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Surgerywww.bjoms.com**Leading article****Meeting the psychological needs of patients with facial disfigurement**Eileen Bradbury^{a,b,*}^a *The Alexandra Hospital, Mill Lane, Cheadle, Cheshire SK8 2PX, United Kingdom*^b *Fernleigh Consulting Centre, 77 Alderley Road, Wilmslow, Cheshire SK9 1PA, United Kingdom*

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Abstract

Those with congenital or acquired disfigurement are faced with the challenges of social reactions and their own psychological responses to looking different. There is no simple linear relation between the degree of disfigurement and the degree of experienced distress. Factors that influence an individual's ability to cope include the social meaning of the disfigurement, life history, social and family support, and developmental stage. Decision-making about surgery, including that for those seeking aesthetic surgery, should take account of these complex factors to understand the patient's needs, ensure informed consent, and avoid unnecessary or ill-timed surgery. All those working with patients with disfigurement should have an understanding of their psychosocial needs, and there should be access to an identified member of staff such as a clinical nurse specialist with counselling skills, and a recognised referral route to a psychologist or liaison psychiatrist.

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The psychological and social impact of facial disfigurement

Facial disfigurement presents a serious psychological and social challenge to the individual who has to cope with an appearance that is obviously different, hard to conceal, and subject to social stigma. This is not a new phenomenon; human society has a long history of stigmatising facial disfigurement.¹ However, modern day pressures of a celebrity culture that is focused on appearance, the increasing use of aesthetic surgery and minimally invasive procedures, and the ubiquitous camera, combine to increase the pressure on those who look different.

People with facial disfigurement often report increased social anxiety and avoidance, low mood, feelings of low

self-esteem and self-worth, problems with relationships, and difficulties with employment. The responses of the general public to a major facial disfigurement range from intrusive staring through aggression to pity and disgust, in any combination.² Walking down the street past a group of teenagers can be a major trauma, as can standing in a supermarket queue as one by one each person in the queue turns to stare.

The meaning given by others to the disfigurement can affect responses – for example, a young black man with a facial knife wound is often feared. He finds himself turned away from clubs, and people who see him as a fighter square up to him in the street. A woman with traumatic facial injuries can be seen as a victim of abuse and is therefore pitied. Pity is surely one of the hardest responses to cope with as it places a person firmly in the lowest status group. Nobody aspires to be disfigured, and there are few positive role models in the literature, film, or the media. Having a scarred or physically distorted face is seen as a shorthand for evil throughout different cultures, just as the flawless, symmetrical face is a

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shorthand for goodness.^{1,2} It is a lesson that children learn early, and it is reinforced in adult culture.

In the biomedical model there it is a general assumption that those with the most severe disfigurement will suffer the highest levels of distress. However, clinical practice and research have consistently found little relation between the severity of the disfigurement and the associated distress.³ What factors correlate with distress?

The severity of the disfigurement

Those with a major disfigurement are faced with constant social reactions. However, such reactions are, to a great extent, predictable. The individual can learn to predict how others will respond and can develop coping strategies such as explaining, out-staring, or distracting with positive self-talk. They are also generally well supported by the professionals treating them and by family and friends, and feel entitled to that support. Those with minor disfigurement may be very sensitive to others and misinterpret a glance from someone else as a hostile act. They may feel ashamed of their responses when they compare themselves with others in the clinic, but they can learn to manage their responses and interpret them more realistically. Those with moderate disfigurement have been found to have the greatest problems as the reactions of others are unpredictable and more ambivalent, so are more difficult to manage. In addition, moderate disfigurement is likely to elicit increased scanning by strangers who try to make sense of the different appearance, whereas strangers may look and then look away when the disfigurement is more obvious.³

Congenital or acquired disfigurement

It would be reasonable to consider that those born with a congenital disfigurement would have a different psychological responses from those whose facial appearance has traumatically and suddenly changed. However, it seems that while the challenges may be different, one type is not necessarily more difficult than the other. The individual with congenital disfigurement has grown up with a different face, but may have to cope with a sense of fundamental difference or flaw; they may feel abnormal, and there may be genetic implications for any children they may have. When they are infants adults may stare rather than smile at them, and as children going to school other children may isolate them, so they may develop a sense of shame and lack robust ego development.⁴ The individual with a traumatic disfigurement may have a normal early development but then have to cope with a loss of self, and sudden changes in social status and social responses.⁵

Developmental or life stage

Traumatic facial injury is particularly problematic when it occurs at a sensitive developmental stage.⁶ An example from

clinical practice is the mid or late female adolescent who is injured in a car crash, a common occurrence. At this stage she is on the cusp of independence from her family and focused on appearance as a primary regulator of self-esteem. She is developing sexual relationships, is dependent on peers for her social life, and is moving towards the next stage in life – higher education, work, or marriage. All this is disrupted, and she will often remain emotionally fixed in mid-adolescence for years, rebellious yet dependent, while her friends move on and away. In these circumstances there are likely to be high levels of distress about a relatively minor facial disfigurement.

Levels of social support

People do not exist in isolation but in the context of family, friendship groups, and relationships, and they define and narrate their life experience through their thoughts and beliefs about themselves and those around them. Indeed, no man is an island. Those with disfigurement will shape their experience of being disfigured as a result of all these factors. An example would be a man who suffers a traumatic facial injury at work where he has experienced previous problems. He perceives his employers as heartless and culpable, and he becomes angry and obsessed with the accident. His marital relationship is precarious and his anger at home causes it to break down. Whenever he looks at his face he is reminded of all that has happened, and therefore when others comment or stare he becomes enraged. Again, a relatively minor facial disfigurement can cause a major reaction.

Those with a pre-existing history of untreated psychiatric illness such as depression or anxiety are likely to be particularly vulnerable because of their impaired coping skills, the fear of triggering a further psychiatric episode, and the impact their illness has had on their social network.

Type and site of the disfigurement

The closer the disfigurement is to the central facial triangle of the eyes and mouth, the more noticeable it is on casual observation, so a small deficit in a tooth is more noticeable than a similar degree of deficit in the ear. Once something has been noticed, the other person's attention flickers to it to try to understand it. Those with disfigurement are often highly sensitive to the scanning of others. They tend to respond by attempting to cover, conceal, or distract, so will put a hand over the nose or the chin. Unfortunately this tends to draw attention to the part in question. In fact, most concealing behaviours such as wearing sunglasses, having hair over the face, putting a hand over the mouth, or averting the face, will be counter-productive and will maintain tension rather than reducing it.

In addition, even a mild degree of facial asymmetry can be very problematic. There is a considerable amount

of published material from anthropologists, social scientists, and experts in animal behaviour, which suggests that facial symmetry is associated with health and normality, whereas asymmetry can provoke distress and aggression in others. Those with facial asymmetry will often be very self-conscious about moving their faces and will often avoid doing so as it can cause the asymmetry to be more obvious. This can cause them to look hostile to others, and can provoke a negative response.⁷

Sex

The view is widely held that women will be more troubled by facial disfigurement than men because of the female focus on appearance. This is enshrined in law in that women with facial injuries are awarded more compensation than men. However, clinical experience shows that boys and young men are particularly troubled by facial disfigurement, which makes them feel different from others, vulnerable to bullying, physically weaker, and less attractive to girls. While women develop confiding relationships and more habitually discuss and share their feelings, men develop peer relationships based on activity and work and have less opportunity for or tolerance of such support.⁸

Surgical decision-making

Factors that influence and shape the responses of any individual to a facial disfigurement are many and complex. There are those that increase resilience such as good social support, positive feelings of self-worth, and a settled life stage,² and those that increase vulnerability such as type and site of the disfigurement, life-stage, and pre-existing psychological vulnerability. People need to be understood in terms of the meaning that the disfigurement has for them at that time.⁹ A conversation is required and the outcome of that conversation should influence decision-making about surgical intervention.

Consent to surgery

Consent to surgery may seem straightforward and the need may seem obvious; after all, surgeons have the skills to bring about change, but they may be frustrated and troubled by discovering that their assessment of outcome is not shared by the patient. For those with facial disfigurement who have undergone several procedures, there are particular and specific psychological issues.

Although the surgeon may think that the patient understands the technical outcome that can be expected, the patient may have been listening through a filter of hope and distress. Many who have had operations have expressed disappointment that – for example, the face has not been made normal; the congenital condition has not been removed; the undamaged face has not re-emerged. The individual invests so much in the operation, and builds up to it, and eagerly anticipates

it. However, it is also feared, and those who have had several procedures know how they will feel physically afterwards; children in particular can become aversive to the process and need special support. These psychological factors will influence consent to surgery.

In addition, it is possible that successive procedures are being done with very little gain. The surgeon is trying to help, but the patient is postponing the moment of looking in the mirror and accepting that this is it, and is pushing for more surgery.

Is the process of decision-making about surgery essentially different if the patient is seeking a purely aesthetic procedure? Although the attitude of the surgeon to this latter group may be more cautious, the preoccupation with facial appearance, the levels of appearance-related distress, and the efficacy of surgery may be not dissimilar. All 360 prospective aesthetic and reconstructive patients in a recent study showed clinically significant levels of appearance-related distress, with the highest levels in the aesthetic group, and the lowest in the functionally impaired group.¹⁰ Subjective assessment of noticeability and associated distress was found to be useful when prioritising treatment.

Clinical experience with both groups suggests that common features such as shame, social avoidance, and the use of concealing behaviours, are experienced by both groups.¹¹ Factors that influence resilience and vulnerability in individuals with disfigurement, as described above, are also relevant to the aesthetic group. For both groups, the surgeon needs to understand the meaning of the facial problem for that person, the psychological and social impact, and the aims of surgery.

Of particular concern in the decision-making process in the aesthetic group is the possibility of body dysmorphic disorder (BDD). This is defined in DSM-IV as a preoccupation with an imagined or slight deficit in appearance, resulting in significant emotional distress or impairment in functioning.¹² The onset is typically in adolescence with equal incidence in men and women, and it runs a chronic course. Sufferers report impairment in social and occupational functioning and a poor quality of life, with self-harm behaviour commonly a feature. Those with BDD tend to suffer social anxiety, are sensitive to criticism, and perfectionist in behaviour and thought processes. Research studies have found that surgical treatment for these patients is not generally effective and can lead to a worsening of the condition.¹³ A recent study¹⁴ found that minimally invasive procedures are also associated with poor outcome, even though surgeons are more likely to agree to them than to more invasive operations. The net result is still a dissatisfied and potentially litigious patient.¹⁵

Psychological assessment, support and treatment

Given the profound psychological impact of disfigurement and the role of psychological factors in surgical decision-making and outcome, it is important to put in place a protocol

that will meet the needs of individuals and be of help to the surgeons treating them.

A three-staged approach should be considered. All those who work in surgical units (surgeons, trainees, nurses, and therapists) should have some knowledge of the psychological and social factors that influence responses and outcome.

An identified individual should work within the unit, possibly a clinical nurse specialist trained in counselling skills who would support, inform, and counsel patients, and inform and liaise with staff. There should also be an identified psychologist or liaison psychiatrist known to the unit, who has some knowledge of the issues surrounding surgery and treatment, and to whom patients can be referred for more intensive and in-depth therapy.

The approach of a psychologist would involve therapies such as cognitive behavioural therapy, which aims to help individuals identify “dysfunctional” cognitive and behavioural strategies such as denial, avoidance, and projection, and to develop more useful ways of behaving and responding. The role of the psychologist is to aid the processes of adjustment, self-acceptance, and moving forward, in the context of a world that will always be watchful and judgemental.^{8,9,16} While people with disfigurement cannot directly change social attitudes, they can change how they respond. They can also change how they interpret what has happened and can rediscover a sense of identity and self-worth. This can be a strengthening process, and can make a person more resilient, more able to deal with the minor stressors of life, and more able to build meaningful and worthwhile relationships with partners and with friends. Severe appearance-related distress therefore does not need to be a life sentence of despair hoping to be rescued by surgery, but something that can be resolved through therapy with or without surgery. A combined approach can often be a powerful and effective intervention for those who are particularly distressed.

For all patients passing through surgical units, whether for a single procedure or for multiple reconstructions, it is important that those treating them understand their psychological needs in the context of surgery and have systems in place to ensure that their needs are met.

Conflict of interest

None declared.

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