

## Coping with Disfigurement: Psychosocial Mechanisms

### Abstract

Disfigurement is commoner than is generally realised, affecting between one and 10% of the population. This essay attempts to detail some of the important and interesting theories of the psychosocial mechanisms of coping with visible difference. Tasks of psychological recovery, classification of coping, social support, and the fear-avoidance model are discussed in particular.

### Introduction

Estimates vary, but between one and 10 per cent of the UK population are believed to have a disfigurement – such as a scar, blemish, or deformity – which seriously hinders their capacity to lead a normal life (Office of Population Censuses and Surveys, 1988, p.65; Valente, 2004).

Disfigured individuals frequently report severe difficulties in social encounters (Jowett & Ryan, 1985; Lanigan & Cotterill, 1989, Porter et al., 1986, 1987, 1990; van der Donk et al., 1994). Studies using actors made up to look disfigured found that people offered less help and stood further away from people with a visible difference (Bull & Stevens, 1981; Piliavin et al., 1978; Rumsey et al., 1982). Some people whose faces have been disfigured can suffer a so-called 'social death'. Unless they are given psychotherapeutic and social help in time, 'social death' may instigate death by suicide (Konigova & Pondelicek, 1987).

Society encourages us to stigmatize by appearance from childhood, be it Cinderella's (cruel, jealous) Ugly Stepsisters, the terrifying (and hideous) Wicked Witch of the West, or the murderous (and disfigured) Freddy from *A Nightmare on Elm Street*. One of Britain's most successful radio and television personalities, Chris Evans, included an 'Ugly Bloke' feature on his *TFI Friday* television programme for the merriment of viewers. Countless magazines make a living from photographing

celebrities looking less than their best (e.g. Cameron Diaz (acne), Kerry Katona (cellulite)) and encouraging their readers to relish the resulting humiliation. Outfits and hairstyles are deconstructed in exhaustive detail. Documentaries such as *The Boy Whose Skin Fell Off* sensationalize visible difference, constructing barriers to integration. Our obsession with appearance diminishes those who fall short of a perceived ideal, and those with a visible difference, being furthest down the ladder of beauty, are devalued most (McGruther, 1997).

While many seek medical or surgical treatments for disfigurement, there are limitations as to what can be achieved, and for most people affected disfigurements are a lifelong condition (Clarke, 1998). Most of those with a visible difference continue to hope for facial surgery, creating a continued dissatisfaction with self (Richman, 1983). Surgery alone is not sufficient (McGruther, 1997); it does not fix emotions (Hearst, 2007).

### **Psychosocial Mechanisms**

Many disfigured people find that coping with the daily trials of living with their difference is so difficult that aloofness or total withdrawal are their only options. Others use a range of strategies to help them function. Depending on the individual and on the situation, these may be overt or covert, aggressive or passive, hostile or receptive. For example, when stared at, many individuals feign unawareness or look away, whereas others stare back or make defiant remarks, "Take a *good* look" (Macgregor, 1990). Others adopt more positive methods, such as compensating for their difference with charm (Macgregor, 1974), or helping themselves by helping others.

Building on the coping framework formulated by Scott, Oberst, and Dropkin (1980), Callahan (2004) describes five tasks of psychological recovery:

1. *Mourn the loss*, be it of physical attractiveness, a sense of invincibility etc (Nordlicht, 1979). The gravity of the loss must be fully realized (Worden, 1991).
2. *Confront the loss*, that is, deal with it head-on. Patients must be able to look in the mirror and not shrink from their reflection.
3. *Confront possible denial*. The reality of disfigurement can become diminished to a patient who refuses to look in the mirror, interact with others, or go outside. Such avoidance leads to feelings of anger, bitterness, isolation and depression (Gamba, Romano, Grosso, Tamburini, Cantu, Molinari, and Ventafridda, 1992).
4. *Reframe the experience*. The patient learns to redefine the disfigurement in terms that are acceptable, realistic and positive. Patients are able to acknowledge their loss, but find hope and mastery in new-found strengths and skills (Holley, 1983).
5. *Integrate the experience*, that is, incorporate the disfigurement into the person's overall self-concept. Deep acceptance of the disfigurement leads to the intertwining of disfigurement and self such that one becomes inextricable from the other.

### Classifying Coping

Emotion-focused coping (relating to emotions, moods, and attitudes) and problem-focused coping (behaviours) combine to produce varying degrees of adaptation and adjustment or maladaptation and difficulty (Callahan, 2004). Dropkin (1989) gave the following definitions:

*Emotion-focused coping* – regulation of distressing emotions

*Problem-focused coping* – taking action to change the situation

Problem-focused coping appears to be primarily used in encounters that are appraised as being changeable. Emotion-focused coping, in contrast, is used more frequently in situations regarded as unchangeable (Dropkin, 1989).

Thompson, Kent & Smith (2002) examined coping techniques amongst women with vitiligo. Avoiding situations where their difference would be more visible, such as swimming or sexual intimacy, were common. Some participants described escaping from situations where their condition had become visible or noticed. Other behavioural strategies included confronting others' negative reactions/staring, and explaining the nature of their disease.

Avoidance is not always a maladaptive coping mechanism. Konigova & Pondelicek (1987) studied psychosocial adaptation following burn injury. The group which coped the best were the optimists and extroverts, who tended to be younger (under 50) men. These patients were characterised as denying the objectively serious nature of their injury, but never denying the indispensability of intensive and long term therapy. Konigova & Pondelicek suggest that this denial mechanism allowed the patients to endure both their injuries and the subsequent intensive treatment.

Cognitive (emotion-focused) strategies included 'attributional analysis' of staring or discrimination; when participants were the victim of hostility they attributed the problem to the other person, rather than blaming themselves (Thompson, Kent & Smith, 2002).

### Social Support

Social support has been defined as information leading people to believe that they are cared for and loved, esteemed, and a member of a network (Cobb, 1976).

Social functioning is often the ultimate goal for both biomedical and psychosocial interventions for disfigurement (Ong, Clarke, White, Johnson, Withey & Butler, 2007), and the use of avoidance and concealment illustrates the over-riding

concerns of social exclusion among disfigured people (Goffman, 1963). Ong, Clarke, White, Johnson, Withey & Butler (2007) suggest that successful adjustment in disfigurement lies in the ability to interact with other people at various levels, from meeting people for the first time to enjoying an intimate relationship.

The quality of perceived social support has been found to be particularly important to adjustment in a number of studies (Baker, 1992; Blakeney, Portman, & Rutan, 1990; Browne et al., 1985). High-quality social support is a powerful resource aiding adaptation. Reported benefits of social support include encouragement to enter anxiety-producing settings, reassurance of acceptance regardless of appearance, and the development of adaptive cognitions. Carver and Scheier (1981) found that social support can serve to facilitate the development of problem-focused and emotion-focused coping strategies. Helpful comments from friends and relatives were internalized by participants and used as part of their self-talk (Thompson, Kent & Smith, 2002). Poor quality support hinders adjustment e.g. by adding to existing demands and exacerbating or prolonging negative emotions (Furness, Garrud, Faulder & Swift, 2006 [19]).

Driving positive social interactions as a disfigured person involves the use of a variety of socially proactive strategies (or social skills) to help manage the (often intrusive) reactions of others. These skills include educating others, keeping calm, and confronting negative reactions assertively (Partridge, 1994). Possession of good social skills has been found to be related to successful adjustment (Kapp-Simon, Simon & Kristovich, 1992; Robinson, Rumsey & Partridge, 1996).

### *Gender differences*

The literature reveals an unequal impact of social support on adjustment between the sexes. For example, Katz, Irish, Devins, Rodin & Gullane (2003) found that while social support was an important mediator of wellbeing amongst disfigured women, there was no such relationship among men.

### The Fear-Avoidance Model

Newell (2002) explains the variation in ability to cope with visible difference in terms of a fear-avoidance model rooted in cognitive behavioural therapy. Based on Lethem et al's (1983) fear-avoidance model of exaggerated pain perception, the model predicts that fear of, and anxiety in, social situations results in avoidance coping. Because it limits exposure and habituation to others' behaviour (Newell, 1999), avoidance is associated with problematic long-term adjustment, poorer quality of life and negative affect (Cochrane & Slade, 1999; Wahl, Hanestad & Wiklund, 1999). Cahners (1992) argues that avoidance thwarts the development of coping strategies and does not allow for disconfirmation of unrealistic beliefs. Conversely, people predisposed to confront such situations head-on will feel their anxiety decrease as they perform the activity more, and will cope better (the rationale behind exposure therapy in phobias etc) (Newell, 2002). According to Newell, arguably the most important thing about the fear-avoidance model is that it emphasizes the normality of psychological distress following disfigurement (Newell, 2002).

### Age Differences

Thompson & Kent (2001) found some evidence that older individuals may cope better with disfigurement. It is unclear whether this effect is due to the development of coping strategies over time, or simply the passage of time itself (Knudson-Cooper, 1981; Malt, 1980).

The most influential factor in the adaptation of children to visible difference was the ability of their parents to provide 'attuned acceptance' of their child and to encourage him or her towards active mastery of tasks (Beard, Herndon & Desai, 1989).

### Adjustment: A Non-Linear Process

An important concept to understand about adjustment to disfigurement is that most people cannot maintain adaptive cognitions about their difference for all of the time. Potential maladaptive pressures in Thompson, Kent & Smith's (2002) study included instances of stigmatization, times of transition, menstrual periods and general feelings of low confidence. At these times, the patients had to work extra hard to maintain their self-talk, or lost the ability to put their difference in perspective altogether. The authors attribute these difficulties to cognitive (and some adaptive behavioural) techniques' fragility and need for psychological effort, making them hard to maintain at all times. When they could not manage their self-talk, participants sometimes resorted to avoidance techniques. Crucially, these findings belie the idea that adjustment is a linear process and that the use of particular coping strategies is stable.

An ingenious explanation for how stressful events relate to coping ability – the theory of ironic processes of mental control – was proposed by Wegner (1994) and is described in detail by Fauerbach et al. (2002). The theory proposes the existence of two mechanisms to explain the consequences of stressful events on cognition. The consciously controlled *operating system* scans for thoughts that are consistent – and suppresses those that are inconsistent – with the desired mental state. The automatic (i.e. below the level of consciousness) *monitoring system* screens thoughts approaching consciousness for those that are incongruent with the desired state and brings that material into consciousness so that the operating system can suppress it. If available cognitive capacity is limited (e.g. due to stress, pain etc), the operating system's capacity to carry out its suppressive function is diminished, whereas the automatic monitoring system continues to function unaffected. This causes 'rebound' of unwanted thoughts (e.g. Ansfield, Wegner & Bowser, 1996; Wegner, Erber, & Zanakos, 1993; Wegner & Gold, 1995; Wegner, Schneider, Carter & White, 1987; Wenzlaff, Wegner & Roper, 1988).

## Conclusions

Overall, the best social and emotional outcomes were seen in those who had appraised their situation negatively, but, by drawing on optimistic and sociable personality traits as well as good social support, had been able to confront their disfigurement head-on and perceive the benefits of their travails (Furness, Garrud, Faulder & Swift, 2006).

Many disfigured people try valiantly to make their social interactions more pleasant and easier for their non-disfigured counterparts, but at a price. The psychological cost of daily stares, shocked glances, intrusive comments, and social effort often outweighs the social gains, and long term longitudinal studies have demonstrated a trend towards depression, social withdrawal, or even alcoholism (Macgregor, 1990).

There are reports, supported by research into survivors of other health problems and traumatic life events, of people with visible difference perceiving real personal and social benefits from their experiences (e.g. Lansdown, Rumsey, Bradbury, Carr, & Partridge, 1997). Such benefits may include more positive self-perception, interpersonal relationships, and outlook on life (Tedeschi & Calhoun, 1995).

Rehabilitation is defined as help to readapt a disabled person to society (Collins Concise Dictionary). In the case of disfigurement, who has the disability and who should be adapting to whom? Is it incumbent on those with a visible difference to attempt to normalize their appearance to suit the demands of a society that craves and rewards physical attractiveness? Hearst (2007) argues that, ultimately, it is society that must be rehabilitated to reduce its prejudice, foster inclusiveness and increase acceptance of difference.

## References

Ansfeld, M.E., Wegner, D.M., & Bowser, R., 1996. Ironic effects of sleep urgency. *Behaviour Research and Therapy*, 34, pp.523-31.

Baker, C., 1992. Factors associated with rehabilitation in head and neck cancer. *Cancer Nursing*, 15, pp.395-400.

Beard, S.A., Herndon, D.N., & Desai, M., 1989. Adaptation of self-image in burn-disfigured children. *Journal of Burn Care & Rehabilitation*, 10(6), pp.550-4.

Blakeney, P., Portman, S., & Rutman, R., 1990. Familial values as factors influencing long-term psychological adjustment of children after severe burns injury. *Journal of Burn Care and Rehabilitation*, 11, pp.472-5.

Browne, G., Byrne, C., Brown, B., Pennock, M., Streiner, D., Roberts, R., Eyles, P., Truscott, D., & Dabbs, R. (1985). Psychosocial adjustment of burn survivors. *Burns*, 12, 28-35.

Bull, R., & Stevens, J., 1981. The effects of facial disfigurement on helping behaviour. *The Italian Journal of Psychology*, 8, pp.25-32.

Callahan, C., 2004. Facial disfigurement and sense of self in head and neck cancer. *Soc Work Health Care*, 40(2), pp.73-87.

Cahners, S., 1992. Young women with breast burns. A self-help group by mail. *Journal of Burn Care and Rehabilitation*, 13, pp.44-47.

Carver, C. & Scheier, M., 1981. *Attention and self-regulation: A control theory approach to human behaviour*. New York: Springer-Verlag.

Clarke, A., 1998. What happened to your face? Managing facial disfigurement. *British Journal of Community Nursing*, 3, pp.13-16.

Cobb, S., 1976. Social support as a moderator of life stress. *Psychosomatic Medicine*, 38, pp.300-314.

Cochrane, V.M., & Slade, P., 1999. Appraisal and coping in adults with cleft lip: Associations with well-being and social anxiety. *British Journal of Medical Psychology*, 72, pp.485-503.

Dropkin, M.J., 1989. Coping with disfigurement and dysfunction after head and neck cancer surgery: a conceptual framework. *Semin Oncol Nurs*, 5(3), pp.213-9.

Fauerbach, J.A., Heinberg, L.J., Lawrence, J.W., Bryant, A.G., Richter, L., & Spence, R.J., 2002. Coping with body image changes following a disfiguring burn injury. *Health Psychol*, 21(2), pp.115-21.

Furness, P., Garrud, P., Faulder, A., & Swift J., 2006. Coming to terms: a grounded theory of adaptation to facial surgery in adulthood. *J Health Psychol*, 11(3), pp.453-66.

Gamba, A., Romano, M., Grosso, I.M., Tamburini, M., Cantu, G., Molinari, R., & Ventafridda, V., 1992. Psychosocial adjustment of patients surgically treated for head and neck cancer. *Head & Neck*, 14(3), pp.218-223.

Goffman, E., 1963. *Stigma: Notes on the management of spoiled identity*. London: Penguin.

Hearst, D., 2007. Can't they like me as I am? Psychological interventions for children and young people with congenital disfigurement. *Dev Neurorehabil*, 10(2), pp.105-12.

Holley, B., (1983). Counseling the head and neck cancer patient. *Progress in Clinical Biological Research*, 121, pp.215-225.

Jowett, S., & Ryan, T., 1985. Skin disease and handicap: an analysis of the impact of skin conditions. *Social Science and Medicine*, 20, pp.425-9.

Kapp-Simon, K., Simon, D., & Kristovich, S., 1992. Self-perception, social skills, adjustment and inhibition in young adolescents with craniofacial abnormalities. *Cleft Palate-Craniofacial Journal*, 34, 380-4.

Katz, M.R., Irish, J.C., Devins, G.M., Rodin, G.M., & Gullane, P.J., 2003. Psychosocial adjustment in head and neck cancer: the impact of disfigurement, gender and social support. *Head Neck*, 25(2), pp. 103-12.

Königová, R., Pondělíček, I., 1987. Psychological aspects of burns. *Scand J Plast Reconstr Surg Hand Surg*, 21(3), pp.311-4.

Knudson-Cooper, M., 1981. Adjustment to visible stigma, the case of the severely burned child. *Social Science and Medicine*, 15, pp.31-44.

Lanigan, S., & Cotterill, J., 1989. Psychological disabilities amongst patients with port wine stains. *British Journal of Dermatology*, 121, pp.209-15.

Lansdown, R., Rumsey, N., Bradbury, E., Carr, T., & Partridge, J., 1997. *Visibly Different: Coping with disfigurement*. Oxford: Butterworth Heinemann.

Lethem, J. et al., 1983. Outline of a fear-avoidance model of exaggerated pain perception. *J. Behaviour Research and Therapy*, 21(4), pp.401-8.

Macgregor, F.C., 1974. *Transformation and Identity: The Face and Plastic Surgery*. New York: Quadrangle.

Macgregor, F.C., 1990. Facial disfigurement: problems and management of social interaction and implications for mental health. *Aesthetic Plast Surg*, 14(4), pp.249-57.

- Malt, U., 1980. Long term psychosocial follow-up studies of burned adults: review of the literature. *Burns*, 6, pp.190-7.
- McGrouther, D.A., 1997. Facial disfigurement. *BMJ*, 314(7086), pp.991.
- Newell, R.J., 1999. Altered body image: A fear-avoidance model of psycho-social difficulties following disfigurement. *Journal of Advanced Nursing*, 30(5), pp.1230-8.
- Newell, R., 2002. Living with disfigurement. *Nurs Times*, 98(15), pp.34-5.
- Newell, R., 2002. The fear-avoidance model helping patients to cope with disfigurement. *Nursing Times*, 98(16), pp.38-9.
- Nordlicht, S., 1979. Facial disfigurement and psychiatric sequelae. *New York State Journal of Medicine*, 1382-4.
- Ong, J., Clarke, A., White, P., Johnson, M., Withey, S., Butler, P.E., 2007. Does severity predict distress? The relationship between subjective and objective measures of appearance and psychological adjustment, during treatment for facial lipoatrophy. *Body Image*, 4(3), pp.239-48.
- Partridge, J., 1994. *Changing faces: The challenge of facial disfigurement*. London: Changing Faces.
- Piliavin, I., Piliavin, J., & Rodin, L., 1976. Costs, diffusion and the stigmatised victim. *Journal of Personality and Social Psychology*, 32, pp.429-38.
- Porter, J., Beuf, A., Lerner, A., & Northund, J., 1986. Psychosocial effects of vitiligo: a comparison of vitiligo patients with 'normal' control subjects, with psoriasis patients, and with patients with other pigmentary disorders. *Journal of the American Academic Dermatology*, 22, pp.221-2.
- Porter, J., Beuf, A., Lerner, A., & Northund, J., 1987. Response to cosmetic disfigurement: patients with vitiligo. *Cutis*, 39, pp.493-4.
- Porter, J., Beuf, A., Lerner, A., & Northund, J., 1990. The effects of vitiligo on sexual relationships. *Journal of the American Academy of Dermatology*, 22, 221-2.
- Richman, L.C., 1983. Self-reported social, speech, and facial concerns and personality adjustment of adolescents with cleft lip and palate. *Cleft Palate J*, 20(2), pp.108-12.
- Robinson, E., Rumsey, N., & Partridge, J. (1996). An evaluation of the impact of social interaction skills training for facially disfigured people. *British Journal of Plastic Surgery*, 49, pp.281-9.
- Rumsey, N., Bull, R., & Gahagan, D. (1982). The effect of facial disfigurement on the proxemic behaviour of the general public. *Journal of Applied Social Psychology*, 12, pp.137-50.

Scott, D.W., Oberst, M.T., & Dropkin, M.J., 1980. A stress-coping model. *Advanced Nursing Science*, 3, pp.9-23.

Tedeschi, R.G., & Calhoun, L.G., 1995. *Trauma and transformation: Growing in the aftermath of suffering*. London: Sage.

Thompson, A.R. & Kent, G., 2001. Adjusting to disfigurement: processes involved in dealing with being visibly different. *Clinical Psychology Review*, 21(3), pp.663-82.

Thompson, A.R., Kent, G., & Smith, J.A., 2002. Living with vitiligo: dealing with difference. *Br J Health Psychol*, 7(2), pp.213-25.

Valente, S.M., 2004. Visual disfigurement and depression. *Plast Surg Nurs*, 24(4), pp.140-6.

van der Donk, J., Hunfield J., Passcher., Knecht-Junk, K., & Nieboer, C., 1994. Quality of life and maladjustment associated with hair loss in women with alopecia androgenetica. *Social Science and Medicine*, 38, pp.159-63.

Wahl, A., Hanestad, B.R., & Wiklund, I., 1999. Coping and quality of life in patients with psoriasis. *Quality of Life Research*, 8, pp.427-33.

Wegner, D.M., 1994. Ironic processes of mental control. *Psychological Review*, 101, pp.34-52.

Wegner, D.M., Erber, R., & Zanakos, S., 1993. Ironic processes in the mental control of mood and mood-related thought. *Journal of Personality and Social Psychology*, 65, pp.1093-1104.

Wegner, D.M., & Gold, D.B., 1995. Fanning old flames: Emotional and cognitive effects of suppressing thoughts of a past relationship. *Journal of Personality and Social Psychology*, 68, pp.782-92.

Wegner, D.M., Schneider, D.J., Carter, S.R., & White, T.L., 1987. Paradoxical effects of thought suppression. *Journal of Personality and Social Psychology*, 53, pp.5-13.

Wenzlaff, R.M., Wegner, D.M., & Roper, D.W. (1988). Depression and mental control: The resurgence of unwanted negative thoughts. *Journal of Personality and Social Psychology*, 55, pp.882-92.

Worden, J.W., 1991. *Grief Counselling and Grief Therapy*. New York: Springer.