Young people’s perceptions of visible difference

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What is known on this subject

- The experience of being stigmatised may have a harmful effect on the psychological adjustment of those individuals who are affected by a visible difference.
- Adolescence may be a particularly difficult time for those with a visible difference, due to a greater focus on appearance, friendships and romantic relationships.
- Although the processes involved in appearance-related discrimination are currently poorly understood, previous research has indicated that both implicit and explicit perceptions may play a role.

What this paper adds

- Although negative perceptions do occur, reactions to individuals with a visible difference are far more complex than was previously thought.
- Uncertainty about how to respond appropriately stems from a lack of awareness of visible difference and a lack of confidence in knowing how to behave, rather than the intention to discriminate.
- A two-tiered approach may be needed, namely to educate the general public about visible difference, and to equip affected individuals with social skills and appropriate support.

ABSTRACT

Visible facial differences (VFDs) can pose a number of psychosocial challenges for those affected by them. In particular, the experience of being stigmatised may have a harmful effect on the psychological adjustment of the individual concerned. This is especially pertinent for young people, who are at an age where appearance becomes increasingly central to social interaction and self-esteem. Suitable and effective interventions are needed to reduce stigma in general, but in the case of appearance-related discrimination the prevalence and the processes involved are poorly understood. The aim of this research was therefore to explore young people’s perceptions of visible difference.

A mixed-methods online questionnaire was administered to a cross-sectional sample of 412 pupils aged 12–14 years, recruited from three UK schools. Participants were asked to look at five photographs of people with VFDs and to indicate their level of agreement with 30 statements using a 5-point Likert scale. They were also asked to answer the open-ended question ‘What do you think when you see people with facial differences?’ Although quantitative responses were overwhelmingly neutral, inductive content analysis revealed a number of insights. Four main themes were identified: them and us, initial reactions, common assumptions and behavioural intentions.
Participants reported a wide range of complex responses. Although negative reactions and judgements were described, these were often due to seeing something unusual, or to a lack of understanding, rather than to the intention to cause harm. Conflicting emotions led to uncertainty and lack of confidence about how best to behave around people with VFDs. The findings suggest the need for a two-tiered approach to intervention: first, to raise awareness of VFDs and to facilitate the development of appropriate social skills within the general population, and secondly, to provide support to enable those with VFDs to cope with any negative reactions they may encounter.

**Keywords**: adolescence, appearance, attitude, disfigurement, stigma

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**Introduction**

In today’s society, interest in appearance has never been more prevalent. In 1984, Rodin and colleagues were the first to describe dissatisfaction with appearance as ‘normative’ within the general population, whereas physical attractiveness is now consistently linked to success and happiness (Rodin et al., 1984; Rumsey, 2008). Given that appearance ‘ideals’ are becoming more extreme in westernised nations, and that an increasing number of people are aspiring to these ideals (Grogon, 2008), the current focus on being physically attractive and the belief that ‘what is beautiful is good’ (a term coined by Dion et al., 1972) may be harmful to individuals whose appearance is perceived to be outwardly different from the norm.

This focus on appearance may be particularly pertinent for young people. Due to changes in body shape during puberty, adolescence is arguably one of the most difficult life stages in terms of physical adjustment. The desire to ‘blend in’ and be perceived as ‘normal’ is a central facet of well-being in adolescence (Liossi, 2003), and physical appearance has become the prime focus for evaluating this. The added focus on friendships and dating exacerbates the importance of self-presentation and has a significant impact on the daily life of teenagers (Lovegrove and Rumsey, 2005). According to the most recent estimations by the UK-based charity Changing Faces (Partridge and Julian, 2008), approximately one in 111 people in the UK have a significant visible facial difference (VFD). A large proportion of VFDs are present from birth, but many others are acquired through injury or a health condition. The noticeability of a VFD may provoke unwelcome interest from others, including staring, unwanted questioning, audible comments and avoidant behaviour by members of the general public, leading to a loss of anonymity which can be uncomfortable for many (Rumsey, 2002).

A number of studies investigating the perceived social experiences of individuals with a VFD have reported frequent stigmatisation and apparent acts of discrimination (e.g. Carroll and Shute, 2005; Strauss et al., 2007). Concurrently, early research demonstrated that people may behave differently when coming into contact with a person with a VFD. For example, members of the public were less likely to answer questions when approached by a ‘market researcher’ with a VFD compared with a market researcher without this difference (Rumsey and Bull, 1986), and significant numbers of people would avoid sitting next to someone on a train who appeared to have a port-wine stain (Houston and Bull, 1994). The presence of a VFD may also influence people’s expectations. For example, teachers may underestimate the intellectual ability of children who have a VFD (Richman, 1978), jurors may offer less sympathy to people with VFDs who are victims of crime (Kerr et al., 1985), and employers may reject suitably qualified job applicants who have a VFD (Stevenage and McKay, 1999).

More recent investigations have employed Implicit Association Tests (IATs) with members of the general public, as a way of gauging their subliminal beliefs. A study by Grandfield et al. (2005) claimed that participants displayed significant implicit preferences for people with clear skin compared with those with a dermatological condition. Similarly, an online survey investigating implicit attitudes among the general public (Changing Faces, 2008) concluded that the majority of participants found it more difficult to attach positive characteristics to images of people who were visibly different compared with those without VFDs.

How and why appearance-related stigma occurs is unclear (see Box 1). Theories derived from evolutionary psychology indicate that biases such as these may be inherent and fixed, where stigma is conceptualised as a natural reaction to something that is different or potentially threatening (e.g. Gilbert, 1997). In contrast, explicit discriminatory behaviour, such as deliberate avoidance or making derogatory comments, may be a mechanism of social conditioning (e.g. Bernstein, 1976; Langer et al., 1976). For example, a number of studies have suggested that unfavourable societal stereotypes may be reinforced by negative representations of visible difference in the media (Black and Pretes, 2007; Wardle and Boyce, 2009).
Despite the lack of consensus about the causes and prevalence of visible stigma, the negative effects of perceived and/or real differences are not in dispute. Not only does social stigma have a negative impact on how others might behave, but it also may have a harmful effect on the psychosocial development and well-being of the individual (Link and Phelan, 2011). Given that social involvement and perceived social support account for a significant proportion of the variance in psychosocial adjustment to visible difference and quality of life (e.g. Corry et al, 2009), it is clear how the impact of social stigma may be extremely damaging. Negative social interactions have been shown to provoke negative emotions (e.g. social anxiety), maladaptive thought processes (e.g. fear of negative evaluation), unfavourable self-perceptions (e.g. lowered self-esteem and unfavourable body image) and negative behaviour patterns (e.g. excessive social avoidance or aggression) in individuals with a visible difference (Rumsey and Harcourt, 2004).

As the effect of social stigma on individuals can be far reaching, there is a need to provide suitable and effective interventions to reduce both stigma and its impact. Given that appearance-related discrimination is currently poorly understood, there is a real need for further exploratory work to inform such interventions. This paper examines from an exploratory qualitative perspective the perceptions and behavioural intentions of young people towards those affected by a VFD.

**Conduct of the study**

**Design and method**

Cross-sectional data exploring the perceptions and intended behaviours of young people towards individuals with a VFD were collected through the use of an online mixed-methods questionnaire, as part of a project commissioned by Changing Faces and funded by the Department for Education. The study adhered to the *Code of Ethics and Conduct* of the British Psychological Society (2009) at all times, and was granted approval by the Research Ethics Committee at the University of the West of England in Bristol. Formal permission was obtained from each of the participating schools, and oral consent was obtained from all of the participating teachers.

For children under the age of 16 years, parental consent should normally also be sought (British Psychological Society, 2009). For this study, an opt-out approach to parental consent was used. Parents were informed about the study via an information sheet a number of weeks before the study was conducted, and were given instructions on how to opt their child out of the study if they chose to do so. Parental consent was thus assumed if no opt-out request was received. Participants received a separate information sheet and were offered the option of declining on the day if they chose not to take part in the study.

Each participant was linked to a unique participant code before any data collection began. Participants’ names and codes were stored together on a password-protected database to which only the chief researchers had access. Once collected, the raw data were stored in an anonymous database alongside each participant’s code. If the parent or participant chose to opt out of the study after data collection had taken place, the participant was identified using their unique code, and their data were subsequently deleted.

Data were analysed independently by two researchers from the Centre for Appearance Research, based at the University of the West of England in Bristol.

The opt-out approach is generally considered to be acceptable in cases where high response rates are crucial to the study, where the study has been assessed as ‘low risk’, and where the participants are at an age at which they are considered to have the capacity to decide for themselves whether or not to give consent (see www.ethicsguidebook.ac.uk). This approach has also been used previously in large-scale studies involving children in schools (e.g. Halliwell and Diedrichs, in press; Stallard et al, 2012). However, the importance of voluntary participation in the case of minors should not be overlooked, particularly when issues of coercion and/or social acceptability may influence their decision to participate (Ungar et al, 2006). Although care was taken to inform the participants of the study procedure in order to allow them to make their own decision, children are used to carrying out instructions from their teachers, and therefore may not have raised any concerns. The classroom-based method may also have invited an element of peer pressure to participate. In addition, it is possible that not all of the parents received the participant information sheet from their children.

In order to address this main ethical concern as fully as possible, prior consultations were held with teachers and headteachers from each participating school, as well as with representatives from the Department for Education and members of the Changing Faces Young People’s Council. Methodological and ethical issues were discussed at length. After careful consideration of

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**Box 1 Definition of stigma**

Stigma occurs when an individual is identified as somehow ‘deviant’ from the social norms of society (Goffman, 1963), based on aspects such as behaviour, attributes, reputation or appearance (Link and Phelan, 2011).
the issues raised above, and following extensive consultation with various stakeholders, a pragmatic approach to obtaining assent was considered to be acceptable for this study. In the future, research such as this could advertise studies within school newsletters or bulletins, via school SMS or email services, or by hosting an information evening for parents.

Participants

Three schools took part in the study. All three schools were non-fee-paying and attended by boys and girls aged 11–18 years, but they varied with regard to type of school (secondary modern, selective grammar or comprehensive academy) and geographical location (South-East England, North-West England or South-West England). Participants were recruited from Years 8 and 9, where the mean age of participants was 13 years. Data were initially excluded if pupils or parents chose to opt out or if an incomplete data set was submitted ($n = 5$). A further seven participants were excluded from the qualitative analysis on the grounds that they provided a generic response (e.g. ‘Nothing’ or ‘I don’t know’). In total, data for 405 pupils (197 girls and 208 boys) were included in the final analysis. Of these pupils, 14 identified themselves as having a visible difference; one had a cleft lip, one had acne, nine indicated varying forms of facial scarring, and three pupils did not specify the VFD. In addition, 84 participants claimed to know someone with a VFD. This was largely due to one of their classmates being born with a ‘cleft lip’ or having a facial ‘birthmark.’

The online questionnaire

The questionnaire was originally designed and piloted by researchers from the Centre for Appearance Research (Fox et al, 2010), and was later adapted for online use (Stock et al, 2010). Perceptions of individuals with a VFD were surveyed across the whole sample. Participants were asked to look at five photographs of people with a VFD, and then to complete the questionnaire. Five adults (two men and three women) with a variety of congenital and acquired VFDs were shown in the photographs. All of the photographs were cropped to show only close-up shots of each person’s face, and to eradicate any potential cues in the background. All five people in the photographs had neutral expressions. Images were obtained from Changing Faces and are available on request.

For the quantitative component, participants were asked to indicate their level of agreement with 30 statements about people with VFDs (e.g. ‘People with disfigurements are shy’) on a Likert scale ranging from 1 (‘strongly agree’) to 5 (‘strongly disagree’). For the qualitative component, participants answered the question ‘What do you think when you see people with facial differences?’ Questionnaires were completed within the normal classroom environment with a teacher present.

Data analysis

Quantitative analysis revealed that the majority of the participants’ responses were neutral ($n = 355; 88\%$). This perhaps reflects the difficulty involved in capturing complex perceptions using quantitative measures. To explore young people’s perceptions of VFDs in more depth, qualitative responses were analysed using inductive content analysis. Codes were allocated separately by two researchers and then cross-checked for agreement. Any disagreements were discussed and adjusted accordingly. A summary of the total number of comments found in relation to each theme and subtheme is presented in Table 1.

Results

Four major themes were identified, namely them and us, initial reactions, common assumptions and behavioural intentions. These themes reflected the responses received from all three schools. Responses from those who identified themselves as either having a VFD or knowing someone with a VFD did not differ significantly from the majority of responses, although a very slight increase in the level of knowledge and expressed sympathy was observed. No significant gender differences were found. The themes and their corresponding subthemes are discussed below and illustrated with quoted extracts.

Them and us

Two contrasting standpoints that were commonly articulated by participants were those of ‘difference’ and ‘similarity.’ The participants commented on how they viewed people with a VFD, while also reflecting on how the images made them feel about themselves.

Different but the same

People with VFDs were described by some participants as ‘normal people’ or as being ‘just the same’ as everyone else ($n = 211$). Although these statements focused on parity, this is at odds with the way that the young people seemed to implicitly separate themselves from those with a VFD, by using the terms ‘them’ and ‘us.’
In contrast, 30 participants explicitly described people with VFDs as being very ‘different’ to themselves, or ‘not normal people.’ Other participants talked about people with VFDs being ‘special’ and ‘unique’, expressing how their facial differences set them apart from other people and made them distinctive in a positive manner.

Interestingly, a juxtaposition between the notions of similarity and difference was also observed, with 21 participants expressing both viewpoints within the same response: ‘They are different but they are still normal people.’

In conjunction with this, the participants in this study often stated that although people with VFDs looked ‘different’ from the outside, they were still ‘the same’ and ‘good’ on the inside.

Irrespective of their individual standpoint, the majority of the participants stated that everyone should be treated equally and accepted for who they are, regardless of appearance:

I believe everybody is equal whatever the case.

They are human beings like you and me and we should treat them equally.

It doesn’t matter what they look like, we should always treat them with respect.

Although the participants clearly felt quite strongly about this subject, many of them seemed to experience conflicting feelings when trying to express their views.

### Table 1 Content analysis

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Number of comments</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Them and us</td>
<td>Different, but the same</td>
<td>72</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social comparison</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(same, n = 21; different, n = 30; same but different, n = 21)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial reactions</td>
<td>Sympathy</td>
<td>258</td>
<td>420</td>
</tr>
<tr>
<td></td>
<td>Shock</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fear</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Curiosity</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amusement</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Aversion</td>
<td>52</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(strong, n = 20; mild, n = 14; weird, n = 18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common assumptions</td>
<td>Social challenges</td>
<td>91</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>Admiration and respect</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Behavioural intentions</td>
<td>Uncertainty</td>
<td>14</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td>Avoidance</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Compassion</td>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

### Social comparison

In total, 48 participants reflected on how they felt about themselves after viewing the images of people with VFDs; this prompted them to engage in downward social comparison (Festinger, 1954). The young people commonly stated that they felt ‘glad that it hasn’t happened to me’, while expressing feelings of gratitude for ‘the way I am’ and ‘what I look like.’

Seeing images of people whom they considered to be less fortunate than themselves encouraged the participants to view things from an altered perspective:

I feel lucky for myself just to be healthy. I start thinking of the little things in life that make me happy.

I think about how lucky we are not to have to live with extreme conditions like these. I should be more grateful.

Some participants expressed feelings of guilt for investing in and worrying about their own appearance:

I feel guilty in a way, as I take my looks for granted.

I feel a bit silly now because I get worried if I just have a little spot on my face.

Generally, the participants seemed to feel ‘humbled’ by the images of people with VFDs. Three participants went on to comment on the role of society in creating and maintaining concerns about appearance:

I think there is too much pressure on people to be pretty. It should be the personality and what’s inside that counts.
Initial reactions

A number of conflicting emotions and cognitions were reported by the participants when thinking about how they might feel if they came into contact with someone with a VFD.

Sympathy

By far the most common reaction was sympathy, with 258 participants reporting that they ‘felt sorry’ or ‘felt sad’ for people with VFDs. These feelings primarily originated from the belief that it was unfair for anyone to have a VFD:

I feel a bit upset because why did these people have to have a facial disfigurement? What have they done to deserve this?

I feel very sad for them because it’s not their fault.

Shock

In total, 34 participants also talked about feeling ‘shocked’ and ‘surprised’ when presented with the images of people with VFDs:

I get speechless and don’t know what to say. I would be shocked if I saw them in the street.

When I saw them I was just like ‘woahhh’, I didn’t know people could look like that.

I feel a bit shocked because it is something that you don’t see every day.

Fear

Feelings of fear were cited by 27 participants as their first response when encountering a person with a VFD, using words such as ‘unsafe’ and ‘frightening’:

I would feel a bit uneasy.

I think it’s a bit disturbing and I would be scared to meet any of them.

Scary, must be photoshop edited.

One participant commented on how their fear stemmed from the link between VFDs and villains in the media:

I am unintentionally scared because often in films and books, the bad characters have some sort of facial disfigurement.

Curiosity

Another common response was that of curiosity. In total, 46 participants asked questions relating to the images of people with VFDs. For example:

It looks like they must be in a lot of pain. I wonder does it hurt?

Were they born with it? How did it happen?

These people must have life-threatening illnesses and I would think ‘Could I catch it?’

Other participants were curious as to why the people with VFDs had not sought treatment to ‘fix’ or ‘cure’ their difference:

Is there a way of getting rid of it? Why haven’t they got surgery or something?

Can’t they afford to have surgery? I hope their face changes the way they want.

Amusement

Three of the participants admitted that laughter would be their primary reaction. However, this was often quickly followed by admissions of guilt about such a response:

As soon as I saw them I actually laughed, but then I realised I shouldn’t and it’s not funny.

I would feel the laughter coming up ... but I know it’s not right of me to be mean.

Aversion

In total, 52 participants expressed aversive feelings towards the images of people with VFDs, using terms such as ‘disturbing’, ‘nasty’ and ‘horrible.’ Other participants said that the pictures made them feel ill:

I don’t mean to be rude but it makes me feel sick.

However, it is important to note the distinction between those who were strongly averse to the images (e.g. those who stated ‘It’s disgusting’) (n = 20), those who were mildly averse (e.g. ‘It doesn’t look very nice’) (n = 14) and those who thought the people in the images looked slightly ‘weird’ or ‘strange’ (n = 18).

Although this theme has primarily described individual responses, these commonly appeared in a sequence, with the initial shock or surprise quickly giving way to curiosity and sympathy. Participants who found the photographs frightening or aversive in the first instance often went on to say that they would soon ‘accept the difference’ and ‘grow fond of the person due to their personality’:

At first I would be startled, but then I would just feel sorry for them and want to know what happened.

My first impression is of surprise, but then I check myself, and think that it really doesn’t matter.

Many of the quotes illustrating this theme also reveal the participants’ lack of knowledge and understanding of the aetiology and treatment of VFDs. However, two young people offered additional insights into their reactions. For example:

I think it’s strange mainly because I’ve never met anyone with a disfigurement.
Common assumptions

The emotions and cognitions described by the participants often seemed to originate from, or be linked to, a number of common positive and negative assumptions.

Social challenges

As described previously, the most common initial reaction was that of sympathy. Although this can be seen as a mildly positive reaction, it also encompasses the more negative assumption that people with VFDs are more likely to have ‘unhappy’ and ‘difficult’ lives because of the way they look. This concern was expressed by 91 participants. For example:

I feel upset and sorry for them because they must have had a hard life and they could have been bullied at school, college and university.

I feel sorry for the people because they will never have the same life I will.

It would be hard to get a boyfriend/girlfriend.

They can’t do some stuff like other people can.

Many of the young people were concerned that those with VFDs would face discrimination based on their appearance:

I feel sorry for them because they are usually not fully accepted into society.

I think it’s horrible when I see people with facial differences because they won’t get the opportunities that we get.

I feel sorry for them because they are discriminated against for something they can’t change.

Admiration and respect

Due to the assumption that people with VFDs would experience difficult social encounters and inequity, nine participants expressed feelings of admiration and respect, believing those with VFDs to be ‘brave’ and ‘strong’:

I feel proud of them for being proud of who they are.

It just makes me think how hard it must have been to grow up with a facial disfigurement and to face life with courage and determination ever since they were little.

Having to go out each day, living your life yet knowing that everyone is staring at you, anyone who has facial disfigurements are very, very brave for going out and showing the world who they are.

Although apparently not ill-meaning, this theme revealed some of the assumptions that appear to be implicitly embedded in these young people’s understanding of the world.

Behavioural intentions

Young people’s reflections on how they thought they might behave if they met someone with a VFD were strongly highlighted by the data. For many, this was an important topic, due to the confusion and anxiety that they thought they would experience due to not knowing how to behave appropriately or how to overcome social barriers.

Uncertainty

Being uncertain about what to say and how to act around people with VFDs was a commonly reported behavioural response. For 14 participants, this stemmed from a lack of confidence and a lack of understanding about how to approach and interact with someone who was visibly different.

Many of the participants were curious and therefore wanted to talk to the people with VFDs and ask them questions about their condition:

I have the urge to touch it and ask lots of questions about it.

I would like to speak to them and ask them if it affects their life and how they deal with it.

Despite this curiosity, the young people in this study did not want to cause offence or embarrassment by appearing to be too interested:

I feel nervous and a bit guilty for being curious, and I wouldn’t know what to say.

I wouldn’t want to make them feel different by drawing attention to it.

You feel a bit embarrassed and you don’t know what to do. You try not to look at them because you don’t want it to feel like you’re staring at them.

If they came over to talk to me I would panic because I don’t know whether they don’t want me to look directly at them.

Avoidance

As a means of coping with this uncertainty, and with their feelings of fear or unease, 13 participants stated that they would resort to avoiding the person who was visibly different:

I don’t look at them, I would just look away.

I know this is a little harsh but I would try and avoid them. It makes me feel uneasy and I don’t know what to say to them and if what I say would offend them.

I don’t think I would go up to them or start a conversation. I would probably just keep my distance.

One or two of the participants felt that this concern might prevent them from forming a longer-term relationship with a person who was visibly different:
I know this is bad, but I would be a little reserved about making friends with them because I wouldn’t know how to act around them.

**Compassion**

In total, 21 participants talked about wanting to help or to do something positive for those with VFDs. Often these intentions related back to the feelings of sympathy and concern that people with VFDs might face discrimination. Equally, the participants felt that these people did not deserve to live with such conditions and therefore merited compassion and kindness:

- It must have been hard. It makes me feel I should help, but how?
- I wish I could help them somehow. I wish this didn’t happen to people. I feel sad and I want to help them.

These comments demonstrate how a lack of awareness and confidence may result in behavioural responses such as avoidance, which may be interpreted negatively by people with VFDs. Five young people felt that the way in which they behaved would be influenced by how severe they perceived the difference to be:

- Some of them aren’t that bad, but others are more scary so I wouldn’t want to be near them.

However, six participants stated that the person’s difference would not affect how they behaved towards them:

- I would treat them like I would treat anybody else.
- I’m going to go over and say ‘Hi.’

**Discussion**

Qualitative analysis revealed the range and complexity of young people’s responses to the VFDs of others. This highlighted a number of challenges for those wishing to intervene, and provoked a number of suggestions as to how this intervention might be achieved.

As described in the first theme, participants frequently used the terms ‘them’ and ‘us’ when describing how they felt about people with VFDs. Although many of the participants insisted that people with VFDs were ‘normal’ and should be ‘treated equally’, the use of these terms illustrated the way in which the young people had constructed those with a VFD as belonging to a separate group from themselves. This was also the case for those participants who described people with a VFD as being ‘special’ or ‘unique’, despite the likelihood that these statements were intended to be positive in nature.

The young people in this study expressed a range of initial reactions to the photographs of people with VFDs, many of which were quite emotive. The most common response was shock or surprise, with some participants also citing fear as their first response. These initial reactions are likely to stem from seeing something different or unusual, and although such responses may not be ill meant, they may be inherent and resistant to change (Gilbert, 1997). Since the way in which the person with a VFD perceives and interprets social encounters is a clear predictor of outcome in visible difference (Billaud Feragen et al, 2009), it may be beneficial to help the person with the VFD to understand the range of natural reactions to their difference, and to reframe their interpretations of these social situations in a positive and constructive manner, rather than believing them to be entirely challenging or stigmatising.

In addition, a number of studies in the field of appearance have examined the influence of the affected person’s own behaviour on the success of social encounters with others. For example, the early work of Rumsey et al (1986) examining the effect of the presence or absence of an artificially applied facial birthmark in combination with a high or low level of social skill found the most positive social encounters to occur with those who had a VFD and a high level of social skill. This highlights the main methodological weakness of the present study in its use of photographs as opposed to real-life encounters. Seminal research has shown that although appearance is important for forming initial impressions of others, numerous other factors, including social skill and indicators of temperament, become more important after the first 15 seconds of meeting someone new (Bull and Rumsey, 1988). As well as helping those with a VFD to counteract the potentially negative effects of other people’s initial reactions to their difference, interventions could also address the opportunity for them to make the most of each social experience by using encouraging body language and proactive conversational skills in order to overcome social barriers and to instigate and maintain positive social encounters (see also www.ypfaceit.co.uk).

Many of the young people provided evidence of their belief that those with a visible difference would face discrimination and ‘have a hard life.’ This assumption resulted in a number of conflicting emotions and judgements. The participants felt saddened by the fact that these people were affected by a VFD, and believed this to be ‘unfair.’ This also led them to express a desire to help those with a VFD, although they were unsure how they might be able to do this. Participants described their feelings of admiration and respect towards people with a VFD, based on the assumption that these individuals would have to endure discrimination on a daily basis. This also led
to participants engaging in some downward social comparisons, in which they expressed gratitude that they were not affected by a VFD, and guilt for being so concerned about their own appearance.

Although some of the participants clearly held some unhelpful assumptions about individuals with VFDs, this was mostly related to the fact that they had little knowledge, understanding or experience of these types of conditions. One participant commented on the influence of the media in maintaining unhelpful stereotypes of people with a VFD. Some participants believed that a ‘quick fix’ was available in the form of surgical intervention. Others were afraid that they might ‘catch’ the VFD, reflecting the possibility that people have an unconscious desire to avoid anything that might be contagious (Rumsey and Harcourt, 2004). There is clearly a need to continue to raise awareness about visible differences among the general public, and to encourage the adoption of an inclusive social environment both in schools and in society as a whole (Frances, 2004).

The range of conflicting emotions and assumptions that the participants described appeared to provoke uncertainty about how best to behave. Participants were inquisitive about the condition but did not want to cause offence or embarrassment by appearing to be too interested or asking too many questions. Similarly, participants stated that they would not want to upset the person with the VFD by staring at them, but would find it difficult not to look at them out of curiosity. In some cases this conflict led to participants feeling nervous or guilty, which in turn resulted in them stating that they might avoid the person with the VFD. Consequently, it may be beneficial to teach young people social skills to encourage appropriate behaviour towards those with an appearance different from the norm, and to build young people’s confidence in these types of social situations. Lovegrove and Rumsey (2005) demonstrated the potential of such an intervention in a school setting. After seven 1-hour sessions, young people’s levels of confidence about approaching someone who looked different to them had significantly increased compared with the non-intervention group.

Although the majority of the participants’ reactions, assumptions and anticipated behaviours were not intentionally harmful in nature, a small minority of the young people in this study did express more negative views and emotions. These participants used some judgemental adjectives to describe the people with VFDs, such as ‘disgusting’ or ‘weird.’ These descriptions were linked to laughter or aversion as the primary response, which in turn may result in behaviours that are unhelpful to people with VFDs. According to a key paper by Clarke (1998), it can only take one unhelpful person, or one negative incident, to destabilise a person’s self-esteem and confidence. Although this group represents a very small proportion of the participants in this study, there is a strong need to emphasise this element in intervention design.

A number of additional limitations of this study must be acknowledged. Although the study attempted to capture the views of a diverse group of young people, the identification of cultural differences was not a specific focus of the research. Although little research in this area has been conducted within minority-ethnic communities, some studies have found interesting and insightful variations that are important to investigate further (Hughes et al, 2009). In terms of methodology, the researchers had little control over the manner in which responses were collected, due to the school setting. Although care was taken to deliver appropriate instructions to teachers, the responses may not have been as confidential and unbiased as one would hope. Finally, the potential for questions to be leading is always a concern in this type of investigation. However, an equal number of positive and negative statements were presented to participants in an attempt to reduce this potential effect. Although the study invited self-reported responses, which must be interpreted with some caution due to the potential for an effect of social desirability, this study did not replicate the picture of predominantly negative perceptions and high levels of stigma that has been indicated in some of the previous research. Rather, the data revealed the issue to be far more complex, with the majority of the initial reactions and unhelpful behaviour being associated with a lack of understanding and confidence, rather than being intentionally harmful. This study has also highlighted some of the problems inherent in the methods previously and currently used to examine people’s perceptions of VFDs. Future research in this area should consider more appropriate ways of capturing the complexity of responses.

The findings of this study can help to inform the design of interventions to promote positive attitudes to diversity in appearance. They suggest that there is a need for intervention at a number of different levels, including the level of awareness and education about VFDs among the general public, the behavioural skill and confidence of others in approaching and interacting with someone with an unusual facial appearance, and, for those who have a VFD, an understanding of the complexity and range of responses that they may receive from others.

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CONFLICTS OF INTEREST

None.

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