then I went on to marry her, which I shouldn't have done (David, Cleft)*

Whilst it is possible that the breakdown of these relationships contributed to these feelings, it was evident that these participants believed that they had entered and continued with relationships because they felt no-one else would accept them, with three participants believing this led to their ill-advised marriages. Unlike those three participants, Valerie, who we have already learned felt that future relationships were an impossibility, did not state that she would not have married her husband but for her difference. She did, however, describe an abusive relationship and pondered whether she would now feel able to proceed with a new partnership if she looked different:

> *'I think it's very difficult for me to go into another relationship, and if I looked normal maybe it wouldn't, maybe I'd have got over it years ago but I think I've got these things that come back into my mind over and over, [husband] was the womaniser, was the wife-beater, you know? It's all confidence, it's all a lot of confidence and the way I look (Valerie, Facial Palsy and Breast Cancer)*

In summary, the contents of this theme may thus be interpreted as evidence that the impact of participants' difference upon their confidence and self-esteem, their feelings of being devalued, and of luck and gratitude all have conspired to create a situation in which some participants had felt vulnerable, willing to accept unfulfilling, unrewarding relationships.

5.3. Looking Different: Physicality and Physical Reality

This theme is devoted to the physical consequences of living with a visible difference so far as these relate to romantic, intimate relationships. Some participants talked about the self-care routines, treatment requirements, and health implications connected to their conditions. Whilst the research was concerned with appearance these matters offered a valuable reminder that visible differences may exist within the broader context of a health condition. Accordingly, some acknowledgement is given to these issues at appropriate junctures.

The first sub-theme to be introduced is ‘the Disclosure Dilemma.’ This theme was relevant where visible difference was not immediately obvious to others. It includes reference to the difficulties and uncertainty associated with making a new partner aware of the presence of visible difference. The second sub-theme, ‘Invading Physical Intimacy’ referred to the perceived impact upon sex and physical intimacy. This was of relevance both within the context of existing intimate relationships and to those contemplating new partnerships. Finally, the ‘Our Selfish Genes’ sub-theme incorporates participants’ thoughts and feelings about the heritability of their condition and the possibility of their children also living with a visible difference as a result.

5.3.1. The Disclosure Dilemma

The testimony of just over half of the participants contributed to this sub-theme which was, by definition, primarily relevant to those whose difference was not ordinarily visible or who reported concealing or disguising it. The sub-theme featured heavily in the testimonies of those to whom it was applicable, whether reflecting on historical scenarios, their present situation, or contemplating the future. For those participants, this theme assumed central importance to their experiences of visible difference within their romantic, intimate life.

‘The Disclosure Dilemma’ was characterised by participants expressing uncertainty and doubt about how and when to tell a new partner or show a new partner their visible difference. Uncertainty over the optimal time, how to present themselves on internet dating site profiles, nervousness about the reaction of the other, feelings of being dishonest, and the idea that this is an additional hurdle to overcome in the difficult pursuit of initiating a new relationship all typified the concerns expressed. Previous experiences of disclosure were not uniformly met by overtly negative reactions from others, with supportive responses being described by some, though others reported a cooling of interest often masked behind a façade of acceptance.

Participants recounted concern about having to contend with their visible difference and make a new partner aware of it at the start of a relationship:

> *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)*

Similarly, single participants discussed how this may impinge upon their ability to form a new relationship:

> *it's not even getting over the fact that they can see your face or whatever, I know that and they might accept "Oh that's how she looks" and blah, blah but then it's the intimacy bit isn't then? 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 (Valerie, Facial palsy and Breast Cancer)*

Whilst those that reflected on historic disclosure presented the scenario as difficult, it was particularly salient to those who were single and for whom it was likely to be or become an imminent situation to negotiate.

Participants expressed a great deal of uncertainty over how to broach disclosure, but it was clear from that they would rather tell a new partner than have them discover the difference. This was because it was felt that such a discovery would be likely to occur during physical intimacy, which may be impeded:

> *I probably didn't even give him a chance to notice it, I immediately talked about it. It's just, you know when you start a relationship with someone and you know that things are going to go to the bedroom at some point and you're like, I don't want it to just break the moment… "Oh wow! What is that?" So I just prevent that by explaining first (Vanessa, Psoriasis)*

Exercising control over the situation may also have enabled participants to prepare themselves emotionally for a negative response, to address the topic at a time at which they felt most comfortable, and to protect themselves from overtly aversive reactions. This sub-theme indicates the desire to exert control over a difficult situation in order to minimise the likelihood of the disclosure being poorly received due to their partners' shock or surprise.

It was clear, however, that the act of disclosure was not considered straightforward. This was, in part, attributable to the disconnect between establishing a relationship with a new partner, cementing feelings of mutual attraction, moving towards physical intimacy, and making them aware of a characteristic considered undesirable, unattractive, and that may engender aversive responses:

> *it's always kind of a tricky thing, you know, because obviously you're in seduction relation with someone and you have to tell them "Well listen I've got something a bit funny on my body" and also because I don't want it to freak them out, I don't want to scare them by*

> *saying "I've got to tell you something. I've got to tell you about my condition" (Vanessa, Psoriasis)*

Participants to whom this sub-theme was relevant possessed a stigmatised characteristic but were ordinarily able to control whether or not this was seen by others. Disclosing their difference necessitated that the variance between participants' prior presentation and the reality of their appearance was made explicit. This was addressed directly by only a minority of participants but underpinned the sub-theme:

> *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)*

Deciding how to manage the situation invoked much uncertainty:

> *I said to the kids "I really have got to tell him haven't I?" you know. When's a good time to broach it? You just don't know do you? And how, how is the best way to broach it? Face-to-face, phone call, text? I suppose it's cowardly of me but I think I'm going to do it by text and then they can panic and do whatever they need to do without me knowing about it sort of thing, rather than… I think if I do all face to face it's awkward for them to show a true reaction of how they really feel about it (Michelle, Alopecia)*

For some, the disclosure requirement could be very off-putting, and even diminished Ruth's interest in pursuing a relationship:

> *It's put me off forming a new relationship. I mean I've tried internet dating and I'm always conscious of when I, if I meet somebody I'm thinking about whether or not I want to tell them and actually maybe the first thing that you're thinking about, I'm just thinking "no, I don't like this person enough to tell them" (Ruth, Alopecia)*

In light of the difficulties and uncertainties introduced, it is not surprising that several participants spoke about planning disclosure. Beth spoke about meeting partners from on-line dating sites:

> *before we meet, this has been an issue in the past with other people, I just want to say "I've got, you know, a rather large scar on my face and it's not for everybody and I'd rather be upfront before we met than feel like the date went well and not get a second date." And I kind of said "this has happened in the past. It's nothing personal but I'd rather you*

> *know rather than go through the whole stress of meeting and then not get a second date because of it" (Beth, Facial Scarring)*

An early disclosure is thus seen as serving a protective function, insulating Beth from future rejection. Other participants spoke about becoming skilled at turning conversation during early dates toward their appearance:

> *I've probably been seeing this guy since before the summer, which is the longest ever. And by the way the first thing, he knew I was doing the run and when I met him he said "Oh, so who are you running for?" so literally within the first… I said "Yeah, I'm running for [charity] because I've got no hair. I'm wearing a wig by the way" (Anna, Alopecia)*

The disclosure itself was premeditated but the exact manner remained flexible and fluid in nature. Anna had made the other person aware that she was undertaking a charity run and so it was likely that they would ask that question, providing an opportunity to disclose. Likewise, Michelle spoke about leading the conversation towards her dating profile pictures which provided a similar opportunity. This planning and these deliberate strategies introduce a related idea, that of timing:

> *I've not been that close with anyone, or certainly not close enough to tell them and that's been my big thing, is going on dates, when, when do you tell somebody? It's quite a big thing to tell somebody that you don't really know. But then, if you go on for too long are you lying to them? (Ruth, Alopecia)*

Florence even carefully considered the exact point during a date when this conversation would be best had:

> *I did it at the right point in the evening. I didn't do it in the restaurant or in the club or anything like that. I did it when I dropped him off and we were just chatting in the car and we chatted for ages and I did it then. In private. It was like "If you don't want to do this you can just get out of the car and I don't have to see you again" (Florence, Alopecia)*

Concern about the potential reaction of the other motivated Florence to disclose at the end of the evening, where there existed an immediate escape route for both herself and the other. The disclosure was only made at a time and in a place where it would be possible to minimise the adverse consequences of negative response. At other times the physical environment could be a factor that may lead to an undesirable, inadvertent disclosure and therefore could dictate the timing of disclosure:

> *I actually met one man off the internet, I met him the first time somewhere or other and the next time we were going to go punting. So I said to him "oh there's something I'm going to have to tell you." "Oh well wait 'til you see me then, tell me on the date." I said "Well I didn't want to bring it up on the first date because I didn't want to frighten you or anything but we're going punting, I think I ought to tell you" and my thought was if anything happens and I'm punting, with the pole and I get it stuck in the bottom of the river and I fall in, it's likely going to fall off and he's going to have a bit of a shock, so I'd better just tell him (Elaine, Alopecia)*

It was clear that participants did not feel that they could delay disclosure indefinitely. Aside from the possibility of an inadvertent or accidental disclosure, earlier disclosure was understood as serving a protective function:

> *I did it early on. I did it on the second date because I knew that… it just felt like it was going to continue and I thought "right, let's do it now because if I do it a little bit down the line and he's not accepting of it, I'll be more upset." Yeah, of course, I would be upset anyway of somebody going "well actually I don't want to be part of that" but I thought let's not get into something and then have it fall apart because of alopecia when I can do it at an earlier stage and maybe it hurt a little bit less (Florence, Alopecia)*

This exemplifies the balancing act that participants made when deciding how soon to disclose their difference. The opportunity to have a relationship develop without being overtly influenced by visible difference was weighed against the additional pain that may be experienced if that relationship ceased as a result of a later disclosure.

Questions concerning when to disclose difference appeared to be somewhat amplified for those using on-line dating services. As a decision about the viability of potential partners' is usually based on a picture (or several) and, often, a short biography, the issue of visual presentation becomes immediately salient. Participants were very conscious of their choice of pictures:

> *I'd been to the races and my friend's a professional photographer so I used that picture as my main picture and then I kind of did pictures that didn't really have close-ups of my face, I'll be quite honest, but then I had a picture of me walking up [redacted] coz I'm into walking so again you could tell it was me but it wasn't really close-up on my face (Beth, Facial Scarring)*

Beth deliberately chose pictures which minimise the visibility of her difference and emphasis other aspects of her life, her interests and activities. Some participants could not countenance the thought of using a picture that included their visible difference:

> *I go through phases where I date and I have used on-line dating sites and things like that and I, I obviously I do not post a picture on there with me without my hair. I don't say anything that I have alopecia but I do feel like if I do decide to meet them it has to be one of the first things I tell them (Anna, Alopecia)*

This reaffirms the idea that disclosure represents a milestone that some participants felt must be addressed early in a new relationship and also alludes to the perceived impossibility of utilising a photo that identifies the difference. Anna's use of the word 'obviously' highlights just how incompatible she considered the use of such a photograph to be with dating sites. Michelle's experience of using a site where her friends wrote her profile and chose her pictures confirmed this:

> *I have no thoughts on the best approach because I get different thoughts off different people. Yes, tell them, be honest from the start, which I tried with my lovely friends and the [website name] and I got no response whatsoever. Lots of people having a look but then nothing. So, yeah, I think, I think at the moment I've got photos of me with hair and a couple of daft ones without so if they want to ask me about it it's there and they can (Michelle)*

Michelle's reference to the 'daft' photos is an example of her deliberately creating a situation in which she can disclosure. The photos she talked about included one without a hairpiece and in which she is polishing her head. On dates, Michelle encouraged the conversation towards profile pictures. It seemed that some people assumed she had shaved her head for charity and using the photo in this way introduced the subject of Michelle's Alopecia in a controlled and relaxed manner.

Uncertainty over the use of profile pictures prevented Ryan from using dating sites at all. Whilst not necessarily being mirrored in the experiences of other participants it is illuminating to illustrate just how debilitating appearance concerns and the nuances of the disclosure dilemma could be. Ryan did not wish to use pictures that he felt misrepresented his appearance but also was not comfortable using pictures of him as he had looked previously (before he had Facial Palsy). This encapsulates the essence of the disclosure dilemma, being caught between two options neither of which are considered conducive to establishing a new relationship:

> *if I went on a dating site or anything like that or, I would want to, if I put pictures on of myself, I would want to use pictures where you can't tell or pictures before I got it but then obviously that's not necessarily telling someone the whole story… I wouldn't go on a dating site [using pictures] I wouldn't want to put pictures of myself as I am at the moment or as I have been because I think that portrays me in my best way but therefore, I'm, therefore, not using the dating website or not going forward with things (Ryan, Facial Palsy)*

Ryan was in a very small minority of the participants who spoke about this sub-theme and whose difference was normally visible. He was, however, in certain situations (such as the use of dating profile pictures) able to minimise its visibility. When interviewed Ryan, had lived with his difference for approximately one year and had spent some of that time in his prior relationship. It is possible that his lack of familiarity and exposure to difficult and challenging situations had left him feeling ill equipped to manage them and so contributed to this avoidant response.

Whilst the issues discussed within this sub-theme so far may be characterised by uncertainty, one topic was not considered to be open to debate. This was whether disclosure was required. In addition to practical considerations and the risk of inadvertent discovery, there also existed an ethical or a moral dimension. It was clear participants felt a degree of responsibility regarding disclosure:

> *I think that's almost what I hope for, is that somebody takes that responsibility away from me so that they know already and I don't have to explain it to them (Ruth, Alopecia)*

> *I'd want my friend to tell them everything. If they said yes then fair enough, if no then I wouldn't want to know whether… the Bell's Palsy was part of the issue (Ryan, Facial Palsy)*

This responsibility could extend beyond responsibility into obligation:

> *When you start staying over with someone new then I felt like I have to tell them (Chloe, Facial Birthmark)*

Chloe was talking within the context of describing her desire to escape accidental discovery but there is also a suggestion that something so fundamental could not be withheld from a new partner even if, as in the case of Chloe, this may have been possible. It was striking that it was considered an act of honesty to fulfil this obligation in a timely manner:

> *my friends are saying "You're selling yourself short, don't let them… why tell them that?" But then I just thought I'd rather be upfront and honest because I am quite an honest person (Beth, Facial Scarring)*

As disclosure was seen as an act of honesty, not disclosing was sometimes spoken about as constituting a dishonest act:

> *so I've just got to be honest. I just think I've just got to get it out there really straightaway so that they can't say oh you've concealed it or you've hidden it from me or you're living a lie or you're, whatever (Elaine, Alopecia)*

Whilst participants desired a sense of normality (examined within 'Comparative Normality' in 'Our Socially Situated Appearance'), acting and appearing 'normal' would involve not disclosing their difference. This was considered dishonest and participants felt that this option was not available. This dissonance between the desire for normality and the obligation to disclose was invariably resolved by sacrificing the desire for normality and disclosing at an early stage in fledgling relationships. Speaking again about dating profile pictures (and her strategy of including one 'daft' photo amongst others where she is wearing a hairpiece) Michelle said:

> *I've 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 (Michelle, Alopecia)*

She felt obligated to disclose her difference early, despite concerns over how this may impact the level of interest in her as a potential partner. Her strategy provided an opportunity for her to raise the issue with a potential partner, but it is clear that her desire to not act dishonestly was a motivating factor, dictating the timing of her disclosure.

Whilst participants did not explicitly make this connection, these thoughts are consistent with the idea that establishing mutually satisfactory partnership represents a negotiation or transaction. One attribute that is afforded high regard and that is used in this transaction is physical appearance. To misrepresent oneself was therefore considered by participants to be a transgression and early disclosure was necessary.

Having established how the disclosure dilemma was experienced, as a stressful event characterised *by* uncertainty, it is interesting to consider participants accounts of actually disclosing their difference to a new partner. Despite the concern and uncertainty that disclosure engendered, some participants reported experiences that suggested the reality of disclosure could be less threatening than feared:

> *None of my partners have known I've had a birthmark until later, either when I've told them, well normally I've told them before they've seen, but no-one's been put off or bothered by it (Chloe, Facial Birthmark)*

This inconsistency between actual experiences and nervous contemplation or anticipation is interpreted as being a further example of the strength of association that is believed to exist between attractiveness and worth as a partner (see 'Appearance Attracts and Detracts')

Florence offers a description that encapsulates the sense of obligation felt by participants, her surprise at the positive reaction of the other party and the supportive, understanding reaction that was sometimes received when engaging in the disclosure scenario:

> *you almost start thinking 'Oh God' if you start seeing this person continually at some point you've got to say, and I told him on the second date. I just came out with it. I just said to him "look, I've got alopecia, I've got lupus" and do you know what he said…? "My Mum's got lupus. She's got the other type, which is really not great" and I said to him "look, I don't know what's going to happen to my hair. It's very unpredictable, it does what it wants, I'm on medication at the moment but it might not be long term." He sat there and he went "It doesn't bother me." I think he said "thank you for telling me something very personal" (Florence, Alopecia)*

This opens up a new possibility, that disclosure can be a positive and personal intimate exchange. Florence continued, describing how her partner had been very supportive and helped her buy accessories related to her condition, attended support groups, regularly shaved her head, and defended her from the intrusive comments or stares of others. This ability to act in a supportive and understanding manner was evident from the very moment of disclosure. Vanessa, who generally experienced little distress as a result of her visible difference, also spoke of not receiving any negative reactions to the disclosure of her Psoriasis and, uniquely, was able to recount an incident of mutual physical revelation with a partner who also had a visible difference:

> *when we came to intimate relationship and we got undressed, I was looking at him and he was looking at me and it was quite odd. Show me your scars, I'm showing you mine. So, yeah, we were just observing. It was, it was quite interesting in a way because we're both scarred in a way although I feel much luckier than him. But yeah, it was quite odd and I think that he felt quite great about it because, well because he probably has never*

> *been with another woman who had scars or anything like that and he's really not good with his physical aspect and so the way his scars are affecting him is really bad. So that was quite odd but quite soothing in a way (Vanessa, Psoriasis)*

Whilst both Vanessa and her partner were previously aware of one another's difference the act of physically revealing difference for the first time was presented as being a rewarding interaction. This is, of course, founded and dependent upon a positive and supportive reaction being provided by the recipient. It suggests that under certain conditions, participants found disclosure had the potential to be a positive experience that enhanced feelings of closeness.

The reliance on another person and their reaction to help facilitate an affirmative, encouraging and beneficial disclosure may explain, in part, the anxiety participants felt in connection with disclosure. Participants felt compelled to disclose early in a relationship when their knowledge of the other person may necessarily have been limited. They understood appearance to be crucial to attractiveness and felt dishonest, despite not being confident in predicting the reaction of the other. This unpredictability may be considered central to the distress experienced. This is borne out in the descriptions of less constructive reactions:

> *I was quite honest, with internet dating I kind of went on a few dates and then didn't get second dates and I was wondering was it because of how I looked so then, as soon as people messaged me and it got to the point of meeting up, I was quite open about my scar with them. Some didn't then respond back and blocked me on the site, which I felt was a bit harsh, and never an explanation (Beth, Facial Scarring)*

That this was done by some but not all of the persons that Beth entered into contact with and illustrates the apparent unpredictability which can only serve to make disclosure more challenging and prescient. Where reactions were negative, they were not necessarily overt and explicit. It is possibly because it is not considered socially acceptable to offer a visible difference as an express rationale for discontinuing romantic interest:

> *I suppose a bloke doesn't want to turn round and go "Well actually I'm not interested because you're bald" (Anna, Alopecia)*

Whilst appearance was considered by participants to be fundamental to attraction, they perhaps viewed it as taboo or uncomfortable for others to acknowledge this.

Returning to Michelle's use of humour in order to introduce disclosure seems a fitting way to conclude the examination of this sub-theme. Michelle's extract includes references to her anticipation of the moment of disclosure and her strategic use of the unusual photo to introduce the topic, her direction of the conversation towards it, allusions to previous instances of disclosure being poorly received and a veiled but discouraging reaction which, led to the conclusion of the exploration of a possible relationship:

> *I did say to him "oh, while we're talking about pictures…" he went "yeah?" I said "That one on my profile with the brasso…" and I could see straightaway he was like "phoar, bloody hell, yeah, I was a bit worried about that because I only flicked back through your photos after you'd agreed to meet me!" and I thought "oh no! Here we go, here we go, here we go again!" He said "I was wondering what was that all about?" and I thought "oh" and I said "oh well that's me, that's me as I am in all my glory!" and I could see like… confused and like "I'm wearing a wig!" "Ohh!" like it was dreadfully uncomfortable… I could see he was really uncomfortable right from that point. Thankfully, he had another pint and seemed to calm down a little bit and I had a nice couple of texts off him on the evening after we'd parted ways and I sent him a text on the Sunday and it's just another one, fell by the wayside again, again. But hey-ho (Michelle, Alopecia)*

5.3.2. Invading Physical Intimacy

A strong majority of participants talked about how they believed their visible difference impacted upon sex and physical intimacy. This occurred in three main ways. The first was to act to reduce participants' desire to engage in physical intimacy, primarily as a result of their discomfiture surrounding their difference. These feelings feature in the second-order sub-theme 'Corporeal Disinclination.'

Secondly, a smaller number of participants described unease at their difference being seen by their partner during sexual encounters. Strategies were employed to avoid this occurrence. The second-order sub-theme entitled 'The Shrouding' addresses participants' compulsion to cover themselves in this way. Finally, 'Stealing the Moment' is dedicated to reflecting how appearance concerns and preoccupations were understood to act to reduce some participants' sexual enjoyment and pleasure, and detract from their ability to be in the moment.

Before discussing each of these second-order sub-themes it is important to acknowledge that a small number of participants alluded to non-sexual contact with people other than their partner and how this could also be challenging. Whilst this does not form a substantial part of this theme, it is important to acknowledge that these forms of physical contact may also be affected:

> *I work in a school and the kids come and give you hugs and stuff and if it was on this side I'd be like… I mean you know they were only "Oh Miss [name] can you give me a big hug?" I was like that "Oh my gosh" because it wasn't… but obviously they wouldn't know that. And it's not because there was pain or it was a risk to… it was just that, you know, feeling of "No I don't want you to be near me" (Karen, Breast Cancer)*

It is also crucial to recognise that some participants did not consider their difference to have impacted upon physical intimacy in any way. This represented a diversity of experience and illustrated that the impact of living with a visible difference varied greatly between participants:

> *it's never held me back sexually either. Without mentioning a number, I don't know exactly, but I've had quite a, quite a good sex life, if you like (Luke, Cleft)*

> *So, intimacy, no I think that's never been an issue. And most of the time I forget it's there, it's only when I see pictures or I catch my reflection and I think "Oh, yeah, I forgot about that." So a lot of the time that I do forget about it if I'm comfortable with someone (Beth, Facial Scarring)*

5.3.2.1. Corporeal Disinclination

This was discussed by approximately half the participants. These participants spoke about experiencing a reduction in their desire for sexual contact:

> *I have at times not wanted to take someone home, especially when I was particularly suffering, and then you do your best to try to forget it and get on with it, but it can be inhibiting (Austin, Psoriasis)*

Participants closely associated their disinclination towards physical intimacy with feelings of being unattractive:

> *I just went off things, yes. I just did not feel attractive at all (Elaine, Alopecia)*

> *I think, you're not ill the whole time. You can do whatever but when you haven't got any hair on any part of your body and you've got one breast, sorry, you're not going anywhere near me! (Karen, Breast Cancer)*

The specific impact of Breast Cancer and its treatment upon the hair and breast seemed particularly important to the participants who had experienced this condition. The physical consequences impacted substantially upon appearance and this explained the marked effect upon sexual activity within a relationship:

> *our sex life has been completely interrupted during all this. Making love and what have you, it is very sporadical really and I kind of know when we're going to do it because I leave a bra on I suppose. You know, it's, yeah, I think the whole situation, the chemotherapy and all that, just has taken away every idea of femininity completely and left you with… 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, things like that, it just strips you of all that and it is tricky. It is hard to actually come back from that (Jodie, Breast Cancer)*

Jodie clearly expressed the denial of her sense of femininity occasioned by alterations to her appearance. Sitting alongside 'the Disclosure Dilemma,' which was discussed in some considerable depth by women with Alopecia, this suggests that conditions which affect gendered or sexualised areas of the body presented particular and acute challenges in negotiating sexual intimacy.

It was evident that participants understood both their own feelings and those of partners to be influenced by their difference:

> *I think if there is ever any rejection it comes from me rather than him, because of my self-consciousness I suppose (Eleanor, Psoriasis)*

> *I don't want to speak badly about her but I think it did because it does affect things. You know, definitely the sex side of it changed. Again, whether that was just the way the relationship was going or it was a contributing factor it's hard to pinpoint but we didn't have sex at all really in the last year of it (Ryan, Facial Palsy)*

Whilst Ryan entertained the possibility that the relationship was deteriorating regardless of his difference, he empathised with any reluctance to engage in sexual activity that others may demonstrate:

> *I couldn't see why someone would want to have sex with me when I wouldn't if I… sort of I thought if I was in their shoes. Yeah, my sex drive definitely dropped down quite considerably (Ryan, Facial Palsy)*

For Austin, whose condition fluctuated, physical intimacy was only possible when his Psoriasis was subdued:

> *there have been times, especially when I'm having therapy when I've just thought "Oh well, sod this, I'm not going to try to approach anybody until it's better". And there are times when I'm very, very bad where I don't at all because it just, it just scares me I just think to everyone I look like a monster (Austin, Psoriasis)*

Whilst Austin was talking about initiating a relationship, participants also spoke about rejecting their partners' sexual intimations:

> *it was two months after me moving in it all went haywire, at which point he as thinking, well I moved in, I suppose he was thinking I'd be jumping on him sexually all the time and, of course, I was in such a complete state of, well, devastation so I just didn't feel at all sexy or attractive or anything so that side of things was really struggling (Elaine, Alopecia)*

> *I've rejected him, sort of rejected his advances from time to time, simply because I feel unattractive (Eleanor, Psoriasis)*

5.3.2.2. The Shrouding

This sub-theme was spoken about by approximately one-quarter of the participants. Despite this it forms an intriguing component of the 'Invading Physical Intimacy' sub-theme. These participants spoke from within relationships that they described as stable and supportive but felt uncomfortable at being seen naked by their partner. Pointedly, their concern was specific to their visible difference:

> *I think it's feeling how I felt about myself and worrying what he would think about that, because for a woman that's part of who you are in a weird sort of way and I just didn't really want him to… I mean he's never, he never actually saw 'it' (Karen, Breast Cancer)*

By 'it' Karen was referring to the scar tissue and unreconstructed breast that followed her mastectomy. Being unable or unwilling for a partner to see a difference may suggest that it is considered in some way taboo or unacceptable. Participants were therefore very deliberate in concealing their difference in this way:

> *I've got very conscious of my body. [partner]'ll say to me "why are you covering yourself up?" He'll walk in a room and I'm like that or wrap my towel round me or whatever "why're you doing that?" and I can't say, I'm just not comfortable and he doesn't like it when I don't feel comfortable because I weren't like that when I met him (Sian, Ankylosing Spondylitis)*

Participants felt compelled to shield themselves from the very intimate gaze of their partners, though they acknowledged that their partners would probably not have had any issue with seeing their difference as they were supportive and understanding in other ways. For Sian, however, being seen could remove the feelings of closeness, intimacy, and trust that characterised this 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)*

Jodie spoke about how she did not want to be seen naked by her partner, how she wore a bra during sexual activity in order to cover her difference, and of her continual hope that the next operation or procedure would restore her physical normalcy. She believed that if this was achieved physical intimacy would return to her relationship and she would be comfortable being seen:

> *then the implants came and then they weren't what I thought they were, and then one rejected so then it's a few months on and then I had to wear a prosthesis for six months, which was abs… I hated, that was terrible because I was completely flat on one side and that was horrible. I just didn't even want to let him see me naked then because I felt awful. So it's kind of an on-going thing where it probably is an excuse "oh well just another operation and then I'll be better and another operation and then I'll be better and then we'll get back to normal" (Jodie, Breast Cancer)*

Karen spoke in a similar manner and for some time her sexual life remained dormant whilst she awaited reconstructive surgery:

> *I joked with my friends, like women do, just joke about stuff, and I'd said "oh yeah, haven't had sex for three years, ha! ha" and tried to turn it into a joke… but I kind of in my head kept thinking "well once I've had my reconstruction…" you know, I couldn't even think about it until then (Karen, Breast Cancer)*

Whilst Jodie had appeared to recognise the cyclical nature of these thoughts, later in the interview she subscribed to the contradiction that she had previously exposed:

> *I'm just really looking forward to getting my surgery completed and then, and then finally saying right that's it. No more. No more now, let's just be happy with what I've got and just get the intimacy back (Jodie, Breast Cancer)*

5.3.2.3. Stealing the Moment

Half the participants spoke about their visible difference acting to detract from their ability to enjoy physical and sexual contact. The presence of a visible difference was experienced as something that could cause participants to feel self-conscious and uncomfortable, stealing the moment from them.

Within ‘the Disclosure Dilemma’ Vanessa described how the disclosure of her Psoriasis to a new partner was motivated by a desire not to “*break the moment.”* Other participants discussed concern about unintentional disclosure:

> *I remember one guy, we went on this date… and he launched in to kiss me, you know, we’d only been out for a couple of hours or something and it was like he just thought he’d… and he kind of put his arms into, you know, grabbed my neck and stuff and it was like and I screamed! I screamed because I just suddenly panicked that he was going to put his hands in and send my wig flying and I screamed and jumped back and then I obviously had to explain to him and he, he couldn’t cope with it either (Anna, Alopecia)*

The ability of visible difference to impinge upon moments of intimacy was not limited to circumstances where disclosure was a concern. Luke spoke about feeling excessively nervous when he first kissed somebody as he felt this act focussed attention on his difference:

> *My first kiss was probably more nerve-wracking that the first time I had sex, to be fair (Luke, Cleft)*

This was not necessarily the result of a partner noticing the difference or behaving in a way that made participants feel uneasy:

> *I still feel like this from occasions now with intimacy, sorry. But I know he’s not looking at it, or my ex-boyfriend wasn’t looking, obviously busy doing what else! But I’m… 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)*

When talking about having to move, Charlotte was referring to adopting an alternative position during sex so that her Cleft was not visible to her partner, reasserting that she does not believe this originated from her partner:

> *Well I don’t kind of go “by the way, I’ve got this, I’m turning” or whatever “I’m moving” but, I don’t know, we’ve never had a conversation about it. Maybe he doesn’t even notice. I don’t mean that… oh, I don’t know how I mean that. Yeah I don’t know how to respond*

> *to that without being… I don't suppose he, obviously the deed that's being done, he notices, you know? It's me and then I obviously feel fine once I've turned… whatever and then off we go and it's fine. So I don't think he is worrying (Charlotte, Cleft)*

A limited number of the accounts indicated that this unease could manifest itself as a physical sensation experienced as and when the affected body part may be touched:

> *if ever he goes to touch my breasts I feel [gasps] "oh" kind of thing. I like to keep a bra on. I don't know why because I just really don't like the look of what I've got at the moment and until I'm kind of completed with nipples then I feel quite conscious (Jodie, Breast Cancer)*

As such, it is possible that the 'The Shrouding' is motivated in part by a desire to minimise the likelihood that participants' consciousness of their appearance may break or prejudice intimate moments. In addition to covering a difference, some participants spoke of adopting deliberate strategies to reduce this consciousness and increase the chances of their sexual activity proceeding uninterrupted:

> *I've had another occasion where I've had a fair amount of it and what I did was, I did make sure that I had a shower before, before congress, as I think they call it! But on the whole people were ok about it... But it was more me and my self-consciousness more than the lady concerned (Austin, Psoriasis)*

Some participants, however, were able to integrate their difference into intimate exchanges:

> *when the wig is there I don't want, you know, him to knock… I suppose… I think at one point I think one guy that I slept… I didn't sleep with hundreds, by the way, it's just like [inaudible] and I asked him to take it off… we ended up in this position and I was just like "I'm not going to keep this on, you've got to undress me, all of me and take my hair off" and it was just like "it's part of the whole thing" (Anna, Alopecia)*

Like Anna's clothes, her hairpiece must be removed in order for true intimacy to be achieved and her partner's acceptance of her and her Alopecia confirmed. Whilst other participants may not have integrated their difference into a sexual encounter in this way, Florence experienced non-sexual physical intimacy with her husband:

> *He shaves my head every few weeks and we laugh about that (Florence, Alopecia)*

It is therefore apposite to conclude the examination of this issue by highlighting the potential for a visible difference to be acknowledged within and integrated into sexual and intimate activity and even create new occasions and activities where closeness, trust, and support may be shared.

5.3.3. Our Selfish Genes

This theme was spoken about by just under half the participants. Its applicability was restricted to those with conditions with a genetic component. Participants considered the possibility that their children may acquire the same condition and visible difference as they had:

> *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. So, that's probably the only time that we've really discussed it to any extent (Anthony, Cleft)*

Anthony's comment about not necessarily having done anything different may be interpreted as Anthony saying, covertly, that he and his partner would not have considered a termination if the child had a Cleft. Acknowledging that this may have been a possibility could be distressing so Anthony was not asked to explain further what he meant by this. A little later he did say that:

> *…..it wasn't something that we contemplated, not having a family because of it or anything (Anthony, Cleft)*

and, more explicitly:

> *…..would we have considered termination or anything if either of the girls had been diagnosed as having a cleft? No. (Anthony, Cleft)*

These comments were not provided in response to a direct questions about their choice to have children. The options of not having children or terminating a pregnancy may have been explicitly and immediately dismissed, but their very existence speaks to the power and importance ascribed to the possibility of children being born with an appearance altering condition. Anthony's comments were not unique:

> *it's a good thing that you're having a child and there was never ever any, I was never, [wife] never ever said 'oh well do you think it's wise that we have kids because they could be born like you,' or whatever. It was never ever implied, it was never ever that way (Pete, Cleft)*

Pauline did not have children and spoke candidly on this topic:

> *I actually made a choice not to have children and I made that choice very, very young. a) I wouldn't have been able to cope but b) I didn't want to pass this on. I wasn't even aware that I could pass it on but I wasn't taking any chances. That wasn't a hard decision to make, I'm not that maternal but if I ever mention this to other women they are, rather sadly, very proud of me for doing that. You know, really "good for you! Really good that you did that." It's this sort of unspoken, eugenics (Pauline, Ichthyosis)*

It would be remiss, however, not to state that Pauline was talking as much about the health implications associated with her condition as she was about appearance concerns. The potential impact that living with a visible difference might have upon their children's lives was important to participants:

> *(I) wouldn't have wanted them to have had a hare lip cleft, it would've been a disaster for me thinking well they've got to go through all this (David, Cleft)*

> *I always knew there was a chance that [daughter] could have inherited it. She has and that side of it I beat myself up about because I don't want her to go through what I go through (Sian, Ankylosing Spondylitis)*

Pete speaks of being *'terrified'* during all of his wife's pregnancies and echoes the idea that appearance is very important in a girl/woman'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 did not wish their children to be subjected to the unpleasant experiences and feelings they had endured. The implication was that society and its structures are unforgiving and contribute to a sense of misery and exclusion that living with a visible difference can engender. The participants did not express personal prejudice or indicate they would care for their children any less but wished to protect their children from negative experiences. This could extend beyond Anthony's immediate disavowal of the options available and Pauline's decision not to have children to Charlotte expressly considering the viability of a pregnancy:

> *I do remember going to the hospital, I know this sounds so bad, thinking, because they can check on the scan if they've got it. And I know now, I don't know what I would do actually if they picked it up and they said "yes it has got a cleft lip and palate." It is the*

> *first question I asked on both my boys, not has he got arms, legs or… has he got a bone in his mouth? (Charlotte, Cleft)*

> *I know it's wrong but I don't know if I could say hand on heart if I would follow through with the pregnancy if they had said yes. Purely on the basis I know what it was like to go through it and I wouldn't (Charlotte, Cleft)*

Despite being entirely outside of their control and no participant expressing any anger or assigning any responsibility to their parents for their own difference, the participants' testimony may be interpreted as describing a sense of responsibility that they would feel if a child were to 'inherit' their condition. This was evidenced in the concern and fear felt about the effect it may have had upon their children's lives, the consideration given to termination of pregnancy, and the reluctance to contemplate their own child having to live with a visible difference. Whilst this was not overtly discussed, the one participant whose child had the same condition as she did, spoke about deriding herself for this and feelings of guilt were evident. It is possible that concern about the genetic legacy a parent leaves for their children coupled with the social world into which they are born, goes some way towards provoking the distress that participants felt their selfish genes created.

5.4. Looks Help Delineate and Define Relationships

This final theme encapsulated participants' understanding that relationships could serve to enrich their lives and offer some protection against the negative aspects of living with a visible difference. Whilst some participants felt restricted in their ability to engage in a healthful partnership, participants currently in relationships believed that they benefited from the support and acceptance offered by their partner.

The ability of a partner or potential partner to offer support, acceptance, and understanding was conceptualised as providing some kind of insight into the character and qualities of that other person. As such it constituted a 'Litmus Test' and offered insight into the likelihood of the relationship flourishing. This early acted as filter, whereby those demonstrating insensitive reactions could be rejected or discarded

Where the Litmus Test was satisfactorily negotiated, nurturing relationships were highly valued and viewed as exerting a positive influence upon participants' lives, in some cases, even lessening the impact of visible difference. Visible differences were also understood to be capable of influencing relationships positively, providing them with a sense of legitimacy. These ideas are discussed within the second sub-theme, 'Enriching and Fortifying Us.'

Finally, 'Treasured Support' encompasses participants' descriptions of the support that they received from partners. Experiences of the support provided and participants' feelings regarding the ability of the healthcare profession to offer support are also explored here.

5.4.1. The Litmus Test

The reaction and sensitivity of a partner or potential partner to a visible difference and their treatment of participants was understood as an indication of the nature of that person and their suitability as a partner. This acted to sort caring, committed, viable partners from others. This applied irrespective of whether disclosure was required, though naturally a disclosure situation brought the reaction of the other into specific and sharp relief.

More than half the participants spoke about the idea that another person's reaction to their difference could relay a message about that other person and their suitability as a partner:

> *I've got to just be myself, this is it, you know, take it or leave it kind of thing. If someone can't stand the fact that it is what it is then they're not right for me (Elaine, Alopecia)*

In addition, this response communicated information about the likelihood of the relationship progressing. Anna spoke about taking off her hairpiece in front of her partner:

> *I don't want to give up but maybe I should I think... it's quite a difficult thing and you'd like to think that someone would try and make me feel a bit more comfortable but then he's not really engaged on that emotional level with me at all so I kind of think sometimes we're just friends (Anna, Alopecia)*

As well as providing an indication of the potential of a relationship it was clear participants considered a partner's reaction to say something about the character of that other person:

> *some of them I thought was a bit sly because they would say it wasn't an issue but then would be very cruel with their messages. You'd get the messages through, you're on line, they'd tail the message off. I thought that was more their issue that you can't even be honest to just be upfront and say "no it's not for me." That annoyed me a little bit. I'd think I've been upfront and honest and yet you can't do that back (Beth, Facial Scarring)*

These comments illustrate the disappointment and distress that such responses may entail but also, crucially, allude to an assessment or reassessment of that other person. A poor response was capable of inducing a negative appraisal of their character:

> *if I get to know them and for some reason they just… are a bit superficial about things then you'd know if they're not the kind of person like you'd want to be with so… You really tell someone's personality if you get to know them and they're liking someone for who they are rather than what they look like really (Ryan, Facial Palsy)*

Correspondingly, participants valued and appreciated those who did treat them well and who did respond and react well to their difference:

> *I think the people you end up with as friends and partners are extremely genuine people. The people you've got in your life are probably pretty, they're quality stuff, they're really nice people (Pauline, Ichthyosis)*

> *so, for me, I've found the right person for me because he's totally accepting of it and even when we're out and about and I'm stared at he'll have a go at people (Florence, Alopecia)*

The reaction of the other may thus be interpreted as representing a test they must pass in order to be adjudged suitable for a relationship. Participants presented the response of another as being something for which that other was ultimately responsible. Participants' accounts contained a strong sense that visible difference could detract from their self-worth, self-confidence, and value as a partner (see 'The Discounted Self'). It was only rarely that those who made such judgements or encouraged such thinking were held as being culpable for their actions. Such culpability was discussed in connection with negative reactions:

> *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)*

and with reference to an unkind comment (on social media) of an ex-partner:

> *"you know what? You've just proved that I don't, that I shouldn't be with someone like you'. So, he kind of... It's a bit sort of cathartic really that that was the end and that "Yeah, you're not worth it mate. You don't deserve someone like me" (Beth, Facial Scarring)*

This represented a paradigm shift in responsibility. Where participants were able to respond in this way, they could override the social pressure they felt to look a certain way and instead place an expectation upon the potential partner that they would value them for who they are, not what they look like. Where negative reactions were contemplated they were not presented as reflecting a lack of value and worth inherent within participants, but a failing on the part of the partner.

Whilst this sub-theme may be considered positive in nature and hint at a level of resilience, Michelle did ponder whether a positive response may result in her finding another person more attractive than would otherwise be the case:

> *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 hope. 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)*

Despite this possibility being presented in a constructive manner, such feelings may contribute to the idea of vulnerability that was introduced in 'Lucky in Love' within 'The Discounted Self'. Being especially accepting of another because of their reaction to one's appearance may lead to other aspects of their character or suitability being given insufficient attention, potentially increasing the chances of one settling for, compromising, or entering unrewarding relationships, as per the 'Lucky in Love' sub-theme.

5.4.2. Enriching and Fortifying Us

The acceptance of a visible difference by a partner was considered to indicate a level of depth and legitimacy within a relationship and that it would endure. Some participants also attributed positive elements of their personality to their experiences of having visible difference and argued that they and their relationship may have been less robust if they had not had these experiences.

When speaking about their current and desired relationships several participants spoke about their need for emotional intimacy, companionship, and a mutual connection extending beyond appearance:

> *I think as long as I can go and climb with him and walk up mountains with him that's more important than how I look (Chloe, Facial Birthmark)*

This could be understood to transcend and even supersede physical intimacy and sex and to form a fundamental component of a shared humanity:

> *I think everyone is… we're social animals, we need this loving and companionship. Not just sex or anything else like that, it's the companionship (Anna, Alopecia)*

There was a sense that others, especially those who place much importance upon appearance, may concentrate upon looks with their eventual relationships being vacuous and lacking in substance:

> *At the end of the day, looks don't matter. It's what the person's like inside. I know it sounds trite but I think it's probably true. 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)*

> *You watch something like The Only Way is Essex and you see idiots on there who're all about their appearance and one way or another relationships never last because they're in love with themselves more than they are their partner, if that makes sense? And you see that in every-day life. You see good-looking people getting with good-looking people and it's never going to work (Luke, Cleft)*

The ideas expressed here suggest that visible difference was considered beneficial in this respect. Whilst deficits in the ability to initiate a relationship and the potential for negative impacts were discussed at length, a corresponding benefit of not being in an appearance centred relationship could emerge:

> *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 etc, etc so, to my mind once that's got the relationship then the, disfigurement more or less disappeared (David, Cleft)*

Whilst David was speaking about the negative impact of his difference subsiding, some participants ventured further and argued that a positive effect can become apparent. Speaking about his marriage Pete said:

> *it's lasted 30 odd years, 33/34 years and I've known her a lot longer than that. And a lot of marriages around us have crumbled along the wayside and they've gone for looks and it hasn't, perhaps it hasn't work….. it makes the relationship much stronger in that it's not shallow, because a lot of people I know, you go for looks, they go for money or they go for a combination of both and you cannot then, if the relationship has a slightest bump in the road it derails and they're either going off with somebody else, or they're divorcing or whatever (Pete, Cleft)*

Participants were thus able to recognise and articulate certain advantages of having a visible difference, even where the overall impression their testimony gives is that it presents a challenge in their lives and their intimate relationships. The reference to other relationships being derailed is mirrored by other participants expressing the idea that their relationship has been, or could be, strengthened by facing the adversity of a visible difference together:

> *I think it's made us closer because not everybody, you know, has to go through something like this. Everyone's got their own struggles and problems but not everyone has to go through something like this (Florence, Alopecia)*

> *You know it would be harder to get to the end product but once you got there you'd feel a lot more confident that, you now, you'd got something that potentially could be lasting or, at least, go far as it could (Ryan, Facial Palsy)*

This may extend to providing a sense of perspective and help counter any uncertainty or doubt regarding a partner's feelings or commitment:

> *I believe that it's made us stronger and we've gone through everything together and I think the silly things before this happened, any trust issues and things like that, that I may have had, really have just disappeared, knowing that [partner] stood by me throughout all this. It still doesn't take away the fact that every time I think a big busty blonde walks past I think he's looking but it's just one of those things. It's me again putting my insecurities onto him (Jodie, Breast Cancer)*

Whilst Jodie had Breast Cancer, she spoke about appearance being the greatest challenge she faced and much of what Jodie referred to facing together was the impact on her appearance. The reference to her insecurities, coupled with an explicit reference to the appearance of other women, reiterated the point that participants continued to view their difference as being undesirable and unattractive even where it had in some way reinforced or underlined the strength of their relationships.

The idea that their relationships were characterised by meeting adversity (with visible difference cast implicitly as adversity) and by depth contributed to participants conceptualising their own relationships as enduring and authentic:

> *To 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… I mean none of us are perfect, and to know that some of our imperfections are more obvious than others and somebody that has asked you to spend the rest of your life with them doesn't care is quite, yeah,*

> *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)*

These feelings added a real weight and legitimacy to relationships. It is noticeable, however, that visible difference itself is still presented with undercurrents of being unattractive and undesirable, it is part of the '*warts and all'* (itself a phrase that carries appearance related connotations) and one of the imperfections that Eleanor's partner has accepted. It is still understood as being relevant to, and undermining, one's attractiveness and the testimonies continued to provide a sense of being accepted *despite* participants' differences.

In addition to a visible difference contributing to a sense of being valued by partners for who they are and acting as a catalyst to bring couples closer, there was a suggestion that a difference may also positively impact upon relationships in an indirect way. This occurred through the experience of living with a difference acting to shape and form the participants' own personality and characteristics:

> *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 it 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….. The cleft's just part of who I am and being who I am has led us to be in the relationship that we're in. (Anthony, Cleft)*

> *it was good because then it made me strong about it and it made me confident so yeah I would say altogether it's positive. It's probably not the best thing to brag about [laughs] although it's nothing dirty or, you know, but why not? (Vanessa, Psoriasis)*

> *I think relationship-wise I've always had good, strong relationships really and I would say because of my personality, because of this really, to be honest. So I would say that was a hidden plus side really (Luke, Cleft)*

These participants saw difference as in some way galvanising them, conferring certain strengths, and attributes upon them. The qualities may then be perceived as being attractive or assist in the initiation and maintenance of rewarding relationships.

5.4.3. Treasured Support

Participants devoted some attention to describing the support that they had received from partners. For most this was entirely beneficial in nature, although a minority described ex-partners who were not supportive. Even where support was provided, participants' concerns were not always explicitly discussed with their partner. This seemed particularly pertinent with regards to concerns about physical intimacy and feelings of unattractiveness. Some participants also conveyed the view that healthcare professionals seemed unwilling or unable to discuss intimacy concerns.

Participants described how the support of a partner could serve a protective function, for example, through the provision of explicit, practical support in response to staring:

> *I got really badly stared at when I was in a queue in the building society, really bad. And my husband noticed it and he went up and said to them "If you do that any longer we're going to start charging £3.50 for a photo." So you make it a little bit humorous but you also shock them (Florence, Alopecia)*

Whilst participants did doubt whether anybody who has not got a visible difference can truly empathise with those that do, it was clear that they valued the knowledge that that there was someone who cared for them and offered their understanding. Speaking about her periods of social withdrawal, Sian compared her husband to a previous partner:

> *I always say "I'm really, really sorry – I'm embarrassed" and everything "Don't feel like that, don't feel like that. You know. It's you – you're my wife, it's part of you, don't worry about it" and so [partner] is really good like that, whereas he wouldn't have been. He would've gone down the pub and left me in every night, sitting in, whatever (Sian, Ankylosing Spondylitis)*

Florence also described how her partner attended support groups with her, shaved her head and full immersed himself in her life with her condition. She expressly considered this to have allowed her to live a fuller, more confident life:

> *I think if I'd have been in my life now single, I think I would have hidden away from my alopecia a lot. I wouldn't be talking to you about it, I wouldn't be as open as I am with people about it if I want to be (Florence, Alopecia)*

Whilst the support received from their partners may have had different effects upon these two participants (with Sian having someone provide comfort and quiet company and Florence having someone whose support meant she felt more able to face and engage with the world) this demonstrated how valued partners' support was. Some participants felt comfortable enough with their partners to enjoy affectionate teasing or joking about their appearance:

> *one of my partners did refer to me as monkey but I mean it, I think it was done affectionately rather than being unpleasant about it. Which you can live with, I mean, acknowledging that you have a condition and somebody occasionally making a joke about it is not the same thing erm, you know, I rather imagine other people with disabilities amongst their friends will live with the odd bit of ribbing, you know? (Austin)*

Whilst it is uncertain whether this kind of interaction would have been possible with anyone but a partner, it suggests a level of comfort and familiarity that permitted good hearted but humorous treatment of the condition. Austin was not the only participant to recount such incidences:

> *we're very tongue in cheek with each other anyway and it was "oh he'll have a shock if [own name] takes her dress off" kind of thing, but it's very jokey and I do take it jokingly I suppose but it's always stayed with me and it wasn't meant in any malice, we are a very jokey kind of sarcastic couple together, so it is something that, that [partner] would say without any underlying tones that was meant to be funny. That's, me being me, it kind of always sticks with me and I do look, read into that a little bit and think "Oh, are you really thinking that then?" but I know deep, deep down that he doesn't. But hmm… (Jodie, Breast Cancer)*

Jodie seems to want to be able to attribute the comment to a relaxed joke but remains unable to do so. Perhaps, as Ruth expressly acknowledged, it isn't possible to feel entirely relaxed and confident in the playful and light-hearted nature of such interactions whilst harbouring some degree of personal discomfort about one's appearance:

> *we did used to joke about it. He did try and make me feel better about things and say "it doesn't matter" but it's good to have somebody who says that to you but you have to believe it yourself. And I didn't really believe it myself (Ruth, Alopecia)*

It was also noticeable that a number of participants could reflect upon receiving support from ex-partners who they were no longer with, alluding to just how valuable this support was considered:

> *I think if it wasn't for him I might well have driven down to Beachy Head and driven over the edge, not that I ever did. I've never taken any overdose, never tried to kill myself but I did feel very, very low and that's why I think the doctor sent me to the counsellor. He was asking me you know, had I thought about killing myself. So I think*

> *he was there for me in my time of need and he helped me kind of decide that it was worth carrying on, kind of thing (Elaine, Alopecia)*

Some participants who had not or did not benefit from a partner's support contemplated how their lives may be different if they had a partner and a strong relationship:

> *I always sometimes think well maybe if I was in a loving relationship, married and everything else, then maybe I wouldn't worry so much (Anna, Alopecia)*

Despite the support that was provided, the value placed in a relationship, and the belief that a relationship could help one with their difference, some participants described how they had not discussed their difference with their partners:

> *I'm not one for overly talking about feelings or anything like that at the best of times, so I do think I generally avoided the subject and didn't really talk about it much with her (Ryan, Facial Palsy)*

Whilst Ryan attributed this to his own personality, other participants understood this as evidence that their partner is not concerned by and has little interest in their difference because, to them, it was irrelevant:

> *he obviously has listened to me if I've… in our very early relationship sort of thing, when I've got down. Because I met him shortly after the other one then, yeah, worries then, you know, but he's fully… it's never come up in a conversation. I don't think he cares (Charlotte, Cleft)*

> *when I asked him to participate in the study he said "what's the point, I don't see it." He said "there's no point me, you know, saying things because I don't see it as an issue" (Karen, Breast Cancer)*

A sense of benign indifference pervades these extracts. The partners are presented as not being interested because it is not an issue to them. They see past or through the difference or consider it irrelevant to their feelings for the participants. This, in one way and within the context of the relationship, can be understood as supportive and accepting. It did, however, risk leaving conversations unspoken and introduce some uncertainty in particular areas within some participants' relationships, such as reduced physical intimacy:

> *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)*

It is therefore possible that an inability to acknowledge the difference as relevant, even when an avoidance of the topic was adopted in a supportive manner, may have contributed to a sense that the topic of appearance as 'off limits' within some relationships. If appearance is defined as a non-issue by one partner within a relationship it may become increasingly difficult to talk about it or to discuss any impact it may have on the relationship.

Other partners had been unable to understand participants' feelings or offer them the support they required:

> *think he couldn't comprehend the enormity of it all. I think he just thought I was making a fuss over not a lot really (Elaine, Alopecia)*

Elaine experienced this as a frustration and it highlights a distinction between a partner not considering the participant's appearance to be problematic or concerning for themselves and an inability to appreciate that it may be difficult and upsetting for the participant.

Other participants described more explicit and derogatory remarks from ex-partners:

> *I was still married, when my hair was obviously going from just the occasional patch to it was all coming out and it was blatantly obvious that that was the direction it was going in, I think my ex-husband struggled with it while we were out and about more than I did. It would be him saying to me "For God's sake cover your head up" (Michelle, Alopecia)*

It was not just partners who did not discuss visible difference and their romantic life with participants:

> *appearances and intimacy because it doesn't get discussed, does it really? No-one talks about it. No-one asks me that private stuff because they don't know, they just think… they're not thinking about it because they're in their own little lives doing their own thing and they just think you're alright and you're happy and everything's fine (Valerie, Facial Palsy and Breast Cancer)*

This was also specifically the case in respect of healthcare professionals who were reported as having paid little attention to intimate considerations. Valerie also illustrates this point:

> *they showed me pictures of ladies who'd had a mastectomy on one side and none on the other and got a reconstruction, and I said "that looks bad. That's horrible" and she looked at me this cancer nurse and said "well it's ok when she's got a bra and it looks normal." I said "well it's not normal is it? You can tell which one's been reconstructed*

> *and which one hasn't." So I've actually said to him "I want the other one doing" because I'm already not looking normal and I want to look as normal as I can. So he's promised that he will do but they don't see that side of it, they just see the side "let's get this tumour out. Yeah, she's fine now" but they wouldn't ask you how you're feeling about your appearance. They never ask you that question (Valerie, Facial Palsy and Breast Cancer)*

This idea recurred amongst all three participants who had breast cancer:

> *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. And, to be honest, I didn't realise that it would be as on-going… the surgery would be as on-going as it was. Two years later and I'm still not right, not, you know, as, you know, I want to be (Jodie, Breast Cancer)*

Clearly some participants felt that some healthcare professionals implied that those receiving treatment for an appearance altering condition should not hold specific or personal hopes or expectations about their final appearance but should be content with whatever their healthcare workers deemed acceptable. It was clear that these participants harboured concerns about how they would look naked and how they may feel when viewed by long-term partners. The lack of information about the reconstructive process is also noteworthy and Jodie described experiencing a significant and ongoing adverse effect upon her physical relationship during this long period. Whilst this may have been a particularly relevant concern for these participants due to the sexualised nature of female breasts and the invasive surgery and reconstructive process that they underwent, it was not unique to those with breast cancer:

> *he (doctor) said "I'll refer you to dermatology. How are you feeling?" and I said "oh just distraught" and he goes "oh!" and I said "have you any idea…" because I actually worked in this doctor's as well "…how your wife would feel if suddenly her hair had dropped out. If she didn't feel very attractive and didn't want to go to bed with you, it would kind of impact on your life wouldn't it?" And he sort of stared at me and didn't know what to say (Elaine, Alopecia)*

The lack of empathy that was recounted and the implicit assumption that sex and attractiveness were not relevant issues are evident from these testimonies. It was also apparent that the healthcare professionals that participants spoke about did not seem to have been prepared for the topic:

> *I've been to the doctor's before and said about things, how they're affecting me, I'm asked quite personal questions and I answer them and they kind of they don't want to give you any help or anything (Sian, Ankylosing Spondylitis)*

This contributed to the sense that some participants had that some topics were not for discussion in the healthcare context and not one for which any dedicated support was available. Sian argued that it was as if healthcare professionals didn't 'want' to offer any help which implies that this was perceived as a choice rather than it being something that was beyond the knowledge or capabilities of the healthcare system.

When participants were asked to consider what they felt may be of benefit to those in their position there was a sense that anything which may increase individuals' confidence could be effective though it was difficult to contemplate how this could be achieved:

> *Going back into support, every person's different. It does come naturally to a lot of people to be able to speak to the opposite sex. And going back to, say, my first kiss compared to my late teens, it's not something that any amount of work or speech or therapy can help you to do but if you were to be able to knock the self-confidence issues out of a child at an early age, if that was even a possibility… if that was ever a possibility one way or another I think that would greatly improve a lot of people's lives (Luke, Cleft)*

In a similar vein to more generic appearance support needs, there was a sense that those with a visible difference would obtain the greatest benefit from learning from and having contact with those that were in a similar position:

> *It's an awkward conversation at the best of times but I think, like I said earlier, someone like me who's not particularly with things generally, I think the person I'd most open up to about all of this is probably my Mum and then obviously I'm not necessarily going to… she's not someone I talk to about relationships or anything, I just talk to her generally about how I feel. So if you could have someone or a group there to talk about relationships and anything like that then I think it can only be beneficial really (Ryan, Facial Palsy)*

This reinforces the idea that it can be difficult for others to fully comprehend how it is to live with an altered appearance and so support is most effective if provided by others who are similarly affected. It also suggests that intimacy may be an area where usual support mechanisms may be liable to fail. Just as Karen did not discuss issues in her relationship that relate to her difference with her supportive and accepting partner, the more explicit and vocal support that Ryan's Mother provided failed to offer him any support within his intimate life. The consensus was that:

> *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)*

As a final point to note, one participant also referred to the lack of support or services aimed at the partners of those that have a difference and considered that this could also serve a valuable function in the wake of illness, treatment regimens and visible difference.

6. Qualitative Study: Discussion

6.1. Introduction

The research presented in the two proceeding chapters represented the first dedicated exploration of visible difference, intimacy, and romantic relationships in adults. Participants understood these domains to be inexorably connected. Participants were able to reflect on beneficial effects they believed their difference had exerted on their relationships and their resultant positive adjustment, whilst the detrimental impacts they discussed demonstrated concepts identified as relevant to other contexts within the visible difference literature. These will be examined alongside other empirical studies to which the findings relate, the theoretical and clinical implications considered, and limitations of and reflections on this research proffered.

6.2. Links to Relevant Research

Concern about the negative evaluation of potential partners was expressed within the "Looking to Love" sub-theme. These findings were consistent with previous work conducted with adolescent populations (Fox et al., 2007; Griffiths et al., 2012) and to some extent echoed the sentiment expressed in the accounts of Tindle et al. (2009) and referred to by Davey et al. (2019), that concerns regarding attractiveness to new partners can prove debilitating. The intimation that it is necessary to befriend a potential partner to create an opportunity for a relationship to develop also finds a parallel. Shuttleworth (2000) found that an initial friendship was the most likely route to sexual intimacy for men with cerebral palsy but considered this something of a double bind as friendship may symbolise asexuality and preclude romantic relationships. This platonic bind has also been evidenced in interviews with adults who have Russell-Silver syndrome (Ballard et al., 2019). The participants in the current research did not discuss this, conceivably because they contemplated romantic relationships as being characterised by intimacy and emotional closeness rather than purely by sexual intimacy.

The fear of negative evaluation was also pertinent to 'The Disclosure Dilemma.' This was experienced when participants imagined making public to a romantic partner a previously private aspect of the self (Kelly, 1992). This issue has been discussed by participants in studies of specific conditions such as prosthesis users (Murray, 2009), those with below the knee prosthesis (Mathias & Harcourt, 2014), alopecia (Davey et al., 2019), and breast cancer (Holmberg, Scott, Alexy, & Fife, 2001; Laura-Kate Shaw et al., 2016), where disclosure also included the disclosure of their cancer diagnosis. Women participants with microtia have even indicated that, alongside experiences of employment, the challenge of disclosure to a romantic partner was particularly sentient, with the concealable but visible nature of the condition being especially significant within this context (Hamlet & Harcourt, 2020).

Participants experienced both felt and enacted stigma (Scambler & Hopkins, 1986) in connection with this revelation. Felt stigma was experienced via anticipatory anxiety prior to disclosure and the enacted stigma via negative reactions. The latter were not always explicit, and participants interpreted an ambiguous subsequent cooling of interest or loss of contact with the other as such. This scenario induced considerable anxiety for those to whom it was relevant, as participants contemplated the voluntary but necessary transition from being a person who is discreditable by their existing but unknown stigmatised characteristic to one that can be discredited by a known stigmatised trait (Goffman, 1974).

For some participants these fears occupied a central position within their lives and, in the case of participants whose conditions had a congenital or genetic component, this extended to concern about their children ('Our Selfish Genes'). This mirrored the findings of Stock, Feragen, and Rumsey (2015) whose participants contemplated the possibility of their child having a cleft but, as with the present participants, only a small proportion suggested such concerns may impact upon their decision to have children. Whilst the medical consequences may also have contributed to these feelings, the discussion pertinent to this sub-theme illustrated the depth of concern that those contemplating parenthood felt at the thought of their child sharing their appearance altering condition and experiencing negative judgements, reactions, and stigmatisation.

The analysis indicated that participants internalised the pervasive social standards and meanings that they understood to be attributed to visible difference and that contributed to explaining why negative evaluation and stigma were encountered. This was despite participants arguing that they did not personally subscribe to these ideals and led to 'The Discounted Self.' The devaluation of the self within 'Deficient Me' evidenced a negative self-concept and echoes the accounts of young men with testicular cancer who considered themselves 'damaged goods' as a result of the physical sequela (hair loss, scarring, orchiectomy) of their cancer (Carpentier et al., 2011). This personal deficiency appeared to underscore the need to offer other valuable characteristics to a partner to compensate for the perceived deficiencies appearance.

The possibility of a continuing impact upon established romantic relationships was evident from the participants who remained in unsatisfactory relationships because of how they felt about themselves ('Lucky in Love'). Whilst the interviews were retrospective in nature and the history of a given relationship may influence how it is spoken about, it was striking that three of the 22 participants spoke about getting married to partners who they may not have married were it not for their feelings about themselves and their appearance.

The ongoing impact of visible difference upon established relationships and the manifestation of participants' concerns about their attractiveness and adequacy as partners were further evident from the sub-theme 'Invading Physical Intimacy.' Anxiety about partners perceiving difference during sexual activity alluded to feelings of embarrassment, inadequacy, shame, and the response predicted by Kent (2000) and Kent and Thompson (2002). This took the form of participants limiting and avoiding sexually intimate contact with their partners, concealing their difference, and the interruption of participants' enjoyment of physical intimacy. This supports the claims of Batty et al. (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 relevance and immediate visibility of the perceived deficiency.

It is unsurprising that such feelings and behaviours were evident within the context of bodily exposure and sexual intimacy. Magin et al. (2010) argued that the relationship between nakedness and intimacy meant that physical exposure and scrutiny within an intimate encounter are qualitatively different from public contexts, such as the beach and the swimming-pool. The intimate sexual context may be experienced more intensely and magnify concerns attached to one's visible difference. Additionally, Wahl, Gjengedal, and Hanestad (2002) argued that participants with psoriasis transferred their experiences of their bodies as disgusting and unattractive to their sexual partners, creating a barrier to physical intimacy.

This barrier resembles the phenomena of 'spectatoring' (Masters & Johnson, 1970), the intense fixation upon and monitoring of bodily parts during sexual activity. Indeed, covering up areas of the body impacted by visible difference, conscious efforts to make such locations less salient, and being unable to enjoy sexual encounters would suggest an overt consciousness of the impacted area impinged sexual activity. This may represent anxious self-evaluation and self-focus in turn causing cognitive distraction that adversely affected sexual function (Woertman & Van den Brink, 2012). The spectatoring phenomena is one that is more commonly encountered within the field of body image and the current research suggests some overlap between that field and visible difference within the domain of sexual activity.

Whilst a minority of participants expressed some uncertainty regarding how their partners viewed them sexually, the stronger sense was that it was participants' feelings about themselves that explained the impact upon sexual activity. This occurred without evidence of a tendency to transfer or project participants' feelings onto their partners. In addition to being consistent with spectatoring, this paralleled the findings of Loaring et al. (2015), gleaned from dyadic interviews of women with breast cancer and their partners. Whilst the women with breast cancer were understood to harbour considerable anxiety about their changed bodies underpinned by normative and implicit ideals, felt insecure and uncomfortable, and expressed disbelief that their partners could still find them attractive, their partners provided reassurance and described their continued attraction to the women. The authors highlight that the women were aware of their partners' positions but found it difficult to accept their reassurances. Unfortunately, the inability to recruit partners and the fact that the current research was never envisaged as being dyadic in nature precludes more definitive parallels being drawn, although dyadic interviews may offer a potentially rewarding avenue for future research examining this issue.

Participants' sexual concerns coupled with the tendency to speak of partners looking past or not seeing their difference may have contributed to some participants feeling unable to discuss these feelings and the impact upon their sexual relationship with their partners. The participants in this position therefore experienced something of a relationship disassociation. They described being in supportive relationships that were presented as serving a protective function ('Treasured Support'), supporting the argument of Egan et al. (2011) that the consideration, support and acceptance of significant partners may help facilitate positive adjustment to visible difference. They considered that their partners valued them for who they were and placed little value or meaning on their visible difference.

Where participants' sexual lives were impacted they were not able to discuss this openly with their partner, perhaps because their partner saw past their appearance in all other respects. The topic become somewhat inaccessible within the relationship. An interpretative phenomenological analysis of those who have experienced amputation has identified a similar phenomenon. Ward Khan, O'Keeffe, Nolan, Stow, and Davenport (2019) describe experiences of a reduction in sexual desire and activity, to the extent that some participants wanted a relationship without sex, but also a level of guilt and discomfort in communicating with their partner about their sexuality. The authors considered that this was because to do so requires accepting one's own vulnerability and that the threats posed to participants' body-image and self-worth made this difficult to do as they did not want to compromise or jeopardise their partners' feelings about them.

In the current study, this issue was particularly salient in the accounts of participants who had breast-cancer related visible difference. This is consistent with the work of Buković et al. (2005) and Winch et al. (2016). Buković et al. (2005) found that female participants with breast cancer recognised the supportive role of their partners but experienced a reduction in satisfaction with their sexual life and indicated that discussions with their partners relating to sexual dysfunction were rare. Similarly, Winch et al. (2016) spoke with women with lower limb lymphedema (which affects the feet, legs, buttocks, and/or genitals). Whilst the majority spoke about supportive partners and a smaller number reflected upon unsupportive partners, only a minority had openly discussed sexual and appearance issues with their partners. It is possible that the sexualised nature of these bodily areas and their importance to traditional conceptions of femininity make this a particularly difficult situation to navigate. Whilst it is beyond the scope of this thesis, further research may consider focussing more intently upon the process through which such acquired differences are integrated into pre-existing relationships.

Any inability to communicate with partners in this way was replicated in participants' interactions with healthcare professionals. Participants had spoken about a general lack of professional support and this extended to the realm of intimacy and romantic relationships. Some participants recounted unsympathetic reactions, and none spoke of receiving support that they considered to be adequate and appropriate. Although drawn from several territories, literature related to various forms of cancer and those with amputated limbs makes a similar point. Penner (2009), Sheppard and Ely (2008), Tindle et al. (2009), and Verschuren, Enzlin, Geertzen, Dijkstra, and Dekker (2013) all comment on the lack of such support from the healthcare profession.

Some of the responses suggested that participants felt that their sexuality was not adequately acknowledged. This may be in part a consequence of the clinical nature of healthcare settings (Dixon & Dixon, 2006) but can be amplified in respect of those with disabilities such as cerebral palsy (Shuttleworth, 2000), physical disabilities (Milligan & Neufeldt, 2001; Taleporos & McCabe, 2001), and 'cosmetic disabilities' such as burn scarring (Worthington, 1988). These patients may implicitly be considered asexual beings by and within a society that privileges those that are regarded as able bodied, contributing towards a taboo of disability and sexuality that makes discussing the intersection of these topics both unlikely and difficult (Mathias & Harcourt, 2014; Milligan & Neufeldt, 2001).

The 'Enriching and Fortifying Us' sub-theme introduced an idea closely connected to support, that the presence of a visible difference could itself help strengthen romantic relationships and facilitate a sense of legitimacy, acceptance, depth, and confidence in their enduring nature. These findings materialise the anticipated confidence expressed by single women with breast cancer that a new partner would be interested in them on all levels, as a person and not just because of how they look (Ginter & Braun, 2017). Similar feelings of trust, commitment, acceptance, and depth of connection have previously been identified amongst a small number of participants with lower limb prostheses (Mathias & Harcourt, 2014), who have had testicular cancer (Carpentier et al., 2011), testicular cancer and Hodgkin's disease (Hannah et al., 1992), and breast cancer (Laura-Kate Shaw et al., 2016). Whilst being presented by participants as an overwhelmingly positive consequence of visible difference, the supposition also implicitly indicates that participants did not believe that their partners were or could have been attracted to them on a primarily physical basis. To some extent this reinforced the romantic self-devaluation of participants, understood to occur on the basis of their appearance.

The sub-theme also included the proposition that romantic relationships can benefit indirectly from the positive personal growth facilitated by a visible difference. This finding adds specificity to and reinforces the claims of Egan et al. (2011) that such growth can extend into improved relationships with others, although this claim is, of course, substantiated upon participants' beliefs and interpretations rather than any measure of this effect.

It was also notable that the other party to a romantic relationship was scrutinised by participants who assessed them on their reaction to their difference. 'The Litmus Test' provides evidence that, like Mathias and Harcourt (2014) found, this reaction was considered a screening mechanism or filter, used to identify those who may be viable long term partners and provide an indication of the feasibility of a relationship. Crucially and in contrast to feelings expressed within other sub-themes, the partners' responses were seen as being reflective of the character of the respondent rather than the innate value or worth of the participant as a romantic partner. Thompson and Broom (2009) identified a similar tendency amongst those with a visible difference and interpreted this as a self-protective strategy, utilised to decrease the emotional discontent experienced as a result of negative reactions through an external attribution. Their work was not, however, concerned with the reactions of potential partners. The current research suggested some participants employed this strategy within this domain.

Whilst participants envisioned and even understood negative judgements and reactions from others in general, 'The Litmus Test' indicated that they expected greater understanding, compassion, and acceptance from those with whom they had some personal relationship and could conceptualise any failure to supply these reactions as the responsibility of the other. This finding reinforced that of Thompson and Broom (2009), who identified a similar phenomenon and argued that these negative attributions were self-protective and acted to reduce the emotional discontent that negative reactions could otherwise stimulate. The research of Thompson and Broom (2009) was not specifically concerned with the romantic context and so the identification of these findings within that sphere complements and extends their work into this particular realm.

6.3. Theoretical and Clinical Implications

Whilst this study was exploratory in nature it is important to consider its theoretical implications as research activity in the field of visible difference has been dominated by empirical studies (Kent, 2000; Thompson, 2012). Kent (2000) identified four models of social and psychological functioning (a social anxiety model, the sociological models of stigma, social skills training and the body image schema model). Furthermore, Newell and Clarke (2000) and Newell (1999) introduced the fear avoidance model whilst other models focus upon the development and impact of stigmatisation, anxiety and impression management (Kent, 2002) and shame (Kent & Thompson, 2002).

The proliferation of theoretical models led (Thompson, 2012) to argue that an inclusive and integrative framework capturing significant theory in the area was required. This need has been partially fulfilled by the ARC framework (reported by Clarke et al., 2014). This details predisposing factors, intervening socio-cognitive processes and psychosocial outcomes in positing a framework for adjustment to disfiguring conditions. The framework, however, has been reported in at least four variations (two in each of Clarke et al. (2014) and Thompson (2012)) and the authors acknowledge that as a working framework, it is not comprehensive (Clarke et al., 2014) but argue that it has utility in directing future research (Thompson, 2012) and interventions (Clarke et al., 2014).

The current research may be interpreted as supporting those tentative claims. This has already been considered in respect of the non-intimacy related themes (Sharratt et al., 2019) (see Appendix A7b). Briefly considering the framework as presented by Clarke et al. (2014) in relation to intimate, romantic relationships, the participants understood the predisposing factors of gender, relationship status, societal and media influence, and visibility to be relevant to experiences of visible difference and intimacy. The analysis suggested these predisposing factors impacted the socio-cognitive processing envisaged within the framework. For example, satisfaction with social support appeared connected to relationship status. Likewise, visibility to others was relevant to when, how, and under what circumstances the fear of negative evaluation arose. Appearance specific-cognitions such as social comparisons to beauty ideals and the resultant appearance discrepancy were also highlighted. In line with the framework the outcomes experienced included intimacy and intimacy related anxiety, avoidance of intimacy and sex, feelings of embarrassment and shame in exposing the body, and feelings of inadequacy as a partner.

Whilst the theoretical landscape remains in need of further development and the framework of Clarke et al. (2014) may of itself lack some specificity and explanatory power, the present research demonstrates that it incorporates a number of concepts that participants understood as central to their experiences of visible difference and intimacy. The framework thus finds tentative support from this work and corroborates the authors' recommendation that the framework has utility in directing future developments in research and interventions.

In terms of relationship theory, the results indicated an implicit and experiential understanding of the 'what is beautiful is good' (Dion et al., 1972) 'mating market' (Swami, 2016; Swami & Furnham, 2008) and 'filter' (Feingold, 1988; Kerckhoff & Davis, 1962) theories. This indicated that participants were intuitively aware of their own romantic capital and that relationship formation involved a bargain, negotiation, or cost-benefit analysis. This was generally within the context of participants considering themselves to be of diminished worth as a result of their difference and therefore being assessed negatively by others and devaluing themselves. The idea that they needed to compensate for their appearance via other characteristics also complements these theories.

In addition to the implications regarding reduced attractiveness and relationship formation, the description participants offered of staying in unsatisfactory relationships may have reflected their attachment to their partner, formed at least in part through proximity (Hazan & Shaver, 1994), the lack of a strong belief in a more beneficial comparison level of alternatives under social exchange theory (Thibaut & Kelley, 1959) and/or the degree of prior investment they had made into those relationships along with the resulting commitment towards their continuation (Rusbult et al., 2011). Future investigations could focus specifically on this phenomena and its theoretical foundations.

The importance assigned to the response to the disclosure of visible difference and to support provided by partners more generally may indicate the operation of the interpersonal process model (Reis & Shaver, 1988) in which partner responsiveness is a critical component of the development of intimacy. The relative importance of self-disclosure and the response of the partner to those with visible difference and their partners would represent an interesting avenue for future research, and the potential for differences between men and women in this respect could be explored.

Turning to participants' experiences of healthcare, the analysis suggested that the impact of their visible difference upon their romantic life was not something that was acknowledged by the professionals they had encountered. A level of dissatisfaction was expressed, either because the topic not been discussed clinically, or if raised, had been inadequately addressed. This suggests that further work to raise awareness amongst healthcare professionals and to promote skills and resources to facilitate effective support would be beneficial.

This issue has received relatively little attention in the research literature, though the level of psychosocial support available in respect of visible differences generally has been shown to vary between European countries (Harcourt et al., 2018) and healthcare professionals have called for more information and training regarding appearance concern (Williamson et al., 2018). More specifically with romantic and intimate concerns and working in the Netherlands with those providing care to patients with lower-limb amputations, Verschuren et al. (2013) identified the rarity with which sexual issues are discussed, labelling this a 'conspiracy of silence' between professional and patients. They argued that it is necessary to increase healthcare professionals' comfort in speaking about this topic. The professionals themselves believed that procedural and structural factors, such as having defined responsibilities, a protocol, and addressing the matter systematically, would help facilitate the issue being given more clinical attention. Pandya, Corkill, and Goutos (2015) reviewed the literature relevant to burn injuries and sexual function and concluded that awareness, education, and a holistic approach adopted by a multidisciplinary team are the prerequisites for addressing issues of intimacy.

Whilst those requirements may represent an ideal state or long-term goal, it is conceivable that organisational, structural, and financial barriers may impinge on the provision of such care. Identifying solutions which require limited additional resources may therefore be important. One such possibility, recommended by Clarke et al. (2014) for facilitating psychosocial adjustment to visible difference, is the adoption of the stepped-care model entitled PLISSIT (Annon, 1976). Briefly, this model contains four levels of care, each of increasing intensity and requiring increasing levels of specialist skill and knowledge. Level one, permission, and level two, limited information, are envisaged as being applicable to all healthcare professionals and encompass communicating to the patient that these issues are a legitimate focus for concern and discussion with their care providers. This may include responding to basic questions, an exploration of psychosocial impacts and concerns, written information and referral to websites and support groups (Clarke et al., 2014). Subsequent levels include specific suggestions and, if appropriate, intensive treatments including social skills training provided by clinical nurse specialists or individualised cognitive behavioural therapy provided by a clinical psychologist.

The use of this model has been advocated in patients following radical surgery (Dixon & Dixon, 2006) and it originates from the realm of sexual therapy. Furthermore, an extended version, Ex-PLISSIT (Davis & Taylor, 2006; Taylor & Davis, 2006) has placed permission at the heart of each stage and has been specifically conceptualised as being suitable for use with patients who have an acquired disability or a chronic illness (Taylor & Davis, 2007). Whilst there exists little empirical evidence for the benefits of its use or its effectiveness within the sphere of visible difference, the exploration and application of this model would be an interesting and potentially fruitful avenue to pursue.

In addition, and to provide some context to the lack of professional support received, visible difference was a subject that participants said was rarely discussed by anyone, sometimes not even by the parties within an impacted relationship. In considering support needs, the desire for peer-to-peer support is consistent with that expressed by adolescents (Griffiths et al., 2012) and highlights the great value participants placed upon the empathy and shared personal experience that such interactions may facilitate.

6.4. Limitations and Reflections

Whilst the study provides novel insight, its limitations must be acknowledged. The participants and the data were heteronormative and may reinforce traditional conceptions of monogamous relationships. This was not by design but a factor of the nature of the accounts that were provided. Whilst one participant discussed being attracted to people of the same sex, the range of sexual experiences was not diverse. The participants were primarily drawn from those that have some connection with support groups and charities operating in the field. Furthermore, most advertisements were placed via social media or other electronic communication. Whilst some effort was made to advertise more broadly, the range of experiences represented is reflective of those that are connected to such organisations and are IT literate. Despite this limitation, the contribution of these organisations in promoting the research resulted in the study attracting participants with a range of different visible differences, relationships status, and with a relatively wide age range.

It is also likely that the 22 participants interviewed generally considered their visible difference to be salient to their lives and were motivated to discuss the intersection with intimacy and romantic relationships. Whilst a small minority of participants considered the connection between their difference and their romantic life to be relatively minimal, it is conceivable that the participants' experiences do not reflect the experiences of many others. Indeed, most people who viewed the information sheet on the Qualtrics site did not proceed to interview, deciding not to contact me, or not to arrange an interview, or not to proceed with an interview once arrangements were made.

The choice to offer a range of media through which participants could conduct their interviews appeared to be a valuable one, with the majority of participants (15) opting to speak on the phone, two via Skype, and five in person. The preference for the phone may not be surprising especially as the phone may be understood as removing the immediacy and salience of appearance (Fox et al., 2007) and makes visual scrutiny impossible. When Winch et al. (2016) offered participants a corresponding choice, 18 chose the phone and only one spoke in person. I did not ask participants to justify this choice to avoid this being interpreted as pressure to alter the decision (if done prior to interview) or implying some judgement. Nonetheless, participants' responses would have been interesting, and this research cannot speak as to why the phone proved so popular, although I suspect participants thought at least partially of my convenience.

I adjudged the interactions and data quality and quantity produced by phone and Skype interviews to be good and to be in no apparent way inferior to face-to-face interviews. It is possible that the two Skype interviews, however, may have been slightly impacted by my, slightly unexpected, relative unease using this medium. Using the phone and face-to-face interviews felt more natural and organic to me, although this may have simply been a slight feeling on my part rather than something that had an appreciable impact upon the quality of those two Skype interviews and there was no indication of which I was aware that the participants shared this feeling.

During one phone interview it became that the interview was being conducted within the hearing of the participant's partner. This may have influenced the participants' willingness to speak candidly and illustrates that a limitation of the phone interview is that the researcher cannot control the physical environment surrounding the participant. Such issues, however, are not unique to phone interviews. One interview conducted at the home of a participant was interrupted (at different times) by their (adult) children who lived there. Whilst I did not experience this as disruptive, nor (so far as was apparent) did the participant, and it did not seem to affect the nature of the data provided, it did represent something of an unexpected scenario and the possibility that it impacted the account provided cannot be entirely discounted.

It is also noteworthy that I felt a little uncomfortable asking personal questions in the first couple of interviews. Whilst I have experience in discussing sensitive and personal issues with members of the public, most of this experience comes from a responsive role in which service users contacted a service because they want to talk. I was a little conscious that the current context involved me asking questions for my purposes. Whilst exposure to the situation and discussions with NR helped alleviate these concerns, it is plausible to suggest that I might have used more probing questions in the first couple of interviews before I became more accustomed to the study. A small section of the data may therefore have been impacted by these feelings.

The research attracted a greater number of women (16) participants than men (6). This imbalance and the difficulty reaching men is not unique to this study and has been encountered in previous appearance research. For example, the ARC (reported in Clarke et al., 2014) sample of 1,221 participants was only 28% male. Of the 535 participants with a visible difference contributing to the validation of the DAS24 (Carr et al., 2005), 27.5% were male. In the present study (albeit with a much smaller number of participants) the figure was a little over 27%. Whilst experiences of male participants are therefore captured within the data, it is possible that the relative lack of male representation influenced the analysis. This assumes particular relevance as the participants understood appearance, visible difference, and the interaction with intimacy and romantic relationships to be a gendered issue.

Whilst experiences of romantic concern, such as fearing that others will adjudge them as unattractive, were common to women and men participants, certain nuances within the findings appeared somewhat gendered in nature. These included the proposition that differences, especially that impact highly sexualised or gendered parts of the body, were capable of disturbing participants' sense of femininity. Similarly, appearance pressures, expectations, and ideals were understood as applying somewhat differently to men and to women and the contention that visible difference is generally more difficult for girls/women than boys/men was articulated. The relatively small number of men therefore means that the perspective of men may be somewhat occluded in the analysis.

Whilst I was aware of this during the process of conducting the analysis, and attempted to give all participants and their accounts due representation and consideration, it is possible that the nature of thematic analysis and its focus upon patterns of meaning within and across the data-set may have resulted in the voice of men speaking relatively quietly within the analysis. Future work focussing upon on the experiences of men and employing more idiographic qualitative methodologies such as interpretative phenomenological analysis, would help address this concern. In light of these comments and as the items for the EFA were developed primarily with reference to the analysis of this qualitative work, and so may also have captured the experiences of women in preference to those of men, it was important to examine the data used in the EFA for differences between women and men and to ensure that the factor structure that was adopted is consistent for and between women and men.

I was responsible for liaising with potential participants and arranging interviews, conducting the interviews, and primarily responsible for conducting the analysis. It is therefore conceivable that my gender identity and sexuality, heterosexual cisgender man, impacted on this process, affecting potential participants' decision as to whether to engage with the research, the research interview itself, the nature of the data collected, and its interpretation. Whilst I believe that participants spoke candidly and honestly, the subjectivity inherent in qualitative work means that it is very likely that the research would have attracted different participants, the interviews generated different data, and the data differently interpreted were I, for example, a heterosexual cisgender woman. Similarly, no participant reported being from a marginalised or minority community, culture, or ethnicity and so such experiences and cultural nuances are not reflected. This is not to devalue the research that was conducted but to delimit it and acknowledge that it is situated in and a product of the context and was shaped by the actors, circumstances, and relationships of its performance.

My goals are also relevant to the conduct of the analysis. Whilst I consciously attempted to remain vigilant to both positive and negative experiences and thoughts, the content of the existing literature, the goal of the research programme (to examine the impact of visible difference upon romantic relationship, and the intention to, eventually, develop a measurement scale), may have influenced the design, data collection, and analysis of the data. The influence may have been a tendency towards and focus upon negative consequences that were described by participants. It is hoped that the overall thematic structure demonstrates that beneficial effects were represented and the member checking exercise (despite its limitations) and involvement of the supervisory team in the analysis may have also helped minimise this possibility, by ensuring I felt accountable and was able to justify the outcomes. It must also be acknowledged, however, that the goals of the supervisory team may have been somewhat similar to those of my own. Likewise, the potential for it to be intimidating for a participant to actively challenge and contest the research findings during this process, may act to weaken these checks and balances put in place to ensure the analysis remained rooted in, and defendable with, the data.

Having discussed the analysis of the qualitative data, the next section of this thesis will move on to the quantitative, scale development work that followed. At this point in the thesis, a transition is made from the QUAL to the QUANT within this mixed-methods research, rooted in Pragmatism.

7. Exploratory Factor Analysis: Item Development and Data Collection

Having conducted the qualitative study and in the absence of an existing research tool designed to assess experiences of visible difference and intimate, romantic relationships, I decided to continue with the planned work and develop a parsimonious research measure for use in this area. This was eventually named the Centre for Appearance research Romantic Relationships and Intimacy Scale (CARRIS) and will be referred to as such from here on. In order to maximise the applicability of the scale and in recognition of the research evidence suggesting objective factors related to visible difference are not the best predictors of psychosocial outcomes, the measure was intended from the outset to be broadly applicable regardless of demographic or other distinguishing characteristics.

7.1. Definition of the construct and development of the items

The construct that the measure was intended to measure was appearance distress experienced within the context of romantic relationships. The construct was considered likely to be multi-factorial and would include concepts identified from a process in which the qualitative study, previous empirical research, and relevant theory were consulted. A draft list of relevant issues and areas to be included in the measure was created (see Appendix B1). This included concepts drawn from the qualitative study conducted as part of this thesis and already reported, as well as those from existing literature identified in the review of the literature referenced above. Appendix B1 indicates the source of each such concept.

The concepts referred to in Appendix B1 were then used to inspire the generation of items that may be used to measure and assess their relevance to an individual. For example: the concept of appearance being important to initial impressions and judgements about someone as a potential partner (drawn from Looking to Love) was reflected in a draft item that read ‘a potential new partner would judge me negatively because of my appearance’ whilst the related idea that this means that only realistic way into a relationship is by being friends with someone first (drawn from the same sub-theme) became ‘the way I look means that I would need to be friends with someone before they would consider me as a romantic partner.’

The items were written from the perspective of the individuals who would be asked to respond to them and so employ personal pronouns and, where appropriate, refer to ‘appearance’ rather than to alternatives such as ‘visible difference.’ This was done in consultation with NR with the intention of the items being clear and simple and avoiding complications arising from circumstances where individuals may have more than one appearance altering condition.

In formulating the draft items I was careful to ensure that each of the concepts included within Appendix B1 was reflected in at least one item. Where there was substantial overlap between ideas and sources of these ideas, items were drafted so as to capture the inherent meaning. For example, the idea that disclosure may be a difficult came from both 'the Disclosure Dilemma' and the work of Mathias and Harcourt (2014) and Tindle et al. (2009) and informed the draft item 'I would not know how to tell a new romantic partner about my appearance'. Once satisfied that the concepts identified from the qualitative study and from previous literature were each represented within at least one item I had generated a 'long' list of 146 draft items (Appendix B2).

These draft items were revised, in form and substance, and consolidated to reduce duplication and avoid over-burdening participants. This was important as whilst it is generally better to use too many than too few items in EFA, my goal was to produce a parsimonious scale and other measures would be administered at the time the EFA data were collected. This consolidation was done with regular input from NR, and the draft items reviewed by clinical psychologist AC, and visible difference researchers EJ and TM who provided feedback on the form and substance of the items during this process. Together with the origin of the items, this satisfied the recommendation of Streiner et al. (2015) that focus groups or interviews, clinical observations, theory, research, and expert opinion are all harvested in developing the items. The process resulted in the retention of the 73 unique items contained within Appendix B3, which also illustrates the hypothesised concept associated with each.

Hypotheses were not made about the precise organisation and structure of the proposed measure and construct, as the EFA would provide this, the provisional concepts that were included (together with an indication of the main source of the ideas that featured within the items associated with each concept) were:

1. Considering oneself to be of diminished romantic worth (The Discounted Self):
    a. evaluating oneself in this way; and
    b. considering oneself to have a reduced choice of partners
2. Being negatively evaluated romantically by others (Looking to Love);
3. Exhibiting apprehension and caution in relationship initiation (Appearance Attracts and Detracts);
4. Anxiety in connection with disclosure of a visible difference (The Disclosure Dilemma);
5. Trusting supportive relationships (Enriching and Fortifying us, Treasured Support);
    a. being able to communicate openly with a partner; and

    b. availing oneself of a partner's support;
6. Impacted sex and physical intimacy, including (Invading Physical Intimacy):
    a. safety behaviours;
    b. sexual inactivity/avoidance;
    c. sexual anxiety/discomfort;
    d. sexual appearance consciousness.

As part of the process of item development, and in accordance with the recommendations of Tabachnick and Fidell (2007), I was mindful to include at least five or six items in respect of each of the concepts detailed above. This was necessary to ensure that each could potentially substantiate a factor if justified by the data.

7.2. Response Categories

To ensure the final scale was user friendly the same response categories were employed for each item. Gaskin and Happell (2014) place the optimal number of responses for Likert-type items at four-seven, Streiner et al. (2015) five-seven. The nature of the options are also important as methods of FA assume interval data (Reise, Waller, & Comrey, 2000). Whilst data generated from Likert-type scales may be subject to some ambiguity in this respect (Tabachnick & Fidell, 2007), they are often assumed to be interval in nature (Field, 2013) and subjected to methods of FA and PCA (Carr et al., 2000, 2005; Moss-Morris et al., 2002).

In identifying potential responses the work of Spector (1976) was consulted. This identified Likert-style responses that most closely resemble interval data. Of those that Spector (1976) assessed the 'agreement' options were considered most applicable. Six options were selected. The options that represented the least agreement 'slightly,' and one that represented a modest level of agreement 'moderately' were each selected. It was noted, however, Spector's work placed 'slightly' as closer to 'moderately' than to the extreme agreement option, 'very much.' The 'very much' option was thus discarded in favour of 'strongly.'

A 'not applicable' option was also included. Whilst participants would be instructed to imagine so far as possible that a particular scenario, context, or question applied, this may not always be possible. A similar option was presented in respect of a number of items in both iterations of DAS (DAS59 and DAS24) (respectively Carr et al., 2000, 2005), which also measure appearance distress. As is consistent with the way in which DAS (Carr et al., 2000, 2005) is scored, this response was taken to indicate the item concerned was not associated with distress. Whilst Merz et al. (2018) have suggested that this scoring of 'not applicable' impacted the DAS24 factorial solution of Moss et al. (2015), their argument centred upon the fact that only some items include this option and the large differentials in endorsement rates. In the present study the option was available in respect of every item and the analysis examined endorsement rates. The response options are shown alongside the draft items in Appendix B4.

7.3. Demographic details

Participants were asked to provide demographic details (Appendix B4 items 1-15). This included their sex, age, ethnic group, religion, sexual identity, relationships status, and questions about their visible difference including its: visibility; cause; how long present for; description; location on the body; whether currently receiving treatment from a healthcare professional in connection with it; and an indication of how different from normal they considered their visible difference and their overall appearance (adapted from Moss, 2005).

A number of these (e.g. ethnic group, sex, sexual identity, relationship status) were adapted from those recommended by the Office for National Statistics. Other details more closely connected to the presence of a visible difference (e.g. cause, description/type, location) were drawn from relevant literature (the ARC study reported by Clarke et al., 2014) and developed specifically for the study, with input from NR. One description ‘paralysis or muscular weakness’ was added shortly after the study opened at the request of an organisation that publicised the research.

7.4. Pilot testing

The draft scale and the other measures that were administered (see below) were piloted with members of CAR. They were asked to consider the clarity of the items, the appropriateness of the available responses, and the burden of completing the whole battery of measures. This resulted in minor changes to the items. In light of this and the input received from experienced researchers and clinicians in developing the items, no further pilot study was performed. The responses of participants were monitored as they were received (including a free-text response) to ensure nothing problematic arose.

7.5. Face and Content Validity

The involvement of NR and AC in the development of the items, together with the review by EJ and TM, (all experts in the field) established the face and content validity of the items. Their review and input ensured the items were each relevant, likely to contribute to the measurement of the construct of interest, and that no important domains were overlooked.

As an example, AC suggested that discomfort caused by non-sexual contact with a partner should be included, so item 25 was added:

(25) Non-sexual physical contact with a romantic partner would make me feel uncomfortable

Furthermore, participants were provided with a free-text response box in which they could comment on the scale and the items. The responses to this are considered later and help establish the face validity of the scale.

7.6. Construct Validity

The construct validity of the scale was assessed by several mechanisms. The first of these was through the performance of the EFA. This process indicates whether a conceptually coherent and acceptable factor structure exists and provides a basis to assess the number of factors within the construct. Also, participants were asked to complete other measures to demonstrate convergent and divergent validity. Finally, test-retest reliability was examined at the CFA stage.

7.6.1. Convergent Validity

The following measures were selected to be administered with the draft scale items in order to assess convergent validity:

7.6.1.1. Appearance Distress

DAS24 (Carr et al., 2005). The more parsimonious version of the original 59 version DAS59 (Carr et al., 2000). DAS24 assesses distress and difficulties experienced in living with problems of appearance.

DAS24 is scored through 24 items scored 0/1-4 with a maximum score of 96. Greater scores indicate greater distress. It was validated with a large UK sample taken from the general population and a clinical setting with patients with a range of visible differences. It has Cronbach's alpha of α=.92 (Carr et al., 2005). The mean DAS24 score for the general population was 30.99 whilst the clinical sample scored significantly higher (outpatients *M*=47.2, waiting list *M*=48.2) than the general population. In both populations, women scored more highly than men and there was a small, negative correlation with age, as younger people scored more highly than older people.

This measure was used rather than DAS59 to reduce the burden on the participants but without negatively impacting the resulting data (Carr et al., 2005). Furthermore, DAS24 has been shown to be comprised of two factors: general self-consciousness and sexual self-consciousness (Moss et al., 2015), although this has been challenged by Merz et al. (2018). Notwithstanding this challenge, DAS24 was hypothesised to correlate positively with CARRIS (in which a greater score would indicate greater distress). Such correlation was expected as DAS24 was considered likely to be relevant to several of the concepts within the construct:

2. Being negatively evaluated (romantically) by other people;
3. Exhibiting apprehension and caution in romantic relationship initiation;
4. Concern and anxiety in connection with disclosure of a visible difference; and
6. Impacted sex and physical intimacy (associated with high appearance distress).

7.6.1.2. Fear of Negative Evaluation

The Fear of Negative Evaluation – Brief (FNE-B) (Leary, 1983). This represents the brief version of the scale developed by Watson and Friend (1969) to measure apprehension about being evaluated unfavourably by others.

Whilst the original version (Watson & Friend, 1969) was used in the validation of DAS24 (Carr et al., 2005), that version included binary rather than Likert-style responses and 30 items rather than the 12 of FNE-B. Despite being less burdensome on participants the FNE-B has been reported to correlate very highly with the original version and demonstrate similar psychometric properties including a Cronbach's alpha of α=.90 with *M*=35.7 (albeit amongst an undergraduate sample from the U.S.A) (Leary, 1983). FNE-B has a maximum score of 60 with higher scores indicating more apprehension.

The measure has previously been utilised in investigating associations between body image, attachment, fear of intimacy, and social anxiety (Cash, Theriault, & Annis, 2004) (Cronbach's Alpha α=.89-.90) and in UK populations with visible difference (Bessell & Moss, 2007; ARC: Clarke et al., 2014) who demonstrated pre-intervention baseline means of 38.74-41.04 and also with participants with head and neck cancer (Clarke, Newell, Thompson, Harcourt, & Lindenmeyer, 2014) (*M*=30.06).

FNE-B was hypothesised to correlate positively with CARRIS as it was considered relevant to the following concepts within the target construct:

2. Being negatively evaluated (romantically) by other people (this was considered the concept most closely related to FNE-B);

4. Concern and anxiety in connection with disclosure of a visible difference;

6. Impacted sex and physical intimacy (associated with a fear of being negatively evaluated by others).

7.6.1.3. Body Self-Consciousness During Physical Intimacy

The Women's Body Image Self-Consciousness During Physical Intimacy With a Partner Scale (WBISCDPIWPS) (Wiederman, 2000) or *The Male Body Image Self-Consciousness During Physical Intimacy Scale (MBISCDPIS)* (McDonagh et al., 2009) as appropriate depending upon participants' sex (anyone identifying as non-binary would not complete either). Both scales measure body image self-consciousness during physical intimacy.

WBISCDPIWPS is a 15-item scale developed in the USA with which participants score between 0-75 (a higher score indicates greater self-consciousness) which was validated in 209 female North American college students and demonstrated strong psychometric properties with a Cronbach's Alpha of α=.93 and a mean of *M*=26.89 (*SD*=16.08). Whilst WBCSDPIWPS has been seldom used and to my knowledge has not been validated in a UK/Irish population, there existed few alternatives. Whilst the Body Exposure during Sexual Activities Questionnaire (Hangen & Cash (1991) cited in Cash, Maikkula, & Yamamiya (2004)) may represent a viable alternative and may be used by both women and men, to my knowledge this has not been validated in a UK/Irish population and is subject to the criticisms of McDonagh et al. (2009).

The MBISCDPI, however, was developed from WBISCDPIWPS and includes 17 items (minimum score 17, maximum score 85). This was validated in the Republic of Ireland (McDonagh et al., 2009) with a Cronbach's Alpha of α=.92 and a mean score of (*M*=35.89, *SD*=12.12). As MBISCDPI was derived from the WBCSDPIWPS and is the only such scale known to me that has been validated in a UK/Irish population, the decision was made to use MBISCDPI and WBISCDPIWPS, although it would be important to ensure their Cronbach's Alphas demonstrated good internal reliability (especially regarding WBISCDPIWPS).

MBISCDPI and WBISCDPIWPS were hypothesised to correlate positively with CARRIS as they would be relevant to the following concepts included within the target construct:

2. Being negatively evaluated (romantically) by other people;

6. Impacted sex and physical intimacy.

7.6.1.4. Fear of Intimacy

The Fear of Intimacy Scale (FIS) (Descutner & Thelen, 1991). This 35-item measure assesses fear of intimacy within, and at the prospect of, close relationships. It was developed in the USA using data generated from North American college students and demonstrated a Cronbach's Alpha of α=.93. The minimum score is 35, maximum 175. Greater scores indicate a greater fear of intimacy. Participants' mean score was *M*=78.75. FIS was further validated in a sample of North American men and women aged 35-55 with similar results (Cronbach's Alpha α=.92, *M*=79.58) (Doi & Thelen, 1993), with North American lesbian and gay participants (Cronbach's Alpha α=.91, *M*=74.23,) (Greenfield & Thelen, 1997) and also used in investigating associations between body image, attachment, fear of intimacy, and social anxiety (Cash, Theriault, et al., 2004).

FIS has been used in UK populations of young adults (Lyvers, Edwards, & Thorberg, 2017), and men (Sullivan, Camic, & Brown, 2015) (*M*=83.0) with these studies demonstrating Cronbach's Alphas of α=.9 and α=.95 respectively. Furthermore, the work of Hook, Gerstein, Detterich, & Gridley (2003) suggests that FIS pertains to three of four domains of intimacy: self-disclosure, trust, and personal validation.

The FIS was therefore hypothesised to correlate positively with CARRIS as it was relevant to the following concepts included within the target construct:

1. Considering oneself to be of diminished romantic worth;

3. Exhibiting apprehension and caution in romantic relationship initiation;

5. Trusting supportive relationships.

7.6.1.5. Social Intimacy

The Miller Social Intimacy Scale (MSIS) (Miller & Lefcourt, 1982). This 17-item scale measures the maximum level of intimacy experienced by an individual at the time of completion. The minimum score is 17 and maximum 170 (a greater score indicates a greater presence of social intimacy). Validated primarily in unmarried (*M*=137.5) and married (*M*=154.3) students in the USA the scale carries a Cronbach's Alpha of α=.86-.91 and was considered by Hook et al. (2003) to relate to their final component of intimacy, love and affection. It was therefore considered complementary to the FIS in the present research and has been utilised in the UK by Popovic, Milne, and Barrett (2003).

MSIS was hypothesised to correlate negatively with CARRIS and was thought to be relevant to the following concepts included within the target construct:

5. Trusting supportive relationships.

7.6.1.6. Divergent validity

The 'hysteria' sub-scale contained within the *Crown Crisp Experiential Index* (CCEI-H) (Crown & Crisp, 1979) purported measure of hysteria was used to demonstrate discriminant validity. This was used for the same purpose by (Carr et al., 2005) in developing DAS24, where no significant correlation was observed. It was hypothesised that CCEI would not correlate with CARRIS.

7.7. Data Collection

7.7.1. Recruitment of Participants

Participants self-identified as having a visible difference, were based in the UK/Ireland, aged 18 years or older, and did not have a diagnosed, untreated mental health issue which interfered with their activities of daily living. The study was advertised via the social media and newsletters of CAR and support groups, charities, and organisations operating in the field. Five organisations that were approached either did not respond or declined to advertise. At least 23 such groups advertised the study. Furthermore, a small number of individuals with a professional interest in the field also publicised the study via social media. These participants were directed to a link and could then find information, consent, and complete the study within the Qualtrics platform. Those that completed the study and provided contact details were provided with a £10 Amazon voucher as a 'thank you.'

The study was also advertised on the Prolific website. Prolific recruits potential research participants who provide demographic data and answer screening questions. Having ensured that appropriate screening questions were in place, eligible Prolific members were able to participate in the study. Prolific was paid £10 per participant plus a service charge. Each participant whose response was approved received £10 from Prolific. Of circa 38,000 members of Prolific (September 2018), approximately 50% were UK resident. Prolific has been demonstrated to replicate known effects, produce data superior to the Crowdflower site and comparable to MTurk but with participants who were more naïve and less dishonest than MTurk's (Peer, Brandimarte, Samat, & Acquisti, 2017). Prolific has been used by Swami, Weis, Barron, and Furnham (2017) in a study focussing on body image, sexual liberalism, and unconventional sexual practices in the USA. Participants recruited via Prolific completed the study by following a link to Qualtrics.

Having screened (as described in Chapters 8 and 9) the data provided by 275 participants who completed all sections of CARRIS items, the final sample consisted of *N*=253. Of these *n*=142 were recruited via Prolific, and *n*=111 via other means. Participants' age ranged from 18-66 (*M*=38.46, *SD*=12.28); *n*=176 participants were women, *n*=77 men.

Although *n*=22 did not answer these questions *n*=133 indicated their difference was visible to others during everyday life (or was normally visible), *n*=98 that it was not and when asked if they were receiving treatment from a healthcare professional in connection with their difference *n*=162 were not, *n*=69 were. Other participant details are included in Tables 7.1-7.4 which include demographic information and Tables 7.5-7.7 which detail information pertinent to participants' visible differences.

Table 7.1

EFA Participant Demographics: Ethnicity

Ethnicity	Asian / Asian British	Black / African / Caribbean / Black British	Mixed / multiple ethnic groups	White	Total
n	10	3	9	230	252

Table 7.2

EFA Participant Demographics: Religion

Religion	Christian (all denominations)	Hindu	Jewish	Muslim	Sikh	Other	No religion	Total
n	98	1	1	2	1	3	146	252

Table 7.3

EFA Participant Demographics: Sexuality

Sexuality	Bisexual	Gay or Lesbian	Heterosexual or Straight	Other	Total
n	12	7	230	3	252

Table 7.4

EFA Participant Demographics: Relationship Status

Relationship Status	In a relationship and living together	In a relationship but living separately	Married or in a civil partnership	Separated, divorced, or widowed (no current partner)	Single	Total
n	48	27	94	14	70	253

Table 7.5

EFA Participant Visible Difference: Cause

Cause of Visible Difference	Congenital / inherited / genetic	Disease process	Multiple	Traumatic injury	Treatment / surgery	Other	Total
n	71	51	8	35	35	31	231

Table 7.6

EFA Participant Visible Difference: Location

Location of Visible Difference	Limbs	Torso	Head/face	Whole body	Limbs and torso	Limbs and head/face	Torso and head/face	Total
n	30	33	97	52	9	20	10	251

Table 7.7

EFA Participant Visible Difference: Nature

Nature of Visible Difference	*n*
Alopecia / hair loss	40
Birthmark	6
Burn injury	4
Cancer related	10
Craniofacial condition	13
Dermatological / skin condition	44
Limb loss or amputation	2
Paralysis or muscular weakness	7
Scarring	49
Skeletal condition	10
Other	30
Multiple	35
Total	250

7.8. A False Start

The study was opened and then closed after only a few hours. Initially the advertisement on CAR’s social media mentioned the £10 thank you voucher. Inconsistencies in the early responses (specifically the demographic information provided), together with the rapid recruitment rate led me to suspect that the responses were not genuine. The study was therefore closed, and these suspicions confirmed the next day when I received an email suggesting all the responses were from people located outside the UK/Ireland and requesting a reward for this information.

After discussions with NR, I introduced new text into the information sheet and Qualtrics pages explaining that vouchers would only be provided to those participants who could be contacted on a UK/Irish phone number. A new Qualtrics survey was created with a new link and the existing data examined. Only one response looked genuine. That was retained and the participant sent a thank you voucher. Future publicity and advertisements concerning the study made no mention of the voucher. On reflection, this was probably a more ethical position in any event. I emailed the other respondents saying that concerns about the data meant that their response could not be used and no voucher provided. They were invited to contact me if they felt this unjust. No responses were received. Future data were examined with a combination of participant's demographics, the provision of a UK phone number (which I called where doubt existed and in a random selection of responses), their server's IP address, their response to duplicate and attentional check questions (referred to in the following section of this chapter), and the response to a free text question relating to CARRIS, all contributing towards a decision as to whether to retain or discard each response. The result is that, despite the early issues, I am confident that the final data are genuine.

7.9. Procedure

An application for ethical approval (Appendix B5) and risk assessment (Appendix B6) was submitted to the University of the West of England: University Research Ethics Committee: Faculty of Health and Applied Sciences and approval granted (Appendix B7).

Having accessed the participant information sheet (Appendix B8), confirmed their eligibility for the study, and consented to participation (Appendix B9) all participants then provided demographic details related to themselves and details of their visible difference and completed the CARRIS items and existing measures (Appendix B4).

The following measures were administered along with the draft items: DAS24 (Carr et al., 2005); FNE-B (Leary, 1983); WBCSDPIWPS (Wiederman, 2000) / MBSCDPIS (McDonagh et al., 2009); FIS (Descutner & Thelen, 1991); MSIS (Miller & Lefcourt, 1982); and CCEI-H (Crown & Crisp, 1979). The instructions and logic within Qualtrics ensured that participants who indicated that they were a woman answered only WBCSDPIWPS and not MBSCDPIS, vice versa for men.

All participants responded first to the items written for CARRIS. In Qualtrics these were presented in blocks of 12-14 questions with the order of the blocks randomised. The other measures were then presented. Again, the order of presentation was randomised. This was done to maximise the data collected in response to the CARRIS items, reduce order effects, and ensure that attrition did not adversely affect the amount of data collected in respect of any particular measure. The order was not randomised in hard copy versions as these were completed by only two participants.

With regards to the CARRIS items, participants were asked to read the items and consider how strongly they agreed or disagreed with each of them. Participants were also instructed to imagine how they would feel if a question that was not applicable because of their current circumstances did apply to them. For example, if a question was about a new relationship but the participant was currently in a relationship, they were asked to imagine how they would feel if it was applicable. If the question was otherwise not applicable or participants felt unable to do this, the not applicable option was available.

The CARRIS items included two attentional checks and one duplicate question in order to assess whether participants were paying sufficient attention to their responses and would answer a duplicate item in a broadly consistent manner. The attentional checks were compromised of an instruction that participants provide a particular response. For example:

Please confirm that you are reading the questions carefully by selecting 'slightly agree'

Participants that did not answer at least one attentional check correctly were excluded from the study. Those that answered the duplicate questions inconsistently were also excluded. This was defined as failing to provide answers to the duplicate items that were within two Likert-type scale points or one another (with those that were two Likert-type scale points apart being considered to satisfy this criterion). This standard was adopted as it was at this level of discrepancy (three or greater Likert-style scale points apart) at which a response which indicated the strongest agreement in one instance would necessarily indicate disagreement in the next (and vice-versa). Similarly, adopting this level of discrepancy meant that the data pertaining to any participant whose responses consistently indicated either agreement or disagreement, would be retained. The duplicate item was item 40 and item 52. Both read:

Item 40/52: I feel discomfort at being seen naked by a partner

The data were thoroughly checked for accuracy to ensure any errors in coding or exporting the data were corrected. It became apparent that the question asking where on the body the difference was located required consolidation. The number of options offered (11) and the ability for participants to combine multiple responses, meant that any meaningful analysis of this variable would be difficult to perform. As a result, the data were recoded into:

i. legs, feet, arms, hands, shoulders, and/or neck (limbs);
ii. genitals, buttocks, stomach, chest, and/or back (torso);
iii. head and/or face (head/face);
iv. whole body (meaning at least one of the options that constitute each of categories i-iii was selected); and
v. combinations of any two of i.-iii. (i.e. i&ii, i&iii, ii&iii).

The original options and categories offered dictated that some subjectivity was inherent in this process and it must be acknowledged as imperfect. For example, shoulders and neck were originally included together and so could not be separated. The inclusion of shoulders and the visibility of the neck suggested to me it should be grouped within 'limbs' rather than 'torso.'

Where there existed missing data, for example, if participants had not indicated the location of their difference, their complete response was examined and the data completed if possible. For example, one participant did not complete the location of their difference but indicated (in DAS24) that their teeth were affected and so they were coded as having a difference affecting their head/face. In instances where I could not be reasonably confident that such coding was accurate, the data were left incomplete. Three responses were considered acceptable but did involve a level of subjective judgement that requires disclosure. Two participants indicated they had acne and were coded as 'head/face.' One participant indicated they had stretch marks and so were coded as 'torso.'

All data were exported from Qualtrics into SPSS for Windows or (where hard copies were used) input directly into SPSS, the programme used in its analysis.

7.10. Research Questions

The research questions adopted for this phase of the research were:

- Can the draft scale items be used in order to make a parsimonious measure of appearance distress within a romantic context?
- How many factors relevant to the experience of appearance distress within a romantic context will be retained following an EFA performed on the data collected in pursuance of the development of CARRIS?
- What concepts will be represented within these factors?

It was hypothesised that participants' total CARRIS scores would correlate positively with DAS24, FNE-B, WBCSDPIWPS/MBSCDPIS, and FIS.

It was hypothesised that participants’ total CARRIS scores would correlate negatively with MSIS.

It was hypothesised that participants’ total CARRIS scores would not correlate significantly with CCEI-H

8. Exploratory Factor Analysis: Analysis Strategy

Having discussed the development of the items for CARRIS and the methods of data collection employed in the previous chapter, this chapter will focus upon the EFA analysis strategy and the decisions made in conducting these analyses before the next goes on to present the results of the analyses conducted.

8.1. Exploratory Factor Analysis

Yong and Pearce (2013) state that FA operates upon the basis that observable variables can be reduced to fewer, unobservable, latent variables sharing common variance. These latent variables, or factors, are hypothetical constructs that cannot be directly measured. Methods of EFA and PCA highlight patterns of correlations among observed variables, grouping together those that correlate. This enables the consolidation of a large number of observed variables into a smaller number of factors and provides insight into underlying processes and constructs (Tabachnick & Fidell, 2007). These techniques help understand the structure of a set of variables, to construct questionnaires measuring latent variables, and to reduce data-sets (Field, 2013).

EFA is widely used in the construction and interpretation of measurement instruments (Brown, 2015; Williams, Onsman, & Brown, 2010), indicating the utility of individual items (Tabachnick & Fidell, 2007) and the underlying factor structure of an instrument, which may be confirmed with CFA (Costello & Osborne, 2005). FA involves numerous decisions addressing the following five issues (Williams et al., 2010), which I will address in turn such as they relate to the EFA conducted as part of this thesis:

1. Is the data suitable for factor analysis?
2. How will the factors be extracted?
3. What criteria will assist in determining factor extraction?
4. Selection of rotational method
5. Interpretation and labelling

8.2. Is the data suitable for factor analysis?

Williams et al. (2010) refer to: sample size; the factorability of the correlation matrix; and formal metrics such as KMO and Bartlett's. Along with issues such as normality and missing data, these are each discussed below.

8.2.1. Sample Size

Whilst specific cases-to-variables ratio requirements can be adopted, this criterion enjoys relatively little support (Costello & Osborne, 2005; Field, 2013) and rules of thumb ratios are often violated (Costello & Osborne, 2005). The general recommendations of Comrey & Lee, (1992) (cited in Tabachnick & Fidell, 2007) that 50 is 'very poor,' 100 'poor,' 200 'fair,' 300 'good,' 500 'very good,' and 1,000 'excellent,' have been subject to refinement as the nature of the data may be more important than absolute sample size.

Guadagnoli and Velicer (1988) identified the magnitude of item-factor/component loadings, as critical. It was only when these were low (.4) that sample size impacted the solution. At .4 sample sizes of ≥300 were considered necessary to obtain consistent and reliable outcomes. At ≥.6 and with four or more variables loaded on each factor the solution was stable regardless of sample size.

Similarly, MacCallum, Widaman, Zhang, and Hong, 1999 demonstrated that sample size rules of thumb are less important than the communalities when conducting EFA. Communalities refer to the proportion of a variable's variance which is unique to that variable. They found that consistently high communalities (above .6) reduced the impact of sample size upon the stability of factor solutions with samples 100 providing accurate solutions. They argue that with well determined factors (a small number of factors with only a few variables each) and communalities of .5 only require 100-200 cases. Fabrigar, Wegener, MacCallum, and Strahan, (1999) offer similar conclusions, suggesting that with optimal conditions of communalities of .7 and three-five variables loading on each factor, samples of 100 can be sufficient. Where communalities are .4-.7 and at least three variables load on each factor, a sample of at least 200 should prove sufficient. With low communities (<.4) and two variables loading on some factors, 400 or more may be required.

In light of the advice of Fabrigar and Wegener (2012) that researchers do not assume optimal conditions, a sample of at least 200 participants was sought. Examining the communalities and qualities of the resultant factors enabled a *post-hoc* assessment of sample size.

8.2.2. Missing Data

Tabachnick and Fidell (2007) state that if few, random, data points are missing (≤5%) from a large data-set then the issue of missing data is not serious and any procedure for dealing with it will result in a similar outcome. The final data-set was examined in light of these comments and where appropriate and in order to retain the sample size achieved, mean substitution was preferred, as previously employed in FA studies (i.e. the EFA and CFA of Moon, Moss-Morris, Hunter, & Hughes, 2017).

8.2.3. Normality

Items which are endorsed in the same way by 95% of respondents would not be used (Clark & Watson, 1995; Streiner et al., 2015), neither items in which either extreme option was endorsed by more than 40% of the participants (Petrillo, Cano, McLeod, & Coon, 2015). To ensure the scale was capable of discriminating participants and avoid heavily skewed items, these criteria were adopted.

Whilst it has been argued that EFA is relatively robust to violations of normality (Floyd & Widaman, 1995) EFA may assume univariate normality, particularly when generalisations beyond the immediate sample are made (Field, 2013). In assessing normality, Petrillo et al. (2015) consider absolute figures of skewness <+/-2.0 acceptable. Fabrigar and Wegener (2012) concur adding the equivalent value for kurtosis is <+/-7.0. In assessing the distribution of the data these absolute values were consulted along with histograms. Highly skewed items were considered for elimination (Clark & Watson, 1995). Given the robustness of EFA to issues of non-normality, where distribution was somewhat problematic but not extreme the number of related items was considered so that no potential factor fell below four items.

As Tabachnick and Fidell (2007) advise, the data was also examined for univariate outliers. Where identified a decision was made as to whether to delete the case or amend the data to reduce the extremity of outliers.

8.2.4. Inter-item correlations / Factorability of R

As FA requires correlations between variables that are not too high nor too low the correlation matrix was consulted and offending items considered for removal (Field, 2013). A lack of correlations ≥0.3 as warrants deletion of the variable (Field, 2013; Tabachnick & Fidell, 2007).

Bartlett's tests the hypothesis that the correlations in a correlation matrix are significantly different from zero (different to an identity matrix) and should be significant for FA (Field, 2013; Tabachnick & Fidell, 2007). Whilst these commentators note the test is sensitive and likely to be significant with large sample sizes it retains some utility if <5 cases (participants) per variable.

KMO measures the proportion of variance attributable to underlying factors with values of >0.6 indicating the data are suitable for FA (Worthington & Whittaker, 2006). Field (2013) cites Hutcheson and Sofroniou (1999) who suggest KMO be interpreted in the following manner: values in the .90s, marvellous; .80s meritorious; .70s, middling; .60s, medicore; .50s, miserable; below .50 unacceptable.

8.2.5. Multicollinearity and singularity

The presence of items that correlate too strongly (multicollinearity) or perfectly (singularity) may be detected by examining the determinant of the *R*-matrix. This should be >0.00001 (Field, 2013). If this is identified, then the SMC for each variable as a dependent variable with all other variables acting as independent variable was examined. An SMC of one demonstrates singularity, near one, multicollinearity and the relevant variable should be deleted (Tabachnick & Fidell, 2007). Similarly, multicollinearity and singularity can be detected via the examination of the inter-item correlations. Items correlating >0.8 being candidates for deletion (Field, 2013).

8.2.6. Item-total correlations

Items should be removed if their item-total (total of all other items) correlation is <0.3 (Field, 2013; Streiner et al., 2015).

8.3. How will the factors be extracted?

8.3.1. Principal Components Analysis or Factor Analysis?

The phrase ‘exploratory factor analysis’ encompasses several distinct methods of analysis. The most fundamental distinction is between methods of FA and PCA. The essential difference relates to how the variance that is analysed is calculated (Tabachnick & Fidell, 2007). PCA assumes that all variance is common variance and there is no error or unique variance (Field, 2013). FA relies on the use of communalities (the SMC of each variable with all others) to estimate shared variance and analyses only this shared (common) variance (Field, 2013). FA therefore provides a solution based on the analysis of communalities (or covariance) and excludes error and unique variance (Tabachnick & Fidell, 2007).

The significance of this is that PCA may be considered distinct from FA (Costello & Osborne, 2005; Fabrigar et al., 1999; Field, 2013). PCA acts to arrange a large number of variables into a smaller number of components (Henson & Roberts, 2006; Reise et al., 2000) and so is primarily a data reduction technique (Costello & Osborne, 2005; Floyd & Widaman, 1995), appropriate where this is the goal (Fabrigar et al., 1999). PCA does not permit conclusions to be drawn concerning underlying latent constructs and structures (Henson & Roberts, 2006). Where an examination of underlying latent variables is desired, FA should be employed (Fabrigar et al., 1999; Floyd & Widaman, 1995; Kahn, 2006; Pett, Lackey, & Sullivan, 2003). FA is more appropriate in such cases as factors can be conceptualised as having ‘caused’ the variables whilst PCA’s components are aggregates of correlated variables, sharing an empirical but not necessarily theoretical association (Costello & Osborne, 2005; Tabachnick & Fidell, 2007).

There does exist, however, some debate about the practical importance of the choice between FA and PCA. Clark and Watson (1995) argued that this was one of a number of ‘perplexing decisions’ that generally has little effect upon the resultant factor structure. This argument echoes that of Kline (2014) and Guadagnoli and Velicer (1988) that PCA and FA produce similar solutions, particularly where there are ≥20 variables and communalities are ≥.4 (Field, 2013; Tinsley & Tinsley, 1987). Despite this, FA was adjudged appropriate as the analysis had a dual objective, to reduce the number of items contained within the measure and to examine the underlying latent structure of the scale. Furthermore, CFA would later be employed and Worthington and Whittaker (2006) argue FA is more closely aligned than PCA to the development of new scales, and is therefore recommended for this purpose.

It is, however, important to acknowledge that Eigenvalues produced by SPSS upon which the decision concerning how many factors to retain was based are generated via PCA and this procedure was used in developing the *scree-test* (O’connor, 2000a, 2000b). This is consistent with the recommendations of Ferguson and Cox (1993), Gaskin and Happell (2014), Pett et al. (2003), and the example analysis provided by Tabachnick and Fidell (2007). PCA was thus used in generating Eigenvalues and determining how many factors to retain but FA employed in the analyses of the composition of the factors. Furthermore, analyses were performed using the correlation rather than covariance matrix. Whilst the same scale was used for each variable, the correlation matrix minimises problems caused by differing variances (Field, 2013) and use of the covariance matrix is not generally advised for EFA (Pett et al., 2003) with correlation-matrices being more readily interpretable (Yong & Pearce, 2013).

8.3.2. Form of Factor Analysis

Whilst PCA and FA have been distinguished, there exist several forms of FA. These include the three most widely used forms PAF (also called principal factor analysis), IPAF, and ML (Fabrigar & Wegener, 2012). They typically produce similar results, though there exists something of a consensus that ML and PAF are the preferred methods with PAF coping better where assumptions of data normality are jeopardised (Costello & Osborne, 2005; Fabrigar & Wegener, 2012; Fabrigar et al., 1999; Floyd & Widaman, 1995; Kahn, 2006; Yong & Pearce, 2013) and, as Moss et al. (2015) note, may be considered the preferred method of FA (Tinsley & Tinsley, 1987). For the current analyses, I decided that ML or PAF would be employed with an examination of the distribution of the data determining between these two approaches.

8.4. What criteria will assist in determining factor extraction?

When performing FA, it is necessary to determine how many factors to retain. This requires a balance to be sought between the variance in the data that is accounted for by the solution and parsimony (Tabachnick & Fidell, 2007). A greater number of factors will result in a more comprehensive solution but greater complexity. To account for all variance it would be necessary to adopt a solution with as many factors as variables (Tabachnick & Fidell, 2007), undermining the utility of the analysis in the process of scale development.

A number of methods have been proposed to achieve this balance. Brown (2015) reports that three commonly used methods are the *Kaiser-criterion*, the scree-test, and parallel analysis. First, Kaiser (1960) proposed retaining all factors with an eigenvalue greater than one. Secondly, the scree-test Cattell (1966) requires that the factors are plotted on an x-axis, their eigenvalues on the y-axis, and the researcher search for the point at which a line starting at the first factor and drawn through subsequent points, changes slope (Tabachnick & Fidell, 2007). The factors on the steep slope are retained, those that are not (the 'scree') are discarded. For example, if the slope alters (becomes markedly less steep) after the sixth point, a six-factor solution would be indicated.

Finally, the parallel analysis of Horn (1965) involves comparing eigenvalues from a given data-set with those that are estimated using means generated from random data-sets that share parameters, such as sample size and number of variables, with the data-set (Brown, 2015). A rigorous application of parallel analysis involves the adoption of eigenvalues at the ninety-fifth percentile of the distribution of the means (Fabrigar & Wegener, 2012).

The *Kaiser-criterion* consistently overestimates the number of factors that should be retained (Brown, 2015; Fabrigar & Wegener, 2012; Ferguson & Cox, 1993), the *scree-test*, remains somewhat subjective (Fabrigar et al., 1999; Williams et al., 2010) with low inter-rater agreement (Gaskin & Happell, 2014). Parallel analysis, however, is generally recommended as the most accurate and consistent method of determining factors (Fabrigar et al., 1999; Ferguson & Cox, 1993; Field, 2013; Gaskin & Happell, 2014; Kahn, 2006; Williams et al., 2010), has fared well in Monte-Carlo simulations (Floyd & Widaman, 1995), and been used in health related EFA studies (Moon et al., 2017).

As it is not possible to consider any one of these methods a complete or fail-safe option, I decided to apply a combination of the three most popular methods. The *Kaiser-criterion* was adopted only in so far as no factor was retained with an Eigenvalue <1.0. The results of the *scree-test* and parallel analysis were compared, and a consensus sought. In the case of uncertainty or disagreement parallel analysis was to be used to set a maximum number of factors (Fabrigar & Wegener, 2012) and would be afforded priority where uncertainty existed. To perform parallel analysis the syntax of (O'connor, 2000a, 2000b) was employed.

8.5. Rotation

Having determined the appropriate form of FA and number of factors to be extracted the next step was to rotate the solution. This is necessary if the solution includes more than one factor and assists in distinguishing factors and increasing the interpretability of the solution (Brown, 2015). The initial solution is liable to include many variables with high loadings on the first factor and few upon subsequent factors (Field, 2013). Rotation of the factors (which can be conceptualised as axes upon which variables are plotted) maximises large factor loadings and minimises smaller ones and increases the likelihood of obtaining simple structure. Rotation, however, does not increase the variance explained by the solution (Kline, 2014).

When selecting a method of rotation, the primary decision is between an orthogonal and oblique method. Orthogonal rotation may offer more interpretable and simpler solutions (Tabachnick & Fidell, 2007) but assumes the factors do not correlate with one another (Fabrigar & Wegener, 2012) and so in rotating the factors (axes), keeps them perpendicular (Field, 2013). Oblique rotation, however, permits the factors to correlate (Tabachnick & Fidell, 2007), and does not require the axes remain perpendicular (Brown, 2015; Field, 2013).

The choice between orthogonal and oblique rotation thus depends upon whether the factors may be expected to correlate with one another (Field, 2013). Commentators in the field express a marked preference for oblique rotations as data from the social sciences, involving humans, that purports to measure related constructs may be expected to correlate in some way (Brown, 2015; Costello & Osborne, 2005; Fabrigar & Wegener, 2012; Fabrigar et al., 1999; Williams et al., 2010). Furthermore, as oblique rotation does not force factors to correlate, it will produce an almost identical solution to an orthogonal rotation where they do not correlate and a more accurate one where they do (Brown, 2015; Fabrigar & Wegener, 2012).

It was, however, not necessary to make an *a priori* choice between oblique and orthogonal rotation (Tinsley & Tinsley, 1987). An oblique rotation was performed, and the factor correlation matrix examined. As the factors were correlated the oblique rotation was preferred (Fabrigar et al., 1999; Pett et al., 2003; Tabachnick & Fidell, 2007). In assessing whether the factors were correlated, a correlation coefficient of >.32 was used (Tabachnick & Fidell, 2007).

There exist several methods of both orthogonal and oblique rotation. Whilst some commentators express a preference for Direct Oblimin within the oblique school of rotation (Field, 2013; Kline, 2014) this appears contrary to the slight trend, albeit in the nursing literature, for Promax that Gaskin and Happell (2014) identified. Tabachnick and Fidell (2007) attribute this to the ability of Promax to retain factor correlations whilst maximising simple structure. Others claim that both Direct Oblimin and Promax are commonly employed (Yong & Pearce, 2013) and both function well (Fabrigar & Wegener, 2012) though tend to produce similar results (Fabrigar et al., 1999). In light of these discrepancies it was determined follow the recommendations of Tabachnick and Fidell (2007) and 'experiment' with both Direct Oblimin and Promax rotations. Doing so is consistent with the exploratory nature of the analysis and the lack of an effective mechanism or rule choosing between these options (Gaskin & Happell, 2014). This flexibility enabled the method that offered the most conceptually coherent solution to be adopted.

An oblique rotation generates two outputs in SPSS, the factor pattern matrix and the factor structure matrix. It is the pattern matrix which is usually reported and examined for item and factor loadings (Costello & Osborne, 2005) as it is easier to interpret, with differences between high and low loadings more apparent (Tabachnick & Fidell, 2007). The pattern matrix was therefore consulted in determining whether simple structure was achieved (Pett et al., 2003) and was of primary interest (Fabrigar & Wegener, 2012).

8.6. Interpretation and labelling (including item deletion and retention)

In interpreting the outputs, it was necessary to reduce the number of items (variables) to produce a parsimonious scale. This required the deletion of items that did not perform well and the selection of the final items. In assessing the performance each item, the principal mechanism was an examination of the item's loading on its primary factor, its 'loading,' and its loadings on the other factors, its 'cross-loading(s).' Items with problematic cross-loadings were candidates for deletion (Costello & Osborne, 2005; Williams et al., 2010) and threats to simple structure.

Loadings ≥.32 may be considered acceptable and, conversely, cross-loadings at this level problematic (Costello & Osborne, 2005; Yong & Pearce, 2013). Tabachnick and Fidell (2007) concur citing Comrey and Lee (1992) who suggested that loadings in excess of .71 may be considered 'excellent,' .63 'very good,' .55 'good,' .45 'fair,' and .32 'poor.' Other recommendations include that loadings of ≥.4 be required and variables be considered problematic where they load ≥.4 on two or more factors (Ferguson & Cox, 1993). They do, however, argue that cross-loadings can be accepted where the discrepancy between the primary and secondary loading(s) is at least .2.

As already intimated, loadings and cross-loadings were critical in evaluating simple structure (Thurstone, 1947), with the criteria summarised by Kline (2014):

1. each row of the rotated matrix should contain at least one zero
2. in each factor the minimum number of zero loadings should be the number of factors in the rotation
3. for every pair of factors, there should be variables with zero loadings on one and significant loadings on the other
4. for every pair of factors, a large proportion of the loadings should be zero (in a matrix with large number of factors)
5. for every pair of factors, there should be only a few variables with significant loadings on both factors.

Essentially this means that 'several variables correlate highly with each factor and only one factor correlates highly with each variable' (Tabachnick & Fidell, 2007, p.647) or each variable loads only on one factor (Pett et al., 2003). Simple structure is desirable as it helps ensure solutions are interpretable and replicable (Kline, 2014).

In addition to loadings, cross-loadings and the discrepancy, it is important that each factor remains stable. This is achieved by ensuring that multiple variables load onto each factor. Williams et al. (2010) say that traditionally two or three variables must load onto a factor for it be interpretable and others argue that the stability of a factor requires at least three variables load onto it (Costello & Osborne, 2005; Yong & Pearce, 2013).

Where loadings and cross-loadings were acceptable, and a choice existed between multiple viable items whilst maintaining the stability of a factor the strength of the loadings and cross-loadings, the items' conceptual importance and similarity to other items that may be retained, the desire for parsimony, and its distribution were examined in selecting items. This was a somewhat subjective process though the criteria detailed below were applied.

Given these considerations, items were deleted if they:

1. did not load on any factor at ≥.4; and/or
2. cross-loaded at ≥.4 on any other factor.

Following this, the decision regarding which items to retain considered the:

1. strength of the loading (a greater loading being preferable);
2. desirability of having no cross-loadings ≥32;
3. size of the loading to cross-loading discrepancy;
4. number of zero or close to zero loadings on other factors (more being preferable and zero or close to zero being taken to be <+/- .1)
5. strength and number of any cross-loadings of .1-.32
6. item's meaning in the context of its main factor
7. item's conceptual similarity with other items (less similar items being preferred)
8. item's data distribution (normally distributed items being preferred).

The analysis was re-run when items were discarded and the eventual solution re-checked with only the final items included (Costello & Osborne, 2005; Pett et al., 2003). This iterative process of deletion and repetition until an acceptable solution is reached mirrors the recommendation of Worthington and Whittaker (2006) that FA be repeated after items are deleted and resembles that conducted by other researchers utilising FA/PCA in scale development (Bogosian, Moss-Morris, Bishop, & Hadwin, 2014). Following this process, the factors' meanings were then interpreted and appropriate names assigned (Ferguson & Cox, 1993).

The analysis is described in the following chapter, and utilised the decisions and process detailed above.

9. Exploratory Factor Analysis: Results

Having previously detailed the decisions that were made in performing the EFA, this chapter presents the results of that analyses and how these analyses led to the development of a 17-item version of CARRIS. The questions presented in the preceding chapter and relevant to EFA will be used to structure the presentation of the analyses.

9.1. Is the data suitable for factor analysis?

9.1.1. Sample size and missing data

Potentially useable responses were collected from 275 participants. Of these, 3 participants failed both attentional checks included within the draft intimacy scale and were deleted. One attentional check was answered correctly by 93.4% of the remaining participants, the other by 97.8%. Overall, the attentional checks were therefore answered correctly 95.6% of the time with no remaining participant answering both incorrectly.

The data from 18 participants who responded inconsistently to the duplicate question were removed. This was defined as differing by three or greater response options on the Likert-type scale. This left a remainder of 254 participants. The responses to the duplicate item were examined. They were found to correlate in a highly significant manner *r*=.884 *p*=<.001 and via a paired samples *t*-test were shown to not differ significantly item 40 (*M*=3.79, *SE*=0.107) item 52 (*M*= 3.72, *SE*=0.104) *t*(251) = 1.325, *p*=.186.

Participant data were examined for missing data. Data relating to one additional participant was deleted as they had failed to answer an entire Qualtrics page of CARRIS items and two other items (12.2% of the CARRIS items). In all other cases missing data was <5% of the draft scale items. This resulted in 253 cases being retained for analysis. These included a total of 43 (or 0.23%) missing items spread amongst 32 participants with the remaining 221 responding to all items. Missing data per CARRIS item ranged from 0% (41 items), through 0.4% (26 items missing one response), 0.8% (four items missing two responses), to a maximum of 1.2% (three items missing three responses).

As the total level of missing data were well within 5%, no participant’s data included >5% missing data, no item included >5% missing data, and the incidence of missing data were not concentrated within a small number of items, mean substitution was considered an acceptable method of addressing missing data. The impact of means substitution as opposed to listwise deletion was monitored by visually comparing the two solutions the initial stage of the analysis and by completing parallel analyses using both mean substitution and listwise deletion at all stages of the analysis. No substantial differences in the solution were noted and the parallel analyses (using the syntax of O'connor (2000a, 2000b)) generated the same results whether mean substitution or listwise deletion was used. All subsequent references in this chapter are therefore to analyses completed using mean substitution.

The use of mean substitution enabled a sample of *N*=253 to be retained. This was above the minimum of 200 that had been sought and suggested that neither the level of missing data nor the sample size rendered the data unsuitable for factor analysis.

The communalities and number of items loading upon each factor are described below but at each stage of the iterative analysis few individual items had communalities under 0.4 and at no point was any single factor composed of fewer than three variables. This satisfied the stipulations of Fabrigar et al. (1999) concerning the conditions required for a sample of ≥200 to prove sufficient for FA. Similarly, Bartlett's and KMO indicated at each stage that the data were suitable for FA.

9.1.2. Inter-item correlations / factorability of R

A correlation matrix from a PCA including all 74 items was examined. Ignoring the correlation between the duplicate items, there were no correlations > .8. Two items did not correlate at ≥.3 with any other items. The following items were deleted:

- *Item 55: It is important that I have attractive qualities that are not to do with my looks*
- *Item 58: I would be attracted to somebody because they expressed romantic interest in me*

9.1.3. Normality

No items included any responses selected by ≥95% of participants. The following items were deleted as either extreme response option (as indicated) was selected ≥40% of participants:

- *Item 5: I will never have a rewarding romantic relationship (strongly disagree)*
- *Item 13: I have a wide choice of partners (strongly disagree)*
- *Item 15: I would be comfortable hugging and holding my partner's hand (strongly agree)*
- *Item 16: I have experienced prolonged spells of limited or no sexual activity (strongly agree)*
- *Item 19: I am careful about who I become romantically involved with (strongly agree)*

- *Item 25: Non-sexual physical contact with a romantic partner would make me feel uncomfortable (strongly disagree)*
- *Item 27: I would fear being rejected by a potential partner (strongly agree)*
- *Item 73: The first time I engage in sexual activity with a new partner, I would worry that my partner would find me unattractive (strongly agree)*
- *Item 74: I would feel comfortable kissing my partner (strongly agree)*

The absolute values of skew and kurtosis for the remaining items revealed none exceeded +/-2. An examination of the histograms for the remaining items, however, suggested some were not normally distributed. As EFA is relatively robust to such violations an inclusive approach was adopted. Despite this, some items were removed because of their non-normal distribution. This was done in light of the intention to conduct a CFA, which may be a little more sensitive to deviations from normality, at a later date and the desire for the scale to discriminate between participants. Before eliminating items, the hypothesised group of related items to which they belong was consulted to ensure at least three items remained and that conceptually similar items subsisted. On this basis the following items were removed:

- *Item 4: I would fear being rejected by a partner*
- *Item 21: A partner or ex-partner could use the way I look against me or to hurt me*
- *Item 26: I deserve the romantic interest and attention of others*
- *Item 28: I would find it difficult to choose a picture of myself to present to potential partners*
- *Item 34: I would avoid using dating websites*
- *Item 37: It would be deceitful not to tell a new partner about my appearance very early in the relationship*
- *Item 39: I prefer sexual activity with the light off so that I cannot be seen*
- *Item 44: I welcome sexual contact with a partner*
- *Item 47: I would be comfortable engaging in a casual or fleeting sexual relationship*
- *Item 49: I would be worried about a potential or new partner seeing me naked*
- *Item 50: I would need to be friends with someone before becoming partners*

As detailed above, the responses to the duplicate item were highly and significantly correlated with one another and did not differ significantly so, as planned, only one such item was retained. Examining their distribution revealed that item 52 was slightly more evenly distributed than item 40 and so this was retained and item 40 deleted.

9.1.4. Multicollinearity and singularity

Whilst this is reported in respect of each analysis that was performed, it was notable that the determinant of the *R*-matrix in respect of the initial PCA performed (to produce the correlation matrix) was <0.00001 and this persisted through early analyses, suggesting multicollinearity and singularity may be problematic. Where this was indicated as potentially problematic the examination of items' SMCs and the fact that no items correlated with one another at >0.8 quelled any concerns. In addition, the determinant of the *R*-matrix for the final two iterations of the analysis was >0.00001 and so multicollinearity and singularity were not adjudged to render the data unsuitable for FA.

9.1.5. Item-total correlations

An examination of the item-total correlation of each of the remaining items revealed that three items failed to correlate at ≥.3 with the total. The item with the weakest correlation (item 41 (*r*=.285)) was removed and new item-total correlations examined. Two items now failed to correlate in this way. The item with the weakest correlation (item 18 (*r*=.280)) was removed and the process repeated. Item 2 (*r*=.295) was removed. Finally, no item failed to correlate at >0.3 with the total. The following items had been removed:

- *Item 41: I would feel comfortable telling a partner my innermost thoughts and feelings about how I look*
- *Item 18: Speaking to a new partner about my appearance would bring us closer together*
- *Item 2: Showing a new partner my body would bring us closer together*

The deletion of Item 2, however, reduced the items related to one hypothesised concept, disclosure, to three items, one fewer than the four required to establish a reliable factor. In consideration of this, Item 28 (previously deleted due to concerns over its distribution) was reinstated as, of the related items that had been deleted, this was adjudged to not be captured by the remaining items. The process relating to item-total correlations was repeated (with items 41, 18, and 2 included again). This had no impact upon the process described above nor the items that were deleted. The correlation coefficients detailed above include Item 28.

9.1.6. Outliers

The data were examined for univariate outliers. Boxplots revealed that three of the remaining 49 items contained responses that may be considered outliers. This includes four responses to item 29 and 11 responses to each of items 38 and 71. Examining the histograms relevant to these items and associated z-scores indicated that these were not problematic. Only item 29 included any responses with a z-score >+/-2.58 and in this case 2% of responses carried a z-score of 2.63 rather than the 1% Field (2013) indicates as indicative of a normal distribution. In light of these z-scores, the histograms, and the minimal number of outliers indicated by the boxplots, the responses were retained.

9.2. How will the factors be extracted?

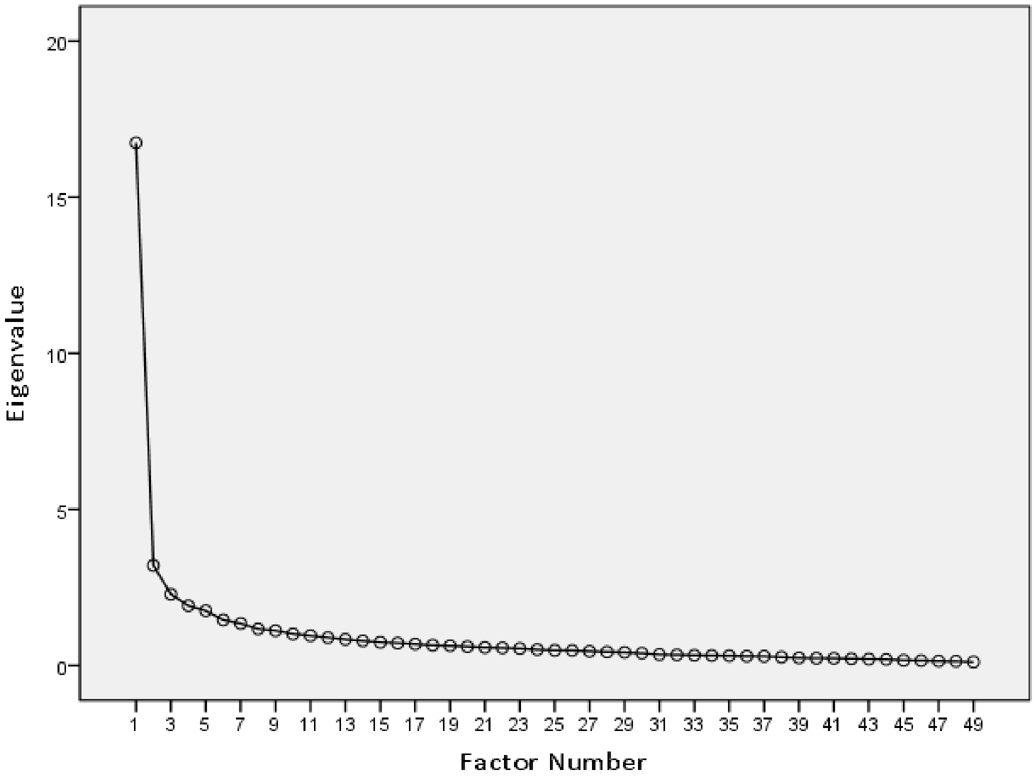
The process described above led to the retention of 49 items. Checks for multicollinearity and singularity, and communalities were repeated. The communalities were not of concern with only three items having a communality <.4 with *M*=.562. The data were therefore not liable to produce different solutions under FA and PCA. Checks for multicollinearity and singularity revealed that despite the determinant of the *R*-matrix remaining <.00001 only one item had an SMC >.800 (item 52, SMC=.801) and so multicollinearity and singularity were not adjudged problematic.

Residual concerns relating to the distribution of the data led to the utilisation of PAF rather than ML in all analyses.

9.3. What criteria will assist in determining factor extraction?

The eigenvalues from an initial analysis including these 49 items are included at Appendix C1. The eigenvalues greater than 1.0 rule (the *Kaiser-criterion*) indicated a maximum 10 factor solution. The scree plot (Figure 9.1) suggested that either a two, three or five factor solution would be the most appropriate.

Figure 9.1: Scree Plot: EFA CARRIS: 49 ITEMS



Parallel analyses (Horn, 1965), utilising the syntax of O'connor (2000a, 2000b) and using i) random data and ii) permutations of the raw data indicated a 5 factor solution. Table 9.1 illustrates the outcome of these analyses. A solution with the number of factors indicated may be accepted where the CARRIS Eigenvalue from the analysis exceeds the random data and raw data Eigenvalues at the 95% confidence internal level. Along with subsequent presentations of parallel analyses, Table 9.1 shows the Eigenvalues that meet this criteria and the first one that does not.

Table 9.1

Parallel Analysis: EFA CARRIS: 49 Items (variables), 253 Participants (cases)

Factor Number.	CARRIS Eigenvalue	Parallel Analysis Random Data Eigenvalues (95% C.I.)	Parallel Analysis Raw Data Eigenvalues (95% C.I.)
1	16.737	2.083	2.079
2	3.205	1.948	1.946
3	2.284	1.861	1.857
4	1.920	1.786	1.784
5	1.757	1.720	1.722
6	1.463	1.664	1.662

Using the *Kaiser-criterion* as a maximum number of factors, in light of a five factor solution being one of the solutions indicated by the scree test, and following parallel analyses, a five factor solution was accepted. This explained 52.9% of the variance.

9.4. Selection of rotational method

A PAF with a fixed five factor extraction was performed using the oblique rotational methods of Direct Oblimin and Promax. As planned, the resultant solutions were examined for correlations between the factors in order to consider whether an orthogonal rotation would be more appropriate. The Promax rotation resulted in a more interpretable factor structure and a greater number of correlations ≥.32 between the factors (7/10 as opposed to 3/10 with Direct Oblimin rotation). This dictated that an oblique method of rotation be utilised and Promax was adopted. Factor correlations are contained within Table 9.2

Table 9.2

EFA CARRIS 49 Items: PAF, Promax Rotation: 5 Factor Solution, Factor Correlations

Factor	1	2	3	4	5
1	-	.616	.560	.467	.302
2	.616	-	.428	.478	.281
3	.560	.428	-	.373	.213
4	.467	.478	.373	-	.372
5	.302	.281	.213	.372	-

9.5. Interpretation and labelling

9.5.1. CARRIS 49 Items

This initial analysis therefore constituted a PAF on the 49 retained items that were designed to measure appearance distress within the context of romantic relationships. The suitability of PAF was assessed prior to analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient >0.3 and all correlated with the scale total at >0.3. Whilst the determinant of the R-matrix was <.00001 examination of the items' SMCs revealed that multicollinearity was not a problem. The overall KMO =.926 ('marvellous'), and communalities averaged .562. Bartlett's was statistically significant χ2(1176)=7178.04 (*p*<.001), indicating that the data were suitable for factor analysis.

As detailed above, the analysis revealed ten factors that had eigenvalues greater than one. Visual inspection of the scree plot and parallel analysis indicated that five factors should be retained. A five factor forced PAF was performed. These factors explained a total of 52.9% of the variance (34.2%, 6.5%, 4.7%, 3.9% and 3.6% respectively).

Following this analysis the item-loadings and cross-loadings were examined in order to remove poorly performing items from then scale and to create a parsimonious, useable instrument. Consulting Appendix C2, the pattern matrix (loadings suppressed at <.1), led to the deletion of the following items as they did not load on their primary factor at ≥.4:

- *Item 68: During sexual activity, I would use clothing, lighting or choose certain positions to hide aspects of my appearance*
- *Item 3: I would reject the romantic approach of another person*
- *Item 30: I would withhold my feelings about how I look from a romantic partner*
- *Item 36: It is normal for people like me to be single*
- *Item 9: A partner of mine would be embarrassed or ashamed to be seen with me in public*
- *Item 67: I am satisfied with my intimate and romantic life*
- *Item 11: I find it difficult to talk to people that I am attracted to*
- *Item 38: The romantic or sexual interest of others in me is genuine*
- *Item 51: I grow apart from my partners or experience conflict in my relationships because of my appearance*
- *Item 20: Discussing my appearance with a partner would make me less attractive to them*

- *Item 10: I would know when to tell a new partner about my appearance*
- *Item 63: I would approach someone that I was attracted to*

One additional item was removed as it cross-loaded on a second factor at >.4 this was:

- *Item 31: I need to put extra effort into my relationships because of how I look*

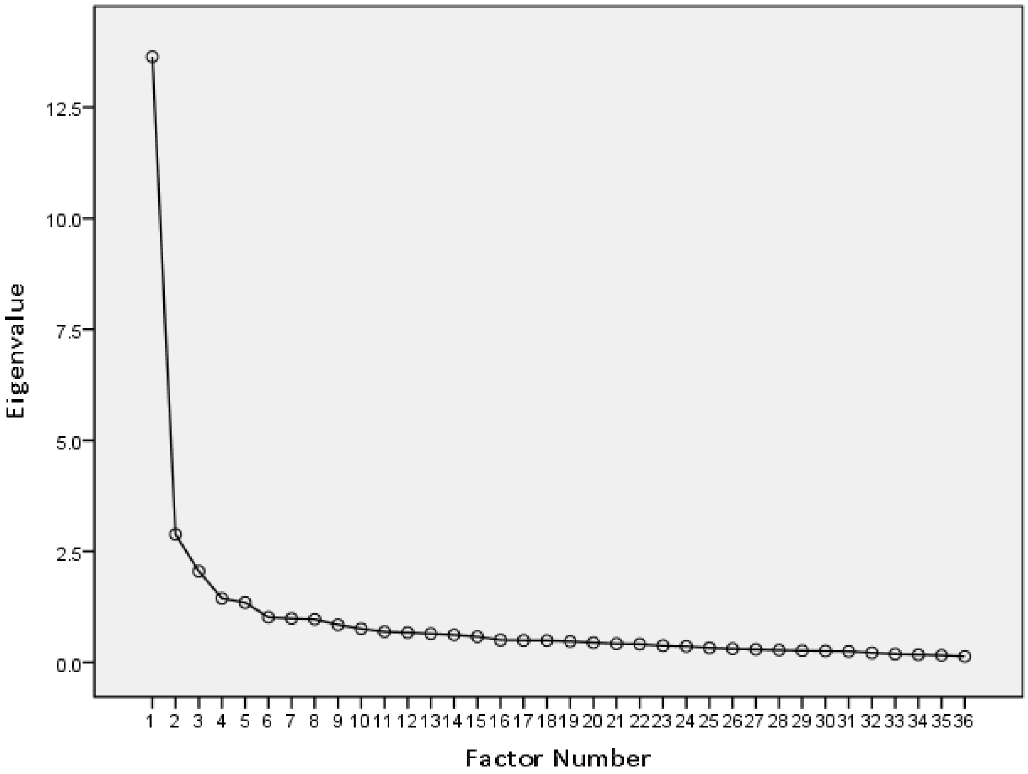
No other item cross-loaded at >.4 onto a second factor. The deletion of these 13 items required that the analysis be repeated in order to examine the factor structure of the remaining 36 items.

9.5.2. CARRIS 36 Items

Repeating the PAF with the remaining 36 items resulted in six factors being indicated by the *Kaiser-criterion.* Eigenvlaues are illustrated in Appendix C3.

An examination of the scree plot (Figure 9.2) indicated a three or five factor solution.

Figure 9.2: Scree Plot: EFA CARRIS: 36 Items



Parallel analysis conducted in respect of both raw data permutations and random data (Table 9.3) using the syntax of O'connor (2000a, 2000b) specified a three factor solution. It explained 51.6% of the variance.

Table 9.3

Parallel Analysis: EFA CARRIS: 36 Items (variables), 253 Participants (cases)

Factor Number.	CARRIS Eigenvalue	Parallel Analysis Random Data Eigenvalues (95% C.I.)	Parallel Analysis Raw Data Eigenvalues (95% C.I.)
1	13.641	1.888	1.892
2	2.883	1.766	1.767
3	2.054	1.678	1.678
4	1.443	1.611	1.609

A three-factor forced PAF was conducted and subjected to Promax rotation. Appendix C4 contains the pattern matrix.

All three correlations between the three factors were >.32 (Table 9.4) and so the oblique Promax rotation was deemed appropriate.

Table 9.4

EFA CARRIS 36 Items: PAF, Promax Rotation: 3 Factor Solution, Factor Correlations

Factor	1	2	3
1	-	.627	.426
2	.627	-	.413
3	.426	.413	-

A PAF was performed on the 36 remaining items. The suitability of PAF was assessed prior to analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient >0.3 and all correlated with the scale total at >0.3 except one item (item 46 which loaded onto the third factor at .286) which was retained in order to maintain the stability of the factor to which it belonged as its deletion would have meant the factor had <4 items loading onto it. Whilst the determinant of the R-matrix was <.00001 an examination of the items' SMCs revealed that multicollinearity was not a problem with all SMCs being <0.8. The overall KMO =.933 ('marvellous') and communalities averaged .547. Bartlett's was statistically significant $\chi 2(630)=5338.22$ ($p<.001$), indicating that the data were suitable for factor analysis.

The analysis revealed six factors that had eigenvalues greater than one. Visual inspection of the scree plot and parallel analysis indicated that three factors should be retained. A three-factor forced PAF was performed. These factors explained a total of 51.6% of the variance (37.9%, 8%, and 5.7% respectively).

Following this analysis the item-loadings and cross-loadings were examined in order to remove poorly performing items and to create a parsimonious, useable instrument. Consulting Appendix C4 (the pattern matrix, loadings suppressed at <.1) led to the deletion of the following items as they did not load on their primary factor at >.4:

- *Item 65: I would know how to speak to a new partner about my appearance*
- *Item 72: Receiving the romantic attention of another person would make me feel anxious*

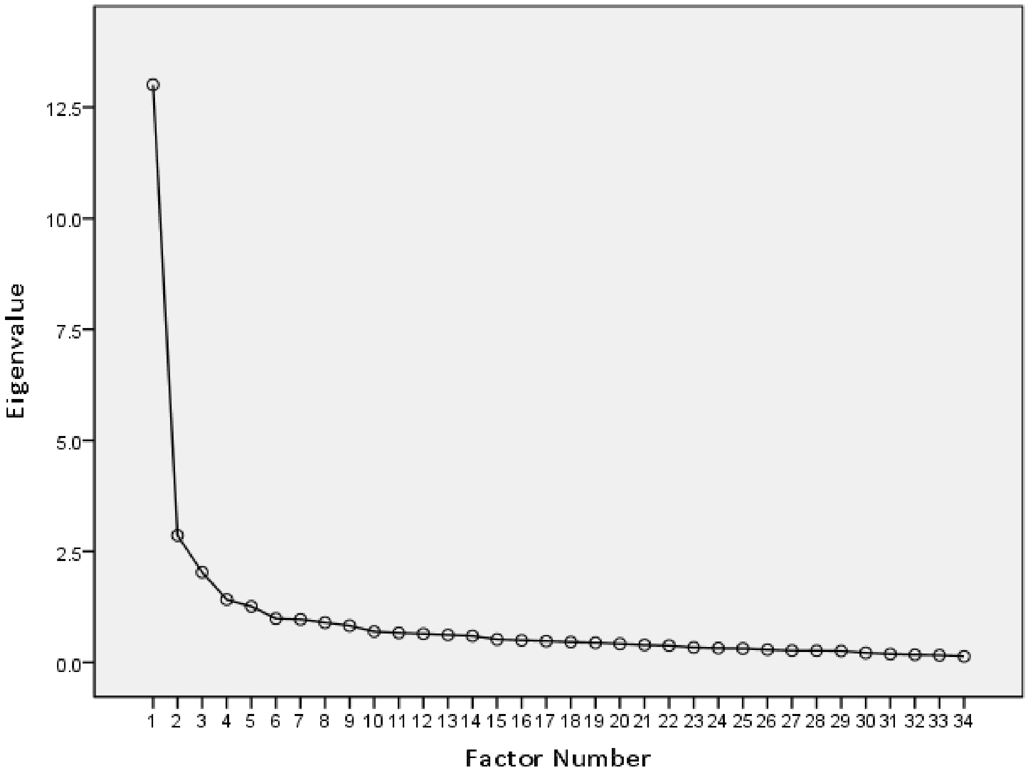
No item cross-loaded at >.4 onto a second factor and 34 items were retained.

9.5.3. CARRIS 34 Items

Repeating the PAF with the remaining 34 items resulted in five factors being indicated by the *Kaiser-criterion.* Eigenvalues are illustrated in Appendix C5.

An examination of the scree plot (Figure 9.3) indicated a three or five factor solution.

Figure 9.3: Scree Plot: EFA CARRIS: 34 Items



Parallel analysis conducted in respect of both raw data permutations and random data (Table 9.5) using the syntax of O'connor (2000a, 2000b) specified a three factor solution that was adopted. It explained 52.7% of the variance.

Table 9.5

Parallel Analysis: EFA CARRIS: 34 Items (variables), 253 Participants (cases)

Factor Number.	CARRIS Eigenvalue	Parallel Analysis Random Data Eigenvalues (95% C.I.)	Parallel Analysis Raw Data Eigenvalues (95% C.I.)
1	13.009	1.860	1.864
2	2.860	1.740	1.735
3	2.032	1.652	1.646
4	1.417	1.581	1.578

A three-factor forced PAF was conducted and subjected to Promax rotation. Appendix C6 contains the pattern matrix (loadings suppressed at <.1).

All three correlations between the three factors were >.32 (Table 9.6) and so the oblique Promax rotation was retained.

Table 9.6

EFA CARRIS 34 Items: PAF, Promax Rotation: 3 Factor Solution, Factor Correlations

Factor	1	2	3
1	-	.612	.400
2	.612	-	.380
3	.400	.380	-

A PAF was performed on 34 remaining items. The suitability of PAF was assessed prior to analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient >0.3 and all correlated with the scale total at >0.3 except one item (item 46 which loaded onto the third factor at .279) which was retained in order to maintain the stability of the factor to which it belonged as its deletion would have meant the factor had <4 items loading onto it. Whilst the determinant of the *R*-matrix was <.00001 an examination of the items' SMCs revealed that multicollinearity was not a problem with all SMCs being <0.8. The overall KMO =.930 ('marvellous') and communalities averaged .536. Bartlett's was statistically significant χ2(561)=5069.01 (*p*<.001)), indicating that the data were suitable for factor analysis.

The analysis revealed five factors that had eigenvalues greater than one. Visual inspection of the scree plot and parallel analysis indicated that three factors should be retained. A three factor forced PAF was performed. These factors explained a total of 52.7% of the variance (38.3%, 8.4%, and 6% respectively).

Examination of item-loadings and cross-loadings revealed that all items loaded >.4 onto their primary factor and no items loaded >.4 onto a secondary factor.

As a parsimonious scale was desired and two of the factors appeared over specified with the first and second factors being constituted of 17 and 13 items respectively, the criteria for item selection were invoked.

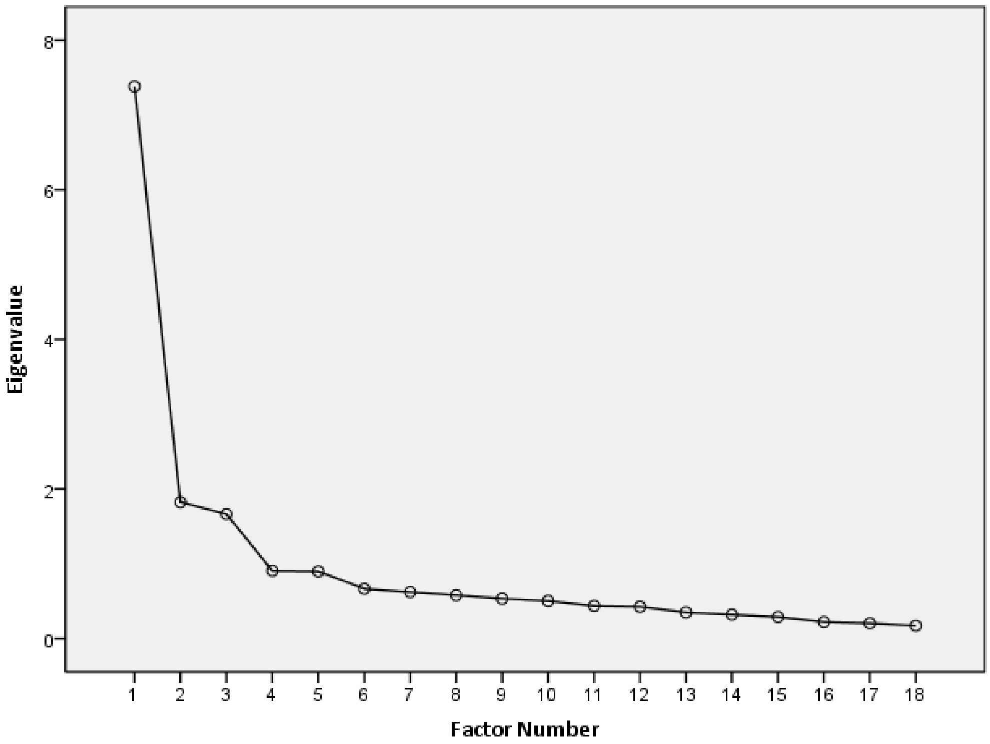
Decisions regarding which items to retain and which to discard were made in view of the pre-determined criteria. Appendix C7 illustrates the decision that was made regarding each item and the rationale for the deletion of discarded items.

9.5.4. CARRIS 18 Items

Following deletion of these items, 18 items remained. These were subjected to a further PAF to determine the structure of the scale. This resulted in three factors being indicated by the Kaiser-criterion. Eigenvalues are illustrated in Appendix C8.

An examination of the scree plot (Figure 9.4) indicated a three-factor solution.

Figure 9.4: Scree Plot: EFA CARRIS: 18 Items



Parallel analysis conducted in respect of both raw data permutations and random data (Table 9.7) using the syntax of O'connor (2000a, 2000b) specified a three factor solution that was adopted. It explained 60.3% of the variance.

Table 9.7

Parallel Analysis: EFA CARRIS: 18 Items (variables), 253 Participants (cases)

Factor Number.	CARRIS Eigenvalue	Parallel Analysis Random Data Eigenvalues (95% C.I.)	Parallel Analysis Raw Data Eigenvalues (95% C.I.)
1	7.381	1.585	1.586
2	1.824	1.461	1.459
3	1.665	1.380	1.381
4	.906	1.307	1.308

A three factor forced PAF was conducted and subjected to Promax rotation. Appendix C9 constitutes the pattern matrix for this analysis (loadings suppressed at <.1).

All three correlations between the three factors were >.32 (Table 9.8) and so the oblique Promax rotation was deemed appropriate.

Table 9.8

EFA CARRIS 18 Items: PAF, Promax Rotation: 3 Factor Solution, Factor Correlations

Factor	1	2	3
1	-	.625	.445
2	.625	-	.448
3	.445	.448	-

A PAF was performed on 18 remaining items. The suitability of PAF was assessed prior to analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient >0.3 and all correlated with the scale total at 0.3 or greater. The determinant of the *R*-matrix was acceptable at .0000557 and an examination of the items' SMCs confirmed that multicollinearity was not a problem with all SMCs being <0.8. The overall KMO =0.89 ('meritorious') and communalities averaged .524. Bartlett's was statistically significant χ2(153)=2372.34 (*p*<.001), indicating that the data were suitable for factor analysis.

The analysis revealed three factors that had eigenvalues greater than one. Visual inspection of the scree plot and parallel analysis indicated that three factors should be retained. A three factor forced PAF was performed. These factors explained a total of 60.4% of the variance (41%, 10.1%, and 9.2% respectively).

Examination of item-loadings and cross-loadings revealed that all items loaded >.4 onto their primary factor and no items loaded >.4 onto a secondary factor.

Despite the apparent fit of the items and factor loadings, concern subsisted in respect of one item (item 32). This item had a relatively low loading, being the weakest item that loaded onto the first factor, and the highest cross loading, loading on a secondary factor at >.32. Furthermore, in consultation with NR and AC, NR (independently and without knowledge of the item's loadings) suggested that the item may benefit from being re-worded and considered it mirrored in another item. Given these concerns, a decision was made to delete:

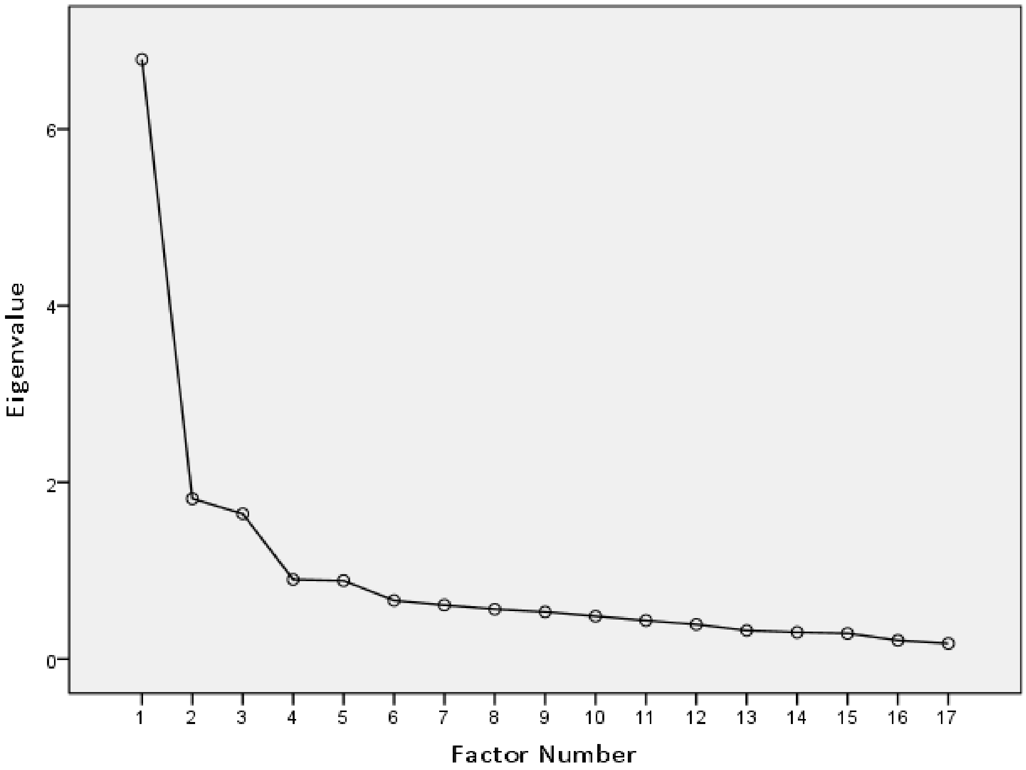
Item 32: I avoid certain sexual activity because of how I look

9.5.5. CARRIS 17

17 items remained. These were subjected to a further PAF to determine the structure of the scale. This resulted in three factors being indicated by the Kaiser-criterion. Eigenvalues are contained within Appendix C10

An examination of the scree plot (Figure 9.5) indicated a three-factor solution.

Figure 9.5 Scree Plot: EFA CARRIS: 17 Items



Parallel analysis conducted in respect of both raw data permutations and random data (Table 9.9) using the syntax of O'connor (2000a, 2000b) specified a three factor solution. It was adopted and explained 60.3% of the variance.

Table 9.9

Parallel Analysis: EFA CARRIS: 17 Items (variables), 253 Participants (cases)

Factor Number.	CARRIS Eigenvalue	Parallel Analysis Random Data Eigenvalues (95% C.I.)	Parallel Analysis Raw Data Eigenvalues (95% C.I.)
1	6.787	1.579	1.575
2	1.814	1.440	1.448
3	1.643	1.356	1.361
4	.899	1.290	1.291

A three-factor forced PAF was conducted and subjected to Promax rotation. Appendix C11 contains the pattern matrix for this analysis (loadings suppressed at <.1).

All three correlations between the three factors were >.32 (Table 9.10) and so the oblique Promax rotation was deemed appropriate.

Table 9.10

EFA CARRIS 17 Items: PAF, Promax Rotation: 3 Factor Solution, Factor Correlations

Factor	1	2	3
1	-	.596	.461
2	.596	-	.469
3	.461	.469	-

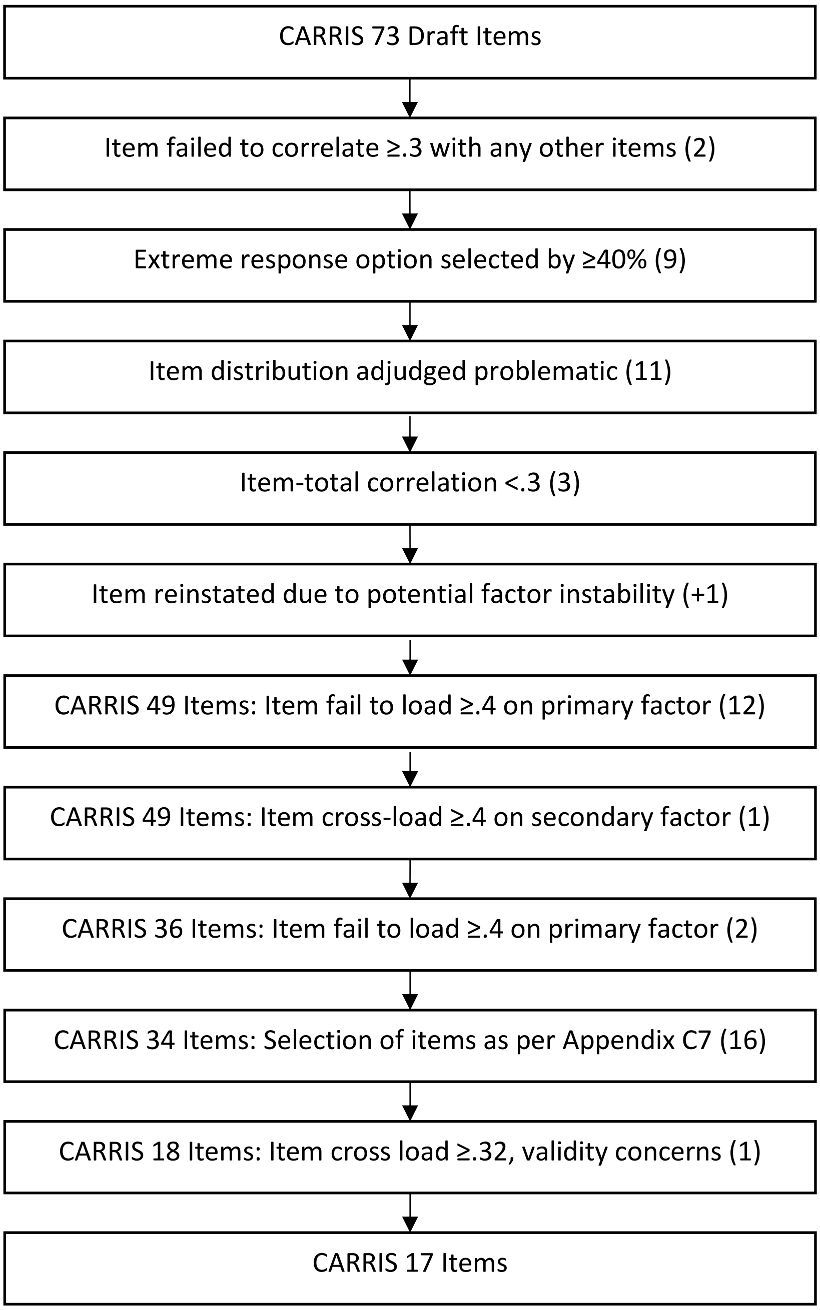
A PAF was performed on 17 remaining items. The suitability of PAF was assessed prior to analysis. Inspection of the correlation matrix showed that all variables had at least one correlation coefficient >0.3 and all correlated with the scale total at 0.3 or greater. The determinant of the *R*-matrix was acceptable at .0000557 and an examination of the items' SMCs confirmed that multicollinearity was not a problem with all SMCs being <0.8. The overall KMO =0.89 ('meritorious') and communalities averaged .518. Bartlett's was statistically significant χ2(136)=2113.21 (*p*<.001), indicating that the data were suitable for factor analysis. Individual KMO values were also investigated at this stage. KMO for all items was >.5 recommended by Field (2013), the lowest being Item 46 with an individual KMO =.768.

The analysis revealed three factors that had eigenvalues greater than one. Visual inspection of the scree plot and parallel analysis indicated that three factors should be retained. A three-factor forced PAF was performed. These factors explained a total of 60.3% of the variance (39.9%, 10.7%, and 9.7% respectively).

Examination of item-loadings and cross-loadings revealed that all items loaded >.4 onto their primary factor and no items loaded >.4 onto a secondary factor. Furthermore, every item had a discrepancy of at least .2 between its main and secondary loading. The smallest such discrepancy was .375 (item 43).

This analysis was accepted and the 17 items (pattern matrix in Appendix C11) thus constituted CARRIS. The process of item deletion, described above, is illustrated in Figure 9.6

Figure 9.6 CARRIS item deletion process (number of items deleted shown in parentheses)



9.6. Interpretation of CARRIS: 17 Items

An examination of each factor (pattern matrix in Appendix C11) led to the first factor being interpreted as representing participants' sexual anxiety and sexual self-consciousness. It included items addressing anxiety felt prior to (item 59) and during sexual activity (item 45), as well as the idea that participants may alter their sexual behaviour as a result of their appearance (item 53), and their ability to relax (item 33) and feel comfortable with their appearance in sexual situations (item 33). Items assessing participants' sense of vulnerability at being seen naked by their partner (item 52) and related propensity to avoid undressing under their gaze (item 24) completed this factor that was entitled 'Sexual Anxiety and Self Consciousness.'

The second factor was labelled 'Negative Evaluation and Being Judged as Unattractive' and was primarily concerned with participants' feelings of being negatively evaluated by others. This included items indicating that a new partner may be dissuaded by participants' appearance (item 70) and that other people, more generally, may be repelled (item 35). The possibility of appearance therefore representing an additional barrier to the formation of romantic relationships was captured (item 29), and anxiety about the disclosure scenario, which carries the implicit potential for negative evaluations and reactions to be experiences, incorporated into the factor (item 62). Two further items assessed feelings of being attractive (item 56) and partners' sexual desire for participants (item 43). Whilst these may, intuitively, seem to overlap with the first factor, they were included in the second factor as feeling physically attractive (item 56) implies that one feels this way to another or in the eyes of another. Similarly, concerns over the sexual desire of a partner (item 43) may be inherently related to those regarding that other person's assessment of one's attractiveness.

The final factor contained only four items and was labelled 'Benefiting from Partner Empathy.' These items addressed participants' ability to speak openly with a partner about their appearance (item 12), to view such discussion positively (item 57), the belief that a partner could offer a degree of empathy in connection to feeling about appearance (item 46) and provide support and comfort when required (item 71). In common with the previous two factors, these items were considered conceptually related to one another and also to be dissimilar enough from the other factors as to confirm and reaffirm the structure indicated by the FA. This analysis and its interpretation were therefore accepted. An assessment of the structure, reliability, and validity of the solution is presented in the following chapter.

9.6.1. Scoring of CARRIS and its Factors

Participants' total CARRIS scores have been calculated by summing their individual scores for each item, resulting in a total score being generated. The available responses to each item carry a score of between '0' (not applicable) and '6' (strongly agree / strongly disagree, depending upon the specific item. The sum of the seventeen items therefore provides a participants' total CARRIS score. Similarly, the scores of the items of which each factor is comprised have are summed in order to generate a score for each participant in respect of each factor. This will enable participant scores in respect of their total CARRIS scores and scores allocated to each factor to be compared on a between-groups basis. Whilst the first factor included a greater number of items (seven) than the second factor (six) and the third factor (four) and therefore is more powerful in determining a participants' total CARRIS score, this is considered acceptable as it accounted for the greatest proportion of the overall variance and individual items were selected in accordance with the iterative and organic process detailed above.

9.7. Not Applicable Response Options

In light of the concerns of Merz et al. (2018) regarding the analysis of DAS24 performed by Moss et al. (2015) the level of 'not applicable' responses provided for the final 17 items were examined. The level of endorsement of this option was much lower than with DAS24. Merz et al. (2018) reported that the analysis of Moss et al. (2015) included an average endorsement of 'not applicable' of 13% in the first factor and 26% in the second. It was this disparity, the fact 'not applicable' was available for 14 of the 24 items, and an unequal distribution of these items between the two factors that caused Merz et al. (2018) to argue that the two-factor solution of Moss et al. (2015) may reflect shared method variance. In the present data the endorsement of the 'not applicable' response ranged from 0% (0 responses) to 4% (10 responses) with an average of 2.07% (5.17 responses). Looking at each factor, the first factor averaged 2% (5 responses), the second 2.67% (5.67 responses), and the third 1.9% (4.75 responses). Such discrepancies were therefore not inherent within the present data.

10. Exploratory factor Analysis: Reliability, Validity, and Indicative Findings

10.1. Introduction

Having conducted and reported the EFA in the previous chapter, this chapter will examine the reliability and the validity of the 17 item version of CARRIS through a consideration of whether simple structure was achieved, CARRIS' internal reliability and construct validity, and its face and content validity. It will also briefly examine how EFA solutions conducted within sub-sets of the data compare to CARRIS before introducing some provisional, indicative findings and insights that the EFA data supported.

10.2. CARRIS: Reliability and Validity

10.2.1. Structure of the model: Simple structure

Referring to the pattern matrix for the final FA conducted in respect of CARRIS 17 items, Appendix C11, which suppresses loadings <.1), Thurstone's (1947) criteria (summarised by Kline, 2014, pg.65) can be applied. Whilst these criteria are more easily met with solutions containing a greater number of factors, the current analysis performs well. Considering each criterion in turn:

1. *Each row of the rotated matrix should contain at least one 'zero'* (<.1): of the 17 rows (items) only two rows did not contain a zero. Despite there only being three columns (factors), 15/17 rows satisfied this criterion.

2. *In each factor the minimum number of zero loadings should be the number of factors in the rotation:* there were three factors in the rotation. The first factor contained eight zero loadings (from the ten items that did not load on that factor), the second contained five (maximum of 11), and the third contained eight (maximum of 13). This criterion was satisfied.

3. *For every pair of factors there should be variables with zero loadings on one and significant loadings on the other:* This criterion was satisfied.

   Factor one and factor two: three (of seven items loading on factor one) items loaded significantly on factor one and at zero on factor two. Four (of six) items loaded significantly on factor two and at zero on factor one.

Factor one and factor three: five (of seven) items three items loaded significantly on factor one and at zero on factor three. Four (of four) items three items loaded significantly on factor three and at zero on factor one.

Factor two and factor three: three (of six) items three items loaded significantly on factor two and at zero on factor three. Two (of four) items three items loaded significantly on factor three and at zero on factor two.

4. *For every pair of factors, a large proportion of the loadings should be zero, at least in a matrix with a large number of factors:* the matrix contained only three factors. The proportion of the maximum zero loadings (excluding the loading of each item onto its own factor) in respect of each pair of factors was:

Factor one and factor two:	13/21
Factor one and factor three:	16/23
Factor two and factor three:	13/24

5. *For every pair of factors there should be only a few variables with significant loadings on both factors.* No factor loaded significantly on more than one factor. This criterion was satisfied.

This assessment therefore revealed that simple structure had, to the extent that may reasonably be expected in a three-factor model, been achieved.

10.2.2. Internal Reliability

In order to assess the internal reliability of the scale, Cronbach's alpha, α, was examined in respect of each factor and CARRIS globally (Cronbach (1951), cited in Field (2013)) (see Table 10.1)

Table 10.1

CARRIS Factors: Eigenvalues, Variance, and Cronbach's α

Factor	Eigenvalue	% of variance	Cumulative % of variance	α
CARRIS Factor 1	6.787	39.93	39.93	.897
CARRIS Factor 2	1.814	10.67	50.59	.859
CARRIS Factor 3	1.643	9.67	60.26	.726
CARRIS (total)	-	60.26	60.26	.908

In interpreting these values commentators offer general guidelines that >.7, >.8, or >.9 may be acceptable (Field, 2013; Streiner et al., 2015). They acknowledge, however, that the number of items loading on a factor can impact Cronbach's α. For this reason, the approach of Ponterotto and Ruckdeschel (2007) was adopted in assessing α for research measures. This dictates that the interpretation be informed by sample size and the number of items loading upon a factor or present within the scale in question. In respect of scales and subscales of 12 items or greater they advocate interpreting an α of ≥.90 as 'excellent' ≥.85 'good' ≥.80 'moderate' and ≥.75 'fair,' with anything that does not qualify as 'fair' being 'unsatisfactory.' For 7-11 items these α values are reduced by .05 so ≥.85 is 'excellent' through to ≥.70 'fair' and for 6 or fewer items they are reduced by another .05 (e.g. ≥.80 is 'excellent' ≥.65 'fair').

CARRIS (17 items) therefore demonstrated 'excellent' internal reliability: Cronbach's α = .908. The first factor (sexual anxiety and sexual self-consciousness) (7 items) demonstrated 'excellent' internal reliability: Cronbach's α = .897. The second factor (negative evaluation and being judged as unattractive) demonstrated 'excellent' internal reliability: Cronbach's α = .859. The third factor (benefiting from partner empathy) (4 items) demonstrated 'moderate' internal reliability: Cronbach's α = .726. The examination of Cronbach's α therefore suggested satisfactory internal reliability.

An examination of indices demonstrating the impact that deletion of an item would have upon Cronbach's α illustrated that the deletion of one item (Item 46) would increase the CARRIS α from .908 to .910. This would, however, reduce α for the third factor from .726 to .683 and result in the factor being comprised of only three items, potentially reducing its stability. The item was therefore retained. There was no other item whose removal would increase Cronbach's α for CARRIS or the factor upon which it loaded.

Test-retest reliability of CARRIS was assessed at the CFA stage in order to avoid asking participants to complete all the original items twice.

10.2.3. Construct Validity

In order to demonstrate construct validity, correlations between CARRIS and the other measures that were completed by participants were examined. Participants who did not answer all of the items were excluded from that analysis on a listwise basis, so *n* = <253.

10.2.3.1. The Derriford Appearance Scale 24

The internal reliability of DAS24 (Carr et al., 2005) was assessed via α =.902 ('excellent'). A total of *n*=230 participants completed all items within CARRIS (*M*=59.17, *SD*=17.13) and DAS24 (*M*=53.62, *SD*=13.61).

Prior to conducting correlational analyses between participants' total scores for CARRIS and DAS24, the assumption of linearity was examined. Boxplots revealed no outliers, and consulting histograms led to the variables being adjudged to be normally distributed. A Pearson's product-moment correlation was performed. There was a strong positive correlation between participants' scores on CARRIS and DAS24 *r*(228)=.729, *p*<.001.

It had been hypothesised that CARRIS would correlate positively with DAS24. This hypothesis was retained.

10.2.3.2. Women's Body Image Self-Consciousness During Physical Intimacy With a Partner

The internal reliability of WBSCDPIP (Wiederman, 2000) was assessed via α =.957 ('excellent'). A total of *n*=158 participants completed all items within CARRIS (*M*=60.90, *SD*=16.18) and WBSCDPIP (*M*=36.72, *SD*=20.39).

Prior to conducting correlational analyses between participants' total scores for CARRIS and WBSCDPIP, the assumption of linearity was examined. Boxplots revealed no outliers, though consulting a histogram led to concern over the distribution of WBSCDPIP. A Spearman's rank-order correlation was performed. There was a strong positive correlation between participants' scores on CARRIS and WBSCDPIP *rs*(156)=.756 *p*<.001.

It had been hypothesised that CARRIS would correlate positively with WBSCDPIP. This hypothesis was retained.

10.2.3.3. Male’s Body Image Self-Consciousness During Physical Intimacy

The internal reliability of MBSCDPI (McDonagh et al., 2009) was assessed via α =.951 (‘excellent’). A total of *n*=71 participant*s* completed all items within CARRIS (*M*=54.61, *SD*=17.68) and MBSCDPIP was completed by *n*=73 (*M*=47.08, *SD*=16.90).

Prior to conducting correlational analyses between participants’ total scores for CARRIS and MBSCDPIP, the assumption of linearity was examined. Boxplots revealed no outliers, and consulting histograms led to mild concern over the distribution of the CARRIS total. A Spearman’s rank-order correlation was performed. There was a moderate-strong positive correlation between participants’ scores on CARRIS and MBSCDPI *rs*(69) =.693 *p*< .001.

It had been hypothesised that CARRIS would correlate positively with MBSCDPIP. This hypothesis was retained.

10.2.3.4. Fear of Negative Evaluation

The internal reliability of FNE-B (Leary, 1983) was assessed via α =.937 (‘excellent’). A total of n=233 participants completed all items within CARRIS (*M*=59.09, *SD*=17.06) and FNE-B *n*=242 (*M*= 44.38, *SD*=11.04).

Prior to conducting correlational analyses between participants’ total scores for CARRIS and FNE-B, the assumption of linearity was examined. Boxplots revealed one outlier for FNE-B and consulting histograms led to FNE being adjudged to be non-normally distributed. A Spearman’s rank-order correlation was performed. There was a moderate positive correlation between participants’ scores on CARRIS and FNE-B *rs*(231)=.456, *p*< .001 (excluding the outlier made no discernible difference to this analysis so it was retained).

It had been hypothesised that CARRIS would correlate positively with FNE-B. This hypothesis was retained.

10.2.3.5. Fear of Intimacy

The internal reliability of FIS (Descutner & Thelen, 1991) was assessed via α =.945 (‘excellent’). A total of *n*=221 participants completed all items within CARRIS (*M*=58.58, *SD*=16.91) and FIS *M*=92.24, *SD*=25.22).

Prior to conducting correlational analyses between participants' total scores for CARRIS and FIS, the assumption of linearity was examined. Boxplots revealed that there was one slight outlier for FIS, and histograms led to FIS being adjudged to be normally distributed. A Pearson's product-moment correlation was performed. There was a moderate positive correlation between participants' scores on CARRIS and DAS24 *r*(219) =.572 *p*<.001 (excluding the outlier made no discernible difference to this analysis so it was retained).

It had been hypothesised that CARRIS would correlate positively with FIS. This hypothesis was retained.

10.2.3.6. Miller Social Intimacy Scale

The internal reliability of MSIS (Miller & Lefcourt, 1982) was assessed via α = .922 ('excellent'). A total of *n*=234 participants completed all items within CARRIS (*M*=59.12, *SD*=16.81) and MSIS (*M*=132.79, *SD*=20.90).

Prior to conducting correlational analyses, the assumption of linearity was examined. Boxplots revealed that there was one MSIS outlier, and histograms led to the variables being adjudged to be normally distributed. A Pearson's product-moment correlation was conducted. There was a moderate negative correlation between participants' scores on CARRIS and MSIS *r*(232) =-.418 *p*<.001 (excluding the outlier made no discernible difference to this analysis and so it was retained).

It had been hypothesised that CARRIS would correlate negatively with MSIS. This hypothesis was retained.

10.2.3.7. Subjective Assessment of Difference

Correlations were examined between CARRIS and the individual items adapted from Moss (2005) measuring participants' subjective rating of how different from normal:

i) the area of their body affected by their difference ('affected difference') was; and
ii) their overall appearance ('overall difference') was.

These were measured on a seven-point Likert-style scale from 'not at all different' (1) to 'extremely different' (7). A total of *n*=221 participants completed all items within CARRIS (*M*=60.34, *SD*=16.88) and affected difference (*M*=5.08, *SD*=1.42) and *n*=243 participants completed all items within CARRIS and (*M*=59.09, *SD*=17.11) and overall difference by (*M*=4.31, *SD*=1.59).

Prior to conducting correlational analyses, the assumption of linearity was examined. Boxplots revealed one slight outlier for affected difference, and histograms led to affected difference being adjudged to be non-normally distributed whilst overall difference was normally distributed.

A Spearman's rank-order correlation was performed to assess the relationship between CARRIS and affected difference. There was a moderate positive correlation *rs*(219)=.355, *p*<.001 (excluding the outlier made no discernible difference to this analysis and so it was retained).

A Pearson's product-moment correlation was performed to assess the relationship between CARRIS and overall difference. There was a moderate positive correlation *r*(243)=.441 *p*<.001.

It had been hypothesised that CARRIS would correlate positively with both affected and overall difference and so these hypotheses were retained.

10.2.3.8. Crown Crisp Experiential Inventory: Hysteria

The internal reliability of CCEI:H (Crown & Crisp, 1979) was assessed via α =.446 ('unsatisfactory'). A total of *n*=237 participants completed all items within CARRIS by (*M*=58.95, *SD*=16.97) and CCEI:H (*M*= 4.11, *SD*=2.90).

Prior to conducting correlational analyses between participants' total scores for CARRIS and FIS, the assumption of linearity was examined. Boxplots revealed that there were three outliers for CCEI:H, and histograms led to CCEI:H being adjudged to be non-normally distributed. A Spearman's rank-order correlation was performed. There was no significant correlation between participants' scores on CARRIS and CCEI:H *rs*(235)=.02 *p*>.05 (excluding the outliers made no discernible difference to this analysis and so they were retained)

It had been hypothesised that CARRIS would not correlate with CCEI:H. This hypothesis was retained.

10.2.4. Face and Content Validity

Face and content validity were established when drafting the initial items that were used in developing CARRIS. It was, however, important to ensure that the final version of the measure demonstrated good face and content validity. In addition to this being incorporated into item selection, specifically at the stage of reducing the number of items from 34 to 18, the 18 item version of CARRIS was reviewed by NR and AC. During this review and as mentioned above, NR suggested that upon reflection one item:

Item 32: I avoid certain sexual activity because of how I look

would benefit from being re-worded and that the content was conceptually similar to another:

Item 53: I would alter my sexual behaviour because of how I look

Item 32 had already been identified as somewhat problematic and so a decision was made to delete the item. Both AC and NR considered that the remaining 17 item scale contained items that were sufficient to measure appearance distress within a romantic context and so demonstrated good face validity. Furthermore, both AC and NR considered that the scale contained items sufficient to measure all facets of this phenomena as they understood it and so demonstrated good content validity.

In order to further assess face and content validity, the responses of participants to a free-text item included at the end of CARRIS were reviewed. This item asked if participants would like to add anything or there was anything that the preceding questions had not addressed. Participants that responded tended to elaborate upon what the most important issue was to them and give some indication of their experience.

This included some comments that were not directly relevant to the construct being measured by CARRIS (e.g. that there was little support available from healthcare professionals or that not all romantic concern was attributable to appearance). Most comments, however, related to issues that were covered by and incorporated into the final version of CARRIS (e.g. feeling unattractive, not believing others could find one attractive, feeling ‘unsexy,’ not communicating with partners, feeling anxious about physical intimacy).

A small minority of comments did indicate that how the individual felt about their appearance and romantic life may vary according to the severity of the condition (*n*=2) or with age (*n*=1). Whilst not addressed in the items, the scale measures current feelings about appearance and romantic relationships and is therefore considered to be concerned with a potentially variable and changeable state rather than an enduring and immutable trait. Three participants specifically wrote about the idea that they must compensate for their appearance in some way (improving themselves or accepting less desirable qualities in a partner). Whilst this idea does not explicitly form part of CARRIS, it was originally included in:

Item 55: It is important that I have attractive qualities that are not to do with my looks

The item did not correlate with any other item at >0.3 and was deleted. It was also considered reasonable to connect this need to compensate with feelings of being devalued and unattractive. These ideas are incorporated into F2 (negative evaluation and being judged as unattractive) and so it was not considered necessary to re-instate the item.

Whilst it must be acknowledged that the comments of participants were requested after they had completed the full 74 items and not the final 17 item version of CARRIS, the nature of participants' responses to the free-text item at the end of CARRIS and their tendency to reiterate the most important aspects of their experience provided a strong indication that the items included within CARRIS carried good face and content validity.

10.2.5. The Stability of the Solution: Splitting the Sample

As the indicative findings section will demonstrate, *t*-tests indicated significant differences in participants' total CARRIS scores based upon three characteristics. These were participants' sex, the method of recruitment (prolific-other), and whether they were currently receiving treatment for their difference or associated condition. To assess the stability of the factor solution and whether different solutions may be relevant to groups with different scoring profiles, three additional abbreviated (e.g. parallel analysis was not performed, communalities were not explored and individual item KMOs not examined) exploratory analyses were performed.

The data were split according to each of these three dichotomous variables in turn and separate EFAs performed on the CARRIS 17 items. This necessarily reduces the sample size for each analysis and so some instability may be expected in the solutions generated. In consideration of the small sample sizes and the confirmation of the structure via the subsequent CFA, the comparison was limited to a visual examination of the solutions and the factors upon which each item loaded to identify obvious and substantive discrepancies. No formal metric of similarity was sought or calculated. Due to the sample sizes involved, it was not considered feasible to perform even this visual inspection in respect of differences indicated by ANOVAs.

10.2.5.1. Sex

Splitting the data by sex and performing two separate EFAs and comparing these solutions to the full EFA, suppressing loadings at <.32 ('loading,' 'loaded,' 'cross-loading,' and 'cross-loaded' shall mean at >.32 in this section), resulted in the following observations:

Female: KMO was 0.860 ('meritorious') (Field, 2013, citing Hutcheson & Sofroniou, 1999) Bartlett's was significant χ2(136)=1437.77 (*p*<.001), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from *n*=168 female participants. Visual inspection of a scree plot (Appendix D1) and applying the Kaiser-criterion (three factors had Eigenvalues >1, (Appendix D2)) indicated a three-factor solution was appropriate. These factors explained a total of 59.8% of the variance (38%, 11.6%, and 10.2% respectively).

Comparing the solution (pattern matrix at Appendix D3) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were very similar. All items loaded onto the same factors as in the full analysis with no cross loadings. No substantive discrepancies were observed.

Male: KMO was 0.842 ('meritorious') (Field (2013), citing Hutcheson & Sofroniou (1999)) Bartlett's was significant χ2(136)=770.52 (*p*<.001), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from *n*=75 male participants. Visual inspection of a scree plot (Appendix D4) and applying the Kaiser-criterion (four factors had Eigenvalues >1, (Appendix D5)) indicated a one, three, or four factor solution as appropriate. A three-factor solution was adopted to mirror the main analysis. These factors explained a total of 63.4% of the variance (43.8%, 10.6%, and 9% respectively).

Comparing the solution (pattern matrix at Appendix D6) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were somewhat similar. The order of F1 and F2 was reversed in this analysis. Two items (items 33 & 53) that loaded on F1 in the full analysis loaded upon the equivalent of F2, though one of them (item 53) also cross-loaded back onto the equivalent of F1. Furthermore, two items (items 35 & 43) that loaded upon the equivalent of F2 cross-loaded upon F3 and one item from F3 (item 71) cross-loaded on F2.

These deviations may have resulted from the small sample size. The reversal of F1 and F2 is not considered overly problematic and, whilst undesirable, neither are the cross-loadings. The two items that loaded onto substantively different factors may be considered more problematic. Overall, however, the solutions were rather similar.

10.2.5.2. Recruitment Method

Splitting the data by recruitment (via Prolific and via other means) resulted in the following observations:

Prolific: KMO was 0.892 ('meritorious') (Field, 2013, citing Hutcheson & Sofroniou, 1999). Bartlett's was significant χ2(136)=1375.44 (*p*<.001), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from *n*=138 participants recruited via Prolific. Visual inspection of a scree plot (Appendix D7) and applying the Kaiser-criterion (three factors had Eigenvalues >1, (Appendix D8) indicated a three-factor solution was appropriate. These factors explained a total of 63.4% of the variance (44.8%, 10.4%, and 8.3% respectively).

Comparing the solution (pattern matrix at Appendix D9) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were very similar. Although the order of F1 and F2 was reversed, all items loaded onto the same substantive factors as in the full analysis with only one item cross loading (item 53).

Other sources: KMO was 0.812 (‘meritorious’) (Field, 2013, citing Hutcheson & Sofroniou, 1999). Bartlett's was significant χ2(136)=770.70 (*p*<.001), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from *n*=104 participants recruited via other sources. Visual inspection of a scree plot (Appendix D10) and applying the Kaiser-criterion (three factors had Eigenvalues >1, (Appendix D11) indicated a three-factor solution was appropriate. These factors explained a total of 56.1% of the variance (32.5%, 13.7%, and 9.9% respectively).

Comparing the solution (pattern matrix at Appendix D12) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were very similar. With one exception, all items loaded onto the same factors as in the full analysis with no cross loadings. Item 29, however, failed to load onto any factor.

10.2.5.3. Treatment Status

Splitting the data by treatment status (those that indicated that they were not/were receiving treatment in connection with their visible difference) and performing two separate EFAs resulted in the following observations:

Not receiving treatment: KMO was 0.877 (‘meritorious’) (Field, 2013, citing Hutcheson & Sofroniou, 1999). Bartlett's was significant χ2(136)=1405.97 (*p*<.001), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from *n*=159 participants that were not receiving treatment in connection with their visible difference. Visual inspection of a scree plot (Appendix D13) and applying the Kaiser-criterion (three factors had Eigenvalues >1, (Appendix D14) indicated a three-factor solution was appropriate. These factors explained a total of 60.7% of the variance (41.4%, 10.2%, and 9.1% respectively).

Comparing the solution (pattern matrix at Appendix D15) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were very similar. All items loaded onto the same factors as in the full analysis with no cross loadings. No substantive discrepancies were observed.

Receiving treatment: KMO was 0.774 ('middling') (Field, 2013, citing Hutcheson & Sofroniou, 1999) Bartlett's was significant $\chi2(136)=564.73$ ($p<.001$), indicating that the data were suitable for factor analysis. A PAF was therefore performed on data from $n=62$ participants that were receiving treatment in connection with their visible difference. Visual inspection of a scree plot (Appendix D16) and applying the Kaiser-criterion (five factors had Eigenvalues >1, Appendix D17) indicated a three- or five-factor solution was appropriate. A three-factor solution was adopted to mirror the main analysis. These factors explained a total of 58.3% of the variance (33.1%, 15.3%, and 10% respectively).

Comparing the solution (pattern matrix at Appendix D18) to the EFA performed on the full data-set (Appendix C11) it was apparent that the solutions were similar. With two exceptions, all items loaded onto the same factors as in the full analysis with no cross-loadings. The exceptions were item 35 which formed part of F2 but, here, also cross-loaded onto the first factor. Item 43 loaded upon F3 in this analysis but upon F2 in the main analysis.

10.2.6. Summary

In light of the similarity between the observed factor solutions and the instability of these provisional analyses that may be expected given the smaller sample sizes involved, the series of EFA completed with sub-sets of the data split according to sex, recruitment source, and treatment status was considered to help reinforce and verify the solution that had been adopted. It was particularly notable that substantive deviations, where items loaded on to a different factor than in the main analysis, were observed only in the two analyses with the smallest sample sizes (males and those receiving treatment).

This section has confirmed that CARRIS demonstrated simple structure, had good internal reliability, correlated with related measures thus evidencing its construct validity, was adjudged to carry strong face and construct validity by both experts in the field and participants, and remained relatively robust to analyses conducted with sub-sets of the data despite this compromising the applicable sample size. The next section goes on to examine some indicative findings indicated by analysis of the CARRIS data.

10.3. CARRIS: Indicative Findings

Having examined the reliability and validity of CARRIS and its relationships with other measures, participants' total CARRIS (17 items) scores were utilised to provide an indication of whether certain relationships within the data and group differences were apparent.

10.3.1. Correlations

Correlational analyses were performed in respect of participants' total CARRIS score and each of their age and the number of years since they acquired their visible difference.

10.3.1.1. Age

A total of *n*=243 participants completed all CARRIS items (*M*=59.09, *SD*=17.11) and provided their age in years (Age) (*M*=38.58, *SD*=12.38). The assumption of linearity was examined, boxplots revealed that there were no outliers and consulting a histogram led to Age being adjudged to be non-normally distributed. A Spearman's rank-order correlation was performed to assess the relationship between CARRIS and Age. There was no significant correlation *rs*(243)=.075 *p*=.243.

10.3.1.2. Years since acquired visible difference

Participants with an acquired visible difference were asked to indicate for how many years they had a visible difference (Years Since Acquisition). Those who indicated their condition was congenital were assumed to have had it since birth. Where this was unclear, participants were not included in the analysis.

A total of *n*=202 participants completed all CARRIS items (*M*=60.43, *SD*=16.91) and provided Years Since Acquisition data (*M*=19.10, *SD*=15.57). The assumption of linearity was examined, boxplots revealed one slight outlier in the CARRIS scores, and consulting a histogram led to Years Since Acquisition being adjudged to be non-normally distributed. A Spearman's rank-order correlation was performed to assess the relationship between CARRIS and Years Since Acquisition. There was no significant correlation *rs*(202)=.041 p=.566.

Performing the analysis with the outlier removed revealed no substantive impact upon the correlation coefficient nor its significance, so it was retained.

10.3.2. T-tests

In order to examine potential group differences independent samples *t*-tests were performed to compare the total CARRIS score of participants that belonged to various dichotomous categories.

10.3.2.1. Visibility of difference

An independent-samples *t*-test determined whether there were group differences in the total CARRIS score between participants that indicated that their difference was visible to others in everyday life (Normally Visible) and those that indicted it was not (Normally Non-visible). Boxplots revealed one outlier within the Normally Visible group. An examination of histograms revealed slight issues of non-normal distribution of the data of the CARRIS scores for the Normally Visible group. This was not considered problematic as the *t*-test is relatively robust to issues of normality (especially in samples of >30, (Pallant, 2016)). There was homogeneity of variances, as assessed by Levene's test (p=.09).

There was no statistically significant difference between the CARRIS scores of Normally Visible n=126 (M=61.04, SD=15.53) and Normally Non-visible (M=59.41, SD=18.56) participants, the mean difference of 1.63 (95% CI,-2.90 to 6.15), $t(219)$=0.710, p=.479 being non-significant.

Performing the analysis with the outlier removed revealed no substantive impact upon the significance of Levene's test nor the *t*-test so the outlier was retained.

10.3.2.2. Sex

An independent-samples *t*-test determined whether there were differences in the total CARRIS score between females and males. Boxplots revealed no outliers, although an examination of histograms revealed some slight issues of non-normal distribution of the data of the CARRIS scores for males. This was not considered problematic as the *t*-test is relatively robust to issues of normality (especially in samples of >30, (Pallant, 2016)). There was homogeneity of variances, as assessed by Levene's test (p=.549).

Women (n=168, M=60.92, SD=16.66) had a greater CARRIS score (indicative of more distress) than Men (n=75, M=54.99, SD=17.49), a statistically significant difference of 5.93 (95% CI, 1.304 to 10.56), $t(241)$=2.523, p< .05, d_{Cohen}=0.35 (a small effect).

10.3.2.3. Treatment status

An independent-samples t-test determined whether there were differences in the total CARRIS score between those who were receiving treatment from a healthcare professional in connection with their visible difference (Treatment) and those that were not (No Treatment). Boxplots revealed no outliers and an examination of histograms revealed the data to be normally distributed. There was homogeneity of variances, as assessed by Levene's test (p=.321).

The Treatment group (n=62, M=64.29, SD=15.62) had a greater CARRIS score (indicative of more distress) than the No Treatment group (n=159, M=58.80, SD=17.14), a statistically significant difference of 5.49 (95% CI, .55 to 10.43), $t(219)=2.192$, $p<.05$, $d_{Cohen}=0.33$ (a small effect)

10.3.2.4. Recruitment source

An independent-samples t-test determined whether there were differences in the total CARRIS score between those who were recruited via Prolific (Prolific) and those recruited via other means (primarily support groups and charities) (Other). Boxplots revealed that there was one outlier within the Other group. An examination of histograms revealed the data to be normally distributed. There was homogeneity of variances, as assessed by Levene's test (p=.171).

The Other group (n=105, M=63.97, SD=15.63) had a greater CARRIS score (indicative of greater distress) than the Prolific group (n=138, M=55.37, SD=17.30), a statistically significant difference of 8.60 (95% CI, 4.37 to 18.84), $t(241) = 4.001$, $p<.001$, $d_{Cohen}=0.52$ (a medium effect).

Performing the analysis with the outlier removed revealed no substantive impact upon the significance of Levene's test nor the t-test so the outlier was retained.

10.3.3. ANOVAs

In order to explore group differences where three or more groups existed, ANOVAs were performed. Although there were insufficient data to meaningfully examine participants' ethnicity (over 90% of the participants were white), sexuality (over 90% indicated they were heterosexual) and religion. Furthermore, examining the location of participants' visible difference required that the raw data were consolidated into fewer categories to allow meaningful analysis. In light of concerns about the sample size and associated issues relating to the distribution of the data, groups of ≤10 participants were excluded from each analysis.

As sample sizes within each group in each ANOVA were very different and in accordance with the advice of (Field, 2013), the Hochberg's GT2 *post-hoc* procedure was utilised where the samples demonstrated homogeneity of variance. It was planned to employ the Games-Howell procedure where variances were unequal, but this eventuality did not materialise.

10.3.3.1. Relationship Status

A one-way ANOVA determined whether the total CARRIS score was different for groups with different relationship status. Participants indicated whether they were: single (n=66); separated, widowed or divorced (n=14); in a relationship and living separately (n=25); in a relationship and living together (n=46); or married/in a civil partnership (n=92).

There was one outlier, assessed by boxplots, within the 'in a relationship and living separately group.' An examination of histograms revealed some issues of non-normal distribution, but this was not considered problematic as ANOVAs may be considered relatively robust to issues of normality (Blanca, Alarcón, Arnau, Bono, & Bendayan, 2017; Glass, Peckham, & Sanders, 1972). Levene's test (*p*=.240) demonstrated homogeneity of variances.

The CARRIS score was significantly different between different relationships status groups, *F*(4, 238)=4.239 p<.005, (partial) η2=.07 (a medium effect). CARRIS scores were lowest (indicating lower levels of distress) amongst those in a relationship and living together (*M*=51.87, *SD*=16.41), then those who were married/in a civil partnership (*M*=58.20, *SD*=17.61), then those who were in a relationship and living separately (*M*=60.88, *SD*=10.80, then those who were separated, widowed or divorced (*M*=61.86, SD=13.12), and were highest (indicating higher levels of distress) in those that were single (*M*=67.78, *SD*=17.01). Hochberg's GT2 *post-hoc* analysis revealed that the difference in CARRIS scores between those that were in a relationship and living together and those that were single (12.90, 95% CI(3.97 to 21.83)) was statistically significant (*p*<.005) with those that were single scoring more highly. No other group differences were statistically significant.

Whilst excluding the outlier did impact upon Levene's test (so that it became significant at *p*<0.5), this did not impact upon the significance of the ANOVA nor upon the *post-hoc* procedures (with both analyses indicating the same group differences). The outlier was therefore retained.

10.3.3.2. Cause of visible difference

A one-way ANOVA determined whether the total CARRIS score was different for groups with different causes of their visible difference. Participants indicated whether they considered the cause to be: congenital, inherited or genetic (*n*=68); disease (*n*=47); injury (*n*=34); treatment/surgery (*n*=35); other (*n*=30) or multiple (*n*=7, excluded from analysis).

There was one outlier, assessed by boxplots, within the congenital, inherited or genetic group and two within the disease group. An examination of histograms revealed some issues of non-normal distribution of the data, but this was not considered problematic as ANOVAs may be considered relatively robust to issues of normality (Blanca et al., 2017; Glass et al., 1972). Levene's test (*p*=.382) demonstrated homogeneity of variances.

The CARRIS scores were lowest (indicating lower levels of distress) amongst those whose difference resulted from an injury (*M*=57.47, *SD*=16.93), then those whose difference resulted from treatment/surgery (*M*=57.51, *SD*=18.62), then those whose difference resulted was 'other' (*M*=58.33, *SD*=19.05), then those whose difference resulted from congenital, inherited or genetic conditions (*M*=62.57, SD=15.50), and were highest amongst those whose difference resulted from disease (*M*=63.26. *SD*=15.77) groups. The ANOVA revealed, however, that there was no significant effect of cause of visible difference and so the differences between these groups were not statistically significant, *F*(4, 209)=1.246, *p*=.293.

The analysis was performed twice, once with the outliers excluded. Excluding all the outliers did not impact substantially upon the significance of Levene's test nor upon the significance of the ANOVA. The outliers were retained.

10.3.3.3. Nature of visible difference

A one-way ANOVA determined whether the total CARRIS score was different for groups with different types of visible difference. Participants indicated whether they considered their visible difference to be: alopecia (*n*=39); birthmark (*n*=5, excluded); burn (*n*=4, excluded); arising from cancer (*n*=10, excluded); craniofacial (*n*=13), dermatological (*n*=39), limb-loss (*n*=2, excluded); paralysis (*n*=7, excluded); scarring (*n*=47); skeletal (*n*=10, excluded); other (*n*=30), or multiple visible differences (*n*=34).

Boxplots revealed that there were two outliers in the alopecia group, three in the other groups, one in the craniofacial group, and one in the multiple group. The analysis was performed twice, once with the outliers excluded. An examination of histograms revealed some issues of non-normal distribution of the data in respect of the craniofacial, dermatological and multiple groups but this was not considered problematic as ANOVAs may be considered relatively robust to issues of normality (Blanca et al., 2017; Glass et al., 1972). Levene's test (p=.392) demonstrated homogeneity of variances.

The CARRIS score was statistically significantly different between different nature of visible difference groups, $F(5, 196)$=5.504 $p<.001$, (partial) η2=.12 (a medium effect).The CARRIS score were highest (indicating higher levels of distress) amongst those whose visible difference was ‘other’ (M=49.60, SD=17.11), then those whose visible difference resulted from scarring (M=53.94, SD=17.32), then those whose visible difference resulted from craniofacial conditions (M=59.85, SD=14.06), then those whose visible difference resulted from dermatological conditions (M=62.59, SD=15.56), then those whose visible difference resulted from alopecia (M=63.87, SD=15.18), and were highest (indicating higher levels of distress) amongst those whose visible difference resulted from multiple conditions (M=65.56, SD=12.83) groups,. Hochberg’s GT2 *post-hoc* analysis revealed that the differences between the other and the alopecia groups (14.27, 95% CI (3.01 to 25.53), $p<.005$), the other and the dermatological groups (12.99, 95% CI (1.73 to 24.25), $p<.05$), the other and the multiple causes groups (15.96, 95% CI (4.34 to 27.28)<.005), and the scarring group and the multiple causes groups (11.62, 95% CI (1.18 to 22.06) $p<.05$), were statistically significant ($p<.005$), with the other group and the scarring group respectively scoring more lowly. No other group differences were statistically significant.

Excluding the outliers did impact upon Levene's test (so that it became significant at $p<0.5$). This did not impact upon the significance of the ANOVA but impacted upon the *post-hoc* procedures. The analysis that excluded the outliers and used the Games-Howell *post-hoc* procedure (as the assumption of homogeneity of variances had been violated) indicated two additional differences between groups than the analysis that included the outliers (and utilised Hochberg’s GT2). As excluding the outliers did not impact the significance of the ANOVA but impacted Levene’s test and therefore indicated the use of the Games-Howell *post-hoc* procedure, the outliers were retained and Hochberg’s GT2 utilised as this is more able to accommodate large differences in sample sizes (Field, 2013).

10.3.3.4. Location of visible difference

A one-way ANOVA was conducted to determine if the total CARRIS score was different for groups with visible difference affecting different locations on the body. Participants indicated whether they considered their visible difference to affect their:

i) legs, feet, arms, hands, shoulders, and/or neck (limbs) (n= 27);

ii) genitals, buttocks, stomach, chest, and/or back (torso) (*n*=33);
iii) head and/or face (head/face) (*n*=95);
iv) whole body (*n*=49);
v) i and ii (limbs and torso) (*n*=9, excluded)
vi) i and iii (limbs and head/face) (*n*=19); or
vii) ii and iii (torso and head/face) (*n*=9, excluded)

Boxplots revealed one outlier within the limbs and head/face group. An examination of histograms revealed issues of non-normal distribution of the data in respect of the limbs and head/face group. This was considered severe enough to warrant transforming the data. The negative skew meant that both Lg10 and Sqrt transformations were attempted, but they did not improve the distribution of the data. Whilst ANOVAs may be considered relatively robust to issues of normality (Blanca et al., 2017; Glass et al., 1972), the nature of the distribution in this case demanded that any significant effects be considered provisional in nature. Levene's test (*p*=.889) demonstrated homogeneity of variances.

The CARRIS score was statistically significantly different between groups with visible differences affecting different locations of the body, *F*(4, 218)=2.444 p<.005, (partial) η2=.04 (a small effect). The CARRIS score were lowest (indicating lower levels of distress) amongst those whose visible difference affected their limbs (*M*=51.78, *SD*=17.22), then those whose visible difference affected their whole body (*M*=57.43, *SD*=18.48), then those whose visible difference affected their head/face (*M*=58.87, *SD*=16.07), then those whose visible difference affected their torso (*M*=59.55, *SD*=17.24), and highest amongst those whose visible difference affected their limbs and head/face (*M*=67.37, *SD*=16.68). Hochberg's GT2 *post-hoc* analysis revealed that the difference between those whose visible difference affected their limbs and those whose visible difference affected their limbs and head/face (15.59, 95% CI (1.21 to 29.97), *p*<.05) was significant, with those whose visible difference affected their limbs and head/face scoring more highly. No other group differences were statistically significant. This is qualified by the observation regarding the distribution of the data.

The analysis was performed twice, once with the outlier excluded. Excluding the outlier did not impact upon the significance of Levene's test nor upon the significance of the ANOVA. The outlier was retained

10.3.4. Summary of Indicative Findings

Examining the CARRIS data led to the identification of a number of indicative findings. Whilst these must be treated with caution, it was apparent that neither participants' age not the length of time for which they had their visible difference correlated significantly with their total CARRIS score. Whilst the visibility of their condition was not associated with differences in their total CARRIS score, women scored more highly (indicative of more distress) than men, those receiving treatment scored more highly than those that were not, and those recruited through means other than Prolific (primarily support groups and charities) scored more highly that those recruited via Prolific. Effect sizes were relatively small with only the source of participants (Prolific/other) being a little larger.

The data also indicated relationship status to be important. Those who were single scored more highly than those that were in a relationship and lived together. With regards to characteristics connected to participants' visible difference, there was no effect associated with its cause, though the nature of the difference was associated with a significant effect. Participants with alopecia, dermatological, and multiple visible differences all scored more highly than those who responded 'other' (tending to indicate weight/shape concerns) visible differences. Similarly, the significant effect of the location of their visible difference revealed that participants with visible differences affecting their limbs and head/face scored more highly than those whose difference affected their limbs alone. No other significant between group differences were observed.

10.4. Summary

Having established the reliability and validity of CARRIS and offered some provisional findings with respect to group differences (albeit on an indicative and provisional basis) in this chapter, the next will discuss the implications suggested by this phase of the research and consider the indicative findings in more detail.

11. EFA: Discussion

Having previously introduced the development of CARRIS, the analysis strategy employed, the EFA performed, the scale's reliability and validity, and the indicative findings suggested by the study, this chapter will now discuss the implications and conclusions that may be drawn from this phase of the research programme.

11.1. CARRIS

Turning first to CARRIS, the EFA indicates that it constitutes a parsimonious, 17 item, three-factor measure of appearance distress within the context of intimacy and romantic relationships. Whilst some debate may be entertained, the final sample of 253 participants is considered adequate. The communalities and number of items loading onto each factor minimised any residual concerns in this respect and all metrics signified the data were suitable for EFA. The low levels of missing data and the responses to the duplicate question and attention checks provide confidence in the quality of the data.

The final factor structure was considered to demonstrate simple structure, with any slight deviations being attributed to the three-factor solution. Similarly, CARRIS' internal reliability was excellent overall and for two of the factors and moderate for the third factor. Splitting the data where significant differences in scoring profiles were indicated by *t*-tests revealed relatively stable factor solutions despite the smaller sample sizes. It must be acknowledged, however, that this was not feasible where ANOVAs had revealed significant differences between groups. CARRIS may benefit from future research examining and validating the structure in specific populations.

The existence of the hypothesised correlations between the total CARRIS scores and each of DAS24, WBISCDPIWPS/MBISCDPIS, FNE-B, FIS, and participants' subjective assessments of both affected difference and overall difference (positive correlations) as well as MSIS (negative) and the absence of any significant correlation with CCEI:H helped demonstrate that CARRIS measured the construct it was designed to measure. The patterns and strength of the observed correlations were considered consistent with CARRIS' conceptual position.

F1 was the first factor in the adopted solution, explains the greatest amount of variance, and was the factor that included the greatest number of items. WBSCDPIP/ MBSCDPI are focussed upon issues of physical intimacy and bodily self-consciousness. It is therefore considered conceptually coherent that, along with DAS24, they were the strongest correlates with CARRIS. The strong correlation with DAS24 was also interpreted as reflecting the conceptual ground shared by DAS24 and CARRIS. The existence of F3, CARRIS' exclusive focus on intimacy and romantic relationships, the distinction between each of CARRIS' factors, and the critique by Merz et al. (2018) of the two-factor DAS24 solution proposed by Moss et al. (2015), differentiates CARRIS and DAS24 despite the strong correlation.

It was hypothesised that the construct being measured by CARRIS would include the following concepts:

1. Considering oneself to be of diminished romantic worth:
2. Being negatively evaluated (romantically) by other people;
3. Exhibiting apprehension and caution in romantic relationship initiation;
4. Concern and anxiety in connection with disclosure of a visible difference;
5. Trusting supportive relationships; and
6. Impacted sex and physical intimacy.

The analysis revealed a three factor structure, interpreted as:

1. Sexual Anxiety and Self Consciousness (F1);
2. Negative Evaluation and Being Judged as Unattractive (F2); and
3. Benefiting from Partner Empathy (F3).

It is evident that the fifth and sixth hypothesised concepts informed, or were evident, in F3 and F1 respectively. In addition, the second hypothesised concept was evident in F2 and F2 also included items consistent with the first, third, and fourth hypothesised concepts. The hypothesised concepts were all relevant, though some were conjoined through the analysis. Reflecting on this process, it is apparent that hypothesised concepts 1-4 seem related to one another. All pertain to issues that may be especially pertinent to the initiation of a relationship and are less distinct than 5 and 6. The factor structure is therefore coherent and somewhat consistent with that which was hypothesised. This must be tempered with the acknowledgement that the process of factor analysis is subjective and that the item selection stage, especially, relied upon my interpretation and judgement. The analysis may therefore have been influenced by my preconceived ideas about the nature and content of possible factors. For this reason, it was particularly important to confirm the factor structure via the CFA (reported in the final empirical chapter of this thesis).

The three-factor structure acts to demonstrate that visible difference carried the potential to impact upon intimate and romantic life in a variety of ways. Broadly, these include the feeling that others will judge such difference negatively and as unattractive (F2), concerns related to physical and sexual intimacy (F1), and the ability to communicate with and avail oneself of a partner's support (F3). In common with the qualitative work reported within this thesis, this demonstrates the potentially difficult and debilitating nature of visible difference upon multiple aspects of this sphere of life.

F1 overlaps heavily with the 'Invading Physical Intimacy' sub theme and so those that score highly on this sub-factor may be expected to experience the difficulties and concerns described within that section of the qualitative analysis. Likewise, F2 includes many of the ideas expressed within the 'Appearance Attracts and Detracts' theme, including items that address the negative evaluation of others ('Looking to Love') and the self ('The Discounted Self'). F2 also incorporated an item that refers to the disclosure dilemma and, given that this may also entail fears about negative evaluation, this was conceptually coherent. Individuals that score highly on F2 may therefore be liable to have concerns related to how they are evaluate and judged, within a romantic context, by others and themselves. Those that score highly on F3 may be struggling to benefit from the support that is described within the 'Treasured Support' sub-theme and may require assistance in communicating their feelings to a partner in an attempt to avail themselves of their support. CARRIS now offers a parsimonious way to assess these impacts across these three related sub-domains.

11.2. Convergent Measures

It was apparent from the other measures employed that the present sample scored rather highly on a number of these scales. Whilst statistical analyses may be inappropriate due to discrepancies in the composition of the samples, year, and location of data collection it is noteworthy that the overall mean for participants on DAS24 (*M*=53.4) exceeded the general population (*M*=30.99) and both clinical samples used in the development of that measure (outpatient *M*=47.32, waiting list *M*=48.2) (Carr et al., 2005), indicating generally high levels of appearance distress within the current participants. Similarly, scores on FNE-B (Leary, 1983) were relatively high (*M*=44.10), exceeding those recorded in samples of those with visible difference by ARC (Clarke et al., 2014) and Bessell and Moss (2007) (pre-intervention baselines of *M*=38.74-41.04).

Whilst I am not aware of WBISCDPIWPS having been used in a UK/Irish population and the comparator is North American College students (*M*=26.89) (Wiederman, 2000), the present female mean (*M*=36.57) was considerably higher. This pattern was consistent with the MBISCDPIS which was validated in a sample of Irish men (*M*=35.89) indicating less bodily self-consciousness, than the male participants (*M*=47.25). Given that the populations used to validate WBISCDPIWPS/MBISCDPIS were not populations with visible difference and the ARC

(Clarke et al., 2014) reported different scoring profiles a preliminary intimacy scale, with those with visible difference indicating greater concern than the general population, these discrepancies are considered to be consistent with the contention that visible differences are generally associated with challenges in physical intimacy.

Participants' scores on FIS (*M*=92.06) were, again, high, indicating a greater fear of intimacy than those obtained in validating the scale in North American college students (*M*=78.75) (Descutner & Thelen, 1991) and adults aged 35-55 (*M*=79.58) (Doi & Thelen, 1993), and UK men (*M*=83.0) (Sullivan et al., 2015). Scores on MSIS, however, (*M*=132.39) were only slightly lower than the overall mean for unmarried students in the USA (*M*=137.5) but considerably lower than for married students (*M*=154.3) (Miller & Lefcourt, 1982). As the current sample included participants with a variety of relationship statuses from single (*M*=120.87) to in a relationship and living together (*M*=142.94), the figures seem relatively low, suggesting participants experienced low levels of social intimacy.

Unfortunately, the comparative data referred to above is, in some instances, rather unsatisfactory. With this caveat at the forefront the overall pattern and scoring profile is indicative of a population that experienced relatively high levels of appearance distress, feared negative evaluation, experienced bodily self-consciousness during physical intimacy, feared intimacy, and enjoyed low levels of social intimacy. The consistency of the scoring profile facilitates a tentative and provisional argument to be made that the current participants, those with a visible difference, may experience appearance related distress and find physical intimacy and intimate relationships challenging. Whilst a comparison between those with and without visible difference on such metrics is not the focus of this research, the data suggests that this as an important avenue for future research.

11.3. Indicative findings

These analyses were exploratory in nature, were not the subject of prior hypotheses, and therefore were performed to provide an initial indication of group differences and so, for example, regression analyses were not performed. The findings described are preliminary in nature. Where group differences are considered factor solutions using split-samples indicated that the structure of CARRIS remained stable.

11.3.1. Variables that could not be analysed

The composition of the sample prevented any analysis of ethnicity and sexuality being performed. Previous research has reported culturally sensitive and contextualised findings. Furr (2014) identified that female, Indian victims of domestic assaults with fire experienced their visible difference as central to their identity and resulting in stigma, exclusion, excommunication, and undermining their fitness as a wife and mother. Such values may persist amongst communities living within the UK/Ireland. Thompson et al. (2010) found British South Asian women with Vitiligo experienced stigma resulting from cultural values and beliefs about the cause of the condition and this impacted their intimate relationships and lives. It would therefore be appropriate to ascertain any cultural specifications or adaptations to CARRIS may be required for its use in specific populations. The lack of an exploration of the experiences of and applicability of CARRIS to minority groups is therefore a limitation inherent within the current research.

11.3.2. Age and years since acquired visible difference

The absence of a significant correlation between participants' CARRIS score and their age challenged the belief expressed by participants in the qualitative study that visible difference becomes less important and that adjustment improves with age. This belief garners mild support from the ARC (Clarke et al., 2014), which indicated that positive adjustment to visible difference increased with age but stressed that the relationship was not dramatic and many older people also experienced appearance concern and distress.

Within the realm of romantic relationships Low et al. (2009) found head and neck cancer patients' intimacy related problems declined with age whilst a review of burns literature suggested that sexuality was more problematic for younger patients (Gonçalves et al., 2014). The opposite, however, was found by Connell et al. (2013) who reported those with burns who were older experienced a greater impact upon sexuality whilst Gupta, Gupta, and Watteel (1998) examined Psoriasis and sexual functioning, finding that the groups categorised as having unproblematic and problematic sexual functioning did not differ by age. The lack of a significant correlation in the present research and the low coefficient mirrors the latter findings most closely, although CARRIS is not a measure of sexual functioning. What is more unequivocal is that the current data suggests that assumptions about adjustment to visible difference and appearance distress within a romantic context, should not be made based upon the age of an individual. Similarly, there was no significant correlation between the total score on CARRIS and the number of years an individual had lived with their difference, indicating that ideas expressed in the qualitative interviews; that one habituates to visible difference, were not supported.

11.3.3. Variables relevant to participants' visible difference

Other variables related to the nature of participants' visible difference, namely its cause, visibility, location, and nature, demonstrated few significant effects. To summarise these findings, there were no significant differences in participants' total CARRIS scores related to the cause (e.g. injury, congenital) of their visible difference nor to whether it was ordinarily visible. Whilst there was a significant effect of the location of visible difference, *post-hoc* tests revealed only that those whose limbs and head/face were affected scored more highly than those whose limbs (only) were affected. The nature of participants' visible difference was similarly significant, with alopecia, dermatological, and multiple all scoring more highly than those who selected 'other' and those with multiple visible differences also scored more highly than those with scarring.

For completeness and from the available data, the 30 participants in the 'other' category included those expressing dissatisfaction with their height, weight, body-shape, un-toned stomach, cellulite, penis size, asymmetrical and different sized breasts, excessive hair, a slight limp, jawline, microtia, and an open wound due to ileostomy.

Few other differences were highlighted by the analysis; multiple differences scored more highly than scarring (nature of difference), and those with differences on the limbs and head/face scored more highly than those who reported differences only on the limbs (location of difference). Participants reporting multiple differences scored more highly than participants reporting any single type of visible although this was only significant with regards to scarring and 'other.' Existing research from both qualitative and quantitative paradigms generally focusses either upon visible difference or upon a specific condition (or group of related conditions), potentially neglecting those with multiple differences.

The difference identified between those whose difference was located on the i) limbs and ii) limbs and the head/face, may proffer some support within the romantic domain to those who have argued that differences located on the head/face can hinder communication and be especially problematic (Clarke, 1999; Jensen & Harder, 2011; Newell & Clarke, 2000; Penner, 2009). There was no significant difference, however, between those whose visible difference was on the limbs (only), and the head/face (only). As with the finding related to the nature of one's visible difference and the indication that multiple differences may be particularly challenging, more research would be required to confirm and explore this preliminary finding.

Despite these considerations, the preliminary findings largely reflect those of Low et al. (2009) who reported issues connected to intimacy and sexuality were largely unrelated to the site, stage of disease, treatment modality, and time since surgery amongst head and neck cancer patients. Participants' total CARRIS score was, however, correlated significantly with their subjective rating of how different from normal i) the area of their body affected by their difference and ii) their overall appearance was. Taken together these findings are generally consistent with those that demonstrate that measures of the nature, size, and severity of a visible difference do not function as good predictors of distress (Moss, 2005; Ong et al., 2007; Rumsey et al., 2003, 2004). They suggest that, as that previous research has demonstrated in connection with other issues of adjustment, the characteristics of an individual's visible difference are not necessarily associated with greater or lesser appearance anxiety within a romantic context.

11.3.4. Sex

The significant difference identified between women and men, with women indicating significantly more distress than men, is consistent with some of the findings introduced in Chapter 2 (Connell et al., 2013). Furthermore, the findings seem to affirm the views of the participants in the qualitative study included within this thesis, that appearance is a gendered issue and that the pressure to conform to an ideal and the impact of failing to do so, both generally and within the romantic domain, is experienced more intensely by women. The review of the literature, however, also identified research suggesting that men with appearance altering conditions experience greater difficulty with adjustment than women (Low et al., 2009; Porter et al., 1990).

The relationship sex and appearance distress in a romantic context was examined within the context of the CFA and, based upon the EFA data, is an area that should receive further research attention.

11.3.5. Relationship Status

The effect of relationship status and the fact that those that were single indicated the most distress; followed by those that were divorced, separated or widowed; then those in a relationship but living separately; those that were married; and finally, those that were in a relationship and living together, offers some tentative support for previous research findings. These include that those in relationships prior to a burn injury were less likely to suffer negative outcomes within the domains of affect and relationships (Connell et al., 2014), that dermatological conditions are particularly stressful for single persons as one's appearance is central to the initiation of romantic or sexual relationships (Porter et al., 1990), that limb-loss and absence is romantically undesirable and so of particular concern to those that are unmarried or single (Batty et al., 2014; Murray, 2005), and a partner can serve a protective function and encourage effective coping methods and acceptance (Thompson et al., 2002).

What is important to acknowledge, however, is that the *post-hoc* analysis revealed that the only significant between groups difference was between those that reported being single (higher distress) and those that were in a relationship and living together (lower distress). Given the cultural and social background of participants (being primarily a Christian/non-religious, white, heterosexual sample living in the UK/Ireland) this may be considered somewhat surprising as there may exist an assumption that those that are married would experience the lowest levels of romantic distress in connection with their appearance.

Alternatively, it may be argued that many people in the UK/Ireland choose to live together without being married and so this does not necessarily reflect on the strength of that relationship. Whilst data pertaining to the length of participants' relationships were not collected and so any effect of the length of their current relationship could not be examined, the raw scores indicated that a larger sample may have resulted in more significant between-groups differences being identified. Whilst the final study contained within this PhD re-examined these findings with fresh data, the sample was smaller so future research utilising CARRIS, may be required to examine relationship status in a more authoritative manner.

11.3.6. Treatment Status

Whilst there was no significant correlation between the length of time participants had their visible difference for and scores on CARRIS, those who were receiving treatment in connection with their visible difference indicated significantly more distress than those that were not. The question asked was somewhat rudimentary in nature *"Are you currently receiving treatment from any healthcare professional in connection with your visible difference?"* No further details were requested. There may exist a number of possible but speculative explanations for the finding, including explanations that refer to the physical severity of a condition, its salience, or the possibility that individuals whose difference exerts a greater psychosocial impact upon their life (including upon their romantic life) may be more liable to seek treatment. Whilst the effect size was relatively small, this indicative finding suggests that healthcare professionals providing care to patients with visible differences should be aware of and willing to assist with concerns related to patients' romantic lives as they may be likely to encounter those experiencing this domain as problematic.

This also suggests that further research is required to compare the scoring profiles of those who are receiving treatment to those that are not. This suggestion is strengthened by the preliminary finding of the ARC (Clarke et al., 2014), that scoring profiles of plastic surgery outpatient clinic attendees differed markedly from those of a sample without visible difference on the provisional scale used to measure intimacy and appearance distress. The current findings highlight the possibility that this difference arose because participants with visible difference were drawn from those receiving treatment. Further research is warranted examining respective levels of appearance distress within a romantic content amongst those without a visible difference, those with a visible difference, and those receiving treatment in connection with their difference.

11.3.7. Recruitment Source

The greater distress evident in participants recruited via means other than Prolific (primarily through the advertisements placed by relevant support groups and charities) than those recruited via Prolific was intriguing. Upon becoming aware of this finding, the first inclination may be to question the data obtained via Prolific, especially as the majority of participants within the 'other' group (nature of visible difference) were recruited via Prolific (although an independent samples *t*-test excluding the 'other' participants conducted purely to exclude this as an issue resulted in a very similar and highly significant group difference between those recruited via Prolific and those that were not).

This would ignore, however, the existing evidence signifying the relative reliability of the Prolific portal (Peer et al., 2017) and work on an assumption that those recruited primarily via the advertisements of support groups and charities represent the visible difference population. It is equally plausible, that those recruited via these other means differ from the general visible difference population, perhaps identifying with or by their difference in some more salient way, and that this drives the difference between these two groups. Whilst the factor solution remained relatively stable between these populations, research comparing the CARRIS scores and other markers of appearance distress of participants recruited via a variety of different sources should be conducted before claims related to having or knowing population norms can be made with confidence.

11.4. Conclusion

The EFA has revealed a stable, simple, and sensible structure to CARRIS. Furthermore, participants' total CARRIS scores correlate with other, related measures, in a consistent and coherent manner. The indicative findings indicate some interesting between-group differences that are, generally, congruent with existing literature. Whilst the factor structure of CARRIS was examined with fresh data via CFA, more research is required to investigate a number of the indicative findings in more depth.

12. Confirmatory Factor Analysis

12.1. Introduction

In light of the results of the EFA, I proceeded with a CFA examining CARRIS. This entailed the collection of fresh data, and the examination of the factor structure of CARRIS, revealed during the EFA, specified *a priori,* and assessed via goodness of fit indices. It was therefore hypothesised that the three-factor model specified in Figure 12.1 and Table 12.1 would show acceptable fit to data collected from participants who self-identified as having a visible difference. Table 12.1 also includes the new item numbers assigned to the 17 items that constituted CARRIS at this stage.

Figure 12.1 CARRIS 17 Items Factor Structure

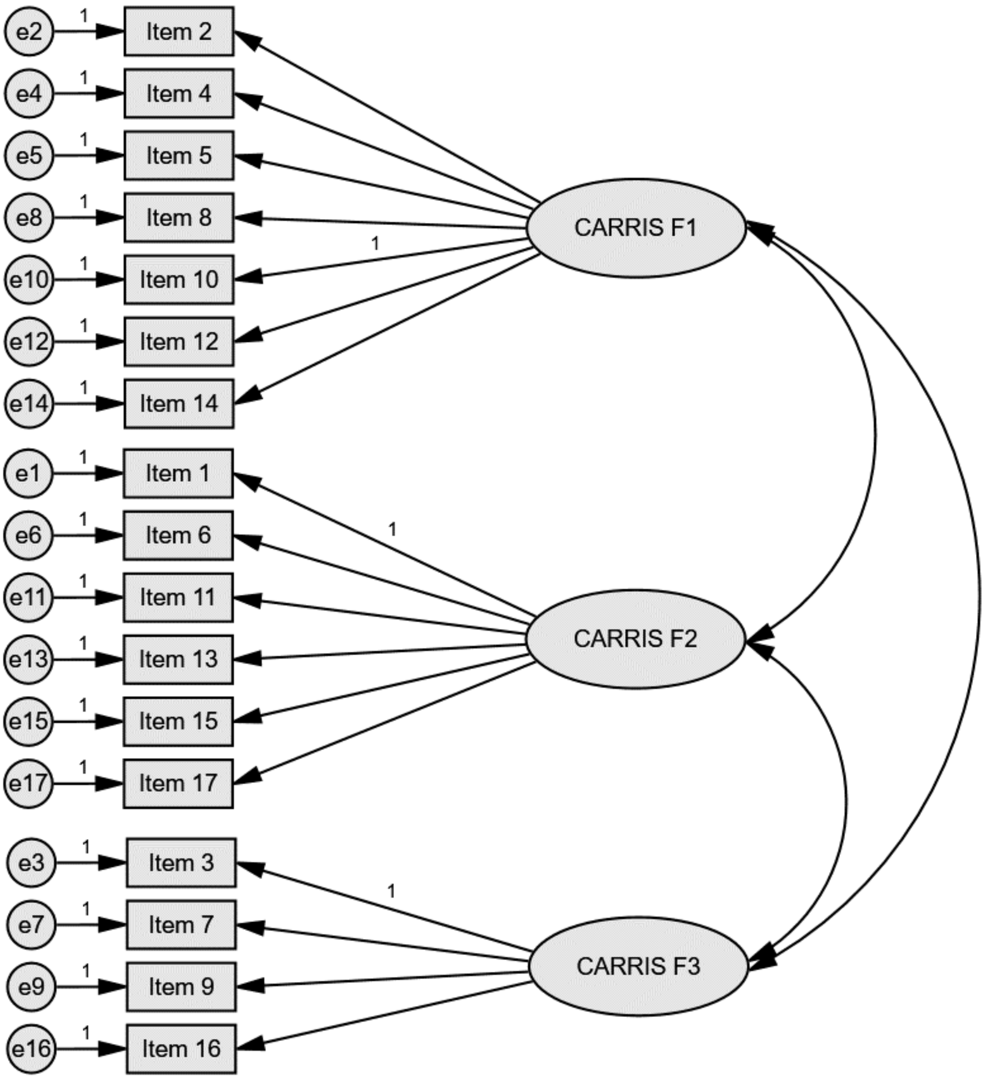


Table 12.1

CARRIS 17 Item Factor Structure and Items

Factor	Item No.	Item
F1 sexual anxiety and self-consciousness	2	I feel discomfort at being seen naked by a partner
	4	I would alter my sexual behaviour because of how I look
	5	I feel anxious during sexual activity
	8	I would avoid undressing in front of a partner
	10	I feel anxious immediately prior to sexual activity
	12	I feel comfortable with my appearance in sexual situations (x)
	14	I am able to relax and fully enjoy sexual activity (x)
F2 negative evaluation and being judged as unattractive	1	A new partner would be put off me by my appearance
	6	I feel physically attractive (x)
	11	A partner would feel little sexual desire for me
	13	Other people are repelled by my appearance
	15	I would be worried about telling a potential or new partner about my appearance
	17	My appearance is an extra barrier to me developing romantic relationships
F3 benefiting from partner empathy	3	I would feel able to openly discuss my appearance with a partner (x)
	7	My partner would be able to provide me with support and comfort if I felt unhappy about how I look (x)
	9	Speaking about how I look with a partner would be a positive experience (x)
	16	My partner could understand how I feel about my appearance (x)

(x) reverse scored items

CARRIS’ stability over time, its test-test reliability, was also assessed as part of this study. It was hypothesised that the total scores and scores obtained on each factor of participants who completed CARRIS at two time points would correlate significantly.

12.2. Method

12.2.1. Ethical Approval

This research received ethical approval from the University of the West of England: University Research Ethics Committee: Faculty of Health and Applied Sciences pursuant to an amendment to the EFA ethical approval (Appendix E1). Participants were not offered a voucher to thank them for their participation but had the opportunity to leave their details so that a random selection of those that participated could be provided with an Amazon voucher to thank them for their participation.

12.2.2. Participants

As each participant was not provided with a token of thanks, Prolific Academic could not be used. Participants were therefore recruited through advertisements placed on the social media of CAR and 22 support groups and charities within the field. Social media posts were also shared and retweeted by a number of individuals interested in the area. Whilst the EFA had suggested individuals recruited in this manner may score more highly on CARRIS than those via Prolific, the examination of EFA solutions including participants from each source had suggested a very similar factor solution. This method of recruitment was therefore considered acceptable, although perhaps liable to lead to some skew towards greater distress.

One-hundred and ninety-five potential participants indicated they were eligible and consented to take part in the CFA study. One-hundred and eighty-eight participants provided demographic details although seven did not provide any response to CARRIS. One-hundred and eighty-one participants therefore responded to the 17 CARRIS items and one attention check item. In light of the brevity of CARRIS, any participant that failed or did not respond to the attention check was excluded. Thirty-one participants did not progress as far as the attention check, failed to respond, or failed it. This left *N*=150 although an additional six participants were excluded as part of the data screening process (see below) leaving *n*=144.

The 144 participants included *n*=123 women, *n*=20 men, and *n*=1 unspecified, aged from 18-68 years (*M*=37.47). *n*=102 participants indicated their difference was normally visible to others in everyday life and *n*=42 confirmed otherwise. Sixty-three were receiving treatment from a healthcare professional in connection with their difference at the time of participation, *n*=81 were not. Further demographic characteristics of the 144 participants are reflected in Tables 12.2-12.7.

Table 12.2

CFA Participant Demographics: Ethnicity

Ethnicity	Asian / Asian British	Black / African / Caribbean / Black British	Mixed / multiple ethnic groups	White	Total
n	5	1	4	134	144

Table 12.3

CFA Participant Demographics: Sexuality

Sexuality	Bisexual	Gay or Lesbian	Heterosexual or Straight	Other	Total
n	9	6	127	1	143

Table 12.4

CFA Participant Demographics: Relationship Status

Relationship Status	In a relationship and living together	In a relationship but living separately	Married or in a civil partnership	Separated, divorced, or widowed (no current partner)	Single	Total
n	35	13	46	12	38	144

Table 12.5

CFA Participant Visible Difference: Cause

Cause of Visible Difference	Congenital / inherited / genetic	Disease process	Multiple	Traumatic injury	Treatment / surgery	Other	Total
n	65	23	9	9	8	28	142

Table 12.6

CFA Participant Visible Difference: Location

Location of Visible Difference	Limbs	Torso	Head/face	Whole body	Limbs and torso	Limbs and head/face	Torso and head/face	Total
n	7	3	53	62	4	11	4	144

Table 12.7

CFA Participant Visible Difference: Nature

Nature of Visible Difference	*n*
Alopecia / hair loss	39
Birthmark	13
Burn injury	5
Cancer related	1
Craniofacial condition	3
Dermatological / skin condition	46
Lymphedema	2
Paralysis or muscular weakness	14
Scarring	4
Skeletal condition	1
Other	9
Multiple	7
Total	144

For test-retest reliability participants who completed CARRIS were asked to indicate whether they were willing to complete CARRIS again four weeks later. All participants that indicated their acquiescence to this were emailed a link to a second Qualtrics site four weeks after submitting their CARRIS response. This interval exceeded the 2-14 days Streiner et al. (2015) identified as typical and was intended to minimise the possibility of participants' circumstances being materially altered but ensure they would not recall their original response. These participants were asked to complete CARRIS again and to indicate any material changes in their circumstances since providing their initial data. Whilst two individuals indicated a material change one did not complete CARRIS at the retest stage and the other failed an attention check so neither formed part of the test-retest analysis.

Re-test data were recorded from *n*=73 participants. Seven participants provided no response to the CARRIS items and five either failed (two) or did not respond to (three) the attentional check. The remaining 61 participants were matched to their original CARRIS data via a combination of their email addresses and a code that they were asked to provide at both time-points. Twelve participants could not be matched with one of the 144 participants whose original CARRIS data were retained. This left complete data for *n*=49 in order to assess CARRIS' four-week test-retest reliability.

The 49 participants included *n*=42 women, *n*=6 men, and *n*=1 unspecified, aged 18-57 years (*M*=37.73). *n*=38 participants indicated their difference was normally visible to others in everyday life and *n*=11 confirmed otherwise. *n*=19 were receiving treatment from a healthcare professional in connection with their difference at the time of participation whilst *n*=30 were not. Further demographic characteristics of the 49 test-retest participants are reflected in Tables 12.8-12.12.

Table 12.8

CFA Retest Participant Demographics: Ethnicity

Ethnicity	Asian / Asian British	Black / African / Caribbean / Black British	Mixed / multiple ethnic groups	White	Total
n	1	-	2	46	49

Table 12.9

CFA Retest Participant Demographics: Sexuality

Sexuality	Bisexual	Gay or Lesbian	Heterosexual or Straight	Other	Total
n	5	4	40	-	49

Table 12.10

CFA Retest Participant Demographics: Relationship Status

Relationship Status	In a relationship and living together	In a relationship but living separately	Married or in a civil partnership	Separated, divorced, or widowed (no current partner)	Single	Total
n	9	7	16	4	13	49

Table 12.11

CFA Retest Participant Visible Difference: Cause

Cause of Visible Difference	Congenital / inherited / genetic	Disease process	Multiple	Traumatic injury	Treatment / surgery	Other	Total
n	25	6	3	2	3	9	48

Table 12.12

CFA Retest Participant Visible Difference: Location

Location of Visible Difference	limbs	torso	Head/face	Whole body	Limbs and torso	Limbs and head/face	Torso and head/face	Total
n	1	-	20	22	2	1	3	49

Table 12.13

CFA Retest Participant Visible Difference: Nature

Nature of Visible Difference	*n*
Alopecia / hair loss	14
Birthmark	4
Burn injury	2
Cancer related	-
Craniofacial condition	2
Dermatological / skin condition	12
Lymphedema	1
Paralysis or muscular weakness	5
Scarring	2
Skeletal condition	1
Other	3
Multiple	3
Total	49

12.2.3. Materials and procedure

CARRIS was presented to participants via the Qualtrics platform. Potential participants accessed the site and were presented with the Participant Information Sheet (Appendix E2), asked to indicate their eligibility, and provide consent (Appendix E3). After participants provided demographic details and had the opportunity to leave contact details if they wished to be eligible for a thank you voucher, CARRIS (Appendix E4) was presented to participants in an on-line form. Appendix E5 includes the CARRIS items in the order presented to participants along with the factor upon which they were each hypothesised to load and an indication of which items are reverse scored. The presentation of the items ensured that neither all the items loading on any factor nor all the reversed scored items were presented sequentially.

Participants that provided retest data were provided with access to the Participant Information Sheet, reminded of the consent that they had provided, and asked if their circumstances had altered in any material way since they completed CARRIS. They were then asked to respond to CARRIS once again.

Data were exported into IMB SPSS Statistics 24 for the purposes of data screening and compiling descriptive statistics. The SPSS module IBM SPSS Amos 25 Graphics was used to conduct the CFA and assess goodness of fit.

12.3. Statistical Method

12.3.1. Data Analysis

CFA is a form of structural equation modelling concerned with the relationship between observed and latent variables (Brown, 2015) which, like EFA is grounded in the common factor model. CFA is performed to test hypotheses (Field, 2013) and is thus driven by prior research and/or theory (Brown, 2015), requiring *a priori* specification of the model, dictating the number of factors and the relationship between the observed and latent variables. As Fabrigar and Wegener (2012) explain, cross loadings of observed variables (here the CARRIS items) onto the factors onto which they do not load are specified as 0 and no rotation is performed meaning that the solution is more parsimonious than EFA.

In the current analysis loadings of items onto their factors were freely estimated (Brown, 2015). This means that the relationship between each item and each factor was specified but the magnitude and relative size of the loadings if items onto their primary factors was not.

The loading of one item per factor, however, was set to 1.0 in order that these may function as marker indicators. These were chosen with reference to the EFA data and were items that had loaded strongly upon their primary factors (Brown, 2015; Kenny, 2015).

The CFA was performed using maximum likelihood (ML) analysis. This is the most commonly utilised CFA estimation method in applied research and acts to find the freely estimated parameter values that make the observed data most likely (Brown, 2015; Flora, LaBrish, & Chalmers, 2012). ML is robust to some deviations in normality but should not be used in respect of categorical data (Brown, 2015). As discussed within the context of the EFA, the data were considered interval level data.

Issues with the distribution of some items indicated that an estimator method such as robust ML may have been appropriate (Brown, 2015). The software available to me, however, meant that this was not feasible. Instead, Bollen-Stine Bootstrapping (Bollen & Stine, 1992) was employed. This entails random samples, each equal to the original sample size, being drawn from the data, and the results from multiple analyses being compared to those obtained with the original sample (Brown, 2015). The output will provide an overall assessment of the goodness of fit of the model. This may also be considered to allay concern over the relatively small sample.

12.3.2. Indices of Fit

The specified solution is then assessed in terms of how accurately it mirrors the sample correlation matrix of the observed variables (Brown, 2015). This is assessed via the significance of the classic goodness-of-fit index (X^2) and indices that evaluate absolute fit (standardised root mean square residual: SRMR), those that penalise models for lacking parsimony (root mean square error of approximation: RMSEA (Steiger & Lind, 1980)), and comparative fit (comparative fit index: CFI (Bentler, 1990); Tucker-Lewis index: TLI (Tucker & Lewis, 1973)). As an examination of these indices and their alternatives is beyond the scope of this thesis, the four preferred (and cited) by Brown (2015) were used.

12.3.2.1. Interpreting Indices of Fit

Brown (2015) highlights that a significant X^2 indicates that the model does not fit the data well but that this metric is problematic (especially with a small sample and non-normal data), stringent, and rarely relied upon in deference to other fit indices. Whilst he argues that the fit indices are each differently affected by factors such as sample size, model complexity, data normality, and estimation Brown (2015) cites Hu and Bentler (1999), whose Mote-Carlo simulations informed the choice of the indices detailed above, suggest that SRM values of close to .08 or below, RMSEA of close to .06 or below, and CFI/TLI of close to .95 or greater indicate good fit. The use of 'close to' indicates these are not intended to be absolute values and some researchers argue these guidelines are too conservative. Indeed, Bentler (1990) (reported in Brown, 2015) argues that CFI/TLI of .90-.95 suggest acceptable model fit and Browne and Cudeck (1992) (also cited by Brown, 2015) argue an RMSEA <.08 is indicative of adequate model fit.

Turning to a CFA conducted within visible difference research, Moss et al. (2015) cite MacCallum, Browne, and Sugawara (1996) as indicating RMSEA values >.1 indicate a poorly specified model with values <.01, <.05, and <.08 suggesting excellent, good and mediocre fit respectively. They also argue that as per Bentler (1990), Cole (1987), and Marsh, Balla, and McDonald (1988) a CFI of >.9 suggests good fit between the specified model and the data.

12.3.3. Modification Indices

Whilst the EFA data suggested CARRIS' items' cross-loadings to be minimal, Brown (2015) highlights that EFA cannot indicate how reasonable it is to set such items cross-loadings to 0 (as in the CFA model) nor to fix all error covariance at 0, the latter meaning that all covariation is attributed to the latent dimension and all error is random (Brown, 2015). Covarying errors acts to attribute a portion of such covariance to other causes. Where this is indicated as necessary it suggests the original model demonstrates localized poor fit. Brown continues, giving examples of the potential causes of error covariance (or correlated errors), such as the similar wording of items.

In light of the EFA being unable to indicate error covariance, the modification indices generated by AMOS were consulted. These provided an indication of the magnitude by which the model X^2 will decrease (and be less likely to be significant) were a fixed parameter (such as error covariance) allowed to be freely estimated (Brown, 2015), suggesting possible improvements to the model.

Whilst modification indices >4 may be considered to offer improvements to the model it is important to note, however, that errors should only be covaried between items that load upon the same factor and that it is necessary to provide a substantive rationale beyond improve model fit for permitting this (Brown, 2015). Furthermore, any rationale must be applied consistently to all pairs of items to which it applies and being guided primarily by modification indices may improve model fit but lead to issues with replicability of the model.

12.3.4. Standardized Residuals

Brown (2015) explains that the standardized residual matrix is another indicator of localized strain, or poor fit, within a model. They illustrate the magnitude of deviation in the residuals between a given pair of items and the zero-value residuals which would be present in a perfectly fitting model and may be considered analogous to *z*-scores with scores of +/-2.00 or 2.58 used in interpreting them. AMOS' guidance suggests most such values should be under 2.00 in a well specific model. With the guidance of Field (2013) in mind, we would thus expect approximately 5% to be >+/-1.96 (or 2.00), 1% >+/-2.58, and none >+/-3.29.

12.3.5. Other Causes of Poor Model Fit

A number of other causes and indicators of poor model fit have been identified by Brown (2015) and include specifying an improper number of factors, an incorrect specification of the relationship between items and factors (caused by cross loadings, items loading on the 'wrong' factor, and items not loading on any factor), Heywood cases with a standardized loading >1.0 and a lack of positive definitiveness. Brown advises that the latter can be accessed via the performance of PCA on the covariance matrix, with positive eigenvalues >0 indicating positive definitiveness. Issues of incorrect specification should be apparent from the goodness of fit indices as well as the modification indices and standardized residuals, with Brown (2015) acknowledging that it may be appropriate to eliminate bad indicators (items) from the model. Likewise, an improper number of factors would result in a poor goodness of fit indices and suggest a fundamental issue with the model.

12.4. Data Screening

12.4.1. Missing Data

In line with the approach taken in conducting the EFA data from any participant with >5% missing data was discarded. Due to the brevity of CARRIS, each item constitutes >5% of the scale and so 3/150 responses were discarded. One further response was discarded as it included the N/A response to 13/17 items and was therefore adjudged unreliable. This resulted in a complete data-set in respect of *n*=146 participants with no missing data. The re-test data (*n*=49) included no missing data.

12.4.2. Sample Size

After excluding a further two responses (see below) the final sample of *n*=144 that was used in the CFA represented 8.47 responses per item and broad compliance with rules of thumb that suggest 100-150 responses be considered the minimum acceptable for CFA and that samples of <100 are associated with a real danger of improper solutions (Ding, Velicer, & Harlow, 1995). The sample size, however, did not satisfy the goal of having 5 cases per freed parameter (the final model had 41 freed parameters with a ratio of 3.51:1) nor a sample of 200 (Kenny, 2015), although the strength of correlations present within the EFA data and the relative simplicity of the CFA model counter this concern (Kenny, 2015).

The work of Ding et al. (1995) demonstrated that once sample sizes reach 200 or loadings were .7, non-convergent and improper solutions were rare. Furthermore, such issues arose infrequently when the ratio of indicators to factors was >2:1. The authors interpreted this to confirm previous research and recommend this ratio be >3:1, particularly where N=<200. Whilst a sample size of 200 may have therefore been desirable the ratio of indicators to factors in the current study (where no factor had fewer than 4 items load upon it) and the loadings demonstrated in the EFA (.503-.935, *M*=.688) suggested that the sample size of *n*=144 be considered adequate. In addition, Ding et al. (1995) indicate that the utility of goodness-of-fit indices (introduced below) may be negatively impacted by a high indicators-factors ratio but that this is limited to situations where N=<100 and so should not be considered problematic in the current case.

12.4.3. Normality

As with the EFA data, items were examined for univariate normality with no items in either the CFA data or the re-test data demonstrating absolute values of skew or kurtosis >+/-2. In light of the use by Curran, West, & Finch (1996) of absolute values of skew =2 and kurtosis =7 to represent moderately non-normal data in a Monte Carlo study, the present values in which no item demonstrated an absolute value of skew >1.32 or kurtosis >1.20 were considered to demonstrate acceptable levels of normality. Visual inspection of histograms for each variable revealed some concerns regarding the distribution of a number of the items. It is possible that, as discussed, this was at least partly attributable to the composition of the sample.

Transformation of the data was not considered desirable due to warnings related to its appropriateness and its effectiveness offered by both Brown (2015) and Tabachnick and Fidell (2007) and as the skew detected was not consistent across all items. In light of these concerns, the relatively small sample size, the limited availability of alternative methods of conducting a CFA, and the recommendation of Brown (2015) a Bootstrapping procedure was performed to minimise any impact of these factors upon the analysis.

12.4.4. Outliers

An examination of boxplots created for each of the CARRIS items in respect of the CFA data and the retest data indicated that the CFA data included outliers on items 1 and 17. The associated *z* scores included two responses where *z*=-2.62 and two where *z*=-3.37. As Field (2013) highlights that one would expect 1% of these *z* values >+/- 2.58 but none >+/-3.29 and the desire was to retain data where possible in conformity with arguments that it is preferable to retain unusual cases rather than delete them (Flora et al., 2012), only the two responses that provided the extreme *z* scores >+/-3.29 were discarded. None of the *z* scores pertaining to item 17 were >+/-2.58. The removal of the two responses resulted in a final *n*=144.

Following the removal of these two responses the normality and presence of outliers was re-examined for all CARRIS responses (CFA and retest data). No additional issues were identified, and the remaining outliers suggested by the boxplots for items 1 and 17 carried no *z*-scores <+/-3.29 with only two responses to item 1 >+/-2.58.

12.4.5. Linearity

As with the EFA linearity was examined via pairwise scatterplots for a selection of the items (Tabachnick & Fidell, 2007). There appeared to be no evidence of curvilinearity and, if at all, the items were related in a linear fashion.

12.4.6. Multicollinearity, singularity, positive definitiveness

The determinant of the sample covariance matrix provided by AMOS was positive and greater than zero (6838.751, in the final model) indicating that multicollinearity was not an issue. Similarly, the fact that the solution converged dispelled any suggestion of singularity (Tabachnick & Fidell, 2007). All Eigenvalues associated with a PCA performed on the data (given in both SPSS and AMOS) were positive and >0.

12.5. Results

12.5.1. CFA: Specified Model

Goodness-of-fit indices from a ML CFA performed on the specified model (Figure 12.1) demonstrated a significant X^2=237.4 (116) *p*=<.001 with goodness of fit metrics indicating it approached acceptable model fit SRMR=.0663, RMSEA =0.086 90% (CI=0.7-1.01), TLI=.874, CFI=.893. Whilst a significant X^2 was anticipated and not considered highly problematic, only SRMR was within the pre-defined acceptability criteria and each of the RMSEA, TLI, and CFI indicated issues with the model. As no individual goodness-of-fit indices is comprehensive and those utilized should be taken together to inform assessments of model fit, the model was not considered acceptable.

Modification indices were consulted (Appendix E6) and it was noted that the value associated with covariance between items 2 and 8 was by far the greatest value both globally and amongst those items loading upon the same factor and so these were potentially eligible to be co-varied.

These items were:

Item 2: I feel discomfort at being seen naked by a partner

Item 8: I would avoid undressing in front of a partner

Item 8 was also associated with the fourth greatest eligible modification index (with item 14) and was one half of one of only three pairs of standardized residuals >2.00 (from a standardized residual matrix containing 136 pairs). Item 8 was therefore considered problematic and to indicate a level of local strain within the model.

Items 2 and 8 were reconsidered and adjudged conceptually similar, both pertaining to a sense of vulnerability at being seen naked by a partner despite one being affective in nature and the other behavioural. Co-varying these items would, however, require that such rationale be applied to other pairs of items, even where this was not indicated by the modification indices. For example, the following items could be co-varied under the same rationale:

Item 5: I feel anxious during sexual activity and *Item 14: I am able to relax and fully enjoy sexual activity (F1)*

Item 1: a new partner would be put off me by my appearance and *Item 13: Other people are repelled by my appearance (F2)*

Since the first factor had seven items load onto it, item 8 was problematic both in view of the modification indices and one of its associated standardized residuals, and item 8 may be considered conceptually similar to item 2, the decision was made to delete item 8 from the model rather than co-vary the items. This has the advantages of being the more parsimonious option and less likely to introduce parameters into the model that may not be reproduced with future data.

12.5.2. CFA Re-specified Model

ML CFA was thus performed on a re-specified model (Figure 12.2 and Table 12.14) which was identical to the original model but with item 8 deleted.

Figure 12.2 CARRIS 16 Items Factor Structure

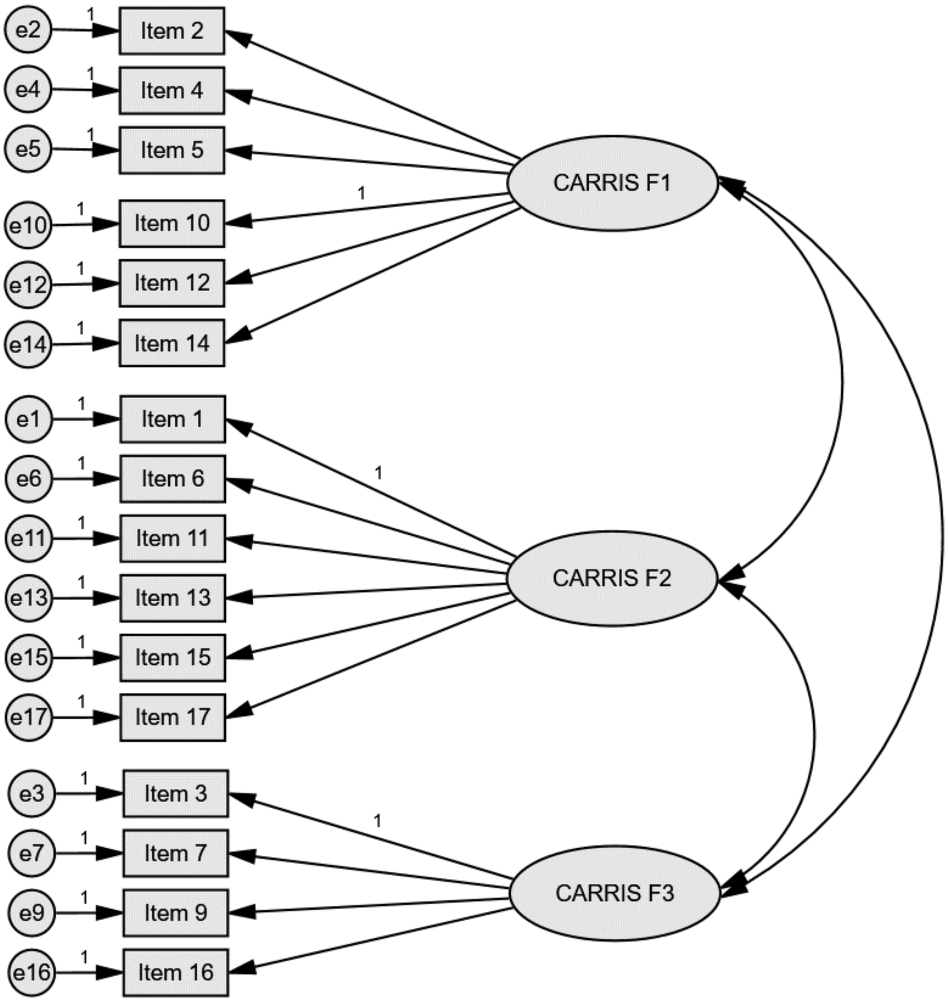


Table 12.14

CARRIS 16 Item Factor Structure and Items

Factor	Item No.	Item
F1 sexual anxiety and self-consciousness	2	I feel discomfort at being seen naked by a partner
	4	I would alter my sexual behaviour because of how I look
	5	I feel anxious during sexual activity
	10	I feel anxious immediately prior to sexual activity
	12	I feel comfortable with my appearance in sexual situations (x)
	14	I am able to relax and fully enjoy sexual activity (x)
F2 negative evaluation and being judged as unattractive	1	A new partner would be put off me by my appearance
	6	I feel physically attractive (x)
	11	A partner would feel little sexual desire for me
	13	Other people are repelled by my appearance
	15	I would be worried about telling a potential or new partner about my appearance
	17	My appearance is an extra barrier to me developing romantic relationships
F3 benefiting from partner empathy	3	I would feel able to openly discuss my appearance with a partner (x)
	7	My partner would be able to provide me with support and comfort if I felt unhappy about how I look (x)
	9	Speaking about how I look with a partner would be a positive experience (x)
	16	My partner could understand how I feel about my appearance (x)

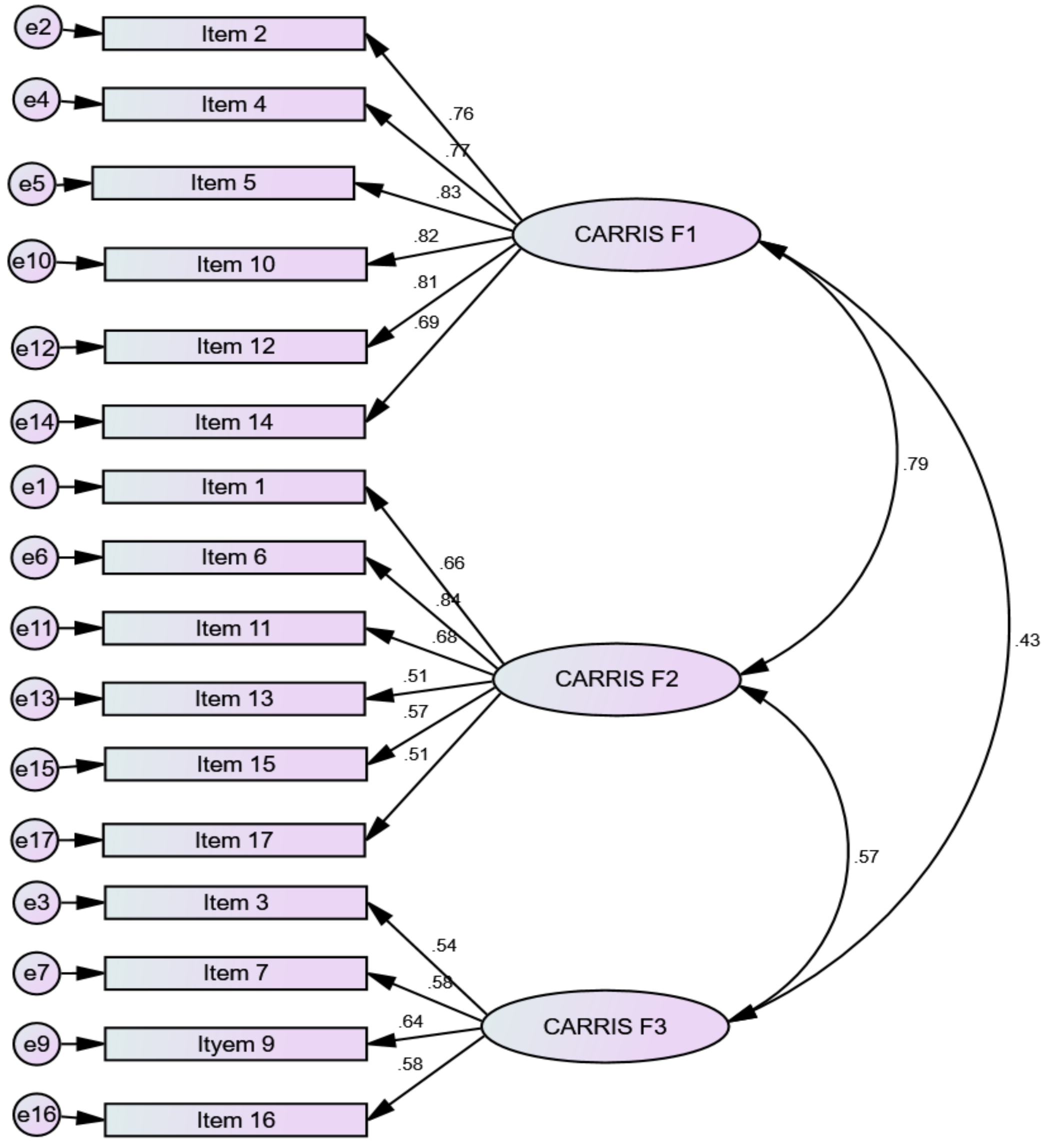
(x) reverse scored items

The specified model demonstrated a significant X^2=165.2 (101) *p*=<.001 with goodness of fit metrics indicating it an acceptable model fit SRMR=.0648, RMSEA=0.067 90% (CI=0.48-0.85), TLI=.920, CFI=.933. The significant X^2 was not considered problematic, the other metrics all indicated acceptable model fit, and the model was accepted.

Modification indices (Appendix E7) were examined and whilst some of the values suggested improvements that would lead to the model being better specified in respect of the CFA data-set and five of these related to items that loaded onto the same factor as one another, the possibility that these were the result of sampling error and therefore not replicable, the lack of clear, coherent, and consistent rationale for such covariance, and the desire for a parsimonious model meant that further re-specifications were not entertained. The matrix of standardized residuals (Appendix E8) illustrated that one of the 120 relationships was +/-2.00-2.58 and one >+/-2.58. Considering the interpretation of these figures discussed above, this was not considered problematic and was within acceptable bounds.

The unstandardized and standardized regression estimates (Appendix E9) were examined. All unstandardized estimates were highly significant (p<.001). Standardized estimates (also displayed in Figure 12.3), may be considered akin to factor loadings (demonstrating the relationship between increases of 1 standard deviation in the factor and increase in the standard deviation of individual items) and were all >.5, and therefore indicative of items that load well onto their factors. The estimated correlations between the factors are also included within Figure 12.3 and Appendix E9 and whilst F1 and F2 were strongly correlated, this was <.85, the cut-off that may indicate problematic discriminant validity (Brown, 2015).

Figure 12.3 CARRIS 16 Items Factor Structure: including standardised regression estimates



12.5.3. Bootstrapping

In order to provide another indication of model fit and to minimize concerns related to the normality of the data and (to a lesser extent) the slightly low *n*, 500 bootstrapped samples were specified (Brown, 2015). A Bollen-Stine Bootstrap tested the null hypothesis that the model was correct (and thus the hypothesis that it was incorrect) and was non-significant (*p*=.132) indicating that the model was a good fit to the data.

12.5.4. Internal Reliability Analysis

As with the EFA, Cronbach's alpha was assessed for CARRIS and each of its factors. Again, the criteria of Ponterotto and Ruckdeschel (2007) were used in assessing each. CARRIS (with 16 items) demonstrated 'good' internal reliability: Cronbach's α=.893. The first factor (sexual anxiety and sexual self-consciousness) (6 items) demonstrated 'excellent' internal reliability: Cronbach's α=.902. The second factor (negative evaluation and being judged as unattractive) (6 items) demonstrated 'good' internal reliability: Cronbach's α=.787. The third factor (benefiting from partner empathy) demonstrated 'fair' internal reliability: Cronbach's α=.677. Whilst these values of Cronbach's α were generally a little lower than at the EFA stage, it should be noted that the criteria of Ponterotto and Ruckdeschel (2007) that were utilised apply in respect of samples of 100-300 and that greater α levels are expected with greater sample sizes. The CFA data were toward the lower end of this range.

Whilst deletion of two of the items (7 and 16) would have increased α for the entire scale to .894, deleting either of these would reduce α for the third factor to <.65. The deletion of any individual item would have had a negative impact upon the internal reliability of the factor onto which it loads.

The internal reliability of CARRIS and its factors was also confirmed via an examination of the item-total correlations. All items correlated with the CARRIS total >.3, and each item also correlated >.3 with the factor onto which it loaded.

12.5.5. Test-Retest Reliability

In order to assess the four week test-retest reliability of CARRIS the total CARRIS scores of participants who provided data at both time-points were correlated. This was done in respect of the total CARRIS score and each individual factor. Whilst every correlation reported was highly significant, Streiner et al. (2015) argue that the magnitude of the correlation coefficient is critical rather than its significance. They indicate that a correlation coefficient of 0.7 is often considered acceptable for research tools but that a test with fewer items will be more likely to be associated with a lower coefficient than one with a greater number.

An examination of histograms suggested the distribution of participants' total CARRIS scores at test and retest was normal and the three outliers identified on a boxplot of retest scores were retained as their associated *z* scores were <+/-2.58. A Pearson's correlation was performed. There was a statistically significant correlation between participants' total CARRIS scores at test *n*=49 (*M*=56.02, *SD*=15.91) and retest *n*=49 (*M* = 54.55, *S* =15.16) *r*(47)=.819, *p*=<.001.

A paired samples *t*-test was performed to test for a statistically significant difference in participants' total CARRIS scores at these two time points but revealed no significant difference between participant's mean scores at these times *t*(48)=1.096, *p*=.278.

An examination of histograms suggested some non-normality in the distribution of participants' CARRIS first factor scores at test and retest, though no outliers were identified via boxplots. A Spearman's rank-order correlation was performed. There was a statistically significant correlation between participants' CARRIS first factor scores at test (*M*=20.02, *SD*=9.13) and retest (*M*=19.16, *SD*=8.31) *rs*(47)=.716, *p*=<.001.

A Wilcoxon signed-rank test was performed as the non-parametric equivalent of a paired samples *t*-test (Field, 2013) to test for a statistically significant difference in participants' CARRIS first factor scores at these two time points. Having established that difference scores were approximately symmetrically distributed this revealed that there was no statistically significant difference in participants CARRIS first factor scores at test (*Mdn*=21) and retest (*Md* =19), *T*=530.5, *z*=-0.11, *p*=.913.

An examination of histograms suggested some non-normality in the distribution of participants' CARRIS second factor scores at test and retest and two outliers were identified on a boxplots of retest scores. Only one of these had a *z*-score that was marginally >+/-2.58 (2.59) and so this was considered within acceptable bounds and the outliers retained. A Spearman's rank-order correlation was performed. There was a statistically significant correlation between participants' CARRIS second factor scores at test (*M*=24.73 *SD*=7.16) and retest (*M*=24.00, *SD*=6.94) *rs*(47)=.754, *p*=<.001.

A Wilcoxon signed-rank test was performed to test for a statistically significant difference in participants' CARRIS second factor scores at these two time points. Having established that difference scores were approximately symmetrically distributed this revealed that there was no statistically significant difference in participants CARRIS second factor scores at test (*Mdn*=25) and retest (*Mdn*=25), *T*=340, *z*=-1.40, *p*=.162.

An examination of histograms suggested some non-normality in the distribution of participants' CARRIS third factor scores at test and retest, though no outliers were identified on boxplots. A Spearman's rank-order correlation was performed. There was a statistically significant correlation between participants' CARRIS third factor scores at test (*M*=11.27, *SD*=4.40) and retest (*M*=11.39, *SD*=4.41) *rs*(47) =.663, *p*=<.001.

A Wilcoxon signed-rank test was performed to test for a statistically significant difference in participants' CARRIS third factor scores at these two time points. Having established that difference scores were approximately symmetrically distributed this revealed that there was no statistically significant difference in participants CARRIS third factor scores at test ($Mdn=11$) and retest ($Mdn=11$), $T=500.5$, $z=065$, $p=.949$.

The correlation coefficients associated with the total CARRIS score, the first factor, and the second factor all exceeded the criteria of being >.7, though the coefficient associated with the third factor was beneath this level.

The paired samples t-test and Wilcoxon signed rank tests revealed no significant difference in participants' total CARRIS scores nor their scores on any one factor, further indicating the test-retest reliability of CARRIS and its constituent factors.

12.6. Indicative Findings

Having confirmed the factor structure and model fit of CARRIS, the CFA data were also investigated for group differences, although this was not appropriate in respect of some demographic characteristics such as ethnicity (93.1% of the sample being White) or sexuality (88.2% being heterosexual). In light of the greater sample size, all data reported and analyzed in this section relates only to test data, not retest data and focusses upon the CARRIS total test score ($n=144$) ($M=59.51$, $SD=16.85$) which was adjudged to be normally distributed and included no outliers.

12.6.1. Age

Prior to conducting correlational analyses between participants' total scores for CARRIS and their age in years (Age) $n=144$ ($M=37.47$, $SD=10.90$), the assumption of linearity was examined with no issues of a non-linear relationship being identified. Consulting a histogram led to Age being adjudged to be normally distributed. Furthermore, examination of a boxplot revealed that there were no outliers. A Pearson's product moment correlation was thus performed. There was no significant correlation between participants' scores on CARRIS and Age $r(142)=.103$ $p=.219$.

12.6.2. Treatment status

An independent-samples t-test was run to determine if there were differences in the total CARRIS score between those who were receiving treatment from a healthcare professional in connection with their visible difference (Treatment) and those that were not (No Treatment). An inspection of boxplots revealed that there were no outliers within either group and an examination of histograms revealed some slight issues of non-normal distribution of the data of the CARRIS scores for those receiving treatment but this was not considered problematic as the t-test is relatively robust to issues of normality (especially in samples of >30, (Pallant, 2016)). There was homogeneity of variances, as assessed by Levene's test (*p*=.497).

There was no statistically significant difference between the Treatment group (*n*=63, *M*=62.49, *SD*=16.19) and the No Treatment group (*n*=81, *M*=57.23, *SD* = 17.10) the mean difference of 5.19 (95% CI, -0.36 to 10.7, *t*(144) = 1.580, *p*=.066 being non-significant.

12.6.3. Visibility

An independent-samples t-test was run to determine if there were differences in the total CARRIS score between those whose difference was ordinarily visible (Visible) and those whose difference was not (Not Visible). An inspection of boxplots revealed that there were no outliers within either group and an examination of histograms revealed the data to be normally distributed in respect of both groups. There was homogeneity of variances, as assessed by Levene's test for equality of variances (*p*=.661).

There was no statistically significant difference between the Visible group (*n*=102, *M*=58.40, *SD*=16.95) and the Not Visible group (*n*=42, *M*=62.19, *SD*=16.51), the mean difference of 3.79 (95% CI, -2.31 to 9.89, *t*(144) = 1.228, *p*=.221 being non-significant.

12.6.4. Sex

One participant indicated their sex as unspecified so was not included in this analysis. Whilst an inspection of boxplots revealed that there were no outliers within either the women (*n*=123) or men’s (*n*=20) total CARRIS scores, an examination of histograms revealed the men’s data to be non-normally distributed. In consideration also of the small sample size for men, a Mann-Whitney U test was run to determine if there were differences in total CARRIS scores between women and men. Distributions of the CARRIS scores were not similar, as assessed by visual inspection and so only mean-rank comparisons could be utilized. The mean-rank of the CARRIS scores of women (mean rank =74.36) and men (mean rank =57.50) were not statistically significantly different, *U*=940, *z*=-1.689, *p*=.091.

12.6.5. Relationship Status

The sample recruited for the EFA dictated that it was less feasible to perform ANOVAs to explore group differences than it was with the EFA data. Only Relationship Status was comprised of >4 groups of >10 participants and so in view of the small number of groups of this size and the number of participants comprising each group, ANOVAs were not performed in respect of participants' total CARRIS score and the Location, the Cause, or the Nature of their visible difference. Although relationship status was investigated the small group sizes demand that it be interpreted cautiously.

A one-way ANOVA was conducted to determine if the total CARRIS score was different for groups of different relationship status. Participants indicated whether they were: single (*n*=38); separated, widowed or divorced (*n*=12); in a relationship and living separately (*n*=13); in a relationship and living together (*n*=35); or married/in a civil partnership (*n*=46). In accordance with the advice of (Field, 2013), the Hochberg's GT2 *post-hoc* procedure was utilised due to the uneven group sizes.

There was one outlier, assessed by boxplots within the separated, widowed or divorced group. The analysis was performed twice, once with the outlier excluded. Excluding the outlier did not impact upon Levene's test of homogeneity of variances, the significance of the ANOVA, nor upon the *post-hoc* procedures. The outlier was therefore retained. An examination of histograms revealed approximately normal distribution of the data which was considered acceptable as ANOVAs may be considered relatively robust to issues of normality. Levene's test (*p*=.242) demonstrated homogeneity of variances.

There was a statistically significant effect of relationships status upon participants' total CARRIS score at test, *F*(4, 139)=3.322, *p*<.05, (partial) η2=.09 (a medium effect). CARRIS scores were lowest amongst (indicating lower levels of distress) those in a relationship and living separately (*M*=48.54, *SD*=12.30), then those who were married/in a civil partnership (*M*=55.98, *SD*=17.46), then those who were in a relationship and living together (*M*= 60.80, *SD*=16.53), then those who were separated, widowed or divorced (*M*=64.58, SD=11.92), and highest in those that were single (*M*=64.74, *SD*=16.98). Hochberg's GT2 *post-hoc* analysis revealed that the difference between those that were in a relationship and living separately to those that were single (16.20, 95% CI (1.28 to 31.11)) was statistically significant (*p*<.05), with those that were single scoring more highly. No other differences between groups were statistically significant.

12.7. Discussion

The CFA that was performed provided support for the factor structure of CARRIS with the re-specified model demonstrating acceptable model fit across a range of indices assessing its absolute fit (SRMR), parsimony (RMSEA), and comparative fit (CFI; TLI). This was despite the assertion of (Kenny, 2015) that some of these metrics (RMSEA and SRMR) are often inflated, and therefore suggest a poorer fit, with smaller sample sizes. Furthermore, CARRIS and each factor demonstrated at least acceptable internal reliability and the correlation coefficients between each factor indicated that each was sufficiently distinct from the others to signify acceptable discriminant validity, although the correlation between the first two factors was towards the upper bounds of acceptable levels in this respect. Whilst the model was re-specified as part of this CFA (via the deletion of one item) the hypothesis relating to the factor structure of CARRIS and model fit found support from this analysis.

The analysis of CARRIS' test-retest reliability was also satisfactory and supported the hypothesis made at the beginning of this section with no significant difference being identified in respect of the total CARRIS score or any factor between test and retest. Similarly, correlations between each of participants' total CARRIS score and their scores on the first and second factors at test and retest were all >0.7. The coefficient associated with the third factor was, however, <0.7. This may be a function of the number of items loading on that factor and the relatively small sample size. Whilst the coefficient was >.5, a level that has previously been used after a two-week test-retest interval as a reasonable minimum acceptable level within health psychology research focussing on illness representations (Mc Sharry, Bishop, Moss-Morris, Holt, & Kendrick, 2015), the test-retest reliability of the third factor may require further investigation before it may be considered to have been emphatically evidenced.

The removal of one item from CARRIS during this CFA was not unprecedented and, for example, in comparing model fit of several alternatives using CFA, Picariello, Moss-Morris, Macdougall, and Chilcot (2016) consulted modification indices and, with a sound rationale in place, amended their model by loading items with correlated errors onto a new factor. They also removed a low loading item from the model. Similarly, during a CFA Moon et al. (2017) removed the lowest loading item on each of three (of eight) sub-scales as they desired a more parsimonious scale and greater equality of length amongst the sub-scales. In the current case the conceptual similarity of another item was considered adequate grounds for deletion in light of modification indices suggesting the model's fit was impacted negatively by a lack of covariance between the deleted item and another. This does, however, mean that the CFA was not entirely confirmatory in nature and, ideally, should be confirmed in the future with fresh data.

The indicative findings demonstrate a level of concordance with the EFA data. As with the EFA, there was no correlation between participants' age and their total CARRIS score and neither were there any group difference between those whose visible difference was normally visible and those whose visible difference was not.

Whilst the EFA data indicated that those receiving treatment in connection with their visible difference experienced significantly more appearance related romantic distress than those who were not receiving treatment, no parallel significant difference was observed with the CFA data.

Whilst those receiving treatment (*M*=62.49) scored more highly than those not receiving treatment (*M*=57.23), this was not significant. It is noteworthy, however, that the analysis approached significance (*p*=.066) with the non-significant difference in the same direction as within the EFA data. Further research should examine for this potential group difference.

With regards to sex, issues relating to sample size and the distribution of the data demanded that the comparison using the CFA data could only be performed using a Mann-Whitney U test rather than an independent samples *t*-test. This did not demonstrate any significant difference between the groups although, again, the mean for females (*M*=60.66) was higher than for males (*M*=52.35) and thus the trend was in the same direction as in the EFA. Again, issues connected to the data and sample size, with only *n*=20 men participating at CFA stage, may be pertinent here.

The ANOVA examining relationship status was undergone tentatively as the group sizes were small. It did, however, reveal a significant effect and *post-hoc* tests demonstrated that those participants that were single experienced significantly more appearance related romantic distress than those who were in a relationship and living separately. Whilst at the EFA stage the significant *post-hoc* difference was between those that were single and those that were in a relationship and living together, the pattern across the EFA and CFA was broadly consistent. Both analyses indicated that relationship status exerted a significant effect, those that were single experienced the most distress, followed by those that were separated, divorced or widowed, than those in relationships (although the precise ordering of these three categories altered). In each case being single was indicative of significantly more distress than one of the relationships groups in *post-hoc* tests. Notwithstanding the issue of small group sizes, the results indicate a level of consistency and agreement between the data collected pursuant to the EFA and the CFA. In addition, it is considered consistent with the proposed structure and composition of CARRIS that those who were single indicated as experiencing more distress than other groups.

Whilst these indicative findings remain somewhat provisional in nature and are subject to some limitations inherent in the nature and amount of the data collected, the level of agreement between the EFA and CFA data begins to hint at consistent effects and groups differences in appearance related romantic distress amongst those with visible difference.

Furthermore, the similarity in trends across the CFA and EFA stages may act as a further indication of the consistency and validity of CARRIS.

12.7.1. Limitations

The limitations of this CFA must be acknowledged and the above statements considered to be contextualized and delimited by these issues. Whilst the data were fresh data, they were drawn primarily from those with some connection to or interest in specific charities and support groups that operate within the field of appearance altering conditions. Whilst the EFA data suggested otherwise with regards to those recruited via Prolific Academic, it is conceivable that the factor structure may differ amongst other populations. It is also likely that mean scores and the distribution of data may vary in other groups. Indeed, the EFA data from those recruited via Prolific Academic indicated this may be so and that the sample used in the current study may be likely to experience greater levels of distress. This may have impacted upon the distribution of data and whilst a Bootstrapping procedure was utilized, issues with the distribution of some items may have impacted the analysis.

The sample used was unequal in that it was constituted primarily of females and included relatively few males. The question of how to effectively engage males in research connected to visible difference may be an interesting channel to explore in future work. Furthermore, it was relatively small in terms of sample size.

12.7.2. Conclusion

The factor structure of CARRIS and its potential utility have been further evidenced by this CFA. This CFA supports the utility of using CARRIS as a research tool for measuring appearance related romantic distress amongst those with visible differences. Furthermore, and whilst acknowledging the issue connected to the removal of one item, it supports and confirms the factor structure revealed by the prior EFA. Such support comes from a new data-set and includes an assessment of test-retest reliability over a four-week period.

Having concluded the final empirical study presented within this thesis, the final chapter will go on to consider the implications of the programme of research that has been presented.

13. Thesis Summary and Discussion

13.1. Thesis aims

The aims of this thesis were to explore the literature describing the intersection of visible difference and romantic relationships. Having identified this topic as being under researched and reliant on a disparate collection of condition specific studies, this thesis aimed to show an understanding of the perceived impact of visible difference upon the romantic and intimate experiences of those with visible differences. This understanding was then utilised in the development and validation of a scale designed to record, measure, and quantify such impact.

Due to the disparate nature of the literature a traditional literature search was performed, and I monitored subsequent publications during the completion of the thesis. No previous research had specifically examined visible difference and romantic relationships in adults. The literature was drawn from a range of appearance altering condition specific studies, or those examining a group of related studies. These were rarely focussed explicitly on intimacy and romantic relationships. Instead, these topics were commonly referred to or discussed as part of a broader sphere of investigation. The literature search thus indicated the need for dedicated exploratory research focussing specifically on visible difference and romantic relationships in adults. It was therefore appropriate to conduct a detailed and thorough investigation, and the qualitative study was performed in response to this need.

The findings from the qualitative phase indicated that a number of participants were experiencing or had experienced romantic difficulties and associated these with their visible difference. As there existed no comprehensive research measure or scale pertinent to this domain, the development of a measurement tool based heavily upon the qualitative findings was considered to represent a logical progression from the exploratory work. Having developed the items, the likelihood of the scale being multi-dimensional indicated EFA as an appropriate method to derive the factor structure and through which to select appropriate items and produce a parsimonious tool. The next step was then to confirm the factor structure and model fit, in fresh data, via a CFA thus comprising the initial stages of validating the resultant scale. This mixed-methods approach was considered consistent with the overarching epistemological paradigm for this thesis, that of Pragmatism (Morgan, 2007, 2014).

13.2. Contributions to knowledge

This thesis represents original research that has led to the creation and interpretation of new knowledge. It has also provided an original contribution to knowledge. The qualitative work is the first dedicated study of the topic in adults and has highlighted that the impact on romantic relationships is a fundamental aspect of the experience of living with a visible difference. Whilst Griffiths et al. (2012) had investigated the romantic experiences of adolescents with a visible difference, their data was collected on-line and in a written form. Consequently it may have lacked some of the depth of the present research. This thesis elaborates upon and extends their findings, re-specifying them within the context of its adult participants.

The indication that participants felt the healthcare profession had not offered appropriate support in connection with the psycho-social and emotional impact of the invisible difference, and specifically with regards to their intimate, romantic relationships, was also notable. This is considered further below but may take on particular importance when combined with the findings from the EFA, that participants who were receiving treatment in connection with their difference reported higher levels of distress within the romantic domain via the CARRIS items. This is consistent with work concerned with the Italian (Sampogna et al., 2007) and Netherlands (Verschuren et al., 2013) healthcare contexts, and indicates a dedicated study of this topic within the UK may be beneficial.

Furthermore, as advocated by Egan et al. (2011) the possibility of positive experiences and adjustment was also explored, and the findings indicate ways in which participants believe their difference to have exerted a beneficial impact upon their romantic life. In addition to offering unique findings, the research therefore contributes to the literature discussing the potential positive side of living with a visible difference. This has been further evidenced via the publication of the results of the qualitative study in *Body Image*, (Sharratt et al., 2018) (Appendix F) as the first focussed exploration of visible difference and romantic relationships amongst adult participants. My belief is that the rigour, care, and attention that went into collecting and analysing the data dictates that the findings be considered well grounded, enlightening, and reflective of the experiences of the participants.

The development and validation of CARRIS represents the first research tool relevant to the sphere of visible difference and romantic relationships. Whilst there is some evidence that DAS24 may be comprised of two factors with the second, six item factor being labelled sexual and body self-consciousness (Moss et al., 2015), this finding has been questioned empirically (Merz et al., 2018) and only two items within the scale focussed on the romantic/sexual domain (covering an adverse effect on sex life and distress at undressing with a partner). The remaining four are concerned with other contexts and concerns (the beach, communal changing rooms, sports/games, and clothing limitations). CARRIS therefore represents an original and novel research tool.

The process of developing and validating CARRIS built upon the qualitative findings and provides insight into the components of and main challenges associated with appearance distress within a romantic context. The factor structure of CARRIS was elucidated by the EFA and confirmed during the CFA, indicating the reliability of the original findings. Whilst it cannot conclusively be claimed that all important challenges and domains are represented within CARRIS or, indeed, were caught within the original long list of items at the EFA stage, the items were developed from the high-quality qualitative study and with input from experienced academics and from a leading research active clinician. It is therefore argued that CARRIS represents an appropriate, adequate, functional, and parsimonious tool.

This claim is supported by the measures of convergent and discriminant validity demonstrated as part of the EFA, the internal reliability of CARRIS (EFA and CFA), and the test-retest reliability (CFA). Whilst validating a measure is an ongoing undertaking and further research would be beneficial, this thesis has established CARRIS and performed the initial validation of the measure, signalling its worth and potential to become a useful research measure offering researchers an opportunity to study an historically neglected domain.

Whilst the indicative findings generated in the performance of the EFA and CFA must be interpreted cautiously, they do suggest at some group differences in appearance distress within a romantic context. This represents a further contribution of this thesis, albeit one that may require further exploration. The visibility of a difference was not associated with any significant differences at either EFA or CFA. Similarly, and contrary to the beliefs of participants in the qualitative study, there was no correlation between age and CARRIS scores. At the EFA stage there was some indication that the nature of a visible difference and, to a lesser extent, its location may be factors relevant to participants' romantic experiences. There was also evidence that those with alopecia, dermatological conditions, and multiple visible differences may experience greater distress than those with other conditions and having a difference that impacts one's limbs and head/face was also associated with greater distress.

Despite their tentative nature, the findings indicate that in some contexts the physical manifestation of visible difference may be important in ascertaining likely levels of distress. Such findings are not unprecedented. Amongst those with normally visible conditions Moss (2005) identified a relationship between objective severity of visible difference and distress and the ARC Framework (Clarke et al., 2014) posits that visibility of one's difference an important factor contributing to adjustment. Whilst the EFA data cannot explain why these findings emerged, comments from a small number of participants in the qualitative study may provide provisional explanations that could be further explored in later research. The potential impact of alopecia upon women's sense of femininity and the relevance of hair to intimate and physical attraction and cultural perceptions of what is beautiful, may be relevant to the distress evidenced by those with alopecia. Similarly, the potential for dermatological conditions to fluctuate and be somewhat unpredictable, possibly making it difficult to predict with any long-term certainty the reactions of others (as alluded to within the qualitative study and by Moss (2005), the reported connection with experiences of disgust, and the incompatibility of this emotion with romantic and physical intimacy may account for the distress experienced by those with such conditions.

The small effects of treatment status and sex evident at EFA were not replicated during the CFA but similarities in the trends within the raw data were observed. This thesis therefore highlights the possibility of these characteristics being pertinent and warranting further investigation. It may be interesting to investigate patients' motivations for treatment and to consider whether appearance concerns and specifically appearance distress within a romantic context, may act as a motivation for individuals to seek treatment. At both EFA and CFA, relationship status was a significant factor and both data-sets evidenced that those who were single experienced significantly greater distress than others. This was consistent with the testimonies of the participants in the qualitative study and the fact that some of the items in CARRIS focus upon the early stages of relationships.

Finally, it is hoped that this thesis and the work that underpins it has, to some small extent, helped raise the profile of the issue of visible difference and romantic relationships. The dissemination activities undertaken (detailed below) may have contributed to a growing awareness and willingness to discuss the topic. This growing willingness is evident in the on-line environment with a number of recent blogs, articles and personal accounts addressing the area. Whilst it is certainly not argued that this thesis has contributed to their existence, it is hoped that it has helped mirror this openness within a small section of the academic and clinical community.

13.3. Implications for research / future research

With visible difference and romantic relationships having been further established as a legitimate topic of research interest, this thesis carries a number of implications for future work. The ongoing nature of scale validation dictates that further work to validate CARRIS would be beneficial. This should include research focussing on its ability to detect change and would require a longitudinal study in which CARRIS was paired with other relevant measures, previously demonstrated to detect change, with its ability to do likewise assessed. Of course, identifying those other change sensitive relevant measures would be of fundamental importance. Additionally, CARRIS' predictive validity could be assessed via the assessment of the extent to which it predicts participants' satisfaction with their relationship status and/or existing romantic relationships. Again, this would require that an appropriate measure of such satisfaction be identified.

Moving from validation towards utilising CARRIS to further improve our understanding of visible difference and romantic relationships and to examine the scores of research participants attributable to each of the three factors that comprise CARRIS. Whilst validation is an ongoing process and the sensitivity of CARRIS to change over time should be established, the measure may be used with some confidence to establish levels of appearance distress within a romantic context, and to apportion that distress amongst and between the three factors contained within CARRIS. This can provide more definitive and comprehensive evidence of the nature of romantic distress, and the use of larger and more representative sample sizes may be considered a priority. The CFA was conducted using a sample size of 146 and test-retest reliability relied on 47 participants. Whilst this was sufficient to examine the factor structure of CARRIS, a larger sample and larger sub-samples would be necessary in order to comment more conclusively on the nature of appearance distress within this context and on any group differences that may exist.

As alluded to above, the group differences that this thesis has highlighted could be reconfirmed in research aimed specifically at examining characteristics that may be relevant to experiences and levels of appearance distress in a romantic context. The indicative findings portions of this thesis have indicated characteristics that should be included in any such analysis (including sex, relationship status, treatment status, and the nature and location of one's difference). Further analysis in this area could be more dedicated and the relationships between, and relative weight or importance of, these factors examined. Similarly, the scoring profiles of those whose demographic details and visible differences vary in these ways may be examined so that any difference in the scores attributable to each of the three factors can be explored. This may help tailor and target additional research and, eventually, interventions towards those that would most benefit from the performance of such research and the delivery of such interventions.

Additionally, the parsimonious nature of the scale means that it could be used in research that is not focussed specifically upon the romantic sphere, for example in any future studies that seek to extend or replicate the ARC study findings (Clarke et al., 2014). Using CARRIS in such work would enable the romantic domain to be included in any extension of or revision to the ARC framework with more specificity than was possible prior to the development of CARRIS. This is an important outcome as funding for visible difference research can be limited and so the availability of a short, useable scale that can help in model or theory development has the potential to contribute to the field of study. It is also my hope that its inclusion would serve to acknowledge this as an important area of study, to researchers and participants alike.

CARRIS may also be used to compare the experiences of those with visible differences to those without. Whilst the items were generated with a focus upon the visible difference population, they refer to 'appearance' rather than visible difference. CARRIS could therefore be validated in a more general population and comparisons made between participants' total CARRIS score and their score in respect of each factor. Research suggests that those with negative body image may experience higher levels of sexual avoidance (La Rocque & Cioe, 2011) and self-monitoring or fixation on bodily parts during sexual activity, *spectatoring* (Masters & Johnson, 1970; Woertman & Van den Brink, 2012) and so use of CARRIS in this way may help facilitate an investigation into areas of overlap and difference between those with visible difference, those with a more negative body image, and those with neither. This would also help confirm more globally whether and to what extent overall differences may exist between those with and without visible differences and provide population norm data.

The work contained in this thesis suggests other avenues of more exploratory research that could be followed. For example, the 'Disclosure Dilemma' sub-theme relates to a scenario that may also be relevant to contexts and relationships outside of the romantic sphere, which has not been investigated within the visible difference literature. The exploration of these topics also indicates that dedicated materials and support resources may be helpful to some individuals who have a visible difference and experience appearance distress within a romantic context. Investigating how this support may be provided, what resources may be beneficial, and ultimately developing and evaluating such materials must be considered a legitimate research goal and would be beneficial to those with visible differences, and those operating in the field, clinicians, charities and support-groups alike.

The examination of attachment theory provided in the introduction and the availability of CARRIS to measure appearance anxiety within a romantic context also points towards further work considering the role of adult attachment in visible difference and romantic relationships.

The potential for salient experiences of visible difference and romantic relationships to function as stressors that encourage the demonstration of prototypic attachment behaviours (Simpson & Rholes, 2012, 2017) would represent a valuable contribution to knowledge. It would also be enlightening for a relationship between attachment profiles and CARRIS scores, both overall and on each of the sub-factors. Recent work by Shaw, Sherman, Fitness, Elder, & The Australian Breast Cancer Network (2018) found that amongst women with breast cancer, un-partnered women had higher levels of dating anxiety and anxious attachment.

Another area that may justify further exploration is the impact of an acquired visible difference upon existing intimate relationships. The testimony of several participants alluded to the potential for changes in appearance to impact upon physical intimacy within an established relationship beyond the period during which a lack of sexual contact was ascribed to treatment and ill health. What was particularly arresting was the suggestion that this issue was sometimes not discussed within that relationship. Understanding more about these experiences, how such changes are incorporated into a partnership, and, possibly, what support or communication could prove beneficial, would represent interesting and useful future work, and carry implications for research, clinical practice, and relevant support organisations.

More broadly, this thesis highlights the multifactorial nature of adjustment to visible difference and signifies that any attempt to theorise and model the psychology of visible difference should incorporate romantic and intimate life. It therefore offers support to such theories or models that include the potential for this emphasis. For example, the ARC Framework (Clarke et al., 2014) includes intimacy as an outcome in its working framework of adjustment and represents a good candidate for further development and one that may guide future research (Thompson, 2012) and intervention development (Clarke et al., 2014). This framework also has the potential to inform, and perhaps evolve into, the integrated theory of adjustment to visible difference that Kent (2000) has called for.

The research contained in this thesis generally supports the contention that the characteristics of an individual and/or their visible difference are not critical to their adjustment to their difference. It is possible, however, that the focus upon visible difference rather than a particular condition or group of related conditions, might have deprived the work of nuance specific to people’s experiences of certain visible differences. There were benefits in taking this approach. The findings are of broader applicability and transferability and CARRIS may be capable of use with a greater number of individuals than if the focus were upon only one condition.

As discussed in the first chapter of this thesis, this approach finds support from research indicating much similarity of experience and few differences in adjustment to visible difference between those with different conditions. There exists, however, the potential for those with different conditions to have divergent experiences and further work could be dedicated to exploring condition specific experiences and refining CARRIS for use with particular conditions if this appears necessary. Naturally, this would require greater levels of resourcing and may result in some conditions receiving more attention than others, dependent upon the availability of funding. The utility of working across conditions within this PhD is therefore something that I consider to be important, especially for a topic, such as visible difference and romantic relationships, which is very much in its infancy. That is not to deny the value of refocussing upon specific conditions within subsequent research.

The between-group differences that have been indicated in this thesis, including those related to the gender of participants, their relationship status, and certain characteristics of their visible difference will, if confirmed in subsequent work, mean that it will be incumbent upon those developing such theory to examine and allow for situationally contextualised between-group differences. It will be crucial to identify what factors are important, and which are not, within each domain and each area of adjustment. This research, conducted in developing CARRIS, has begun to do so in respect of the romantic sphere.

This work also emphasises that there is a need to consider the variability of adjustment to visible difference. Such variability subsists across and between individuals but may also be evident across different domains of one individual’s life. That some participants in the qualitative study described their intimate and romantic lives as being the most difficult and most impacted sphere of their life demonstrates that adjustment cannot be considered to be a singular phenomenon. The theory of visible difference must explore and account for a variety of domains in which appearance may be relevant and impactful, intimate and romantic relationships represent one such realm.

13.4. Implications for clinical practice

Though this was not the primary focus of this thesis, the applicability of this research programme to clinical practice and to the work of lay-led support organisations was never far from the surface. The experiences detailed within the qualitative study indicate that, in respect of visible difference more broadly and specifically within the field of intimacy and romantic challenges, interactions with healthcare professionals had been experienced as unsatisfying, that dedicated support was often not received, and that participants expressed a preference for peer-to-peer or expert patient led support groups. This preference was connected to the understanding that only those with lived experience can fully understand and empathise with the impact of visible difference.

The research demonstrates that intimacy and romantic relationships are of concern to some individuals with visible difference and that members of the healthcare profession may sometimes fail to acknowledge and assist with these difficulties. Indeed, participants communicated that appearance concern broadly (Sharratt et al., 2019) and romantic concern more specifically, were not met responsively. Whilst some of the experiences documented may have occurred some years prior, is important that the healthcare profession ensures such concerns are addressed sensitively and responsibly and that patients feel able to communicate openly with their carers about such topics. The testimony of some participants, specifically that had experience of treatment for cancer and sought care for alopecia, along with the personal experiences included within existing literature highlight the prominence that such concern may assume to some patients, Tindle et al. (2009) being a prime example. Healthcare professionals must appreciate that such concern may subsist alongside concerns related to patients' health status and survivorship and should not assume that these health concerns are more (or less) important than those connected to appearance within any given patient's framework of values or self-concept.

The indication that participants' experiences differed from this desired state may be considered especially problematic given that the EFA data demonstrated that those who were currently receiving treatment from the healthcare profession in respect of their visible difference experienced greater distress than those who were not. It is my hope that the published qualitative study (Sharratt et al., 2018) together with the (non-empirical) contributions I have made to the Journal Of Aesthetic Medicine (Sharratt, 2015, 2017) can help raise awareness amongst healthcare professionals and highlight the broad range of experiences an adjustment that may subsist amongst their patients.

I have developed an awareness session that incorporates my findings and references the Ex-PLISSIT model (Davis & Taylor, 2006; Taylor & Davis, 2006) and delivered this to a good reception from a broad range of healthcare professionals and trainee healthcare professionals as part of a training school for the COST Action European Cleft and Craniofacial Initiative for Equality in Care. I was also privileged for CAR to be provided with the following (now anonymised) feedback from a healthcare professional after I had presented the qualitative findings at the Appearance Matters conference:

> *I was particularly inspired by Nicks Sharratt's session. It really got me thinking as the ladies we see with [condition] have negative body image (focused on not feeling*

> *feminine & wanting to cover up) as well as [description of physical manifestation] but we don't tend to ask about intimacy or functionality. I am googling the topic at the moment.... We certainly at the very least need to be giving people permission to talk about it which after today I have really realised we are not doing- if anything we are making it as tricky as possible (there is usually 2 members of the clinical team in each consultation so people aren't going to find it easy to bring up).*

This highlighted the potential impact of this research. Whilst further research centred on the patient-healthcare professional interaction is warranted, the possibility of some practical changes flowing from the work conducted to date is apparent.

Notwithstanding this need for further research, the feasibility of using CARRIS as a tool to open up the potentially difficult discussion (for both parties (Verschuren et al., 2013)) between healthcare professionals and those they provide care to would represent a potentially valuable application of CARRIS. The inclusion of CARRIS within a standard set of questionnaires used by clinical teams could act to highlight that patients' romantic experiences are legitimate topics of conversations and help turn the minds of healthcare professionals and patients to the topic. For some patients, naturally, this may prove unnecessary but for some others it may be of benefit. The qualitative findings indicated that this would have been considered beneficial to some of the participants and so CARRIs may have potential as a 'conversation starter,' with any indication of distress being used as a springboard for healthcare professionals to enquire further, understand the patient's experience, and strive towards the provision of holistic, patient-centred care. This could help ensure that all patients are given the explicit opportunity to discuss this facet of their lives.

CARRIS is parsimonious, with the CFA participants spending on average approximately 10 minutes within the Qualtrics site. This suggests that CARRIS can be completed quickly and may be incorporated into a clinical or health assessment with minimum disruption. The potential for CARRIS to therefore be combined with a stepped care model and/or used to initiate discussion and help establish the explicit permission that the Ex-PLISSIT model (Davis & Taylor, 2006; Taylor & Davis, 2006, 2007) requires, together with the development, acceptability, and efficacy of providing training for healthcare professionals connected to this topic, should be explored.

Further research could also be conducted in order to examine whether CARRIS may be used clinically to provide an initial indication of distress. Once again, the three factor structure may indicate the nature of such distress and suggest which patients may benefit from more focussed, or more specific care in connection with their romantic lives. This would also be compatible with the use of the Ex-PLISSIT model (Davis & Taylor, 2006; Taylor & Davis, 2006, 2007), suggesting those who would benefit from more individualised care. The utility and efficacy of CARRIS as a screening tool and/or a measure of clinical distress would, however, require the performance of further research focussed specifically upon the clinical application of the tool.

Future research within the healthcare professions should aim to ensure that a broad spectrum of healthcare professionals that have contact with those with a visible difference are equipped to deal with romantic concern as dedicated psychological support for visible difference requires extensive resources and may not always be readily. Access to this care may depend, to some extent, upon the nature of the visible difference. For example, psychological support is now embedded within the multidisciplinary care that NHS Cleft Lip and Palate services provide to children and young people and may feature relatively prominently within services providing care for Burns and Cancer. The extent to which these services address patients' needs related to their intimate, romantic life is, however, a subject that could be addressed in future work.

Patients presenting with other conditions may be less likely to receive psychological support and the extent to which appearance concerns are addressed may vary from service to service or clinician to clinician. Any such inconsistencies in the level of support that is provided should be considered against the existing research (and the broadly consistent indicative findings presented at EFA and CFA in this thesis) suggesting adjustment and appearance distress are not necessarily associated with the nature of a condition or its severity, visibility, or location nor the age or gender of the presenting patient. Similarly, whilst a dedicated service named 'Outlook' has been established in Bristol to provide psychological support to those with visible difference, it remains unique within the UK and elsewhere and, of course, has finite resources.

In light of such considerations and the desire expressed by participants for peer and expert-patient support, it may be that a model should be considered in which healthcare professionals (including psychologists) could facilitate the care that participants preferred by guiding and supporting peer-to-peer and expert patient led group sessions. Furthermore, the adoption of such a model suggests that the healthcare profession and the support groups and charities that operate within the field, whose members have (or have an interest in) an appearance altering condition, could collaborate towards the provision of patient-centred and patient-requested care. Alternatively, on-line, mobile and other less resource intensive interventions may represent an efficient and feasible mode of delivery with regards to those experiencing less severe levels of distress. More intensive, expensive, one-on-one sessions may then be provided to those in the most need.

13.5. Strengths and limitations of the thesis

13.5.1. Strengths

The work that constitutes this thesis has a number of considerable strengths but is also subject to a number of limitations. Dealing first with the strengths of this work, the research conducted was novel and represented the first dedicated exploration of these issues in adults with visible differences. The comments of some participants, that their interview represented the first opportunity they had been afforded to really discuss their thoughts and experiences and that they had not previously had such conversations with friends, family, or partners reinforced the importance of the topic and the need for the research world to contribute to further understanding in this field.

The qualitative, exploratory work generated rich data and was conducted in a rigorous manner to a high standard. The analysis of the data was conducted with sensitivity and with a desire for the findings to be firmly grounded in the accounts of participants. They have now been published in a leading journal within the field confirming that this research programme has produced novel, insightful findings that have made a contribution to the literature. Furthermore, subsequent conversations with and contact with other individuals who have a visible difference, both on social media and in person, have provided informal feedback mechanisms which have acted to further verify the veracity of the findings.

The qualitative work was influential in the development of CARRIS and CARRIS' items. This meant that not only were the scale items informed by the experiences of those with visible differences but also that the adoption of a mixed methods approach and a pragmatic epistemology were both appropriate. The involvement of the supervisory team and their availability to comment on the draft CARRIS items and contribute to the analysis of the qualitative data also represents a strength of this work. Such involvement means that that qualitative analysis and the final version of CARRIS both benefited from their considerable knowledge and experience and helped ensure that the decisions and the interpretations of the author were considered and justifiable.

The collection and use of two different data-sets in the performance of the EFA and CFA also represents a major strength of this thesis. The use of 'fresh' data at the CFA stage is considered highly desirable and preferable to using the same data upon which the EFA was performed. The outcomes of the EFA made conceptual sense and the CFA provided reassurance that the factor structure was appropriate, although one item was deleted at that stage. Consequently, a new research measure exists, can be further validated, and used in future research projects. The future potential for CARRIS to be used to facilitate a discussion within a clinical setting highlights that this thesis has improved the appearance psychology community's knowledge and understanding of visible difference and romantic relationships in a practical way, providing a scale with which to measure appearance distress within a romantic context for research purposes, and presenting an opportunity for the integration of this topic into clinical discussions. The thesis has thus provided understanding, a research tool, and carries the potential for practical application. These multiple outcomes are a real strength of the work.

13.5.2. Limitations

The limitations of this work must also, of course, be recognised. Whilst these have been addressed in respect of the individual studies, some of the major limitations are rehearsed here. Both the qualitative study and the CFA drew participants almost exclusively from the adverts and communications of CAR and support groups and charities operating within the field. The EFA data suggested that this population experienced greater distress (measured by CARRIS) than those recruited via Prolific Academic. Whilst the factor structures of participants recruited through these sources were similar at EFA, the scoring profiles were different. This may indicate that the participants recruited in this manner and who have an interest in and connection to such organisations and groups are a distinct population. This raises some questions over the extent of the representativeness and transferability of the findings.

The studies comprising this thesis attracted only a relatively small proportion of men as participants. The qualitative work included interviews with six men (22 interviews in total), for the EFA there were 77/253 men and the CFA 20/143. Whilst these levels of representation may not be unique to this thesis, they do indicate that the research studies did not result in high levels of engagement amongst men. Similarly, the research lacked representation from BAME populations with over 90% of participants in the EFA (91%) and CFA (93%) participants being White. ONS (2012) indicated that 86% of English and Welsh census respondents were White. Similarly, all participants in the qualitative study were heterosexual, as were the majority at EFA (91%) and CFA (88%). ONS (2019) estimates 93% of the UK to be heterosexual. These discrepancies were not large or, in the case of sexuality at EFA and CFA, not evident (at least when considering the proportion of participants that were white/heterosexual and those that were not which, admittedly, is a rather crude measure of ethnicity/sexuality and does not represent the full spectrum and diversity of ethnicity/sexuality). It is still important to acknowledge that the research reflects primarily white, heterosexual experiences and that, to varying degrees, the views of men, those with BAME identities, and those of LGBTQ+ sexualities are under-represented in this thesis.

It is in response to concerns such as the nature, size, and composition of the sample, that the indicative findings must be interpreted with caution and that a relatively simple analysis strategy was chosen. Participants were grouped by individual demographic characteristics and the indicative findings each present insight into only once characteristic, considered in isolation. Whilst the goal of the thesis was to develop a measurement scale, with the incidental findings being presented to provide only an initial indication of group differences, the results do not allow for the intersection or combined contribution of multiple characteristics upon appearance concern within a romantic context. In addition to being somewhat ancillary to the development of CARRIS the sample sizes collected precluded a more meaningful examination of the data in this respect. For example, the predominance of women within the sample (at both the EFA and CFA stage) dictated that no meaningful comparison would have been possible between women and men with a certain condition or with a difference affecting a certain area (or certain areas) of the body.

The result is that the indicative findings at both stages may also be considered somewhat reductionist in nature, with only individual, simple personal and demographic characteristics informing each analysis. Messages centred upon these indicative findings should contain appropriate caveats and efforts to avoid presenting them as universal ‘truths’ should be made whenever I may refer to them. The current analysis does not determine whether one effect was driven by another. For this reason, and still being careful to avoid reductionist claims, further dedicated studies exploring these findings more purposively would be beneficial. For example, regression analyses designed to control for the effect of variables that this thesis has indicated as important could be performed in order to isolate the contribution of the respective demographic and personal variables and explore them in a more robust manner. In light of the number of factors that this work has indicated may be of relevance, this would require larger sample sizes and a more purposive and targeted recruitment strategy that dedicated much time and effort to engaging with harder to reach, under-represented, and minority groups. Such research is required before the existence of consistent and reliable group differences may be demonstrated and claimed with more confidence.

Whilst a thorough literature search and qualitative study were conducted, it is not possible to claim that all relevant and pertinent items and domains were included within the long form version of CARRIS, used at EFA. There may, therefore, be domains of activity and concern that are not included within CARRIS. It is possible that this limitation could have been mitigated by a greater emphasis on patient and public involvement (PPI) in the research. The CARRIS items were derived from the initial qualitative work, during which I provided those participants with the opportunity to comment on the analysis; expert input was sought and participants at the EFA stage were asked to provide comments on the items. It would have been desirable, however, to increase the level of PPI in the overall research programme, for example through the incorporation of an expert-participant or panel in the planning, interpretation, and reporting phases. This is an issue that I have become increasingly aware of during the research programme and it is my intention to place further weight on this aspect in future research, where appropriate.

A further limitation is that this thesis has not sought any comparative data and so cannot provide any indication of how the level of appearance distress experienced in a romantic context by those with visible difference may compare to a population without visible difference. Whilst the ARC Study (Clarke et al., 2014) has provided preliminary evidence that those with a visible difference may experience greater distress, this comparison requires further research and could be incorporated into a study that investigates the validity of CARRIS amongst a non-visible difference population.

As discussed within the introduction, this thesis does not focus on nor fully capture the experience of functional impairment. Some of those with visible difference will experience functional impairment and this does carry the potential to impact upon their romantic lives. Neither the qualitative study nor CARRIS fully explores this issue. Whilst the thesis was centred upon visible difference and not all visible differences are associated with functional impairment, this represents a limitation as and where relevant. Of course, future research could explore this intersection in more detail, focus on and emphasise the experiences of those with visible difference and functional impairment, and examine the applicability of CARRIS for those with functional impairments. Modifications or revised versions of CARRIS that address functionality alongside appearance concern may be valuable extensions of this work.

As briefly alluded to, this thesis is also limited in that it does not offer a focus on the experiences of marginalised groups, such as those within BAME groups and the lesbian, gay, bisexual, transgender, queer, or questioning LGBTQ+ communities. Within such communities and, indeed, within other marginalised and minority communities, appearance, visible difference, and romantic relationships may have different meanings and operate in different ways. Such participants were not actively excluded from this research and (based on the demographic information provided) a small number of participants were drawn from some of these communities, though concentrated effort was not made to engage and involve these communities. Future research should address this issue and explore these issues and the applicability of CARRIS within more tightly defined groups.

Finally, this thesis does not answer to the call of Kent (2000) for an integrated theory of visible difference. A call that could only be fully answered were connected issues, such as functional impairment, are fully captured and theorised. Whilst it may support the claim that such theory is required and add some weight to assertions regarding the utility of the ARC framework (Clarke et al., 2014), it does not provide that integrated theory. Future research should aim to meet the challenge of harnessing theoretical current understandings before driving the area forward in a unified way.

13.6. Personal reflection

The process of performing and writing up the research that contributes to this thesis invites a level of self-reflection and I feel it would be remiss to fail to include some here. As part of doing so I would re-iterate my gratitude to all those who participated in the studies, who gave of their time and experience, all those who helped advertise and promote the studies, and all those who have helped me in this endeavour.

Precisely because of the generosity of those mentioned above, because I have been embedded in a supportive research centre and benefitted from the guidance offered by colleagues and supervisors, and as an invited member of an EU COST programme, I have been fortunate enough to be in a position to disseminate this work and connected issues in a variety of ways. This includes presenting some of what I have learnt and found in peer reviewed literature, awareness articles in a nursing journal, at national and international academic conferences, at European project meetings, conferences and training sessions, via electronic means (contributing to a 'personal experience article' and Appearance Matters the Podcast), and at several conferences run by charities and organisations that operate within the field. I have enjoyed such opportunities and the work has been well received, by clinicians, researchers, and members of the public alike.

Despite this reception, and the encouragement and support of my colleagues, supervisors, and contacts within the field, I have found the completion of this thesis, specifically writing it up, more challenging than I anticipated. I intend to learn from this experience and use it to help me empathise and support those who may be in a similar position in the future. It has also ensured that I fully appreciate and value those that have done likewise for me.

13.7. Thesis short summary

This mixed-methods thesis has focussed upon the important, potentially challenging, but previously neglected area of visible difference and romantic relationships. In addition to exploring the romantic experiences of twenty-two participants with a variety of visible differences and considering the research, theoretical and clinical implications of participants' accounts, this thesis has led to the development of a novel research scale, CARRIS. The development of CARRIS was grounded in the qualitative data and analysis generated in the exploratory study. CARRIS may be used to assess appearance distress experienced within the context of romantic relationships by those who have a visible difference and suggests three primary areas of concern. These are sexual self-consciousness, negative evaluation, and accessing and benefitting partner support and empathy. An EFA and a subsequent CFA, conducted upon independent data, suggest CARRIS to be a reliable and valid measure. Those quantitative studies also indicate group differences that may be further explored in subsequent research, as may the clinical utility of CARRIS. It is hoped that this thesis has begun to open up the intersection of visible difference and romantic relationships as an important area of focus for subsequent research and that it demonstrates this is a topic deserving of the attention of clinicians and healthcare professionals.

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