Research paper

Positively managing intrusive reactions to disfigurement: an interpretative phenomenological analysis of naturalistic coping

Andrew R Thompson BA(Hons) DClinPsych CPsychol
Senior Lecturer in Clinical Psychology and Chartered Clinical Health Psychologist

Lucy Broom BA(Hons) DClinPsych
Clinical Psychologist

Department of Psychology, University of Sheffield, Sheffield, UK

What is known on this subject
- People with a disfigurement can experience being staring at or being ignored, as well as outright discrimination.
- Those living with a visible difference can experience significant psychosocial distress.
- There is marked individual variability in the psychological impact associated with disfigurement, with some people clearly coping well. This variability is not accounted for by simply clinical or demographic factors.

What this paper adds
- Uniquely, it provides an insight into the experiences of people with a disfigurement who perceive themselves as successfully managing the intrusive reactions of others.
- It identifies positive coping strategies that are naturally used, and identifies ‘adjustment’ as an ongoing process.
- It provides qualitative support for emerging stigmatisation theory.

ABSTRACT
There is a dearth of research that has explored how people with a visible difference naturally manage the reactions of others. In this study the experience of people with a visible difference who felt that they successfully managed the reactions of others was explored. Six women and two men with a variety of disfiguring conditions participated in a semi-structured interview, which aimed to explore their experience of managing others’ reactions. The interview transcripts were analysed using interpretative phenomenological analysis (IPA). The participants used a range of emotion-focused and problem-focused strategies to cope. Despite selecting themselves on the basis of self-perceived coping, it was apparent that some of the participants were still experiencing difficulties in adjusting. The findings suggest that adjustment to disfigurement is an ongoing process. They also have the potential to inform the development of clinical interventions for people who are struggling to cope with stigmatising reactions.

Keywords: disfigurement, interpretative phenomenological analysis, positive psychology, stigma
Introduction

Visible difference or disfigurement can arise from congenital malformation, trauma or disease, or it may be iatrogenic (i.e. a result of medical intervention). Studies demonstrate that those living with a visible difference can experience significant psychosocial distress (Thompson and Kent, 2001; Kent and Thompson, 2002; Rumsey and Harcourt, 2004, 2005). People with a disfigurement may experience being stared at or ignored (Bull and Rumsey, 1988; Rumsey, 2002a,b), as well as outright discrimination (Jowett and Ryan, 1985; Turner et al., 1983). Indeed, there is some evidence to suggest that reactions towards people with a disfigurement may be automatic (Grandfield et al., 2005).

Given the reality of experiencing such negative reactions, it is not surprising that higher than average levels of psychological distress have been reported, including anxiety (Jowett and Ryan, 1985), depression (Hughes et al., 1983) and low self-esteem (Porter and Beuf, 1988). However, in their review, Thompson and Kent (2001, p. 677) note that there is marked variability in the impact of disfigurement, with some people clearly coping well:

clearly, the way that disfigured persons think about their disfigurement, their self and their encounters with others will be influenced by the interaction of self-schemas with the social context. Such schemas are acquired through early experience, and will vary in the degree to which they predispose individuals to be concerned with the approval of others and the importance of appearance.

However, such ideas have yet to be rigorously tested.

Most disfigurement research has employed quantitative methodology, and it has been suggested that there is a need for qualitative studies to facilitate further understanding of the adjustment processes described above (Thompson and Kent, 2001; Rumsey and Harcourt, 2004). In addition, both Thompson and Kent (2001) and Rumsey and Harcourt (2004) have called for research that focuses on exploring positive adjustment.

Only recently has research started to take a positive stance and pay attention to protective factors, rather than focusing on deficits. For example, Meyerson (2001) interviewed people with Moebius syndrome, a condition associated with facial paresis, and identified a range of psychosocial factors, including humour and faith, as being linked to positive adjustment. Similarly, a study by Thompson et al. (2002) of women living with vitiligo reported that the participants had spontaneously developed coping skills akin to the types of strategies often taught as part of therapy, and that social support had been instrumental in facilitating this process. Lobeck et al. (2005) reported that men who initially felt different as a result of their stroke developed a variety of strategies, including humour, to manage this. Recently, Saradjian et al. (2008) have reported how men who have lost an arm employ a range of strategies to minimise their distress.

The small amount of research in this area has been conducted with people who are currently engaging with the healthcare system (Saradjian et al., 2008) or contact support organisations (Lobeck et al., 2005), and there is a need for community-based studies. Consequently, the aim of this study was to explore the experience of people with a disfigurement who successfully manage the intrusive reactions of others, without the need for service intervention. A qualitative methodology is the most appropriate approach to meet this aim of gaining an in-depth understanding of people’s lived experiences of managing the reactions of others.

Method

An interpretative phenomenological analysis (IPA) was used (Smith, 1996; Biggerstaff and Thompson, 2008; Eatough and Smith, 2008). This approach facilitates in-depth exploration of individual experience, placing emphasis on identifying meaning, so was ideal for the aims of this study. IPA has been used in other similar studies (Thompson et al., 2002; Lobeck et al., 2005; Saradjian et al., 2008), and it draws on the philosophical traditions of both phenomenology and hermeneutics. As in the phenomenological tradition, the meanings that an individual ascribes to events are the central concern, but IPA also acknowledges the hermeneutic tradition, in embracing the role of the researcher in the interpretative process. Further discussion of the epistemological underpinnings of IPA can be found in articles by Eatough and Smith (2008) and by Smith (2007).

Participants

Individuals were considered for inclusion in the study if they had an appearance-altering condition that was visible to other people, if they had experienced negative reactions and if they perceived themselves as managing these reactions well. Individuals were excluded if they were currently receiving or had ever received formal psychological support. The study employed a purposive sampling technique and recruited through the media. This method of recruitment was used because of the focus on recruiting individuals who were coping well, without intervention from healthcare professionals or self-help organisations. After obtaining ethical approval for the study from the University of Sheffield, participants were recruited via community radio station, a regional daily newspaper and a BBC regional
radio station with audiences in the north of England. The radio interview was also posted on BBC web and teletext pages, which extended recruitment.

Potential participants were screened via telephone for eligibility. All of the participants gave informed consent for extracts from their interviews to be published. Six women and two men took part in the study. The participants were white and spoke English as their first language, were aged between 20 and 69 years, and lived in a range of geographical locations. Two participants had congenital conditions and six had acquired conditions. Further details of the characteristics of the participants are shown in Table 1.

**Procedure**

Individual, semi-structured interviews were conducted, during which the participants were invited to talk about their experiences of managing negative reactions to their visible difference. The interview schedule was developed using the guidelines recommended for IPA (Smith, 1996), with specific questions being tailored to the individual account. The interview process was further informed by the critical incident interview technique (CIT; Flanagan, 1954), with participants being asked to discuss two or three recent critical incidents. Flanagan (1954, p. 327) originally defined an incident as ‘any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act’. In this study, critical incidents referred to the way in which episodes of intrusive reactions from others were experienced and managed.

The average duration of interviews was 90 minutes. All interviews were recorded and process notes were made. The interviewer was a 31-year-old, white, middle-class, female psychologist, without any disfigurement, who had clinical experience of conducting sensitive interviews.

**Data analysis**

The interviews were transcribed verbatim and analysed using IPA. The latter is a systematic approach to the analysis of idiographic data (Eatough and Smith, 2008), which assumes that verbal reports can reflect individuals’ underlying cognitions, but that these will be affected by the interaction in which the interview takes place, and the sense that the researcher makes of the information (Smith, 1996). It has been suggested that data analysis within a critical incident technique framework can be approached in a similar way to other qualitative studies (Schluter et al., 2008), although Flanagan (1954) clearly devised the procedure from a direct-realist position, which does not sit comfortably with the more critical-realist stance of IPA. Consequently, the guiding framework of analysis used here was drawn from IPA.

The analysis began with the second author reading the first interview transcript, while listening to the audiotape, in order to check the script for errors. The first transcript was then read a number of times and, during this close reading, preliminary thoughts, observations and attempts at early interpretations were noted alongside the text. Eventually, a number of themes emerged from the data, which were clustered together in a hierarchical fashion. A table of master themes was produced containing all super-ordinate and sub-ordinate themes, as well as a key quotation and page and line numbers for all supporting data. This process was repeated for each participant. At this point, to explore reflexivity, the table of master themes and transcripts for two randomly selected participants were audited by the first author. This both ensured the credibility of

<table>
<thead>
<tr>
<th>Table 1 Biographical characteristics of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pseudonym</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>Nick</td>
</tr>
<tr>
<td>Louise</td>
</tr>
<tr>
<td>Andrea</td>
</tr>
<tr>
<td>Frank</td>
</tr>
<tr>
<td>Emma</td>
</tr>
<tr>
<td>Yvonne</td>
</tr>
<tr>
<td>Gail</td>
</tr>
<tr>
<td>Linda</td>
</tr>
</tbody>
</table>
the findings and allowed discussion of the rationale for the results in relation to the reflexive journal kept by the second author (Mays and Pope, 2000). A descriptive theme table consisting of key quotes and brief summaries was prepared for each participant.

Participants were sent their descriptive list of themes for member validation, and their comments were incorporated into the analysis. The emergent themes were then revisited with a view to grouping and making interpretations across all transcripts, while remaining grounded in the individual participants’ accounts.

**Findings**

Two broad process themes emerged, namely managing the internal impact and managing the external impact. These processes were not mutually exclusive. Table 2 provides a summary of the key super-ordinate and sub-ordinate themes within each process (these are elaborated on below). In order to protect anonymity, pseudonyms have been used.

**Managing the internal impact**

**Adjustment to difference**

The majority of the participants described adjusting to life with a visible difference as an ongoing journey that took time. It was evident that it might also not have a definitive end point, and could be somewhat fragile.

For example, Nick talked about the first five years after his accident:

‘I would have been far too self-conscious and also not confident enough to come in here and talk to you.’

(Nick)

Nick considered corrective surgery for his scar, but realised that the scar could not be completely removed. It was this realisation that started the ongoing adjustment process, which appeared to culminate in adaptation, although clearly not in complete acceptance:

‘You’re just going to have to live with it ... but it takes such a long time for that, that doesn’t happen in weeks or months.’

(Nick)

Similarly, Linda made an unsuccessful attempt to change the appearance of her skin with prescribed creams, which led to the realisation of the irreversibility of the disfigurement and the start of the adjustment journey. An important part of Linda’s journey was the discovery of make-up:

‘There wasn’t anything anybody ... could do about it, and so I then felt that I had to do a cover-up job and it was a very difficult ... that was the first part of my overcoming.’

(Linda)

After 20 years, Linda’s journey had culminated in self-acceptance of her difference, but nevertheless there was a sense of fragility to this and a dependence on concealment:

<table>
<thead>
<tr>
<th>Process</th>
<th>Super-ordinate theme</th>
<th>Sub-ordinate theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing the internal impact</td>
<td>Adjustment to difference</td>
<td>The ongoing journey of adjustment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-acceptance</td>
</tr>
<tr>
<td></td>
<td>Helpfulness in adjustment</td>
<td>Positive cognitive processes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inclusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Value of appearance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personality style</td>
</tr>
<tr>
<td>Managing the external impact</td>
<td>Interpreting reactions</td>
<td>Negative reactions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shock, shame and humiliation</td>
</tr>
<tr>
<td></td>
<td>Coping with reactions</td>
<td>Acceptable reactions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Engagement, concealment and avoidance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Normalising reactions, external attribution and humour</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social support</td>
</tr>
</tbody>
</table>
Many participants talked about self-acceptance in its own right. One of the participants, who had been born with a birthmark, described how her face would look odd without the birthmark, and how it was society who could not accept it. Other participants, who had acquired their disfigurement, also clearly felt that they were the same people as they were before the disfigurement appeared, and the same as everyone else. There was a sense of them defending themselves in anticipation of potential stigmatising reactions from others:

'It don’t feel no different. I know I might look different ... I don’t let it bother me, I never have done, I can’t turn [the] clock back ... you’ve got to live with what you’ve got.'

(Frank)

'You’ve got the scars, you’re still the same person, I mean it never stopped me doing anything.'

(Emma)

**Helpful factors in adjustment**

The participants talked about psychological, social and cultural factors that helped them to adjust to having a disfigurement. These factors involved the use of positive cognitive processes such as external attributions, downward social comparisons, positive meaning making, and growth. Additional helpful factors included the degree of inclusion felt, and the value attached to appearance, as well as personality characteristics. The participants made external attributions about the cause of their difference, attributing it to unforeseeable events, or to an accident of birth. Louise’s scars were acquired through corrective surgery, ‘so it was beneficial to me to have scars.’

Some of the participants made downward social comparisons with people with more severe disfigurements, or with life-threatening health problems, in order to minimise their own difference. Finally, some participants attached positive meanings to their visible difference and found ways to use it to their advantage. This was particularly well illustrated by Nick, who described how his scar gave him kudos among the biking community and was a useful way of assessing potential relationships:

'It is more beneficial to have the scar because you know that people aren’t looking for something else ... it’s not going to be ... such a shallow relationship.'

(Nick)

All of the participants talked about their experiences of inclusion, in terms of both acceptance by others and inclusion in society. On a personal level, the participants felt accepted by partners, friends, family and colleagues. They also felt accepted by other people with similar differences, and by the communities in which they lived and worked:

'I’ve been a member of this community for seven years ... rarely will people stare at me for a very long time, even the new students. ... I’m playing on a more level playing field I think when it comes to meeting people, like we’re meeting as minds and personalities.'

(Gail)

Some of the participants described the influence of positive role models during their childhood. Gail’s parents facilitated her inclusion in society from an early age:

‘You’re going to go out there ... we’re behind you if you need anything and ... you’re a strong person and you’ve got a lot to offer and this is when you’re like ... six or seven and you think, okay, fine ... and so I wasn’t afraid, I had a very social life from the very beginning.’

(Gail)

Lastly, there was an acknowledgement of the need to be connected to others. As Gail stated, ‘Being needed and wanted and having a role in society is a very good answer to feeling alienated’.

The value that participants attached to their appearance seemed to have a significant effect on adjustment. For example, although it was important to Gail to look nice, she placed a lesser value on appearance than on other aspects of herself, and she discussed this within a social context of experiencing pressures to value appearance highly:

‘I make certain choices about what to get sort of worked up about and right now I’m far more concerned that intellectually I have a long way to go, than I do sort of physically to meet some sort of physical perfection. ... It’s amazing, I mean people really think that happiness ... equals ... appearance.’

(Gail)

Two participants appeared to attach a relatively high value to appearance, which seemed to have made adjustment difficult at times. For Linda, this might have been learned through upbringing: ‘I had a mother who insisted that I always had to look the part, so that’s kind of inbred.’

Nonetheless, the participants appeared to have brought other aspects of themselves to the fore, which had enabled them to develop and maintain their self-esteem by combating a narrow definition of themselves in relation to their appearance alone. These aspects included focusing on occupational, intellectual and family aspects of self:
‘I’m married, I’ve got kids, got a house, a job and you know, some ... post-qualification courses ... I do this and I do that ... I’ve got friends and ... so you become defined, not just by how you look but by what you do.’

(Yvonne)

Nearly all of the participants talked about their personalities, and personal characteristics that had helped them, which included courage, gregariousness, self-assurance, maturity, determination, emotional openness, stubbornness and confidence. This self-identification of positive attributes could be viewed as a positive cognitive process:

‘I’m a stubborn old bleeder (laughs) ... very stubborn ... doctors will say one thing and I think another. If they say, you might be able to walk, I will walk, it’s all up here, state of mind.’

(Frank)

Managing the external impact

Interpreting reactions

All of the participants talked about the negative reactions they had experienced, but different participants had different beliefs about what made a reaction negative. For some it was simply when such reactions were perceived as breaking social rules, whereas for others it was when they were perceived as personal affronts. In either case, participants often felt shock, shame and humiliation:

‘I was in a sauna, and this lady said: “Oh, what have you done to your neck?” [laughs] I can’t believe it. I wouldn’t dare ask anybody about that.’

(Andrea)

‘It had not happened for a long, long time that and, I’ve said to you, I felt dirty. ... I can’t describe the feeling, just feel, ashamed and dirty.’

(Emma)

Not all reactions were interpreted as negative, and participants described some potential intrusive reactions as acceptable. For some, ‘up-front’ questions were perceived as acceptable:

‘If somebody asks like ... fair enough. That’s where somebody is asking a question, not criticising.’

(Frank)

Coping with reactions

Participants described a range of coping strategies to manage negative reactions, which are categorised as engagement, concealment and avoidance, normalising reactions and making external attributions.

A range of engagement strategies were used, which were largely determined by the perception of the reaction received. The most popular strategies were smiling and ignoring people. Smiling was mainly used in response to staring, and ignoring was used when it seemed difficult to engage with someone, or to reduce the likelihood of further comments:

‘I just ignored him, it’s just the easiest way ... I think with people like that, even if I’d explained it was through surgery, it wouldn’t have made any difference.’

(Louise)

Giving an explanation was another strategy, which was mainly used when people were perceived as asking acceptable questions. Giving explanations had had positive consequences for many participants, leading to friendships and even marriage, but was also described as being burdensome:

‘Do I have some moral responsibility to be this educator because I have the birthmark, you know? And that’s the tension I feel sometimes.’

(Gail)

Some participants described weighing up this burden and taking others into consideration in doing so:

‘I just decided it wasn’t really worth it ... and so he went off on his merry way.’

(Gail)

This is in contrast to more combative strategies that were sometimes used. In particular, the two male participants occasionally used aggressive strategies, ranging from intimidating eye contact, through to physical action, in response to feeling humiliated:

‘Ten minutes later he’s got his head in the urinal and I’m ... peeing down the back of his neck.’

(Frank)

The use of such strategies is likely to be seen as unhelpful by professionals, but was perceived as positive by the participants, as they deemed themselves to have dealt with a humiliating other, thereby regaining their social status. It is likely that socio-cultural factors are at play in such responses:

‘We were rogues, loveable rogues, my ... youngest uncle and myself, used to go poaching ... it taught us a way of life ... being independent.’

(Frank)
A number of participants used some form of concealment as a way of coping with people’s reactions. For Linda, concealing her skin damage with make-up was a way of coping with reactions. Louise used a range of concealing safety strategies on holiday, which were both a consequence of experiencing negative reactions and a way of avoiding further comments. They included wearing jeans, hiding one leg behind the other and standing in the middle of her friends:

‘I’m going to cover them up and try and reduce them as much as I can.’

(Louise)

Andrea used running away as an avoidant coping strategy when she was bullied at school. She attributed this to a lack of confidence, which she feels made the bullying worse. Andrea wished she had been more confrontational in those situations, but feels that this was not part of her character:

‘I’m not really the type of person to say what’s it to do with you [laughs].’

(Andrea)

Nick and Yvonne concealed their differences with clothes, but were clearly aware of the potential for concealment to be unhelpful:

‘I did go through a period of ... wearing scarves and high collars and things, but I realised it, you know, my daughters would say, look mum, frankly, it just makes you look worse [laughs].’

(Yvonne)

‘If there’s an 18-year-old lad with a scar on his neck and he’s wearing polo necks, I’d get that ... polo neck off.’

(Nick)

The majority of the participants adopted a normalising view as a way of coping with people’s reactions. Staring was the main reaction that people saw a normal human reaction:

‘They are going to look because I look different and that’s okay because it’s normal for people to notice something that’s anomalous and try and make sense of it ... people very quickly get ... habituated to that, and will start to see you, to see other aspects of you if they have a chance to get to know you.’

(Yvonne)

Some of the participants externally attributed negative reactions to the other person, linking this to that person having negative characteristics:

‘Just really rude and sort of common type of people.’

(Louise)

Three participants used humour during the interview as a strategy for minimising the impact of people’s reactions on themselves in front of the interviewer. The particular tools used were sarcasm, understatement, self-deprecation and laughter:

‘I’ll be all right speed dating with a blind woman [laughs].’

(Nick)

Participants found that social support helped them to cope with other people’s reactions. Louise felt supported by her friends on holiday because they accepted her and shared her battles:

‘I reckon it was probably my friends because ... they were obviously there with me all the time and they heard the reactions and they know why I’ve got the scars, so they were quite supportive ... saying, “Oh, don’t let people get you down”.’

(Louise)

Discussion

Previous research on visible difference and more broadly on stigmatisation in general has focused largely upon negative reactions. This study is unique in that it has explored the experience of successfully managing the intrusive reactions of others. The results suggest the presence of two overarching processes that were labelled as managing the internal impact and managing the external impact.

The first of these processes refers to the participants’ experience of stigmatisation and the need to adjust to this. Some participants described adjustment as a journey from initial self-consciousness and psychological distress through to the incorporation of their condition into their self-image, while for others age played a role in this process.

However, despite perceiving themselves as coping well, the participants described an ongoing process that was in some cases fragile. This suggests that people find living with a condition that is potentially stigmatising to be psychologically demanding, which is consistent with reports from some previous studies (Thompson et al., 2002). It is also consistent with the seminal theory of Goffman (1963) about stigmatisation, which posits that a central concern of people who are stigmatised is anxiety about acceptance and a fear of being discredited. Goffman’s theoretical model still seems to be applicable in relation to making sense of avoidance, although it does not take into consideration the role played by dispositional characteristics.

Social inclusion and acceptance were important for all of the participants, and came from a range of
Individuals were recruited to this study if they actually experienced negative reactions. Participants described using a range of cognitive and behavioural coping strategies to manage this external impact. This is consistent with the categories of problem-focused and emotion-focused coping described by Lazarus and Folkman (1984) and Lazarus (1993). Participants used a range of pro-social engagement strategies, such as smiling, giving an explanation and confrontation. The use of these strategies tended to vary according to the situation. Partridge (1997) has discussed the use of a variety of socially pro-active skills to manage the intrusive reactions of others, such as educating, staying calm and assertively confronting negative reactions. Research suggests that the possession of positive social skills is related to successful adjustment and can actually reduce the social impact of a disfigurement by facilitating more open and friendly behaviour in others (Rumsey et al., 1986; Robinson et al., 1996). Some of the participants used concealment and avoidance strategies that might lead to psychological difficulties, because people with hidden differences have less opportunity to face the reactions of others and thereby adapt to an altered appearance (Cahners, 1992).

Although this study utilised a small sample and qualitative methods, there appeared to be a gender-related difference in the way in which the participants dealt with disfigurement. Cultural norms were evident in this. For example, women were more likely to use make-up to conceal, and men were more likely to use aggression. The two male participants used engagement strategies that were further towards the anti-social end of the continuum, and which may have been linked to feeling humiliated. Gilbert (1997) suggested that one of the ways in which shame and humiliation differ from each other is in variations in the defensive strategies. For instance, people who feel humiliated tend to react with aggression rather than in a submissive fashion. Normalising other people’s reactions, particularly staring, was a popular strategy used by participants, and involved the belief that people who stare are motivated by curiosity rather than by malice. Another popular strategy was attributing people’s negative behaviour to some character flaw or negative attribute that the other possessed, rather than engaging in personalising. According to attributional models of emotion, negative outcomes attributed to external factors are less likely to lead to negative emotion than are negative outcomes attributed to internal factors (Weiner, 1985). Three participants used humour as a coping strategy. Some studies of humour have been reported in the psychological literature (Kuiper et al., 1993; O’Connell and Baker, 2004; Lobeck et al., 2005; Saradjian et al., 2008), and humour appeared to be a useful strategy for the participants in this study.

Sources. Argyle (1988) has suggested that social support may help people by providing a sense of being accepted through the maintenance of self-esteem, and the participants who felt accepted and included did also appear to have high levels of self-esteem. The psychological literature suggests that generally higher levels of social support are related to better adjustment in disfigurement (Thompson and Kent, 2001), and for the participants in this study, social support provided both a sense of being accepted and reassurance at times when the participants were subjected to humiliating reactions.

Most of the participants attached as much (or more) value to other aspects of themselves as they did to appearance, such as career success and family roles, and these played an important part in developing and maintaining their self-esteem. The value that participants attached to their appearance seemed to have a significant impact on their adjustment to visible difference, with participants who placed a lower value on appearance finding it easier to adjust to looking different, and those who placed a higher value on appearance finding it harder to adjust. This lends support to other emerging evidence that adjustment is linked in part to the degree of emphasis placed on appearance aspects of self-concept (Thompson and Kent, 2001; Moss and Carr, 2004). Altabe and Thompson (1996) have demonstrated that people may have appearance schemas, that is, specific cognitive structures associated with appearance. People with negative or/and highly valued appearance schemas are likely to become hyper-vigilant, and to interpret others’ behaviour negatively in socially activating situations. Both of these behaviours were described by the more appearance-conscious participants.

Most of the participants felt that their personality style had helped them to adjust to and cope with having a disfigurement, and they described a range of personality characteristics. The literature on personality and coping (e.g. Kobasa et al., 1981) has identified hardiness as a characteristic found in people who are less likely to become ill in times of stress. Several studies suggest that dispositional optimism is related to the use of active coping strategies (e.g. Carver et al., 1989). These constructs may be similar to the ‘dogged’ determination and ‘bloody-mindedness’ described by the participants in this study, which are essentially about resilience and which require further investigation.

As reported in some other studies (e.g. Thompson et al., 2002), the participants used a variety of cognitive mechanisms, such as making external attributions about the cause of their difference and making downward comparisons, which were both social and personal. Lazarus and Folkman (1984) and Lazarus (1993) has described these strategies as emotion-focused coping strategies, because they involve thinking about the problem in a way that alters the perception of it, which then reduces its emotional impact.
Limitations of the study

Several limitations of the present study require discussion. First, the participants were self-selecting in terms of identifying themselves as coping well with others’ reactions. Although such a selection process fits with the underlying aims of the study, and indeed raises interesting questions about adjustment, there may be merit in replicating this study with people selected on the basis of a psychometrically defined measure of adaptation. Secondly, the causes of disfigurements in this sample varied widely, and it is usual for IPA to be performed with a homogenous group. That said, as with other studies in this field, the aetiology of the disfigurement did not appear to be a particularly significant factor in adjustment. Finally, the study is based on interviews with a small group of participants, and consequently further research is needed to test the applicability of the findings.

Conclusion

Future research needs to explore how personality styles and social contextual factors influence adjustment and the management of intrusive reactions. There is a difference between enduring personality traits such as resilience, and the coping strategies that people use, and further studies need to explore the influence of the former on the latter (Tugade et al, 2004). The findings of this study have implications for informing psychological theories of adjustment to disfigurement, and also have implications for wider stigmatisation theory. Recently, Richman and Leary (2009, p. 365) have described a new global model of reactions to stigmatisation, which posits that ‘people’s reactions are influenced by construals of the rejection experience that predict three distinct motives for prosocial, antisocial and socially avoidant behavioural responses.’ The findings here are commensurate with the contextual and dispositional factors described by Richman and Leary as accounting for these motives, although clearly further studies are needed to test this model.

The findings of this study are also useful clinically in suggesting that the assessment of individuals with stigmatising conditions should include greater consideration of personality and social variables. Therapeutic approaches should encourage people to use cognitive techniques, such as making external attributions and normalising reactions, and assist in the learning of social skills (Partridge, 1998). Individuals with stigmatising conditions could also be encouraged to develop additional elements of their selves in order to enhance their self-esteem, combat feelings of shame and reduce the value given to appearance.

REFERENCES


**CONFLICTS OF INTEREST**
None.

**ADDRESS FOR CORRESPONDENCE**
Andrew R Thompson, Senior Lecturer in Clinical Psychology, Department of Psychology, University of Sheffield, Western Bank, Sheffield S10 2TP, UK. Tel: +44 (0)114 2226637; fax: +44 (0)114 2226610; email: a.r.thompson@sheffield.ac.uk

Received 20 April 2009
Accepted 17 June 2009