Griffiths, C., Williamson, H. and Rumsey, N. (2012) The romantic experiences of adolescents with a visible difference: Exploring concerns, protective factors and support needs. Journal of Health Psychology, 17 (7). pp. 1053-1064

Competing interests: None declared.

Address: Correspondence should be directed to:

Catrin Griffiths, Centre for Appearance Research, University of the West of England, Bristol, UK. **(Email:** catrin.griffiths@uwe.ac.uk**, Tel**:+44 (0)117 32 83947**)**

Abstract (100 words)

Injuries or conditions that affect appearance can increase adolescents’ risk of psychosocial and interpersonal difficulties and may also impact on romantic relationships - an important aspect of adolescent development. A mixed method online approach explored the romantic experiences of 40 adolescents with a variety of visible differences. Young people identified appearance-related romantic concerns that cause distress, and impede the development and enjoyment of romantic relations. In contrast, some shared positive experiences and evidence of attitudes and behaviours that appear to protect against these concerns. Adolescents requested online peer support specific to their appearance-related needs. These findings can inform intervention development.

Key words:

Adolescents, romantic relationships, visible difference, disfigurement, qualitative

Introduction

Whether between mixed or same sexed individuals, romantic relationships are characterised by affectionate behaviours, a distinct intensity and anticipated or current sexual behaviour (Collins, Welsh & Furman, 2009). Healthy romantic relations are considered to be one of the most important developmental experiences during adolescence in that they promote peer relationships, are a source of emotional support, improve self esteem, interpersonal skills, they help develop self identity and the ability to establish stable and committed relationships in adulthood (Sorenson, 2007).

Appearance becomes increasingly salient during adolescence. Physical changes combined with cultural pressures to conform to beauty ‘ideals’, often result in teenagers becoming disproportionately preoccupied with their own and others’ appearance (Brown & Witherspoon, 2002). Possibly as a result, a disparity in opportunities to develop romantic relations has been observed between those judged to be more attractive compared with those considered to be less so. A meta-analysis of 30 attractiveness stereotyping studies revealed that less physically attractive people (measured by judges using rating scales and self reported measures) reported fewer sexual experiences and were less popular with the opposite sex than those more physically attractive (Feingold, 1992).

Adolescents with an appearance that differs to societal expectations of beauty because of a congenital or an acquired visible difference (disfigurement) may therefore be disadvantaged when it comes to dating (Rumsey & Harcourt, 2005). Congenital disfigurements are either evident from birth (e.g. a cleft lip), or become more noticeable over time (e.g. neurofibromatosis). Acquired disfigurements can be caused by trauma (e.g. burns injuries), result from genetic predispositions that develop later in life (e.g. vitiligo; a skin disorder in which white patches appear on the skin), a disease process that alters appearance directly (e.g. dermatological conditions) or indirectly through surgical or medical treatment (Rumsey & Harcourt, 2005).

These young people may be further disadvantaged by psychosocial difficulties associated with experiencing appearance dissatisfaction (Dalgard, Gieler, Holm, Bjertness, & Hauser, 2008) and the stigma associated with looking different to their peers. Compared to the general population, those with a variety of visible differences have been found more likely to encounter discrimination, unsolicited and often negative attention from other people (Bull & Rumsey, 1988). Appearance-related teasing and bullying can cause considerable distress for young people (Lovegrove & Rumsey, 2005), increasing the risk of low self esteem, low self-confidence and negative self-appraisals (Magin, Pond, Smith, Watson & Goode, 2008; Turner, Thomas, Dowell, Rumsey & Sandy, 1997). Fear of negative evaluation and social anxiety can result in social avoidance and interpersonal difficulties which may impede the development of social skills and lead to isolation from peers (Chamlin, 2006; Tan, 2004).

Dissatisfaction with appearance also underpins a variety of negative health-related behaviours; for example some adolescents with weight concerns use smoking and diet pills and laxatives in order to lose weight (Amos & Bostock, 2007; Neumark-Sztainer, Wall, Eisenberg, Story & Hannan, 2006). For others, appearance dissatisfaction can influence health treatment decision making and adherence to medication (Rumsey, 2008). For example, in a variety of conditions (including cancer and organ transplantation), some young people resist medical treatments that have cosmetic side effects in order to preserve their appearance; even though this might be detrimental to their health (e.g. chemotherapy can result in hair loss and anti-rejection drugs prescribed for organ transplant recipients can result in unwanted facial and bodily hair) (Dolgin, Katz, Doctors & Siegel, 1986; Friedman, et al, 1986). Health Psychologists therefore have a vital role to play in developing and providing psychological support for young people with appearance concerns.

However not all young people with visible differences experience difficulties (Locker, Jakovic & Tompson, 2005). For example, some report similar and sometimes higher levels of self esteem compared to their non-affected peers (Walters, 1997). In contrast to the expectations of many, research shows that adjustment to a disfigurement relates to individual psychological characteristics such as subjective ratings of the severity of the visible difference, subjective appraisal of situations and appearance related cognitive processes, rather than the objective severity, cause or location of the difference (Appearance Research Collaboration (ARC), in submission 2011; Moss, 2005). Differences in patterns of psycho-social responses to a visible difference are therefore more influential in determining adjustment than the type of condition. Recent studies have identified attributes and behaviours in those who cope well which may aid adjustment (Egan, Harcourt, Rumsey & ARC, 2011). For example in Egan, et al’s (2011) interview study, adults who were positively adjusted to their difference placed more importance on attributes other than appearance (e.g. personality) and did not regard their difference as the cause of any difficulties they experienced. They made downward comparisons to others, appreciated social support provided by family, friends and romantic partners and particularly benefited from talking to people who had similar experiences.

Few studies have focused specifically on the impact of having a visible difference on the development of romantic relationships during adolescence. However the indications are that having a visible difference may be an additional concern during an already challenging life stage and may impede the development and enjoyment of romantic relations.

Interviews with teenagers with epidermolysis bullosa simplex (a group of genetic disorders which cause the skin to be fragile and blister easily) indicated that some participants felt their difference was inhibiting the formation of romantic relationships (Williams, Gannon & Soon, 2011). During a qualitative exploration of general appearance-related concerns, adolescents with psoriasis (a skin condition resulting in raised red patches of skin, covered with silvery white scales)reported concealing their condition from partners and avoiding intimacy (Fox, Rumsey & Morris, 2007). Similar avoidant behaviours were identified by Magin, Heading, Adams and Pond (2010) among adults and adolescents with a variety of skin conditions. As the result of low perceived attractiveness, self-consciousness and fear of rejection, participants frequently felt their appearance adversely impacted upon their romantic lives. In a retrospective account of the impact of cancer treatment during their late teens, Tindle, Denver and Lilley (2009) described the negative impact that appearance changes (scarring and hair loss) had on their self worth, feelings of attractiveness and sexual identity.

In an interview study, adolescents and young men with testicular cancer revealed how appearance changes after treatment (e.g. hair loss, scars and orchidectomy (the removal of one or both testicles) had impacted their masculinity; resulting in a hesitation or postponement of romantic relationships and concerns about how and when to disclose their cancer history to partners (Carpentier, Fortenberry, Ott, Brames & Einhorn, 2011). These findings present a compelling case for developing specific support for young people with romantic concerns as a result of visible differences.

Not all studies reflect a negative picture, Robert, Blakeney & Meyer’s (1998) quantitative study found no difference in sexual experiences between adolescents with and without burn scars. Clearly the issue is complex and in need of more focused and in-depth exploration.

This study explored the romantic experiences of adolescents with a variety of visible differences, with the aim of informing the provision of appropriate support for those with romantic concerns.Adolescents with a range of visible differences were recruited; since individuals with a variety of conditions tend to report similar psychosocial difficulties (ARC, in submission 2011) and research indicates that adjustment to a disfigurement relates to the individual’s subjective rating of severity, rather than the objective severity, cause or location of the visible difference (Moss, 2005).

The following questions were addressed.

1. What are the appearance-related romantic concerns of adolescents with a visible difference?
2. What attitudes or behaviours are associated with positive romantic experiences?
3. What support would adolescents recommend for those with romantic concerns related to having a visible difference?

#### Method

*Design*

A parallel mixed method, qualitative dominant, online survey was employed to collect the data. The survey was created and hosted online by ‘Qualtrics’ ([www.qualtrics.com](http://www.qualtrics.com)).Mixed methodologies are particularly useful for investigating new or complex research areas such as this; the quantitative data can reveal exact frequencies of a studied behaviour, while qualitative data can provide a richer understanding of the feelings and emotions behind the behaviour (Greene & Caracelli, 1997).

*Participants*

Forty participants (22 males and 18 females), aged between 13 and 20 (M = 15.68, SD = 1.79) and who identified themselves as having a visible difference consented to take part. Adolescence is a flexible concept for which there are no universally accepted age boundaries. It ranges between 10 and 24 years old (American Psychological Association, 2002; Lewis, 1996). However, in this study a minimum age of 13 and a maximum age of 20 years were used as this range has been employed in the majority of studies (Miauton, Narring & Michaud, 2002; Robert, et al, 1998).

Participants were English speaking. A range of perceived visible differences were reported although the majority (26 participants) had a cleft lip. The remaining participants reported having an unspecified skin condition (n= 3), eczema (e.g. skin condition resulting in dry, red, sore and itchy skin) (n = 2), freckles (n = 2), ichthyosis (e.g. skin disorder where most or all areas of the skin are continually scaling) (n = 2), a birthmark (n = 1), cleft lip repair and a bent nose (n = 1), eczema and freckles (n = 1), a scarred hand and a lazy eye (n = 1) and psoriasis (n = 1).

Only participants who identified themselves as having a visible difference and were aged between 13 and 20 were included in the study. Participants who did not self report a visible difference and who were under 13 or over 20 years old were excluded from the study.

**Materials**

Involving adolescents with visible differences in research can be challenging (Williamson, Harcourt, Halliwell, Frith & Wallace, 2010). This group often resent being approached directly and identified on the basis of their difference. Appearance and intimacy are also highly sensitive issues for any young person to discuss face-to-face (Wallace, 2004). Online surveys are therefore useful for investigating potentially sensitive topics (Schaefer & Dillman 1998). Their anonymity facilitates the disclosure of potentially sensitive information (Joinson, 2001) and this medium has proved successful for recruiting adolescents with visible differences (Williamson, et al, 2010).

The online survey was developed using Qualtrics. Members of the Changing Faces charity Youth Council assisted with the design of the survey. The questions explored participants’ experiences of romantic relationships, focused on identifying any concerns and support needs and explored positive coping strategies (attitudes or behaviours). Participants were encouraged to consider past or current romantic experiences, or, if they had not had any, their feelings about the prospect of future relations. There were 6 closed ended questions (which included, *have you ever had a boy/girl friend? Is your visible difference getting in the way of having a boy/girl friend?* ***When you have spent time, seen or gone out with someone in the past, has your visible difference ever stopped you from getting closer or intimate with that person?)*** and 17 open ended questions (which included, *do you have any worries about spending time with, seeing or going out with someone?* ***Are there any strategies that you have found useful for developing romantic relationships?*** *What kind of support for developing relationships do you think would be useful for young people with visible differences?).* Depending on their response to the closed questions, participants were directed to other relevant closed and open-ended questions (using the logic function available on Qualtrics). This allowed some of the survey questions to be individually tailored to each participant.

Participants received a £5 Play.com voucher for completing the survey.

**Procedure**

University ethical approval was obtained prior to recruitment.

Adolescents were recruited via advertisements posted on the websites of support groups for conditions that affect appearance (eg: Ichthyosis Support Group, Vitiligo Society) and letters sent out to adolescents attending a regional cleft lip and palate centre. Both contained a summary of the study and a web link which participants clicked on/ typed into their web browser to access the survey. Participants were informed that the research centre was developing an online support programme for young people with a visible difference and wanted to identify whether support for developing romantic relationships should be included. They were told that the survey explored their romantic experiences in order to identify any concerns, or support needs they might have together with coping strategies utilised to overcome romantic concerns.

*Data analysis*

Quantifiable data from closed questions were reported as percentages generated by Qualtrics.

Inductive thematic analysis (ITA) was used to analyse the qualitative data using Braun and Clarke’s (2006) guidelines. ITA is a flexible method used to identify themes or patterns within data, providing a rich description of the phenomenon. An inductive approach is the most suitable for exploring under-researched areas like this study, where no pre-existing theoretical framework is available.

The analysis began with the researcher repeatedly reading each participant’s responses. Relevant aspects were allocated initial codes and codes that were similar and appeared frequently in the data were developed into potential themes. Themes were also developed from less common codes when they provided interesting insights into the aims of the study (Braun & Clarke, 2006). To increase the validity of data interpretation, the findings were reviewed by two other members of the research team which resulted in a 95% inter-rater reliability. Remaining differences in themes were negotiated between researchers and amendments were cross checked and feed back into the analysis.

**Findings**

Quantitative findings

Of the 40 participants, 29 (73%) had experience of having a boy or girlfriend and 9 (23%) were currently in a relationship. Of the 31 participants who were single, 28 (90%) wanted to be in a relationship. Of the 29 participants who had experience of romantic relationships, 7 (24%) felt that their visible difference was or had prevented them from becoming intimate with their partner. Frequency counts from the qualitative data indicated that 17 of the 40 participants (43%) reported concerns about current or future romantic relationships (8 adolescents had a cleft lip repair and 9 had a skin condition: multiple freckles, psoriasis, ichthyosis, eczema, psoriasis and scarring). In contrast, 23 out of 40 adolescents (58%) reported feeling confident in romantic relationships (19 adolescents had a cleft lip repair and 4 had a skin condition).

Qualitative findings

*Romantic concerns*

Six themes were identified among those with concerns about their current or future romantic lives.

# 1. ‘Appearances are important’

This group strongly subscribed to the belief that within wider society, and especially among teenagers, having an attractive physical appearance was an important quality required to secure a relationship and this appeared to increase the importance of their own appearance and their worries about their visible difference. Both girls and boys appeared sensitive to this pressure: ‘*I would be up for hearing anything about girls who don’t have a problem with guys who have visible differences, but we all know girls like that are so rare*’ (13, male, ichthyosis).

### 2. ‘I am unattractive’

Irrespective of the type of visible difference, those with romantic concerns were typically conscious of their difference and worried they were unattractive to others. This belief appeared to be reinforced by the great importance they placed on physical appearance for developing romantic relationships and this increased their worries about their visible difference: ‘*I feel that no one would ever want to kiss me; that I look repulsing and my lip is gross’* (16, female, cleft lip repair). Some participants expressed a sense of hopelessness at ever finding romance: ‘*I always feel like every girl is out of my league due to my condition*’ (18, male, ichthyosis)*.*

Whereas, despite concerns about their immediate situation, others were more hopeful about their future prospects; believing that an attractive appearance becomes less crucial during adulthood. As such they would be more likely to find a partner when they were older:

*‘I don't think young people look at things like personality, they just look for the best looking people to make themselves look good. When you get older you will find a nice person who loves you for who you are’* (15, female, psoriasis).

**3. Fear of negative evaluation**

Those concerned about their appearance worried about what current (or potential) partners might think of their difference and feared partners would view them negatively: *‘Will they look at my eczema? Do they talk about it behind my back? What do they say?’* (17, female, eczema and freckles). These fears appeared to be driven by the *anticipation* of negative responses rather than reality, as none of the participants in the study reported that past or current partners had ever made any negative comments about their visible difference.

Nonetheless, fear of negative evaluation adversely affected confidence in initiating relationships and for some fuelled fears of becoming intimate or being rejected during intimacy: ‘*I feel nervous to take it any further because I am worried that being turned down would be due to my physical appearance*’ (18, male, freckles)

For others, fear of negative evaluation prompted a more considered approach to relationships and a delay rather than a complete avoidance in revealing their difference, with some waiting until they felt they could trust their partner to respond appropriately: *‘I'm very concerned about revealing my condition to anyone. Especially when it comes to sexual relations.* *I delay such relations for as long as possible till I have built a solid relationship with my partner in hopes they will not 'run away' when I tell them of my condition. So I limit my relations with girls to only serious relationships’* (18, male, ichthyosis).

**4. Concealment & Avoidance**

Concealing their difference with clothes or make-up and avoiding activities that risked exposing their difference were behaviours inextricably linked with a fear of negative evaluation by their partner. Many avoided social activities which necessitated removing clothing or make up, such as swimming.

Concealment was perceived as helpful in the short-time (when attracting a partner) but ultimately increased anxiety when the relationship became more intimate and the adolescent felt compelled to reveal their condition. Participants feared that revealing their condition may end the relationship: ‘*I can hide it as it is in places that you can cover. I didn't tell my boyfriend I had it so I don't know what he would have thought if he saw it..I did worry that he might think it was ugly...if you really like the boy you don't want to risk letting him see it’*’ (15, female, psoriasis).

Concealment also resulted in feelings of guilt and confusion. Adolescents felt guilty that they had not told their partners about their difference at the beginning of the relationship and feared they may be considered deceitfulfor not revealing the condition earlier.Yet they were also concerned that they may be rejected if they told their partner about their condition too early in the relationship - anxieties regarding when and how to tell their partner about their condition were therefore particularly consuming: ‘*If I tell him straight away he might not stay with me but if I wait until we have been together for longer he might think I have been lying. It's hard to know when is the best time’* (15, female, psoriasis).

## 5. Teasing & bullying

The impact of past or current experiences of appearance related bullying or teasing appeared to reinforce participants’ perceptions that they are unattractive, reduce their self-esteem and their confidence at talking to partners when initiating and reciprocating romantic intentions: *‘My friends sometimes ridicule me because of my freckled face and it damages my confidence in talking to other people, especially the opposite sex’* (18, male, freckles).

## 6. Difficulty talking to the opposite sex

## A preoccupation with their difference and a fear of negative evaluation resulted in difficulties in instigating conversations with the opposite sex. Adolescents recognised that this was reducing their opportunities to meet partners and form relationships: ‘*My only worry is that I’d have the uphill battle again, with every girl that I’m around, and they may not want to stick around like the first girl did for months waiting for me to come out of my shell’* (16, male, cleft lip)*.* This quote also illustrates how persistent these concerns can be for this group, despite previous romantic successes.

Those who concealed their difference expressed difficulties in raising the issue of their difference once they were in a relationship. *‘I wonder when I should tell them, how to tell them, how they'd react, etc’* (13, male, ichthyosis).

# *Protective Factors*

Participants who appeared less concerned about their romantic lives displayed evidence of behaviours and attitudes that appeared to buffer or protect against the impact of having a visible difference on romantic relationships.

## 1. Good social skills

Many attributed their confidence to good social skills when approaching or talking to potential partners. Confidence in social situations resulted in increased self-efficacy in romantic relationships: ‘*(romantic relationships) have been easy for me as I’m a very sociable person so I’m not really worried about meeting people’* (17, female, cleft lip repair).

### 2. ‘People don’t notice it’

Some felt their visible difference was not very noticeable, therefore were not self conscious of it and did not believe that it impacted their ability to attract others: ‘*It has been relatively easy* (romantic relationships) *because…. my cleft lip is not very noticeable’* (15, male, cleft lip repair). As such, any worries they did have about romantic relationships were not attributed to their visible difference.

### 3. ‘Feeling unattractive is normal for teens’

It might be reasonable to expect that participants without romantic concerns did not worry about being unattractive - this was not the case. Although a minority of participants never or rarely worried about being unattractive, the majority did. However these were general worries rather than specific to their visible difference and were rationalised as normal feelings, experienced by all teenagers from time to time: ‘*I don't think that I am very attractive, but many teenagers feel like this, I don't think I feel much different than everybody else’* (15, female, cleft lip repair).

### 4. ‘It’s a part of who I am’

The majority accepted their visible difference as part of their identity, ‘*I am not bothered by this, because as far as I am concerned my cleft is just part of who I am*’ (14, male, cleft lip repair); or perceived it to be a unique attribute to be celebrated rather than considered as a deterrent to forming romantic relationships: ‘*If you fit into the crowd then there’s no flare to your life, so go out and enjoy being different’* (13, male, cleft lip repair). Some minimised their concerns by making downward comparisons to those worse off than themselves. This reinforced an acceptance of their appearance: ‘*I tend to just think; it could be a lot worse, so be happy as I am’* (15, male, cleft lip repair)*.*

***5.* Valuing attributes other than physical appearance**

This group held the belief that other attributes and qualities such as having a ‘*good personality’* were more important for developing romantic relationships than physical appearance: ‘*Relationships aren’t about ‘looks’, it’s about getting on with the person and getting to know them’* (16, male, cleft lip repair). As such they felt confident they had other qualities that they could bring to a relationship.

### 6. ‘I’m in control’

These positive attitudes and behaviours appeared to contribute to greater self-efficacy regarding romantic relationships. Compared to those with romantic worries, this group were able to shrug off inappropriate questions or negative comments related to their appearance ‘*If someone likes my looks that’s good, but if they don’t I don’t get bothered.*’ (15, female, cleft lip repair).They felt sufficiently confident to dismiss partners who prioritised physical appearance as not worthy of their romantic attention, and felt in control of this aspect of their lives: ‘*If they’re too shallow to accept you for who you are and how you look then they don’t deserve you’* (16, male, cleft lip repair).

### 7. Perceptions of social support

This group frequently described the benefits of support they had received from friends, family and partners relating to their difference and compared to those with concerns appeared to be more satisfied with this support. Having friends of the opposite sex reinforced feelings of acceptance and buffered appearance-related worries: ‘*Yes* (Ifeel unattractive sometimes*) but I have lots of friends, boys and girls. The guys I’m friends with accept me for who I am’* (14, female, skin condition). Others benefited from being honest and open about their worries. This provided an opportunity for friends to offer reassurance and support: ‘…*because I can speak candidly about my appearance with my friends, it had made it a lot easier to deal with’* (18, male, cleft lip repair).

*Recommendations for support provision*

Young people were clear about the type of support needed for those with romantic concerns. They wanted support and information *specific* to adolescents with visible differences, which targets self-esteem, confidence and poor body image. ‘*Self esteem is probably the most important support because everything else leads on from that*’ (17, female, cleft lip repair).

Consistent with themes identified in both the ‘romantic concerns’ and ‘protective factors’, developing strong social skills was an popular target for support; in particular adolescents wanted advice about how to approach potential partners and how to discuss their visible difference with their partner. ‘.*the best sort of skill you could try and imbue in people with visible differences is ..the ability to communicate normally about their differences’* (18, male, cleft lip repair). Participants who concealed their difference specifically requested advice for how and when to reveal their visible difference during intimacy.

Rather than receiving support through contact with an adult, most preferred to receive advice and learn from older adolescents or young people with visible differences who had experience of romantic relationships. *‘…older teenagers or people in their 20s who have had the experiences that we have had..so we can see how people have come through the problems we are having…’* (15, female, psoriasis). Participants also wanted to read positive comments about adolescents with visible differences from the opposite sex, ‘*..hearing anything about girls who don’t have a problem with guys who have visible differences, but we all know girls like that are so rare*’ (19, male, ichthyosis).

Online delivery was preferable to face-to-face support because it offers anonymity, confidentially and access to advice at any time of day. *‘Online discussions/ forums.. could be achieved within the comfort of their own home and would have a better impact than going to a 'special meeting' that they would feel embarrassed about’* (15, male, cleft lip repair). Online discussion forums were popular because they allow young people to post questions anonymously, look up other’s questions and solutions, facilitate real-time interaction with peers experiencing similar problems and provide the opportunity to receive and offer support. *‘ ..some stories from other young people with a visible difference to say how they have coped/ not coped etc. Also it would be good if there was an agony aunt type person that could answer people’s questions anonymously’* (15, female, cleft lip repair).

# Discussion

This study provides a unique and practical insight into the romantic lives of adolescents with conditions that affect appearance. Having a visible difference did not seem to prevent the majority of adolescents from developing romantic relationships: 73% of young people had experience of romantic relationships, which is comparable to trends for adolescents in the general population (Joyner & Udry, 2000). However, a substantial number of participants (43%) felt that their appearance prevented relationships from developing or interfered with their enjoyment of intimate relations.

Differences in the attitudes and behaviours between those with and without romantic concerns can contribute towards understanding the differential impact of a visible difference on romantic relationships. In considering these differences, Moss and Carr (2004) and the ARC (in submission 2011) studies have developed a framework which suggests that differences in adaptation to an altered appearance are influenced by the organisation of and importance attributed to appearance-related information within the self-concept. Compared to those with a self-concept that is dependent on a variety of non-appearance attributes, those with a high degree of investment in appearance are more likely to access appearance-related information when interpreting social situations, evaluate their appearance negatively and believe others are doing so too. This process is likely to lower self-esteem and, as this study would suggest, self confidence in relation to romantic experiences. Poarticipants who value other aspects of their selves appear confident in their ability to attract a partner. This self-confidence is in itself attractive and is likely to contribute to romantic success and increase self-esteem. Although the ARC framework was developed using evidence from adult participants, it appears applicable to the current findings.

Among those with romantic concerns, a belief that attractiveness is highly valued in romantic relationships underpinned feelings of unattractiveness and increased self consciousness about their difference. In contrast, adolescents displaying greater self-efficacy in romantic experiences appeared to value the contribution of other non-appearance-related attributes (for example, personality) in attracting a partner and normalised any romantic anxieties they experienced by rationalising them as typical of all teenagers, rather than attributing these concerns to their visible difference (Egan et al, 2011).

This disparity in cognitive processing between the groups appeared to result in distinct differences in behaviour when interacting with romantic partners. Some adolescents with concerns concealed their condition and avoided social situations and intimate encounters which would expose their difference (Magin et al, 2010). Although adolescents believed these behaviours were helpful when attracting a partner, they recognised that ultimately these actions increased their fears about revealing their condition. This scenario is consistent with Newell’s (2000) fear avoidance model of adjustment to disfigurement - where an individual avoids and therefore fails to habituate to anxiety provoking situations. These situations then become increasingly threatening and evoke greater anxiety.

The beliefs of those with appearance concerns also appeared to inhibit communications with the opposite sex, increase fears of being rejected by partners and reduce confidence in initiating and reciprocating romantic behaviours (Carpentier et al, 2011). In contrast, those without concerns employed good social skills to manage unwanted attention or questions concerning their difference. These findings support previous literature which indicates that good social skills are important for positive adjustment to a disfigurement (Bull & Rumsey, 1988; Kapp-Simon, 1995).

*Future directions*

The current findings have the potential to inform interventions for young people struggling to cope with their visible difference. Interventions should aim to reduce the perceived importance of appearance by promoting the value of other attributes in relationships, such as personality and social skills, and should help the adolescent to improve self-esteem and self-efficacy in relation to romantic experiences by engaging social support, developing social skills to build platonic relations and strategies to cope with negative appearance-related attention or teasing. Guidance on how to raise and discuss their difference with current or potential partners and how to reveal concealed differences in more intimate situations should also be included. Online interactive support from their peers or those with shared experiences who have ‘been through it’ was recommended (Egan, et al, 2011).

*Limitations*

As with all qualitative findings one cannot generalise the conclusions of this study to all young people with a visible difference. However the present findings have established that some young people with a visible difference experience difficulties with developing romantic relationships, which suggests that this is an area of functioning that Health Professionals who work with these young people should assess and if required, address in their support provision. The current findings can provide guidance about the specific issues to address. Researchers are currently reviewing the support needs of young people within the NHS Cleft Lip and Palate services (Williams, et al, 2011). A substantial number (30%) of adolescents with a cleft lip repair in this study reported romantic concerns relating to their visible difference, indicating that this is an appropriate area in which to develop support and intervention.

The use of an online survey to engage adolescents in research provided the expected benefits in terms of anonymity and freedom to discuss sensitive issues; it was particularly pleasing to see that 55% of respondents were males, a significant achievement for appearance research which typically appeals to females to a greater extent than males (Rumsey & Harcourt, 2005). However the survey method was noticeably limited when the researchers wanted to explore responses in more depth. Real-time e-mail interviews or online forums would have the benefits of anonymity while allowing the researcher to explore participants’ experiences further.

The researchers own interests and background are recognised as influencing the collection, analysis and interpretation of qualitative data (Finlay, 2002). The authors of this study are experienced in appearance and applied research and are currently developing an online support programme (YP Face IT) for young people struggling to cope with a visible difference. This study was designed to inform the development of a romantic relationships module within this programme. The analysis and interpretation of the qualitative data will therefore have been influenced by this aim. Nonetheless all members of the research team independently reviewed the findings in order to minimise any potential individual biases.

YP Face It is currently being evaluated by young people.

Acknowledgements

We would like to thank the charities Changing Faces, IFace, the Vitiligo Society, the Children’s Burns Trust, the Ichthyosis Support Group, the National Eczema Society, Talk Eczema, Talk Psoriasis, Talk Acne, the South West Cleft Lip and Palate Unit and the Changing Faces Youth Council who assisted with recruitment and helped us design the survey.

References

Amercian Psychological Association (2002). *A reference for professionals developing adolescents.* The Maternal and Child Health Bureau, Health Resources and Services Administration,U.S. Department of Health and Human Services.

Amos A, and Bostock Y (2007) Young people, smoking & gender: A qualitative exploration. *Health Education Research* 22: 770- 81.

Appearance Research Collaboration (ARC) (in submission, 2011). *Factors associated with distress and positive adjustment in people with disfigurement.*

Braun V, and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3: 77- 101.

Brown JD, and Witherspoon EM (2002) The mass media and American adolescents’ health. *Journal of Adolescent Health* 31: 153-170.

Bull R, and Rumsey N (1988). *The social psychology of facial appearance*. New York: Springer-Verlag.

Carpentier M, Fortenberry J, Ott M, Brames M, and Einhorn L (2011) Perceptions of masculinity and self-image in adolescent and young adult testicular cancer survivors: implications for romantic and sexual relationships. *Psycho-Oncology* 20: 738–745.

Chamlin SL (2006) The psychological burden of childhood atopic dermatitis. *Dermatologic Therapy* 19: 104 -107.

Collins WA, Welsh DP, and Furman W (2009) Adolescent Romantic

Relationships. *Annual Review of Psychology* 60: 631–52.

Dalgard F, Gieler U, Holm JO, Bjertness E, and Hauser S (2008) Self-esteem and body satisfaction among late adolescents with acne: Results from a population survey. [*Journal of the American Academy of Dermatology*](http://www.sciencedirect.com/science/journal/01909622)59*:* 746-751.

Dolgin MJ, Katz ER, Doctors SR, and Siegel SE (1986) Caregivers’ perceptions of medical compliance in adolescents with cancer. *Journal of Adolescent Health Care* 7: 22–27.

Egan K, Harcourt D, Rumsey N, and the Appearance Research Collaboration (2011) A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference. *Journal of Health Psychology* 16: 739 – 749.

Feingold A (1992) Good looking people are not what we think. *Psychological Bulletin* 111:304-341.

Findlay L (2002) ''Outing'' the Researcher: The Provenance, Process, and Practice of Reflexivity.*Qualitative Health Research* 12: 531 – 545.

Fox F, Rumsey N, and Morris M (2007) ‘Ur skin is the thing that everyone sees and you can’t change it!’: exploring the appearance-related concerns of young people with psoriasis’. *Developmental and Neurorehabilitation* 10: 133-141.

Friedman IM, Litt IF, King DR, Henson R, Holtzman D, Halverson D, and Kraemer, HC (1986) Compliance with anticonvulsant therapy by epileptic youth. *Journal of* *Adolescent Health Care,* 7: 12–17.

Greene JC, and Caracelli VJ (1997) "Defining and describing the paradigm issue in mixed-method evaluation." In J. C. Greene and V. J. Caracelli (eds.). *Advances in mixed-method evaluation: The challenges and benefits of integrating diverse paradigms.* New Directions for Program Evaluation, No. 74. San Francisco, CA: Jossey-Bass, pp. 5-18.

Joinson AN (2001) Self-disclosure in computer-mediated communication: The role of self awareness and visual anonymity. *European Journal of Social Psychology* 31: 177–192.

Joyner K, and Udry JR (2000) You don’t bring me anything but down: Adolescent romance and depression. *Journal of Health and Social Behavior* 41: 369–391.

Kapp-Simon K (1995) Psychological interventions for the adolescent with cleft lip and palate. *Cleft Palate Craniofacial* *Journal* 32: 104–108.

Lewis IJ (1996) Cancer in adolescence. *British Medical Bulletin* 52: 887 – 897.

Locker D, Jakovic A, and Tompson B (2005) Health- related quality of life of children aged 11 -14 with orofacial conditions. *Cleft Palate-Craniofacial Journal* 42: 260-266.

Lovegrove E, and Rumsey N (2005) Ignoring it doesn’t make it stop: adolescents, appearance and anti-bullying strategies. *Cleft Palate-Craniofacial Journal* 42: 33-44.

Miauton L, Narring F, and Michaud P (2002) Chronic illness, life style and emotional health in adolescence: results of a cross-sectional survey on the health of 15-20-year-olds in Switzerland. *European Journal of Pediatrics* 162: 682-689.

Magin P, Heading G, Adams J, and Pond D (2010) 'Sex and the skin: A qualitative study of patients with acne, psoriasis and atopic eczema'. *Psychology, Health & Medicine* 15: 454 - 462.

Magin PJ, Pond CD, Smith WT, Watson AB, and Goode SM (2008) A cross-sectional study of psychological morbidity in patients with acne, psoriasis and atopic dermatitis in specialist dermatology and general practices. *Journal of the European Academy of Dermatology and Venereology* 22: 1435–1444.

Moss TP (2005) The relationships between objective and subjective ratings of disfigurement severity, and psychological adjustment. *Body Image* 2: 151–159.

Moss T, and Carr T (2004) Understanding adjustment to disfigurement: The role of the self-concept. *Psychology and Health* 19: 737–748.

Neumark-Sztainer D, Wall M, Eisenberg ME, Story M, and Hannan P (2006) Overweight status and weight control behaviours in adolescents: Longitudinal and secular trends from 1999-2004. *Preventive Medicine* 4*3*: 52-9.

Newell RJ (2000) *Body Image and Disfigurement Care*. London: Routledge.

Robert RS, Blakeney PE, and Meyer WJ (1998) Impact of disfiguring burns scars on adolescent sexual development. *Journal of Burn Care and Rehabilitation* 19: 430-435.

Rumsey N (2008) The psychology of appearance: Why health psychologists should “do looks”. *The European Health Psychologist* 10: 46- 50.

Rumsey N, and Harcourt D (2005) *The psychology of appearance*. England: Open University Press.

Schaefer DR, and Dillman DA (1998) Development of a standard e-mail methodology results of an experiment. *Public Opinion Quarterly* 6*2*: 378–397.

Sorenson S (2007) Adolescent romantic relationships. *Research Facts and Findings*, June.

Tan JKL (2004) Psychosocial impact of acne vulgaris: evaluating the evidence. *Skin therapy* 9: 7-13.

Tindle D, Denver K, and Lilley F (2009) Identity, image, and sexuality in young adults with cancer. *Seminars in Oncology* 36: 280 – 287.

Turner SR, Thomas PW, Dowell T, Rumsey N, and Sandy JR (1997) Psychological outcomes amongst cleft patients and their families. *British Journal of Plastic Surgery* 50: 1–9.

Wallace M (2004) *The appearance related concerns of adolescents who have undergone treatment for cancer*. Paper presented at the British Psychological Society Division of Health Psychology Annual Conference, Edinburgh, September, 2004.

Walters E (1997) Problems faced by children and families living with visible differences. In R. Lansdown, H. Rumsey, E. Bradbury, T. Carr, & J. Partridge (Eds.), *Visible difference: Coping with disfigurement* (pp. 112 -120). Oxford: Butterworth-Heinemann.

Williams L, Dures E, Waylen A, Ireland T, Rumsey N, and Sandy J (2011) Approaching Parents to Take Part in a Cleft Gene Bank: A Qualitative Pilot Study. *The Cleft Palate-Craniofacial Journal*, in press. doi: 10.1597/10-086.

Williams EF, Gannon K, and Soon K (2011) The experiences of young people with Epidermolysis Bullosa Simplex: A qualitative study. *Journal of Health Psychology* 16: 701 – 710.

Williamson H, Harcourt D, Halliwell E, Frith H, and Wallace M (2010) Adolescents’ and parents’ experiences of managing the psychosocial impact of appearance change during cancer treatment. *Journal of Pediatric Oncology Nursing* 27: 168-75.

Table 1

*Sample of survey questions*

|  |  |
| --- | --- |
| Question | Question type |
| Have you ever had a boy/girl friend? | Closed: yes/no |
| Do you think your visible difference is getting in the way of getting a boy/girl friend? | Closed: yes/no |
| **Some people think that their visible difference affects their relationship, whereas others don't. Does it affect your relationship? How well do you feel you are coping? Are there any strategies that you have found useful when coping in your relationship?** | Open ended |
| **When you have spent time, seen or gone out with someone in the past, has your visible difference ever stopped you from getting closer or intimate with that person?** | Closed: yes/no |
| If yes, in what way? | Open ended |
| What are the good things about spending time with/ seeing/ going out with someone? | Open ended |
| Do you have any worries about spending time with, seeing or going out with someone? If so, what are worried about? | Open ended |
| What kind of support for developing relationships do you think would be useful for young people with visible differences? Is there any specific information or skills that would be good to learn?From who? (psychologist, counsellor, nurse, parent, teacher, young person with a visible difference, young person without a visible difference, etc) | Open ended |
| In what form would you like to receive the information? (leaflets, individual/group session, online, telephone) | Open ended |