

**The University of Hull**

**FACIAL DISFIGUREMENT AND AVOIDANCE:  
A COGNITIVE BEHAVIOURAL APPROACH**

**being a Thesis submitted for the Degree of  
DOCTOR OF PHILOSOPHY  
in the University of Hull**

**by**

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## LIST OF FREQUENTLY USED ABBREVIATIONS

TERM	ABBREVIATIONS
Body Attitudes Test	BAT
Body dysmorphic disorder (dysmorphophobia)	BDD
Body Self-Relations Questionnaire	BSRQ
Brief Standard Rating Scale for Phobics (Fear Questionnaire)	FQ
Cognitive-behaviour therapy	CBT
The Face Attitudes and Avoidance Checklist	FAAC
General Health Questionnaire	GHQ
Hospital Anxiety and Depression Scale	HAD
Maudsley Obsessions Checklist	MOC
Social Adjustment Questionnaire	SAQ
Suicide Probability Scale	SPS

# **PART 1**

## **INTRODUCTION AND LITERATURE REVIEW**

## CHAPTER 1

### INTRODUCTION

#### **Section 1.1     Introduction to the study area**

This study is a quantitative examination of the experiences and behaviours of facially disfigured people, with particular regard to social situations. The social difficulties of disfigured people are well documented, principally by a handful of qualitative researchers and from first-hand accounts of sufferers. This is invaluable descriptive information which gives a considerable insight into the experiences of sufferers. It is, however, anecdotal and unsystematic, and there is no current picture of either how widespread these difficulties are or of the role played in them by anxiety and avoidance. This study seeks to elucidate these issues through the use of survey and quasi-experimental means. No coherent model of social difficulty in facially disfigured people has been developed, and existing general models of disturbed body image are incomplete. This study examines the applicability of a fear-avoidance model of psychosocial difficulties in facial disfigurement. Treatment studies in the field of facial disfigurement are few, and are poorly designed. The current study examines a minimal intervention for facial disfigurement, using brief guidance delivered by leaflet. Since the leaflet is based on cognitive-behavioural principles, evaluation of its effectiveness also offers a further method of examining the fear-avoidance formulation of psychological difficulties in facial disfigurement. Finally, the study of facial disfigurement and its treatment is hampered by the absence of any validated, reliable instrument to assess the impact of disfigurement on sufferers' experiences and behaviours. Moreover, there is some suggestion in the literature that broad measures of psychological distress do not adequately detect such distress in facially disfigured people. The current study examines some psychometric properties of a new questionnaire designed to examine the experiences and behaviours of facially disfigured people.

In the conclusion to the first and most influential of the few UK PhD theses concerned with social aspects of facial disfigurement, Rumsey (1983) describes herself as unrepentant in refraining from setting her work within a single theoretical framework. Nevertheless, she describes numerous relevant theoretical perspectives during the course of the thesis, and notes in particular the



importance of Symbolic Interaction to her work. As we shall see in the following chapter, this school of thought has also influenced one major British nursing writer in the field of body image and its care (Price 1990a, b). However, the predominant influence on Rumsey's work, both in her PhD and her later work, appears to be an emphasis on the empirical tradition which underlies much of experimental and clinical psychology. Certainly it is true that much of her work is driven by the data of other studies, rather than by theoretical considerations.

In the same way, the current study is primarily driven by the findings of others, many of which spring from this rich empirical tradition. However, the study is also grounded in the therapeutic tradition of behaviour therapy, which in turn has its roots in behaviourism as a theoretical standpoint and in experimental method as its chief mode of research and therapeutic expression (Newell, 1996). Behaviour therapy has itself weathered numerous theoretical debates, which are briefly examined in Chapter 7, which considers behavioural and cognitive-behavioural treatment. In attempting a definition of behaviour therapy, some commentators have even argued that the use of the experimental method, particularly the single case experiment, is more accurately definitive of the behaviour therapist's position than any single theory such as conditioning or social learning (Yates, 1981). Of the many strands of cognitive-behavioural theory, the current work owes most to the three systems theory of Lang (1971), which states that human experience comprises the autonomic (physical), behavioural (observed) and cognitive (verbally reported) systems. This method of examining human experience and assessing and addressing human problems has proved useful within the field of cognitive-behaviour therapy, but has not been widely explored in nursing, outside the field of nurse behaviour therapy (Marks et al., 1977), although some attempts have been made to apply it to the more general activities of the nurse (e.g. Newell, 1994a). The three systems account is examined in more detail in Chapter 7.

The three systems model finds a parallel in the work of Dropkin, a major nurse researcher in the field of disfigurement and cancer (Dropkin, 1989; Scott et al., 1980). Her approach is itself based on Lazarus's (1966) well-known cognitive-transactional model of stress and coping. Lazarus's model sees the activity of coping as a series of cognitive and behavioural attempts to deal with threats to the person. Whilst Lazarus's model appears cognitively led, a feature which is reflected

in Scott et al.'s (1980) model of coping with changes to body image, Dropkin (1989) describes coping responses according to the three systems: 'neurocognitive, affective and physiological responses.....which may be observed in the behavioural response dimension'. Dropkin's ideas are described more fully in Chapter 2, but it is worth noting the similarity of her theoretical framework to the three systems model which guides much of the investigative and therapeutic intent of this study.

The work of Selye (1980), a major figure in the application of notions of stress to nursing in particular, has also influenced the current study. Of particular relevance is the distinction described by Bailey and Clarke (1989) and adapted to the consideration of body image by Price (1990a), between direct and indirect coping on the one hand and palliative coping on the other. The largely maladaptive tactic (at least in the long term) of palliative coping appears to share features with the avoidance tactics of phobic patients, and with the use of similar tactics by sufferers from chronic pain (Lethem et al., 1983) and by the facially disfigured individuals whose difficulties and coping tactics are examined in the current thesis. The ideas of Price with regard to body image and its disturbance are described in Chapter 2, whilst those of Lethem et al., which are more focal to the development of the current study, are examined in Chapter 8.

More than from these different approaches, however, the main impetus for the current study has come from clinical practice and a desire to answer questions raised by that practice. As will be seen in later chapters, a great deal of our knowledge regarding body image comes from examination of its disturbances. In clinical practice, the behaviour therapist comes into contact with considerable numbers of individuals with disturbed body image. Predominantly, these are clients with eating disorders, although nurse behaviour therapists are increasingly involved in the treatment of body dysmorphic disorder (BDD) (Gournay et al., 1997) and in liaison psychiatry, which often brings the therapist into contact with patients from the fields of medicine and surgery who have received some threat to the integrity of their body image. Nurse behaviour therapy was originally initiated as a method of intervening with clients suffering from focal anxieties such as agoraphobia and social phobia (Marks et al., 1977). It therefore seemed quite natural to extrapolate from the clinical features of these focal anxieties and from difficulties such as BDD (where actual physical

abnormality is absent) to the difficulties of facially disfigured people, where both physical abnormality and difficulties of social interaction are present. The literature suggests that facially disfigured people experience social difficulty and avoid social situations. Since cognitive-behaviour therapy has developed an effective treatment regimen for addressing social phobia (see Chapter 7), speculating that the difficulties and avoidances of facially disfigured people are phobic (in other words mediated by focal anxiety) has potentially positive consequences in terms of treating these problems. Such speculations exist in the literature to a small extent (Newell, 1991; Gournay et al., 1997; Newell, 1997), but have not been tested. The current study represents a series of attempts to test these speculations through a number of connected elements which together comprise a small research programme within the area of facial disfigurement and its psychosocial sequelae, with particular emphasis on behavioural avoidance. The study attempts to identify the relationship, if any, between this avoidance and the psychosocial difficulties experienced by facially disfigured people, essentially examining the contention that their difficulties are phobic in nature.

## **Section 1.2      Organisation of the literature review**

### *1.2.1      Content*

The literature review seeks to establish the current state of our knowledge of the nature of the psychological and social difficulties experienced by facially disfigured people. The concept of body image is important to understanding these difficulties, and major elements of this concept are described prior to the review of empirical work. The review then follows the procedure of a number of previous writers (e.g. Rumsey, 1983) by first examining aspects of the literature pertaining to attractiveness, before focusing on disfigurement. The review of the disfigurement literature proceeds from the general to the specific, looking finally at attempts to intervene with the psychosocial problems of disfigured people. The focus on treatment is further explored by an examination of selected relevant aspects of the cognitive-behaviour therapy outcome literature. These treatments are then set in the context of cognitive-behavioural approaches to disturbed body image. Finally, the fear-avoidance model, the assumptions of which this thesis attempts to examine, is presented.

### 1.2.2 Search Method

Initially, references for this study were found in the course of the investigator's clinical work, and citations from these initial sources were found and examined for further information.

A formal search was carried out during the initial period of the study. The following computerised citation databases were examined:

Medline

Cinahl

ASSIA

PyscLit

Dissertation Abstracts

The search employed the following keywords, which were also used in combined searches:

face, facial, facially, fac\*

disfigure, disfigurement, disfigured, disfiguring, disfig\*

scar, scars, scarring, scarred, scar\*

attractiveness, attraction, attract\*

plastic surgery

surgery

mutilating, mutilation mutilat\*

psychosocial

psychological

social

disturbance, disturbed, distur\*

adjustment

behavioural, behavioral, behav\*

cognitive

cognitive-behavioural, cognitive-behavioral

social skill\*

eating disorder\*

anorexia

bulimia

body dysmorphic disorder

dysmorphophobia

(Asterisks indicate the use of extension markers)

No field limiters were employed during initial searching other than publication in English language journals. Unlimited initial searches which yielded over 500 references were limited using further keywords. Where use of additional keywords led to a large decrease in the number of references generated, the references were scrutinised and alternative keywords employed with the aim of increasing the inclusiveness of the reference lists generated. All searches which generated lists of less than 500 references were examined. Where the title readily indicated that a paper was irrelevant to the study, it was excluded from further consideration. Abstracts of all other papers were read. Where the abstract indicated that a paper was irrelevant to the study, it was discarded. All other papers were obtained, including those where the abstract was either not present in the computer database or was insufficiently explicit to indicate the relevance or otherwise of the subject matter. References found from the examination of papers were obtained where the title indicated relevance to the study or where the title was insufficiently explicit to allow an opinion as to relevance to be gained.

The search procedure was repeated on 7 subsequent occasions during the life of the study, in order to monitor other work in the subject area.

### *1.2.3 Unpublished works*

No specific attempt was made to obtain unpublished materials other than when these were cited in published works. However, the investigator's involvement in the fields of behaviour therapy and body image disturbance led to a number of informal contacts. These in turn provided some unpublished material, including important reading lists relevant to facial disfigurement and self-help materials, and drafts of academic papers in preparation. The resulting published papers are cited in the current thesis.

## CHAPTER 2

### ELEMENTS OF BODY IMAGE

#### **Section 2.1     The concept of body image**

Body image is central to the consideration of facial disfigurement and to many elements of the literature on attractiveness, disfigurement and its treatment, even when it is not explicitly identified. For example, studies of attractiveness suggest that people carry common concepts of what constitutes attractiveness, the psychological attributes which accompany attractiveness, and the appropriate ways of behaving towards more and less attractive people. In facial disfigurement, it appears that preferences for non-disfigured individuals are learnt early in life and demonstrable across a wide range of situations, again suggesting abiding shared attitudes about what constitutes acceptable and unacceptable appearance. The difficulties experienced by disfigured people may represent a mismatch between their appearance and that shared perception of what is acceptable, a perception which they themselves share. In Price's (1990a, b) model, explored later in this chapter, this represents a mismatch between the body ideal and body reality components of body. General aspects of body image are therefore explored here, in order to provide a context for the consideration of the empirical studies of attractiveness and disfigurement presented in later chapters.

Numerous commentators agree that body image as an expression has often been used in a loose, ill-defined way (Lacey & Birchnell, 1986, Cumming, 1988, Brown et al., 1990), although it is generally agreed that the term is separate from, although related to, such concepts as self-image, self-esteem and self-concept (Dewing, 1989). The classic definition of body image is Schilder's (1935): 'The picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves.' He also describes body image as a 'tri-dimensional image every body has about himself'. For much of his writing, Schilder (1935) uses the term body image interchangeably to apply to physical perception of the body and psychological attitudes to it. Whilst the earlier part of his book is devoted to description of elements of the physical aspects of body image, such as phantom phenomena in amputees, the latter part describes psychological and sociological elements. It is with the incorporation of these additional elements into the idea of body image that

Schilder is usually credited. In particular, he notes that body image is dynamic, changing both during the life cycle and in response to short term alterations such as changes of mood or even changes of clothing or the use of instruments such as tools, which extend that image. Although the terms are sometimes used interchangeably by Schilder (1935), body schema is most often currently used to refer to the perceptual elements of body image, whilst body image often includes both these elements and evaluative components (see, for example, Cumming, 1988, and Slade, 1988).

Much of Schilder's description of the psychological elements of body image is in the psychoanalytical tradition and is drawn from observations of clinical populations. The drawing of inferences from such populations to general ideas about body image in well individuals is a common strand within the body image literature, and numerous authors have noted these origins in the description of clinical problems. For example, Macgregor (1989) has noted that interest in psychological aspects of body image derived in part from the desire of surgeons to screen out unsuitable potential patients, whilst the availability of effective surgery for the correction of childhood deformities has demanded an examination of the effects of such corrections on psychological well-being (Barden et al., 1989). Finally, the rise in interest in the treatment of eating disorders has led to a further recent rise of examinations of the nature of body image disturbance, which is said to contribute to the disorders (Brown et al., 1990).

From the psychoanalytical standpoint, Schilder (1935) notes the relationship between attitudinal elements of body image and libidinous drives within the body. Similarly, many such attitudes are also seen as linked to bodily sensations. It seems that he views bodily sensations, psychological body image and the ego as being intimately related, a view consistent with the Freudian formulation of the ego as principally deriving from bodily phenomena, as described by Bronheim et al. (1991). Schilder, however, goes beyond this view of body image as an internally driven phenomenon in the latter part of his book. Here, he notes that body image is essentially a public phenomenon. According to Schilder, the body image is in a state of continuous construction, destruction and reconstruction by virtue of its reciprocal interaction with the body images of those with whom we come into contact (Schilder 1935, p241). Part of this reciprocity involves the imitation of others, whose body images come to be incorporated within our own, either through integration within or



addition to our previous views of ourselves. In his conclusion, Schilder emphasises the relatedness of the somatic, psychological and interactional aspects of body image, thus giving an early bio-psycho-social account of the phenomenon, which is also an analogue of the three systems approach to human difficulties outlined in the previous chapter and examined further in Chapter 7.

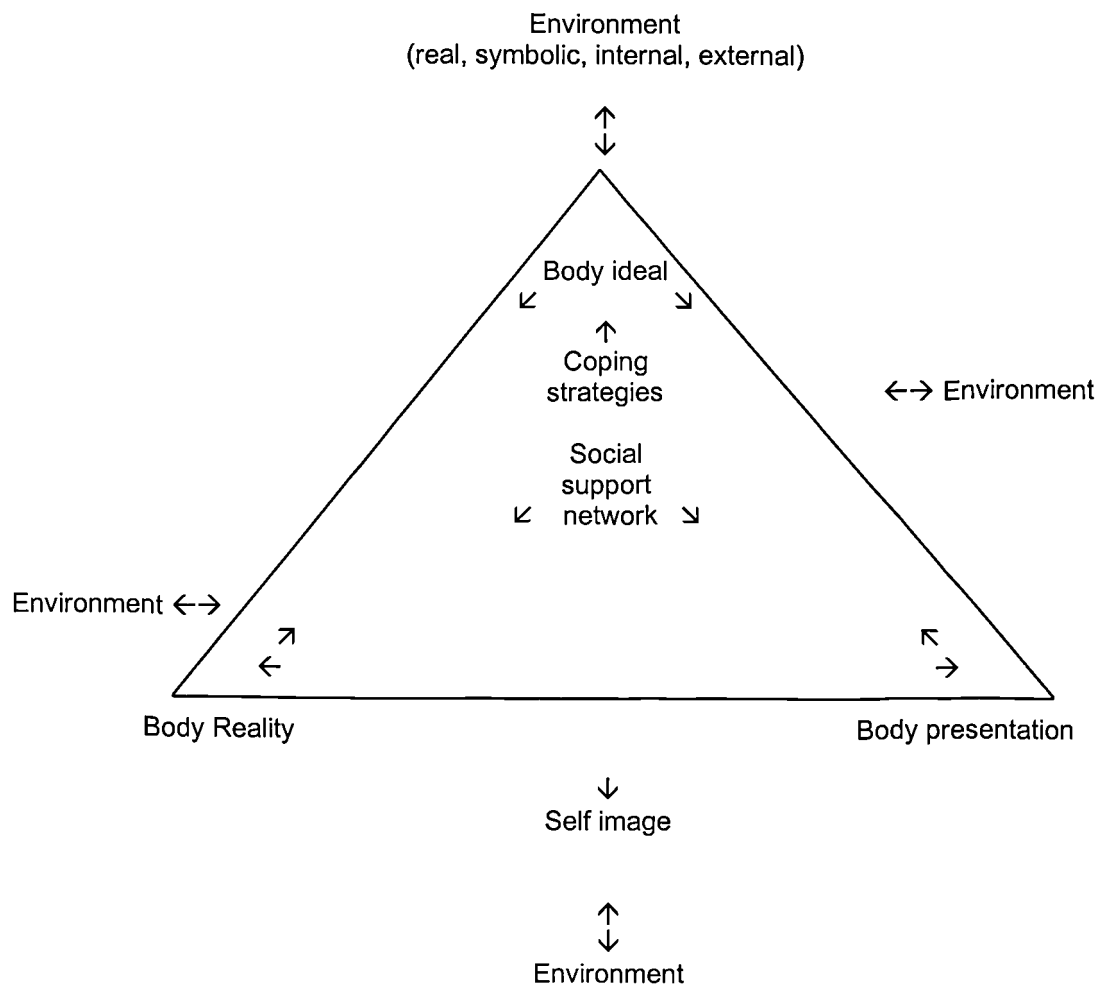
Several writers have attempted to draw distinctions between aspects of body image. Perhaps the most basic distinction is that between perception and appraisal or attitude described by Schilder (1935). Cumming (1988) has pointed out that, for practical purposes, the distinction refers to whether we are considering body image in a neurological or psychological sense. In the first instance, we are talking of perceptual facts, whilst in the second, we are describing subjective experiences. It may, of course immediately be seen that this is an incomplete distinction, which Schilder has acknowledged in his description of the reciprocity of the somatic, psychological and social elements in body image. As an example, neurological disorders which distort our physical appreciation of the body's position in space will influence our confidence in interactions and our satisfaction with our body. Nevertheless, the distinction has been widely applied. In the field of eating disorders, for example, the difference between attitude to body size and misperception of that size is regarded as a key empirical distinction (Keeton et al., 1990), with considerable evidence to show that anorexics overestimate body size (Gardner & Montcrieff, 1988), as well as being dissatisfied with that size.

## **Section 2.2 Models of body image**

In nursing, perhaps the clearest and most comprehensive account of body image comes from Price (1990a, 1990b). At the root of his model is a view of body image as consisting of three related components: body reality, body ideal and body presentation (see Figure 2.2.1).

Whilst much of Price's discussion of the body image which consists of these elements is in terms of psychological experiences, physical perceptions of the body are not excluded. *Body reality* is described as the body as it is constructed, and includes both external elements such as height and weight and internal elements such as organs of the body and functions such as digestion or fluid balance.

**Figure 2.2.1: Price's model of body image**



*Arrows indicate direction of influence or interaction.*

*(Adapted from Price, 1990a)*

By inference, then, elements of the body schema, such as awareness of spacial characteristics of the body (Cumming, 1988), are likewise bodily functions and are, therefore, part of body reality in Price's model. This reality is recognised as being both changeable throughout the life cycle and in immediate response to our interactions with the environment. Naturally, body reality can also change as a result of insults to the body through disease or trauma. The defining characteristic of body reality is that it is not consequent upon our attitudes to it, but consists of physical attributes of the body.

By contrast, *body ideal* is attitudinal, and represents the way we would wish the body to be. Like Schilder (1935), Price sees this ideal as being gained through a process of identification with the body ideals of others, as revealed to us through our interactions with the rest of society. Our body ideal thus reflects a set of internalised societal norms of how society as a whole thinks we should look and the way in which it thinks our bodies should function. Newell (1991) has noted the behavioural view of how individuals might acquire such ideas through the process of differential reinforcement of behaviours which reflect attitudes consistent with the prevailing norms of body image. Since it is likely that behaviours themselves affect attitude formation and change (Festinger, 1957, Zimbardo & Ebbeson, 1970), the reinforcement of behaviours consistent with such norms may then alter people's own body ideals. Conversely, people whose appearance deviates from the attractive body ideal of society are generally sanctioned by the lack of availability of reinforcement opportunities in such diverse aspects of social life as work (e.g. Raza & Carpenter, 1987), socialising (Kleck & Rubenstein, 1975) and dating (Reis et al., 1980). Body ideal appears a largely learnt phenomenon, contingent upon societal definitions of the ideal. It may be influenced by changes in body reality, but is not necessarily matched to this reality. Indeed, a mismatch between the reality and the ideal may be the cause of considerable personal difficulty.

Finally, *body presentation* refers to how we present all aspects of our bodily appearance, including dress, grooming and behaviour. It is, to a marked extent, under the conscious control of the individual, who may, within limits, alter the presentation of the body reality in the direction of conformity with the ideal.

To these three linked elements, Price (1990a) has added several contributing components which influence them. *Coping strategies* direct how individuals will respond to threats to body image integrity in the context of their *social support network*, which forms part of a more general *influence of environment*. Price also emphasises the related nature of body image and self image.

Price (1990a, b) clearly outlines the notions of body reality, body ideal and body presentation, which are described as comprising body image. He sees the three elements as existing in a state of tension or balance which together make up a satisfactory body image which humans strive to

maintain. Thus, we may suppose that alterations to body reality (for example from surgery or disease) will lead to increased tension between that reality and body ideal. The individual may attempt to decrease that tension by altering body presentation to compensate for the deficiency in body reality, or may change their own attitudes to what constitutes their body ideal, invoking particular coping strategies and social supports in order to help make these compensatory changes.

Price's model has considerable appeal. As noted above, the description of the body ideal and its acquisition may be accounted for by appeals to theories of conditioning and attitude change, whilst body reality is apparently comprehensive in its inclusion of bodily attributes and functions. Finally, body presentation as an aspect of body image corresponds to Schilder's description of appearance and behaviour contributing to body image. More debatable, however, are the way in which these elements might be said to influence each other and the putative consequences if one or more of the elements are disturbed. Price (1990a, b) provides numerous clinical examples of disturbance in body image and its effect in terms of the three elements. Similarly, he provides examples of how the elements relate to a model of care. However, these are largely anecdotal and designed to illustrate particular aspects of both disturbance and care. We have no sense of whether they are in any way typical, and no systematised empirical examinations of Price's model exist. Thus, we do not know, for example, whether changes in one aspect of body image are causative of changes in another, consequent upon such changes or independent of them. Indeed, it may prove difficult even to ask such questions in ways which operationalise the various elements of Price's model to a sufficient degree to make specific predictions which can then be tested. The general construction of the model is somewhat circular, with the consequence that prediction of possible responses which might result from its assumptions is difficult. As an example of this circularity, the model lacks an adequate definition of satisfactory body image. On the one hand (Price, 1990b), we are told that balancing the three components of body image is a state of well-being or body image health, and, later, that tension and balance between the three elements are necessary to sustain a satisfactory body image. However, what is this satisfactory state which the balance seeks to maintain? Balance itself cannot be sufficient for satisfactory body image, since we could conceive of a person who had a very low body ideal, very poor body reality and very poor body presentation.

This individual would have a perfectly balanced body image which we would not describe as being satisfactory.

In the absence of a clear definition of 'satisfactory body image', it is also difficult to argue which behaviours will have either a positive or negative effect on such an image. The existence of potential changes in body ideal and body presentation in the face of threats to body image through changes in body reality represents a problem for the model. If an individual's body presentation changes in response to a change in body reality, we might justifiably say he was attempting, through manipulation of body presentation, to narrow an increased discrepancy between ideal and reality resulting from the change in reality. This would support the notion of satisfactory body image relying on balance between the three elements. However, if body presentation did not change, this would not necessarily constitute a refutation of the model, since we could argue that the person had instead modified their body ideal, restoring balance between the three elements in this way. Both these occurrences are indeed possible. However, in the absence of tight specification of the circumstances in which attitude rather than behaviour change would be expected, the model possesses the weakness that it does not predict whether behaviour change (or, indeed, attitude change) will occur or not under a given set of circumstances. Empirical investigation of Price's model, involving such tight specifications and consistent measurement tactics, should now be undertaken.

Despite these difficulties, Price's (1990a, b) model is important for several reasons. First, it is one of very few such models to go beyond simple statement of the distinction between perceptual and evaluative aspects of body image. Second, it has a high profile amongst British nurses at a time when comparatively little emphasis is placed on body image outside the field of eating disorders. Third, it is explicitly tied to clinical practice, from whose observations it is drawn and to which its implications are linked in the form of recommendations for nursing activity. Finally, it has been influential in increasing nurses' awareness of body image issues and stimulating debate. In spite of these strengths, however, because of the shortcomings outlined above, Price's model of body image remains a set of untested assumptions and is, in consequence, purely speculative (Gournay et al., 1997).

An important further account of body image disturbance and adaptation from the nursing literature is suggested by Dropkin (1989). As noted in Chapter 1, Dropkin's model draws considerably on Lazarus's (1966) formulations of stress and coping, and is also related to Lang's (1971) three systems model. Dropkin's model was developed principally in the context of post-operative recovery following head and neck surgery for cancer. Using Lazarus's model, the surgical procedure for removal of cancer is seen as the stressor to which adaptation is required. The person's cognitive appraisal of this threat leads to a series of affective and physiological responses which interact with behavioural responses. These behavioural responses are seen as indicative of adaptation, or what Dropkin describes as body image reintegration, when they involve 'confrontation, compliance and redefinition'. The redefinition element involves a changing of the person's value system following disfiguring surgery towards an appreciation that change in appearance or function does not change the nature of the person. Self care, grooming and socialisation are viewed as key elements of this process, although the role of the nurse in facilitating these behaviours and attitudinal changes is not described in any detail. Dropkin has extensively investigated the postoperative behaviours of head and neck patients, using this stress-coping model (Scott et al., 1980), and reported the need for the performance of self care tasks, including socialisation tasks during the first 8 postoperative days (Dropkin & Scott, 1983). Dropkin (1989) suggests that these tasks, when successfully completed, are associated with adaptation and reintegration.

From the view point of the cognitive-behavioural approach to be introduced in this study, Dropkin's approach has considerable attraction. As noted above, it shares a similar general view of human behaviour and experience with the three systems model often practised in cognitive-behaviour therapy. More critically, it emphasises the importance of behavioural confrontation and, to a lesser extent, attitude change. The first of these, in particular, is seen as important in cognitive behavioural approaches, for reasons described in Chapter 7. However, Dropkin's approach has a number of shortcomings. First, her investigations are almost exclusively in the field of cancer surgery, where the patient may have to adapt to many stressors other than those involving disfigurement (e.g. loss of function, receiving a diagnosis of a life-threatening disease; the necessity to change lifestyle radically; persistent fear of recurrence). Second, Dropkin is concerned primarily with short-term

adjustment during the post-operative period. This is an extremely important area, but is not the focus of the current study, which is interested in the processes governing long term adjustment or disturbance. Third, although the role of self care tasks and socialisation are explained in terms of Lazarus's model, the precise process by which such tasks lead to adaptation is not described. More importantly, despite considerable close descriptive examination of the performance of such tasks by patients, no adequate investigation of cause and effect relationships between these tasks and psychosocial adjustment exists. Despite these difficulties, Dropkin's work has been an important influence upon the current study, because of the emphasis on confrontation and its supposed effect on successful adjustment.

As noted earlier, a considerable amount of interest in body image has been generated by the clinical needs of those involved in treatment of its disturbances, in particular the eating disorders. From a cognitive-behavioural perspective, Slade (1994), who has written extensively about eating disorders, describes an account of body image development and disturbance which, whilst not explicitly labelled as such, has considerable concordance with a cognitive-behavioural approach. Indeed, the organisation of the components of the model are very similar to an earlier fear and avoidance model of pain perception in whose formulation Slade participated (Lethem et al., 1983; Slade et al., 1983). In outlining his approach, Slade (1994) notes the convergence of approaches from observations of perceptual defects in of neurological disorders, the body image distortion in eating and weight disorders and the 'delusional misperception' of BDD. This convergence has led, according to Slade, to a notion that body image disorder is primarily perceptual in nature. However, he argues that this is not only a mistaken emphasis, but that even the apparent measurement of perceptual phenomena involves subjects in judgements which owe a great deal to issues such as attitude, affect and cognition.

Much of the rationale for Slade's emphasis on these components of body image rather than perceptual aspects is derived from work with eating disorders and relates to interventions with these conditions, and so is not reported here. He draws the following general conclusions regarding body image. The mental representation of the body is not fixed but fluctuates within a limited range (body image band). In the absence of emotional and attitudinal bias, estimates of that representation will

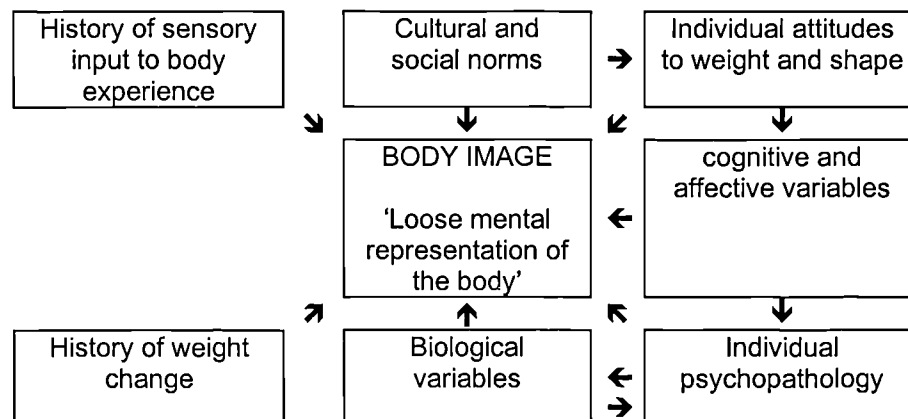
be in the middle of the band. Strong concern about body size will result in judgements of size at the limits of the range. Thus, the judgement of size in eating disorders is contingent upon emotional and attitudinal biases. In the context of eating disorders, Slade characterises sufferers as possessing not the fixed distorted body image of delusional proportions suggested by Bruch (1962) and widely regarded as a defining feature of anorexia nervosa, but an uncertain, unstable and weak body image. This, he suggests, is translated into overly cautious perceptual estimates. This view might possibly be extended to apply to BDD sufferers who, it might be suggested, have a similarly unstable image of a particular bodily attribute or function which is likewise over-emphasised in situations of stress such as social interaction. Turning to disfigured people, Reich (1969) has suggested that the frequently reported finding of greater psychological disturbance in less severely disfigured individuals might be accounted for by the lack of predictable responses of others to their disfigurement. It is tempting to suggest that the notion of loosened body image limits proposed by Slade provides a mechanism by which such less predictable responses might be expected to lead to greater disturbance, since these responses might be expected to lead to a loosening of limits of the body image. However, as we shall see in Chapter 4, the finding of greater pathology in less severely disfigured individuals is itself a weak effect, and so any speculations based upon it should be cautious.

The general model of body image development which Slade (1994) has constructed consists of the following seven components, which all influence the 'loose mental representation of the body' he says best describes body image. A history of sensory input to the body regarding its form, size, shape and appearance gives a general mental representation of the body. Cultural and social norms about the body inform both attitudes to weight and shape and the general body image, whilst individual attitudes both input directly to body image and affect cognitive and affective variables. Biological variables also impact on body image. In the context of eating disorders, one such factor might be basal metabolic rate. The final two elements of Slade's model are both particular to disorders of body image. Individual psychopathology such as anorexia nervosa both influences body image and is influenced by factors such as cultural norms and cognitive and affective variables, whilst, in eating disorders, a history of weight change is construed as leading to a



broadening of the body image band, and thus a loosening of the body image. The arrangement of the various elements is shown in Figure 2.2.2.

**Figure 2.2.2: Slade's model of body image disturbance**



*(Adapted from Slade, 1994)*

Like Price's (1990a, b) model, Slade's view of body image has not been subjected to empirical testing. However, confidence in its utility as a way of examining body image may be strengthened by two factors. First, Slade has drawn considerably on empirical evidence from both clinical and experimental studies of eating disorders in the construction of the model. Second, it is closely related to an earlier fear and avoidance model of pain perception (Lethem et al., 1983; Slade et al., 1983) which has proved of some use in predicting results in the examination of pain in clinical settings (Rose et al., 1992). However, unlike Price's approach, Slade's (1994) model is narrow in focus in two senses. First, it is essentially a model of bodily perception, in which attitudes and other elements of appraisal or satisfaction with the body play a secondary part, being contributing factors to the development of the representation of the body. Although the expression 'loose mental representation of the body' appears sufficiently broad to include attitudinal and affective elements of body image, the general text of Slade's paper makes it clear that the main focus of his model is upon perception in general and size in particular. This leads to the second limitation of his approach. Since it is based on the pathology of eating disorders, from which all the supporting examples are drawn, extrapolations to other disorders of body image must be made with caution.

Generalising to body image in a well population is even more problematic. Whilst Price's model is perhaps too broad in focus, Slade's seems to be too narrow to be of general applicability without modification.

Nevertheless, such modification need not be drastic. Exchanging *individual psychopathology* for *personality variables* as in the Lethem et al. (1983) model of pain perception (see Chapter 8) and changing *history of weight change* to *history of bodily changes* together serve to illustrate how the model might be applied more broadly to body image disturbance, such as facial disfigurement. With this greater generalisability, the model might be appropriately extended to include well populations. Moreover, it is not necessary to retain Slade's (1994) emphasis on the perceptual element of representation. Indeed, one of the aims of his paper is to demonstrate how perceptual judgements are influenced by such factors as attitude and affect. In consequence, there is no need for us to assume that the perceptual element has any primacy in the resulting 'loose mental representation'. Thus, the seven elements of Slade's (1994) general model of body image may be construed as contributing equally to a body image which is both perceptual and 'attitudinal, affective and cognitive' (Slade, 1988).

### **Section 2.3      Approaches to measurement of body image**

Measurement of body image has moved from earlier, more general approaches towards multidimensional measures of body image, and this trend is described in this section. Where very specific tools and approaches have been developed to investigate particular aspects of body image in defined populations, these will be described in later chapters, during examination of the associated studies.

Measurement of body image has generally reflected the division between perceptual and attitudinal/affective components. A review of measurement techniques by McCrea et al. (1982) dealing mainly with measurement of body perception, concluded that the great breadth of sources from which investigation of body image has occurred has led to a tendency towards vague, equivocal definitions of the concept. Moreover, this has led to a proliferation of measurement approaches, which has itself become a handicap within the field. However, this issue has mainly

affected judgement of perception rather than attitude. The current study is concerned exclusively with individuals' attitudes, cognitions and feelings regarding their bodies, as applied to facial disfigurement, and with behaviours which reflect those attitudes, cognitions and feelings. Thus, for the rest of this thesis, the expression 'body image' will be used to mean such evaluative components, rather than the perception of the body. Similarly, this section will deal only with the measurement of these evaluative aspects of body image, rather than the individual's ability to perceive the body's shape and size.

Secord (1953) constructed the earliest systematised scale to examine elements of body image. It was designed as a modification of Jung's word association methods to allow this technique to be used in a reliable way across groups of subjects, rather than the ideographic approach of Jung's earlier work. Seventy five homonyms with either body or non-body meanings were presented to subjects. High scores on body referent meanings were interpreted as reflecting either narcissism or anxiety, whilst low scores suggested overcontrol. There are considerable difficulties with the lack of specificity of the language of the paper, which reflects the analytical tradition from which it springs and thus makes use of a grammar which avoids the use of predictive expressions in favour of such phrases as 'may indicate' (Cioffi, 1978), robbing the scale of much of its predictive value. However, it was important as an early attempt to systematise examination of attitudes to the body. Furthermore, it was the forerunner of the Body Cathexis Scale (Secord & Jourard, 1953) which overcame many of these difficulties and became a widely used tool in the investigation of body image.

The Body Cathexis Scale investigated only cathexis (the level of feeling of satisfaction or dissatisfaction with bodily parts or processes) and consisted of 5 point scales related to 46 body parts or functions (8 of which related to the face), indicating different levels of satisfaction. The authors hypothesised that bodily feelings would be similar to feelings about the self, that negative feelings about the body would be associated with anxiety and with negative feelings about the self. Thus, a second part of the scale contained 55 items related to aspects of the self. The 126 subjects also received the homonym test described above and the authors attempted to establish convergent validity between the two tests, as well as reliability of the Body Cathexis Scale.

A correlation (-.41) between the homonym scale and body cathexis was found for females, but not for males. The authors suggest that this is because females are more likely to develop anxiety about their bodies than males. However, even in the case of females, the correlation is relatively modest, which might lead us to doubt the convergent validity of the Body Cathexis Scale with the homonym test. Correlations between the homonym test and anxiety elements of body cathexis were likewise modest. Split half reliability tests, however, demonstrated coefficients between .78 and .92 for both the body cathexis and self cathexis elements of the scale. Moderately strong correlations were found between the body cathexis and self cathexis elements (.58 for men and .66 for women) indicating a correspondence between satisfaction with the body and with the self. This finding adds weight to the assertion of the relationship between body image and self image in Price (1990a) and the Freudian notion that the ego is predominantly an expression of the body (Bronheim et al., 1991). In a later study (Jourard & Secord, 1954) body cathexis was found to be moderately but significantly related to many aspects of body size (height, shoulder width, chest, biceps, muscular strength) in 62 male undergraduates.

Bruchon-Schweitzer (1987) notes that although it has remained the most frequently used such measure, the Body Cathexis Scale measures only one dimension of body image: satisfaction. This is not quite accurate, since elements of the scale have been used as proxy measures of anxiety (Secord & Jourard, 1953), but it is true that this latter aspect of the scale has received considerably less attention than the more general concept of bodily satisfaction. Bruchon-Schweitzer (1987) suggested that body image was multidimensional and derived a body image questionnaire of 19 items from interviews with 137 high school students. This questionnaire was then administered to 619 subjects and the results factor analysed. Four stable factors were found: accessibility/closeness; satisfaction/dissatisfaction; activity/passivity; relaxation/tension. The identification of these component factors of body image enables investigators to move away from a global examination of the phenomenon towards more precise specification both of elements of body image and their possible relationships with other variables. For example, the Bruchon-Schweitzer study found a positive correlation between body satisfaction and extroversion on the Eysenck Personality Inventory (EPI) and negative correlations between body activity and relaxation and EPI neuroticism scales. Although the identification of such possible dimensions is potentially important,

as a means of examining body image and its disturbance with greater focus and sensitivity, it should be noted that the Bruchon-Schwietzer (1987) questionnaire (the Body Image Questionnaire) has not found its way into general use in clinical literature in the field of body image disturbance.

The multidimensional nature of body image has also been explored by Cash (1989) and Brown et al. (1990). Cash et al.'s (1986) Body Self Relations Questionnaire (BSRQ) was designed to take into account cognitive and behavioural factors as well as the affect examined by the Body Cathexis Scale, in order to reflect the concept of an *attitude* towards the body more accurately, and consists of 54 items from an earlier 69 item scale (with weight and specific body area-related items removed). The scale was tested on 2052 subjects and factor analysed to yield 7 factors: appearance evaluation, appearance orientation, fitness evaluation, fitness orientation, health evaluation, health orientation and illness orientation, which were consistent across the sexes. There were thus separate affective and evaluative elements for the appearance, fitness & health/illness domains, whilst cognitive and behavioural dimensions converged to produce a 'dispositional orientation' for each of the domains. The authors conclude that their findings support the existence of separate dimensions of body image experience and that investigators should both beware of the 'uniformity myth' of the body image construct and distinguish between perceptual and attitudinal modalities. It is worth noting that, although Cash, who originated the scale, has worked a great deal in the field of body image *disorder* and anorexia nervosa, the scale's norms were established on general population samples (Cash et al., 1986) and the Brown et al. (1990) study likewise used such normal subjects, in this case stratified to represent the sex and age distribution of the US population. Thus, their conclusions regarding dimensions of body image are based upon the general population rather than clinical population subjects, adding to its generalisability. It is also worth contrasting the empirical basis for the different elements of body image they assert with the speculative approach of Price (1990a, b) and, to a lesser extent, Slade (1994).

The Cash (1989) paper further adds to our understanding of the multidimensional nature of body image by demonstrating that, whilst assessment of body image attitudes may be divided into examination of the whole body and of individual body parts, the individual elements do not contribute equally to overall evaluation of the body. Specifically, he found, using a multiple

regression approach, that weight, upper torso, face, mid torso, lower torso and muscle tone (in descending order of importance) predicted overall appearance satisfaction and self rated attractiveness in men, with only height satisfaction making no predictive contribution. In women, weight, upper torso, mid torso, lower torso and face predicted the general measures, with height and muscle tone making no contribution. Cash concluded that body part and global satisfaction converge, and that most body parts make a unique and additive contribution to the general appraisal of the body, but these contributions are not equal. Indeed, it is interesting, given accounts of greater difficulty experienced by facially disfigured women (see Chapters 4 and 5) that the face makes a relatively small contribution to overall satisfaction, both when compared with other body parts and when compared with its contribution in males (.26 versus .15).

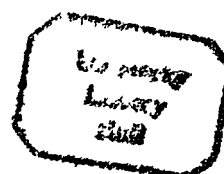
### **Summary**

Body image is important to the study of facial disfigurement. It is generally divided into the consideration of perceptual and evaluative aspects, and much of the study of these elements is derived from an examination of their disturbance, particularly from the field of eating disorders. Two models of body image have been used to demonstrate the possible difficulties of either too broad a speculative account, which lacks predictive value, or an account based on too narrow a focus and an emphasis on pathology. Some possible modifications to this latter account were suggested as a way of broadening its applicability.

Measurement of body image reflects the distinction between perceptual and attitudinal/affective elements, although only the latter are examined in this study. The works of Secord and his collaborators and, much more recently, Cash and his collaborators provide us with a means of investigating normal body image, in order to give a source of information against which to examine its disturbances.

The models and measurement approaches described above introduce the study of body image and its disturbance. The following chapters describe a number of key studies of the effects of attractiveness and of disfigurement on attitudes and social interactions, and of interventions with the psychological difficulties of disfigured individuals. In Chapter 8, the concept of body image is

revisited, and a cognitive-behavioural formulation of body image disturbance based on a fear-avoidance model, particularly as it relates to facial disfigurement, is offered, together with some possible predictions derivable from the model.



## **CHAPTER 3**

### **STUDIES OF FACIAL ATTRACTIVENESS**

#### **Section 3.1 Introduction**

Researchers in the field of disfigurement have often examined studies of attractiveness. It seems intuitive that disfigurement is at the other end of a continuum from attractiveness, and that studies of attractiveness are therefore relevant. However, few studies have empirically examined the attractiveness or otherwise of disfigured people, and many studies of attractiveness exclude disfigured people from the pool of stimulus persons (e.g. Dion, 1973)). Notwithstanding these difficulties, it has been suggested that facially disfigured people are at the bottom of the attractiveness scale (Barden et al., 1989). This chapter presents a brief overview of the attractiveness literature and relates it to disfigurement. In particular, the 'attractiveness stereotype' is examined as it affects social interaction in various contexts.

#### **Section 3.2 Attribution of positive characteristics to attractive people**

If people attribute positive characteristics to more attractive individuals, this has potential consequences for both such individuals and their less attractive counterparts, including disfigured people. Less attractive people may expect negative responses from others, and may need to be more socially adept than attractive people to achieve the same social effect. This might have implications for attempts to ameliorate the difficulties of disfigured people through, for example, exposure therapy or social skills training.

Attractive people are reliably favoured over less attractive individuals across a wide variety of situations. Dion et al. (1972) found that attractive people presented in photographs were judged significantly more socially desirable in a variety of contexts, regardless of gender of stimulus person or subject. Dion et al. proposed a stereotypical response to attractiveness, and further noted that this stereotype might become predictive, since if 'the physically attractive person is consistently treated as a virtuous person, he may become one.' (Dion et al., 1972), a prediction which has received some support in studies of the interaction between attractiveness, social skills and



attraction (Snyder et al., 1977; Snyder, 1984) and, most pertinently, in attempts to diminish the negative psychosocial effects of facial disfigurement (Rumsey, Bull & Gagahan, 1986a).

Jones et al. (1978) examined whether subjects would attribute psychological disturbance to unattractive rather than attractive targets. Subjects designated significantly more unattractive targets as having had psychiatric treatment, and did not realise that attractiveness had played any role in their decision making. Subjects' empathy, knowledge of psychopathology and self esteem made no difference to their judgements. A second experiment provided similar results, even following an injunction to ignore appearance. These preferences may extend to disfigured people, leading to their being disadvantaged even *before* they interact with others. Another photographic study of deviancy (Unger et al, 1982) provided modest further support for the contention that attractive people are favoured in the attribution of positive characteristics, although confusion over the role of the independent and dependent variables weakened their findings.

Further evidence for the attractiveness stereotype is provided by Moore et al. (1987). Whilst methodological problems make it difficult to support some of the specific findings of the study with regard to sex role, the existence of the attractiveness stereotype is supported by their results.

Snyder et al (1985) examined the effect of high versus low self-monitoring on subject preferences for internal or external characteristics. High self-monitoring individuals attempt (Snyder, 1979) to respond to any given situation by responding to interpersonal and situational variables of 'behavioural appropriateness', controlling the image they present to make it fit what they believe is required. Low self-monitoring persons attempt to behave in ways which 'consistently and accurately reflect their enduring attitudes, traits and dispositions'.

As predicted, low self-monitoring subjects were more likely to choose low attractiveness/ desirable personality targets than were high self-monitoring individuals, who preferred the high attractiveness/undesirable personality targets. This paper clearly suggests that individual personality variables can affect biases based upon attractiveness, which may influence judgement of others.

Whilst attractiveness generally confers benefits upon the attractive, it may, in certain situations, lead to a reversal of the usual 'beautiful is good' stereotype. Dermer and Theil (1975) investigated the attribution of both desirable and undesirable characteristics to attractive and unattractive people. Whilst subjects reliably attributed vanity and egotism to attractive subjects, and believed attractive women more likely to have a divorce or extramarital affair, the remainder of the results continued to support the attractiveness stereotype.

The impact of perceived similarity between subject and target has been considered. Byrne (1961) found that targets believed to have similar attitudes to subjects were thought to be significantly more intelligent, informed about current events, moral and better adjusted. In a further study (Byrne et al., 1968), these four judgements were found to be influenced by attitude similarity, but only intelligence and morality were affected by attractiveness, and then only via interaction with sex - attractive male targets were seen as less intelligent and less moral, whilst attractive female targets were seen as more intelligent and moral than their unattractive counterparts. The authors conclude there are some sex specific stereotypes associated with physical attractiveness, as well as an effect of attitude similarity.

The Byrne et al (1968) findings provide further support for the notion of preference for attractive over unattractive persons. There was some suggestion in the study that this was mediated more by unattractiveness than attractiveness of the stimulus persons, and by attitude similarity, although this latter finding was disconfirmed by Kleck and Rubenstein (1975), who demonstrated that such similarity did not affect overt behaviour.

## **Summary**

There is a general preference for attractive over unattractive individuals in terms of the ascription of positive characteristics. Although there is some suggestion that there are differences between high and low self-monitoring individuals, there is a general lack of reliable findings to suggest that some groups are more likely than others to ascribe positive characteristics to attractive people. Even in those cases where, in Dermer and Theil's (1975) words 'beauty may fail', the attractiveness stereotype is only attenuated, and least attractive people are uniformly poorly rated. More

worryingly, there is some suggestion that a parallel 'unattractiveness stereotype' exists (Byrne & Nelson, 1965; Dermer & Theil, 1975). If so, the consequences for disfigured people are potentially serious. They do not merely suffer because attractive people are favoured over them, but are themselves directly associated with negative characteristics. These findings are important if we consider the potential impact on disfigured persons, either in terms of their interactions with others or attempts we might make to change the nature of such interactions, either by education of others or changing the behaviour of disfigured people themselves.

### **Section 3.3     Studies of children**

The effects of the attractiveness stereotype may mediate the reinforcement opportunities available to attractive, unattractive and disfigured people. This may be particularly important during the early years, when personality and characteristic patterns of behaviour are being formed.

The preference for attractive over unattractive people apparently begins at an early developmental stage. Dion (1973) found that pre-school children made similar judgements of attractiveness to adults and rated attractive targets as more desirable as friends, and more likely to dislike aggressive behaviour and to refrain from retaliation if attacked.

Stereotyping of the less attractive by adults extends through life, but begins with the stereotyping of children. Dion et al. (1972) found that attractive children were more likely to be judged by student subjects as having a transient behavioural problem than unattractive children, who were more likely to be deemed naughty, antisocial and deserving of punishment. In a partial replication which extended the external validity of the study, Rich (1975) used experienced teachers as judges, varying both the attractiveness of the report card photograph and the content of the report itself. In the presence of a good report card, there was no difference between the attractive and unattractive conditions. However, teachers in the bad report card condition suggested more severe punishment for the unattractive than attractive children.

The preference for attractive over unattractive individuals is maintained to some degree in judgements of academic performance. Landy and Sigall (1974) investigated the effect of

attractiveness on essay grading. They found that essays apparently by attractive students received higher ratings throughout, but that this was mainly accounted for by differences between the grading of poorer essays of supposedly attractive and unattractive students.

### **Summary**

Attractive children are favoured over unattractive. Children demonstrate numerous preferences for attractive peers, and rate unattractive children as more deviant. Adults likewise favour the attractive child and judge unattractive individuals more harshly, in terms of deciding punishment, attributing deviancy and grading academic work. For the unattractive or disfigured person, it is particularly disturbing to note that these judgements may be mediated by perceptions of the child's quality of work, with the attractiveness stereotype being observed only in the presence of poor work. An optimistic interpretation of this is to assert that the unattractive or disfigured person can overcome stereotyping by their own efforts, and this assertion is implied in some of the social skills literature (see Chapter 6). Caution is probably required in such an assertion, however, and we should be concerned that it is more vulnerable (in terms of achievement) individuals who are likely to suffer most as a result of the attractiveness stereotype.

### **Section 3.4 Social interactions and dating**

An examination of the literature investigating social behaviour, particularly dating, reveals advantages for attractive people which are similar to those seen in the literature concerning more general preferences and in studies investigating childhood experiences. The literature on social interaction is, however, particularly important, since disfigured people repeatedly report difficulties in socialising (e.g. Andreason & Norris, 1972; Rumsey & Bull, 1986; Macgregor, 1990; Partridge, 1993).

Walster et al. (1966) conducted a 'computer dance' study in which freshman university students were randomly paired with dates with whom they were told they shared common interests. The study indicated that physical attractiveness of the partner was the most important predictive element with regard to liking, date preference and attempts to date. Significant correlations were

found between actual physical attractiveness and self reports of popularity in both males and females.

Mathes (1975) expanded on the Walster et al. (1966) study, examining whether the effect of attractiveness was retained over more than one encounter. In fact, attractive and unattractive individuals were equally liked in the first encounter, but liking favoured the attractive with further encounters.

Kleck and Rubenstein (1975) attempted to examine how far our attitudes to attractive individuals are reflected in our behaviour towards them, in a study manipulating attractiveness and attitude similarity. Attractiveness exerted a significant effect on ratings of general attraction, dating and marriage desirability, and on frequency of gaze and smiling. Ratings of perceived similarity, and the interaction between attractiveness and similarity, exerted no such effects.

Once again, these results have depressing implications for disfigured people. Subjects not only hold more positive attitudes towards attractive people, but interact with them in more positive ways. Furthermore, attractiveness is a more powerful determinant of positive attitudes and behaviours than personal attributes such as perceived similarity.

Reis et al. (1980) examined the social interactions of attractive and unattractive male and female students through the use of diaries. They predicted that attractive people should have more social encounters with the opposite sex. Furthermore, there would be differences between males and females, since physical attractiveness is more valued in our society in females. They found that attractive males socialised more with females and engaged in more mixed sex behaviours, but less with other males. Not all these patterns were shown for females, but attractive females reported more dates. The pattern for male interactions continued over time, although it is worth noting that the correlations involved, whilst reaching significance, were very low. Moreover, although described in terms of differences between attractive and unattractive people, no independent variable was actually manipulated, and the study was, in fact, entirely correlational.

A retrospective questionnaire study of sexual behaviour amongst females had also suggested that attractive individuals were likely to have more active social behaviour with the opposite sex. Kaats and Davis (1970) found that more attractive subjects were non-virgins and were more likely to report having a favourable self-picture. They were more likely to rate themselves as physically attractive, and reported having more friends of the opposite sex and having more friends that had had sexual intercourse. They also reported that they dated more often, had been in love more often and had had more non-coital sexual experiences.

Snyder et al. (1977) proposed that the positive stereotype for attractiveness results in a self-fulfilling prophecy, as a result of which attractive people come to exhibit the positive characteristic which raters attribute to them. They studied the effect of stereotypical attributions in dyadic interactions, in order to investigate the *consequences* upon others of our impressions of them. They found male subjects rated purportedly attractive partners as significantly more sociable, poised, humorous and socially adept than unattractive ones. During telephone conversation, however, the purportedly attractive women were also rated by blind raters as expressing these characteristics significantly more than the unattractive. The men themselves, according to raters, appeared significantly more sociable, sexually warm, interesting, independent, sexually permissive, bold, outgoing, humorous, obvious and socially adept when speaking to the attractive women. Thus behaviour which confirmed preconceptions about (supposedly) attractive people's behaviour was elicited by males and displayed by females in this study.

A later study by Andersen and Bem (1981) largely confirmed Snyder et al.'s findings, but also found that interaction patterns were mediated by sex-typing measured by the Bem Sex Role Inventory. Sex typed subjects were rated as more responsive to all attractive stimuli than to all unattractive. Whilst androgynous male subjects did not differentiate in their responses, androgynous female subjects were more socially responsive to unattractive than to attractive stimuli. This study is important because it confirms the finding that interactions with apparently attractive individuals evoke responses from them which are congruent with the attractiveness stereotype. It is also one of few studies to use both male and female subjects and targets.

Evidence for biased behavioural responding is suggested by Brundage et al.'s (1977) study, which demonstrated that female subjects self-disclosed more when they believed they would be meeting an attractive, rather than an unattractive male. This effect was heightened by subjects' need for social approval.

The possible influence of need for social approval is further suggested by Sigall and Landy (1973), who examined the effects of having an attractive romantic partner on how stimulus people were judged. They suggested one reason for choosing a date/spouse might be the hope of receiving the attribution of favourable characteristics by people who are aware of the relationship, since we may impute such characteristics to a person with an attractive date, on basis that an attractive person has reasons for being with him - she 'testifies to his competence.' (Sigall & Landy, 1973) Target persons in this study were judged least favourably in terms of overall impression when attached to an unattractive woman, and most favourably when attached to an attractive woman. Targets were most liked when associated with an attractive woman, but there was no effect for attachment to an unattractive woman. In a second experiment, those who believed they would be paired with an attractive female thought they would be judged most positively by subjects, whilst those who believed they would be paired with an unattractive female thought they would be judged most negatively.

Some support for their findings is found in Bar-Tal and Saxe's (1976) study, which demonstrated that unattractive males assumed to be married to attractive women were believed to have higher incomes, occupational status and professional success than attractive men married to attractive women.

## **Summary**

As in the studies of general attribution, attractive people are generally favoured in social encounters. Moreover, attractive people are not only perceived as more socially skilled, but actually appear to demonstrate higher levels of such skills. These may in turn be elicited by the social behaviour of those with whom the attractive individuals are in contact.

More attractive people report more active social lives, in particular opposite sex encounters. The superior attributions offered to attractive people in social situations are to some degree mirrored amongst individuals thought to be associated with them.

For disfigured people, the implications if we extrapolate from these findings are clear. We should expect disfigured people to be judged less favourably in social settings, to have these judgements reflected in the behaviours of others, including, crucially, a decreased level of behaviours likely to elicit socially skilled behaviour from the disfigured person. Although the presence of an attractive partner might reduce negative judgements of a disfigured person, the potential difficulties in social situations suggested here may greatly reduce the opportunity for disfigured individuals to attract such partners in the first place.

### **Section 3.5      Employment suitability**

Work-related situations demonstrate further the use of the attractiveness stereotype across a variety of situations. These results are of potential importance since employment takes up a substantial amount of daily activity, and contributes to opportunities for social interaction and economic achievement.

Dipboye, Arvey and Terpstra (1977) had curricula vitae (including photographs of varying attractiveness) rated for trainee jobs in sales management. Significantly more attractive candidates and more men were chosen for hiring and given higher salary ratings. In a real life setting, Raza and Carpenter (1987) asked eight industrial interviewers for ratings of actual job applicants. Attractiveness and employability were significantly correlated for both male and female applicants. For hireability for the specific job for which they were candidates, this finding only held for male applicants.

Cann et al. (1981) attempted to moderate the effects of biases towards attractive and male applicants by ensuring that interviewers paid attention to specific job-related aspects of applicants. A forced delay in the decision making-process involving attention to specific attributes reduced the



benefits associated with being *averagely* attractive but did not diminish bias towards *attractive* individuals or towards males.

In a study of personnel selection, Snyder et al. (1988) examined the influence of personality variables on biases in accordance with the attractiveness stereotype. They employed the concept of high and low self-monitoring (Snyder [1979] and see Section 3.2, above) and hypothesised that it would identify people who adopt different strategies in personnel selection. High self-monitoring subjects were more likely to choose attractive applicants whilst low self-monitoring subjects chose the candidate with appropriate personal attributes, even though both applicants were rated as appropriate in appearance for the job. The authors note that, according to the concept of self-monitoring, it should be the case that attractiveness would not matter to the high self monitoring subjects, but only *appropriateness* of appearance. In a further experiment reported in the same paper, this was investigated explicitly, and appropriate appearance was found to be more important than attractiveness by high-self monitoring subjects. This second study offers some evidence that attractiveness effects are sometimes mediated by appropriateness of appearance. However, it should be noted that, in this study only a male target was used, and the mediating effects may well not apply for females.

Frieze, Olson and Russell (1991) investigated the effect of attractiveness on the incomes of men and women in management, via a retrospective analysis of both their career paths and wages. Facial attractiveness had a significant effect on male starting salaries, but this finding did not hold for women. Attractive men continued to receive higher salaries throughout job changes and job progression, independent of starting salaries. Frieze, Olson & Russell (1991) also note, however, that issues of work experience are more important than attractiveness in determining size of salary.

## **Summary**

Attractive people are regarded as more suitable employment candidates and are more likely to be hired, in simulations involving both students and actual managers. There is little evidence that manipulating the way in which employers attend to particular characteristics is of any use in moderating the attractiveness stereotype. The advantage for attractiveness in these simulations is

borne out in a study of actual earnings. There appears to be *less* of an advantage for attractiveness in women in studies of employment suitability.

If these findings for attractiveness hold for disfigurement, the picture, although somewhat more mixed than in previous sections of this chapter, still appears dismal. The comments of Cann et al. (1981) regarding the unlikelihood of the emergence of either legislation or a popular movement to eradicate such differences in opportunity underlines the need for considerable effort in terms of consciousness-raising regarding the effects of attractiveness. Self-help groups working in the arena have only begun to address this problem, and, at least in the UK, do not have the same high profile as, for example, groups of mentally ill people, many groups of disabled people, or those with learning disabilities.

### **Section 3.6     Helping behaviour**

Individuals make judgements about whether or not to help others in a range of situations, and attractive target persons are generally favoured. Helping behaviour occupies a considerable place in the social psychology literature, but comparatively little effort has been devoted to the attractiveness variable in these studies. Although studies in the helping literature concerning attractiveness are often more naturalistic than those we have encountered earlier in this chapter, they nevertheless suffer from some weakness of external validity, principally derived from the low levels of interpersonal contact required in many of the studies. This is particularly relevant when applying findings of studies of helping behaviour to disfigured individuals, where such factors as revulsion or fear may lead to a desire to decrease contact (see Chapters 4, 5 and 6).

Sroufe et al. (1977) examined whether target attractiveness affected subjects' honesty in two experiments. In both, significantly more people returned money left in telephone boxes to attractive than unattractive targets. Harrell (1978) employed a two factor experiment in which a confederate made to appear attractive or unattractive asked 218 male students directions to a local health service facility whilst either disclosing her name or not. There was a main effect for attractiveness, with more time being spent with the attractive confederate, but not for disclosure.

West and Brown (1975) also examined helping behaviour and attractiveness, but varied the severity of the emergency requiring help. The aim of the experiment was to test the two-stage model of helping posited by Piliavin et al. (1975) which states that level of arousal /distress in an observer mediates the likelihood of helping. This likelihood is then further mediated by an estimate of the profit and loss likely to accrue from intervention or non-intervention. Piliavin et al.'s model was advanced as an alternative to the proposition that helping is increased by greater liking of the victim, which in turn is mediated by greater victim attractiveness. Piliavin et al.'s model is further examined in Chapter 6, which considers studies of the impact of facial disfigurement on helping behaviour. West and Brown (1975) hypothesised that attractive targets would be more likely to be helped in high emergency situations, but not more likely in low emergency situations, since onlookers would be more thanked in high emergency situations, and such gratitude would be more valued from attractive persons.

Subjects helped confederates in the high severity conditions more. No main effect for attractiveness was found, but there was an interaction between attractiveness and severity in the predicted direction. The report thus supports the contention that, in high rather than low emergency situations, more attractive people are more likely to be helped.

A further field study (Benson et al., 1976), much quoted in the literature, and partially replicated with disfigured people (Rumsey 1983), required airport passer-by subjects to respond to an application form apparently left by a traveller in the airport. The measure of helping was posting or otherwise furthering the form to its destination. Part of the form contained a clearly visible photograph of either an attractive or unattractive male or female person from one of a number of different races. Attractive people and whites were more helped, but there was no effect for sex and there were no interactions between the three variables. The Benson et al. (1976) study was carefully conducted and supports the existence of the attractiveness stereotype. Nevertheless, its relevance is somewhat diminished by the lack of interaction required with the stimulus person.

## **Summary**

Attractive people are more likely to be helped than unattractive across a range of situations, including varied levels of contact with the target person. Although the level of contact is typically low, most studies involve some level of social interaction.

The greater help offered to attractive people may be particularly apparent where the perceived severity of the situation requiring help is greater, which may particularly disadvantage disfigured people because their disfigurement may increase arousal amongst potential helpers.

### **Section 3.7 Summary discussion of key studies of attractiveness**

Investigation of the effect of attractiveness on our judgements of others, and of the attractiveness stereotype, still represents a small area of psychological research. Moreover, there are numerous practical difficulties in investigating attractiveness. We lack any general theories or definitions of beauty within psychology, with the result that studies have used normative definitions of attractiveness (Dermer & Theil, 1975). Nevertheless, a good proportion of the studies reviewed here have used careful checks of the manipulations involved, in order to ensure that, within these normative values, subjects did indeed perceive supposedly attractive subjects as attractive.

Although the practical difficulties of manipulating attractiveness in real life have been addressed by numerous investigators, the majority of studies remain simulations of one kind or another. Whilst some of these, for example those using human confederates and deceived subjects, approach in vivo studies, a considerable number have involved the use of photographic and written materials. Such artificial settings do not necessarily compromise the external validity of a study, since the critical variable being examined may not itself vary across settings (Newell, 1996). However, in most cases, we should expect that the further removed the experimental setting becomes from that of real life, the less confident we should be in our generalisation from the former to the latter setting. It would be wise, therefore, to apply caution to the conclusions drawn from, for example, photographic studies of the attribution of characteristics to attractive and unattractive people. The need for caution is particularly important given that some authors draw quite liberal conclusions on the basis of relatively modest studies. Moreover, these studies are not always conducted with

sufficient rigour of design or analysis to allow us to be confident about their findings (Bull & Rumsey, 1988).

Despite these caveats, a number of coherent findings emerge from this chapter. Attractive people are reliably favoured over unattractive in the majority of studies. This preference for attractive individuals is formed early in life and appears consistent between children and adults, although there has been little work in this area. The preference is maintained across many variables, including, for example, judgements of intelligence, social skill, deviancy and behavioural variation, and in the contexts of dating, social interaction, school, work and helping behaviour. Many of these preferences do not vary between the sexes, and the role of individual differences such as personality remains unclear. Only a very few instances of stereotyping *against* attractive people have been demonstrated, and even here the *least* attractive target persons are very infrequently favoured. It is thus safe to conclude that an attractiveness stereotype has been demonstrated within the bulk of the literature, and that attractive people are generally favoured above others.

Attractive people, because of our preferences towards them, and the opportunities to which these preferences give rise, have greater ability to administer rewards and punishments, which in turn places them in a powerful social position (Sigall & Landy, 1973). Throughout the current chapter, the implications of the attractiveness literature for disfigured people have been suggested, and these implications appear, in general, profoundly negative. The following three chapters examine studies of facially disfigured individuals. Almost all authors within the field of facial disfigurement have examined the attractiveness literature, with the result that many of their assumptions come from that literature. Likewise, many of the same constraints within the literature exist as within the attractiveness literature, and we shall see similar kinds of difficulty with regard to the design, conduct and analysis of these more focal examinations of facial disfigurement.

## CHAPTER 4

### GENERAL EFFECTS OF DISFIGUREMENT

#### **Section 4.1     Introduction**

This chapter begins an examination of the psychosocial consequences of disfigurement which form the rationale for pursuing the current study. Such consequences are common and pervade all aspects of the lives of sufferers, and the literature, although sparse, covers the broad range of these areas of difficulty. This chapter begins by examining general aspects of disfigurement, disability and stigma, as well as examining the potential size of the problem of disfigurement and its psychosocial sequelae. The chapter then offers some developmental context to the study through the examination of children's experiences of disfigurement, whilst a final section considers early qualitative studies of disfigured people's experiences, and accounts by disfigured people themselves. The chapter thus provides a general context for the current study. This context is focused further in Chapter 5, which mainly explores quantitative studies of adult psychological difficulties.

Frances Macgregor (1951) noted that less attention is paid by researchers to disfigurement than to other forms of handicap. Nevertheless, she believed, the problems faced by this group might at least be the equal of those experiencing other bodily impairments. She noted that the face has profound social significance, and that the attitudes and prejudices of society towards those of atypical appearance are both negative and potentially of great consequence to the sufferer. The majority of her respondents' complaints related to their social interactions with others.

Macgregor has returned to the theme of the need for further research in her later writings, focusing particularly on the need for studies of the social interaction of disfigured people (Macgregor, 1990).

According to Rumsey (1983), such research as exists is limited, characterised by poor methodological approaches and biased sampling techniques and speculation. This research has generally been confined to small reports of physical problems by surgeons and anecdotal accounts of observations of general problems experienced by handicapped people. Rumsey (1983) notes

that most studies have been of outpatient clinic attenders in the USA, who may well have been atypical, since they had the economic resources to pay for surgery and wished to correct their disfigurements.

Bull and Stevens (1986) and Houston and Bull (1994) describe the comparative neglect of the area of facial disfigurement, and it seems that little has changed since Macgregor's early comments.

#### **Section 4.2     Disfigurement as disability**

Whilst the disabling effects of disfigurement may not be immediately obvious, it seems clear from the literature that researchers either explicitly or implicitly examine disfigurement in the context of disability, drawing, for example on the concept of stigma of disabled people to account for attitudes to disfigured individuals and examining social, psychological and behavioural consequences in terms of impairment of functioning. Disfigured people themselves often report the consequences of their disfigurement in terms of such impaired functioning. The Office of Population Censuses and Surveys' examination of disability in the UK (Martin, Meltzer, & Elliot, 1988), outlining patterns of disability based on a national survey, defined disfigurement as disability if an individual: 'suffers from a scar, blemish or deformity which severely affects ability to lead a normal life.'

No distinction is made in the survey between disfigurement resulting from different causes. The authors report a total prevalence of 9 per 1000 in the population, which breaks down by age as follows: age 16-59 - 5 per 1000; age 60-74 - 18 per 1000; age 75 and above - 27 per 1000. They estimate the total number of sufferers within the population as 391,000 (age 16-59 - 163,000; age 60-74 - 141,000; age 75 & over - 87, 000. A global assessment of impairment of performance was presented, and is shown in Table 4.2.1.

**Table 4.2.1: Impairment of performance by disfigurement according to age**

Severity level:	1-2*	3-4	5-6	7-8	9-10	Total (all severity levels)**
Frequency at each level (% of disabled people with disfigurement as their disability)						
All ages:	4	6	7	11	16	7
16-59:	7	8	9	13	19	9
60-74:	4	7	8	12	20	7
75 & over:	2	2	4	8	12	4

\*Severity is defined as the extent to which an individual's performance is limited by impairment. 10 = most severe.

\*\*Total percentages are not simple summations of category percentages because the base samples vary across severity levels.

(Figures extracted from Martin, Meltzer, & Elliot [1988])



A limitation of the survey is that site of the disfigurement is not recorded. Thus, we cannot know what percentage of the disfigured individuals surveyed had facial disfigurement, and therefore cannot examine whether disfigurement of one area led to more impairment than another. Whilst Partridge et al. (1994), referring to this survey, suggest that perhaps 250000 of the total of individuals with disabling disfigurement may have facial disfigurements, they offer no empirical support for their estimate, which must, therefore, remain speculative. If it were accurate, it would represent a substantial number, with the obvious consequences for the nation, both in terms of economic burden and human suffering.

The tendency to consider different areas of disfigurement together is an abiding problem within the literature, and gives rise to difficulties both in conducting a review of the area and in arriving at reliable estimates of the extent of the problem. For example, in the review which follows, a good deal of material related to burns injuries is covered, since such injuries represent a considerable source of disfigurement. However, many of the studies do not differentiate between the areas burned, with the result that any conclusions drawn from such studies about reaction to disfigurement in terms of psychosocial adjustment are at best tentative. Nevertheless, the studies offer important information about the adjustment of a group of people many of whom are disfigured (Brown et al., 1988), and for whom disfigurement is a major issue (Weston, 1989). Moreover, some studies which *do* differentiate between areas of the body burned suggest that the face is a major area in predicting later adjustment (Roca et al., 1992, Williams & Griffiths, 1991).

#### **Section 4.3     Disability, disfigurement and stigma**

Numerous commentators have suggested that disfigured people are stigmatised persons. Since stigmatised status might be expected to affect their social interactions, attempts to improve such interactions may usefully explore the idea of stigma, as providing a context within which such attempts occur. In an early review article of the effects of stigma and of other psychosocial sequelae of disability, Barker (1948) suggests that the effects of an unusual appearance have preoccupied people for many years. He notes that Francis Bacon had stated that 'deformed people are commonly vengeful - returning in coin the evil that nature has visited upon them'. Although this is clearly an anecdotal opinion from well before the beginning of systematised examination of

disfigurement, or indeed of disability and illness in general, it is, however, an interesting early example of negative stereotyping of disfigured people. The use of the word 'evil' in this context is likewise instructive, suggesting a belief that physical beauty is good, and deformity bad.

Although he offers no precise evidence, Barker (1948) also suggests that disabled people occupy a similar situation in society to other despised groups such as Negroes and Jews. His assertion was not demonstrated at that time, but has been cited by subsequent authors in support of the inclusion of disfigured people under the category of stigmatised minority groups (e.g. Goffman, 1963) and later studies have indeed confirmed the existence of both prejudice against and stigmatisation of disfigured people.

Stigma were originally marks deliberately inflicted on slaves (Goffman, 1963) so that others would be aware of their station in life. Goffman's (1963) collection of essays about stigma and stigmatised people has influenced researchers in the field of facial disfigurement (e.g. Rumsey, 1983). He combines a number of groups (e.g. criminals, disfigured people, ethnic and religious groups) under the heading of stigmatised people and defines stigma as the situation whereby an individual is 'disqualified from full social acceptance'. Goffman (1963) distinguishes between two categories of person, those whose stigmatised status is readily apparent to others, who respond to it (the discredited), and those whose status is not apparent, but towards whom others would respond with stigmatisation if it were (the discreditable). For most purposes, disfigured individuals fall into the former category, since perceptibility is regarded as a crucial aspect of stigmatisation. This should, however, be distinguished from obtrusiveness - the degree to which the stigma obtrudes upon our interactions with stigmatised persons. Thus, disfigured people are discredited because their disfigurement is both visible and, since it is liable to interfere with social intercourse (for example, by interfering with eye contact because people stare at it or seek to avoid looking at the face), obtrusive. Goffman (1963) also asserts that stigmatised people share with 'normals' their views of the significance of the stigma, since they have incorporated the standards of society as a whole.

Goffman (1963) describes the role of control of information by the stigmatised person in maintenance of personal identity. This control relates to such issues as being able to pass as non-

stigmatised in certain situations. Considerable effort seems to go into such control of information, and members of stigmatised groups are often concerned with being discovered. The ability to control information about stigmatised group membership is obviously limited for disfigured people, but does yield an interesting speculation about behavioural avoidance. In a discussion about the nature of perceptibility, Goffman (1963) notes that the stigmatisation of race becomes invisible under certain circumstances, for example during telephone conversations and in writing. Interactions of this kind represent one way in which disfigured people can control information about their disfigured status, through avoidance of face to face contact. The use of camouflage tactics may represent a similar attempt. By contrast, Goffman (1963) notes that disclosure of stigmatised status, for example through deliberate wearing of stigma symbols, may enable the use of adaptive actions by the stigmatised person.

He also notes the use by stigmatised individuals of in-group and out-group alignments. The in-group is the group to which an individual naturally belongs. In-group alignment is reported as more characteristic of politicised movements, such as those of different ethnic groups, who seek to gain self-esteem through this identification. The spread of in-group alliance to groups such as psychiatric patients and ex-patients, disabled people and disfigured people is comparatively recent, and may become important to the cessation of avoidance behaviours amongst disfigured people.

Whilst disclosure tactics may help adaptation, the status and adjustment of the stigmatised person, particularly in the absence of a strong in-group to which to relate, are also likely to be mediated by the responses of the out-group. Novak and Lerner (1968) hypothesised that people stare at handicapped individuals because they fear the disability could happen to them. This in turn violates their belief in a 'just world' where individuals are responsible for and in control of their fates. Violation of this belief leads to dysphoria, since it is uncomfortable to live in a world where events are random. In order to maintain their belief in a just world, they then derogate/stigmatise the disabled person.

In a study of helping behaviour and stigma, Piliavin et al. (1975) investigated the role of their two stage model of helping behaviour in predicting responses to facially disfigured people in an

emergency situation. Their study is described more fully in Chapter 6, but it should be noted here that they were able to demonstrate that it was the physical stimulus of the stigma (a port wine stain) which led to a decrease in helping behaviour, rather than any perceived feared consequence of intervention or attribution of reprehensibility to the victim in the simulated emergency which constituted their investigation. Their study suggests, therefore, that facial disfigurement leads to a perceived lack of reward for interacting with the victim. Equally, it might be that refraining from helping represents a way of decreasing arousal created by violation of the just world belief, via passive avoidance of an anxiety-provoking interaction.

The above accounts of stigmatisation of disabled and disfigured people might be said to share a single broad feature: the desire to maintain comfort or to decrease uncomfortable arousal in the presence of the untoward stimulus of disfigurement. An alternative to the notion of stigma/derogation as an explanation of bias against disabled or facially disfigured individuals is advanced by Langer et al. (1976). They propose that people stare at disfigured or disabled people not because they derogate them, but because disabled people represent novel stimuli, which elicit exploratory behaviour in order to render the world more regular and, thus, predictable. The discomfort experienced by people in the presence of physically atypical individuals derives, according to Langer et al. (1976), from the contradiction between the desire to stare and the general social prohibition against staring. Their study consisted of experiments: two involved the examination of photographs in a picture gallery, whilst the third involved interacting with either a disabled or non-disabled person.

In their first experiment 15 male and 15 female subjects viewed photographs of a normal, a pregnant and an obviously disabled woman in a photographic gallery. Since photographs are intended to be looked at, no social norm is thus offended. Female subjects were significantly more likely to look at the disabled woman than the pregnant woman, and least likely to look at the normal. In male subjects, the normal woman and the disabled woman were equally likely to be looked at. The authors speculate that the novelty of the disabled woman was equalled, for men, by their desire to look at an 'attractive normal female' (Langer et al., 1976).

The second experiment, using male subjects only, expanded on the first by manipulating the sanction on staring, through the introduction of an observer. Forty males looked at photographs of a normal male and a hunchback whilst an observer (apparently another viewer in the gallery) was present on 50% of occasions. Subjects spent significantly more time observing the hunchbacked man when alone, but significantly more time observing the normal man when observed, thus offering support for the notion that desire to stare at a novel stimulus is suppressed by the perception of a social norm against staring as represented by the presence of another person.

In the final experiment, 36 male and 36 female subjects interacted with a pregnant, normal or apparently disabled confederate, with or without prior exposure to the stimulus person via a one-way screen. Subjects sat significantly further away from the most novel stimulus (the disabled person) and from those stimulus persons to whom they had not had access. The two variables interacted, so that distances were virtually the same for all levels of the novel stimulus condition when prior exposure had been given. The authors state they found no evidence of derogation, as assessed by a measure of liking. However, this is rather weak evidence for the absence of derogation, since responses to a pen and paper test could merely have been ones perceived by subjects as socially acceptable.

Whilst the first two experiments offer quite convincing evidence for the novel stimulus hypothesis, the third is less convincing. Whilst it is indeed encouraging to see that even brief prior exposure to the disabled stimulus person led to greater physical proximity, Langer et al.'s (1976) novel stimulus hypothesis is not necessary to account for this. If we assume that greater proximity represented decreased discomfort in the presence of the stimulus person, this *might* result from decreased contradiction between the desire to stare at a (no longer novel) stimulus and desire not to contravene the social norm against staring. However, this greater proximity is equally explicable in conditioning terms. Individuals with prior exposure have had an opportunity to habituate to the uncomfortable arousal caused by violation of the 'just world' beliefs posited by Novak and Lerner (1968). Of course, habituation is itself a phenomenon consequent upon decreasing novelty of a stimulus, but is a much more basic, physiological process than that implied by the novel stimulus

hypothesis, since the component of conflict between desire to stare and desire for conformity with the social norm against staring is not required by the conditioning account.

The authors suggest that discomfort and avoidance applied to physically stigmatised people has in the past been confused with derogation. Whilst it is quite possibly the case that, as the authors suggest, novelty needs to be taken into account to fully understand stigmatisation, it is not accurate to state that derogation of physically stigmatised people does not occur. As we shall see later in this chapter, accounts of negative verbal and non-verbal behaviours in response to facially disfigured people are frequent.

To summarise this important and frequently-cited study, all three experiments offer support for a role for novelty in the mediation of responses to disabled and disfigured people, and the first two suggest the operation of a mechanism additional to the decrease in arousal associated with decreased novelty, whilst the third is explicable in such conditioning terms alone. There is no support, however, for an absence of derogation with regard to physically stigmatised individuals.

It is worth noting, in conclusion to the examination of the role of stigma in disfigurement, that the elements of Novak and Lerner's (1968) fear/arousal and Langer et al.'s (1976) novel stimulus accounts might both be usefully and economically explained by Gray's (1982a, 1982b) description of the role of the hippocampus and septal area in regulating autonomic arousal. This account hypothesises the existence of a 'comparator' within the hippocampus, whose role is to compare 'stored regularities' about the environment within the brain with occurrences in the actual environment, and to detect the occurrence of mismatches between the two. In the event of such mismatches, behaviour is inhibited, arousal and attention are increased, and control over a number of behaviours passes to the autonomic nervous system, in preparation for fight or flight, giving rise to what is often construed, in psychological disorder, as anxiety. If we accept that disfigured people represent novel stimuli, we might speculate that Gray's (1982a, 1982b) comparator detects a mismatch between the stored regularities of what constitutes normal human physiognomy and the actual example of a disfigured person. This, in turn, leads to anxiety and to a series of related behaviours such as avoidances and derogation.

In this context, it is interesting to note that habituation leads to a decrease in such anxieties as phobias and compulsions (Marks, 1987), which are believed by Gray (1982a, 1982b) to be mediated by the comparator. Since the key components of phobias and compulsions are avoidance and repetitive behaviours such as checking respectively, it is tempting to speculate once again that habituation is the mechanism responsible for the decreased avoidance behaviour shown to disabled people following exposure in Langer et al.'s third experiment. Habituation might also lead to a decrease of derogation (if this is viewed as a kind of cognitive avoidance [Williams et al., 1988]) or, indeed, of staring behaviour, if this is viewed as a form of checking ritual.

Whilst these comments are highly speculative, Kleck et al. (1966) did find increased autonomic arousal in the presence of a handicapped rather than a non-handicapped confederate, regardless of whether subjects described themselves as uncomfortable in the presence of the handicapped individual, again suggesting a relatively simple physiological underpinning to some responses to disfigured people, although it is unlikely that a conditioning account will ever offer a full explanation of these complex interactions.

### **Summary**

Disfigured people are believed to be stigmatised in the same way as other despised groups such as racial and ethnic minorities or those of different sexual orientations, and usually fall into the 'discredited' group, since their deviance from the norm is visible. It may be that they are denigrated because their appearance challenges people's assumptions about a just world, although at least one account suggests that novelty of the stimulus offered by disfigured people accounts for such phenomena as staring. This account does not, however, explain the derogatory remarks which disfigured people report. An expanded interpretation of the novel stimulus hypothesis has been suggested here, based on a simple physiological account of anxiety arousal and reduction. Once again, this account does not alone account for derogation of disfigured individuals. Any attempt to address the social difficulties of disfigured people needs to take account of both stigmatisation and anxiety and its reduction.

#### **Section 4.4     Disfigurement and children**

Although the current study is exclusively concerned with adults, the literature regarding disfigurement in childhood is relevant because of the importance of childhood in the development of personality and social competence. Childhood is crucial to the acquisition of those skills which individuals will use to establish independence and social contact in adult life.

Unattractive children are apparently disadvantaged from an early age (see Chapter 3), whilst a study specifically of children with craniofacial abnormalities (Field & Vega-Lahr, 1984) offered evidence that mothers of such children are less active during interactions with their infants than mothers of normal children at age three months.

Barden et al. (1989) argue that corrective surgical intervention with disfigured children will improve interactions. The argument assumes: that the infant-caregiver relationship is a key determinant of psychological adjustment and personality development into adulthood; that physical attractiveness is a demonstrated determinant of later success in social relationships; that craniofacially abnormal children are rated at bottom of the attractiveness continuum prior to surgery.

Barden et al. (1989) examined mother-child interactions and self-report ratings of maternal general life and parental satisfaction, involving 5 mother-infant dyads where the children had a craniofacial abnormality and 5 where they did not. Mothers of children with craniofacial abnormalities were consistently less nurturant - mothers of non-disfigured children scored more positively overall on every measure and on 26 of 27 possible individual comparisons. The authors also found significantly less tactile/kinetic stimulation, less affectionate touching, less time demonstrating a toy, less holding of the child in a face to face position, less responsivity to behavioural cues. The children with craniofacial abnormalities themselves touched their parents less and were less likely to smile/laugh and less responsive to mothers. However, the mothers of craniofacially abnormal children reported being more satisfied with parenting than the mothers of non-disfigured children, and reported more positive life events after pregnancy .



The authors wonder whether the discrepancy they found between self-report and observation is a time-limited coping mechanism or is indicative of subsequent dysfunction. They note that not holding in face-to-face contact limits chances of reinforcement of the mother by infant smiling and that craniofacially abnormal children smile less and so may be less able to give reinforcement. They suggest that such children may be less socially responsive to caregivers, and so mothers' attempts at nurturing go unrewarded and thus decrease in frequency.

Whilst this is a small study, from which any conclusions must be extremely limited, it is nevertheless potentially important because the observational element was well conducted, and, despite the suspect use of parametric tests with extremely small groups, considerable differences were noticeable simply from visual inspection of the data. However, it should be noted first that the discrepancy between observations and self-reports is not necessarily important, since it may have been caused by a social desirability response, and the observational element has low ecological validity owing to its short duration and artificial situation. The raters were not blind to the condition of the experiment, and may well have applied biased ratings to the interactions of the dyads including craniofacially abnormal children. Finally, the authors' suggestions regarding the non-reinforcing behaviours of the children are highly speculative, not only because of the size of the groups, but also because the alternative argument (that mothers do not reinforce craniofacially abnormal children, whose own interactive behaviour is thus extinguished) is equally persuasive, but is not mentioned.

It has already been noted that children express a preference for attractive peers at an early age (Dion, 1973). Children also notice disfigurement from early in childhood (Conant & Budoff, 1983). The preference of children for attractive peers is apparently reflected in their attitudes toward facially deformed people. Rumsey et al. (1986b) examined children between the ages of 5 and 11 in an attempt to observe the age at which stereotyping of facially disfigured individuals commenced. Using before/after photographs of adults who had received facial surgery for minor facial abnormalities, they asked 168 children (24 from each year within each age range) to choose either 'before' or 'after' photographs in response to positive and negative questions regarding the potential stimulus persons. Whilst younger children chose at a chance level, 11 year olds chose in the

stereotyped direction at a rate of 75%, choosing 'before' photographs in response to negative questions and 'after' photographs in response to positive questions. Analysis of variance revealed a significant effect of age of subjects (with 11 year olds showing more stereotyping) and sex of the stimulus materials (with female photographs receiving more stereotyping) on stereotyping of responses by the children.

The authors of this carefully conducted study conclude there may not be stereotyping against facially deformed people until after age 11. However, it may be wise to be cautious in accepting this finding. Children discriminate with regard to attractiveness from a young age (See Chapter 3) and, although these studies generally do not include disfigured stimulus persons, such individuals are often reported as being less attractive (Barden et al., 1989). Furthermore, the authors note that their stimulus photographs showed people whose deformity was a 'minor irregularity of the jaw'. Indeed, the surgery performed upon the target persons amounted only to a revision of the mandible of up to half an inch, without concurrent superficial plastic surgery (Bull & Rumsey, 1988). The children might well have shown stereotyping at an earlier age if the level of deformity in the 'before' photographs had been higher.

In an element of her 1983 PhD thesis, Rumsey showed 7 year old (n=84) children male and female non-disfigured, trauma scarred and birthmark disfigured adult stimulus photographs, and asked them to compose stories about the individuals shown in the photographs. She carried out content analysis of the resulting stories. Inspection of the themes most frequently arising suggested the children saw disfigured individuals as more likely to be unhappy/nasty people, more likely to assume negative roles in the stories, and possibly (in the case of female stimuli) more likely to be single (Rumsey, 1983). These findings seem to suggest that children form stereotyped views of disfigured individuals at an earlier age than that suggested by the Rumsey et al. (1986b) study.

With increasing age, children show bias towards competence and aversion to physical disability (Sigelman & Singleton, 1986), whilst Richman and Eliason (1982) suggest parents and teachers have lower expectations of facially disfigured children.

It is also possible that severity of disfigurement is correlated with degree of psychological difficulty. In a study of children with cleft lips and palates, Broder and Strauss (1987) compared 13 children with cleft lips, 13 with cleft lip and palates, 14 with cleft palates and 18 controls aged from 6-9 years with regard to their scores on the Primary Self Concept Inventory, which consists of three domains: personal self, social self and intellectual self.

Subjects with cleft palate only were judged as being of normal appearance by the interviewer. Those with cleft lips had lower self report scores on the personal, social and total scales than controls, but not lower intellectual scores. Children with cleft palates had lower scores than controls on the social self scale only. No significant differences were found between those with cleft lips and those with cleft palates in any domain. Children with cleft lip and palates scored lower in all domains than controls, and also lower in most domains than those with cleft lips or cleft palates alone.

The authors suggest that these findings support the notion that greater psychological difficulty is found in those with visible rather than invisible defects. However, the results are by no means unequivocal, since the only differences of this kind are between controls and those with defects, not between those with visible and invisible defects. Likewise, the results do not, contrary to the authors' suggestion, fully support the 'beauty is good' hypothesis, since those with visible defects do *not* perceive themselves more negatively than those with invisible defects, only more so than controls. Similarly, those with *invisible* defects also perceive themselves more negatively than controls within the social domain, once again not supporting the 'beauty is good' hypothesis. Finally, the authors suggested that their findings showed the stigmatising consequences of facial disfigurement. In fact, they show no such thing, both because of the equivocal nature of the findings themselves, and since stigmatisation was never directly investigated in the study.

A small survey by Noar (1991) of 32 patients with cleft lips and palates (mean age 19.9) and their parents shows findings which contrast with those of Broder and Strauss (1987). If we take teasing as an instance of stigmatising behaviour, Noar found that only some 25% of the patients reported having been teased by peers. He also noted that cleft patients have a generally similar body image

to normal subjects, with the exception that whilst those with clefts are concerned about the cleft itself, normal subjects tend to be more preoccupied with growth and with stylised standards of beauty. It is, however, difficult to draw direct comparisons between the study samples without knowing how comparable the level of disfigurement was between the two groups.

The tendency for children to show increasing aversion to physical disability with age (Sigelman & Singleton, 1986) is perhaps reflected in the experiences of children with facial deformities. Pertschuck and Whitaker (1982) found more disturbed functioning in older children in their sample of 51 patients referred for reconstruction of craniofacial abnormalities. Although almost all the children reported teasing, adolescents were markedly more disturbed than younger children. Whilst the authors note that this may have been a procedural artefact arising from the need to use different measures in the two groups, they also stress that corroborating interviews, observed behaviour and parental reports appear to confirm their findings. Alternatively, they suggest younger children may have been better able to deny their problems, although this is clearly not amenable to investigation without both a reliable operationalisation of the concept of denial and a specific element of the study to test for its presence. Surprisingly, though they acknowledge that opposite sex relationships increase during adolescence, the authors do not stress this as a possible reason for greater difficulties in older children, nor do they mention the likely broadening of social life in adolescence or the lessening of dependence on parents and family. It seems worthwhile to speculate that the increased difficulty in this sample is a consequence of having to deal with the developmental tasks of adolescence whilst having the additional burden of a facial disfigurement. The authors also report that, in common with some other studies, little correlation was found between level of disfigurement and disturbance.

In an examination of psychosocial adjustment following surgery, Pillemer and Cook (1989) studied 25 patients with craniofacial abnormalities, using standardised tests of intelligence and self concept and a series of projective tests (the Tasks of Development (TED) test). They examined 12 males and 13 females age 6-16 years. Subjects' scores for intelligence and self concept were the same as normative data, with the exception of a single subscale (inhibition), on which they scored lower. On the TED, they scored lower than normative values on the socialisation, trust and separation

subscales. No normative values have been obtained for the self-esteem subscale of this test and so no comparisons were possible. Although no statistical tests for difference were performed, inspection of the means reveals very large differences from the normative values where these are described as different by the authors.

The adjustment of parents was also examined. Sixty per cent reported shock, sadness, disbelief, worry, disappointment around the time of birth. However, 92% reported generally pleasant memories of their child's later development. It should be remembered, however, that these reported percentages relate to small actual numbers. Parents also rated their children as less socially skilled and more depressed than normative groups. The children's teachers rated subjects as having moderate to significant problems in task competence (63.6% of children), peer relations (59.1%), and adult relations (54.5%). They also described 36.4% of children as wanted as a group member by class mates, 50% as tolerated, 9.1% as avoided and 4.5% as actively rejected.

The authors note that disturbance is more likely to be picked up by the projective tests than by the psychological scales. This is supported by McWilliams (1982), who notes that studies may have failed to detect difficulties amongst facially disfigured people because such individuals have difficulty expressing their concerns. However, the projective test and psychological scale approaches in Pillemer and Cook (1989) do not measure the same things, and differences in the rate of detection of disturbance are as likely to spring from this difference as from genuine differences in the abilities of the two approaches to detect disturbance. Moreover, there is no evidence that the disturbance allegedly detected corresponded to actual difficulties amongst the children.

Pillemer and Cook (1989) suggest that, in addition to the lower expectations of teachers, noted from other studies, underachievement may be caused by overdependence on teachers to structure environment and limited peer support. However, there is no demonstration in their study that underachievement, overdependence or lack of support have taken place, since estimates of these are based on the reports of teachers, which are suspect because of the very problems to which their lower expectations might give rise. The teachers were not 'blind', and so might be expected to

underestimate competencies in the disfigured group. This possibility is supported by the test of intelligence, which was in the normal range. The only other possible source of information about social performance in the study is the socialisation scale of the TED, which, whilst possibly indicative, is not an empirical test of the children's social interactions or support at school, or elsewhere. Finally, parents' ratings of their children's depression and social skills are likewise suspect, since they may simply reflect parents' notions of how disfigured children *might be expected* to feel. The study reported gives very modest support for the notions of increased psychosocial difficulty in disfigured children, or for the greater ability of projective tests to detect such difficulties, because of the methodological difficulties described.

In a commentary on this study, Tobiasen (1989) discusses the use of the expression 'psychopathology' by Pillemer and Cook (1989), since the shyness and withdrawal shown by disfigured children is not necessarily pathological. He goes on to remark, however, that a Diagnostic and Statistical Manual of Mental Disorders (DSMIII-R) diagnosis of avoidance disorder in childhood does exist (essentially involving 'obsessive shrinking' from contact with unfamiliar others and peers [American Psychiatric Association, 1987]). Whilst it might be tempting to ascribe such 'pathology' to this group, and to attempt to trace avoidance behaviour into adulthood, in line with the predictions of the present thesis, it should be remembered that the subjects in this study were not, in fact, examined for such a disorder in accordance with DSMIII-R guidelines, and the ascription to them of psychopathology therefore remains extremely suspect.

There is, however, some indication that social skill in disfigured children might be linked to adjustment. Kapp-Simon et al. (1992) explored the relationship between self-perception, social skills and adjustment in a study of 45 young adolescents (mean age 12.3 years) with craniofacial abnormalities. They gave their sample measures of personality and self-perception and a behaviour problem checklist, and found that whilst social skills, self-perception and behavioural inhibition were within the normal range, the average adjustment score was 1.5 standard deviations below the average of a normative population. The best predictors of adjustment were social skills and athletic competence scores, which together accounted for 73.5% of the variance of adjustment scores. The social skills scores made the only significant impact, however, with athletic

competence adding little to the predictive value. The authors concluded that a significant number of children with craniofacial abnormalities were at risk of poor adjustment, and further suggested that improving their social skills might increase their adjustment levels.

Kapp-Simon et al. (1992) draw our attention to the fact that theirs was a convenience sample and that, crucially, it was essentially correlative in design. In consequence, their use of the expression 'predictive' is within a regression paradigm, not an experimental one. Unfortunately, they do not comment upon one important possible consequence of this element of the study. It could well be the case that the children are better adjusted for some other (uninvestigated) reason, and that this improves their social skills. This is always a problem with drawing inferences from correlational studies, but is particularly problematic in this instance, since there is evidence of reciprocity in social interactions, particularly with regard to the perception of attractive people as more socially skilled, and the possibility that such people indeed possess greater social skills. Since no ratings of the attractiveness of the subjects in the current study were undertaken, varying levels of such attractiveness is one simple possible source of the correlation between social skill and adjustment. We should expect more attractive individuals to have more access to social reinforcement and therefore be more likely to respond with greater skill as a result of more rewarding practice opportunities (see Chapter 3). This greater social approval might also account for their greater social adjustment, whether or not they showed greater skill. However, the Kapp-Simon et al. (1992) study does offer some tentative support for such initiatives as have been undertaken to improve the social skills of disfigured individuals.

Although a review by Lefebvre and Arndt (1988) of 15 years of psychiatric consultation in the care of children with facial disfigurement does not specifically comment on the role of social skills in mediating adjustment, they do identify a number of protective factors, including intelligence, positive mood, sense of humour, strong parental marital relationship, family and community support, and personality characteristics. Whilst a number of these factors can be seen as directly or indirectly related to social interaction, the paper is weakened by the fact that only the first two of these asserted protective factors are substantiated by citations. Despite this shortcoming, the assertions

of Lefebvre and Arndt are generally consistent with both the Kapp-Simon et al. (1992) findings and the few empirical studies of social skills training in adults with disfigurements (see Chapter 6).

Macgregor et al. (1953) suggested that mild deformity might be harder to cope with than severe disfigurement. Reich (1969) has speculated that this is because severely deformed individuals can predict adverse responses with more regularity. They are thus more prepared for negative responses than the more mildly disfigured. Whilst this argument is attractive from a conditioning perspective, since we should expect more prolonged and regular exposure to an anxiety-provoking stimulus such as the negative reactions of others to give rise to habituation and, therefore, to anxiety reduction (Walker, 1984, 1987), it is not universally supported by the evidence, since more severe disfigurement is sometimes associated with worse psychological adjustment (see Chapter 5).

In an investigation of the contention that less severity of deformity leads to worse psychological adjustment in childhood, Lansdown et al. (1991) rated the intelligence, self concept and behaviour of 27 facially disfigured children, 12 control children, 26 siblings and 12 control siblings. The facially disfigured children were classified for deformity according to parental account of amount stared at in public, which accorded significantly with raters' opinions of their photographs.

No significant differences in intelligence were found between the groups. Whilst there was no significant association between severity of disfigurement and scores on the total self concept scale, a non-significant trend was found for mildly disfigured children to report a lower self concept on 7 items related to appearance and popularity from the scale. There were no differences between the behaviour scale scores of any groups. The authors do not report any findings with regard to differences in self concept or behaviour between experiment subjects as a whole and controls. Significant differences were found between siblings, with siblings of mildly disfigured children showing most disturbances. These siblings were more disturbed than any patients! None of the statistical tests employed were reported.



Despite this, the authors conclude the results support the contention of greater disturbance in mild disfigurement, and posit that this is because more disfigured individuals have learnt to cope with a 'consistent reality' of being stared at, pitied, shunned and insulted, whilst the mildly disfigured might worry about whether their deformity has been noted. This is an intriguing idea, which supports a behavioural explanation based upon habituation. However, the authors present *no* actual evidence for their speculation in this much-cited study. They found no differences according to level of deformity, which does not support their hypothesis.

In another study of factors suspected of influencing outcome, this time examining family influence, Blakeney et al. (1990) gave 44 adolescents who had suffered full thickness burns to 60 % of body area a battery of psychological tests: a clinical interview, Culture Fair Intelligence Test, Family Environmental Scale (FES), Suicide Probability Scale (SPS). They found that better and worse psychosocial adjustment patients as measured by the SPS were differentiated by greater family cohesion, independence and more open expressiveness within the family, and concluded that these variables were, therefore, predictors of better adjustment.

The Blakeney et al. (1990) study suggests that family cohesion, independence and expressiveness are associated with adjustment as measured by the SPS. However, two moderating elements should be noted. First, the SPS measures only a small range of elements, which are principally related to depression, rather than more general elements of adjustment, such as ability to carry out activities of daily living. Second, part of the statistical treatment used in the study was suspect, since t-test was used to compare the scores of individuals designated as well or poorly adjusted on the basis of a cut-off point on SPS scores. These two groups then formed levels of the independent variable. The implication behind this is that the measures of family cohesion and so on were *dependent variables*. Although the authors indeed describe these measures as dependent variables, they then go on to interpret them, in their discussion, in the *role* of *independent* variables (i.e.; as predictive of adjustment). Adjustment is thus placed in the role of a dichotomous *dependent* variable, but has not been statistically treated as such. The prediction *actually* investigated by t test in this context is whether being designated more or less well adjusted according to SPS affects levels of cohesion, independence and expressiveness. This is neither

what the authors intended nor what they describe in the discussion. The most we can say from this study is that there is a relationship between adjustment (or depression, if we interpret the intent of the SPS more conservatively) and family cohesion, expressiveness and independence, as revealed by multiple regression. Some other, uninvestigated variable (e.g. site of burn) could have been responsible for this observed relationship. However, Orr et al. (1989), in a study using different measures, did find a relationship between family social support and self esteem and low scores on the Beck Depression inventory in their group of 121 burn injured adolescents and young adults.

### **Summary**

Facially disfigured children receive less early nurturant behaviour and stimulation from caregivers. It has been suggested that this may be because disfigured children are less reinforcing. This speculation is suspect, since reinforcement in such situations is likely to be reciprocal, and may even be mediated more by the caregiver than the child. Disfigured children are likely to be recognised as less attractive by their peers, and preference for non-disfigured children and the ascription of stereotypes to disfigured individuals apparently exist from an early age. Disfigured children are apparently less well adjusted than controls, but the ascription of psychopathology is dubious. There is no unequivocal evidence that level of adjustment is related to level of disfigurement. The relationship between family variables and adjustment is likewise weak.

Despite the sparse amount of evidence, and its methodological difficulties, the emerging trend suggests disadvantage for disfigured children, which is reflected in their own adjustment. In consequence, those involved with such children need to consider this context during attempts to aid psychosocial development. Similarly, those working with adults who were disfigured in childhood will want to consider the effect of their possible history of disadvantage and stigmatisation as part of the context within which they work. This contextual element forms a part of the model of adjustment to disfigurement presented in Chapter 8.

### **Section 4.5 First-hand accounts by disfigured people**

The current study uses an almost exclusively quantitative approach to its examination of the experiences of facially disfigured people. However, considerable qualitative research has informed

both the work of quantitative researchers in the area and the current study. Indeed, Macgregor, one of the most influential commentators on the plight of disfigured people, approaches her work from the sociological tradition and from a largely qualitative standpoint. Whilst these qualitative studies lack the predictive power of quantitative research, they nevertheless provide a fascinating, detailed account of the experiences of small groups of disfigured individuals, and have been helpful in indicating areas to which more systematic research should be addressed. Similarly, first hand accounts by disfigured people demonstrate the range and degree of difficulties they experience more forcefully than quantitative approaches can.

This brief section focuses, largely without comment or analysis, on a small selection from the literature of first hand accounts, in order to demonstrate in detail the personal ramifications of the experiences to be summarised in the quantitative studies described in Chapters 5 and 6. The focus of the selection is on social interactions. Although there are a considerable number of brief accounts of personal experiences of disfigurement available, particularly in the popular press, these generally lack detail or depth and are not reported here, since an extensive appraisal of this literature is outside the scope of this study. This section focuses particularly on the work of one respected qualitative researcher, Frances Macgregor, who has been active in disfigurement research for over forty years, and on two well known detailed first hand accounts from the UK. General themes from the selections are then summarised.

In her earliest major contribution to the area, Macgregor ((Macgregor, 1951; Macgregor et al., 1953) interviewed 74 plastic surgery patients suffering from four levels of deformity. Whilst a number of structured psychological tests were used and reported, most of the work involved qualitative reports of the interview content, from which Macgregor identified themes such as social disadvantage, expectancies, modes of response and adjustment. In particular, Macgregor et al. (1953) offered 4 case histories representing the four levels of disfigurement identified in the study. Whilst the material is presented in a highly integrated way, so that it is often difficult to discern between results from various elements of the empirical work and comments on the work of earlier commentators and research projects, considerable use is made of direct quotes from sufferers, many of which

attest to the degree of social performance difficulty, isolation and stigma experienced. The following are illustrative examples:

*People think I'm a tough character because I talk out of the side of my mouth.*

*I avoid restaurants as people may think I have a disease and won't want to eat with me.*

(Macgregor et al. , 1953, p 71)

*Children would make fun of the way I looked and say I wasn't normal.*

*People seem to think I've changed because my face has.*

(Macgregor et al., 1953, p 72)

*When I have an appointment with a new contact, I try to manage by standing at a distance and facing the door, so the person entering will have more time to see me and get adjusted to my face before we start talking.*

(Macgregor et al., 1953, p 85)

*Before (plastic surgery), when I was with people I used to put so much energy into putting on an act and pretending I was happy when I wasn't.*

(Macgregor et al., 1953, p 90)

The above examples illustrate the impact of disfigurement on sufferers' social lives. The outstanding feature of the study as a whole, and the quote material in particular, is the broad range of areas of interaction with others that are affected. Thus, the work and social lives of sufferers are affected, throughout the life cycle, and sufferers engage in such tactics as avoidance of social

situations and avoidance of particular activities within these situations, whilst adopting defensive manoeuvres. They are subjected to repeated verbal abuse, disgust and pity from others. The rigour of Macgregor's (1951) approach to the subject group cannot be overlooked, since the project involved some 1400 interviews, with the time accruing to each subject ranging from 2 to 30 hours. Whilst an examination of the theoretical underpinnings of reliability and validity in qualitative studies is beyond the scope of this study, the coherence and consistency with which the picture of social disadvantage emerges from these interviews should itself serve to increase our confidence in the representativeness of these findings, at least with regard to the sample Macgregor investigates in such commendable depth. The final quote presented above indicates the degree to which sufferers' lives are apparently dominated by the need to adapt to social interactions. As Macgregor comments elsewhere (Macgregor, 1990), it appears that disfigured people are denied the social anonymity that most of us enjoy in public situations.

In 1979, Macgregor published a 20 year follow-up study of 16 of the participants in the original 1951 study, examining their views following plastic surgery. Once again, the major content of study is qualitative, and, indeed, Macgregor notes her belief that, whilst not 'representative' in the traditional sense required by quantitative scientific approaches current in medicine, the focusing of inquiry onto a few subjects who are examined in detail is more revealing than large scale questionnaire studies which, by their nature, compress complex data into summary form. The superiority of in-depth interviews, for Macgregor, lies in their ability to elucidate personal elements of 'the human struggle and what it means to be visibly impaired'. Nevertheless, her approach is eclectic, and she does note that quantitative data from some interviews with some 300 patients and relatives have been used to provide 'quantitative checks' on the qualitative data, although the process by which these were carried out is not described.

Seven full case histories are presented. In all these presentations, as well as in the isolated quotes in other parts of the text, the problematic nature of interactions with others forms the major strand of the respondents' narratives. Thus:

*I suffer tremendous fatigue, especially when I have to travel on subways. I have such anxiety facing people. I'm afraid of new people and I won't go anywhere.*

(Macgregor, 1979, p 13)

*I wanted to show her I was a human being - never mind the face.*

(Macgregor, 1979, p 21)

*The kids were making fun of me; I had no friends. .... I built a wall around myself - maybe I didn't want to associate with them, but I thought they didn't want to associate with me....*

(Macgregor, 1979, p 35)

*When I'm introduced to the girl's parents, they smile sheepishly and seem at a loss for words.*

(Macgregor, 1979, p 44)

*I can't afford to get angry, because this attracts more attention.*

(Macgregor, 1979, p 45)

*It never leaves you. You're always self conscious about it ....*

(Macgregor, 1979, p 61)

As in the earlier selections from Macgregor et al. (1953), not only is the breadth of the range of interactions affected clear, but the *preoccupation* of disfigured individuals with the reactions of others apparently accounts for the expenditure of much energy in social situations, as they are apparently both vigilant and prepared to react defensively to slights by others.

The notion of preoccupation with and preparation to respond to the reactions of others in social situations occurs in other first hand accounts. James Partridge was severely burned in a car accident at age 18, and has spent a number of years campaigning on behalf of disfigured people. Partridge's account is not so much an autobiography as a series of suggestions for action for disfigured people, but is intimately based on his personal experiences. Thus, Partridge (1990) describes the 'SCARED' syndrome of social interactions between facially disfigured people and others. This model of social interaction with disfigured people is further described in Chapter 6, but is noted here since it is part of Partridge's description of his own experiences of coming into contact with others during the years following his own severe facial burns. He describes members of the public as exhibiting the following characteristic behaviours when coming into contact with disfigured people: staring, curiosity, awkwardness, rudeness, evasiveness, distance, whilst disfigured people themselves are submissive, clumsy, apathetic, regressive, excluded and defenceless. These personal notes, which became the core of Partridge's approach to treatment of social difficulties amongst disfigured people present an often graphic account of his own difficulties, and more especially, his views of the reactions of others:

*'Their eyes will feel like drills, adding psychological pain to your physical injuries. Even twenty years on, I do turn away from staring sometimes because of its intensity.'*

(Partridge 1990, p 90)

The impact of the behaviour of others on one's feelings is equally clear:

*The most frustrating thing about being stared at is that in only a few instances do you get the chance to explain that you are quite a normal person underneath.*

(Partridge 1990, p 90)

In describing the curiosity which he has met in the eyes and words of others, Partridge offers an interesting first-hand description of behaviours which are entirely consistent with the novel stimulus hypothesis described earlier in this chapter:

*There will always be people who will blink hard at the sight of you, take a step backwards, avert their eyes, gasp, refuse to sit next to you, shield their children from you ..... None of these responses should surprise you. ....they are part of the disfigured's lot.*

(Partridge 1990, p 93)

The echoes of the novel stimulus hypothesis are particularly strong when he describes the way this curiosity interacts with anxiety and an embarrassed desire on the part of others not to stare, through the account of a personal friend's recollection of a first meeting with him:

*I'd have liked to have been able to look at you closely but was too self-conscious to do so - and too concerned as to what was the right course.*

(Partridge 1990, p 95)

Perhaps the most notable feature of his account, however, is the depth and sympathy with which he has examined the possible feelings of those who come into contact with disfigured people. He appears concerned not only with the ways in which non-disfigured people react to him, but with the anguish these people may themselves be undergoing. Nevertheless, it seems possible, from some of the other accounts, both by Partridge and by others, of the behaviours displayed towards disfigured people, that Partridge may be too kind in his ascription of positive motivations to non-disfigured people in their interactions with disfigured individuals. Descriptions of insulting behaviour towards disfigured people, whilst not systematically investigated, are common.

In the latter part of his book, and in his later writings (Partridge, 1991,1993; Partridge et al. 1994), Partridge has increasingly turned towards an examination of what may be done to help disfigured



people, particularly in their social interactions with others. His approach to treatment is described in Chapter 6.

Christine Piff (1985) formed an influential self-help movement for facially disfigured people. Her approach, like Partridge's, focuses to a great extent on the social lives of sufferers, although 'Let's Face It' groups function much more as support and awareness raising groups, rather than offering formal treatment in the way that Partridge now does. Piff writes movingly of her experience of disfigurement when her palate, eye socket, eye and much of one side of her face were removed for facial cancer in her 30s. Although Piff's experiences appear to be as much responses to being diagnosed with cancer and having to live with this life threatening illness, her descriptions of these experiences are consistent with those of other disfigurement sufferers.

Piff's account presents graphic descriptions of the social difficulties faced by disfigured people. Perhaps the key element in her account is the range of situations affected. Thus, she found socialising difficult, but was also inhibited with her own family, whose possible reactions made her apprehensive, and was unable to return to her work as a nursery nurse. As in the various Macgregor accounts, a picture emerges of someone who spends considerable time monitoring the responses of others to her appearance.

Whilst health professionals are often praised in Piff's account, she is also aware of the shortcomings of the attempts by these clinicians to engage with the social difficulties of their patients. In an interview with Holmes (1986), she comments: 'I genuinely think most consultants involved with the facially disfigured think their patients cope beautifully.' This is perhaps overgenerous, since she recounts, in the same interview, a conversation with a young girl who describes how a ward sister, when asked how she might improve her looks, after surgery for brain tumours, suggested, in front of a group of students, that she put a bucket over her head. Whilst it may be the case that health professionals are simply unaware of the emotional difficulties of disfigured people, it may also be that they deliberately avoid engaging with such emotions, because of the anxiety responses which they create in professionals themselves. Certainly, Bernstein

(1976) has noted both the universality of such anxious responses to disfigured people, and the tendency of professionals to taunt disfigured children, which may likewise be a defensive reaction.

The formation of *Let's Face It* proved to be a significant turning point in Piff's adjustment to disfigurement. Bernstein (1976) describes a patient who coped with disfigurement by a process of self-objectification, involving allowing himself to be the subject of much experimentation, which might ultimately benefit other sufferers. As well as providing purpose, *Let's Face It* appears to have brought Piff into contact with many people, thus exposing her to potentially damaging or offensive reactions, which dangers she has overcome to create an influential nationwide network.

### **Summary**

The selections in this section provide examples of the individual consequences of disfigurement which may underlie many of the group results provided by quantitative studies. Disfigured people are constantly under the scrutiny of others, and are restricted across the broad range of social situations. They are acutely aware of the responses of others and the generally negative attitudes these reveal. Social avoidance is a frequent consequence, and this can be either the total avoidance of social situations or withdrawal and lack of interaction within them. Disfigured people are constantly vigilant, and are denied the privacy of being ignored in social and public situations which non-disfigured individuals enjoy. As Partridge puts it:

*When you face the public, you will be scrutinised and automatic associations will be made in the public mind between your looks and your character. These connections are rarely flattering, and will persist unless you challenge them.*

(Partridge, 1990, p 123)

### **Section 4.6 Chapter summary**

Disfigurement is a major source of distress and disability in the UK, even by the most conservative estimates, and disfigured people almost certainly share with other disabled groups the stigma of disability. The visibility of disfigurement in all probability contributes towards this. Whilst it may be

that the novel stimulus hypothesis accounts for some of the behaviour of others towards disfigured people, many of these reactions are best accounted for by fear and by negative attributions made towards disfigured individuals. Moreover, these reactions are, in all probability, acquired early in life and shared by both non-disfigured and disfigured individuals. A picture of enduring disadvantage for disfigured people emerges, over time and across a range of settings, from their own accounts and those of qualitative researchers. The following chapter examines adult psychosocial adjustment to facial disfigurement.

## CHAPTER 5

### DISFIGUREMENT AND PSYCHOSOCIAL DISTURBANCE IN ADULTHOOD

#### **Section 5.1 Introduction**

Psychosocial disturbance is a particularly important element of the literature for the current study, and so is examined at some length. In consequence, this element of the literature review is divided into a number of sections. General reviews are discussed in the following section, whilst two further sections examine attempts to define particular predictive factors of disturbance amongst disfigured people.

#### **Section 5.2 The nature and extent of psychosocial disturbance**

Accurate estimation of the prevalence and individual level of psychological disturbance amongst disfigured people is hampered by a number of difficulties within the literature. Martin, Meltzer and Elliott (1988) provided only a general index of handicap from their comprehensive sample, without providing specific measures of any domains of disturbance (e.g. physical, social, psychological). Studies which have focused more precisely on types of difficulty have, by contrast, used samples drawn from particular patient subpopulations (e.g. burns survivors, port wine stain sufferers). Whilst these studies have provided more detailed information regarding patterns of difficulty, they are typically of small numbers of subjects. Moreover, they cannot, alone, allow the drawing of any general conclusions about the effects of disfigurement, since these effects are likely to be mediated by differing factors amongst the different subject groups. However such conclusions are potentially valuable since they will affect planning of resources for interventions aimed at addressing such psychological effects. General conclusions about psychological difficulties faced by disfigured people must arise from a synthesis of the studies of these different subpopulations.

Andreason and co-workers examined adaptation mechanisms (Andreason and Norris, 1972) and psychiatric morbidity (Andreason et al., 1971) in 20 patients following severe burn injuries. Whilst important because they represent early attempts to follow up burns disfigured people in a systematic way, the findings should be treated with care because of the low numbers involved and the tendency of the authors to make generalised assertions based on these small numbers and to

mix comment apparently derived from the literature or opinion with discussion based on the results they have presented. Nevertheless, the findings of Andreason and Norris (1972) suggest that a majority of patients adjust well, despite the difficulty of the task involved. Of particular note is their use of the expression 'progressive desensitisation' to describe the process whereby patients become accustomed to their appearance, overcoming anxiety when faced with the changed appearance. Although not described precisely in the terms used by Wolpe (1958) in his formulation of systematic desensitisation as a treatment for phobic disorders, it is clear from the context that Andreason and Norris have in mind the process of overcoming anxiety through repeated exposure, in a way similar to that explored in the current study. This represents an extremely early instance of the application of behavioural principles to an explanation of the process of adaptation in disfigured people, and is particularly interesting because it is presented alongside reference to defence mechanisms derived from psychoanalytical theory. In this context, the authors refer to desensitisation, as revealed by lower ratings of deformity by subjects than by the examiner, as permitting the use of *denial*. It is difficult to see the rationale behind the assertion that denial is being used here. Denial, in this context, appears to be used in a sense consistent with the psychoanalytical sense of denying the existence of some painful perception, or denying the severity of such a perception, in order to protect the self from conflict (Freud, 1927/1977; Rycroft, 1983). However, no evidence is presented for the operation of such a mechanism. The behavioural view does not require the use of such a construct, since the process of habituation alone accounts adequately for the waning of arousal/anxiety in these circumstances. This in turn accounts for lower ratings by the patient, who is more accustomed to seeing his disfigurement than is the rater. Moreover, the ascription to the patient of denial implies that it is the *rater's* perception of the patient's level of disfigurement that is the correct one. This assertion is again difficult to justify.

In a paper focusing particularly on the psychiatric profiles of the subjects in Andreason and Norris (1972), Andreason et al. (1971) attempted to examine the incidence and types of psychiatric complications arising and to determine whether these problems were predictable. The paper consists of a number of case histories and a table of pathological and demographic characteristics of the participants. Of their sample, 5 individuals had psychiatric problems which predated their burn, whilst a further 5 had acquired psychiatric diagnoses subsequently. Unfortunately the report

does not make clear which diagnoses predated and post-dated the burns. The occurrence of psychiatric complications following burns, even in the study population, is thus uncertain, and the issue is further complicated by the description of only 6 of these individuals as having current emotional problems. In fairness, the authors do note the conceptual difficulty of defining what constitutes a problem in this context. The authors examined work, recreation and social interaction, and noted that interaction was most disturbed, affecting 6 of the subjects. In general, however, they conclude a generally optimistic prognosis for burns victims, with comparatively mild psychological discomfort among affected individuals. Once again, the numbers involved are too small to permit definitive conclusions.

Malt's (1980) review of follow-up studies of burns patients concluded that the overall incidence of psychosocial difficulties amongst burned adults was unlikely to be less than 30 per cent in an unselected group. Their difficulties were likely to comprise anxiety syndromes, reduced social interaction without specific mental illness and possible organic psychosyndromes. Furthermore, the rate and severity of problems was likely to increase with level of severity of disability. However, Malt also noted that the seven long term follow-ups he was able to identify contained numerous methodological flaws. Most were of small numbers, obtained small participation rates from the parent populations, and often investigated only more serious burns. Demographic descriptions were inadequate and the use of different methods made it difficult to draw conclusions across studies, with no consistency in the definition of problems. No comparisons of rates of disturbance with the general population were undertaken. The study groups were not divided into adults and children, or by aetiology of the burn. Taken together, these problems limited the conclusions that Malt was able to draw from the studies reviewed.

In a later empirical study, Malt and Ugland (1989) addressed some of these shortcomings. They examined a group of 70 (57 males 13 females) burned adults at between 3 and 13 years post injury. The majority of the group had sustained minor injuries. At follow-up, 23% suffered definite psychosocial adjustment problems sufficient to interfere with life in a significant way, and patients with more severe injuries had a higher rate of disturbance (44%) than those with minor injuries (16%). None of those rated as severe were working (11.4%). The authors noted that their overall

rate of 23% corresponded well with a US study (Blumenfield & Reddish, 1987). The source of the disturbance, whether from disfigurement, physical impairment or post-traumatic reaction is not, however, investigated.

In a smaller study of a clinical group, Faber et al. (1987) screened 42 burned adults for psychological and social problems and followed them up, finding that 21% needed psychological help at 18 months post injury. This seems a considerable percentage, even allowing for the small sample, given that the authors attempted to increase validity by triangulating between a semi-standardised interview, psychological questionnaires and patients' own report of need for help. However, the authors report mismatches between these three methods, with psychologists apparently overestimating difficulty and patients underestimating it, compared with the questionnaire approach.

Unfortunately the authors' discussion of their findings is not illuminating. They reported 'moderately acceptable' agreement between interviewer and questionnaire, and between questionnaire and patient, and suggest that the poor agreement between interviewer and patient may have been attributable to chance. The results do not, however, necessarily support these interpretations. A positive correlational relationship between variables shows merely that as one increases, so does the other. This is not the same as stating that the two agree. For example in the questionnaire/patient report relationship, there were as many matches as mismatches for judgement of need for treatment (8 versus 8). The positive association was almost certainly caused by the large agreement over not requiring treatment (25 versus 1). The same picture is present, to a lesser degree, for the questionnaire/interview comparison. Finally, it is not permissible to conclude that the lack of concordance between psychologist interview and patient self report is attributable to chance. The lack of significance of Cohen's K is simply a recognition that there was no relationship *detected* between them, not that this lack of relationship was owing to chance. Overall, it must be concluded that this study can tell us little about the prevalence of psychosocial disturbance or the most appropriate way of screening for such disturbance.

However, the Faber et al. (1987) study is somewhat supported by Wallace's (1988) findings of psychosocial disturbance in a group of 45 discharged burns patients 6 months after discharge and a further 40 at 2 years post discharge. The Wallace study, although once again small, is strengthened by the use of discharged patients, since there is possible bias in studies of patients currently attending, for example, plastic surgery outpatients (Rumsey, 1983). One might expect that current attenders would differ from discharged patients in a number of ways. They might be hopeful, since treatment was still in progress and they might continue to have possibly unrealistic expectations about the possible benefits of treatment. They might also be in a state of denial of their difficulties as part of grieving over their lost appearance (Bernstein, 1976). Conversely, their ratings might be high because of the effect of undergoing treatment. The use of a post-discharge group reduces this source of variability.

At 2 years post-discharge, 30-40% of adults showed severe psychological difficulties, whilst 75% of children aged under one year when burned showed severe emotional and behavioural disturbance. In spite of this, *none* were receiving professional help related to their psychological difficulties, and over half relied on fellow patients as sources of support. Furthermore, although half were in regular contact with health professionals at 6 months and 40% at 2 years post discharge, less than 25% felt they had useful contact with any professional related to their burns. At 6 months, all patients would have valued some form of help, including staff led talks (95%), individual professional help (75%), newsletter (63%), self-help group (60%). At 2 years, 80% would have liked newsletter, 68% staff talks, 50% professional help, 5% further information. In a similar survey of ex-patients at one year follow-up, Williams and Griffiths (1991) found that practical advice (52%), information (17%), and emotional support (17%) were the most wanted interventions, whilst 26% were interested in staff led talks, 22% in self-help groups or a newsletter and 9% in individual help. Most significantly, 30% of respondents wanted intervention prior to discharge, 30% at discharge and a mere 4% at six months after discharge, indicating that respondents would greatly value timely interventions regarding potential sources of post burns difficulties.

As in the Faber et al. (1987) study, the site of the burn is not identified by Wallace (1988), although the inference from her paper is that disfigurement is a major issue for respondents. Although



numbers in both the Wallace (1988) and Williams and Griffiths (1991) studies were small, and further reduced on many of the specific questions by incomplete responses, the sheer size of the discrepancies between the perceived need of respondents and responses to that need should give professionals working in the area considerable pause.

In a study of people with port wine stains, Kalick et al. (1981) suggested that the level of distress described by sufferers is sometimes out of proportion to the extent of the disfigurement, although they do not cite any evidence for this assertion. Kalick et al.'s study showed sufferers did not differ from normative groups on a number of scales for which normative data exist, measuring introversion, neuroticism anxiety and depression. Indeed, of the battery of tests they gave, only one anxiety subscale differed from such normative data. However, 43 of the eventual 79 respondents reported that their port wine stain had affected the way in which others treated them.

The authors suggested several reasons for the lack of correspondence between their study findings and those of several earlier papers. The kinds of individuals attending clinics since the earlier studies might have changed, the interviewing in these earlier studies might have been biased, or the measures of their own study too insensitive. Finally, it was considered possible that port stain patients were more resilient than other disfigured individuals, partly because of a high level of family support. These suggestions are, however, largely without basis. Neither of the two studies they mention (Edgerton et al., 1961; Reich, 1969) were of port wine stain patients, so suppositions about the role of changing clinical attenders over the years are irrelevant. The two types of sample are simply different, regardless of time. Speculation about differences in the adequacy of the measurement approaches applied across the studies are likewise rendered impossible by the differences between the sample groups. The differences found might, as the authors suggest, lead us to suppose that port wine stain patients are more resilient than others, but, since no measure of *level* of disfigurement was made in any of the studies, this, rather than *cause* of the disfigurement might have led to score differences. The authors' rationale for suggesting greater family support is extremely limited, being supported only by the anecdotal noting, by the authors, that port wine stain patients were invariably accompanied to the outpatients' clinic by family members.

The possible difficulty of using questionnaires to investigate psychological adjustment is highlighted in a study of patients with port wine stains by Lanigan and Cotterill (1989). They followed the assertion by Kalick et al. (1981) that psychological disturbance may be missed by insensitive tests, and reported a discrepancy between two standardised measures of minor psychological morbidity (General Health Questionnaire and Hospital Anxiety and Depression) and their own 26 dichotomous question instrument. Considerable numbers of their 71 respondents reported difficulties, stating, for example, they would feel better about themselves if their birthmarks were improved by treatment (92%), more comfortable with the opposite sex (83%), and with the same sex, (71%). Respondents also believed that people stared at them because of their birthmarks (75%), and that it had affected their self-confidence (71%), and reported the need to hide the mark (72%). Low numbers reported difficulties related to work (15%), people avoiding choosing them as friends (20%) or avoidance of sexual activity (23%) because of their birthmark. These suggestions of disturbance were in contrast to the small numbers of positive scores on the HAD (5) and GHQ (3).

The authors conclude that their study represents a further instance in which the use of questionnaires aimed at specific areas of disturbance in port wine stain individuals reveals such difficulties, whilst these are not detectable on standardised psychological tests. They suggest this discrepancy is a consequence of denial on the part of sufferers, resulting in normative responses to standard screening tools, whilst focal questionnaires reveal the extent of their difficulties.

The study is important, since it focuses on the area of social difficulty, a matter of specific concern to this group. However, the study also appears to examine many elements which relate not to current distress, but to past experiences and perceptions of the attitudes of others. These are not necessarily indicative of distress. Thus, it is not necessarily the case that responses to this questionnaire are either different from the findings of standard tests, or more revealing about current psychological adjustment. It is quite possible that the responses are different because they are measuring different things, rather than because of denial or other concealment by the respondent. Similarly, the authors were comparing global abnormality on the HAD and GHQ with single item responses to their questionnaire. This seems an inadequate method of comparison

between the two methods of assessment. Thus, there is no reason to conclude that standardised tests are failing to detect psychological disturbance when it is present.

### **Summary**

The early work in this field is to be praised for raising the issue of psychosocial disturbance in disfigured people. However, these early studies are too small to allow definitive conclusions about either the prevalence of disturbance or the mechanisms which maintain it. Further difficulties within the literature have included low participation rates, inadequacy of description of sample characteristics and lack of comparability between studies. In spite of these difficulties, a picture of the commonness of psychological disturbance emerges. Two surveys of the provision of psychological support services for disfigured individuals suggest that such provision is insufficient to meet the need.

Identification of psychosocial disturbance in disfigured people represents a continuing challenge. The number of studies is small, no validated measures to examine the impact of facial disfigurement have developed, and the use of different measures of global disturbance across different studies continues. It has been suggested that standard measurement tools are insufficiently sensitive to detect the difficulties suffered by disfigured individuals. However, the studies which purport to demonstrate this are of insufficient rigour to support this contention unequivocally. It may be that many individuals will suffer considerable difficulty below the level measured by standard scales of, for example, dysphoria. Nevertheless, it is still useful to be able to identify the numbers who *do* experience sufficient distress to register on such scales, both for epidemiological reasons and in order to identify individuals in need of particular interventions. Ideally a combination of standardised general measures and measures specific to the face will eventually be used. One important part of the current study is the combination of measures of these two kinds, including the development of a new specific scale.

### **Section 5.3    Severity and location of disfigurement as predictors of psychosocial disturbance**

It may be, as Piff suggested (Holmes, 1986) that professionals underestimate the level of disturbance experienced by people with facial disfigurements. The lack of concordance between level of injury and level of psychological disturbance is often mentioned in the literature, and indeed, is cited by Pruzinsky (1992) as one of the most consistent findings in the field of body image study. Moreover, preoccupation by patients with what is regarded by health professionals as minimal disfigurement is often taken as a sign of psychopathology. Nevertheless, criteria for determining an acceptable level of disfigurement do not exist, the number of studies examining extent and site of disfigurement as variables possibly affecting psychosocial adjustment is small, and the conclusions regarding the impact of level and site of disfigurement on adjustment are mixed.

Andreason and Norris's (1972) examination of adjustment in burns provides a detailed tabular account of the areas of injury suffered by the subjects. This is particularly important in judging the authors' assertion that their results offer some support for Macgregor et al.'s (1953) suggestion that patients with less deformity may be more disturbed. As has been noted earlier, numbers in the Andreason and Norris (1972) study were small, and so any suggestion that general trends about behaviour and experience might be drawn from it should be modest. Furthermore, although the authors *suggest* that some of their results support Macgregor et al. (1953), this is not apparent when the data are scrutinised. The evidence the authors offer is potentially biased, since the examiner's ratings of both disfigurement and disturbance are used throughout the discussion, and the illustrative instances of supposed high disturbance with low disfigurement and low disturbance with high disfigurement amount to a mere two cases in each instance. Furthermore, examination of the tabular results shows that of those judged to have emotional problems, only one had an examiner rated level of disfigurement of less than 3 on a 1 to 4 scale, with 4 representing maximum disfigurement level, and this individual *self*-rated at 3. Likewise, visual inspection of the relationship between ratings of disfigurement level and poor adjustment indicates that these appear to be positively related. Thus, inspection of Andreason and Norris's (1972) data does not support their conclusion that these data support Macgregor et al.'s (1953) contention that lower levels of

disfigurement are associated with higher levels of disturbance. Indeed, the examiner attributions of emotional problems appear to refute it. Later in their discussion of these elements of the data, the authors retreat somewhat from their position of support for Macgregor et al. (1953), suggesting that in many cases no evidence of a relationship between minimal deformity and maximal adjustment problems can be found. Even this is an incomplete representation of the data, however, since those with high levels of difficulty have amongst the highest ratings of disfigurement. The safest course of action may be to conclude that these data provide no systematic evidence of a relationship between levels of disfigurement and adjustment. However, it should be clarified that the reason for such an assertion is largely based not on positive findings from Andreason and Norris, but on the unreliability of data and interpretations which seem to assert the reverse.

In an important study of psychosocial adjustment among burns survivors, Browne et al. (1985) examined previous studies in the area and found only three which were not weakened by design difficulties, small sample size, biases in approach to sampling or measurement. Their own study attempted to assess levels and predictors of psychosocial adjustment in burns victims. They gave 340 randomly selected adult burn survivors and the parents of 145 child burn survivors with either major or minor burns a battery of validated questionnaire measures, in order to determine whether adjustment was affected by severity of and time since the injury, coping methods and social resources. In the case of children, they also examined the mothers' coping methods and social resources. In adults, they found that poor adjustment was associated with avoidance coping, little use of logical analysis or problem solving, high information seeking, affective distance from life problems, recency of burn, fewer recreations, less perceived family, friend and peer support. Size of the burn made no difference to adjustment.

In the child sample, there was again no association between size of burn and adjustment, but mothers of less adjusted children demonstrated greater avoidance coping, affective distance, fewer recreations and less moral or religious emphasis within the family.

The authors state, therefore, that socio-economic and psychological variables should be considered when attempting to identify those at risk, not the size or severity of the burn. In their study, the

presence of avoidance and poor problem solving were the most consistent explanatory factors with regard to poor psychosocial adjustment. It is tempting, therefore to suggest that this study offers support for a behavioural approach to the amelioration of psychological difficulties following burn disfigurement, given the emphasis within behaviour therapy upon problem-solving and confrontation. It is, however, noteworthy that the study did not identify, discuss or control for the site of the burn amongst respondents.

However, Love et al. (1987) in an investigation of whether individuals burned in childhood were less well adjusted than others as adults, did attempt to distinguish between levels of disfigurement amongst their 42 burns survivor subjects, to whom they administered the Billings & Moos Coping Scale and the Psychosocial Adjustment to Illness Scale (PAIS). All had scores within the normal range, indicating that all were well-adjusted, and there were no differences according to severity of the burn. However, dividing the group at the median PAIS score revealed a difference in interviewer ratings of their level of disfigurement. The less disfigured were better adjusted ( $X^2=10.21$ ,  $p=0.01$ ). The distinction is, however, somewhat dubious, since the whole group were well-adjusted.

In a follow-up of burned patients, Blumenfield and Reddish (1987) identified 16 patients who were unable to resume their jobs or social activities after several months and also had symptoms of psychological disturbance, from a group of 68 patients with mild/moderate burn injuries. Using a database of 250 questionnaire items, the authors compared these 'small burn, big problem (SBBP)' patients with others who did not have difficulties. They reported no differences in age, sex, race, length of stay, circumstances of injury, extent of burn or amount of disfigurement between the groups. There were, however, significant differences on measures of regression, displacement and seeing injury as a narcissistic injury. The mechanism of displacement was regarded by authors as important because they state it is a major component of phobic behaviour. Many of the SBBP patients were identified as phobic.

The study is weakened by lack of description of the development of the scale. The 250 items were simply noted as being related to the study variables in previous literature, and no account of the

instrument's validity or reliability is given. The patients' difficulties were elicited via interview, but no discussion of possible bias is given. The manner of operationalising and identifying regression, narcissism and displacement from interview is not described. A considerable number of comparisons appear possible, and we do not know how many were made prior to reporting, and therefore if those actually reported were likely to be artefacts of the number of comparisons made, and significance levels are given without a note of the tests employed. The data themselves are inadequately reported. Only percentages are given, without any description of the kinds of scale from which they were derived. The finding that some of the SBBP patients were phobic is potentially interesting, from the viewpoint of the current thesis, although numbers of such patients were, of course, small. A detailed description of the kinds of avoidances used by these individuals would have been potentially important in yielding information regarding treatment.

The role of the face in determining psychosocial difficulty after burns is supported in Williams and Griffiths's (1991) examination of adjustment in 23 representative burns patients from a series of 55. They administered the Hospital Anxiety & Depression Scale (HAD), Impact of Event Scale (IES) and a series of questions related to the burn itself to respondents in an attempt to ascertain both the extent and nature of psychosocial difficulties and the possibility of being able to predict them from patient variables. They found 3 HAD depression and 8 HAD anxiety cases and 4 IES avoidance and 3 IES intrusion cases one year after discharge, and found that the best predictor of difficulty was visibility of the area. Both hands and face were included on the visibility scale, but the authors note that the greatest number of patients expressing difficulties came from the 'face only' group, and conclude that it is likely that facial involvement is the best predictor of psychosocial difficulty.

Whilst the numbers in this study are small to justify such an assertion, taken along with the similar finding by Roca et al. (1992), it may be argued that there is support for the belief that facial involvement is a major cause of post-burn psychosocial disturbance. It is likewise interesting to speculate that much of the disturbance found in studies which do not differentiate according to site of the burn may also be caused by facial disfigurement, and particularly unfortunate that these studies have not allowed a more definitive examination of the role played by the face in determining psychosocial adjustment.

Unfortunately, such speculation is weakened by the findings of Blakeney et al.'s (1988) study of adjustment in 38 burns patients. Although the numbers were again small, they found no differences between individuals with (n=20) and without (n=18) facial burns, when examined at least 2 years after the burn according to a battery of validated instruments. Nor did severity of the burn predict greater psychological disturbance. However, as noted earlier in our discussion of Blakeney et al.'s (1990) study, the use of the SPS to determine adjustment may be both imprecise and less than comprehensive.

Nevertheless, further support for the notion that locus or severity of burn do not predict adjustment is found in a study by Orr et al. (1989) who found no effect of locus of burn injury on the body image and self-esteem of 121 burn injured adolescents and young adults. They noted that the evidence regarding relationships between locus of burn injury and self esteem was equivocal, although depression after illness had been found to be greater when the illness or disfigurement was visible, and related to total body surface affected in burns (Chang & Hertzog, 1976). Nevertheless, their own study, which had expected lower self esteem, less positive body image and greater depression amongst those burned on socially sensitive (i.e.; visible) areas, found no such correlations. Nor were these variables associated with time elapsed since the burn or total surface body area burned. The relationship between burns and psychosocial adjustment is clearly more complex than the influence of a single factor such as site of the burn.

An earlier study by White (1982) examined the effects of area of burn and gender on psychological disturbance, using both a clinical assessment and an adaptation of the GHQ to assess psychological change between the accident and one year follow-up in 142 burn victims and 136 age and sex-matched victims of non-burn accidents. Burns patients had a non-significant trend towards greater psychological disturbance than non-burns patients, but there was no difference according to area of burn, with the single exception that males with leg burns had less difficulties than other groups. However, severity of injury was predictive of disturbance.

If site of burn does not always predict later adjustment, the salience of the face as a determinant of such adjustment (and the possible speculation that it plays a role in descriptions of such adjustment



in elements of the burns literature which do not differentiate according to site) is suggested strongly by Hughes et al.'s (1983) study of dermatology patients. Administration of GHQ 30 to 196 out-patients and 40 in-patients revealed that 30% of the outpatients and 60% of in-patients had high scores, with a higher level than the general population and general hospital in-patients respectively. Most importantly to the discussion of the relevance of site to psychological disturbance, 70% of patients with hand and face involvement (n=47) showed high scores. Furthermore, disfigurement and stigma, along with inconvenience, were the most frequently cited causes of the psychiatric symptoms reported by high scorers, whilst some 34% of high scorers reported avoiding people.

The importance of the face in determining psychological reactions to illness is underlined by other dermatological studies. Shuster et al. (1978) examined the role of skin complaints in self image, asking acne, eczema and psoriasis sufferers and normal controls to rate schematic faces previously scored by independent judges on such characteristics as happiness, intelligence, good looks. Subjects rated the pictures on such dimensions as 'like me' , 'like someone I like', 'me in 10 years time'. Their perceptions of the pictures might thus be taken as indices of their self-image. Whilst controls demonstrated correlations between judges' ratings of characteristics such as good-looking and likeable and ratings of 'like me' and 'desirable', in the acne patients, there was a significant decrease in correlations with positive attributes of the pictures as acne severity increased, with similarly increasing correlations with attributes of 'someone I dislike', more markedly affecting females. Eczema and psoriasis sufferers were less severely affected, a difference the authors attribute to the possibility of differing sites of the complaints, although no note of site is recorded.

That psychological difficulties are related to visibility to others is suggested by Porter et al.'s (1986) comparison of vitiligo patients with controls and psoriasis sufferers. All subjects rated lower than controls on a validated measure of self-esteem, but psoriasis sufferers reported significantly more discrimination against them than vitiligo sufferers, including being stared at and job discrimination. They were also more likely to report embarrassment, and scored lower on a measure of adjustment to the disorder. Psoriasis sufferers were less likely to use make-up as camouflage, presumably

because their complaint involves changes in skin texture and skin lesions, rather than simple pigmentary change. Thus visibility was increased in the psoriasis group.

Modest further support for the role of the face in determining psychosocial adjustment is found in a study of recovery after treatment of cystic acne. Rubinow et al. (1987) suggested that clinical experience indicates that acne sufferers report self-consciousness and fear of social rejection and are socially isolated and limited in their activities owing to embarrassment and mental or physical discomfort. They examined 55 sufferers using a range of questionnaires and found that whilst pain from the lesions was a major difficulty for 55% of respondents, some 91% reported embarrassment, whilst 40% noted self-consciousness, 29% social isolation and 20% anxiety with the opposite sex. A subject group of 66 patients also scored higher than normals on the Hopkins Symptom Checklist, but lower than psychiatric patients. Whilst none of these scores differed between those with facial lesions and the rest of the group, those with facial lesions did show greater improvement in depression following treatment. However, this effect is perhaps confounded by the fact that patients with facial lesions also showed greater dermatological improvement.

There are difficulties in examining the psychosocial difficulties of head and neck cancer patients in relation to disfigurement, because many other factors contribute to their difficulties (e.g. difficulties with speaking and eating, fear of a life-threatening complaint). However, a study by Cassileth et al. (1983) of the impact of differing levels of disfigurement on melanoma patients' perceptions of the cosmetic impact of their operations focused specifically on disfigurement. They administered questionnaires to 181 patients, obtaining their opinions of the size and cosmetic impact of wide lesion excision scars. As well as completing a 10 item report of the impact of the scar, subjects drew the size of their scar on a figure outline in a method similar to that of Rumsey (1983). Clinic nurses assessed the degree of indentation associated with graft closures. The major findings were that although length of scar did not distinguish between high and low impact individuals, the highest impact group were distinguished from lowest impact by greater degree of indentation, type of closure (graft) and lack of correspondence between expected and actual scar size (where this was larger). Patients' drawings corresponded well with actual size of scars (a ratio of 1.01 where 1.0 would be perfect) indicating that disfigured individuals have an accurate perception of their bodily

appearance. Women were significantly more distressed than men even though their scars were smaller.

There are, however, some difficulties with the study, since the statistical tests used are not described adequately. Moreover, although the authors describe the correlations noted as 'significant', they do not give correlation coefficients, and so we cannot tell how large the correlations were. Finally, there were difficulties with some of the scales used. The rating of surgical indentation used a 3 point ordinal scale (none, moderate, severe), yet measures of central tendency and spread based on an interval level of measurement (mean and standard deviation) are used, leading one to suspect that the inferential tests employed might have been parametric tests, which would likewise have been inappropriate. The expectation of scar scale is unlikely to be valid, since it contained only the following possible responses: 'not larger', 'a little larger', 'somewhat larger' and 'a lot larger'. Respondents thus had no opportunity to state that they expected a smaller scar than that which in fact resulted from the operation, with the resultant possibility of skewing in favour of expectation of larger scars. Finally, there was no investigation of any difference made by site of the scar, although this may impact upon ratings of level of disfigurement (Dropkin et al., 1983). Nevertheless, the possibility that expectation might affect perception of impact has possible implications for preparation for surgery, and merits further investigation.

If the ratings were suspect in the above study, the investigation by Baker (1992) represents a careful attempt to distinguish between levels of facial disfigurement, in examining the effect of differences in such levels on rehabilitation of head and neck cancer patients. A convenience sample of 51 patients completed a self-report questionnaire regarding 12 activities of daily living. Baker rated patients' level of disfigurement by comparing their operation site with Dropkin et al.'s (1983) position/severity scale. However, the study found no correlation between either a total score of rehabilitation based on activities of daily living or its physical or psychological dimensions and level of facial disfigurement. There was a correlation between the eating item of the questionnaire and disfigurement. The absence of other correlations with disfigurement might also be explained by the general low to moderate levels of disfigurement (mean of 3.9 from a 0-11 scale), which might have decreased the likelihood of finding differences. This study represents one

of few studies which focused specifically on facial disfigurement *and* used a sufficiently robust method to allow us to have confidence in failure to find a relationship between level severity of disfigurement and subsequent rehabilitation, including measures of psychological functioning.

A further study of head and neck patients, by Gamba et al. (1992), also focused specifically on disfigurement. The authors compared groups of patients with minor versus extensive disfigurements. Although the method of classification was dubious, being based on 'evident perception of facial deformity' by the clinician, the authors also took account of type and site of surgery, using Dropkin et al.'s (1983) approach to classification, and all patients had tumours of greater than 3 centimetres removed. Sixty-six patients were interviewed at between 6 months and 8 years post surgery. Those with extensive disfigurement reported greater change to self image, worse relationships with partner, reduced sexuality, and increased social isolation, whilst 18% of respondents felt the disadvantages of treatment outweighed the advantages. Self image was cited as the most important change by more respondents with extensive than minor disfigurement, and those with extensive disfigurement were more likely to avoid touching the operation area, avoid looking in mirrors and to no longer feel attractive. Of those reporting major disadvantages following treatment, 79% were accounted for by patients who felt differently about their body image.

## **Summary**

The literature examined in Section 5.3 is often flawed. The contention that more psychosocial disturbance might be associated with less disfigurement is not supported. Macgregor's (1953) assertion of this negative relationship comes very early in her extensive exploration of this area, and is based on clinical impression alone, whilst the studies which purport to support it are flawed with regard to both method (Blumenfeld & Reddish, 1987; Blakeney et al.; 1988) and interpretation (Andreason & Norris, 1972). This picture is similar to that found in the literature in disfigurement in children (Chapter 4). There is, therefore, likewise no support in the adult literature for the proposition suggested by Reich (1969) that this supposed greater disturbance in less disfigured individuals results from the unpredictability of people's reactions to them. Whilst this might be thought to present difficulties for a conditioning theory of such disturbance, this is by no means so, particularly if we suggest that the social difficulties of disfigured people are connected with phobic

avoidance. The reactions of others may be unpredictable not because of reactions to a greater or lesser level of disfigurement, but because disfigured people are in diminished contact with others. The role of this proposed avoidance is part of the current study.

The majority of the literature suggests that level of disfigurement has no relationship with level of disturbance. However, it should be noted that several of the studies have investigated only small subject groups and might have had insufficient power to detect differences where these were present. Furthermore, the studies are often flawed in other respects, including inadequate specification of method and analysis, and the use of unvalidated measures.

Two studies directly suggest that greater disfigurement might be associated with worse adjustment. Of these, the evidence from the Cassileth et al. (1983) favours this assertion on two out of three measures of extent of disfigurement, whilst the Gamba et al. (1992) study, which is generally better constructed than many of the investigations, supports a relationship between greater disfigurement and poorer adjustment across a range of measures.

With regard to site of disfigurement, there seems reasonable support for the notions that visibility and, in particular, facial involvement are associated with worse adjustment. It might be speculated that these studies in fact offer indirect support for the notion of a relationship between high disfigurement and high levels of disturbance, if we regard visibility of the change in appearance as an index of level of disfigurement.

Given the equivocal nature of these studies, the most conservative interpretation is to conclude that there has as yet been no demonstration of any relationship between level of disfigurement and level of psychosocial disturbance. Attempts to establish the existence or otherwise of such a relationship will be important to our understanding of the experiences of disfigured people and the targeting of those potentially most at risk from psychosocial difficulties. An important element of this may be the education of the medical and nursing professions with regard to both these experiences and potential risk factors. Assertions of a negative relationship between level of disfigurement and level of psychosocial disturbance should currently be strongly resisted, particularly given the tendency to

ascribe psychopathology to individuals describing psychosocial disturbance or requesting medical and surgical interventions to ameliorate facial abnormalities (see Section 5.5).

#### **Section 5.4 Other predictors of psychosocial difficulties following disfigurement**

Examination of the effect of level of severity and site of the disfigurement represents one tactic in attempting to predict who will develop psychosocial difficulties following disfigurement. Many of the studies in this area investigate numerous different variables, and so there is some overlap between this and the previous section. In general, however, the current section examines the possible effect of gender, personality variables and social support amongst disfigured people upon their psychosocial well-being. Personal variables of this kind are of importance in informing fear-avoidance models of pain and of body image disturbance (Lethem et al. 1983; Newell, 1991; Slade 1994 and see Chapter 8).

Gender is perhaps the most extensively investigated of these variables, and it has been suggested that females suffer greater psychosocial disturbance, possibly as a result of the greater emphasis placed by society on female appearance (Andreason & Norris, 1972). Whilst Andreason and Norris argued that women in their own study did indeed show greater disturbance, this assertion was based on extremely small numbers (4 women versus 2 men showing 'complications') The study by Orr et al. (1989) described earlier offers some support for their contention. Females in the Orr et al. study had more negative body image, depression and lower self esteem than males. By contrast, the White (1982) study did not find differences between men and women.

A major study by Brown et al. (1988) also focused on gender and psychosocial difficulties. In their study of 260 burned individuals (209 males and 51 females), functional disability, disfigurement, coping responses and social resources were examined for their effect on adjustment. They used validated measures of coping and adjustment and rated disfigurement on a scale which ran from no visible scarring through several gradations of altered skin texture to missing body parts or facial disfigurement. From their description of the scale it is impossible to judge how many individuals had facial disfigurements.

Both males and females were generally found to be adjusted, whilst high levels of adjustment were correlated with less functional disability in males ( $r=.57$ ,  $p<0.001$ ) and greater problem solving in women ( $r=.57$ ,  $p<0.001$ ). Females used more cognitive coping and information seeking than males. Psychological adjustment to illness was the same across genders, with the exception of a vocational disruption subscale, which showed more disruption in females. Multiple regression investigated which combinations of variables best explained psychological adjustment. A combination of low functional disability, more recreational activities, greater friend support, less avoidance coping, more problem solving accounted together for 55% of variance. Within this model, functional disability accounted for 29% of variance, whilst avoidance coping and greater problem solving added a further 7% each. Friend support accounted for 12%. In men less functional disability was the most important predictor of adjustment, accounting for 32% of variance in a model which also comprised less avoidance, more recreations, more friend support and more problem solving, to account for a total of 55%. In women, however, the most important predictor was problem solving (32% of variance) in a model also consisting of less functional disability, greater family support and more recreational activities, which accounted for a total of 63% of variance.

It may be concluded from this study that some variables associated with better psychosocial adjustment are different between the sexes, although the overall effect of disfigurement is not different across the genders. This finding, the authors note, does not confirm Andreason and Norris's (1972) contention regarding gender and disfigurement. The study also suggests that variables associated with tactics often employed in cognitive-behaviour therapy (non-avoidance, problem-solving, recreational activity) are likewise implicated in better adjustment. In the case of females, problem-solving accounts for the highest proportion of variability. This was generally a well conducted study, from which we may conclude that, whilst there are differences in coping styles between males and female, these are not associated with different levels of disturbance.

A physical variable which might be expected to distinguish between more and less psychological disturbance amongst disfigured people is level of attractiveness. Starr (1980) examined the effect of facial attractiveness on the behaviour of 49 patients with cleft lips, cleft palates and cleft lips and

palates. They gave subjects structured measures of behaviour and of self esteem, and compared their scores according to attractiveness. There were no differences between matched scarred and non-scarred subjects, nor any between the attractive and unattractive groups. However no subject gained a rating of over 15/20 on the rating scale used by the investigators, indicating that none of the subjects was highly attractive. This might lead us to conclude that the lack of significant differences between attractive and unattractive individuals was an artefact of the subjects occupying less than the total range of possible different attractiveness levels. Splitting the group into two on the basis of high and low attractiveness ratings which were quite close to each other may have lessened the sensitivity of the study's ability to detect differences between the groups.

The role of demographic factors in mediating adjustment found general support in the White (1982) study mentioned earlier, which found greater difficulty amongst those with pre-existing anxiety, depression or personality disorder, in age range 36-45 and living alone or with three children.

A further study by Tucker (1987) examined several possible predictive factors in determining psychosocial difficulties in burns survivors, and suggested the role of personality variables such as neuroticism, trait anxiety and hypochondriasis, as well as individual variations such as the presence of pre-morbid psychiatric disorder (PTSD), post-traumatic stress disorder, compensation claims and severity of the burn. From this study of 31 patients, he notes that depression and anxiety are moderately elevated in pre-discharge patients but drop to normal or low levels with the passage of time, whilst there is a significant incidence of PTSD. However, neither PTSD nor severity of burn were predictors of psychosocial difficulty (although numbers were very small for such comparisons), whilst the personality variables which predicted difficulty yielded moderate correlations at best.

A later investigation of the role of PTSD (Roca et al., 1992) in post burn adjustment obtained a slightly larger sample (n=41) and examined them at discharge and 4 month follow-up. PTSD was found in 7% of patients at discharge and 22% at follow-up, but was not strongly associated with poor psychosocial adjustment. This is one of comparatively few studies to identify areas and type of burn specifically. Whilst neither of these variables was associated with level of PTSD symptoms, facial involvement was correlated with low scores on the social (0.68) and sexual adaptation (0.65)



domains of the survey, lending further support to the notion that visibility is associated with greater difficulty suggested in the previous section.

Moore et al. (1993) suggested that personality traits might predict adjustment following changes to their lives caused by burns. To test this, they gave 32 patients a validated measure of personality and divided them into well adjusted and poorly adjusted according to the Suicide Probability Scale (SPS). They noted that patients regarded as well adjusted on this basis had significantly higher scores on the H scale (which measures a tendency towards boldness and impulsivity) and on a higher order factor of 'extroversion'. However a measure of emotional lability did not significantly differentiate between the groups, resulting in only a non-significant trend towards such a differentiation.

The authors conclude specific character traits 'seem to be' related to adjustment after burns, although they are careful not to attribute any causality, owing to the regression paradigm used to examine the relationships. However, their study comprised small numbers. Moreover, the division of subjects into more and less well adjusted subjects on the basis of the SPS, is, as has been noted earlier, suspect, since it is primarily a measure of suicidal ideation and other concepts related to depression. This study also may, therefore, simply be an examination of the character traits of a sample of more and less depressed individuals.

The role of social support as a determinant of better adjustment is suggested by a survey by Davidson et al. (1981) of 314 burns injured people treated over the course of 20 years. Respondents were interviewed using a 519 item schedule which ranged from socio-economic variables to satisfaction with treatment, and also measured life satisfaction, self-esteem, participation in social and recreational activities and social support. Severity of injury was also rated, but site of the injury was not reported.

Social support was found to be related to life satisfaction ( $r=.37$ ), self-esteem ( $r=.40$ ) and social and recreational participation ( $r=.14$ ). The authors conclude that identification of the patient's social network is important in facilitating rehabilitation. It is, however, interesting to note that the

correlation between support and social and recreational activity, though significant, was extremely modest.

### **Summary**

Support for the notion of differences in level of disturbance between men and women is equivocal, despite the undoubted pressure on women from the media to conform to particular stereotypes of attractiveness. However, it does appear, from one well conducted study, that they may employ *different* coping tactics from men. Whilst an examination in detail of these tactics is beyond the scope of the current study, a limited attempt to examine different levels and patterns of disturbance between men and women will be undertaken, since the literature is divided and establishing the existence or otherwise of such differences is of potential importance in responding to the needs of disfigured people.

Other individual variables are possibly better predictors of difficulty after disfigurement. Pre-existing psychopathology appears predictive of later difficulties, whilst there is some suggestion that particular personality traits might also have such a role. Social support seems modestly associated with better adjustment. Whilst none of these issues are investigated in the current study they have clear bearing on a fear-avoidance model of disturbance to be described in Chapter 8 and whose assumptions underpin much of the rationale for the current study. These variables represent a potentially fruitful area of future study, both as a source of potential predictions about development of difficulty following disfigurement and in terms of further exploration of the fear-avoidance model.

### **Section 5.5 Responses of plastic surgery patients and relevance to studies of disfigurement**

It has been suggested earlier that health professionals may underestimate the degree of psychosocial difficulty experienced by disfigured people, and that the response of health professionals to such difficulties is inadequate. In this context, it is instructive to consider studies of those who have received plastic surgery. Considerable effort has been applied towards establishing the existence of psychopathology in patients seeking plastic surgery for cosmetic reasons. Despite evidence that plastic surgery benefits patients, there is a tradition within the

literature which suggests that undertaking such surgery is fraught with problems, chiefly related to the psychological motivations of those seeking surgery. Although it is difficult to imagine such a view being applied to patients with facial disfigurements, agreement as to the correspondence between level of disfigurement and life handicap is not always easy to arrive at (see Section 5.3). Thus, the arguments surrounding the attribution of psychopathology to individuals seeking plastic surgery are likely to be relevant to an examination of the psychosocial concomitants of disfigurement, since these arguments may influence health professionals' attitudes to the disfigured people they treat.

Early studies emphasise the role of unconscious conflicts in determining requests for cosmetic surgery and responses to it. One group of authors has been widely quoted by subsequent commentators, who often report their work in support for the contention that seekers of plastic surgery are responding to psychopathology. This work is now reviewed. Jacobson et al. (1961), in their report of 157 patients seeking cosmetic plastic surgery, described four roles for the psychiatrist in such cases: identification of severe personality problems, clarification of expectations and motivations, psychotherapeutic interventions, and facilitation of 'healthy psychologic development' following surgery. Whilst their paper is a pioneering attempt to examine the psychological difficulties of such patients, its usefulness is limited by several factors. The report of the psychological profiles of the patients is confined to a few case histories, which are not sufficiently detailed to allow the patients' stories to emerge. As a result they are of limited value in increasing our understanding of patients' experiences. The description of treatment is vague, and no estimate of its effectiveness or otherwise can be made.

In a further paper (Edgerton et al., 1961), the issue of psychopathology is aired more fully, this time in a subject group of 98 consecutive patients with 'minimal deformity'. The majority of subjects had requested facial plastic surgery, mainly for rhinoplasty, but the sample also included 25 mammoplasty patients and a further 19 for whom the area of surgery was not specified in the report. The authors state that 71% of the group acquired a psychiatric diagnosis, an assertion which commentators have revisited and accepted in describing the relationship between psychopathology and plastic surgery requests (Birchnell, 1988; Hay, 1970a; Lacey & Birchnell,

1986). However, Edgerton et al. themselves note that some 50% of these diagnoses were of 'personality trait disorder', and that the criteria for this diagnosis are arbitrary. Furthermore, they assert that these individuals would 'at most, come to non-psychiatric attention as 'shy', 'rigid', 'timid' and so forth'. Whilst the remaining 50% still represents a high proportion of psychiatric morbidity (36%) from the total sample, the ascription of these other diagnoses is not necessarily unproblematic. For example, we are told that 16% of the sample were psychotic. Specific diagnoses are not provided, nor is any notion of whether this group had required treatment or hospitalisation for psychosis in the past. The authors conclude that the '*average patient seeking cosmetic surgery does indeed have serious problems of personality function.*' (my italics). It is difficult to justify this assertion, given that, according to the authors' own account, 29% received no diagnosis at all and the diagnosis of a further 35% consists of being 'shy', 'timid' and so on! To the contrary, we should be justified in concluding that the majority of patients in this series had either no such problems or minor difficulties within the normal range of behaviours.

Despite this, it is suggested by Edgerton et al. (1961), for rhinoplasty patients, that their sense of nasal deformity is a symbolical expression of an unconscious conflict. The notion of such unconscious conflicts fuelling overt symptoms is common in psychoanalysis, and it is perhaps because of this that the authors find the improvement in the patient's self esteem and psychological functioning following surgery so impressive. If the patients' difficulties were indeed symptomatic of some underlying conflict, it would be predicted that these difficulties would be unlikely to be ameliorated by the removal of their symptom. According to the authors, the results of cosmetic surgery are particularly impressive because a) patients had asserted, prior to surgery, that psychotherapy had nothing to offer them and b) their 'emotionally crippling' attitudes had been channelled into their 'sense of physical deformity'. It might be noted, however, that the improvement was not in response to the psychotherapy regarded as useless by the patients, but to surgery, that the 'crippling attitudes' referred to were not, in fact demonstrated within the study, and that, even if they had been present, no evidence other than authorial assertion had been offered regarding the 'channelling' of such attitudes into the nose. In conclusion, despite the regularity with which it is quoted, there is no evidence from this paper of the levels of psychopathology which the authors claim to have found in plastic surgery requesters. Similarly, since the underlying conflicts

purported to contribute to that pathology are not demonstrated, it is likewise impossible to find any support for the assertion that either psychotherapy or surgery affect such putative conflicts. However, 41 of 48 patients followed up 6 months post-operatively judged surgery as having had excellent results (as did their surgeons) , whilst a further 4 were highly pleased even though the surgeons believed further anatomical improvement could have been achieved.

Another study of the Edgerton et al. (1961) cohort of patients (Meyer et al., 1960) reported on 30 female applicants for rhinoplasty. The theme of requests for plastic surgery as indicative of unconscious conflict is repeated here, and it is noted by the authors that the group 'not uncommonly' suggested that their noses would look better on a male face. The finding that two thirds of the group identified their nose with their father's is regarded (Edgerton et al., 1961) as evidence that a previously useful identification with the opposite sex parent had now become problematic and required resolution, part of which involved application for surgery. Unfortunately, no evidence is offered for this vague assertion. In contrast to the attention paid to interpreting putative inner conflicts in this series of papers, the fact that the researchers themselves regarded the applicants' appearance as 'plain or homely', and the expression by applicants of the desire not to appear 'foreign' or 'alien' receive little comment, even though the authors were aware of the early work of Macgregor (Macgregor & Schaffner, 1950) in identifying sociological determinants of the desire to seek surgery.

Although the supposed symbolic significance of the nose is returned to in Reich's (1969) examination of a series of 750 patients seeking plastic surgery, this comprehensive account concentrates more on conscious motivations for seeking surgery and stresses the role in such requests of the desire to avoid embarrassment and self-consciousness, and to be physically inconspicuous. As in the above studies of the Edgerton/Jacobson/Meyer group, the ascription of psychiatric diagnoses was somewhat problematic, but the key difference between the studies was the much smaller number of subjects in Reich's study diagnosed as psychotic. This represented 2%, rather than 16% in earlier studies, and is probably not noticeably different from the percentage of people being so diagnosed in the general population, although precise comparison is not possible because of the vagueness of psychosis as a diagnostic descriptor. Furthermore, Reich

(1969) found no evidence of untoward reactions following successful surgery, and satisfaction at up to four and a half years follow-up was 85.5%.

In a much quoted study into plastic surgery patients, Connolly and Gipson (1978), in what is described as a study of dysmorphophobia, examined the mental health of patients given rhinoplasties for either disease/injury ( $n = 101$ ) or for cosmetic reasons (86) 15 years after operation. They found that of the injury/disease group, 9 were severely neurotic and 1 was schizophrenic, whilst of cosmetic surgery patients 32 were severely neurotic and 6 schizophrenic. Subjects were traced via family doctors, who were asked about the mental health of each group. The authors state that the severely neurotic group were all well known, frequent surgery visitors and all were taking psychotropic medication and had been for many years. Differences between the two groups were statistically significant, and we might, therefore, be led to believe that cosmetic surgery patients were more liable to psychological difficulties than the other group. The authors cite Hay (1970a) as regarding surgery in minimally disfigured individuals as risky, whilst those with more marked deformities would be likely to benefit. This is an inaccurate representation of Hay's position, since he both describes this 'two group' view point, and refutes it, noting patients are likely to do well *regardless* of degree of deformity and, suggesting that surgery should *not* be reserved for any particular disfigurement level. This is an important issue given the lack of agreement in the literature regarding which levels of disfigurement lead to more adjustment.

Apart from this inaccurate citation of Hay (1970a), the Connolly and Gipson (1978) study also contains considerable methodological difficulties. There were no initial assessments of psychopathology, so we do not know how many were initially disturbed, although we are told that those originally thought to be disturbed were not operated on, and were therefore excluded. The way in which disturbance was estimated is not stated. The interviewed sample was taken *only* from the disturbed post-operative population, and that population was defined by general practitioners' information rather than direct access to patients. The undisturbed were likewise defined. There is no indication that the investigators were blind to the reasons for surgery when they undertook follow-ups with either the general practitioners or the patients. Thus we have no idea as to whether either the selection or the interviewing process was unbiased. Given this

difficulty and the fact that there is no indication that any standardised interview procedures or measures were used, we might well conclude that the researchers biased the selection process by making practitioners aware of the purpose of the study and biased the interview process through their knowledge that the subjects were a) considered disturbed by the general practitioner and b) members of the post-cosmetic surgery group. The authors also note that no attempt was made to grade the deformity, though it was 'obvious' from preoperative photographs. In the absence of reliable estimates of deformity, assertions about the consequences of greater and less deformity are unreliable. Finally, the authors assert that the increased incidence of schizophrenia confirms the view that dysmorphophobia is an ominous symptom. However, there is no evidence that there were any dysmorphophobics in their study, either at surgery or at interview. Even if we accept the view that the deformities of patients in the Connolly and Gipson (1978) study were, in fact, originally minimal, this does not equate to dysmorphophobia, particularly since there are so many societal reasons for seeking plastic surgery (Macgregor & Schaffner, 1950; Macgregor, 1989).

A much more recent case study (Cohen et al., 1991), in which a woman with acne rosacea is described as suffering delusions of disfigurement is instructive. Whilst she described her face as ugly and covered with rosacea, the clinicians claimed it could only be noticed 'under closest scrutiny'. Yet the patient described people asking her what had happened to her face. Despite the detailed nature of this case presentation, this is not pursued further, and possible social consequences of the complaint are ignored at the expense of discussion of assumed pathology. Although it would be naive to draw too many conclusions from a single study of this kind, it does illustrate the difficulty in arriving at an objective appraisal of level of disfigurement, and the potentially serious consequences of a mismatch of such judgements between patient and clinician in making subjective decisions in situations where the clinician has considerable power in determining the future treatment and defining the current legitimate level of disfigurement of the patient.

The Hay (1970a) study referred to by Connolly and Gipson (1978) is much more considered in the conclusions it seeks to draw. Hay suggested that the rationale for expecting greater psychological disturbance in less disfigured patients came in part from an assumption that their requests for

intervention were a reflection of unconscious responses to such psychological problems. He compared referrals to plastic surgeons and a psychiatrist of 45 patients complaining about the size or shape of their noses, with a control group of nurses. He administered a standard psychiatric interview, a battery of psychological tests and objective and subject ratings of their noses based on anchored photographs. Objective ratings were obtained from 6 independent judges.

All patients were rated as objectively more disfigured than controls ( $t=4.05$ ,  $p<0.001$ ) and rated themselves as more disfigured than raters did ( $t = 4.25$ ,  $p< 0.001$ ). Patients were more disturbed than controls on all scales, but objective ratings of disfigurement did not correspond to any differences in scores on the psychological measures. The majority of patients (26) received no psychiatric diagnosis, 9 had mild or moderate personality disorders, 9 had severe personality disorders and 1 was psychotic. Disfigurement ratings did not differ between the no diagnosis and mild/moderate personality disorder groups, whilst those with severe personality disorder were more disfigured than those with no psychiatric diagnosis.

As the author notes, the study is weakened by the possibility of bias in ascribing diagnoses to more disfigured individuals, which might have accounted for the discrepancy between scores on structured psychological tests and the ascription of diagnoses. Nevertheless, both the objective measures and the ascription of diagnoses in this study contradict the assertion that less disfigured individuals are more disturbed. Furthermore, scapegoating was described by patients of all levels of disfigurement. Thus, Hay (1970a) concludes, the reservation of surgery for the most disfigured is an oversimplification.

Macgregor (1989), in a typically thoughtful review, notes the importance of cultural norms in determining the seeking of surgery, and counsels against over-emphasis on individual psychological determinants. She notes that interest in psychological variables of seekers of surgery originated in part from a concern of surgeons to screen and identify "those whose motivations were questionable, who were neurotic or who might be 'troublemakers' ". She contrasts the Meyer et al. (1960) study, with its emphasis on inner conflicts and sexual identification, and the ascription, in a further study (Edgerton et al., 1961) of psychiatric diagnoses to 71% of cosmetic surgery



requesters, with the follow-up of this group of patients which found a satisfaction rate of 94%. Despite many references to this study in support of the notion of psychological disturbance amongst plastic surgery applicants, no commentator apart from Macgregor (1989) has cited the high level of satisfaction with surgery found within Edgerton et al. (1961). Macgregor notes that it is 'of singular interest' that notions of psychopathology underlying requests for surgery continue to hold such sway with medical practitioners, given the high levels of post-operative satisfaction found.

Macgregor (1989) draws attention to almost total absence of sociological studies of consequences of facial deviations. In an earlier study, Macgregor (1967) had noted that some 72 per cent of a series of rhinoplasty patients seen in her facility were of Jewish (59%), Armenian, Greek, Iranian, Lebanese, Syrian or Italian background & possessed the 'Armenoid' nose. Rather than acting at the mercy of some unconscious motivation, her respondents were clearly consciously aware of prejudice and discrimination and expressed the desire to 'look American'. The study concluded that motivations were more often sociogenic than psychogenic (Macgregor, 1967). Given the remarks of Barker (1948) regarding the similarity between stigma experienced by disfigured and disabled people and other minority groups, it is interesting to speculate that the motivations of others seeking cosmetic surgery may closely resemble the desire to appear like others expressed by Macgregor's ethnic minority respondents. The desire for surgery may be as likely to reflect a need not to be seen as socially deviant than a response to inferred unconscious motivations.

In an attempt to move away from earlier illness models of plastic surgery patients, Burk et al. (1985) construed desire for surgery and alterations in self esteem and body image afterwards within a self consistency model, drawing on the ideas of Lecky (1945) and on Festinger's (1957) cognitive dissonance approach to attitude formation and change to provide an account of what happens when people seek plastic surgery. Burk et al. (1985) hypothesised that the body part for which surgery was desired will be less valued than the person's general self-perception, that the rest of the body will become affected by this lack of value and that general body image will also be less favourable than self concept. This would be expected to resolve after surgery.

Their findings were consistent with these predictions. Subjects scored higher on general self-esteem than self-esteem for the body part for which surgery was desired, or general physical self-esteem pre-treatment, and showed lower physical self-esteem than the general population. They showed increased esteem for the body part at 2 and 4 months post surgery and increased physical self esteem. Moreover, the disparity between general and body part self esteem was decreased at 2 and 4 months.

A departure from an illness model in plastic surgery is welcome, and should certainly be extended to consideration of disfigured individuals who present for corrective surgery. The Burk et al. (1985) study demonstrates that surgical improvement increases self esteem related to the body, but no complicated cognitive underpinning of the kind described in their study is necessary.

A simpler account, such as conditioning, could account for the association of the esteem placed upon the body part for which surgery was desired with esteem for the body in general. This could easily be at a level of physiological arousal, with anxiety experienced as a result of either the reactions of others or one's own appraisal of the body part generalising to the physical body as a whole, whilst the more diffuse concept of general self-esteem remained relatively untouched. The notion that reinforcement is responsible for altered adjustment in plastic surgery patients is supported by anecdotal accounts (Harris, 1992) which suggest that rhinoplasty patients' self-consciousness is reinforced with both friendly and hostile criticism, and leads to a restriction of life's activities, artificial behaviour, difficulties in interpersonal behaviour and unavoidable distress to the individual concerned.

Improvement in appearance and appraisal of the altered body part would likewise lead to reduced anxiety, particularly in the presence of positive feedback from others, and would both generalise to the physical body as a whole and lead to a lessening of the discrepancy between general and body part self-esteem. Generalisation phenomena of this kind are commonly reported both in the laboratory conditioning studies which underpin conditioning theory (Walker, 1984) and in accounts of treatment based upon it (Marks, 1987), and have been applied to cognitive events as well as overt behaviour (Jaremko, 1986).

General improvements in mental state after surgery also appear in a study of 22 rhinoplasty patients by Robin et al. (1988). This study demonstrated that such patients perceived their appearance similarly to controls, but had higher GHQ ratings pre-treatment. These ratings were not, however, correlated with degree of impairment to appearance. Moreover, whilst patients' ratings of their appearance were lower than those of controls, these ratings were matched by those of independent judges, who also rated their attractiveness as lower than that of controls.

Following treatment, ratings of appearance and GHQ scores both improved significantly. The authors conclude that their study shows that observers objectively confirm the defective appearance of rhinoplasty patients compared with controls. It is worth noting that, whilst this difference in appearance was indeed confirmed by observers, rhinoplasty patients rated their appearance as less attractive than did the observers. This was also true of the control group, indicating that this sensitivity is not peculiar to the patient group. This might usefully be borne in mind when considering those presenting for plastic surgery. Clinicians unaware that this down-rating might be a general, rather than patient specific phenomenon might otherwise assume that their disfigured patients are overestimating their level of disfigurement and the reactions of others, and resulting difficulties might be ascribed to other personal variables in a way similar to that in early studies of plastic surgery requesters.

## **Summary**

Early examinations of the psychological profiles of plastic surgery patients have focused on psychopathology, and such patients' motivations in seeking surgery are often described in these terms. A close reading of the key papers from this early literature reveals that they are weak in their methods and biased in their interpretations. The ascription of psychopathology is often made on the flimsiest evidence and appears to be asserted in line with theoretical standpoints, rather than on the basis of what is found within the studies themselves. The general satisfaction of plastic surgery patients with their surgery receives little attention. The other major deficit within these accounts relates to social variables. Despite accounts of such social difficulties, little credence is given to the notion that these social variables rather than psychological motivations (particularly

psychopathology) might lead people to seek surgery. Rather, the emphasis is placed on attempts to find purely intrapersonal variables.

There has been little investigation of response to surgery using models derived from normal rather than abnormal psychology, although the Burk et al. (1985) study is a welcome exception. Similarly, an account based on conditioning principles has potential explanatory power, although no studies have used such a framework. The current study addresses this deficit within the literature.

## **Section 5.6      Summary discussion of studies of disfigurement**

The literature related to disfigurement has often been criticised for its sparseness. Nevertheless, this literature covers a broad range of subject groups and experiences. It is, however, often divided in its findings. Similarly, the studies are of variable quality, and this and the previous chapter have explored the methodological and interpretational difficulties of the most frequently cited of these investigations.

It was noted at the conclusion to Chapter 4 that disfigurement is a source of widespread actual and potential difficulty. This picture is reinforced by the studies presented in the current chapter, but the provision of psychological services for disfigured people is basic, and many are not in contact with any professional support. Examination of the difficulties faced by sufferers requires continuing effort to establish basic elements of such difficulties and potentially useful responses to them. No validated measure specifically examining attitudes and behaviours associated with facial disfigurement exists, whilst the exploration of individual variables which might be associated with adjustment has only begun. Level of disfigurement, which might be expected to be associated with level of difficulty, has not proved fruitful as yet, principally because of the methodological difficulties of many studies. In particular, there is currently no good evidence for the asserting that less disfigurement is associated with greater difficulty.

Considerable effort has been directed towards asserting that those seeking plastic surgery, particularly in the context of minimal deformity, have raised levels of psychopathology. This literature is not only potentially damaging to disfigured people, because of the possible negative

attitudes it may give rise to amongst clinicians, but is also too methodologically flawed to merit serious consideration. The literature on personality and social support is more promising. Similarly, the suggestion that women are more likely to suffer disturbance, whilst equivocal, requires considerable further examination, as do models of response to disfigurement which draw on the study of normal psychology.

Many of these issues bear directly on the cognitive-behavioural approach, which is itself based primarily on approaches to normal rather than abnormal psychology and indeed does not recognise the distinction between the two as particularly meaningful (Newell & Dryden, 1991). The future examination of personal and environmental variables such as those described in this chapter will undoubtedly have a considerable contribution to make to the development of this cognitive-behavioural approach.

## CHAPTER 6

### DISFIGUREMENT AND SOCIAL INTERACTIONS

#### Section 6.1 Introduction

This chapter focuses on experimental and quasiexperimental studies of social interaction with disfigured people in naturalistic and laboratory settings, and on attempts to alter patterns of such interactions. Where relevant, studies which examine interaction with people experiencing a disability or a disfigurement not directly related to the face are included.

The social difficulties experienced by disfigured people are a major source of complaints by them, both in structured investigations by researchers and in the first hand accounts written by disfigured individuals or recorded by such authors as Macgregor (e.g. Macgregor, 1951) and Bernstein (1976) and reported in the previous chapter. Macgregor (1989) describes the key role of the face in regulating social interaction, including the importance of paralanguage and reliance by humans on the mediating effects of facial muscles on such communications as gaze and facial expression. In many cases (e.g. burns, palsy) such mediating movements are unavailable. Macgregor (1989) suggests that this leads to difficulty in 'reading' the faces of disfigured people, which in turn results in hesitancy and awkwardness. She sees disfigured people as consequently acutely aware of the reactions of others and expending much energy in attention to the reactions of others, preoccupation with appearance, and 'defence mechanisms'. She concludes by suggesting that potentially fruitful areas of investigation include the effect of non-verbal communication on interactions with disfigured people and study of the extent to which the social distance experienced by disfigured people is a consequence of their appearance or their demeanour. A number of studies exist which demonstrate that the stigmatisation recounted by disfigured people is generally observed in both laboratory and field studies.

The quality of such studies is variable. One fascinating account, whilst barely rising above the level of anecdote, gives an insight into the social world of the disfigured person. Carlisle (1991), a member of the staff of 'Nursing Times', donned makeup to simulate a scar and entered a variety of social situations. Whilst her account is certainly consistent with the accounts of many disfigured

people, its chief relevance is to draw our attention to the possibility of bias in such studies. Whilst it would be strange if the repeated reports by disfigured people of stigmatising behaviour were all inaccurate, the Carlisle report reads as an object lesson in the inappropriate use of an assumed causative factor to explain observations. Thus, the presence of a scar is recounted by the author as a cause of both staring and looking away, and of both offering more and less help. Whilst these differing responses might well both be generated by the presence of a scar, considerable experimental control would be needed in order to exclude the effects of expectation on the part of the author.

## **Section 6.2      Experimental and field studies of social interactions with disfigured people**

The strength of the experimental and quasi-experimental literature lies in its attempts to exclude such bias from its examination of the difficulties faced by disfigured people. Kleck and Strenta (1980) showed that subjects believed reactions were being made to their simulated disfigurement even after this had been secretly removed. Twenty four females interacted with confederates, having been led to believe that these confederates were also volunteers who had been informed subjects in one condition had epilepsy and in a second had an allergy. A third condition involved applying make up to subjects to simulate the disfigurement. In fact, the confederates were unaware of the presumed status of the subjects and the simulated disfigurement had been removed under a pretext. Subjects in the epilepsy and disfigurement conditions reported significantly greater tenseness from confederates than allergy subjects, and disfigurement subjects made significantly greater reference to gaze behaviour. However, one major shortcoming of the experiment indicates that we should be cautious in extrapolating this conclusion to include genuinely disfigured or otherwise stigmatised people. The subject groups here did not, in fact, belong to such stigmatised groups. As a result, there is no reason to suppose that their perceptions and reactions would be similar to those of stigmatised people, unless it could be demonstrated that members of stigmatised groups shared the same expectancies of others' reactions to disfigurement as did non-members. A further distinction between the experimental group and stigmatised individuals is that the attention of the former has been drawn to the stigma as an active element of the experimental situation (in the case of the disfigured individual, involving considerable time and attention in the application of the disfigurement). It seems unlikely that this would not exert some influence on subject responses.

In consequence, any generalisations to disfigured individuals from this study are extremely speculative. The difficulty in drawing conclusions from even carefully controlled experiments such as this indicates that anecdotal, journalistic accounts such as the Carlisle (1991) report do little to elucidate our knowledge of people's reactions to facial disfigurements.

Nevertheless, a body of research appears to offer objective support for the subjective experience of stigma described by disfigured people. We may infer from the studies of more and less attractive people described in Chapter 3 and those of stigmatisation of visibly disabled individuals examined in Chapter 4 that people's reticence in interacting with such individuals is likely to be extended to the facially disfigured.

It has been suggested that people avoid contact with disabled people because such individuals give rise to autonomic arousal and uncomfortable feelings of uncertainty (Kleck et al., 1966). Langer et al. (1976) suggested disabled people are avoided because they cause an unpleasant tension between the desire to stare at a novel stimulus and fear of offending the social prohibition against staring. Both these contentions seem relevant to an examination of reactions to disfigured people, whose 'disability' is highly visible. Worthington (1974) demonstrated that people choose greater interpersonal distance from an apparently disabled individual asking directions than from a control. Since the amount of personal space afforded the handicapped individual was greater, the author concluded that subjects were equally keen to help the stigmatised person (as shown by spending the same amount of time in contact), but did not want to catch whatever the person had. Although it is apparent that subjects reacted with avoidance to the stigmatised person, the study does not, in fact clarify whether this was owing to fear of contamination, since less time spent with the individual would also be expected if this was the operative motivation.

Building on Bernstein's (1976) observation that people tend to choose no closer than 'neutral' distance from disfigured people, Rumsey (1983) constructed an experiment to investigate such proxemic behaviour empirically, by observing the distance consecutive arrivals at a pedestrian crossing chose when standing next to a confederate waiting there, apparently with no visible facial defect, a birthmark, or scarring and bruising. Early arrivals stood significantly further from the



confederate in both the birthmark and the scarring condition than the no disfigurement condition and further in the birthmark than the scarring condition. Furthermore, first arrival subjects chose significantly more often to stand next to the non-disfigured side of the disfigured confederates.

This experiment suggests that subjects exhibit greater distance from disfigured individuals than non-disfigured. Although it might be argued that there is a potential source of bias in reporting the distances involved, since the observers could never be truly blind to the conditions of the experiment, the index of stigmatising behaviour used (distance in centimetres) is sufficiently objective to allow us to be reasonably confident of this aspect of internal validity. Moreover, although the use of Mann-Whitney U is non-standard with what is essentially nominal level data in examination of frequency of choice of disfigured or non-disfigured side for standing by subjects, an examination of the raw data renders such considerations almost redundant, since the differences in percentages of sides chosen were sufficiently large to render statistical treatment superfluous.

In a later study, Houston and Bull (1994) also investigated proxemic preferences of members of the public, by examining train seat occupancy in seats surrounding a confederate apparently with no visible defect, a birthmark, scarring or bruising. They found an overall effect of facial appearance on occupancy of seats, and examination of means indicated that this was accounted for by the difference between the birth mark and no defect conditions. Moreover, frequency of occupancy increased the more normal the facial appearance became. Taken together, these two experiments support the contention that disfigured people are avoided in public situations of minimal social interaction.

A laboratory study by Kleck (1969) suggests that disabled people are given greater social distance in more intimate settings. Twenty students were instructed in Origami and required to teach it to a confederate either with or without a simulated leg amputation, ostensibly as part of a study of teaching. Amputees were afforded significantly greater social distance on the first of two trials, but not the second. This is particularly interesting given that subjects also formed a more positive impression of the disabled than the non-disabled confederate during the first trial, but not the second. The authors suggest that this formation of a more positive impression of the disabled

confederate may conform to our tendency in society to be kind to disadvantaged individuals. Moreover, the finding of increased proximity on the second trial is consistent with the findings of Langer et al. (1976) and with the interpretation of these findings in conditioning terms offered in Chapter 4. It is possible to speculate that the initial favourable evaluation of the disabled confederate is itself an anxiety reaction, and, like social avoidance, decreases on subsequent exposure because anxiety reduces. This in turn leads to the speculation that our norm of kindness to disadvantaged individuals is, in general, an anxiety based response. The tendency to 'kindness' was not translated into action, in terms of physical proximity, in the Kleck et al. (1969) study. Indeed, it seemed to be inversely related to it, taking, as the authors do, positive impressions of the disabled person as the index of this tendency. Koster and Bergsma (1990) note that positive reactions such as sympathy and pity are displayed to disfigured people. It is over-simple to assume that such displays are positive. The supposed tendency to kindness may, indeed, be little more than an aspect of establishing our dissimilarity from the disabled person, and an aspect of stigma, or indeed of anxiety reduction via cognitive avoidance through the establishing of that differentness, with consequent lessening of the fear that what has befallen the disfigured individual might happen to ourselves. Certainly, disfigured individuals report resenting both the pity of others (Andreason & Norris, 1972) and their *unkind behaviour* (see Chapters 4 and 5). An empirical evaluation of the interaction between autonomic arousal, self reports of anxiety and ratings of disabled or disfigured individuals on repeated trials would be instructive.

The above studies together support the notion that disfigured individuals are indeed stigmatised in public social situations, at least if we regard avoidance of contact as an indicator of stigmatisation. It should be noted, however, that these studies involved relatively superficial contact. There are no field studies which directly demonstrate avoidance of disfigured people in situations where more intimate social interaction is present, although anecdotal accounts are frequent (see Chapter 4).

Kleck et al. (1966) suggested that the behavioural repertoire displayed with disabled people will be stereotyped, inhibited and overcontrolled. They examined these assertions in two laboratory studies, in which an interviewer appeared either disabled or able-bodied. In the first experiment, the study was presented to 56 undergraduates as an opinion survey. Contrary to expectations,

subjects talked for longer and reported liking the interviewer more in the disabled condition, although the same confederate took both roles. There was, however, less variance in answers to closed questions in the disabled condition, indicating more over-control of responses. There were two methodological difficulties, noted by the authors, which led them to discount the results of this first experiment. The behaviour of the confederate was not consistent across the conditions, and there was the possibility that desire to help a disabled person may have caused the longer answers in the disabled condition. Since there is a correlation between length of answers to open questions and perception of positiveness of the interview by interviewees, this might have influenced interviewee liking of the interviewer. Moreover, the authors wished to make the disability of the interviewer more obvious.

The second experiment was generally similar to the first, but with less emphasis placed on verbal behaviour in explanations to subjects, less information regarding the interviewer's adjustment to disability and a more visible disability (apparent amputee). Subjects who interacted with the disabled confederate were also subsequently divided by the researchers into groups who did (H+) or did not (H-) express subjective discomfort in the presence of the handicapped interviewer.

Psycho-galvanic skin response of the 46 subjects was measured and was significantly different between the disabled and non-disabled conditions in both H+ and H- groups. Thus, both those who expressed discomfort and those who did not were equally physiologically aroused in the presence of the disabled confederate.

Those in the disabled group took significantly longer to complete a question selection task than those in the non-disabled group, and terminated the interview sooner. This latter feature was more marked in the H+ group. Visual inspection of data suggested that the H+ group showed less variance in their responses than the H- group, who in turn showed less than the non-disabled group, indicating greater over-control of their behaviours. Finally, H+ showed more distortion of their expressed opinions from those later reported outside the experimental situation than H- subjects, who showed less than those in the non-disabled condition, suggesting greatest desire to make the disabled person feel comfortable on the part of H+ subjects.

The authors note that post hoc definition of subgroups (H+ and H-) for comparisons is difficult, because some other variable, such as personality, may have led to the differences in their scores, but suggest that this is mitigated by fact that H+ subgroup results confirm rather than contradict trends in other areas of the data. This is possibly an inadequate justification for this methodological difficulty. It might reasonably be expected that anxious people would behave in this way regardless of condition, and no attempt was made to isolate an uncomfortable group from subjects in the non-disabled condition. Moreover, the authors do not report whether subjects said they were uncomfortable *because* of the handicap of the interviewer. Finally, H+ were not more physiologically aroused than H-, so that the observed differences might simply be a consequence of differences between individuals who do or do not admit to discomfort, rather than those who are or are not uncomfortable.

This makes it extremely difficult to draw any conclusions as to whether or not level of discomfort affects level of interaction with a disabled person. The H+ group did, however, report less previous experience of disabled people, which makes a valid prospective distinction between the two groups possible, on the basis of this past exposure rather than discomfort.. The work of Langer et al. (1976) is relevant here. Their paper was described in Chapter 4 because of its relevance to their novel stimulus hypothesis of people's reactions to disabled individuals. The third experiment involved face-to-face interaction with an apparently disabled person, and prior visual exposure resulted in a diminution of the difference between interpersonal distances in the disabled and non-disabled groups to non-significant levels. If we accept the novel stimulus hypothesis, the differences between the behaviours of H+ and H- subjects in the Kleck et al. (1966) experiment may have been caused by lack of previous exposure to disabled individuals. However, this past exposure did not lead the behaviour of the H- group to resemble that of subjects in the non-disabled group. The effect of prior exposure seems modest in the Kleck et al. (1966) experiment.

Despite methodological difficulties, The Kleck et al. (1966) investigation is an important study, which suggests people behave differently in the presence of disabled individuals, showing more over-controlled behaviour and seeking to avoid contact, whilst also having a desire to help by setting the person at ease through expressing similar opinions.

## **Summary**

The general picture provided by the above studies of social interactions with disfigured people supports anecdotal reports of their stigmatisation by others, and the evidence that disfigured people mistakenly attribute the behaviours of others to their own disfigurements is slight. Bernstein's (1976) contention that disfigured people are afforded greater social distance by others is supported by studies of proxemic behaviour both in public situations and more private one-to-one encounters. The repertoire of behaviours exhibited in the presence of disfigured people may be reduced and over-controlled. However, the possible mechanisms which might underlie these behaviours have not, as yet, been satisfactorily investigated, although it seems probable that anxiety might play a part in responses to disfigured people. Similarly the effect of previous contact with disfigured people, which may be related to level of anxiety, requires further examination. We have little further information as to how far facial disfigurement hinders disfigured people in more intimate social circumstances. There are no experimental or simulation studies of activities such as casual social interactions (in the public house, workplace, shop, etc.), in friendship or in dating, courtship and sexual behaviour. Despite potential methodological difficulties, such studies would be welcome, given the reported difficulties of disfigured people in such areas of interaction.

## **Section 6.3    Helping behaviour**

Helping behaviour has received considerable study in the literature concerning disability and disfigurement, and an understanding of the conditions under which disfigured people are or are not helped might both elucidate the motivations involved in helping and aid in developing ways of altering public attitudes to disfigured people and interactions with them.

The possibly contradictory elements of desire to terminate contact and desire to help a stigmatised person were investigated by Doob and Ecker (1970) in a study which offered 121 housewife subjects the choice of returning a questionnaire through the post or completing it in an interview by a confederate either wearing or not wearing an eye patch. In the interview condition, there was no difference between the disfigured/non-disfigured groups, but in the postal return condition more subjects both accepted and returned the questionnaire in the disfigured group, a finding the authors conclude indicates that subjects are likely to offer *more* help to a disfigured person, providing no

additional contact is required. The concomitant conclusion is that the competing desires to be helpful and to avoid contact cancel each other out in the interview condition, where additional contact is required. By contrast, Soble and Strickland (1974) found that confederates who appeared to have a hunchback were less likely to gain agreement from doorstep solicitation for an interview at a later date with themselves than control confederates. In this study, it does not appear that desire to end contact was mediated by any greater willingness to help the stigmatised person, merely desire to avoid contact both on the current and subsequent occasions.

The possibility that disfigured individuals might be no more likely to be helped in situations where contact was required was further investigated by Samerotte and Harris (1976), who also examined the role of perceived responsibility and requesting help in determining the likelihood of help being offered. One hundred and twenty subjects were exposed to a confederate dropping envelopes in a shopping centre. The confederate was either a non-disabled control, or had an arm bandage or an eye patch and facial scar. In each of these three conditions, the confederate either did or did not blame subjects for causing the envelopes to be dropped and did or did not request help. Although requests for help did not affect compliance, subjects were more likely to help the bandaged confederate than either the disfigured or control confederates (who received equal help), and were more likely to help if blamed for causing the envelopes to be dropped.

The authors suggest that the tendency to avoid a disfigured person may have counteracted any increased sympathy felt for them. However, although the researchers were careful to ensure that the arm bandage did not interfere with ability to pick up the envelopes, it could nevertheless have led to a perception of more difficulty in so doing, since a bandaged arm might reasonably be supposed by subjects to indicate weakness or impairment of this area. By contrast, the disfigured confederate might not have been assumed to be handicapped in the task by lacking the sight of an eye. Rather than being counteracted by a desire for avoidance, neither desire for avoidance nor increased sympathy for the disfigured confederate need have been present. The disfigured confederate, unlike the bandaged confederate, may simply have been perceived as being as able to perform the task as the control. However, the study does offer a further demonstration that disfigured people receive no more help than non-disfigured.

Levitt and Kornhaber (1977), in a study of handicap not related specifically to the face, attempted to examine whether a non-stigmatising handicap would produce as much compliance as a stigmatising one. The stigmatising handicap was wearing of leg braces and half crutches, to denote a permanent handicap, rather than a plaster cast and wooden crutches to denote a temporary and, therefore, non-stigmatising incapacity. A control confederate was also used. The confederates approached 60 male and 60 female pedestrians and asked for spare change. Significantly more people gave money to both handicapped confederates than to controls, but there was no difference between the stigmatised and non-stigmatised confederates. However, significantly more *money* was given to the non-stigmatised than the control confederate, although there was no significant difference either between the stigmatised and non-stigmatised or the stigmatised and control confederates. The paper offers some support for the contention that both stigmatised and non-stigmatised handicapped individuals are likely to receive more help than controls, but it should be noted that the degree of interaction required for helping was minimal.

In another, better conducted, study which again involved face-to-face contact, but with slightly more interaction, Shaw et al. (1980) investigated frequency of petition signing in response to male and female petitioners with or without a facial disfigurement (burn scar, birthmark or protruding teeth), dividing the petition condition itself into contentious and non-contentious issues. They approached 7200 potential signatories, to explore the hypothesis that disfigured individuals would be more avoided and get fewer signatures, and divided subject response into a five point scale, from evasion (no acknowledgement of the confederate) through polite refusal, reasoned refusal, hostile refusal, to signing.

Contrary to expectations, there was no significant effect of disfigurement on evasion, although controls obtained significantly more signatures than did disfigured confederates in the uncontentious petition condition. There was no such effect in the contentious petition. The authors suggest that the uncontentious petition maximised the salience of the disfigurement cue. The authors account for lack of avoidance of disfigured individuals by suggesting that this may have resulted from a suspension of the ban on staring, allowing them to indulge their desire to look. However, the result is equally well accounted for by at least two other suggestions. Subjects might

have responded to a general tendency to comply at least to the extent of polite refusal (which might even, as the authors suggest, have been enhanced by desire to appear sympathetic to a stigmatised person). Alternatively, the desire to avoid disfigured people might only be apparent in situations where there is considerable anxiety. This anxiety might only be aroused in situations of interaction more intimate than passing on the street.

Piliavin et al. (1975) suggested a two-stage model of helping behaviour which asserted that emergency situations exert on bystanders a desire to decrease arousal felt in the presence of such situations. The particular circumstances of the emergency will combine with personality characteristics of the bystander to influence either rapid helping or escape. The bystander will respond so as to reduce arousal as rapidly as possible and incur as few other costs as possible. Costs may be incurred by helping (e.g. danger, exposure to revolting experiences) or not helping (e.g. continued arousal, self-blame, blame from others). These two stages of arousal and calculation of profit and loss are seen as an alternative to the notion that helping is simply mediated by greater liking. Liking and attractiveness of the helped person are merely elements of the profit and loss equation in the Piliavin et al. (1975) account.

This model has considerable explanatory power in considering the responses of individuals to facially disfigured people, who may be associated both with greater loss in the equation, if their appearance gives rise to greater arousal in the potential helper, and with less profit, if they are perceived as unattractive. Piliavin et al. (1975) investigated the relevance of the two-stage model to helping behaviour with facially disfigured individuals in an experiment which sought to isolate the effect of stigmatisation in reducing helping behaviour from the possible effects of perceived worthlessness of or danger from the helpee. In their study, a confederate either with or without a 'large, red birthmark' (a feature construed by the authors as unrelated to either character of the victim or potential danger of the crisis to the helper), apparently fell on a subway train, and the frequency of helping behaviours was recorded. The unmarked victim was helped on 86.4% of trials, whilst the marked individual was helped on 60.7%, a highly significant difference, indicating clear support for the notion that facial disfigurement constitutes a cost in helping situations.



In an attempt to account for findings such as Doob and Ecker's (1970) in terms of the Piliavin et al. (1975) model, Ungar (1979) examined the amount that a confederate with a medical eye patch was helped by passers-by following inaccurate directions received from a further confederate. The author predicted that the stimulus person with the eye patch would be helped less than a control *only* under a high effort condition. Under this condition, passers-by seeking to correct the incorrect directions had to follow the confederate along a subway platform. In the low effort condition, the confederate remained standing next to the chosen passer-by. It was found that the eye patch confederate was helped less in the high effort condition. The author concluded that this stigma led subjects to attend more to the additional cost involved in the high effort condition. However, it might equally well be suggested, from the results, that contact with an individual bearing a stigma itself constitutes a cost (as seems apparent from, for example, Piliavin et al., 1975; Rumsey, 1983; Houston & Bull, 1994), which, when added to the cost involved in spending time following the individual is sufficient to inhibit helping behaviour. No concept of increased sensitivity to already existing costs is necessary; the stigma constitutes an additional cost.

In Bull and Stevens's (1981) study of helping behaviour in collecting for charity, they suggest that expected duration of contact is likely to be an important aspect of such behaviour. However, it should also be noted that duration should be expected to interact with other indices of intimacy, such as spacial proximity. The authors studied the interactions of a confederate either with or without a simulated port wine stain with subjects from whom they collected money door-to-door for a children's charity. There was what the authors describe as an 'almost significant' ( $p < 0.10$ ) effect of disfigurement on amount of money donated, with more money donated to non-disfigured than disfigured. It is interesting to note, given the suggestion in the literature that social skills training might be a useful component in helping disfigured people cope with negative interactions with others, that there was no interaction between disfigurement and gaze, nor any main effect of gaze on contribution. The authors suggest that their data support the notion that facial disfigurement may lead to less helping behaviour. However, although they note that, in several of the locality subgroups they investigated, less money was donated, they do not provide significance levels for these differences. In any event, the most conservative interpretation, given the lack of a *significant* main effect for disfigurement, is that it does not lead to any difference in helping behaviour.

In a series of three experiments which examined levels of helping behaviour at different levels of interaction, Rumsey (1983) first undertook a partial replication of Benson et al.'s (1976) study of helping of more and less attractive individuals by retrieval of lost application forms from telephone booths, on this occasion comparing non-disfigured photographs with those of individuals with either a birthmark or trauma scarring. As in the original Benson et al. (1976) study, number of applications forwarded was the index of helping behaviour. Rumsey (1983) found no significant effect of disfigurement on helping behaviour, although she does note that some subjects may have been more motivated to help the confederate's father, who was presented as having been responsible for leaving the application, rather than the confederate. However, it should be noted that this did not appear to have been the case in the Benson et al. (1976) study, which, it will be recalled, *did* find significant differences in the help received by attractive and unattractive confederates. Other aspects of Rumsey's (1983) discussion of the non-significant finding are illuminating from a methodological standpoint, since she notes that sympathy for a disfigured person might have outweighed bias against them, and balanced the desire to help the more attractive non-disfigured target person. She also suggests that, in the privacy of the booth, the suspension of the norm against staring may have led subjects to attend more closely to the information about the disfigured person, and thus increase the likelihood of their returning the form, in a manner similar to that suggested by Benson et al. (1976) as a possible reason for their findings of greater helping of attractive individuals. It should be noted that, as in the Benson et al. study, no interaction is required in Rumsey et al.'s first study, and so generalisations from it to more intimate forms of helping should be modest.

In the second experiment in Rumsey et al. (1983), a minimal level of interaction was introduced, as disfigured (birthmark) and non-disfigured confederates collected in the street for a children's charity. She points out that no social interaction was necessary in order to contribute. The level of interaction was thus marginally lower than either the Bull & Stevens (1981) or Shaw et al. (1980) studies. Subjects were passers-by, whose numbers were counted by discreet observation. There was no difference in the percentage of individuals helping nor in the amount of money donated in each condition, although there was a general tendency for more people in the non-disfigured condition to be helped, but for more money to be given by those who did help in the disfigured

condition. These results are, therefore, generally similar to those of Bull and Stevens (1981), who likewise found no effect of disfigurement on helping.

In the final study, Rumsey (1983) had a disfigured (birthmark) or non-disfigured confederate solicit respondents for a survey on television viewing and current affairs. The potential level of interaction in this study was, therefore, greater than in Bull and Stevens (1981) and perhaps as great as in other mock survey studies (Doob & Ecker, 1970; Soble & Strickland, 1974). Rumsey (1983) cites the former of these studies as an example of disfigured individuals receiving more help, although it should be noted that this was only the case in the postal questionnaire return element of this study. In the element requiring continuing face-to-face interaction, and thus most similar to Rumsey's third study, no difference was found between the conditions. In Rumsey's own study, although there was a marked tendency for disfigured people to be helped less, this did not reach significance. Once again, there is no unequivocal evidence from this study that disfigured individuals are helped more or less than non-disfigured persons. Nevertheless, it should be noted again that the level of interaction in the final study was still fairly small when compared with most social interactions.

### **Summary**

Although it has been suggested (Rumsey, 1983) that, under certain circumstances, disfigured people might be afforded more help than their non-disfigured counterparts, the evidence for this is slight. Of the studies here, those which require any major level of personal contact suggest that the disfigured person is afforded no advantage (Doob & Ecker, 1970; Bull & Stevens, 1981; Rumsey, 1983) or is discriminated against (Soble & Strickland, 1974; Levitt & Kornhaber, 1977; Piliavin et al., 1976; Ungar, 1979).

Moreover, it appears that desire to avoid contact with disfigured people, rather than simply cancelling out some proportion of the amount of desire to help, often eliminates that desire completely. It also seems, from the Piliavin et al. (1976) study, that this desire is mediated by revulsion caused by the disfigurement, rather than either derogation of presumed personality characteristics or perceived dangerousness of the disfigured person, although the first contention should be treated with caution, given the tendency to derogate less attractive individuals and the

likelihood that a disfigured person will be viewed as unattractive (see Chapters 3 and 4). It is interesting to note that this experiment required considerably more close contact with confederates than did investigations of helping behaviour which found little or no negative effect or a positive effect of disfigurement on helping. It may be the case that disfigured people only enjoy the same or better social responses compared to other members of the population in conditions where minimal contact is required. This is congruent with Bernstein's (1976) assertion of the preference for neutral social distance in interacting with disfigured people.

From the therapeutic perspective, we have no reason to suppose that the disfigured person will be afforded any advantage in any situations involving interaction. Indeed, the helping behaviour literature suggests that it is entirely possible that situations where help is required will represent a further instance where disfigured people are disadvantaged, and that this disadvantage may increase as more social interaction is required.

#### **Section 6.4 Judgements of social competence of disfigured people**

The subjective accounts of disfigured people of their experiences in social interactions have been summarised in Chapter 4. It has also been noted that some commentators have cast doubt on the accuracy of disfigured people's perceptions of the reactions of others to them (e.g. Kleck & Strenta, 1980; Shaw, 1986). Rumsey et al. (1986a) explored the effect of the behaviour of facially disfigured people on the reactions of others in a videotaped study of a confederate with or without a port wine stain who demonstrated either good or bad social skills with 12 female subjects. The socially competent confederate was rated as more warm and friendly by subjects and as more warm, friendly, likeable, interesting and competent by independent observers. Moreover, subjects smiled more and showed lower response latencies towards the socially competent confederate. These findings were *not* influenced by whether the confederate was facially disfigured. They conclude that social skill might exert sufficient influence to override the negative influence of stigmatisation as a result of facial disfigurement and suggest the use of a social skills training programme to help disfigured people in learning to be active in overcoming such stigmatisation.

This suggestion receives tangential support from the finding that social skill is possibly interactively linked with attractiveness. It will be remembered from Chapter 3 that attractive people are generally perceived as more socially skilled. Moreover, people who are *believed* by subjects to be attractive are rated as more socially skilled, sight unseen, by independent raters, than people believed to be unattractive. This appears to be a response to confirmatory behaviour elicited by those who interact with the target individuals believing them to be attractive or unattractive (Snyder et al., 1977). Furthermore, attractive individuals actually do display greater social skill, even when they are unseen by those with whom they interact (Goldman & Lewis, 1977). The Snyder et al. study (1977) has been described earlier. However, the Goldman and Lewis study is particularly concerned with social skills, and is therefore described now. Goldman and Lewis had independent observers rate the attractiveness of 60 male and 60 female participants engaged in 5 minute telephone conversations with each other, whilst subjects rated their partners for social skill and according to their desire to interact with them again in the future. There was high inter-rater reliability for measurement of attractiveness of the subjects, and these ratings were positively correlated with ratings of their social skills by the other subjects with whom they interacted ( $r = 0.31$  males,  $r=0.29$  females). Although these correlations are low, the authors note that this could have been caused by the naturalistic way in which the interactions were allowed to progress. In any event, the study offers some support for the contention that attractiveness may be genuinely associated with greater social skill, possibly as a result of greater opportunities for successful social interaction experienced by attractive people in early life. On this basis, it may be argued that those who come into contact with attractive people believe they are likely to be socially skilled at least partly on the basis of previous interactions with attractive, socially skilled people, and believe the reverse of unattractive people with whom they interact. In consequence, they encourage both attractive and unattractive people to exhibit behaviours consistent with either their stereotypes or genuine previous experiences of such people. Extrapolating this finding to disfigured people, it is possible to argue that an enhancement of their social skills may be necessary in two ways: to counteract the negative expectations of others and, for those who have been disfigured for a considerable time, to improve upon the impoverished social skills they actually possess as a result of previous exposure to non-rewarding social interactions with those who expect them to be socially unskilled or unrewarding and thus elicit such unskilled behaviours from them.

The notion that judgements of attraction are subject to influence from judgements of social competence receives further support from Bull and Brooking's (1986) study, in which 60 psychology undergraduates were shown photographs of interview participants and were asked to evaluate them. Stimulus photographs were represented to subjects as either married or unmarried and were edited to look physically disfigured on 50% of occasions. Stimulus people were thus either paired with a married or unmarried partner (the titles Miss and Mrs being used to distinguish between conditions), with either the male or female partner appearing disfigured. The male disfigured participant was judged to be significantly more intelligent and attractive when married (to a non-disfigured partner). Females were judged to be significantly less likeable when the male partner was disfigured, whether married to him or not. However, when females were represented as married to a non-disfigured male, the fact that the females themselves were or were not disfigured had no effect on judgements of their attractiveness. When unmarried, they were judged significantly less attractive when disfigured. There were no conditions in which both males and females had a disfigurement. The authors conclude that facial disfigurement does not influence judgements of attractiveness if you are married, and that this may mean that judgements of the disfigured may be influenced by their achievements and skills. This in turn may mean that, through such achievements, they may be able to overcome society's prejudice against them. This last suggestion is perhaps overoptimistic. Although the authors do not say so, it appears to be related to the contention in Sigall and Landy (1973) that we may impute positive characteristics to people associated with attractive partners. This possibility is also implied by Bar-Tal and Saxe (1976). However, the evidence from these studies is equivocal and is restricted to relatively narrowly focused experimental situations which may lack external validity, although the Bull and Brooking (1986) study overcame several impediments to external validity. It *may* be that disfigurement made no difference to attractiveness judgements of disfigured people in the presence of non-disfigured partners because they were assumed to have positive qualities which compensated for their disfigurement, but there is no direct evidence for this in the Bull and Brooking (1986) study, since such assumptions were not tested.

## **Summary**

Social skill may influence stigmatising judgements applied to disfigured people by others, although investigation of the role of social skill in this context is at an early stage. Moreover, given the possibility that disfigured people, like unattractive individuals, may be perceived as less socially skilled than others, the disfigured person may require training in social performance in order to offset this perception. The fact that disfigured people may, in fact, have less opportunity to practice and receive reinforcement for appropriate socially skilled performance potentially increases the need for such training, although this last contention is speculative and itself requires further investigation. Although the suggestion that achievement may enable disfigured people to overcome society's prejudice is intriguing, it requires much more investigation.

## **Section 6.5 Addressing the psychosocial difficulties of facially disfigured people**

The descriptions of social interaction with disfigured people given earlier in this and previous chapters, and the potentially negative consequences of such interactions, indicate that intervention to alter the quality of such interactions is potentially an important contribution to the lives of disfigured people. Similarly, the current study is essentially concerned with examining and elucidating the difficulties experienced by disfigured people with the intention of contributing to our ability to address those difficulties. However, the systematic investigation of treatment of psychosocial consequences of disfigurement is in its infancy. Facial disfigurement has been the subject of little research, and psychological treatment is even less thoroughly investigated, despite the fact that the difficulties of facially disfigured people have been described, at least in anecdotal form, in the literature since at least the early works of Macgregor in the 1950s.

In view of this it is surprising to find that more recent accounts of both the extent of treatment provision and the interventions themselves remain extremely rare. It must be presumed that they reflect our actual treatment provision which is equally fragmented and inadequate. Two surveys from the 1980s reported a lack of focus upon emotional difficulties. Wallace (1988), in a study of 43 United Kingdom burns units, found that, of the 28 replies received, only two units provided specialist counselling, whilst only seven had some form of lay support. This lack of emphasis on emotional support was also found in a US study (Kaplan, 1985) which found that only 70 per cent of

burns units gave *any* information about emotional aspects of burn injuries. It will be remembered from Chapter 4 that Wallace (1988) also found that almost all the burns patients in her survey of their psychosocial needs reported a desire for some form of emotional intervention or support, whilst less than 25% reported *any* useful contact with any professional with regard to their burns. Many of her findings regarding identified psychological intervention needs were confirmed by Williams and Griffiths (1991). A further, larger survey of the psychosocial needs of disfigured people would now be timely.

Studies of the role of psychiatrists and psychologists focus chiefly on assessment of suitability for surgery (Jacobson et al., 1961), general liaison roles within plastic surgery units (Goin and Goin, 1981) and descriptions of psychological difficulties such as those described in this chapter. Accounts of treatment are almost exclusively restricted to single case studies or collections of such studies (Jacobson et al., 1961; Bernstein, 1976,1982; Cohen et al., 1991; Shakin Kunkel et al., 1995), or to general descriptions of therapeutic approaches (Bronheim et al., 1991). These studies do not always differentiate between pre-existing psychological difficulties and the consequences of disfigurement, nor between the consequences of the disfiguring aspects of impairments and functional aspects such as difficulty with speech and eating following oral surgery. Some include patients with active or terminal malignant disease, and likewise focus on a broad range of issues. They are thus not studies of therapy for disfigurement, and are not reviewed here.

As noted in Chapter 4, Lefebvre and Arndt (1988) outlined a number of tactics which might be employed to increase life skills in adolescents with facial disfigurements, based on 15 years of liaison psychiatry in this area. These included: helping strangers handle shock and fear, handling teasing and name-calling, making new friends, talking to members of the opposite sex, handling job interviews. Unfortunately, although their review is extensively referenced, none of these citations refers to therapeutic intervention. In consequence, their account of these interventions remains at an anecdotal level, and no conclusion can be drawn about the effectiveness or otherwise of the treatment suggestions they make, which are further weakened by inadequate description of the interventions undertaken.



One study specifically addresses the social skills of disfigured individuals (Feigenbaum, 1981), in the context of a 'social training' program which also included elements of anxiety reduction, following Meichenbaum's (1977) stress inoculation approach to cognitive-behaviour therapy. Although the groups were not analysed using a statistical model which would allow direct comparison of differences in the changes between the two groups over time, the results demonstrated significant differences both between pre- and post-training scores for the experimental group and between the experimental and control groups post-treatment across a variety of measures of anxiety. The analysis would have been strengthened by the inclusion of data from the initial time point for the control group, and by the examination of any possible effects of differences between experimental and control groups pre-treatment. Despite this methodological weakness, the range and number of significant results which favour the intervention allow us to have reasonable confidence in its effectiveness.

The lack of systematic examination of psychosocial interventions with people with facial disfigurements, and the absence, with the exception of the Feigenbaum (1977) study, of attempts specifically to address issues of social isolation, mean that the work of Rumsey, Partridge and their various collaborators is particularly welcome. Partridge is a burns survivor who has developed an approach to treatment based on a group approach which involves social skills training of the kind advocated by Rumsey (1983) but also such diverse elements as role modelling, imitation, instruction, brainstorming, role-plays, creative problem-solving and feedback (Partridge, 1993). His approach is clearly focused on the interpersonal consequences of disfigurement, which are outlined in the 'scared' model of reactions (see Figure 6.5.1). Workshops address elements of this 'scared' responding.

**Figure 6.5.1: The Scared Syndrome**

	<u>you</u>		<u>they</u>
<u>feel</u>	<u>behave</u>	<u>feel</u>	<u>behave</u>
self conscious	submissive	sympathy	staring
conspicuous	clumsy	caution	curiosity
angry	apathy	anguished	awkwardness
resentful	regressive	reluctant	rudeness
empty	excluded	embarrassed	evasiveness
different	defenceless	dread	distance

(Adapted from Partridge, 1993)

The workshops are now part of a continuing programme of therapeutic evaluation which builds on Rumsey's research work (Rumsey, 1983; Rumsey et al., 1986a) and Partridge's personal experiences (Partridge, 1990) and work with social skills training. In a review of this group's work to date, Partridge et al. (1994) note that the 'Changing Faces' project had developed a series of workshops for disfigured people which, during the first two years of the project, some 88% of attenders found useful, whilst 77% reported using the skills and information they had gained on the course in real life situations.

In a further account of the work of the project (Robinson et al., 1996), a consecutive series of 112 attenders at 'Changing Faces' workshops were examined using the HAD and the Social Avoidance and Distress Scale (SADS) as well as open ended questions regarding quality of life. Respondents reported difficulties in social situations, particularly with regard to meeting new people and being with strangers. Of the original group, 64 completed both a 6 week and a 6 month follow-up. Six weeks after the workshops, HAD anxiety had fallen significantly, and was no longer different from normative samples. Similarly, high levels of SADS social avoidance and distress had significantly reduced after treatment, and attenders felt significantly more confident in the presence of strangers and when meeting new people. Improvements were maintained or increased at 6 month follow-up. Age of participants and duration of disfigurement were unrelated to extent of psychological difficulties both before and after treatment. The study lacks a control group, but the comparison with normative data on the HAD increases our confidence that participant improvements represent a genuine effect, although the possibility that this improvement is an artefact of attention or time cannot definitively be refuted.

The authors conclude that social skills training workshops offer a 'promising' intervention. Whilst this is certainly an appropriately conservative assertion, given that the study represents an uncontrolled design, it should be considered within the context both of the levels of improvement reported and the current lack of any other systematic studies. Taking this into account, social skills training represents the most important step to date towards addressing the psychological difficulties of disfigured people. Whilst caution should be urged, in the light, for example, of Bernstein's (1976) remarks regarding the possible arrogance of assuming that such social manipulations could

materially change the psychological well-being of disfigured people, two factors should give increased cause for optimism. First, despite its simplicity as an intervention, social skills training has a considerable record of clinical effectiveness across a broad variety of difficulties. Second, the workshops offered by Partridge's group appear to offer a flexible, eclectic approach to social skills training which goes beyond the simple training of interaction skills via role-play, to include brainstorming and creative problem solving. Whilst there is little specific reference to anxiety management, the inference is clear that anxiety reduction is an aim of the workshops, whose key elements appear to be rooted firmly within the cognitive behavioural tradition.

There is some suggestion that recognition of the value of such a behaviourally oriented approach has filtered into the therapeutic awareness of health professionals. Griffiths (1990) writing before publication of the 'Changing Faces' project's work, suggested a series of tactics a nurse might use in helping disfigured people. These included:

not giving in to avoidance

using controlled breathing to control fear & anxiety

using positive self-talk

concentrating on relevant information to distract from upsetting thoughts.

avoiding misinterpreting the discomfort of others as rejection

finding a way to acknowledge the disfigurement

congratulating success.

These suggestions are once again clearly rooted in cognitive behavioural interventions, but this is not specifically acknowledged in Griffiths's (1990) article. Nor are any of the suggestions referenced. There is no sign from either the nursing or medical literature that either these suggestions or any other cognitive-behavioural interventions have been adopted.

## **Summary**

Treatment provision for the psychosocial consequences of disfigurement has been subjected only to the most minimal investigation, but appears rudimentary. There is little description of the role of

psychiatrists and psychologists in the provision of care to disfigured people. Considerable numbers of disfigured people appear not to have the benefit of contact with services designed to address their psychosocial needs.

Description of treatment interventions is sketchy. The only systematic programme of work is that of the Rumsey/Partridge group in the field of social skills training. Although work in social skills training is hampered by the lack of adequately controlled trials, this work still shows considerable promise, with apparent benefit to disfigured people. The treatment programmes appear to contain several elements of a cognitive behavioural approach. This approach to treatment is also implicitly suggested in Griffiths's (1990) paper. However, empirical investigation of her suggestions is lacking.

#### **Section 6.6 Chapter summary of studies of disfigurement and social interaction**

The subjective experiences of stigma reported by disfigured individuals are generally supported by empirical studies examined here, provided that we allow that decreased interaction time and increased social distance are valid indices of stigmatisation. It seems possible that increased contact with disfigured people may lead to a reduction in stigmatising behaviour, possibly as a result of decreased anxiety. Studies of helping behaviour are divided in their findings, but the most optimistic interpretation is that there is no advantage for disfigured people in such studies, although even this interpretation may be too optimistic. The evidence that either social skill or achievement can affect the extent of people's negative judgements of disfigured people is highly speculative.

The potential value of social skills training following disfigurement receives support from the contention that such skill may be lacking in disfigured people and that they may be perceived as less skilled, as well as from the empirical studies of social skills training and their impact upon the psychosocial well-being of disfigured individuals..

In closing this examination of intervention with the psychological sequelae of facial disfigurements, it is difficult to be optimistic regarding the future of such interventions. Whilst the work of the Rumsey/Partridge group is no doubt an important contribution to this area, and demonstrates

positive results, there is no indication that the general adoption of psychosocial treatment for disfigured people had been either introduced or evaluated. Despite Macgregor's (1951) recognition of the important role of psychological interventions for facial disfigurement, there is no indication from the accounts of disfigured people that over 45 years have led to significant recognition of the difficulties they face, the need for health professionals to address such difficulties, or the development of methods to enable them to do so. This recognition of the amount of work still to be done in addressing the psychosocial needs of disfigured people represents an important backdrop to the current study, which attempts both to map these needs and to offer a model for intervention. The next chapter explores the possible contributions which a cognitive-behavioural approach might make to such interventions.

## **CHAPTER 7**

### **THE COGNITIVE BEHAVIOURAL APPROACH TO BODY IMAGE DISTURBANCE AND ITS TREATMENT**

#### **Section 7.1 Introduction**

This chapter deals with the potential contribution of cognitive-behaviour therapy (CBT) to our understanding and treatment of psychological consequences of disfigurement. It has been seen from Chapter 6 that none of the intervention studies with such psychological disturbances have specifically defined their theoretical underpinnings in cognitive-behavioural terms. Similarly, there has been no specifically cognitive-behavioural formulation stated in the literature for the genesis and maintenance of these difficulties. However, cognitive-behaviour therapy approaches to a number of other psychological problems offer potential insights into the difficulties of disfigured people.

This chapter traces the development of the CBT approach from its roots in behaviour therapy, and outlines the main treatment techniques used to address focal anxieties such as phobias. A brief synoptic account is given of the empirical status of these techniques. Studies of social phobia, eating disorders and body dysmorphic disorder are considered in slightly more detail, since they represent the nearest approximation in clinical populations to the difficulties with body image and social situations reported in facially disfigured people. Finally, the implications of the cognitive-behavioural approach for the examination and treatment of psychosocial difficulties following disfigurement are outlined. These implications are further explored in Chapter 8, where a cognitive-behavioural, fear-avoidance formulation of these difficulties is described.

#### **Section 7.2 Development of behaviour therapy**

Modern behaviour therapy consists of a number of elements which are typically derived from learning theories, especially those concerned with operant and classical conditioning, and, more recently, with social learning theories (Newell, 1996). Strict behaviourists argue that internal motivating processes such as thoughts and feelings are both opaque to the client and therapist and possibly irrelevant to the process or outcome of therapy. Although agreement with such assertions

varies amongst therapists, they are generally united in their belief that client *behaviour* is the most important aetiological and maintaining factor in problematic client behaviour. Thoresen and Coates (1978) argue that behaviour therapy is best sited within the scientific tradition of empiricism. Individual client problems are seen as instances of inappropriate learning, with treatment seeking to either undo the effects of such learning or to initiate new learnt behaviours incompatible with problematic aspects of the client's life.

Problem behaviours are always the direct focus of treatment, and little discussion of underlying causes will take place (Marks, 1986). Most behaviour therapists minimise or deny the importance of such assumed causes, and some assert that the notions of cause and symptom are inappropriate applications of medical models to psychological distress. Behavioural theorists argue that all human behaviour is either innate or the result of learning. This is as true of maladaptive behaviours as of adaptive ones. We do not describe *adaptive* behaviours as symptomatic of some underlying pathology, so there is no logical reason to do so with problem behaviours (Newell, 1996).

Behaviour therapy is a wide-ranging approach, and has been applied to many different client difficulties, from anxiety based disorders to education of people with learning disabilities to behavioural medicine. Since the current study focuses principally on social anxiety in facially disfigured people, only those elements of the behavioural approach concerned with anxiety are addressed here, and in this connection, arguably the most significant therapeutic advance was the notion of 'reciprocal inhibition', developed by Joseph Wolpe (1958). Wolpe was originally trained in psychoanalysis, but came to be critical of the apparent lack of ability of this therapy to alleviate the problems of clients. He derived the concept of reciprocal inhibition from observations, during animal work on induced fear, that feeding behaviour was inhibited during induction of the fear response. He hypothesised that anxiety might therefore be inhibited by feeding, and that such inhibition of anxiety, if demonstrated, might prove useful in clinical treatment of neurotic complaints (Wolpe, 1952).

Wolpe extended his animal work to address the difficulties of human clients, typically using relaxation (Wolpe, 1958) as the response said to reciprocally inhibit anxiety. In psychotherapy by

reciprocal inhibition, the client visualises a hierarchy of situations which successively approximate to the feared situation, relaxing at each stage. When each situation can be visualised without anxiety, the client progresses to the next. Finally, the situations are confronted in real life. This form of 'systematic desensitisation' has an excellent success rate with many anxiety based disorders (Rachman & Wilson, 1980), and has been demonstrated to have outcomes superior to traditional verbal psychotherapies, even in reviews conducted by commentators sympathetic to such psychoanalytically-oriented treatments (Smith & Glass, 1977). It also appears that treatments based upon reciprocal inhibition are as effective as more modern cognitively-led interventions (see Section 7.3, below).

Reciprocal inhibition is said to operate principally by the mechanism of extinction, whereby an organism ceases to demonstrate a conditioned response (fear) to a conditioned stimulus (say a large store, in the case of an agoraphobic) when it is presented in the absence of its associated unconditioned stimulus (e.g. autonomic arousal). By contrast, flooding, and the more recent exposure therapies (Marks, 1987), are described as operating principally as a consequence of habituation, that most basic process of learning, whereby an organism ceases to respond to a repeatedly presented stimulus (Walker, 1987). Thus, in exposure, the individual is confronted, typically in real life, rather than in imagination, by the feared situation, and encouraged to remain there until such time as anxiety subsides as a consequence of habituation. It has been demonstrated that the results of this approach are, in phobias, at least as effective as reciprocal inhibition. Moreover, the approach avoids the necessity to teach relaxation exercises or to construct complicated hierarchies, with resulting saving in time for both client and therapist. Exposure instructions can be offered both by a human therapist and by the use of proxies such as computer programs and self-help manuals (Marks, 1987).

The dominant theoretical model of the acquisition and maintenance of problematic behaviours was, for a considerable time, the two factor (Mowrer, 1960) or two process theory (Gray, 1975), which asserted that problems such as phobias arose as a result of classical conditioning, but were maintained by operant conditioning, principally through the mechanism of negative reinforcement. Thus, the agoraphobic in the example above *acquires* the fear of shopping in a large store by



pairing the unconditioned stimulus of, for example, the chance occurrence of untoward bodily symptoms (perhaps a consequence of some minor physical illness) with the conditioned stimulus of the surroundings of the store, which in turn comes to elicit a conditioned response of subjective feelings of anxiety, even in the absence of the original eliciting bodily symptoms. This response is repeated in similar situations through the process of generalisation, in which organisms respond to stimuli similar to the one to which their conditioned response has been trained (Walker, 1984). However, the agoraphobic response is generally *maintained* by active and passive avoidance. When in the feared situation, the client experiences the aversive physical sensations of anxiety, and rapidly leaves the situation. This leads to a diminution in the aversive sensations, a situation which, according to the operant principle of negative reinforcement, increases the likelihood of future instances of the behaviour which has led to this diminution, in this case, escape behaviour.

Whilst exposure theory relies principally on the notion of habituation, it may be seen that the action of remaining in the feared situation until anxiety has subsided also stops the reinforcement of escape behaviour, because the client does not experience anxiety reduction as a result of escape, but as result of remaining in the situation and allowing habituation to occur. Since escape behaviour is no longer reinforced, its frequency reduces.

Behaviour therapy has been historically an eclectic tradition, drawing on numerous elements of learning theory. The social learning theory of Albert Bandura (1977a) was incorporated into behaviour therapy practice at a relatively early date and marks a progression from behaviour therapy to cognitive-behaviour therapy. Both social learning theory and the therapeutic use of modelling (the process whereby individuals imitate behaviours which they have observed being reinforced in others) have a clear basis in operant conditioning. However, social learning implies considerable cognitive processing by the client, whose own behaviour is not itself directly reinforced. The client thus has to construct, through observation, an expectation of reinforcement. Bandura's work both recognises the existence of such processes and describes them as influencing the surrounding environment as well as being influenced by it. Social learning theory is thus less deterministic than operant and classical learning theories. Bandura has developed treatment interventions based on social learning theory and modelling, involving acquisition of desired

behaviours such as social skills or approach to feared situations following demonstration and reinforcement of these skills by the therapist or some other appropriate model. This modelling may also be carried out via cognitive rehearsal of desired behaviours, symbolic modelling through writing and speaking, or the processes of self-monitoring, self-modelling and self-reinforcement (Bandura, 1986). The link between the work of Bandura and that of the cognitive theorists and of cognitive and cognitive-behaviour therapists, lies in his acknowledgement of the importance of internal processes in determining behaviour. However, the role accorded to these processes remains comparatively modest in Bandura's (1977a) essentially conditioning based formulation, when this formulation is compared with later, more fully realised accounts of a cognitive contribution to human behaviour.

### **Section 7.3 Behaviour therapy and cognitive therapy**

A number of criticisms of behaviour therapy and behavioural accounts of human experiences have been advanced. Behaviour therapy is by no means universally effective, even where it is the treatment of choice. There are numerous conditions which, whilst causing significant distress, contain little, if any observable behaviour upon which treatment can focus. Insufficient detail is said to be paid by behaviour therapy to the client-therapist relationship and adherence to therapeutic instructions (Hawton et al., 1989). Each of these arguments is capable of refutation (Newell & Dryden, 1991). Although few would argue that behaviourism (or indeed any other account) is a complete description of human experience, the imperfection of behaviour therapy as a treatment is not necessarily an indication of this lack of completeness, but could equally be caused by such issues as inadequate assessment of the problem, therapist inexperience or lack of adherence to clinical instructions by the client. Similarly, the lack of emphasis upon the therapeutic relationship is not a criticism of the theory of behaviour therapy itself, but of the way in which it may sometimes be practised, and indeed, behaviourists have expended a good deal of energy in attempting to understand this relationship, particularly as it bears on adherence. The most that can be said is that behaviour therapy does not primarily use the relationship as the mechanism by which treatment is expected to work. Finally, whilst lack of observable behaviour has in the past represented both a therapeutic and a theoretical problem for behaviour therapists, some disorders without such behaviour have nevertheless been successfully addressed, most notably obsessional thoughts

(Salkovskis & Kirk, 1989). Moreover, some behaviourists explicitly admit the existence of and work with cognitive processes, but simply assert that these processes are subject to the same laws of conditioning as overt behaviours (Jaremko, 1986). Nevertheless, for many researchers and therapists, strictly behavioural accounts of human distress have come to be regarded as too simple to account for the complexity of many everyday human behaviours, such as speech.

Bandura's (1977a) social learning theory represented an early move towards the incorporation of notions of internal processing of events into both theories of human behaviour and the practice of therapy. However, both cognitive therapy and cognitive-behaviour therapy contain more fully developed accounts of such internal processes.

Cognitive therapy consists of a broad range of accounts of the genesis and maintenance of human difficulties and of their treatment. For example, Rachman and Wilson (1980) noted that the founders of two dominant forces, Beck's cognitive therapy (1976) and Ellis's (1962) rational-emotive therapy had their professional beginnings in psychoanalysis, whilst Meichenbaum (1977), who developed self-instructional training and cognitive behaviour modification, came from the behavioural tradition. Their therapies reflect some of this difference in origins, but are united to a considerable degree by their development principally from clinical situations and observations. By contrast, later accounts have attempted to integrate such observations with developments in cognitive psychology, using computer analogues of human information processing and empirical studies of the cognitive processes of non-clinical populations (Newell & Dryden, 1991). Nevertheless, these varying approaches share at least four key similarities. They all agree that thoughts exist, mediate client problems, are capable of change by therapist and client and are the primary focus of therapeutic endeavours toward such change (Newell & Dryden, 1991).

The cognitive therapies stress the importance of a mediating, or even causative role for cognitions. Beck's (1967) description of the 'cognitive triad' of negative thoughts about the self, the world and the future as the key feature of depression is now widely accepted, both in cognitive therapy and in mainstream psychiatry, whilst his notion of 'modes' of thinking (subdivisions of his 'schema' or processing rules in long term memory) offers a rationale for the development of different client

problems. Thus, if an individual is overactive in terms of an anxious mode of thinking, this might both activate anxiety schema in the presence of relatively trivial threat and lead to continuing activity of this schema after the threat has passed (Beck & Emery, 1985). This conceptualisation of anxiety is, like much of the work of Beck and Ellis, based primarily on observation of clinical populations, and owes comparatively little to cognitive psychology. Whilst there is some evidence that the cognitive therapies of Beck and Ellis are effective, at least in depression, this success may owe as much to pragmatic elements of the therapy as to the purported theories of cognition embodied in them. However, some studies do suggest the existence of cognitive biases such as those suggested by cognitive therapists. Thus, Bradley and Mathews (1988) found depressed subjects recalled more negative material referring to the self than did either recovering depressed clients or controls, whilst the recovering depressives recalled more negative material related to others. For cognitive therapy, this study is important in two ways. First, it supports the existence of two aspects of Beck's cognitive triad (negative thoughts about the self and others) in depressed and recovering depressed individuals and, more importantly, it suggests, in the finding for recovering depressed individuals, the existence of some mediating element in this response bias which is more enduring than a simple effect of mood. A Beckian 'schema' could represent such an element. The Bradley and Mathews (1988) experiment represents one of a number of attempts to investigate the assumptions of cognitive therapy using the methods and theoretical constructs of academic cognitive psychology. These attempts are reviewed by Brewin (1988).

In brief, behaviour therapy may be characterised as a concentration on modification of the effects of faulty conditioning, whilst cognitive therapy may be summarised as a concentration on addressing the effects of faulty thinking. Thus cognitive therapists educate clients as to this model for their difficulties and train them to recognise, monitor and challenge such dysfunctional thinking when it occurs. Since cognitive therapists regard errors in thinking as causative of client difficulties such as depression and anxiety, the modification of such errors in thinking is believed to lead to improvement. However, criticism of cognitive therapy has arisen from a variety of sources. Wolpe has been extremely sceptical of the claims of cognitive therapy in treatment of anxiety, and questioned its distinctiveness as a form of intervention (Wolpe, 1978), whilst Marks (1987) has noted that many of the supposed effects of cognitive therapy could be accounted for by a simpler

mechanism, such as habituation. Furthermore, cognitive therapies have always included elements of behavioural experimentation (aimed at testing faulty cognitions), increasing the likelihood that such mechanisms as anxiety reduction through habituation, rather than restructuring of dysfunctional cognitions, might be responsible for improvement. A number of studies have attempted to dismantle the differing elements of treatment, but this is not always easy, because of the insistence of cognitive therapy on the use of behavioural experimentation. However, a meta-analysis of studies examining cognitive therapy with a range of anxiety-based disorders (Berman et al., 1985) found no difference between cognitive therapy, systematic desensitisation and a combination of these treatments. The analysis was well-conducted, taking reasonable care to include well-conducted studies. It differed from an earlier analysis by Shapiro and Shapiro (1982) which found an advantage for cognitive therapy. Berman et al. (1985) suggest that this discrepancy was caused by the inclusion in the Shapiro and Shapiro (1982) study of a majority of studies conducted by supporters of cognitive therapy.

Caution is, however, required in interpreting the Berman et al. (1985) finding, since it is apparent that these authors themselves have a bias - this time towards finding no difference between the therapies. They discuss previous findings of equivalence between psychotherapies, but their examination of these misses the methodological weaknesses and biases of the major study in the field (Smith et al., 1980). Rachman and Wilson have described the problems of the work that led to this publication in their own review of psychotherapy and also reviewed the shortcomings of inadequate meta-analyses such as the Smith and Glass (1977) review (Rachman & Wilson, 1980), and these issues will not be repeated here. It suffices to say that Berman et al. (1985) both accept the precepts of the Smith et al. (1980) review without reservation and ignore the substance of the Rachman & Wilson (1980) critique entirely, focusing on and criticising its conclusion without examination of the arguments which led to it. It may be concluded from this approach to the debate on therapeutic equivalence that Berman et al. (1985) are predisposed to see all therapies as equivalent, and that this may have influenced their analysis.

#### **Section 7.4 Cognitive-behaviour therapy**

Whilst cognitive therapy has been characterised as emphasising the primacy of cognitions in determining client difficulties and behaviour therapy as stressing the primacy of behaviours, cognitive-behavioural approaches take both a more varied view of causation and a more pragmatic approach to therapy. These approaches certainly retain an emphasis on cognition, but are likely to examine other response systems when arriving at a formulation of the origins and maintenance of particular client difficulties. A relatively durable approach to the assessment and treatment of client difficulties is the three systems model advocated by Lang (1971) and later refined by Rachman and Hodgson (1974). Lang (1971) divided human experience and client problems into three systems: physiological activity (in particular, in the context of anxiety, autonomic activity), behaviour, and cognitive activity (as revealed by verbal report). Intervention by the therapist might be directed at whichever of the systems appeared primarily affected, employing a primarily physiologically, behaviourally or cognitively oriented set of interventions, such as relaxation, exposure, or cognitive restructuring respectively. It is this flexibility and willingness to embrace differing techniques which distinguishes cognitive-behavioural approaches from more traditional behaviour therapy or cognitive therapy. However, it is worth repeating that cognitive therapy had contained behavioural elements since its inception, whilst cognitive aspects of experience were integrated into behaviour at a very early stage, through the use, for example, of modelling, teaching new skills, self-monitoring. This suggests that differences between the practice of cognitive and behaviour therapy may have been less than an examination of their theoretical standpoints would lead the observer to expect. Indeed, a major review (Berman et al., 1985) found considerable overlap in terms of the procedures employed by the two orientations. It has been suggested that, rather than speaking of a distinct cognitive-behaviour therapy, it may be more appropriate to refer to cognitive-behavioural orientations (Newell & Dryden, 1991). Such orientations will lead to treatment interventions which take account of cognitive elements of human experience to various degrees.

Whether the addition of cognitive to behavioural elements is, in fact, a requirement for therapeutic efficacy is a matter of considerable debate. Berman et al.'s (1985) assertion of equivalence between the approaches is based on the notion that failure to detect differences between two treatments is indicative of such equivalence. Clearly, this is not necessarily the case. If one

treatment consisted, for example, of in vivo exposure, whilst the comparison treatment consisted of cognitive restructuring *plus* in vivo exposure one might certainly conclude that the two packages of care were of equivalent effectiveness. However, no conclusion could be drawn about the efficacy or otherwise of cognitive restructuring. Indeed, it would be tempting to assert that it added nothing to the efficacy of exposure. The effects might be the same not because cognitive and behaviour therapies are equivalent, but because the cognitive and behaviour therapies both include an effective component (behaviour therapy), whilst the cognitive and combined treatments include an additional ineffective element (cognitive therapy).

The Berman et al. (1985) review did, in fact include a handful of dismantling studies of this form, which demonstrated a modest but statistically significant benefit from the addition of cognitive elements to desensitisation, but no such benefit from the addition of desensitisation to cognitive therapy alone. The difficulty in accepting these findings lies, however, in the common inclusion of behavioural elements in treatments described as cognitive therapy. Since the Berman et al. study inadequately explores this issue, it is entirely likely that the presence of behavioural elements within the cognitive therapies in this study accounts for the lack of difference between cognitive therapy and cognitive therapy and desensitisation combined, as well as the lack of difference between the two main treatments (cognitive therapy and desensitisation) shown in other elements of the study.

The assertion that cognitive components of therapy do not add to the effectiveness of behavioural interventions with anxiety is controversial at a time when cognitive therapy and cognitive-behaviour therapy enjoy great popularity. However, there have been a number of persuasive dissenting voices. A review by Beidel and Turner (1986) did not find any evidence for the greater effectiveness over behaviour therapy claimed by advocates of cognitive-behaviour therapy. Similarly, an earlier study by Latimer and Sweet (1984) had found cognitive methods to be superfluous. A more recent and wide-ranging review (Sweet & Loizeaux, 1991) re-examined this contention of greater efficacy for cognitive-behaviour therapy in considerable detail. A key element of the review was careful definition of behaviour therapy, cognitive therapy and cognitive-behaviour therapy, in order to avoid the confusion inherent in examining ill-defined treatments. They examined 40 studies which compared cognitive therapy, behaviour therapy and combined cognitive

and behavioural packages, in order to determine whether the addition of cognitive elements increased the effectiveness of behavioural interventions and whether such combined interventions were superior to cognitive therapy alone.

In 24 studies which allowed comparison of behaviour therapy and combined intervention 83% showed no benefit from the addition of cognitive elements. No difference was found between cognitive therapy and behaviour therapy in 9 out of 13 studies which allowed comparison of the separate treatment elements, and 7 of 22 studies demonstrated a 'substantial but not superior clinical improvement' for cognitive therapy when compared with behaviour therapy or cognitive behaviour therapy. It should be noted throughout, however, that the lack of demonstrable difference is not the same as the demonstration of equivalence, which requires precise definition of the criteria by which such equivalence is to be judged. Rather it is the simple noting that a study has failed to find differences, an occurrence which could, for example, be caused by lack of statistical power to detect change within the experiment. Of the studies in which cognitive therapy was effective, 6 were studies of social anxiety, and, of these, 3 studies indicated differences of clinical importance. However, of the 10 reports of treatment of social anxiety, the majority did not show superior results for either cognitive therapy or cognitive behaviour therapy over behaviour therapy.

The Sweet and Loizeaux (1991) study is a careful, well constructed qualitative literature review, which is conservative in the conclusions it draws from the literature. They note that whilst the majority of studies fail to find an incremental therapeutic effect for cognitive interventions, a few do. In consequence, they conclude that the earlier findings of Latimer & Sweet (1984) of no advantage for the inclusion of cognitive elements in therapy might be slightly modified. However, this may be too optimistic a view, both since the number of studies which show an advantage for cognitive additions is modest (4 out of 24 comparisons between behaviour therapy and cognitive behaviour therapy) and because, as they rightly comment this modest clinical advantage over behaviour therapy has taken some 20 years to accrue. They conclude that there is little justification for the 'wholesale adoption of cognitive terminologies, explanations and procedures', but also note that cognitive therapy has shown some indications of efficacy in the field of social anxiety. They also



note that, in unipolar depression, they found no justification for Dobson's (1989) assertion that cognitive therapy should be regarded as the treatment of choice. In the current review, the 8 studies of depression did not show advantages for one mode of intervention over another. Since depression is the complaint for which cognitive therapy has been most frequently advocated, this adds considerable weight to the suggestion that caution should be exercised before the addition of possibly unnecessary and time consuming elements to behavioural interventions.

Behaviour therapy and cognitive-behaviour therapy today are generally eclectic approaches (Newell, 1996), in which the therapist chooses from a range of techniques which have generally been empirically tested and received some level of support. In examining unfamiliar client difficulties, the therapist attempts to proceed in a way which draws on these techniques and applies them in unfamiliar circumstances whilst attempting to construct treatment in an experimental way which allows both client and therapist to assess the effectiveness of the interventions used. In particular, behaviour therapists have advocated the use of single case experimental designs (Kazdin, 1976). These methodological tactics attempt to adapt the scientific rigour of the experimental situation to the examination of individuals, and are asserted to be of particular relevance to the clinician, since they can be integrated into everyday clinical practice (Newell, 1992). Both the use of empirically tested treatment methods and the continuing use of scientific method to test new treatment approaches have been continuing themes which have lasted from the inception of behaviour therapy in the middle of this century until the present day, when cognitive-behaviour therapy represents the most widely investigated and supported mode of intervention for a wide range of client difficulties (Rachman & Wilson, 1980). As with medicine and nursing, behaviour therapy and its variants face a continuing challenge to ensure that clinically effective practices gain acceptance amongst practitioners whilst approaches which have the support of clinicians from their often biased experiences fade from their therapeutic armamentaria. Debate over both theory and clinical efficacy have been part of behaviour therapy and its successors since its inception, and it is important to recognise that the therapeutic orientation of behaviourism is sufficiently concerned with scientific rigour to allow such debate to continue. For the remainder of the current study, the term cognitive-behaviour therapy (CBT) will be used to refer to all those

treatment methods which derive their main impetus from work in conditioning theories of learning, but include some level of examination of cognitive elements as part of treatment.

### **Section 7.5 Cognitive-behavioural approaches to treatment of disturbed body image and disfigurement**

The general aims of the current study were described in Chapter 1, and the specific objectives are outlined in Chapter 9. In essence, the study aims to establish the features and frequency of avoidance behaviours in disfigured individuals and to offer a formulation of possible intervention based on those features. There are, however, no published studies of the treatment of psychological sequelae of facial disfigurement from a specifically cognitive-behavioural viewpoint, with the exception of Robinson et al.'s (1996) recent study and the studies of Fiegenbaum (1981), both of which focus on social skills training as the main treatment element. In particular, there is neither any specific reference to the use of exposure therapies in addressing social or other behavioural avoidances in disfigured individuals, nor of the role that such therapies might play in illuminating the processes which mediate the psychosocial difficulties of disfigured people. There are, however, studies of cognitive-behavioural interventions in areas of relevance to disfigurement, if we assume the occurrence of social avoidance and body image dissatisfaction in disfigurement. The main treatment studies which bear upon these difficulties are in the area of social phobia, eating disorders and, most recently, body dysmorphic disorder (BDD). Since the intervention examined in the current study involves a self-help manual along CBT lines, the effectiveness of such manuals in other contexts will be examined in the method section of Chapter 9.

Phobic disorders in general are characterised by irrational fear and avoidance of particular objects or situations. It has been suggested by Seligman (1971) that phobias, although learned and maintained through the processes of classical and operant conditioning, are also genetically prepared. The phenomenon of preparedness leads humans to be more likely to develop phobias towards entities or situations which are potentially dangerous to the species. Thus, such phobias as fear of heights, enclosed spaces, certain animals, are likely to occur commonly because fear and avoidance of these things has a potential survival value for the species.

The case of social phobia is more complex, since fear of social situations is most often coupled with fear of some more abstract entity such as negative appraisal or ostracism by others (Butler, 1989). Sufferers typically avoid social situations, and this may be highly specific, being confined, for example, to eating with others, being in group situations or dating, or may extend to a broad range of social situations. The sufferer may fear negative appraisal, rejection, inability to perform, panic or even collapse, and the complaint is often accompanied by severe situational autonomic arousal (Butler, 1989). However, fear of negative appraisal in social situations may indeed have survival value. The human species is highly social, and isolation from others as a result of their negative appraisal has obvious negative consequences with regard to the survival of both an individual and his/her genetic material. Individuals who are negatively appraised might be deprived of the support of the group in times of hardship and less likely to mate. Thus there may be good reason to speculate that fear of negative social appraisal is genetically prepared. Unfortunately, as in many other phobias, the avoidance behaviours associated with this fear lack survival value, since they are themselves associated with isolation.

Cognitive-behaviour therapy is the treatment of choice for social phobia and typically contains major components of exposure to the feared situations. It has been noted earlier that cognitive therapy alone may also have a therapeutic effect in social anxiety, although the value of adding cognitive components to behaviour therapy is uncertain (Sweet & Loizeau, 1991). In a recent review of CBT approaches to anxiety, Chambless and Gillis (1993) conclude that CBT has consistently demonstrated results superior to waiting list and placebo controls and to supportive psychotherapy. However, the addition of specifically cognitive elements did not unequivocally appear to contribute to treatment effectiveness, with only 2 out of 8 comparative studies resulting in greater improvement with such additions. One of these studies (Butler et al., 1984) was particularly well carried out, using a demonstrably credible ineffective 'filler' treatment to control for the extra time involved in adding group anxiety management to exposure treatment. The addition of anxiety management appeared to lead to greater resilience against relapse. Differences between exposure alone and exposure plus anxiety management were apparent on more measures at follow-up than post treatment and considerably more exposure patients sought further treatment during the follow-up. However, the numbers in the study were small (15 per group) and a replication of this study would

be welcome, particularly since Chambless and Gillis (1993) alert us to the dangers of introducing combination treatments without good evidence. Addition of elements within a fixed number of sessions may lead to superficial coverage of each, with reduced opportunity for the client to master any, and may also obscure clarity of delivery of the treatment rationale which, Chambless and Gillis note, is itself therapeutic. To these criticisms it should be added that, even where session numbers are not specifically limited, the addition of ineffective or minimally effective elements wastes therapist and client time. In the case of the therapist, this means that treatment can be offered to fewer clients, whilst for the client increased therapeutic time might foster dependence or lead to a decrease in the impetus of the therapy and thus of client adherence to clinical instructions. The Chambless and Gillis (1993) review adds strength to the admonition of Sweet and Loizeaux against adding therapy elements of dubious incremental effectiveness. However, in minimal contact settings such as bibliotherapy and the independent use by phobics of self-help publications, the addition of promising but as yet unproven elements may represent less of a drawback.

A great deal of work in the area of body image has come from studies of *disturbance* of body image in general, and from studies of eating disorders in particular. Much of the treatment of such disturbance has likewise been conducted in the area of eating disorders, an area in which cognitive-behavioural interventions are now pre-eminent, both in terms of amount of study devoted to them, and of the success of their approaches.

Treatment of eating disorders, in particular anorexia nervosa and bulimia, by behavioural means has a long history (Fairburn & Cooper, 1989). The relevance of such treatments to facially disfigured people lies in the negative appraisal of their body by sufferers from anorexia and bulimia, and in their behavioural avoidances. Negative body appraisal and body image distortion by anorexics were noted in Chapter 2. The behavioural avoidances of anorexia in particular are a distinctive feature, and the complaint has variously been described as a weight phobia (Crisp, 1967) and a fear of fatness (Russell, 1970), as well as possessing obsessional features (Fairburn & Cooper, 1989). The chief avoidances are of eating and weight gain, whilst there are often such other avoidances as specific foods, eating in front of others, wearing revealing clothes. All these avoidances are said to be fuelled by the inappropriate perception of ideal body size and negative

appraisal of the sufferer's own body. Other clinical features such as vomiting, abuse of purgative agents, dieting and extreme exercise are likewise considered to be secondary to these overvalued ideas regarding appropriate shape and weight. However, clinicians in the field both acknowledge the importance of other difficulties less obviously related to body image (e.g. disordered family functioning, fear of loss of control), and address these issues during treatment (Fairburn & Cooper, 1989).. Thus, extrapolations from treatment of people with eating disorders to those with facial disfigurement should be made with caution, and this literature will not be examined here. The CBT approach is well summarised by Fairburn and Cooper (1989) and involves a variety of elements such as retraining eating habits, the use of stimulus control techniques, cognitive restructuring and self-monitoring, many of which involve the client in exposure to feared situations such as weight gain, shape change and eating.

The success of CBT in addressing anorexia nervosa and other eating disorders is relevant to the study of psychosocial difficulty following disfigurement because of the presence within these disorders of both disturbance of body image and the behavioural avoidances which are said to be consequences of this disturbance. Indeed, the investigation of facial body image disturbance, avoidance, psychosocial difficulty and their possible relationships forms part of the current study. A similar pattern of disturbed body image and behavioural avoidance has also been found in body dysmorphic disorder (BDD). This complaint, referred to as dysmorphophobia in earlier studies but described as BDD throughout this review, is an irrational fear that a bodily attribute is offensive to others. Since the complaint usually centres around a single attribute, such as a facial feature, the growing success of CBT in treatment is of particular potential importance with reference to psychosocial difficulties following disfigurement.

Although some commentators have denied that BDD is truly phobic, since the body attribute is not itself feared, Hay (1970b) rightly comments that the phobic element is present, but in the patient's fear of offending others aesthetically. It is interesting, in this connection, to recall the fear of negative appraisal by others present in social phobia. It may be possible that the fear of offending others in body dysmorphic disorder might be prepared for in Seligman's (1971) sense of having species survival value in the same way that was suggested of socially phobic fears earlier in this

chapter. The existence of the attractiveness stereotype described in Chapter 3 and the great importance attached to physical, and particularly facial appearance by humans add considerable weight to the speculation that preparedness plays a part in the development of BDD, particularly given the support for early development of this stereotype in children (Dion, 1973). Certainly the complaint shares a considerable number of features with social phobia, since social activity is often avoided, for fear that the body attribute will offend others. As with anorexia nervosa, it can be suggested that in BDD these avoidances are secondary to the overvalued idea of bodily deformity. Diagnostically, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1995) attempts to distinguish BDD, in which this idea although extremely fixed is amenable to rational argument, from Delusional Disorder, Somatic Type, in which the idea has reached delusional proportions and so cannot be so modified. Clinically, this is a difficult distinction to make, given that fixity of ideation and amenability to persuasion are, by their nature, continuous rather than dichotomous. It has also been suggested that the term BDD be used exclusively for dissatisfaction with bodily *parts*, with the term Delusional Disorder, Somatic Type being reserved for overvalued ideas of delusional intensity about both body *parts* and bodily *functions*. In the current thesis, the expression bodily attributes is used to imply both parts and functions for three reasons. First, in non-clinical populations, including disfigured people, dissatisfaction is expressed both with appearance and function. Dropkin (1989) has suggested that it is possible to identify two separate scales relating to the severity of disfigurement and disturbance of function, but her study is flawed by the rating of functional disturbance by nurses, rather than the patients themselves. Whilst it seems intuitively that form and function might well be separate dimensions and therefore amenable to separate rating, the two issues are often difficult to disentangle clinically, particularly where appearance and function are closely linked (Newell, 1991). It is also worth remembering that appearance is itself a function, that of social expression of the self. Second, Marks and Mishan (1988) and Newell and Shrubb (1994) have argued that individuals who fear that they smell from halitosis, body odour or flatus are simply reflecting an overvalued idea regarding the body's ability to offend others via a sensory modality other than sight. Older studies (e.g. Beary & Cobb, 1981), as well as the Marks and Mishan (1988) and Newell and Shrubb (1994) papers have included such patients in their series, and used similar treatment approaches to those with people with a concern over bodily appearance, with similar levels of success, indicating that the

modality debate in BDD may be unimportant for treatment. Finally, Newell and Shrubb (1994) have noted that, with regard to bodily functions, there is no non-psychotic diagnosis equivalent to Delusional Disorder, Somatic Type in the same way that BDD is said to represent such an alternative in the case of body parts. Whilst hypochondriasis is a contender, it should be noted that, unlike hypochondriacs, individuals who claim offensive bodily functions do not necessarily claim illness. In view of this, it is concluded here that BDD represents complaints and fears that some bodily attribute (part or function) is offensive to others. This fear drives a series of behavioural avoidances and excesses (such as checking rituals, repeated washing, wearing of excessive make-up) which handicap the person's life in a manner similar to social phobia and obsessive compulsive disorder, but with an overvalued idea related to body image similar to that in anorexia.

Although isolated treatment studies of successful pharmacological intervention for BDD exist (e.g. Hollander et al., 1994), these are small in scale and do not, as noted by Gournay et al. (1997), adequately take into account the co-morbidity with depression often present. Thus, improvement in client well-being as a result of medication might be the result of improvement in their depression, rather than of BDD. By contrast, an expanding body of work supports the usefulness of a cognitive-behavioural approach to BDD, addressing both behavioural avoidance and the overvalued idea. The earliest accounts of successful behavioural treatment for BDD date from a single case report by Munjack (1978) using systematic desensitisation, and a small case series by Beary and Cobb (1981) using a variety of behavioural approaches, whilst Marks and Mishan (1988) reported success for exposure therapy in a study of five patients. The exposure treatment used was derived from work with phobic patients, and involved BDD sufferers deliberately entering situations which had previously been avoided because of what clients believed to be the reactions of others to their supposed deformities. However, patients in the Marks and Mishan (1988) study consumed many hours of therapist time, and recovery was incomplete in some cases. Moreover, several individuals had concurrent medication, which may have contributed to their improvement with exposure therapy. Nevertheless, these studies, and those of Neziroglu and Yaryur Tobias (1993a, b) indicated considerable promise for exposure therapy. The first accounts of an integrated CBT approach which addressed the issue of the overvalued idea directly are attributed in the Gournay et al. (1997) review to Newell and Shrubb (1994) and Cromarty and Marks (1995). Newell and Shrubb

(1994) combined the exposure technique of encouraging clients to enter situations avoided because of their assumed deformity, with generation of coping tactics, primarily through a series of role-play exercises in which the client would argue *against* the overvalued idea with the therapist, who would argue that the client's worst fears of bodily impairment were, in fact, true. As part of this exercise, clients were required to research and present evidence which refuted their overvalued ideas of deformity. The Cromarty and Marks (1995) case study was essentially a replication of this approach. Results from these small studies indicated considerable clinical improvement, with relatively modest therapeutic input compared with the Marks and Mishan (1988) series. The promise shown in these studies was supported in a small randomized controlled trial by Gournay et al. (1997). Clients received a 12 session cognitive behavioural intervention package employing exposure and elements of the technique introduced by Newell and Shrubbs (1994), and were compared with a waiting list no-treatment control. Clients in the treatment group fared significantly better than controls at the post-treatment point on all measures, and showed improvement over time between pre- and post-intervention scores on 5 of the 7 measures. Clients in the control group showed no such improvements. Although the Gournay et al. (1997) study lacked a follow-up, the magnitude of the treatment gains, coupled with the continuing improvement of the two Newell and Shrubbs (1994) cases at up to 18 month follow-up indicate continuing promise for the CBT approach to BDD.

This cause for optimism is strengthened by the findings of Rosen et al. (1995) in a study of 54 female BDD sufferers which randomly allocated clients to CBT or no treatment. Clients in the active treatment group received 8 two-hour group sessions. These included an integrated BT package, with more marked emphasis on behavioural components of treatment than the Gournay et al. (1997) trial. Thus exposure instructions and exercises were combined with thought-stopping and response prevention, although instruction in challenging negative thoughts was also included in the package. Clients in the active treatment group fared better than controls on all 5 measures employed, at post treatment and 4 month follow-up. Additionally, clinically significant improvements were found in 82% of the treated cases at post-treatment and 77% at follow-up, an excellent result in treatment of a normally intractable complaint.



However, although Rosen et al. (1995) excluded anorexics and bulimics from their study, they included mildly obese individuals and it is clear from an examination of the subgroups that a considerable number had primary concerns regarding weight and weight-related appearance. Most other studies have treated only those with concerns about specific bodily features or functions. Thus, the Rosen et al. (1995) group may well differ considerably from other BDD series. Nevertheless, taken together, these results represent an encouraging picture for CBT intervention with BDD.

Gournay et al. (1997) have suggested that the approach taken with BDD sufferers might be extended to include those suffering from actual disfigurement, although one commentator (Latham, 1997) has noted that since the defining characteristic of BDD is the absence of such physical abnormalities, such extension of the approach should be cautious, whilst another (Newell, 1997) has suggested that in the light of the work of Rumsey (1983) and Robinson et al. (1996), both Gournay's assertions and, by implication, Latham's commentary, are too conservative.

An earlier controlled study (Butters & Cash 1987) used a mixture of in vivo desensitisation, relaxation and cognitive therapy techniques to address the body image difficulties of 31 respondents to a request for participants interested in intervention for body image disturbance. Inclusion criteria included scores higher than the 25 percentile of the Body Self Relations Questionnaire, absence of paranoid or psychotic symptoms, weight within 25% of the desirable median for height and absence of current psychotherapeutic treatment. The 15 patients receiving active treatment fared significantly better than 16 waiting list controls across a range of measures, including BSRQ appearance satisfaction, the Body Parts Satisfaction Scale (Berscheid et al. 1973), and numerous body related cognitions and behaviours. These results were largely repeated when the waiting list controls were offered an abbreviated version of treatment. However, as the authors suggest, the use of a non-clinical population limits the applicability of the study to actual patients. There is no indication that the subjects in this study would have been regarded as similar to a patient population. Nevertheless, the ability of a cognitive-behavioural intervention to effect changes in body image contributes to confidence in the effectiveness of such interventions where disturbed body image is a major feature, even where this disturbance does not amount to the

grossly overvalued idea present in BDD. Similarly, Tarrier and Maguire's (1984) study of post-mastectomy patients, which demonstrated significant improvement after treatment, suggests that, particularly if avoidance is a major factor of the client's difficulties, the effectiveness of exposure oriented approaches which emphasise confrontation of the disfigured area is not confined to psychiatric populations.

## **Section 7.6 Chapter summary**

The development of behaviour therapy from early accounts based on conditioning to the current emphasis on cognitions represents a gradual integration of an increasing number of cognitive elements into these initial approaches to treatment. Thus, the influential work of Bandura (1977a) marked a comparatively early departure from purely conditioning accounts of human experience, but was still grounded in operant theory. By contrast, cognitive therapies have typically included complex, rich accounts of human cognition, and have increasingly relied on information processing theories.

Behaviour therapy denied the value of attributing causes to problem behaviours, arguing that *all* behaviours, including problems, were a product of heredity and learning. Although cognitive therapies have introduced a certain causal element into cognitive-behaviour therapy, the emphasis in both the cognitive-behavioural approach in general and its treatment interventions remains on those behaviours, cognitions and physical phenomena which *maintain* client difficulties. The CBT approach remains rooted in normal psychology rather than psychopathology.

The effectiveness of the cognitive behavioural approach to focal anxieties such as phobias and obsessive compulsive disorders is beyond dispute (Marks, 1987), and cognitive-behavioural treatments usually do better than other interventions and substantially better than controls (Smith & Glass, 1977; Smith et al., 1980; Rachman & Wilson, 1980; Marks, 1987; Chambless & Gillis, 1993; Eysenck, 1994). It is not clear whether the addition of purely cognitive elements to the treatment approach has any additive effect. The position is complicated by the routine inclusion of conditioning oriented elements such as exposure within cognitive therapy, with the aim of behavioural testing of faulty cognitions. Since exposure therapy itself often includes elements such

as modelling, tuition in coping tactics and other cognitive interventions, the mechanisms underlying improvement are further obscured. However, elements of exposure to feared situations appear essential to clinical improvement, regardless of the mechanism said to be operating.

Two major reviews of psychotherapy became available to the author only during the late stages of preparation of this thesis (Roth & Fonagy, 1996; Parry, 1996), and so are not reviewed in detail here. However, both these reviews substantially confirm the status of cognitive-behaviour therapy described in this chapter. For example, whilst Roth and Fonagy are by no means unsympathetic to forms of therapy other than the cognitive-behavioural approach, they are generally unable to advance any coherent body of evidence for the effectiveness of these other approaches, merely noting that their lack of effectiveness has not been demonstrated, and that the therapies therefore deserve further investigation. By contrast, the evidence for the effectiveness of cognitive-behaviour therapy is regarded by Roth and Fonagy as considerable, particularly in focal anxiety disorders such as phobias and compulsions. A similar picture is found in Parry (1996), in that cognitive-behavioural interventions once again emerge both as having received the most attention in terms of the number of outcome studies conducted and the greatest amount of support for their effectiveness. The effectiveness of the addition of cognitive elements to behaviour therapy is not specifically examined in these reviews, and the value of adding such still requires further investigation.

Three clinical problems seem particularly relevant to the study of psychosocial problems following disfigurement. Social phobia involves avoidance of social situations and, on many occasions, fear of negative evaluation by others, whilst anorexia nervosa and other eating disorders combine avoidances with disturbance of body image, although it must be admitted that a considerable number of other difficulties typically influence the course of the eating disorders. In BDD these three elements come together. In all three difficulties, cognitive behaviour therapy is the intervention of choice, and the examination and modification of avoidance behaviours is generally a major feature in treatment.

The presence of disturbed body image, avoidance and fear of negative evaluation in these complaints has two consequences for those suffering from psychosocial disturbance following disfigurement. First, these features are similar to those described in accounts of the difficulties of disfigured people, and we may wish to argue that elements of the mechanisms involved in maintaining the difficulties of social phobia, eating disorders and BDD sufferers are similar to those involved in the difficulties of disfigured individuals. We may conclude that a major common factor in all these difficulties is anxiety. Second, the effectiveness of cognitive-behavioural approaches in addressing social phobia, eating disorders and BDD suggests that a similar approach may be of value in intervention with psychosocial disturbance following disfigurement. The existence of a therapeutic approach with demonstrable effectiveness is of great potential benefit to sufferers from such difficulties, provided it can be demonstrated that it is valid to extrapolate conclusions regarding the maintaining factors involved in those complaints for which CBT is effective to sufferers from psychosocial disturbance following disfigurement. Chapter 8 presents a fear-avoidance model for the development of psychosocial difficulties following disfigurement, and seeks to suggest that this extrapolation is indeed valid, whilst the empirical element of this study seeks to investigate this suggestion.

## CHAPTER 8

### TOWARDS A COGNITIVE-BEHAVIOURAL APPROACH TO PSYCHOSOCIAL DIFFICULTIES AFTER FACIAL DISFIGUREMENT

#### **Section 8.1     Introduction**

In Chapter 2, a number of general approaches to body image and its measurement were described. In the intervening chapters, a broad range of studies relevant to the field have been described. Several things are clear from this review. First, there are shortcomings with current models of body image and its disturbance. Second, there are no widely used or validated measures which specifically examine attitudes and behaviours related to the face. Third, the majority of accounts of the social encounters of disfigured people suggest that they are disadvantaged in these encounters and that many report them as a source of difficulty. Fourth, there is some indication that many disfigured people experience psychosocial difficulties, and that treatment provision is patchy at best. There is, however, no indication of the source of their difficulties, no large scale description of its elements, nor any coherent set of recommendations for treatment. Fifth, the number of treatment studies is small, probably contributing to the lack of recommendations for provision.

Finally, It has been argued in Chapter 7 that cognitive-behavioural interventions in fields which might be seen as relevant to psychosocial difficulty following disfigurement offer a potentially powerful form of intervention, provided that anxiety proves to be a key component of the difficulties faced by disfigured people. In consequence, a comparison between such individuals and those for whom treatment with cognitive-behavioural interventions is effective might be useful in determining the relevance of cognitive-behavioural treatment to facially disfigured people. However, no investigations of either the role of anxiety in maintaining the psychosocial difficulties of disfigured people or of the role of CBT in addressing those difficulties have been undertaken. In the current chapter, a cognitive-behavioural, fear-avoidance approach to psychosocial difficulties following facial disfigurement is described, including a formulation of factors maintaining the difficulties experienced by sufferers, a rationale for treatment and a number of predictions which may be made from the approach.

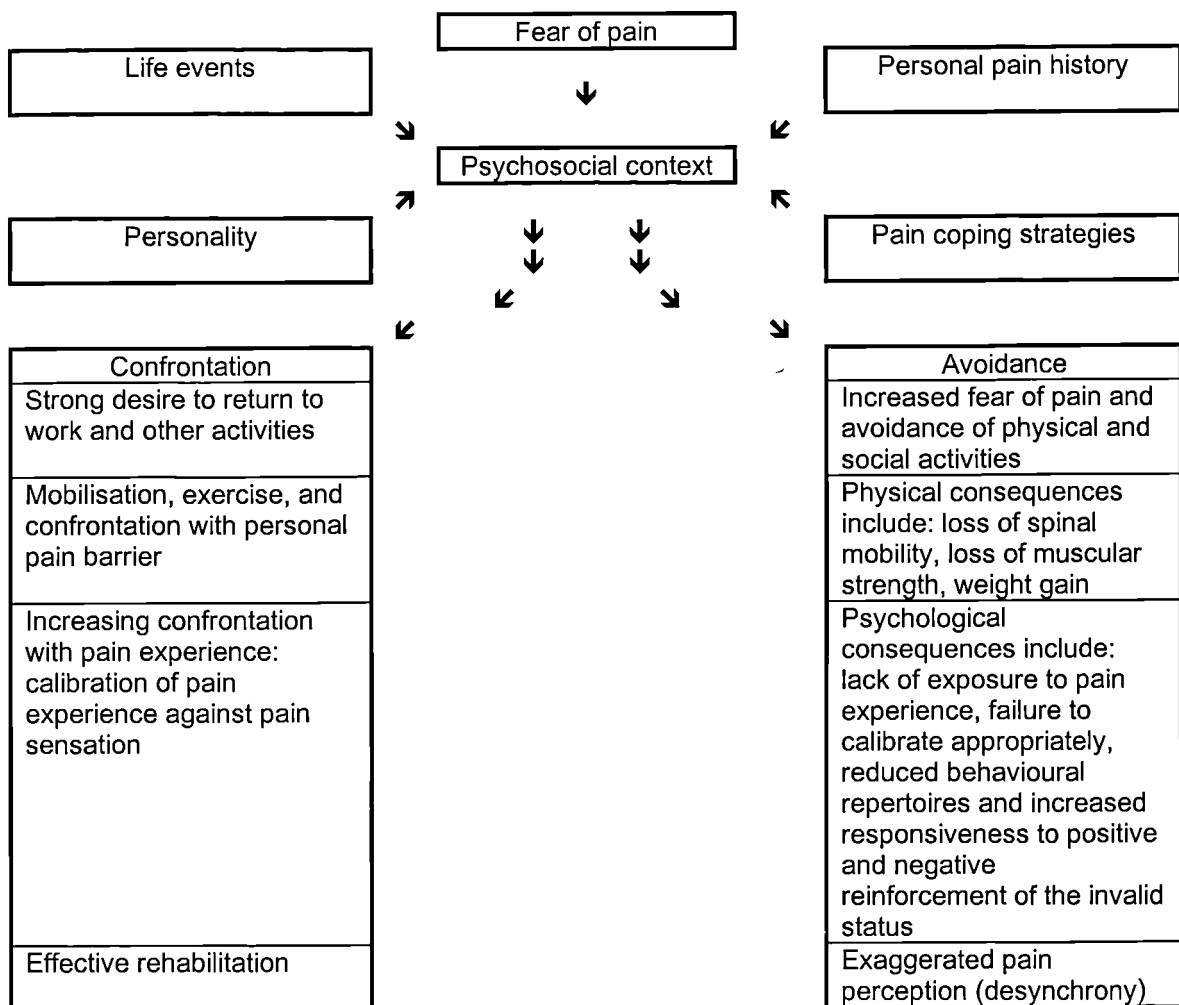
## **Section 8.2    Development of the cognitive-behavioural model of psychosocial disturbance following disfigurement**

The models of body image outlined in Chapter 2 contain within them descriptions of what might be expected in cases of disturbance of that body image. Of the two main models described, it was suggested that Price's (1990a) broad approach, whilst useful and important in nursing, contained a number of flaws, including circularity of argument and inadequate definition, whilst Slade's (1994) was, by contrast, too narrow, being derived from and applicable principally to eating disorders, whilst concentrating chiefly on perceptual elements of body image and the contribution of the other components to this aspect. However, it was also suggested that the Slade approach could be expanded to include both normal body image and difficulties other than eating disorders. This broadening of the Slade model included reference to Lethem et al.'s (1983) fear-avoidance model of exaggerated pain perception, a model with many elements in common with that of Slade, who was, in fact, part of the Lethem et al. group (Slade et al., 1983).

The Lethem et al. (1983) model provides a useful starting point for the cognitive-behavioural approach to facial disfigurement to be described in this chapter. Lethem et al. (1983) proposed that people who make adequate recovery from illness are those who tend to exhibit confrontation rather than avoidance, and that the tendency to confront rather than avoid is determined by interacting factors from the individual's background and environment (see Figure 8.2.1). The key contributing elements (life events, personality, pain history and coping strategies) produce a psychosocial context for the pain event which determines the individual's response to it along a continuum from avoidance to confrontation. Since they were working principally with back pain patients when they devised the model, confrontation and avoidance are described principally in terms of pain-related activity, and the consequences of avoidance are examined mainly in terms of changes to the body and failure to rehabilitate physically. However, the key element in the model is that avoidance takes place because of *fear* of pain, rather than because of pain itself. The patient *predicts* that pain is likely to occur if a particular behaviour is performed, and consequently avoids that behaviour. Similarly, if an activity is being performed and the patient predicts that pain is likely to ensue, then that activity will be ceased. Cognitive-behavioural accounts of the genesis and maintenance of anxiety through passive and active avoidance predict that, in consequence, the

range of permissible activities will become more and more restricted, and increasingly innocuous stimuli will be interpreted as threatening. Strict behaviourists will attribute these occurrences chiefly to the processes of generalisation and discrimination, and of negative reinforcement of avoidance (Walker, 1984). Whilst a number of cognitive interpretations are possible, perhaps the most relevant is derived from Bandura's self efficacy theory (1977b), which states that the likelihood of an individual performing an activity is based not only on reinforcement but on the individual's perception of their ability to carry out the activity. Repeated avoidance not only decreases the opportunity for reinforcement, but lowers the individual's perception that the activity is within their capability. In the context of back pain, Lethem et al. (1983) note the importance of physical changes resulting from avoidance, such as increased weight and decreased muscle tone. Moreover, a number of psychological changes, such as failure to calibrate pain and increased responsiveness to reinforcement of invalid status, are likely to arise, as the range of perceived abilities decreases. The model is related to the three systems model of Lang (1971), described in Chapter 7, and, in particular to the notion of desynchrony between the systems (Rachman & Hodgson, 1974). In essence, this model argues that client difficulties are due to such desynchrony. For example, a phobic person in a feared situation might misinterpret relatively mild autonomic symptoms of arousal as indicators of some catastrophic occurrence, such as heart attack, indicating desynchrony between the autonomic and cognitive system. In the case of the Lethem et al. (1983) approach, the desynchrony is between the physiological aspects of pain, on the one hand, and the subjective and behavioural aspects on the other. In Lethem et al.'s (1983) model, the key element said to maintain and increase disability and pain perception is not the pain itself, but the *fear* of that pain.

**Figure 8.2.1: Lethem et al.'s model of exaggerated pain perception**



(adapted from Lethem et al. [1983])

A recent test of the model (Rose et al., 1992) demonstrated significant differences between recovered and non-recovered patients. Moreover, these differences held good across three different pain problems (post-herpetic neuralgia, low back pain and reflex sympathetic dystrophy[RSD]) indicating that the applicability of the model is not restricted to types of pain associated with physical activity. A questionnaire reflecting the four elements of the model was given to 34 sufferers and a control group of recovered individuals. Statistically significant differences were found between the recovered and chronic low back pain and neuralgia groups on each of the model components (no differences were found between RSD sufferers and controls). Moreover, a discriminant function analysis correctly predicted chronicity or recovery in 82% of the sample. Taking the groups as a whole, differences were found between chronic and recovered



patients on measures of pain history and life events. The authors conclude that their model is useful as a predictor of psychological contributions to pain states regardless of pathology.

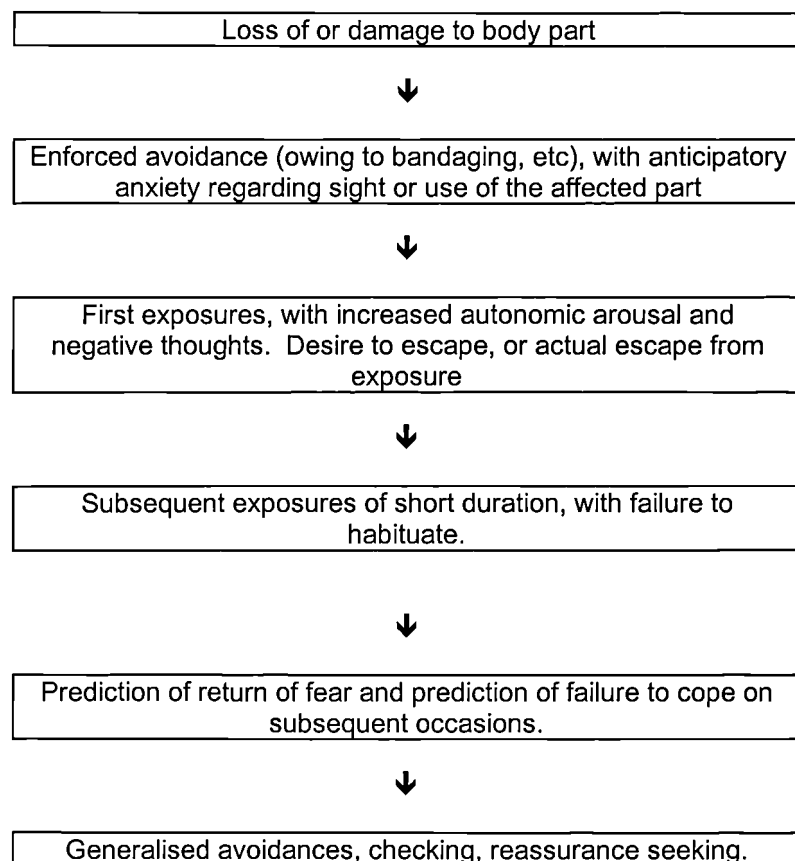
An examination of the studies in Chapters 4, 5 and 6 suggests that avoidance and anxiety may be widespread amongst sufferers from facial disfigurement. Thus, Gamba et al. (1982) report avoidance of examining operation sites and looking in mirrors by head and neck cancer patients, whilst complaints of social difficulties are the most frequently reported difficulties amongst disfigured people (Macgregor, 1951; Malt 1980; Rumsey, 1983; Rubinow et al., 1987; Kalick et al., 1991; Partridge et al., 1994; Robinson et al., 1996). Furthermore, good social skills have been found to be the best predictor of adjustment in one study (Kapp-Simon et al., 1992). Social skills training has been shown to be effective in increasing well-being and social competence amongst facially disfigured people (Feigenbaum, 1981; Robinson et al., 1996). Nevertheless, as has been demonstrated in previous chapters, no systematised investigation of avoidance behaviour in general and social avoidance in particular by disfigured people has been undertaken which has sought to relate this avoidance to anxiety and body image.

### **Section 8.3 The fear-avoidance model of psychosocial difficulties following disfigurement**

Newell (1991) has offered a cognitive-behavioural approach to body image disturbance which draws on clinical studies of phobic disorders in general and BDD in particular, and upon conditioning accounts of phobias, the fear avoidance model of exaggerated pain perception (Lethem et al., 1983), the three systems model of Lang (1971) and the social learning and self-efficacy theories of Bandura (1977a, 1990b). Since these constructs are themselves largely convergent, it is perhaps best to see Newell's (1991) formulation of body image difficulties as being derived from Lethem et al. (1983). As discussed in Chapter 2, this is itself similar to Slade's (1994) model of body image. Newell's (1991) approach assumes that many of the psychological difficulties experienced by people who have suffered a threat to body image are similar to those suffered by phobics. In other words, these difficulties are mediated primarily by fear and avoidance, which are themselves primarily maintained by conditioning and the dysfunctional thoughts which often accompany avoidance learning in phobias (Butler, 1989). Newell's (1991) cognitive-behavioural

formulation asserts, for disfigured people, that activities associated with the lost or damaged part of the body are avoided, because they have been found to give rise to autonomic features of anxiety and to anxiety-provoking thoughts. Further activities which remind the person of the lost or damaged area, even though not directly associated with it, are likewise avoided. For example, a person might, following mastectomy, avoid reading women's magazines in which articles about cancer, breast augmentation, swimsuits or lingerie might be present. Similarly thoughts associated with the damaged area are resisted, since they also come to be associated with autonomic arousal and anxiety. The process proposed in the 1991 paper for the development of disturbed body image is presented in Figure 8.3.1.

**Figure 8.3.1: A model of disturbed body image**



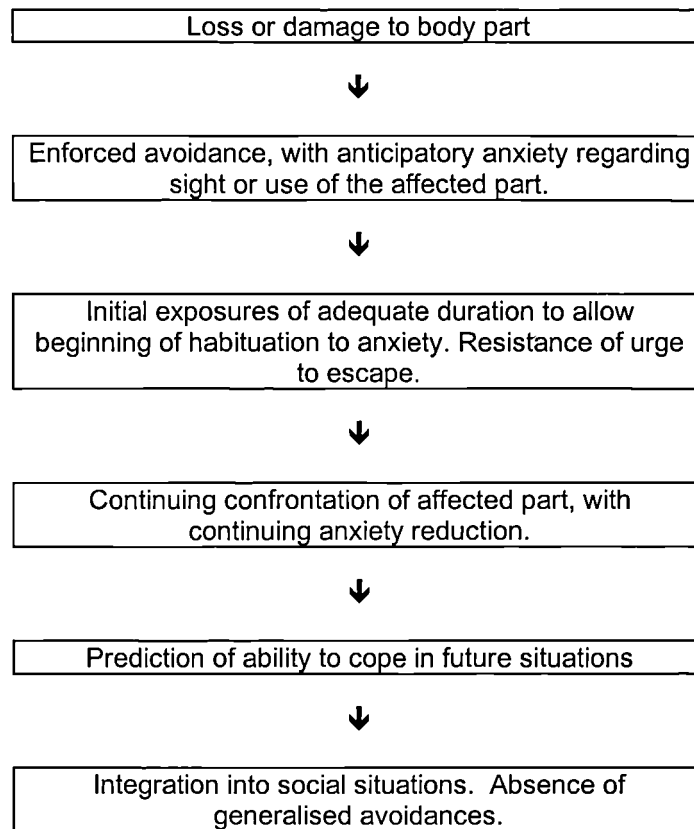
*(Adapted from Newell, 1991)*

This formulation is limited in several ways, and requires refinement, expansion and testing. In the first instance, the 1991 article makes no reference to *how* its formulation is related to Lethem et al.'s

(1983) model, and only mentions the development of disturbance. It will be recalled that Lethem et al. describe a psychosocial context comprising a number of elements (e.g. previous pain experiences, coping strategies, life events, personality) which lead to either disturbance or recovery. It is now suggested that this psychosocial context is equally applicable to body image, with the following amendments. 'Pain history' is replaced with 'history of changes to body image', following Slade's (1994) model of body image in eating disorders. 'Fear of pain' is changed to 'fear of changed body and reactions of others'. This amendment reflects the likelihood that disfigured people will share the same cultural and social norms related to body image as the rest of society. This might contribute to a negative appraisal by disfigured people of their own changed body part. Additionally, the concern of disfigured people with the responses of others is reflected in this amended element. 'Pain coping strategies' is changed to 'body image coping strategies' reflecting the ways in which people have learnt to deal with changes to or imperfections in the body in the past'. Lethem et al. (1983) also propose two ends of a continuum of results of pain events: confrontation (and recovery) or avoidance (and chronicity). The process shown in Figure 8.3.1 should be regarded as an adaptation of the description of the consequences of avoidance in chronic pain described in the Lethem et al. article. By contrast, confrontation (or exposure) is associated with a body image which is not disturbed (i.e.; which does not interfere with physical and psychological functioning [Goin & Goin, 1981]). This process of successful adaptation through confrontation is outlined in Figure 8.3.2. The fear avoidance model of response to disfigurement was originated to account for difficulties following insults to body image as a result of surgery, trauma or disease, and Figure 8.3.2 therefore represents an account of successful adaptation following such insults. In a slightly altered form, the model accounts equally well for such occurrences and for body image disturbance as a result of disfigurement from birth. In this latter case, since the disfigurement is present from birth, the potential for confrontation or avoidance likewise exists from this time, rather than from the time of occurrence of disfigurement at some later date. Thus, in the case of the person disfigured from birth, elements of the psychosocial context of disfigurement do not predate the occurrence of disfigurement. Instead, the disfigurement itself may be a major contributing factor in the psychosocial development of the individual. Also, specific elements such as enforced avoidance, which may be present following injury, are unlikely to be a major factor. Figure 8.3.3 reflects the most recent version of the fear-avoidance model.

**Figure 8.3.2.**

**A model of successful adaptation following change of body image**



**Figure 8.3.3: A fear-avoidance model of psychosocial difficulties following disfigurement**

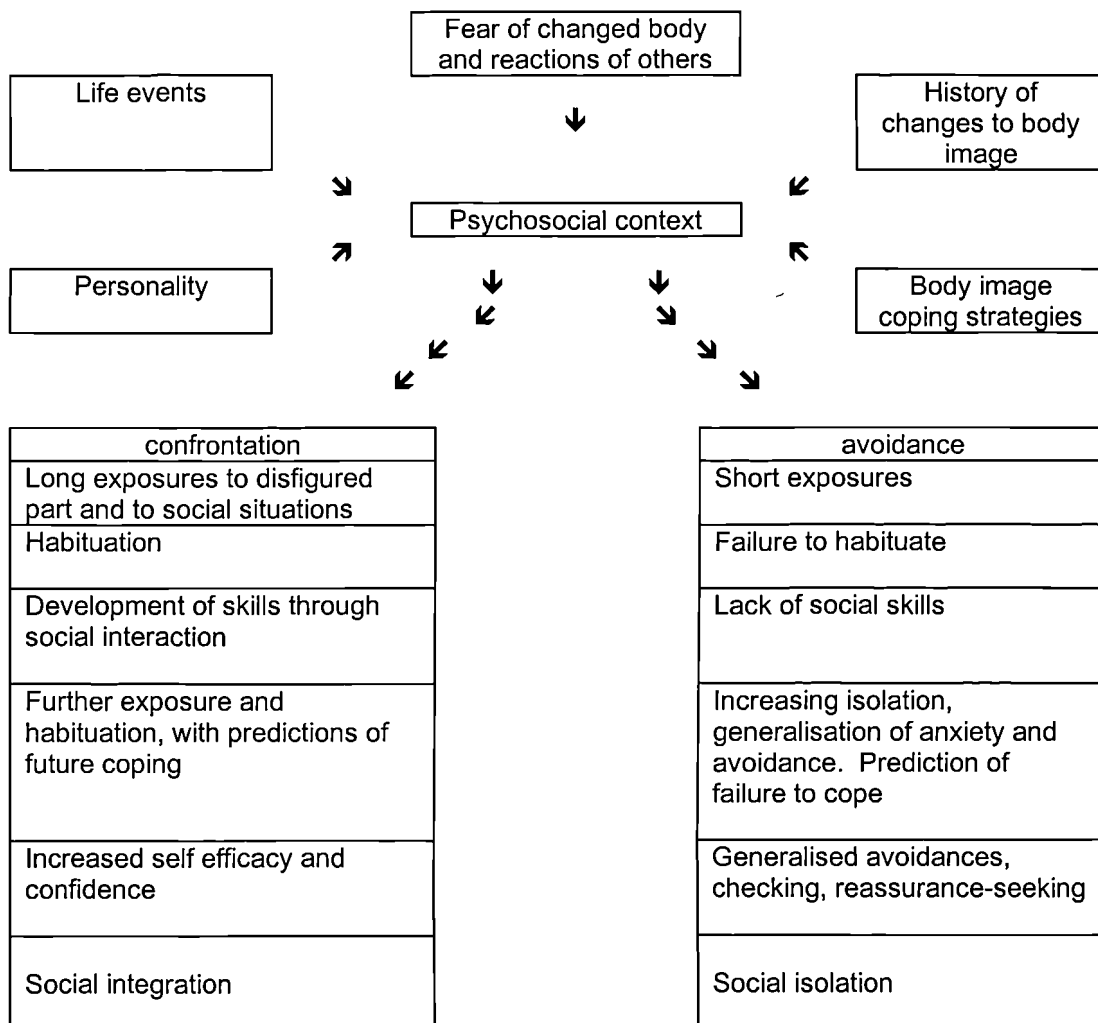


Figure 8.3.3 has been slightly expanded to illustrate the particular role of social avoidance. This should not be regarded as the sole aspect of avoidance, but is offered as an illustration because of its potentially damaging consequences across a range of activities such as work, leisure, dating. It is suggested that other avoidances (for example of grooming, looking in mirrors, exposing the affected part) are associated with anxiety in the same way and have similar kinds of consequences in terms of limitation of the individual's life and disturbance of body image. Certainly an examination of the behaviour of BDD sufferers reveals a great deal of anxiety and specific avoidances, albeit in the context of the overvalued idea, and these avoidances are a source of significant handicap to the sufferer. Just as the notion of *fear* of pain and consequent avoidance is the key aspect of Lethem

et al.'s (1983) fear-avoidance model of exaggerated pain perception, the currently presented fear-avoidance model of psychosocial difficulty following disfigurement has as its central feature *fear* of the changed body and the responses of others. The *actual* responses of people to the disfigured individual are almost certainly often negative. This does not alter the model presented here. Just as Lethem et al. (1983) recognise the role of others in maintaining avoidance behaviour in the person with chronic pain, so the model presented here accepts the role of others in the maintenance of the psychosocial difficulties of disfigured people. Indeed, the reactions of such people are likely to have a profound effect in terms of increasing the disfigured person's fear of such reactions. Nevertheless, it is suggested that such fear is likely to lessen with continuing exposure and to increase with avoidance, the reactions of others being held constant. As an example, people inevitably stare at disfigured people. The fear-avoidance model attempts to account for why actions such as staring contribute to greater psychosocial disturbance in some individuals than others.

The fear-avoidance model outlined here is attractive in several ways. Whilst the Newell (1991) formulation is limited, the expanded account offered here is potentially capable of accounting for the psychosocial difficulties experienced by disfigured people regardless of the specific cause of the disfigurement. The general underpinnings of the approach, grounded in the cognitive-behavioural approach to phobias and anxiety, have received considerable support both from clinical and laboratory studies of the acquisition of fears and phobias (Marks, 1987). The avoidances described by social phobics are similar to anecdotal accounts of many of the social difficulties of sufferers from disfigurement. If the formulation proves robust, it has immediate consequences in terms of interventions with disfigured individuals, including preparation for surgery, recovery from disfiguring trauma, developmental work with children disfigured since birth, and interventions with people actively suffering the psychological sequelae of disfigurement, since the associated treatment interventions have demonstrated effectiveness. However, apart from the limitations noted above, the approach possesses the great weakness that it is, like Price's (1990a, 1990b) model, almost entirely speculative. The Newell (1991) study contained a single illustrative case example, from which no conclusions can reasonably be drawn, and there have been no treatment reports of an approach based on the fear-avoidance model with disfigured people. Although

numerous papers have suggested that exposure is likely to be important in addressing disfigurement issues (e.g. Tarrier & Maguire 1984; Price, 1986, 1991; Griffiths, 1990), the suggestion is rarely accompanied by evidence. The Rumsey/Partridge group, who do provide encouraging initial evidence of effectiveness, do not clearly report the contribution of specific instructions in exposure to their skills training oriented package.

Not only is the use of cognitive-behavioural interventions based on exposure principles for people with facial disfigurements itself speculative, the assumption that the clinical picture of disfigured individuals will be similar to those for whom cognitive behavioural interventions have been effective (e.g. social phobics, agoraphobics, BDD sufferers) is itself open to debate. It has already been noted that Latham (1997) has pointed out that BDD sufferers are by definition different from disfigured individuals, since they lack any visible deformity. There is no reason to suppose that disfigured people have an overvalued idea related to their appearance. Whilst the literature suggesting that level of disfigurement is not always related to level of psychosocial difficulty, although equivocal, allows us to suggest that individual attitude may play a part, as it clearly does in BDD, this is unlikely to reach the level of importance it does in BDD. Balanced against this, it must be noted that the lack of physical deformity in BDD is not necessarily a problem for the fear-avoidance model. Whilst the model was indeed derived in part from clinical work with this group, the key point of contact between BDD sufferers is seen as the anxiety and avoidance which it is suggested they share with disfigured people. No doubt this anxiety and avoidance are fuelled in BDD sufferers by the overvalued idea, but it is equally possible to postulate that this overvalued idea is itself maintained by avoidance. Equally, it was noted in the literature review that disfigured people report being preoccupied with the responses of others to their appearance. Arguments about whether this preoccupation constitutes an overvalued idea, given that disfigured people do indeed have visible deformity, may be of more theoretical than therapeutic importance. The central issue which leads to the contention that treatment interventions valuable in BDD may likewise be valuable with disfigured people lies in the contention that disfigured people, like BDD sufferers are anxious and avoid because of disturbances to their body image and their fears of their reactions to others. This issue also applies to the comparison with social phobia and its treatment. It may well

be that disfigured people are indeed subject to the negative evaluations that they and social phobics fear. The critical issue is how they respond to such negative evaluations.

The presence or otherwise of avoidance perhaps represents a more practically important difficulty for the model. We do not have evidence that the undoubted avoidances described in first-hand accounts, anecdotal reports and small studies, are actually socially phobic or agoraphobic in nature. In other words, we do not know whether or not these avoidances are maintained through a *fear* of entering social or public situations, which is in turn related to expectations about ability to cope in such situations. A finding that disfigured people who avoided did not do so because of anxiety would both contradict the formulation of their difficulties outlined above and cast in doubt the rationale for treatment using exposure principles. By contrast, the skills based approach of the Rumsey/Partridge group would be largely unaffected by such a finding, since it is principally designed around evidence that socially skilled disfigured people are better accepted in social situations (rather than less anxious in them) and may benefit from that greater acceptance.

#### **Section 8.4      Examination of the fear-avoidance model**

The current study attempts to make and test predictions based on a cognitive-behavioural formulation of the experiences and difficulties of facially disfigured people. A number of general predictions expected from this formulation will be stated, together with the hypotheses derived from them and tested in the current study.

##### *8.4.1      General aims of the empirical study*

To examine the role of anxiety and avoidance in facial disfigurement.

To describe the types of psychosocial difficulties experienced by people with facial disfigurements.

To identify the frequency of these difficulties in a plastic surgery outpatients population.

To identify whether individual variables (e.g. age, gender, time since disfigurement) are related to the level of difficulty.

To identify whether self-help information along cognitive-behavioural lines alters the level of difficulty experienced.



To compare the level of phobic difficulties experienced by facially disfigured people with those of a group of diagnosed agoraphobia and social phobia sufferers.

These general study aims are operationalised as more specific aims in various parts of the programme of study, and are presented in the relevant parts of Chapter 10.

#### *8.4.2 Predictions from a fear-avoidance approach to psychosocial difficulties in disfigurement*

Since the psychosocial difficulties experienced by people with facial disfigurements are predicted to be maintained by anxiety, raised levels of anxiety are expected. Likewise, since it is suggested by this thesis that this anxiety is principally phobic in nature, it is predicted that subjects will report, in response to the questionnaire, that avoidance is a major feature of their difficulties. Since social difficulties are often reported by facially disfigured people, and the opportunities for avoidance learning through punishment and negative reinforcement for entering and escaping from social situations are likewise great, social avoidance is expected to be particularly marked. In consequence, it is predicted that levels of social avoidance will be similar to those of diagnosed social phobics. If the difficulties experienced by facially disfigured people are indeed anxiety-based and phobic in origin, a treatment intervention with a marked component of exposure therapy should improve these difficulties. Therefore, provision of exposure information is predicted to reduce avoidance, anxiety and psychological disturbance. Finally, there is some suggestion from the literature that disfigured people engage in checking of their appearance. This is likewise seen in the obsessional features observed in BDD sufferers. Accordingly, it is predicted that facial disfigurement sufferers will report obsessional checking because of anxiety.

#### *8.4.3 Description*

One simple way to examine the fear avoidance-model is through observation and description of the kinds of patterns of psychosocial difficulty that emerge amongst people with facial disfigurement. At a basic level, the sorts of difficulties described anecdotally need to be demonstrated to be present in a large sample, at least to some degree, in order for any model based on fear and avoidance in social situations to be tenable. Frequencies of responses and summary statistics of responses to the various scales will be presented.

#### 8.4.4 Hypotheses

It has been argued (Gardner & Altman, 1989) that hypothesis testing as a strategy in health care has less to recommend it than does the examination of how far results found in particular samples are accurate estimates of population values, through the use of confidence intervals. However, although this approach is gaining in popularity, particularly in reports of medical studies which examine clinical effectiveness, it is by no means widespread in other disciplines relevant to facial disfigurement such as nursing and psychology. In view of this, the hypothesis testing approach to prediction will be retained in this study, although confidence intervals will also be reported where appropriate.

Burns and Grove (1993) have argued that hypothesis statements do not require the specification of the measure used, since this specification relates to issues of sampling and data analysis. By contrast, hypotheses are statements of intended tests of the *relationships* between the: 'variables (or concepts) and population outlined in the research purpose' (Burns and Grove, 1993, p 221), not descriptions of the *procedures* by which these relationships are tested. However, Newell (1994b) has argued that, where it adds clarity to the description of the entity under investigation, the inclusion of the unit of measurement in the hypothesis statement is not only permissible, but extremely helpful. As an example, there is clearly little point in including in a hypothesis which states that time taken in a reaction time experiment will be longer *in seconds* since this introduces no further information. However, noting, for example, that one group of subjects will show greater neuroticism than another *on scores on the Eysenck Personality Inventory* does impart more information, since it reminds the reader that we have chosen to define neuroticism in this particular way, rather than according to some other index of this inferred human characteristic. Accordingly, measures will be stated in the hypotheses below when to do so will add clarity to the definition of the variables being examined. Experimental hypotheses only will be stated, and the null hypothesis should be assumed, in all cases, to be a state of no difference between the groups examined.

Hypothesis 1: Subject anxiety and depression as measured on the anxiety and depression subscales of the Hospital Anxiety and Depression Scale (HAD) will be higher than population norms.

Hypothesis 2: Subjects will show higher psychiatric morbidity as indicated by higher scores on the General Health Questionnaire (GHQ) than population norms.

Hypothesis 3: Women will show higher levels of disturbance than men across the range of measures.

Hypothesis 4: There will be a positive correlation between scores indicating negative attitudes and behaviours related to the face as measured by the Facial Attitudes and Avoidance Checklist (FAAC) and age, time since disfigurement and the range of general measures of disturbance.

Hypothesis 5: Persons having different causes of facial disfigurement will show different levels of disturbance across the range of measures.

Hypothesis 6: Subjects receiving cognitive-behavioural advice via a leaflet will show lower scores on a range of measures of handicap at three month follow-up after receiving the leaflet than subjects not receiving such a leaflet.

#### *8.4.5 Equivalence*

Estimating equivalence is problematic. The simple prediction of the null hypothesis is not a prediction of equivalence, since, by its nature, the null hypothesis does not predict similarity, but simply asserts that no difference has been found (Dunnett & Gent, 1977). This may have occurred for reasons other than similarity between the groups - for example, because of sampling or other methodological difficulties, or inadequate power of the study to detect differences (Senn, 1993). It may, however, be possible to assert equivalence on the basis of no significant difference being found between the groups when the sample sizes are sufficiently large to find such differences, provided that an adequate definition of equivalence is made beforehand (Gould, 1993). Adequacy of the sample size might be asserted if, for example, a power calculation has demonstrated that the sample sizes are sufficiently large to allow an acceptably small risk of missing significant effects, or where it can be demonstrated that the measures used discriminate between different groups of size similar to those examined in the samples under consideration. Additional information regarding

equivalence may also be gleaned from the examination of group means, particularly in the case of smaller samples, where the power to detect equivalence is likely to be low. This approach is taken in the current study, following statistical advice. The appropriate power estimates are reported in Chapter 10. The following predictions are made:

In a sample of a size where differences between the groups might be expected to be found, no significant differences will be found between facially disfigured people and diagnosed social phobics on the social phobia and agoraphobia subscales of the Fear Questionnaire.

Examination of group means for these scales will not show clinically important differences between the groups.

# **PART 2**

## **EMPIRICAL STUDIES**

## **CHAPTER 9**

### **GENERAL METHODOLOGICAL ISSUES**

#### **Section 9.1 Introduction**

The empirical work conducted for this thesis consists of a series of 6 connected pieces of work, which together form a small research programme within the area of facial disfigurement and its psychological sequelae, especially behavioural avoidance. Together, these elements aim to examine behaviour and experiences following facial disfigurement in the context of a cognitive-behavioural formulation of body image disturbance (Newell 1991). Following initial development of the measurement instrument and self-help leaflet, the programme consisted of the following elements:

- 1 Pilot study of administration of the measurement instrument in a sample of dermatology out patients.
- 2 Examination of prevalence and features of psychological disturbance in a consecutive sample of plastic surgery ex-patients.
- 3 Examination of features of psychological disturbance in a self-selected sample of people defining themselves as suffering from a facial disfigurement in response to media articles and interviews by the investigator.
- 4 Examination of the properties of a new measure of avoidance and distress in facial disfigurement.
- 5 Pilot study of brief written cognitive-behavioural guidance via a self-help leaflet to people identifying psychological problems.
- 6 Comparison of the avoidance behaviours and psychological well-being of facially disfigured people and phobic patients.

#### **Section 9.2 General methodological considerations**

Consideration was first given to the general approach to be taken to the study area. The investigator had decided to explore predictions to be expected from a cognitive-behavioural approach to disturbed body image through exploration of participant characteristics and response to

a treatment approach based on cognitive behavioural lines. These approaches, derived principally from conditioning theory and social and cognitive learning theories, constitute the theoretical framework which informs the questions addressed in this study.

With regard to examination of characteristics of respondents, there were a number of viable possible approaches: interviews of varying levels of structure, questionnaires delivered face-to-face and postal questionnaires. Unstructured interviews were soon rejected. First, much of the information yielded would be qualitative accounts of respondents' personal experiences. Valuable material of this kind already exists within the facial disfigurement literature, along with small surveys. What is singularly lacking from the literature is a systematic investigation of the patterns of experiences of and responses to facial disfigurement of a large group of disfigured individuals. Such surveys as do exist suffer from the flaws described in the literature review.

Second, the current study aimed to build on earlier accounts of the experiences of disfigured people (which have often allowed participants to make wide-ranging responses across a variety of topics) by chiefly addressing a single aspect which was of particular interest in the context of the cognitive-behavioural model: the role, if any, of avoidance behaviour and anxiety in mediating the psychological well-being of people with facial disfigurement. Unstructured interviews would be uneconomical in terms of time and focus on the areas of avoidance and anxiety, since they would, by their very nature, examine these particular aspects less focally.

A third consideration in rejecting of interviews came from the clinicians consulted early in the development of the project, who uniformly feared that interviews might be too intrusive with this client group, and would be likely to lead to a poor response rate to invitations to participate. Finally, the investigator wished to include as large and broad a cross section of sufferers as possible, including those not usually in contact with services and voluntary organisations. This represented a serious potential practical drawback to the use of interviews.

Initially, offering questionnaires on a face-to-face basis seemed an excellent approach, possessing the advantages of a high likely response rate, and the ability of the interviewer to correct

misconceptions about the questionnaire, offer feedback about performance, and offer advice in the event of negative reactions to emotional material (Newell, 1993). However, the drawbacks attached to face-to-face completion were eventually judged to outweigh the advantages. The clinicians felt the same disadvantages of intrusion and poor uptake rate might be present as for interviews. There also exists a possibility of introducing bias when administering questionnaires face-to-face, in much the same way as in interview situations. Finally, face-to-face questionnaires are extremely expensive of researcher time, and do not yield any more information than their postal equivalents in return for that time investment, although the overall return rate, following engagement of participants is, naturally, much higher than for postal surveys. Anything other than a fairly local survey would likewise be impossible with this method, and early discussions had suggested that likely numbers would be small, particularly for the treatment component of the study. In the end, face-to-face questionnaire administration was indeed used during the initial stages of piloting the questionnaire in dermatology outpatients, and the clinicians' predictions regarding the preference of respondents for the time and anonymity of completion at home were fully borne out.

The eventual choice of a postal survey was suitable to the needs of the study. It was predicted that a large initial pool would be needed in order to generate sufficient participants for the treatment component of the study. A postal survey allowed the investigator to reach large numbers of individuals, including those who were unlikely to be reached by any face-to-face approach, as they lived at a great distance, or were not in contact with any services.

The great difficulties of postal questionnaires are poor response rate and bias of the sample. The second issue has been common to all studies of facial disfigurement to date. As noted in the literature review, Rumsey (1983) claimed that her sample of consecutive outpatients' attenders was superior to samples in previous studies, since these earlier studies had been carried out in the USA, where such attenders necessarily formed a biased group, because of economic considerations. However, the current study's ex-patient sample, whilst still potentially biased by the poor likely response rate of a postal questionnaire is arguably less biased again than that of Rumsey, since the current sample were *ex-patients*, rather than current attenders awaiting surgery whose opinions might be influenced by continuing expectations of surgical improvement. As a



result, the current plastic surgery ex-patients sample might be thought to offer an examination of the experiences of facially disfigured people from a more representative group than has hitherto been reported in the literature. With regard to the media sample, clearly they are a convenience sample, and quite likely to be biased. Indeed it will be noted in the results section that their characteristics in terms of frequency of occurrence of psychological and behavioural disturbance are different from the other groups. However, this is not necessarily too difficult a flaw for the study, since the purpose of inclusion of a media group was specifically to gain an appreciation of the *types* of problems occurring amongst those experiencing psychosocial difficulties following disfigurement, not to draw any conclusions regarding the prevalence of such problems in the population of disfigured people as a whole. With regard to response rate, this was, as might be expected, poor in response to the ex-patients element of the survey, despite the inclusion of attempts to increase response (see below), but comparatively good in the media-recruited group. A fuller examination of the ramifications of the sampling methods employed is included in the discussion (Chapter 12).

In the case of examination of the effects of treatment, there was really only one option which possessed the ability to tease out the cause and effect relationships the investigator wished to study in order to examine the cognitive behavioural formulation. This was the use of an experimental approach or some quasi-experimental variant of it. In the current study, it was possible to use a true experimental approach, involving random allocation to conditions, manipulation of the independent variable and the use of a control condition (Oldham, 1994). Whilst it is clearly not possible to control all the extraneous variables operating in the lives of individuals in the field, rather than a laboratory situation, the use of this approach allows us to have considerable confidence that actions of the independent variable are, in fact, causative of changes in the dependent variables being measured. Furthermore, the relative absence of control over extraneous variables in the study means that the experimental situation is a closer approximation to real life situations, increasing our confidence in the external validity of the study. Naturally, this confidence is itself at the expense of some degree of confidence in the internal validity of the study.

### **Section 9.3      Choice of treatment intervention**

If the choice of the experimental approach was simple for the treatment intervention study, the choice of one particular form of intervention over another was less clear cut. The use of a self-help leaflet was eventually chosen as the intervention method for the current study. However, there were several other candidates, many of which initially appeared more promising, namely: individual therapy, group therapy, self-help groups, telephone therapy. All of these were rejected fairly early in the design of the study programme. These interventions share a number of characteristics which represent significant drawbacks to a study of this kind. First, all were extremely expensive of therapist time, with the exception of self-help groups (if these were to be non-facilitated). Unfortunately such non-facilitated groups would, by their nature be outside the control of the investigator. As a result, it would not be possible to specify the components of the group programme, with the result that investigation of a cognitive-behavioural approach would be impossible. Although the last option, telephone therapy, appears less time consuming, the savings are likely to be trivial, since intervention can still only be offered to one individual at a time. Group face to face intervention may, in fact, be more economical of time. Second, all the interventions posed considerable organisational difficulties, principally as a result of the likelihood of small numbers of suitable participants being forthcoming. In order to generate sufficient numbers for a comparative study, it was predicted from the frequency of patients presenting with difficulties during the pilot study that several years would be required to get participants through treatment, given the likely recruitment rate and the necessity of part-time working on this clinical component by the investigator. There was also the problem of an increased likelihood of rating bias, since the investigator would be intimately clinically involved with participants, as opposed to the comparative detachment of offering a leaflet. The enlistment, training and retention of independent raters to be involved in evaluation of a face to face intervention was outside the practical scope of the limited project called for by the time and resource restraints of a research degree programme which was to include several elements other than the treatment outcome pilot.

By contrast with these methods, the offering of a self-help leaflet possessed considerable advantages. Firstly, the practical difficulties noted above are all either absent or much diminished in the case of a leaflet. Even the possible rater bias is likely to be diminished to some degree, since

the investigator, whom participants have never met, is not intimately associated by them with the treatment, and has a much smaller personal investment in the successful outcome of treatment, since his input is limited to design and distribution of the leaflet, rather than many hours of therapeutic time. Second, considerable control of the stimulus material is possible. The leaflet, unlike individual treatment plans, is unvarying across participants in the treatment study, whilst even the most assiduous therapists are likely to vary their approach in the face of individual client difficulties. Whilst this is an entirely appropriate way to conduct therapy, it increases the likelihood of the intrusion of unwanted intervening variables within the treatment group. The use of a leaflet gives a relatively clear operational definition of the treatment condition of the independent variable. Third, the selection of a control group is made much easier. In all the alternatives to a leaflet considered above, there exists the possibility of the confounding effect of attention within the experimental group. People who are offered attention reliably report therapeutic improvements, and this effect is well documented in psychotherapy literature (Rachman & Wilson, 1980). Thus, some placebo would need to be devised in order to compensate for this effect. In the case of a study using a leaflet, the additional attention offered to the experimental group, when compared with the control group, is minimal, since the experimental group simply receive an eighteen page leaflet through the post. There are also advantages to the use of a leaflet which are of therapeutic importance. Leaflets are economical and may, therefore, be made widely available at little cost. They may also reach and help sufferers who would otherwise not engage with treatment for reasons of distance or social reticence, or lack of the availability of a therapist. A brief examination of the effectiveness of self-help leaflets is presented later in this section.

The major potential drawback of the use of a self-help leaflet is uncertainty about its potential to effect change. If a leaflet is, in fact, a weak treatment, it will not constitute a fair test of the assumptions it claims to test - in this case, the ability of a cognitive-behavioural approach to address the psychosocial difficulties of disfigured people. Bernstein's (1976) comment regarding the grandiose nature of expecting to change large area of people's lives merely by altering elements of their social skills has already been noted. It might be considered even more grandiose to expect to perform such a transformation merely by use of a simple leaflet. However, four reasons suggested that the use of this minimal intervention might nevertheless be worthwhile. First, the

general aims of cognitive-behaviour therapy are much more modest than the kinds of global change implied by Bernstein's (1976) remarks. Typically, CBT is directed towards discrete but important changes in behaviour which represent significant improvements to the client's difficulties, although generalisation to other areas of functioning is sometimes seen. Second, during the time since Bernstein's remarks, a number of clinicians and researchers (reviewed in Chapter 6) have found support for the potential of social skills approaches to enhance the well-being of disfigured people. Thus, given a focal approach to specific areas of difficulty, this approach may not be as grandiose as Bernstein originally foresaw, in terms of either its aims or its achievements. Third, as suggested above, the ability of a leaflet to reach a wide audience of people with difficulties who otherwise might not engage with treatment is a powerful argument for its use, since its therapeutic potential, if effective, would be enormous. It may be argued that this potential to effect change at little cost in terms of therapeutic time or money weighs heavily against the risk of possible weakness of the approach, particularly where there are reasonable grounds to suspect that the tactics outlined in the leaflet are themselves effective. Finally, there is a body of evidence that written information is able to effect therapeutic change, provided that the information which it delivers is based upon sound therapeutic techniques. It is suggested that the cognitive-behavioural approach represents such a range of sound techniques, which have demonstrated effectiveness in a range of client difficulties similar to those experienced by facially disfigured people. Evidence for the effectiveness of self-help leaflets, either alone or in combination with minimal therapist contact is now briefly reviewed, with particular reference to CBT.

Perhaps the most frequent application and evaluation of self-help methods in CBT has been by Marks and his various collaborators. A self help book (Marks, 1980) contains a chapter devoted to self treatment, which has been used as a self treatment manual in several studies. Ghosh et al. (1984) compared three groups of phobic patients (n=88) of at least one year's duration who were randomly allocated to receive either the self-help book, a computer mediated exposure treatment package or therapist assisted exposure. Seventy patients reached 6 month follow up, and treatment gains were significant and no different between the three groups at each post-treatment and follow-up point. There was no difference in dropout rates between the three conditions, suggesting that they were equally acceptable to patients. Although patients were initially screened

for suitability for behavioural interventions according to current clinical criteria, therapeutic instruction at this interview was minimal, reducing the likelihood that this contributed significantly to the effectiveness of the self-help conditions. The authors note the implications for cost-effectiveness of behavioural interventions. In a further, similar study of agoraphobics, Ghosh and Marks (1987) once again demonstrated that the self-help book was no different in effectiveness from either therapist or computer delivered treatment. The authors again note the cost-effectiveness implications of this innovation, and also favourably contrast the time consumed by their patients with those of Mathews et al. (1977) and Jannoun et al.'s (1980) replication study. Both these studies employed the Mathews et al. (1977) self-help treatment manual, but with the addition of therapist intervention. Although not itself a study of self-help using a leaflet, a later study by Al-Kubaisy et al. (1992) confirmed that the addition of therapist-assisted exposure did not enhance self-exposure advice.

By contrast, Hellstrom and Ost (1995) found that improvements in spider phobic patients following treatment with a specific manual aimed at such phobias were extremely modest. The improvements were roughly equal to those following administration of the general phobia treatment manual of Marks (1980) also offered in this study. In both the specific and general manual groups, improvement was greatly enhanced if the manual was used in the clinic, and even further enhanced if therapist-assisted. Despite this negative finding, Hellstrom and Ost (1995) still stress the potential for manual-based treatment, whilst Al-Kubaisy et al. (1992) have pointed out that phobics' response to treatment is extremely variable, with some requiring only instruction in exposure tactics whilst others need continuing therapist assistance to make any therapeutic gains. The ability to predict from client characteristics who benefits from particular levels of input represents an important potential contribution to the investigation of cost-effectiveness in the delivery of cognitive-behavioural interventions.

Effectiveness of self-help literature in CBT is by no means confined to the treatment of phobias. Whilst some of the evidence for the effectiveness of such bibliotherapy is equivocal (see, for instance, Forest (1987) and Forest (1988) for contradictory findings regarding the impact of reading self-help paperbacks upon personality ratings), appropriately constructed manuals and leaflets can

be helpful across a range of areas. Whilst a full examination of this extensive literature is beyond the scope of this thesis, a few illustrative examples suggest the potential of the self-help manual or leaflet. In an examination of controlled drinking, Heather et al. (1986) offered media-recruited problem drinkers a self-help booklet either based upon behavioural principles or giving general information about alcohol problems. The behaviourally-based booklet was superior in reducing drinking, regardless of the level of problem severity. Furthermore, this superiority was maintained to one year follow-up (Heather et al., 1987). Taken together, the superiority of behavioural advice over general information and the lack of difference in response between participants with different problem severity seem to indicate both that the nature of the advice given is the therapeutic factor, rather than attention, and that this advice is of wide applicability to the client group. This latter factor, combined with the apparent satisfaction of the patients in the Ghosh et al. (1984) and Ghosh and Marks (1987) studies, suggests that possible concerns over the lack of flexibility of booklet delivery of treatment advice may not be a significant issue, provided the core information provided is appropriate. Although the evidence for the effectiveness of treatment of obesity is generally equivocal, and particularly so with self-treatment, the use of manuals has gained some support in this field. Brownell et al. (1978) found difficulty in inducing weight loss in their sample of 29 females averaging 63.6% overweight. Those receiving a manual plus minimal therapist contact did worse than attenders at behavioural group therapy at discharge, but there were no differences between the groups at six month follow-up. Thus, whilst the authors conclude that the lot of the 'do-it-yourself' dieter may be poor, it appears that, in this study, even therapist supervision did not effect lasting change. By contrast, both Hagen (1974) and Pezzot-Pearce et al. (1982) found no differences between therapist assisted and self-help manual treatment. Whilst the Hagen (1974) study included a shorter follow-up than Brownell et al. (1978), Pezzot-Pearce et al. (1982) followed-up their subjects to 16 months post treatment, and included a non-behavioural control condition. They concluded that the behavioural manual could be used with minimal or no therapist guidance and that its use facilitated modest, sustained weight loss in their group of 126 subjects who were an average of 48.31% overweight. Although this group was both less overweight and younger than the Brownell et al. group, this study nevertheless demonstrates the ability of a self-help intervention to effect change in a complaint which is recognised as being considerably resistant to intervention.

In the light of this generally modest but nevertheless broad support for the use of self-help treatment information in CBT, it was decided that the many advantages of employing such information in leaflet form outweighed the disadvantages and might reasonably be taken to constitute a fair test of the ability of behaviour therapy to address the difficulties of a geographically widely distributed, potentially diverse and potentially socially isolated client group, using an approach requiring minimal clinical input. The construction of the leaflet is described in Chapter 10.

#### **Section 9.4 Ethical considerations**

A number of common ethical questions relate to all the studies carried out as part of this research programme. Since the majority of common ethical themes arose in the media recruited and plastic surgery samples, these groups are described first, in Sections 9.4.1 and 9.4.2, whilst, for the sake of brevity, the particular issues relating to the self-help group pre-piloting and dermatology out-patients pilot are added later, in Sections 9.4.3 and 9.4.4. Section 9.4.5. examines ethical issues related to the adequacy of the design of the study.

The studies aimed to use well volunteer participants solicited chiefly through the post. Participants were to be requested to complete questionnaires which might potentially have given rise to negative emotional reactions. In consequence, three ethical considerations seemed worthy of particular consideration: consent, inconvenience and harm. These considerations form the main focus of the discussion of ethical considerations in Sections 9.4.1 to 9.4.4.

##### **9.4.1 *Media-recruited sample***

In the case of the media-recruited sample, there seems a fair rationale for assuming that individuals have agreed to consent to participate, given that they themselves have replied to one or other of a number of articles and interviews in the press. However, that consent is enhanced as the level of knowledge about the project and the content of its instrument increases. In consequence, all questionnaires were not only accompanied by a brief explanatory letter (Appendix 1), but included a front sheet which repeated details of the study (Appendix 2). The letters to media respondents were often personalised to address particular concerns of respondents in their initial inquiries, but all letters nevertheless included the following elements: a note of the possible inconvenience to be

caused by time taken to complete the questionnaire; a note of the fact that personal issues were covered; a note that full completion, whilst desirable, was not mandatory. Since some respondents during initial piloting with the self-help groups had revealed slight concerns about what they regarded as the unusual, stilted wording of some of the validated forms in particular, respondents' attention was also drawn to this in the body of the questionnaire, with the chief aim of avoiding offence, as well as the subsidiary aim of increasing response and completion.

#### *9.4.2 Plastic surgery ex-patients' sample*

In the case of the ex-patients' sample, the assumption of consent is less easy to make. Participants in this study were contacted as a result of an examination of medical records, and did not initially come forward in order to participate. Thus, they were not volunteers in the same sense as media participants. Whilst a higher response rate might have been gained from simply sending questionnaires to all eligible ex-patients identified, this was considered by the investigator to offer inadequate opportunity to give consent.

First, potential respondents would be confronted with a document which they had not requested, which is in itself an invasion of privacy. If they then examined the document, whatever the introduction made by a covering letter, they might be exposed to emotionally disturbing material, once again without having in any way sought it. Second, this material might be felt to have little relevance to them, if they did not consider themselves to be disfigured, thus compounding the intrusion.

Numerous factors might have negatively influenced potential respondents' ability to give consent to participate. First, they might have believed that participation was a part of follow-up to their treatment. Second, they might have believed that it would enhance any possible treatment in the future. Finally, and perhaps most importantly, they might have believed non-participation would negatively affect such possible future treatment. As a result of these factors, potential respondents might have been placed in a position of coercion to participate, thus eroding their ability to give free consent.



In order for any research involving the postal service to take place, it is necessary to ensure a response rate. It is not in the interests of either investigators (who cannot do without participants), nor in the interests of participants (who collectively, if not individually, benefit from well-conducted research of all kinds) if the researcher sets the criteria for consent so high that they are virtually impossible to meet, or presents an overly negative picture of the likely intrusion and harm to be experienced by participants. Nevertheless, the opportunity for consent must reflect a genuine opportunity to engage in informed participation. Part of this notion of being informed involves an adequate description of any likely untoward responses.

In an attempt to address these issues with the ex-patients' sample, the two stage contact agreed with the responsible consultants and described in Chapter 10 was used. Essentially, participants were deemed to consent to receive the study questionnaire if they did not return an initial contact letter offering brief details of the study. A questionnaire was then sent, but non-respondents at this stage were not followed-up. The initial contact letter emphasised that the investigator had the agreement of the consultant, which might be expected to offer potential respondents some security about the legitimacy of both the study and the investigator. The letter also addressed the issue of possible coercion, by outlining the voluntary nature of participation and the lack of any effect, positive or negative, of participation on further treatment. Further details of the contact method are given in Chapter 10, and a copy of the initial contact letter is included as Appendix 3. Arrangements for future contact with respondents are likewise detailed in Chapter 10, but were once again designed to minimise intrusion and maximise consent.

Questionnaire completion takes time, a fact which can cause inconvenience to respondents. Therefore, the covering letter, whilst expressing the hope that participants would complete, explained that the questionnaire was time consuming. An estimate of likely completion time was given.

An instrument which asks about sensitive material may give rise to distress. This may be particularly an issue when the instrument is delivered through the post, so that access to help is limited. The following measures were taken to address this issue in the current study. In both the

self-help group pre-pilot and dermatology pilot phases, respondents were asked for their comments about the questionnaire. In the case of the self-help groups, they were specifically asked by group leaders about their views of potential distress which might be caused by the instrument. Recognition was made on the questionnaire cover sheet that distress might occur in response to the material contained within, and participants were advised that they might wish not to continue in this event. It was initially intended to include the address of several well-known self-help organisations in the field of facial disfigurement with the questionnaires. However, it was felt that this might actually raise distress in some individuals, by encouraging them to view themselves as likely candidates for such organisations, whilst they had not previously regarded themselves as having a disfigurement. Paradoxically, this would be particularly so for those individuals who had not sought involvement with the project (i.e.; the ex-patients' sample), since a considerable number of them might be expected to have had no initial concerns about their facial appearance, in contrast to the media-recruited sample, who might be supposed to have at least some interest in the topic. In consequence, such addresses were not included as a matter of routine. However, each of the few individuals who expressed concerns in their responses to the questionnaire received a personalised letter from the investigator, which included at least the addresses of the relevant self-help groups, but often specific advice about where they might seek help. Individuals who were identified as having difficulties as a result of their facial appearance by virtue of their high scores on the questionnaires rather than their comments about the questionnaire were, of course, enlisted into the self-help leaflet study in any case, and did not receive personalised letters of the kind described here until after final ratings had been received, as they were receiving self-help guidance through the study, and in order to avoid contamination.

#### *9.4.3 Self-help groups initial piloting*

The investigator had little control over presentation of the materials, other than briefing the group leaders. However, these individuals were experienced leaders, with close, often long-term relationships with their group members. During pre-meeting discussions with the investigator, they repeatedly stressed the importance of protecting group members from unwarranted intrusion or distress, and also stated that participation either during the groups or by taking questionnaires away

to comment on would be entirely at members' discretion. They volunteered to deal with any untoward reactions which might arise.

#### *9.4.4 Dermatology outpatients' pilot*

Patients approached face to face during the pilot phase in a dermatology outpatients department might have their ability to consent compromised by the presence of an interviewer perceived as official. The procedure detailed in the relevant section of Chapter 10 was followed. The point of ethical issue is the inclusion of a written consent form to be signed by respondents completing face-to-face questionnaires. The interviewer also explained verbally his role as independent from the clinical team, and confirmed that participants were under no obligation to participate, that participation was unrelated to treatment, and that they were free to discontinue even if they gave consent at the beginning of completion.

#### *9.4.5 Ethical issues regarding design*

Method is described in Chapter 10. However, good design in research has increasingly become an ethical issue, principally because ethics committees often see it as part of their remit to comment on the methodological adequacy of the studies which come before them. This in turn is because it is generally assumed to be unethical to expose participants to studies which are insufficiently well designed to yield interpretable results. Participation is thus a waste of participant time. Poorly designed studies are also ethical threats because they potentially lead to the adoption of clinical or other interventions which are based on invalid methods of investigation, and are thus potentially of no value, or are detrimental, to those clients with whom they come to be used.

In view of this, the current study programme was designed by the investigator, but with consultation from numerous clinical and research colleagues, and, of course, the investigator's academic supervisor. Whilst the study is not without considerable weaknesses, which are discussed in Chapter 12, it was considered to be of sufficient strength to yield useable results in all the areas which it sought to investigate, particularly given the rudimentary state of investigations in the area. Additionally, the investigator had, by commencement the study, considerable experience in

research design, particularly using experimental and survey methods. These included the following.

- 1 Four years classes in experimental and other psychological research design as an undergraduate.
- 2 Participation in data collection and instrument selection in two clinical trials.
- 3 Co-ordination of two funded research projects, involving survey and experimental methods.
- 4 Co-ordination and conduct of several smaller non-funded projects.
- 5 Supervision of the work of undergraduate and post-graduate taught course research dissertations.

As the current project progressed, the investigator also gained the following experience, which informed the development of the project design and methods.

- 6 Further co-ordination of funded projects
- 7 Supervision of postgraduate degrees by research
- 8 Participation in a regional mental health research funding committee
- 9 Publication of methodological articles in peer-reviewed journals and presentation of conference papers on methodological issues
- 10 Co-ordination and teaching of research methods courses to undergraduate, postgraduate and professional groups.

The investigator and his supervisor believed, therefore, that the investigator had sufficient experience and expertise to produce a project which would have, despite the presence of some unavoidable flaws, sufficient methodological rigour to meet the ethical requirement of adequate design.

#### *9.4.6 Ethics committee approval*

A proposal outlining the project was first submitted to the Departmental Ethics Committee of the Institute of Nursing Studies, Hull University (now the School of Nursing, University of Hull). At the

time of submission, this was an informal, ad hoc committee which met on an occasional basis to consider the research projects of staff members and students. A broader School Ethics Committee was in the process of forming within the School of Life Sciences at the time of submission, but had yet to agree its terms of reference at the time of submission of the current study. The chief reason for this lack of formality and hierarchical structure within the ethical arrangements of the Institute and School at the time was that the majority of projects within the Institute were expected to be clinical in nature, and therefore to go before the relevant Health Authority Ethics Committees. However, the investigator was aware of the need to secure ethical approval for those elements of the current study which did not involve access to participants via the mechanisms of the National Health Service, and therefore sought approval within the University in the first instance. Approval for the project was granted and recorded within the minutes of the Departmental Ethics Committee meeting.

The proposal was subsequently sent to the Local Health Authority Ethics and Clinical Trials Committee, and was given approval following a few queries which were resolved by liaison with the Chair of the Committee. A copy of the letter granting ethical approval is presented as Appendix 4.

## CHAPTER 10

### METHOD

#### Section 10.1 Introduction

Since the study consists of six linked elements, the measures employed, which were common to all, are described first. The self-help leaflet is also described at this point, since it is relevant to two elements of the study (the pre-pilot phase and the treatment study). Further aspects (aims, participants and sampling, access and procedure) are described separately for each study.

#### Section 10.2 Measures

The measures used were collated together into a single instrument which comprised:

The Body Attitudes Test (BAT) (9 elements)

The Face Attitudes and Avoidance Checklist (FAAC)

The Brief Standard Rating Scale for Phobics (Fear Questionnaire [FQ])

The Social Adjustment Questionnaire (SAQ)

The Maudsley Obsessions Checklist (MOC)

The General Health Questionnaire [12] (GHQ)

The Hospital Anxiety and Depression Scale (HAD)

Demographic details and details of disfigurement.

A monochrome facsimile of the complete instrument is presented as Appendix 5.

##### *10.2.1 Rationale for Selection of measures*

###### General

Measures were selected with the following reasons in mind:

Congruence with the study focus and aims (ie; a primary focus on anxiety and avoidance, rather than physical or socio-economic considerations).

Congruence with cognitive-behavioural approaches to human experience.

Ease of completion in the absence of an interviewer and likelihood of compliance with completion.

Likelihood of sensitivity to treatment change.

Presence of previous validation studies or evidence of long-term clinical use in other populations.

#### 10.2.2 *Specific measures*

##### 1 The Body Attitudes Test (BAT) (Probst et al., 1995)

This instrument formed the basis for the wording of elements of the Face Attitudes and Avoidance Checklist (FAAC). In addition some elements of the BAT were included with the FAAC, for comparison purposes, forming the first 9 elements of a combined Face and Body Attitudes and Behaviours instrument. Permission to use the BAT was obtained from the author (Appendix 6).

The BAT was chosen for its simplicity of completion and its current use as a clinical tool in the field of behaviour therapy. For the current study, however, it was inappropriate as a stand alone instrument, either for survey/screening purposes, or as an instrument of change. The BAT is weak in two ways in the current context. First, it contains a number of elements specific to eating disorders, a feature common to most of the body image related measures reviewed earlier. Eleven items were removed from the BAT following initial instrument development discussions (see below). Six of these were specific to eating disorders. A further five items were seen by the pilot groups and professional experts as being ambiguous, insufficiently related to people with facial disfigurement or repetitive.

At the commencement of measure construction, full testing of reliability and validity of the BAT had not been carried out. Although there were early validation study results which indicated that validity and reliability of the BAT were likely to be acceptable, these were only complete for the Dutch language version of the instrument (Probst et al., 1992). However, subsequent examination of the factor structure of the BAT (Probst et al., 1995) showed that the majority of the elements retained within the current study loaded on two factors: 'lack of familiarity with one's own body' and 'general body dissatisfaction' (seven items). A further item, although it achieved its highest loading on 'negative appreciation of body size' (.56), also loaded high on 'lack of familiarity with one's own body' (.54). The final item loaded on a 'rest factor'. Of the omitted items, the six apparently eating

disorder specific ones all loaded highest on the factor: 'negative appreciation of body size', whilst three of the others loaded on 'lack of familiarity with one's own body', and one each on 'general body dissatisfaction' and 'rest'. Thus, had this information been available at time of test construction, four further elements might have been retained, despite the misgivings of the pilot group.

Generally, however, there is reasonable retrospective support from the factor analysis data for the choices made in excluding some elements of the BAT whilst retaining others. Six of the discarded elements loaded heaviest on a factor related to concepts repeatedly associated with eating disorders, whilst a seventh belongs in a general 'rest' factor. Of the included items, eight are strongly related to factors of relevance to general body image disturbance, rather than eating disorders specifically. The ninth, although only a member of the general 'rest' factor, nevertheless is likely to be of considerable interest in an examination of body image concerns ('My bodily appearance is very important to me').

A final modification was made to the wording of the BAT elements, on the advice of the pre-pilot group. Where the words 'my body' appeared in the element, the words 'as a whole' were added, in order to facilitate respondents in making the distinction between being asked for a general response with regard to their bodies and specific one related to the face, as in the FAAC elements of the instrument. A direct comparison between the BAT and the FAAC had originally been considered, in order either to establish convergent validity of the FAAC or to establish a relationship between aspects of general body image and body image specific to the face. However, given the large number of items discarded from the BAT, these considerations were abandoned. However, comparisons between some specific BAT and FAAC items were made, and are reported in the results chapter.

## 2 The face attitudes and avoidance checklist (FAAC)

This 19 element, 6 point rating scale was developed by the researcher as an extension of the BAT, and formed the final 19 elements of the combined Face and Body Attitudes and Behaviours instrument. It was designed to be as close to the BAT as possible in wording, capitalising on the



simplicity of phrasing, and the role of the BAT in clinical practice, whilst allowing for comparisons between specific BAT and FAAC items relating to general body experiences and behaviours and face specific experiences and behaviours to be made with clarity. Most of the elements of the FAAC are essentially adaptations of similar elements on the BAT, rendered specific to the face. Further elements used the same general format of words and the same measurement scale, but extended the focus of the instrument to examine more elements of overt behaviour, as well as attitudinal aspects derived from the BAT. The relevance of each FAAC element to the issue of adaptation to facial disfigurement, principally in the light of cognitive behavioural approaches, is now presented. FAAC items begin with item 10 on the combined instrument and are numbered 10 to 28.

*Item 10: When I compare myself to others, I'm dissatisfied with my facial appearance*

*Item 14: I hide my face (e.g. special clothes, turning face away).*

*Item 20: I envy others for their facial appearance.*

These elements were directly derived from BAT elements which loaded on general body dissatisfaction. Inclusion of the items allows for comparison between attitudes and avoidances related specifically to facial appearance and attitudes and avoidances related specifically to the body as a whole in people with facial disfigurement. Additionally, anecdotal and some qualitative evidence (see Chapter 4) suggested that people with facial disfigurements were likely to compare themselves with others in an unfavourable light. Hiding the face is a highly specific avoidance behaviour, which is worthy of examination in the context of the cognitive-behavioural approach to disturbed body image. The addition of an open-ended part to this element was intended to give rise to a wide range of responses from which the most common avoidance tactics could be gleaned. These could also later be related to level of handicap.

*Item 11: I wear facial prostheses (excluding wigs & special make-up)*

*Item 12: I wear a wig*

*Item 13: I wear special make-up*

There is no established relationship between severity of disfigurement and level of handicap, and no agreed measure of level of disfigurement. Whilst some complaints which affect the face are indeed subject to clinical scaling, these are typically specific to a single complaint, and are therefore not capable of use for comparisons of impairment across a heterogeneous sample of facially disfigured people. Despite a recognition of this as early as 1986, in the commentary on Rumsey and Bull's (1986) paper (Shaw, 1986), no such measure has yet been forthcoming. Dropkin et al.'s (1983) classification system represents one attempt at such a measure, and Dropkin et al. were able to demonstrate that their 100 nurse subjects rated different facial disfigurement sites in a transitive way. Transitive scaling is demonstrated if respondents who rate item A higher than item B and item B higher than item C also rate item A higher than item C ( $A > B$ ,  $B > C$ ,  $A > C$ ). Essentially, in the Dropkin et al. (1983) study, damage to major structures such as eyes, close to the mid-line was rated as more disfiguring than minor disfigurements of peripheral areas of the face and neck. However, this system is reliant on either on a photograph or drawing of the subject or on rater knowledge of the position of the disfigurement. It was hoped that the eliciting of the use of the comparatively major adaptation tactics in Items 11-13 might give a very rough guide as to severity of disruption of appearance. There is only intuitive evidence for this, in that people are unlikely either to have facial prostheses made, or to go to the inconvenience of wearing them, in the absence of considerable disruption of appearance. The same is likely, to a lesser degree, of wig and camouflage makeup wearing. In the event of sufficient numbers being forthcoming, it might then be possible to categorise study participants according to their responses to questions 11-13 and then use these categories to compare their responses to other elements of the questionnaire. The use of the 6 point scale was retained for the sake of consistency within the measure, although it was expected that responses would essentially be dichotomous.

The best way of assessing level of disfigurement would be by the use of photographs, since it might be expected that level of rater agreement as to level of disfigurement shown in photographs would be high, in the same way as it is in ratings of attractiveness (although attractiveness studies do not include disfigured subjects [Rumsey, 1983]). Moreover, Dropkin et al.'s (1983) approach could then be used. However, this suggestion met with universal disapproval from the expert clinicians canvassed during test construction, on the grounds of being threatening and possibly stigmatising.

A further practical and ethical element ruled out the use of photographs. One element of the study involved collection of data from plastic surgery ex-patients. Many of these individuals, whilst possibly familiar with photography as part of treatment, would a) have minor remaining visible disfigurement, if any and b) not consider themselves disfigured. The request to supply photographs would represent a significant intrusion and might also possibly raise issues in respondents' minds with regard to their appearance which had not previously been present. Finally, it is likely that compliance with a request to provide a photograph would be poor and lead to an extremely skewed sample.

*Item 15: My face is a barrier to me with others*

*Item 17: My face is a threat to others*

These items were included to reflect anecdotal accounts of the negative experiences of facially disfigured people in social interactions with others.

*Item 16: My face is a threat to me*

*Item 18: My face appears as if it's not mine*

These items were direct adaptations of BAT items which loaded highly on the 'lack of familiarity with one's own body' factor. Comparisons between these items and their BAT counterparts were intended.

*Item 19: My facial appearance is very important to me*

This item is a direct adaptation of a BAT item in the 'rest' factor. Once again, comparison between this item and its BAT equivalent was intended.

*Item 21: I have become used to the way my face looks*

*Item 22: Other people have become used to the way my face looks*

These items were included to investigate the assertion that people with facial disfigurements might come to an acceptance of their appearance over time, and that people they knew might come to a similar acceptance. These assertions occur in the literature (Tucker, 1987), but have not been adequately investigated .

*Item 24: I avoid looking at my face*

*Item 25: I avoid walking in the street because of my facial appearance*

*Item 26: I avoid social situations because of my facial appearance*

*Item 27: I avoid sexual contact because of my facial appearance*

*Item 28: I avoid certain kind of clothes because of my facial appearance*

These items are commonly reported avoidance behaviours by people with facial disfigurements (Macgregor et al., 1953; Macgregor, 1979), and by patients with body dysmorphic disorder (Marks & Mishan, 1988; Gournay et al., 1997) They have not been systematically investigated in facial disfigurement prior to the current study. Their inclusion facilitates investigation of elements of the assertion, in cognitive behavioural approaches, that avoidance, anxiety and handicap are linked.

*Item 23: I check my face in mirrors*

This item is included to reflect a specific behavioural excess associated with body dysmorphic disorder.

### 3      The Brief Standard Rating Scale for Phobics (Fear Questionnaire)

This is a scale commonly used in behaviour therapy practice, which consists of four elements:

a rating of the severity of the phobic difficulty the patient wants treated

a fifteen item list of commonly avoided situations, grouped under three subscales of 5 items each:

agoraphobia, social phobia, blood and injury phobia.

a 5 item rating of anxiety and depression

a rating of the global impact of the patient's problems.

The scale has been used for over 25 years in clinical practice, although it has never been formally tested for its psychometric properties, other than an examination of test-retest reliability in a small sample (Marks and Mathews, 1979). All items are rated on 0-8 scales. Although there is no formal cut-off point for 'caseness' (representing a case of clinical severity), higher scores denote greater pathology, and a score of 4 on the global phobia scale has been considered in clinical practice to indicate sufficient severity of a problem to warrant treatment. The scale was included to permit quantification of avoidances and problem severity, and comparisons between various subgroups in the study.

The initial rating of the phobia for which treatment was required was omitted in the current study as irrelevant to a well population. The final item (global phobia) was slightly modified. The word 'phobia' was omitted and the word 'problem' substituted, since it was considered unlikely that respondents would have ever considered their difficulties (if present) in terms of phobic avoidance. This modification has been used in clinical practice where the measure has been used outside the context of treatment of phobias (e.g. Corney et al., 1990). This item is referred to as 'global problem severity' for the remainder of this thesis.

#### 4      The Social Adjustment Questionnaire

This is a measure used in clinical practice for over 20 years (Marks et al., 1977), consisting of four 0-8 scales measuring avoidance and discomfort in the following situations: work, home management, social leisure, private leisure. The psychometric properties of the scale are untested. It was included here to permit quantification and comparison of these difficulties.

#### 5      The Maudsley Obsessions Checklist

This is a 37 item checklist consisting of four point scales measuring the respondent's tendency to avoid performing certain activities or to repeat such activities. Although considerably used in clinical practice (Marks et al., 1977), no psychometric testing of the measure has been reported. The measure was included here to allow quantification and comparison of compulsive phenomena, with the intention of examining the contention that such activities might occur in disfigured people, in a manner similar to that found in BDD sufferers.

## 6 The General Health Questionnaire (12)

This is a brief screening tool for use in detecting minor psychiatric disturbance across a variety of clinical settings. The tool is available in 60, 30, 28 and 12 item versions. The 12 item version was chosen for the current study because it is described as being as valid, reliable and sensitive as the longer versions (Goldberg & Williams, 1991) and because its quick completion time makes it appropriate for postal self administration as part of a larger battery of measures. The measure examines inability to carry out normal functions and the occurrence of distressing symptoms. Each item on the scale may be scored either continuously or dichotomously (GHQ scoring), and the results summed for the whole measure. Several 'caseness' cut-offs may be derived from GHQ scoring with a cut-off of more than 1, 2 or 3 for the total scale indicating caseness. (Goldberg & Williams, 1991), with the higher scores being the more conservative estimates of caseness. The scale has been extensively tested for validity and reliability in different populations, and has been used in previous studies of facial disfigurement. It is included in the current study with the aim of identifying minor psychiatric morbidity and comparing levels of its occurrence between subgroups.

## 7 The Hospital Anxiety and Depression Scale

This is a 14 item rating instrument with 7 items each devoted to anxiety and depression and rated on 0-3 scales. The instrument may be self administered. Respondents may be divided into normal (0-7), mild (8-10), moderate (11-14), and severe (15-21) scoring bands. Like the GHQ, the HAD has been extensively tested to establish its reliability and validity (Zigmond & Snaith, 1983, Snaith & Zigmond, 1994), and has been used in previous studies of facial disfigurement (Robinson et al., 1996). It is included in the current study to detect the presence of depression and anxiety amongst respondents and to compare subgroups.

### **Section 10.3 The self-help leaflet**

The leaflet was an 18 page A5 document aimed at the lay reader. Consistent with the aim of providing an intervention with the eventual potential to be made available to large numbers of sufferers, the leaflet was constructed so as to be similar to those found in general practitioner surgery waiting rooms.

The leaflet offered a cognitive behavioural explanation of:

- the nature of anxiety,
- the relationship of anxiety to everyday life and to changes in facial appearance,
- the relationship of anxiety to avoidance,
- the relationship of anxiety to changes in facial appearance.

The leaflet described the following elements of a cognitive-behavioural approach to tackling anxiety and avoidance:

- confronting feared situations,
- anxiety reduction as a consequence of exposure,
- instructions in exposure emphasising frequency and duration of exposure task completion,
- explanation of coping tactics for use during exposure tasks,
- suggestions about relaxation, reading a self-help book, joining a self-help group,
- a self-treatment progress checklist.

A monochrome facsimile of the leaflet, amended to read continuously in A4 format, is included as Appendix 7.

Within budgetary constraints, issues of presentation were addressed. Thus, the leaflet was written in plain, colloquial English, with therapeutic terms explained, in Arial font 14 point size. A recent review of leaflets used in general practice (Albert and Chadwick, 1992) suggested that general practitioners would be well advised to examine how far their patients might be able to access such information. Whilst most leaflets were acceptable, some had a FOG (Gunning 1968) index as high as 15, putting them at the same level of reading difficulty as the *British Medical Journal*. The authors also noted the importance of attending to legibility and layout of the leaflet. The typeface used for the current leaflet is plain and modern, whilst 14 is a relatively large point size. The readability statistics for the leaflet are presented below (Figure 10.3.1). These are generally slightly higher than standard writing. Although the number of words per sentence and the Flesch reading

ease score were both close to standard ratings, the Flesch Kincaid grade, at 9.0, is rated as fairly difficult, whilst the FOG index was slightly higher than the 'satisfactory' 11.6 found in Albert and Chadwick's (1992) review. These high levels were partly attributable to polysyllabic clinically-oriented descriptive words (such as 'anxiety' and 'exposure') which were explained in the text and used on several occasions. In particular, the word 'anxiety' was used on 58 occasions. An analysis of the readability with the words 'anxiety', 'anxious', 'avoidance' and 'exposure' replaced with single syllable dummy words (to retain sentence length) yielded the results shown in Figure 10.3.2. These results are now at or close to the standard range and support the contention that the higher statistics originally shown were contributed to by the clinical descriptor words. The text was thus retained in its originally tested form, since the explanation of the clinical terms 'anxiety', 'avoidance' and 'exposure' was central to the rationale of the intervention. As a check, a question was included on the follow-up questionnaire asking respondents' views on readability of the leaflet, and this information is presented in Chapter 11.

**Figure 10.3.1 Anxiety and changes in facial appearance: Readability figures**

SCALE	SCORE	STANDARD RANGE/RATING
Words per sentence	16.6	17
Flesch reading ease scale	58.7	60-70
Flesch-Kincaid Grade	9.0	7-8
FOG index	12.3	-

Note: high scores denote more difficult material throughout.

**Figure 10.3.2 Readability statistics following removal of clinical descriptors**

SCALE	SCORE	STANDARD RANGE/RATING
Flescher reading ease scale	65.4	60-70
Flescher-Kincaid Grade	8.2	7-8
FOG index	11.4	-

#### Development and pre-piloting of the instrument and leaflet content

The initial impetus for the facial avoidance behaviour element of the questionnaire battery, and for the inclusion of particular measures within the battery, came from clinical experience, and from familiarity with and subsequent examination of the behaviour therapy related literature described in Chapters 7 and 8. The battery was developed to examine the prediction that people suffering a facial disfigurement would exhibit avoidance behaviour associated with anxiety and analogous to



that demonstrated by phobics. The reasoning behind this prediction was described in Chapter 8. The leaflet to be used in the treatment phase of the study had its origin in the same experiences, literature and prediction.

Initial drafts of the questionnaire battery and leaflet were assembled on the basis of the literature review and clinical experience. These drafts were discussed with a number of professionals active in the fields behaviour of therapy, of body image disturbance in general and of facial scarring in particular. These were:

A professor of dermatology

A professor of psychiatry

A nurse specialist and theorist in oncology and body image disturbance

Two occupational therapists and one nurse specialist in the field of rehabilitation after facial disfigurement

Members of two self-help groups for facially disfigured people (Let's Face It, Changing Faces,).

Aims of the initial discussions were:

To establish face validity of the instruments selected.

To establish appropriateness of the self-help leaflet content for the target client group.

To elicit comments for further drafts of questionnaire and leaflet.

To secure access to a small clinical population in order to seek further comments regarding validity of the measures and leaflet.

Subsidiary aims of the discussions were:

To determine the approximate likely frequency of difficulties with adjustment following facial disfigurement.

To determine the likely accessibility of potential survey and treatment sample groups.

The experts' comments were incorporated into the next draft questionnaire battery and leaflet, which were then shown to members of two self help groups (N=14) for further comments and revisions. In both cases, access to the groups was controlled by the group facilitators. They reported that group members were reticent about professional 'guests' within the groups, as considerable personal and emotionally laden material was discussed. The researcher provided facilitators with the general brief of eliciting group comments with regard to the appropriateness and acceptability of the measures, and requested that particular attention be paid to:

length of the instrument

comprehensiveness of the instrument

intrusive nature of questions

possible harm resulting from intrusive questions

perceived applicability of the elements, with special reference to the standard scales (e.g. HAD, GHQ)

With regard to the draft leaflet, the facilitators were briefed to ask simply if the group considered the content a) sufficiently focal to problems resulting from facial disfigurement and b) likely to be of use in dealing with such issues.

The facilitators met the researcher following group sessions at which the documents were discussed and provided verbal feedback on the comments of group members, who had either examined the documents during the group meetings or taken them away for further examination and reported back to the facilitators. Members of one group also completed specimen copies of the questionnaire, and an estimate of completion time was made at 20 minutes.

Surprisingly, few issues were raised. The chief concern was length of the questionnaire, although no group members felt this would be a barrier to completion by respondents. It was determined not to omit any elements of the questionnaire, since each element had been included in response to concerns (see Section 10.2.2, above) which the study explicitly wished to address, in response to the proposed cognitive-behavioural formulation and to the literature. Group members recognised

the study as a potentially important contribution, and felt that the questionnaire covered areas which were likely to be of concern to facially disfigured people. They recognised that some of the material included was sensitive, but also believed that respondents would see the need for the inclusion of such sensitive material.

Three specific changes were made in response to comments from the groups regarding the questionnaire. First, one item of the FAAC ('My face is a burden to me') was omitted from the final version, since group members generally reported that this item did not appear relevant to them. Surprisingly, no such comment was made about the equivalent item from the BAT, which was retained. Second, details regarding the nature of respondents' disfigurement had previously been placed at the beginning of the questionnaire, along with basic demographic information. This was felt to be intrusive and was moved to the end of the questionnaire, leaving just the demographic questions before commencement of the scale measures. Finally, the wording of some of the previously published scales was felt by group members to be unusual in construction. Since the wording could not be changed, a brief note to respondents noting the unusual phrasing in some of the questionnaires was included (see Appendix 5).

The self-help leaflet was reported by group members to be readable and of relevance and interest to people with facial disfigurements.

## **Section 10.4 Pilot study**

### *10.4.1 Aims*

- 1 To determine the reactions of a group of dermatology outpatients attenders to the questionnaire, with particular reference to negative emotional reactions and difficulties in completion.
- 2 To estimate the likely completion rate through the post.

- 3 To gain an initial estimate of numbers of respondents likely to be suffering psychological difficulties as a result of facial disfigurement, and thus, the likely numbers to be needed to generate a sample for the leaflet study.
- 4 To describe the psychosocial difficulties of respondents, with particular reference to behavioural avoidance and psychosocial disturbance.
- 5 To identify respondents suitable for inclusion in the study of written guidance in behavioural interventions for avoidance and anxiety.

#### *10.4.2 Sample*

Sixty two consecutive male and female attenders at a dermatology outpatients clinic who consented to participate.

Inclusion criteria:

17 years of age or over (age agreed with ethics committee as the minimum required for independent informed consent)

no current malignant disease

agree to participate

identified from clinical notes as having a skin complaint primarily or exclusively affecting the face and currently receiving treatment for this complaint (i.e. not in remission/follow-up)

no diagnosis of learning disability recorded in clinical notes (this criterion used in order to avoid possible difficulties with consent and understanding of questionnaire)

#### *10.4.3 Access*

Following approval by the local Health Authority Ethics Committee, the two consultant dermatologists with clinical responsibility for the dermatology outpatients clinic and its patients were approached by letter and in person, and the aims and methods of the study were explained. They granted access to the clinic. The clinic nursing and clerical staff were then consulted and their co-

operation was sought. The clinic nurses were extremely enthusiastic, and, despite considerable difficulties over clinic space, were able to make available a room for administration of the measures. Clinic details and access to patient records were negotiated with the clinic clerical staff, who also demonstrated use of the computerised appointments system.

#### *10.4.4 Procedure*

Potential participants meeting the inclusion criteria were identified from patient records before each day's clinic over a period of three months. They were then approached by the investigator whilst awaiting their appointments and invited to participate, with a verbal description of the study. Those agreeing to participate were offered any of three alternatives: to complete the questionnaire as a structured interview from the investigator, to complete the questionnaire alone whilst awaiting their appointments, to take the questionnaire away and complete it at home. Those completing the questionnaire in the clinic, either by interview or as a pen and paper test, were asked to read and sign a consent form (Appendix 8), in order to minimise possible investigator coercion to participate, whilst those who took the questionnaire away were deemed to have consented by their return of the questionnaire, in light of the verbal and written information given about the study. These methods of obtaining consent were agreed with the Ethics Committee.

One aim of the pilot was the estimation of likely untoward responses to the questionnaire. In consequence, it was originally envisaged that all the early questionnaires would be offered in the presence of the interviewer, before proceeding to postal administration. However, almost all respondents requested postal completion from the beginning. This enabled the pilot to proceed to an examination of postal return rates very early, but did lose valuable potential data relating to Aim 1, which could not be realised. One possible reason for requesting home completion might have been a desire for privacy and the opportunity to withdraw from participation. However, it is also possible that participants were aware that their clinic appointments were looming, and did not want to be delayed by questionnaire completion after the appointment had taken place. Certainly, this particular dermatology clinic, although extremely busy, was very efficiently run, and waiting times were generally under fifteen minutes. This is less than the estimated completion time of 20-25

minutes required for the questionnaire as a pen and paper test. Interview format completion is, of course, considerably longer than this.

#### *10.4.5 Changes to the questionnaire and study*

The pilot study revealed no untoward reactions to the questionnaire, with the exception of one respondent, who noted that some of the scales led him to feel 'inferior'. Since the scales were included with regard to the specific aims which the study wished to investigate, no changes were made. Two respondents noted that rating boxes on a number of the scales were small. This was known to the researcher, but a decision had been made to retain the small size, since enlargement would have led to a further increase of 2 sides in an already long instrument. There was no indication that respondents found the instrument difficult to comprehend, and two respondents spontaneously commented that completion had helped them consider difficulties related to their dermatological complaint. It was concluded that the questionnaire was generally acceptable to respondents.

Despite 3 times weekly attendance at clinics by the researcher, few patients with dermatological complaints involving the face were identified. Of these individuals, few experienced problems of sufficient severity to warrant inclusion in the treatment element of the study (see Chapter 11). This, combined with a completion rate of only 58.06 per cent (36 respondents) of the 62 patients who initially agreed to complete questionnaires confirmed initial impressions that it was unlikely that local clinics would be able to generate sufficient numbers for either a large survey or a treatment study. Complete findings from the pilot study are presented in Chapter 11.

### **Section 10.5 Survey of plastic surgery ex-patients**

#### *10.5.1 Aims*

- 1 To identify the prevalence & features of psychosocial difficulties in a sample of plastic surgery ex-patients, with particular reference to behavioural avoidances.
- 2 To examine the test-retest reliability of the FAAC.

- 3 To identify patients suitable for participation in the study of written guidance in behavioural interventions for avoidance behaviours.

#### *10.5.2 Sample*

The sample group consisted of 253 consecutive patients drawn from the list of patients treated by two consultant plastic surgeons in the period between 5 years six months and six months prior to the commencement of the study. The maximum cut off time was chosen arbitrarily, and corresponded with the length of time during which the most recently appointed consultant had been in post, and thus for which records were most readily available. The minimum was decided upon in order to allow sufficient time to have elapsed between operation and questionnaire for any post-operative tissue inflammation or post-operative complications to have subsided. This time limit was agreed following discussion with the plastic surgeons involved. The sample frame represented the vast majority of the patients seen in the plastic surgery department during the nominated time limits, with exceptions being patients seen by the two involved consultants privately and those seen by a recently appointed third consultant, who had, at the inception of the study, seen very few patients through to operation and follow up, having been appointed only a few months prior to commencement of the study. Inclusion criteria were:

17 years of age or over (age agreed with ethics committee as minimum required for independent informed consent)

no current malignant disease

agree to participate

no diagnosis of learning disability recorded in clinical notes (this criterion used in order to avoid possible difficulties with consent and understanding of questionnaire)

identified from clinical notes as having received plastic surgery to the face within the identified time frame

not currently receiving ongoing treatment

In the case of basal cell carcinoma (BCC) patients, having received excision plus skin graft, rather than direct closure.

The final inclusion criterion was chosen following clinical discussion with one of the involved surgeons, who felt that excision and direct closure was unlikely to result in appreciable scarring. Although it was noted in the literature review that extent of disfigured area has often been regarded as a poor predictor of reaction in terms of dysphoria or other handicap, this criterion was adopted for the following reasons. Following direct closure, which is invariably for very small lesions, removal of BCCs often leaves so little scarring as to be, to all practical purposes, invisible. Furthermore, there is some evidence in the literature (Cassileth et al., 1983) that direct closure leads to considerably less psychosocial disturbance than does grafting.

#### *10.5.3 Access*

Following ethics committee approval for the study, the two plastic surgeons were approached, and the study was explained in person and in writing, with a request to allow access. The surgeons were extremely interested in the study and agreed access to clinical notes and to patients by post. Discussions were subsequently held with the clinic nurses and medical secretaries, who were very helpful in defining the best manner of tracing suitable patients from the records system.

#### *10.5.4 Procedure*

A record of all admissions to the operation lists of both consultants is maintained by the medical secretariat of the plastic surgery unit. This record was examined, and all patients who had received plastic surgery to the face during the time frame were recorded by the investigator. This gave information as to name, age, date of admission and diagnosis. Addresses were obtained from the hospital records. In cases where the diagnosis was in doubt, the investigator liaised with the medical secretaries, who accessed their discharge and follow-up letters and confirmed diagnoses. Where doubt remained either as to diagnosis or the presence of recurrence or persistence of active malignancy, the medical records of the patients were consulted.

Patients who fulfilled the inclusion criteria for the study were approached via the mail in a two stage approach procedure. An initial letter was sent, under the name of the patient's consultant, explaining the study and seeking participation. A FREEPOST envelope and tear-off slip were included for the patient to return if he or she *did not wish to participate*. The letter emphasised that



participation would in no way affect further treatment, and that the patient was under no obligation to participate, even if he or she did not return the tear-off slip, which was appended simply in order to offer a further safeguard to the patient against receiving unwanted mail. The investigator's name and contact details were also included if the patient wished to discuss the project further (See Appendix 3). This method of initial contact had been agreed by the ethics committee.

After a fortnight, a further letter was sent to those potential participants from whom tear-off non-participation slips had not been received, under the investigator's signature, thanking the patient for participation. The letter also repeated that there was no compulsion to participate, but stressed the importance of the study to clinicians (Appendix 9). The questionnaire was included with this letter, again with a FREEPOST envelope included for return. The questionnaire also contained sections asking if the participant was willing to be involved in the leaflet study or retesting of the measure.

The two stage process was designed in order to minimise intrusion into the lives of a well population via unsolicited mail. Similarly it was agreed with the responsible consultants that no follow-up letters would be sent to non-respondents during this stage of the study. As is common with many postal questionnaires, consent is not sought other than the consent implicit in returning the questionnaire. It was felt, therefore, that those who had not responded, after having received both the initial letter and the questionnaire, should fairly be deemed to have withheld consent, and should not, therefore, be troubled further. This was made clear in the original approach letter. It was, however, recognised that the lack of a follow-up of non-respondents would lower the likely eventual response rate considerably, but the ethical consideration described here rendered this difficulty unavoidable.

A number of commonly-accepted tactics to maximise the likelihood of response were used. Thus, covering letters stressed the potential importance to the nursing and medical professions of the information the respondent would be providing, and its likely usefulness to a client group similar to the respondent, as well as suggesting the competence of the investigator to carry out the research and mentioning the investigator's clinical background. Potential respondents were offered copies of the research findings following completion. The letters and questionnaires were printed on good

quality stationery, and the letters were personally headed to participants and signed. FREEPOST envelopes were included at all stages and further discussion was invited. The investigator had previously used these tactics in a nationwide twenty year postal follow-up of nurse therapists (Newell & Gournay, 1994) which received fairly respectable 79.5% return rate. The general utility of these measures in increasing response rate is widely accepted amongst survey researchers and is reviewed by Newell (1993).

## **Section 10.6 Media recruited questionnaire study**

### *10.6.1 General*

As expected from examination of the literature, the rate of psychological disturbance in respondents to the plastic surgery ex-patients survey was fairly low (see Chapter 11). One important consequence of this was that the number of potential individuals for participation in either a study aimed at establishing general features of psychological disturbance in people with facial disfigurements, or a treatment study, could be expected likewise to be low. In order to generate sufficient numbers for either of these elements of the programme, it was determined, on the basis of this prevalence rate, to proceed to recruitment of subjects via the media, using a variety of approach tactics.

### *10.6.2 Aims*

- 1 To identify the features of psychosocial difficulties in a sample of media recruited persons with facial disfigurements, with particular reference to behavioural avoidances
- 2 To investigate the structure of the FAAC by means of factor analysis.
- 3 To investigate the test-retest reliability of the FAAC.
- 4 To identify patients suitable for participation in the study of written guidance in behavioural interventions for avoidance behaviours.

### *10.6.3 Sample*

The sample group consisted of 420 respondents to a variety of calls for participants placed by the researcher in the media. They were thus a convenience sample, and therefore subject to the limitations associated with such a sample (Newell, 1993; Politt & Hungler, 1991; Reaves, 1992).

Inclusion criteria were:

over 17 years of age (age agreed with ethics committee as minimum required for independent informed consent)

agree to participate

identify self as having undergone a change in facial appearance as a result of surgery, accident or skin complaint, or having a facial disfigurement from birth.

Participants were deemed to have agreed to participate in the study if they replied to the calls in the media by writing or telephoning to request copies of the questionnaire. Copies of the questionnaire contained an initial page describing the contents and noting possible distress, as in the dermatology outpatients and plastic surgery ex-patients groups (Appendix 2). No check on the level of disfigurement of respondents was possible, for the reasons described in section 10.2.2, above.

### *10.6.4 Procedure*

A variety of media outlets were approached by the investigator, including radio, television, local and national newspapers and magazines. Although many did not respond, sufficient interest was shown to generate a considerable number of responses from the public. The following organisations broadcast or published details of the studies.

#### Radio

The investigator was interviewed by BBC Radio Humberside, BBC Radio Newcastle, BBC Radio Lincoln, BBC Radio 5, often in conjunction with members or founders of self-help groups concerned with facial disfigurement. The interviews included details of the study, a contact address and number, as well as general discussion and advice about facial disfigurement issues.

### Television

A BBC national television documentary programme (QED) about facial disfigurement and recovery included a leaflet outlining the current study along with their regular factsheet, for which viewers could write following broadcast of the programme.

### Newspapers

The *Daily Mail*, *Guardian*, *Yorkshire Post*, and *Hull Daily Mail* agreed to publish short pieces about the study. The *Daily Mail*, *Yorkshire Post*, and *Hull Daily Mail* eventually published such pieces, in their health sections (Appendix 10), whilst the *Guardian* did not pursue the matter further. In each case, a contact address was included.

### Magazines

A large number of magazines were approached, but most did not respond, or declined to accept a piece about the study, because it did not fit their publication profiles or schedules. Two large circulation women's magazines, *Best* and *Woman*, published short pieces about the study, including a contact address. No men's magazines expressed any interest in the study. The possible consequences of this bias towards female sources of respondents to this section of the study programme are noted Chapter 12.

Each respondent was sent the questionnaire with a personalised covering letter and FREEPOST envelope. Potential respondents who identified themselves as under 17 years of age were each sent a personal letter, requesting them to gain parental support before a questionnaire was sent (see Appendix 11 for an anonymised example). Although they were ineligible for participation, the questionnaire was then sent to such individuals in order to a) demonstrate respect for their interest in responding to the call for participants and b) identify potentially psychologically disturbed respondents with a view to either sending a copy of the leaflet or offering individual postal advice about issues such as self-help groups. Respondents who requested that questionnaires be sent to others (e.g. friends, spouses, children) received a personal letter, which included a copy of the questionnaire, explaining that questionnaires could not be sent directly to persons for whom they had been requested by a third party.

## **Section 10.7 Treatment leaflet pilot study**

### *10.7.1 Aims*

- 1 To examine the effect of a self-help leaflet based upon cognitive behavioural principles on the avoidance behaviours of people with facial disfigurements.
- 2 To examine the effect of a self-help leaflet based upon cognitive behavioural principles on the general psychological well-being of people with facial disfigurements
- 3 To compare the avoidance behaviours and psychological well-being of those receiving the self-help leaflet with a control group.

### *10.7.2 Sample*

Participants were 18 males and 88 females recruited from participants in the pilot, plastic surgery and media-recruited surveys. Participants were admitted to the treatment leaflet study if they fulfilled the following criteria:

17 years of age or over (age agreed with ethics committee as minimum required for independent informed consent)

agree to participate (gained by ticking the appropriate box in the initial questionnaire)

identified from ratings of global problem severity of the FQ as having difficulties of clinical severity sufficient to warrant minimal intervention by the provision of the treatment leaflet (3 or more on a 0-8 scale).

No formal cut-off point for inclusion in treatment exists for the FQ. However, a problem severity score of 4 or more appears to be commonly used to determine disturbance of sufficient intrusiveness to warrant intervention by clinician (this figure also appears to be used to determine difficulty of clinical severity on subscales of the SAQ). The cutoff of 4 was arrived at following discussion with the originator of the scales and other behaviour therapists, and by examination of previous studies using the scales (Marks, 1987). Given that the treatment element of the current study involved much less intervention than that offered in clinical practice, a cut-off of 3 was chosen

for this part of the study (although the cutoff of 4 is retained in discussion of level of clinical severity in all other elements of the study), reflecting the argument that it may be of value to intervene with less severely disturbed individuals when the therapeutic investment required is small.

#### *10.7.3 Access*

Access to participants was gained by the method described in Sections 10.5, 10.6 and 10.7, above.

#### *10.7.4 Procedure*

Respondents to the plastic surgery ex-patients and the media-recruitment elements of the study were randomly allocated to either receive a copy of the self-help leaflet (experimental condition) or not (control condition). The experimental group received the leaflet through the post, along with a covering letter (Appendix 12). Those in the control condition were sent a letter explaining the importance of piloting the leaflet, that a follow-up questionnaire would be sent to them in three months, and that the leaflet would be included with this (Appendix 13). They were asked to complete the follow-up questionnaire immediately upon receipt, before reading the leaflet or acting on any of its advice. Whilst there was a slight risk that they might derive benefit from reading the book before completing the questionnaire, this was judged to be slight, since the advice offered is essentially practical, and needs to be carried out in order for any benefit to be likely to be derived. Balanced against this, it was felt to be unethical further to delay sending the leaflet to the control group, since controls might justifiably feel they were being asked to go through yet a further stage in an already prolonged study. One inevitable consequence of this decision was that a follow-up contact with non-respondents could not be made, since their responses would be contaminated by exposure to the leaflet and possible practising of its suggestions for treatment.

### **Section 10.8 Comparison of facially disfigured people with phobic patients**

#### *10.8.1 Aim*

To compare the patterns and severity of avoidance behaviours of people with a facial disfigurement with those of a group of phobic patients.

### 10.8.2 Sample

Participants with facial disfigurements were 25 male and 87 female participants from the pilot study, the plastic surgery ex-patients survey, the media recruited survey and the treatment leaflet study, who recorded a global problem severity score of 4 or above on the FQ. They thus satisfied the problem severity criterion described above for inclusion in treatment by behaviour therapists. In the case of facially disfigured participants who had been drawn from the treatment leaflet study, and who were then included in the comparison with phobic patients study, *pre-treatment* scores were used to compare them with phobic patients. Phobic participants were 66 agoraphobic patients and 68 social phobic patients who had received treatment at the Psychological Treatment Unit, Maudsley Hospital, London and who were entered into the current version of that department's computerised database at the time of the study. They were randomly selected from this database for comparison with disfigured individuals. The extraction of these patients' data from the database occurred before the final number of eligible respondents with facial disfigurements could be identified, and the number of phobics to be extracted was selected on the basis of the *likely* predicted number of such eligible respondents. In fact, the *actual* number of eligible participants from the facially disfigured group was greater than expected. For practical reasons, it was not possible to again access the Maudsley database, in order to identify further data from these patients' anonymised records, within the time constraints of the study. As a consequence, it was envisaged that a number of subjects equal to those available from the phobic patient database should be randomly selected from the eligible facially disfigured respondents (those who met the cut-off criterion for clinical severity), in order to maintain equality of the group sizes in the comparison with phobics study. However, statistical advice was sought, and it was agreed that difference in group sizes was extremely unlikely to be of importance to the statistical approaches chosen, given the overall size of the groups involved. In view of this, all eligible respondents from the facially disfigured group were retained for comparison with the phobic database patients.

### 10.8.3 Access

The Director of the Psychological Treatment Unit, Maudsley Hospital was approached by the investigator, who described the rationale behind the study. The Director was enthusiastic and gave

his consent to access the Unit database of clients treated. Since the extracted data was anonymised, ethical approval for its use was not required.

#### *10.8.4 Procedure*

The Psychological Treatment Unit Patient Database had been maintained since 1972, first in pen-and-paper form, and latterly on computer. It contains the details, in numerical form, of all the patients treated within that institution since its inception, using standardised rating scales. From the computer database, the following patient information was extracted:

age at entry into treatment

sex

diagnosis

pre-treatment scores on the following measures:

FQ global phobia (global problem severity) score

FQ agoraphobia subscale

FQ social phobia subscale

These scores were compared with pre-treatment scores of the facial disfigurement group.

### **Section 10.9 Data analysis**

The approach to data analysis outlined in this section was informed by a number of sources. First, the author has participated in 4 years of undergraduate statistics classes as part of a psychology degree. Second, specialist statistical advice was taken where appropriate, in consultation with the author's supervisor. Third, a number of standard statistical and research texts were referred to in construction of the general statistical approach (Burns & Grove, 1993; Bryman & Cramer, 1992; Kinnear & Gray, 1995; Munro & Page, 1993; Politt & Hungler, 1993; Reaves, 1992). Finally, where specific statistical tests or approaches demanded further support from the literature, appropriate specialist texts were consulted. Child (1970), Kline (1994) and Surwillo (1980) provided further sources of specialist information regarding factor analysis, whilst additional information specific to



the use of factor analysis in questionnaires similar to the FAAC was gained from Meadows (1994) and Probst (1995). Additional statistical information regarding the process of power calculation was gained from Cohen (1977) and Kraemer & Thiemann (1987). The question of equivalence between two groups required considerable examination. No standard text which adequately outlined the arguments surrounding the measurement of equivalence could be found. As a consequence, a search was made of the past five years' editions of *Statistics in Medicine*. Relevant papers were examined and further references sought and examined. The arguments debated in Dunnett & Gent (1977), Gould (1993) and Senn (1993) concerning the assertion and estimation of equivalence and the calculation of appropriate sample sizes for the demonstration of equivalence were reviewed in detail and discussed with a statistician during the course of seeking statistical advice for the project.

#### *10.9.1 Level of measurement and general approach to choice of statistical tests*

Much of the data gathered during this programme of studies is at ordinal level, sometimes involving the use of extremely short scales (e.g. GHQ, MOC). Despite this, data of this kind has often been examined in previous studies using parametric tests. Furthermore, even the construction of some of the scales has relied on parametric tests (Goldberg & Williams, 1991; Probst et al., 1995; Snaith & Zigmond, 1994). The use of parametric statistics with ranked data has become conventional in a great deal of the literature of psychotherapy and psychology. The current study retains this approach to ranked data in most cases.

The use of a parametric approach has several advantages. It allows the possibility of using a greater range of tests in examining the data. This in turn allows the choice of a greater range of design approaches, since there are some approaches (most notably factorial designs) for which no suitable non-parametric treatments are readily applicable. Given that data derived from questionnaire responses are relatively infrequently at the interval level for which parametric statistics were originally intended, adopting a parametric approach to ordinal level data has considerable appeal because of the greater flexibility in the choice of design such an approach to data analysis offers. Parametric approaches are also more likely than their non-parametric equivalents (where these exist) to be sensitive to comparatively small differences. Once again,

treatment studies are often interested in such small differences, particularly at an early stage in the development of an intervention.

This sensitivity is, however, not necessarily an advantage. An approach which is sensitive to an apparent change when such a sensitivity is, in fact, caused by misapplication of a statistical test is without validity. However, over and above the pragmatic advantages described above, some researchers and statisticians have advanced more convincing reasons for the use of parametric statistics with non-interval data.

It has been argued that, whilst we ascribe values to numbers (e.g. strongly agree = 1, agree = 2, neutral = 3, disagree = 4, strongly disagree = 5), these numbers are simply ranked, since there is no reason to assume equality of the intervals between them. The size of the interval (in terms of how far the respondent agrees) between the '1' and '2' is here unlikely to be the same as that between '3' and '4'. Nor is it likely to be half the difference between '1' and '3', and so on. Since parametric tests work with the assumption of this kind of equality, it is argued to be inappropriate to use them when such assumptions are breached (Hollis, 1994; Coolican, 1991).

However, there are numerous compelling counter-arguments. First, although labels have been applied, in the above example, to each number, it is argued that it is not, therefore, necessarily correct to assume that there is lack of equality when these numbers are then used in calculating the statistical test. This is because the test works *only with the numbers* not the designations ascribed to them by respondents. Even though the numbers might represent unequal intervals, and be dealt with in a parametric test as though these intervals were, in fact, equal, this would, at worst, give rise to an *interpretational*, not a *calculation* error. The formula doesn't *know* what the numbers represent, nor does this matter for the calculation (Lord, 1953).

Second, it is argued that data based on ranked scores, particularly in small samples, are rarely normally distributed. Normality of distribution in the data to be examined is important because of the relationship between the normal distribution and measures of spread such as the variance and standard deviation, and the relationship of these measures to many parametric tests. However, in

some cases, ranked data *can* be demonstrated to be normally distributed. In such cases, there is no reason why the prohibition of parametric tests should apply. Moreover, offences against normality of distribution have not generally been found to have major effects upon results from parametric tests (Bryman & Cramer, 1990). Finally, and perhaps most compellingly, a number of studies have empirically investigated parametric treatments of data sets with their non-parametric equivalents without finding significant differences between the test results. The key issues which do seem empirically to lead to spurious results with parametric tests are the concurrent lack of homogeneity of variance within the study groups and existence of large differences between sample sizes in different conditions (Bryman & Cramer, 1990).

In view of these considerations, the following approach has been taken to the use of parametric statistics with ranked data. Wherever possible, previous well-conducted studies have been accepted as authoritative precedents for the use of such statistical treatments, within the context of the discussion above, and their statistical treatment of the measures used in the current study has been followed. In the case of studies involving the FQ, the MOC and the SAQ, the many studies conducted by Marks and colleagues, and reviewed in Marks (1987), are the principal authorities, whilst for the GHQ12 and the HAD, the relevant administration handbooks and the works reviewed within them represent these authorities (Goldberg & Williams, 1991; Snaith & Zigmond, 1994). In the interests of conservatism in the choice of tests, non-parametric tests have been used in examining elements of the FAAC which, as a new test, has no history of the application of parametric tests to its ordinal level scales.

In general, a conservative approach (involving the use of the best-supported relevant approaches) has been adopted to the data, and the most conservative tests (i.e. those whose appropriateness has received most support in terms of their applicability to the levels and types of data being examined) have been applied, consistent with offering a comprehensive account of the data within the constraints of the design approaches taken.

### 10.9.2 *Comparative studies and statistical power*

Statistical power refers to the ability of a statistical approach (and, by implication, the experiment with which it is associated) to detect effects of the independent variable when these are, in fact, present. The greater the power, the greater likelihood of detecting change. A full discussion of statistical power is beyond the scope of this thesis, but is well summarised in Burns and Grove (1993) and extensively explored in Kraemer and Thiernann (1987). In comparative studies, one key role of power is in determining the likely number of subjects required to detect differences between experimental groups. The calculation of the number of subjects required is based upon: the desired level of significance (conventionally 5 per cent); the acceptable level of risk of a type 2 error (conventionally better than 80 per cent probability of *avoiding* such a risk); the effect size (the result of a calculation involving the minimum differences between the group means considered to be of importance and the pooled variance of the experimental groups). The first of these figures related to effect size is typically derived, in clinical practice, from a consideration of the therapeutic value of a given level of difference, whilst the second is taken from the variance found in earlier studies, wherever possible (Kraemer & Theimann, 1987).

### 10.9.3 *Power in the leaflet intervention study*

In the treatment booklet study, the number of subjects was, in fact, determined (as in many pilot studies) by their availability within the time constraints. Moreover, there were no figures available from previous studies to indicate the likely variance of their scores on any of the key measures. As a consequence, the following approach to power calculation was adopted. The variance was calculated from data obtained from subjects eligible to enter the current study, whilst the minimum mean difference likely to give rise to therapeutic gain was set at 2 points on the 9-point scales used. On the basis of the investigator's personal experience in clinical practice, and discussion with other behaviour therapists, it is believed that phobic patients do not report that differences of less than 2 points have made any difference to their well-being. Given the minimal intervention involved, this seemed a reasonable minimum level of return for the therapeutic investment, and sufficient to indicate promise for the treatment in the context of a pilot study. Clearly the findings from the power calculation could not *affect* the size of the sample, which was already determined by availability. However, an exploration of available power in a study does allow the estimation of a type 2 error.

At its worst, this might lead to an abandoning of the experimental part of a study such as the current one, if the power was found to be unacceptably low. Similarly, power calculations based on a group to be included in the eventual study are not prohibited, provided that insights into the nature of the group examined in the course of such calculations are not used in the generation of predictions which are then tested *post hoc* on the same group. In the current study, this is not an issue, since the predictions tested were generated from clinical practice and the literature long before carrying out the power calculation.

Two key measures were chosen on which to conduct power calculations: the Social Leisure subscale and the Global Problem Severity measure of the Fear Questionnaire. The calculation method of Kraemer and Thiernann (1987) was used. Using the conventional alpha and beta levels of 5% and 80% respectively, the following estimates of necessary sample size were obtained:

**Table 10.9.1: Sample sizes likely to be necessary to detect differences between treated and untreated groups where such differences are present.**

MEASURE	EFFECT SIZE	REQUIRED SUBJECTS PER GROUP
Social Leisure (FQ)	0.38	42
Global Problem Severity (FQ)	0.54	24

No further calculations were undertaken, since these two measures are regarded as the key outcome measures in the study. Moreover, the standard deviations (the key measure required to compute power calculations) were broadly similar in the other measures.

The sample size in each group was, in fact, 53. Although the use of multiple outcome measures may increase the size of the sample required, this is not generally a major difficulty when the measures are expected to be correlated, as is the case with many of the measures in the current study which essentially measure different aspects of anxiety and avoidance. In view of this, it is concluded that the sample size was adequate to detect effects of the independent variable where these are present.

#### 10.9.4 Power in the comparison of facially disfigured people with phobic patients

Difficulties related to the study of equivalence have already been noted in Chapter 8. The three key problems relate to the need for precise specification of what constitutes equivalence, the inadequacy of predicting the null hypothesis and the likelihood of a need for large samples in order to demonstrate equivalence using an estimation approach. The general approach to the last two of these matters has been described in Chapter 8. It involves the possibility of asserting equivalence on the basis that no differences between groups have been found in samples where a power calculation would lead us to expect that such differences would be found, if present. The estimates based upon this calculation are presented in Table 10.9.2. The conventional alpha and beta levels were used. The effect sizes for the chosen subscales were calculated to find the number of participants needed to find a difference between the groups of 8 points on these subscales. A difference of 10 points would be a precise reflection of the 2 points difference on the 0-8 scales chosen to examine differences in the treatment study, and regarded as clinically important (see Section 10.9.3). However, since the assertion of equivalence requires that *no* difference of clinical significance between the groups should be found, the figure of 8 points was chosen as representing a relatively tight definition of equivalence, reflecting a difference of 1.6 on each of the elements which make up the subscales, and clearly less than the 2 points difference regarded as being of clinical importance. Thus, the power calculation was performed with a figure *less* than that required to indicate clinically significant differences, *decreasing* the likelihood of detecting no difference, and so representing a more stringent test of equivalence.

Since the actual numbers entered into this element of the study were 66 agoraphobics, 68 social phobics and 112 facially disfigured people, it may be concluded that the study possessed sufficient power to detect differences between the groups where these were present, with the exception of the agoraphobia subscale as a measure of difference between agoraphobics and facially disfigured people.

**Table 10.9.2: Minimum numbers necessary to detect differences between facially disfigured people and agoraphobics or social phobics where such differences are present.**

<b>Comparisons between facially disfigured people and agoraphobics</b>		
Measure	Effect size	Required subjects per group
Agoraphobia subscale (FQ)	0.29	74
Social Phobia subscale (FQ)	0.36	47
Anxiety/Depression (FQ)	0.32	60
<b>Comparisons between facially disfigured people and social phobics</b>		
Measure	Effect size	Required subjects per group
Agoraphobia subscale (FQ)	0.35	50
Social Phobia subscale (FQ)	0.37	45
Anxiety/Depression (FQ)	0.33	60

\* Note: all group size calculations allow for the different sizes of the groups in this element of the study.

With regard to specification of the criteria for judging equivalence, this has been achieved in part by the choice of an effect size based on the minimum difference between the groups assumed to be of clinical importance (8 points). By implication, the criterion for equivalence is that the two groups do not show mean differences greater than this.

Lack of difference on the chosen measures (agoraphobia, social phobia and anxiety/depression subscales) may in itself be an adequate criterion for equivalence. If it can be demonstrated that these measures distinguish between agoraphobics and social phobics (whom we know display distinct clinical pictures), but not between these phobics and disfigured people, it may be justifiable to regard this as a reasonable criterion by which to consider the phobic groups and facially disfigured group equivalent with regard to the characteristics measured by these subscales.

## CHAPTER 11

### RESULTS

#### Section 11.1 Introduction

This chapter presents the results of the studies described in Chapter 10. The sequential arrangement of results inevitably leads to some repetition, particularly with regard to the descriptive elements of the results of the studies. However, the alternative of combining some descriptive elements of the studies into a single series of summary tables was not acceptable, since the groups involved were both differently sampled and yielded different response patterns which would in any case have required further separate examination.

Results from the Maudsley Obsessions Checklist (MOC) are not reported in full, but brief summary statistics are provided. Contrary to expectations, scores on this element of the questionnaire were uniformly extremely low in the pilot study and in further samples. The instrument was retained in the later samples merely to ensure that the pilot results were not atypical and caused by the low numbers involved. The implications of the universally low scores are discussed in the following chapter.

The major reason for including elements of the Body Attitudes Test was the possibility of comparisons with the FAAC. Direct comparisons between the FAAC and the BAT proved more limited than was initially anticipated, because of alterations to the instrument early in the project. However, such comparisons were possible between a number of such elements, and these are included.

For clarity, a similar presentation of results is used for each study, wherever possible. Where responses for a particular item do not equal total respondents, some respondents have omitted that item from their replies. The Statistics Package for the Social Sciences (SPSS) was used for all data analysis. Results are presented in tabular form but also briefly described in the text. However, discussion of the results is reserved for Chapter 12. In particular, Chapter 12 examines the extent



of support provided by the findings for the fear-avoidance model, and the constraints imposed upon this support by methodological limitations of the study are also examined.

Since the FAAC was used across elements of the study, the examination of its properties is presented first. The other elements of the study are presented in the following order:

Pilot study (dermatology out-patients)

Plastic surgery ex-patients survey

Media-recruited subjects survey

Pilot study of treatment leaflet

Comparison between facially disfigured people and phobic patients.

## **Section 11.2 Characteristics of the FAAC**

As noted in Chapter 10, attributes of this element of the questionnaire battery were investigated as part of the empirical study. Since this part of the study involved several of the sample groups and is relevant to the results of all aspects of the study to be considered later in this chapter, it is considered first. Three characteristics were examined: internal association, internal consistency and test-retest reliability.

### *11.2.1 Internal association and factor analysis*

In assessing construct validity, the investigator attempts to determine whether an instrument measures the abstract concept it purports to measure (Burns & Grove, 1993). Whilst construct validity is a complex area of study and cannot be established by a single test or approach, one element of establishing such validity involves the use of factor analysis to examine the internal association between items. The principle behind this is that items in a questionnaire which purport to measure some underlying construct should be highly inter-related. Factor analysis examines such relationship patterns and reduces the numerous items in a test battery to a smaller number of 'factors' which represent broader elements to which items loading on such factors contribute. Accordingly, items 10 and 14-28 of the FAAC were submitted to a principal components analysis following the general method outlined by Child (1970) and the specific approach used by Probst et

al (1995) on a similar questionnaire. Items 11-13 were excluded from the analysis from the outset, since they were not expected to perform like other elements of the questionnaire, but were included purely with the aim of identifying different subgroups of respondents (ie; users of prosthetics, wigs and camouflage make-up), who were, in fact, few in number.

The media-recruited sample was chosen for factor analysis, as being of sufficient size to permit this procedure. Further criteria for suitability for factor analysis were determined by examination of the correlation matrix (Appendix 14) and the use of the Kaiser-Meyer-Okin Measure of Sampling Adequacy and Bartlett Test of Sphericity. These three criteria were met, since the overwhelming majority of correlations exceeded 0.30 (Tabachnick & Fidell, 1983), whilst the Kaiser-Meyer-Okin Measure (0.89584) and Bartlett Test (1623.2890,  $p = 0.00000$ ) both achieved the criteria required for appropriateness of the data set for factor analysis ( $> 0.5$  and  $< 0.05$  respectively). Following the method of Probst et al (1995), a varimax rotation was used, and factors with an eigenvalue greater than 1 were extracted. Together these factors accounted for 60 per cent of the common variance of the 16 items (Table 11.2.1).

**Table 11.2.1**                      **Variance by Rotated Factor (n = 199)**

Factor	Eigenvalue	% variance	Cumulative %
1	6.93423	43.3	43.3
2	1.43358	9	52.3
3	1.22600	7.7	60.0

The item loadings suggest that the three factors may be considered as independent subscales (Table 11.2.2), although the loadings on items 16 and 18 are somewhat equivocal. The analysis achieved Thurstone's (1947) simple structure, indicating distinctiveness between the factors: each row had at least one loading value close to zero; each column had at least as many variables with near-zero loading as there were columns (factors) in the matrix; each column pair had several values that load on one column and not the other (Munro & Page, 1993).

**Table 11.2.2**                      **Item loading on the three FAAC factors**

Item	Description	Factor 1	Factor 2	Factor 3
10	When I compare myself to others, I'm dissatisfied with my facial appearance	0.25620	<b>0.81078</b>	0.05528
14	I hide my face	0.47604	<b>0.59428</b>	0.06817
15	My face is a barrier to me with others	<b>0.65658</b>	0.56050	0.11513
16	My face is a threat to me	0.57334	<b>0.58285</b>	0.15132
17	My face is a threat to others	<b>0.60972</b>	0.13756	0.02969
18	My face appears as if it's not mine	<b>0.43054</b>	0.42632	0.06989
19	My facial appearance is very important to me	0.10937	0.45271	<b>0.57461</b>
20	I envy others for their facial appearance	0.18865	<b>0.81899</b>	0.07460
21	I have become used to the way my face looks	0.41333	<b>0.55745</b>	0.01501
22	Others have become used to the way my face looks	<b>0.65262</b>	0.13318	-0.06638
23	I check my face in mirrors	0.01511	0.01624	<b>0.86111</b>
24	I avoid looking at my face	0.18678	<b>0.63669</b>	-0.55900
25	I avoid walking in the street because of my facial appearance	<b>0.79917</b>	0.19272	0.10093
26	I avoid social situations because of my facial appearance	<b>0.82012</b>	0.32382	0.01248
27	I avoid sexual intercourse because of my facial appearance	<b>0.73818</b>	0.23676	-0.01920
28	I avoid certain kinds of clothes because of my facial appearance	<b>0.50833</b>	0.24767	-0.04037

**Bold print** indicates factors where items loaded highest.

From an examination of the factor structures, and from understanding of the fields of facial disfigurement and behaviour therapy, the factors were named as follows:

Factor 1: Anxiety and avoidance with regard to others' reactions (Face/others)

Factor 2: Negative appreciation of one's face (Face/self)

Factor 3: Rest.

It may be suggested, therefore, that high scores on *Face/others* indicate high levels of anxiety and avoidance, consequent upon one's perceptions of the reactions of others to the face. The scale items do not ask about anxiety or fear directly, in order to avoid leading respondents towards particular responses. Instead, more oblique words such as 'threat' are used. The presence of anxiety is inferred from the presence of avoidance (which is associated with fear in phobics [Marks, 1987]) and the perception of the presence of threat (which is associated with items measuring fear on the BAT [Probst et al, 1995]). The validity of these inferences is explored by examination of the

relationship between FAAC scores and other measures later in this chapter and during the discussion in Chapter 12. High scores on *Face/self* indicate negative attitudes towards one's face.

High scores on both these scales suggest a mismatch between body reality and body ideal in Price's (1990a, 1990b) terms, and may, therefore, be taken as an indicator of disturbed body image with regard to the face. They likewise suggest an increased likelihood of psychological disturbance, according to the model of the development of such difficulties presented in Chapter 8, principally through fear of the changed body and the reactions of others.

### 11.2.2 Reliability: internal consistency

Cronbach's alpha is the test of choice in investigating the internal consistency of scale items. Eight tests were undertaken, in order to examine the consistency of the entire scale and the three subscales identified by factor analysis, in both the plastic surgery ex-patients and media-recruited samples. Results are shown in Tables 11.2.3 and 11.2.4.

An acceptable criterion for internal consistency is a value of Cronbach's Alpha is between 0.80 and 0.90 (Burns & Grove, 1993). Thus, these results generally support the internal consistency of the FAAC total score and for the Face/others and Face/self subscales. The Rest subscale has poor internal consistency. As a result it was decided to exclude its items from further analysis.

**Table 11.2.3: Cronbach's Alpha coefficient: plastic surgery ex-patients**

Scale	n	alpha
Total score	97	0.8853
Face/others	99	0.8519
Face/self	100	0.8488
Rest	103	0.2996

**Table 11.2.4: Cronbach's Alpha coefficient: media-recruited sample**

Scale	n	alpha
Total score	199	0.9009
Face/others	209	0.8601
Face/self	220	0.8520
Rest	236	0.4585

### 11.2.3 Test-retest reliability

The most generally accepted method of examining the reliability of a measure over time is through the examination of correlation coefficients between successive administrations of the measure. However, Altman and Bland (1983) have argued that correlation does not necessarily constitute agreement, and that a repeated measures paradigm constitutes a better method of examining test-retest reliability. Several prominent British medical publications have adopted this policy as a requirement for contributors. However, the method of Altman and Bland (1983) has not as yet achieved widespread acceptance either in non-British medical publications or in the nursing or psychology literature. Thus, the more conservative approach is retained in this study. This is also consistent with the Probst et al (1995) analysis of the BAT. Test-retest reliability was examined in a randomly sampled subgroup of 40 plastic surgery ex-patients one month following initial administration of the instrument, using Kendal's Tau as the correlational test appropriate to ordinal level data, particularly when dealing with potentially large proportions of tied ranks (Bryman & Cramer, 1990). Thirty one respondents returned the second questionnaire, representing a response rate of 77.5%. There was no difference in age between respondents and non-respondents ( $t = 0.15$ ,  $df = 37$ ,  $p = 0.884$  (NS), CI 95% (-12.474, 14.426)) but respondents had been disfigured significantly less recently than non-respondents ( $t = 2.32$ ,  $df = 31$ ,  $p = 0.026$ , CI 95% (0.688, 9.905)) This latter finding represented a mean difference of 5.29 years between the groups (respondents = 9.29 yrs, non-respondents = 4.0 yrs). Whilst expected cell sizes were too small to permit chi square analysis of differences in cause of disfigurement between the two groups, visual inspection indicated that there were no differences between respondents and non-respondents (Table 11.2.5). The same was true for sex of respondents and non-respondents (Table 11.2.6). Results are shown in Table 11.2.7, and scattergrams of the correlations on the total scores and subscales in Figures 11.2.1 to 11.2.4. The correlations for the total and all subscales are somewhat below the generally acceptable level of 0.70 in preliminary studies of measures quoted by Politt & Hungler (1991). This slightly low reliability should be borne in mind when interpreting the relevant results.

**Table 11.2.5: Causes of disfigurement: retest respondents and non-respondents**

<b>Cause of disfigurement</b>	<b>Responder</b>	<b>Non-responder</b>
From birth	2 (2.4)	1 (0.6)
Accident or injury	10 (8.7)	1 (2.3)
part of a skin complaint	4 (3.9)	1 (1.1)
From surgery	14 (15)	5 (4)

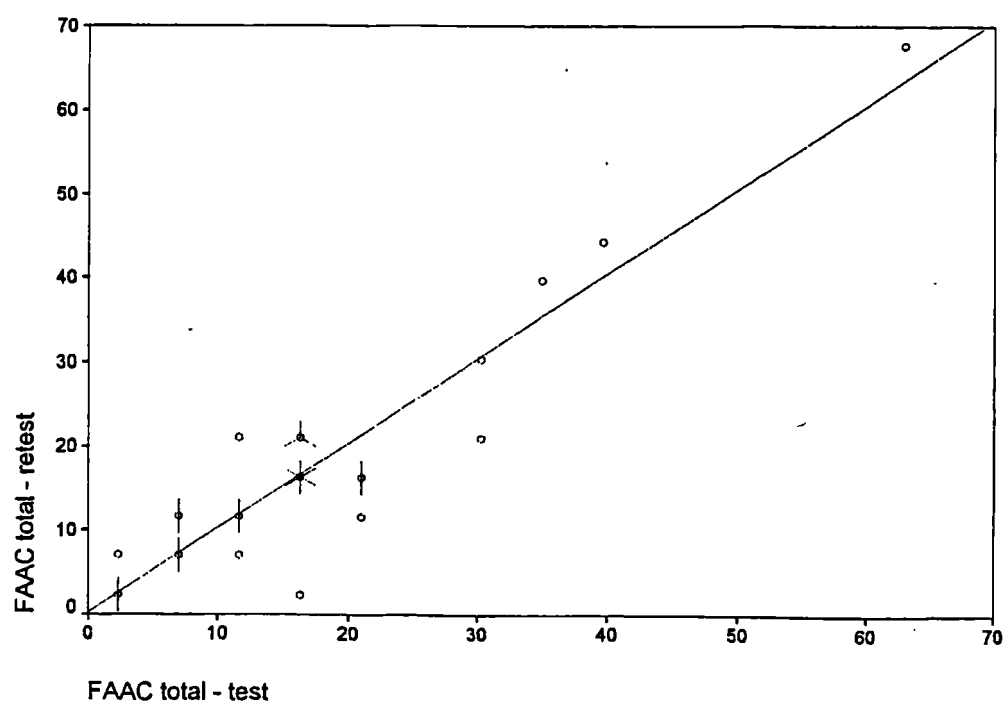
**Table 11.2.6: Sex of respondents and non-respondents**

<b>Sex</b>	<b>Responder</b>	<b>Non-responder</b>
Male	15 (12.7)	1 (3.3)
Female	16 (18.3)	7 (4.7)

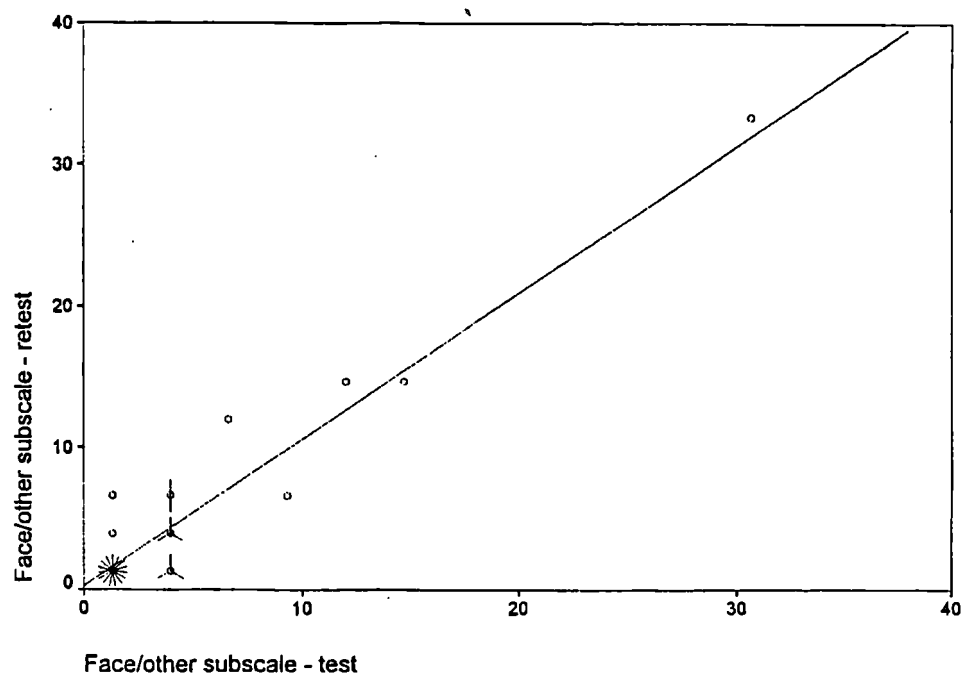
**Table 11.2.7: FAAC: test-retest reliability: correlations between time 1 and time 2 administration**

<b>Scale/item</b>	<b>Kendal's Tau</b>	<b>p</b>
Total	0.6616	0.000
Face/others	0.6215	0.000
Face/self	0.6967	0.000
Rest	0.6060	0.000
10	0.7549	0.000
14	0.7135	0.000
15	0.8372	0.000
16	0.8780	0.000
17	0.5272	0.002
18	0.8359	0.000
19	0.6247	0.000
20	0.7749	0.000
21	0.5194	0.001
22	0.4748	0.004
23	0.5681	0.000
24	0.3996	0.018
25	0.9480	0.000
26	0.7733	0.000
27	0.6962	0.000
28	0.7418	0.000

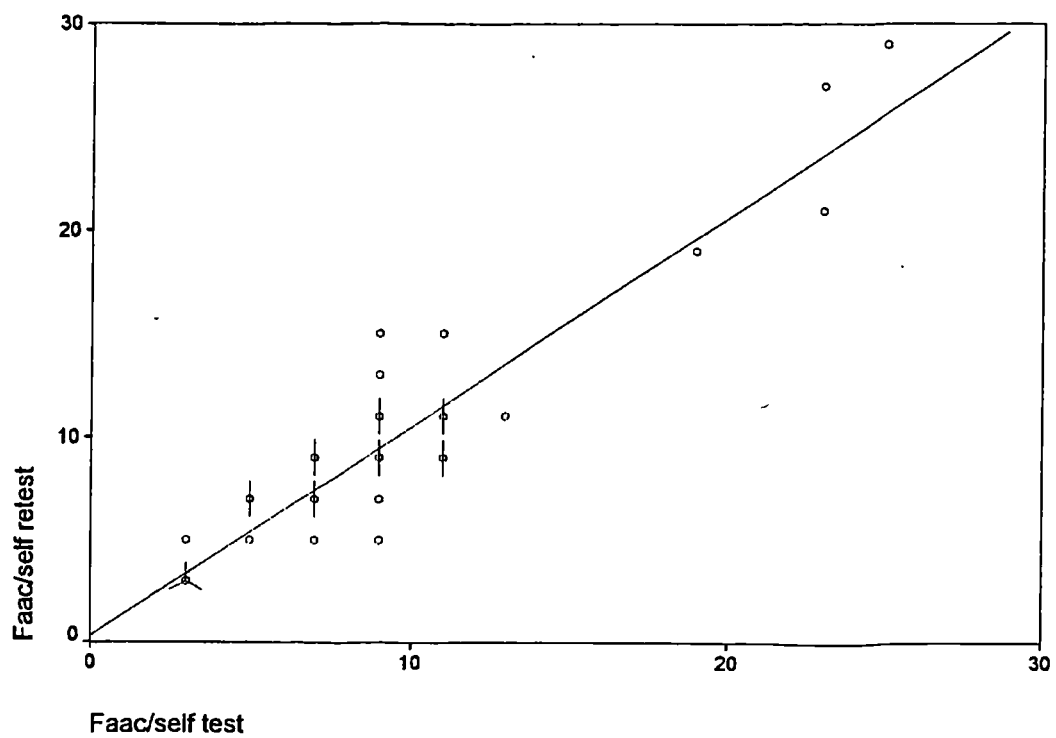
**Figure 11.2.1: Scattergram of test/retest correlations - FAAC total score**



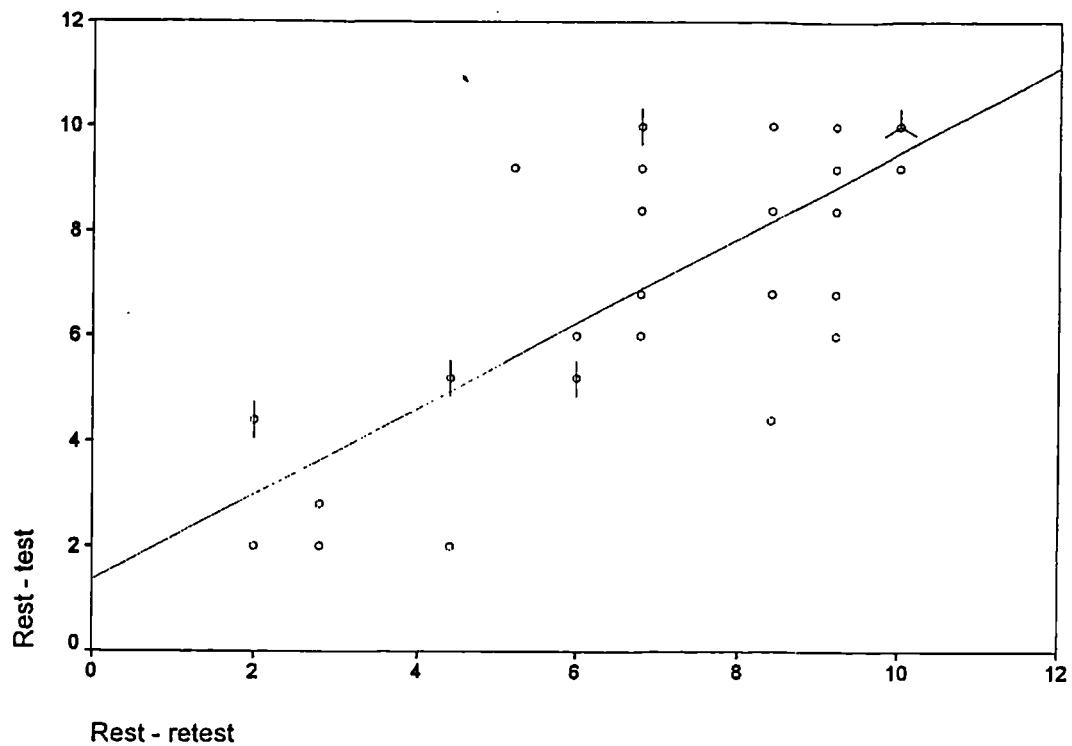
**Figure 11.2.2: Scattergram of test/retest correlations - FAAC face/others subscale**



**Figure 11.2.3: Scattergram of test/retest correlations - FAAC face/self subscale**



**Figure 11.2.4: Scattergram of test/retest correlations - FAAC rest subscale**





## **Section 11.3 Pilot study (dermatology outpatients)**

### *11.3.1 Characteristics of the sample*

Respondents were 11 male and 25 female dermatology outpatients who were approached in the outpatients clinic according to the procedure described in Chapter 10. They represented 58.06 per cent of the 62 patients originally approached. Unfortunately, no data were collected about non-respondents, and it is not possible to say how representative respondents were of the group originally approached. Mean age of respondents was 31.89 years (range 17 to 64 years). Mean age for males was 26.81 years and for females was 34.21 years.

### *11.3.2 Levels and patterns of psychological disturbance*

Responses to the FAAC, FQ, SAQ, GHQ, HAD and MOC are shown in Tables 11.3.1. to 11.3.6. It may be seen from FAAC responses that the majority of participants showed little disturbance. However, considerable numbers of responses did indicate some level of disturbance. This was particularly marked in dissatisfaction with the face and envy of the facial appearance of others. The general picture of low levels of disturbance was repeated in the FQ, GHQ, HAD and MOC, although once again there was a broad range of responses, and some individuals showed considerable difficulty (i.e. high scores of the FAAC, FQ and SAQ; caseness on the GHQ and HAD). Four elements of these results are important for a fear-avoidance model of psychological difficulty following disfigurement. First, elements concerned with social interaction (FQ social phobia subscale, SAQ social leisure subscale) show more disturbance than other elements. Second, anxiety is more elevated than depression on the HAD. Both these findings tend to suggest that, amongst disfigured people who experience psychological difficulty, anxiety, particularly in social situations, is a major factor. These issues are discussed in Chapter 12. Third, caseness on the GHQ and HAD scores are higher than the general population but comparable with other patient groups (see Chapter 12, Section 12.3 for a discussion of levels of GHQ and HAD caseness in the current study and in other clinical groups). Fourth, levels of obsessional behaviour, as measured by the MOC, were, contrary to predictions, extremely low in this sample. Whilst the specific FAAC item 'I check my face in mirrors' showed high numbers of respondents reporting this, this checking was not reflected in more general ritualising behaviour as measured by MOC. Although the MOC was retained in the battery of questionnaires given to later samples, it was decided at this point in the

study not to examine further any possible relationships between this scale and other scales within the battery, since it was clear from visual inspection alone that no such relationship was likely to exist, given the uniformly low scores on the MOC. The implications of these low scores are discussed in Chapter 12.

Table 11.3.1: Pilot study FAAC responses

FAAC element	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Usually (4)	Always (5)	Total	Mean ranks*	Range	Mode
When I compare myself to others, I'm dissatisfied with my facial appearance	6	5	12	4	3	6	36	2.3	5 (0-5)	2
I wear facial prostheses	34	1	0	0	1	0	36	0.1	4 (0-4)	0
I wear a wig	36	0	0	0	0	0	36	0	0	0
I wear special make-up	30	1	2	1	0	1	35	0.4	5 (0-5)	0
I hide my face	19	5	10	2	0	0	36	0.9	3 (0-3)	0
My face is a barrier to me with others	16	6	8	6	0	0	36	1.1	3 (0-3)	0
My face is a threat to me	19	6	8	2	1	0	36	0.9	4 (0-4)	0
My face is a threat to others	20	4	9	2	0	1	36	0.9	5 (0-5)	0
My face appears as if it's not mine	23	3	9	1	0	0	36	0.7	3 (0-3)	0
My facial appearance is very important to me	2	2	4	4	8	16	36	3.7	5 (0-5)	5
I envy others for their facial appearance	6	2	15	4	1	8	36	2.4	5 (0-5)	2
I have become used to the way my face looks	3	2	6	3	13	9	36	3.3	5 (0-5)	4
Others have become used to the way my face looks	3	1	2	4	14	11	35	3.7	5 (0-5)	4
I check my face in mirrors	2	1	9	9	6	9	36	3.2	5 (0-5)	2
I avoid looking at my face	21	4	7	0	3	1	36	1	5 (0-5)	0
I avoid walking in the street because of my facial appearance	23	3	9	1	0	0	36	0.7	3 (0-3)	0
I avoid social situations because of my facial appearance	21	4	6	3	2	0	36	0.9	4 (0-4)	0
I avoid sexual intercourse because of my facial appearance	22	3	4	4	0	0	33	0.7	3 (0-3)	0
I avoid certain kinds of clothes because of my facial appearance	23	2	4	5	0	2	36	1	5 (0-5)	0

\* Data derived from FAAC are at ordinal level. Mean scores refer to this ranked data.

**Table 11.3.2: Pilot study Fear Questionnaire responses**

FQ subscale *	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Agoraphobia	5.7	40 (0-40)	8.221	0	0.25, 3, 6
Social phobia	11.6	26 (0-26)	7.295	2,4 **	6, 11, 18
Total phobias	24.4	84 (0-84)	18.269	6	8.75, 24.5, 31
Anxiety/depression	10.2	29 (0-29)	8.551	8	3, 8, 14.75
Global problem severity	2.6	7 (0-7)	1.786	2	1, 2, 4

\* The fear questionnaire phobias section consists of three elements: agoraphobia, social phobia and blood/injury phobia, each with possible score range of 0-40. Thus the Fear questionnaire maximum possible score is 120. The blood/injury subscale is not reported separately in this study, but its score is combined with the agoraphobia and social phobia subscales to give the total phobias score reported. The anxiety/depression section of the questionnaire consists of 4 elements which together yield a maximum possible score of 40.

\*\* Multiple modes exist. All values are given.

**Table 11.3.3: Pilot study Social Adjustment Questionnaire (SAQ) scores**

Social Adjustment subscale *	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Work	1.5	7 (0-7)	1.821	0	0, 1, 3
Home Management	1	8 (0-8)	1.971	0	0, 0, 1.75
Social Leisure	2	7 (0-7)	2.242	0	0, 1.5, 4
Private Leisure	0.8	7 (0-7)	1.485	0	0, 0, 1

\* Note 1: 0-8 scales. High scores denote severity.

**Table 11.3.4: Pilot study General Health Questionnaire Scores**

Mean*	Range*	Standard deviation*	Mode*	Quartiles (25%, 50%, 75%)*	Cases**	Non-cases**
13.75	28 (4-32)	6.934	12	8, 12, 18.5	12	22

Note: Maximum possible score 36.

\* Summary statistics calculated using Likert scoring (Goldberg & Williams, 1991).

\*\* Caseness calculated using 'GHQ' scoring (range 0-12) and caseness cutoff of > 3 (Goldberg & Williams, 1991).

**Table 11.3.5: Pilot study Hospital Anxiety & Depression Scale Scores**

Scale *	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)	Normal	Mild	Moderate	Severe
Anxiety	7.57	17 (1-18)	4.192	7	5, 7, 10	18	10	5	2
Depression	3.44	12 (0-12)	2.971	2	1, 2, 5	32	2	2	0

\* Note 1: Maximum possible score 21 points on each scale. Cut-off points for severity for each scale: Normal: 0-7; mild: 8-10; moderate: 11-14; severe: 15-21.

**Table 11.3.6: Pilot study Maudsley Obsessions Checklist Scores**

Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
4.78	56 (0-56)	11.338	0	0, 1, 2

Note: Maximum possible score 111.

The Mann Whitney-U test, a non-parametric test for comparing two independent groups, was used to examine differences between male and female responses to the Face/self and Face/others subscales of the FAAC. These comparisons are shown in Table 11.3.7. Responses to the Rest scale were not tested because of doubt about the internal consistency of the scale. The Mann Whitney-U test was used to compare scores of males and females on the following variables: FQ (total score, agoraphobia and social phobia subscales and global problem measure), SAQ (Work, Home management and Social Leisure subscales), GHQ, HAD (anxiety and depression subscales. Differences between males and females on these measures of disturbance are shown in Table 11.3.8. Mann Whitney-U was chosen because the combination of ordinal level data, small numbers and differences in number between the two groups to be compared indicated that a non-parametric test was most appropriate. In the ex-plastic surgery patients and media-recruited samples, numbers were larger, and the use of t-test was more appropriate, despite the ordinal level of the data, for the reasons described in Chapter 10. Following statistical advice, this test was chosen to examine these variables between males and females in the ex-plastic surgery patients and media-recruited samples.

In the pilot group, differences between males and females were found for only 1 of the 13 comparisons conducted (HAD depression, on which females showed greater difficulty than males). This is quite possibly a type 1 error resulting from multiple comparisons. A Bonferroni correction was considered, and would certainly have led to a non-significant finding. However, following statistical advice, it was considered that this method of correcting for the risk of type 1 error in multiple comparisons was overly conservative in this aspect of the present study, which involved a priori decisions to make comparisons across a number of different elements of a data set.

The hypothesis that females would show greater difficulty than males is disconfirmed in the majority of instances in this sample.

**Table 11.3.7: Pilot study male/female differences 1: FAAC scores**

Scale		Mean rank	n	Test	Value	Significance *
Face/others	Males	19.60	10	Mann Whitney U	Z = -1.2672	p = 0.1026 (NS)
	Females	15.09	22			
Face/self	Males	21.18	11	"	Z = -1.0162	p = 0.1048 (NS)
	Females	17.32	25			

Notes: Higher ranks denote greater difficulty. \* 1-tailed values throughout.

**Table 11.3.8: Pilot study male/female differences 2: Other measures**

Scale		Mean rank	n	Test	Value	Significance *
Agoraphobia (FQ)	males: females:	14.82 20.12	11 25	Mann-Whitney U	Z = -1.4070	p = 0.1594 (NS)
Social phobia (FQ)	males: females:	16.09 19.56	11 25	"	Z = -0.9121	p = 0.3617 (NS)
Total phobias (FQ)	males: females:	16.05 19.58	11 25	"	Z = -0.9283	p = 0.3532 (NS)
Anxiety/depression (FQ)	males: females:	18.77 18.38	11 25	"	Z = -0.1033	p = 0.9178 (NS)
Problem Severity (FQ)	males: females:	17.90 18.04	10 25	"	Z = -0.0373	p = 0.9703 (NS)
Work (SAQ)	males: females:	17.50 18.23	11 24	"	Z = -0.2066	p = 0.8363 (NS)
Home Management (SAQ)	males: females:	17.68 18.86	11 25	"	Z = -0.3794	p = 0.7044 (NS)
Social Leisure (SAQ)	males: females:	18.14 18.66	11 25	"	Z = -0.1417	p = 0.8873 (NS)
GHQ Total	males: females:	16.50 19.38	11 25	"	Z = -0.7604	p = 0.4470 (NS)
Anxiety (HAD)	males: females:	14.95 19.40	11 24	"	Z = -1.1952	p = 0.2320 (NS)
Depression (HAD)	males: females:	13.59 20.66	11 25	"	Z = -1.8743	p = 0.0305

Notes: Higher ranks denote greater difficulty. \* 1-tailed values throughout.



Correlations between FAAC subscale scores and other key measures were examined using Kendal's Tau (a non-parametric test of correlation) and are shown in Table 11.3.9. Correlations between items on the FAAC and similar items on the BAT were examined using Kendal's Tau and are shown in Table 11.3.10.

Despite low numbers, significant, though modest, correlations were found between the FAAC and several other measures. It is worth noting that the FQ anxiety/depression and social phobia subscales correlated with both subscales of the FAAC. This suggests that both *Face/others* and *Face/self* are related to dysphoria, and, in particular to anxiety in and avoidance of social situations. This is not surprising in the case of the *Face/others* subscale, which asks about social avoidance directly, although it does offer evidence of convergent validity of that scale. In the case of the *Face/self* subscale no such direct questions about social avoidance are asked. It *may* be considered that the correlations observed here suggest that negative attitudes towards one's own face are associated with social difficulties, thus supporting a fear-avoidance model of psychological difficulties following disfigurement.

With regard to the BAT, moderately strong correlations between all but one of the BAT elements included in this questionnaire ('I hide my body as a whole') and its FAAC counterpart are seen. This might be considered as evidence for convergent validity between these elements of the two scales. It might also be suggested that there are close relationships between attitudes and behaviours regarding the face and those regarding the body as a whole in this sample, and that the FAAC is accurately examining these elements of body image as they relate to the face.

**Table 11.3.9: Pilot study Correlations with FAAC subscales (Kendal's Tau)**

Correlated	Variables	Correlation	Significance
Face/others	Anxiety/depression (FQ)	0.3419	p = 0.008
"	Social phobia (FQ)	0.3046	p = 0.019
Face/self	Total score (GHQ)	0.3600	p = 0.003
"	Depression (HAD)	0.2482	p = 0.046
"	Anxiety/depression (FQ)	0.4901	p = 0.000
"	Social Phobia (FQ)	0.3532	p = 0.003
"	Agoraphobia (FQ)	0.3427	p = 0.006

Note: Non-significant tests of correlation:

- 1 With Face/others: Global problem (FQ), Agoraphobia (FQ), Total score (GHQ), Anxiety (HAD), Depression (HAD), Social Leisure (SAQ), time since disfigurement, age.
- 2 With Face/self: Global problem (FQ), Anxiety (HAD), Social Leisure (SAQ), time since disfigurement, age.

The appropriate correlation summary table is presented in Appendix 15.

**Table 11.3.10: Pilot study Correlations between FAAC and BAT items**

<b>Correlated</b>	<b>Variables</b>	<b>Correlation</b>	<b>Significance</b>
When I compare myself to others, I'm dissatisfied with my facial appearance	When I compare myself to others, I'm dissatisfied with my body as a whole	0.4437	p = 0.001
I hide my face	I hide my body as a whole	0.1775	p = 0.212 (NS)
My face is a threat to me	My body as a whole is a threat to me	0.4029	p = 0.006
My face appears as if it's not mine	My body as a whole appears as if it's not mine	0.5253	p = 0.001
My facial appearance is very important to me	My bodily appearance is very important to me	0.6489	p = 0.000
I envy others for their facial appearance	I envy others for their physical appearance	0.5678	p = 0.000

Question 14 of the FAAC contained an open-ended element asking about the tactics employed by respondents in hiding their faces. Several respondents identified such tactics, and these are displayed in Table 11.3.11.

From the view point of the fear-avoidance model of psychological difficulty following disfigurement, the striking finding is that the number of respondents not reporting the use of any tactics to hide the face is a very large proportion (80.5%) of the admittedly small sample. However, given that the majority of respondents in the pilot study did not display high levels of psychological difficulty, it may be that this finding has little to tell us about the role of avoidance in such difficulty. The lack of attempts to hide the face should, however, be contrasted with the levels of social avoidance shown in response to other parts of the questionnaire battery (e.g. FQ social phobia subscale, avoidance elements of FAAC), which suggest that avoidance is a major part of respondents' psychological difficulty, when such difficulty is present.

**Table 11.3.11: Pilot study avoidance tactics**

<b>Tactic Used</b>	<b>Respondents (n)</b>
Avert affected side	4
Wear thick make-up	2
Avoid strong lights	1
No tactics identified	29

## **Section 11.4 Survey of plastic surgery ex-patients**

### *11.4.1 Characteristics of the sample*

Respondents were 43 male and 62 female plastic surgery ex-patients who responded to a request to participate delivered through the post according to the procedure described in Chapter 10. They represented 41.8 per cent of the 251 ex-patients originally contacted. Mean age of respondents was 44.51 years (range 17 to 73 years), and was 49.93 years for males and 40.84 years for females. Causes of disfigurement are displayed in Table 11.4.1. Respondents and non-respondents were compared with regard to age, sex and diagnosis. There were no significant differences between respondents and non-respondents according to age ( $t=1.61$ ,  $df=248$ ,  $p=0.108$  (NS)) or sex ( $\chi^2=1.87474$ ,  $df=1$ ,  $p=0.17093$  (NS)). The number of cells with expected frequencies

of less than 5 was too great to permit statistical testing of differences in diagnosis. Collapsing of some diagnostic categories did not sufficiently increase expected numbers to allow such testing. However visual inspection of the expected and actual cell frequencies suggests little departure from the expected frequencies for each cell (See Table 11.4.2). In view of these findings, we can be reasonably confident that respondents were representative of the original study group according to age, sex and diagnosis.

**Table 11.4.1: Plastic surgery ex-patients: causes of disfigurement**

Cause of disfigurement	Respondents (n)
From birth	5
accident or injury	33
part of a skin complaint	13
Surgery	51
Not stated	3

**Table 11.4.2: Plastic surgery ex-patients: Comparison of questionnaire respondents and non-respondents according to diagnosis.**

Diagnosis	Respondents*	Non-respondents*
Basal Cell Carcinoma + skin graft	19 (14.3)	21 (25.7)
Dermabrasion	9 (10.3)	20 (18.7)
Creation of eye prosthesis	0 (0.4)	1 (0.6)
Scar revision	27 (34.6)	70 (62.4)
Malignant melanoma	4 (2.1)	2 (3.9)
Revision of cleft lip	3 (2.1)	3 (3.9)
Revision of road dirt tattooing	2 (2.5)	5 (4.5)
Excision of neurofibroma	1 (0.7)	1 (1.3)
BCC and flap rotation	5 (4.3)	7 (7.7)
Excision of other lesions	5 (6.8)	14 (12.2)
Squamous cell carcinoma	2 (2.5)	5 (4.5)
Mandibulectomy	0 (0.4)	1 (0.6)
Other	9 (5)	5 (9)

\* Note: expected cell numbers in parentheses throughout.

#### *11.4.2 Levels and patterns of psychological disturbance*

These data were analysed in the same way as for the pilot study, and the results are presented in Tables 11.4.3 to 11.4.12. Responses to the open-ended element of item 14 of the FAAC are shown in Table 11.4.13.

The general pattern of results is similar to those from the pilot study. Once again it will be noted that, whilst levels of difficulty are generally low, there are again considerable numbers of respondents showing such difficulty. On the FAAC, high levels of dissatisfaction with the face and envy of others again occur. Elements of the questionnaire battery concerned with social interaction again show greater disturbance, on visual inspection, than other elements, and HAD anxiety is again higher than depression. Caseness on both GHQ and HAD are higher than the general population and higher than or similar to patient groups (see Chapter 12, Section 12.3 for discussion of relationship between GHQ and HAD scores in the current study and those of other patient groups). It will be remembered, however, that the sample in this element of the study are *ex-patients*. Once again MOC scores were extremely low, indicating an absence of generalised checking, and are not discussed further here.

**Table 11.4.3: Plastic surgery ex-patients' study FAAC responses**

FAAC element	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Usually (4)	Always (5)	Total	Mean ranks*	Range	Mode
When I compare myself to others, I'm dissatisfied with my facial appearance	26	16	39	6	7	8	102	1.8	5 (0-5)	2
I wear facial prostheses	96	1	2	1	2	3	105	0.2	5 (0-5)	0
I wear a wig	101	1	0	0	0	0	102	0.01	1 (0-1)	0
I wear special make-up	89	3	4	1	3	3	103	0.4	5 (0-5)	0
I hide my face	76	7	12	4	1	2	102	0.6	5 (0-5)	0
My face is a barrier to me with others	72	16	8	3	2	2	103	0.6	5 (0-5)	0
My face is a threat to me	82	8	8	2	0	3	103	0.4	5 (0-5)	0
My face is a threat to others	84	8	8	2	1	0	103	0.3	4 (0-4)	0
My face appears as if it's not mine	80	10	10	1	1	1	103	0.4	5 (0-5)	0
My facial appearance is very important to me	6	5	8	12	29	43	103	3.8	5 (0-5)	5
I envy others for their facial appearance	30	16	33	15	2	9	105	3.9	5 (0-5)	5
I have become used to the way my face looks	6	7	9	4	29	47	102	3.8	5 (0-5)	5
Others have become used to the way my face looks	3	1	7	1	40	48	100	4.2	5 (0-5)	5
I check my face in mirrors	19	11	22	15	13	23	103	2.6	5 (0-5)	5
I avoid looking at my face	67	17	14	3	0	2	103	0.6	5 (0-5)	0
I avoid walking in the street because of my facial appearance	94	2	5	2	0	0	103	0.2	3 (0-3)	0
I avoid social situations because of my facial appearance	86	4	7	3	3	0	103	0.4	4 (0-4)	0
I avoid sexual intercourse because of my facial appearance	85	7	7	2	0	1	102	0.3	4 (0-4)	0
I avoid certain kinds of clothes because of my facial appearance	91	5	1	2	0	3	102	0.3	5 (0-5)	0

\* Data derived from FAAC are at ordinal level. Mean scores refer to this ranked data.

**Table 11.4.4:** Plastic surgery ex-patients' study Fear Questionnaire responses

FQ subscale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Agoraphobia	3.2	24 (0-24)	4.584	0	0, 1, 5
Social phobia	8.2	34 (0-34)	7.932	0	2, 7, 12
Total phobias	18.3	65 (0-65)	15.680	0	6, 15, 27
Anxiety/depression	7.3	34 (0-34)	8.090	0	1, 5, 10
Global problem severity	1.5	8 (0-8)	1.702	0	0, 1, 2

**Table 11.4.5:** Plastic surgery ex-patients' study Social Adjustment Questionnaire scores

Social Adjustment subscale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Work	0.4	8 (0-8)	1.320	0	0, 0, 0
Home Management	0.2	5 (0-5)	0.765	0	0, 0, 0
Social Leisure	1.0	7 (0-7)	1.743	0	0, 0, 2
Private Leisure	0.5	8 (0-8)	1.309	0	0, 0, 0

**Table 11.4.6:** Plastic surgery ex-patients' General Health Questionnaire Scores

Mean*	Range*	Standard deviation*	Mode*	Quartiles (25%, 50%, 75%)*	Cases**	Non-cases**
12.5	35 (1-36)	6.357	6	8, 12, 16.5	33	72

\* Summary statistics calculated using Likert scoring (Goldberg & Williams, 1991).

\*\* Caseness calculated using 'GHQ' scoring (range 0-12) and caseness cutoff of > 3 (Goldberg & Williams, 1991).

**Table 11.4.7:** Plastic surgery ex-patients' Hospital Anxiety & Depression Scale Scores

Scale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)	Mild	Moderate	Severe
Anxiety	6.8	18 (0-18)	4.677	7	2, 7, 10	22	17	7
Depression	3.4	11 (0-11)	3.070	1	1, 2, 5.75	12	1	0



**Table 11.4.8:                   Plastics surgery ex-patients' Maudsley Obsessions Checklist Scores**

Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
3.18	47 (0-47)	7.224	0	0, 0, 3

Note: Maximum possible score 111.

The comparison of males and females yielded different results from the pilot group. Significant differences between the sexes were found in 7 of the 13 comparisons made. With one exception (SAQ home management subscale) all the significant differences reflected greater difficulty in females. As in the pilot group, there is an increased risk of type 1 error owing to multiple comparisons. Balanced against this, examination of the group mean differences, which are moderately large, might support the suggestion that the significant differences between found between males and females represent actual differences between them, rather than type 1 error. However, the *overall* levels of difficulty were generally low, regardless of the significance of the results. The prediction that females would show greater psychological difficulty than males receives modest confirmation in this sample.

**Table 11.4.9:** Plastic surgery ex-patients: male / female differences 1: FAAC scores.

Scale		Mean rank	n	Test	Value	Significance *
Face/others	Males	46.72	40	Mann Whitney U	z = -0.9629	p = 0.1678(NS)
	Females	52.22	59			
Face/self	Males	40.01	41	"	Z = -3.0281	p = 0.0013
	Females	57.79	59			

Notes: Higher ranks denote greater difficulty. \* 1-tailed values throughout.

**Table 11.4.10:** Plastics surgery outpatients: male/female differences 2: Other measures (t-test)

Measure	Critical Value	df	Significance*	Group Means	CI (95%)
Agoraphobia (FQ)	t = -1.73	102	p = 0.043	male 2.30 female 3.87	-3.360, 0.227
Social phobia (FQ)	t = -2.27	99	p = 0.013	male 6.1 female 9.67	-6.695, -0.443
Total phobias (FQ)	t = -2.37	102	p = 0.010	male 14.02 female 21.26	-13.299, -1.179
Anxiety/depression (FQ)	t = -2.05	98.82	p = 0.022	male 5.23 female 8.57	-6.190, -0.101
Total Problem Severity (FQ)	t = -2.15	92	p = 0.017	male 1.1 female 1.86	-1.446, -0.058
Work (SAQ)	t = 1.35	54.63	p = 0.091 (NS)	male 0.71 female 0.31	-0.1955, 0.996
Home Management (SAQ)	t = 1.67	47.12	p = 0.050	male 0.37 female 0.08	00.060, 0.643
Social Leisure (SAQ)	t = 0.95	103	p = 0.171 (NS)	male 1.23 female 0.9	-0.357, 1.016
GHQ Total	t = -0.50	103	p = 0.310 (NS)	male 12.16 female 12.79	-3.019, 1.884
Anxiety (HAD)	t = -0.66	102	p = 0.255 (NS)	male 6.38 female 7.00	-2.479, 1.241
Depression (HAD)	t = -0.86	102	p = 0.197 (NS)	male 3.07 female 3.59	-1.744, 0.693

Note: \* 1-tailed values throughout.

Probably as a consequence of a larger sample, many more significant correlations between the FAAC and other measures were found here than in the pilot study. The correlations with measures of psychological difficulty and phobic avoidance were, as in the pilot study, generally modest (Table 11.4.11), but, on this occasion were significant on the majority of occasions (18 of 20 tests). This suggests considerable correspondence between attitudinal and behavioural aspects of body image concerning the face (as measured by FAAC) and the broad range of psychological disturbance measured by the other scales, including measures of phobic avoidance. Moreover, it may be asserted that negative body image regarding the face is associated with higher levels of psychological avoidance and disturbance. These findings are supportive of the fear-avoidance model of increased psychological difficulty following disfigurement, which suggests that negative attitudes towards the face, fear and avoidance (particularly in social situations) are associated. The extent to which data from the current study may be construed as support for the fear-avoidance model is discussed in Chapter 12, Section 12.6.4. The fact that the correlations with measures of behavioural avoidance apply equally to the *Body/others* and *Body/self* subscales indicates that this correspondence is not an artefact of the inclusion within the *Body/others* subscale of items which specifically ask about such avoidances. These results also offer further support for the convergent validity of FAAC.

Correlations between BAT and FAAC items were broadly similar to those in the pilot study, yielding moderately strong correlations in all but one instance ('I hide my body as a whole'). This offers further support for the contention that there are close relationships between attitudes and behaviours related to the face and those related to the body as a whole in this sample, and the usefulness of the FAAC in examining elements of body image related to the face.

**Table 11.4.11: Plastic surgery ex-patients: Correlations with FAAC subscales (Kendal's Tau)**

Correlated Variables		Correlation	Significance
Face/others	Global problem (FQ)	0.4413	p = 0.000
"	Social Phobia (FQ)	0.2830	p = 0.000
"	Agoraphobia (FQ)	0.2419	p = 0.003
"	Anxiety/Depression (FQ)	0.2871	p = 0.000
"	Social Leisure (SAQ)	0.4843	p = 0.000
"	Anxiety (HAD)	0.2480	p = 0.001
"	Depression (HAD)	0.2724	p = 0.001
"	Total Score (GHQ)	0.2709	p = 0.000
"	Age	-0.1093	p = 0.142 (NS)
"	Time since disfigurement	0.1611	p = 0.049
Face/self	Global problem (FQ)	0.5161	p = 0.000
"	Social Phobia (FQ)	0.4470	p = 0.000
"	Agoraphobia (FQ)	0.3939	p = 0.000
"	Anxiety/Depression (FQ)	0.4098	p = 0.000
"	Social Leisure (SAQ)	0.4843	p = 0.000
"	Anxiety (HAD)	0.3749	p = 0.000
"	Depression (HAD)	0.3570	p = 0.000
"	Total Score (GHQ)	0.3461	p = 0.000
"	Age	-0.1710	p = 0.016
"	Time since disfigurement	0.1403	p = 0.73 (NS)

**Table 11.4.12. Plastic Surgery ex-patients Correlations between FAAC and BAT items**

<b>Correlated</b>	<b>Variables</b>	<b>Correlation</b>	<b>Significance</b>
When I compare myself to others, I'm dissatisfied with my facial appearance	When I compare myself to others, I'm dissatisfied with my body as a whole	0.4546	p = 0.000
I hide my face	I hide my body as a whole	0.3307	p = 0.000
My face is a threat to me	My body as a whole is a threat to me	0.4106	p = 0.000
My face appears as if it's not mine	My body as a whole appears as if it's not mine	0.5267	p = 0.000
My facial appearance is very important to me	My bodily appearance is very important to me	0.5216	p = 0.000
I envy others for their facial appearance	I envy others for their physical appearance	0.5401	p = 0.000

Responses to Question 14 of FAAC showed a generally similar picture to responses in the pilot study, with the great majority (85.7%) of respondents not identifying any measures taken to hide the face. However, the number of respondents noting that they hid their faces (26) , was, as in the pilot study, considerably greater than the number identifying tactics (15), indicating that this low response may have been caused by either a reticence in answering the open-ended question or a difficulty in identifying tactics.

**Table 11.4.13: Plastic surgery ex-patients' avoidance tactics**

<b>Respondents (n)</b>	<b>Tactic used (n)</b>
Avert affected side	2
Wear thick make-up	3
Use hair as camouflage	4
Avoid eye contact	3
Cover face with hand	2
Avoid being photographed	1
No tactics identified	90

## **Section 11.5 Media recruited questionnaire study**

### *11.5.1 Characteristics of the sample*

Respondents were 46 male and 197 females who completed questionnaires in response to the requests for participants placed in the media in accordance with the procedure described in Chapter 10. Two respondents did not record their sex. The respondents represented 58.33 per cent of the original 420 enquiries and requests for details of the study received in response to the various media requests. Mean age of respondents was 47.10 years (range 17 to 83 years), and was 51.80 years for males and 46.11 for females. Causes of disfigurement are displayed in Table 11.5.1. No details are available of those who did not eventually return questionnaires, and so no comparisons between respondents and non-respondents may be made.

**Table 11.5.1 Media group causes of disfigurement**

<b>Cause of disfigurement</b>	<b>Respondents (n)</b>
From birth	45
Accident/injury	73
Part of skin complaint	56
Surgery	52
Not stated	19

### 11.5.2 *Levels and patterns of psychological disturbance*

These data were analysed using similar procedures to the pilot study, and are presented in Tables 11.5.2. to 11.5.16. Responses to the open-ended element of item 14 of the FAAC are shown in Table 11.5.17.

As might be expected from a self-selected sample, results from the media-recruited sample showed higher levels of disturbance than either the pilot or plastic surgery groups, although, as before, the majority showed low levels of disturbance. In response to the FAAC, dissatisfaction with the face and envy of others for their facial appearance again scored high, but considerable numbers of respondents also reported disturbance on almost every element of the scale, as demonstrated by the mean ranks of the scale items. The more general measures of difficulty confirm this picture. Mean scores approached clinical levels of severity on all subscales of the Fear Questionnaire, with the exception of the agoraphobia subscale. Examination of the quartiles for these subscales confirmed this picture, with 25% of the group reaching clinical severity on all subscales but the agoraphobia subscale. In response to the SAQ, only the social leisure subscale mean approached clinical severity, with 25% of respondents scoring 6 or more, although 25% of respondents scored 4 or more on the work subscale, suggesting avoidance levels of clinical severity, if we take 4 or more as the accepted clinical cutoff for problem severity meriting clinical intervention (see Chapter 10, Sections 10.7.2 and 10.8.1). Responses to the GHQ indicated some 114/233 cases, even using the stringent criterion for casehood chosen in this study. Responses to the HAD were particularly interesting from the view point of a fear-avoidance approach to disturbance following facial disfigurement. Although the numbers of cases of both anxiety and depression were considerable, it is important to note that anxiety was far more frequently reported. Indeed, the *majority* of respondents attained scores indicating mild, moderate or severe anxiety on the HAD anxiety scale. With regard to the MOC, scores were once again low, with less than 25% of the sample scoring greater than 10/111 and a mean of 7.51.

These results, in a self-selected group, may not be generalised as indicators of prevalence of difficulties amongst disfigured people. However, they do show the nature of the particular *patterns* of disturbance when it occurs. As in the samples described earlier in this chapter, there is a marked tendency for these difficulties to involve social situations. Avoidance and anxiety are the most

frequent features, lending support to the fear-avoidance formulation of psychological disturbance following facial disfigurement.



**Table 11.5.2: Media Group FAAC responses**

FAAC element	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Usually (4)	Always (5)	Total	Mean ranks*	Range	Mode
When I compare myself to others, I'm dissatisfied with my facial appearance	8	12	36	31	45	104	236	3.7	5 (0-5)	5
I wear facial prostheses	209	2	4	2	4	12	233	0.4	5 (0-5)	0
I wear a wig	236	0	1	0	0	0	237	0	2 (0-2)	0
I wear special make-up	169	9	21	6	11	20	236	0.9	5 (0-5)	0
I hide my face	58	15	62	37	36	25	233	2.2	5 (0-5)	2
My face is a barrier to me with others	32	20	82	30	30	39	233	2.5	5 (0-5)	2
My face appears is a threat to me	80	25	47	24	20	34	230	1.9	5 (0-5)	0
My face is a threat to others	85	40	51	23	10	15	224	1.5	5 (0-5)	0
My face appears as if it's not mine	112	19	38	22	15	27	233	1.5	5 (0-5)	0
My facial appearance is very important to me	2	5	26	12	46	145	236	4.2	5 (0-5)	5
I envy others for their facial appearance	24	15	49	31	24	94	237	3.3	5 (0-5)	5
I have become used to the way my face looks	51	17	44	11	67	42	232	2.7	5 (0-5)	4
Others have become used to the way my face looks	4	8	42	27	103	44	228	3.5	5 (0-5)	4
I check my face in mirrors	27	38	56	32	37	47	237	2.7	5 (0-5)	2
I avoid looking at my face	65	41	58	22	28	23	237	1.9	5 (0-5)	0
I avoid walking in the street because of my facial appearance	138	28	37	19	4	8	234	0.9	5 (0-5)	0
I avoid social situations because of my facial appearance	84	26	51	29	30	15	235	1.7	5 (0-5)	0
I avoid sexual intercourse because of my facial appearance	118	19	39	21	21	13	231	1.3	5 (0-5)	0
I avoid certain kinds of clothes because of my facial appearance	128	22	40	14	13	19	236	1.2	5 (0-5)	0

\* Data derived from FAAC are at ordinal level. Mean scores refer to this ranked data.

**Table 11.5.3: Media Group Fear Questionnaire responses**

FQ subscale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Agoraphobia	6.96	40 (0-40)	8.583	0	0, 4, 10
Social phobia	14.97	40 (0-40)	9.570	18	7, 14, 21
Total phobias	28.78	110(0-110)	20.720	6	13, 26, 39
Anxiety/depression	12.40	40 (0-40)	10.288	3	4, 10, 19
Global problem severity	3.13	8 (0-8)	2.078	2	2, 3, 4

**Table 11.5.4: Media Group Social Adjustment Questionnaire scores**

Social Adjustment subscale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
Work	2.1	8 (0-8)	2.318	0	0, 2, 4
Home Management	1.1	8 (0-8)	1.826	0	0, 0, 2
Social Leisure	3.22	8 (0-8)	2.541	2	1, 3, 6
Private Leisure	0.84	8 (0-8)	1.661	0	0, 0, 1

**Table 11.5.5: Media Group General Health Questionnaire Scores**

Mean*	Range*	Standard deviation*	Mode*	Quartiles (25%, 50%, 75%)*	Cases**	Non-cases**
16.25	36 (0-36)	7.490	12	11, 15, 20	119	114

\* Summary statistics calculated using Likert scoring (Goldberg & Williams, 1991).

\*\* Caseness calculated using 'GHQ' scoring (range 0-12) and caseness cutoff of > 3 (Goldberg & Williams, 1991).

**Table 11.5.6:** Media Group Hospital Anxiety & Depression Scale Scores

Scale	Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)	Normal	Mild	Moderate	Severe
Anxiety	9.69	21 (0-21)	4.809	6	6, 10, 13	85	48	61	45
Depression	5.77	20 (0-20)	4.325	1	2, 5, 8	170	33	31	7

**Table 11.5.7:** Media Group Maudsley Obsessions Checklist Scores

Mean	Range	Standard deviation	Mode	Quartiles (25%, 50%, 75%)
7.51	62 (0-62)	10.916	0	0, 4, 10

Note: Maximum possible score 111.

Differences between males and females were examined in the same way as for the pilot study, using the Mann Whitney-U test, and t-test. The results are shown in Tables 11.5.8. to 11.5.9. Numbers were also sufficient to allow a comparison between different causes of facial disfigurement, using the Kruskal Wallis test (a non-parametric test for difference in more than two independent groups) in the case of the FAAC, and one way analysis of variance (ANOVA) in the other measures examined. These results are presented in Tables 11.5.10. to 11.5.14. Correlations between the FAAC and other key measures are shown in Table 11.5.15.

The differences between males and females found in the plastics surgery ex-patients' sample are not repeated here. Only one difference was found (Face/self), on which women showed greater difficulty than men. As noted previously, there is the risk of type 1 error owing to multiple comparisons, although the mean rank differences are considerable. The prediction that females would show greater psychological difficulty than males is not confirmed in this sample. The differences between results of comparisons between males and females in the various samples are discussed in Chapter 12.

**Table 11.5.8: Media group male/female differences: FAAC scores**

Scale		Mean rank	n	Test	Value	Significance
Face/other	Males	106.53	35	Mann Whitney U	Z = -0.2743	p = 0.3920 (NS)
	Females	103.49	172			
Face/self	Males	94.44	39	"	Z = -1.6934	p = 0.0452
	Females	113.37	180			

Notes: Higher ranks denote greater difficulty. \* 1-tailed values throughout.

**Table 11.5.9: Media group male female differences: Other measures (t-test)**

Measure	Critical Value	df	Significance*	Group means	CI (95%)
Agoraphobia (FQ)	t = -0.17	241	p = 0.434 (NS)	male 6.80 female 7.04	-3.019, 2.547
Social phobia (FQ)	t = 0.66	56.29	p = 0.260 (NS)	male 15.93 female 14.72	-2.476, 4.909
Total phobias (FQ)	t = 0.56	241	p = 0.279 (NS)	male 30.37 female 28.47	-4.817, 8.612
Anxiety/depression (FQ)	t = 1.19	58.69	p = 0.119 (NS)	male 14.33 female 11.9845	-1.594, 6.277
Total Problem Severity (FQ)	t = 1.02	57.10	p = 0.155 (NS)	male 3.48 female 3.07	-0.392, 1.213
Work (SAQ)	t = 1.96	58.95	p = 0.27 (NS)	male 3.09 female 2.15	-0.018, 1.899
Home Management (SAQ)	t = 1.61	59.79	p = 0.056 (NS)	male 1.54 female 0.99	-0.132, 1.230
Social Leisure (SAQ)	t = 0.54	238	p = 0.293 (NS)	male 3.39 female 3.16	-0.593, 1.046
GHQ Total	t = 1.03	236	p = 0.153 (NS)	male 17.24 female 15.97	-1.164, 3.695
Anxiety (HAD)	t = -0.77	58.85	p = 0.221 (NS)	male 9.13 female 9.84	-2.556, 1.131
Depression (HAD)	t = 0.84	237	p = 0.202 (NS)	male 6.26 female 5.66	-0.807, 2.002

Note: \* 1-tailed values throughout.

**Table 11.5.10: Media group FAAC differences according to cause of disfigurement 1: FAAC: Kruskal Wallis**

FAAC subscale	Comparison	Mean Ranks	n	Test	Critical Value	Significance
Face/others	Disfigurement: <i>from birth</i>	93.54	40	Kruskal Wallis	$X^2 = 12.3732$ (df = 3)	p = 0.0062
	<i>from accident/injury</i>	82.06	64			
	<i>from a skin complaint</i>	117.74	49			
	<i>from surgery</i>	107.73	44			
Face/self	Disfigurement: <i>from birth</i>	94.88	42	"	$X^2 = 5.2463$ (df = 3)	p = 0.1546 (NS)
	<i>from accident/injury</i>	97.57	68			
	<i>from a skin complaint</i>	119.64	51			
	<i>from surgery</i>	104.50	46			

Visual inspection of the mean ranks for cause of facial disfigurement did not alone immediately show which levels of this variable were accounting for the significant difference found on the Face/other subscale.. Accordingly, Mann Whitney-U tests were performed to compare each pair of levels of this variable. The performance of such tests increases the likelihood of a type I error, because of the number of tests performed. A Bonferroni adjustment was applied to these results (Bryman & Cramer, 1990). Whilst this might be considered a conservative approach to the problem of increased type 1 errors, it was considered appropriate during post hoc investigations of differences between pairs following analysis of variance (see Table 11.5.11.). One difference was found, in that those suffering disfigurement as the result of a skin complaint scored higher on the Face/self subscale than those disfigured following accident or injury, indicating that they reported greater negative attitudes to their facial appearance. The difference between these two groups was apparently responsible for the overall significant difference found in the initial Kruskal-Wallis test.

The more general measures of disturbance examined in Tables 11.4.12 to 11.5.14 showed several differences between the groups as a whole, and these were once again further investigated using the Bonferroni adjustment. These results suggest that, in general, the group disfigured from birth do best, showing lower scores than those disfigured by surgery or skin complaint in most of the significant differences, with those disfigured following accident injury also faring better than those disfigured by surgery or skin complaint. Those disfigured by skin complaint seem to do worst, showing higher scores on the majority of the significantly different measures.

The pattern of correlations confirms the results seen in the plastic surgery ex-patients' sample in many respects. Modest but significant correlations were again found between FAAC subscales and most measures of psychological difficulty and phobic avoidance (Table 11.5.15), being statistically significant on 18 of 20 tests. Thus, the suggestion, from the results of the plastic surgery ex-patients' group that there is correspondence between attitudinal and behavioural aspects of body image concerning the face (measured by FAAC) and the broad range of psychological disturbances measured by the other scales, including measures of phobic avoidance receives further support, as does the assertion that negative body image regarding the face is associated with higher levels of psychological avoidance and disturbance. These findings provide further support for the fear-avoidance model of increased psychological difficulty following

disfigurement and for the convergent validity of FAAC. Correlations between BAT and FAAC items were likewise similar to those in the plastic surgery ex-patients' group, once again supporting the notion of close relationships between attitudes and behaviours concerning the face and those concerned with the body as a whole.



**Table 11.5.11:** Media group disfigurement differences according to cause of disfigurement 2: FAAC Face/other subscale: Mann Whitney-U

FAAC subscale	Pair Comparison	Mean ranks	n	Z	Significance*
Face/others	from birth:	56.95	40	-1.1912	p = 0.9344 (NS)
	from accident or injury:	49.72	64		
	from birth:	38.28	40	-2.2209	p = 0.1056 (NS)
	part of skin complaint:	50.49	49		
	from birth:	39.31	40	-1.1437	p = 1.0108 (NS)
	surgery:	45.40	44		
	from accident or injury:	48.56	64	-3.1324	p = 0.0068
	part of skin complaint:	68.02	49		
	from accident or injury:	48.78	64	-2.2940	p = 0.0872 (NS)
	surgery:	62.82	44		
	part of skin complaint:	49.23	49	-0.8436	p = 1.5956 (NS)
	surgery:	44.51	44		

\*p values following Bonferroni correction.

**Table 11.5.12:** Media group disfigurement differences according to cause of disfigurement 3: Fear Questionnaire subscales: one way ANOVA

Comparison	Groups	Group Means	n	Test	Critical value	df	Significance	Bonferroni *
Agoraphobia (FQ)	Disfigurement: from birth	6.31	45	1 way ANOVA	F = 0.7251	3, 222	p = 0.5380 (NS)	
	from accident/injury	5.71	73					
	from a skin complaint	7.14	56					
	from surgery	7.83	52					
Social Phobia (FQ)	Disfigurement: from birth	13.16	43	"	F = 0.8741	3, 218	p = 0.4553 (NS)	
	from accident/injury	14.13	71					
	from a skin complaint	16.04	56					
	from surgery	15.02	52					
Total Phobias (FQ)	Disfigurement: from birth	26.67	45	"	F = 0.2089	3, 222	p = 0.8267 (NS)	
	from accident/injury	26.89	73					
	from a skin complaint	29.21	56					
	from surgery	29.44	52					
Anxiety/ depression (FQ)	Disfigurement: from birth	9.95	43	"	F = 1.5250	3, 218	p = 0.2089 (NS)	
	from accident/injury	12.01	72					
	from a skin complaint	14.41	56					
	from surgery	12.31	51					
Problem Severity (FQ)	Disfigurement: from birth	2.40	43	"	F = 5.1794	3, 204	p = 0.0018	from birth < skin complaint
	from accident/injury	2.81	64					accident/injury < skin complaint
	from a skin complaint	3.92	52					
	from surgery	3.04	49					

\*Differences shown between groups are significant at 5 per cent level.

**Table 11.5.13:** Media group disfigurement differences according to cause of disfigurement 4: Social Avoidance Questionnaire subscales: one way ANOVA

Comparison	Groups	Group Means	n	Test	Critical value	df	Significance	Bonferroni *
Work (SAQ)	Disfigurement: from birth	1.57	44	1 way ANOVA	F = 5.6603	3, 217	p = 0.0009	from birth < from surgery accident injury < from surgery
	from accident/injury	1.78	72					
	from a skin complaint	2.82	55					
	from surgery	3.26	50					
Home Management (SAQ)	Disfigurement: from birth	0.48	44	"	F = 3.5097	3, 219	p = 0.0161	from birth < from surgery
	from accident/injury	0.97	72					
	from a skin complaint	1.05	56					
	from surgery	1.64	51					
Social Leisure (SAQ)	Disfigurement: from birth	2.89	44	"	F = 3.8870	3, 219	p = 0.0098	accident/injury < skin complaint
	from accident/injury	2.47	72					
	from a skin complaint	3.88	56					
	from surgery	3.51	51					

\*Differences shown between groups are significant at 5 per cent level.

**Table 11.5.14:** Media group disfigurement differences according to cause of disfigurement 5: General Health Questionnaire and Hospital Anxiety and Depression scores: one way ANOVA

Comparison	Groups	Group Means	n	Test	Critical value	df	Significance	Bonferroni *
GHQ Total	Disfigurement: from birth	14.02	45	1 way ANOVA	F = 3.7417	3, 217	p = 0.0119	from birth < skin complaint
	from accident/injury	15.32	71					
	from a skin complaint	18.66	56					
	from surgery	16.06	49					
Anxiety (HAD)	Disfigurement: from birth	8.16	45	"	F = 2.4301	3, 217	p = 0.0662 (NS)	
	from accident/injury	10.14	70					
	from a skin complaint	10.60	55					
	from surgery	9.51	51					
Depression (HAD)	Disfigurement: from birth	3.98	45	"	F = 3.4637	3, 219	p = 0.0171	from birth < skin complaint
	from accident/injury	5.51	72					
	from a skin complaint	6.44	55					
	from surgery	6.22	51					

\*Differences shown between groups are significant at 5 per cent level.

**Table 11.5.15: Correlations with FAAC subscales (Kendal's Tau)**

Correlated Variables		Correlation (Tau)	Significance
Face/other	Global problem (FQ)	0.3911	p = 0.000
"	Social Phobia (FQ)	0.4994	p = 0.000
"	Agoraphobia (FQ)	0.4496	p = 0.000
"	Anxiety/Depression (FQ)	0.4317	p = 0.000
"	Social Leisure (SAQ)	0.6005	p = 0.000
"	Anxiety (HAD)	0.3849	p = 0.000
"	Depression (HAD)	0.4132	p = 0.000
"	Total Score (GHQ)	0.3720	p = 0.000
"	Age	-0.1282	p = 0.007
"	Time since disfigurement	-0.0760	p = 0.126 (NS)
Face/self	Global problem (FQ)	0.4308	p = 0.000
"	Social Phobia (FQ)	0.4824	p = 0.000
"	Agoraphobia (FQ)	0.3518	p = 0.000
"	Anxiety/Depression (FQ)	0.4749	p = 0.000
"	Social Leisure (SAQ)	0.5012	p = 0.000
"	Anxiety (HAD)	0.4032	p = 0.000
"	Depression (HAD)	0.4749	p = 0.000
"	Total Score (GHQ)	0.3963	p = 0.000
"	Age	-0.1074	p = 0.021
"	Time since disfigurement	-0.0381	p = 0.430 (NS)

**Table 11.5.16: Media Group Correlations between FAAC and BAT items**

<b>Correlated</b>	<b>Variables</b>	<b>Correlation</b>	<b>Significance</b>
When I compare myself to others, I'm dissatisfied with my facial appearance	When I compare myself to others, I'm dissatisfied with my body as a whole	0.3998	p = 0.000
I hide my face	I hide my body as a whole	0.1319	p = 0.012
My face is a threat to me	My body as a whole is a threat to me	0.3834	p = 0.000
My face appears as if it's not mine	My body as a whole appears as if it's not mine	0.4535	p = 0.000
My facial appearance is very important to me	My bodily appearance is very important to me	0.5622	p = 0.000
I envy others for their facial appearance	I envy others for their physical appearance	0.6340	p = 0.000

Responses to the open-ended question revealed a far greater number and range of tactics employed to hide the face than in either the pilot or plastic surgery ex-patients' groups. The percentage of respondents *not* identifying avoidance tactics was far lower than in these two groups (50.8%). Thus, almost half this self-selected group identified using some specific tactic to hide the face. Since there are greater numbers within the media group experiencing psychological disturbance than in the pilot and plastic surgery ex-patients' groups (as measured by FQ, SAQ, GHQ and HAD), it may be suggested that such disturbance and the use of tactics to hide the face are connected.

**Table 11.5.17: Media group avoidance tactics**

<b>Tactic</b>	<b>Number</b>
Avert affected side	44
Use heavy make-up	10
Use hair as camouflage	14
Avoid eye contact	12
Wear beard	3
Wear glasses/sunglasses	7
Cover face with hand	25
Avoid strong lights	3
Avoid being photographed	7
Use clothing as camouflage	3
Other	12
No tactics stated	145

## **Section 11.6 Treatment leaflet pilot study**

### *11.6.1 Characteristics of the sample*

Participants were 11 male and 59 female respondents to the questionnaire studies, selected according to the procedure described in Chapter 10, who returned a three month follow-up questionnaire. Thirty four participants from the treatment group (6 males, 28 females) and 36 from the control group (5 males, 31 females) returned follow-up questionnaires at the 3 month follow-up point. Mean age of respondents was 42.01 years (range 17 to 81), and was 43.73 years for males and 41.69 for females. The response rate was 66 percent of the original 106 questionnaire respondents who met criteria for inclusion in the treatment study. Respondents and non-respondents at follow-up were compared according to a number of characteristics, and these comparisons are displayed in Table 11.6.1. Variables at interval level were examined using t-test and those at nominal level using chi square.

**Table 11.6.1: Comparisons between follow-up respondents and non-responders**

	Critical value	df	Significance	CI (95%)
Age	$t = -0.07$	94.43	0.945 (NS)	(-5.939, 5.578)
Years since disfigurement	$t = 0.88$	95	0.379 (NS)	(-4.214, 10.973)
Pre-treatment problem severity	$t = -1.22$	103	0.317 (NS)	(-1.014, 0.243)
Pre-treatment social leisure	$t = -0.15$	103	0.878 (NS)	(-1.094, 0.937)
Cause of disfigurement	$X^2 = 4.25$	4	0.373 (NS)	-
Sex	$X^2 = 0.186$	1	0.666 (NS)	-

There were thus no significant differences between follow-up respondents and non-respondents.

#### 11.6.2 Comparisons between treatment and no treatment groups.

The main rationale behind the provision of the self-help leaflet was to decrease anxiety and avoidance of social and other public situations. Scores of the treatment and non-treatment groups on measures of global problem severity, Fear Questionnaire agoraphobia and social phobia subscales, Social Adjustment Questionnaire work, home management and social leisure subscales, GHQ scores and HAD anxiety and depression subscales were compared. The rationale for use of several of these scales is self-evident. However, the choice of the SAQ home management subscale, GHQ, and the HAD depression subscale requires brief explanation. The home management subscale was included because it cues respondents to respond, amongst other items, to shopping, a public activity which is often affected in agoraphobia. The GHQ and the HAD depression subscale have both been used in previous studies of disfigured people and those with skin complaints (Lanigan & Cotterill, 1989; Lewis & Wessely, 1990; Robinson et al, 1996; Williams & Griffiths, 1991) and also offered an opportunity to examine possible relationships between disfigurement, avoidance and depression.

Use of analysis of covariance was originally considered, in order to exclude the possible confounding effects of age, sex, time since disfigurement and cause of disfigurement. However, no significant differences were found between the groups on these four variables (See Table 11.6.2). Nevertheless, the group means for time since disfigurement were considerably different on visual inspection (19.66 yrs treatment subjects, 27.67 yrs controls), and such differences may still exert a



confounding effect (Politt & Hungler, 1991). Further examination of the data revealed that correlations between time since disfigurement and the variables under examination were uniformly extremely low (see Appendix 16), suggesting that the non-significant difference in time since disfigurement between treatment and control subjects was unlikely to contribute a confounding influence. Differences between treatment and control groups regarding the tactics used to hide their faces were examined by visual inspection and did not generally appear appreciably different, although more control subjects indicated using no such avoidance tactics, whilst more treatment subjects averted the face. (Table 11.6.3). As a consequence of this general correspondence between characteristics of the treatment and control groups, and after seeking statistical advice, independent groups t-tests between the treatment and control groups were performed utilising pre-post intervention difference scores obtained by subtracting the post intervention from the pre-intervention score for each participant. All tests were one-tailed, reflecting the prediction that treated participants would fare better than untreated. The results of these comparisons are displayed in Table 11.6.4.

**Table 11.6.2: Comparisons between characteristics of treatment and control groups**

	Critical value	df	Significance	CI (95%)
Age	$t = -0.05$	68	0.985 (NS)	(-7.680, 7.281)
Sex	$X^2 = 0.18646$	1	0.66588 (NS)	-
Time since disfigurement	$t = -1.74$	63	0.087 (NS)	(-17.207, 1.186)
Cause of disfigurement	$X^2 = 0.39489$	3	0.70673 (NS)	-

**Table 11.6.3: Avoidance tactics of treatment and control groups (pre-treatment)**

Tactic	Treatment (n)	Control (n)
Avert affected side	6	11
Use thick make-up	1	0
Use hair as camouflage	2	4
Avoid eye contact	4	3
Wear a beard	1	0
Wear glasses/sunglasses	1	1
cover face with hands	6	6
use clothing as camouflage	0	2
other	1	2
No tactics stated	12	7

**Table 11.6.4: Comparisons between outcomes of treatment and control groups**

Measure	Critical Value	df	Significance	Group means*	CI (95%)
Global Problem Severity (FQ)	t = 1.11	61	0.136 (NS)	** Rx 0.70 Cont 0.18	(-0.416, 1.453)
Agoraphobia subscale (FQ)	t = 1.00	57.47	0.161 (NS)	Rx -0.41 Cont -1.68	(-1.269, 3.809)
Social Phobia subscale (FQ)	t = 1.16	65	0.125 (NS)	Rx 1.09 Cont -0.36	(-1.039, 3.943)
Work subscale (SAQ)	t = 0.59	66	0.277 (NS)	Rx 0.55 Cont 0.26	(-0.682, 1.259)
Home Management subscale (SAQ)	t = -0.37	67	0.357 (NS)	Rx - 0.15 Cont 0.03	(-1.132, 0.781)
Social Leisure subscale (SAQ)	t = 2.31	66	0.012	Rx 1.03 Cont 0.03	(0.136, 1.864)
GHQ total	t = 1.60	65	0.056 (NS)	Rx 3.47 Cont 0.51	(-0.728, 6.637)
Anxiety subscale (HAD)	t = 2.22	63	0.015	Rx 2.29 Cont 0.2941	(0.197, 3.795)
Depression Subscale (HAD)	t = 1.83	63	0.036	Rx 1.00 Cont - 0.42	(-0.129, 2.977)

Notes: \*Negative mean scores indicate deterioration over time.

\*\*Rx = Treatment, Cont = Controls.

Participants given the treatment leaflet offering advice along cognitive-behavioural lines showed modest, statistically significant gains on 3 of the 9 measures examined. Of these significantly different measures, two (Social Leisure subscale (SAQ), Anxiety subscale (HAD)) may be considered as key tests of the fear-avoidance model of psychological disturbance following disfigurement, since they examine discomfort and avoidance in social situations and anxiety respectively, and the fear-avoidance model predicts that anxiety and phobic avoidance will be major features in the psychological difficulties of disfigured people. Of the non-significant results, all but one favoured the treatment group. There is thus modest support for the effectiveness of the treatment leaflet, and, by inference, for the fear-avoidance model, since improvement in the difficulties of facially disfigured people in response to a treatment which reduces anxiety suggests that anxiety is indeed an important component of these difficulties. The implications and limitations of these findings are examined in Chapter 12.

### 11.6.3 *Acceptability of the leaflet*

Of the 34 follow-up respondents in the treatment group, 33 completed a one-page addition to the questionnaire soliciting their reports of their use and views of the leaflet. Frequencies of responses are presented in Tables 11.6.5 and 11.6.6. The responses shown in these figures indicate that the leaflet was generally perceived as understandable and helpful. Although the vast majority of respondents read the leaflet in total, adherence to its instructions was modest, with only half the respondents reporting undertaking half or more of the practical suggestions described by the leaflet. Whilst this may have affected the potential effectiveness of the leaflet, it is equally possible that participants followed only those suggestions which directly addressed their particular difficulties, ignoring those which were not relevant.

**Table 11.6.5: Treatment group's use of treatment leaflet**

	All	About 3/4	About 1/2	About 1/4	None
I did things suggested in the leaflet	3	4	9	11	5
I read the leaflet	28	4	1	0	0
	Yes			No	
I learnt a relaxation exercise	12			20	

**Table 11.6.6: Treatment group's opinion of leaflet**

	Very easy	Quite easy	Neither easy nor hard	Quite hard	Very hard
The leaflet was understandable	20	10	2	0	0
	Very helpful	Quite helpful	Neither helpful nor unhelpful	Quite unhelpful	very unhelpful
The leaflet was helpful	4	18	7	3	0

## **Section 11.7 Comparison of facially disfigured people with phobic patients**

### *11.7.1 Characteristics of the sample*

The study group consisted of two groups. Phobic patients were 27 male and 39 female agoraphobic patients and 28 male and 40 female social phobic patients from whom anonymised data were obtained in the manner described in Chapter 10. The facially disfigured participants were 25 male and 87 female subjects whose data were extracted from the entire study group of dermatology outpatients attenders, plastic surgery ex-patients and media respondents described above. Subjects from this group were selected for comparison with phobic patients on the basis of a global problem score of 4 or more, in the absence of a formal cut-off point on this scale for entry into treatment. As noted in Chapter 10, this figure has been used as a cut-off point clinically. In the interests of consistency, 15 potential participants from 74 agoraphobic and 75 social phobic patients originally selected did not achieve this cut-off point, and so were also excluded, leaving the final groups of 66 agoraphobics and 68 social phobics. Presumably the 15 low-scoring patients had originally been included for treatment, irrespective of their low global phobia scores, in response to the clinical judgement of the therapists involved.

### *11.7.2 Comparisons between disfigured and phobic groups*

Construction of the power calculation for this section of the study was described in Chapter 9, and it was noted that adequate power to detect differences was a prerequisite for even the limited assertion of equivalence which might be made from a finding of no difference between groups. Further discussion of equivalence in Chapter 9 involved the suggestion that the definition of a further criterion according to which to make such an assertion might be made by identifying that

the scales under consideration differentiated between two complaints known to have different features but not between facially disfigured people and phobics. Comparison between social phobics and agoraphobics was made in order to establish whether the scales under consideration indeed made this distinction.

Scores on the agoraphobia and social phobia subscales of the Fear Questionnaire adequately discriminated between agoraphobic and social phobic patients with the numbers of subjects available in the current study. The anxiety/depression scale narrowly failed to show such a difference ( See Table 11.7.1). In consequence, it was considered that the likelihood of a type 2 error being made as the result of too few subjects being available was small. These subscales were chosen as the measures for comparison between such patients and the facially disfigured group. The other potential source of comparison data, the Social Avoidance Questionnaire, was not available from the computer database for phobic patients at the time of data collection, and time constraints did not allow its subsequent collection.

It was considered that subjects might differ in age, sex and problem severity, and indeed, this proved to be the case. (See Table 11.7.2). The facial disfigurement and agoraphobia groups were significantly different in problem severity, whilst the facial disfigurement and social phobia groups were significantly different in both problem severity and age. Since these differences might be expected to interact with the independent variables (facial disfigurement versus agoraphobia; facial disfigurement versus social phobia), the agoraphobia and social phobia Fear Questionnaire subscale differences between groups were investigated using an analysis of covariance approach, using problem severity as the covariate in comparisons between the facial disfigurement and agoraphobic groups and problem severity plus age as the covariates on comparisons between the facial disfigurement and social phobic groups. Since sex is a dichotomous categorical variable and is, in consequence, not generally recommended for consideration as a covariate (Munro & Page, 1993), it was entered into the analysis as a further independent variable for both comparisons between facially disfigured people and agoraphobics and facially disfigured people and social phobics. These results are displayed in Table 11.7.3, and the full ANCOVA tables are shown as Appendices 18 and 19.

**Table 11.7.1:** Fear Questionnaire agoraphobia, social phobia and anxiety/depression subscales: comparisons between social phobic and agoraphobic patients.

Scale	Critical value	df	Significance	Group Means	CI (95%)
Agoraphobia subscale (FQ)	t = 9.26	141	< 0.001	Agora 24.21 Social 8.40	(12.439, 19.195)
Social Phobia subscale (FQ)	t = -4.92	141	< 0.001	Agora 15.77 Social 24.11	(-11.691, -4.985)
Anxiety/depression (FQ)	t = 1.92	138	0.057 (NS)	Agora 24.93 Social 21.33	(-0.116, 7.316)

Note: Agora = Agoraphobia, Social = Social phobia, Facial = Facially disfigured people throughout chapter.

**Table 11.7.2:** Age and Problem severity of agoraphobic, social phobic and facially disfigured groups

Comparison	Critical value	df	Significance	Group Means	CI (95%)
Facial disfigurement/agoraphobia groups					
Age	t = 0.69	176	0.493 (NS)	Facial 42.21 Agora 40.70	(-2.839, 5.874)
Problem Severity	t = -5.74	176	< 0.001	Facial 5.20 Agora 6.47	(-1.711, -0.835)
Sex	X <sup>2</sup> = 6.93837	1	0.00844	*	-
Facial disfigurement/social phobia groups					
Age	t = 4.18	178	< 0.001	Facial 42.21 Social 33.68	(4.507, 12.568)
Problem severity	t = -5.12	178	< 0.001	Facial 5.20 Social 6.31	(-1.542, -0.683)
Sex	X <sup>2</sup> = 7.24061	1	0.00713	*	-

Notes: \* These results indicated a difference in the overall proportions of males and females from those to be expected by chance. Visual inspection suggested that these differences were accounted for by the greater proportion of female facially disfigured people.

**Table 11.7.3: Fear Questionnaire agoraphobia and social phobia subscales: Comparisons between facially disfigured and phobic groups.**

Comparison	Critical value	df	Significance	Group Means
Facial disfigurement/agoraphobia groups*				
Agoraphobia Subscale	F = 52.24	1	0.000	Agora 25.4 FD 10.5
Social Phobia Subscale	F = 11.33	1	0.001	Agora 16.32 FD 19.55
Anxiety/depression	F = 0.70	1	0.404 (NS)	Agora 25.68 FD 20.06
Facial disfigurement/social phobia groups**				
Agoraphobia Subscale	F = 3.49	1	0.063 (NS)	Social 8.8 FD 10.5
Social Phobia Subscale	F = 0.081	1	0.368 (NS)	Social 24.3 FD 19.6
Anxiety/Depression	F = 2.78	1	0.097 (NS)	Social 21.32 FD 20.06

\* Note 1: Main effects of independent variables only shown. Within the analysis of covariance, these reflect the exclusion of the mediating influence of different levels of problem severity between the groups. See Appendix 17 for full ANCOVA tables.

\*\* Note 2: Main effects of independent variables only shown.

Within the analysis of covariance, these results reflect the exclusion of the mediating influences of different levels of problems severity and different ages between the groups. See Appendix 18 for full ANCOVA tables. The results indicate that people with facial disfigurement with global problem severity of clinical severity demonstrate similar levels of socially phobic and agoraphobic avoidance to social phobic patients but higher levels of social avoidance and lower levels of agoraphobic avoidance than agoraphobic patients. This resemblance between socially phobic patients and facially disfigured people offers general support for a fear-avoidance model of psychological difficulty following disfigurement, since phobias are believed to be caused and maintained by fear and avoidance (Marks, 1987), and specific support for the suggestion that the social difficulties faced by disfigured people are, in those who report psychological distress, socially phobic in nature. Facially disfigured people who experience psychological distress do not, however, resemble agoraphobic patients. The anxiety/depression subscale showed no differences between facially disfigured people and either phobic group.

The following chapter examines the implications of the findings described in this chapter in detail, as well as examining methodological issues pertinent to the current study.



## **CHAPTER 12**

### **DISCUSSION**

#### **Section 12.1 Introduction**

This chapter examines the findings of the various elements of the study in the context of the literature on facial disfigurement and its psychological sequelae and of the cognitive-behavioural model. In particular, comparisons between the facially disfigured people in the current study and the behaviour of phobic individuals are drawn.

The previous chapter was separated into descriptions of the separate elements of the study, for reasons of simplicity. This policy is followed in this chapter, with one modification. Survey elements of the study may, in many cases, be usefully combined when discussing the ramifications of the study findings. In consequence, all survey elements are presented in a single section, and findings of the separate survey elements (pilot study, plastic surgery ex-patients survey and media recruited survey) are compared and contrasted.

#### **Section 12.2 Questionnaire characteristics**

One purpose of the study was an exploration of the characteristics of a new questionnaire devised in the absence of any suitable measure of attitudes to facial disfigurement or of avoidance after facial disfigurement. As has been noted in Chapter 11, the comprehensive testing of validity and reliability of an instrument is generally a continuing exercise, and is beyond the scope of a single study, particularly one which includes other aims. However, the issues of internal association, internal consistency and test-retest reliability were examined.

With regard to internal association, factor analysis identified three stable factors, which were named: anxiety and avoidance with regard to others reactions (face/others); negative appreciation of one's face (face/self); rest. A number of elements of the FAAC were derived from Probst et al.'s BAT (1995), and the factor structure of the FAAC is somewhat similar with regard to these elements, despite the differing focus of the two measures.

This is most marked with regard to FAAC Factor 2 (face/self). Thus, items 10, 14 and 20 of the FAAC ('When I compare myself to others, I'm dissatisfied with my facial appearance'; 'I hide my face'; 'I envy others for their facial appearance') load on Factor 2. Similarly, items 1, 7 and 18 of the BAT ('When I compare myself with my peers' bodies, I'm dissatisfied with my own'; 'I'm inclined to hide my body'; 'I envy others for their physical appearance') load on a single factor (general body dissatisfaction [Factor 3]). The slight linguistic differences between BAT and FAAC on these items results from use of an earlier, unpublished version of BAT in deriving the items for FAAC. The later version was not published until well into the current study (Probst et al., 1995).

By contrast, item 16 of FAAC ('My face is a threat to me'), which also loads on Factor 2, has a BAT analogue (item 14: 'My body is a threat to me'), which loads on a different factor from the BAT items described above (lack of familiarity with one's own body [Factor 2]). However, it could be argued that the factor names of the FAAC are rather broader, and that elements of both Factors 2 and 3 of the BAT reflect a construct of 'body/self' similar to the face/self construct proposed for FAAC. The remaining items of FAAC Factor 2 (item 21: 'I have become used to the way my face looks'; item 24: 'I avoid looking at my face') have no direct analogue items in BAT.

The Rest factors of FAAC and BAT contain similar elements. FAAC Factor 3 consists of only items 19 and 23 ('My facial appearance is very important to me'; 'I check my face in mirrors') whilst BAT Factor 4 contains only items 15 and 20 ('My bodily appearance is very important to me'; 'I observe my appearance in the mirror').

One further area of contrast between the two measures concerns item 18 of FAAC ('My face appears as if it's not mine') and item 12 of BAT ('My body appears as if it's not mine'). This element loads strongly on Factor 2 of BAT. If the argument above with regard to FAAC 16 and BAT 14 is extended, we should expect FAAC 18 to load on Factor 2, since FAAC 18 might be argued to reflect an element of face/self in the same way as item 16 ('My face is a threat to me'). However, FAAC item 18 loads on Factor 1 (Face/others). Nevertheless, its loading is equivocal, loading only fractionally more on Factor 1 rather than 2 (see Chapter 11, Table 11.2.2). This is in marked contrast to its BAT equivalent. Interestingly, the only other equivocal item in FAAC is item 16 ('My

face is a threat to me'). It may be worth considering dropping both these equivocal items from further versions of the FAAC. No other items from FAAC Factor 1 had BAT equivalents, and so are not considered in the context of the factor structure of the BAT.

Seven of the 8 items on FAAC Factor 1 loaded very heavily. Four items asked directly about behavioural avoidance, whilst 3 others explicitly referred to respondents' assumptions about the reactions of others to their facial appearance. In consequence, it seems safe to conclude that, with the possible exception of item 18, Factor 1 validly represents a dimension of people's experience and behaviour with regard to their facial appearance and that the name ascribed to this factor is an adequate description of its elements.

Similarly, with the exception of item 16, all items in FAAC Factor 2 loaded unequivocally on this factor. Of the 6 items in this factor, items 10, 14, 21 and 24 appear to involve the respondent either in making judgements about their appearance or engaging in avoidance because of such self-appraisals. Item 16 appears to involve a similar kind of judgement, but is equivocal. The remaining item (item 20: 'I envy others for their facial appearance'), superficially appears to be a face/others item, yet loads extremely strongly on Factor 2. On further consideration, however, envy of others might be considered as an element of judgement about one's *own* appearance. In consequence, it is concluded that, with the possible exception of item 16, Factor 2 is an adequate and appropriately named description of an element of experience and behaviour regarding facial disfigurement.

The Rest factor is interesting in that its elements, like their BAT equivalents, load unequivocally on the same factor. Probst et al. (1995) excluded the Rest score from further analysis because of the small number of items and low alpha coefficient. Both of these findings were repeated in the Rest factor of the FAAC, and the Rest scale was dropped from further analysis in the current study, in terms of subjects' responses to it as a subscale. The principal difficulty with both these items (and their BAT equivalents) lies in the ambiguity inherent in any interpretation of responses to it. Other elements of the FAAC and the BAT are clearly directional, with a negative response at one end of the scale and a positive one at the other. For example, feeling one's face (or body) is a threat appears intuitively to be a negative perception of it. By contrast, the information revealed by

particular responses to FAAC 19 and 23 is by no means clear. If one always feels the face is extremely important, is this a negative or positive attitude towards it? Similarly, if one checks the face in mirrors, is this from the desire to ensure that its appearance is not offensive to others (or to oneself), as it might be in body dysmorphic disorder, from normal fastidiousness about appearance, or from positive regard for one's appearance and enjoyment of seeing it? In the case of item 19, the responses of participants in all elements of the study suggests that they understood the wording of the item clearly, since there is a very clear tendency (from visual inspection alone) to answer strongly in the affirmative. The ambiguity lies, in this case, not in respondents' understanding of the question but our ability to interpret their answers. Certainly, most respondents find their facial appearance important, but, unfortunately, the item, as worded, tells us nothing about why they do so. By contrast, visual inspection of responses by participants to item 23 demonstrates a broad, even range of responses, which might suggest that the question lacked face validity with participants, who seemed to answer in an almost random fashion, perhaps indicating lack of clarity about their understanding of the relevance of the question.

Turning to examine internal consistency, this was high with regard both to the FAAC total scale and for Factors 1 and 2, across both the plastic surgery ex-patients and the media recruited samples, and seems comparable with the BAT, although direct comparison is not possible because of the different items and factor structures of the two instruments. As noted above, Factor 3 had low internal consistency. This was true for both samples, but particularly in the smaller plastic surgery ex-patients sample. However, it may be concluded that both the total score and the two subscales reliably measure homogeneous elements of experience and behaviours with regard to facial appearance. The similarity of the findings between the two groups increases our confidence in this reliability.

By contrast, test-retest reliability was poor. Moreover, examination of scatter plots suggested that there were numerous outlying responses. Although the number of eventual respondents to this element of the study was small ( $n = 31$ ), this should not be regarded as unduly influencing the findings. First, as noted in Chapter 11, there were no significant differences between responders and non-responders across the range of variable investigated, so we may not conclude that

responders differed from the original group chosen for the test-retest study in ways which might have affected the results. Second, other studies have attained good test-retest reliability on similarly small samples. Most relevant to the current study are the results of Marks and Mathews (1979) regarding the Fear Questionnaire, and Probst et al.'s (1995) study of the BAT. These investigators achieved correlation coefficients of over 70 per cent (and indeed over 80 per cent on most subscales) with samples of 20 and 31-35 (three different samples) respectively. However, the current study differs from those of Marks and Mathews (1979) and Probst et al. (1995) in one major respect, in that both these groups of researchers used a shorter test-retest interval - one week, compared with four weeks in the current study. Similarly, Rosen et al. (1991) achieved good test-retest reliability for their Body Image Avoidance Questionnaire with a test-retest interval of two weeks, as did Lanigan and Cotterill (1989), with a variable test-retest interval of between 2 and 4 weeks. It is recognised that test-retest reliability decreases with the passage of time, and 4 weeks is near the upper limit regarded as useful in test-retest studies (Burns & Grove, 1993), since any intervention of events in the respondent's life between test and retest renders comparison between the time 1 and time 2 tests an invalid measure of the consistency or otherwise of the measure over time. Although it is argued that a longer interval lessens the possibility of memory effects from time 1 affecting scores on time 2, the possibility of changes in the respondent's circumstances influencing their responses is likely to increase over time, as more life events intervene. However, only one of the group noted any such changes having occurred between time one and time two, in response to a question to this effect included with the retest questionnaire. The four week interval was, in fact, chosen largely for practical reasons. Since the study was undertaken part-time through the post, the longer test-retest interval allowed more time for the researcher to identify potential participants in the test-retest element of the study and respond to them. It may have been that a shorter interval would have yielded a higher test-retest correlation.

The two subscales of the FAAC were also compared with the Social Leisure subscale of the SAQ, subscales of the FQ, and HAD, the GHQ, age and time since disfigurement in the pilot study, plastic surgery and media samples. No measures were included in the questionnaire battery specifically in order to test convergent validity, since this would have involved further extending an already lengthy battery. Nevertheless, the correlations examined between the FAAC subscales and these other

variables represent a test of the convergent validity of the FAAC. Whilst attempts to establish convergent validity with an accepted measure of body image disturbance would have offered the potential for a clearer result, it may be argued that it is still valid to examine correlations with more general measures, provided they still aim to investigate underlying constructs of relevance to the subject area. Indeed, Probst et al. (1995) used such general measures (Hopkins Symptom Checklist (SCL-90), Beck Depression Inventory (BDI), Dissociation Questionnaire (Dis-Q), Borderline Syndrome Inventory (BSI)), as well as eating disorder oriented measures in their investigation of the convergent validity of the BAT. Following the practice of Probst's similar study and using Surwillo's (1980) criteria for size of correlations (low = 0% - 39%; moderate to substantial = 40% - 69%; high to very high = 70% - 100%), it will be seen that moderate correlations occurred in the plastic surgery group between face/others and global problem severity (FQ) and social leisure (SAQ) and between face/self and global problem (FQ), social phobia (FQ), anxiety/depression (FQ) and social leisure (SAQ). In the media group, there were moderate correlations between face/others and global problem severity, social phobia, agoraphobia, anxiety/depression (FQ), social leisure (SAQ) and depression (HAD), and between face/self and global problem, social phobia, anxiety/depression (FQ), social leisure (SAQ), anxiety (HAD) and depression (HAD). All other correlations (where present) were low.

Six specific items on the FAAC had close BAT analogues ('When I compare myself to others, I'm dissatisfied with my body as a whole', 'I hide my body as a whole', 'My body as a whole is a threat to me', 'My body as a whole appears as if it's not mine', 'My bodily appearance is very important to me', 'I envy others for their physical appearance'), and were examined for evidence of correlation between the two sets of scale elements. Moderate correlations using Surwillo's criteria were found in all three samples, with the exceptions of: 'I hide my body as a whole', which had low correlations throughout and: 'My body as a whole is a threat to me', which had moderate correlations in the pilot study and ex-plastic surgery patients samples but a low correlation in the media sample. It appears that body image specific to the face makes a considerable contribution to image of the body as a whole.

It is interesting to consider what these correlations might represent. It appears that the FAAC subscales are measuring attitudes, behaviour and experience related to the face which are related to general scores of avoidance and dysphoria, and that negative body image regarding the face (as measured by high FAAC scores) is associated with higher levels of psychological avoidance and disturbance, across the range of measures employed. It is particularly instructive to note that amongst the highest of these correlations are those with aspects of social difficulty, suggesting that the FAAC is particularly addressing issues of facial disfigurement which relate to social interaction and anxiety. These findings support the fear-avoidance model of increased psychological difficulty following disfigurement. That this is not confined to the Face/others subscale (which contains items which explicitly ask about social avoidance) is illustrated by the observation that correlations are generally similar across both subscales.

In conclusion, the FAAC shows internal associations and consistency which are comparable with current instruments in the field (Probst, 1995, Rapoport et al., 1993, Rosen et al., 1991), but slightly low test-retest reliability, possibly as a consequence of the long test-retest interval. There is some evidence of convergent validity from the examination of correlations with more general measures of avoidance and dysphoria and from examination of the correlations between single items and their BAT analogues. Finally, correlations between FAAC and the general measures also support the fear-avoidance model of psychosocial difficulties following disfigurement.

### **Section 12.3 Characteristics of the study group**

No attempt has yet been made to define cut-off points which might indicate pathology in response to the FAAC and its subscales. However, some examination of particular items is of interest in addressing issues of avoidance as a consequence of concerns about the face. First, the general experience of respondents, according to FAAC, is of low levels of disturbance, as revealed by their mean and modal scores on FAAC elements. Whilst this might be expected in the pilot study and plastic surgery samples, which are relatively free from the difficulty of self-selection, the finding also holds for the media recruited sample, which might have been expected to be skewed towards greater pathology.

Within this general appearance of adjustment, however, there are clear areas of difficulty, particularly amongst the media recruited group. Clearly, this group is in no way representative, being entirely self-selected. However, it is not intended that the results from this group should be taken as indicative of the prevalence of difficulties in the population of facially disfigured people as a whole, merely as descriptive of the *pattern* of such difficulties within this sample. It *may* be possible to draw tentative conclusions about the experiences of disfigured people as a whole in terms of the extent of problems experienced, but the confidence we might have in such conclusions is determined solely by how far we might argue that the sample are likely to be representative of disfigured people. In all probability, respondents are *not* representative, given that they have troubled to reply to attempts to solicit participants. Presumably people who experienced no difficulty are less likely to respond, particularly since they may not regard themselves as disfigured. Any inferences drawn from the eventual sample of media respondents regarding the frequency of difficulties in the larger population should therefore be extremely conservative.

In response to elements of the Face/others factor, considerable numbers of respondents reported difficulty with multiple elements of this factor, suggesting disturbance of their interactions with others across a range of activities, as a result of facial appearance. As might be expected, disturbance is rarer in the pilot and plastic surgery sample, with small numbers reporting difficulty. In the media group, however, a substantial *majority* (77.68 per cent) of respondents reported their face was a barrier with others at least sometimes, with 42.48 per cent reporting this was *often*, *usually* or *always* a problem. Similarly, a substantial proportion reported their face was a threat to others at least *often* (20.60 per cent). Perhaps more significantly for a cognitive-behavioural account based on a fear-avoidance model of disturbance in facial disfigurement, responses to the 4 elements of Face/others related to behavioural avoidance all showed considerable levels of difficulty, with 29.06% avoiding walking in the street because of facial appearance at least sometimes, 53.19% avoiding social situations, 40.34% avoiding sexual intercourse and 36.91% avoiding certain clothes to a similar frequency. Once again, these levels were much lower in the pilot and plastic surgery groups. A generally similar pattern was found in the Face/self subscale, most notably in response to item 10 (When I compare myself to others, I'm dissatisfied with my facial appearance), with 76.27% of the media group reporting feeling like this at least *often* and 24.45% reporting they



*always* felt like this. Interestingly, negative responses to this item were also quite high in the pilot and plastic surgery groups (36.11% and 20.59% at least *often* respectively).

Perhaps most important of all is the number of individuals who report difficulty *usually* or *always* in response to FAAC elements, since this level of frequency of disturbance might be taken, in many cases, as indicative of considerable emotional and behavioural handicap. These figures have been reported in Chapter 11, and will not be repeated here, except to note the following. These numbers were extremely low in the pilot plastic surgery ex-patients groups, and this is encouraging. We might be justified in concluding that a considerable majority of people experiencing skin complaints or the results of plastic surgery do not exhibit high levels of the kinds of difficulty FAAC attempts to capture, and so are well-adjusted. In the case of the plastic surgery group, the lack of difference between responders and non-responders (on the small number of variables it was possible to compare) could somewhat increase our confidence in this. By contrast, the media recruited responses indicate that substantial numbers of this sample, at least, are experiencing considerable difficulties, especially in social relations. Responses to the open ended question regarding tactics used to hide the face are likewise predominantly focused on social situations, and support the qualitative findings of other studies which report the high levels of social vigilance engaged in by disfigured people (Macgregor et al., 1953; Partridge, 1990).

Turning to examine the more general measures of avoidance and dysphoria, the general pattern of scores on the FQ was low in all groups, particularly the plastic surgery ex-patients' group, where the modal score was 0 on each element, indicating no problems. There were, however, notable exceptions to this general picture of little handicap. This was most marked in the media recruited group. In particular, the social phobia subscale showed a modal response of 18, whilst the mean was 14.97. These scores are slightly lower than the midpoint on this 0-40 scale, and this midpoint might be considered, from clinical experience, as a useful cutoff from which to determine the level of difficulty requiring formal intervention. However, an examination of quartiles is, perhaps, more revealing, since this indicates that a considerable percentage of respondents are experiencing difficulties. As an example, 25 per cent of the sample were accounted for by scores of over 21/40, 19/40 and 4/8 on the social phobia, anxiety/depression and total problem severity subscales

respectively. Whilst no formal cut-off points exist for the Fear Questionnaire and its subscales, these scores would generally be regarded as indicative of difficulty approaching clinical severity. Confirmation of this exists both in the scores from the original validation study (Marks & Mathews, 1979) and the mean scores of agoraphobics and social phobics entered into the current study (Appendix 19). In the Social Adjustment Questionnaire, the most striking finding is in the social leisure subscale, which aims to elicit responses about activities performed for pleasure with others. Whilst the scores are again mainly low, the cut-offs for the 75% quartile are 4, 2 and 6 in the pilot, plastic surgery and media groups respectively. Thus in the pilot group 25% of the sample are experiencing definite difficulty, and in the media group marked difficulty, in this area of their lives.

Taken as a whole, therefore, it may be tentatively concluded from the FQ and SAQ that social interaction is the major area of life (of those examined by these measures) affected in facially disfigured people. Although, as has been noted earlier, sampling inadequacies prevent firm conclusions, our confidence in this finding might be increased both by the frequent anecdotal and small study reports of social difficulties amongst disfigured people and by the stability, across the three sample groups examined in the current study, of the finding that social aspects most frequently score high. Even where scores are low, as in the plastic surgery ex-patients' group, the highest scores are generally for social difficulties.

The final measure of focal anxiety, the Maudsley Obsessions Checklist, showed low levels throughout the three samples, and, in consequence, was excluded from further analysis. It had originally been envisaged that facially disfigured people would exhibit checking rituals similar to those seen in obsessive compulsive disorder and body dysmorphic disorder, but this was not found. It may, however, be the case that disfigured individuals engage in highly specific rituals which are not adequately examined by this general measure of compulsive activities. The current study did not offer the opportunity to examine this, except in response to the FAAC item: 'I check my face in mirrors' and the open-ended question examining tactics used to hide the face. Whilst considerable numbers reported checking the face, it is not clear, because of a shortcoming in the questionnaire noted in Section 12.2, whether this represents obsessional behaviour. Of the tactics identified none

may be unequivocally construed as compulsive in nature, although they clearly may require a high level of self-monitoring.

Turning to more general measures of dysphoria, GHQ and HAD responses were both examined. The most striking finding here is the large number of 'cases' detected in response to the GHQ, across all sample groups. This finding is particularly disturbing, given that the most stringent definition of caseness for GHQ12 suggested in the literature was used (cut-off 3/4). In the GHQ, the percentage of cases was 33.3%, 31.4% and 51.1 per cent in the pilot, plastic surgery and media groups respectively. Whilst the high percentage in the media recruited group is certainly worrying, even in an unrepresentative sample, the two hospital recruited samples are more revealing, especially when compared with other studies of the GHQ in hospital in-patient and general practice populations. The current figures are considerably higher than those found in the general population (11 per cent [Goldberg et al., 1976]), and comparable with general practice attenders (30 per cent, [Goldberg et al., 1976]) and hospital in-patients (33 per cent [Maguire et al., 1974]), with the exception of the media group, who score considerably higher than all these groups. It will be remembered that the plastic surgery group were *not* current attenders, and we might, therefore, expect them to be nearer to general population samples and less likely to be liable to the false GHQ positives found amongst physically ill people (Goldberg & Williams, 1991). However, it will be noted that they in fact most closely resemble the in-patient and general practice attenders groups. It is also useful to compare these findings with the outpatients sample of Hughes et al. (1983), who found a 30% incidence of caseness in dermatology outpatients, of which 70% of cases occurred in those whose face or hands were affected. In the current study, the dermatology outpatients (pilot) group was somewhat higher than the overall figure in the Hughes et al. (1983) study. Furthermore, White's (1982) study of burn injured patients yielded a rate of approximately one third with psychological disturbance one year after injury, although the group cannot be directly compared with the current study both because site of the injury was not identified in the analysis and because an 'adaptation' of GHQ was used. By contrast, the incidence of caseness in Lanigan and Cotterill's (1989) study was considerable lower than the current study, with 3 (10%) of their 30 port wine stain respondents questioned achieving caseness on GHQ30. In summary, both the pilot group and the plastic surgery ex-patients group scored similar levels of GHQ caseness to hospital in-patient and

GP samples. The finding for the ex-patients group is particularly interesting given that they were not currently receiving treatment, and so might have been expected to be more like a general population sample (than whom they score much higher) than to either of these groups. Moreover, although results are not directly comparable, given that different versions of the GHQ and different cut-off points were used in various studies, the current study used the most stringent cut-off point for GHQ12 reported in the literature, and would, in general, tend to ascribe caseness to fewer respondents than the cut-off points used in other studies.

High scores were also frequent on the HAD anxiety subscale, across all three subject groups. Seventeen respondents (48.57%) from the pilot group showed at least mild anxiety, and 46 respondents (44.66%) from the plastic surgery group and 154 (64.43%) from the media group showed similar levels of anxiety. The inclusion of 'mild' cases in these figures is somewhat confusing, since they reflect Snaith and Zigmond's most recent (1994) classification, and would have been regarded as 'doubtful cases' in earlier studies (Zigmond & Snaith, 1983). However, even restricting the definition of caseness to those in the moderate and severe categories yields considerable numbers of affected individuals (7/35 (20%), 24/103 (23.30%) and 106/239 (44.35%) in the pilot, plastic surgery and media groups respectively), leaving 10 (28.57%) pilot mild cases, 22 (21.36%) plastic surgery group mild cases and 48 (20.08) media group mild cases. Williams and Griffiths (1991) found 5 'possible' (21.7%) and 3 'definite' cases (13.0%) from their sample of 23 burn injured patients. By contrast, participants in Robinson et al.'s (1996) treatment study of facially disfigured people obtained a pre-treatment mean HAD anxiety level of 9.0 (indicating mild anxiety or 'doubtful' caseness according to the 1983 and 1994 HAD classifications respectively). Unfortunately, no actual numbers in the various categories are given. It may be seen, therefore, that proportions of cases are considerably higher in the current study than in the Williams and Griffiths (1991) study, whether or not 'doubtful' or 'mild' cases are included. This is consistent across all three respondent groups, although the media groups are again higher, as would be expected. With regard to the Robinson et al. (1996) study, the mean pre-treatment score there is comparable with the media group mean (9.69) and higher than in the pilot group (7.57) and plastic surgery group (6.8). This possibly reflects the fact that the Robinson et al. group, like the media group in the current study, were self-selected.

Depression scores on the HAD were generally lower than for anxiety, with 4 (11.11%), 13 (12.62%) and 71 (29.46%) of respondents in the pilot, plastic surgery and media groups respectively showing at least mild depression. These figures consisted of 2 (5.55%) mild and 2 (5.55%) moderate/severe pilot cases, 12 (11.65%) mild and 1 (0.97%) moderate/severe plastic surgery group cases and 33 (13.69%) mild and 38 (15.76%) moderate/severe media group cases. With the exception of the media group, HAD depression scores (including mild cases) were comparable with the Williams & Griffiths (1991) study (3/23 [13%]). HAD depression mean scores in the current study were also comparable with the Robinson et al. study (1997) mean score (4.8 compared with 3.44 [pilots], 3.4 [plastic surgery] and 5.77 [media]).

Two additional sources of comparison between the current study and disfigured groups may be mentioned. Lanigan and Cotterill (1989) found only 4 'doubtful cases' (16%) and 1 case (4%) in their group of 25 port wine stain patients. However, a direct comparison with the current study is not possible, since these authors did not report which of the two HAD scale results was being described. A comparison study between HAD and GHQ by Lewis and Wessely (1990) involving 117 dermatology out-patients attenders (site of skin complaint not stated), showed mean levels of 6.9 for HAD anxiety and 3.9 for HAD depression, comparable with the groups in the current study.

The original validation study by Zigmond and Snaith (1983) found levels of doubtful caseness and definite caseness of 20% and 34% for anxiety and 18% and 13% for depression in their sample of general medical outpatients. These scores are generally higher for both anxiety and depression than in the current pilot and plastic surgery groups. This is particularly interesting in the case of the pilot group. Since these respondents were active outpatients' attenders like those in the Zigmond and Snaith (1983) sample, we might have expected the scores of the two groups to be similar. However, from the small current pilot sample, it appears that dermatology outpatients show *lower* HAD anxiety and depression scores than general medical outpatients.

Community samples show rates of anxiety either similar to or lower than those shown by respondents in the current study sample groups. Dowell and Biran (1990) found rates of 22% doubtful cases and 23% anxiety cases from their 94 postal respondents and 21% doubtful cases

and 25% anxiety cases from their 300 consecutive general practice consultation sample. In a Swedish general population sample (n = 624), Lisspers et al. (1997) found anxiety rates of 12% (doubtful cases) and 8% (cases), albeit with a low response rate (48%), whilst El-Rufaiel et al.'s (1998) study yielded rates of 10% doubtful cases and 16% cases in a sample of 100 Saudi primary care patients. A comprehensive review of the HAD (Herrmann, 1997) reported anxiety case rates in German studies of 9% (medical students) and 7% (general population). In general, then, these rates are lower than any sample group in the current study. This is most pertinent with regard to the plastic surgery ex-patients sample, who might be most expected to resemble primary care and general population samples.

The picture regarding comparisons between HAD depression scores and community samples is more mixed. Thus, the Dowell and Biran (1990) study showed depression rates of 8% (doubtful cases) and 13% (cases) in the postal sample and of 11% (doubtful cases) and 10% (cases) in the consultation sample, higher than either the pilot or plastic surgery groups in the current study, but lower than the media group. The rate of caseness is generally lower in the Lisspers et al. (1997) study, which found rates of 9% doubtful depression cases and 6% cases, but higher in the El-Rufaiel et al. (1988) study which found 28% doubtful cases and 17% cases - higher than any group in the current study. Finally, the German studies reviewed in Herrmann (1997) found rates of 2% caseness in medical students and 5% caseness in the general population.

Taking the dysphoria measures as a whole, considerable difficulty is experienced by people with facial disfigurement. From the standpoint of a fear-avoidance model, the outstanding feature of this pattern is the large number of respondents experiencing anxiety as measured by the HAD. A considerably larger percentage of cases of HAD anxiety than HAD depression were detected, suggesting that anxiety is the more likely consequence of disfigurement across these three sample groups. This is consistent with the earlier, smaller studies described above. Whilst the HAD is not *intended* to measure the somatic symptoms of anxiety states (Snaith & Zigmond, 1994), since these overlap with physical illness, it does examine anxious mood, restlessness and anxious thoughts and autonomic concomitants (butterflies in the stomach, feeling tense and 'wound up', sudden feelings of panic). It is thus a reasonable measure of the three systems said by behaviour

therapists to be involved in clients' distress in general and in anxiety in particular. However, there is no way of distinguishing from this measure alone whether this anxiety is focal to particular situations or general. Nevertheless, if the high rate of elevated HAD anxiety scores is considered in the light of the avoidance behaviours described by respondents and discussed earlier in this chapter, these high scores lend weight to the assertion that the avoidance behaviours reported by facially disfigured people both in the current study and in earlier anecdotal and small survey reports are the consequence of anxiety focal to those situations. That these avoidances are greater in social than in other situations increases our confidence in the contention that the social difficulties of disfigured people are essentially phobic in nature.

As noted in Chapter 4, it has been asserted by some commentators that women are likely to be more affected by facial disfigurement than men (Andreason & Norris, 1972; Shuster et al. (1978; Orr et al., 1989), although others have found no differences (White, 1982). The Face/self subscale might be considered to reflect in part the issue of self-esteem, whilst the Face/other subscale focuses more on social interactions and avoidances. Since the Andreason and Norris (1972) and Orr et al. (1989) studies found that self esteem was lower in women than men, we might expect the Face/self subscale in particular to show sex differences. This proposition found support in the current study in both the plastic surgery ex-patients and media recruited samples, suggesting that women showed more negative attitudes towards their faces than men.

In the Face/others subscale, no differences were found. Moreover, on examination of the mean ranks across males and females, it was found both that the groups were usually extremely close in terms of scores and that, of the non-significant results of comparisons between males and females, women showed less difficulty than men on almost as many occasions as they showed more difficulty. Whilst the estimation of equivalence is difficult, particularly in the absence of large samples, as discussed in Chapter 8, it is worth noting that the finding of no difference between the sexes on the Face/others subscale is consistent with the literature on the prevalence of social phobia (Marks, 1987) which is generally evenly distributed between the sexes, although not with the prediction of greater social difficulty in females derived from the disfigurement literature.

The measures of avoidance and dysphoria (FQ, SAQ, GHQ, HAD) likewise show a mixed picture, but the general tendency across the three samples as a whole is towards no differences between the genders. Thus the pilot study group shows a single difference between the groups (HAD depression). Whilst it might be tempting to attribute these non-significant findings to low numbers in the pilot group, attention should be drawn to the comparative mean ranks of the subgroups, which are extremely similar in most cases, increasing confidence that the lack of difference between the groups in the pilot study is a genuine effect, rather than a type 2 error. Similarly, the media recruited group show no differences between the sexes, once again tending to refute the notion of greater disturbance among women. The ex-plastic surgery group, however, show a different pattern, with statistically significant differences between males and females on 6 of the 11 scales examined (agoraphobia (FQ), social phobia (FQ), total phobias (FQ), anxiety/depression (FQ), problem severity (FQ) and home management (SAQ)). In each case except home management, females showed greater disturbance than males. Two issues should be noted with regard to the plastic surgery ex-patients results. First, this group are the most representative of the three samples in the current study, and, arguably, more representative of the general population of disfigured people than samples in other studies, which have typically used *current* patients. In consequence, it may be permissible to draw conclusions about differences between the sexes in general, with regard to psychological disturbance in facial disfigurement. Moreover, it should be more permissible to draw such conclusions from this sample than from either of the samples in this study which did not show differences, since the pilot group was small and the media recruited group was self selected and probably represents a group of untypically disturbed individuals. In consequence, it may be concluded that there is some further support for the contention that females show greater disturbance than males. By contrast, however, it should be noted that, despite differences between the groups in the plastic surgery ex-patients sample, the scores throughout were actually fairly low, certainly when compared with the media recruited sample, and most of the mean scores would be unlikely to be regarded as of sufficient severity to warrant intervention. It appears, therefore that, amongst the *most* affected individuals (the media recruited sample), there is no difference between males and females, but that when less affected people (the plastic surgery ex-patients) are examined, such sex differences emerge on a considerable number of measures.



In view of this, these results, taken as a whole, offer, at best, only modest support for the findings of greater psychological difficulty and disturbance amongst females than males reported in earlier literature (Andreason & Norris, 1972; Shuster et al., 1978; Orr et al. 1989). Moreover, the clinical importance of this may not be great, given the comparatively low levels of disturbance in the sample where these differences are seen. Whilst it may well be the case that attractiveness is more highly prized in women than in men, the evidence from the current study that this is reflected in different levels of psychological distress, is equivocal, and possibly restricted to women's self-perception of their faces as measured by the Face/self subscale of the FAAC.

The examination of different perceptions and behaviours according to cause of disfigurement is potentially important for two reasons. First, there is almost no examination in the literature of differing responses to different causes of facial disfigurement, although Shuster et al. (1978) found lower self image in eczema and psoriasis sufferers than acne sufferers. Second, a fear-avoidance model of psychological distress following disfigurement suggests that different causes of disfigurement might lead to different patterns of difficulty, since they would contribute differently to elements of the model outlined in Chapter 8. For example, disfigurement from birth might lead to greater opportunities for habituation than traumatic or surgical disfigurement occurring later in life. By contrast, a remitting complaint, such as a skin disorder, might lessen such opportunities. Numbers were sufficiently large to allow comparison according to cause of disfigurement only in the media sample, and a number of significant differences were found. Thus, there were differences in ratings by cause of disfigurement, on the FAAC Face/others subscale, the FQ Total problem severity subscale, the SAQ Work, Home management and Social leisure subscales, the HAD depression subscale and the GHQ total score. Additionally, the HAD anxiety subscale difference just failed to reach significance ( $p = 0.06$ ).

Examination of the relationships between pairs of subgroups revealed that in the case of the FAAC Face/others subscale this difference was accounted for by the significantly greater disturbance (in terms of anxiety and avoidance with regard to others' reactions to the face) in the skin complaint group than the accident/injury group. In those results examining avoidance and dysphoria, a consistent picture emerges, with the group disfigured from birth showing less disturbance than other

groups. Less disturbance amongst those disfigured from birth contributed to 5 of the 6 significant overall differences, and were 5 of the 8 significantly different pairs. Less disturbance amongst those disfigured by accident/injury was responsible for the other 3 pair differences, and contributed to 3 of the 6 overall differences (Chapter 11, Tables 11.5.12 to 11.5.14). Moreover, there were no pair differences between disfigurement from birth and accident/injury. Both disfigurement from birth and disfigurement from accident/injury respondents showed consistently better adjustment across a range of measures than people disfigured from skin disease or surgery, whenever such differences were present.

The overall pattern of these results, coupled with the use of the Bonferroni method, which is a conservative method of accounting for the effects of multiple comparisons, increases our confidence that they represent genuine differences between the groups, rather than being the result of type I errors. It may be speculated that the consistent finding of less disturbance amongst people disfigured from birth can be accounted for by a fear-avoidance model, since these individuals will have had more opportunity to habituate to the responses of others to them, and to their anxiety responses to the situations where such responses occur. This assertion is somewhat weakened, however, by the finding of no differences in the phobia subscales of the FQ, or the HAD anxiety subscale. The finding that people disfigured by accident/injury generally also do better than those disfigured from surgery or skin complaint is not readily explicable by a fear-avoidance model. It may be that those scoring higher have other difficulties not related to facial disfigurement, but to other aspects of their complaint. These may have played a role in the difficulties of the surgery and skin complaint groups examined in this element of the study. The current study did not, for example, ask specifically about the involvement of other body areas or about other related complaints such as pain or itching.

An alternative interpretation of the findings is to describe them not as a comparative *lack* of difficulty for the disfigured from birth and accident/injury groups but as comparatively *greater* difficulty for the other two groups. The disfigured from skin complaint group fared worse than others in 5 of the 8 pair differences in the Bonferroni tests, whilst the surgery group did so on 3. No test showed a difference between the skin complaint and surgery groups. Similarly, the skin complaint group did

worse than the accident/injury group on the FAAC Face/others subscale group pair comparisons. The greater disturbance experienced by the skin complaint group may be explicable in terms of habituation, since skin complaints are often remitting complaints, where the sufferer has less time to become habituated to their appearance and its consequences before the complaint remits, only to return again. Clearly this interpretation is highly speculative, but offers tentative support for a fear-avoidance model of disturbance following disfigurement, in the form of disturbed body image (as measured by FAAC Face/other), avoidance and general dysphoria. The difficulties of the surgery group might be explicable in terms of concerns about aspects of the surgery they had undergone (for example, pain, difficulties with activities of living), rather than concern about disfigurement. Although these aspects were not specifically investigated in the current study, several respondents did spontaneously mention both such concerns and difficulties such as pain, discomfort and inconvenience.

The role of habituation in mediating the difficulties of disfigured people may be further investigated by the correlation of subscales with age and length of time since disfigurement occurred. In the interests of keeping an already large number of potential comparisons as low as possible, and thus decreasing the likelihood of Type I error, correlations of this kind were not carried out across the entire possible range of measures. However, since age and time since disfigurement had already been correlated with the FAAC subscales as part of determining convergent validity, these correlations are now considered again in the context of the role of habituation. We might expect older people and, in particular, those who have had greater experience of disfigurement, to have had more opportunity both to learn about the anxiety-reducing effects of habituation in general and the relevance of these to their disfigurement. Unfortunately, the usefulness of this prediction is lessened by the observation that such learning is not contingent upon time alone, but also upon opportunities for such learning, and, in part, constitutional variables such as extroversion and neuroticism (Marks, 1987). In the current study, the picture is not clear, but strongly suggests that no such correlations exist. No correlations were found between either subscale and age or time since disfigurement in the pilot group. In the plastic surgery and media groups, the position is confused. Age was negatively correlated with FAAC face/self scores in both samples, and with face/others in the plastic surgery group, indicating less disturbance with greater age, whilst time

since disfigurement was negatively correlated with Face/other in the media group, indicating decreasing disturbance with the passage of time, but positively correlated with passage of time in the plastic surgery ex-patients group, indicating the reverse. Given the small size of the pilot group, it might be tempting to ignore their responses (which were also non-significant for most other correlations) in attempting to interpret the pattern of findings for age and time since disfigurement. This leaves us with the suggestion that the negative correlation between age and FAAC subscales is relatively consistent, whilst that for time since disfigurement is less so. However, it should be noted that, although significant, the actual size of the correlations was low (under 0.2 in all cases), indicating that these correlations are weak effects. It is concluded, therefore, that the effects of age and time since disfigurement on FAAC scores are negligible, if present at all. In the case of time since disfigurement, the contradiction between the two groups in the current study is mirrored in the literature, since Browne et al. (1985) and Tucker (1987) found decreased disturbance with increased time since disfigurement, but Orr et al. (1989) did not. However, these studies were of burn-injured subjects only, and so are not directly comparable with the current study.

A final element of the characteristics of facially disfigured people which relates to the fear-avoidance model of distress in disfigurement is the specific tactics employed by disfigured people. When we examine these tactics, we find that whilst the majority in all samples report no such tactics, the numbers in the media group are considerable. Most tactic descriptions involve avoiding having the affected part seen by other people, and the range of tactics used to effect this outcome is broad. The description of avoidance tactics used suggests that these are common and pervade disfigured people's lives, in a way similar to the description of constant examination of one's appearance and the reactions of others to it suggested by Macgregor (1951, 1979).

#### **Section 12.4 Treatment leaflet study**

There is modest support for the contention that the very limited intervention of a self-help leaflet may be helpful for those experiencing such difficulties. Whilst it is disappointing that only 3 of the 9 outcome measures employed showed significant advantages for the active treatment group over time, several issues should be borne in mind. First, of the outcome measures employed, the agoraphobia subscale and the home management subscale were unlikely to detect change, since

scores on these measures were initially low in both groups, whilst the social leisure subscale, the scale most likely to be affected if social interaction is a major feature of the psychological difficulties of facially disfigured people, did, in fact show change in the predicted direction, as did the HAD anxiety scale, a key *general* measure of change in anxious subjects. Thus, two important measures showed support for the fear-avoidance model. Second, of the non-significant findings, it is worth noting that all but one favoured the active treatment group. Balanced against this, of course, it should be noted that even the significant results were modest, and would be unlikely to represent clinical improvement. A power calculation was performed at the beginning of the treatment study, and a moderate effect size was required to detect differences between groups of the size available for the treatment study, increasing the possibility that actual differences between the groups might not be detected. The issue of power is considered in Section 12.7. Likewise, the follow-up time was short, and further improvement may have been found at a later point. Finally, several respondents from the control group noted, spontaneously, on their follow-up questionnaires, that completion of the initial questionnaire had been helpful, by allowing them to focus on their difficulties.

Taking these issues together, two things may be concluded. The self-help leaflet approach showed changes on two key measures of change and one other, and may in consequence, be considered as worthy of more exploration as an intervention with facially disfigured people. This issue is further discussed in Section 12.7. Changes over time in the treatment group are also interesting from the perspective of the fear-avoidance model. The finding that this group improve following advice along cognitive-behavioural lines, emphasising confrontation of feared situations, suggests that their avoidances are the result of anxiety which is focal to those situations, and is relieved following exposure treatment. Naturally, this assertion must be tentative, given the modest nature of the gains in the current treatment study, but the presence of such improvement in response to exposure adds another source of evidence that the avoidances of disfigured people contain a phobic component. In the context of the results of other elements of the current study, it appears that this component may be considerable.

A further possible contributing factor to the modest advantage for the treatment group concerns acceptability of the leaflet. Whilst this was agreed by the pre-pilot group as being an acceptable and relevant approach to the difficulties of disfigured people, this view may not have been shared by respondents. Empirical investigation of acceptability of the leaflet and compliance with its contents shows two clear findings. The leaflet was clearly understandable and perceived as useful by the majority of respondents. However, the range of adherence to its instructions was very variable. Indeed, only 50 per cent of respondents reported doing about half the things suggested in the leaflet or more, with 5 respondents having followed none of the suggestions at all. It is tempting to speculate on the influence these respondents might have had on the eventual comparisons between the groups, but no examination of subgroup differences of this kind was undertaken, given the small numbers involved. It is also interesting to note the general high level of satisfaction with the leaflet, given that treatment gains were modest. This suggests that measures of satisfaction are not necessarily reliably related to measures of clinical improvement or quality of intervention (Eriksen, 1987).

## **Section 12.5 Comparison of facially disfigured people with phobic patients**

Disfigured people who experience difficulties of clinical severity (as suggested by a global problem severity cut-off of 4 or above) show significantly less agoraphobic features than agoraphobia patients, but significantly *more* social phobic features than this patient group. By contrast, disfigured people show no significant differences from social phobia patients on either of these measures. Moreover, the *mean* differences between social phobic patients and disfigured people were low enough to be regarded as without clinical significance (Agoraphobia subscale 1.7/40; social phobia subscale 4.7/40). Taken together, these findings suggest that the difficulties shown by people with facial disfigurement are more similar to social phobia than to agoraphobia. This adds further support to the assertion that the difficulties of facially disfigured people mainly relate to social situations and are phobic in nature, thus supporting the fear-avoidance model of psychosocial disturbance following disfigurement. There were no differences between disfigured people and phobics on the anxiety depression subscale, suggesting they were similar in levels of dysphoria.

## **Section 12.6 Summary of support provided by the study for a fear-avoidance model of psychological difficulty in disfigurement.**

In Chapter 8, a number of predictions were made which might be expected from the fear-avoidance model. These predictions were examined in the empirical element of this thesis, and supported to varying degrees. Each prediction is stated here, with the support received in the current study.

### *12.6.1 Description (Chapter 8, Section 8.4.3, Page 169)*

Descriptive elements of the study confirm the existence of difficulties in social situations described in earlier anecdotal accounts and small surveys. Evidence of such difficulties is found in the FAAC, FQ, SAQ. Scores on the FQ and SAQ suggest that phobic avoidance may contribute to the maintenance of these difficulties. That these difficulties are associated with dysphoria is suggested by scores in the GHQ and the HAD. Scores on the HAD suggest that anxiety is of particular importance, again supporting the fear-avoidance model. Low levels of compulsive behaviour were found on the MOC, contrary to expectations from clinical practice, but not directly affecting the fear-avoidance model, other than to suggest that such behaviours are unlikely to be a major feature. It appears that the focal anxiety displayed by disfigured people is more phobic than compulsive in nature. The broad range of descriptive results support the fear-avoidance model.

### *12.6.2 Hypotheses (Chapter 8, Section 8.4.4)*

Five hypotheses relevant to the fear-avoidance model were generated. A further hypothesis (regarding gender differences), less directly relevant to the fear-avoidance model, was also included, in view of the lack of agreement in the literature about the possible role of gender in mediating the psychological difficulties of disfigured people.

Hypothesis 1 (page 170): Subject anxiety as measured on the Hospital Anxiety and Depression Scale (HAD) was higher than in most of the population norms examined. Subject depression as measured on the HAD was generally lower than or similar to the population norms examined. The hypothesis is substantially supported with regard to anxiety, but not to depression.

Hypothesis 2 (page 170): Subjects showed higher GHQ scores of psychiatric morbidity than general population norms, across all samples, levels comparable with GP attenders and hospital in-patients in the pilot study and plastic surgery ex-patients samples and higher scores than GP attenders and hospital in-patients in the media-recruited sample. The hypothesis is substantially supported.

Hypothesis 3 (page 170): Women showed higher levels of disturbance in a minority of measures. The most consistent finding of difference was on the Face/self subscale. The picture is mixed, but the hypothesis is substantially not supported.

Hypothesis 4 (page 170): There were positive correlations between scores indicating negative attitudes and behaviours related to the face as measured by the FAAC and the range of general measures of disturbance on the great majority of comparisons. Correlations between subscales of the FAAC and age, and time since disfigurement were also found, but the picture differed in the three samples. The hypothesis is substantially supported.

Hypothesis 5 (page 170): Persons having different causes of facial disfigurement showed different levels of disturbance across the range of measures on the majority of comparisons. The hypothesis was partly supported.

Hypothesis 6 (page 170): Subjects receiving cognitive-behavioural advice via a leaflet showed lower scores on only a minority of measures of handicap following administration of this advice than subjects not receiving such advice. However, two of these were key tests of the fear-avoidance model. The hypothesis is partly supported.

The broad range of results of hypothesis tests support the fear-avoidance model.

### *12.6.3 Equivalence (Chapter 8, Section 8.4.5, Page 170)*

No significant differences were found between facially disfigured people and diagnosed social phobics on the social phobia and agoraphobia subscales of the FQ, even though the sample sizes were demonstrably large enough to detect such differences if they were present. Examination of



group means for these scales did not show differences between the groups likely to be regarded as clinically significant. The result of this prediction of equivalence supports the fear-avoidance model.

#### *12.6.4 Extent of the support provided for the fear-avoidance model*

In general, the fear-avoidance model predicts that disfigured people who experience psychological difficulties, particularly in social situations, are experiencing high levels of anxiety, which contribute to these difficulties and are associated with behavioural avoidances. In consequence, results are regarded as being supportive of the fear-avoidance model when they demonstrate the presence of anxiety amongst people with facial disfigurement, particularly in social situations. The degree of support received by the model may be judged by an examination of the broad range of supporting evidence. Thus, it may be felt, for example, that greater support is shown for the model if, as the current study demonstrates, disfigured people not only show high levels of negative attitudes towards their faces, but these attitudes are seen to correlate with measures of anxiety and avoidance behaviour. Similarly, the lack of difference between phobic patients and facially disfigured people, and the response of facially disfigured people to exposure treatment offer additional sources of support for the fear-avoidance model, which asserts that facially disfigured people's avoidances are mediated by phobic anxiety. It is not possible, however, to make a definitive assertion of a direction of causality on the basis of these results, since the study does not have a design capable of assessing whether, for example, social avoidance is a consequence of anxiety or a cause of it. This mirrors the situation often seen in phobic patients, and described in Chapter 7 during discussion of two-process theory (Section 7.2). In such patients, it is often not clear how far avoidance is maintained by fear and fear maintained by avoidance. It is generally regarded that, in such patients, fear of particular situations has originally led to avoidance, whilst avoidance maintains this fear during the later course of the phobia (Mowrer, 1960; Gray, 1975; Marks, 1987). The similarity between phobics and facially disfigured people who experience psychological difficulties may provide some evidence that similar directions in the processes of the genesis and maintenance of fear and avoidance are active in both groups, even in the absence of a definitive demonstration of causality in the current study.

## **Section 12.7 Limitations of the study**

Compared with many of the studies in the field of facial disfigurement, the current study represents a larger, more systematic approach to the difficulties of this group. Nevertheless, it contains a number of shortcomings, which might be rectified by future studies.

### *12.7.1 Validity and reliability of the FAAC*

The current study has made a useful start in establishing the psychometric properties of this measure. However, the one weakness apparent from these preliminary areas is in the somewhat low level of test-retest reliability. Issues concerning this have been discussed in Section 12.2. Because of low test-retest reliability, it was not considered feasible to use aspects of the FAAC as outcome measures, during the current study. With hindsight, this may have been overly conservative, and is unfortunate, since any improvement on particular elements of this measure might have provided interesting insights into the process whereby change had occurred in the more general measures. For example, it would have been interesting to see whether changes in specific avoidances concerned with the face were reflected in decreased social avoidance, agoraphobic avoidance or global problem severity. However, this would have been a dubious procedure, given the low test-retest reliability of the measure, with the possibility that actual differences between the groups over time might have remained undetected, as a result of lack of stability of the measure. It has been noted that the 4 week test-retest interval was chosen largely for practical reasons. With hindsight, it may have been preferable to identify a further, small group of suitable respondents and undertaken an examination of test-retest reliability with them in a way which allowed for the use of a briefer interval, perhaps incorporating face-to-face administration of the questionnaire.

### *12.7.2 Sample*

Sampling difficulties have been a feature of almost all studies of facial disfigurement, whether concerning the use of biased sample groups (Rumsey, 1983) or analogue subjects in experimental studies (Rumsey, Bull & Gagahan, 1986a). The current study experienced a number of sampling difficulties. First, the numbers available for study were established in the pilot study as likely to be low, especially within the time available, and a number of different sampling approaches were used in order to address this issue. One consequence of this variation in approaches is that the samples

were of different levels of representativeness. Of the three groups, only the plastic surgery ex-patients group is likely to be representative. The use of a consecutive sample of all eligible patients, increases our confidence in this representativeness, whilst the low response rate need not diminish this confidence greatly, given the demonstration that respondents were not significantly different from non-respondents on the small number of relevant variables available for comparison. We cannot draw similar conclusions about the pilot group, since no features of the non-respondent group were collected. The position is similar for the media group, with the addition of the potential source of bias that this group were not systematically selected, but were, rather, a self-selecting sample from a potential population of unknown size and characteristics. Thus, we may draw conclusions about the prevalence of psychological disturbance amongst facially disfigured people only from the ex-patients group. As has been noted earlier, the extent of the possible generalisability of these conclusions to the general population is somewhat strengthened by the fact that these individuals were not *current* attenders. Amongst the media group, conclusions are limited to the group itself with regard to frequency of disturbance. We may, however, reasonably extend conclusions about the *characteristics* of these disturbances, provided we are clear that these relate only to a general population of facially disfigured people who *show* psychological disturbance. We may thus draw general conclusions about the likely characteristics of such disturbances in terms of, for example, anxiety rather than depression, or focal rather than general anxiety. Conclusions have been expressed within these limitations during the current study.

A further difficulty in sampling arises in the criteria used to select subgroups for further examination. This is an issue in two parts of the current study. In the treatment leaflet study, a cut-off of 3 on the global problem severity scale of the FQ was used, for reasons outlined in the methods section. However, it might be argued that, since this cut-off is slightly lower than would be expected in clinical practice, it might have given rise to a floor effect. Since floor effects will tend to reduce the power of an experiment, this may have led to an increased risk of Type 2 error in the findings of this part of the study. Certainly the occurrence of repeated non-significant results in favour of the intervention group might lead us to suspect the lack of significant findings was caused by a source other than lack of actual difference between the groups. However, this suggestion is both generally speculative and, with regard to the specific issue of floor effect, was incapable of investigation. The

possibility of reanalysing the data with a cut-off of 4 was considered, but rejected, following discussion with a statistician, on the grounds that this would represent an unwarranted increased risk of Type I error.

In the comparison with phobics, a more usual cut-off of 4 was used to define the comparison group of facially disfigured people. In consequence, no cross comparisons with other elements of the study may legitimately be made. The comparison with phobic patients is thus solely with disfigured people who are experiencing considerable disturbance. The argument that similarities would be expected as a simple *result* of the level of global problem severity selected as a cut-off (particularly given that this was entered as a covariate) is not, however, a difficulty for the study. Firstly, the scales used for comparison purposes adequately distinguished between social phobics and agoraphobics, who themselves had similar levels of global problem severity. Secondly, there are clear differences between the agoraphobics and facially disfigured people, which global problem severity again does not account for. In consequence, the similarity between facially disfigured people and socially phobic people is unlikely to be attributable to similarities in global problem severity scores.

A final limitation of the sample involves the inclusion of a majority of female respondents in each element of the study. Clearly, this should be borne in mind when interpreting the findings. However, the general lack of difference between the responses of male and female respondents should also be considered.

#### *12.7.3. Loss of participants at follow-up and power*

The power of a study to detect change where it is present represents a considerable challenge in psychotherapy outcome research in general (Kazdin & Bass, 1989). As noted in Chapter 10, the current study achieved an acceptable beta level (80%) with the assumption of a effect sizes of 0.38 on one of the key measures and 0.54 on the other. Subjects were unavoidably lost at follow-up, decreasing the power of the study to detect differences where these were present. Using the lower of the two effect sizes calculated (0.38) to estimate the power of the study with its final number of follow-up completers (treatment group  $n = 34$ , control group  $n = 36$ ) yields a beta level of

approximately 75% (Kraemer & Theimann, 1987). This represents a fairly small reduction in the power of the study, with similarly minor implications for the increased risk of type 2 error.

#### *12.7.4. Follow-up duration*

A further difficulty with the follow-up part of the intervention study concerns its short duration. It might be considered, for example, that gains amongst the treatment group might have been consolidated over time. The shortness of the follow-up was entirely driven by the practical time constraints upon this element of the project. However, a longer follow-up might also have been considered an unreasonable commitment to ask from a volunteer population in general not specifically identifying themselves as requiring intervention, in return for the minimal treatment intervention of a leaflet. The degree of commitment required would be particularly great for the control group, and continuing involvement in return for the eventual administration of a brief leaflet may once again be thought of as an inadequate recompense for involvement. As well as potentially being regarded as unethical, the paucity of the recompense may have led to an effect on return rates over an extended follow-up period, a possibility supported by the follow-up rate gained even over 3 months in the current study.

By contrast with the above argument, it might equally well be suggested that differences between the groups might have *decreased* over time, particularly if apparent advantages for the treatment group were caused by some placebo effect such as enthusiasm for a new way of addressing problems or desire to score positively as a result of gratitude for *any* input. This latter possibility is lent some support by the high level of satisfaction with the leaflet in the presence of only modest clinical change. Such non-specific factors might be considered likely to decrease in importance over time, as the participant's enthusiasm and gratitude wane in the absence of enduring changes in behaviour and experience. A short follow-up does not allow for the exploration of any of the above possibilities.

#### *12.7.5 Treatment leaflet*

The rationale for the choice of this means of intervention has been fully described in Chapter 9. However, it may be asserted that, regardless of this, the leaflet is an inappropriate test of the

effectiveness of cognitive-behavioural intervention. There is no doubt that, to a limited extent, this is so. Despite the positive findings described in Chapter 10, the literature in support of such self-help interventions, although encouraging, is limited when compared with literature in support of cognitive-behavioural interventions by more traditional means. Furthermore, the leaflet in the current study was brief. Balanced against this, the brevity of the leaflet made it a closer approximation to the type of leaflet likely to be made available on a wide scale, such as in general practice surgeries, with a consequent increase in external validity. Apart from the arguments in favour of use of a leaflet outlined in Chapter 9, it is also worth noting two things in defence of the leaflet. First, although satisfaction is generally a poor measure of outcome, it should be remembered that a considerable majority of respondents reported finding the leaflet helpful, suggesting that it was not perceived as therapeutically weak. Second, even this brief document was not read in total by all respondents. We may only speculate as to the likely reduction in completion of a longer, more complicated self-help booklet, and any possible decrease in adherence. This said, the use of so brief a leaflet may have reflected confusion between an examination of the utility, *in principle*, of a cognitive-behavioural approach (and the inferences which might be drawn from such utility about the fear-avoidance model of disturbance in facial disfigurement), and examination of the pragmatic implementation of a self-help approach in clinical practice. A longer, more comprehensive leaflet may have demonstrated more obvious clinical benefit, even in a pilot study of this kind, even if its use might have been limited in clinical settings. Alternatively, a face-to-face intervention might have been more appropriate, within the context of a pilot intervention study. However, given the small number of potential participants likely to become available during the life of the project, plus the time necessary to undertake face-to-face treatment, the eventual study group would have been likely to be small. This in itself would have resulted in difficulties regarding the power of the study. Thus, whilst this approach might have represented a purer test of the cognitive-behavioural intervention, there is no guarantee that it would have been more likely to achieve clear results, within the time constraints, than the more pragmatic approach adopted.

## Section 12.8 Future research

### 12.8.1 Reliability and validity of the FAAC

Preliminary findings indicate acceptable internal consistency and internal relationships of this measure, and some suggestions regarding convergent validity have been made. Further work should now be undertaken to establish this convergent validity, and divergent validity, sensitivity and specificity of the FAAC. A cut-off score might be identified to distinguish between those experiencing and not experiencing difficulties. A further examination of test-retest reliability should be undertaken, using a shorter interval between tests. The two items of the Rest subscale (items 19 and 23) should probably be dropped from further versions of the FAAC, unless it can be demonstrated that they serve some useful function such as discriminating between distressed and non-distressed individuals. Alternatively, items 19 and 23 may benefit from being reworded to address more clearly the notions of *anxiety* in the context of feeling that facial appearance is important or of checking in mirrors, rather than a result of normal, even pleasurable attention to appearance. Since clinical experience suggests that people with body dysmorphic disorder engage in checking rituals associated with their beliefs and anxieties about their bodies, a question item which *validly* investigates such issues will be a useful addition to the instrument. Consideration should be given to the status of the two ambiguous scale items (items 16 and 18).

These further investigations represent a considerable further examination of the properties of the measure, but are probably worthwhile, given the absence of such a measure in the literature. This is particularly important given that, whilst there are important qualitative studies which attest to the difficulties of facially disfigured people, quantitative work which would allow us to assess the extent of these difficulties requires adequate measurement which addresses issues of reaction to disfigurement directly, rather than through the use of measures of more general psychological disturbance such as GHQ. Only in this way may we build on the qualitative work towards a more general picture of the responses of disfigured people. An adequate focal measure is a prerequisite of this quantitative work.

### 12.8.2 *Characteristics of facially disfigured people*

As noted above, qualitative work has been of considerable importance in elucidating some of these characteristics, and the relevance of this idiographic approach should not be underestimated. Nevertheless, much of this work is unsystematic, with the result that we do not know either how typical the particular difficulties described are of those experiencing difficulty, nor how frequent difficulty is amongst the general population of disfigured individuals. This study has gone a small way towards rectifying that situation, particularly through the examination of prevalence of psychological disturbance in plastic surgery ex-patients.

Two further investigation strategies will be important. First, the retrospective examination of ex-patients can be usefully extended to different populations, (for example; dermatology ex-patients and those at head and neck surgery clinics) allowing an examination of the prevalence of psychological disturbance related to disfigurement in those groups. The question of whether to examine specific diagnostic groups (for example; cleft lip and palate revision ex-patients) should receive consideration. There is doubtless value in this approach, since such specific groups will bring with them attendant difficulties other than disfigurement, which are important for the clinician to understand. It may be argued, however, that alongside this approach based on diagnostic category, it is important to examine disfigured people *in general* in order better to understand the common difficulties experienced as a result of disfigurement itself, rather than illness-specific issues which may co-exist with disfigurement and its sequelae. From a theoretical perspective, relying exclusively on studies of specific diagnostic groups is problematic, since, for many, the difficulty which caused their disfigurement is now past. They are simply disfigured *people* not patients with any complaint. The cognitive-behavioural perspective on psychological disturbance argues that grouping people together into diagnostic categories is often of less value than, on the one hand, grouping them together according to the areas of difficulty they share, and, on the other, examining them individually, using functional analysis, to ascertain the specific maintaining factors associated with their difficulties. In more practical terms, reliance on a diagnostic approach alone in investigation of disfigurement will rarely yield sufficient numbers to allow rigorous quantitative examination of the characteristics of such groups. The two approaches need to continue concurrently.



Second, prospective studies of individuals who have experienced the broad range of facial disfigurements are important. These will best be undertaken through collaboration between investigators and clinicians across a range of clinical specialities and geographical settings, in order to address as representative a picture of disfigurement as possible. Good information regarding the extent of both the needs of disfigured people and responses to them is necessary in order to organise future services for disfigured people and to press for the funding necessary to secure such services. Standardisation of the measures to be used across such studies will ensure greater comparability between studies. From a cognitive-behavioural perspective, the inclusion of measures which attempt to examine specific issues related to the face and anxiety consequent upon those issues is indispensable in building a coherent picture of the experiences and needs of disfigured people.

#### *12.8.3. Treatment of psychological sequelae of facial disfigurement*

The current study gives considerable support for the place of a cognitive-behavioural perspective based on a fear-avoidance model in the treatment of psychological difficulties of facially disfigured people. This is apparent from the characteristics of the various sample groups, the responses (albeit modest) to cognitive-behavioural intervention, and comparison with phobic patients. In view of this, further, more systematic investigations of cognitive-behavioural intervention are clearly warranted. The use of a self-help intervention is of importance given the possible extent of the problem and the current level of services. This issue should, however, be separated from the issue of treatment effectiveness, and this latter issue should be clearly elucidated in the first instance, through a randomised controlled trial of cognitive-behavioural intervention based upon exposure principles. Both individual and group interventions are good candidates for methods of delivery of the treatment, which should be in accordance with a manual, thus clearly identifying treatment components in the same way as leaflet administration does and minimising therapist variability. With regard to the design of the study, it may be valuable to include, as well as a no-treatment control, a group which receives treatment delivered via leaflet, in order to examine the optimum level of intervention needed by sufferers. Clearly this once again has implications for recruitment and retention strategies, and a large scale collaboration will be required to mount such a study. The current study suggests that the cognitive-behavioural approach has promise. Similarly, the work of

Feigenbaum (1981), Rumsey, Bull & Gagahan (1986a) and Robinson et al. (1996) with social skills work training for people with facial disfigurement offers indirect support for the cognitive-behavioural approach, as does the work of such researchers as Marks and Mishan (1986), Newell and Shrubbs (1994), Rosen et al. (1995) and Gournay et al. (1997) with people with body dysmorphic disorder. In view of this support, the effort required in mounting such a large scale investigation is merited.

#### *12.8.4. Comparison with phobic patients*

The current study has established that people with facial disfigurements who experience psychological difficulties are not different from social phobic patients on two key measures, but do differ from agoraphobic patients. Whilst strongly indicative, this is not the same as establishing similarity between the two groups. In order to do this, two further activities could be undertaken. First, the computerised database of phobic patients is a valuable resource which could be used as a further source of comparisons with disfigured patients identified in future studies. Indeed, the responses to such studies could, for some purposes, be legitimately combined with data from the current study. This would then yield a high enough number of facially disfigured people experiencing difficulties to allow more formal examination of similarity between the groups. Second, a wider range of appropriate measures could be identified, both from the Maudsley database and from other sources, with which comparisons could be made. This would greatly increase our confidence in assertions of equivalence between the two groups.

### **Section 12.9 Concluding remarks**

Examination of the psychological effects of disfigurement remains at an early stage. A small number of qualitative researchers have contributed comprehensive accounts of the difficulties of disfigured people. Similarly, some disfigured individuals have provided their own accounts of their lives, in the form of biographies or descriptions of living with disfigurement. However, this work tells us little about the *general* experiences of the great majority of such individuals. The quantitative literature is limited in several ways. The overall amount of this literature is itself small, a fact noted by successive commentators over the years, and this has led many researchers to explore the related field of attractiveness as a source of speculation about the social experiences of disfigured people. Such literature as does exist about disfigurement is essentially divided into three parts:

experimental work generally using non-disfigured people and make-up or similar subterfuges to make them appear disfigured; survey studies, typically of clinical populations, often from a single diagnostic category; treatment studies using a variety of interventions. Some of the strengths and shortcomings of these elements of the literature have been examined in the relevant chapters of this thesis.

The current study represents a small but useful extension to this body of work. A measure of attitudes and avoidances related to the face (FAAC) has been devised and preliminary testing of its psychometric properties undertaken. Further testing is still needed, but the instrument appears to hold promise as a clinical tool, particularly in the field of cognitive-behavioural interventions with disfigured people.

The cognitive-behavioural approach to disfigurement has been examined in detail for the first time in the literature, drawing on cognitive-behavioural approaches to pain and to body image, particularly in body dysmorphic disorder. The model resulting from this approach, based on a fear-avoidance formulation of psychological disturbance following disfigurement, has found some support as a result of the current study. Thus, disfigured people engage in considerable behavioural avoidance. Moreover, the levels of their specific avoidances (reported on the FAAC) are generally correlated with other, more general measures of avoidance, and of dysphoria. In consequence, it may be concluded that their psychosocial difficulties, including disturbed body image related to the face, are associated with avoidance, although the direction of this association was not investigated. This association is particularly apparent in social situations. Similarly, disfigured people also experience considerable levels of social anxiety. Behavioural intervention by means of a simple self-help leaflet had a modest impact upon these difficulties. Finally, disfigured people with difficulties resemble social phobics according to two key measures. Considered together, these findings indicate that the current study offers the first available evidence that the difficulties experienced by disfigured people may be construed as phobic in nature. Further elements of the cognitive-behavioural model described in Chapter 8, such as the role of personality and early learning, remain to be explored. Further work is also required to elucidate whether

measures of avoidance adequately distinguish between people with disfigurements who describe psychological disturbance and those who do not.

The current results offer considerable support for the consideration of exposure therapy as a first choice intervention with disfigured people experiencing psychological difficulties. Moreover, it may be argued that behavioural principles could usefully be explained to disfigured people at the time of disfigurement, as prophylaxis. This approach will, in itself require rigorous testing. If the routine offering of cognitive-behavioural guidance to newly disfigured people proves of value, this might represent a major contribution to our management of disfigurement across a broad range of complaints. In consequence, the potential implications for service provision are far-reaching.

In this context, the role of brief guidance, whether face-to-face or via literature or electronic means, is of considerable importance. Resources to provide comprehensive advice to all newly disfigured individuals, or formal counselling for those who develop difficulties, are unlikely to become available. The treatment package offered in the current study was not potent, and few significant changes were found, although almost all non-significant trends also favoured cognitive-behavioural intervention along exposure lines. Reasons for the possible weakness of the treatment have been discussed earlier in this chapter. If, as the current study suggests, interventions based on a cognitive-behavioural formulation of psychological distress in disfigurement are likely to prove of value, economical methods of treatment delivery to a large potential client group will become increasingly important. For this reason, it is important that investigation of treatment packages which do not require specialists to deliver them continue. This may be in the form of self-help literature, self-help groups or brief individual and group interventions offered by non-specialists. All these resources will benefit from a thoroughly investigated model of distress in disfigurement, with equally thoroughly investigated associated interventions.

The current study has attempted to combine several elements important to the progress of research into the psychological sequelae of facial disfigurement: examination of a model for understanding these sequelae; examination of their characteristics and prevalence; development of a measure suitable for their continuing specific investigation; introduction of a treatment approach. These

elements are interlinked, and all require future development and testing. One further important element, which was not examined in the current study, is the current level of psychological provision for disfigured people. Most writers in the field paint a dismal picture (Wallace, 1988; Williams & Griffiths, 1991) of patchy services and a general lack of consideration for psychological factors in disfigurement, and it has been noted that this latter trend has been present in the literature since its beginning. However, this is in striking contrast to the reaction of clinicians from all disciplines to the current project at all stages. Anecdotally, two issues stand out in this connection. First, clinicians were generally concerned about their patients' psychological well-being, but lacked any strong sense of what they might do to address such issues. Where attempts were being made to address clients' psychological needs, this was generally being done in an ad hoc fashion, with little reference to any literature or other framework for action. Second, clinicians were generally enthusiastic about the current project and its possible implications for their patients. Their general feeling was that it was extremely unusual, and welcome, for a researcher to take an interest in their area of work.

Interestingly, this last perception was echoed repeatedly in the many unsolicited comments appended by respondents to their questionnaires. The congruence of their remarks with those of clinicians suggests the magnitude of the challenge of working with psychological care in facial disfigurement. The volume of research into people's difficulties remains low, and we have little idea of the current level of service provision for these difficulties. The current study represents a small addition to a small body of literature. Researchers in the field need to expand the literature as a whole, but also to disseminate widely, both to clinicians and to disfigured people themselves, in order to ensure the widest and most effective provision of services in an area where an appropriate therapeutic response is currently inadequately defined, described or delivered.

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# **APPENDICES**

## APPENDIX 1

### Example brief explanatory letter. Media study

Dear

*Study of changes in facial appearance at Hull University*

Thank you for your interest in this study. I enclose a copy of the questionnaire, which asks about aspects of your personal life, your mood and spirits. As you can see, the questionnaire is quite long, but I do hope you will feel able to take the time to complete it. Your contribution will be important in helping doctors and nurses who work with people who have experienced a change in facial appearance, since it will give them a better idea of the emotional and social difficulties which arise following these changes. This is currently something about which we do not know anything like as much as we would wish to. Some of the questions are quite personal, so please do not feel you have to complete the whole questionnaire. Even an incomplete questionnaire is useful to the study.

At the end of the questionnaire you are asked whether you would be willing to receive a further copy of this questionnaire or to receive a brief self-help leaflet and be followed up by post in a few months' time, to see if it has been useful. You are also asked whether you would like to receive a copy of the results of the study when it is complete (in about 1 year's time). If you do, just tick in the box provided and add your address.

Many thanks once again for your interest in this study.

Yours sincerely

Rob Newell  
Lecturer in Nursing

## **APPENDIX 2**

### **Questionnaire front sheet study details. Media study**

#### **ABOUT THE STUDY**

Thank you for reading this questionnaire. As you can see, it is quite long, but I very much hope you will be able to take the time to fill it out, since your participation will greatly increase nursing and medical understanding of people who have difficulties with feelings about their facial appearance

I am a nurse lecturer and therapist at Hull University, and I am hoping to find out about changes in the social lives of people who have facial problems like severe acne, birthmarks or scars, and also about their feelings about their bodies. This is a subject about which nurses and doctors have little knowledge as yet. I hope my research will eventually enhance the care given by nurses and doctors, especially as it relates to the psychological and social aspects of patients' lives.

Because of the subject, many of the questions are quite sensitive in nature. For example, some of the questions ask you about things you might avoid doing because of the way you feel about how you look, while other questions ask quite directly about your feelings. Naturally, I appreciate that, as a result, there may be some questions you do not feel able to answer, so please don't feel under any obligation to complete the whole questionnaire. I will, however, be very grateful if you fill it in as completely as you feel able, since your response will greatly enrich our knowledge of the difficulties faced by people in similar circumstances to yourself.

Your responses will be treated in complete confidence, and any report of my findings will preserve the anonymity of all participants. If you wish, I will send you a brief summary of my findings at the end of the study (in about a year's time). There is a box at the end of the questionnaire for you to tick if you want to receive this.

I am also asking for people to fill in the questionnaire a second time, in the near future. This helps to ensure that the questionnaire is as well-constructed as possible, which in turn will lead to the best possible information about people's difficulties. If you would be prepared to repeat the questionnaire in a couple of weeks time, there is another box at the end of the questionnaire to tick.

Finally, I shall be offering some people a free leaflet giving details of how to cope with anxiety about facial appearance, then following them up in six months' time (by asking them to complete this questionnaire again) to see if the leaflet has helped. If you would be willing to receive details of this follow-up study, please tick the box at the end of the questionnaire

Thank you once again for your help.

Rob Newell

### APPENDIX 3

#### Example initial contact letter. Plastic surgery ex-patients study

Dear

#### Study of changes in facial appearance at Hull University

I am writing to ask whether you would be willing to participate in a study which we are doing along with the Nursing Department at Hull University. Rob Newell is a nurse lecturer and therapist there, and is interested in giving a questionnaire to people who have experienced a change in their facial appearance, either as a result of surgery or injury.

Whilst some people experience great difficulties as a result of changes to their appearance, others seem to have much less disturbance. We are interested in the whole range of people's experiences, *not* just those who have had considerable difficulties. We hope the research will eventually enhance the care given by nurses and doctors, especially as it relates to the psychological and social aspects of patients' lives. As a result, we are writing to people who have had facial surgery or injury in the past few years.

*Please note that you are under no obligation whatsoever to participate in the study. However, we do hope you will feel able to participate. Details of how to receive the questionnaire are given later in this letter.*

Because of the subject, some of the questions are quite sensitive in nature. For example, some of the questions ask you about things you might avoid doing because of the way you feel about how you look, while other questions ask quite directly about your feelings. Naturally, we appreciate that, as a result, there may be some questions you do not feel able to answer, so please don't feel under any obligation to complete the whole questionnaire. Even an incomplete questionnaire will be useful to us. Of course, we will be very grateful if you fill it in as completely as you feel able, since your response will greatly enrich our knowledge of the difficulties faced by people we treat.

All your responses will be treated in complete confidence. We shall be making the findings of the study available to all participants, should they wish to receive them, as well as using your information to refine a self-help guide for those who suffer social difficulties as a result of their feelings about their facial appearance. This guide will be available in the future to all participants in the study, without charge.

**If you are happy to receive a questionnaire, you don't have to anything more,** and we shall send out the questionnaire over the next few weeks, along with a prepaid envelope for its return.

**If you do not wish to receive a questionnaire** just tear off the slip at the end of this letter and return it to Rob Newell in the next fortnight, in the prepaid envelope provided. He will then be sure **not** to send you a questionnaire. If you **do not** return the slip, you **will**



*receive a questionnaire, but once again this does not place you under any obligation to complete it or return it.*

*If you receive a questionnaire, but no longer wish to return it, just throw it away. We shall treat your decision with respect, and will not contact you further in any way regarding the study.*

Having said all that, we do hope you will feel able to participate in the study. The more people who do return questionnaires, the broader a picture we will get of their experiences. If you want more information about the study, you are very welcome to contact Rob Newell on 01482 465538. If he is not there, a secretary will take your call on 01482 466220.

Thank you once again for your help.

Yours sincerely

Mr N Hart FRCS  
Consultant Plastic Surgeon

\_\_\_\_\_Tear here if you don't want to receive a questionnaire\_\_\_\_\_

*I **do not** want to participate in the study of people's attitudes to changes in their facial appearance. Please **do not** send me a questionnaire.*

Name .....

Address .....

.....

.....

## APPENDIX 4

### Letter granting ethical approval

#### HULL AND EAST RIDING RESEARCH ETHICS COMMITTEE

c/o East Riding Health,  
Grange Park Lane,  
Willerby,  
HULL, HU10 6TD

Our Ref: MRFR/AMP/96/6  
Your Ref:

Phone: 01482 672070  
Fax: 01482 672062

20 February 1996

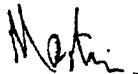
Mr R Newell  
Lecturer in Nursing  
Institute of Nursing Studies  
University of Hull  
Cottingham Road  
HULL HU6 7RX

Dear Rob

96/6 ANXIETY, AVOIDANCE BEHAVIOUR AND DISTURBED BODY IMAGE IN  
PEOPLE WITH FACIAL DISFIGUREMENT: INVESTIGATION OF ASPECTS  
OF A COGNITIVE-BEHAVIOURAL FORMULATION

Thank you for your letter following our recent correspondence and telephone call. I am pleased to report that the Committee has noted all the points that you have made and accepted them without further hesitation. You may now take it that ethics approval is granted for you to proceed with this study.

Yours sincerely



Dr Martin R F Reynolds  
Chairman  
Hull and East Riding Research Ethics Committee

cc Royal Hull Hospitals Trust

# FACE AND BODY ATTITUDES AND BEHAVIOURS QUESTIONNAIRE

Rob Newell  
School of Health  
Hull University  
Cottingham Road  
Hull  
HU6 7RX

## ABOUT THE STUDY

Thank you for reading this questionnaire. As you can see, it is quite long, but I very much hope you will be able to take the time to fill it out, since your participation will greatly increase nursing and medical understanding of people who have difficulties with feelings about their facial appearance

I am a nurse lecturer and therapist at Hull University, and I am hoping to find out about changes in the social lives of people who have facial problems like severe acne, birthmarks or scars, and also about their feelings about their bodies. This is a subject about which nurses and doctors have little knowledge as yet. I hope my research will eventually enhance the care given by nurses and doctors, especially as it relates to the psychological and social aspects of patients' lives.

Because of the subject, many of the questions are quite sensitive in nature. For example, some of the questions ask you about things you might avoid doing because of the way you feel about how you look, while other questions ask quite directly about your feelings. Naturally, I appreciate that, as a result, there may be some questions you do not feel able to answer, so please don't feel under any obligation to complete the whole questionnaire. I will, however, be very grateful if you fill it in as completely as you feel able, since your response will greatly enrich our knowledge of the difficulties faced by people in similar circumstances to yourself.

Your responses will be treated in complete confidence, and any report of my findings will preserve the anonymity of all participants. If you wish, I will send you a brief summary of my findings at the end of the study (in about a year's time). There is a box at the end of the questionnaire for you to tick if you want to receive this.

I am also asking for people to fill in the questionnaire a second time, in the near future. This helps to ensure that the questionnaire is as well-constructed as possible, which in turn will lead to the best possible information about people's difficulties. If you would be prepared to repeat the questionnaire in a couple of weeks time, there is another box at the end of the questionnaire to tick.

Finally, I shall be offering some people a free leaflet giving details of how to cope with anxiety about facial appearance, then following them up in six months' time (by asking them to complete this questionnaire again) to see if the leaflet has helped. If you would be willing to receive details of this follow-up study, please tick the box at the end of the questionnaire

Thank you once again for your help.

Rob Newell

## FACE AND BODY ATTITUDES AND BEHAVIOURS

The next few pages ask you a series of questions about things you do and feel as a result of the way you feel about your body in general and your face in particular. Some of the questions are taken from standard questionnaires, and so you may feel that some of the wording is strange or does not apply to you. This is unfortunate but unavoidable, so I would be very grateful if you could try to answer the questions as best you can. Although it is important that you concentrate when filling in the questionnaire, it is *not* necessary to spend a great deal of time on each question. What I am looking for are the replies which best reflect your responses to feelings about your body and face *most of the time*, and first impressions are often the most accurate ratings of these. There are no right or wrong answers. Generally speaking, it is only questions which you are unsure about how to respond to which will take up much of your time. As a guide, the whole series of questionnaires should not take longer than 20 minutes to complete.

Thank you once again for your time.

Age .....

Sex .....

Occupation .....

Age left school .....

Qualifications .....

On this part of the questionnaire, you are asked to respond to each of the questions using the following scale:

<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>
Never	Rarely	Sometimes	Often	Usually	Always

Your answer depends on *how often* you experience the feelings or perform the behaviours described by each question. For example, if you *often* hide your body (Question 3) you would score a 3 in the box for that question, if you *never* do, you would score 0, if you *always* do, you would score a 5, and so on. Likewise, if you *always* feel comfortable within your body (Question 2) you score a 5, if you usually do, you score a 4.

Please read the whole questionnaire quickly, then return to the beginning and fill in each of your responses.

- 1 When I compare myself to others, I'm dissatisfied with my body as a whole ☐
- 2 I feel comfortable within my own body as a whole ☐
- 3 I hide my body as a whole (e.g.; loose clothing) ☐
- 4 It's easy for me to relax physically ☐
- 5 I feel my body is a burden ☐
- 6 My body as a whole is a threat to me ☐
- 7 My body as a whole appears as if it's not mine ☐
- 8 My bodily appearance is very important to me ☐
- 9 I envy others for their physical appearance ☐

- 10 When I compare myself to others, I'm dissatisfied with my facial appearance ☐
- 11 I wear facial prostheses (excluding wigs & special make-up) ☐
- 12 I wear a wig ☐
- 13 I wear special make-up ☐
- 14 I hide my face (e.g.; special clothes, turning face away) ☐

(Please describe the tactics you use, if any, on the line below)

- .....
- 15 My face is a barrier to me with others ☐
- 16 My face is a threat to me ☐
- 17 My face is a threat to others ☐
- 18 My face appears as if it's not mine ☐
- 19 My facial appearance is very important to me ☐
- 20 I envy others for their facial appearance ☐
- 21 I have become used to the way my face looks ☐
- 22 Other people have become used to the way my face looks ☐
- 23 I check my face in mirrors ☐
- 24 I avoid looking at my face ☐
- 25 I avoid walking in the street because of my facial appearance ☐
- 26 I avoid social situations because of my facial appearance ☐
- 27 I avoid sexual contact because of my facial appearance ☐
- 28 I avoid certain kind of clothes because of my facial appearance. ☐

The next part of the questionnaire (over the page) uses a 0-8 scale. The first section measures the amount that you would avoid each of the activities on the list, whilst the second measures how much you are currently troubled by each of the symptoms.

Choose a number from the scale below to show how much you would avoid each of the situations listed below because of anxiety or other unpleasant feelings. Then write the number you choose in the box opposite each situation.

0	1	2	3	4	5	6	7	8
would not avoid it		slightly avoid it		definitely avoid it		markedly avoid it		always avoid it

Injections or minor surgery	<input type="checkbox"/>
Eating or drinking with other people	<input type="checkbox"/>
Hospitals	<input type="checkbox"/>
Travelling alone by bus or coach	<input type="checkbox"/>
Walking alone in busy streets	<input type="checkbox"/>
Being Watched or stared at	<input type="checkbox"/>
Going into crowded shops	<input type="checkbox"/>
Talking to people in authority	<input type="checkbox"/>
Sight of blood	<input type="checkbox"/>
Being Criticised	<input type="checkbox"/>
Going alone far from home	<input type="checkbox"/>
Thought of injury or illness	<input type="checkbox"/>
Speaking or acting to an audience	<input type="checkbox"/>
Large open Spaces	<input type="checkbox"/>
Going to the dentist	<input type="checkbox"/>
Other situations (describe)	<input type="checkbox"/>

Now choose a number from the scale below to show how much you are troubled by each problem listed, and write the number in the box opposite.

0	1	2	3	4	5	6	7	8
hardly at all		slightly troublesome		definitely troublesome		markedly troublesome		very severely troublesome

Feeling miserable or depressed	<input type="checkbox"/>
Feeling irritable or angry	<input type="checkbox"/>
Constant tension wherever I happen to be	<input type="checkbox"/>
Sudden surges of panic regardless of where I am	<input type="checkbox"/>
Upsetting thoughts coming into your mind	<input type="checkbox"/>
Other feelings (describe)	<input type="checkbox"/>

How would you rate the present state of your problems on the scale below (please circle one number between 0 and 8)?

0	1	2	3	4	5	6	7	8
no problems present		slightly disturbing/ disabling		definitely disturbing/ disabling		markedly disturbing/ disabling		very severely disturbing/ disabling

Once again a 0-8 scale is used. here you rate how much each aspect of your life is affected by permanent change in your facial appearance.

*Once again, this part of the questionnaire uses a 0 - 8 scale. Here, you rate how much each aspect of your life is affected by permanent change in your facial appearance. In each case, you ring the number which you feel best applies to you.*

### Work

*'Because of my problems, my ability to work is impaired.'*

0	1	2	3	4	5	6	7	8
not at all		slightly		definitely		markedly		very severely I cannot work

### Home Management

*(E.g.; cleaning, tidying, shopping, cooking, looking after home or children, paying bills)*

0	1	2	3	4	5	6	7	8
not at all		slightly		definitely		markedly		very severely I cannot do it

### Social Leisure Activities

*(with other people, e.g.; parties, pubs, clubs, outings, visits, dating, home entertainment)*

0	1	2	3	4	5	6	7	8
not at all		slightly		definitely		markedly		very severely I never do these

### Private Leisure Activities

*(done alone, e.g.; reading, gardening, collecting, sewing, walking alone)*

0	1	2	3	4	5	6	7	8
not at all		slightly		definitely		markedly		very severely I never do these



In the next questionnaire (over the page), a 0-3 scale is used, to indicate how much of a problem each of the activities is to you. In each case, you just put a tick in the box which best corresponds to your answer. So, if taking a bath takes you the same amount of time as the average person, tick the 0 column, if it takes twice as long, you repeat it twice or tend to avoid it, tick the 1 column, and so on.

Two final questionnaires follow it, printed on yellow and green paper. These are standardised, published questionnaires, and contain some unusual wording which I am not permitted to change. I hope you will not be put off by this and will try and answer as best you can. Please do not put your name on the HADS scale.

The final page of the questionnaire asks some more general questions and also contains the boxes you can tick if you want to receive a summary of the findings of the study, if you are willing to fill in the questionnaire a second time or if you are willing to receive information about the study of advice about anxiety.

## KEY

0 = "I have no problems with this activity - takes me about the same time as an average person. I do not need to repeat it or avoid it."

1 = "This activity takes me about **twice** as long as most people or I have to repeat it **twice** or **tend** to avoid it."

2 = "This activity takes me about **three times** as long as most people or I have to repeat it **three** or more times or I **usually** avoid it."

3 = "I am **unable** to attempt or complete this activity"

0	1	2	3	ACTIVITY
				Having a bath or shower
				Washing hands and face
				Care of hair (e.g. washing, combing, brushing)
				Brushing teeth
				Dressing and undressing
				Using toilet to urinate
				Using toilet to defaecate
				Touching people or being touched
				Handling waste or waste bins
				Washing clothes
				Washing dishes
				Handling or cooking food
				Cleaning the house
				Keeping things tidy
				Bed making
				Cleaning shoes
				Touching door handles
				Touching your genitals, petting or sexual intercourse
				Visiting a hospital
				Switching lights or taps on or off
				Locking or closing doors or windows
				Using electrical appliances (e.g. heaters)
				Doing arithmetic or accounts
				Getting to work
				Doing your work
				Writing
				Form filling
				Posting letters
				Reading
				Walking down the street
				Travelling by bus, train or car
				Looking after children
				Eating in restaurants
				Going to public toilets
				Keeping appointments
				Throwing things away
				Buying things in shops
Total				
				Others (fill in)

(Authorial note: The Hospital Anxiety and Depression Scale (Zigmond & Snaith [1983]) and General Health Questionnaire (12) (Goldberg & Williams [1991]) were administered at this point in the battery of tests, but are not reproduced here for copyright reasons.)

Changes to your facial appearance were caused:

From Birth ☐

Accident or other injury ☐

Part of a skin complaint ☐ Please state a diagnosis if you know it .....

Result of surgery ☐ Please state a diagnosis if you know it .....

Other (Please specify) .....

How long ago did this happen? (If not from birth) .....

Have you any comments about the questionnaire? If so, please write them in the space provided, but also feel free to continue over the page.

.....  
.....  
.....  
.....  
.....

\*\*\*\*\*

Would you be prepared to receive information about a further study involving you in receiving written information giving advice about how to cope with anxiety caused by feelings about facial appearance?

Yes ☐

No ☐

Would you be prepared to fill in this questionnaire again in two weeks time, as part of helping me to test its usefulness? Yes ☐ No ☐

Would you be interested in receiving a summary of the findings of this study? Yes ☐ No ☐

If yes to any of these, please write your name and address below. If you are willing either to complete the questionnaire again or to participate in the study of written advice on anxiety, I will contact you again in two or three weeks' time. If you want to receive a summary of the results, I will send these to you in about a year's time, when the study is complete.

.....  
.....  
.....  
.....  
.....

Thank you once again for filling in this long questionnaire.

## APPENDIX 6

### Letter granting permission to use the BAT

UNIVERSITAIR  
CENTRUM  
ST.-JOZEF v.z.w.

Leuvensesteenweg 517  
3070 Kortenberg  
Tel. (021) 758105.11



Kortenberg, 29th august 1996

Mr Robert Newell  
Lecturer in Nursing  
The University of Hull

Dear Mr. Robert Newell,

Yesterday I receive your letter via prof. W. Vandereycken. We give you permission to use our "Body Attitude Test" in your further research. I send you two papers concerning the test. I wish you succes with your study and hope to heard about your research.

Yours sincerely,

  
Michel Probst

# **Anxiety and Facial Appearance**

## COPING WITH ANXIETY AND CHANGES IN FACIAL APPEARANCE

### ***About this booklet.***

This booklet aims to give you basic information about anxiety, its relationship with changes in facial appearance and things you can do practically to combat anxiety. It is based on our knowledge of anxiety and the thoughts of people who have experienced changes in facial appearance.

### ***Anxiety is normal.***

Everyone experiences fear and anxiety. The body has developed effective ways of dealing naturally with them. So, to be anxious, or even very afraid, in certain situations is not dangerous, although it may feel very unpleasant. It does not mean you are weak if you feel anxiety and fear.

### ***Anxiety and everyday life.***

Anxiety is a part of life. Job interviews, examinations, appointments with the doctor or dentist. All these make most of us anxious. Sometimes we actually seek out situations which cause anxiety. We may want the positive results that go with these situations (for example when we meet new people, go on dates, speak in public, act in a play). We may even *enjoy* the physical sensations which accompany fear and anxiety (as in driving fast or riding a rollercoaster). We call *these* feelings of fear 'excitement', but the actual physical sensations are much the same.

### ***Physical anxiety.***

We all know about 'butterflies in the stomach', and this is a very common physical feature of anxiety. People also get breathlessness, rapid heartbeat, feelings of faintness, tingling in the hands and feet, headaches, feeling 'twitchy'.

You may have feelings which are special to you which tell you you are getting anxious. It is important to remember that these feelings are not dangerous. They are just extremely unpleasant. They are the body's natural way of preparing to take action to meet a threat - either by fighting the thing which is threatening us, or by running away.

### ***Anxious thoughts.***

As well as physical feelings, we all experience particular thoughts when we get anxious or fearful. Typically, these thoughts are negative, so that we may say to ourselves: 'I can't cope with these feelings.', 'People think I am useless.', 'I am going to faint.', 'Everyone is looking at me and knows how anxious I am.' and so on. Although it is perfectly natural to have these thoughts, they can make us feel low, or lead us to avoid our daily activities. These negative thoughts are believed to add to physical feelings of anxiety.

### ***Anxiety and changes in physical appearance.***

Almost any change in our lives can cause anxiety. Perhaps you remember starting a new school or job. Of course, these things are small, compared with undergoing a permanent change to physical appearance. People who have survived such changes describe them as the greatest challenge they have had to meet.

The anxiety can often seem impossible to conquer, whether it takes the form of concern about one's appearance, fear about what others will think, or fear about the future. Perhaps the worst part of fear is that it makes us want to avoid those situations which make us afraid.

### **Anxiety and avoidance.**

Avoiding things which make us afraid is an attempt to ensure safety. Avoidance of this kind is often a very sensible thing to do: at other times, less so. For instance, if I lived in a country which had a great many poisonous scorpions, it would make perfect sense to keep away from them, to check my bedding before going to sleep, and so on. It would make much less sense to do so here in the UK. A lot of avoidance caused by anxiety is of this second kind. Sufferers often see their fears as irrational. This does not make the *fear* any less real.

### **Avoidance and changes in facial appearance.**

The biggest difficulty which people who have undergone a permanent change in facial appearance describe is in social situations, particularly when these involve being close to others. Worry about how they will feel in the company of others, and worry about how others will react to their appearance, can lead people to avoid a whole list of everyday activities.

These can be shopping, going to the pub, eating out, even walking down the street. In fact, anything where others are present. There may be almost total avoidance of allowing others to see them close up. Some people cannot even bear to look at themselves, because of their distress about how they appear to themselves and others.

Of course, it is quite reasonable to be concerned about changes in our appearance, particularly when these are recent, sudden or extensive. It has often been suggested that this is part of a grieving process for the 'lost' appearance, just as we might grieve for a lost friend or relative. This grief is probably part of adjusting to changes in appearance. It stops being reasonable when *we ourselves recognise it* as being abnormal. We may want desperately to go out, but feel so afraid of what will happen ("I'll faint", "people will stare", "people will pass remarks") that we are unable to get outside the front door. Even looking at ourselves may come to spark off these concerns.



In these cases, anxiety has become so great that it interferes with our daily lives to a great extent, by stopping us doing things we would otherwise want to.

### ***Tackling anxiety and avoidance.***

*The big problem is that avoidance just makes us more afraid - the more we avoid the frightening situations.*

*On the other hand, if we confront the fears, they tend to subside.* This is because we learn, through our own experience, that we can cope with the things we previously found so frightening. This is no different from the advice we received as children - "if you fall off a bicycle, get straight back on". We all have experiences of having been anxious about certain activities. Most often, we overcome these anxieties, usually through repetition. Once again, job interviews and examinations are common examples.

Although it is *not* dangerous, the human body cannot keep on having high levels of anxiety indefinitely. *Physical anxiety (churning stomach, racing heart, etc) gradually fades away, provided you enter and stay in the situations*

*which cause you to be afraid.* Entering frightening situations and staying there for long

enough for anxiety to go down has become a mainstay in treatment of phobias (including agoraphobia and social phobia). This treatment is sometimes called 'exposure therapy' (because the person deliberately exposes themselves to the things they fear), or 'behaviour therapy' (because the person tries to change the way they feel through changing their behaviour). It has a very good success rate.

Staying in frightening situations is often very hard to do, because the natural impulse is to escape. However, escape just makes the problem worse. It makes you *more likely to feel frightened* the next time you confront the frightening situation. Because of this, many people find that a gradual approach is the best way for them. They learn to cope with situations which cause comparatively little anxiety, before going on to more and more difficult ones.

### ***A step-by-step approach - what you can do.***

It helps to be systematic in tackling anxiety. Begin by making a list of things you avoid because of fears about changes in your appearance (or which cause you so much anxiety that you do them only rarely, or leave the situation quickly because of fear). Then arrange the list in order of difficulty, putting the hardest at the top and the easiest at the bottom.

Things that you always avoid should usually be higher on the list than things you only occasionally avoid.

Remember that we are concerned here *only with things that you yourself believe it is not reasonable to avoid*. If you are relatively happy not doing a certain thing, you will probably find it best to concentrate on tackling those things which make a greater impact on your life.

Decide on a date to start tackling the things you avoid through fear. Begin on that date, by entering one of the situations or doing one of the things at the bottom of the list.

Expect to feel anxious. Remember, if you didn't feel anxiety, there wouldn't be a problem with this situation. Also expect that the anxiety will go down, if you remain in the situation long enough. Be sure you don't leave the frightening situation until your anxiety has gone down, at least by a bit. This way, you prove to yourself that you can cope with the fears.

### ***The longer the better.***

Psychologists have proved, over the years, that working with anxiety in this way works best if you can stay in the feared situation for *as long as possible*. *Anxiety does go down by itself, but it takes a time*. This can be anything from twenty minutes to an hour and a half. It depends on the individual. Most people start to experience anxiety reduction, and feel calmer, within the first twenty minutes. If anxiety is taking a long time to go down, you should choose a simpler task, or break the task you're working on down into simpler ones.

It is much better to go to the corner shop (easier task) and get home having successfully experienced anxiety reduction, than to go to a big store (more difficult task) and have to leave because of anxiety.

Set aside at least an hour to work on anxiety by entering a feared situation. Two hours is better.

### ***The more the better.***

There is no doubt that tackling anxiety through 'exposure therapy' is best done through very frequent sessions. This gives you the chance to get lots of practice, and helps you learn that you can cope with the fear.

Set aside time every day to practise doing things you have been avoiding through anxiety. Set regular times each day - remember it is very easy to 'forget' to do things which cause us fear and anxiety.

### ***The sooner the better.***

It may be that you are not avoiding many things at the moment. This is great, and even more reason to start confronting the fears right now. It is much easier to nip a problem in the bud than to wait until it may develop into a series of major problems handicapping our lives.

Examine your life for evidence of avoidances starting to creep in, and deliberately confront each one. Similarly, if you have been working on your anxieties for some time and been successful, be watchful for avoidances reappearing. Confront the feared situations sooner rather than later.

### ***Never too late.***

By contrast, some people may feel that their problems of anxiety and avoidance are so great and have been with them for so long that they will never be able to overcome them. The evidence we have from people with agoraphobia and social phobia indicates that this is not so. Even people who have suffered with severe anxiety in public and social situations for many years are able to benefit from gradual confrontation of things they fear, and to make great changes to their lives. The principles are the same, whatever the degree of anxiety.

- \* ***Never avoid feared situations, never try to escape from them.***
- \* ***Never put off confrontation of anxiety.***
- \* ***Work gradually from easy tasks to hard ones.***
- \* ***Work on anxiety every day.***
- \* ***Small tasks attempted successfully are better than big tasks attempted unsuccessfully.***

### ***Coping tactics .***

Just going into the feared situations, and *staying there* for long enough will lead to reduction in anxiety. But staying there is often hard work. To ease this difficulty, you can: *Change what you say to yourself* - make a list of 'coping thoughts' and carry these with you into the feared situations. Some you might try to begin with are:

- "Anxiety never killed anyone"
- "The longer I stay, the less anxious I will be"
- "This feels bad, but I've coped with worse things."
- "No matter how anxious I get, I'm going to carry on."

These are only examples. Think of your own coping thoughts and use the ones which work for you in the anxiety provoking situations to *stop yourself adding frightening thoughts.*

*Attend to your breathing.* Many people breathe hard and fast when they get anxious. This is not dangerous, but does give rise to unpleasant physical

feelings. Slow your breathing down and allow the breathing to be as gentle as possible.

*Learn a relaxation exercise.* Many magazines give advice on relaxation, and there are also a number of tapes available. Almost all the exercises are based on the idea of tensing then relaxing each group of muscles in the body in order. No one method is better than another, and it may be that tensing and relaxing your muscles without formal instruction or reading written instructions is effective for you. Remember to do the exercises in the feared situations. Doing them at other times is just for practice.

*Rate your anxiety.* Many people find that using a rating scale helps them control their anxiety. It certainly gives you feedback on how your anxiety is decreasing as a result of confrontation. This feedback can be a very useful reminder in the feared situations. Some of the questionnaires you did at the start of this study used a 0-8 scale, which you may want to use. 0 could be used to equal 'no anxiety', whilst 8 would be 'worst anxiety I've ever had'. Rate your anxiety repeatedly whenever you are in a situation which causes you anxiety, and note how it

goes down the longer and more often you are in the situation.

*Read a self-help book about anxiety.* "Living With Fear", by Isaac Marks (Published by McGraw-Hill) is a very good one. You don't have to buy it - your local library will order it for you.

Finally, remember that these last few suggestions do not, in themselves, take away anxiety. They are just to help you stay in the anxiety-provoking situations. It is entering these situations as *frequently as possible*, and *staying for as long as possible*, that leads to anxiety reduction. This needs a great deal of effort, but is not a special skill or knack. It is the constant confrontation, with all the hard work that implies, which eventually leads us to conquer our fears.

Good Luck.

Over the page is a checklist of things to do to help overcome anxiety.

### ***Anxiety & coping checklist***

- 1 Make a list of things you avoid and situations which cause anxiety. ☐
- 2 Put the list in order of difficulty (remember that things you totally avoid are most likely more difficult than things you don't) ☐
- 3 Set aside time each day to practise confronting the things that make you anxious ☐
- 4 Make a list of coping thoughts to use when you get anxious ☐
- 5 Practice slow, gentle breathing ☐
- 5 Decide on a date to start practising confronting the anxiety ☐
- 6 On this day, start with the easiest situation on your list. Be sure to stay in the situation for long enough for anxiety to go down. ☐

- 7 Keep a diary of how you get on in confronting your fears. ☐
- 8 When you feel you can reasonably tolerate a particular situation on your list, move on to the next. ☐  
(Remember it is not necessary to feel *no* anxiety before moving to the next situation on the list. For some people this state of no anxiety takes years to achieve. This is unfortunate, but do not be put off, because it should *not* be your aim to experience *no* anxiety, but to *cope* with anxieties that do arise.)
- 9 Each time you move up to a more difficult situation, keep practising the other items, to make sure your anxiety does not return, but tick each situation off the list as you move to the next, to keep a record of your successes ☐

## APPENDIX 8

### Pilot study consent form

#### FACE AND BODY ATTITUDES AND BEHAVIOURS

##### ABOUT THE STUDY

I am a nurse lecturer and therapist at Hull University, and your consultant has given permission for me to contact you in the clinic. I am hoping to find out about changes in the social lives of people who have facial problems like scars, severe acne, or birthmarks, and also about their feelings about their bodies. In order to do this, I am asking patients who have experienced changes in their facial appearance to fill in a questionnaire. You can either complete the questionnaire here, or take it away and return it in a prepaid envelope I will provide. Whilst some people experience great difficulties as a result of changes to their appearance, others seem to have less disturbance. I am interested in the whole range of people's experiences, not just those who have had considerable difficulties. I hope my research will eventually enhance the care given by nurses and doctors, especially as it relates to the psychological and social aspects of patients' lives.

*Please note that although your consultant has agreed to my speaking to you, you are under no obligation whatsoever to participate in the study. Whether you participate or not will have no effect on the treatment you receive. However, I do hope you will feel able to participate.*

Because of the subject, many of the questions are quite sensitive in nature. For example, some of the questions ask you about things you might avoid doing because of the way you feel about how you look, while other questions ask quite directly about your feelings. Naturally, I appreciate that, as a result, there may be some questions you do not feel able to answer, so please don't feel under any obligation to complete the whole questionnaire. I will, however, be very grateful if you fill it in as completely as you feel able, since your response will greatly enrich our knowledge of the difficulties faced by people in similar circumstances to yourself. All your responses will be treated in complete confidence. I shall be making the findings of the study available to all participants, should they wish to receive them, as well as using your information to refine a self-help guide for those who suffer social difficulties as a result of their feelings about their facial appearance. This guide will be available in the future to all participants in the study, without charge. There are boxes on the questionnaire to tick if you wish to receive either the results of the study or the self-help guide.

Thank you once again for your help.

*I agree to participate in the study by completing the questionnaire as explained to me by Robert Newell. I am aware that participation in the study does not affect my treatment in any way. I realise that I am under no obligation to participate and may withdraw at any time, even if I give my consent now.*

Name ..... Date ..... Signed .....

*I confirm that I have explained the nature of this study.*

Robert Newell

Date ..... Signed .....

## APPENDIX 9

### Follow-up letter. Plastic surgery ex-patients study

Dear

#### **Study of changes in facial appearance at Hull University**

I am writing follow up Mr Hart's recent letter to you about this study. Since you did not indicate that you were unwilling to participate, I am enclosing a questionnaire, which I would be most grateful if you could complete and return to me in the enclosed FREEPOST envelope. If you have already written, indicating that you did not wish to participate, and I have not received your letter, or if Mr Hart's initial letter describing the study did not reach you, please accept my apologies. Similarly, even if you did not write to me declining to take part, *please note that you are under no obligation whatsoever to participate in the study*. In any event, if you do not wish to reply, please rest assured that I will not trouble you further in anyway, and accept my thanks for your time in considering this letter.

As the earlier letter stated, we are very keen to find out about the experiences of people who have had surgery or injury to the face, and so, if you are able to return the questionnaire, your responses will help us a great deal. We are interested in *all* people who have had facial surgery, including both those who have and have not experienced difficulties, so, your response will certainly be important. We hope to get a broad, general picture of people's experiences. We will be making a copy of the main findings of the study available to all those who took part, if they so wish.

If you want more information about the study, you are very welcome to contact me on 01482 465538. If I am not there, a secretary will take your call on 01482 466220, or there is an Ansafone.

Thank you once again for your help.

Yours sincerely

Robert Newell  
Behaviour Therapist/Lecturer in Nursing



## **APPENDIX 10**

### **Text of contact articles published in papers for media study**

Altered facial appearance can have a traumatic and lasting effect on our lives, but is an area often neglected by doctors and nurses. The Nursing Department at Hull University is keen to contact people who have experienced a facial disfigurement, either as a result of injury, surgery, skin complaint or from birth. They are looking at sufferers' attitudes and how well they cope with social and other public situations. If you would like to receive a questionnaire, please contact: Rob Newell, Lecturer in Nursing, Institute of Nursing Studies, University of Hull, Cottingham Road, Hull, HU6 7RX. Tel:0482 465538.

## **APPENDIX 11**

### **Anonymised reply to under 17 year old respondent to media study request for participants**

Dear

#### **Study of changes in facial appearance at Hull University**

Thank you for your interest in this study. I should like very much to send you a copy of the questionnaire, but I am obliged, because of your age, to ask you to ask for your parents' consent to your participating. A FAX or letter from them to this effect would be fine, and I should then send you the questionnaire. In any event, I will keep your name on file and send you information about the results of the study when it is completed.

Many thanks once again for your interest in this study.

Yours sincerely

Rob Newell  
Lecturer in Nursing

## APPENDIX 12

### Letter sent to treatment group with treatment leaflet

Dear

#### **Study of changes in facial appearance at Hull University**

Thank you very much for completing your questionnaire. You may remember there was a section at the end, which asked if you wished to receive a brief self-help booklet. You ticked this section, and I now have much pleasure in enclosing the booklet. It is based on a psychological approach to anxiety and avoidance, and also on the responses made to earlier versions of the questionnaire you completed. Most of the suggestions in the booklet are based on the best current research into anxiety, and so I hope very much that you will find it useful. The best way is to read the booklet through quickly, then read it again with a plan in mind about how you will follow the various suggestions made. It may be that you are also interested in joining a self-help organisation, in which case the two best known are:

Changing Faces, 27 Cowper Street, London EC2 4AP (0171 251 4232)  
Let's Face It, 10 Wood End, Crowthorne, Berks (01344 774405)

I also ask in my original leaflet if you will be willing to complete a further copy of the questionnaire in a few months time, to see whether the booklet has been of any use. Therefore, I hope you won't mind if I write again in three months' time with the questionnaire. I do appreciate that it takes some time, but your responses will be helpful in further refining our understanding of the emotional difficulties of people who have experienced a changing in facial appearance, and also in making continuing changes to the booklet.

Many thanks and good luck once again

Yours sincerely

Rob Newell  
Lecturer in Nursing

## APPENDIX 13

### Letter sent to control group

Dear

#### **Study of changes in facial appearance at Hull University**

You may remember there was a section at the end of the questionnaire, which asked if you wished to receive a brief self-help booklet. You ticked this section, and I will send you the booklet in three months' time, when it has finished being tested with another group of people who replied to me. I also asked in my original letter if you would be willing to complete a further copy of the questionnaire in a few months time, to see if any of your feelings and other circumstances have changed over that time. Therefore, I hope you won't mind if I include a further copy of the questionnaire when I write again in three months' time with the booklet. In part, this will also help me to tell if the booklet has benefited those people taking part in testing of it, since I will eventually compare their questionnaire responses with yours.

I do appreciate that it takes some time to complete the questionnaire, but your responses will be helpful in further refining our understanding of the emotional difficulties of people who have experienced a changing in facial appearance, and also in making continuing changes to the booklet.

Although I am sure you are aware that I am asking you to wait a little longer than the current test group to receive the booklet, I hope you will bear with me, since it is important to be able to make this kind of comparison between groups, so that we can see whether or not the booklet really does make a difference to people. The advantage from your point of view is that, as part of the *second* group to receive the booklet, I shall ensure that you receive a copy which includes any improvements made as a result of the current testing.

Many thanks once again.

Yours sincerely

Rob Newell  
Lecturer in Nursing

## APPENDIX 14

### Media sample correlation matrix prior to factor analysis

	FACDIS	FACHID	FACBAR	FACTHRME	FACTHROT	FACNOT	FACIMP	FACUSED	FACOTUS	FACMIR	FACAVOI	WALKAVOI	SOCAVOI	SEXAVOI	CLOTAVOI
FACENV															
FACDIS	1.00000														
FACHID	.63406	1.00000													
FACBAR	.65108	.64702	1.00000												
FACTHRME	.58482	.54984	.75020	1.00000											
FACTHROT	.25861	.30070	.51419	.54714	1.00000										
FACNOT	.43392	.35121	.47329	.55336	.30664	1.00000									
FACIMP	.26799	.30964	.38281	.38524	.16181	.18985	1.00000								
FACUSED	-.42920	-.42572	-.53353	-.52664	-.23426	-.39295	-.35070	1.00000							
FACOTUS	-.28696	-.35091	-.47556	-.40876	-.33742	-.29524	-.13816	.45660	1.00000						
FACMIR	.12284	.07082	.07372	.10917	.00847	.08514	.26762	-.01383	.05358	1.00000					
FACAVOI	.47031	.39158	.37959	.38212	.20253	.29501	.03454	-.39251	-.20457	-.32743	1.00000				
WALKAVOI	.38896	.56484	.58939	.52221	.34803	.42012	.22947	-.43100	-.47603	.12362	.28091	1.00000			
SOCAVOI	.48113	.63581	.70786	.57064	.41586	.41362	-.50029	-.50297	.04095	.36317	.73993	1.00000			
SEXAVOI	.37004	.42821	.55914	.53358	.38351	.36296	.22527	-.42276	-.40111	.00011	.30086	.52775	1.00000		
CLOTAVOI	.34688	.35160	.42103	.34605	.29331	.29165	.11895	-.26754	-.14630	.03492	.27460	.43960	.43645	1.00000	
FACENV	.66707	.51203	.53250	.55294	.28647	.36783	.37080	-.49608	-.28987	.08247	.42995	.28454	.38741	.33473	1.00000

# APPENDIX 15

## Pilot study: non-significant correlations with FAAC subscales (Kendal's Tau)

Correlated Variables		Correlation	Significance
Face/others	Global problem (FQ)	0.2086	p=0.132 (NS)
"	Agoraphobia (FQ)	0.1912	p=0.154 (NS)
"	Social Leisure (SAQ)	0.1477	p=0.285 (NS)
"	Anxiety (HAD)	0.1906	p=0.153 (NS)
"	Depression (HAD)	0.0850	p=0.528 (NS)
"	Total Score (GHQ)	0.2193	p=0.096 (NS)
"	Age	-0.0945	p=0.472 (NS)
"	Time since disfigurement	0.1546	p=0.281 (NS)
Face/self	Global problem (FQ)	0.2251	p=0.080 (NS)
"	Social Leisure (SAQ)	0.2031	p=0.113 (NS)
"	Anxiety (HAD)	0.2216	p=0.073 (NS)
"	Age	-0.1496	p=0.226 (NS)
"	Time since disfigurement	0.0045	p=0.973 (NS)

# APPENDIX 16

**Treatment study participants: correlations between time since disfigurement and outcome measures (Pearson's Product moment coefficient)**

Correlated	Variables	Correlation	Significance
Time since disfigurement	Global Problem Severity (FQ)	-0.0249	p=0.809 (NS)
=0.809	Agoraphobia subscale (FQ)	0.0597	p=0.563 (NS)
"	Social Phobia subscale (FQ)	-0.0075	p=0.942 (NS)
"	Work subscale (SAQ)	-0.0461	p=0.655 (NS)
"	Home Management subscale (SAQ)	-0.1253	p=0.224 (NS)
"	Social Leisure subscale (SAQ)	-0.0192	p=0.853 (NS)
"	GHQ total	-0.0442	p=0.674 (NS)
"	Anxiety subscale (HAD)	-0.0503	p=0.630 (NS)
"	Depression Subscale (HAD)	-0.0691	p=0.506 (NS)

## APPENDIX 17

### ANCOVA table for comparisons between agoraphobics and facially disfigured people

Fear Questionnaire agoraphobia subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	17309.77	173	100.06		
REGRESSION	845.11	1	845.11	8.45	p=0.004
SEX	144.78	1	144.78	1.45	p=0.231
GROUP (AGORAPHOBICS V FACIALLY DISFIGURED)	5227.25	1	5227.25	52.24	p=0.000
SEX BY GROUP	31.81	1	31.81	0.32	p=0.574

Fear Questionnaire social phobia subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	14656.59	173	84.72		
REGRESSION	1192.69	1	1192.69	14.08	p=0.000
SEX	128.59	1	128.59	1.52	p=0.220
GROUP (AGORAPHOBICS V FACIALLY DISFIGURED)	959.99	1	959.99	11.33	p=0.001
SEX BY GROUP	38.64	1	38.64	0.46	p=0.500

Fear Questionnaire anxiety/depression subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	17381.19	173	100.47		
REGRESSION	2448.47	1	2448.47	24.37	p=0.000
SEX	71.14	1	71.14	0.71	p=0.401
GROUP (AGORAPHOBICS V FACIALLY DISFIGURED)	70.44	1	70.44	0.70	p=0.404
SEX BY GROUP	64.56	1	64.56	0.64	p=0.424



## APPENDIX 18

### ANCOVA table for comparisons between social phobics and facially disfigured people

Fear Questionnaire agoraphobia subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	15912.68	174	91.45		
REGRESSION	635.57	2	317.79	3.47	p=0.033
GROUP (SOCIAL PHOBICS V FACIALLY DISFIGURED)	319.04	1	319.04	3.49	p=0.063
SEX	309.07	1	309.07	3.38	p=0.068
GROUP BY SEX	103.28	1	103.28	1.13	p=0.289

Fear Questionnaire social phobia subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	13022.89	174	74.84		
REGRESSION	642.73	2	821.37	10.97	p=0.000
GROUP (SOCIAL PHOBICS V FACIALLY DISFIGURED)	60.88	1	60.88	0.81	p=0.368
SEX	75.43	1	75.43	1.01	p=0.317
GROUP BY SEX	194.18	1	194.18	2.59	p=0.109

Fear Questionnaire anxiety/depression subscale as dependent variable

Source of Variation	SS	DF	MS	F	Significance
WITHIN+RESIDUAL	15649.19	171	91.52		
REGRESSION	2700.92	2	1350.46	14.76	p=0.000
GROUP (SOCIAL PHOBICS V FACIALLY DISFIGURED)	254.24	1	254.24	2.78	p=0.097
SEX	0.04	1	0.04	0.00	p=0.984
GROUP BY SEX	289.63	1	289.63	3.16	p=0.077

## APPENDIX 19

### Fear Questionnaire subscale scores of agoraphobic and social phobic samples

#### Agoraphobic Patients

<b>Subscale</b>	<b>Mean</b>	<b>Range</b>	<b>Standard Deviation</b>
Agoraphobia	23.63	40 (0-40)	10.69
Social phobia	14.62	36 (0-36)	9.59
Anxiety/depression	23.43	40 (0-40)	10.55
Fear Questionnaire Total	52.53	103 (4-107)	21.42
Global phobia	6.12	8 (0-8)	1.86

#### Social Phobic Patients

<b>Subscale</b>	<b>Mean</b>	<b>Range</b>	<b>Standard Deviation</b>
Agoraphobia	8.13	40 (0-40)	9.30
Social phobia	24.00	40 (0-40)	9.80
Anxiety/depression	20.68	38 (2-40)	9.27
Fear Questionnaire Total	40.61	84 (3-87)	20.45
Global phobia	6.00	8 (0-8)	1.75