

# Disfigurement — neglected in primary care?

Rumsey, N. , Charlton, R. , Partridge, J. , Barlow, J.H. and Saul, K.

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## Disfigurement — neglected in primary care?

**T**HE membership examination of the RCGP lays particular emphasis on advocating that a practitioner explores the ideas, concerns, and expectations of a patient and so reaches a shared understanding within a consultation. However, training at any level, undergraduate or postgraduate, should further increase the insight of general practitioners (GPs) concerning the psychosocial consequences surrounding objective and self-perceived disfigurement and of the methods of help available.

Although research into the psychological and social aspects of appearance and disfigurement presents a range of difficulties, it is important for GPs to increase their understanding of body image dissatisfaction. In addition, GPs should be aware of its potential to reduce an individual's functioning and possible presentation as illness, together with effective methods of support and intervention.

During a person's life, dissatisfaction with or impairment of the body image or face may result from a congenital condition, trauma, obesity, acute or chronic disease, or the developmental changes associated with adolescence and ageing.<sup>1</sup> Following a Government survey in the late 1980s, it was estimated that about 400 000 children and adults in the United Kingdom have a scar, mark or deformity which severely affects their ability to lead a normal life. Many oth-

ers have more minor but nonetheless noticeable disfigurement.<sup>2,3</sup> This statistic excludes those with the kind of disfigurement that can be covered by clothes and may reflect just the 'tip of an illness iceberg', as there is also a group of people who, although not objectively disfigured, perceive their appearance in very negative terms.

The psychological and social effects of disfigurement are well charted.<sup>4</sup> People who have an objective disfigurement may present to a GP with a range of physical and psychosocial problems.<sup>5-7</sup> The impact varies between individuals and the severity of the disfigurement need not equate to the level of distress; a counter-intuitive finding from research that has important implications. So, for example, some people with multiple plaques of psoriasis and possible associated stigma may not consult, while those with more minor blemishes consult frequently. Patients with potentially serious skin lesions may delay seeking treatment, fearing scarring following possible surgical excision.

There are body image issues associated with chronic diseases, such as diabetes, especially in the newly diagnosed. Adherence to a recommended treatment regime may also be poor, as people may wish to avoid the weight gain often associated with insulin. Diseases such as cancer may cause a rapid change in appearance; similar effects may occur

after a cerebrovascular accident. In conditions such as arthritis, a GP's attention is frequently focused on the pain and lack of mobility, but not on the distress caused by the associated distortion of joints and change in gait.

Those disfigured by accidents, such as those scarred from burns, may consult wishing to reduce or remove the signs of trauma. Parents of children born with congenital disorders (for example, Down's syndrome) may seek interventions to make their child look 'normal'. They may face a range of challenges in supporting their children through surgery, school, and adolescence when teasing and bullying is commonplace. People who have disfigurements, in particular to the face, may be disadvantaged through first impressions of appearance and so gaining employment can be a significant challenge,<sup>9</sup> despite the fact that severe disfigurement is covered under the Disability Discrimination Act.

The high and unrealistic pressures exerted by the media and society, to have a youthful and unblemished appearance make children, adolescents, and adults without objective disfigurements vulnerable. They may believe that others evaluate their worth, largely on the basis of their looks. These issues can form the hidden agenda of a consultation in which they fear that dissatisfaction with their appearance or body image may not be considered 'legitimate'. There is an almost unnatural preoccupation to physical appearance in the mass media. Some children recall the agony of their school days and powerlessness through teasing and bullying resulting from apparent disfigurement. Exposure to the 'ideal' portrayed contributes to body image disturbance and associated eating disorders.<sup>9</sup> This may have an influence on the increase in demand for plastic surgery in Westernised countries. With an increasing market in this field of medicine, there is a potential for a conflict of interest with financial gain.<sup>10</sup>

Thus, where surgical intervention is sought for disfigurement or appearance-related concerns, individuals should be carefully counselled as to the possible degrees of success and severe NHS resource limitations, so that they can adjust their possibly unrealistic expectations and focus on additional strategies to come to terms with their feelings about their appearance.

Whatever the cause, concerns about appearance and inability to cope can predispose people to substantial impairment in personal, social, and occupational functioning, and may result in anxiety, depression, and social isolation.<sup>4</sup> Those affected can feel trivialised by healthcare professionals and may become increasingly distressed.

Consultations involving body image concerns present a practitioner with a number of dilemmas: either to implicitly acquiesce with 'social norms' by referral to a specialist surgeon; or to challenge them, helping people to increase their social confidence and avoid inappropriate medicalisation. Referral to a specialist clinic is clearly an option, but this biomedical approach may not be the most appropriate. While efforts to 'normalise' the appearance of those with marked disfigurements are often beneficial, few medical interventions completely remove a disfigurement and most are left with residual marks and scars. Promises of a 'cure' may even exacerbate existing problems by promoting unrealistic expectations of change. By treating the physical aspects of disfigurement in isolation, there is a danger of reinforcing the

'myth' of a simplistic relationship between improvements to physical appearance and enhanced quality of life.<sup>11</sup>

Other possibilities for support and intervention include referral to organisations that have developed self-help leaflets, books and videos. These are designed to enable children, young people and adults, who have disfigurements of any kind, to acquire improved social skills and self-esteem (see, for example, the resources of the UK charity, Changing Faces — [www.changingfaces.co.uk](http://www.changingfaces.co.uk)). Workshop and family activities in disfigurement have also been shown to facilitate the sharing of experiences and offer a safe, non-threatening environment for emotional disclosure and social skills development.<sup>12</sup>

Encouraging this self-management approach appears to hold considerable potential for people with body image concerns of all sorts. The emphasis of these interventions is on increasing an individual's ability to manage the symptoms, treatment, psychosocial consequences, and lifestyle changes associated with a particular condition. The participant is encouraged to acquire the cognitive, emotional, and behavioural responses necessary to achieve an enhanced quality of life through a continuous process of self-regulation.<sup>13</sup> Community-based programmes that have been subjected to randomised controlled trials include Arthritis Self-Management Programmes<sup>14</sup> and the Chronic Disease Course.<sup>15</sup> Perhaps the time is now right for a community-based self-management programme to be developed in relation to disfigurement and body image.

Another way forward is for a partnership between the skills of plastic surgeons and those of social skills trainers, helping people to come to terms with their appearance.<sup>16</sup> The Disfigurement Support Unit, known as the Outlook Unit, at Frenchay Hospital in Bristol, is a unique prototype of what can be achieved.<sup>17</sup> Gaining self-confidence and learning to live with disfigurements enables people with any form of disfiguring condition to strengthen their self-esteem and overcome perceived and actual social interaction problems, such as in the school playground or in gaining employment.<sup>18</sup>

Assessing the impact of a disfiguring condition and the results of various interventions requires repeated in-depth interviews, together with standardised measures of emotional (e.g. social anxiety, depression) and behavioural (e.g. social avoidance, occupational effects) impairment. Far more research is needed at a primary care level to assess the extent and types of need, beliefs, and different interventions. This is a particular challenge for the Centre for Appearance and Disfigurement Research (CADR) at the University of the West of England, Bristol, which at present is the only centre of its kind in the world engaged in this research. ([www.uwe.fas/cadr](http://www.uwe.fas/cadr)) It is allied to the work of the charity Changing Faces, and is actively seeking funding. There is also a real need to educate both practitioners and the wider public to promote awareness of disfigurement, its impact, and how it can be managed.

For GPs and other service providers, the dilemma to fully inform those requesting surgery should be carefully balanced against the need to provide a positive approach to disfigurement and on how they can promote additional strategies for enhancing their self-confidence and self-esteem.

RODGER CHARLTON

Director of Undergraduate GP Medical Education and  
Senior Lecturer, University of Warwick

NICHOLA RUMSEY

Professor in Psychology and Research Director,  
Centre for Appearance and Disfigurement Research,  
University of the West of England, Bristol

JAMES PARTRIDGE

Chief Executive, Changing Faces

JULIE BARLOW

Professor and Director of Psychosocial Research Centre,  
School of Health and Social Sciences, Coventry University

KRYSIA SAUL

Research Administrator, Warwick West Midlands  
Primary Care Research Network

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## Address for correspondence

Dr Rodger Charlton, Centre for Primary Health Care Studies, University of Warwick, Coventry CV4 4AL. E-mail: rodger.charlton@warwick.ac.uk