

Coping with changing faces in adolescence

Abstract

For adolescents, a disfigurement can pose uniquely challenging situations with which to cope as they pass through a period of transition in terms of actual physical changes and changes in the world around them. The importance of coping in this vulnerable group has been well documented, but until recently there has been a distinct lack of knowledge about why some cope better than others. This essay draws together studies which have identified factors leading to a better quality of life for the disfigured adolescent, and interventions which may help daily living, including examples of the work of *Changing Faces*, concluding that further research is warranted into coping with changing faces in adolescence.

Coping with changing faces in adolescence

Facial disfigurement is not a medical condition but is a collective term used to describe the visual effect of a facial feature (1). To “change faces” is to come to terms with facial injury or deformity (2) and not to physically change a disfigured face, which is what many may first believe to be the work of the charity, *Changing Faces*, established by James Partridge OBE in 1992. Although the advents of surgery today must be acknowledged as a vital part of the recovery process for anyone who has to come to terms with disfigurement, *Changing Faces* works to support children, young people, adults and families through disfigurement and campaigns for social change working towards a culture of inclusion for disfigured people (3), showcased by the recent appearance of James Partridge reading the channel five news.

Approximately one in 500 children in the UK live with facial disfigurement (4), which can be caused by either congenital defects, for example cleft lips, birthmarks and neurofibromatosis, or acquired conditions such as those of the skin, or those which are the result of an accident or surgical treatment. For most people affected, facial disfigurements are a lifelong condition (5).

For adolescents, a disfigurement can pose uniquely challenging situations with which to cope as, according to Erikson (1959), “adolescence is characterised by the individual’s search for identity during the teenage years” (6). Adolescents pass through a period of transition in terms of actual physical changes to themselves and changes in the world around them. Challenges such as forming new relationships, dating, and changing schools may prove difficult if confidence has been eroded (7). Changes in body shape, the growth of hair, and alterations in skin condition are all bound to heighten appearance concerns in adolescence, so changing faces at this time will act as an extra challenge in an already ever-changing environment.

The importance of coping mechanisms for adolescents has been bolstered by studies which have shown that facial disfigurement from birth is associated with lower self-esteem, high social inhibition and anxieties regarding personal relationships in this group (8). Rusch et al (2000) found that following a traumatic disfiguring injury to the face or extremities, 44% of children still reported anxiety-related psychological symptoms, such as post-traumatic stress disorder, depression, fears of re-injury and phantom pain, after 12 months (9). Implications of a traumatic event can include a delayed return to school, poor academic performance, impaired socialisation, substance abuse and personality change (10-14). Furthermore, it should be noted that parents tend to under-report the frequency and intensity of their children’s behavioural and emotional reactions (15), which may be exacerbated during adolescence as parents attribute these reactions to hormonal changes rather than their adolescent’s disfigurement. Kapp (1979) found that female cleft adolescents experience deeper unhappiness and dissatisfaction, greater anxiety and poorer school performance than male cleft adolescents (16), which may be in part due to society’s preoccupation with female physical appearance.

On the contrary, some have postulated that adolescents cope better in some ways than younger children and adults. Despite initially expressing greater concern about the social implications of

their injury than younger children, adolescents express less concern at 12-month follow up visits, perhaps due to better developed coping mechanisms. The same study found that adults remain apprehensive about social reactions to their injuries for longer (9), suggesting that adolescents may be better at adapting to their disfigurement. Further investigation into this vulnerable yet seemingly resilient group is warranted to discover how adolescents cope with facial disfigurement in their daily lives.

Until recently, there has been a distinct lack of knowledge about what actually leads to a better quality of life for a disfigured adolescent. It has been demonstrated that the physical severity of the disfigurement, including size and location, does not impact on quality of life or psychosocial adjustment which may be due to the increasing obtainment of satisfactory cosmetic results via new developments in cosmetic surgery (17). Coping is in fact more dependent upon a variety of contextual factors which often change during adolescence (18), and so therapeutic mechanisms are becoming increasingly based on psychosocial models. These have largely focussed on the strengthening of communication skills and self-esteem, and the support of family and friendship networks.

Physical appearance contributes more than any other factor to levels of overall self-esteem in adolescents (19), and it has been suggested that older children may have difficulties with the need to change an already internalised body image following disfigurement (20). Thus, the need to address self-image and self-perceptions may be particularly important in this group.

Developing a repertoire of social behaviours which will elicit a positive response from others is likely to enhance an adolescent's self-esteem and result in more effective social behaviour in the future (21, 22). Rumsey et al (1986) found that behaviour is more open and friendly in response to positive social skills regardless of disfigurement (23). So-called "self-presentation strategies" can be used to maintain a level of self-esteem against the impact of others' reactions (24), and include educating others, staying calm and confronting negative reactions (2), allowing

the disfigured person to influence reception by the way he or she behaves (25). As James Partridge put it: “the only way I could escape my isolation was to become proactive in every single social situation, to take the initiative” (1).

Social interaction-skills training enables people with disfigurements to develop a better understanding of social interaction and practice effective strategies for managing these more successfully (25). Robinson et al found that anxiety levels had fallen significantly by 6-weeks post workshop and even further after 6 months in a group of facially disfigured people, suggesting that this cognitive-behavioural therapy may have long term therapeutic use, with participants citing that they were able to take away ideas and strategies for daily living (21). Furthermore, others have found significant improvement one year after the intervention in burned adolescents (26). However, disfigured people have problems other than those which revolve around social interaction, which may not be responsive to cognitive behavioural therapies, and a well developed support network may be crucial in overcoming these.

Cobb (1976) defined social support as information leading people to believe that they are cared for and loved, esteemed, and a member of a network (27). Landolt et al (2002) found that greater family cohesion, higher expressiveness, and fewer conflicts within the family were the best predictors of quality of life and psychosocial adjustment in paediatric burn survivors (17). Furthermore, mothers are essential in planning ahead, which may involve liaising with professional help (18). The role of peers is also important both inside and outside of school. For young people with facial disfigurements, friends play an important role in maintaining a positive attitude to body image (18, 28). Friends outside of school can be an important buffer to ‘hardtimers’ inside of school (18), where the playground provides many opportunities for teasing and bullying (29). Having a close friend in school helps facially disfigured children deal with others’ curiosity and unkindness about their appearance, as does having friends who intervene in bullying situations (18). A study into adolescent burn survivors’ perceptions of a patient

support group found that 90% would attend again citing the opportunity to meet others with similar experiences and discuss coping strategies (30).

The Adolescent Resilience Model developed by Haase (2004) attempts to explain resilience in adolescents who have coped well with a traumatic life event and was first applied to those experiencing cancer. It takes account of many of the factors aforementioned here; self-esteem, confidence, support program participation, the influence of others with a similar condition, and perceived support of family and friends (31).. Perhaps this model could be applied to adolescents facing disfigurement as a guide to therapeutic intervention? *Changing Faces* seeks to encourage many of the factors which Haase identifies, through the use of its booklets, amongst other methods, designed for young people. Whilst downplaying looks as less important than they are often perceived in modern society, *Changing Faces* has developed a set of booklets which provide practical advice for coping with disfigurement through the use of self help exercises and case scenarios, and have recently launched their face equality campaign for children.

Developing coping strategies for this vulnerable group is becoming an increasingly popular area of research, as scientists and clinicians realise various interventions which can have a real impact on the lives of the disfigured adolescent. When James Partridge met Nichola Rumsey in 1990, personal experience met research, and the conclusions which they had independently reached were remarkably similar (25). Surely this more than anything else fully vindicates further research into coping with changing faces in adolescence.

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