SPECIAL ISSUE

Helping people with an unusual appearance

Esther Hansen and **Alex Clarke**, clinical psychologists in a hospital department of plastic and reconstructive surgery, on what they have to offer

How can psychologists contribute to people's understanding of the effects of their unusual appearance, and help them to modify its impact on their lives? How do their beliefs shape their hopes for the future? This article compares and contrasts different models of service delivery in the area – specialist units, lay-led organisations, and a multidisciplinary unit. It highlights how different service models offer different opportunities for patients and their families, and identifies areas for further research.

questions

What do different service models offer to people with an unusual appearance? Is surgery an effective way of treating psychological problems? How does the media influence perceptions of appearance?

resources

Veale, D., Willson, R. & Clarke, A. (2008). *Overcoming body image problems including body dysmorphic disorder*. London: Constable & Robinson.

www.thefacetrust.org

The effective management of a visible difference in appearance relies strongly on an individual's ability to build a positive identity. Appearance is only one of the many attributes that define us, and although constantly reinforced by media images, it is far less important than we may think in living a positive and successful life. A good social support system, effective social skills and the ability to interact with others successfully are also important in adjustment to a visible difference in appearance, whilst social avoidance and a belief that life's opportunities are restricted by an unusual appearance are, not surprisingly, linked with psychological distress (see Rumsey & Harcourt, 2004). The challenge for those of us working in a clinical setting is to enable people to frame any problems they experience not only in terms of their objective appearance, but in terms of the impact that it is having on their lives, and to minimise this impact.

Most of the people who come to the Plastic and Reconstructive Surgery Department have concerns about their appearance and have identified surgery as the solution. They, and those who are close to them, often believe that plastic surgery is a way of managing their appearance concerns and any ensuing psychosocial difficulties, whether these are around staring and comments made by others, feeling down about the way they look, or frustration because they feel that they cannot get jobs that others have.

We work closely with people to identify the problem, which is rarely the disfigurement itself, rather the beliefs and behaviours associated with it. For example, many patients and their relatives still believe that if the observer can't see the disfigurement then their problem will be perceived as insignificant or irrelevant; whereas we know that how the disfigurement is perceived and experienced by the individual is what determines distress or predicts difficulties.

Plastic surgery has an almost mythical status in our culture and the media credits it with the ability to achieve remarkable results, but this makes the inability to alter what seems like a simple thing (for example removing a birthmark without leaving a scar) something that is very difficult for people to comprehend. Explaining the concept of improvement in appearance without producing unrealistic expectations of outcome is a real challenge. In reality, surgical interventions are not always effective at enabling the person to have a 'normal' appearance. This means that we need to help our clients to view treatment as consisting of one element (surgery) which will modify their appearance, and a second element (psychology) which will modify the importance and impact of appearance on them and others.

Our work helps people to understand the effects of disfigurement on their lives and how their beliefs can shape their experiences and hopes for their future. This enables them to understand what difference surgery is likely (and unlikely) to achieve and how psychology can contribute to a successful outcome. Occasionally individuals decide not to have surgery or to delay it, whilst they focus on a psychological approach to their issues.

There are different models of delivering psychology services for people with disfiguring conditions, varying from a specialist NHS service such as Outlook, to a lay-led organisation such as the charity Changing Faces, or an embedded service within the multidisciplinary team, such as the one we have developed within the Plastic and Reconstructive Surgery Unit at the Royal Free Hospital.

A specialist unit

The role of Outlook, a specialist NHS service in Bristol, is to support anybody with a disfigurement and their family and friends through the use of psychological assessment and interventions. Outlook offers services at both group and individual levels across the lifespan, with a designated team for children (see Maddern et al., 2006). This unit is in many ways a gold standard of care,

references

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Clarke, A. & Cooper, C. (2001). Psychological rehabilitation after disfiguring injury or disease: Investigating the training needs of specialist nurses. *Journal of Advanced Nursing, 34,* 18–26.

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Rumsey, N. & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image, 1,* 83–97.

because of the specialism of those working within it. However, as with all tertiary services that require referral from other health professionals, it relies on a good understanding of what psychologists in the unit can offer (and what they do not) for the service to be really effective. This requires the specialist service to be proactive in disseminating what they do through teaching and the provision of good-quality information.

A lay-led organisation

Within a lay-led environment such as the charity Changing Faces, those in need of information or support have the advantage of self-referral to a specialist resource staffed by qualified psychologists and people with personal experience of visible difference. Changing Faces not only provides support and advice but also takes a vital role in representing individuals with a disfigurement on a national level.

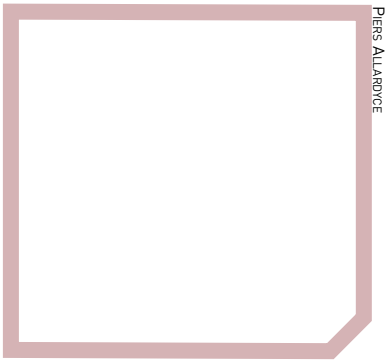
Having worked both in this lay-led setting and in the NHS (AC: Clarke 1999), it is interesting to note the strengths and weakness of each. A major benefit of the lay-led model is the ability to link directly with the individual at the outset, thus framing issues in terms of a psychological formulation. The fact that someone has a burn injury is only one piece of information and not the whole explanation for problems in, for example, social interaction. Within the NHS, people have often seen their GP, waited for an appointment and been assessed by the surgical team before psychology is introduced. It can be harder at this point to introduce the person to a combined surgical and psychological model of care. Changing Faces also operates without the layers of bureaucracy that characterise the NHS. Its primary goal is the population that it serves, and there is no competition for resources with other services.

However, a disadvantage for a lay-led organisation is the erroneous perception by some clinicians that the problems and concerns of the population are less significant or that it is a 'support group' providing non-directive counselling. In fact it can offer practical and effective ways of managing the problem, produce changes in behaviour and reduce disability.

A multidisciplinary team approach

In a multidisciplinary setting, clinical psychologists work with clients (and sometimes their families) individually and in groups, using models of care similar to those described above. However unlike these other models of care, a multidisciplinary setting provides a unique opportunity where clinical psychologists manage patient pathways and integrate the psychological intervention within the stages of surgical reconstruction.

Psychological approaches to the problems associated with disfigurement are often presented as an alternative to surgery, but in practice much of our work is done as a combined psychological and surgical intervention. For example, a request for revision of scarring after removal of a facial lesion has goals which are clearly surgical, but the ultimate goal may be, for example, to reduce preoccupation with appearance and social anxiety. So while individuals often assume that plastic surgery automatically impacts on psychological well-being, this is not necessarily achieved without direct psychological input.



PIERS ALLARDYCE

Some of the team from Outlook in Bristol receiving the Catalyst For Change Award from Changing Faces for the unit's work

Our method of multidisciplinary team working provides many opportunities to talk to our colleagues, and this enables us to challenge inaccurate assumptions they may hold about psychological issues and for them to challenge our assumptions about surgery. While the fact that the size and severity of disfigurement does not predict psychological adjustment used to be a considerable surprise to some clinicians in our team, this has changed.

Different health professionals are only experts in their own field and may have very varying ideas about the kinds of help that other members of the team can provide. Historically, psychologists have often received inappropriate referrals since there is a misunderstanding of our skills and the interventions we offer. However, working within a team (as opposed to a separate service) has been a very effective method in demonstrating clearly what clinical health psychology can offer in an acute surgical setting; really effective multidisciplinary team working, with physiotherapists, occupational therapists, specialists in hand therapy, specialist nursing colleagues and surgeons has important benefits for patients.

But psychologists are not the only people who deliver psychological care. Other health professionals also acquire psychological skills that can benefit patients. For example, we might talk to patients whilst dressings are being completed in order to model the kinds of responses our colleagues can use when answering questions about appearance. Since the individual, their families and friends need to have a set of skills they can use to manage the challenges they experience, some input can be usefully provided during contact with other therapy or nursing colleagues. This might include providing individuals with examples of how to manage the natural curiosity others have about unusual appearance, and so help prevent this having a negative impact on mood and identity.

In previous research (Clarke &

Vignettes

A 37-year-old man was referred with unusual marks on his forearms that0 surgery was unable to change. Psychological intervention focused on enabling this man to lessen the interference of these marks on his day-to-day life. He is now able to wear T-shirts in certain circumstances, no longer avoids situations where his marks could become visible and is progressing towards going to the sauna with friends. In our work together, we have challenged the unhelpful assumptions he has made (e.g. everybody will notice them and think they are contagious) and have built on his social skills (e.g. how to respond to questions).

A 29-year-old woman was devastated by the change in her facial appearance following a car accident. She became preoccupied by objectively very minor scars, and started to wear a baseball cap to reduce eye contact and 'hide' from other people. Psychological intervention allowed her to eliminate her safety behaviours, resume social activity and moderate her beliefs that she needed further surgery.

Cooper, 2001) we have shown that nurses identify themselves as the people best placed to deliver this kind of information, but they lack confidence in how to do it. However, these skills can be easily acquired. We might also spend time teaching others how to use distraction or relaxation skills when changing a dressing, or model advice about smoking cessation or weight management. An informal approach to referrals ('Can you come and join me today?') has also made psychology an accessible resource, and this has increased the number of individuals who eventually benefit from a holistic approach that includes psychological skills.

Multidisciplinary working and joint working also enable us to highlight areas where service development can take place and the ways in which the person's experience of the unit can be improved. For example, the pathway for women requesting bilateral breast reduction surgery has been redesigned using multiprofessional screening through one outpatient clinic. This identifies those individuals who meet the criteria for this procedure and invites them to a breast education seminar that provides information on the procedure and risks, post-surgical care and psychosocial adjustment to altered appearance. This multiprofessional screening and education pathway has several benefits – women are better informed and therefore able to decide whether to opt for surgery; we can coordinate expectations between staff and patients about the post-surgical outcomes; time is saved in clinics; patients report increased satisfaction with the surgery; there is better management of complications; and fewer people withdraw from surgery at later stages in the process.

"research funding for the psychological aspects of appearance-related distress is extremely hard to access"

Future challenges

Whatever the model of service delivery, the challenges of this work remain very similar. The intense media interest in appearance and cosmetic surgery is increasing the number of people who are dissatisfied with how they look and the challenges for those who have disfigurements. Thus we face an increase in demand at a time when resources for health care are under pressure.

Unfortunately, and despite public interest and growing anxiety about appearance, there is still a perception that these difficulties are only quality-of-life issues, and of secondary importance to life-threatening illnesses. But people may also make important health decisions that are influenced by the impact of treatment on appearance, a fact that emphasises how important these matters are. For example, appearance factors may influence choice of drugs, adherence to medication and decisions about undergoing chemotherapy.

Cultural issues are also important. Whilst we have some evidence for the benefits of our approaches (see Clarke, 1999), we know very little about whether these remain appropriate or beneficial to different cultural or ethnic groups within the UK. We urgently need to develop our understanding of the impact of disfigurement in these groups so that we can improve their access to psychological care and ensure the provision of appropriate support.

The psychology team at the Royal Free has expanded as the Plastic Surgery Unit has developed. We place a strong emphasis on research, teaching and publishing our work, and we are also working to increase access for people with disfigurement through facilitating primary care referrals. Unfortunately, not only are clinical services increasingly stretched, but research funding for the psychological aspects of appearance-related distress is extremely hard to access. However, we believe that although this is a relatively new area, the role of clinical psychology in disfigurement and altered appearance is a specialism that is very effective, highly valued and a good model of integrated holistic health care.

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Special issues sought

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