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Psychological management and body image issues in facial transplantation

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Abstract

Facial transplantation, although controversial, is proposed as a major advance in facial reconstructive surgery, with the first partial transplant having taken place in France in November 2005. Although the psychological impact of facial transplantation will not be understood until several procedures have been carried out, this article examines the psychological issues likely to arise with particular reference to body image. A detailed framework for anticipation and management of psychological change is proposed. Pre-operative preparation must include thorough psychological preparation for the patient and their family. The immediate post-operative period is likely to be challenging, and a detailed management plan is proposed emphasising early return to function; subsequent psychological issues including altered body image, anxiety, shame, depression, communication and behavioural avoidance are discussed and a management strategy based on cognitive behavioural principles is proposed for the first post-operative year. Previous discussion frames psychological outcome in terms of complication and risk, tending to downplay the potential advantages of a successful procedure; the focus of this paper is on ensuring psychological adjustment as an inevitable consequence of change.

Keywords: Facial transplantation; Transplantation; Psychology; Body image

Background

Following reports of successful composite tissue allograft, in particular bilateral hand transplantation (Dubernard et al., 2003), facial allograft (cadaveric whole face transplantation) was proposed as the next logical step in facial reconstructive surgery (Hettiaratchy & Butler, 2003). The first partial face transplant (of the nose, lips and chin) was carried out by Dubenard and colleagues, in France, in November 2005. As this first patient demonstrates, facial transplantation will be used to alleviate functional impairment, for example, where burns contractures prevent mouth opening or other facial movement, where the eyelids have been lost (leading to corneal ulceration and blindness) or where the nose or ears have been lost. It provides opportunities for functional improvement and improved cosmesis currently impossible with other surgical techniques. The final appearance is likely to be a composite of donor and recipient faces, not identical to either original face but retaining some superficial donor characteristics such as eyebrows (Clarke & Butler, 2005).

Like any new radical procedure, face transplantation has excited considerable interest and debate. In order to present the potential risks and benefits of the procedure,

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the Royal College of Surgeons of England (2003) published its Working Party Report on facial transplantation. This, with others (e.g. Furness, 2003), raised the issue of the psychological impact on the recipient, and concluded that more research and planning was needed before the procedure should be carried out. Among the major concerns identified were the problem of informed consent for a new procedure, the impact of lifelong immunosuppression in a 'quality of life' procedure and the psychological problems of altered appearance. These concerns have been discussed in an earlier paper (Clarke & Butler, 2004) and recently expanded (Clarke & Butler, 2005). However, face transplant has not yet been discussed specifically with regard to body image. Nor has there been any attempt to describe the potential management of a patient undergoing this new procedure.

This paper from the UK facial transplantation team therefore forms a further part of the response to the Working Party Report, specifically the call for a more comprehensive psychological management strategy post-operatively.

Using available evidence and tools, the aim of this paper is to provide an integrated and detailed approach to psychological management which is flexible enough to adapt to meet unforeseen challenges. Emphasis is placed on the integration of a new facial appearance into the recipient's body image. Milestones for personal and social re-integration following recovery, along with some tools for psychological assessment post-operatively, are provided. While problems must be anticipated and treated, the aim is to keep the patient psychologically healthy during the recovery process and to promote a positive experience without overemphasis on perceived problems. The experimental nature of the operation means that the psychological impact is hypothetical, and will moreover be different for every patient. This is therefore a plan for psychological management rather than clinical intervention, and is intended to facilitate the early detection of problems while at the same time returning the patient to an independent and fulfilling life.

Pre-operative preparation

Psychological management starts with an assessment procedure to establish that the operation is an appropriate treatment option for a given patient, and is part of routine care for all reconstructive procedures (Clarke & Alexander, 2003). The process of assessing patients should also begin the process of education and psychological preparation for the operation, and provide an opportunity to re-visit any psychological issues unresolved from the original trauma which may be re-awakened by the transplant (Burloux & Bachmann, 2004). The detailed candidate selection process is currently being finalised, and will include body image assessment tools such as the Appearance Schemas Inventory (Cash & Labarge, 1996), the Derriford Appearance Scale (Carr, Harris, & James, 2000) and other standardised measures. The operation will be performed only for the improvement of facial function where current surgical techniques are limited, as in the case of the first French procedure. Facial transplantation is not, at present, indicated for cosmetic reasons, i.e.: in the absence of facial pathology, because of both short and long-term risk, in particular the consequences of life long immunosuppression. As with screening for any transplant procedure, pre-operative assessment will consider psychiatric history, previous treatment compliance, social support, intolerance of uncertainty and difficulty adapting to change. Any candidate must be able to understand and accept all the known implications of the procedure; further discussion can be found in Clarke and Butler (2004).

Motivation for surgery has been studied in different cosmetic and reconstructive populations and is reviewed by Sarwer (2006). The differentiation of internal motivations (related to increasing self-esteem) from external motivations (related to secondary gains such as greater social success, job prospects, etc.) is a valuable part of pre-operative assessment, with patients motivated by internal factors more likely to achieve their post-surgery goals (Edgerton, Langman, & Pruzinsky, 1991). Pruzinsky (1996) has categorised post-surgical goals as physical, psychological and social, and there is evidence that people who focus on the physical change post-surgery tend to be more satisfied with the outcome. There is no evidence that surgical change predicts an improvement in social functioning although this is a common belief in requests for cosmetic procedures. In contrast, there is evidence that psychological approaches to the management of disfigurement and body image distress do result in improved social functioning, without modification of external appearance (Cash, 1997, 2006; Kleve, Rumsey, & Wyn-Williams, 2002; Robinson et al., 1996). The preparation of patients for facial transplant therefore includes not only an assessment of the motivation for surgery with emphasis placed on physical change, but the extent to which psychosocial intervention has been explored as an alternative to surgery is also included, with provision for this intervention to be offered as a first line of treatment. It has been suggested that an individual who is functioning well socially is unlikely to

request face transplantation, while a patient who is not functioning well may not be the ideal candidate for a radical surgical procedure (Royal College of Surgeons Working Party Report). This is the reason that face transplantation is framed as a procedure offered for severe functional impairment, with cosmetic advantages seen as secondary rather than primary goals for surgery (Clarke & Butler, 2004). In the future, it is likely that facial injury will be treated with immediate rather than delayed reconstruction. However, for the first cohort of patients, it is essential that we understand the motivation for surgery as well as possible in order to maximise the chances of good outcome. This information will eventually provide the evidence base from which we can more accurately identify psychological risk factors and therefore those most likely to benefit from the procedure.

In summary then, patient motivation, expectations and understanding of the procedure and post-operative regime together with expectations of perceived outcome and potential risk are likely to be the best predictors of post-operative satisfaction (Clarke & Butler, 2004).

With this in mind, the candidate must be fully counselled about:

- The limitations of the procedure, and the likely outcome and appearance of the new face.
- The source of the donor face, and the criteria for choosing it.
- The time-scale likely for:
  - the immediate post-operative period;
  - graft healing and functional recovery;
  - post-operative pain;
  - psychological re-adjustment.
- Compliance with a complex and lifelong immunosuppression regimen even when otherwise healthy—and its attendant side effects.
- The likelihood of, and plan in the event of, graft failure.

Understanding of all of the above must be achieved before consent is given for the procedure, and psychological input, beginning at this point, should continue as a part of the long-term treatment plan. Since there will be some urgency in performing the operation once a donor is found (to prevent deterioration of the graft), all the necessary preparations should be made prospectively once a suitable recipient is identified.

Preparations must also be made for/with the family and partner of the patient. Poor social support is identified as a likely predictor of subsequent non-compliance in transplant populations generally (Clarke & Butler, 2004), and so it is important to engage with the family from the outset. They must have the same understanding of the procedure as the patient, and all should preferably be counselled together, and by the same team that will conduct the post-operative management. The family should understand that psychological support is key to rehabilitation and offered routinely at all stages of the recovery process. The patient's partner will have specific support to help him/her accept the graft and regain an intimate relationship. Opportunity should be given at all stages to elicit concerns, in private if necessary.

Body image and face transplant

The impact of face transplant on body image needs to be considered within a conceptual framework which is derived from current models of body image and the impact of altered appearance, and the evidence that underpins them.

Multidimensional construct of body image

Cash (2006) describes body image as a multidimensional construct derived from two different components, the "outside, body-in-society view" and the "inside, body-in-self view" which together create a sense of embodiment. The first perspective, generally discussed in the disfigurement literature in terms of objective appearance, is highly influential in determining the attitudes of others, particularly in first encounters (Rumsey & Harcourt, 2004). Clarke (1999) has pointed out that it also drives medical and surgical interventions in settings where biomedical models predominate. Thus, the prevailing belief that people with severe disfigurements will experience greater distress, which is generally not supported in the literature, makes no allowance for the individual's self-perceptions and attitudes which relate to the second, inside body-in-view dimension of body image. Rumsey, Clarke, White, Wyn-Williams, and Garlick (2004) examined the appearance related concerns of 650 patients attending routine outpatient appointments for conditions that impacted on appearance. Their findings, that 60% of patients had appearance related concerns significant enough to impact on their day to day life, once again demonstrated that the severity of pathology did not predict distress, but they also found that where psychological resources were available to patients, they were often targeted at the wrong groups. In one example, psychological input was available for people undergoing surgical excision and loss of an eye, but not for people with thyroid eye disease who as a group were

more distressed. Thus, the failure to acknowledge the multidimensional nature of body image and to target intervention on the basis of individual need, impacts on treatment decisions and health care resources. Clarke and Butler (2004) have stressed the importance of patient selection criteria which make a full assessment of all aspects of body image, in particular, highlighting the limited value of assessing potential face transplant patients through photography or functional facial movement analysis without any assessment of how the individual perceives their own face.

Body image and sensation

The origins of the study of body image in neuropsychological research in the early part of the 20th century provided the first evidence of how the sense of embodiment might be mediated by cortical processes (Fisher, 1990). Thus, it was research with clinical problems such as phantom pain and agnosia which provided the foundation for the study of body image, rather than the studies of eating disorders which are prevalent in the field today. Face transplant is interesting in its potential to explain more about the cortical processes that underpin facial identity and the relationship to altered sensation. Pruzinsky (personal communication) has noted that patients undergoing face lift as a cosmetic procedure may become disoriented and distressed by altered sensation in the face. For people who have undergone hand transplantation, there are reports that patients' acceptance of the hand as 'my' hand can be influenced by MRI feedback of cortical activity and improvement in sensation and function (Burloux & Bachmann, 2004). This suggests a process of cognitive relabelling on the basis of changing information and adaptation of proximal determinants of body image (see section on long-term psychological adaptation). These findings support Kinsbourne's (2002) interpretation of body awareness as a dynamic phenomenon which develops, particularly in infancy, as the child becomes able to attend selectively to different body parts, and which is capable of adaptation throughout the lifespan. While adapting to a new face has been framed in terms of gradually adjusting to a new appearance, it is equally important to consider how closely this might be linked to the alteration and development of sensation. Facial phantom pain as opposed to altered sensation has been infrequently reported in clinical populations. Where it has occurred, it is associated with size distortion and an unpleasant affective component to the agnosia, with patients describing their face as 'alien' or 'foreign'. They frequently become very distressed by this, in the same way as patients may respond to the experience of hemianopeias (Ramachandran & Hirstein, 1998; Sacks, 1992). Veale (2004) reports that patients diagnosed with body dysmorphic disorder commonly describe an urge to 'surgically remove' the part of their body which causes such intense distress, often using the same kind of emotive vocabulary, e.g.: alien, 'not part of me'. For those involved in the day to day management of a patient after face transplant, the evidence that body parts construed as foreign may generate such a profound emotional response is a very important determinant of how patients are both prepared and managed post-operatively. Just as Schilder widened the focus of early neurological studies to include attitudes and feelings about the body, the opportunity to study the relationship between internalised body image and representation of emotion is provided by advances in technology such as functional MRI. This may allow us to explore information processing and the cortical basis of body image much more fully in patients undergoing all kinds of reconstructive surgery, not only face transplantation.

Psychoanalytic and cognitive behavioural models of body image

Concurrent with the neuropathological approach to body image, psychoanalytic theory at the beginning of the 20th century focussed on the way in which the body is boundaried. Freud's studies in hysteria challenged conventional understanding of sensation, and Fisher (1990) published widely on the body boundary construct. Sarwer and Crerand (2004) describe psychoanalytic approaches as the 'first generation' of studies examining body image disturbance, but they note that there was little work published examining the efficacy of such approaches. Similarly Cash (2006), reviewing the contribution of psychodynamic approaches to the management of eating disorders, makes the same point. While cognitive behavioural approaches provide the best evidence of effectiveness in the modification of body image distress (Cash, 2006; Cash, Phillips, Santos, & Hrabosky, 2004; Rumsey & Harcourt, 2004), the study of adaptation to hand transplantation in France is presented within a psychoanalytic framework (Burloux & Bachmann, 2004). It will be interesting to see the utility of this approach in patient assessment and prediction of good outcome as more patients undergo the procedure. In China, Zhu, Pei, Gu, and Hong (2002) used a cognitive behavioural framework with hand transplant patients, training the management of emotional response pre-operatively and reappraisal and positive labelling of

cognitions post-operatively. Our own approach is similarly based on a cognitive behavioural model, and derives from earlier work in the area of disfigurement (Clarke, 1999). Given that both perceptual processes and attitudes are important in studying body image, a cognitive behavioural approach provides the most logical framework within which to explore the thoughts, feelings and behaviours associated with altered appearance in face transplant and to allow the development of theoretically driven management strategies.

The cognitive–behavioural approach suggests that body image depends on the interaction between historical factors, i.e. those beliefs about the self which are shaped by previous experience and are gradually modified over time as this accumulates, and proximal factors which result from current situations, thoughts and events, and include precipitating or maintaining influences on body image (Cash, 2002a). Any bias in the way that individuals attend to information or the value that they place on the information that they access will shape the way in which body image is determined. Adaptation of the body image to a new appearance will therefore require re-evaluation of historical factors and reappraisal of ongoing change, in which the sources of information about facial appearance will be very important, and will include reflected images (self-appraisal) and the reaction of others.

In planning a practical management programme for face transplantation, the UK team proposes that a cognitive behavioural model best explains and predicts the small amount of data available from outcome studies of analogous populations such as hand transplantation. Evidence that successful body image integration depends not only on the recipient's experience but on social factors (e.g. the family's reaction, as below) similarly supports Cash's (2002a) explanation of how body image is determined and adapts.

Clearly facial transplantation represents a completely new opportunity to study models of body image. Not only is the individual adapting to change as in other reconstructive procedures such as skin grafting, but the assimilation of change must incorporate the idea that, however minimal, the body image is in some ways derived from that of another individual. Interestingly, while this is represented as a negative prospect in the literature so far, it is evident that where this occurs naturally, i.e.: in the inheritance of familiar family features, it is often seen as desirable and reassuring. Thus, we should not assume that this experience will necessarily be a negative one for the recipient. While racial characteristics will be matched during donor selection, we would suggest that assimilation of a new face with unfamiliar characteristics will depend on the evidence that the face 'functions'. For example, that it is sensate, mobile, expressive, provides the individual with an identity, facilitates communication and is acceptable to other people. This is analogous to other transplantation populations, for example, where a new kidney is seen to function once urine starts to be excreted.

The early post-operative period

The early post-operative period (1–2 weeks following the operation) will focus mainly on returning the patient to a basic level of health and function, while further recovery will focus on physical and psychological rehabilitation. The psychological needs of the patient will be different for these periods and so these are addressed separately below.

Experience with hand transplantation, another highly visible form of allograft, has shown that the immediate post-operative period can be extremely difficult. There may be severe psychological distress, exacerbated by post-operative delirium and the effects of immunosuppressants, which can require heavy sedation. Psychological effects include neglect (being unable to look at the graft, even turning the head away in sleep), troubling dreams and hallucinations of flying disembodied hands, unexplained somatic symptoms in the hand and elsewhere, delusions (that the hands were in fact the patient's own, re-planted), anxiety, depression, agitation, horror and psychosis (Burloux & Bachmann, 2004; Zhu et al., 2002). These effects are despite a detailed programme, in Chinese patients, to train them to resolve distressing emotional states prior to surgery, and persisted for weeks after surgery. Such symptoms, in response to an obvious stressor, would be labelled as an adjustment disorder under the DSM-IV criteria (Salomon & Salomon, 2002). The degree to which this is likely to occur following facial transplantation is unknown, but for this reason the selection process includes major emphasis on, and preparation for, disruption in facial recognition (Clarke & Butler, 2004). However, a facial transplant is not the same as a hand transplant; only the skin is involved, and the graft is not directly visible to the patient. Thus, a facial graft may prove less traumatic in the early stages. Meticulous pain control is also important, since pain may contribute to any re-awakening of the original trauma.

Immediately following the operation to implant the allograft, the patient is likely to be on the intensive care unit (ITU) for 24 h, and remain heavily sedated for another 24 h. In order to protect the airway and reduce movement of the graft, a tracheostomy and feeding tube

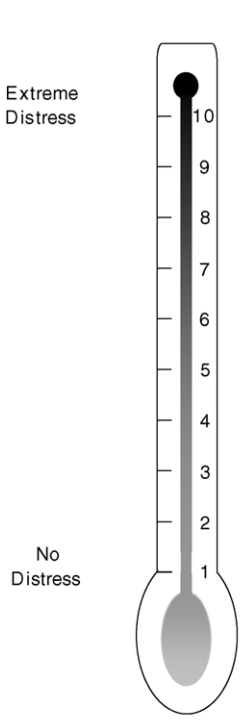
will be in situ, and the graft, which will be swollen early on, will be covered to keep it warm. The patient will therefore be incapable of speech or facial movement, although the eyes will remain uncovered and it is anticipated that in the absence of any immediate complications the patient will be able to move around by 2 days post-operatively. Nonetheless, this creates difficulties in allowing the patient to take early steps to assess their new appearance, and is also likely to re-awaken memories of the original trauma (Burloux & Bachmann, 2004). It becomes important that they take every opportunity to look in the mirror when the bandages are changed, and also with the bandages in situ, so that they can begin the process of understanding the detail of how their appearance is changing, and integrating this into their internalised body image. Since there should not be a mirror permanently in the room (see section '*Post-operative environment*') there may be a role for photography (digital or Polaroid) to enable familiarisation with the new appearance; this will also allow charting of the post-operative progress of the graft.

Communication

The fact that the patient will be unable to speak following surgery may increase the psychological impact of the post-operative period, although some of these patients may have already developed new communication strategies following their original injury. Difficulty in communicating will potentially make it harder to articulate needs and problems, and will also make assessment of mood and mental state more difficult. In order to prevent the patient becoming self-focussed and withdrawing from interaction with others (see below), it is important to encourage communication with those around him/her, even if only by written word. The patient should be encouraged to keep a daily log of their activities, and to complete a 'mood thermometer' assessment daily. This was developed by Tuckman (1988) and modified by Roth et al. (1998) for use in cancer patients. It provides an easy and quick assessment of the source and intensity of any distress, and can be swiftly filled in by a patient who cannot speak. Fig. 1 shows a version of the thermometer adapted to include the issues likely to be salient to a patient in the first few days following facial transplantation.

Post-operative environment

With the potential for a heightened sense of change that is likely for these patients – even their reflection



Please indicate your level of distress on the thermometer to the left, and tick any relevant boxes below to indicate the causes of this distress.

Appearance
- ☐ With bandages
- ☐ Without bandages

Communication
- ☐ Your speech
- ☐ Your facial expression
- ☐ Reactions of others to you

Personal activities
- ☐ Washing
- ☐ Dressing
- ☐ Managing Tracheostomy
- ☐ PEG tube

Emotions
- ☐ Frustration
- ☐ Anger
- ☐ Loneliness
- ☐ Depression
- ☐ Boredom
- ☐ Fear/Nervousness
- ☐ Homesickness
- ☐ Memories from previous hospitalisation
- ☐ Other _____

Social interactions
- ☐ With relatives/friends
- ☐ With your partner
- ☐ With your children
- ☐ With hospital staff

Thoughts about the future
- ☐ Going home
- ☐ Coping alone
- ☐ Graft failure

Medical
- ☐ Nausea & Sickness
- ☐ Facial pain
- ☐ Pain elsewhere
- ☐ Drowsiness
- ☐ Headache
- ☐ Other _____

Any other causes:

_____

_____

_____

Is there anything else important you would like to add?

_____

_____

_____

_____

Fig. 1. Post-operative rating 'thermometer' for assessing distress. After Roth et al. (1998).

will be different – the environment in which they are to recover is important. Patients undergoing facial transplantation should be allocated their own room on the ward, which provides an opportunity to ensure that the patient's living space has plenty of familiar cues to help ground the patient psychologically regardless of how strange s/he may feel. Williamson, Stewart, White, and York-Crowe (2002) have discussed the way that body image is underpinned by cognitive schemas or mental representations which are modified by information, a similar concept to Cash's model of adaptation of body image via proximal factors. The impact of mood on body schemas is interesting, with negative mood state having been demonstrated to impact negatively on estimations of body size, although other aspects of body image appear more robust. The extent to which low mood might impact on post-operative recovery is important, since the engagement of the patient in self-care routines and social interaction at an early stage predicts good outcome in other facial reconstruction procedures such as head and neck surgery (Dropkin, 1989). Whether low mood would also influence attitude to the facial graft itself and delay integration into body image is an interesting possibility and an additional reason to monitor mood closely, and promote effective interventions to elevate it. These include simple strategies such as providing a pleasant, well-ventilated room with a window, access to some of his/her own music, family photographs, books and pillow cases. The availability of communal activities, particularly, e.g. videos and board games, will help to alleviate some of the inevitable awkwardness when family and friends come and visit and provide a stimulus to help social interaction and focus the patient's attention externally.

With a mirror in the room, the patient may become preoccupied with their appearance and spend much time mirror gazing. However, this must be weighed against mirror avoidance. One compromise is to have a mirror available on demand, which is then removed after a set period of time (e.g. 15 min). This, coupled with the daily mirror checks proposed below, strikes a balance which will allow the patient to become familiar with their new appearance in a controlled way. A patient might also check repeatedly by feeling their face with their fingers or seeking excessive reassurance from others, and such behaviours should be monitored.

Plan for post-operative care, days 1–14

Exploration of patients' coping strategies after head and neck cancer surgery suggests that patients respond to the stress of surgery by forming an appropriate early coping response (Dropkin, 1989); certain behaviours can be used to predict outcome. For example, early socialising carries a positive prognosis while prolonged avoidance carries a negative one. This was used to formulate a post-operative schedule for early rehabilitation, which Clarke and Alexander (2003) adapted for use in maxillofacial (trauma and surgery) patients. Motor behaviours, self-care activities and social interaction are monitored from immediately post-recovery, and active encouragement starts on day 5 to achieve those objectives not yet met, with all intended to have been met by day 7. A modified version of this schedule, extended to 2 weeks and adapted for the post-operative requirements of the facial transplant patients, is shown in Fig. 2. Close observations should be made every day, with active encouragement to be commenced at about day 7 (to allow for the 48 h that the patient is likely to be sedated); this encouragement should increase in those areas where the patient is observed to be avoidant, such that by about day 10, help is being given to ensure that all activities have been performed by day 14. Clearly these timings cannot be prescriptive before the procedure has been undertaken, and this is a suggested format based on care in head and neck surgery. Emphasis is given to exposure of the patient to their new appearance in the mirror, identified as a positive prognostic factor, in the context both of self-care activity and simply looking. This should facilitate early identification of poor prognostic behaviours and allow prompt encouragement to be given.

Family and very close contacts should visit regularly once the patient is medically stable, wider friends and relatives less so in the initial stages. Young children, who (with the face swathed in bandages or unrecognisable) will rely on vocal cues to identify the patient, should wait until the tracheostomy is reversed and the patient can speak again before visiting. By the end of the first 2 weeks, the patient should also have started to move beyond the confines of the ward, including outside, while accompanied by family or nurses.

Longer-term psychological rehabilitation

After the immediate post-operative period, when (assuming a smooth post-operative course) the graft is healing well, physical rehabilitation will start. This process is mirrored by one of psychological adjustment, and is therefore an appropriate time to commence a structured psychological programme to facilitate acceptance of the graft and integration of the new face into the patient's body image. The most frustrating scenario would be for a patient with a well-healed,

	Postoperative days													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Activities														
Sitting in chair														A
Ambulation in room							A			A				S
Ambulation beyond room							S			S				S
Listen to music							S			S				E
Reading							E			E				S
Other (specify)							S			S				S
Self-care behaviours							S			S				M
Look in mirror (1 minute)							M			M				E
Brush hair							E			E				N
Dress unaided							N			N				T
Manage PEG							T			T				
Tracheal toilet														
Assist changing bandages														P
Social interaction							P			P				O
With staff:							O			O				I
Eye contact							I			I				N
Posture							N			N				T
Verbal/written initiated							T			T				
With relatives:														
Eye contact														T
Posture							O			T				H
Verbal/written spontaneous							N			W				R
Logbook:							E			O				E
Mood scale completed														E
Activities recorded														

Fig. 2. Behavioural observation and action plan for facial transplant patients in post-operative days 1–14. After Clarke and Alexander (2003).

immunologically well-controlled, functionally and cosmetically acceptable facial graft to become housebound by distress resulting from psychological non-acceptance of that graft.

Long-term adaptation of the body image to integrate altered appearance after reconstructive surgery is likely to be influenced by several factors. These include pre-disfigurement appearance, level of investment in appearance, social skill and psychosocial functioning, social support and patient expectations of the operation and associated risks (Pruzinsky, 2002). It is also likely to be affected by how the patient has adapted following the original disfigurement, and their post-disfigurement, pre-operative level of functioning. Thus, thorough pre-operative assessment and education is vital. As with most reconstructive surgery, modification of the body image is further complicated by a long healing process until the final appearance is reached. There is often a variable recovery period with measurable gains in appearance and function, followed by static periods with little obvious change, or even reversal (e.g. tissue swelling, new scars). For face transplantation there is also likely to be impact on physical wellbeing (e.g. post-operative illness, graft rejection, immunosuppressant side effects), or memories of the original trauma. Facial transplantation is also likely to be the latest in a series of appearance-changing reconstructive operations undergone by the patient. The concept of one's own appearance therefore becomes a feedback loop in which the body image is being constantly revised in response to perceived information about the new appearance (Rybarczyk & Behel, 2002), and is vulnerable to cognitive bias and negative emotional influences. This series of different, transient appearances delays final integration of the body image (Pruzinsky, 2002). As with changes in the immediate post-operative period, the emphasis will therefore be on restored function and positive appraisal of change.

There are several specific issues which seem likely to arise following facial transplantation. These are discussed separately below (although most are likely to be interlinked) along with specific management strategies; a long-term management plan is discussed later.

Avoidance

Avoidance (of looking at or interacting with the graft) has been identified in the hand transplant populations as a powerful factor preventing integration of the graft into the patient's body image (Burloux & Bachmann, 2004; Zhu et al., 2002). The face is strongly associated with individual personality, and there are

likely to be strong feelings of depersonalisation when one's own face is replaced by another. The feeling of detachment may be exacerbated by the fact that the graft is unlikely to gain motor or sensory capability for many months. The non-functioning nature of the graft will reduce the capacity for non-verbal communication with others (see section '*Communication*') and the hormonal responses proven to be normally present with facial expressions will also be absent (Royal College of Surgeons, 2003). A feeling of 'not the real me' can also paradoxically stem from the loss of the old disfigured body image, even when that transformation has been greatly anticipated and is objectively successful (Rumsey & Harcourt, 2004). The result of this may be that the patient avoids the emotional stress brought on by looking at or touching the graft by simply refusing to acknowledge it.

Cognitive–behaviour therapy (CBT), including graded exposure, may be helpful here. This will encompass measures such as looking in the mirror and encouragement to 'use' the face, e.g. applying make-up, shaving, managing scars and other self-care activities. Different styles of hair and make-up may be useful to facilitate adjustment to the new appearance. The use of topical immunosuppressant preparations (e.g. creams or lotions applied directly onto the graft, not possible in most other forms of transplantation), while useful to reduce systemic side effects, will also encourage the patient to interact with the graft. Other strategies that may be helpful to prevent avoidance behaviours focus on reinforcing information that the graft is part of the patient's own body. Physiological measures, particularly functional magnetic resonance imaging (fMRI) scanning, showing changing activity in the motor cortex as the graft recovers movement, have been highly effective in promoting acceptance of hand grafts by 'proving' to the patient that there is an interaction between their brain and the new graft (Burloux & Bachmann, 2004). A technique demonstrated to improve early remodelling of the motor cortex in response to the new graft (as shown by fMRI) has been the use of a 'sensor glove' which transformed tactile feedback (which at that stage could not be perceived by the patient) to auditory feedback via earphones (Lanzetta et al., 2004a); this is likely to have benefits for psychological as well as physiological integration of the graft and could be adapted for use on the face.

Anxiety

During the months following facial transplantation, anxiety is likely to result from many stressors present around the patient. These could include unwanted media intrusion, reactivation of post-traumatic symptoms, family difficulties, fears about the future and any other body image issues likely to be raised by facial transplantation. One particularly salient fear, common in all transplant populations, is that of graft rejection (Clarke & Butler, 2004). Even in a wholly successful hand transplant (Jones, Gruber, Barker, & Breidenbach, 2000) there were four episodes of moderate acute rejection (manifested as a rash on the skin at the wrist) in the first 27 weeks post-transplantation. Of the first 18 hand transplants performed all suffered at least one episode of acute partial rejection, at a mean of 40 days post-operatively (Lanzetta et al., 2004b). This could maintain a state of high anxiety which would interfere with psychological recovery and could lead to behaviour such as compulsive mirror checking (or conversely avoidance of reflective surfaces). However, both hand and face transplants have the advantage that the graft is visible and early evidence of acute rejection is very easily observed by the patient. It can be argued therefore that this group of patients is less likely to ruminate about possible graft rejection than solid organ transplant populations where the patient has less control and is unable to self-monitor in such a straightforward way. Teaching the patient exactly what to look for and what to do about it is likely to reduce excessive anxiety and rumination. There obviously remains the very real possibility that the graft will be rejected, perhaps leaving the patient requiring further facial surgery, and while anxiety must be treated false reassurances should therefore be avoided.

Anxiety may also result from fear of potential or actual side effects of the immunosuppressive medication and this may lead to non-compliance with the regime, possibly with disastrous consequences.

Experience with hand transplant patients has shown that high levels of post-operative anxiety often presented with somatic symptoms such as vomiting or difficulty swallowing (Burloux & Bachmann, 2004). This could confound early identification of the problem, particularly due to the difficulties of differentiating it from side effects of immunosuppression, and will necessitate careful monitoring.

Management of the symptoms of anxiety will be crucial to allow the underlying problems to be adequately addressed. If the patient is very agitated or suffering significant somatic symptoms, pharmacological therapy is likely to be appropriate (e.g. benzodiazepines or a low dose of an anti-psychotic

drug) to overcome the acute episode. Specific psychological measures (e.g. relaxation, visualisation, CBT) can also be used to develop coping strategies.

Depression

This, like anxiety, is likely to be multi-factorial. The stress of the procedure, post-operative regime, pain and temporarily enforced social isolation are risk factors for low mood, and this is not unusual, in the short term, after any reconstructive procedure. A sense of guilt or responsibility to the donor is common in transplant populations, or may relate to the original disfigurement. However, low mood should not be confused with clinical depression where the individual meets the criteria for a DSM-IV-TR (American Psychiatric Association, 2000) diagnosis. Low mood can be anticipated, the patient prepared for 1 or 2 'down' days, and efforts made by staff and relatives to provide additional input. Treatment should be aimed at identifying the factors maintaining a depressed mood, especially the inactivity, social withdrawal and ruminations (e.g. ''If only I didn't have this operation''), and conducting a contextual functional analysis of the symptoms. In the longer term, patients undergoing surgical reconstruction have to cope with long time frames in which there may be multiple procedures, everyday life is disrupted and the ultimate surgical result may not match their expectations. They may be acutely aware of minor changes which family and health professionals do not notice, or there may be long periods of time in which they are unable to identify any significant change or progress. This makes them a vulnerable group in terms of long-term depression, and those undergoing facial transplantation are likely to meet many of these challenges. A diagnosis of clinical depression, with its consequent feelings of excessive guilt or worthlessness and effects on motivation, appetite, sleep and social interaction, should be considered where symptoms persist for at least 2 weeks and cause significant distress, impact on social functioning or disrupt medication compliance. Graft survival after facial transplantation is dependent on a rigorous immunosuppressant regime, and depression has been noted as predictor of non-compliance in other transplant populations (Baines, Zawada, & Jindal, 2005). The early identification and treatment of depression is therefore crucial to prevent this. Cognitive behaviour therapy or anti-depressant medication may be used either alone or in conjunction for depression. Pre-operative assessment to identify a history of depressive episodes and careful monitoring post-surgery are vital in managing depression and reducing the potential for graft loss.

Body image and shame

A negative perception of appearance may result from cognitive bias and potentially low mood as described above. In facial transplantation it may also be associated with feelings of guilt or unworthiness, and exacerbated by the knowledge of the cadaveric nature of the graft. Shame, both as cause and consequence of altered appearance, is also likely. Gilbert (2002) differentiates between internal and external shame depending on whether the problem to the patient is their perception of him/herself or their perception of how others perceive them. Conceptually therefore, shame is about social comparison, related to, but not the same as the external and internal dimensions of body image described by Cash.

Internal shame results from one's own negative feelings about one's appearance, and can lead to feelings of disgust and self-loathing. The 'Frankenstein' aspect (Burloux & Bachmann, 2004) identified in the hand transplant patients, particularly early on when the scar demarcation between donor and recipient skin can be clearly seen, is likely to apply strongly to the face transplant patients. It may arouse feelings of disgust directed against the graft itself. Excessive rumination is likely, and may result in anxiety or depression and a reduction in activity.

Psychological therapies aimed at reducing internal shame and increasing satisfaction with all dimensions of body image in facial transplant patients should first identify the underlying problem. Tools such as the body image diary (Cash, 1997, 2002b), the Body Image Disturbance Questionnaire (Cash et al., 2004), the Derriford Appearance Scale (Carr et al., 2000) and others (see, e.g. Kent & Thompson, 2002) provide situational assessment of negative self-schemas. Cognitive–behavioural therapy, including behavioural experiments to challenge beliefs and avoidant behaviours, can then be used to modify these (Kent & Thompson, 2002). Self-help interventions have also been shown to be beneficial in facial disfigurement (Newell & Clarke, 2000), and Cash (1997) provides a comprehensive self-help programme for improving body image satisfaction.

External shame refers to one's perception of being viewed negatively by others, and results in the expectation that others will not want to interact with one in a positive way. This is seen often after disfigurement (Kent & Thompson, 2002), and also

results from internal shame and negative body image. It can lead to social isolation where the individual is so afraid of social interaction that complete withdrawal occurs. Treatment for this should include behavioural experiments, graded exposure to situations avoided and communication skills training to help others adapt to the new appearance, as below. The patient's support network and opportunities to share experiences with others are essential (Kent & Thompson, 2002). It is also important that all the health professionals and ward staff caring for these patients are prepared for the procedure, the likely appearance of the patient at all stages, and do not show evidence of excessive staring, curiosity or startle reactions.

Communication

Because facial transplantation is unfamiliar to the staff treating the patient the language used to communicate with the patient may not be helpful; for example, it is conceivable that the patient is asked ''how is *the* face today?'' or the graft be referred to as ''*the* new face''. This may reinforce the patient's sense of the graft as foreign and should be avoided. The graft should always be referred to as ''*your* face'' and the patient encouraged to use such language (''*my* face'').

The fact that the graft will not fully function for several months post-operatively will necessitate communication without facial expression. The patient will have to learn to verbalise many of the expressions previously used in order to facilitate communication, for instance, expressing pleasure where previously smiling would suffice. This is a strategy used with patients who have Moebius Syndrome where facial nerves are not fully developed or absent (Clarke, 1999). The patient's relatives should also be made aware of this, and that, for example, a flat facial expression does not necessarily indicate low mood or dissatisfaction. Providing verbal prompts, such as asking ''how are you feeling?'', will help by allowing the patient to verbalise in a way that fits easily within the conversation.

The rehabilitative environment can be over-protective, and patients will need eventually to be exposed to in social situations (Rybarczyk & Behel, 2002). A strategy developed to aid social integration following disfigurement is the learning of social skills, and this can prove highly effective at ameliorating excessive self-consciousness and social anxiety (Coughlan & Clarke, 2002; Rumsey & Harcourt, 2004). Patients are taught to anticipate and manage social situations and to be pro-active, taking charge of the conversation before any awkwardness has a chance to develop. This includes strategies to start conversations (e.g. ''I am enjoying myself this evening. Often I find these events difficult because of my face, but everyone seems very friendly tonight ...''), focussing attention on the other person (e.g. ''I like your tie''), positive use of body language and dealing with awkward questions (e.g. ''what happened to your face?'') and situations (e.g. how to challenge people staring) (taken from Clarke & Cooper, 2000). In the first few cases of facial transplantation this seems particularly important since the procedure will be highly publicised and likely to attract much curious attention to the patient; if it is successful enough to disguise any previous disfigurement then the issue of whether, when and how to tell people about the operation becomes relevant. At a minimum Clarke and Alexander (2003) suggest that upon hospital discharge (following maxillofacial surgery or other disfigurement) patients should be prepared to answer simple questions about their condition.

Attitudes of family, friends and staff

If positive, the support network surrounding the patient is widely acknowledged to act as a buffer for stress and improve recovery (e.g. Furness, 2003; Rumsey & Harcourt, 2004). One milestone in the acceptance of bilateral hand grafts by a patient was identified as the moment his son reacted with joy to the new hands upon his return home (Burloux & Bachmann, 2004). However, facial transplantation is likely to provide a unique set of stressors for those surrounding the patient (Royal College of Surgeons, 2003); these need to be anticipated and managed appropriately.

Those close to the patient may need their own psychological support to cope with what may prove to be a profoundly disturbing procedure, and to enable them to interact with the patient in a positive way (and in turn aid the patient's own recovery). Monitoring of psychological status should be routinely offered to the family and/or close friends of the patient and provided by professionals who are familiar members of the transplant team. Intervention, when necessary, might take the form of family therapy, perhaps with and without the patient present, where issues could be raised before they impact on the relationship between the patient and those close to him/her. It would offer an opportunity for the family to voice their concerns (for example, their own feelings of revulsion/pity/guilt) and obtain support without any admission of weakness or stigma, and would involve family and friends in solving problems experienced by the patient. There may also be intrusive media and other attention focussed on the patient's family, who may need

help or media training to formulate coping strategies for answering or deflecting this intrusion; strategies similar to those described in section '*Communication*' can be used. The important point is to have a flexible and attentive support network in place throughout the procedure, which can adapt to meet specific problems before, during and after the event.

The post-operative period will be particularly difficult for the patient's partner, and has important implications for the subsequent resumption of the intimate relationship between them. A study of patients surgically treated for head and neck cancer (Gamba et al., 1992) reported worsening of patients' relationships with their partners (although in the case of facial transplantation the intention is for the patient's appearance to improve). The effect of sudden large changes in body image on intimate relationships has rarely been examined to date, but it is likely that that they will be profound. The partner will have to adapt to the patient's new appearance, as well as coping with any early dependency and healthcare needs, at a point when the primary focus of the health care team will be the patient. It is important therefore that early exercises to promote the patient's acceptance of the graft also involve the partner. S/he should be present at early mirror checks (when the bandages are removed) and should learn to help with changing the dressings. The aim is to learn, specifically, to become comfortable touching the graft, which will enable the same physical intimacy as was present before the operation and/or original disfigurement. Importantly, a positive reaction by the patient's partner is likely to have a highly beneficial effect on the patient's own body image.

Attitudes of treating staff are also important. Burloux and Bachmann (2004) cite the example of a treating physician who was horrified when a patient started to bite the nails of his new hand; however, to a psychologist this represents good evidence that the hand is integrated into the body image. All staff interacting with the patient should be primed to use appropriate language in referring to the graft (as described in section '*Communication*'); this will also give them an opportunity to examine their own feelings about the operation and to hide any negative feelings they may have which could influence the patient. It is important that the treating team is a multidisciplinary one, with good pre-emptive communication between the professionals so that the medical, surgical, rehabilitative and psychological aspects of the patient's care can be dealt with in an integrated, consistent and efficient manner by all involved.

Finally, the donor family must be considered. Because of the strong media interest, particularly in the first few procedures undertaken, it will be very easy

Aims	Potential Problems	Interventions	
		For the patient	For the relatives
First Two Weeks			
Medical/surgical stabilisation Early return to function (self-care activities, eating, ambulation etc) Tolerance of graft appearance	Adjustment disorder Delirium Denial/avoidance High anxiety with somatisation Re-emergence of original trauma	See Figure 2 Sedative/anxiolytic medication Mirror exposure training – looking, touching, self-care behaviours	Close contacts to visit Social activities – games, videos Help with care Support as needed
Two Weeks - Two Months			
Early social re-integration (interaction with close contacts) and staff Integration of graft into body image Graft rehabilitation Re-establish intimacy with partner and immediate family	Denial/avoidance/donor guilt Anxiety especially re body image Depression Shame Management of drug regimen	CBT to include: Advanced mirror exposure including shaving, makeup Donor issues Strategies for intimacy Pacing activities and goal setting Anxiolytic medication if needed	Communication skills to deal with outside attention Re-establish intimacy with partner and immediate family Pacing activities and goal setting Elicit concerns and support as needed
Two Months - Six Months			
Gradual advanced social re-integration (going out, social gatherings) Continued graft integration into body image Continuing family acceptance	Donor superstitions Shame Social withdrawal Depression Family difficulties Maintenance of drug regimen	Continue as above and add: Social skills training Social interaction training	Elicit concerns and continue support as needed
Six Months - One Year			
Continued social re-integration (return to work, meeting new people, talking about experiences) Treatment of any remaining problems Ensuring long-term medication compliance Establish long-term support network	Social withdrawal Shame Depression Frustration with progress including: Body image problems Dissatisfaction with graft function and appearance	Continue as above and add: Preparation for return to work Advanced social skills training	Elicit concerns and continue support as needed

Fig. 3. Psychological management plan for first post-operative year.

for the family to identify the recipient of the graft in a way that is not possible with regular organ transplant. For this reason, it is proposed that a similar management programme is set up, mirroring the programme for the recipient, and keeping the donor family fully informed about the successful milestones in post-operative recovery for the recipient. It may be both appropriate and helpful for the two families to meet, and this should be managed by the transplant team.

Outline of care in year 1

Experience with hand transplants suggests that psychological integration has taken place by 1 year post-operatively (Burloux & Bachmann, 2004; Jones et al., 2000; Zhu et al., 2002); integration of a facial graft may take longer. Using this as a guide, however, Fig. 3 proposes a framework for psychological management in the first year post-operatively, suggesting aims of therapy, potential problems and therapeutic methods likely to be useful at different stages in recovery. It is no more than a guide, and strategies must be devised for those problems not anticipated here, or discarded for those proved in retrospect not to arise. The importance of involving the patient's family and partner is stressed, although considerable flexibility will be required to provide the support needed. Media training may be useful for the first few patients who wish to assist the media; for example, there may be interest in making a documentary. Equally every effort should be made to keep confidential the details of patients who do not want any media intrusion. The patient may want to write a book or a diary about their experience; writing can also be significantly therapeutic in adapting to any trauma or event (Pennebaker, 1997). Psychological support should not cease at 1 year; beyond this point it should be tailored to specific needs.

Conclusion

The small amount of relevant research in analogous populations such as facial reconstruction, head and neck cancer, organ and hand transplant patients suggests the utility of a cognitive behavioural model in explaining adaptation to change and good outcome, particularly with regard to assimilation of a new and positive body image. This cognitive behavioural framework has therefore been used to develop a management plan for patients undergoing face transplantation.

It is important to remember that in spite of the huge psychological impact of an operation such as this, the aim, as with any reconstructive procedure, is to restore function and appearance to enable the individual to resume his/her normal life. The outcomes for the first partial face transplant patient will provide the first indication of how well these objectives have been met. The procedure will not be successful if one set of problems (facial dysfunction) is exchanged for another (psychological distress), but the first indications are that this procedure has been successful, certainly in the short term. The long-term success of the procedure will be measured in terms of technical success, patient satisfaction with outcome, compliance with immunosuppression and a return to normal social function.

Psychological issues in facial transplantation can be anticipated and planned for, and the expectation is that the overall experience will be a positive one. By breaking down the post-operative process into stages, it becomes clear that different issues will be important at different stages and that careful monitoring and intervention can potentially manage them. Thus, the focus of this review is conceptually different from previous reports which frame psychological issues as problems, in that psychological issues are presented here as the expected sequelae of major change, particularly with relation to appearance and body image, which can be managed.

The controversy surrounding the issue of whether or not facial transplantation is an appropriate path to follow has not been addressed here, but can now be discussed with the benefit of experience of at least one case (Butler, Clarke, & Hettiaratchy, 2005). This, together with a detailed discussion of the strategy for psychological management in place, means that debate can continue in an informed and strategic manner. The experience of patients undergoing facial transplantation will have much to contribute to our understanding of the development and adaptation of body image, particularly after reconstructive surgery.

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