Background Reading

The Psychosocial Impact of a Visible Difference

Recent figures estimate that in excess of 1.3 million people in the UK have a significant disfigurement to the face or body (Changing Faces; 2010), including birthmarks, burn scarring, skin conditions such as vitiligo, acne, eczema and psoriasis, cleft lip and palate and other craniofacial conditions. In addition there are around one million presentations to hospital for treatment associated with some form of facial injury as a result of accidents, falls or assaults (Cartwright & Magee; 2006)

Although many adjust well, some individuals struggle to come to terms with their visible difference and irrespective of whether present at birth or acquired later in life, their appearance can have a profound psychological and social impact (Rumsey & Harcourt; 2007).

Appearance is also a highly sensitive and private subject and one which many people are reluctant to raise as a concern; particularly those with the perception that their concerns will be minimised or disregarded as trivial or vain and secondary to issues of physical well-being or even survival (Bessell et al, 2010). Health professionals who are aware of the potential psychosocial impact of a visible difference therefore have a vital role to play in validating and de-stigmatising appearance concerns among their patients. By being proactive and providing opportunities to discuss appearance, they can encourage their patients to express and identify their appearance–related worries and if necessary help them access specialist support.

Although the range of psychosocial difficulties experienced by those with a visible difference may vary from condition to condition, there are more similarities than differences. Common difficulties are discussed below.

Social Discrimination and Stigma

We live in a culture that values beauty, places a high degree of importance on appearance and has a tendency to mock or denigrate those deemed unattractive. Those who have assimilated these cultural norms into their own belief system are likely to find it difficult to accept their visible difference (Rumsey; 1997) and many of the problems faced by people with a visible difference are related to social situations and their experience of discrimination and stigma.

From an early age, the use of beautiful heroes and heroines (such as snow white) in Fairy Tales fighting against ugly villains (such as the wicked witch) teaches us to respond to physical differences with suspicion and uncertainty. These stereotypes continue into adulthood with the idea of beauty representing good being a running theme throughout many films and television programs.

There is often a great deal of uncertainty when people view something different, or out of the ordinary. This can lead to some of the negative responses you may experience from other people.

Research studies that have investigated the impact of our appearance, specifically how others see us have identified that when forming first impressions we tend to predict people's behaviour (both personality and intelligence) based upon their looks. These impressions can change on further contact.

There can also be problems in areas such as employment (Stevenage & McKay, 2009), with individuals with physical differences being less likely to be chosen for employment despite their qualifications or previous experience.

Permanently on Public Display

Staring from members of the public is one of the most common problems experienced by those with a visible difference (Rumsey et al; 2004) and is frequently combined with unsolicited questioning or comments about appearance, often in inappropriate settings. Members of the public may also feel the need to offer words of pity or sympathy for their plight or alternatively advise the person that their appearance is not actually that noticeable (Partridge; 1994). Again these comments are usually unsolicited.

Responses such as staring or questioning are not always intended to cause distress or offence (Bernstein; 1976). They can result from a lack of understanding about disfigurement and reflect concern or curiosity and a desire to seek explanation for the cause of the visible difference, or the individual's past experiences of treatment and treatment intentions (Partridge; 1994). But, irrespective of the motives behind these public responses, they can increase an individual's sense that they are permanently on public display, heightening feelings of self-consciousness and negatively impacting upon self-confidence.

Similar difficulties can arise as a result of "institutional gaze", a term used to describe an individual's experience of the intense scrutiny and constant involvement of health professionals in their lives (Hearst & Middleton; 1997). For example an individual who has scarring as a result of a road traffic accident, may undergo numerous surgeries over a long period of time which requires repeated trips to hospital and multiple assessments. This can be even more intense in the case of individuals with craniofacial abnormalities, who may undergo assessments and surgery over many years. This regular and repeated focus on the 'difference' may be unwelcome.

Psychological Distress

Being labelled as 'different' and experiencing social discrimination can have a wide variety of negative psychological consequences. Individuals may experience anxiety, depression, and low self-esteem. Some can feel angry about the reactions of others or angry and resentful that they have a visible difference or an appearance-altering condition (Kent; 2000, Newell & Clarke; 2000, Kent & Thompson; 2002, Lawrence et al; 2006, Blakeney et al; 2008).

Body Image Dissatisfaction

'Body image' refers to an individual's perception of how they look (Schilder; 1935) and is affected by an individual's emotions, attitudes and cognitions (Slade; 1994).

According to Higgins' (1987) self-discrepancy theory, there are three components to body image:

- Actual self (one's objective appearance)
- Ideal self (how an individual would like to look)
- Ought self (how one feels they ought to look)

For any individual, irrespective of whether they have a disfigurement, a discrepancy between the ideal self (body ideal) and the actual self can lead to body image dissatisfaction, low self-worth and distress (Altabe & Thompson; 1996, Rumsey; 1997). For those with a congenital or acquired visible difference, the risk of body image dissatisfaction is greater because their actual self may not match up to social norms (Gilbert; 1997) or, for those with an acquired difference, because their actual self no longer resembles their self-schema: their internal perception of how they think they look (Moss; 2005).

These outcomes will very much depend on the content and organisation of the individual's self-concept (Moss & Carr; 2004). If an individual values appearance highly and invests a lot of time and energy in their looks whilst investing less in other aspects of themselves, they are more likely to experience body image dissatisfaction and distress associated with having a visible difference (Lawrence et al; 2006).

Avoidant behaviour

Fear of negative reactions to their appearance by other people can lead to increased social anxiety (Langley et al; 2005). Social anxiety can then distort the focus of their attention and interpretation of events (Rapee & Heimberg; 1997). This can result in a heightened awareness of negative reactions, a tendency to look for and attend to such responses and heightened sensitivity to any reactions that may be perceived as negative (Kent & Keohane; 2001).

Newell's (1999) fear avoidance model suggests that if an individual finds that they can successfully reduce their anxiety by removing themselves from the anxiety-provoking situation, this (avoidant) behaviour will become reinforced and will be more likely to be used again in the future if the individual fails to manage their anxiety. This avoidant behavioural response can lead to self-imposed social isolation (Kent; 2000).

The Impact of the Severity of a Disfigurement on Adjustment

Many assume that the degree of severity or visibility of a disfigurement predicts the extent of psychological distress; that those with a minor disfigurement, or those with conditions that are not very noticeable, will probably adjust more effectively to their appearance than those with a major disfigurement. However, research consistently finds that this is not the case. An individual's subjective assessment of how noticeable the difference is to others tends to be a far better predictor of distress (Moss; 2005). In fact some research has suggested that those with more noticeable differences can learn to adjust more positively, because the responses of others tend

to be predictable and individuals know what reactions to expect - they are therefore forewarned and prepared.

In contrast, for those whose visible difference is not always noticeable, perhaps because the condition can flare up or subside over time (for example skin conditions, such as psoriasis or eczema), the unpredictable nature of others' reactions can make it difficult for them to adjust to their altered appearance (MacGregor; 1990, Lansdown et al; 1997).

Rather than relying on objective clinical assessments or personal judgements made by clinicians, it is therefore important to routinely ask young people how they judge and feel about their appearance.

The Therapeutic Framework of Face IT@home

Research has identified the importance of psychosocial support, particularly from health professionals, in helping individuals adjust to an altered appearance and supports the view that individuals need to develop a tool box of self-management skills, rather than a reliance exclusively on medical and surgical solutions (Argyle 1988; Bowden et al; 1980; Cobbs; 1976, Kleve & Robinson; 1999).

The first step in the developmental process of Face IT was therefore to assess the methodological validity of existing psychosocial interventions for young people in this area. A systematic review of the literature by Bessell & Moss (2007) found that there is a lack of evidence-based interventions and support services specifically designed for people with disfigurements. Of the few available for evaluation, most lack methodological rigour.

The authors did however conclude that cognitive behavioural therapy (CBT) and social skills based interventions, delivered within a package of care, are the most promising type of intervention and that this approach is worthy of more systematic investigation.

This view is consistent with, and reinforced by the success of Face IT, an online intervention for adults, designed by the Centre for Appearance Research, Bristol in consultation with the charity Changing Faces and other expert clinicians in the field of appearance psychology (Bessell et al, 2010). Face IT provides self-management skills via social interaction skills training (SIST) and cognitive behavioural therapy (CBT) techniques. In a randomised controlled trial, Face IT was found to be effective at reducing levels of depression, anxiety and appearance concerns when administered in an adult clinic setting and facilitated by an appropriately trained health care professional (Bessell et al, 2012).

In developing an intervention for people that is easily accessible without the need for psychological referral, we believe that the online mode of delivery of the Face IT@home intervention will be particularly appealing. Studies have indicated that many people prefer to seek health-related support and information via the internet, rather than talking directly to healthcare professionals (Weber et al, 2000). Online interventions are available at a time and place convenient for the user and are easily

accessible and interactive, a benefit over paper-based material. Online access can also overcome the difficulty of reaching a population people for whom social avoidance is a defining characteristic (Newell, 1999), and a population reluctant to seek help due to the perceived stigma associated with therapy - a perception commonly experienced by those with disfiguring conditions (Wright & Bell, 2003). A systematic review of the computerised cognitive-behavioural therapy (cCBT) literature has also found this mode of delivery to be effective at treating mild-to-moderate levels of anxiety and depression amongst young people (Richardson et al, 2010) and the National Institute for Health and Clinical Excellence recommend its use (NICE, 2005).

The therapeutic content of Face IT@home is therefore based on the Face IT intervention and focuses on a combination of cognitive restructuring and social skills training. With the help of people with visible differences, its visual design, functionality, features and the presentation of its content have been made accessible to people aged between 18 and 91 years of age. The program has a reading age of 12 years.

Theoretical Models That Have Informed the Development of Face IT@home

There are many different models that contribute to our understanding of the difficulties experienced by young people with visible differences. These include the social anxiety model (Baumeister & Leary; 1995), Goffman's (1968) model of stigma, the social skills model (Bull & Rumsey; 1988) and the model of body image disturbance (Cash; 2001, Cash; 1996). Face IT@home adopts an integrated approach to support that addresses aspects associated with all four models and is largely based on the theoretical approach illustrated by Kent's (2000) Integrated Model of Psychosocial Distress & Intervention for Individuals with Visible Differences.

Social Anxiety Model (Baumeister & Leary; 1995)

This model suggests that social anxiety is a universal occurrence amongst humans. The social nature of the species and our desire to fit in can lead to fears of rejection by others and a fear of being excluded. Young people with visible differences experience social anxiety, at least in part, because they are fearful of being rejected or excluded on the grounds of having an unusual or different appearance (Kent; 2000). The level of social anxiety an individual experiences acts as a mediating factor between the severity of their visible difference (how objectively noticeable the appearance concern is) and their emotional response (Leary et al; 1998). This model promotes the use of interventions that reduce social anxiety by regularly exposing the individual to social situations (Newell & Marks; 2000).

Stigma Model (Goffman; 1963, 1968)

In many ways the stigma model fits with the social anxiety model, but rather than suggesting that social anxiety is simply a universal occurrence, it relates social anxiety to the social stigma of having an unusual appearance. Having a different appearance is a characteristic that is "devalued" by society and as such those with a visible difference are more likely to have real experiences of being excluded, rejected or misjudged. These experiences can undoubtedly lead to social anxiety.

Social Skills Model

Research suggests that those with visible differences can become preoccupied with their own appearance due to high levels of distress (Acton; 2004). When in public, this preoccupation can make individuals appear distracted, anxious or lacking in confidence (Kent; 2000). The social skills model suggests that many of the negative reactions these individuals experience are less to do with stigma and more a reaction to poor social skills that can create tension and inhibit social interactions (Rumsey & Bull; 1988). The social skills model and the stigma model are not mutually exclusive. The reality of the situation for many people with a visible difference is that they do indeed experience some level of rejection and exclusion, but in some cases this effect is exacerbated by inadequate social skills (Kent; 2000). This model therefore promotes the use of interventions that improve social skills (Rumsey et al; 1993).

Body Image Disturbance Model

This model suggests that the high value placed on appearance within certain societies makes body image disturbance (discontent with one's own appearance) relatively commonplace. Individuals with a visible difference may experience additional dissatisfaction with their body image because they do not conform to the cultural norms of attractiveness imposed by their society. Social pressure to look a certain way, alongside a more personal form of stigma (where they themselves feel they should look "normal") can lead to high levels of body image disturbance. Body image disturbance is associated with poorer adjustment (Altabe & Thompson; 1996) particularly among individuals heavily invested in their own appearance (White; 2000). This model suggests that interventions should focus on addressing the way individuals feel about their appearance and the negative assumptions they make about the importance of appearance.

Integrated Model (Kent 2000)

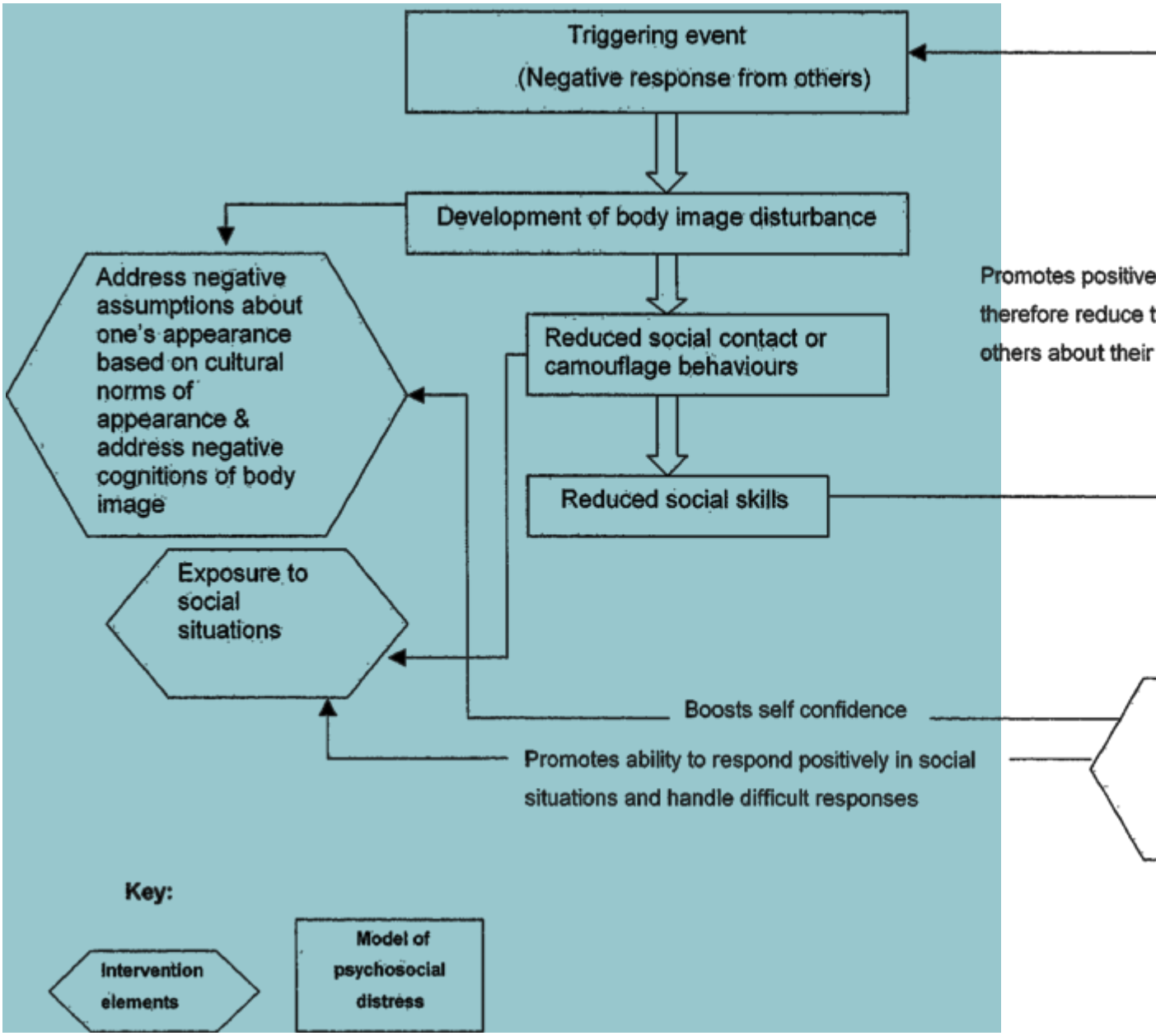
All these models are helpful in describing some of the difficulties faced by individuals with a visible difference, but no one model completely encapsulates the lived experience. Kent (2000) therefore recommends an inclusive model incorporating key features of all four models. Kent's theoretical model has been adopted for Face IT, see Figure 1.

Social interaction skills training (SIST) is proposed to address the inappropriate social skills that some individuals with visible differences may have developed and can help people interact more positively with others and overcome the social stigma attached to looking 'different'.

CBT is advised to address negative thoughts about one's own appearance and the assumptions individuals with visible differences make about the behaviour of others towards them (Thompson & Kent, 2001). CBT also offers individuals an opportunity to test out social situations they may be fearful of due to negative past experiences.

The process of exposure is crucial in helping individuals to engage more fully in social situations and to reduce the limitations that they may be imposing upon their own lives (Kent 2002). As research has shown that some individuals do not have the necessary social skills to effectively engage with others (Rumsey et al, 1993), there is a risk that social exposure without first addressing any limitations in social communication skills might lead to more negative experiences and greater social withdrawal. SIST is therefore not only an integral part of Face IT but is also addressed prior to social exposure activities.

The program acknowledges that reducing the social stigma attached to visible differences is an important part of improving the lived experience of people with visible differences. Users are informed and reassured that interventions to raise public awareness and acceptance of appearance diversity by the Centre for Appearance Research (CAR) and other organisations such as Changing Faces are being developed. However these interventions cannot change society overnight. The program therefore emphasises the importance of people developing strategies that can improve their current situation.



A Summary of the Content of Face IT@home

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